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KARAIKUDI – 630 003



Directorate of Distance Education

M.A. (Child Care & Education)

IV - Semester

312 43

PRACTICES OF CHILD REARING

SYLLABI-BOOK MAPPING TABLE

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Model Question Paper

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BLOCK I – IV

UNIT I PARENT EDUCATION

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1.1 INTRODUCTION

In this 21st century, one of the most significant changes over the past hundred years has been the shift from large families living in one community to smaller family units as a result of economic necessity and urbanization. An extended family network has become lighter, due to which parents are unable to obtain the support of children's grandparents, aunts and uncles, and often parenting becomes very isolating.

In today's setting, where both the parents are working, the saddle of child rearing has to be shared by both the couple. Changes in parenting patterns, styles and priorities have been influenced by wider alterations in society setup.

Self-instructional material

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Today, Parenting must be viewed in a wider setting. Parenting requires several interrelated functions related to the nurture, care, training and socialising of children. Parenting calls for helping children acquire the social and emotional competencies they need to connect to others, including parents, siblings, extended family, peers, teachers, and eventually life- married people and employers.

The immense influence of technology and changing structure of family demands more emphasis on parenting as an art to be nurtured. The importance of quality parenting, the role expectations of family members and the society as a whole in parenting a child from birth to adulthood is a theme of debate today. This course explores what parenting means, concept of parenthood, influence of parent-child relationship, purpose of parenting education, how it can be enhanced, and how services intended to promote quality parenting can be fortified.

1.2 OBJECTIVES

After going through this unit, you will be able to;

- Understand the concept of parenting
- Appreciate the need for parenting education
- Analyze the concept of parent and parenthood
- Comprehend the characteristics of parenthood and parenting
- Evaluate the importance of parent child relationship
- Understand the significance of parenting in child rearing

1.3 MEANING OF PARENT EDUCATION

Parenting is the process of fostering and supporting the physical, emotional, societal, and intellectual development of a child from babyhood to maturity. Parenting refers to the intricacies of raising a child and not solely a biological relationship. “Parent education” is the plan to bring about changes in parents to rectify and improve their parenting skills. Such courses may be wide-ranging, covering the most common issues parents may encounter in various developmental stages of infants, toddlers, childhood, and adolescence to adulthood with or without disabilities.

Parenting education can be described as: “The purposive learning activity of parents who are attempting to change their method of interaction with their children for the purpose of encouraging positive behaviour in their children.

The National Parent Education Network defines Parent Education as “A process that involves expansion of insights, understanding and attitudes and the acquisition of knowledge and skills about the development of both parents and of their children and the relationship between them”.

Encyclopaedia Britannica defines Parenting as “the process of raising children and providing them with protection and care in order to ensure their healthy development into adulthood”.

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Parent training in family literacy programs provides opportunities for parents (or children’s primary health professionals) to find their own intensity levels; to enhance their parenting skills and life competencies; and to find out more about children’s cognitive, literacy and developmental growth.

Parent education can take place either at home, or in a group setting in the parenting education training centre. When parent education occurs in a group setting, it also provides opportunities for bonding with other parents for support and friendly relationship. Parent training is projected to help parents discover how to better their skills in being the principal teacher for their children and assist them to become associates in the holistic growth of their children.

Parent education reduces the risk of child abuse and neglect by encouraging positive parenting practices that promote safety, well-being, and emotional wellbeing for children and families. Parent education provides caregivers with knowledge, resources, and support to develop parenting skills to enhance child and family well-being. It can also help parents or caregivers learn the tools and strategies to provide a positive and nurturing family environment.

Parent education programs are designed to help parents understand their children’s individual needs and development, as well as their own roles and responsibilities, by offering tools and strategies aimed at maximizing positive outcomes for children and families.

Check your progress I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the various definitions of parent education.

1.4 BENEFITS OF PARENT EDUCATION PROGRAM

Parent education programs have shown significant benefits for parents, caregivers, children, and families, such as the following (Wilder Research, 2016):

- More positive parenting style as a result of greater parental or caregiver understanding of child development and effective communication styles.
- Enhanced social connections as parents exchange ideas, provide and obtain support, and share resources.
- Improved child behavior: as children whose parents participate in these programs show greater pro-social behavior and less negative externalizing behaviors.
- Better quality parent-child interactions as a result of parents learning how to engage with their children
- Enhanced parental mental health and well-being, as improved skills and parenting knowledge help to reduce caregiver depression, anxiety, anger, guilt, and stress.

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- New way of thinking about appropriate family roles and expectations of children.
- Parental self-confidence and empowerment as care-giving skills progress and parents grow more competent and comfortable in their roles

1.4.01 Elements of Effective Parent Education Programs

Certain program characteristics and practices help make parent education programming successful. There is no “one-size-fits-all” approach. Programs have to be programmed to meet the community and cultural needs; have available staff and adequate resources; and, also offer individualized interventions for the parents and children at risk of potential or repeated maltreatment.

1.4.02 Roadmap for success of parenting programs and services

As stated by NASEM in 2016, the roadmap for success of parenting programs are-

- Providing parents with an opportunity to network with and receive support from parents who have been in similar circumstances.
- Efforts to engage both the parents in the parenting process
- Treating parents as equal partners in determining services that would be most beneficial for them and their children.
- Designing programs to meet the specific needs of families
- Addressing trauma to ensure that it does not interfere with parenting and healthy development.
- Ensure that families with multiple needs receive coordinated services.
- Collaborate with professionals in rehabilitation of children with special needs.
- Integrate community as a partner in raising children with special needs.

Check your progress- II

Note: A. Write your answer in the space given below.

B. Compare your answer with those given at the end.

i) Analyse the benefits of Parenting Education

1.5 NEED FOR PARENTING EDUCATION

No one person can claim to be an expert in all aspects of rearing children. There are no fast and hard rules that constitute an appropriate family environment and effective rearing technique for the development of well-adjusted, happy, and productive human beings. Providing education to parents in order to improve their parenting skills, has gained momentum during the last ten years.

While parenting may come naturally to some, others may need additional support and guidance to understand child development, to respond appropriately to their child’s needs, and to cope with the

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challenges of parenting. Parenting education improves parents' sense of self-efficacy and competency, as well as parental satisfaction. It also results in positive changes in parents' attitudes about parenting as well as their self-esteem and feelings of self-mastery with regard to parenting. Parenting education promotes the use of positive parenting practices, such as using positive language, planned discipline, and family routines. It also encourages nurturing behaviour and increase parents' knowledge of child development and communication styles.

Parent education programs focus on enhancing parenting practices and behaviours, such as developing and practicing positive discipline techniques, learning age-appropriate child development skills and milestones, promoting positive play and interaction between parents and children, locating and accessing community services and supports. Of all the modifiable factors that influence the course of a child's development, none is more significant than the quality of parenting a child receives.

Parenting education may be defined as any deliberate effort to help parents be more effective in caring for children. There are many different processes for educating parents, including group meetings, resource centres, newsletters, radio programs, home visits, mentoring, Internet resources, support groups, and books. The content of these different efforts varies substantially, ranging from behaviour-management approaches to relationship enhancement approaches. What the programs have in common is the conviction that parents play a vital role in the development of children and that it is possible to help parents be more effective through training and education.

1.5.01 People involved in Parenting

Another interesting question remains: can only a parent or parents provide these necessities? (We are leaving on one side for the moment the issue of which parent.) Clearly the answer has to be no. There are many people involved in parenting who is not a child's biological parent. For example:

- Stepparents
- Grandparents
- Aunts and uncles
- Siblings
- Friends
- Adopters
- Caretakers
- Child minders
- Teachers
- Childcare workers
- Nurses and doctors and
- Social workers and health visitors also play their role in parenting the children

There are organisations which care for children alongside or in lieu of their parents, for instance:

- Voluntary organizations, such as the Children's Society, NCH Action for Children

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- Independent communities, which provide residential care for children with exceptional physical, behavioral or emotional demands
- Local authorities, especially local authority social services departments are responsible for looking after children in foster care or residential settings.
- Corporate parents: This last group is sometimes called corporate parents, an organization or body of people acting as parents for some children.

Numerous studies suggest that the best-adjusted children are reared by parents who find a way to combine warmth and sensitivity with clear behavioural expectations. Parenting education programs offer multiple benefits to parents (and other primary caregivers) and children. Parents may develop new skills that can lead to increased competence and positive parenting practices, while children may indirectly benefit from changes or improvements in their parents' behaviour.

1.5.02 Four C's of Parenting

A high-quality parent-child relationship is critical for healthy development of physical, emotional and mental wellbeing of a child. The Four C's for rearing the children in a positive way are

- Care (showing acceptance and affection),
- Consistency (maintaining a stable environment),
- Choices (allowing the child to develop autonomy), and
- Consequences (applying repercussions of choices, whether positive or negative).

Check your progress- III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end

i) Analyse the need for Parenting education

ii) List out the people involved in parenting a child

1.6 IMPORTANCE OF PARENTING EDUCATION

Parenting education often results in more social connections among parents. Parents use these connections to exchange parenting advice, provide emotional support, and share resources. It also encourages nurturing behaviour and increase parents' knowledge of child growth and communication modes.

1.6.1 Key benefits of Parent Education

The benefits of parent education programmes are;

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- A. **Improves parental empowerment and competency:** Parenting education improves parents' sense of self-efficacy and competency, as well as parental satisfaction. It can also result in positive changes in parent's attitudes about parenting as well as their self-esteem and feelings of self-mastery regarding parenting
- B. **Increases positive parenting practices:** Parenting education promotes the use of positive parenting practices, such as; using positive language, planned discipline, and family routines. It also encourages nurturing behavior and increase parents' knowledge of child development and communication styles.
- C. **Increases social connections:** Often parenting education, results in more social connections among parents. Parents use these connections to exchange parenting advice, provide emotional support, and share resources. This can lead to more positive feelings about parenting overall.
- D. **Improves child behaviour:** Children of parents who participate in parenting education programs often demonstrate increases in their pro-social behaviors (e.g., empathy, sharing, helping others) and decreases in negative externalizing behaviors (e.g., aggression, delinquency, hyperactivity). Parents can make changes in their child's behavior after undergoing the training.
- E. **Improves parent-child interactions:** Parenting education programs can help improve communication skills between parents and children, and result in an overall better understanding between family members.
- F. **Improves parental mental health and well-being:** Parents may also experience short-term improvements in mental health, including a decrease in depression, anxiety, anger, guilt, and stress.
- G. **Decreases use of corporal punishment and risk of child abuse:** Parent education programs help parents learn alternatives to physical punishment

1.6.2 Best practices of Parenting Education

Research has found that the following strategies or practices used in parenting education programs are consistently associated with positive outcomes for families.

- A. **Actively engage parents**
Successful parenting programs provide opportunities for parents to practice the skills they are learning, either with a professional, at home, on-site with their child, or in a group context.
- B. **Early Intervention**
Programs directed at assisting new parents or parents of young children are better able to address a challenge early, which lays the level for more positive experiences later in life.

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C. Cultural Adaptive Programs

Effective programs adapt materials and other program elements to accommodate the unique needs and cultural tradition of the families they are serving. Programs that run over several months and meet at least weekly tend to have the best outcomes.

D. Promote family routines

Effective parenting programs emphasize the importance of family roles, regular family routines, and family activities.

E. Use skilled parent educators

Parents benefit most from programs that use trained parent education facilitators.

Check your progress- IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end

i) Examine the importance of parenting education

ii) Analyse the best practices of parenting.

1.7 CONCEPT OF PARENTHOOD AND PARENTING

“You’ll notice that there is a gap between pregnancy and parenting. It is called parenthood”. Ely Taylor, Author of Becoming Us

The parent is one who has begotten offspring, or one who occupies the role of a mother or a father. In Western societies, parenthood, with its respective obligations, rests strongly on biological relatedness. This is not the case in all societies: in some, a distinction is drawn between a biological parent and social parent, with the former producing the child and the latter bringing up the child and acting as a mother or father in an affective or legal a sense as biological parents are required to practice in Western order.

What is the point of parenthood? Parenthood is the state of being a parent. It involves the role; a person is taking, as a mother or father and as a co-parent with the partner. Parenthood entails changing identities, facing unrealistic expectations, taking care of oneself so that he/she can assume care of others, and working together with the partner to navigate the journey of becoming a parent. This concept focuses on relationships with the partner, family and friends, colleagues, the community, and most importantly oneself.

Being a parent is often depicted as the most difficult, yet most rewarding, experience a person can experience. There are many ways that a person can become a parent: giving birth, adoption, third party reproduction, fostering, etc.

1.7.01 Research on Nurture and Nature of Parenting

There is a long-standing assumption that parents assert a direct and powerful influence on their children through the process of socialization. Theory has saturated presumption on human development as well the influence of cultural belief systems.

This assumption has been challenged by researchers who highlight the role of biological influences on children's development. Behavioural genetic studies show that adopted children are more like their biological parents than their adoptive parents in basic characteristics such as personality, intelligence, and mental health. To boot, some scholars have criticised the emphasis on parenting by asserting that other elements, such as peer relationships, exert a strong influence on evolution. Researchers who examine the meaning of parenting emphasize several issues.

Foremost, in biologically related families, genetic and socialization influences are hard to distinguish. For example, a child who is musically talented may have inherited that tendency from parents who are also musically gifted. Those same parents would be likely to emphasize music at home, which makes it difficult to determine whether the musical child is a product of genetics, the environment, or both working together. If instead that child was adopted and is being raised by parents who are not musically inclined, the expression of that talent might take a different form or might be actively suppressed. Therefore, genetic strengths and vulnerabilities are often modified through experiences created by parents.

Second, the stream of influence between parents and children is bi-directional rather than unidirectional (e.g., from parent to child). A parent who is impatient may cause an infant to react with distress, but an infant who is constitutionally prone to distress may elicit impatience from the parent. Regardless of who has initiated the chain of events, parents and children often become locked into escalating cycles of action and reaction and as a result ends up with distress and impatience. Yet, parents are more mature and experienced than children, they run a more substantial part in setting up the initial interaction patterns and can more effectively induce change by changing their responses (e.g., responding with patience to the distressed infant).

Ultimately, parents play a substantial part in influencing the child's environments and thus get exposure to other agents that influence growth, such as peer relationships, married life and so on. For instance, parents make decisions around the neighbourhood in which the family resides, the schools that children attend, and many of the activities in which children engage; in these ways, parents expose children to certain matches and not others. Additionally, children are more likely to select friends who have similar interests and values, which are rooted primarily in early family experiences. In lieu of looking at it in a broad contextual factor, such as poverty and culture, are mediated by parents, equally in American psychologist Marc Bornstein's words, are the final common pathway to children's growth and stature, adjustment and success.

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Parents play a key role in children's development. Instruction on the parent-child relationship invariably points to two fundamental components of parenting that are systematically referred to child and youth outcomes:

- A supportive component, including passion, tenderness, and involvement, and
- A controlling factor, including preparation of structure to the environment, limit setting, monitoring, and supervision.

Specifically, Amato and Fowler (2002) suggest that children and adolescents do best when parents support them, spend quality time with them, avoid harsh punishment, and emphasize communication. The research literatures uncharacteristically refer to these dimensions as support and control that lays parenting literature in the dimensions of nurture and guidance, respectively. Overall, there is much evidence that higher levels of parental support or nurture combined with higher levels of behavioural control or guidance are related to more positive outcomes for children and families.

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1.7.02 Difference between Parenting and Parenthood

Let's learn about the difference between parenting and parenthood?

Parenting involves rearing a child from infancy to adulthood. It includes the techniques, methods, and skills used for raising a child. Learning how to bath, feed, and soothe a baby, facilitating cognitive, affective and psychomotor domains, ensuring mental and physical health of the child from infancy to adulthood is all part of parenting. Providing direction and instilling family values along with teaching consequences, discipline, and responsibility are also a part of parenting task.

Check your progress- V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end

i) Analyse the concept of parenthood

1.8 CHARACTERISTICS OF PARENTHOOD

Parenthood refers to motherhood and fatherhood that is, equated with the people who become the mothers and fathers of children. Therefore, a lot of the literature on parenthood focuses on the adults' experience of bearing children. Parenting, by contrast, might be taken to refer to the process whereby a kind of nurturing is provided for children.

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Parenting is derived from the verb to parent, meaning to provide care and bringing up children. As a verb, it is a neologism, that is, a new word. It is considered necessary since there is a need to challenge the former view that the term 'parent' always refers to one of two particular people. Both parents and parenthood are important concepts for developing a child in a holistic individual.

1.8.1 Child-caring

Caring for children involves various activities; attending the needs of the child, feeding them, protecting them, giving them social recognition, offering them education and values. Child-tending can be a better term, since it focuses on parental activities, not the sentiments that 'caring' may suggest.

The child-caring activities are in part defined by law, religion, and analogies with other employment. The law regards parents as their children's guardians from birth until adulthood at the age at which young people officially no longer call for parental protection or reinforcement. As a child-rearer, parents are traditionally compared to gardeners planting and tending saplings and offshoots, or to shepherds tending their flocks. On certain religious views, God the Creator appoints parents to protect the innocent souls and spiritual wellbeing of the children whom He entrusts to them.

One salient feature of child-caring is its temporal focus on a child's present need, especially those that involve continuous or frequent satisfaction. Previously, mothers are especially open to such critiques. They were taken to a strict standard often pictured by doting mothers serenely cradling a nursing child, or securely holding the hand of a yearling. Fathers are held to a lesser measure of care, perhaps because of stereotypes of masculinity that make them less suited for attentiveness, responsiveness, and patient tending of the helpless or dependent. But as now with both the parents working, the scenario has changed, and fathers have also been trained to handle and nurture their children.

1.8.2 Raising good children

Most parents form and guide their parental activities by ideas of what they want their children to grow in adulthood. They try to shape their growing child's character, values, and tastes to favour or exclude certain adult outcomes. Parenting a child, in short, is conjuring up an adult. In the child-raising process, parents are subject to various distinctive appraisals. They are evaluated to be realistic or unrealistic in their hopes for a child; open- or narrow-minded in the interests they allow or foster, or the lessons they instil; supportive or retarding of a child's development; skilfully guiding or relentlessly pushing a child in certain directions.

It is striking how many of these same assessments apply to teachers, but this should not be surprising. Parents are their children's earliest and often their most influential teachers in an assortment of matters; language, emotional expression, domestic sciences, moral and societal issues. To what extent, parents may control their children's education is, of course, a complex legal and moral issue. Some parents struggle with schoolteachers over books and themes they think morally

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subversive, or they try to supplement the standard "one-sided" curriculum. In some home, against their child's wish, parents may transfer their children from public to private school to prepare them for life in a special social class, or retire them from school altogether so that they can begin to get their allotted offices in a spiritual community. Once more, such parental efforts at developing their children may extend through a lifetime, prompted especially by emerging or persisting political and spiritual conflicts.

1.8.3 Parenthood as family-making

These first two parental concepts are child-centred, the first focused on the current demands of a child, the second along the adult prospects of a minor. But for many people, parental thoughts have a wider, longer family-focus on the family.

Such familial thoughts about parenthood reflect the fact that all births are familial events; a few children adopted into a family of parents and siblings, and first children have a larger family of grandparents, aunts and uncles, and cousins. And if death or separation deprives a child of immediate relatives, the children will nonetheless feel their presence through the narratives they are told or invent and the prayers they are instructed.

Parenthood is conceived as a family-making or enlarging has its own distinctive temporal features. Beginning a family receives a point in time, but the family one starts or enlarges may have no intended or foreseen end. Indeed, bearing children may be a means of making or continuing a family with no conclusion--for some people, a reassuring kind of immortality in the facial expression of death, or, at least, a possible perpetual continuity with subsequent generations.

In addition to these temporal features, parenthood as family-making carries distinctive spatial or topological features. Child-tending may require fences and shelter that protect children from the elements, animals, while child-rearing requires rooms and other offices for teaching, practice, study, and playful time-off. But for family-making and asserting, what matters most is a home.

Check your progress- VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end

i) List out the characteristics of Parenthood.

1.9 PARENT- CHILD RELATION

The term parent-child relationship refers to the unique and enduring bond between a caregiver and his or her child. To understand the parent-child relationship, we must look at the ways that parents and children interact with one another physically, emotionally, and socially. Many psychologists believe that the relationships between parents and children

are very important in defining who we become and how we connect to others and the universe.

1.9.1 Parent-Child Relationship Types

Parent-child relationships can be biological or adopted. Biological parents and children share genetic material, while adoptive parents and children usually do not. Adoptive parent-child relationship is most often legal agreements that make a permanent parent-child relationship. The relationship between parents and their children is important to count when discussing physical, cognitive, and social growth in children.

1.9.2 Parent-Child Relationship Theories

Theorists in developmental psychology examine the parent-child relationship as an important instrument in understanding how individuals get over time. Sigmund Freud thought that adult development was largely determined by the relationships that children share with their parents. Erik Erikson's psychosocial theory of evolution suggests that infants who have caregivers meeting their basic needs will grow into trusting adults, but infants whose needs are not met will develop feelings of mistrust in future relationships.

Other important theories on relationships between children and parents focus on parents as teachers. In other words, we are taught how to behave and relate to others through our relationships with our parents. Lev Vygotsky viewed parents as professionals and the child as an apprentice in learning. Albert Bandura's social learning theory likened parents to models who demonstrate behaviour that children then copy. For example, if we are hugged by our parents and see our parents being physically affectionate toward others, Bandura's theory would assume that we would become huggers too.

1.9.3 Ecological influences on parenting and child development

The demands of children change with the developmental milestones and parenting must be modified accordingly. For instance, an important developmental issue for an infant is attached, whereas a salient task for an adolescent is individualization.

Parenting is at its greatest degree of intensity during infancy and toddlerhood. In the first few years of life, children depend entirely on their caregivers, who decide most of the children's experiences. Caregivers decide, for instance, whether an infant is held, spoken to, or ignored and in what kinds of activities the toddler will engage. Because of the tremendous flexibility of the human nervous system during the early years, this period offers unparalleled opportunities for learning and growth, which are best defended by an enriched but not pressured environment.

Further, although some theorists argue that later experiences can completely alter children's developmental pathways, many asserts that the experiences over the first few years of life lay the foundation on which the rest of the development builds. Like compounding interest, the investment

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that warm, engaged, and sensitive caregivers make during the early years pays huge dividends toward a strong, self-confident child.

1.9.4 Influence of parent-child relationship at various developmental stages

In the beginning few months of life, parenting focuses on the preparation of basic maintenance, ideally from a tender and responsive primary care provider. The caregiver sensitivity to the child's cues helps the child learn basic regulation and predicts the security of the child's attachment to the caregiver, which becomes organized toward the end of the first year. In the second year of life, the utterly dependent infant becomes the passionately autonomous toddler, inviting increasing opportunities for discipline. Early and middle childhood brings new challenges as children move farther out into the world. School adjustment and peer relationships become central, and the children benefit from parents who are involved and supportive.

Adolescence, once characterized as a time of storm and stress, is now seen as a period of dynamic modification, merely one that most children (75.80 percent) navigate successfully. This period was once also characterized by a severing of ties between parents and their children. Contemporary studies, nevertheless, show that adolescents benefit from maintaining close and connected relationships with their parents even as they go toward greater independence. The American psychiatrist Lynn Ponton, a specialist in adolescent development, noted that risk taking is a normal component of the important exploration in which teens engage.

Parents play a critical role by encouraging their children to take positive risks, such as trying out for a sports team, running for a position in student government, or working on a special project. Adolescents engaged in a challenging but positive endeavour are less likely to be drawn to negative risk taking, such as alcohol and drug use.

Check your progress- VII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end

i) Examine the importance of parent-child relationship

1.10 KEY CONCEPTS OF PARENT EDUCATION

Parent education emphasizes these dimensions:

A. Social learning theory

The focus is on encouraging positive behavior through building the parent-child connection. Parents learn how to understand and respond to a child's cues so they can be more attentive to his or her needs. The resulting improvements in the child's behaviour in turn reinforce positive parental attitudes and lead to more successful parenting.

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B. Skills-based interventions and family system approaches

Parent education helps to improve child behaviour, parent-child relationship, and equip parents and caretakers with interventions to improve safety at home and recognize and respond to symptoms of trauma and other challenges of child rearing.

C. Training and consultation

Parent Education programs aim to help families to better understand children's emotions and needs, improve attachment between parent/caregiver and child, reduce problem behaviors in children, and enhance placement stability.

1.11 LET US SUM UP

In the globalised socioeconomic milieu, the progresses in scientific discipline and applied science have changed the cognitive affective perceptions and motivations of the individuals, families and social club at large. The emergence of individualism, materialism, and consumerism has run to the dissolution of the joint family system, degeneration of moral values and psychological alienation. Still, in such an arena, we necessitate to know more and more about child raising patterns. Child rearing practice is an innate process of raising, protecting, guiding and raising the child through its developmental phases. It is a synergistic interplay of nature and nurture between the parent and the child entangled with joys, sorrows and challenges.

Researchers who have focused most directly on patterns of child rearing practices have identified several major dimensions on which families differ and which seem to be important for the small fry. These admit the emotional spirit of the family, the reactivity of the parent to the minor, the way control is practised and the tone and quantity of communication. In this unit, we have analysed the meaning and need of parent education, concepts related to parenthood, diverse characteristics of parenthood and the significance of parent-child relationship in developing a child into a holistic individual.

1.12 UNIT END EXERCISES

- A. List out the significance of Parent Education.
- B. State the factors contributing for the holistic development of a child.
- C. Explain the ecological influences on parenting and child development.
- D. Analyze the characteristics of Parenthood.
- E. State the importance of Parent Education.

1.13 ANSWER TO CHECK YOUR PROGRESS

Parenting today must be considered in a wider setting. Parenting requires several interrelated functions related to the nurture, care, training and socialising of children.

Parenting helps children to acquire the social and emotional competencies they need to connect to others, including parents, siblings,

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extended family, peers, teachers, and eventually life- married people and employers.

Parenting education can be described as: “The purposive learning activity of parents who are attempting to change their method of interaction with their children for the purpose of encouraging positive behaviour in their children.

Parent education programs focus on enhancing parenting practices and behaviours, such as developing and practicing positive discipline techniques, learning age-appropriate child development skills and milestones, promoting positive play and interaction between parents and children, locating and accessing community services and supports. Of all the modifiable factors that influence the course of a child’s development, none is more significant than the quality of parenting a child receives.

Parenting education may be defined as any deliberate effort to help parents be more effective in caring for children. There are many different processes for educating parents, including group meetings, resource centres, newsletters, radio programs, home visits, mentoring, Internet resources, support groups, and books.

The content of these different efforts varies substantially, ranging from behaviour-management approaches to relationship enhancement approaches. What the programs have in common is the conviction that parents play a vital role in the development of children and that it is possible to help parents be more effective through training and education.

1.14 SUGGESTED READING

- Matthew R. Sanders, Alina Morawska, Handbook of Parenting and Child Development across the Lifespan, Springer International Publishing AG, part of Springer Nature 2018
- Ehrensaft, Diane, Mommies, Daddies, Donors, Surrogates: Answering Tough Questions and Building Strong Families, Guilford Press, 2005
- Pettle, S. and J. Burns. Choosing to Be Open: The Experiences of Parents Donor Conception Network, U.K, 2005
- Evans, J.L. (2006), ‘Parenting Programs: An Important Early Childhood Strategy’, Education for All Global Monitoring Report, UNESCO, Paris
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UNIT II

Structure

- 2.1 Introduction
- 2.2 Objectives
- 2.3 Historical Perspectives on Parenting
- 2.4 Variables imparting Parenthood
 - 2.4.1 Family Structure's influence on parenthood
 - 2.4.2 Psychological characteristics relating to parenthood
- 2.5 Theories of parenting
- 2.6 Qualities of a good Parenting skill
- 2.7 Parenting styles
 - 2.7.1.1 Baumrind parenting style
 - 2.7.1.2 Eleanor McCoy and John Martin parenting style
 - 2.7.1.3 Le Masters' five parenting style
- 2.8 Impact of Parenting Styles
 - 2.8.1 Social Class and Parenting Styles
- 2.9 Parenting tips
- 2.10 Let us sum up
- 2.11 Unit end exercises
- 2.12 Answers to check your progress
- 2.13 Suggested readings

2.1 INTRODUCTION

Parenthood is understood as a complex cultural phenomenon whose boundaries and content are formed through discourse. At the present time, parenthood can be considered as an observable fact that is actively being rethought and reconstructed. New values, meanings, comprehension and the fixation of new practices of parenting challenge the old and new emerging categories describing the experience of motherhood and fatherhood.

Educational scholars say that this process can be called a “turn to parenthood” during which the old notion of “parenthood” is being revised and filled with new content, this content primarily relates to the processes and outcomes of education and to the desire and willingness of parents to invest large resources in the development of their children [Daly, 2013]. This turn has been especially relevant in the past few decades.

Today, particularly in case of developing countries, there is a “parenting boom” characterized by the rapid growth in the number of activities targeted at the whole family, which in turn, increases the demand for psychological counselling and training for parents, epitomized by the growing number of books and journals on parenting issues. The coexistence of a large number of parenting models and

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parenting cultures requires parents to build their position actively. These models are not mutually exclusive, but rather overlap, making it difficult for parents to make any decision.

Further, in the unit, we will consider the main stages in the development of parental education. We will focus on the features of the modern parent programs and will offer guidelines for developing such programs. To develop some perspective on the topic of this chapter, let's first briefly consider the history of parenting education.

2.2 OBJECTIVES

Going through this unit, you will be able to

- Outline the historical Perspectives on Parenting
- Analyse the variables imparting Parenthood
- Organize the various Theories of parenting
- Discuss about the different Qualities of a good Parenting skill
- Relate Parenting styles with the past and present
- Propose mixed Parenting tips

2.3 HISTORICAL PERSPECTIVES ON PARENTING

Parent education as a phenomenon is very old. Prior to 1800 information on childcare was available to the American mothers from Europe. The first record of group meetings of parents in America dates from 1815 in Portland, Maine (Bridgman, 1930). Before 1820, mothers met regularly in study groups called "maternal associations" to discuss child rearing problems. These early groups were concerned about the religious and moral improvement of their children (Sunley, 1955).

Mother's Magazine was first published in 1832, Mother's Assistant in 1841, and Parents' Magazine ran from 1840 to 1850 (Sunley, 1955). These and other mass media efforts were begun and eventually foundered during the 1800's. In 1888 the Society for the Study of Child Nature was founded. This organization, known today as the Child Study Association of America, is the oldest organization in the United States to have a continuous parent education program from the time it began to the present.

Federal support for parent education predated private organizations' efforts to enter parent education activities on a large scale. Thus, in 1909 the first White House Conference on Child Welfare was held; the Children's Bureau was created in 1912; and in 1914 the Smith-Lever Act provided for 2,000 County Home Demonstration Agents as part of the Department of Agriculture; in 1917. "Homemaking" was defined as a basic vocation for women and educational provisions were implemented; and in 1918 the United

States Public Health Service began support for health-oriented programs of parent education (Brim, 1965).

Before the 1920's parent education was still primarily informal and unorganized, but as more parents began to ask for help, educators and social workers recognized the need for parent education and gradually began to collect and disseminate organized materials. *Preschool and Parent Education*, the twenty-eighth yearbook of the National Society for the Study of Education was published in 1929 and made available a valuable resource for parent education (White House Conference, 1932). Even as professional research and training declined, however, the extent of parent education continued to grow with support from public organizations. Agriculture, Education, and Mental Health have been the primary supporters of continuing parent education endeavours (Brim, 1965).

Parent education efforts have continued to expand from the late 1940's to the present, with both public and private participation from national to local levels. A variety of professionals and non-professionals teach in parent education programs under the patronage of mental health, schools and other associations using nearly every imaginable form of media

Decades of parenting research clearly identifies the important role of parents in promoting children's well-being. Children and adolescents are faced with opportunities and sometimes pressures to select destructive behaviours. Education for parents has undergone a number of changes in its development, which are discussed in this unit.

Check your progress I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the role of parenting education in rearing children

2.4 VARIABLES IMPARTING PARENTHOOD

The family is the first social institution where the child is nurtured. Parent senter into the bliss of parenthood with euphemistic notions of pleasant parent-child relationships and family bonding. While some of us are aware of what constitutes a healthy relationship, be it with a child or an adult, many of us are clueless of the subconscious patterns of control, abuse, and dysfunction that exist in families around us, sometimes, even our own.

A. Family Structure's influence on parenthood

The family is the most fundamental of society's institutions, for it is within the family setting that character, morality, responsibility, ability, and wisdom are nurtured best in children. There is a direct correlation between a family founded on a lifelong marriage and low incidences of crime, addiction, abuse, illness, and underachievement. Type of family also has a direct impact on parenthood.

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B. Cross-generational families or joint families

In cross-generational families, family members experience the high level of emotional bonding and closeness across generations. Grandparents, aunts and uncles provide important role models in the socialization of children. Children learn how to care and respect their elders. The saddle of parenthood is shared by others.

C. Nuclear Families

The individual nuclear family is a universal social phenomenon. It can be defined as “a small group composed of husband and wife and immature children who constitute a unit apart from the rest of the community.” (Duncan Mitchell in his “Dictionary of Sociology”). Couples prefer to have a nuclear family for being able to give individual attention to each child in the family. However, it has its own pros and cons when compared with a joint family. In this type of family, parenthood becomes the sole responsibility of the parents.

D. Single-Parent Families

Over the past 20 years single-parent families have become even more common than the so-called "nuclear family" consisting of a mother, father and children. Today we see all sorts of single parent families: headed by mothers, headed by fathers, headed by a grandparent raising their grandchildren. Life in a single parent household can be quite stressful for the adult and the children.

Members may unrealistically expect that the family can function like a two-parent family and may feel that something is wrong when it cannot. The single parent may feel overwhelmed by the responsibility of juggling caring for the children, maintaining a job and keeping up with the bills and household chores.

E. Adoptive/Foster Families

Adoption and long-term fostering are both situations which can provide a permanent home for a child, but there are some differences. Adoption is a process which legally removes the rights and responsibilities of the child's birth parent(s) and transfers them to adoptive parent(s). The child will lose all rights of inheritance from their birth family and will take the surname of their adoptive family. Parents must take moral responsibility of parenting the child with care and responsibility.

F. Co-Parent Families or Never-married parents

Not all co-parents are divorced. In fact, co-parents never had to be married in the first place to share parenting responsibilities after separating. Never-married parents face similar challenges to parents going through a divorce, yet some issues are even more complex in a never-married parenting situation. Never-married parents may face certain obstacles.

NOTES**G. Blended Families**

The simple definition of a blended family, also called a stepfamily, reconstituted family, or a complex family, is a family unit where one or both parents have children from a previous relationship, but they have combined to form a new family. Conflicting family values and responsibilities arises among each family member about daily chores, appropriate behavior, and other expectations.

A social etiquette difficulty between the non-involvement of biological parent and the new stepparent, in serving as a role model for the child lays stress on the family. Stress on the biological parents when balancing the needs of their children and the new partner(s), particularly where values may conflict.

Check your progress -II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i). What is meant by Adoptive/Foster Families?

2.4.2 Psychological characteristics relating to parenthood

Every family and every child are unique in its own way. There are various types of psychological characteristics related to parenthood. They are:

A. Mental health status

Parents' mental health status is often directly correlated with parenting styles. As can be seen, parents affected with psychological distress may treat their own children with hostility and rejection. Such parents may adopt harsh disciplinary rules and probably make use of physical punishment. Moreover, depressed parents do not show proper sentiments or emotions towards their children or their feelings about parenting responsibilities are assumed negative. These parents may have low self-esteem, reduced self-efficacy, negative emotions, more anger, and distress, as well as negative worthlessness to themselves or negative attitudes towards their parenting abilities which have an impact on the trust between parents and children.

B. Negative parenting

Such parents may use harassment of their children as the first choice of parenting, or parents' interactions with children and their parenting may be accompanied by excessive control and rejection. One of the serious problems in the domain of parents' mental health affecting parenting can be schizophrenia. In this regard, it has been shown that children that have schizophrenic parents grow up with many environmental stressors, such as parental dysfunction.

C. Parenting stress.

One of the factors associated with parents' characteristics is parenting stress. Parenting stress arises when parenting demands exceed the actual resources available to parents that permit them to succeed in

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parenting. Accordingly, parents with higher parenting stress are more rejectionists and less protective. Greater parenting stress tends to use more punishment and less affection toward children. Stresses affecting parenting also include child-rearing stress as well as a sense of being restrained due to the presence of children.

D. Personality traits

Parental personality traits are among the most important factors influencing parenting styles. According to the existing literature, the personality traits of extraversion, conscientiousness, agreeableness, and openness to experience can be accompanied by greater intimacy in parenting styles and a neurotic personality trait can be seen in less intimate parents. Parents with agreeable personality traits, due to their ability to obtain more social support and avoid social conflicts, generally are less likely to develop depression. Agreeable parents also try to have flexible and child-centered parenting.

E. Childhood trauma

The history of physical, sexual, or emotional abuse among parents in their childhood is considered as a risk factor leading to negative parenting styles. In this respect, perceived childhood maltreatment towards parents can influence creating interpersonal problems including interactions with their own children. It is also a risk factor for subsequent emotional defects, which can result in a series of interpersonal difficulties such as distrust, uncertainty, and avoidance of intimate relationships.

F. Marital satisfaction

Among the parental characteristics contributing to parenting styles is marital satisfaction. In this respect, parents with satisfactory marital relationships are said to exhibit positive behaviors with their children. Conversely, when parents are dissatisfied with marital relationships, negative emotions and behaviors can be transferred through parent-child interactions. Marital conflict as a stressor can affect couples and increase their anger.

G. Parents' attachment style

Parental characteristics including their attachment style and family conditions in the past such as stress or supportive relationships in their immediate family can determine their parenting styles. People with secure attachment styles towards their own parents consider their relationships, whether positive or negative, clear, consistent and coherent. These parents have more intimate parenting style and they are responsive to their children. However, parents with insecure or anxious attachment in their childhood can have pervasive anger as well as lower intimacy and participation in their current relationships with their children. These problems can have long-term consequences in mental health and interpersonal relationships in terms of parenting.

H. Self-efficacy

Parents with higher self-efficacy are endowed with more self-confidence in order to achieve effective parenting skills and competence

and they are also likely to have more success with positive parenting. Parental self-efficacy may affect parenting satisfaction and such an impact on coping ability can be positive.

I. Perfectionism

Perfectionism is a parental characteristic and a personality trait. Accordingly, perfectionist parents try to be perfect and unflawed. They are extremely critical of themselves and their behaviors. These parents similarly consider wishes and goals they could not reach for themselves and apply their own standards to the children. Moreover, these parents may show their love for their children when children act in accordance with parents' expectations. In order to maintain their self-esteem, they also put more pressure on their children to avoid failures, characterizing authoritarian parenting styles.

J. Perceived parenting style

Individuals that have loving and responsive childhood with no severe restrictions on them are endowed with healthy socio-emotional development; they also have high self-esteem and internalized control. As a result of emotional security, behavioral independence and social competence created in them can lead to the formation of a healthy personality and personal maturity and these people can rely more on others. Eventually, these individuals have active interactions as well as more intimacy and acceptance towards their children in the future and ultimately adopt a positive parenting style.

K. Substance abuse

Substance abuse is considered as a factor affecting parenting. Substance abuse is also recognized as a risk factor for maltreatment of children and may cause the use of violence. Marital problems, as well as psychological disorders of substance-abusing individuals, are related to poor parenting.

L. Begetting a child with Developmental and mental disabilities

Illnesses and disabilities of children can cause emotional distress in parents, which may lead to psychopathology, such as more anxiety, in both parents. This mental disorder can also result in negative and inappropriate parenting styles. For example, children with disabilities such as Down's syndrome may have more behavioral problems than children without this disability, and their parents overprotect them, which can lead to improper parenting.

M. Child temperament

Child temperament such as negative emotions, maladjustment, and anger can make it difficult to care for children. It can also undermine parents' performance particularly in childhood and their behavior may become more hostile lacking love and affection. Parents of children with a difficult temperament also have higher parenting stress and psychological problems, such as feeling negative about their parenting.

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N. Anxiety

Anxiety disorder in children may lead to the adoption of a negative parenting style, such as more control. For example, a study revealed that parenting was significantly correlated with children's anxiety disorder. Such a disorder, regardless of the level of anxiety in parents, is associated with a less intimate relationship with children.

Check your progress -III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i). State how Parents' attachment style influence child development.

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2.5 THEORIES OF PARENTING

There is no single "theory of parenting," although in the social-work literature social systems theory, Erikson's stage of generativity, Bronfenbrenner's work on human development, Vygotsky theories, and Adlerian theory are invoked. Attachment theory is commonly used to understand the importance of parenting and is cited in relationship to parents and children in the child welfare system.

The twentieth century witnessed a dramatic growth in efforts to develop and empirically validate early theories of child socialization. The two major theoretical perspectives in psychology in the early twentieth century, behaviourism and psychoanalytic theory, had much to say about parental socialization methods.

Psychoanalytic theory saw parents as importantly influencing children's success in negotiating psychosexual stages of development (oral, anal, phallic, latency, and genital), which in turn was believed to exert a strong (and irreversible) influence on later personality.

2.6 QUALITIES OF A GOOD PARENTING SKILL

The child-parent relationship has a major influence on most aspects of child development. When optimal, parenting skills and behaviours have a positive impact on children's self-esteem, school achievement, cognitive development and behaviour... Decades of research reveal nine essential parenting skill sets.

- a) Love and affection
- b) Stress Management
- c) Relationship skills
- d) Autonomy and Independence
- e) Education and learning
- f) Life skills
- g) Behavior management
- h) Health
- i) Safety

NOTES**Check your progress -IV**

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the qualities of Good Parenting skill.

2.7 PARENTING STYLES

A parenting style describes a certain set of behavioral, psychological, philosophical and moral strategies that parents use in their efforts of raising their child. Sometime these strategies are very conscious, have been critically examined and specifically chosen.

"There is no one universally accepted "best" style of parenting," writes author Douglas Bernstein in his book *Essentials of Psychology*.

Good parenting is parenting that prepares children to meet the demands of the specific culture or subculture in which they live. We can nonetheless draw some conclusions about the ingredients of good parenting that will apply in most settings. We can go far in understanding which parenting styles are effective to prepare the children to meet the society. Darling and Steinberg (1993) defined parenting style as overall climate of parent child interactions. It is an affective context of sorts that sets the tone for the parent's interactions with the child. Parenting style is a determinant factor in child development. It affects psychological and social functioning of the children.

Parenting style is largely being affected by the influence of one's own parents. Temperament, educational achievement, culture, socioeconomic status and the influence of their spouse affects parenting style as well. Temperament of the parent and the child affects style of parenting, and the mother and father may differ in style as well (Belsky, 2005). Let's take a closer look at each of the parenting styles and the impact they can have on a child's behaviour.

2.7.1.1 BAUMRIND PARENTING STYLE

Baumrind in 2001 identified three patterns of parenting styles namely:

A. Authoritarian Parenting

In authoritative style of parenting, children are expected to follow the strict rules established by the parents. Failure to follow such rules usually results in punishment. Authoritarian parents don't explain the reasoning behind these rules. If asked to explain, the parent might simply reply, "Because I said so."

While these parents have high demands, they are not very responsive to their children. They expect their children to behave exceptionally and not make errors, yet they provide very little direction about what their children should do or avoid in the future. Mistakes are

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punished, often quite harshly, yet their children are often left wondering exactly what they did wrong.

According to Baumrind, these parents "are obedience- and status-oriented and expect their orders to be obeyed without explanation". Parents who exhibit this style are often described as domineering and dictatorial. Their approach to parenting is one of "spare the rod, spoil the child." Despite having such strict rules and high expectations, they do little to explain the reasoning behind their demands and simply expect children to obey without question.

B. Authoritative Parenting

Like authoritarian parents, those with an authoritative parenting style establish rules and guidelines that their children are expected to follow. However, this parenting style is much more democratic. Authoritative parents are responsive to their children and willing to listen to questions. These parents expect a lot of their children, but they provide warmth, feedback, and adequate support.

When children fail to meet the expectations, these parents are more nurturing and forgiving rather than punishing. Baumrind suggested that these parents "monitor and impart clear standards for their children's conduct. They are assertive, but not intrusive and restrictive. Their disciplinary methods are supportive, rather than punitive. They want their children to be assertive as well as socially responsible, and self-regulated as well as cooperative." It is this combination of expectation and support that helps children of authoritative parents develop skills such as independence, self-control, and self-regulation.

C) Permissive Parenting

Permissive parents sometimes referred to as indulgent parents, have very few demands to make of their children. These parents rarely discipline their children because they have relatively low expectations of maturity and self-control.

According to Baumrind, permissive parents "are more responsive than they are demanding. They are non-traditional and lenient, do not require mature behaviour, allow considerable self-regulation, and avoid confrontation. "Permissive parents are generally nurturing and communicative with their children, often taking on the status of a friend more than that of a parent.

2.7.1.2 Eleanor Maccoby and John Martin Parenting Style- Uninvolved Parenting

Psychologist Eleanor Maccoby and John Martin proposed a fourth style that is known as uninvolved or neglectful parenting. An uninvolved parenting style is characterized by few demands, low responsiveness, and very little communication.

While these parents fulfil the child's basic needs, they are generally detached from their child's life. They might make sure that their children have food and shelter but offer little to nothing in the way of guidance,

structure, rules, or even support. In extreme cases, these parents may even reject or neglect the needs of their children.

2.7.1.3 E. E. Le Masters' Five-Parenting Style

E. E. Le Masters' listing of five parenting styles: the martyr, the pal, the police officer, the teacher-counsellor, and the athletic coach. Individual parents probably combine elements of two or more of these styles in their own personal Parenting styles.

The Martyr	The Police Officer	The Pal
Parents will do anything for their child. They always do what the children want them to do.	Parents make sure the child obeys all the rules at all times, and they punish their children for even minor offences.	They are friends to their children. They adopt a laissez-faire discipline policy, and allow their children setting their own goals, rules and limits, with little or no guidance from parents.

The Teacher Counsellor	The Athletic Coach
This model conceptualises the parents as almost omnipotent in guiding children's development. If they do the right things at the right time, their children will more than likely be happy, intelligent and successful.	The coach (parent) is expected to have sufficient ability and knowledge of the game (life) and to be prepared and confident to lead players (children) to do their best and it is hoped, to succeed.

The outcomes of any given parenting style on any given child depends on many factors that interact with each other, including the child's age, sex, and temperament.; the parents' personality characteristics, personal history, economic circumstances, and the like; the needs of all the family members; and the values of the culture.

Check your progress V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Evaluate the E. E. Le Masters' Five Parenting Style

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2.8 IMPACT OF PARENTING STYLES

What effect does the above said parenting styles have an impact on child development outcomes?

- Authoritarian parenting styles generally lead to children who are obedient and proficient, but they rank lower in happiness, social competence, and self-esteem.
- Authoritative parenting styles tend to result in children who are happy, capable, and successful.
- Permissive parenting often results in children who rank low in happiness and self-regulation. These children are more likely to experience problems with authority and tend to perform poorly in school.
- Uninvolved parenting styles rank lowest across all life domains. These children tend to lack self-control, have low self-esteem, and are less competent than their peers.
- The parent as martyr face some problems like, the goals the martyring parents set are impossible to carry out and the parent always feel guilty. The parent as pal style points out that there are some relationship risks.

Of course, the parenting styles of individual parents also combine to create a unique blend in each family. For example, the mother may display an authoritative style while the father favors a more permissive approach.

This can sometimes lead to mixed signals or even situations where a child seeks approval from the more permissive parent to get what they want. In order to create a cohesive approach to parenting, it is essential that parents learn to cooperate as they combine various elements of their unique parenting styles. These parenting styles might also not be necessarily universal. Cultural factors also play an important role in parenting styles and child outcomes.

2.8.1 Social Class and Parenting Styles

The ideas that parents have about parenting and the ways in which parents perform their parenting functions differ across socioeconomic strata. Parents from different socioeconomic strata rear their children differently, partly in response to the different circumstances in which they live as well as ways of interacting with the world, including their children.

Socioeconomic status (SES) remains a topic of great interest to those who study children's development. This interest derives from a belief that high SES families afford their children an array of services, goods, parental actions, and social connections that potentially redound to the benefit of children and a concern that many low SES children lack access to those same resources and experiences, thus putting them at risk for developmental problems (Bradley and Carwyn, 2002). Parenting styles are shaped in part by socioeconomic factors. Middle class and lower-class

parents often pursue different goals and emphasize different values in raising their children.

Parents from lower socioeconomic groups may quite sensibly emphasize obedience to authority figures because their job demands it. Middle- and upper-class parents may reason with their children and stress individual initiative, curiosity and creativity more because these are the attributes that count for business executives, professionals, and other white-collar workers. Both middle- and lower-income parents have devised styles of parenting that are well adapted to the distinctive demands of their socio-cultural setting.

Society often assumed that parenting came naturally, and parents just knew what to do when it came to discipline, nurturing, toilet training, esteem building and so forth. This perception is slowly changing. Today's parents are quicker to acknowledge that they don't always have the answers or that they may not want to raise their children as they were raised. Societal changes have made it more difficult to rely on parenting techniques from the past. The pace of social change is increasing as India opens to western influences. The rapid pace at which these changes occur, leave children facing issues their parents never dreamed of.

The root cause of most of the mental health problems of children and adolescents are related with parenting styles adopted in their families. So, the parents should be more aware of the different parenting styles and their impacts on child development. The impact on social change on childhood and parenting styles needs to be further examined. Nowadays the parenting styles are different from those early existed ones. At early times the lower- and working-class parents tend to stress obedience and respect for authority, be more restrictive and authoritarian, more frequently using power assertive discipline and show less warmth and affection. Meanwhile the upper and middle class followed the authoritative or permissive parenting styles. However, the modern families are giving more freedom and relaxed discipline practices to their children irrespective of their income.

Parenting style overlap depending upon several factors, such as the number of children, the unique personalities of the parents and child, parents' attitudes and the structure of the family (Schwartz and Scott, 1994). The parenting style needs change according to the societal changes. Awareness regarding parenting style is very important in modern parenting. Parenting style is an important factor in child development. Socio-emotional development of the child is influenced by the type of parenting style used in families. Parents, teachers and the mental health professionals must give more importance to the parenting styles and the parenting practises.

Check your progress V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is meant by SES?

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2.9 POSITIVE PARENTING TIPS

Positive parenting is an approach built on mutual respect. According to author Debbie Godfrey, positive parenting techniques are “for parents who want to discipline their children without breaking their spirit.” Parenting means diverse things to dissimilar people. Research classifies competence and skills required in parenting as follows:

- **Parent-child relationship skills:** quality time spent positive communications and delighted show of affection.
- **Encouraging desirable behavior:** praise and encouragement, nonverbal attention, facilitating engaging activities.
- **Teaching skills and behaviors:** being a good example, incidental teaching, benevolent communication of the skill with role-playing and other methods, communicating logical incentives and consequences.
- **Managing misbehavior:** establishing assertive ground rules/limit setting, directed discussion, providing clear and calm instructions, communicate and enforce appropriate consequences for problem behaviour, using restrictive means like quiet time and time out with authoritative stance but not authoritarian.
- **Anticipating and planning:** advanced planning and preparation for readying the child for challenges, finding out engaging and age appropriate developmental activities, preparing token economy for self-management practice with guidance, holding follow-up discussions, identifying possible negative developmental trajectories.
- **Self-regulation skills:** Monitoring behaviors (own and children's), setting developmentally appropriate goals, evaluating strengths and weaknesses and setting practice tasks for skills improvement, monitoring & preventing internalizing and externalizing behaviors, setting personal goals for positive change.
- **Mood and coping skills:** reframing and discouraging unhelpful thoughts (diversions, Goal orientation, and mindfulness), stress and tension management (for self and in the house), Developing personal coping statements, and plans for high-risk situations, developing mutual respect and consideration between members of the family, positive involvement: engaging in support and strength oriented collaborative activities/rituals for enhancing interpersonal relationships.
- **Partner support skills:** improving personal communication, giving and receiving constructive feedback and support, avoiding negative family interaction styles, supporting and finding hope in problems for adaptation, collaborative or leading/navigate problem solving, promoting relationship happiness and cordiality. Consistency is considered the “backbone” of positive parenting skills and “overprotection” as the weakness.

2.10 LET'S SUM UP

In this unit, we have learnt the History of parenting that clearly identifies the important role of parents in promoting children's well-being. Children and adolescents are faced with opportunities and sometimes pressures to select destructive behaviours. Parenting education improves parents' sense of self-efficacy and competency, as well as parental satisfaction. It can also result in positive changes in parents' attitudes about parenting as well as their self-esteem and feelings of self-mastery with regard to parenting. It often results in more social connections among parents. Parents use these connections to exchange parenting advice, provide emotional support, and share resources. This can lead to more positive feelings about parenting practise.

Children of parents who participate in parenting education programs often demonstrate increases in their pro-social behaviours (e.g., empathy, sharing, helping others) and decreases in negative externalizing behaviours (e.g., aggression, delinquency, hyperactivity).

Parenting education programs can help improve communication skills between parents and children, and result in an overall better understanding between family members. what to do when it came to discipline, nurturing, toilet training, esteem building and so forth. This perception is slowly changing. Today's parents are quicker to acknowledge that they do not always have the answers or that they may not want to raise their children as they were raised.

Societal changes have made it more difficult to rely on parenting techniques from the past. The pace of social change is increasing as India opens up to western influences. The rapid pace at which these changes occur, leave children facing issues their parents never dreamed of. The root cause of most of the mental health problems of children and adolescents are related with parenting styles adopted in their families. So, the parents should be more aware of the different parenting styles and their impacts on child development. Despite of the high importance of this issue, research on parenting in India is sparse (Sharma, 2003). ‘

The impact on social change on childhood and parenting styles needs to be further examined. Nowadays the parenting styles are different from those early existed ones. At early times the lower- and working-class parents tend to stress obedience and respect for authority, be more restrictive and authoritarian, more frequently using power assertive discipline and show less warmth and affection. Meanwhile the upper and middle class followed the authoritative or permissive parenting styles. However, the modern families are giving more freedom and relaxed discipline practices to their children irrespective of their income.

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2.11 UNIT END EXERCISES

1. Trace the history of parent education programme.
2. Analyze the influence of Family Structure's on parenthood.
3. Evaluate the various parenting styles.
4. Analyze Baumrind Parenting Style.
5. Analyze the impact the parenting styles
6. State the relationship between social class and parenting styles.

2.12 ANSWERS TO CHECK YOUR PROGRESS

Parent education efforts have continued to expand from the late 1940's to the present, with both public and private participation from national to local levels. A variety of professionals and non-professionals teach in parent education programs under the patronage of mental health, schools and other associations using nearly every imaginable form of media.

Adoption and long-term fostering are both situations which can provide a permanent home for a child, but there are some differences. Adoption is a process, which legally removes the rights and responsibilities of the child's birth parent(s) and transfers them to adoptive parent(s). The child will lose all rights of inheritance from their birth family and will take the surname of their adoptive family. Parents must take moral responsibility of parenting the child with care and responsibility.

Parental characteristics including their attachment style and family conditions in the past such as stress or supportive relationships in their immediate family can determine their parenting styles. People with secure attachment styles towards their own parents consider their relationships, whether positive or negative, clear, consistent and coherent. These parents have more intimate parenting style and they are responsive to their children. However, parents with insecure or anxious attachment in their childhood can have pervasive anger as well as lower intimacy and participation in their current relationships with their children.

The child-parent relationship has a major influence on most aspects of child development. When optimal, parenting skills and behaviors have a positive impact on children's self-esteem, school achievement, cognitive development and behavior. Decades of research reveal nine essential parenting skill sets: Love and affection, Stress Management, Relationship skills, Autonomy and Independence, Education and learning, Life skills, Behavior management, Health and Safety.

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Socioeconomic status (SES) remains a topic of great interest to those who study children's development. This interest derives from a belief that high SES families afford their children an array of services, goods, parental actions, and social connections that potentially redound to the benefit of children and a concern that many low SES children lack access to those same resources and experiences, thus putting them at risk for developmental problems.

2.13 SUGGESTED READINGS

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Structure

- 3.1. Introduction
- 3.2 Objectives
- 3.3 Role of Culture and Tradition in Parenting
 - 3.3.1 The Culture-Parenting Nexus
 - 3.3.2 Culture-Specific Parenting
- 3.4 Contemporary Families
 - 3.4.1 Features of Contemporary Families
 - 3.4.2 Diversity in Contemporary families
 - 3.4.3 Distribution of parenting roles
 - 3.4.4 Parenting Stress associated with Contemporary families
- 3.5 Family systems Theory
 - 3.5.1 Family Life cycle
 - 3.5.2 Stages of Family Life cycle
- 3.6. Systemic Family Development Theory
 - 3.6 .1 Common developmental process in families
- 3.7 Common Developmental Process in Families
- 3.8 Family Ecology Theory (Brofenbenner) and Parenting
- 3.9 Let us sum up
- 3.10 Unit end exercises
- 3.11 Answers to check your progress
- 3.12 Suggested Readings

3.1 INTRODUCTION

Every culture is characterized, and distinguished from other cultures, by deep-rooted and widely acknowledged ideas about how one needs to feel, think, and act as a functioning member of the culture. Parenting experiences vary considerably by culture, tradition, gender and social category. People may consider parenthood as “accomplishing a moral duty”.

Vygotsky argues that human knowledge is rooted in culture, which means children derives customary information from their families, such as, how to celebrate the holidays; how to appreciate elders, food; and how to behave in the public places. On many social occasions, children’s behaviours are generally based on their parents’ expectations and demands. Values and ideals of a culture are carried to the succeeding generation through child-nurturing patterns. Thus, children in different cultural contexts are being trained by their parents to behave culturally appropriately. In this sense, it is necessary to take into consideration the importance of culture when evaluating parenting behaviours.

“Cultural models of individualism and collectivism” can bring direct as well as indirect impacts on parenting behaviours. “Its direct influence on parenting behaviour could be explained by drawing on the values of a polish to their youngsters to get productive and integrated members of their culture”; its indirect influences on parenting behaviour

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are via “more societal forces such as speech patterns and customs, and economic structure indirectly. To this extent, parents can unite up their parenting with those direct and indirect cultural effects. This unit will have a discussion of the effect of culture in determining parenting.

3.2 OBJECTIVES

Going through this unit, you will be able to

- Delineate the role of Culture and Tradition in Parenting
- Analyse the variables imparting Parenthood in Contemporary Families
- Categorize the various Theories of the family system
- Discuss about the different Common Developmental Process in Families
- Relate Family Ecology Theory (Bronfenbrenner) and Parenting

3.3 ROLE OF CULTURE AND TRADITION IN PARENTING

Culture is often visualized as a set of distinctive patterns of beliefs and behaviours that are adopted by a group of people that serve to standardize their daily living. These beliefs and behaviours determine the way parents rear their children. This unique pattern of care giving inherited from the community is the principal reason behind the difference in parenting styles. Culture helps to construct and transmit parental cognitions that in turn are thought to shape parenting practices (Bornstein & Lansford, 2010). Children’s experiences with their parents within a cultural context consequently shape them to become culturally competent members of their society.

Care giving by the parents is based on indigenous cultural belief systems and behaviour patterns. Indeed, culturally constructed beliefs can be so powerful that parents are known to act on them, setting aside, what their senses might tell them about their own children.

In India, the family is a central unit of social existence and the socialization of children is a key function. Cultural scripts, parents own experiences, family situations and location guide parenting and familial practices. Parents' beliefs and ethnos theories contain explicit and implicit ideas about the manner in which children ought to be raised. With increasing global interaction and urban movement, the urban family is continually faced with the challenge of keeping up with the fast pace of change. Such change exerts tremendous pressure on the ethos of the family as well as on parenting goals and motivations.

Family, directly and indirectly, reflects the state of society and the conditions that society creates for it. In the course of the last twenty years, changes have been noticed in the context of the transformation of the whole society, which were not noticed in decades before. According to

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Fukuyama, all of the serious problems that accompany the transformation of society in recent years (such as individualisms, society's dynamics, including the shifts in standards and values, liberalisms, consumerist style of life, etc.) have mostly affected the aspects of

- a) Reproduction,
- b) Family, and
- c) Relationships between a man and a woman.

One of the significant impacts of the social changes in the family life is its disintegration. The living of the contemporary family is often described as "living next to each other" rather than "living together". There are a growing number of families where the individual members only encounter, correspond, or cease to communicate with each other at all.

All parents have some idea about the way children ought to be raised, about what they feel must be an essential part of their children's lives, about the goals and values that they consider important about children and childhood. These culturally shared ideas that parents have about children and their development are referred to as beliefs. They include parental explanations and understandings of everyday events, childcare customs and choices and are often implicit, "taken for granted ideas" about the "right" way to think or act.

3.3.1 The Culture-Parenting Nexus

There is a definite need and significance for a cultural approach to parenting science. Descriptively it is invaluable for revealing the full range of human parenting. The study of parenting across cultures also furnishes a check against an ethnocentric world view of parenting. Parental ideas or beliefs have been labeled differently by researchers: parental cognitions, psychology of the caretaker, beliefs or belief orientations, naive theories, ethnic theories (Sigel, 1992). Each of these refers to the cognitive domain of parenting behavior; parents thinking about parenting; the naive psychology that influences what parents do.

Parental beliefs are of value because they acknowledge the cognition of parents and recognize them as thinking beings. Additionally, these beliefs guide parental behavior and activity. Because of their link with parental goals and values, parental beliefs influence developmental outcomes directly or indirectly. Parents' beliefs are expressed in the way the everyday lives and activities of children are organized; these routine activities are the visible representations that serve to convey beliefs to both parents as well as children. In their model of the developmental niche, Super and Harkness (1986) refer to the culturally determined customs and practices followed by parents as the "cultural septs" for parenting. Parenting needs to be considered in its socio-cultural context, and this study provides the variability necessary to expose the process.

3.3.2 Culture-Specific Parenting

The main goal of cultural approaches to parenting is to evaluate and compare culture-common and culture-specific modes of parenting. Culture-

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specific influences on parenting begin long before children are born, and they shape fundamental decisions about which behaviors parents should promote in their children and how parents should interact with their children. Thus, care giving varies among cultures in terms of opinions about the full range of care giving and child development, including the significance of specific competencies for children's successful adjustment, the ages expected for children to reach developmental milestones, when and how to care for children, and the like.

Many parenting cognitions and practices are likely to be similar across cultures. Even though, they vary in form and the degree to which they are shaped by experience and influenced by culture. Parenting might reflect inherent attributes of care giving, or they could be a by-product of information dissemination via the forces of globalization or mass media or migration, socialization models, issues, and challenges.

In the end, all parents must help children meet similar developmental tasks, and all people wish to have physical health, social adjustment, educational achievement, and economic security for their children. For example, social learning theorists have identified the pervasive roles that conditioning and modeling, play as children acquire associations that subsequently form the basis for their culturally constructed selves. By watching or listening to others who are already embedded in the culture, children try to replicate our model the behavior.

Attachment theorists propose that children develop internal working models of social relationships through interactions with their primary caregivers and that these models shape children's future social relationships with others throughout the balance of the life course. With so much emphasis on identification of differences among peoples, all the parents, regardless of culture seek to lead happy, healthy, fulfilled parenthoods and to rear happy, healthy, fulfilled children.

Check your progress I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i). Discuss about Parenting beliefs.

ii) Analyse the role of culture in determining parenting practises

3.4 CONTEMPORARY FAMILIES

Families are the most controversial social institutions (Gilding 1997). Each of us has connections to a 'family'. A contemporary family is any family living in the current time period. Families are changing in many ways across the Organisation for Economic Cooperation and Development (OECD) countries and its enhanced-engagement partners. Most countries have seen a decline in the fertility rate over the past three decades. As a result, the average household size has also declined over this period. At the same time, there has been a sharp increase in the proportion of women entering the labour force.

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The evidence on trends in child well-being is mixed, and important challenges remain. Family formation patterns are also changing. Increasingly, both men and women want to first establish themselves in the labour market before founding a family. Hence, the age of mothers at first childbirth has risen and with it the probability of having fewer children than previous generations.

3.4.1 Features of Contemporary Families

Contemporary issues and transitions taking place in the larger society as well as in families are discussed below. Considering the exercise of parenting, married, separated, remarried, and single and, more recently, homosexual-parent families, there are an increasing number of parents who are confused and ambivalent regarding their parental duties. The contemporary family is relational and structured on the mutual recognition of people who live together (Singly, 2015). In addition, parental authority is challenged, and the child is promoted to a new position inside this dynamic system.

In contemporary times, families are raising children in diverse and unique ways. Single parents are experiencing role strain as they juggle between their finances, household chores, and childcare responsibilities. Blended families experience confusion regarding their roles and gradually learn how to communicate expectations to one another. Homosexual parents have to decide who the primary caretaker should be and how they should negotiate traditional roles and responsibilities.

The process of socialization in the family is connected with the overall socio-psychological climate in the family. According to Cherrie, 2008, the culture of parenting includes four basic aspects: the family atmosphere, family cohesion, communication within the family, and process of learning.

3.4.2 Diversity in Contemporary families

Contemporary families are inclusive of single parent families, blended families, stepfamilies and homosexual families to name a few. To define the concept of the family as consisting of one pattern of attributes leads to controversial discussions pertaining to the ideologies of marriage, divorce, sex and children. The family is no longer a concept that can be contemplated within an essentialist notion, rather the concept of the contemporary family has evolved into a fluid ideology that is constantly shifting and changing throughout society. Summing up the problems in the functioning of contemporary families, a classification of the variants of types of dysfunctional families according to J. Kucírek is suggested as:

- Asymmetrical family of type A (a father, mother, and one child, in a coalition against the second child/children).
- Asymmetrical family of type B (a father or mother in a coalition with all the children against the other parent).
- Generation gap (a strong bond between the father and mother – child/ children are strongly marginalized).

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- Uncommitted family (a family with indifferent relationships, without bonds or family cohesion).
- Non-integrated family (chaotic relationships, conflicts, lack of cohesion, hostility within the family, none of the family members have responsibility).
- Schismatic family (two coalitions, one child with father, the other child with mother, or father in coalition with daughter and mother with son).
- Family with unclear intergenerational borders (children are being manipulated into inappropriate roles and parents temporarily pose themselves as “friends”).
- Externally integrated family (immature parents who are dependent on the social and economic support of their families and social services, and also children dependent on their parents).
- Socially closed family (excessive cohesion in families, disrupted contacts with the outer world because of the risks of society).
- Repressive family (anxiously neurotic, perfectionists; a family who refuses to give vent to negative feelings so that they can be transformed into a variety of somatic or mental symptoms).
- Pseudo-democratic family (even relationships between parents and children, generational boundaries, loss of parental authority)
- The disintegration of family life affects mainly the children. They experience the absence of a stable background the most.

3.4.3 Distribution of parenting roles

In connection with the issue of parental roles' organization in contemporary families, the following three models of distribution of roles within the family are stated by Marikova:

- The most common model is the one, which may be described as: “most things are up to the woman “. Even though men engage in the child's upbringing and care in this model, they function as helpers to women (mothers), not as equal partners. In principle, they hold the traditional view that caring for a child is primarily a matter of its mother. They take part in it only if needed, or when they want to.
- In a part of families, there is still a fairly conservative model of childcare, which might be described as: “everything is up to the woman “. She spends the most time with the children; the major share of the responsibility for the children's upbringing rests on her shoulders.
- The least common model is the partnership model, where the parents' involvement in the care for the child and its upbringing is relatively the most balanced. The men are convinced that they

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should actively participate in the care for the children and the running of the household, and they do so.

3.4.3 Parenting Stress associated with Contemporary families

Families are increasingly experiencing a wide variety of stressors associated with both positive and negative events. Advances in technology, industrialization, urbanization, increased population density (including housing, traffic, and demand on the infrastructures), terrorism, and economic issues are frequently identified as making daily life more complicated and impersonal. Family roles are more fluid and diverse than the past, resulting in fewer social norms and supports.

Families have become more diverse as a result of changing family structures (e.g., divorce, single-parent families, LGBTQ families, remarriage, cohabitation, and intergenerational reciprocity), immigration, economics (e.g., increased cost of living and two earner families), geographic mobility, and other macro level factors. In addition to natural disasters (e.g., hurricanes, tornadoes, earthquakes) and everyday stressors (e.g., accidents, discrimination based on race, religious beliefs, gender, and sexual orientation).

Predictable family problems would include those stresses that are inherently stressful, even though they are foreseen. Unpredicted problems include physical or mental illness, death, substance abuse, war, violence, economic insecurity, divorce, and remarriage. Many of these problems are interrelated and often combine to produce stress-related responses.

Contemporary families are experiencing economic insecurity and stress due to the Great Recession and the severe economic downturn in the global economy. The mismatch between the work environments that family members inhabit, and the needs of contemporary families creates a context in which every day hassles emerge and multiply (Perry-Jenkins et al., 2013). The policies most effective at improving family wellbeing take a holistic approach by integrating service delivery, prevention programs, universal high-quality services, and programs that are flexible to families' needs.

Check your progress -II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Discuss about the role of parents in contemporary families

ii) List out the four basic cultural aspects of parenting

3.5 FAMILY SYSTEMS THEORY

The UNESCO report stated that a family is a kinship unit and that even when its members do not share a common household, the unit may exist as a social reality. Desai (1994), defined the family as a unit of two or

more persons united by marriage, blood, adoption, or consensual union, in general consulting a single household, interacting and communicating with each other.

Families can be classified in several different dimensions, for example, by marriage type (monogamous, polygamous), by location (patrilocal, matrilineal, and avunculocal), authority (patriarchy, matriarchy), and by kin composition (nuclear, joint).

According to Burgess and Locke, "Family is a group of persons united by the ties of marriage, blood or adoption; that consist a single household, interacting and intercommunicating with each other in their social roles of husband and wife, mother and father, son and daughter, brother and sister creating a common culture".

A. What Is Family Systems Theory?

Family systems theory is a concept of looking at the family as a cohesive emotional unit. According to the FST, family members are intensely emotionally connected. Psychiatrist Murray Bowen developed the family systems theory. Concerning the family systems theory, Dr. Bowen was described as "one of those rare human beings who had a genuinely new idea."

B. Family Systems Theory Definition

The family systems theory states that a family functions as a system wherein each member plays a specific role and must follow certain rules. Based on the roles within the system, people are expected to interact with and respond to one another in a certain way. Patterns develop within the system, and each member's behaviors impact the other members in predictable ways. Depending on the specific system, these behavioral patterns can lead to either balance or dysfunction of the system- or both, at various points in time.

C. Why Is Family Systems Theory Important?

According to Dr. Bowen's theory, even when people may feel they are disconnected from members of their family, the family still has a profound impact on their emotions and actions- whether positive or negative. And, a change in one person sparks a change in how other members of the family unit act and feel as well. Though the degree of interdependence can vary between different families, all families have some level of it among the members.

Dr. Bowen believes that perhaps humans evolved to be interdependent on family members to promote cooperation among families that are necessary for things like shelter and protection. But, in stressful situations, the anxiety that one person feels can spread among family members and the interdependence becomes emotionally taxing rather than comforting.

Life has become more impersonal as human connections are replaced by virtual relationships. Industrialization and urbanization have expanded, leading to denser living environments and the associated stressors of expensive housing, traffic congestion, and increased cost of living. Extended longevity is offering the benefit of more time with family

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members yet there are added costs (e.g., chronic and degenerative illness, care giving demands, health care costs). Based on multiple indications, the stress and change that families are experiencing appear to be intensifying.

Stressors inherent to daily life include the discrimination families often face based on race, religious beliefs, gender, and sexual orientation as well as the unpredictable yet stressful events of ongoing natural disasters including hurricanes, tornadoes, storms, floods, and earthquakes. With the blurring of gender roles and the increased diversity in family structure, the basic conceptualization of “family” has evolved. Although the family system may still be viewed as a “haven” from external stressors, families are also challenged to meet their increasingly complicated needs.

3.5.1 Family Life cycle

Family life cycle stages are a theoretical framework to describe the formation, maintenance, change, and dissolution of marital and family relations. The concept of the life cycle was originally developed for individuals and was then extended to an aggregate, the family, in influential articles published in the 1930s. The life cycle for a family includes three major phases.

- The first, family formation extends from marriage to the birth of the first child.
- The second phase, family development, consists of extension as children are born and contraction as they leave home.
- The third phase, family dissolution, extends from the death of the first spouse to the death of the second spouse.

As originally formulated, the concept of a family life cycle was crucially linked to the nuclear family, the events of marriage and childbearing, and a presumed continuity of membership. Later social scientists broadened the definitions of the family and its phases and avoided restrictive or normative definitions that require formal marriage or childbearing. Many individuals never marry, many couples never have children, and many couples divorce and remarry with or without children. It is common to encompass these broad variations under the rubric of the life course, rather than the life cycle, for families as well as for individuals.

3.5.2 Stages of Family Life cycle

The emotional and intellectual stage, ever parent passes through from begetting their child till their age of retirement is termed as family life cycle. The family life cycle stage perspective is probably the most famous part of the family development theory (Rodgers & White, 1993). The classification table lists eight stages of the family life cycle:

- a. Beginning families (married couples without children)
- b. Childbearing families (oldest child, birth to 30 months)
- c. Families with preschool children (oldest child 2½–6 years)
- d. Families with school children (oldest child 6–13)

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- e. Families with teenagers (oldest child 13–20)
- f. Families as launching centers (first child gone to the last child's leaving home)
- g. Families in the middle years (empty nest to retirement)
- h. Aging family members – retirement to death of both spouses.

The concept of family life cycle uses a development framework to explain peoples' behavior in families. Families change over time in terms of both the people and the roles they play. The key factor in terms of the developmental tasks of family is the presence of children.

The family organizes itself around its child rearing responsibilities. Family systems theory also assists in assessing the nature of a relationship by examining the interactions that occur between individuals. Interactional processes such as triangles, coalitions, pattern, redundancy, multiple levels of meaning, and observer-imposed punctuation can be observed as family systems theory enables these relationship processes to be conceptualized.

Check your progress -III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Classify the various dimensions of family

ii) What is meant by family life cycle?

3.6. SYSTEMIC FAMILY DEVELOPMENT THEORY

Systemic family theory and therapies pay close attention to repeating transactions that connect the problem behaviour of one person with the behaviour of other people within the family or other primary group.

In 1926, pioneer sociologist Ernest Burgess described the systemic family development as a "unity of interacting personalities". In his observation, he discovered that family time serves an important role in the family system. A family systemic function is expressing two family members' emotional needs and wants for personalities, which summarizes that family members are dynamic developing changing individuals.

A family systemic approach means that each member of the family has an equal chance of being nurtured while the individual is still developing their emotional needs/wants. While the idea of unity among interacting personalities says that a family is a dynamic system that changes within as well as outside the family's setting depending on the impact that the stress/change has on the family.

Systemic family theory and therapies pay close attention to repeating transactions that connect the problem behaviour of one person with the behaviour of other people within the family or other primary

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group. In contrast to individually oriented theories of behaviour, which focus on what is happening inside the individual as a primary point of reference, family systems theory intentionally shifted from a lineal causal to a circular conception of causality that connects the problem behaviour of one person with the surrounding behaviour of the other family members.

This intentional shift in primary data from the individual to observable behavioural exchanges between members of the family makes explicit the quid pro quo quality of such repeating transaction exchanges such that the nature of the self-perpetuating pattern in which problem behaviour is manifested becomes observable. These repeating patterns of interaction are the focus of family systems theory.

Check your progress - IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Discuss about the dimensions of family.

ii) Analyse the term family life cycle.

3.6 .1 Common developmental process in families

According to Bowen, a family is a system in which each member had a role to play and rules to respect. Members of the system are expected to respond to each other in a certain way according to their role, which is determined by relationship agreements. Within the boundaries of the system, patterns develop as certain family member's behaviour is caused by and causes other family member's behaviours in predictable ways. Maintaining the same pattern of behaviours within a system may lead to balance in the family system, but also to dysfunction. For example, if a husband is depressive and cannot pull himself together, the wife may need to take up more responsibilities to pick up the slack. The change in roles may maintain the stability in the relationship, but it may also push the family towards a different equilibrium. This new equilibrium may lead to dysfunction as the wife may not be able to maintain this overachieving role over a long period of time.

There are eight interlocking concepts in Dr. Bowen's theory:

- **Triangles:** The smallest stable relationship system. Triangles usually have one side in conflict and two sides in harmony, contributing to the development of clinical problems.
- **Differentiation of self:** The variance in individuals in their susceptibility to depend on others for acceptance and approval.
- **Nuclear family emotional system:** The four relationship patterns that define where problems may develop in a family.
 - Marital conflict
 - Dysfunction in one spouse
 - Impairment of one or more children

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➤ Emotional distance

- **Family projection process:** The transmission of emotional problems from a parent to a child.
- **Multigenerational transmission process:** The transmission of small differences in the levels of differentiation between parents and their children.
- **Emotional cut-off:** The act of reducing or cutting off emotional contact with family as a way managing unresolved emotional issues.
- **Sibling position:** The impact of sibling position on development and behaviour.
- **Societal emotional process:** The emotional system governs behaviour on a societal level, promoting both progressive and regressive periods in a society.

The concepts of family systems theory not only apply to families but non-family groups such as workers in an office. Even outside of the family, emotional processes influence behaviour and lead to progressive and regressive periods in society.

Check your progress -IV

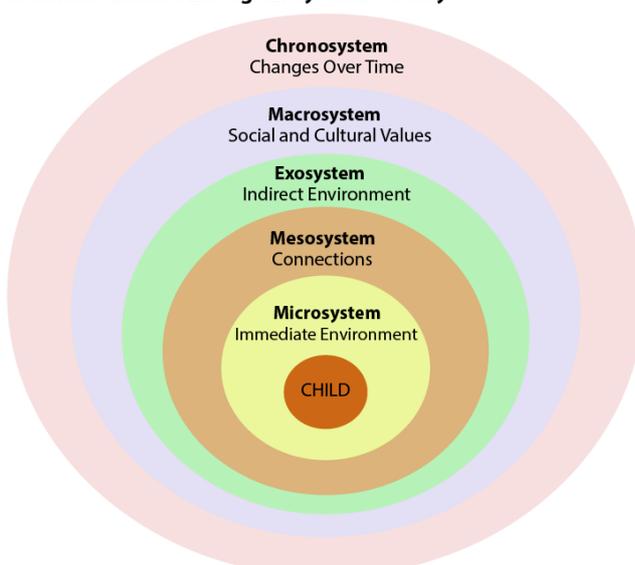
Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is meant by family systemic theory?

3.7 FAMILY ECOLOGY THEORY (BROFENBENNER) AND PARENTING

Bronfenbrenner's Ecological Systems Theory



(C) The Psychology Notes Headquarters <https://www.PsychologyNotesHQ.com>

American psychologist, Urie Bronfenbrenner, formulated the Ecological Systems Theory to explain how the inherent qualities of children and their environments interact to influence how they grow and develop. The Bronfenbrenner theory emphasizes the importance of studying children in

Self-instructional material

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multiple environments, also known as ecological systems, in the attempt to understand their development.

According to Bronfenbrenner's Ecological Systems Theory, children typically find themselves enmeshed in various ecosystems, from the most intimate home ecological system to the larger school system, and then to the most expansive system which includes society and culture. Each of these ecological systems inevitably interacts with and influences each other in all aspects of the children's lives.

Bronfenbrenner's ecological model organizes contexts of development into five levels of external influence. These levels are categorized from the most intimate level to the broadest.

A. The Bronfenbrenner Ecological Model: Microsystems

The Bronfenbrenner theory suggests that the Microsystems are the smallest and most immediate environment in which children live. As such, the Microsystems comprise the daily home, school or daycare, peer group and community environment of the children.

Interactions within the Microsystems typically involve personal relationships with family members, classmates, teachers and caregivers. How these groups or individuals interact with the children will affect how they grow. Similarly, how children react to people in their Microsystems will also influence how they treat the children in return. More nurturing and more supportive interactions and relationships will understandably foster they children's improved development.

One of the most significant findings that Urie Bronfenbrenner unearthed in his study of ecological systems is that it is possible for siblings who find themselves in the same ecological system to experience very different environments. Therefore, given two siblings experiencing the same Microsystems, it is not impossible for the development of them to progress in different manners. Each child's personality traits, such as temperament, which is influenced by unique genetic and biological factors, ultimately have a hand in how he/she is treated by others.

B. The Bronfenbrenner Ecological Model: Mesosystem

The mesosystem encompasses the interaction of the different Microsystems which children find themselves in. It is a system of Microsystems and as such, involves linkages between home and school, between peer group and family, and between family and community.

C. The Bronfenbrenner Ecological Model: Exosystem

The exosystem pertains to the linkages that may exist between two or more settings, one of which may not contain the developing children but affect them indirectly, nonetheless.

D. The Bronfenbrenner Ecological Model: Macrosystem

The macrosystem is the largest and most distant collection of people and places to the children that still have significant influences on them. This ecological system is composed of the children's cultural

patterns and values, specifically their dominant beliefs and ideas, as well as political and economic systems.

E. The Bronfenbrenner Ecological Model: Chronosystem

The Bronfenbrenner theory suggests that the chronosystem adds the useful dimension of time, which demonstrates the influence of both change and constancy in the children's environments. The chronosystem may include a change in family structure, address, parents' employment status, as well as immense society changes such as economic cycles and wars.

By studying the various ecological systems, Bronfenbrenner's Ecological Systems Theory can demonstrate the diversity of interrelated influences on children's development. Awareness of the contexts that children are in can sensitize us to variations in the way children may act in different settings.

Check your progress - V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) How is Bronfenbrenner's Ecological Systems Theory classified?

3.8 LET US SUM UP

One way to conceptualize the process of caring for the next generation is to ask what families do for or contribute to their children to promote healthy child development and children's ability to form culturally appropriate family ties in adulthood. Parents contribute shared genes and a family environment in which the types of time and money investments parents make in their children depend, in part, on what parents believe will help their children have a good life.

Cultural factors and belief systems, including religious beliefs, affect parents' understanding of how to meet children's needs. Child-rearing practices also depend on the children's own characteristics. For instance, parents may spend more time with children who are having trouble with schoolwork than with their siblings who complete school assignments effortlessly. Although parents, especially those who live with their offspring, are vitally important factors affecting children's welfare, they are not the only relevant actors.

A key issue, considering the high incidence of divorce and non-marital childbearing and childrearing, is the role of such factors as non-biological parents and nonresident parents. In addition, grandparents, other kin, and unrelated actors and institutions, include peers, schools, neighborhoods, and media, also influence children's development. Theory and research on child rearing and child well-being must consider the *linked lives* of parents, children, and other kin and must acknowledge that these relationships occur in a family system. For example, a mother's psychological state affects how she spends time with children, her child-rearing practices, the quality of her relationship with the children's father,

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and, as a result, the father's relationship with the children. In addition, parents' mental health may be a function of children's health as well as a determinant of child outcomes, including the quality of the relationships they form in adulthood.

3.9 UNIT END EXERCISES

1. Analyse the significance of culture and tradition in Parenting
2. Explain the various dimensions of family system theory
3. Comprehend Family ecology theory in current context

3.10 ANSWERS TO CHECK YOUR PROGRESS

Parental beliefs influence developmental outcomes directly or indirectly. Parents' beliefs are expressed in the manner in which the everyday lives and activities of children are organized; these routine activities are the visible representations that serve to convey beliefs to both parents as well as children.

Parenting cognitions and practices are likely to be similar across cultures. Even though, they vary in form and the degree to which they are shaped by experience and influenced by culture. Such patterns of parenting might reflect inherent attributes of care giving, or they could be a by-product of information dissemination via the forces of globalization or mass media or migration, socialization models, issues, and challenges.

The contemporary family is relational and structured on the mutual recognition of people who live together (Singly, 2015). In addition, parental authority is challenged, and the child is promoted to a new position inside this dynamic system. In contemporary times, families are raising children in diverse and unique ways.

Families can be classified in several different dimensions, for example, by marriage type (monogamous, polygamous), by location (patrilocal, matrilocal, and avunculocal), authority (patriarchy, matriarchy), and by kin composition (nuclear, joint).

Family life cycle stages are a theoretical framework to describe the formation, maintenance, change, and dissolution of marital and family relations.

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The emotional and intellectual stage, every parent passes through from begetting their child till their age of retirement is termed as family life cycle.

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developing their emotional needs/wants. While the idea of unity among interacting personalities says that a family is a dynamic system that changes within as well as outside the family's setting depending on the impact that the stress/change has on the family.

According to Bronfenbrenner's Ecological Systems Theory, children typically find themselves enmeshed in various ecosystems, from the most intimate home ecological system to the larger school system, and then to the most expansive system which includes society and culture.

3.10 SUGESTED READING

- Amato, P. R. (2004). Divorce in social and historical context: Changing scientific perspectives on children and marital dissolution. In M. Coleman & L. Ganong (Eds.), *Handbook of contemporary families: Considering the past, contemplating the future* (pp. 265–281). Thousand Oaks, CA: Sage
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UNIT IV

Structure

- 4.1. Introduction
- 4.2 Objectives
- 4.3 Developmental Theories and their application to Parenting
 - 4.3.1 Erikson's theory of psychosocial development
 - 4.3.2 Lev Vygotsky Social Development Theory
 - 4.3.3 Jean Piaget's Theory of Cognitive Development
- 4.4 Evolving Concepts of Parenthood
 - 4.4.1 Behaviour problems
 - 4.4.2 Transition to Parenthood
 - 4.4.3 Adjusting to Parenthood
 - 4.4.4 Parenting in Adoptive Family Systems
- 4.5 Stages of Parenting
- 4.6 Modern parenting styles
- 4.7 Let us sum up
- 4.8 Unit end exercises
- 4.9 Answers to check your progress
- 4.10 Suggested Readings

4.1 INTRODUCTION

Until the 19th century, parents raised their children based much on their instinct and the influence of their own parents. Or, if they had a trouble in upbringing, they raised their children the opposite of how they were raised.

In 1958, the first known use of the word “parenting” occurred. It remained an uncommon word until sometime in the 1980s when “parenting” gained momentum as a verb and became something parents *do* instead of something they *are*. Parents' perceptions of their role are not only affected by their own developmental experiences, changes, and needs, but also by their changing, growing, developing child. For example, children need continuous care as infants, but as they grow their parental needs change. Thus, parents of infants spend a good deal of time tending to their children by feeding, diapering, cuddling, and holding. As infants become toddlers and then preschoolers, their developmental needs change and parents increasingly focus their efforts on encouraging, guiding, and supervising child exploration.

Parental awareness of their child's developmental changes and corresponding needs, not to mention each child's unique characteristics, is tempered by the ongoing yet evolving parent-child relationship. For instance, family dynamics such as spousal or partner conflict over issues can affect parents' interactions with their children as well as their parenting perceptions. In addition, the broader social-cultural context also influences parents' views of their parenting role; parents' religious orientation, for example, potentially affects parents' perceptions of their role as well as associated parenting activities (Levine, 2003).

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The child-parent relationship has a major influence on most aspects of child development. When optimal, parenting skills and behaviors have a positive impact on children's self-esteem, school achievement, cognitive development and behavior. In this unit, we are going to discuss about the various theories associated with child development and their application to parenting practices.

4.2 OBJECTIVES

On completion of this unit, the students will be able to

- Analyze various developmental theories and their application to Parenting
- Understand the application of Erikson's theory of psychosocial development
- Understand the application of Lev Vygotsky Social Development Theory
- Understand the application of Jean Piaget's Theory of Cognitive Development
- Comprehend the evolving concepts of Parenthood
- Recognize the various stages of Parenting

4.3 DEVELOPMENTAL THEORIES AND THEIR APPLICATION TO PARENTING

Parents play an important role in the overall development of their child. Appropriate guidance and care of the parents scaffolds the child into a blossoming individual. Parenting is a never-ending job. It is not something you can get away after few years; it is a lifelong process from marriage to tomb. All development is interrelated and cannot be defined under one water-tight category. So, let us focus on how parents can actively participate to ensure that the child's growing years are commendable. The role of parents in child development is responsive, responsible and never-ending. It governs responses, actions, thinking and decision making of a child from infancy to adulthood in the areas of; Cognitive Development, physical development, socio-cultural development, mental and spiritual development. In this chapter, we will learn about the various theories of development and the role of parents in the development of their child.

4.3.1 Erikson's Theory of Psychosocial Development

Erik Erikson, a German psychoanalyst heavily influenced by Sigmund Freud, explored three aspects of identity: the ego identity (self), personal identity (the personal idiosyncrasies that distinguish a person from another, social/cultural identity (the collection of social roles a person might play)

Erikson defined the parent-child interaction as central to early childhood development at multiple stages. The family is the most important social setting until age five, according to this theory. That

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precious relationship between the parent and the child has a major influence on the child's development. Erikson's psychosocial theory of development considers the impact of external factors, parents and society on personality development from childhood to adulthood.

According to Erikson's theory, every person must pass through a series of eight interrelated stages over the entire life cycle.

1. Infancy: Birth to 18 Months Old: Basic Trust vs. Mistrust – Hope

During the first or second year of life, the major emphasis is on the mother and father's nurturing ability and care for a child, especially in terms of visual contact and touch. The child will develop optimism, trust, confidence, and security if properly cared for and handled. If a child does not experience trust, he or she may develop insecurity, worthlessness, and general mistrust to the world.

2. Toddler / Early Childhood Years: 18 Months to 3 Years - Autonomy vs. Shame – Will

The second stage occurs between 18 months and 3 years. At this point, the child has an opportunity to build self-esteem and autonomy as he or she learns new skills and right from wrong. The child, who is cared by the parents, carries himself or herself with pride rather than shame. Children tend to be vulnerable during this stage, sometimes feeling shame and low self-esteem during an inability to learn certain skills.

3. Preschooler: 3 To 5 Years: Initiative vs. Guilt – Purpose

During this period, the child experiences a desire to copy the adults around us and take initiative in creating play situations. The child begins to make up stories with Barbie's and Ken's, toy phones and miniature cars, playing out roles in a trial universe, experimenting with the blueprint for what we believe it means to be an adult. The child also begins to use that wonderful word for exploring the world—"WHY?"

While Erikson was influenced by Freud, he downplays biological sexuality in favor of the psychosocial features of conflict between child and parents. Nevertheless, he said that at this stage we usually become involved in the classic "Oedipal struggle" and resolve this struggle through "social role identification."

4. School Age Child: 6 to 12 Years: Industry vs. Inferiority – Competence

During this stage, often called the Latency, the child is capable of learning, creating and accomplishing numerous new skills and knowledge, thus developing a sense of industry. This is also a very social stage of development and if we experience unresolved feelings of inadequacy and inferiority among our peers, we can have serious problems in terms of competence and self-esteem. As the world expands a bit, our most significant relationship is with the school and

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neighborhood. Parents are no longer the complete authorities they once were, although they are still important.

5. Adolescent: 12 to 18 Years Identity vs. Role Confusion – Fidelity

Up until this fifth stage, development depends on what is done to a person. At this point, development now depends primarily upon what a person does. An adolescent must struggle to discover and find his or her own identity, while negotiating and struggling with social interactions and “fitting in,” and developing a sense of morality and right from wrong.

Some attempt to delay entrance to adulthood and withdraw from responsibilities (moratorium). Those unsuccessful with this stage tend to experience role confusion and upheaval. Adolescents begin to develop a strong affiliation and devotion to ideals, causes, and friends.

6. Young Adult: 18 to 35 -Intimacy and Solidarity vs. Isolation – Love

At the young adult stage, people tend to seek companionship and love. Some also begin to “settle down” and start families, although seems to have been pushed back farther in recent years.

Young adults seek deep intimacy and satisfying relationships, but if unsuccessful, isolation may occur. Significant relationships at this stage are with marital partners and friends.

7. Middle-Aged Adult: 35 to 55 Or 65 - Generativity vs. Self-Absorption or Stagnation

Career and work are the most important things at this stage, along with family. Middle adulthood is also the time when people can take on greater responsibilities and control. For this stage, working to establish stability and Erikson’s idea of generativity attempts to produce something that makes a difference to society. Inactivity and meaninglessness are common fears during this stage. Major life shifts can occur during this stage. Significant relationships are those within the family, workplace, local church and other communities.

8. Late Adult: 55 Or 65 to Death -Integrity vs. Despair – Wisdom

Erikson believed that much of life is preparing for the middle adulthood stage and the last stage involves much reflection. As older adults, some can look back with a feeling of integrity — that is, contentment and fulfillment, having led a meaningful life and valuable contribution to society. Others may have a sense of despair during this stage, reflecting upon their experiences and failures. They may fear death as they struggle to find a purpose to their lives, wondering “What was the point of life? Was it worth?”

According to Erikson, the main motivation of human is social nature and reflects a desire to connect with others. He gives more emphasis on developmental changes that occur in all human life. The quality of

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child and parent relations influences the development of competence in a long period of time to develop social skills and appropriate emotions.

Erikson states it is critical that parents allow their children to explore the limits of their abilities within an encouraging environment which is tolerant of failure.

Check your progress I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i) List out the eight stages of Erickson

4.3.2 Lev Vygotsky Social Development Theory

Russian psychologist Lev Vygotsky theory is one of the founders of constructivism. The work of Lev Vygotsky has become the groundwork of much research and theory in cognitive development over the past several decades, particularly of what has become known as Social Development Theory.

Vygotsky theories stress the fundamental role of social interaction in the development of cognition, as he believed strongly that community plays a central role in the process of "making meaning. "Unlike Piaget's notion that children's' development must necessarily precede their learning, Vygotsky argued, "learning is a necessary and universal aspect of the process of developing culturally organized, specifically human psychological function". In other words, social learning tends to proceed (i.e., come before) development.

Vygotsky has developed a socio-cultural approach to cognitive development. Social interaction plays a fundamental role in the process of cognitive development. He states: "Every function in the child's cultural development appears twice: first, on the social level, and later, on the individual level; first, between people (inter-psychological) and then inside the child (intra-psychological).

a) First aspect of interaction

Vygotsky believed everything is learned on two levels. First, through interaction with others, and then integrated into the individual's mental structure. Every function in the child's cultural development appears twice: first, on the social level, and later, on the individual level; first, between people (inter-psychological) and then inside the child (intra-psychological). This applies equally to voluntary attention, to logical memory, and to the formation of concepts. All the higher functions originate as actual relationships between individuals.

b) First aspect of interaction

A second aspect of Vygotsky theory is the idea that the potential for cognitive development is limited to a "zone of proximal development"

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(ZPD). This "zone" is the area of exploration for which the student is cognitively prepared but requires help and social interaction to fully develop (Briner, 1999). A teacher or more experienced peer can provide the learner with "scaffolding" to support the student's evolving understanding of knowledge domains or development of complex skills. Collaborative learning, discourse, modeling, and scaffolding are strategies for supporting the intellectual knowledge and skills of learners and facilitating intentional learning.

Vygotsky developed a theory based on the interaction of children with their environment, specifically with people in their environment. He placed a large emphasis on both culture and language. One aspect of Vygotsky theory is scaffolding, which involves a more experienced person teaching a less experienced person how to do something.

However, parents can also incorporate this concept at home. Helping teenagers on tasks that they are struggling with or providing a way for them to receive help can allow them to reach their full potential. For example, students struggling in a subject should have parents willing to get tutoring for their child. Parents should scaffold activities when possible, such as learning to drive, writing college essays, and how to be a good worker.

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is meant by zone of Proximal development?]

4.3.3 Jean Piaget's theory of cognitive development and their application to parenting

Swiss psychologist Jean Piaget (1896-1980) believed that children's intellectual development occurs in stages. Children learn how to interact with the world by moving through four distinct phases, Piaget theorized. During this time, they master certain skills gradually, rather than all at once, or in some cases, not at all.

Jean Piaget's theory of cognitive development suggests that children move through four different stages of mental development. His theory focuses not only on understanding how children acquire knowledge, but also on understanding the nature of intelligence.

Piaget's four stages of development are:

- a) Sensorimotor stage: birth to 2 years
- b) Preoperational stage: ages 2 to 7
- c) Concrete operational stage: ages 7 to 11
- d) Formal operational stage: ages 12 and up

Piaget's stage theory describes the cognitive development of children. Cognitive development involves changes in cognitive process and

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abilities. In Piaget's view, early cognitive development involves processes based upon actions and later progresses to changes in mental operations. Through his observations of his children, Piaget developed a stage theory of intellectual development that included four distinct stages:

Jean Piaget won the Erasmus Prize, awarded for contributions to European culture, for his theory of cognitive development and its four stages: Let us have a deep understanding of the various stages as enumerated by Piaget:

1. Sensorimotor Stage

In the earliest stage of development, children experience six substages of spatial and sensory learning and growth.

a) The first substage – the reflex schema stage – occurs during the first six weeks of life. This stage is characterized by the development of three key reflexes: sucking, following moving objects with the eyes and grasping of objects placed in his palm.

b) The second substage takes place between 6 weeks and 4 months of age. According to Gruber, this is the circular or reaction stage when infants begin to repeat motions that will become habits, such as moving a hand or foot in a similar movement from time to time. Passive reactions, called classical or operant conditioning, emerge at this stage too.

c) The secondary circular reactions stage occurs when the infant is between 5 months and 9 months old. Coordination begins to develop between comprehension and vision. Three new skills become evident. One is the repeated reaching for an object. The second is a secondary repeating motion respecting an external object, such as dropping a rattle repeatedly.

d) What Piaget believed to be the seeds of intelligence, or the coordination between means and ends, starts the fourth substage. Goal orientation reveals a baby's primitive planning to reach desired results.

e) The tertiary reactions phase in the fifth substage is established between 12 months and 18 months. The child learns to explore the world and conduct small experiments to learn how things work.

f) In the sixth phase, the inventions of new means via mental combinations mark the beginning of actual insight, or creativity.

Children no longer resort to simply crying to get their way. They'll try new ideas and work on achieving their goals using complex and innovative methods. The 18-month-old child is capable of cajoling, sweet-talking or even exploiting to obtain what she wants. She has discovered that means aren't concrete and can be manipulated to achieve desired results. Imitation becomes an essential behavior that leads to mental symbolism. As the child discerns the shape of an object and studies its function, he/she gains clarity about what the object represents as well as what might be expected of it.

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2. Preoperational Stage

Late in the second year of a child's development, mental function changes to reveal a higher-order thinking skill. In this stage a child acts on an object. This stage occurs between the ages of 2 and 7 and includes the following processes:

- Animism is demonstrated when children attribute living qualities to inanimate objects, such as toys.
- Centration involves a child's response to an aspect of a situation or object, such as the height versus the height and diameter of an object.
- Classification allows a child to combine similar objects in clusters according to shared criteria such as size and color.
- Egocentrism is the child's self-preoccupation and personal view that does not readily accept another person's view.
- A child's inability to conserve reflects a difficulty with concepts of volume, mass and number. For example, a wide cup and a tall cup holding the same amount of liquid could look different to a child eyeing the difference in height.
- Intuitive thought reveals belief in something without understanding why one believes in it. This is a critical area for the development of trust and faith in what others tell the child.
- Serialization is the ability to organize things by progression, such as by size, numerical values or color shadings.
- Symbolic functioning represents the ability to understand the meaning of something that isn't physically there.

In understanding the preoperational stage, it becomes clear why tasks typically associated with preschool, kindergarten and the lower primary grades focus less on language development skills and more on the learning of colors, symbol identification such as the alphabet and numbers and shapes.

3. Concrete Operational Stage

The third stage of Piaget's theory of cognitive development occurs between the ages of 7 and 11, and illustrates logical thought processes:

- Conservation evolves so that a child retains the understanding of quantity, length or numbers associated with an object or process.
- Decentering is a child's ability to comprehend multiple aspects of a problem while solving it.
- Elimination of egocentrism lets a child understand another person's perspective.
- Reversibility is the understanding that an object or number can change and then reverse into its original state.

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At this stage, the child often understands the concepts of fairness, sharing, empathy and compassion for another person's plight. She learns to focus more on alternative perspectives and can see other possibilities to the problems or situations she faces.

4. Formal Operational Stage

Piaget's fourth and last stage of cognitive development begins at age 11 and continues into adulthood. This is when children entering puberty begin to think abstractly and create meaning from available data. This critical fourth stage is responsible for creating global problem solvers and creative thinkers who can analyze a situation and not be confined by concrete ideas or previously accepted logic.

Successful completion of the formal operational stage is evidenced by appreciation for dissenting views, a general lack of discrimination, creative viewpoints and a confidence in one's differences from the mainstream. These are the children marching to the beat of their own drum, even at an early age. Or they're comfortable coloring outside the lines not because they haven't mastered their sensorimotor skills, but rather because they like the way the new lines look.

Some experts believe that many people fail to successfully complete this stage to varying degrees. Many adults are bound by a rigid sense of order or sequential thinking that prohibits alternative solution development or limits their creative processes.

Piaget believed that children take an active role in the learning process, acting much like little scientists as they perform experiments, make observations, and learn about the world. As children interact with the world around them, they continually add new knowledge, build upon existing knowledge, and adapt previously held ideas to accommodate new information.

Many parents, unfamiliar with the natural order of skill acquisition, rush development of certain skills. So, they often find themselves frustrated that their child hasn't learned his alphabet by age 2 or doesn't play well with others by age.

Piaget's theory differed from empiricist theories of development, which suggest that children learn through experience, and nativist theories, which maintain humans, are born with innate knowledge that gradually matures. Each of the four stages comprises new learning that builds upon prior skills and abilities. The four stages are believed to be universal rather than cultural and follow the same sequence of development despite timing or geographic relevance.

Check your progress-III

Note: A. Write your answer in the space given below

B .Compare your answer with those given at the end of the unit.

i) What is meant by zone of Proximal development?

4.4 EVOLVING CONCEPTS OF PARENTING

Humans are a species characterized by high levels of required parental investment. Offspring are nature's vehicles for gene replication across generations. From an evolutionary perspective, nothing matters more than ensuring the success of offspring. Parenting is one of the most difficult and important work. Parenting is not something that just happens; it takes time, training and practice. Parenting styles have certainly changed, especially in the last half century where roles have changed.

4.4.1 Behavior Problems

According to the American Psychological Association, parenting practices around the world share three major goals: ensuring children's health and safety, preparing children for life as productive adults, and transmitting cultural values (APA, 2018).

Being a successful parent is no small deal and the main cause for a child to become competent, healthy, productive adults depends on a variety of environmental and biological factors. The influences on child outcomes are numerous, but a wealth of literature indicates parenting practices are an important part of the equation. The extent to which parenting practices shape behavioral development in children is a complex question.

Research has found consistent links between parenting and child behavioral adjustment. For instance, a mother's parenting behaviors, including the extent to which she displays affection toward and exerts behavioral and psychological control over her child, when that child is five years of age are linked to later child internalizing and externalizing behaviors. Internalizing, or emotional, behavior problems often refer to anxiety and depression. Externalizing, or disruptive, behavior problems commonly include attention-deficit hyperactivity disorder and conduct problems. To understand and respond effectively to problematic behavior, a parent must think about what came before it, as well as what comes after it. There are three important aspects to any given behavior:

- Antecedents: Preceding factors that make behaviour more or less likely to occur. Another, more familiar term for this is triggers. Learning and anticipating antecedents is an extremely helpful tool in preventing misbehavior.
- Behaviour: The specific actions you are trying to encourage or discourage.
- Consequences: The results that naturally or logically follow behaviour. Consequences either positive or negative affect the likelihood of a behaviour recurring. And the more immediate the consequence, the more powerful it is.

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Check your progress-IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Explain the three goals stated by APA?

4.4.2 Transition to parenthood

The transition to parenthood is one major life transition that has received a lot of attention in adult attachment research. Having a child can be a stressful experience, one that has the potential to tax people's interpersonal resources considerably. Moreover, the birth of a child has the potential to rekindle significant attachment-related experiences from the expecting parent's past, leading the individual to reflect upon his or her own developmental experiences and to consider ways in which one may wish to parent differently.

Becoming a parent has the potential to lead to other social-structural changes as one begins to socialize with other parents with same-age children and interact with local educational communities and teachers. Parenting can also be stressful for couples as they find themselves with less time for adult activities that they may have enjoyed previously (e.g., dining out, theatre) and potentially struggling with the negotiation of childcare responsibilities.

4.4.3 Adjusting to parenthood

The birth of a baby will bring about many changes in the lives of new parents. Many of these changes are ones that new parents are more than willing to make. Many will be easy to adjust to. However, the lives of new parents often change in ways that neither new mothers nor new fathers anticipated. Here are some things new parents should expect and prepare after their children are born:

A. Total exhaustion

Many new parents expect to be tired after their baby arrives, but few are prepared for just how tired they will really be. New mothers are exhausted by not only the hard work of childbirth. They may also find that because of their new babies' schedule, they rarely get to sleep more than a few hours at a time. This is true for new fathers, too. Therefore, it is very important for both parents to get all the rest that they can. New parents should not ignore signs of fatigue, because lack of sleep can lead to more serious problems.

B. Unpredictable emotions

It is estimated that roughly 50% of all new mothers experience some degree of postpartum depression. It most commonly occurs around the third day after delivery, but it can strike at any time during the first year. It is commonly believed that dropping levels of estrogens and progesterone trigger the depression that many new mothers feel.

NOTES**C. Parenting advice from practically everyone**

Everyone from close family members to friends will offer new parents some bit of parenting advice. Some well-meaning friends or family members may even tell new parents what they're doing "wrong." It is best for new parents to tune out most of the advice they will be getting about childcare and parenting. Instead, they should try to get all the facts they need; then make up their own minds about what's right and what's not.

4.4.1 Parenting in Adaptive Family Stages

Family adaptive systems emerge from family interactions to develop and regulate key domains of day-to-day family life including but not limited to meaning, emotion, control, maintenance, and responses to stress.

There will always be one person in the family unit who "absorbs" the bulk of the emotions of other members of the family, and this person is most likely to suffer from things like depression, alcoholism, and physical illness as a result. This shows the importance of families working together to conquer their problems, rather than letting negative emotions stew. Therapy or counseling can help many families work better together and keep anxieties at a minimum.

The various stages are:

Stage	Emotion Issues	Stage Critical Terms
1. Unattached Adult	Accepting parent-adult offspring relationship	a. Differentiation from family of origin b. Development of peer relations c. Initiation of career
2. Newly Married Couple	Commitment to marriage	a. Formation of marital system b. Making room for spouse with family and friends
3. Childbearing	Accepting new member into the system	a. Adjusting marriage b. Taking on parenting roles c. Making room for grandparents
4. Preschool Age	Accepting the new personality	a. Adjusting family to needs of each child b. Coping with energy drain and lack of privacy
5. School-Age Child	Allowing child to establish relationships outside the family	a. Extending family interactions with society b. Encouraging educational achievement

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6. Teenage Youth	Increasing flexibility of family boundaries to allow youth's independence	<ul style="list-style-type: none"> a. Shifting parent-child relationship to balance freedom and limits b. Refocusing on mid-life career and marital issues
7. Launching Center	Accepting exits from and entries into the family	<ul style="list-style-type: none"> a. Releasing young adult children into work, college, marriage b. Maintaining a supportive home base
8. Middle-Age Parents	Letting go and facing each other again	<ul style="list-style-type: none"> a. Rebuilding marriage b. Realigning family to include spouses of children and grandchildren c. Dealing with aging of older generation
9. Retirement	Accepting retirement	<ul style="list-style-type: none"> a. Adjusting to retirement/ old age b. Coping with death of parents and spouse c. Closing or adapting family home d. Maintaining couple and individual

Check your progress- V

Note: A. Write your answer in the space given below
 B. Compare your answer with those given at the end of the unit.
 i) What is meant by family adaptive system?

4.5 STAGES OF PARENTING

Ellen Galinsky an early-childhood specialist focuses in her book “*In Between Generations: The Six Stages of Parenthood*” classified the relationship between parent and child into Six Stages of Parenthood. They are:

Stage 1: The Image-Making Stage

The Image-Making Stage is what happens when we are parents-to-be. It is a stage where we begin to imagine what being a parent will be like, and we think about what kind of a parent we might like to be.

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It is a way of preparing for a major change in our lives. It involves accepting pregnancy, reflecting on the way parents were raised, evaluating relationships with friends and family, and grappling with feelings of control/loss of control and independence/dependence.

Stage 2: The Nurturing Stage

The Nurturing Stage begins when our baby arrives. It's a challenging stage because we now have to deal with the reality of caring for a baby 24/7 – and this reality can be very different to what we imagined in the Image-Making Stage.

This stage is about accepting our new role, enlarging our relationships to accommodate our new baby, and developing a new sense of identity – what kind of a parent do I want to be and who am I now that I am a parent?

Stage 3: The Authority Stage

By this stage our children are toddlers, and we now need to develop our sense of authority. We need to decide when to say 'No', when to say 'Yes', and how to deal with challenging behaviour.

We need to set limits and work out what to do when our children push those limits. We need to learn how to understand our children's behaviour and guide and mentor them as best we can.

Stage 4: The Interpretive Stage

The Interpretive Stage normally hits when our children begin school. When they enter the school system, their world expands. They are open to many more influences and to other relationships and experiences.

In this stage, we need to help our children interpret or understand the bigger and wider world by answering their questions and helping them with problems they face. As they get older, we also need to let them take on more responsibility by redefining our sense of authority. We need to support our children but also begin to let them go.

Stage 5: The Interdependent Stage

The Interdependent Stage begins when our children become teenagers. In this stage, it can feel like we are losing control. Your child is becoming their own person – they are more interested in their friends and their own lifestyle, and they don't seem to need us as much.

We can still guide them, but we need to redefine our relationship by allowing our children to be more independent and separate, all while keeping a connection.

Stage 6: The Departure Stage

This is the stage where our children leave home and move into true adulthood. It's a time when we reflect on a lifetime of being a parent, our successes and failures, our fond memories and regrets. It's a time when we need to adjust our sense of identity once more. Parents no longer need to look after and care for their children and have more time for themselves

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and their own interests. This can feel like an ending but also a new beginning. It can be tinged with sadness but also anticipation.

The six stages of parenting remind us of the bigger picture. One day, children will be out of nappies, and then at school, and then leaving home. It will happen faster than we think. It also reminds us that every stage of our development as a parent is an opportunity to grow with our children.

Check your progress-VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is meant by nurturing stage?

ii) Analyse departure stage.

4.5.1 Modern Parenting Styles

Many modern parenting styles have evolved including:

A. Dolphin Parenting

In 2014, Harvard-trained child and adult psychiatrist Dr. Shimi Kang proposed a new way of parenting in her book “The Dolphin Way: A Parent’s Guide to Raising Healthy, Happy, and Motivated Children – Without Turning into a Tiger”. This parenting style focuses on maintaining a balanced life for children filled with connection, contribution, and purpose while gently guiding them toward long-term health, happiness, and success.

Taking an authoritative yet playful stance, dolphin parents collaborate with their children, nurturing their spirit, individual passions, self-motivation, and independence while still being firm but flexible. Research shows that being raised with an authoritative style of parenting is positively associated with competence, resilience and self-esteem. The dolphin way certainly falls under the authoritative umbrella.

B. Elephant Parenting

In this uber-nurturing method of child-rearing, the focus is on raising children especially those under five in an environment of warmth and encouragement. Citing plenty of time for age-appropriate, “grown-up” expectations, elephant parents just want to nurture, protect, and support their impressionable youngsters, particularly during those precious first few years.

This type of parenting was propounded by Priyanka Sharma-Sindhar in 2014 reflecting on her own upbringing in India. She describes elephant parents as those “who believe that they need to nurture, protect, and encourage their children, especially when they’re still impressionable and very, very young. She points out how, in India, parents tap into their softer side by doting on their young children, nurturing them and allowing them to just be children without all the parental pressure and potentially

age-inappropriate expectations.

C. Free-Range Parenting

In stark contrast to more overbearing and overprotective parenting styles, free-range parenting takes a laid-back approach, where parents raise their children in the spirit of fostering independence in age-appropriate ways.

By trusting in their children' autonomy, free-range parents allow their children reasonable levels of personal freedom and responsibility while keeping them safe, although it involves taking some personal risks. With the underlying motto of "give children the freedom we had as children," free-range parenting aims to raise self-reliant children with a reasonable dose of parental concern along the way. Free-range parents focus on teaching children through trial-and-error, making choices, taking risks and sometimes failing.

D. Helicopter Parenting

This often-disparaged parenting style reflects parents' desire to be overly involved in their children' lives, sweeping away their obstacles, making decisions for them, solving their problems, and violating parental boundaries.

Aptly named, helicopter parents hover overhead, deeply enmeshed in every aspect of their children' lives, especially as they enter adolescence. Technology has further enabled this parenting style by giving 24/7 access to children' lives through GPS-enabled cell phones, texts, apps, computer browsing history, and online grades.

Proponents of this parenting style point to their desire to help their children succeed. Critics highlight its stifling effect on children' autonomy and problem-solving skills.

E. Lighthouse Parenting

Lighthouse parenting propounded by pediatrician Dr. Kenneth R. Ginsburg Using is a collaborative parenting style focusing on guiding children. In this style, Parents provide a lot of unconditional love and protection, lighthouse parents understand that children also need to learn from failure in order to grow. They focus on morality and character, not performance, and strike a balance between guidance and protection.

F. Tiger Parenting

Tiger parenting style is extreme, coercive, competitive parenting style. Like helicopter parenting but on a more extreme level, this rigid parenting style takes a tough-love approach, hyper-focusing on performance, grades, and achievement. The philosophy expects excellence from children and discourages social activities such as sleepovers and playmates.

G. Slow Parenting

At the crux of this parenting style lays balance, simplicity, and mindfulness. Living at a slower, more natural pace, families intentionally

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carve out time to connect. This approach de-emphasizes electronics and over scheduling in favor of simplistic toys that encourage creativity, playing outside and in nature, spending time with friends and family, and allowing children the freedom to pursue their own interests.

The goal of every parent, regardless of how they raise their children, is to grow happy, healthy children. Along the way, they adapt their approach to their changing children and their changing environment. In the end, it's the totality of what parents do over time that shapes who children become. In any given week (and sometimes even in the same day, parents might fluctuate between a helicopter parent, an elephant parent, lighthouse parent and a free-range parent. But it's the cumulative effect of a balanced approach of both warm nurturance and firm discipline that wins out in the end.

Check your progress-VII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse Lighthouse Parenting.

4.6 UNIT END EXERCISES

1. List out the various developmental theories and their application to parenting.
2. Evaluate the concept of parenting
3. Analyze the various stages of Parenting

4.7 ANSWERS TO CHECK YOUR PROGRESS

The eight stages of development as stated by Erickson are: Infancy: Birth to 18 Months Old ,Toddler / Early Childhood Years: 18 Months to 3 Years, Preschooler: 3 To 5 Years, School Age Child: 6 to 12 Years, Adolescent: 12 to 18 Years, Young Adult: 18 to 35, Middle-Aged Adult: 35 to 55 Or 65,Late Adult: 55 Or 65 to Death -Integrity vs. Despair – Wisdom.

According to Vygotsky theory, the potential for cognitive development is limited to a "zone of proximal development" (ZPD). This "zone" is the area of exploration for which the student is cognitively prepared but requires help and social interaction to fully develop (Briner, 1999). A teacher or more experienced peer can provide the learner with "scaffolding" to support the student's evolving understanding of knowledge domains or development of complex skills. Collaborative learning, discourse, modeling, and scaffolding are strategies for supporting the intellectual knowledge and skills of learners and facilitating intentional learning.

According to the American Psychological Association, parenting practices around the world share three major goals: ensuring children's health and safety, preparing children for life as productive adults, and

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transmitting cultural values (APA, 2018).

Research has found consistent links between parenting and child behavioral adjustment. For instance, a mother's parenting behaviors, including the extent to which she displays affection toward and exerts behavioral and psychological control over her child, when that child is five years of age are linked to later child internalizing and externalizing behaviors. Internalizing, or emotional, behavior problems often refer to anxiety and depression.

Family adaptive systems emerge from family interactions to develop and regulate key domains of day-to-day family life including but not limited to meaning, emotion, control, maintenance, and responses to stress.

The Nurturing Stage begins when our baby arrives. It's a challenging stage because we now must deal with the reality of caring for a baby 24/7 – and this reality can be very different to what we imagined in the Image-Making Stage.

Departure Stage is the stage where our children leave home and move into true adulthood. It's a time when we reflect on a lifetime of being a parent, our successes and failures, our fond memories and regrets. It's a time when we need to adjust our sense of identity once more. Parents no longer need to look after and care for their children and have more time for themselves and their own interests.

Lighthouse parenting propounded by pediatrician Dr. Kenneth R. Ginsburg Using is a collaborative parenting style focusing on guiding children. In this style, Parents provide a lot of unconditional love and protection, lighthouse parents understand that children also need to learn from failure in order to grow. They focus on morality and character, not performance, and strike a balance between guidance and protection.

4.8 LET US SUM UP

A parent will always be a parent be it 'then' or be it 'now', and parenting an art. However, with change being the essence of life, nothing remains the same for long. And, parenting has also evolved with time.¹ Most millennial parents tend to play safe if they are not ready physically and psychologically for parenthood.

Financial stability and the right ambience have emerged as benchmarks to be achieved prior to welcoming a child in the world. Family dynamics have also altered drastically. Joint family setups rendering ample support have given way to nuclear families. So, with little or almost no help, couples find it almost next to impossible to strike a balance between nurturing their child and managing their household chores and profession.

Today, parenting is a joint venture with more fathers taking an active part in their child's upbringing. As a result, taking care of a child is no longer considered a 'feminine' thing. Instead of behaving in an

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autocratic manner, new-age parents steer their children in the right direction, while giving them the freedom to learn from their mistakes.

The notion of 'spare the rod and spoil the child' is no more. Nowadays, parents realize that corporal punishment and criticism would not only heighten their child's aggression but also damage her self-esteem. Parents also understand the fact that only children who feel loved learn to reciprocate the feeling.

The advent of media and technological boom has given rise to a situation where tech-savvy children appear more knowledgeable than their elders. At the same time, with rapid digitalization, parents are also trying to keep a check on their child's online presence, lest he falls prey to something undesirable. While the digital revolution has proved to be a boon for children, it has also opened new vistas for parents and broadened their perspectives.

Today parents' no longer crib over marks obtained in exams but believe in the holistic development of their child. They no longer confine their child solely to academics but motivate her to pursue her passion and innovate and think beyond the periphery of the curriculum. They are forever willing to go to any extent to help their child realize her true potential and calling.

4.9 SUGGESTED READINGS

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BLOCK II PARENTING CHILDREN WITH SPECIAL NEEDS

UNIT V NURTURING CHILDREN WITH SPECIAL NEEDS

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- 5.1 Introduction
- 5.2 Objectives
- 5.3 Parenting Children with Special Needs
- 5.4 Changing contexts of childhood health and disability
- 5.5 Concerns related to parenting children with special needs
 - 5.5.1 Common Reactions on knowing that a child has disability
 - 5.5.2 Role Confusion in Parenting Children with Special Needs
- 5.6 UNICEF's Four Pillars of Parenting
 - 5.6.1 First pillar: Nurturing behaviour
 - 5.6.2 Second Pillar: Structure and guidance
 - 5.6.3 Third Pillar: Acknowledging or recognizing
 - 5.6.4 Fourth Pillar: Empowering the child
- 5.7 Working together with other professionals
 - 5.7.1 Communication
 - 5.7.2 Advocating for the Child
- 5.8 Other professional involved with the care of the young child
- 5.9 Role of Professionals
- 5.10 Let us sum up
- 5.11 Unit end exercises
- 5.12 Answers to check your progress
- 5.13 Suggested Readings

5.1 INTRODUCTION

The birth of a child instantly changes how we define ourselves. Women become mothers. Men become fathers. Couples become parents. Our priorities shift in fundamental ways. Parenting may be the most rewarding experience, but it is also the hardest and most humbling says Sheryl Sandberg, *Lean in*.

Children are the foundation of our greatest joys and the source of greatest distress. Many parents consider raising children to be one of the most blissful and gratifying, but also one of the most stressful and challenging undertakings of their lives. Crucial to children's wellbeing is the quality of their family life. Family relationships, but more particularly the relationships children have with their parents, tend to have broad impacts on their wellbeing economically, socially, psychologically and physically.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day when the child is diagnosed as having a disability, most get devastated and so confused. Some parents describe the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been experiences that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

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In this unit, we will discuss about the various issues and concerns related to Parenting Children with Special Needs and Other professional involved with the care of the young child with disability.

5.2 OBJECTIVES

After going through this unit, you will be able to;

- Comprehend the notion of parenting children with special needs.
- Analyse the role confusion in parenting children with special needs.
- Interpret the superstition practices in begetting a child with special needs.
- Analyse the effect of depressive moods of parents.
- Evaluate the need to work together with other professionals.
- Understand the role of other professional involved with the care of the young child.
- Appreciate the roles of various professional involved in rearing children with special needs.

5.3 PARENTING CHILDREN WITH SPECIAL NEEDS

With the birth of the child, every parent is faced with a new role in life and a new challenge to his/ her personal growth. Parents of the child with disability, developmental delay or risks meet with an additional series of unexpected challenges and many questions that are not easy to answer. When parents learn that their child has a disability, they start on a different life journey.

Throughout that journey Parents keep questioning themselves and their actions, endlessly digging up for information and services for their child, meeting with different experts and dealing with strong emotions, both their own and those of the close people around them.

In that process, many rediscovers the sources of inner strength they did not know existed. Nevertheless, parents often feel isolated and alone, without knowing where to start and how to obtain relevant and useful information and support to their specific needs and those of their child. It is important that each parent have someone they can share their emotions with and say whatever worries and troubles them, what they might be afraid and ashamed of.

It is also important that parents rejoice at the success in the development of their child with someone who has a similar experience and understands how one small step is a big one for their child.

Children with disabilities bring a unique set of challenges, and opportunities, to their families. Depending on the nature of the disability, the challenges can be quite significant. Aside from the energy required to manage a child's physical and emotional needs, there are often huge financial considerations. In addition, equipment, social services, and health care are often pricey and are not always covered by insurance or entitlement programs.

NOTES**Check your progress I**

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i. Comprehend the reactions of parents on knowing that their child has a disability
- ii. Analyze the difficulties faced by parents of children with disabilities

5.4 CHANGING CONTEXTS OF CHILDHOOD HEALTH AND DISABILITY

For centuries, disability was understood as a characteristic of an individual. In most of the cultures, until the rise of modern medicine, disability was often interpreted as evidence of God's dismay. Until the Enlightenment period, the birth of a child with disability was perceived as a palpable sign of parental sin. Disability also fed into notions of biological fitness, and the social ills associated with "feeble mindedness," or "degenerative and defective hereditary qualities," evolved in the early twentieth century into the rationale for eugenics and led to social policy that advocated forced sterilization of those considered unfit.

In the 19th Century, children with disabilities were often shunned, removed from their families, and treated, and often warehoused, in specialized institutions. Despite the growing understanding of disability as a dynamic, socially constituted, and culturally mediated process that pivots on each individual's capacity to engage in culturally constituted social roles and realize his or her multi-determined developmental potential, many laws, policies, and programs related to disability require the identification of a specific medical condition for eligibility.

Advent of Persons with disabilities Act, 1995 and Rights of Persons with Disabilities Act, 2016 have mandated equal rights for persons with disabilities on par with their normal peers. Social-Economic support has been extended to the families for rearing children with special needs.

Contemporary notions of childhood disability contend that the nature and severity of disability are not only a product of underlying medical conditions but also a function of the demands, expectations, and social roles that children assume in their daily lives.

Championing an integrated bio psychosocial perspective, the World Health Organization (WHO) in 2001 developed the International Classification of Functioning, Disability and Health (ICF), which describes how health conditions interact with personal and environmental factors to affect functioning at the levels of the body, the person, and the person in social situations. "Disability" is the umbrella term for impairments at the body level, activity restrictions at the person level, and participation restrictions at the person-in-society level.

The ICF defines impairments as "problems in body function or structure such as a significant deviation or loss," activity limitations as

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“difficulties an individual may have in executing a task,” and participation restrictions as “problems an individual may experience in involvement in life situations.” Personal and environmental factors that influence functioning are considered contextual factors.

In 2007, the WHO released the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) in response to the specific and unique aspects of disability in childhood. For children, disability is also explained in the context of delays, deviations, and variations in expected growth and development.

Subsequent work by the UN Convention on the Rights of Persons with Disabilities led to the development and adoption of a new definition of disability in 2010 that is built on the ICF framework. This definition is contained in Article 1 of the UN convention: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State ICF definition of impairment.

ii) State UN convention defined persons with disabilities

5.5 CONCERNS RELATED TO PARENTING CHILDREN WITH SPECIAL NEEDS

The birth of a child with a disability, or the discovery that a child has a disability, can have profound effects on the family. All the parents and the family members long to have a healthy, smart and intelligent child to enter their family as a new member. But, when they come to know that their child has some sort of disability or have special needs, it can have profound effects on the entire family—parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning.

On the positive side, it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a child with disability have far-reaching effects as we describe below. The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available.

5.5.1 Common Reactions on knowing that a child has disability

Families having a child with a disability undergo certain negative emotions. The birth of such a child usually follows five stages: "denial,

anger, bargaining, depression and acceptance." Parents usually react with "psychological stress, a feeling of loss and low self-esteem." The child is "disappointing" and a "social obstacle" leading to shame and embarrassment."

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and this enormous challenge. Some of the parents of children with disabilities are likely to be dealing with the loss of their hopes and dreams for their child.

- A. Denial:** One of the first reactions is denial- "This cannot be happening to me, to my child, to our family." Denial rapidly merges with *anger*, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also colour communication between husband and wife or with grandparents or significant others in the family. Early, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of *grief* and inexplicable *loss* that one does not know how to explain or deal with.

- B. Fear:** Fear is another immediate response. People often fear the unknown more than they fear the known. "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?" Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?"

- C. Guilt:** There is guilt concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" Much self-reproach and remorse can stem from questioning the causes of the disability. Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?" or "Why my child?" many parents are also saying, "Why has God done this to me?"

- D. Confusion:** Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. During such trauma, information can seem garbled and distorted. Hearing new words that you never heard before, terms that describes something that's unknown. Trying to find out what it is all about, yet it seems that it cannot make sense. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's disability.

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E. Powerlessness: Powerlessness to change what is happening is very difficult to accept. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

F. Disappointment: Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

G. Rejection: Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all the potentially troublesome feelings that can arise, so that they will know that they are not alone.

H. Depression: Parental depression is a common condition, for parents of children with developmental disabilities. They will report symptoms of depression than parents of children without disabilities. As providers who care for youth with disabilities, if unrecognized and/or untreated, parental depression can have a huge impact on how the family functions, and on how a parent and child are able to bond. These states do not necessarily occur in any orderly sequence, and they can repeat themselves when a family's child experiences or should be experiencing key milestones or transitions.

5.5.2 Role confusion in parenting children with special needs

Role confusion is a deviation in the parent-child relationship such that a parent looks to a child to meet the parent's emotional needs and abdicates, in part, the parental role in exchange for care, intimacy, or peer support from the child. In addition, a child may initiate role-confused behaviour in order to gain closeness to a parent who is otherwise preoccupied by his or her own needs. Parental behaviours and attitude towards children have become a matter of public policies, not just in terms of protecting children from parental violence and neglect, but also in terms of promoting parental behaviours and attitudes that foster the child's well-being and optimal development.

Check your progress-III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the positive reaction of knowing a child to have disability.

ii) What are the common reactions on knowing that a child has disability?

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5.6 UNICEF's FOUR PILLARS OF PARENTING

Every child has the right to a caring and nurturing parental behaviour, structure and leadership, respect of their personality, and empowerment (Penki, 2007). These categories of parental behaviours and values are the basic principles of parenting that respect and promote the rights of the child in the family. We call them the four pillars of parenting in the best interests of the child.

The parent of the child with disability must look after his/her limitations and well-being even more closely. The limitations of the child are very fragile due to biomedical problems on one hand, and their contacts with several other persons, on the other hand. The child meets a lot of people from the early age and more often than other children. Sometimes these people are not aware enough of the child's limitations or tend to ignore them due to lack of time or excessive workload.

5.6.1 First pillar: Nurturing behaviour

The parent must respond to the child's need for love, emotional warmth, security, belonging, bonding, and acceptance. The child needs their parents' nurturing behaviour as a safe base from which they can explore the world, and to which they can return when they feel fatigue, fear, sadness or some other uncomfortable state or emotion. This requires the parents to be sensitive to their child's messages, and to respond to them appropriately, to show warmth and love, to provide comfort and protection, to accept the child and to provide support. The parent can show consistent emotional warmth and response to the child's needs represent the basis for the development of a safe, stable and emotionally warm bond with the parent. Such a bond enables the child's emotional needs to be satisfied, and the child feels valuable and accepted as a result.

5.6.2 Second Pillar: Structure and guidance

The parent should respond to the child's need for security, predictability and competence, direct the child's space, time and guidance. It enables the child to learn to manage his or her own behaviour. The parents serve as the role model of appropriate behaviour, expressing emotions, and interactions with other persons. The child learns from them and develops his or her own moral values, conflict resolution methods and pro-social behaviour. In order to achieve that, the parent helps the child understand what is and what is not acceptable and sets reasonable and appropriate limits and expectations. In that process, it is necessary to consider the child's opinion and direct him in a positive way, while setting clear limits, offering reasonable explanations, and refraining from corporal punishment and psychological pressure.

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5.6.3 Third Pillar: Acknowledging or recognizing

For the development of the child's self-awareness, the parent needs to notice, acknowledge and confirm the child's personal experience of themselves and/or of the world. Appreciating the child as a person involves respect for the child's limits and making decisions appropriate for their age and maturity. It is also important that the parent take into consideration the child's opinions and needs when making decisions that concern the child and the family. "Appreciating the child as a person" does not mean fulfilling all of their wishes, but rather recognizing, accepting and "seriously considering" how the child sees themselves or a certain situation.

5.6.4 Fourth Pillar: Empowering the child

To enable the child to be empowered, the parent must respond to the child's need to feel personal control, competence and the ability to affect other people and the world around them. In other words, empowerment implies the parents' support to their child's autonomy. This requires parental sensitivity, openness for the child's influence, and cooperation. The parents empower the child when they follow the child's idea with interest, when they join the child's activities if the child allows it, and when they refrain from directing and helping when the child can achieve their aims alone.

Furthermore, the parents may create opportunities in which the child can learn and gain new experiences. This involves broadening the child's experience and acquainting the child with the world, responding to the child's questions, supporting play and enabling the child to experience success. In supporting the growing independence of their child, the parents should not forget that development is not linear. The child may sometimes express the need for autonomy, and later again for a greater protection and presence of the parents (e.g. when they try to put on their shoes by themselves in the morning, and when the parent comes to pick them up in the afternoon, they want the parent to put the shoes on for them, etc.).

Check your progress- IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State why appreciation is important for a child's development.

ii) Empowerment of a child starts with the parents-justify

5.7 WORKING WITH THE PROFESSIONALS

Every child, developing either typically or with disability, deserves to be accepted with enthusiasm and to develop into a happy person. On that journey they are accompanied by parents who grow in these difficult circumstances, deal with endless problems, and cope with both the expected and unexpected difficulties. Fulfilled and adaptable parenting does not depend on the characteristics of the child, but on those of the parent.

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To strengthen their parental skills the parent needs various kinds of support. However, when talking about the need for support, we must ask ourselves what exactly is the nature of the support that the parents of children with disabilities need, and how and where those needs can be met. This leads to the question of what issues the parents are predominantly preoccupied with. It is also important to choose the right techniques of communication with the parents of children with disabilities in order to successfully provide support.

Parents and professionals are joined forces to create a productive working relationship by taking advantage of power over and power together relationships. This mutual process required participants to be aware, empathic, and respectful of one another's needs and limitations; acknowledge the contribution of experiential and professional knowledge; and co-operate in overcoming the effects of ineffective bureaucratic service systems. Interventions geared to contain emotional burden, acknowledge differential knowledge and experience, and structure the use of therapies.

Depending on your child's age and the combination of his/her multiple disabilities, there is a wide range of professionals who may be part of her team. Many children with multiple disabilities have a Para-educator (also referred to as a teacher's aide, paraprofessional, or teaching assistant) who works with them for all or part of the school day.

5.7.1 Communication

Communication is a critical to both the child's medical and educational teams. Building communication and good relationships between the family and team members and among the various members of the team is important.

5.7.2 Advocating for the Child

The word "advocacy" can sound daunting, but it basically means looking out for your child's best interests and making things happen on her behalf. Communication and advocacy are tied together. To be an effective advocate, you'll need to communicate your thoughts to your child's medical and educational team members.

Check your progress V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit

i) What is meant by productive working relationship?

ii) State the importance of communication.

5.8 PROFESSIONAL INVOLVED IN THE CARE OF THE YOUNG CHILD WITH SPECIAL NEEDS

For families with a special child the usual challenges of family life can be further complicated by the fact that they often need access to a wide range of services provided by a wide range of professionals and agencies.

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Whilst these services aim to provide the necessary medical, social, educational, and emotional support to the child and family, this can create a bewildering number of contacts and appointments for parents to manage, maintain, and integrate into family life.

A brief description of the roles of various professionals who serve in the Intervention Team and others work in hospital or community services who work with children with disabilities is stated below. Since every child has different needs each family will meet a variety of different professionals. At times, the professionals are known by various titles and the same service can be provided by different professionals.

a) Audiologist:

An audiologist helps in diagnosing, treating and monitoring hearing needs, loss or impairment.

b) General Practitioner (GP):

General Practitioner is a medical doctor who specializes in family medicine and provides primary care in the community.

c) Cardiologist:

A cardiologist is a specialist doctor who identifies and treats heart problems.

d) Clinical Nurse Specialist:

There are different types of Clinical Nurse Specialists working in different areas including in hospitals and early Services Teams. They assist the child in the areas of physical skills, learning through play, communication, social/emotional skills and everyday independence skills. They liaise with others working with the special child i.e. therapists or preschool teachers.

e) Early Years Interventionist:

Early Years Interventionists have training in child development and learning. They work with the family and the other therapists to help the child gain skills to promote their overall development. They assist the child in the areas of physical skills, learning through play, communication, social/emotional skills and everyday independence skills.

f) Ear Nose and Throat (ENT) Surgeon:

An Ear Nose and Throat Surgeon is a doctor who specializes in problems related to a child's ears, nose or throat.

g) Special Educator

Educators working on Early Intervention Teams have training in child development and learning. They work with the family and other therapists to help the child gain skills to promote their overall development. They assist the child in the areas of physical skills, learning through play, communication, social/emotional skills and everyday independence skills. They liaise with others working with the child i.e. therapists or preschool teachers.

h) Home/Family Support Worker

A home/family support worker provides additional support in caring for the child. This may take the form of training appropriate activities for the child in the home and in the community.

i) Neurosurgeon

A Neurosurgeon is a doctor who specializes in surgery on the brain, spine, and other parts of the nervous system. A Neurosurgeon may

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carry out surgery on problems diagnosed before birth, in infancy, childhood, or adulthood.

j) Occupational Therapist

An Occupational Therapist (or 'OT') can help the special child to increase their level of independence starting with reaching, grasping, picking up small objects, and working on other skills such as feeding, dressing and toileting. They may also work on co-ordination, sensory and other issues. An Occupational Therapist is assisting the family in obtaining specialized equipment that may be needed for the child.

k) Ophthalmologist

An Ophthalmologist is a doctor who specializes in the medical and surgical care of the eyes and visual system. The Ophthalmologist works in the prevention and treatment of eye disease and injury.

l) Orthoptist

An Orthoptist is a health care professional who assesses, diagnoses and manages various disorders of the eyes including extra-ocular muscles (e.g. squint) and problems with vision (e.g. lazy eye /amblyopic). Orthoptist work in closely with Ophthalmologists.

m) Orthopedic Surgeons:

An Orthopedic Surgeon is a doctor who specializes in disorders of the musculoskeletal system. They can review spinal, joint and muscle problems and treat by surgical and non-surgical means.

n) Orthotics:

An orthotics is a specialist in the design, manufacture and fitting of aids, splints and equipment in children and adults to help improve mobility and provide support e.g. splints and special shoes.

o) Pediatrician:

A Pediatrician is a specialist doctor who deals with the health of children. The Pediatrician may have a special interest in an area such as neonatology (the care of newborn infants), neurology (the nervous system) or child development. In the disability field, the Pediatrician carries out medical investigations, makes diagnoses and monitors your child's health and overall development.

p) Physiotherapist:

The Physiotherapist (or 'PT') can help the child with balance and movement and works on activities such as rolling, sitting, crawling, and walking. They look at ways of encouraging your child's independence and mobility. A Physiotherapist may also assist in making recommendations for specialized equipment.

q) Psychologist:

A clinical or educational Psychologist assesses children's thinking, learning and behavior. Psychological assessments teach us about how the child's condition or diagnosis affects his/her overall development and wellbeing. The Psychologist addresses behavioral concerns and offers support which may help the child's overall developmental progress. Later, the Psychologist can support the family in making decisions concerning appropriate pre-school and school placements.

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r) Public Health Nurse:

A Public Health Nurse (PHN) may help and support you with your child at home. This can involve offering practical or nursing support or by obtaining health related supplies e.g. nappies.

s) Rehabilitation Professional

The Rehabilitation Professional carries out an assessment of how a child's vision loss affects their daily life and what supports might be needed to improve the child's overall independence and quality of life. Based on this assessment the Rehabilitation Officer will make recommendations on the services and supports that may be needed.

t) Social Worker:

Many Early Intervention Teams include a Social Worker. The Social Worker is often the first person to introduce the family to the other members of the Early Intervention Team. A Social Worker can provide information, advice and family support. They can provide support and counselling for you and your family in relation to coping with your child's disability. The Social Worker can help the parent to identify, source and access services in the local community that may be helpful.

u) Speech & Language Therapist:

A Speech and Language Therapist (SLT) helps the child to communicate. This may involve working on the child's understanding of language i.e. the words and sentences used around him/her, using language to express him/herself, the sounds of speech or on alternate and augmentative methods of communication.

Check your progress-VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the role of a psychologist.

5.9 ROLE OF PROFESSIONALS IN NURTURING CHILDREN WITH DISABILITY

An African proverb, "It takes a village to raise a child," recognizes the reality that parents, whether they have a disability, cannot and should not parent alone. Indeed, parents without disabilities rely on a variety of formal and informal supports to help them with their child-rearing responsibilities. Supporting parents with disabilities and their families in the community is not only the right thing to do, it is legally mandated

We shall explore various supports that must be available to parents with disabilities and their families. Many of the supports discussed here already exist and need only be expanded or modified to better serve parents with disabilities and their families; others must be established. If these families receive the proper supports, most will undoubtedly thrive.

NOTES

A. Personal Assistance Services

Personal assistance services (PAS) are a crucial support for families with disabilities. PAS help people with activities of daily living (ADLs), such as eating, bathing, dressing, and toileting, as well as with instrumental activities of daily living (IADLs), such as grocery shopping, cooking, and cleaning.

PAS typically fall into two categories: informal (unpaid) services provided by family members, friends, or neighbours; and formal services that are typically paid by public funding, private insurance, or out of pocket. PAS have the potential to be of great help to parents with disabilities and their families.

B. Health Care

Proper health care is crucial for people who want to create and maintain families, but women with disabilities face significant barriers to receiving accessible, affordable, and appropriate health care. Accessible, appropriate, and affordable health care is crucial to the well-being of children with disabilities and their families. However, for most it remains largely inaccessible and inappropriate.

C. Peer Supports

Most parents and prospective parents rely heavily on their peer support network. Peer support provides the opportunity to exchange ideas and experiences with others who are facing similar situations. Peer supports also provide parenting role models.

Some disability organizations and have begun to create networks for parents with disabilities. Peer-professional staffing in programs that serve parents of children with disabilities is an important vehicle for conveying the wisdom of peers and providing role models.

The Internet, especially social networking sites such as Facebook, has greatly assisted parents of children with disabilities who want to connect with their peers.

D. Disability and Mental Health Service Providers

Disability and mental health service providers play a significant role in the lives of many people with disabilities, but the services they offer typically do not address their needs as parents.

E. Mental Health Service Providers

Strong potential exists for collaboration between disability-community-based services and providers of infant mental health services. Infant mental health clinicians typically work with parents and their infants and toddlers to support secure attachment relationships between parent and child. Developmental screening and guidance are usually included. Maternal depression and its impact on infant-parent relationships and interaction is a focus of

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these specialists; it is critical to address this promptly to prevent long-term negative effects on children.

F. Intellectual Disabilities Service Providers

Little focus has been directed at providing parenting support and services as part of general support for people with intellectual disabilities in the community.

Parents who do not have adequate supports are at much higher risk of losing custody or rights to their children. Rehabilitation centres rarely provide parenting skills training, instead focusing on self-care skills training. Perhaps existing parenting education courses offered at hospitals and by local agencies could be modified to address the needs of parents. Regardless of whether they have a disability, all parents need supports, both formal and informal, to help them in parenting.

Check your progress-VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the role of Disability and Mental Health Service Providers.

5.10 LET US SUM UP

Children's development is influenced by a wide range of biological and environmental factors, some of which protect and enhance their development while others compromise their developmental outcomes. Children who experience disability early in life can be disproportionately exposed to risk factors such as poverty; stigma and discrimination; poor caregiver interaction; institutionalization; violence, abuse and neglect; and limited access to programmes and services, all of which can have a significant effect on their survival and development.

Children with disabilities are among the world's most stigmatized and excluded children. Limited knowledge about disability and related negative attitudes can result in the marginalization of children with disabilities within their families, schools and communities. In cultures where guilt, shame and fear are associated with the birth of a child with a disability they are frequently hidden from view, ill-treated and excluded from activities that are crucial for their development.

As a result of discrimination, children with disabilities may have poor health and education outcomes; they may have low self-esteem and limited interaction with others; and they may be at higher risk for violence, abuse, neglect and exploitation. Some children with disabilities may be more vulnerable to discrimination and social exclusion than others due to multiple disadvantages arising from impairment, age, gender or social status.

Stimulating home environments and relationships are vital for nurturing the growth, learning and development of children. Siblings may also feel the effects, with parents having less time to devote to them as they struggle to meet the needs of their child with disability. However, an

emphasis on barriers and problems risks overlooking the joy and satisfaction that can come from having a child with disability.

Children with disabilities are usually loved and valued by their parents and siblings, and mothers may develop many new skills and capacities through their caring roles. Considering that family settings are generally the first learning and protective environments for children, guidance and orientation are critical for families following the immediate identification of a developmental delay or disability in order to promote positive interactions.

In addition to a child's immediate family, his or her neighbourhood, community and societal structures, professional help also need to be considered in nurturing a child with special needs. Coordinated and sustainable responses are required from a range of stakeholders at all levels to ensure that the rights and needs of young children with disabilities and their families are met. Critical are family members and those stakeholders who deal directly with young children to meet their health, education, protection and other needs.

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5.11 UNIT END EXERCISES

1. Analyse the changing contexts of childhood health and disability.
2. Parenting Children with Special Needs has its own unique challenges-justify.
3. State the four Pillars of Parenting.
4. Working together with other professionals helps nurturing child with disability in a healthy way- elaborate.

5.12 ANSWERS TO CHECK YOUR PROGRESS

- When parents learn that their child has a disability, they start on a different life journey. Throughout that journey they keep questioning themselves and their actions, endlessly digging up for information and services for their child, meeting with different experts and dealing with strong emotions, both their own and those of the close people around them.
- Children with disabilities bring a unique set of challenges, and opportunities, to their families. Depending on the nature of the disability, the challenges can be quite significant.
- The ICF defines impairments as “problems in body function or structure such as a significant deviation or loss,” activity limitations as “difficulties an individual may have in executing a task,”
- UN convention defined Persons with disabilities as: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

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- On the positive side, having a child with disability increases family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions.
- Families having a child with a disability undergo certain negative emotions. The birth of such a child usually follows five stages: "denial, anger, bargaining, depression and acceptance." Parents usually react with "psychological stress, a feeling of loss and low self-esteem." The child is "disappointing" and a "social obstacle" leading to shame and embarrassment."
- "Appreciating the child as a person" does not mean fulfilling all of their wishes, but rather recognizing, accepting and "seriously considering" how the child sees them or a certain situation.
- To enable the child to be empowered, the parent has to responds to the child's need to feel personal control, competence and the ability to affect other people and the world around them.
- Parents and professionals are joined forces to create a productive working relationship by taking advantage of power over and power together relationships.
- Building communication and good relationships between the family and team members and among the various members of the team is important.

5.13 SUGGESTED READINGS

Convention on the Rights of Persons with Disabilities. New York, United Nations, 2006.

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UNIT VI

Structure

- 6.1 Introduction
- 6.2 Objectives
- 6.3 Parents as partners in rearing children with special needs
 - 6.3.1 Partnership model
 - 6.3.2 Empowerment Model
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- 6.4 Respecting parent priorities
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6.1 INTRODUCTION

The quality of care and stimulation children receive in their childhood determines much of what a child will become in life. “Family relationships in general and the parent-child relationship have a pervasive influence on the psychological, physical, social and economic wellbeing of children. Parents generally receive little preparation beyond the experience of being parents themselves; with most learning on the job, through trial and error” (Sanders et al 2003). Parents of children with special needs are often exhausted and frequently become depressed. Their reserves of time and resources for self-care are even more depleted than those of parents of typical children. Yet their need for refuelling is also greater. To be sustained through the marathon of caring for a child with special needs, it is essential that parents attend to their own needs.

Role of parents become immensely important in bringing up children with special needs and making them to be a part of the mainstream and contribute to the society. Parents play the role as teachers, health professionals, advocates for their children. Starting from their early infancy, developmental stages in various aspects of life till their education and employment, parents play an important role. “There are many common issues for parents of children with special needs, but no two families are the same or have identical needs. Families can be diverse in terms of their experience, resources and expectations as well as their cultural, religious and linguistic influences.”

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A family's journey may follow a different route to that which they had anticipated prior to the birth of their child who has disabilities, their destination is the same as that for any other child, the fulfilment and celebration of their child's potential. It is the child not the disability that should be uppermost in parent's minds.

Counselling and supportive services are needed for families struggling with marital conflict and dissolution. These services are also needed for families facing the challenges of educating and caring for children with special needs such as disabilities or developmental delays. In addition, many families face major life stressors such as a loss of income, terminal illness, or the death of a loved one. Providing services for families encountering these events should be a top priority for any health care system. This unit throws light on the various facets of parenting.

6.2 OBJECTIVES

- Explore the role of Parents as partners in rearing children with special needs
- Identify variables that support family-centered practice.
- Analyse the various structure of families and their impact on parenting
- Analyse the role played by parents from minority communities
- Analyse the role played by Parents with multiple responsibilities
- Comprehend the influence of family beliefs about parenting, child learning and impairment
- Choose effective ways to support families of children with special needs.

6.3 PARENTS AS PARTNERS IN REARING CHILDREN WITH SPECIAL NEEDS

Parenting takes place in many diverse family contexts (e.g., nuclear family, single parent, adoptive, blended or stepfamily, foster or kinship care, multigenerational or multiple family households).

There is no single right way to raise children and many different parenting arrangements can be made to work or fail. Living arrangements for the care of children can be complex and may change over the course of a child's development by choice or necessity following major changes or transitions in families, such as relationship.

Even though most people become parents and everyone who has ever lived has had parents, parenting remains a most mystifying subject. It is the entrusted and abiding task of parents to prepare their offspring for the physical, psychosocial, and economic conditions in which they will eventually fare and, it is hoped, flourish. Amidst the many influences on

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child development, parents are the “final common pathway” to children’s development and stature, adjustment and success.

Recommendation (2006)¹⁹ of the Council of Europe on policy to support positive parenting lists two basic principles for implementing parenting support programmes: They should be characterized by equal focus to strengths, resources, protection factors and risk factors, which means focus on the recognition and evaluation of the strong points of the parents, stakes in the interpersonal relationships and the community and creation of new possibilities of achieving the parents’ potential.

Experts in parenting support programmes treat the parents who participate in them as active participants, persons who make decisions concerning their lives for which they are responsible, who cope with the circumstances in their lives, who are "experts by experience" and holders of social rights (including the right to support to which they are entitled as parents).

6.3.1 Partnership model

Partnership means that the experts and parents are on the same level; the former are experts on theories on child development and parenting, and the latter are experts on their children and themselves. If the experts are ready to "let go" of their role as experts in raising children and accept that they do not know best, they will be able to engage in an authentic and sincere dialogue with the parents and be prepared to learn from them. This calls for a non-authoritative approach which enables the expert’s personal authority to be established (Breton, 1994).

6.3.2 Empowerment Model

A consistent implementation of the described principles requires a change from the approach to parents which has been traditionally based on the deficit model (where the parents are viewed through the prism of their shortcomings) to the approach based on the empowerment model (Felt, 2007).

In the empowerment model, experts no longer see their role in determining (as experts) the needs of the parents and what they should do to be "better parents". Instead, they view the parents as partners with whom they cooperate so that the parents could find a way to fulfil their parental responsibilities for their child's well-being and their own pleasure.

Experts draw on their professional and personal experience to offer to the parent new ideas for verification, inspiration and orientation, and provide feedback and support. They also learn and develop their own competence from the experience and reactions of the parents.

6.3.3 Collaboration with Health Professionals

When parents are partners with health professionals and educational specialists from the beginning, the process of determining the best pathway for a child with special needs becomes more of a discovery and less of a tumultuous trip. They share their perceptions and concerns with a circle of professionals who help them to navigate the Special Education system. The sooner a parent of a special need’s child becomes part of a team the sooner support for the student can begin to foster professional collaboration.

NOTES**6.3.4 Collaboration with Educational Professionals**

When parents are partners with teachers and with special education administrators a relationship of trust and respect can be developed. The educator can work to provide strategies and the parent can collaborate with the teacher to support those strategies. The relationship between all parties develops into comfortable environment of trial and error, one that involves reciprocity of trust.

6.3.5 Parents as Experts

Parents are experts on their children and possess a great deal of information that teachers do not have. Their insights can be useful in building educational programs that might help their children to succeed. Parents should be asked about their children and listen to what is shared. Individuals' beliefs about parenting arise from a variety of interactions over the life course but may be shaped most prominently by their experiences of being parented in childhood. Interactions with a spouse or partner also can influence parental beliefs.

Without mutual and reciprocal advocacy for the welfare of the special need's child, the partnership will not evolve. When one or more parties are absent or uninvolved the relationship can be strained, adversarial, and non-communicative. The best pathway is a pathway where parents are partners.

Check your progress- I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the role of parents as partners of rearing children with special needs.

ii) State the need to collaborate with educational professionals

6.4 RESPECTING PARENT PRIORITIES

Parenthood is a position whose primary object of attention and action is the child. But parenting also has consequences for parents. Parenthood is giving and responsibility, but parenting has its own intrinsic pleasures, privileges, and profits as well as frustrations, fears, and failures. Parenthood can enhance psychological development, self-confidence, and sense of well-being, and parenthood also affords opportunities to confront new challenges and to test and display diverse competencies.

Parents can derive considerable and continuing pleasure in their relationships and activities with their children. But parenting is also fraught with small and large stresses and disappointments. The transition to parenting is formidable; the onrush of new stages of parenthood is relentless.

A. Recognize parents as ultimate Decision-makers

Parents are the one constant influence and, parents receive a great deal "in kind" for the hard work of parenting they are often recipients of

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unconditional love, they gain skills, and they presence in their child's life. They are actively concerned about all the aspects of a child's life.

At times, parent might act in a way that a teacher and professionals doesn't understand. It might be that the parent's behaviour is based on factors, such as past experiences, of which the teacher is unaware. Each encounter with a parent is an opportunity to build the relationship.

B. Respect differing cultural viewpoints

It is important to develop an awareness of how people of different ethnicities and cultures view disabilities. Various cultures may view disability as:

- ✓ A reflection of individual differences, for which adaptations and accommodations must be mandated.
- ✓ Something that brings shame or pity to families
- ✓ A stigma, particularly as pertains to mental illnesses or developmental disabilities
- ✓ A spiritual event or occurrence
- ✓ A gift or blessing

We need to respect the fact that parents from some cultures will wish to take on the role of active partners with the school, whereas parents from other cultures might tend to view professionals as experts and assume a more deferential posture. The best source of information about the family is the family members themselves. Understanding their own culture and system of beliefs and values will help to recognize how these might influence how they view others.

C. Focus on the positive side

Bugental (1992) proposed that abusive parents have "threat-oriented schemas" that make them prone to attribute high levels of control to their children and low levels of control to themselves when problems arise in interactions with their children. If parents perceive themselves as unable to exert control in care giving situations, they are unlikely to be effective, and viewing their children as blameworthy in these situations is likely to lead to punitive behaviour. Discussions can be designed to explore positive solutions while focusing on the child's strengths rather focusing on their difficulties.

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i) State why parents are called as the ultimate decision makers of a child's growth.

6.4.1 Active Listening

Active listening is a way of listening and responding to another person that improves mutual understanding. Listening is the chief skill that every parent should practise. Hearing empathetically to their disappointment when they do not make the team; accepting their frustration

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when their plans do not work out; and acknowledging their dissatisfaction when they complain are the main components of parenting practise. It can feel like a relief to learn that parents need to “fix” everything. In Active listening, there is no judgment or evaluation of what the child is saying.

Really listening is the best way to create a caring relationship in which they see the listener as a corner to which they can look forward for their support in tough times. Having a secure relationship is a strong factor in developing a resilient, responsible and caring person.

- A. Concentrate completely on what your child is saying
- B. Avoid interrupting
- C. Repeat back to the child what they said

Once the child has finished speaking, say back to them what the parent has understood. We can add details and suggest an emotion that they may be feeling.

6.4.2 Accommodating Special Circumstances

Accommodating children with special needs comes with unique responsibilities and enormous rewards. Modifications both in physical space and to parenting style are often necessary to accommodate them. Modifications mean change, while making accommodations means adapting to those things you can't change existing circumstances. Interventions involve skill-building strategies that are designed to move special children to more advanced levels.

Check your progress-III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the need for active listening.

ii) Examine why accommodations are required to nurture children with special needs.

6.5 PARENTING IN DIFFERENT FAMILY CONTEXTS

Parenting takes place in many diverse family contexts (e.g., nuclear family, single parent, adoptive, blended or stepfamily, foster or kinship care, multigenerational or multiple family households). There is no single right way to raise children and many different parenting arrangements can be made to work or fail.

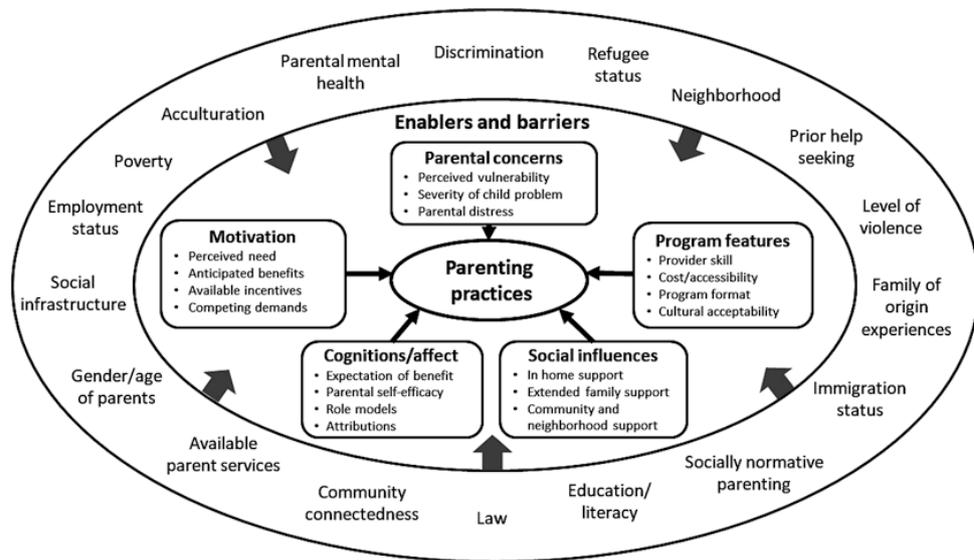
Living arrangements for the care of children can be complex and may change over the course of a child's development by choice or necessity following major changes or transitions in families, such as relationship breakdown, re-partnering of parents, incarceration of a parent, death of a parent, or because of displacement, war, or natural disaster.

Although there is no single-family configuration that is essential to produce healthy, well-adjusted children, there is still some stigma associated with being raised in non-traditional household arrangements in

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any community. For example, an increasing number of children are being raised in households by gay or lesbian couples and, contrary to conservative concerns, parents’ sexual orientation has little if any direct impact on children’s development (Patterson, 2017).

Children can thrive in any environment that creates a loving, stable, secure family context that caters for children’s social, emotional, and physical needs. Conversely, regardless of the type of parenting situation children are raised in, if children experience harsh, coercive, unpredictable, or chaotic parenting and living arrangements, with high levels of family conflict, they are at increased risk for adverse developmental outcomes (Bright & Thompson, 2018). In addition, if parents feel unsupported, judged, criticized, and blamed, and cannot access basic assistance (such as quality parent education support or paid parental leave) they can find the task of raising children a challenging one.



Several society-wide changes all over the world have produced a variety of shifts early family relationships. Fertility rates and family size have decreased, the percentage of women in the workforce has increased, the timing of onset of parenthood has shifted, divorce rates have risen, and the number of single-parent families has increased. The effects of two of these changes: -timing of parenthood and recent shifts in family employment patterns are explored to illustrate the impact of social change on father–child and family relationships. Exploration of these shifts will serve to underscore an additional theme, namely the importance of considering the historical period or era in which social change occurs.

Check your progress-IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Examine the ways of raising a child.

NOTES**6.5.1 Single Parent Families**

Rearing a child with disabilities is a challenge, that too for single parents who most often are women. Stress and negative psychological effects have been considered likely outcomes for parents of children with disabilities. Single mothers of children with disabilities often were younger, had less education, and lower incomes.

Being a single parent is difficult. Raising a child with special needs is challenging. Taking care of a child with medical issues, developmental delays and/or physical limitations requires physical and emotional endurance that is challenging even for a team of parents. The absence of a partner can feel especially stressful because single parents of children with special needs must navigate through the maze of doctors, therapists, social services and special education programs on their own.

Being a single parent with a child with special needs can be very isolating. It is essential to find support through formal support groups, parents of other children with special needs or even with online support groups. It's vital for a single parent of a child with special needs to have at least one person who "gets it" to talk to.

The challenges and struggles of a single parent raising a child with special needs are complex and plentiful, requiring patient navigation through an intricate system of programs and services. Despite the struggles, parenting a child with special needs, as with any child, is full of rewards. Parents describe developing a close relationship with their children, celebrating every milestone, and feeling accomplished and proud of successfully parenting alone under tough circumstances as just a few of the special aspects of parenting a special child.

Single parents may need someone close enough to talk to and to sometimes ask for relief or a respite. A child can never be a substitute for contact with other adults. As a single parent, you run the risk of trying to compensate for the missing parent and binding a child so tightly that breaking free later in life can be threatening."

A. Isolated at home

The ability to contain an autistic meltdown gets much more difficult as the children get bigger and stronger. We need to consider things like wheelchair accessibility, and the amount of sensory stimulation our children will be exposed to before going anywhere.

B. Difficulty faced by single parents

While special children's lives revolve around doctors, procedures, and therapies everyone else is using their time into sports practice, dance lessons, gymnastics, boy/girl scouts and every other "normal" activity children participate in. the single parents feel isolated in managing the requirements of the special children all alone.

C. Financial constraints

Their lives of children with disabilities are filled with medical appointments, procedures, equipment, home modifications, therapies, adaptive devices, time missed at work. The worst part of

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this reality is that when it comes to children with disabilities, therapies, medical help, special education services etc., are added expenses which the parent must manage.

Check your Progress-V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the hurdles faced by single parents in parenting

6.5.2 Working parents

Working parents of children with special needs have lot of questions, anxieties, and tendency to over-identify with their children. Parents with special children will need to be flexible, creative, which working parents find it difficult as their corporate demands pressurize them. There are many other aspects in parenting that erect challenges in parenting and they are:

A. Time- a scarce resource

The most important challenge that many parents face is the scarcity of time. The twenty-four hours in a day must be juggled between, home, office, children and self. It is quite difficult to reserve time for each of such requirements in the best possible way. Better planning management of time may help parents to meet the life with grace and accomplish all the demands and requirements of it. Children are to be considered important elements of life and solid share of time should be reserved for parenting.

B. Imbalanced life

Balancing between all these requirements is a tiresome task, and as a result many parents become highly imbalanced in life. Balancing life by preplanning the ways of performing the required duties is essential key to facing the challenges in life and becoming effective parents. Realize the possible imbalances in life and be prepared to react to them in the best possible, positive manner.

C. Emotional dissolution

The lack of emotional bondage is a challenge many parents face in life. They may lose time and mind to spend with children to create the emotional bondage with them. Knowing the feelings of each other is essential to grow affectionately. When the emotional bond between parents and children get broken, they go astray from parents and live in their own world.

Working parents are very much occupied with their coordination of complex routines. Managing the childcare, observing symptoms, coordinating specialist visits, administering the medications, occupational therapists, behaviour therapist and speech therapists are tedious.

Check your Progress - VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i) State the hurdles faced by working parents in parenting children with disabilities.

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6.5.3 Parents from minority communities

Parenting has increasingly become the focus for policy and academic debate. Although much concern is expressed about 'differential' parenting practices and the poor outcomes relatively little is known about parenting in minority ethnic communities. As the world becomes increasingly multi-ethnic comprising diverse religious and cultural traditions, it is important that an adequate understanding is developed of the needs and concerns of racially and ethnically differing groups.

The racial and cultural heterogeneity of the Indian society also invites considerable attention to many aspects of the lives of minority ethnic families. Yet, there is little empirical evidence into ethnicity, parenting and family life. This study, by Ravinder Barn at Royal Holloway, University of London, explores the views and experiences of 'ordinary' parents to increase our understanding in some key areas, including family support, education, child discipline and the process of acculturation.

- Minority ethnic family life is complex and needs to be understood in the context of migration, ethnicity, socio-economic circumstances, multiculturalism, and racism.
- Contact with family and friends varied across ethnic groupings. Minority ethnic families reported more frequent contacts with the wider family network than white families. White families reported more frequent contact with friends.
- The impact of migration and the fragmentation of families affected the extent to which wider family members were available to support some minority ethnic families.
- The demarcation between public and private concerns seems to be in evidence in different ethnic groups. Some ethnic groups felt able to raise concerns about poor housing and lack of finance; they were less likely to vocalise their children's behaviour as problematic to outsiders.
- The task of ethnic and racial socialisation is a challenging but important one for minority parents and children. In addition to creating a positive, nurturing and supportive environment, minority parents have additional tasks of giving positive messages about difference and diversity and to develop a sense of belonging.
- Parents employ a range of discipline strategies. The findings challenge the supposition that physical punishment is more prevalent or harsh in some minority cultures.

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- Most parents wished to be involved in their children's education, regardless of ethnic background and socio-economic status.

6.5.4 Parents with multiple responsibilities

Parents are responsible to provide the necessary food, clothing, shelter and medical care insofar as they are able. They are equally responsible for providing sound education and a sound knowledge of their religion as well as moral training of their children.

Parents of young children with special needs play multiple roles in their children's life. Often, they are the first people to recognize a developmental problem, and they must pursue their concern until they receive a satisfactory diagnosis and find or develop appropriate services for their child. Once they find a suitable treatment program, parents typically are active partners in their child's education to ensure that skills learned in the educational program transfer to the home setting and to teach their child the many behaviours that are best mastered in the home and community.

As members of the individualized education plan (IEP) team, parents may also be active advocates for the child, ensuring that the educational process goes forward appropriately. These many demands on parents occur in the context of family life, including the needs of other children, the parents as individuals and as a couple, and family needs.

Although every special need child is different and every family is unique, there are some common concerns that link parents. These include getting appropriate care and promoting acceptance in the extended family, school, and community. For some, planning for an uncertain future may be necessary.

In addition, the parents of young children may confront sadness, anger, disappointment, or other complex emotions that can accompany the initial discovery that one's child has a significant developmental problem and the ongoing need to make sacrifices to serve the needs of their child. Most families cope effectively with these demands, but some may encounter very substantial stress as they raise their child with disabilities.

Check your progress-VII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i) State the hurdles faced by parents with multiple responsibilities in parenting children with disabilities.

6.6 INFLUENCE OF FAMILY BELIEFS ABOUT PARENTING, CHILD LEARNING AND IMPAIRMENT

Rearing a child with special needs can have profound effects on the entire family—parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning.

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On the positive side, it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a child with disability have far-reaching effects as we describe below. The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available.

For parents, having a child with disability increase stress, take a toll on mental and physical health, make it difficult to find appropriate and affordable childcare, and affect decisions about work, education/training, having additional children, and relying on public support. It may be associated with guilt, blame, or reduced self-esteem.

Parenting is an emotional experience, at turns joyous and frustrating, and how parents regulate and express their affect is critical for their capacity to care for their children. Similarly, cognition plays a central role in parenting: to be responsive to their children, parents must accurately perceive their needs and know how to respond to them, and reasonable discipline requires parents to understand children's capacities, have appropriate developmental expectations, and make appropriate attributions for their behaviour. However, there have been few attempts to develop conceptual models that link parents' behaviour, affect, and cognition.

Family structure also has grown increasingly diverse across class, race, and ethnicity, with fewer children now being raised in households with two married parents; more living with same-sex parents; and more living with kinship caregivers, such as grandparents, and in other household arrangements.

Lastly, parenting increasingly is being shaped by technology and greater access to information about parenting, some of which is not based in evidence and much of which is only now being studied closely. Other accommodations to special circumstances services are transportation and developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education, and includes...

- Speech-language pathology and audiology services
- interpreting services
- Psychological services
- Physical and occupational therapy
- Recreation, including therapeutic recreation
- Early identification and assessment of disabilities in children
- counseling services, including rehabilitation counseling
- Orientation and mobility services
- Medical services for diagnostic or evaluation purposes
- School health services and school nurse services
- Social work services in schools

There are others that states and schools routinely make available under the umbrella of related services. The IEP team decides which related services a child needs and specifies them in the child's IEP.

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Supplementary Aids and Services

One of the most powerful types of supports available to children with disabilities is the kinds of services that a child needs to be educated with non-disabled children to the maximum extent appropriate. Some examples of these additional services and supports, called supplementary aids and services are:

- ✓ Adapted equipment such as a special seat or a cut-out cup for drinking;
- ✓ Assistive technology such as a word processor, special software, or a communication system;
- ✓ Training for staff, student, and/or parents;
- ✓ Peer tutors;
- ✓ Adapted materials such as books on tape, large print, or highlighted notes; and
- ✓ Collaboration/consultation among staff, parents, and/or other professionals.

Team members talk about the child's needs, the curriculum, and school routine, and openly explore all options to make sure the right supports for the specific child are included.

The above changes in the world's demographic, economic, and technological landscape have created new opportunities and challenges with respect to supporting parents of young children.

Check your progress-VII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State why Family beliefs influence child learning.

6.8 LET US SUM UP

Of all the modifiable factors that influence the course of a child's development, none is more important than the quality of parenting children receive (Collins, Maccoby, Steinberg, Hetherington, & Bornstein, 2000). Being a parent can be a wonderfully fulfilling role that brings immense joy, pride and happiness to the lives of parents. At times, the parenting role can also be challenging, and for some it can become quite overwhelming. In essence, parenting is easier and less stressful when families live in environments that are conducive to good parenting. When parenting occurs in communities that support parenting, and value the parenting role, have safe, low crime neighbourhoods, children, parents and the community benefit.

Conversely, too many children live in homes with few of the advantages above, where daily living is a struggle, and family members are exposed to chronic stress. For example, an estimated 17% of children under the age of 15 live in poverty (up from 15% a decade earlier), and 22% of children are developmentally vulnerable, with more developmentally vulnerable children in low-income areas and Indigenous families. When parents are socially isolated from partners due to

relationship breakdown and have little or no access to extended family support, raising children solo can be a very demanding responsibility.

Other stressful life circumstances include parents being exposed to violence (intimate partner, domestic, or community violence), experiencing or living with someone with serious mental health issues, substance abuse, chronic physical health problems, homelessness, or involvement with the criminal justice system. High levels of stress diminish parental self-efficacy (Crnic & Ross, 2017) and parenting capacity. Children raised in toxic family environments are vulnerable over their life course to developing serious social, emotional, health, and mental health problems (Centre on the Developing Child at Harvard University, 2016).

When parenting occurs in a very low resource setting, children's health and development are adversely affected (American Academy of Paediatrics, 2016). Many very low resource settings are affected by high rates of violence, political instability leading to war and internal displacement of people, natural disasters such as floods and landslides, and few financial resources to tackle complex problems like poor sanitation, water, and food security (Mejia, Calam, & Sanders, 2012). Everyday life is characterized by high levels of toxic stress and ensuring children's survival is the major challenge for parents.

A greater understanding of the fundamental importance of the parenting role itself is required. This includes knowing how parenting shapes children's developmental competence, well-being and life course opportunities. It also includes understanding the determinants of parents' capabilities to raise their children at different developmental stages and promote healthy development. The determinants of parenting are complex (Belsky, 1984).

A host of genetic and biological factors (that are mostly non-modifiable by parents) interact with environmental and cultural factors (that, in theory, can be changed) to determine the kind of parenting children experience as they grow up. This chapter provides an overview of the importance of the parenting role in influencing the course of children's development and the determinants of parental behaviour, parental knowledge, and parenting practices.

6.9 UNIT END EXERCISES

1. Analyse the role of parents in serving as partners in rearing children with disabilities.
2. Accommodating parent priorities enables families to rear children with disabilities-justify
3. What are the difficulties faced by single parents in rearing special children?
4. Family beliefs influence parenting practices-state how.

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6.10 ANSWERS TO CHECK YOUR PROGRESS

- ✓ Parents are experts on their children and possess a great deal of information that teachers do not have. Their insights can be useful in building educational programs that might help their children to succeed. Parents should be asked about their children and listen to what is shared.
- ✓ When parents are partners with teachers and with special education administrators a relationship of trust and respect can be developed. The educator can work to provide strategies and the parent can collaborate with the teacher to support those strategies. The relationship between all parties develops into comfortable environment of trial and error, one that involves reciprocity of trust.
- ✓ Parents are the one constant influence and, parents receive a great deal “in kind” for the hard work of parenting they are often recipients of unconditional love, they gain skills, and they presence in their child’s life. They are actively concerned about all of the aspects of a child’s life. At times, parent might act in a way that a teacher and professionals doesn’t understand.
- ✓ Active listening is a way of listening and responding to another person that improves mutual understanding. Listening is the chief skill that every parent should practice. Hearing empathetically to their disappointment when they do not make the team; accepting their frustration when their plans do not work out; and acknowledging their dissatisfaction when they complain are the main components of parenting practice.
- ✓ Accommodating children with special needs come with unique responsibilities and enormous rewards. Modifications both in physical space and to parenting style are often necessary to accommodate them. Modifications mean change, while making accommodations means adapting to those things you can’t change existing circumstances.
- ✓ There is no single right way to raise children and many different parenting arrangements can be made to work or fail. Living arrangements for the care of children can be complex and may change over the course of a child’s development by choice or necessity following major changes or transitions in families, such as relationship breakdown, re-partnering of parents, incarceration of a parent, death of a parent, or because of displacement, war, or natural disaster.
- ✓ Being a single parent is difficult. Raising a child with special needs is challenging. Taking care of a child with medical issues, developmental delays and/or physical limitations requires physical and emotional endurance that is challenging even for a team of parents. The absence of a partner can feel especially stressful because single parents of children with special needs must navigate through the maze of doctors, therapists, social services and special education programs on their own.
- ✓ Working parents of children with special needs have lot of questions, anxieties, and tendency to over-identify with their children. Parents with special children will need to be flexible,

creative, which working parents find it difficult as their corporate demands pressurize them.

- ✓ Although every special need child is different and every family is unique, there are some common concerns that link parents. These include getting appropriate care and promoting acceptance in the extended family, school, and community. For some, planning for an uncertain future may be necessary.

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UNIT VII

Structure

- 7.1 Introduction
- 7.2 Objectives
- 7.3 Challenges in rearing special needs children
- 7.4 Different concerns related to parenting
 - 7.4.1 Medical Issues
 - 7.4.2 Behaviour Issues
 - 7.4.3 Developmental Issues
 - 7.4.4 Learning Issues
 - 7.4.5 Mental Health Issues
 - 7.4.6 Common Concerns
- 7.5 Management of the Challenges
- 7.6 Role of Professionals
- 7.7 Economic Status
- 7.8 Family structures
- 7.9 Parental attitudes
- 7.10 Parental Participation
- 7.11 Societal Role in Rearing Special Children
- 7.12 Approaches to positive parenting
- 7.13 Let us sum up
- 7.14 Unit end exercises
- 7.15 Answers to check your progress
- 7.16 Suggested Readings

7.1 INTRODUCTION

Children with or without disabilities can thrive in any environment that creates a loving, stable, secure family context that caters for children's social, emotional, and physical needs. Conversely, regardless of the type of parenting situation children are raised in, if children experience harsh, coercive, unpredictable, or chaotic parenting and living arrangements, with high levels of family conflict, they are at increased risk for adverse developmental outcomes.

In addition, if parents feel unsupported, judged, criticized, and blamed, and cannot access basic assistance (such as quality parent education support or paid parental leave) they can find the task of raising children a challenging one. Parenting empowerment is both the 'means' and the 'end' of effective parenting education.

A parenting empowerment philosophy emphasizes the need to help parents analyse and solve their own parenting problems. A definition for parenting empowerment is knowing what families want for their children and having the tools and resources to effectively support these goals.

Parenthood is, perhaps first and foremost, a functional status in the life cycle: Parents issue as well as protect, care for, and represent their progeny. But human development is too subtle, dynamic, and intricate to admit that parental care giving alone determines the developmental course and outcome of ontogeny. It is hard to be a grownup, difficult to be a parent, even more challenging to be a parent of a child with special needs.

The parent has to become the analyst, the interpreter, the problem

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solver, the cheerleader, the lawyer, the psychiatrist, the spiritual advisor, the organizer, the note taker, the friend, companion, advocate, and disciplinarian. Most parents use every resource they have to help their child flourish, and yet, they worry they are not doing enough or a good enough job. Professionals need to realize and appreciate the heavy load carried by parents of children with learning disabilities, ADHD, and other related disorders.

Parenting discussion groups can bring attention to parents' vital roles, as well as strengthen their skills. The parenting curriculum aims to do the following: create awareness of the importance of the caregiver's role in relation to supporting children's wellbeing (growth, development and learning and protection); strengthen or modify caregiver's attitudes, beliefs, and practices in relation to caring for children; and develop motivation to work as a team with other members to address community issues that affect children. It is important to have an outreach strategy because some parents who need parenting education the most might be reluctant to participate in parental skills programs.

7.2 OBJECTIVES

After going through this unit, you will have an understanding about:

- The challenges in rearing special needs children
- Different Concerns related to parenting children with special needs
- Medical Issues
- Behaviour Issues
- Developmental Issues
- Learning Issues
- Mental Health Issues
- Common CONCERNS of parents

7.3 CHALLENGES IN REARING SPECIAL NEEDS CHILDREN

Parenting a child with special needs is challenging. It requires extra effort in time, awareness, and education. These considerations will be quite different from one child to the next because 'special needs' is used as an umbrella term to encompass anything from light learning disabilities to more severe behaviour and sensory issues. Proper diagnoses ensure parents to focus on the right methods and activities for their child.

Special needs are commonly defined by what a child *can't* do milestones unmet, foods banned, activities avoided, or experiences denied. These hindrances can hit families hard and may make special needs seem like a tragic designation. Some parents will always mourn their child's lost potential, and some conditions become more troubling with time.

Children with differences are all around us. These children and their parents probably spend more time trying to fit into the mainstream world than the mainstream tries fitting into theirs occasionally even making

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special needs parents and their children feel like outsiders. There are some unique challenges parents face in rearing children with special needs:

A. Family relationship

Often, raising a special needs child requires so much time, energy, and resources that other relationships within the family start to suffer. Parents will need to remember that their spouse, their relationship, and the children's relationship with their siblings need just as much consideration and effort. Ensuring that everyone is talking and knows what is going on helps a great deal to build patience and understanding for everyone.

B. Social Impact

In many cases, children with special needs require specialized education that keeps them separate from other children. This can make the child's socialization much harder, and it can also alienate and isolate the parents from other parents of children with special needs. This can eventually negatively affect the emotional and psychological state of the parents and the special needs child. Parents should try to find support groups within these specialized programmes in order to be able to connect with other people who are going through the same challenges.

C. Emotional exhaustion

Caring a child with a disability is a stressful experience for parents. It triggers a range of emotions and feelings that require a set of behaviours and attitudes to manage daily life. To face this situation, parents use coping strategies. As per studies 68% of the parents with special needs had anxiety disorder and 52% suffered depression. Depression was frequent among mothers.

D. Physical exhaustion

The parents of children with disability were found to have intense physical and emotional fatigue, agitation, tension and nervousness. The parents described suffering fatigue which goes along with a kind of constant nervousness. Sometimes they felt like all their nerves are agitated. Specific physical symptoms were also reported pain in the neck, tinnitus, and headaches.

E. Stress

The burden of stress is great for parents of those with special needs. A recent study found that mothers of adults with disability had greater levels of stress hormones comparable to soldiers in combat. Finances are often a source of stress. Usually the mother sacrifices her career to attend to the child's needs with a resulting loss of income for the family.

G. Guilt

The limits of the parent's ability to protect the child, the lack of time management to show attention toward other children, spouse and

aging parents, resentment of those with “normal” children leads to a feel of guilt.

H. Feelings of isolation

Missing out on many family-oriented activities because of child’s disability prevents her/him from participating, criticism and judgment faced about parenting from others who don’t understand your child’s disability makes parent feel left out.

I. Grief

The loss of hopes and dreams parents had for their child, not having the normal parenting experience leading to chronic sorrow.

J. Financial Crisis

Financial stressors tend to be higher among parents of children with developmental disabilities, which may negatively impact parents’ mood and well-being.

Check your progress - I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the dimensions of challenges faced in rearing special needs children.

7.4 DIFFERENT CONCERNS RELATED TO PARENTING CHILDREN WITH SPECIAL NEEDS

Children with special needs are more likely to develop significant emotional and behavioural problems than their normal counterparts. These problems are also one of the main predictors of stress and emotional adjustment difficulties in parents of children with disabilities. It is widely recognized by both service providers and parents that, in order to reach their potential, children with special needs require additional support.

However, in their efforts to both support and protect their children, parents of children with disabilities may in fact, inadvertently prevent their children from learning the very skills they require to live independently. If parents attribute a child’s behaviours to inherited factors it may prevent them from trying to change the behaviour. In order to reach their potential, it is important to develop strengths-based focus.

For children with disabilities, developing an effective communication system is essential not only to help children learn but also to prevent behaviour problems that may occur as a result of the frustration that children with disabilities can experience trying to communicate their needs. Visual schedules, forward and backward chaining, and additional rewards, are all important strategies parents can utilize to assist children with disabilities to learn new skills and develop their capacity to work and ultimately live independently.

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7.4.1 Medical Issues

Children with disabilities may also have one or more significant medical problems that require intensive and ongoing care. Medical issues for children with special needs include serious conditions like cancer, heart defects, muscular dystrophy, and cystic fibrosis. It also includes chronic conditions like asthma and diabetes, congenital conditions like cerebral palsy and dwarfism, and health threats like food allergies and obesity. A child may need frequent medical testing, hospital stays, equipment, and accommodations for disabilities. Establishing a good support system is very important when dealing with uncertainty and any medical crises.

Having a child with a developmental disability can be stressful. Some developmental diagnoses are considered life-long chronic conditions that may require ongoing parental support beyond the age that other children reach independence. Furthermore, many of the therapies recommended for young children depend on parents to implement strategies at home throughout the day, presenting additional demands for parents.

7.4.2 Behaviour Issues

Children with behaviour issues may not respond to traditional discipline. Diagnoses like ADHD, foetal alcohol spectrum disorder (FASD), dysfunction of sensory integration, and Tourette's syndrome require specialized strategies that are tailored to their specific needs. Behaviour issues can increase the risk of problems at school. As a parent, you will need to be flexible, creative, and patient.

Challenging behaviours like temper tantrums, repetitive behaviours and aggressive behaviour are being particularly stressful. Tantrums are often being unpredictable and difficult to manage. Some parents get stressed as feel it's atypical, to either the age of the child or the duration of the tantrum. Behavioural difficulties such as aggression, can contribute to the risk of parental depression

7.4.3 Behaviour Issues due to Sensory and social problems

Sensory problems associated with noise, smell, touch, visual sensitivity, vestibular sensitivity which caused some challenges for parents, who had to adapt the environment to suit the needs of the child. Like the use of earmuffs to reduce the auditory sensitivity of the child. The children who were diagnosed with autism found it difficult to relate to others, understand others, or even tolerate the presence of others. Parents described their child as a "loner" or "isolated", at this difficulty in socializing.

7.4.4 Developmental concerns

Developmental disabilities can change your visions of the future and provide immediate difficulties in caring for and educating your child. Diagnoses like autism, Down syndrome, and intellectual disabilities often cause children to be removed from the mainstream. Quite often, parents become fierce advocates to make sure their children receive the services, therapy, schooling, and inclusion they need and deserve. Developmental conditions can affect a child's ability to sleep independently throughout the

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night, contributing to parents' sleep deprivation and exacerbating depressive symptoms.

The stress of a serious illness, developmental disability in a child often causes problems in a family, particularly if each parent or adult caregiver attempts to deal with his or her own fears and frustrations related to the disability alone and without support.

In some instances, mothers and fathers become consumed with the care of their child with a chronic illness or disability, at the expense of nearly everything else in their lives. In these situations, parents may find themselves almost constantly looking for new options, reading about alternative treatments, and thinking about the future.

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the medical issues faced by parents of children with special needs.

ii) What are the Developmental concerns related to parenting children with special needs?

7.4.4 Learning Issues

Children with learning disabilities like dyslexia and auditory processing disorder (APD) struggle with schoolwork regardless of their intellectual abilities. They require specialized learning strategies to meet their potential and avoid self-esteem problems and behavioural difficulties.

Parents of learning-challenged children need to be persistent. This includes working with your child at home as well as teachers and schools to ensure they get all the help they need.

Parenting children with learning disabilities requires a high level of knowledge and access to resources, information and services. Parents in a developing country, face challenges addressing children's learning and other developmental disabilities, including challenges related to preventative and supportive interventions.

They also lacked an awareness of the availability of programmers, services and policies meant to benefit their children with learning disabilities. Participants voiced that they, their children with learning disabilities and community members have stereotypes and prejudices regarding learning disabilities. Majority of them indicated that they struggle to meet the financial and material needs of their children.

7.4.5 Mental Health concerns

Parents and guardians play a major role in helping children grow and develop to their full potential. As children grow in the families they most significantly depend on their parents or guardians for basic needs support such as food, shelter, education, protection and care always, but

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especially during life difficulties and times of crisis. Mental disorders in childhood and adolescence can be chronic and very disturbing, requiring proper attention, help and support from caregivers.

Thus, parents or guardians and relatives living with children with mental illness have additional responsibilities and roles to care for them as they do for other healthy children. In this study 'children' means any male or female persons not more than twelve years of age, and a 'parent' is a biological mother or father or anybody who assumes that role. The importance of family support for the growth and development of children and the role it plays as a determinant of whether children will receive mental health care or not.

Check your progress-III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i) Analyse the mental health concerns faced by parents of children with special needs.
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7.4.6 Common Concerns

These families will have different anxieties than one dealing with mental illness, learning problems, or behavioural challenges. Special needs are a very broad term and every situation is unique. Families should focus on seeking the help and guidance needed for their particular concerns. Other Common Challenges in rearing Children with Special Needs are:²

- Learning about the disability researching
- Locating and accessing effective treatments and resources
- Coping with the emotional and physical demands of caring for an individual with a disability
- Getting to the innumerable appointments with medical providers, therapists, advocates, and school personnel
- Advocating for appropriate school interventions, accommodations, and/or placements
- Paying for the many treatments and interventions not covered by health insurance or the school system

7.5 MANAGEMENT OF THE CHALLENGES

Parents of children with special needs are often exhausted and frequently become depressed. Their reserves of time and resources for self-care are even more depleted than those of parents of typical children. Yet their need for refuelling is also greater. To be sustained through the marathon of caring for a child with special needs, it is essential that parents

attend to their own needs. There is useful information throughout this website on caring for one's self and well-being.

Often the most beneficial support and information parents receive are from other parents of children with special needs. In recognition of this, a group of parents founded a peer support network to help parents connect with other faculty and staff who are caring for a child with a disability. The network created a secure website where parents share their stories and invite other parents to contact them for support, resource information, and guidance.

Families those who communicate openly can be strengthened by experiences associated with managing their child's health condition or disability. In many cases, the family's management of a child's chronic condition may provide them with a sense of cohesiveness, mission, mastery, and pride which builds the resiliency of the family.

7.5.1 Role of Professionals

Physicians, psychologists, social workers, family therapists, and parents of other children with chronic illnesses and disabilities are very important resources for helping to work through family problems. Social networks can also be valuable sources of support for you in your community such as condition specific support groups, faith-based groups, extended family, and friends.

To better support parents and children, then, improved referral mechanisms are needed. Millions of parents interact with health care (e.g., well-child and mental and behavioural health care), education (e.g., early care and education, and other community services).

7.5.2 Economic Status

Parenting of young children today takes place in the context of significant ongoing developments. These include a rapidly growing body of science on early childhood that has provided a more nuanced understanding of the critical periods in early childhood development and parenting.

In addition, while child poverty has increased in recent years, there have been increase in funding for programs and services for families, such as early childhood education, home visiting, and income support programs, which have implications for the development of a framework for better supporting parents of young children.

Check your progress-IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the role played by professionals in parenting children with special needs.

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7.5.3 Family Structure

The strengths of evidenced-based training in parenting skills offer a foundation for improving existing and developing new interventions that can serve greater numbers of families with special needs. The design of new interventions should be informed by elements of successful programs, which include treating parents as equal partners, tailoring interventions to meet families' needs, making programs culturally relevant, ensuring service integration and collaboration for families with multiple needs, providing opportunities for peer support, addressing trauma, and targeting both mothers and fathers.

Substantial evidence shows that young children have optimal developmental outcomes when they experience nurturing relationships with both fathers and mothers. Research also demonstrates that children benefit when the parents who are living in the same household are supportive of each other and are generally consistent in their expectations for the child and in their parenting behaviours. Further, there is evidence that when parents live apart, children generally benefit if they have supportive relationships with each parent, at least in those cases in which the parents do not have negative relationships with each other.

In contrast, children are placed at risk when their parents experience conflict or when they have very different expectations for the child, regardless of whether the parents are living together or apart. Yet despite the importance of the father-child relationship, fathers continue to be underrepresented in research on parenting and parenting support.

Moreover, very few interventions aimed at improving mother-child relationships also target father-child or mother-father-child relationships, whether the parents are living together or apart. When parents are living apart, fatherhood programs typically focus on building fathers' economic capacity to parent, such as through employment or counselling, rather than on fostering father-child relationships that can promote development.

Check your Progress - V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State how Family structure plays a major role in positive parenting of children with special needs.

7.5.4 Parental Attitude

Parents' attitudes about the roles of parents and others in the raising of young children, as well as about specific practices (e.g., breastfeeding, the role of parents in children's education); contribute to some variation in practices and in the uptake of services for families among individuals and subpopulations. Parenting is a major determinant of children's development and life course outcomes, making it an extremely important target for early intervention, prevention, and treatment.

Strengthening the parenting role has the capacity to influence many diverse outcomes for both children and parents. However, there are other

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important influences on children that interact with the effects of parenting to collectively determine outcomes. These include children's biological makeup, temperament, health and nutritional status, peers, the quality of schooling, neighbourhood and socio-economic influences, and the broader physical environment including exposure to toxins, pollution, and climate change.

Parenting is malleable and parents continue to learn to parent throughout their lifetime, from the anxious beginnings of being a first-time parent to the challenge of being a great grandparent in the later years of life. The social role of being a parent and its associated activities is important to not only the next generation; it has a fundamental role in influencing the personal well-being of parents as adults and the quality of community and family life they experience.

7.5.5 Parental Participation

Parents' engagement in young children's learning is associated with improvements in children's literacy, behaviour, and socio-emotional well-being. Parent engagement is a process that can be facilitated by provider skills in communication and joint decision making with diverse families about their children's education, but programs designed to prepare individuals to work with young children do not always include evidence-informed strategies for creating successful partnerships with families.

Despite growing recognition that partnerships with families contribute to the success of early childhood programs and schools in preparing children for academic success, as well as an emphasis on family engagement in statutes and policies, programs designed to prepare teachers and providers often do not include professional development related to working with parents.

Check your progress-VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i) State why parental participation plays a major role in rearing children with special needs
-

7.6 Societal Role in Rearing Special Children

Parents introduce children to the social world where they develop understandings of themselves and their place and value in society, understandings that influence their choices and experiences over the life course. The task of ensuring children's healthy development does not rest solely with parents or families. It lies as well with governments and organizations at the local/community, state, and national levels that provide programs and services to support parents and families.

Society benefits socially and economically from providing current and future generations of parents with the support they need to raise healthy and thriving children. In short, when parents and other caregivers

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are able to support young children, children's lives are enriched, and society is advantaged by their contributions.

To ensure positive experiences for their children, parents draw on the resources of which they are aware or that are at their immediate disposal. Parents play a significant role in helping children build and refine their knowledge and skills, as well as their learning expectations, beliefs, goals, and coping strategies.

Parents introduce children to the social world where they develop understandings of themselves and their place and value in society, understandings that influence their choices and experiences over the life course.

Check your progress-VII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the role of society in rearing a child with special needs

7.7 APPROACHES TO POSITIVE PARENTING

No single approach will yield the same positive results for all parents; rather, the diversity of parent beliefs, needs, and resources requires a menu of approaches. Nonetheless, several elements are found to be successful across a wide range of programs and services for parents:

- ✓ viewing parents as equal partners in determining the types of services that would most benefit them and their children;
- ✓ tailoring interventions to meet the specific needs of families;
- ✓ integrating and collaborating in services for families with multiple service needs;
- ✓ creating opportunities for parents to receive support from peers to encourage engagement, reduce stigma, and increase the sense of connection to other parents with similar circumstances;
- ✓ addressing trauma, which affects a high percentage of individuals in some communities and can interfere with parenting and healthy child development;
- ✓ Making programs culturally relevant to improve their effectiveness and participation across diverse families; and enhancing efforts to involve fathers as equal partners of parenting.

Check your progress-VIII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State why no single approach can be stated to be appropriate in parenting

7.8 LET US SUM UP

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Parents are among the most important people in the lives of young children. From birth, children are learning and rely on mothers and fathers, as well as other caregivers acting in the parenting role, to protect and care for them and to chart a trajectory that promotes their overall well-being. While parents generally are filled with anticipation about their children's unfolding personalities, many also lack knowledge about how best to provide for them. Becoming a parent is usually a welcomed event, but with the advent of a special child, parents' lives are fraught with problems and uncertainty regarding their ability to ensure their child's physical, emotional, or economic well-being. There is also a greater diversity in family structure as a result of increases in divorce, cohabitation, new types of parental relationships (e.g., same-sex parents), and involvement of grandparents and other relatives in the raising of young children. All of the above changes have implications for how best to support the parents and other caregivers of young children.

In the area of parenting knowledge, the extant research suggests that parental knowledge of child development is positively associated with quality parent-child interactions and the likelihood of parents' engagement in practices that promote their children's healthy development. Research also indicates that parents with knowledge of evidence-based parenting practices, especially those related to promoting children's physical health and safety (e.g., injury prevention, how to sooth a crying infant), are more likely than those without such knowledge to engage in those practices.

Decades of research have demonstrated that the parent-child dyad and the environment of the family, which includes all primary caregivers, are at the foundation of children's well-being and healthy development. From birth, children are learning and rely on parents and the other caregivers in their lives to protect and care for them. The impact of parents may never be greater than during the earliest years of life, when a child's brain is rapidly developing and when nearly all of her or his experiences are created and shaped by parents and the family environment.

Parents help children build and refine their knowledge and skills, charting a trajectory for their health and well-being during childhood and beyond. The experience of parenting also impacts parents themselves. For instance, parenting can enrich and give focus to parents' lives; generate stress or calm; and create any number of emotions, including feelings of happiness, sadness, fulfilment, and anger.

Parents differ considerably in their knowledge of child development and effective parenting practices, their self-efficacy, and their emotional resilience in undertaking the parenting role. For example, Morawska, winter, and Sanders (2009) found that parents with greater knowledge about effective parenting strategies tended to use less dysfunctional parenting and reported significantly higher education and income levels.

Parents with low levels of parenting knowledge and confidence in their parenting skills may be at greater risk of dysfunctional parenting and might benefit from interventions designed to enhance both knowledge and confidence. Individual differences in parents' family of origin experiences,

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financial and other personal resources, coping capacities and life opportunities mean that parents start their parenting journey from different starting points. Because of this variability, parents differ in the type of parenting support they need and seek out.

Some parents need a great deal of support and professional assistance, while others need very little. The level and type of support parents need can change at different stages of the life cycle (e.g., toddlerhood, adolescence) and with changed family circumstances (e.g., divorce, death of a spouse or child).

7.9 UNIT END EXERCISES

1. Elaborate the challenges encountered by parents in rearing special children.
2. Analyze the behavioral issues faced by parents of special children
3. Learning issues are more common among special children-state why
4. Emancipate the role of parents in rearing children with onset of disability.

7.10 ANSWERS TO CHECK YOUR PROGRESS

Family relationship, Social Impact, Emotional exhaustion, Physical exhaustion, Stress, Fear and worry, Feelings of isolation, Grief and Financial Crisis etc., are the various dimensions of challenges faced in rearing special needs children.

Medical issues for children with special needs include serious conditions like cancer, heart defects, muscular dystrophy, and cystic fibrosis. It also includes chronic conditions like asthma and diabetes, congenital conditions like cerebral palsy and dwarfism, and health threats like food allergies and obesity.

A child may need frequent medical testing, hospital stays, equipment, and accommodations for disabilities. Establishing a good support system is very important when dealing with uncertainty and any medical crises.

Developmental disabilities can change your visions of the future and provide immediate difficulties in caring for and educating your child. Diagnoses like autism, Down syndrome, and intellectual disabilities often cause children to be removed from the mainstream. Quite often, parents become fierce advocates to make sure their children receive the services, therapy, schooling, and inclusion they need and deserve.

Parent engagement is a process that can be facilitated by provider skills in communication and joint decision making with diverse families about their children's education, but programs designed to prepare individuals to work with young children do not always include evidence-informed strategies for creating successful partnerships with families.

Parents introduce children to the social world. The task of ensuring children's healthy development does not rest solely with parents or

families. It lies as well with governments and organizations at the local/community, state, and national levels that provide programs and services to support parents and families.

No single approach will yield the same positive results for all parents; rather, the diversity of parent beliefs, needs, and resources requires a menu of approaches- Interventions has to be tailored to meet the specific needs of families, integrating and collaborating in services for families with multiple service needs; create opportunities for parents to receive support from peers, address trauma and make programs culturally relevant.

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UNIT VIII

Structure

- 8.1 Introduction
- 8.2 Objectives
- 8.3 Impact of disability on persons with disability and their families
- 8.4 Reaction of parents/family members
 - 8.4.1 Initial reactions
 - 8.4.2 Acceptance of disability in the person by the family
- 8.5 Reaction of school and society
 - 8.5.1 School experience
 - 8.5.2 Community misconceptions and stigmas
- 8.6 Different ways of coping
- 8.7 Needs and problems of persons with disability and their families
- 8.8 Critical stages in the development
- 8.9 Social work intervention at each stage
- 8.10 Let us sum up
- 8.12 Answers to check your progress
- 8.13 Suggested Readings

8.1 INTRODUCTION

With the birth of the child, every parent is faced with a new role in life and a new challenge to his/her personal growth. When the child is born with a disability, in addition to regular adaptation, the family must cope with stress, grief, disappointments, and challenges, which may lead to a serious crisis or even disruption of family life. Parents of the child with disability, developmental delay or risks meet with an additional series of unexpected challenges and many questions that are not easy to answer.

Parents must coordinate assessments, evaluations, and various treatments while maintaining contact with many professionals and numerous institutions or services. They find themselves faced with important decisions on behalf of the child, decisions on management of the child with disability, and economic decisions that will affect the whole family.

In recent years, parents of children with disabilities have grown increasingly vocal in challenging the barriers that they face in fulfilling their parental role. They, and their organizations, have begun to place issues of importance to children with disabilities on national and local policy agendas, often in collaboration with allies in academia and both statutory and voluntary sectors. They have also sought to transform public and professional perceptions of disabilities as the recipients (as opposed to providers) of 'care'. In this unit, we will discuss about the impact of disability on the child and the family and the social interventions that can help to cope up with the disability.

8.2 OBJECTIVES

Going through this unit, you will be able to

- Outline the reaction of family members.
- Analyse the importance coping mechanism
- Discuss about the social work intervention
- Highlight on stages in development of children with disability

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8.3 IMPACT OF DISABILITY ON PERSONS WITH DISABILITY AND THEIR FAMILIES

The birth of a child with a disability can cause disappointment to the parents and the reaction of the families seems to follow the five stages of the Kubler-Ross grief elaboration theory (denial, anger, bargaining, depression, and acceptance). It should be emphasized that the functional crisis experienced by mothers and fathers of children with a disability may be accompanied by psychological stress, a feeling of loss, and low self-esteem. In addition, the fact that the child is unable to fulfil their expectations may also be disappointing.

The birth of a child with a disability may result in a severe blow to the self-esteem of the parents, create disappointment, and result in the child becoming a social obstacle that will also cause feelings of shame and embarrassment.

Parental reactions to the diagnosis of the disability will not be identical. The intensiveness of reactions and their character depend on several dynamic factors, such as individuality, the character of social relations, feelings about the deviation, and the social status.

In the literature, a wide range of reactions are mentioned, some considered more frequent than the others: anger, disappointment, shame, frustration, and grief. The coping process is not static, but a constantly changing cognitive and behavioural effort by the person to manage both external and also internal stress factors and pressures.

One of the supports that they may need for enabling them to continue to care for their family member at home is short breaks. Short Breaks give them a break from their role as career and provide their family member an opportunity to be with others and benefit from new experiences. Although the intensity varies from one to another, it seems that all parents experience grief. Olshansky argued that this type of grief should not be interpreted as a neurotic reaction, but rather it should be a normal and natural reaction to the crisis. The crisis can take the following forms:

- A. **The change crisis:** This crisis takes place immediately after the diagnosis of the disability and is a most difficult experience. The parents are full of expectation for the birth of a normal child, and when they are informed about the disability, all their dreams are ruined, causing the traumatic reactions. This crisis is not a

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reaction to the handicap itself; rather, it is a reaction to the sudden change of reality.

- B. The ideological crisis:** The change crisis is comparatively short; however, after the parents have digested the news, they must confront this experience every day. This confrontation gives rise to strong emotional reactions, leading to an ideological crisis, which may last for a longer period of time. The parents are in a state of constant ambivalence. On the one hand, they feel that they have to love and protect their child, but on the other hand, social values cause them to feel discomfort, feelings of failure, and inability to accept the child as a “beloved” one. Such characteristic reactions as guilt, shame, overprotection, and grief appear at this stage.
- C. The reality crisis:** This crisis is directly related to the objective difficult conditions of bringing up a child with disability. The parents face numerous difficulties that influence their ability to manage the problem. The first difficulty is financial, since expenses grow considerably compared to their previous situation or to that of other families.

Many parents are disturbed by fears related to the influence the child has and will have on their lifestyle. Family members may stay in seclusion at home and avoid spending their time in the way they used to, before the child was born. Many parents express concern regarding the coming of a time when they will not be able to take care of the child themselves.

8.4 REACTION OF PARENTS/FAMILY MEMBERS

The parents must organize a system of roles and a division of the burden of work in order to prevent the burning out of one partner. In addition, devotion of the mother to care for her child may make the father feel neglected, which sometimes can result in violence. Sometimes the core of the conflict stems from the fact that each parent conceives the situation in a different way. One parent may relate to the child as a failed case, while the other as a capable, or even a normal child.

8.4.1 Initial reactions

The initial response of most families to the sudden onset of disability is to pull together and rally around the person affected and provide support to each other.

A. Influence on Parental Married Life

The disability can cause damage to the married life of the parents in several different ways: it can create strong parental feelings, it can be a depressing symbol of a common failure, and it can change the family organization, or create fertile ground for conflicts. One frequent problem is the fact that the burden for childcare is not divided equally between the parents. In the common situation, the father is generally at work, while the mother cares for the child with the disability.

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It is therefore important that as soon as a child is born with a disability, the parents should have the opportunity to talk and discuss the various issues with a competent professional so that many adverse reactions can be prevented. This way the family can be helped to adjust and become realistically involved with the care and development of the child.

B. Implications of disability on the parent’s care

Care-taking responsibilities may lead to changed or abandoned career plans. Female family members are more likely to take on care giving roles and thus give up or change their work roles. When the added financial burden of disability is considered, this is the most efficient way for families to divide role responsibilities.

C. Disproportionate family time

The disability can consume a disproportionate share of a family's resources of time, energy, and money, so that other individual and family needs go unmet. Families often talk about living "one day at a time." The family's lifestyle and leisure activities are altered. A family's dreams and plans for the future may be given up. Social roles are disrupted because often there is not enough time, money, or energy to devote to them.

D. Poor social Acceptance

The burden comes from dealing with people in the community whose attitudes and behaviours are judgmental, stigmatizing, and rejecting of the child with disability and his or her family. Family members report that these negative attitudes and behaviours often are characteristic of their friends, relatives, and service providers as well as strangers.

E. Influence on Siblings

Sibling relationship is one of the most important precursors of peers and adults’ relationships and it represents one of the most powerful bonds and human interactions because siblings act as surrogate parents, informal teachers, and friends. In presence of brothers/sisters with disability, this special bond can be characterized by positive or negative aspects.

The analysis of quality of life in families with child with disability in relation to both factors that positively influence the growth of young people with disability and their siblings such as coping strategies, social adjustment, altruism, resilience, and acceptance of diversity and factors that have a negative impact on the well-being of siblings as stress, social isolation by peers and loneliness.

Check your Progress - I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the Implications of disability on the parent’s care .

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8.4.1 Acceptance of disability in the person by the family

When the family settles into living with the disability, the ultimate challenge to the family is to meet the disability related needs and simultaneously to meet the needs of the family and its members of having a normal life. A metaphor used to describe this challenge is "finding a place for the disability in the family, but keeping the disability in its place"

A. Getting updated on assistance and services

Some or all family members may suspend their daily routines for a period as they focus on the immediate crisis. They gather more information about the condition, its course, treatment options, and where to get services. Often there are new behaviours to be learned, including how to provide care and treatment to the person with the disability, how to interact with health care and other service providers, and how to access needed information.

B. Resilience

Several aspects of family functioning patterns have been associated with good adjustment in the person with the disability and in other family members. This approach emphasizes resilience, or the ability of families to discover resources and overcome challenges. Nine aspects of resilient family process have been described based on the findings from numerous studies of successful family coping with disabilities (Patterson 1991b).

C. Developing communication competence

When disability is present, there are decisions to be made and more problems to be solved. Because there are so many intense feelings associated with living with disability, families do better over the long run when they are able to express feelings openly and respectfully, even when the feelings are negative and seem unjustified.

D. Optimistic approach

In addition to being able to talk openly, families who are able to think positively about their situation and develop positive attitudes manage better. Family members need to acknowledge the positive contributions that the person with disability brings to family life and how they have developed a new outlook on life that has more meaning.

E. Maintaining family flexibility

Flexibility when chronic demands are present and when day-to-day life is not predictable. Being able to shift gears, change expectations, alter roles and rules, and try new things all contribute to better outcomes.

F. Maintaining a commitment to the family unit

Cohesion, or the bonds of unity and commitment linking family members, is probably the single most important protective factor that has been reported in well-functioning families when a member has a chronic condition these families cooperate with and support each other in their efforts to manage the disability. One member does not have a disproportionate burden of care giving. A sense of teamwork prevails. Good family relationships provide a buffer from the stress of caregiving.

G. Maintaining social integration

The ability to maintain supportive relationships with people in the community is a protective factor for the family. There may be less time for

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maintaining social connections, and friends and relatives are not supportive in their responses and old networks are abandoned. Support from other families who have a member with a chronic condition has become a major resource to many families, as evidenced in the many parent-to-parent support programs.

H. Developing relationships with professionals

In addition to informal support from friends and relatives, the quality of the relationships that families have with professionals who provide services to the member with a disability becomes another protective factor for them. Taking time to share information, working together to make decisions about care, respecting differences, avoiding attempts to control other, and sharing risks associated with outcomes are factors that contribute to satisfaction on both sides.

I. Support by the siblings

The siblings often develop certain positive characteristics such as self-control, cooperation, empathy, tolerance, altruism, maturity, and responsibility as a result of dealing with their family situation. They may develop loyalty and a protective attitude towards their sibling. In some cases, these siblings use someone's attitude about special needs as a test for screening friends and mates. Their involvement with their sibling may even lead them to choose future occupations in the helping professions.

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the positive implications of sibling's acceptance.

8.5 REACTIONS OF SCHOOL AND SOCIETY

School and the society as a whole play a major role in raising a child with disability. The common reactions include:

8.5.1 School experience

The school experiences of students with disabilities can be positively or negatively influenced by the attitudes and behaviours of students and staff and by general school policies. School counsellors can take the lead in assessing school climate in relation to students with disabilities and initiating interventions or advocating for change when appropriate.

A. School related challenges

The enrolment rate of children with disabilities in pre-primary, primary and secondary school is very low. It noted that many children with disability fall behind and discouraged by repeated failure, dropout of school. Denying children with disabilities hinder their education is interpreted as denying their way of livelihood. The recognized challenges/barriers include the following;

- The current school curriculum is not sensitive to the educational needs of children with disabilities and opportunities for these children are consequently limited and restricted.

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- The examination system is not flexible and nationally recognized and practiced.
- School infrastructural difficulties are unfriendly to meet the children with disabilities' needs.
- Negative attitude towards children with disabilities by teachers and their fellow colleagues/ peers has affected the retention of children with disabilities in schools.
- Provision of insufficient institutional materials like Braille papers, Perkins Braille's and Braille textbooks to special units to suit the special learning needs of students.
- Lack of/limited involvement in sports disability related activities for children with disabilities hence restricting sports ambitions and poor body healthy set up for such children.
- Few trained sign language teachers.
- Accessibility issues.
- Education is envisaged as an important tool for the socioeconomic and cultural development of an individual and acts as a catalyst for the pace of the development of the country. Keeping this in view, the Government of India has launched several programmes for the promotion of the education among the children as well as adults with or without disabilities in the country.
- To mainstream them on par with the normal population and to make them as partners of the pace of development of the country, the Government of India from time to time launched several programmes and started special schools.
- Sarva Shiksha Abhiyan is one of the programs implemented to create barrier free environment in the school and to promote inclusive education for the children with special needs (CWSN) as one of the components.

8.5.2 Community misconceptions and stigmas

Attitudes and behaviours of neglect, isolation, abuse and marginalization of children with disabilities by communities and families leading to increased discrimination. Children with disabilities are under looked by their fellow peers in the societies that they live as objects of charity worthy of no existence. Parents of children with disability face a lot of difficulty in their accessibility to resources like:

A. Access to information

One dimension of accessibility is the ability to access information and services by minimizing the barriers of distance and cost as well as the accessibility and usability of the interface.

B. Access to transportation

People who are in places that are highly accessible can reach many other activities or destinations quickly, Public transport is either not

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accessible or not enough or irregular in nature. No assistance is provided to ensure on and off-boarding of passengers with disabilities. You also pay more when travelling by a taxi. Train platforms are also not accessible.

C. Access to buildings

Most of the government and private buildings are not accessible to persons with disabilities and disregard regulations relating to the needs of persons with physical and other disabilities.

D. Access to Healthcare

The attitude of healthcare professionals towards persons with disabilities is disrespectful for personal dignity, privacy and makes derogatory remarks especially against persons with intellectual disabilities. Lack of Rehabilitation services, preventative care, early diagnosis and treatment provided to persons with disabilities. Health workers are not skilled to provide support to other family members in dealing with a person with a disability.

Check your progress-III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Analyse the school related issues in enrolment of children with disabilities

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8.6 DIFFERENT WAYS OF COPING

"Coping Strategies" refer to conscious efforts to adopt with/solve stressful situation (Glidden, & Natcher, 2009), they are practical active ways of responding to threatening situations. Coping strategies are divided for two major categories:

(a) Problem-Focused Coping strategies which represent an attempt to do what an individual believes it might affect the circumstances that led to stressful situation, this include re-interpretation, re-evaluation and analysis of the stressful situation.

(b) Emotion-Focused Coping strategies which represent efforts to regulate emotions resulted from the stressful situation, this include feelings of incompetence of changing situation, anger, anxiety, hopelessness, discomfort and stress in general.

The most used coping strategies were:

- Acquiring social support is the family's ability to actively engage in acquiring support from relatives, friends, neighbours, and extended family (e.g., sharing our difficulties with relative).
- Reframing assesses the family's capability to redefine stressful events in order to make them more manageable (e.g., knowing that we have the strength within our family to solve our problems).

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- Seeking spiritual support is finding comfort in a higher belief system (e.g., participating in religious or spiritual activities).
- Mobilizing family to acquire and accept help is the family's ability to seek out community resources and accept help from others (e.g., seeking assistance from community agencies and programs designed to help families in situation).
- Passive appraisal is the family's ability to accept problematic issues that minimizes reactivity (e.g., believing if we wait long enough, the problem will go away).
- Maintaining a positive attitude.
- Professionals support.

Check your progress-IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is meant by Emotion-Focused Coping strategies?

8.7 NEEDS AND PROBLEMS OF CHILDREN WITH DISABILITY AND THEIR FAMILIES

For parents, having a child with disability may increase stress, take a toll on mental and physical health, make it difficult to find appropriate and affordable childcare, and affect decisions about work, education/training, having additional children, and relying on public support. The out-of-pocket costs of medical care and other services may be enormous. All these potential effects could have repercussions for the quality of the relationship between the parents, their living arrangements, and future relationships and family structure.

Having a child with disability may also affect parents' allocation of time and financial resources to their healthy and unhealthy children, their parenting practices, their expectations of healthy siblings in terms of achievement, responsibility, and short- and long-term contributions to the household, and the siblings' health and development.

It is a unique shared experience for families and can affect all aspects of family functioning. On the positive side, it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a child with disability can have far-reaching effects as we describe below. The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available.

The good news for families of child with disability is that there are numerous programs and organizations that provide resources they may need. Medical care may be financed by private insurance companies.

8.8 CRITICAL STAGES IN THE DEVELOPMENT

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When the condition is present from birth, the child's life and identity are shaped around the disability. In some ways it may be easier for a child and his or her family to adjust to never having certain functional abilities than to a sudden loss of abilities later.

When disability has its onset in young adulthood, the person's personal, family, and vocational plans may be altered significantly. When disability occurs at this stage, where there is a long-term commitment, relationships may be in jeopardy, particularly if the ability to enact adult roles as a sexual partner, parent, financial provider, or leisure partner is affected.

When the onset of disability occurs to adults in their middle years, it is often associated with major disruption to career and family roles. Family reorganization of roles, rules, and routines is usually required. The family may face a major loss of income as well as a loss in health and other employee benefits.

Some children will be born with a disabling health condition or impairment, while others may experience disability as a result of illness, injury or poor nutrition. Children with disabilities include those with health conditions such as cerebral palsy, spina bifida, muscular dystrophy, traumatic spinal cord injury, Down syndrome, and children with hearing, visual, physical, communication and intellectual impairments. A number of children have a single impairment while others may experience multiple impairments.

A. Early Childhood

Early childhood spans the pre-natal period to eight years of age. It is the most intensive period of brain development throughout the lifespan and therefore is the most critical stage of human development. What happens before birth and in the first few years of life plays a vital role in health and social outcomes. While genetic factors play a role in shaping children's development, evidence indicates that the environment has a major influence during early childhood.

B. Early Childhood Development

Early childhood development (ECD) is a generic term that refers to a child's cognitive, social, emotional and physical development. The same term is often used to describe a range of programmes which have the ultimate goal of improving young children's capacity to develop and learn and which may occur at many different levels such as child, family and community, and across different sectors such as health, education, and social protection.

C. Developmental Delay

Developmental delay refers to children who experience significant variation in the achievement of expected milestones for their actual or adjusted age. Developmental delays are caused by poor birth outcomes, inadequate stimulation, malnutrition, chronic ill health and other organic problems, psychological and familial situations, or other environmental factors.

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While developmental delay may not be permanent, it can provide a basis for identifying children who may experience a disability. This further emphasizes the importance of early identification to commence timely interventions with family involvement, aimed at preventing delays, promoting emerging competencies and creating a more stimulating and protective environment.

D. Early Childhood Intervention

Early childhood intervention (ECI) programmes are designed to support young children who are at risk of developmental delay, or young children who have been identified as having developmental delays or disabilities. ECI comprises a range of services and supports to ensure and enhance children's personal development and resilience, strengthen family competencies, and promote the social inclusion of families and children.

Examples include specialized services such as: medical; rehabilitation (e.g. therapy and assistive devices); family-focused support (e.g. training and counselling); social and psychological; special education, along with service planning and coordination; and assistance and support to access mainstream services such as preschool and child-care (e.g. referral). Services can be delivered through a variety of settings including health-care clinics, hospitals, early intervention centres, rehabilitation centres, community centres, homes and schools.

E. Parent –Child Relationship development benefits for life

Warm and loving interactions between the parent and the child develop the child's confidence, resilience and communication. This prepares the child for things he/she will come across later in life, like working through problems, dealing with stress and forming healthy relationships with other people in adolescence and adulthood. Strong attachments and relationships early in life also mean that the child is more likely to have better mental health and fewer behaviour problems.

Check your Progress - V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is meant by ECI?

8.9 SOCIAL WORK INTERVENTION AT EACH STAGE

This is integral to deciding social work's contribution to tackling social and personal problems and promoting well-being. The social policy objective of social work intervention is that it should be tailored to a specific situation and that each person is unique. Social work is a collective activity and is consequently dependent on partnerships.

- A.** Social work's role is carried out through direct practice, of various types and techniques, with individuals, families, groups and communities and with provider organization
- B.** State, municipal governments and nongovernmental entities provide a broad range of social services designed to prevent or treat

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family violence. These services include counselling and advocacy for victims of abuse; family and caregiver support programs; alternative living arrangements, including out-of-home placement for children, protective guardianship for abused elders, and shelters for battered women; educational programs for those at risk of abusing or being abused; intensive service programs to maintain families at risk of losing their child; and individual service programs in both family and placement settings.

Conflicting results in evaluation research studies thus may reflect these program differences or variations in the personal histories or types of problems experienced by the clients served. Social workers have a pivotal role in working with parents in diverse settings, and they provide most services to parents in the child welfare system. The professionals must address several challenges to demonstrate its effectiveness in enhancing improvement of parenting and thus the lives of the children touched in this way.

8.9.1 Changing scenario

Families are a critical source of support for children with disabilities. Family members absorb the added demands on time, emotional resources, and financial resources.

There is a growing body of research that emphasizes the many positive ways by which families adapt to disability. Several aspects of family functioning patterns have been associated with good adjustment in the person with the disability and in other family members. This approach emphasizes resilience, or the ability of families to discover resources and overcome challenges.

A. Balancing the condition with other family needs

Because there is a tendency to let the disability dominate daily life, many families learn to meet the normative developmental needs of the person with the disability as well as their disability needs. They plan for and take time for other family needs as well as those associated with the chronic condition. They also try to maintain their normal family routines and rituals to preserve their identity and lifestyle.

B. Maintaining clear family boundaries

A boundary is that psychological line that sets a system, such as a family, apart from its context. While families need to develop connections to the service delivery system to meet the needs of the person with a disability, they also need to maintain their own integrity and sense of control over their lives and not allow themselves to be over directed by what professionals want them to do. In this way the family maintains its external boundary and improves the likelihood that the family will stay intact. Inside the family, it is usually best for family functioning when the parents work together to manage the family. This is called a generational boundary.

C. Developing communication competence

When disability is present, there are often more decisions to be made and more problems to be solved. Many families living with disability

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become more effective in learning to work through these issues. Because there are so many intense feelings associated with living with disability, families do better over the long run when they are able to express feelings openly and respectfully, even when the feelings are negative and seem unjustified.

D. Attributing positive meanings to the situation

In addition to being able to talk openly, families who are able to think positively about their situation and develop positive attitudes manage better. Family members often acknowledge the positive contributions that the person with disability brings to family life and how they have developed a new outlook on life that has more meaning.

E. Maintaining family flexibility

Flexibility is one of those family resources that benefits all families, particularly when chronic demands are present and when day-to-day life is not predictable. Being able to shift gears, change expectations, alter roles and rules, and try new things all contribute to better outcomes.

F. Maintaining a commitment to the family unit

Of all the family resources studied, cohesion, or the bonds of unity and commitment linking family members, is probably the single most important protective factor that has consistently been reported in well-functioning families when a member has a chronic condition. These families cooperate with and support each other in their efforts to manage the disability. One member does not have a disproportionate burden of care giving. A sense of teamwork prevails. Good family relationships provide a buffer from the stress of caregiving.

G. Engaging in active coping efforts

Many different aspects of coping have been studied relating to families' responses to chronic conditions. Those families who actively seek information and services, who actively work to solve problems and express feelings, and who balance their personal, family, and illness needs show better adaptation than do families who engage in passive resignation.

H. Maintaining social integration

The ability to maintain supportive relationships with people in the community is another important protective factor for the family. It is also a resource that often is threatened by the presence of disability in the family. Support from other families who have a member with a chronic condition has become a major resource to many families, as evidenced in the many parent-to-parent support programs.

I. Developing relationships with professionals

In addition to informal support from friends and relatives, the quality of the relationships that families have with professionals who provide services to the member with a disability becomes another protective factor for them.

J. Equal access to education

Education is envisaged as an important tool for the socioeconomic and cultural development of an individual and acts as a catalyst for the pace of the development of the country. Keeping this in view, the Government of India has launched several programmes for the promotion of the education among the children as well as adults with or without disabilities in the country.

To mainstream them on par with the normal population and to make them as partners of the pace of development of the country, the Government of India from time to time launched several programmes and started special schools.

Sarva Shiksha Abhiyan is one of the programs implemented to create barrier free environment in the school and to promote inclusive education for the children with special needs (CWSN) as one of the components. It has to be ensured that every child with special needs, irrespective of kind, category and degree of disability should be provided meaningful and quality education. It has adopted a zero-reduction policy.

Check your progress-VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Explain the role of SSA.

8.10 LET'S SUMUP

Having a family member with a disability can influence the entire family; the parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning.

On the positive side it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community. On the other hand, the time and financial costs, physical and emotional demands, and logistical complexities associated with caring for a child/adult with disability can have far-reaching effects. The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available.

For families, caring for a family member with disability may increase stress, take a toll on mental and physical health, make it difficult to find appropriate and affordable childcare, and affect decisions about work, education/training, having additional children, and relying on public support. It may be associated with guilt, blame, or reduced self-esteem. It may divert attention from other aspects of family functioning. The out-of-pocket costs of medical care and other services may be enormous. All these potential effects could have repercussions for the quality of the relationship between family members, their living arrangements, and future relationships and family structure.

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Education is envisaged as an important tool for the socioeconomic and cultural development of an individual and acts as a catalyst for the pace of the development of the country. Keeping this in view, the Government of India has launched several programmes for the promotion of the education among the children as well as adults with or without disabilities in the country. To mainstream them on par with the normal population and to make them as partners of the pace of development of the country, the Government of India from time to time launched several programmes and started special schools.

Social service interventions may consist of casework as well as therapeutic services designed to provide parenting education, child and family counselling, and family support. Social service interventions also may include concrete services such as income support or material aid, institutional placement, mental health services, in-home health services, supervision, education, transportation, housing, medical services, legal services, in-home assistance, socialization, nutrition, and child and respite care.

8.11 UNIT END EXERCISES

1. Explain the role of social worker?
2. Discuss the problems faced by persons with disability and their families?
3. List some of the coping strategies used at stressful situation.
4. Analyse the reactions of school and society?
5. Highlight the Impact of disability on persons with disability and their families

8.12 ANSWERS TO CHECK YOUR PROGRESS

- The disability can consume a disproportionate share of a family's resources of time, energy, and money, so that other individual and family needs go unmet. Families often talk about living "one day at a time." The family's lifestyle and leisure activities are altered. A family's dreams and plans may be given up. Social roles are disrupted because often there is not enough time, money, or energy to devote to them.
- The siblings often develop certain positive characteristics such as self-control, cooperation, empathy, tolerance, altruism, maturity, and responsibility as a result of dealing with their family situation. They may develop loyalty and a protective attitude towards their sibling. In some cases, these siblings use someone's attitude about special needs as a test for screening friends and mates. Their involvement with their sibling may even lead them to choose future occupations in the helping professions.
- The current school curriculum is not sensitive to the educational needs of children with disabilities and opportunities for these children are consequently limited and restricted. The examination system is not flexible and nationally recognized and practiced,
- School infrastructural difficulties are unfriendly to meet the needs of children with disabilities, Negative attitude towards children

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with disabilities by teachers and their fellow colleagues/ peers has affected the retention of children with disabilities in schools and Provision of insufficient institutional materials like Braille papers, Perkins Braille's and Braille text books to special units to suit the special learning needs of students school related issues in enrolment of children with disabilities.

- Emotion-Focused Coping strategies represent efforts to regulate emotions resulted from the stressful situation, this include feelings of incompetence of changing situation, anger, anxiety, hopelessness, discomfort and stress in general.
- Early childhood intervention (ECI) programmes are designed to support young children who are at risk of developmental delay, or young children who have been identified as having developmental delays or disabilities. ECI comprises a range of services and supports to ensure and enhance children's personal development and resilience, strengthen family competencies, and promote the social inclusion of families and children.
- Sarva Shiksha Abhiyan is one of the programs implemented to create barrier free environment in the school and to promote inclusive education for the children with special needs (CWSN) as one of the components. It has to be ensured that every child with special needs, irrespective of kind, category and degree of disability should be provided meaningful and quality education. It has adopted a zero-reduction policy.

8.13 SUGGESTED READINGS

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UNIT IX

Structure

- 9.1 Introduction
- 9.2 Objectives
- 9.3 Special requirements of families having children with special needs
- 9.4 Intervention
 - 9.4.1 Family crisis intervention
 - 9.4.1.1 Stages of Family Crisis Intervention
 - 9.4.2 Family centered intervention
 - 9.4.3 Family systems programs
- 9.5 Parent guidance
- 9.6 Parent training
 - 9.6.1 The Triple P-Positive Parenting Program
 - 9.6.2 Parent Management Training
 - 9.6.3 Parent-Child Interaction Therapy (PCIT)
- 9.7 Support/self-help groups of parents/siblings
- 9.8 Community level awareness, Education
- 9.9 Let us sum up
- 9.10 Unit end exercises
- 9.11 Answers to check your progress
- 9.12 Suggested Readings

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9.1 INTRODUCTION

Being a parent can be a wonderfully fulfilling role that brings immense joy, pride and happiness to the lives of parents. At times, the parenting role can also be challenging, and for some it can become quite overwhelming. Parenting is easier and less stressful when families live in environments that are conducive to good parenting.

Features of such an environment include living in a stable, supportive home with caring, capable and involved parents that have access to regular employment, secure housing, high quality early childhood education and care, good schools, affordable health and dental care, safe play and recreational facilities, and extended family and social supports. However, parenting takes place in a wide variety of socioeconomic circumstances and children begin life in diverse situations that do not provide equal opportunities to thrive developmentally.

The requirements of the family can be determined by understanding the experiences of family members and their different functions, roles and responsibilities or the differences between the situation expected and the situation that exists. Parents' interactions with their children, family structure, emotional state, resources and

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requirements must be determined for them to ensure and increase their children's contribution to education (Varol 2005).

When parents are socially isolated from partners due to relationship breakdown and have little or no access to extended family support, raising children solo can be a very demanding responsibility. Other stressful life circumstances include parents being exposed to violence (intimate partner, domestic, or community violence), experiencing or living with someone with serious mental health issues, substance abuse, chronic physical health problems, homelessness, or involvement with the criminal justice system. High levels of stress diminish parental self-efficacy and parenting capacity.

9.2 OBJECTIVES

Going through this unit, you will be able to

- ✓ To analyze special requirements of families having children with special needs.
- ✓ To discuss the family crisis intervention and Family centered intervention
- ✓ To strategize parent guidance
- ✓ To highlight the significance of parent training
- ✓ To discuss the Support systems for self-help groups of parents/siblings
- ✓ To raise awareness about the needs of the families with children with disability and educate the community to support.

9.3 SPECIAL REQUIREMENTS OF FAMILIES HAVING CHILDREN WITH SPECIAL NEEDS

Some children will be born with a disabling health condition or impairment, while others may experience disability as a result of illness, injury or poor nutrition. Children with disabilities include those with health conditions such as cerebral palsy, spina-bifida, muscular dystrophy, traumatic spinal cord injury, Down syndrome, and children with hearing, visual, physical, communication and intellectual impairments.

Several children have a single impairment while others may experience multiple impairments. For example, a child with cerebral palsy may have mobility, communication and intellectual impairments. The complex interaction between a health condition or impairment and environmental and personal factors means that each child's experience of disability is different.

The requirements of families with children who have special needs include many aspects; from the basic survival needs of the family to planning the future of the child (Cavkaytar et al. 2012). The requirements of families who have children with special needs are all different , some of

the common requirements of a families are information requirements, support requirements, financial needs, explaining the status of the child to others, family functioning, and requirements related to social services.

From birth, children are learning and rely on parents and the other caregivers in their lives to protect and care for them. Today's family is often far from the stereotypical image of two parents with two children. In the mid-twentieth century there were fewer broken marriages and more extended family members who usually lived nearby and supported their families, particularly the young and elderly.

The impact of parents may never be greater than during the earliest years of life, when a child's brain is rapidly developing and when nearly all of her or his experiences are created and shaped by parents and the family environment. Parents help children build and refine their knowledge and skills, charting a trajectory for their health and well-being during childhood and beyond.

Parenting of young children today takes place in the context of significant ongoing developments. These include a rapidly growing body of science on early childhood that has provided a more nuanced understanding of the critical periods in early childhood development and parenting. According to Turnbull, the requirement of family based on individual characteristics as follows; love needs, self-esteem needs, socialization requirements, information requirements, daily life and maintenance-related requirements, recreation requirements, financial needs.

9.4 INTERVENTION

Child development is a dynamic process through which children progress from dependency on caregivers in all areas of functioning during infancy, towards growing independence in the later childhood. The family is both affected by the disability and is a major source of capabilities for responding to it.

Family support initiatives are a great a way to improve the quality of life for people with disabilities. Families have a key role in identifying the needs and in identifying their strengths. Families help in dealing with their emotional responses or to teach skills and strategies for managing difficult behaviour. There is also evidence to suggest that children with disabilities and their families are more likely to experience economic and social disadvantage than those without disability.

Disability can contribute to increased poverty at the household level as parents take time away from income-generating activities, and families are required to meet the additional costs associated with disability, for example payments for health care and transportation. The family support movement is the concept of family empowerment, which is defined as enabling an individual or family to increase their abilities to meet needs and goals and maintain their autonomy and integrity.

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9.4.1 Family crisis intervention

The crisis following the diagnosis of a child with disability affects the family on many levels. On a behavioural level, the family may need to provide immediate care for the handicapped child, arrange transportation to treatment, alter previous methods of scheduling time and meet new financial needs. On the affective level, the family members begin working through feelings of grief, anger, guilt, helplessness and isolation. On a physical or sensory level, somatic symptoms may arise as a result of the stress of the crisis experience.

On an inter- personal level, the family may have to deal with labelling and stereotyping, a sense of isolation from others, handling "helpfulness" and advice from friends, and providing support for other family members. On a cognitive level, the family is called upon to assimilate technical information about the disability and to deal with the impact of the diagnosis on established values and expectations. A five-stage model which incorporates and clarifies the stages of crisis as found in this literature is proposed.

These stages are then combined with Slaikeu's (1982) modification of Lazarus' (1976) multimodal model to view each stage in terms of behaviour, affect, sensation, interpersonal relationships and cognitions. It is hoped that this model will provide a clearer understanding of how family members progress through the stages of crisis resolution.

9.4.1.1 Stages of Family Crisis Intervention

A. Impact

The impact stage is characterized by anxiety and disorganization in the family. In situations in which the disability is caused by an accident, the anxiety may be manifest by agitation or it may be displayed by body tenseness and withdrawal as if all energy is being used to contain the anxiety. There may also be symptoms of diarrhoea, nausea, or fainting. This acute anxiety can last from a few minutes to several hours. It usually subsides when the family is allowed to see the child.

In such situations, Epperson (1977) recommended that the family be given accurate information about the patient, that methods of treatment be explained, and that family members be encouraged to talk about where they were and what they were doing when the accident occurred.

B. Denial

This denial stage may be necessary to allow the family time to accept the reality of the situation in increments that can be handled. Parents experiencing denial may refuse to accept the diagnosis. 'Shopping around' for another diagnosis is a natural response. Intervention becomes necessary only when the parents remain in this stage and shopping around represents a persistent refusal to accept the reality of the child's condition.

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Another form of denial is refusal to see a new-born. Instead, the parents immediately arrange for the infant to be institutionalized. Denial may also take the form of wishful thinking. The family may imagine that a miracle cure will be found that will make their child normal. Each family must find a comfortable blend of hope and reality

C. Grief

The grief stage is characterized by feelings of anger, guilt and sadness. Parents question "Why?" They are angry that they were singled out by fate, and they seek someone to blame. The grief reaction is not, as was once believed, a result of the parents' inability to accept the handicap. It is helpful to understand and recognize the need for this period of adjustment.

D. Focusing Outward

This is a stage in which adequate coping begins. This stage may determine whether the crisis will resolve in growth or psychopathology. It is during this stage that the individual gives up wishful thinking and begins to formulate plans that are congruent with the reality of the situation.

E. Closure

There is a realistic sense of hope that despite hardship the family can and will survive. This is a stage when mobilization begins which enables the family to adapt to the current situation and cope with what is to come. Family solidarity seems to emerge.

Check your progress- I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Explain the stages of family crisis.

9.4.2 Family centered intervention (FCC)

Family centered intervention is an approach that acknowledges the importance of the family as a recipient of care, ensuring the participation of all its members in the planning of actions and revealing a new model of care, offering the opportunity for the family itself to define its own problems.

Respecting the child's individuality and that of his/her family is decisive and represents a permanent challenge for health services and health workers, as well. It requires the staff to be open and attentive to the interactions and impact of experiences and to provide knowledge concerning the dynamics, beliefs, and ways families can adapt to different situations.

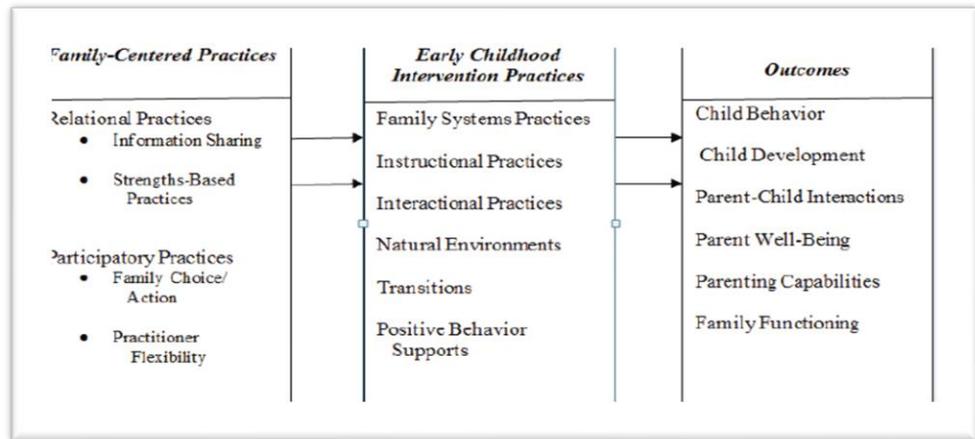
The main aim of family-centred education is to enable parents to meet the information needs of the family; providing notice of their own

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strengths and to prepare the family to cope with their anxieties by being more equipped with the characteristics their children have at birth.

Family Service Plan that includes “family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family’s capacity to meet the developmental needs of the infant or toddler. This provision applies to children with disabilities from birth to age 3. After age 3, children with disabilities may begin special education services that public-school programs are required to provide. Families are involved in the development of their child’s Individualized Education Plan.

Interventions designed to support parents of children with developmental disabilities fall into four overlapping areas: family systems programs, instructional programs, interactional programs, and positive behaviour support.



9.4.3 Family systems program

Family systems programs follow a systems approach in that they most commonly focus on parents’ internal variables, such as stress, depression, or coping, based on the assumption that changes in those variables will affect the quality of parenting. Behavioural parent training (i.e., teaching parents behaviour management skills); coping skills interventions, based on principles of cognitive-behavioural therapy; and a combination of the two. It was found that interventions in all three groups had significant effects on reducing psychological distress among mothers and fathers of children with developmental disabilities.

a. Interactional programs are designed to promote positive social interactions between caregivers and young children with disabilities. The parents are given situations that encourage interaction and to respond in particularly encouraging ways

B. Positive behaviour intervention and support (PBIS) is a multi-component program involving problem-behaviour prevention strategies and increasing levels of behavioral intervention.

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Providing FCC to families of infants and toddlers with disabilities is an essential component of high-quality early intervention services. It allows families to make informed decisions about their child's evaluation and treatment processes and encourages the early interventionist to acknowledge the family as the expert of the child's development.

Check your progress –II

Note: A. Write your answer in the space given below

B Compare your answer with those given at the end of the unit.

I). Describe Family centred care for the persons with disabilities.

9.5 PARENT GUIDANCE

Parents of children with special needs are often exhausted and frequently become depressed. Their reserves of time and resources for self-care are even more depleted than those of parents of typical children. Yet their need for refuelling is also greater. To be sustained through the marathon of caring for a child with special needs, it is essential that parents attend to their own needs. Often the most beneficial support and information parents receive are from other parents of children with special needs.

A. Support services- *The parents can avail support services from pediatrician regarding referrals to specialists. Parents can approach teachers, counselors and special educators for additional suggestions to help your child academically. Brainstorming with spouse or co-parenting partner can bring family solutions.*

B. Use the buddy system- *Parents can invite their friends and take the special child for an outing in their strollers or wheelchairs, this will help the parent get a little break for themselves and for their children.*

C. Play group - *parents can create play group online, inviting parents of children with special needs for as play group, where parents and children with special needs have, games, picnic and fun together.*

Other sources of information and support are:

- ✓ Books by other parents of children with special needs
- ✓ Internet discussion boards or online parent support groups
- ✓ Local support groups
- ✓ Advocacy groups, both general and disability specific.

✓ The PACER Centre for children with disabilities:
<http://www.pacer.org/>

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Check your progress – III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Suggest some ways of guiding parents with special children.

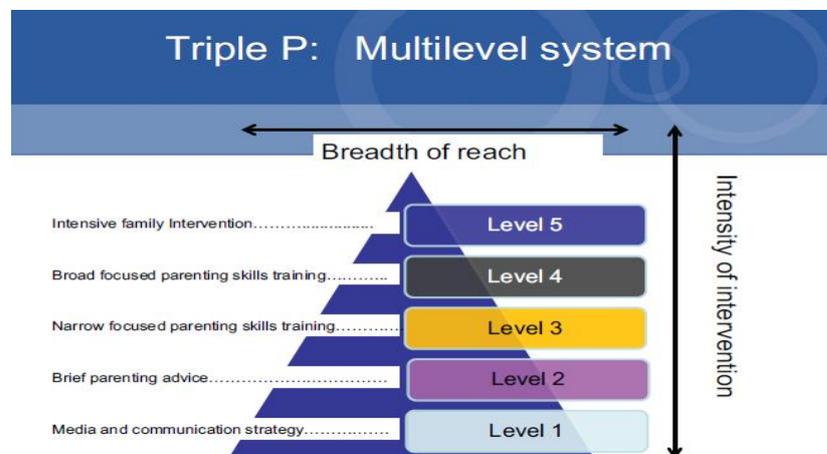
9.6 PARENT TRAINING

Parents have an important role to play in a child’s psychosocial development. Consequently, several parenting interventions for families of young children with neuro-developmental disabilities have been designed and evaluated globally over the past few decades. These interventions are designed to improve a parent’s ability to successfully parent their children, through training, support or education, and the main goal is to influence the parent’s psychosocial well-being.

The majority of these programmes consist of skills training, parent education, parent support and/or parent coaching, and as a result they are said to be focused on the provision of knowledge (parent support) or techniques (parent-mediated intervention).The primary aims of these interventions are to reduce the impact of the challenges faced by the family of children with disabilities through teaching parents new knowledge and skills to reduce the child’s behavioral, emotional and developmental difficulties.

9.6.1 The Triple P-Positive Parenting Program

Triple P is one of the most frequently used and internationally replicated interventions for helping parents prevent and address behavioral challenges in their children. Triple P is designed to prevent and treat social, emotional, and behavioral problems in children by improving parents’ knowledge, skills, and confidence in their parenting role. Drawing on social learning, cognitive, developmental, and public health theories, Triple P incorporates five levels of intervention on a tiered continuum of increasing strength and narrowing population reach for parents of children from birth to age 16.



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Universal Triple P (level 1): Takes a public health approach by using media to increase awareness of parenting resources, programs, and solutions to common child behavioural and developmental concerns at the community level.

Selected Triple P (level 2): Gives parents who are generally coping well advice on practices for accommodating common developmental issues, such as toilet training and minor child behaviour problems, via one to three telephone, face-to-face, or group sessions.

Primary Care Triple P (level 3): Targets parents with children who have mild to moderate behavioural challenges. Parents receive an active skill training that combines advice, skill rehearsal, and self-evaluation in three to four one-on-one sessions in person or by telephone, or in a series of 2-hour group discussion sessions.

Standard and Group Triple P (level 4): Designed for parents of children with more severe behavioural challenges, provides parents with more intensive training in how to manage a range of children's problem behaviours. It is delivered in eight to ten sessions in individual, group, or self-directed (online or workbook) formats.

Enhanced Triple P (level 5): Is designed for families whose parenting challenges are heightened by other sources of family distress, such as parental depression or relationship conflict. This level includes practice sessions to enhance parenting, mood management, stress coping, and partner support skills using adjunct individual or group sessions.

9.6.2 Parent Management Training

Parent Management Training (PMT), involving Parents participate in therapy sessions to learn behaviour management techniques they would use with their children.

9.6.3 Parent-Child Interaction Therapy (PCIT)

PCIT is an evidence-based intervention developed as a treatment for children ages 2-7 with emotional and behavioural disorders and their parents. Parents learn skills to encourage pro-social behaviour and discourage negative behaviour in their children, with the goal of developing nurturing and secure parent-child relationships.

The intervention has two phases. The first phase is child-directed interaction parents learn nondirective play skills and engage their child in a play situation with the objective of strengthening the parent-child relationship. In the second phase: parent-directed interaction. Parents learn to use age-appropriate instructions and consistent messages about consequences to direct their child's behaviour, with the goal of improving the child's compliance with parental instruction.

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Check your progress - IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the importance of parent training.

9.7 SUPPORT/ SELF HELP GROUPS OF PARENTS/ SIBLINGS

Support structures play a vital role in rearing children with disabilities. They are:

A. Self-help groups

Self-help groups are informal groups of people who come together to address their common problems. Outreach workers provide ongoing support and training for group members on disability issues and/or group facilitation. Group members are responsible for directing activities which may include: inviting representatives from local authorities to discuss health services for people with disabilities, working with local authorities to improve the quality and accessibility of health services for people with disabilities, organizing local sports events, participating in national sports events, providing peer education on health care and treatment, creating small business ventures and work opportunities, and promoting a positive image of people with disabilities in the local community.

People with disabilities and their family members participate in groups to resolve common problems, enhance their individual strengths, and improve their quality of life.

- ✓ Self-help groups exist within local communities for people with disabilities and their family members.
- ✓ Self-help group members develop knowledge and skills that enable them to become contributors in their families and communities.
- ✓ People with disabilities and their family members can access mainstream self-help groups that are available to other members of the community.
- ✓ Self-help groups promote Community Based Rehabilitation, and members become involved in the planning and implementation of CBR programmes.
- ✓ Self-help groups join to form federations and become self-sufficient.

B. Include sibling as appropriate care buddy

Siblings need to be educated to care the special needs child; this brings a strong family bonding and shows level of acceptance of the disability.

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C. Empower your family by accepting what is your “normal.”

Every family does things a little differently. A child who is in a wheelchair is the family member; he just has a different way of getting around, which is normal for the family. This lesson teaches other children acceptance, compassion and respect for others who also may do things differently.

D. Solve problem as a team

There are times when challenges arise, empower your children by having them brainstorm solutions with you. It’s amazing what children come up with, usually things we hadn’t considered.

E. Celebrate every tiny accomplishment

Focusing on even the smallest successes or acts of kindness helps a family build each other up.

Check your progress – V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

I) Highlight the significance of Self-Help Group

9.8 COMMUNITY LEVEL AWARENESS EDUCATION

The importance of disability awareness has been given prominence over the recent decades, making it easier for the people with disabilities and the society to develop empathy for one another. Disability awareness helps in subsidizing the stereotypical mindset of the society, hence providing vast opportunities for everyone to get involved in creating a positive, inclusive society for all.

Disability awareness signifies in educating the society regarding disability and how individual can bring about the necessary changes. Acceptance is the fundamental of understanding disability. This awareness can be created such as at home, school, workplace, health institutes, etc. However, we often see discrimination towards the people with disabilities and that can lead to the undesirable outcomes for communities.

BADHTE KADAM is one of the National Community Awareness programmes of India established for Awareness, Community Interaction and Innovative Projects. Badhte Kadam aims at community awareness, sensitization, and social integration and mainstreaming of Persons with Disabilities. It has below mentioned objectives:

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Raise awareness in the public, regarding Person with Disability (PwD) covered under the National Trust Act and encourage their inclusion in the society, social integration and participation of persons with disabilities in all aspects of life.

Category	Activity
In collaboration with Government	<p>Collaboration with the campaigns and disseminate information being run by other ministries, government departments and organizations at national, state, district, block or panchayat level. For example;</p> <p>Ministry of Health (polio campaign, Community Health Centres, Primary Health Centres, Aanganwadis and Asha workers, Blindness Control Program, Leprosy Cure Program, Camp for issue of disability certificate etc.)</p> <p>Ministry of Education (Sarva Shiksha Abhiyan etc.)</p> <p>Ministry of Rural Development (MNREGA, Collaboration with District Rural Development Agency (DRDA) etc.)</p> <p>Ministry of Social Justice and Empowerment</p> <p>Ministry of Labour (Vocational Rehabilitation Centres (VRCs), Special Employment Exchange, Special cell etc.)</p> <p>Ministry of Skill Development and Entrepreneurship</p> <p>Collaborate with existing major Conferences, Meetings, Fairs, Exhibitions and other events</p> <p>Circulars to be sent to concerned departments and Institutions (schools, colleges, banks, transport, hospitals etc.)</p> <p>Handouts, posters, flyers, pamphlets or leaflets at Educational, Financial and Medical Institutes (especially in clinics of physiotherapists, paediatrician, psychologists and psychiatrists</p>

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Category	Activity
In collaboration with NGO's and parents	<ul style="list-style-type: none"> • Collaboration with Corporate and Voluntary Organizations to Organize or participate in events • Conduct presentations or workshops in a private company or institution (documentary or film related to PwDs can also be created and showcased) • Organize special sessions for PwDs like with Make a Difference (MAD), Child Relief and You (CRY) etc. • Handouts, posters, flyers, pamphlets or leaflets at Educational, Financial and Medical Institutes (especially in clinics of physiotherapists, paediatrician, psychologists and psychiatrists)
Media Related	<ul style="list-style-type: none"> • Social Media campaigns • Media campaign - Print, TV, Radio, Cinema, and Internet based (e-mailers, etc.)
ICT enabled initiatives	<ul style="list-style-type: none"> • Information could be spread out via Website • Mass SMS to PwDs, ROs and families to update them about new schemes and other necessary information • Training and awareness videos as per disability to be circulated to parents and guardians and public at large through website or mobile application or through social media
Localized intervention	<ul style="list-style-type: none"> • Participate in Local campaigns like fairs, Exhibitions, Melas, Road shows, Street plays etc. • Organize workshops to spread awareness among following groups: <ul style="list-style-type: none"> • Government officials • Medical fraternity • Legal professionals • Banks / Financial institutions • Educational Institutes, Teachers etc. • Organize Social Inclusion events like cricket match, painting competitions, art exhibitions etc. • Conduct sessions in schools, colleges and other educational institute to sensitize students about PwDs.

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9.9 LET'S SUM UP

Child development is a dynamic process through which children progress from dependency on caregivers in all areas of functioning during infancy, towards growing independence in the later childhood. The family is both affected by the disability and is a major source of capabilities for responding to it. Family support initiatives are a great way to improve the quality of life for people with disabilities. Families have a key role in identifying the needs and in identifying their strengths. Families help in dealing with their emotional responses or to teach skills and strategies for managing difficult behaviour.

A child may also be extremely sensitive (hypersensitive) or not responsive (hyposensitive) to the environment. This means they may have an acute reaction to a minor environmental stimulus such as being distracted by common sounds like the humming of a refrigerator; or they can be unresponsive to the world around them and need additional sensory stimulation to feel content, such as touching things excessively, always turning the volume very loud, or constantly putting objects in their mouth.

It can also be related to emotional issues if the child is sad or unhappy, or to being hypersensitive or hyposensitive to their environment. There can be many causes and it is important to ask a doctor or other specialist in case the behaviour is linked to an illness, injury or other physical cause. Because each child is unique, disability can affect individual children in different ways, even among children with the same type of disability.

Children can also be affected by more than one type of disability; for example, their movement and sight can both be affected. Following the social model of disability, and because individual children develop at different rates, disability is assessed and described in terms of what a child can do and how a child 'functions,' rather than a description of a condition. For example, each child with Down syndrome will have capacities and difficulties in different areas. Disability affects the child, and can affect family, friends and the local community as well. It can have physical, emotional and psychological impacts. Parents play a major role in rearing their children with special needs with the help of the society.

9.10 UNIT END EXERCISES

1. Describe family crisis intervention?
2. Explain the requirement of family having children with special needs?
3. Highlight the need of community awareness?
4. Discuss the parent Guidance and training?

9.11 ANSWERS TO CHECK YOUR PROGRESS

- The various stages of Family Crisis Intervention are Impact, Denial, Grief, Focusing Outward, and Closure.
- Family centered intervention is an approach that acknowledges the importance of the family as a recipient of care, ensuring the participation of all its members in the planning of actions and revealing a new model of care, offering the opportunity for the family itself to define its own problems. Respecting the child's individuality and that of his/her family is decisive and represents a permanent challenge for health services and health workers, as well.
- The most beneficial support and information parents receive is from other parents of children with special needs and Books by other parents of children with special needs, Internet discussion boards or online parent support groups, Local support groups and Advocacy groups, both general and disability specific.
- Parents have an important role to play in a child's psychosocial development. Consequently, several parenting interventions for families of young children with neuro-developmental disabilities have been designed and evaluated globally over the past few decades. These interventions are designed to improve a parent's ability to successfully parent their children, through training, support or education, and the main goal is to influence the parent's psychosocial well-being.
- Self-help groups are informal groups of people who come together to address their common problems. Outreach workers provide ongoing support and training for group members on disability issues and/or group facilitation.
- Disability awareness signifies in educating the society regarding disability and how individual can bring about the necessary changes. Acceptance is the fundamental of understanding disability. This awareness can be created such as at home, school, workplace, health institutes, etc. However, we often see discrimination towards the people with disabilities and that can lead to the undesirable outcomes for communities.

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UNIT X

- 10.1 Introduction
- 10.2 Objectives
- 10.3 Role of family in management of Children with Special Needs
 - 10.3.1 Role of community in management of Children with Special Needs
- 1.4 Access Information and Services
 - 10.4.1 Access to communication and information
 - 10.4.2 Community access
- 10.5 Early intervention
 - 10.5.1 Typical Development Timeline: Birth to Age 8 Months
 - 10.5.2 Types of early intervention
 - 10.5.3 Assessments and planning
- 10.6 Programming for rehabilitation
 - 10.6.1 Stimulation training
 - 10.6.2 Process and Principles of Stimulation Training
- 10.7 Treatment
 - 10.7.1 Medicinal rehabilitation
 - 10.7.2 Therapeutic rehabilitation
- 10.8 Post Evaluation
- 10.9 Let's Sum up
- 10.10 Unit end exercises
- 10.11 Answers to check your progress
- 10.12 Suggested Readings

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10.1 INTRODUCTION

Disability is the complex relationship between the mind, the body and the environment in which a child lives. Children with disabilities has equal rights as their normal peers as stated by United Nations Convention on the Rights of the Child (UNCRC) apply to them.

The UNCRC also makes a specific provision for children with disabilities. Article 23 says that children with disabilities have the right to live full and decent lives with dignity and, as far as possible, independence and to play an active part in the community, and that the State must do all it can to support children with disabilities and their families. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) also supports the rights of children and is designed to expand on and support Article 23 of the UNCRC.

Parents are among the most important people in the lives of young children. From birth, children are learning and rely on mothers and fathers, as well as other caregivers acting in the parenting role, to protect and care for them and to chart a trajectory that promotes their overall well-being.

Children's development is shaped by the independent and combined effects of myriad influences, especially their mothers and fathers

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and the interactions between them. During the early years, parents are the most proximal and most important influence on children's development. Family members are a key source of services and supports for people with disabilities across the life course, helping people to remain living at home and in the community.

Family members are the primary, and, source of support for people with disabilities, assisting with tasks that promote community living and integration across the life course. Parents play major roles as caregivers, advocates, and system navigators. These efforts will help to identify the support needs of care giving families, influence program development and resource allocation, and shape social, health, and family policy.

In adulthood, families also provide a broad range of assistance, helping individuals to lead meaningful lives in the community, including educational attainment and employment, and to avoid unnecessary and undesired institutionalization. The social model is linked to the rights-based model which focuses on the humanity of children with disabilities and their rights. Rights are indivisible and universal and therefore children with disabilities should be included in mainstream systems of development to prevent discrimination and exclusion. In this unit, we will discuss about the role of family and community in management of children with special needs.

10.2 OBJECTIVES

Going through this unit, you will be able to

- Outline the role of family and community in management of children with special needs
- Analyze the importance of accessibility in the life of special persons.
- Discuss about the early intervention of Persons with Disabilities.
- Highlight on evaluation of treatment
- Propose the rehabilitation measures for the Persons with disabilities

10.3 ROLE OF FAMILY IN MANAGEMENT OF CHILDREN WITH SPECIAL NEEDS

Disability is the consequence of an impairment that may be physical, cognitive, mental, sensory, emotional, developmental, or some combination of these. A disability may be present from birth or occur during a person's lifetime. Family is the primary unit in the life of an individual. Parents are the pillars of this unit. Positive attitudes and reinforcement from family members can inspire patients' commitment to recovery and help them adapt to new physical challenges or limitations. Family support and encouragement can also help patients deal with issues

of self-esteem related to their condition. Conceptions of who parents are and what constitute the best conditions for raising children vary widely.

From classic anthropological and human development perspectives, parenting often is defined as a primary mechanism of socialization, that is, a primary means of training and preparing children to meet the demands of their environments and take advantage of opportunities within those environments. As Bornstein (1991) explains, the “particular and continuing task of parents and other caregivers is to enculture children to prepare them for socially accepted physical, economic, and psychological situations that are characteristic of the culture in which they are to survive and thrive.”

All children develop attachments with their parents based on how parents interact with their young children, including the extent to which they respond appropriately and consistently to their children’s needs, particularly in times of distress, influences whether the attachment relationship that develops is secure or insecure.

Young children who are securely attached to their parents are provided a solid foundation for healthy development, including the establishment of strong peer relationships and the ability to empathize with others. Conversely, young children who do not become securely attached with a primary caregiver (e.g., as a result of maltreatment or separation) may develop insecure behaviour’s in childhood and potentially suffer other adverse outcomes over the life course, such as mental health disorders and disruption in other social and emotional domains.

Lack of care for children with disabilities can be related to ignorance about the child’s potential, or a lack of services available, or both. By engaging with the whole community, the parents can help to break down these barriers which contribute to children’s exclusion. The active involvement of all community is important so that children’s right to be included is realized. Inclusive local communities with strong social networks bring rewards for the whole community. For example, a fully inclusive school offers improved opportunities for all students because of improved infrastructure.

Making sure that everyone understands the rights and needs of children with disabilities, including community leaders, religious authorities, as well as voluntary groups, non-governmental organizations and local government authorities, makes change for the better more likely to happen and more likely to be sustained.

Parents of children with disabilities experience challenges that differ from those experienced by parents of typically developing children (Woodman, 2014). When a child with one or more disabilities is born into a family or when parents receive the diagnosis of their child’s disability, they often experience a range of emotions (e.g., shock, grief, anger) that are somewhat similar to those experienced upon learning about the death of

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a loved one (Kandel and Merrick, 2003). Parents experiencing such emotional reactions require a period of time to adjust, and during that time, parenting and care giving may be affected.

Some children with disabilities pose particular challenges because of developmental needs and behaviour's that require specific parenting skills or actions not required for children who are developing typically. In addition, parents of children with disabilities tend to experience challenges at certain points of transition during the early childhood years.

Young children with disabilities affect families in different ways, but a common finding in the literature is that parents of children with disabilities experience more stress than parents of typically developing children (Woodman, 2014). Given the difficulties faced by parents of children with disabilities, a range of programs focus on parenting skills and engagement for these parents.

Check your progress - I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Detail the role of family in management of the children with disabilities?

10.3.1 Role of community in management of Children with Special Needs

UNICEF reports that there are at least 90 million children with disabilities in the world, and that numbers may be much higher. These children are amongst those most likely to experience violation of their rights. Community plays an important role in fostering transformative learning and living environments for children with special needs. Community is conceptualized as a special kind of relationship between people, share common values, concerns, interests, or experiences. This understanding of community as relationship is linked to the importance of empowering family involvement and decision making as children with special needs navigate the educational system that seeks to help them grow and thrive.

Government has opened separate schools for children with physical impairment, School for Blind Children, School for Hearing and Speech Impaired children. They are given reservations in jobs and also free transport facilities. There is a well-established link between the local community context and children's development and learning, largely linked to the availability of opportunities to engage in a range of experiences. There is a current movement to replace the term CBR with Community Based Inclusive Development (CBID) because it describes the approach more positively. When positive relationships are built between families, schools, prior-to-school settings and other community groups,

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there is the potential for collaboration and, through this, information sharing, the establishment of networks, and growing awareness of different contexts and resources. These, in turn, can lead to everyone working towards common goals.

Schools and communities make significant contributions to children's connections with school, in the transition process. Where children and their families feel connected to schools, valued, respected and supported in schools and communities, they are likely to engage positively, with the result that not only children and families but also schools and communities' benefit. When the reverse occurs, with children and families feeling alienated from school and unsupported in the community, communities and those within them suffer.

Families and Communities provide information and resources for parents and families. Children's policy and advocacy organization provides information on child wellbeing, stimulates dialog on children's issues, and promotes accountability and action. Advocates the involvement of parents and families in their children's education, and fosters relationships between home, school, and community to enhance the education of all our nations' young people.

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i) Detail the role of school in management of the children with Disabilities?
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10.4 ACCESS TO INFORMATION AND SERVICES

Accessibility can be defined as the "ability to access" the functionality, and possible benefit, of some system or entity and is used to describe the degree to which a product such as a device, service, and environment is accessible by as many people as possible. The concept of accessible design ensures both "direct access" (i.e. unassisted) and "indirect access" meaning compatibility with a person's assistive technology (for example, computer screen readers).

10.4.1 Access to communication and information

The definition of Accessibility is the degree to which a product, device, service, or environment is available to as many people as possible. It is also considered to be the "ability to access". Signs, public address systems, the Internet, telephones, and many other communication media are oriented toward people who can hear, see and use their hands easily. Making these media accessible to people with disabilities can take some creativity and ingenuity.

- A. Announcements: In public places where announcements may be important, and may target individual's airports, for example they

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- should be both verbal and visual, so that they can be heard or seen by those with vision and hearing difficulties.
- B. The advent of cell phones that can announce calls with vibration, and that have text-messaging capability, has undoubtedly made life easier for many people with hearing impairments.
 - C. ISL interpretation: Deaf individuals may need an Indian Sign Language interpreter for meetings with doctors, lawyers, and other professionals; for lectures and classes; for business transactions; or for public gatherings, such as conferences, performances, or public hearings.
 - D. Readers: People with learning disabilities or vision difficulties may need readers in order to successfully complete courses. By the same token, deaf individuals may need to be provided with lecture notes, or to have an interpreter in lectures.
 - E. Internet: Accessibility includes monitoring content to make it is easily understood by software and hardware devices that make it possible for people with visual or hearing difficulties, or for those who can't use a mouse or keyboard, to have full access to the content of a website. Devices used by people with disabilities to access the Web include screen readers, which translate on-screen text into speech, and voice-command software that translates spoken commands into mouse clicks and keyboard strokes.
 - F. Television: Since 1993, all TV sets sold in the U.S. are required to be equipped with closed-captioning receivers that can be turned on through an on-screen menu or a remote. When turned on, closed captioning displays a text version of what's being said (as well as relevant non-speech sounds) on the screen, enabling deaf or hearing-impaired viewers to experience the any show with captions. Captions can also be helpful to people with some learning disabilities and to literacy learners.
 - G. Concerts and theatre performances. Many venues that house performances, lectures, or public forums offer sound amplifying headphones to those who need them.

People with disabilities have, in the past, often been denied access to services of various kinds from childcare or mental health counselling to help in retail stores to entertainment either due to lack of physical accessibility or because of discomfort, unfamiliarity, or prejudices regarding their disabilities.

10.4.2 Community Access

Everyone should have the right to fully participate in community life, including attending religious services, dining in public restaurants, shopping, enjoying community park facilities, and the like. Even where there are no physical barriers, people with disabilities still sometimes experience differential treatment.

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Accessibility is strongly related to universal design which is the process of creating products that are usable by people with the widest possible range of abilities, operating within the widest possible range of situations. This is about making things accessible to all people (whether they have a disability or not).

Check your progress-III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What are the ways we can help people with special needs in improving their accessibility?

10.5 EARLY INTERVENTION

Early identification and early intervention refer to the process in which the child protection system identifies a congenital disability or a developmental delay and immediately intervenes to help the child and their family. This intervention considers any medical treatment a child might need but also the developmental needs for daily living skills that most children grow up learning naturally in a family and community environment. If a child is born with an obvious disability, intervention has to begin immediately.

From birth to age three, it is a critical period of brain development, and is crucial to encourage and stimulate all children as much as possible during this time. The neural pathways develop with every touch, movement and new sensation; the more experiences a child has during this important period, the better their brain development.

In other cases, it might become obvious over time to a family that the child is not doing the same things as other children would at the same age, such as sitting up, babbling or taking first steps. When a child goes for a regular health check the nurse or doctor might find that the child is not meeting the developmental milestones of a typically developing child.

10.5.1 Typical Development Timeline: Birth to Age 8 Months

NHS Choices Birth to five development timeline Adapted version is given for the reference

- 1–4 weeks old: loves looking at faces and begins to recognize family members/primary caregiver, may be startled if they hear loud and sudden noises
- 4–6 weeks old: starts to smile and respond to the sounds around them
- 4–12 weeks old: lifts their head while lying on their front

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- 3–5 months old: reaches out for objects as their muscles develop
- 4–6 months old: starts making noises, enjoys making new and different sounds 5 months old: lifts objects and tries to suck on them
- 6 months old: hand-to-hand coordination, will learn to pass things from one hand to another
- 6–8 months old: sits without support

It is extremely important to identify a developmental delay as soon as possible in order to provide the necessary support. The cause of delay may not be serious, or it may be a symptom of cerebral palsy, other neurological problem or physical disability. In any case, the child needs attention, stimulation and play in order to be supported and to have an opportunity to develop in a positive way. If the delay is a result of disability, the child needs access to early intervention as soon as possible to ensure that no time is lost. Eligibility for early intervention services is based on an evaluation of the child's skills and abilities. Early intervention services can include:

- Training for medical staff in general disability issues;
- Immediate referral to rehabilitation services;
- Advice pamphlet for families;
- Referral to family support groups; and
- Specialist home-visiting services for children with disabilities.

10.5.2 Types of early intervention

Many children with a disability can benefit from some type of early intervention (or therapy). For example:

- A. Occupational therapy can help with fine motor skills, play and self-help skills like dressing and toileting.
 - B. Physiotherapy can help with motor skills like balance, sitting, crawling and walking.
 - C. Speech therapy can help with speech, language, eating and drinking skills.
- **Family centered:** This means that the intervention includes you and other family members so you can work alongside the professionals and learn how to help your child. It is flexible, it can be offered in your home as well as in other settings such as kindergartens and early intervention centers. It provides your family with support and guidance.
 - **Developmentally appropriate:** This means that the intervention is specially designed for children with disability, it has staff that are specially trained in the intervention and services. They develop an

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individual plan for your child and review the plan regularly and track your child’s progress with regular assessments.

- **Child focused:** This means the intervention focuses on developing specific skills providing strategies to help your child learn new skills and use them in different settings; it helps to prepare and support your child for the move to school. This helps to find ways of getting your child with disability together with typically developing children (ideally of the same age).
- **Supportive and structured:** This means the intervention provides a supportive learning environment. It helps your child feels comfortable and supported and is highly structured, well organized, regular and predictable.

Check your progress-IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the need for early intervention.

10.5.3 Assessments and planning

Early intervention is so important; children who require special services need to be assessed at a young age. Here are six stages in the assessment process, from child-find to program evaluation.

Assessment means the gathering of information to make critical decisions about a child. A variety of methods are used to gather assessment information, including observations of the child, interviews with the family, checklists and rating scales, informal tests, and standardized, formal tests. Assessment information is useful for identifying the child as eligible for special services, planning instruction, and measuring progress.

Stage 1: Child-Find/case finding

The strategies that are used for locating young children in the community who may need special services are: Building community awareness through public agencies and organizations, setting up a system for referrals, canvassing the community for young children who need screening, maintaining local publicity and contacts with sources of referral

Stage 2: Developmental screening

Developmental screening is a cursory method for obtaining general information about a child's development and detecting any potential problems.

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Stage 3: Diagnosis

Diagnosis is a more intensive evaluation than screening. The examiners strive to determine the nature of the child's difficulties, the severity of the problem, and the child's strengths and weaknesses. The diagnosis is conducted by members of a multidisciplinary team. Information collected through the diagnosis leads to decisions about the nature and severity of the problem and assists in planning intervention.

Stage 4: Individual planning of programs and interventions

Diagnosis indicates there is a need for early intervention, planning process for preschool children includes:

- Sensory/physical development
- Language and communication abilities
- Fine and gross motor development
- Cognitive abilities
- Adaptive or self-help skills
- Social-emotional development

Stage 5: Program monitoring

After the child is placed in an intervention program, it is important that the child's progress in monitored frequently by collecting data on a regular basis and analyse to determine mastery of targeted skills.

Stage 6: Program evaluation

Program evaluation is objective, systematic procedure for determining progress of children and the effectiveness of the total intervention program. It may be necessary to make needed changes and modifications in the intervention program.

Check your Progress - V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the need for Program monitoring.

10.6 PROGRAMMING FOR REHABILITATION

Rehabilitation Programs

Rehabilitation literally means “redressing” (Latin habitat dress). While there are many definitions of this concept, the world health organization (WHO) has defined rehabilitation as “a process aimed at enabling persons with disability to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides people with disability with the tools they need to attain independence and self-determination.” Thus, the aim of

rehabilitation has traditionally been facilitating the normalization of human functioning after injury, disease, or due to congenital defects.

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Difficulties faced by the child	Rehabilitation measures	People involved in the measures
Unable to care for self	<ul style="list-style-type: none"> • Therapy Training for the child on different ways to complete the task. • Assessment and provision of equipment, training parents to lift, carry, move, feed and otherwise care for the child with cerebral palsy. • Teaching parents and family members to use and maintain equipment. • Provision of information and support for parents and family. • Counselling the family. • Assistive technology- Provision of equipment for maintaining postures and self-care, playing and interaction, such as sitting or standing (when age-appropriate) 	<ul style="list-style-type: none"> • The child, parents, siblings, and extended family. • Depending on the setting and resources available: physiotherapists, occupational therapists, speech and language therapists, orthotics and technicians, doctors, psychologists, social workers, community-based rehabilitation workers, schoolteachers, teaching assistants
Difficulty walking	<ul style="list-style-type: none"> • Rehabilitation medicine • Surgical treatment of contractures and deformities (therapy interventions usually complement these medical interventions). • Therapy, exercises and targeted play activities to train effective movements. • Assistive technology Orthotics, wheelchair or other equipment. 	Doctor, parents, therapist, orthotics.
Communication difficulties	<ul style="list-style-type: none"> • Therapy Audiology. Activities for language development. • Conversation skills. • Training conversation partners. • Assistive technology Training to use and maintain aids and equipment, which may include hearing aids and augmentative and alternative communication devices. 	Parents, speech and language pathologist/therapist, communication disorders assistant, community-based rehabilitation worker, teachers, and assistants.

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Check your progress VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Explain the rehabilitation measures, and people involved in rehabilitating of people with communication difficulties?

10.6.1 Stimulation training

Stimulation training refers to the interventional therapy for children at risk for developmental delay and periodic developmental assessment, in motor development, cognitive functioning, language or adaptive functioning.

Early childhood stimulation programs can contribute to children's cognitive and socio-emotional development, ultimately enabling them to improve on several future life outcomes. From conception to five years of age, early childhood is an extremely important period for cognitive and psychosocial development. Young children's minds are still learning how to learn, and simple play activities that stimulate the brain through all the senses can help improve their ability to think, communicate, and connect with others.

A. Home environment effects

Weekly home visits promoting psychosocial stimulation changed the way parents interacted with their children and shaped their home environments.

B. Cognitive effects

Children in the psychosocial stimulation group exhibited, on average, immediate and sustained heightened cognitive ability.

C. Schooling effects

Children in the stimulation group improved their reading abilities, were half as likely to drop out, and ultimately attended more years of school.

D. Socio-emotional effects

Psychosocial stimulation may result in less depression and social inhibition up to 20 years later in participants' lives.

E. Physical effects

In general, early childhood stimulation had little effect on children's physical development. Psychosocial stimulation is an effective approach to help children achieve their full developmental potential.

10.6.2 Process and Principles of Stimulation Training

Early stimulation is important both for the growing brain and body. Adequate nutrition and the presence of both parents during the early years

are also crucial to a child's being. All these factors contribute towards a normal healthy adult. The stimulation the child receives depends on life at home the family structure.

- Every child has certain potentials which must be explored.
- Start the training with what the child knows, so that the baby has the feeling of success.
- Proceed to the skills in which the child needs to be trained.
- Appreciate the child for even little efforts.
- Reward is a must once the child masters the skill.
- Involve normal children of the same mental age while training the child.
- Anything appropriate and attractive available at home can be used as training material.

Check your progress VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is your understanding of stimulation training?

10.7 TREATMENT

Children with disabilities generally require the same general health care services needed by every child, but often at increased frequency and intensity, and they also require a variety of specialized services that children without disabilities do not generally need. To ensure optimal health outcomes, all children need access to regular primary health care services, including preventive care, diagnostic care, and treatment.

A. Preventive care focuses on maintaining current health, preventing health problems before they happen, and limiting the secondary consequences of existing health problems. For physical health care, this includes regular checkups; physical examinations; immunizations; and genetic or diagnostic screenings, including testing for infectious diseases in populations believed to be at risk for exposure and screenings for secondary health problems. Preventive services related to mental health care are addressed below.

B. Diagnostic care focuses on understanding the cause of current symptoms and diagnosing illness. When a health problem exists, treatment is provided to control, correct, or reduces the problem.

The needs of children with disabilities and their families often are too diverse and extensive to be met solely by the primary care provider. Although it is not uncommon for primary care paediatricians to treat children with more common potentially disabling conditions, such as severe asthma or motor disabilities originating in the central nervous system, most paediatricians lack adequate knowledge of more rare and complex conditions, including best practices in the treatment and monitoring of these conditions. As a result, many children with disabilities require services from a wide variety of providers.

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10.7.1 Medical Rehabilitation

Medical rehabilitation includes treatment programs that help a person perform better in all his daily physical and mental activities. Medical rehabilitation is a follow up treatment after any kind of treatment program. Programs focus on improving major and minor skills that are required in the basic life. Assessing patient in every step to improve the activities of basic living.

Vocational rehab program is designed to help those people who find it difficult to get employment or retain it after they have gone through certain situation that caused mental or physical disability in them. Providing physiological and medical assessment for Job placement, job training and on job training. It helps in improving the ear deficit by working on the central nervous system. Also deals in improving eye and head coordination. This treatment type helps to restore damage that is caused after a stroke, which is the 3rd leading cause for death worldwide.

- a) **Stroke rehabilitation-** It aims at helping people gain maximum normal functioning after the occurrence of a stroke. Help the person to get back to normal lifestyle and be independent in daily activities.
- b) **Cognitive rehabilitation therapy-** It involves relearning or improving skills, such as thinking, learning, memory, planning, and decision making that may have been lost or affected by brain injury.
- c) **Surgery-**It includes procedures to correct a misaligned limb or to release a constricted muscle, skin grafts for burns, insertion of chips into the brain to assist with limb or prosthetic movement, and placement of skull plates or bone pins.
- d) **Respiratory Therapy-** It is used to aid patients who have breathing disorders or difficulties, this form of rehabilitation therapy works to help them decrease respiratory distress, maintain open airways and, when necessary, learn how to use inhalers and supplemental oxygen properly.
- e) **Cognitive Rehabilitation-** Also commonly called cognitive-behaviour rehabilitation, this type of therapy works with patients to improve memory, thinking and reasoning skills.

10.7.2 Therapeutic Rehabilitation

Rehabilitation medicine uses many kinds of assistance, therapies, and devices to improve function. The type of rehabilitation a person receives depends on the condition causing impairment, the bodily function that is affected, and the severity of the impairment. The following are some common types of rehabilitation:

- Occupational therapy helps a person carry out daily life tasks and activities in the home, workplace, and community.
- Pharma-co-rehabilitation involves the use of drugs to improve or restore physical or mental function.
- Physical therapy involves activities and exercises to improve the body's movements, sensations, strength, and balance.

Rehabilitative/assistive technology refers to tools, equipment, and products that help people with disabilities move and function. This technology includes (but is not limited to):

- a) Orthotics, which are devices that aim to improve movement and prevent contracture in the upper and lower limbs. For instance, pads inserted into a shoe, specially fitted shoes, or ankle or leg braces can improve a person’s ability to walk. Hand splints and arm braces can help the upper limbs remain supple and unclenched after a spinal cord injury.
- b) Prosthetics, which are devices designed to replace a missing body part, such as an artificial limb
- c) Wheelchairs, walkers, crutches, and other mobility aids
- d) Augmentative/Alternative Communication (AAC) devices, which aim to either make a person’s communication more understandable or take the place of a communication method. They can include electronic devices, speech-generating devices, and picture boards.
- e) Hearing aids and cochlear implants
- f) Retinal prostheses, which can restore useful vision in cases in which it has been lost due to certain degenerative eye conditions
- g) Telemedicine and tele-rehab technologies, which are devices or software to deliver care or monitor conditions in the home or community
- h) Rehabilitation robotics
- i) Mobile apps to assist with speech/communication, anxiety/stress, memory, and other functions or symptoms
- j) Recreational therapy helps improve symptoms and social and emotional well-being through arts and crafts, games, relaxation training, and animal-assisted therapy.
- k) Vocational rehabilitation aids in building skills for going to school or working at a job.
- l) Music or art therapy can specifically aid in helping people express emotion, in cognitive development, or in helping to develop social connectedness.

When multiple types of therapy are needed to aid an individual in recovery and rehabilitation or close medical supervision is necessary, seeking services in an inpatient facility is generally recommended as the safest and most efficient means of treatment. Outpatient or home-based services may be most appropriate for patients who need fewer services or less intensive medical/rehabilitative care.

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Check your progress – VII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit

i) Explain Therapeutic rehabilitation?

ii) What is meant by AAC?

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10.8 POST EVALUATION

Rehabilitation Service is skilled professionals providing quality medical, rehabilitative, coordination and educational support services for children with special health care needs and their families. It included transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability, and include speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, early identification and assessment of disabilities in children, counselling services, including rehabilitation counselling, orientation and mobility services, and medical services for diagnostic or evaluation purposes. Post evaluation of therapeutic rehabilitation is mandatory for any services offered to children with disabilities.

10.9 LET'S SUMUP

Family of a child with disability has more responsibilities. Their expense, the time, the energy needed to care for the member with disability and their safety are crucial. They also take up an important role in developing their self-image and social skills, and the providing an appropriate education.

Family is one of the most influential social structures in society, which shape educational aspirations and career choices of children through expectations, support and advice. Young people with disability may not be socialized like their non-disabled peers or siblings due to the influence of medical model thinking. This has left many families unsure of what to expect of children with disabilities, thus excluding them from many important patterns of socialization and social processes.

De-institutionalization and the development of community-based rehabilitation services has received inputs from the 'normalization' principle, which seeks to promote conditions which would allow the person with disability to develop his full potential and live as ordinary life as possible. Interdependent relationship between the people with disabilities and his' family is being recognized as vitally influencing the family's adjustment and role of the child's overall maturation and psychological development.

Lack of care for children with disabilities can be related to ignorance about the child's potential, or a lack of services available, or both. By engaging with the whole community, the parents can help to break down these barriers which contribute to children's exclusion. The active involvement of all community is important so that children's right to be included is realized.

Inclusive local communities with strong social networks bring rewards for the whole community. For example, a fully inclusive school offers improved opportunities for all students because of improved infrastructure. Making sure that everyone understands the rights and needs of children with disabilities, including community leaders, religious authorities, as well as voluntary groups, non-governmental organizations and local government authorities, makes change for the better more likely to happen and more likely to be sustained.

10.10 UNIT END EXERCISES

1. Highlight the importance of family in disability management.
2. What is meant by rehabilitation programmes?
3. Explain assessments and planning for PwD.
4. Give brief note on Medicinal rehabilitation
5. Discuss Therapeutic rehabilitation
6. What is Post treatment evaluation?

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10.11 ANSWERS TO CHECK YOUR PROGRESS

- All children develop attachments with their parents based on how parents interact with their young children, including the extent to which they respond appropriately and consistently to their children's needs, particularly in times of distress, influences whether the attachment relationship that develops is secure or insecure.
- Schools and communities make significant contributions to children's connections with school, in the transition process. Where children and their families feel connected to schools, valued, respected and supported in schools and communities, they are likely to engage positively, with the result that not only children and families but also schools and communities' benefit.
- Accessibility is strongly related to universal design which is the process of creating products that are usable by people with the widest possible range of abilities, operating within the widest possible range of situations.
- Early identification and early intervention refer to the process in which the child protection system identifies a congenital disability or a developmental delay and immediately intervenes to help the child and their family. This intervention considers any medical treatment a child might need but also the developmental needs for daily living skills that most children grow up learning naturally in a family and community environment.
- Program monitoring is essential as after the child is placed in an intervention program, it is important that the child's progress in monitored frequently by collecting data on a regular basis and analyse to determine mastery of targeted skills.
- For Communication difficulties, the rehabilitating measures adopted can be Therapy Audiology, activities for language development, conversation skills, and training conversation partners and provision of Assistive technology Training to use and maintain aids and equipment, which may include hearing aids and augmentative and alternative communication devices. The persons involved are Parents, speech and language pathologist/ therapist, communication disorders assistant, community-based rehabilitation worker, teachers, and assistants.
- Rehabilitation as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments". A distinction is sometimes made between habilitation, which aims to help those who acquire disabilities congenitally or early in life to develop maximal functioning; and rehabilitation, where those who have experienced a loss in function are assisted to regain maximal functioning.
- Augmentative/Alternative Communication (AAC) devices, which aim to either make a person's communication more understandable or take

the place of a communication method. They can include electronic devices, speech-generating devices, and picture boards.

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10.12 SUGGESTED READINGS

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UNIT XI

- 11.1 Introduction
- 11.2 Objectives
- 11.3 Training children with disabilities
 - 11.3.1 Daily living skill training
 - 11.3.2 Role of Therapist
 - 11.3.3 Home based training
 - 11.3.4 Parent training
- 11.4 Inclusive development
- 11.5 Education of children with disabilities
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11.1 INTRODUCTION

Parents play a vital role in the training and development of children with intellectual disabilities. In training of functional skills among children with disabilities parents help a lot in achieving target goals. They are considered as leading mentors for children in their early life as well as later life. Parents can be involved in any part of education and training of their children. There is no boundary for parents' participation.

Parents can provide different information about the developmental characteristics of their children. There are many processes in which parents can be involved, such as, identification, assessment, educational programming, training, teaching, and evaluation. The well-informed parents can identify early signs of disability.

Parents can provide different information about the developmental characteristics of their children. Parents can also provide useful information in assessment of functional skills often otherwise inaccessible to the professional. The training for gives them a chance for a better life with self-reliance, food security and an improved quality of life. Training sessions should create the atmosphere of a large family reunion in order to encourage exchange, sharing, discussion, compassion and emotional strengthening.

This gives them confidence which comes through developing positive attitudes, acquiring relevant knowledge and learning the skills to deal successfully with life and work. If a training programme focuses only on technical skills and neglects the development of attitudes, knowledge and life skills, it is unlikely to succeed in enabling its trainees to find sustainable work and employment.

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11.2 OBJECTIVES

Going through this unit, you will be able to:

- Outline the importance of training children with disabilities
- Discuss the inclusive development of Persons with disabilities
- Highlight the role of Adaptive skills.
- Discuss about the different aspects of education for the persons with disabilities
- Elaborate the various rehabilitation measures available for PWD

11.3 TRAINING CHILDREN WITH DISABILITIES

People with disabilities need skills to engage in livelihood activities. But they start with several disadvantages. Their families and communities may assume that they are unable to engage in such activities. They often lack access to basic education, making them unqualified to join skills training courses. These disadvantages frequently result in a lack of skills, as well as low confidence, expectations and achievement. Hence, they need training in different types of skills for an independent life.

These training include foundation skills acquired through education and family life, technical and professional skills which enable a person to undertake an activity or task, business skills required to succeed in self-employment and core life skills, including attitudes, knowledge and personal attributes.

The training for special needs persons gives them a chance for a better life with self-reliance, food security and an improved quality of life. Training for persons with disability mainly focuses on these skills:

- A. Foundation skills** are those acquired through basic education and family life. They include, for example, literacy, numeracy, ability to learn, reasoning and problem-solving. These types of skills are needed for work everywhere, in all contexts and cultures, in both formal and informal economies.
- B. Technical, vocational and professional skills** are those which equip someone to undertake a task – how to produce or repair something or provide service. Examples are carpentry, tailoring, weaving, metalwork, lathe operation, basket making and shoemaking. More advanced technical skills, such as engineering, medicine, physiotherapy and computer technology, are normally referred to as professional skills. Generally, the more advanced the techniques, the higher the educational level required and the more formal the training, often taking place in technical institutions and resulting in formal certification of competence.
- C. Business skills** (also called entrepreneurial skills) are those required to succeed in running a business activity. They include money and people management, as well as planning and organizational skills. They also include risk assessment, market

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analysis and information-gathering, business plan preparation, goal-setting and problem-solving. These skills usually require a basis of numeracy and literacy. Training courses which teach trades likely to lead to self-employment, such as carpentry, radio repairs, two-wheel motor mechanics and weaving, have an obligation to teach business skills alongside the technical skills.

- D. **Core life skills** consist of the attitudes, knowledge and personal attributes necessary to function in the world. They include how to relate to customers, how to present oneself, learning how to learn, effective listening and communication, creative thinking and problem-solving, personal management and discipline, interpersonal and social skills, the ability to network and work in a team, and work ethics.

Persons with disabilities or their parents must be made aware of their personal limitations and potentials; they must never allow other people to determine what they can and cannot do.

Check your Progress - I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

- i) Why do you think people with disability need training?

11.3.1 Daily Living Skill Training

For people with disability, the most basic skills are called Adaptive Living Skills, or ADLs. More advanced skills, such as doing laundry, catching a bus, or following a daily schedule, are sometimes called Life Skills or Skills of Daily Living. While these skills aren't critical for survival, they are extremely important for anyone who plans to work and recreate in a modern community.

Most people without disabilities learn ADL and many of the skills of daily living at a young age. But children with disabilities lag behind in acquisition of these basic skills. Activities of daily living are crucial for children with special needs to achieve some independence and learn the skills they will need for their adult lives. For special needs children, activities of daily living might require intensive instruction and routines.

Activities of daily living are also referred to as ADL skills. These activities are the basic tasks of everyday life, and they include tasks such as eating, bathing, clothing, and toileting. For most children, these tasks are learned relatively easily and become a part of a daily routine. For children with special needs, these tasks might be more difficult and might require constant reminding or rewards for completing the activities of daily living.

For children with special needs such as motor difficulties, buttoning a sweater might be a very challenging ADL. For special needs children who have trouble interacting socially, they might not care that their peers are performing a certain activity, and they are not motivated to complete

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the same activities of daily living. For children with special needs such as motor difficulties, buttoning a sweater might be a very challenging ADL.

For special needs children who have trouble interacting socially, they might not care that their peers are performing a certain activity, and they are not motivated to complete the same activities of daily living. For children with special needs, such as autism, the communication and attention deficits that are a part of the disorder interferes with their ADL and self-care behaviour.

11.3.2 Role of Therapist

Occupational therapists work extensively for special needs children to improve their ADL. Occupational therapists help children with special needs to become physically, psychologically, and socially independent by working towards specific goals.

For special needs children who have difficulty brushing their teeth, an occupational therapist might teach steps towards achieving this goal. These steps might be broken down into very small pieces, such as reaching out their hands, touching the toothbrush, grasping the toothbrush, picking up the brush, and so forth. Basic ADLs (BADLs) consist of self-care tasks, including:

- Bathing and showering (washing the body)
- Dressing
- Eating/feeding (including chewing and swallowing)
- Functional mobility (moving from one place to another while performing activities)
- Personal hygiene and grooming (including brushing/ combing/ styling hair)
- Toilet hygiene (completing the act of urinating/defecating)
- Instrumental activities of daily living (IADLs) are not necessary for fundamental functioning, but they let an individual live independently in a community. They are
 - Housework
 - Taking medications as prescribed
 - Managing money
 - Shopping for groceries or clothing
 - Use of telephone or other form of communication
 - Using technology (as applicable)
 - Transportation within the community

Training sessions should create the atmosphere of a large family reunion in order to encourage exchange, sharing, discussion, compassion and emotional strengthening. Trainees must learn to listen to the experiences of others in order to learn how to overcome some of the problems and be successful in improving their quality of life.

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Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Highlight the need for PWD to have ADL skills.

i) State the role of occupational therapist in teaching ADL skills to children with disabilities

11.3.3 Home based training

Home-based education is defined as the education of children with severe intellectual/physical disabilities, who can be educated in the combination of home-based and alternate educational settings to enable them to achieve independent living skills. Home-based education aims at school preparedness and preparation for life. Alternate educational settings provide opportunities for learning of social skills, vocational skills and implementation of life skills.

Many young people learn so-called traditional vocational and life skills through home-based activities, where knowledge, skills and attitudes are passed on from parents, siblings and other family members. Home-based “learning-by-doing” is fundamental in preparing a person to learn further skills for a livelihood. However, children and young people with disabilities and people with severe and multiple disabilities, are often excluded from this learning-by-doing process because of preconceived ideas held by parents and family members about what the child or young person can and cannot do.

Parents may be motivated by wanting to protect their child with disability from harm, or they may believe their child is unable to learn or contribute to the household, or they may simply discourage, neglect or ignore him/her. As a result, the child with disability is unable to learn useful skills and is prevented from contributing to the household or family enterprise. This exclusion undermines the person's self-confidence, affecting his/her active participation in the family and community.

CBR programmes can play an important role in helping parents understand the potential of a family member with a disability to learn skills so that he/she can contribute to the household in a productive way. Possible activities are

- identify ways in which the person with disability can be involved in livelihood or support tasks around the home;
- encourage family members to teach and pass on skills that will be useful, add to and enable inclusion in productive household activities;
- Follow up on the level of participation of the individual with a disability in household and livelihood activities.
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Check your progress-III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is Home Based Training?

11.3.4 Parent training

Parent of children with disability need to be educated about their child's type of disability, diagnosis, treatment and ways to manage it. Parents need unique educational program to help them navigate the challenges across the lifespan. Parents need to be trained to handle behaviour issues of children with disability. Parents need careful teaching and support to learn parenting skills and use them consistently. The topics covered in a typical series of parent training sessions include the following:

- Establishing house rules, structure and consistent routines
- Learning to praise appropriate behaviours (praising good behaviour at least five times as often as criticizing bad behaviour) and ignoring mild inappropriate behaviours (choosing the battles)
- Using appropriate commands
- Using "when...then" contingencies (withdrawing rewards or privileges in response to inappropriate behaviour)
- Planning and working with children in public places
- Time out from positive reinforcement (using time outs therefore for inappropriate behaviour)
- Daily charts and point/token systems with rewards and consequences
- School-home note system for rewarding behaviour at school and tracking homework.

Some families can learn these skills quickly in the course of 8–10 meetings, while other families often those with the most severely affected children require more time and energy. Parenting sessions usually involve an instructional book or videotape on how to use behavioural management procedures, an overview of the diagnosis, causes, nature and prognosis of their child.

Parent training can be conducted in groups or with individual families. Parents are taught behavioural techniques that are modified to be age-appropriate for adolescents. After parents have learned these techniques, the parents and teenager typically meet with the therapist together to learn how to come up with solutions to problems on which they all agree.

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Check your progress-IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Give a short note on Parents Training?

11.4 INCLUSIVE DEVELOPMENT

Over the last decade, the United Nations Development Programme (UNDP) has played a positive role at both global and national levels in helping over 70 Member States to implement the Convention on the Rights of Persons with Disabilities (CRPD) both through targeted efforts and through mainstreaming support to PWDs.

The 2030 Agenda's pledge to leave no one behind offers a new opportunity to help strengthen the rights of persons with disabilities. UNDP undertakes disability inclusive development by supporting countries to develop and strengthen disability law and policy frameworks, improve accessibility of services, social protection, livelihood opportunities, and promote the participation of PWDs in political and public life.

Disability-inclusive development means that all stages of development processes are inclusive of and accessible to persons with disabilities. It requires that all persons be afforded equal access to education, health care services, work and employment, and social protection, among others. In both developed and developing countries, the world's more than one billion persons with disabilities are more likely to experience poverty and exclusion than persons without disabilities.

Attitudinal and environmental barriers to participation have profound social, economic and cultural effects on persons with disabilities, resulting in exclusion and creating often insurmountable obstacles in relation to health services, education and employment. Such exclusion and discrimination in turn contributes to poverty and prevents persons with disabilities from participating in public discourse or in development decision-making. As a result, the interests and needs of persons with disabilities are frequently neglected by society.

Women and girls with disabilities, who experience discrimination on the basis of multiple aspects of their identities, often face heightened levels of exclusion in this regard. Although not all persons with disabilities experience poverty and not all persons living in poverty become disabled, poverty and disability are nonetheless linked.

Inclusive development engenders empowerment, through which persons with disabilities move from being considered "vulnerable groups" to becoming resource groups in society and contributors to development. There is growing recognition that disability-inclusive development benefits not only persons with disabilities and their families, but also societies as a whole. Their goal is that persons with disabilities should, at all stages of

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life, realize their rights and participate in all aspects of society and development on an equal basis with others.

- To improve learning for all children both those with and without disabilities.
- To promote understanding, reduce prejudice and strengthen social integration.
- To ensure that children with disabilities are equipped to work and contribute economically and socially to their communities.

Check your progress - V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Give a short note on attitudinal and environmental barriers to inclusion

11.5 EDUCATION OF CHILDREN WITH DISABILITIES

All human rights are interlinked. This includes the right to education. It is not possible to achieve an effective education unless other rights are realized. And if the right to education is fulfilled, it leads to the realization of other rights. An education system should include all students and supports them to learn. This means making sure that teaching and the curriculum, school buildings, classrooms, play areas, transport and toilets are appropriate for all children at all levels. Inclusive education means all children learn together in the same schools.

Inclusive education involves transforming the whole education system - legislation and policy, systems for financing, administration, design, delivery and monitoring of education, and the way schools are organized. To ensure quality education for children with disabilities the following must be addressed:

- Promote accessible and inclusive learning spaces.
- Ensure physical accessibility for children with disabilities, including commuting and moving around in the school environment as well as having safe access to water and sanitation facilities whilst at school. Likewise, learning materials need to be made available in accessible formats to suit the needs of children with different types of disabilities.
- Invest in teacher training for inclusive education - Where available, approaches to education for children with disabilities have changed over the years. While the initial emphasis was on 'special schools', there has been a shifting that indicates a preference towards inclusive education.
- Preparation and orientation of teachers for inclusion should happen through teacher training which, besides the child-centred pedagogy

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will also address attitudes towards children with disabilities, and how to prepare/support families for them to be encouraged to keep their children in school and informed about their children's potential.

- Take a multi-sectored approach - Barriers that prevent children with disabilities to access education are located both within and outside the education system, for example transport, social services for assistive devices, health etc.
- Involve the community - The education of children with disabilities must include a strong involvement from community as well as from parents, being two key factors, which determine the success of Inclusive education.

11.5.1 Pre-Vocational Education

Pre-vocational or pre-technical education programmes are mainly designed to introduce participants to the world of work and to prepare them for entry into further vocational or technical education programmes. Successful completion of such programmes does not lead to a vocational or technical qualification that is directly relevant to the labour market. For a programme to be considered as pre-vocational or pre-technical education, at least 25% of its content has to be vocational or technical.

It's provided for students from 16–18-year-olds who had left the schooling system with few qualifications, is an instructive example—usually provides the student with some limited experience in a chosen vocational area, together with a curriculum which emphasizes the acquisition of the key skills: communication, numeracy, and information communication technology.

Pre-vocational Education is a support program for young persons from special schools and secondary schools with learning difficulties, with permanent learning disabilities, with behavioural problems or psychological disorders and for those, who are not able to work at that time or the first attempt of the preparatory training was not successful. The respective qualification level and the duration of the Pre-vocational education depend on the individual needs, the integration prospects and possibilities of the participant; it is normally 11 months.

11.5.2 Vocational skill training

Vocational training involves teaching people to acquire a particular skill meant to prepare them for a particular Occupation. Vocational training plays a crucial role in the Social and economic development of every country. For example, the provisions of appropriate skills open access for the under-privileged and marginalized groups, such as persons with disabilities, to compete successfully on the labour market.

Vocational education and training are important for giving students with special educational needs the opportunity to access mainstream

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provision during their education and in their future working life. Curricula should include workplace behaviours, occupational skills and careers awareness, as well as provide work exploration opportunities to help learners with special educational needs identify career interests and be proactive in developing the skills critical to a successful transition. Which training is appropriate for Special education needs students, depends on their abilities/disabilities?

According to UNDP report (2012), in India, the skills and potential of most people living with disabilities remain untapped, underutilized or underdeveloped. Vocational training is one of the potential determinants of employment among People with differently Abled. They should get proper vocational training after a full assessment of training needs and suitability, carried out by a multidisciplinary team of doctors, therapists, social workers, counsellors and other professionals. Proper skill training should start from the initial vocational education itself. The main tasks of vocational education include:

- To give a vocational orientation
- The opportunity of getting tested for suitable jobs according to one's skills
- Guiding while making a career choice
- To impart the students with the necessary knowledge and skills for the initial vocational training
- To prepare (as sustainable as possible) and integrate the participants for inclusion in the regular labour market.

Check your Progress - VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Explain Pre-vocational Education?

ii) What is Vocational training?

11.5.3 Co-curricular activities

The benefits of physical and co-curricular activities are universal for all children, including those with disabilities. The goal is inclusion for all children with disabilities in appropriate activities according to their interest and ability.

The students are involved in many co-curricular programs as an integral part of the education and learning. We promote functional learning, which is enabling a child affected with autism or intellectual deficits or multiple disabilities, to meet up the daily life challenges and to be independent in life as far as possible. One-to-one sessions, group sessions, play and water therapy, music, dance, theatre, art and craft classes are regularly incorporated in our structured educational curriculum.

- **Individual Sports:** If the child enjoys sports, consider teams in which the child is performing on his own and competing with his own best outcomes. Options including swimming, martial arts, bowling, track and field, golf, archery, and many more.

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- **Structured Adult-led Clubs and Programs:** Many children with special needs thrive in programs such as Boy Scouts and Girl Scouts. That's because the programs are highly organized, children progress at their own rate, activities are hands-on, and the organizations themselves are dedicated to including children regardless of ability or background.
- **Singing and Instrumental Programs:** Instead of or in addition to music therapy, consider enrolling the child in a singing or instrumental program that actually teaches and celebrates skills. If the child can learn to sing, he will always be welcome in a chorus. If she can play an instrument, she can join the band. These are not only entries into school-based programs, but also hobbies to enjoy throughout life.
- **Volunteer Activities:** Most communities are loaded with opportunities for children (sometimes with parents) to volunteer their time. Children can help clean up trash at the park, help foster kittens, visit nursing homes, or help raise money for school events by washing cars or selling treats. With parental involvement, they can become valued members of the community or school organizations.
- **Visual Arts:** Many children with special needs are really quite talented in the visual arts. Schools and community art centres often offer after-school programs in drawing, painting, clay, and even multi-media art.
- **Video and A/V:** several teens with special needs have great interest and skills in video and a/v. Many middle and high schools have video and A/V clubs, and many towns have local TV stations where children can get involved. Even if the child isn't a creative videographer, she can find opportunities to be confident and valued behind the camera or managing microphones.
- **Special Interest Clubs:** Children with special needs are often fascinated by an area of interest and have a hard time getting interested in anything else. If this describes the child, consider helping her get involved with special interest clubs in areas ranging from mathematics and video gaming to animal welfare, or chess.
- **Horseback Riding:** Horseback riding can be expensive, but it combines several wonderful elements that may be perfect for the child. Equestrians learn to communicate effectively, build strength and balance, and gain skills in an exciting sport that can be individual, team-based, competitive or non-competitive. Ask about scholarships or special programs for children with special needs.

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Check your progress-VII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Do you think persons with special needs need require Co-curricular activities if so Justify

11.6 POST EVALUATIONS –TREATMENTS

To review the guidelines for evaluation of various disabilities and procedure for certification (Ministry of Welfare, Govt. of India, 1986) and to recommend appropriate modification/alterations keeping in view the Persons with Disabilities (Equal opportunities, Protection of rights and Full participation) Act 1995, a committee was set up in 1988 by the Government of India, Ministry of Social Justice & Empowerment under the Chairmanship, DGHS, GOI with subcommittee, one each in the area of Mental Retardation, Locomotors/ Orthopaedic, Visual and Speech & Hearing disability.

In the guidelines, the functional (permanent physical impairment) due to congenital, post disease or trauma have been evaluated. This is commonly interpreted as disability, which is not so, in strict terms. In case of loco motor conditions, broadly, the body has been divided into upper limb, lower limb & trunk.

In view of the various constraints, physical & financial, the 40% disability has been taken as cut off to avail various facilities & concession earmarked by government. The guidelines notified, are for assessment of disability in the respective area/body part (function) and to quantify in terms of percentage of disability, to avail facilities & concessions viz. Reservation in job, Travel concession, soft loan for entrepreneurship development, Scholarship, Income Tax / Custom rebate, Age relaxation in employment etc.

As per the Act, authorities to give a disability certificate will be a medical board duly constituted by the central and state government. The certificate would be valid for a period of five years for those, whose disability is temporary, who means that PPI may change to some extent, but in no way does this mean that disability will be cured.

11.6.1 Overview of Assessment

- Identify disability as identified by the patient.
- Assess patient's ability to communicate and participate in health history and physical assessment.
- Identify accommodations and modifications (e.g., signing, large print, other, etc.) needed by person with a disability to participate in the health history and assessment.
- Include all aspects of health history and physical assessment that would be included for all patients.
- Use “person-first language” in interactions with and about persons with disabilities. (Although some disability groups [e.g., the Deaf community] prefer to be identified by their disability [“the Deaf person”], most prefer NOT to be identified by their disability.

Language that refers to the person first [“person with a disability”] rather than their disability is more acceptable.)

11.6.2 Disability-Specific Issues

- 1) Assess the effect of a patient’s disability on his/her ability to obtain health care. (Assessment should address the interaction of person’s disability and health care, his or her ability to manage self-care activities, follow health care recommendations, and obtain preventive health screening and follow-up care.)
- 2) Assess patient for abuse or risk for abuse (physical, emotional, financial, and sexual) by others (family, paid care providers, strangers).
- 3) Assess the patient for risk of falls.
- 4) Assess patients for depression.
- 5) Assess patient for secondary conditions or risk for secondary conditions.
- 6) Assess what accommodations the patient has made at home or needs at home to encourage or permit self-care and independence. Identify accommodations needed during hospital stay or when out of the home.
- 7) Determine what preparation and accommodations are needed during hospital stays, emergency room or clinic visits, acute illness or injury, and other health care encounters to enable a patient with disability to be as independent as he or she prefers.
- 8) Assess what accommodations and alternative formats of instructional materials (large print, Braille, visual materials, audiotapes, and interpreter) are needed by the patient with a disability.
- 9) Assess engagement of patient with disabilities in health promotion strategies and the patient’s awareness of their potential benefits (e.g., improved quality of life, prevention of secondary conditions.)

11.6.3 Medical Rehabilitation

Rehabilitation and habilitation are processes intended to enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and/or social function. Rehabilitation encompasses a wide range of activities including rehabilitative medical care, physical, psychological, speech, and occupational therapy and support services. People with disabilities should have access to both general medical care and appropriate rehabilitation services.

The Convention on the Rights of Persons with Disabilities requires countries to ensure that people with disabilities are provided with appropriate health services, including general health care, habilitation and rehabilitation services, and are not discriminated against in the provision of health care (Articles 25 and 26). WHO actively supports implementation of the UN Convention in these areas? In order to improve medical care rehabilitation services, WHO:

- Develops normative tools, including guidelines and a global plan of action, to strengthen medical care and rehabilitation services

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- Advocates for the implementation of the Convention on the Rights of Persons with Disabilities
- Supports countries to integrate medical care and rehabilitation services into overall primary health care
- Supports the development of Community-Based Rehabilitation Programs
- Facilitates the strengthening of specialized rehabilitation centres and their links with community-based rehabilitation
- Promotes strategies to ensure that people with disabilities are knowledgeable about their own health conditions, and that professionals support and protect the rights and dignity of people with disabilities

Check your progress-VIII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Explain the term medical Rehabilitation?

11.6.4 Therapeutic Rehabilitation

Therapy is concerned with restoring and compensating for the loss of functioning and preventing or slowing deterioration in functioning in every area of a person's life. Therapists and rehabilitation workers include occupational therapists, orthotics, physiotherapists, prosthetics, psychologists, rehabilitation and technical assistants, social workers, and speech and language therapists. Therapy measures include:

- training, exercises, and compensatory strategies
- education
- support and counselling
- modifications to the environment
- Provision of resources and assistive technology.

Exercise therapy in a broad range of health conditions – including cystic fibrosis, frailness in elderly people, Parkinson disease, stroke, osteoarthritis in the knee and hip, heart disease, and low back pain – has contributed to increased strength, endurance, and flexibility of joints. It can improve balance, posture, and range of motion or functional mobility, and reduce the risk of falls. Therapy interventions have also been found to be suitable for the long-term care of older persons to reduce disability. Some studies show that training in activities of daily living have positive outcomes for people with stroke.

11.6.5 Orthotic & Prosthetic appliances

A. Orthotic & Prosthetic appliances

Prosthetics and Orthotics is a dynamic and expanding allied health science profession. Technically, Prosthetics and Orthotics are separate

disciplines, but their common goals in rehabilitation unite them into one cooperative entity.

B. Prosthetics

Prosthetics involves the use of artificial limbs (protheses) to enhance the function and lifestyle of persons with limb loss. The prosthesis must be a unique combination of appropriate materials, alignment, design, and construction to match the functional needs of the individual. These needs are complex and vary for upper and lower extremities.

Lower limb prostheses might address stability in standing and walking, shock absorption, energy storage and return, cosmetic appearance, and even extraordinary functional needs associated with running, jumping, and other athletic activities. Upper limb prostheses might address reaching and grasping, specific occupational challenges such as hammering, painting, or weightlifting, and activities of daily living such as eating, writing, and dressing.

C. Orthotics

Orthotics involves precision and creativity in the design and fabrication of external braces (orthosis) as part of a patient’s treatment process. The orthosis acts to control weakened or deformed regions of the body of a physically challenged person. Orthosis may be used on various areas of the body including the upper and lower limbs, cranium, or spine. Common orthotic interventions include spinal orthosis for scoliosis, HALOs used in life-threatening neck injuries, and ankle foot orthosis used in the rehabilitation of children with cerebral palsy. More recently, orthosis have been designed to dramatically realign the bones of the skull in infants with positional plagiocephaly.

Check your progress-VIII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is meant by prosthetics?

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11.6.4 SURGICAL TREATMENTS

Surgery is a part of medical care and is usually provided at the secondary or tertiary levels of the health-care system. Some types of surgery can correct impairments or prevent or limit deformities and complications that may be associated with impairments. Examples of surgery include removal of cataracts that are causing visual impairment, orthopaedic surgery to address fractures or spinal deformities and reconstructive surgery for cleft lip and palate, burns, or leprosy.

There are many things to consider before surgery is undertaken. Families may have limited knowledge and understanding regarding surgery, so they must be informed properly about the benefits and consequences. Surgical care is often very expensive, and, without social security or health insurance, it will be difficult to access for poor people.

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Successful outcomes from surgery are dependent on comprehensive follow-up – following surgery, people may require further medical care, therapy and assistive devices, and so close links are required between medical and rehabilitation professionals. It is important to remember that surgery alone cannot address all problems that may be related to impairment and disability.

Surgical Rehabilitation deals with stiffness and weakness caused after a surgery. In this procedure the treatment is given through hand in physiotherapy, hydrotherapy or exercise therapy. This will help in optimizing the pain of patients.

11.7 LET US SUM UP

People with disabilities need skills to engage in livelihood activities. But they start with several disadvantages. Their families and communities may assume that they are unable to engage in such activities. They often lack access to basic education, making them unqualified to join skills training courses. These disadvantages frequently result in a lack of skills, as well as low confidence, expectations and achievement.

Hence, they need training in Different types of skills for an independent life. These training include foundation skills acquired through education and family life, technical and professional skills which enable a person to undertake a particular activity or task, business skills required to succeed in self-employment and core life skills, including attitudes, knowledge and personal attributes.

Vocational education improves the quality of care giving for the young special needs child in several ways: (a) Vocational education is a vehicle to train child care staff who work with the young special needs child; (b) vocational education is an ancillary service that provides child care for single parents who are enrolled in vocational education programs; and (c) vocational education trains future parents who may have a young special needs child.

11.8 UNIT END EXERCISES

- A. Detail the need for adaptive skills?
- B. How can Home base training help in personal development of person with disability?
- C. Discuss the various types of rehabilitation for the people with disabilities.
- D. Explain the skill development process in person with disability.

11.9 ANSWER TO CHECK YOUR PROGRESS

- The training for persons with disabilities gives a chance for a better life with self-reliance, food security and an improved quality of life. Training sessions should create the atmosphere of a large family reunion in order to encourage exchange, sharing, discussion, compassion and emotional strengthening. This gives them confidence which comes through developing positive attitudes,

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- acquiring relevant knowledge and learning the skills to deal successfully with life and work.
- For people with disability, the most basic skills are called Adaptive Living Skills, or ADLs. More advanced skills, such as doing laundry, catching a bus, or following a daily schedule, are sometimes called Life Skills or Skills of Daily Living. While these skills aren't critical for survival, they are extremely important for anyone who plans to work and recreate in a modern community.
 - Occupational therapists work extensively for special needs children to improve their ADL. Occupational therapists help children with special needs to become physically, psychologically, and socially independent by working towards specific goals. For special needs children who have difficulty brushing their teeth, an occupational therapist might teach steps towards achieving this goal.
 - Home-based education aims at school preparedness and preparation for life. Alternate educational settings provide opportunities for learning of social skills, vocational skills and implementation of life skills.
 - Parent of children with disability need to be educated about their child's disability diagnosis, treatment and ways and means to manage it. Parents need unique educational program to help them navigate the challenges across the lifespan. Parents need to be trained to handle behaviour issues of children with disability. Parents need careful teaching and support to learn parenting skills and use them consistently.
 - Attitudinal and environmental barriers to participation have profound social, economic and cultural effects on persons with disabilities, resulting in exclusion and creating often insurmountable obstacles in relation to health services, education and employment.
 - Pre-vocational or pre-technical education programmes are mainly designed to introduce participants to the world of work and to prepare them for entry into further vocational or technical education programmes. Successful completion of such programmes does not lead to a vocational or technical qualification that is directly relevant to the labour market.
 - Vocational training involves teaching people to acquire a skill meant to prepare them for a particular Occupation. Vocational training plays a crucial role in the Social and economic development of every country.
 - The benefits of physical and co-curricular activities are universal for all children, including those with disabilities. The goal is inclusion for all children with disabilities in appropriate activities according to their interest and ability. The students are involved in many co-curricular programs as an integral part of the education and learning.
 - Rehabilitation and habilitation are processes intended to enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and/or social function. Rehabilitation encompasses a wide range of activities including

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rehabilitative medical care, physical, psychological, speech, and occupational therapy and support services.

- Prosthetics involves the use of artificial limbs (prostheses) to enhance the function and lifestyle of persons with limb loss. The prosthesis must be a unique combination of appropriate materials, alignment, design, and construction to match the functional needs of the individual. These needs are complex and vary for upper and lower extremities.

11.10 SUGGESTED READINGS

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UNIT XII

- 12.1 Introduction
- 12.2 Objectives
- 12.3 Importance of Network in rearing children with special needs
 - 12.3.1 Care giving support
 - 12.3.2 Parent's association / Federations
 - 12.3.3 Other parent's support groups
 - 12.3.4 Special school associations
- 12.4 Nutrition consultants
- 12.5 Medical practitioners- Paediatric, Psychiatric and Neurology
- 12.6 Therapist- Speech therapist, Occupational therapist, Physiotherapist
- 12.7 Mobility Rehabilitation personnel
- 12.8 District / State Disability forums
- 12.9 Let us sum up
- 12.10 Unit end exercises
- 12.11 Answers to check your progress
- 12.12 Suggested Readings

12.1 INTRODUCTION

The family of children with special needs often gain strength by networking with others and realizing they are not alone. It is empowering to share the questions, frustrations, tears and celebrations with those facing similar challenges

The major difficulties facing these parents in the past was finding a support group where ideas, success stories, and tips could be shared with others in similar situations. With internet availability becoming more widespread and the growth of social networks like Face book and Twitter, connecting with others and sharing information is becoming easier and easier. While every disability is different, and each child is unique, digital collaboration through online communities has made finding a prescription for success much easier for everyone.

The role of formal and informal intervention system plays a major role in the field of rehabilitation of the people with disability networking provides evidence-based parenting education and life skill training programmes and services to the families with special children.

These networks strengthen family relationship and transform the lives of the families challenged by its complexities of raising and educating special children and special teachers

12.2 OBJECTIVES

Going through this unit, you will be able to

1. Understand the importance of network in rearing children with special needs
2. Highlight on various support organisation for parents, teachers, care givers and special school

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3. Discuss about the different professionals involved in the rehabilitation of the special need personal
4. Educate about the district and state disability forum

12.3 IMPORTANCE OF NETWORK IN REARING CHILDREN WITH SPECIAL NEEDS

Teamwork is working together, agreeing on the approach to parenting, making decisions together and supporting each other. It's about agreeing on things like children's bedtimes, family nutrition or discipline. For most parents of a child with a disability, the desire to secure a life of dignity for their child is at the heart of their personal motivation for ensuring that their child receives a range of quality services which increases his/her quality of life. But to achieve this, many parents find themselves battling with either service overload or service impoverishment.

Many parents have stated that "I was struck by the enormous juggling act that parents are required to perform between appointments, home, work, family life and the needs of other children, as well as the needs of the child. This is a daily reality for many parents; is it any wonder that they feel they are not in control, and as the years pass these feelings may become exacerbated. Olsen and Hwang (2003) have identified risk of Families of a child with disabilities by:

- Financial hardship
- Strained emotional relationships
- Restricted social life
- Higher stress levels
- Modifications to family activities and goals
- Time restrictions caused by care demands.

Runciman and McIntosh (2003) further note that these families are likely to experience:

- Sleep deprivation
- Performing unpleasant procedures
- Lack of baby-sitters.

However well families cope, the trauma of their child's diagnosis remains, and this continues to influence family adaptation. In their empowerment model, Appleton and Minchom (1991) identify the family as a system and emphasize the importance of the families' social network in maintaining that system. Social support is crucial to the quality of family life and in countering negative psychological and social impacts. When one of the children within a family has a disability, the need for that family to be part of an effective social structure becomes even more important.

The uniquely challenging task of raising children is supported within the community; its benefits families and society as a whole. Given that communities are made up of diverse families, it would stand to reason those who care for children and provide opportunities for both parents and children to connect to others are stronger and higher functioning.

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Given the demands they face and the futures they're responsible for, all parents can benefit from support. The first step for parents in getting the support they need is to ask for it. However, many parents are at a loss as to where to look for support, and others may feel uncomfortable accepting support when it is offered.

When parents receive the support they need, they're likely to be more relaxed and healthier, set an example for their children that it is okay to ask for help, and show their children the value in both helping and being helped. However, many families do cope well, and difficulties are not inevitable. Families show how they can overcome feelings of negativity and hopelessness and find joy and love in their child. Relationships are re-cast; families find the power of optimism.

The primary objective of community-based support programs for parents is to increase their capacity to develop the skills to acquire resources, a support network, and services. Community-based parent support programs and initiatives can have a direct impact on child behaviour outcomes in that they enhance parents' capabilities and efficacy, particularly when they are family centered as opposed to professionally centred.

12.3.1 Care giving support

Parents of children with disabilities, like all parents, love their children and want the best for them. They understand that there are challenges in raising all children. But the reality is that parents of children with disabilities and special healthcare needs face both the reality of raising any child, and the reality of the additional responsibilities that come from raising children with special needs.

Community-based parent support programs differ from traditional human services parenting programs in both form and function. The primary goal of parent support programs is to provide support and information in ways that help parents become more capable and competent.

The key characteristics of family-centred practices include: treating families with dignity and respect; providing individual, flexible and responsive support; sharing information so families can make informed decisions; ensuring family choice regarding intervention options; and providing the necessary resources and supports for parents to care for their children in ways that produce optimal parent and child outcomes.

Home visiting programs and community-based parenting support programs are two different approaches to enhancing parents' abilities to support their children's development.

There is now a large and convincing body of evidence indicating that community-based parent support programs operated in a family-centred manner increase parents' sense of parenting confidence and competence. Participatory help-giving practices that actively involve parents in deciding what knowledge is important to them, and how they

want to acquire the information they need, have the greatest positive effect on parents' sense of competence and confidence.

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Check your progress I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State how Community-based parent support programs differ from traditional human services parenting programs.

ii) Analyse your understanding on family centred practices for special needs support?

12.3.2 Parent's Association / Federations

Parent federations/associations play a vital role in supporting and empowering the families of children with disabilities. A few are given below, and the list is not exhaustive: the list of registered parent organizations can be accessed at <http://niepid.nic.in/Parent's%20Orgn.3.pdf>

PARIVAAR – National Confederation of Parents Organizations (NCPO) was formed in the year 1995. It is a Federation of over 245 Parents Associations and Civil Societies in 31 States of India working for Persons with Intellectual and Developmental Disabilities [IDDs] consisting of Intellectual disability, Autism and ASD, Cerebral Palsy and Multiple Disabilities.

PARIVAAR-NCPO is a thought leader in the field of Intellectual & Developmental disabilities with pro-active grass root level organization located in 85 urban, 116 semi-urban and 47 rural parents' associations. Since its inception PARIVAAR-NCPO has established its credibility at the States, National and International forums. Parivaar is the largest confederation in the IDD sector in the world.

Parivaar and its members have been networking with central and state governments and stakeholders in the disability sector to facilitate policies and their implementation for empowering persons with IDD. Parivaar also conducts programs to build awareness among parents and stakeholders regarding rights, policies and schemes for Persons with disability. Parivaar strongly support all round inclusion of Persons with intellectual and developmental disabilities.

“**Menthid**” is another parent association for – Self advocacy for young adults with intellectual and developmental disability is another parent association for the upliftment of the parents of children with disability.

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is your understanding of PARIVAAR?

NOTES**12.3.3 OTHER PARENT'S SUPPORT**

Parent of a child with special needs, may feel isolated and alone. With so many special needs families out there, there are many types of support and advocacy groups to join. Some groups are intended for emotional support while others are more pragmatic. Some are purely local, while others are national or even international in scope. Some are all about political advocacy while others provide buddy programs and outings

A. Emotional Support Groups

There are many reasons why families with special needs might want emotional support. Discovering a child has special needs can be devastating and difficult. Coping with special needs can be exhausting and overwhelming. Dealing with fallout from extended family can be trying. Handling financial worries can be paralyzing. When facing serious emotional difficulties, it's always helpful to meet others who have been there and done that. Sometimes another person's experiences or solutions can be more helpful than any therapist.

B. School-Based Groups

Most school districts have parent groups dedicated specifically to families with special needs students. These groups are, obviously, not anonymous. Rather, their purpose is to discuss and advocate for the needs of special needs children in the local district. They may also invite speakers on relevant topics, including members of the district staff who may be able to answer parent concerns and questions.

School-based groups, while they are by no means therapeutic, can be extraordinarily helpful. Local parents know how to address issues in the school, where to find the best therapists, what kinds of programs are available, and which are worth time. Local parents are also natural friends, and their children may become friends with the child.

C. Regional Groups

Some regions are home to support organizations that provide resources, services, and support to parents in a geographic region. These are usually formal non-profits with at least some paid staff and volunteers. In addition to providing webinars, speakers, and resources, the organization also runs support group programs for a huge range of people.

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D. National Groups

National organizations are full-fledged, large-scale non-profits, but that doesn't mean they can't provide local support to parents. In some ways, getting connected with a national organization can be enormously helpful. Staff members relate to and knowledgeable about everything from social security to adult services to housing, and they can help with finding services, funding, schools, housing, programs, and even employment for the child.

E. Advocacy and Public Policy Groups

Advocacy and public policy groups aren't support groups in the typical sense of the word. While they help support the funding and programs that make daily life possible for many families, they rarely provide any one-on-one advice, groups, or even programs.

F. Online Groups for Specific Needs and Interests

There is a wide range of online groups for helping parents of children with disabilities. Sometimes the best resource for parents and caregivers of children with special needs are others who are facing similar issues and challenges. Families often gain strength by networking with others and realizing they are not alone. A few resources where parents and caregivers can turn to find support are given herewith:

- The Caregiver Action Network
- Complex Child E-Magazine
- The Arc
- 5 Minutes for Special Needs
- About Special Children (ASK)
- Caregiver Assistance Network
- Caring Bridge
- Critically Loved
- Daily Strength: Support Groups
- Family-to-Family Health Information Centres
- Family Voices of Ohio
- Family to Family in Kentucky
- About Special Children in Indiana
- Family Voices of Ohio
- Inspire: Online Health Communities
- The Self-Help Group Sourcebook Online

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Describe the need and importance of Support groups?

12.3.4 Special School Associations

There are five professional associations for special education teachers that can be important resources in the field of educating students with disabilities. The profession has been named one of the nation's top five happiest jobs, meaning that support for these educators will only

increase their efficacy in caring for their students' well-being. Here are just a few of the associations a special education teacher should look at for additional resources.

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A. The National Association of Special Education Teachers

The most important professional association for special education teachers is NASET. This national membership organization is dedicated to supporting these very important educators by advancing professional development and providing training opportunities for new teachers. The organization is well known both for policy and research as well as offering professional resources for teachers; this includes a reference library, an app, conference opportunities and special education board certification requirements. It was the first professional organization that catered to special education teachers and continues to be the leading voice in the country to advocate for teachers and their students.

B. The Council for Exceptional Children

Special education teachers are supported by the Council for Exceptional Students, known as CEC. It carries the claim that it is "the largest international professional organization dedicated to improving the educational success of individuals with disabilities and/or gifts and talents." The organization focuses on providing educational opportunities for educators who have gifted or learners with disabilities as their students and tries to provide as many resources as possible. This includes an overview of special education legislation around the world, access to special education teaching curriculums, conferences, workshops, and online courses.

C. The Association for Persons with Severe Handicaps

While not strictly a professional association for special education teachers, TASH is nevertheless an incredible resource for these educators. Founded in 1982, this international disability advocacy group welcomes educators, advocates, researchers, and other professionals to join its team; the association has a stated goal of changing policy and professional practice to benefit all persons with disabilities around the world, no matter what their handicap may be. Along with conferences and networking events, TASH also offers webinars and internship opportunities for student special education teachers.

D. The National Organization on Disability

Another professional organization that will catch the eye of special education teachers is NOD. It is an organization that is dedicated to further disability employment within the US. It currently focuses on developing creative approaches to finding disabled persons meaningful employment by educating the workforce on opportunities as well as lobbying Congress for better legislation. It's a good organization for special education teachers who work at the high school level, enabling them to address the issues that these students will face when they head out into the workforce.

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E. National Centre for Learning Disabilities

NCLD has a stated goal of "empowering parents and young adults, transforming schools and advocating for equal rights and opportunities." It is focused on learning and attention issues, both of which are issues that special education teachers contend with every day. The centre is a great resource for teachers who are interested in helping their students find schools that can meet their needs, colleges that offer scholarships for them, and more. It is also home to the Get Ready to Read program, which focuses on developing early literacy skills in children with disabilities

Special education professionals are an incredible support system for students with disabilities. As a primary education source for children, they are always looking for a way to develop better techniques to teach their students. With these five professional associations for special education teachers, that job can be done in an efficient and compassionate manner.

Check your progress-III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Describe the Professional Association for special education and brief

12.4 NUTRITION CONSULTANTS

Dietitians are responsible for the nutritional management of individuals who are referred to their care. It is well recognized that people with disabilities are at risk of nutritional problems and therefore it is very important that there is access to dietetic services for this group.

In children with Cerebral Palsy, feeding difficulties have been found to affect 60-90% of children. Many children with Autism Spectrum Disorder exhibit selective eating and therefore have self-limiting diets which are unbalanced and problematic. Equally, children with conditions such as Down's syndrome, Spina-Bifida and Muscular Dystrophy experience a range of nutritional difficulties including under nutrition, eating, drinking and swallowing (EDS) disorders, constipation, vitamin & mineral deficiencies, bone problems, overweight/obesity, among others. A significant number of those presenting with EDS difficulties go on to require tube feeding.

Close communication with the multidisciplinary team is essential for effective management of nutritional problems amongst this group. As problems are multi-faceted and have knock-on effects on other therapies, the team should include Speech & Language Therapy, Physiotherapy, Occupational Therapy, Psychology, etc. Benefits of Nutritional Intervention are:

- Improved food and fluid consumption
- Improved nutritional status (e.g. increases in height & weight)

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- Improved bowel pattern
- Increased immunity
- Lower rates of hospitalization
- Improved health and well-being
- Better quality of life

Qualified dieticians are trained to provide services within medical nutrition therapy, public health nutrition, group nutrition education, individual dietary counselling, and food service management. Dieticians can provide individual or group based dietary advice to help prevent or manage a broad range of health conditions.

Check your progress-IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Why do we need the support of Nutritionist in rearing of persons with disability?

12.5 MEDICAL PRACTITIONERS- PEDIATRIC, PSYCHIATRIC AND NEUROLOGY

Generally, the specialists and therapists are considered experts in their fields; they are not the most important element of early intervention. The most important element is the parents. Parents own their child best and are the most essential members of the child's Early Intervention Team

- **Medical practitioners-** Paediatric, Psychiatric and Neurology
- **Audiologist:** An audiologist helps in diagnosing, treating and monitoring hearing needs, loss or impairment.
- **Cardiologist:** A cardiologist is a specialist doctor who identifies and treats heart problems.
- **Clinical Nurse Specialist:** There are different types of Clinical Nurse Specialists working in different areas including in hospitals and Early Services Teams. Within Early Services Teams, the Clinical Nurse Specialist works with the family and the other therapists to help the child gain skills to promote their overall development. The Clinical Nurse Specialist can assist the child in the areas of physical skills, learning through play, communication, social/emotional skills and everyday independence skills. They may liaise with others working with the child i.e. therapists or preschool teachers. In some services they may also be called an Educator, or an Early Years Interventionist.

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- **Ear Nose and Throat (ENT) Surgeon:** An Ear Nose and Throat Surgeon is a doctor who specializes in problems related to a child's ears, nose or throat.
- **General Practitioner (GP):** A General Practitioner is a medical doctor who specializes in family medicine and provides primary care in the community.
- **Neurologist /Neurosurgeon:** A Neurosurgeon is a doctor who specializes in surgery on the brain, spine, and other parts of the nervous system. A Neurosurgeon may carry out surgery on problems diagnosed before birth, in infancy, childhood, or adulthood.
- **Ophthalmologist:** An Ophthalmologist is a doctor who specializes in the medical and surgical care of the eyes and visual system. The Ophthalmologist also works in the prevention of eye disease and injury.
- **Orthoptist:** An Orthoptist is a health care professional who assesses, diagnoses and manages various disorders of the eyes including extra-ocular muscles (e.g. squint) and problems with vision (e.g. lazy eye /amblyopic). Orthoptist work in closely with Ophthalmologists.
- **Paediatrician:** A Paediatrician is a specialist doctor who deals with the health of children. The Paediatrician may have a special interest in a particular area such as neonatology (the care of newborn infants), neurology (the nervous system) or child development. In the disability field, the Paediatrician carries out medical investigations, makes diagnoses and monitors the child's health and overall development.
- **Psychologist:** A clinical or educational Psychologist assesses children's thinking, learning and behaviour. Psychological assessments teach us about how the child's condition or diagnosis affects his/her overall development and wellbeing. The Psychologist addresses behavioural concerns and offers support which may help with the child's overall developmental progress. Later, the Psychologist can support the family in making decisions concerning appropriate pre-school and school placements.
- **Public Health Nurse:** A Public Health Nurse (PHN) may help and support you with the child at home. This can involve offering practical or nursing support or by obtaining health related supplies e.g. nappies. Public Health Nurses are employed by the HSE and are based in the local Health Centre.

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Check your progress V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the role played by psychologist in the development of persons with disability?

12.6 Therapist

A. Speech & Language Therapist

A Speech and Language Therapist (SLT) helps the child with disabilities to communicate. This may involve working on the child's understanding of language i.e. the words and sentences used around him/her, using language to express him/herself, the sounds of speech or on alternate and augmentative methods of communication. The speech and language therapist may also work with the child to develop communication skills such as turn taking, eye contact and use of gesture. A speech and language therapist may also work with the child if he/she has oral-motor or feeding problems. The speech and language therapist may work directly with the child or indirectly through the parent/s.

B. Physiotherapist

The Physiotherapist (or 'PT') can help the child with balance and movement and works on activities such as rolling, sitting, crawling, and walking. They look at ways of encouraging the child's independence and mobility. A Physiotherapist may also assist in making recommendations for specialised equipment.

C. Occupational Therapist:

An Occupational Therapist (or 'OT') can help the child increase their level of independence starting with reaching, grasping, picking up small objects, and working on other skills such as feeding, dressing and toileting. They may also work on co-ordination, sensory and other issues. An Occupational Therapist can assist the family in obtaining specialized equipment that may be needed by the child.

D. Early Years Interventionist

Early Years Interventionists have training in child development and learning. They work with the family and the other therapists to help the child gain skills to promote their overall development. They can assist the child in the areas of physical skills, learning through play, communication, social/emotional skills and everyday independence skills. They may liaise with others working with the child i.e. therapists or preschool teachers. In some services they may also be called an Educator, or a Clinical Nurse Specialist.

E. Special Educator

Educators working on Early Intervention Teams have training in child development and learning. They work with the family and the other

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therapists to help the child gain skills to promote their overall development. They can assist the child in the areas of physical skills, learning through play, communication, social/emotional skills and everyday independence skills. They may liaise with others working with the child i.e. therapists or preschool teachers. In some Early Intervention services, they may also be called a Clinical Nurse Specialist or an Early Years Interventionist.

F. Social Worker

Many early intervention teams include a Social Worker. The Social Worker is often the first person to introduce the family to the other members of the Early Intervention Team.

A Social Worker can provide information, advice and family support. They can provide support and counselling the family in relation to coping with the child's disability. The Social Worker can help to identify, source and access services in the local community that may be helpful.

G. Assessment of Need Officers

Under legislation, all children with a disability under five years are entitled to an independent assessment of their health and education needs. Each Local Health Office has an Assessment Officer. He/she can assist you with the child's application, arranges for the assessment to be carried out and help and support you through the process. The Assessment Officer is responsible for issuing the child's assessment report.

Check your progress-VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) "Speech Therapist play a vital part in the rehabilitation of children with disability" -justify

ii) State the role of occupational therapist in helping the parents of children with disabilities.

12.7 MOBILITY REHABILITATION PERSONNEL

There is a wide spectrum of services ranging from providing appropriate prosthetic & orthotic devices, wheelchairs and other mobility devices and therapeutically interventions to ensure better participation, leading to good quality of life. Rehabilitation professionals are always advancing towards strengthening and improving the access to appropriate services. World Health Organization (WHO) in partnership with United States Agency for International Development (USAID) has developed the Wheelchair Service Training Package at Basic Level, Intermediate Level and Manager Level training.

The main purpose of the training package is to develop the skills and knowledge required by personnel involved in wheelchair service

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delivery. An important aim of the training package is to get it integrated into the regular paramedical/rehabilitation training programs such as physiotherapy, occupational therapy, prosthetics and orthotics, rehabilitation nursing.

- **Physiotherapy:** Physiotherapy treatment can help people of all ages that are experiencing problems with their mobility. Physiotherapy will improve the mobility and independence with everyday tasks by improving muscle strength, joint flexibility, balance and coordination. The physiotherapist can also provide equipment that will facilitate the mobility and ensure that you are safe.
- **Orthopaedic Surgeons:** An Orthopaedic Surgeon is a doctor who specializes in disorders of the musculoskeletal system. They can review spinal, joint and muscle problems and treat by surgical and non-surgical means.
- **Orthoptist:** An Orthoptist is a specialist in the design, manufacture and fitting of aids, splints and equipment in children and adults to help improve mobility and provide support e.g. splints and special shoes.
- **Prosthetics.** A health care professional who makes and fits artificial body parts, such as an artificial leg or arm.
- **Vocational Therapist.** A counsellor who assists people with disabilities to plan careers and find and keep satisfying jobs.

Check your progress-VII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Name some of the Mobility rehabilitation Person and their Role?

12.8 DISTRICT / STATE DISABILITY FORUMS

The Directorate for the Rehabilitation of the Disabled was established by bifurcating the Directorate of Social Welfare in 1992 to deal exclusively with the Welfare of the Disabled. Subsequently, the Directorate was upgraded as the office of the State Commissioner for the Disabled in 1999 as per the provisions in the Persons with Disabilities Act, 1995.

The Government of India through various policies and initiatives have extended full support to the Differently Abled Persons in their pursuit of full and equal involvement in every aspect of society. Various schemes have been announced by the Government to make sure that the differently abled persons are in equal status to the other people.

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The State Policy for the Differently Abled Persons has been issued by the Government in 1994 considering the latest developments in Science and Technology. This policy also provides for a mechanism for promotion and protection of the rights of Differently Abled Persons and methods for ensuring equal opportunities for their full participation in social life.

History is replete with instance of differently abled persons exhibiting exceptional and extraordinary skills. It is the responsibility of everybody in a civil society to play a vital role in creating an inclusive society where differently abled persons have equal opportunities and full participation in the growth and development of the country. A change of mind set and an approach with human touch towards the challenges faced by differently abled persons are the aims of this Government so that they lead a life of dignity and honour. The thrust areas of Government are as follows:

- Prevention of disabilities;
- Early detection and intervention;
- Rehabilitation measures;
- Providing Special Education;
- Education and economic empowerment including self-employment;
- Development of professionals for rehabilitation;
- Provision of assistive devices;
- Creation of barrier free environment
- Social security.

Check your progress-VIII

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is role of State disability forum?

12.9 LET US SUM UP

The family plays an important role in the development of the child. When a child is born with some disability, it creates a lot of emotional stress in the parents and specifically in the mother of the child in India. In developing countries like India, women are still believed to be responsible for the birth of a child with disability.

A parent's constant grief or guilt because the child was born with a congenital defect, experienced a trauma, or if the child has contracted a chronic disease which may be genetically related, can have a negative impact on the child's development. It is important that parents should have a balanced emotional response and strong positive attitude towards their children and in handling the situation. They can provide more positive feedback to their child, feedback that allows the child to grow and develop appropriately. Parents of children with disability experience shock, denial, grief, and even anger.

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Acknowledging the emotional responses after having a child with disability is very important for parents. This will help them to cope with the disability and try out different facilities available for the child and be supportive to the child. Parents should collaborate with professionals at all levels of health care like, Care of the individual child, Program development, Implementation, and evaluation.

Parents should be sportive to know complete information about their child's progress in a continuing basis. They can seek support from family to family basis. Most research shows that when parents are involved, they themselves experience less anxiety as they feel more in control over what is happening to their own child. In turn they transmit less anxiety to the child.

A parent can become an extra pair of hands for the therapist who can teach the intervention to the parents to practice at home. Most importantly if the parent is accompanying the child for therapy, that will reduce lots of anxiety of the child and they're by reducing development of behavioural problems of the child. Positive attitude of the parents is very important in the rehabilitation of their child.

Active participation in therapeutic program, evaluating the progress of the child, addressing all aspects of a child's life in terms of physical motor developments, other aspects of a child's life, like interaction with peers, social and cultural involvements, education in the school, sports, competitions etc are very important. Parents most importantly mother can play an important role in mediating these aspects of a child's life.

Rehabilitation as a unifying conceptual framework can be described as a range of responses to disability, from interventions to improve body function to more comprehensive measures designed to promote inclusion. Successful rehabilitation requires the involvement of all development sectors including health, education, livelihood and social welfare. This element focuses on those measures to improve functioning that are offered within the health sector. It is important to note however that health-related rehabilitation services and the provision of assistive devices.

12.10 UNIT END EXERCISES

1. Describe the need and importance of networking in rearing children with special need?
2. Who are the practitioners involved in disability management and detail?
3. Explain the role of therapist in the progress of persons with disability?
4. Give a brief note on disability forum?
5. Name some of the Association for professional in Special Education.
6. Elaborate the role of District disability forum.

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12.11 ANSWERS TO CHECK YOUR PROGRESS

- Community-based parent support programs differ from traditional human services parenting programs in both form and function. The primary goal of parent support programs is to provide support and information in ways that help parents become more capable and competent.
- The key characteristics of family-centred practices include: treating families with dignity and respect; providing individual, flexible and responsive support; sharing information so families can make informed decisions; ensuring family choice regarding intervention options; and providing the necessary resources and supports for parents to care for their children in ways that produce optimal parent and child outcomes.
- National Confederation of Parents Organizations (NCPO) was formed in the year 1995. It is a Federation of over 245 Parents Associations and Civil Societies in 31 States of India working for Persons with Intellectual and Developmental Disabilities [IDDs] consisting of Intellectual disability, Autism and ASD, Cerebral Palsy and Multiple Disabilities.
- Parent of a child with special needs, may feel isolated and alone. With so many special needs families out there, there are many types of support and advocacy groups to join. Some groups are intended for emotional support while others are more pragmatic. Some are purely local, while others are national or even international in scope. Some are all about political advocacy while others provide buddy programs and outings.
- Dietitians are responsible for the nutritional management of individuals who are referred to their care. It is well recognized that people with disabilities are at risk of nutritional problems and therefore it is very important that there is access to dietetic services for this group.
- A clinical or educational Psychologist assesses children's thinking, learning and behaviour. Psychological assessments teach us about how the child's condition or diagnosis affects his/her overall development and wellbeing. The Psychologist addresses behavioural concerns and offers support which may help with the child's overall developmental progress. Later, the Psychologist can support the family in making decisions concerning appropriate pre-school and school placements.
- A Speech and Language Therapist (SLT) helps the child with disabilities to communicate. This may involve working on the child's understanding of language i.e. the words and sentences used around him/her, using language to express him/herself, the sounds of speech or on alternate and augmentative methods of communication. The speech and language therapist may also work with the child to develop communication skills such as turn taking, eye contact and use of gesture. A speech and language therapist may also work with the child if he/she has oral-motor or feeding problems.
- Mobility rehabilitation professionals are from the field of physiotherapy, occupational therapy, prosthetics and orthotics, rehabilitation nursing.

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- The State Policy for the Differently Abled Persons has been issued by the Government in 1994 considering of the latest developments in Science and Technology. This policy also provides for a mechanism for promotion and protection of the rights of Differently Abled Persons and methods for ensuring equal opportunities for their full participation in social life.

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UNIT XIII

- 13.1 Introduction
- 13.2 Objectives
- 13.3 Liaison Organizations
- 13.4 Global Perspective: Disability Sport in International Law
 - 13.4.1 Disability Sport in Nations around the World
 - 13.4.2 Paralympics Games
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- 13.6 Special children sports academy
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- 13.9 Let's Sum up
- 13.10 Unit end exercises
- 13.11 Answers to check your progress
- 13.12 Suggested Readings

13.1 INTRODUCTION

Disability sport is a term that refers to sport designed for, or specifically practiced, by people with disabilities. People with disabilities are also referred to as athletes with disabilities. Deaf sport is distinguished from other groups of people with disabilities and in some countries deaf people prefer not to label deafness as a disability. The rules of deaf sport are not altered, only instead of whistles and start guns, athletes and officials communicate through signs, flags and lights. In many developing countries deafness is still considered a disability.

Sports for person with disabilities are necessarily sports organised specifically for persons with disabilities, and hinge based on providing equitable and fair categories, based on ability and disability, in order to provide level playing fields.

Since the 1970s, the concept of organised multi-sport and multi-disability games became popular and several regional games for people with a disability also emerged. Whilst there is limited historical and statistical evidence of the participation of people with a disability in developing countries, in the three largest international competitions – Deaflympics, Paralympics Games and Special Olympics World Games - participation by developing countries has seen the greatest improvement since 1990.

13.2 OBJECTIVES

Going through this unit, you will be able to

- To outline various roles of Liaison organizations working for special needs

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- Analyse the functions of National and State level special Olympic federation
- Discuss about the District / State Children's club
- Understand the role of District Differently abled Welfare Office (DDWO) & its services

13.3 LIAISON ORGANIZATIONS

A liaison organization is an organization who liaises between two organizations to communicate and coordinate their activities. Generally, liaison officers are used to achieve the best utilization of resources or employment of services of one organization by another. Liaison organization often provides technical or subject matter expertise of their parent organization.

The Liaison Service helps people with disability, their families and/or advocates, to address the concerns that they may have about services provided by the Department. Complainants are encouraged to raise their concerns directly with their local service in the first instance, such as a Manager. If concerns remain unresolved or are more complex, then the matter is referred to the Department's Consumer Liaison Officer.

The Liaison Organizations supports effective communication with disability sector, and support disability sector organizations with the development of their complaints policy actively manages the relationship between the Department and external complaint mechanisms and supports referrals to external complaint mechanisms develops, maintains and ensures access to appropriate publications (for example, brochures) to support consumer and staff awareness of complaints rights, options and procedures develops and implements awareness training for disability sector organizations (internal and external).

Liaison Officer

As per the mandate of the Rights of Persons with Disabilities Act, 2016, all the public and private service organizations has to appoint a Liaison Officer who will be responsible for taking initiative and providing the requisite support needed to realize the goals of an inclusive and accessible workplace and reasonable accommodation.

Liaison officer is supposed to collect and maintain data regarding employees with disabilities in relation to their employment, facilities provided and other necessary information as per the RPWD Act.

All employees will be asked to give the Voluntary Disability Self Identification Form in order to give information regarding any disability that she/he may have. The information that an employee shares about her/his disability will be kept confidential.

13.4 GLOBAL PERSPECTIVE: DISABILITY SPORT IN INTERNATIONAL LAW

Around the world, people have recognized that access to sport by people with disabilities provides benefits both to the individual and society.

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Millennium development goal	Contribution of sport
Eradicate extreme poverty and hunger	Reduced stigma and increased self-esteem, self-confidence and social skills, leading to increased employment and lower levels of poverty and hunger
Achieve universal primary education	Reduced stigma preventing children with disabilities from attending school Increased awareness of importance of physical education for all children and ability to adapt activities for children with disabilities
Promote gender equality and empower women	Empowerment of women and girls with disabilities through sport-based opportunities to acquire health information, skills, social network, and leadership experience Loosening of restrictive gender norms by introducing the concept of women playing sports
Reduce child mortality	Improved health of children with disabilities as a result of increased physical activity Reduced likelihood of infanticide by reducing stigma and promoting greater community acceptance of children with disabilities
Improve maternal health	Improved access by women with disabilities to health information and education, using sport as a communication platform
Combat HIV and AIDS, malaria, and other diseases	Improved access to disease prevention and treatment information for persons with disabilities through sport programs with a health education component Reduced stigma associated with HIV/AIDS through inclusion of people with HIV and AIDS in sport activities Improved health for people living with HIV and AIDS due to participation in sport activities
Ensure environmental sustainability	Increased knowledge and action in support of environmental sustainability among persons with disabilities, using sport as an education and social mobilization platform
Develop a global partnership for development	Creation of global sport and disability networks for data collection, awareness-raising, and knowledge exchange

A resolution adopted by the United Nations General Assembly identified “Sport as a means to promote education, health, development, and peace.” Specific to people with disabilities, in the Convention on the Rights of Persons with Disabilities, Article 30, Section 5 says that State Parties will “take appropriate measures:

- To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the

Self-instructional material

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provision, on an equal basis with others, of appropriate instruction, training and resources;

- To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;”
- This was so instrumental to the promotion of education, health, development and peace, that the UN created the International Disability in Sport Working Group. India is a signatory to the Convention on the Rights of Persons with Disabilities, and therefore bound by its direction.

Adaptive sports have formed in various ways around the world, largely dependent on popular sports of the region and the ability to form support systems around those sports. In places with snow and mountains, adaptive skiing is popular while adaptive track and field has found participants around the world.

In the United States, wheelchair basketball is the most popular adaptive team sport in the country, with sled hockey competing for this spot in some places. In India, blind cricket has found strong interest, with the Indian team winning the World Cup in December 2012. This serves as an interactive platform for communities of persons with disabilities who are engaged in the process of collective learning in a shared domain.

Disability wise communities can actively interact on certain common platform in the interest of their welfare and rehabilitation. Hence the Liaison organization often provides technical or subject matter expertise of their parent organization.

In the UN Report “Harnessing the Power of Sport for Development and Peace: Recommendations to Governments”, this chart is presented as an illustration of the policy implications of supporting sporting rights for people with disabilities. The World Health Organization has also identified sports as an important part of life for people with disabilities.

13.4.2 Paralympics Games

The name derives from the Greek "Para" ("beside" or "alongside") and thus refers to a competition held in parallel with the Olympic Games. No relation with paralysis or paraplegia is intended, however, the word Paralympics was originally a portmanteau combining 'paraplegic' and 'Olympic'.

The Paralympics Games are multi-sport disability events for athletes with physical mental and sensorial disabilities. The Paralympics Games are a multi-sport event for athletes with physical, mental and sensorial disabilities. Paralympics Games are sometimes confused with Special Olympics, which are only for people with intellectual disabilities.

Paralympics Games includes mobility disabilities, amputees, visual disabilities and those with cerebral palsy. The Paralympics Games are held every four years, following the Olympic Games, and are governed by the International Paralympics Committee (IPC) - (The Paralympics Games are

sometimes confused with the Special Olympics, which are only for people with intellectual disabilities.)

There are winter and Summer Paralympics Games, which since the 1988 Summer Games in Seoul, South Korea, are held almost immediately following the respective Olympic Games. All Paralympics Games are governed by the International Paralympics Committee (IPC). The Paralympics first started in 1948 when Ludwig Guttman organized a sports competition which involved World War 2 veterans that had spinal injuries.

Afterwards a similar event was organized in Toronto, Canada where different disability groups were added and the idea of merging together and taking part in athletic sports was a success.

13.4.3 Special Olympic

In every corner of the earth, Special Olympics are changing the lives of people with intellectual disabilities. These stories come from all around the world. Through the power of sports, people with intellectual disabilities discover new strengths and abilities, skills and success. Special athletes inspire people in their communities and elsewhere to open their hearts to a wider world of human talents and potential.

13.4.4 International Special Olympic Organization

The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.

The Special Olympics mission remains as vital today as it did when the movement was founded in 1968. Special Olympics strive to create a better world by fostering the acceptance and inclusion of all people. Through the power of sports, people with intellectual disabilities discover new strengths and abilities, skills and success. The athletes find joy, confidence and fulfilment on the playing field and in life. They also inspire people in their communities and elsewhere to open their hearts to a wider world of human talents and potential.

There are as many as 200 million people with intellectual disabilities around the world. Special Olympics' goal is to reach out to every one of them – and their families as well. Special Olympics do this through a wide range of trainings, competitions, health screenings and fund-raising events. They also create opportunities for families, community members, local leaders, businesses, law enforcement, celebrities, dignitaries and others to band together to change attitudes and support athletes.

This year's Special Olympics World Games, 2019, earning a whopping tally of 368 medals, athletes with disabilities from India carved the day in history, scooping a total of 85 gold, 154 silver and 129 bronze medals. These medals were won across sports like power lifting, badminton, cycling, golf, athletics, judo, volleyball, aquatics, table tennis,

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roller skating, basketball traditional, football 7-side female and handball traditional!

While power lifters from India bagged 20 gold, 33 silver and 43 bronze medals, roller skaters grabbed a total of 49 medals—23 gold, 20 silver and 16 bronze. Cycling won Indians 11 gold, 14 silver and 20 bronze medals, and track and field athletes earned 5 gold, 24 silver and 10 bronze medals!

This was India's ninth year of participating at the event, and the first time to be a part of Judo and Futsal in the competition; and yet, the participants managed three gold, one silver and seven bronze medals.

13.5 NATIONAL PERSPECTIVE ON SPECIAL SPORTS

In India, state policy (particularly in the form of the Persons with Disabilities Act, 1995, and the National Policy for Persons with Disabilities, 2006) is supportive of the need for individuals with disabilities to participate in sport, recreational and leisure activities, and includes provisions designed to both encourage development of special recreation centres and ensure accessibility to all public places.

According to Article 16, Right of Children with Disabilities to Leisure, Culture and Sports that all children with disabilities have a right to play and participate in sports, recreation and cultural activities on an equal basis with other children; And appropriate governments and establishments shall provide for disability and age appropriate opportunities for children with disabilities to participate in sports and have access to playgrounds along with other children ensuring that children with disabilities have access to cultural materials in an accessible format and access to cultural activities, performance and services along with other children.

13.5.1 Organizations promoting Sports for Persons with Disabilities in India

A. National Paralympics Committee of India

The Paralympics movement is more than just facts and figures, over 3000 years ago sport was used as instrument to attain physical, mental and spiritual achievement. Today, Paralympics movement has high goals that encompasses the development of sports at all levels for people with a disability, the full involvement of women and girls with a disability and of athletes with a severe disability, the promotion of clean sport and the education of athletes about doping, and educational programmes at all levels to change perceptions about the abilities of people with a disabilities. Paralympics Committee of India is a registered association which has changes its name from Physically Handicapped Sports Federation of India to Paralympics Committee of India in 2003.

B. PCI and FESPIC Games

FESPIC Games were conducted by FESPIC Games Federation and considered as Asian Games for Para Sports where all the Asian Countries and the countries of South Pacific region were allowed to participate till 2006, International Paralympics Committee which is an apex body for Paralympics sports decided in 2000 that all the IPC affiliated members

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became automatic members of Fespice Games Federations and only such members were made authority to send teams to the future games.

PCI had a good team of 63 athletes in different sport and got 3 Gold, 9 Silver and 10 Bronze Medals in Athletics at the 8th Fespice Games which were held in Busan, Korea in 2002. These games which were the first ever big medal haul in a recognized international event for India. 9th FESPIC Games were held at Kuala Lumpur in Malaysia in November 2006 where a special meeting of Fespice Federation and Asian Paralympics Committee was held, and Asian Paralympics Committee took the responsibility of hosting Asian Games for Para sports and the Fespice Games Federation was formally dissolved.

C. Other Achievements and Performance

- Handicapped sports are also included in prestigious ARJUNA AWARDS since 1995.
- There are championships as people with disabilities cricket, blind cricket which are conducted every year.
- There were more than 150 players from 14 countries participated in APC Badminton Cup which was held in December 2008
- In IWAS World Games more than 680 athletes from 43 countries took part and India stood 2nd in Medal Tally with a total of 110 medals which was hosted in the year 2009 at Bangalore.
- Gold Medal with the World Record at the 2004 Athens Paralympics Games.

D. Special Olympics Bharat

Special Olympics Bharat is a National sports Federation, recognized by the Ministry of Sports and Youth Affairs, Government of India. The federation trains both male and female athletes in 25 summer and winter disciplines. The federation has 850000 athletes registered through 35 state chapters. The team representing India at 2011 Special Olympics World Summer Games brought back 243 (78 Gold, 73 Silver and 92 Bronze) medals for the country.

The Roller-Skating team got 31 Gold, 12 Silver and 15 Bronze. whereas in Athletics (6 Gold, 10 Silver, 14 Bronze), Badminton (2 Gold, 4 Silver, 1 Bronze), Basketball (Boys – 10 Silver, Girls 10 Bronze), Bocce (4 Gold, 4 Silver, 1 Bronze), Cycling (7 Gold, 6 Silver, 11 Bronze), Football (5th Place), Handball (Boys – 12 Gold, Girls – 12 Silver), Power Lifting (3 Gold, 5 Silver, 6 Bronze), Table Tennis (4 Gold, 3 Silver, 2 Bronze), and Volleyball (Bronze for Boys and Girls).

Special Olympics Bharat works towards the social acceptance of people with intellectual disabilities, whereby they are respected and given equal chances to become productive citizens. It also encourages our athletes to move from the Special Olympics training and competition into school and community programmes where they can compete in regular sports activities.

E. Indian Blind Sports Association

The Association has always played a prominent role in promoting sports among the visually handicapped. It was the initiative of BRA that

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Indian Blind Sports Association was formed in 1986 as the national level body for the promotion of athletics and different sports for the blind. Indian Blind Sports Association is recognized by the Indian Olympic Association and is affiliated with the International Blind Sports Federation, the apex world blind sports organization, and with Paralympics Committee of India. BRA also hosts jointly with Indian Blind Sports Association, national-level Sports Meets for the Blind once every two years. The Sports Meet is the largest sports event for the visually impaired in the country which attracts hundreds of sports persons from institutions across the country from different states that compete in athletics, chess and swimming.

F. Special Awards / Recognition

Mr. Satish Pillai was honoured for his contribution to the promotion of sports in the country with the Dayan Chand Lifetime award by the President of India He is President of Jharkhand State Chapter in Special Olympics Bharat and a staunch supporter of the SOB Program. He received the award from the President at a National Sports Day ceremony held at Rashtrapathi Bhavan on 26 August 2010.

The De Rozio Award for excellence in Human Enrichment and Education, in the Special Educators Category was awarded to Ms. Lina Bardhan, Area Director SO Bharat – West Bengal who has served the Special Olympics Program for more than 20 years.

Rehabilitation Council of India has recognized training done by Special Olympic Bharat which is an organization recognized by Government of India for approval of education method for the special educators. All the educators undergoing training will be accredited with 30 CRE points to fulfil the requirement of 100 points over period of 2 years for renewal of their education certificate for the training conducted by Special Olympic Bharat at Lakshmi Bai National University of Physical Education, Sports Authority of India and Community Coaches camps.

National Trust felicitates 20 Special Olympians from different states who represented India at the 2007 Special Olympics Summer Games were awarded with a plaque, shawl and rs.25000/- at the functions held in their respective states. Special Athletes participated in the Queen's Baton Torch run in several States during the Commonwealth Games Delhi 2010.

Check your progress -II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Explain the role of International Special Olympics association.

ii) State the achievements made in Special Olympics, 2019.

13.6 SPECIAL CHILDREN SPORTS ACADEMY

The Minister of State (Independent Charge) for Youth Affairs & Sports, under the Scheme of Sports and Games for the people with disabilities, has sanctioned Special Olympic Bharat (SOB), the Nodal Agency of the Department of Sports for organizing coaches training and sports competitions in selected sports disciplines on District, State and National basis to promote the potential of persons with disabilities in sports and games.

Special children's sports Academy was started in the year 2007 by the efforts of Mr. A Durai He is an International Cyclist represented Tamil Nadu and India and won many awards from the state and central Government of India. He saw a vision in bringing up the under Privileged children or so called physically challenged children. With the help of his friends Mr. A. Durai started this academy and running it for the past seven years. This year event will be 7th year sports meet.

13.7 WELFARE CLUBS

India has a population of more than 100 million people with disabilities and yet social isolation and lack of inclusion remains a major issue for the differently abled community. We need to become a more inclusive society to help the community become a part of the mainstream. Off late, some Face book groups have proved extremely helpful by providing a platform for the community to come together and a much-needed discussion on inclusion and diversity. Face book groups like Siblings Support helps the family members and caretakers of people with all kinds of disabilities to voice their opinions and discuss their concerns while specific groups like this list is not exhaustive. There are many more welfare clubs.

A. Autism in India

Autism in India group provides a platform for spreading message about autism, a neuro-developmental disability common in India. From parents to siblings of people facing autism, this group helps people in understanding and participating in discussions around this disability. The group is a collaborative effort to create awareness and educate people about the rights of children and adults with autism.

B. Siblings Support Group

Addressing a massive need for people with disabilities, the Siblings group is a fully inclusive group which allows family members and caretakers of differently Abled people and others to come together on one platform and share their experiences thus helping each other in the process. The group is open to anyone related to people facing disabilities, chronic illnesses or other health issues.

C. Accessibility

If you are looking for any new information, government laws or any other information concerning people with disability in India, chances are you will find it here. One of the most popular Face book groups for people with disabilities in India, Accessibility is also one of the most active

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groups where its members regularly discuss all the relevant issues around inclusion and accessibility for the community in detail and help each other out.

D. Work Opportunities for People with Special Needs in India

A much-needed inclusive platform, the popularity of the group can be gauged from the fact that hundreds of people with disabilities joined the group within minutes of it being formed. Several job opportunities including vacancies are posted by various companies looking for differently abled candidates are regularly posted here. “Job security is a must to ensure proper inclusion for the specially-abled community. There was a massive need for a dedicated group which allowed everyone to mobilize post and discuss about the job opportunities that are available for people with special needs and for those who are differently abled across India.

E. Network Capital

Network Capital is one of the Facebook groups where thousands of new ages thought leaders are actively involved in discussing and taking meaningful actions for the differently abled community. The members are extremely broad minded, diverse and are open to providing internships and job to people with disabilities. From career guidance, to mentoring to peer-to-peer learning, the group includes thinkers and young professionals who believe in making India a truly inclusive society.

F. Social Spaces

Resolving a long-standing issue for the community, Social Spaces, is a top Face book group for people with disabilities and provides a unique platform which provides complete information about all the offline meetups taking place for people with disabilities across India. You can find information regarding the next inclusive party, day meet up or any other specific event that Inclov, world’s first matchmaking app focusing on people with disabilities, organizes for the community across different cities in India.

G. Albinism India Group

This is a specific Face book group working towards helping in inclusion for people living with albinism in India. Albinism India Group helps spread information about this genetic condition and educates family, friends and others about it. From members providing medical information to be a discussion forum, the group is spreading awareness about albinism and helping dispel misconceptions thereby, ensuring the assimilation of its members in mainstream.

H. Informative News for Deaf Persons

This Face book group provides information for people facing hearing impairment and for their families and friends. Sign language videos and other educative support data are regularly shared by its thousands of group members while you will also find details of all the events being conducted across India events especially for deaf persons here.

NOTES**I. Little People of India and around the world**

Tackling a serious issue with a light-hearted approach, this Face book group caters to people facing dwarfism and intends at helping everyone including individual, parents, partners, children, friends by spreading positive news about little people across the world. Members regularly share personal anecdotes, news articles, YouTube videos and other light-hearted stories to help dispel the misinformation about dwarfism in the country.

J. Wheelchair and Mobility Aid Users Support Group

One of the oldest support groups for people using wheelchair and other mobility aid in India, this is one of the biggest Face book groups for people with disability. The members have managed to maintain the sanctity of the group as a forum where they can talk about inclusion, share their personal stories, provide inputs and any relevant information which can help the differently abled community.

Check your progress -4

Note: A Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is your understanding on Welfare clubs?

13.8 DISTRICT DIFFERENTLY ABLED WELFARE OFFICE (DDWO)

In order to provide effective rehabilitation services to the differently abled persons at the District level, a team of Specialists is functioning in all the 32 Districts under the control of District Differently Abled Welfare Officer. This team of Specialists provides rehabilitation assistance to the differently Abled persons in the Districts by organizing camps. This team coordinates with other Government Departments in the districts to tap the available resources for the benefit of the Differently Abled persons.

A. Funded Under SIPDA and DDRS Schemes

DDRCs are presently funded under the “Scheme for the implementation of Persons with Disabilities (Equal Opportunities, Protection of Rights and Full participation) Act 1995” (SIPDA) for the first 3 years for all States excepts in case of North Eastern States, J&K and the UTs of A&N Islands, Lakshadweep, Pondicherry, Dadra & Nagar Haveli and daman & Diu where it is funded for 5 years. Thereafter, DDRCs receive funds under another Scheme namely “Deendayal Disabled Rehabilitation Scheme (DDRS).

B. Role of State Government

State Governments are expected to play a more pro-active role in the effective working of DDRCs. In order to ensure greater involvement of

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State/District Administration, the State Government may suitably supplement the honorarium and other requirements of the DDRCs for undertaking their various activities in an effective manner. State Governments may authorize District Collectors modifications for effective functioning of DDRCs, considering the ground realities within the broad stipulation of the DDRC Scheme.

State Government may also authorize the District Collectors to make interim advances out of the local funds placed at their disposal to tide over the difficulties caused in the field due to procedural delays in release of central funds.

- In the pre-revised scheme 199 DDRCs were approved for setting up in various districts of the country i.e. up to March 2010. Out of which 185 are functional as per records available with this Department.
- 100 more DDRCs were approved for setting up during 2010-11 onwards.
- 15 more DDRCs have been approved in 2012 for setting up in the worst affected by JE/AES districts in the country (including 4 approved before 2010 but were not set up).
- In all DDRCs have been approved for setting up in 310 districts.

C. Equipment

Equipment required for functional DDRC: The equipment for fabrication and fitment of assistive devices related to all kind of disabilities is to be purchased from this scheme. These equipment's will range from Electric oven, workshop anvil, physiotherapy equipment, clinical audiometer, speech trainer, workshop tools and some teaching material for the MR children. Non-recurring expense of Rs.7.00 lakhs per DDRC in the first year has been earmarked for the same. This equipment can also be procured from the ALIMCO (Artificial Limbs Manufacturing Corporation of India, Luck now Road, Kanpur – an organization under the Department of Disability Affairs).

Raw Materials for fabrication of aids & assistive devices as well as prescribed appliances – for persons with disabilities. The assistive devices and the material for fabrication of aids and appliances shall be supplied under the ADIP scheme of GOI.

D. Training to Manpower of DDRCs in Coordination with State Govt.

The staff of the NGO and DDRCs will be provided orientation and training though National Institutes (NIs) for capacity building so as to enable them to initiate activities as per the approved action plan. NIs would undertake the following training programmes in coordination with State Government:

The training programmes would range from one to three day sensitization workshops to one week to 15 days refresher training to 1 year sandwich courses for improving the skills of under qualified manpower in DDRCs, while the participants could vary from Senior Govt. officials like Secretary/Directors/District Collectors to District welfare officers/nodal officer to professionals and other manpower deployed in DDRCs.

Nodal officers in each of the districts will submit half-yearly accounts on programme activities to the Ministry of Social Justice and Empowerment, Government of India.

E. Action plan of DDRCs

- Action plan of DDRCs should broadly be as follows
- Survey of the PwDs and their needs in the districts-10-15 villages per month
- Assessment camps at HQ-Twice in a week;
- At Civil hospital-once every week
- Assessment cum distribution camps at villages-Twice a month
- Awareness generation activities like visits to school/awareness camp in villages for various target groups/training programme of grass root level functionaries-4 times a month.
- Follow up camps in villages-4 times a month

F. Survey of persons with disabilities

For initial planning, the details of district data on disabilities, if available, could be transferred to DDRCs via data could be available with Anganwadi workers/other grassroots level workers like ASHA about the persons with disabilities in each village. The implementing agency should use its discretion in selecting the best possible arrangement for collection of data. As the details of the survey are to be used for Management information system being designed, Performa given at Annexure II is used for collection of data.

G. Assessment/Fitment/Follow-up and repair of assistive devices

Actual fitment of assistive devices would be one of the major activities of District Centre. A blend of camp approach and institutional approach should be used in fitment of assistive devices. The expenditure on materials/assistive devices should be met out of ADIP Scheme. The implementing agency would be responsible for making exact arrangements and following proper procedure in account keeping, as per the ADIP Scheme.

- Persons with disabilities, who are provided assistive devices, should be categorically informed of the follow up/repair/training services available at the district centres.
- PwDs may also be provided training for effective & correct use of assistive devices and therapeutically services. They may also be given instructions in local language in the form of a pamphlet having sketches/pictures for use and upkeep of the device(s).

H. Promotion of Prevention

Prevention has been promoted through various National Health Programmes like programmes of Prevention of Blindness, Leprosy etc. as well as various Routine Immunization programmes like Pulse Polio etc. The orientation of these programmes needs to focus not only on prevention of mortality, but also on disability. The District Centres, therefore, need to modify the information dissemination on prevention to emphasize the linkage between Health Programmes & Schemes and prevention of disability.

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Another important aspect of prevention of disability that needs to be disseminated through the District Centre is environmental sanitation and hygienic living conditions. Thus, DDRCs need to synergize the inputs of Total Sanitation Campaign, Nirmal Gram & other such Central & State Programmes and Schemes on Sanitation with Prevention of Disability particularly School Sanitation Programmes.

The District Centres need to collect and collate the information relating to different aspects of prevention of disabilities and disseminate information in the most suitable form and mode, depending on local conditions.

The District Centres should, therefore, promote prevention by doing following:

- Converge the activities of AWWs, Health Workers, and NGOs in promoting prevention;
- Distribute and publicize the information available with the implementing agencies on prevention and early intervention in local language. The material available with DRCs/National Institutes may be compiled/ prepared within two months of launching of the Scheme.
- The implementing agency may undertake orientation of the grassroots level workers including ICDS workers, Health Workers, CBRWs with a focus on identification, prevention and early detection.
- The District Disability Rehabilitation Centre set up and functioning in the areas having high incidence of Japanese Encephalitis (JE)/Acute Encephalitis (AES) must have Multiple Disability Component from the National Institute for Empowerment of Persons with Multiple Disabilities, M/o Social Justice & Empowerment, East Road, Mullukadu, Kancheepuram, Tamil Nadu.

I. Early Intervention

Early identification of disabilities and early intervention is very important for avoiding secondary disabilities and ensuring successful integration of children with disabilities *with other children at all levels*. Hence each DDRC must set up an early intervention unit. In addition, low cost intervention using locally available material should be suggested to them for continuing the intervention at place of their residence.

J. Barrier Free Environment

- Provision of barrier free environment is the second important compliment of assistive devices for providing accessibility to persons with disabilities;
- All new buildings, especially public sector and public utility e.g. schools and hostels, Panchayat and other Govt. buildings, hospitals, markets, bus stands, parks, public toilets are to be made barrier free, as per the standard byelaws circulated by Ministry of Urban Affairs and Employment.
- The basic responsibility should be of the local governments.

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- Public buildings like Collectorate, District hospital, local bus stand, colleges and schools should be converted into barrier free, to begin with.
- The financial support for Conversion of the buildings into barrier free may be met out of local government funds and/or MPLADS.
- District Centres must be able to provide technical support to implementing agencies. Promoting Education/Vocational Training/Placement

k. Other Activities

Education, training and employment are important components of rehabilitation. The implementing agency should organize orientation-training programme for teachers/communities/families. They may also provide information on suitable vocations, possible job placements and other facilities like soft credit through NHFDC, vocational training through VRCs etc. At least one orientation programme of 3 days to a week should be held once in 6 months. Monitoring & Evaluation of the implementation of the programme for establishing District Centres would be done in terms of the activities enlisted above and the targets laid down for them.

Check your progress – V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is your understanding on the role of DDRC on early

13.9 LET'S SUMUP

UNICEF has estimated that 6 to 10% of children in India are born with some type of disabilities. Physical activity should be a normal part of our everyday routine, whether your child is an athlete or not. But - what about those children with special needs Special children's have the same basic needs and similar desires as any other child. Physical activity is just as necessary, if not more so, for the physically challenged child. It builds strength and endurance, develops coordination and control. Plus, it boosts self-esteem and helps teach skills necessary to conquer shortcomings.

Persons with disabilities are unable to enjoy leisure activities on an equal basis with others if transportation systems and public buildings continue to lack barrier-free access, a problem which has not been addressed on a consistent basis by the Government. However, organizations and establishments like the Wheelchair Sports Federation of India, the Indian Blind Sports Association, and the Special Olympics Bharat do provide opportunities for physically and mentally differently abled athletes to participate in sporting activities.

Inclusion and diversity remain a cause of concern in the Indian society and will take the concerted efforts of us all to being about a positive change for the community.

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Picking a Sport for all children, regardless of race, creed or disability, have different personalities and motivations. The physically challenged child should have the opportunity to try a number of different recreational activities to determine the best option. That's what is done in "Special Children Sports Academy", to attain, to achieve the strength the special children needed. It is also everyone's duty and responsibility to motivate these special children who can become an inspiration to others in their day today life. When the mind is refreshed the whole body is refreshed, when the body is refreshed a whole new life is born to fly with different colours to reach the happiness of life. They need to be supported for this life changing event to change the life of themselves and the life of others by encouraging and supporting these sports events.

13.10 UNIT END EXERCISES

- What do you mean by Liaison organizations?
- What are the responsibilities of Liaison officer?
- Discuss the National level special Olympic federation.
- What are the actives of District Differently Abled Welfare Office (DDWO) & its services?
- List some of the welfare clubs for the special persons?

13.11 ANSWERS TO CHECK YOUR PROGRESS

- As per the mandate of the Rights of Persons with Disabilities Act, 2016, all the public and private service organizations has to appoint a Liaison Officer who will be responsible for taking initiative and providing the requisite support needed to realize the goals of an inclusive and accessible workplace and reasonable accommodation. Liaison officer is supposed to collect and maintain data regarding employees with disabilities in relation to their employment, facilities provided and other necessary information as per the RPWD Act.
- The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.
- This year's Special Olympics World Games, 2019, earning a whopping tally of 368 medals, athletes with disabilities from India carved the day in history, scooping a total of 85 gold, 154 silver and 129 bronze medals. These medals were won across sports like power lifting, badminton, cycling, golf, athletics, judo, volleyball, aquatics, table tennis, roller skating, basketball traditional, football 7-side female and handball traditional.
- Early identification of disabilities and early intervention is very important for avoiding secondary disabilities and ensuring successful integration of children with disabilities with other children at all levels. Hence each DDRC must set up an early intervention unit. In addition, low cost intervention using locally available material should be suggested to them for continuing the intervention at place of their residence.

13.12 SUGGESTED READINGS

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UNIT XIV

- 14.1 Introduction
- 14.2 Objectives
- 14.3 NHFDC (National Handicapped Finance Development Corporation) & its services
- 14.4 Income tax exemption / redemption benefits for Persons with Disabilities
 - 14.4.1 Tax exemption under Section 80U
 - 14.4.2 Deduction under Section 80DD
 - 14.4.3 Section 80V
 - 14.4.4 Section 88B
 - 14.4.5 Difference between Section 80U and Section 80DD
 - 14.4.6 Difference between Section 80DD, Section 80D and Section 80DDB
- 14.5 The Persons with Disabilities (PWD) Act
 - 14.5.1 Main Provisions of the Act
- 14.6 National Trust for Welfare of Persons with Autism, CP, MR and Multiple Disability act, 1999
- 14.7 The Rehabilitation Council of India Act, 1992
- 14.8 The Rights of Persons with Disabilities (RPWD) Act, 2016
- 14.9 Let us sum up
- 14.10 Unit end exercises
- 14.11 Answers to check your progress
- 14.12 Suggested Readings

14.1 INTRODUCTION

Disability in India has a direct correlation with poverty. Disability leads to poverty and poverty causes disability. Persons with disabilities have little or no access to education, vocational training, and livelihood and employment opportunities. Unable to access welfare measures and entitlements, denied social security, treated as recipients of charity and doles, and because of widespread ignorance about their status as rights holders, they stand marginalised and most of their human rights stand violated. Lack of information about laws and their inability to access the justice system completes their marginalisation.

The last decade has brought rights-based advances for the people with disability in India. After the ratification of the UN Convention on Rights of Persons with Disabilities in 2007, the Rights of Persons with Disabilities Act was legislated in December 2016 and the Mental Health Care Act in 2017, raising hopes and aspirations of the community.

The Disability Rights Initiative (DRI) is recognized as the only one of its kind in providing a comprehensive range of socio-legal support services to this special group. DRI provides legal aid, takes up high-impact public interest litigation, provides access to the legal system and campaigns to improve facilities for persons with all types of disabilities. It engages in out-of-court advocacy and has initiated extensive work on law reform for people with disabilities. This unit discusses about the various services offered for persons with disabilities.

14.2 OBJECTIVES

Going through this unit, you will be able to

- Outline the legal services available for the persons with disability.
- Discusses the about the NHFDC services for PWD.
- Organize the various ACT's for persons with disability.
- Discuss about the Benefits and concessions available for PWD.
- Elaborates on the Income Tax exemptions for PWD.

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14.3 NHFDC (National Handicapped Finance Development Corporation) & its services

The National Handicapped Finance and Development Corporation (NHFDC) is a wholly owned company by Government of India. NHFDC functions as an Apex institution for extending financial support for education, employment and entrepreneurship of the persons with disabilities through the State Channelizing Agencies (SCAs) nominated by the State Government(s). Prominent schemes being implemented by NHFDC are given below in brief:

A. Financial Assistance in the form of Education Loan

Loan is given for pursuing higher education in India and abroad. All courses having employment prospects i.e. Graduation courses/ Post graduation courses/Professional courses and other courses approved by UGC/Government/AICTE etc. are eligible. Maximum amount of loan is Rs.10.00 lakhs for courses within India and Rs.20.00 lakhs for courses abroad. The rate of interest is 4% per annum, a rebate of 0.5% on interest can women beneficiaries. The repayment would commence one year after completion of course or 6 months after securing a job, whichever is earlier. The maximum repayment period is 7 years after commencement of repayment.

B. Scholarship Scheme from Trust Fund

Under this scheme financial assistance is given to students with disabilities to pursue degree and/or post graduate level technical and professional courses from a recognized institution. Maintenance allowance, book/stationary allowance and grant for purchase of assistive devices are credited to the student's account. Non-refundable fees are reimbursed to the student on production of proof of deposit of fees or are paid directly to the Institute under intimation to the student. There are provision of 2500 scholarships every year.

C. Scholarship Scheme from National Fund for professional course

Under this scheme financial assistance is given to students with disabilities to pursue technical and professional courses from a recognized institution. There is provision of 500 scholarships every year. The rate of scholarship is Rs.1000/-p.m. for hostellers and Rs.700/- p.m. for day scholars studying in professional courses at graduation and above level, and Rs.700/- p.m. for hostellers and Rs.400/- p.m. for day scholars pursuing Diploma /certificate level professional. Course fee is reimbursed

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up to ceiling of Rs.10, 000/- per year. In addition, financial assistance can be given for computer with editing software for blind/deaf graduate and post graduate students pursuing professional courses and for support access software for cerebral palsy students.

Check your Progress - I

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is the financial assistance available for Persons with disability?

14.4 INCOME TAX EXEMPTION / REDEMPTION BENEFITS FOR PwDs

Tax benefit is available to any resident individual who is certified as “a person with disability” by the “medical authority”. There are certain sections under the income tax laws of India which provide tax benefits to individuals if either they or any of their family members are suffering from certain disabilities

14.4.1 Tax exemption under Section 80U

There are certain sections under the income tax laws of India which provide tax benefits to individuals if either they or any of their family members are suffering from certain disabilities. Section 80U offers tax benefits if an individual suffers a disability, while Section 80DD offers tax benefits if an individual taxpayer’s dependent family member(s) suffers from a disability.

A. Eligibility for tax exemption Under Section 80U; A resident individual who has been certified as a person with a disability by the medical authority can claim the tax benefit under Section 80U. For eligibility of this concessions defined as a person who has at least 40 percent disability, certified by the medical authorities as having one of the following:

- Blindness
- Low vision
- Leprosy-cured
- Hearing impairment
- Loco motor disability
- Mental retardation
- Mental illness
- Multiple disabilities, autism and cerebral palsy.

B. Deduction limit: For deduction under section 80U, individuals or persons with disability are categorized into two types:

C. Person with disability: A person with disability means the person is suffering from at least 40% of a disability. If an individual has at least 40% of a disability, then he is eligible for a deduction of Rs. 75,000.

D. Person with severe disability: A person with disability means the person who is suffering from at least 80% of a disability. If an individual has severe disability (i.e., 80% or more of a disability) then he is eligible for a deduction of Rs. 1, 25,000/.

Quantum of Deduction under 80U

Category	Deduction permitted
40% Disability	Rs.75,000
80 % disability	Rs.1.25 lakhs

NOTES**14.4.2 Deduction under Section 80DD**

Tax deduction under Section 80DD of the Income Tax Act can be claimed by individuals who are residents of India and HUFs for the medical treatment of a dependant with disability. The deduction amount will also cover insurance premium paid towards specific insurance plans designed for a dependant of persons with disabilities.

A. Eligibility Criteria for Deduction under Section 80DD:

Any individual or HUF (Hindu Undivided Family) who is a resident of India can claim this deduction. Non-Resident Individuals (NRIs) cannot claim deduction under Section 80DD of the Income Tax Act, 1961.

B. Terms and Conditions Associated with Claiming Deduction under Section 80DD:

Dependant can be spouse, children, parents, brothers and sisters of the taxpayer. The taxpayer has borne expenses for medical treatment and training & rehabilitation of the dependant with disability or the taxpayer has paid premium for a specific insurance policy designed for such cases. The taxpayer cannot claim this deduction if the dependant has already claimed deduction under Section 80U for himself or herself. The person with disability is wholly or to a large extent dependant on the taxpayer for their support.

C. Disabilities Covered Under Section 80DD:

The following disabilities are covered under section 80DD of the Income Tax Act, 1961:

- Hearing impairment
- Mental retardation
- Mental illness
- Autism
- Cerebral palsy
- Blindness
- Low vision
- Leprosy-cured
- Loco motor disability

D. Certification authorities:

Below mentioned medical authorities can certify a person as having disability;

- Civil Surgeon or Chief Medical Officer (CMO) of a government hospital.
- Neurologist with a Doctor of Medicine (MD) degree in Neurology. If it's for a child, then a Paediatric Neurologist holding an equivalent degree.

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E. **Deduction Amount under Section 80DD:**

The amount of deduction allowed under Section 80DD of the Income Tax Act, 1961, will come down to whether the dependant suffers from disability or severe disability.

F. **Dependant person with disability**

A dependant person with disability is one who has at least 40% of any of the specified disability. The family member who takes care of the medical charges of the dependant person with disability can claim tax deduction of up to Rs. 75,000.

G. **Dependant person with severe disability**

A dependant person with severe disability is one who has at least 80% of any disability. The family member handling the medical expenses of dependant person with severe disability can claim tax deduction of up to Rs. 1, 25,000/.

14.4.3 Section 80 V

A new section 80V has been introduced to ensure that the parent in whose hand's income of a permanently disabled minor has been clubbed under Section 64 can claim a deduction up to Rs.20000/- in terms of Section 80 V.

14.4.4 Section 88B:

This section provides for an additional rebate from the net tax payable by a resident individual who has attained the age of 65 years. It has been amended to increase the rebate from 10% to 20% in the cases where the gross total income does not exceed Rs.75000/- (as against a limit of Rs.50000/- specified earlier).

14.4.5 Difference between Section 80U and Section 80DD:

Section 80DD provides tax deductions to the family members and the kin of the taxpayer with a disability, whereas Section 80U provides deductions to the individual taxpayer with a disability himself. Section 80DD is applicable if a taxpayer deposits a specified amount as an insurance premium for taking care of his/her dependent disabled person. Under section 80DD, the deduction limits are the same as Section 80U. Here, a dependent refers to the siblings of the special child parents, spouse, children or a member of a Hindu Unified Family.

14.4.6 Difference between Section 80DD, Section 80D and Section 80DDB:

Tax deduction under Section 80DD of the Income Tax Act can be claimed by individuals who are residents of India and HUFs for the medical treatment of a dependant with disability. The deduction amount will also cover insurance premium paid towards specific insurance plans designed for a disabled dependant.

Tax deduction under Section 80D of the Income Tax Act can be claimed for premiums paid toward a health insurance policy. The total deductions that can be claimed under Section 80D are as under:

Members insured	Total deduction
Self and family	Rs. 25,000
Self and family + Parents	Rs. 50,000 (Rs. 25,000 + Rs. 25,000)
Self and family + Parents (senior citizens)	Rs. 75,000 (Rs. 25,000 + Rs. 50,000)
Self (senior citizen) and family + Parents (senior citizens)	Rs. 100,000 (Rs. 50,000 + Rs. 50,000)

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An additional tax deduction of up to Rs. 5,000 can be claimed for expenses borne on medical check-ups or preventive health check-ups. Tax benefits under Section 80D can also be claimed for premiums paid toward health insurance riders and critical illness insurance policies. It must, however, be noted that premiums paid for personal accident policies or personal accident riders do not qualify for tax deduction under this section.

Tax deduction under Section 80DDB of the Income Tax Act can be claimed by taxpayers who have dependents suffering from specified diseases. The dependant can be spouse, children, siblings or parents. The tax deduction that can be claimed by individuals is Rs. 40,000 or the sum actually paid, whichever is lesser. If the individual is a senior citizen, the tax benefits that can be claimed is Rs. 1,00,000 or the sum actually paid, whichever is lesser.

Check your progress-II

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) What is the difference between section 80 u and section 80DD?

14.5 THE PERSONS WITH DISABILITIES (PWD) ACT

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995” had come into enforcement on February 7, 1996. It is a significant step which ensures equal opportunities for the people with disabilities and their full participation in the nation building. The Act provides for both the preventive and promotional aspects of rehabilitation like education, employment and vocational training, reservation, research and manpower development, creation of barrier- free environment, rehabilitation of persons with disability, unemployment allowance for the disabled, special insurance scheme for the disabled employees and establishment of homes for persons with severe disability etc.

14.5.1 Main Provisions of the Act

The main provisions of PwDs Act are:

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A. Prevention and early detection of disabilities

- Surveys, investigations and research shall be conducted to ascertain the cause of occurrence of disabilities.
- Various measures shall be taken to prevent disabilities. Staff at the Primary Health Centre shall be trained to assist in this work.
- All the Children shall be screened once in a year for identifying 'at-risk' cases.
- Awareness campaigns shall be launched and sponsored to disseminate information.
- Measures shall be taken for pre-natal, peri-natal, and post-natal care of the mother and child.
-

B. Education

- Every child with disability shall have the rights to free education till the age of 18 years in integrated schools or special schools.
- Appropriate transportation, removal of architectural barriers and restructuring of modifications in the examination system shall be ensured for the benefit of children with disabilities.
- Children with disabilities shall have the right to free books, scholarships, uniform and other learning material.
- Special Schools for children with disabilities shall be equipped with vocational training facilities.
- Non-formal education shall be promoted for children with disabilities.
- Teachers' Training Institutions shall be established to develop requisite manpower.
- Parents may move to an appropriate forum for the redressal of grievances regarding the placement of their children with disabilities.

C. Employment

- 3% of vacancies in government employment shall be reserved for people with disabilities, 1% each for the persons suffering from:
 - Blindness or Low Vision
 - Hearing Impairment
 - Locomotor Disabilities & Cerebral Palsy
- Suitable Scheme shall be formulated for
 - The training and welfare of persons with disabilities
 - The relaxation of upper age limit
 - Regulating the employment
 - Health and Safety measures and creation of a non-handicapping, environment in places where persons with disabilities are employed
- Government Educational Institutes and other Educational Institutes receiving grant from Government shall reserve at least 3% seats for people with disabilities. No employee

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can be sacked or demoted if they become disabled during service, although they can be moved to another post with the same pay and condition. No promotion can be denied because of impairment.

D. Affirmative Action

- Aids and Appliances shall be made available to the people with disabilities.
- Allotment of land shall be made at concessional rates to the people with disabilities for:
 - House
 - Business
 - Special Recreational Centre's
 - Special Schools
 - Research Schools
 - Factories by Entrepreneurs with Disability

E. Non-Discrimination

- Public building, rail compartments, buses, ships and aircrafts will be designed to give easy access to the disabled people.
- In all public places and in waiting rooms, the toilets shall be wheelchair accessible.
- Braille and sound symbols are also to be provided in all elevators (lifts).
- All the places of public utility shall be made barrier-free by providing the ramps.

F. Research and Manpower Development

Research in the following areas shall be sponsored and promoted

- Prevention of Disability
- Rehabilitation including community-based rehabilitation
- Development of Assistive Devices.
- Job Identification
- On site Modifications of Offices and Factories.
- Financial assistance shall be made available to the universities, other institutions of higher learning, professional bodies and non-government research- units or institutions, for undertaking research for special education, rehabilitation and manpower development.

G. Social Security

- Financial assistance to non-government organizations for the rehabilitation of persons with disabilities.
- Insurance coverage for the benefit of the government employees with disabilities.
- Unemployment allowance to the people with disabilities who are registered with the special employment exchange for more than a year and could not find any gainful occupation.

H. Grievance Redressal

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- In case of violation of the rights as prescribed in this act, people with disabilities may move an application to the
- Chief Commissioner for Persons with Disabilities in the Centre, or
- Commissioner for Persons with Disabilities in the State.

Check your progress-III

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State your views on the perspective of education as per PwD Act?

14.6 NATIONAL TRUST FOR WELFARE OF PERSONS WITH AUTISM, CP, MR AND MULTIPLE DISABILITY ACT, 1999

The Central Government has the obligation to set up, in accordance with this Act and for the purpose of the benefit of the person with disability, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability at New Delhi.

The National Trust created by the Central Government has to ensure that the objects for which it has been set up as enshrined in Section 10 of this Act have to be fulfilled. It is an obligation on part of the Board of Trustees of the National Trust so as to make arrangements for an adequate standard of living of any beneficiary named in any request received by it, and to provide financial assistance to the registered organizations for carrying out any approved programme for the benefit of people with disabilities.

Persons with disabilities have the right to be placed under guardianship appointed by the 'Local Level Committees' in accordance with the provisions of the Act. The guardians so appointed will have the obligation to be responsible for the Persons with disabilities and their property and required to be accountable for the same.

A Person with disabilities has the right to have his guardian removed under certain conditions. These include an abuse or neglect of the people with disabilities or neglect or misappropriation of the property under care.

Whenever the Board of Trustees are unable to perform or have persistently made default in their performance of duties, a registered organization for the people with disabilities can complain to the central government to have the Board of Trustees superseded and/or reconstituted.

The National Trust shall be bound by the provisions of this Act regarding its accountability, monitoring finance, accounts and audit.

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Check your progress-IV

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) Highlight the importance of National trust for welfare of persons with Autism, CP, MR and Multiple Disability act, 1999.

14.7 THE REHABILITATION COUNCIL OF INDIA ACT

This Act provides guarantees so as to ensure the good quality of services rendered by various rehabilitation personnel. Following is the list of such guarantees:

- To have the right to be served by trained and qualified rehabilitation professionals whose names are borne on the Register maintained by the Council.
- To have the guarantee of maintenance of minimum standards of education required for recognition of rehabilitation qualification by universities or institutions in India.
- To have the guarantee of maintenance of standards of professional conduct and ethics by rehabilitation professionals in order to protect against the penalty of disciplinary action and removal from the Register of the Council
- To have the guarantee of regulation of the profession of rehabilitation professionals by a statutory council under the control of the central government and within the bounds prescribed by the statute.

A. Objective of RCI

- To regulate the training policies and programmes in the field of rehabilitation of persons with disabilities
- To bring about standardization of training courses for professionals dealing with persons with disabilities
- To prescribe minimum standards of education and training of various categories of professionals/ personnel dealing with people with disabilities
- To regulate these standards in all training institutions uniformly throughout the country
- To recognize institutions/ organizations/ universities running master's degree/ bachelor's degree/ P.G. Diploma/ Diploma/ Certificate courses in the field of rehabilitation of persons with disabilities
- To recognize degree/diploma/certificate awarded by foreign universities/ institutions on reciprocal basis
- To promote research in Rehabilitation and Special Education
- To maintain Central Rehabilitation Register for registration of professionals/ personnel

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- To collect information on a regular basis on education and training in the field of rehabilitation of people with disabilities from institutions in India and abroad
- To encourage continuing education in the field of rehabilitation and special education by way of collaboration with organizations working in the field of disability.
- To recognize Vocational Rehabilitation Centres as manpower development centres
- To register vocational instructors and other personnel working in the Vocational Rehabilitation Centres
- To recognize the national institutes and apex institutions on disability as manpower development centres
- To register personnel working in national institutes and apex institutions on disability under the Ministry of Social Justice & Empowerment.

Check your progress V

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the main objectives of RCI.

14.8 THE RIGHTS OF PERSONS WITH DISABILITIES (RPWD) ACT, 2016

The Rights of Persons with Disabilities (RPWD) Act was passed by both houses of the Parliament on 16th December 2016. The Act has several provisions, which if implemented, could be a “game changer” for people with disabilities in India. The Act lays stress on non-discrimination, full and effective participation and inclusion in society, respect for difference and acceptance of disabilities as part of human diversity and humanity, equality of opportunity, accessibility, equality between men and women, respect for the evolving capacities of children with disabilities, and respect for the right of children with disabilities to preserve their identities. The principle reflects a paradigm shift in thinking about disability from a social welfare concern to a human rights issue.

In the RPWD Act, 2016, the list has been expanded from 7 to 21 conditions and it now also includes cerebral palsy, dwarfism, muscular dystrophy, acid attack victims, hard of hearing, speech and language disability, specific learning disabilities, autism spectrum disorders, chronic neurological disorders such as multiple sclerosis and Parkinson's disease, blood disorders such as haemophilia, thalassemia, and sickle cell anaemia, and multiple disabilities.

The nomenclature mental retardation is replaced by intellectual disability which is defined as “a condition characterized by significant limitation both in intellectual functioning (reasoning, learning, problem-solving) and in adaptive behaviour which covers a range of every day social and practical skills including specific learning disabilities and autism spectrum disorders.”

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The Act provides an elaborate definition of mental illness which is “a substantial disorder of thinking, mood, perception, orientation, or memory that grossly impairs judgment, behaviour, and capacity to recognize reality or ability to meet the ordinary demands of life but does not include retardation which is a condition of arrested or incomplete development of mind of a person, especially characterized by sub normality of intelligence.” Persons with benchmark disabilities are defined as those with at least 40% of any of the above disability. PWD having high support needs are those who are certified as such under section 58(2) of the Act. The RPWD Act provides:

- All rights to persons with disabilities on an equal basis with others, without any discrimination - right to equality, liberty, home and family, participation in sports and cultural life, living in the community, political, financial, legal rights, protection from abuse and violence, health, justice, adequate standard of living and rights specific to women and children.
- Access and accommodations to enjoy their various rights.
- Free and compulsory education for all children with disabilities free education in a neighbourhood school, or in a special school, of his choice up to 18 years of age.
- Admission without discrimination in all recognized schools. Individualized accommodation and support should be provided to children with disabilities.
- 5% reservation in higher education (in government and government aided institutions) for people with benchmark disabilities.
- 4% Reservation in jobs (government and public sector) for persons with benchmark disabilities - one percent for each clause from (a) to (d) namely: a. blindness and low vision; b. deaf and hard of hearing; c. locomotors disability including cerebral palsy, leprosy cured, dwarfism, acid attack victims and muscular dystrophy; d. autism, intellectual disability, specific learning disability, mental illness and multiple disabilities including deaf-blindness.
- 5% Reservation in poverty alleviation and other development programmes for persons with benchmark disabilities.
- All establishments including private establishment should frame an Equal Opportunity Policy and register it with the Commissioner's office and maintain a record of employees with disabilities.
- Every government establishment should appoint a Grievance Redressal Officer.
- Establishments should ensure accessibility of built infrastructure, ICT, transportation and services as per the standards.
- Incentives to employers in private sector to ensure that at least five per cent of their workforce is composed of persons with benchmark disability.
- All service providers (including private) should make their services accessible in two years (i.e. by June 2019).
- All existing buildings accessed by public should be made accessible in five years' time (i.e. by June 2022).
- Free of cost aids and appliances, medicine and diagnostic services and corrective surgery to persons with disabilities with such income ceiling as may be notified.

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- Disability pension and unemployment allowance to persons with disabilities.
- Care-giver allowance to persons with disabilities with high support needs
- Comprehensive insurance scheme for persons with disability.
- Free healthcare in the vicinity especially in rural area subject to such family income as may be notified;
- Barrier-free access in all parts of Government and private hospitals and other healthcare institutions and centres.
- The quantum of assistance to the persons with disabilities under social security schemes and programmes should be at least twenty-five percent higher than the similar schemes applicable to others.
- Central and State Advisory Board and District Level committees with representation from all stakeholder groups should be constituted.
- Chief Commissioner and State Commissioner with the power of the civil court to enforce the Act.
- Special Courts at the District for providing for trying the offences under this Act.
- Authorities to be designated for supporting persons with disabilities in exercise of their legal capacity.
- Executive Magistrates to take specific steps when she/he receives complaints regarding any abuse /violence abuse, violence or exploitation.
- Disaster Management activities should be inclusive. Data of persons with disabilities should be maintained by District level Disaster Management Authority.
- Central and State Funds for ensuring resources for implementing the Act.
- Punishments and penalties for any contravention of provisions of Act.

Thus, with the advent of Rights of persons with Disabilities Act- 2016, the rights of persons with disabilities has been ensured.

Check your progress-VI

Note: A. Write your answer in the space given below

B. Compare your answer with those given at the end of the unit.

i) State the main Role of RPWD Act.

ii) As per the RPWD Act, how many disabilities are being recognized?

14.9 LET US SUM UP

United Nations convention on Rights of Persons with Disabilities is so crucial and how in the 21st century it has brought about a paradigm shift in perspective. "UNCRPD adopts a human rights approach instead of the earlier medical approach to disability. This is a shift from viewing people with disabilities (PWD) as objects needing social protection and medical care to seeing them as subjects having human rights, fundamental freedoms". As a signatory of the UNCRPD convention, The Constitution of India applies uniformly to every legal citizen of India, whether they are healthy or disabled in any way (physically or mentally).

Under the Constitution, people with disabilities have been guaranteed the following fundamental rights: The Constitution secures to the citizens including the people with disabilities, a right of justice, liberty of thought, expression, belief, faith and worship, equality of status and of opportunity and for the promotion of fraternity. Article 15(1) enjoins on the Government not to discriminate against any citizen of India (including people with disabilities) on the ground of religion, race, caste, sex or place of birth. There shall be equality of opportunity for all citizens (including the people with disabilities) in matters relating to employment or appointment to any office under the State.

"The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995" had come into enforcement on February 7, 1996. It is a significant step which ensures equal opportunities for the people with disabilities and their full participation in the nation building. The Act provides for both the preventive and promotional aspects of rehabilitation like education, employment and vocational training, reservation, research and manpower development, creation of barrier-free environment, rehabilitation of persons with disability, unemployment allowance for the people with disabilities, special insurance scheme for the employees with disabilities and establishment of homes for persons with severe disability etc.

As per the Rehabilitation Council of India Act, 1992, it provides guarantee to ensure the good quality of services rendered by various rehabilitation personnel to have the right to be served by trained and qualified rehabilitation professionals whose names are borne on the Register maintained by the Council, to have the guarantee of maintenance of minimum standards of education required for recognition of rehabilitation qualification by universities or institutions in India.

The Rights of Persons with Disabilities Act, 2016 is the disability legislation passed by the Indian Parliament to fulfil its obligation to the United Nations Convention on the Rights of Persons with Disabilities, which India ratified in 2007. The Act replaces the existing Persons with Disabilities Act, 1995.

14.10 UNIT END EXERCISES

1. What are the Income Tax Exemption and redemption benefits available for PWD?
2. Explain NHFDC and its services?
3. Discuss the role of RPWD ACT and PWD Act?
4. Detail on the education and Employment provisions under the PWD act?

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5. Give a brief note on the importance of National trust for welfare of persons with Autism, CP, MR and Multiple Disability act?
6. What RCI and why is it important for the persons with disability?

14.11 ANSWERS TO CHECK YOUR PROGRESS

The National Handicapped Finance and Development Corporation (NHFDC) is a wholly owned company by Government of India. NHFDC functions as an Apex institution for extending financial support for education, employment and entrepreneurship of the persons with disabilities through the State Channelizing Agencies (SCAs) nominated by the State Government(s). Prominent schemes being implemented by NHFDC are Financial Assistance in the form of Education Loan, Scholarship Scheme from Trust Fund and Scholarship Scheme from National Fund for professional courses.

Section 80DD provides tax deductions to the family members and the kin of the taxpayer with a disability, whereas Section 80U provides deductions to the individual taxpayer with a disability himself. Section 80DD is applicable if a taxpayer deposits a specified amount as an insurance premium for taking care of his/her dependent people with disabilities. Under section 80DD, the deduction limits are the same as Section 80U.

As per PwD act, every child with disability shall have the rights to free education till the age of 18 years in integrated schools or special schools. Appropriate transportation, removal of architectural barriers and restructuring of modifications in the examination system shall be ensured for the benefit of children with disabilities. Children with disabilities shall have the right to free books, scholarships, uniform and other learning material. Special Schools for children with disabilities shall be equipped with vocational training facilities. Non-formal education shall be promoted for children with disabilities.

National Trust created by the Central Government has to ensure that the objects for which it has been set up as enshrined in Section 10 of this Act have to be fulfilled. It is an obligation on part of the Board of Trustees of the National Trust so as to make arrangements for an adequate standard of living of any beneficiary named in any request received by it, and to provide financial assistance to the registered organizations for carrying out any approved programme for the benefit of people with disabilities.

The main objectives of RCI is to regulate the training policies and programmes in the field of rehabilitation of persons with disabilities, to bring about standardization of training courses for professionals dealing with persons with disabilities, to prescribe minimum standards of education and training of various categories of professionals/ personnel dealing with people with disabilities, to regulate these standards in all training institutions uniformly throughout the country, to recognize institutions/ organizations/ Universities running master's degree/ bachelor's degree/P.G.

Diploma /Diploma/ Certificate courses in the field of rehabilitation of persons with disabilities.

The RPWD Act lays stress on non-discrimination, full and effective participation and inclusion in society, respect for difference and acceptance of disabilities as part of human diversity and humanity, equality of opportunity, accessibility, equality between men and women, respect for the evolving capacities of children with disabilities, and respect for the right of children with disabilities to preserve their identities. The principle reflects a paradigm shift in thinking about disability from a social welfare concern to a human rights issue.

In the RPWD Act, 2016, the list has been expanded from 7 to 21 conditions and it now also includes cerebral palsy, dwarfism, muscular dystrophy, acid attack victims, hard of hearing, speech and language disability, specific learning disabilities, autism spectrum disorders, chronic neurological disorders such as multiple sclerosis and Parkinson's disease, blood disorders such as haemophilia, thalassemia, and sickle cell anaemia, and multiple disabilities.

14.12 SUGGESTED READINGS

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Alagappa University
Karaikudi, Tamil Nadu
M.A. (Child Care and Education)

Sub. Code
31243

Distance Education

Subject: Practices of Child Rearing

Duration: 3 Hours

Max. Total: 75 Marks

Section A

Answer all the questions. (10 x 2=20)

1. What is meant by parenting education?
2. What is meant by Positive parenting?
3. State the role of physiotherapist.
4. What is Family Systems Theory?
5. Name the authorities who can certify that a person is said to have disability.
6. What is meant by Image-Making Stage?
7. Briefly explain the various Stages of Family Crisis Intervention.
8. State any four provisions of PwD Act.
9. Name UNICEF's four pillars of parenting.
10. Name the Professional involved in the Care of the Young Child with Special Needs.

Section B

Answer all the questions. (5 x 5= 25)

11. a) State the Key benefits of Parent Education.
(or)
b) Explain Parent-Child Interaction Therapy.
12. a) Explain Triple P-Positive Parenting Program.
(or)
b) Analyze the importance of Network in rearing children with special needs
13. a) Discuss about the need for Vocational training
(or)
b) Evaluate Therapeutic rehabilitation
14. a) Difference between Section 80DD, Section 80D and Section 80DDB
(or)
b) Evaluate the role of Paralympics in promoting sports among persons with disabilities.
15. a) State the objective of RCI.
(or)
b) Explain the Financial Assistance given in the form of Education Loan for students with disabilities.

Section C

Answer any three questions. (3 x 10 = 30)

16. Critically evaluate the special requirements of families having children with special needs.
17. Explain the critical stages in the Development.
18. Parents are partners in rearing children with special needs-justify
19. Explain Jean Piaget's theory of cognitive development and their application to parenting.
20. Critically evaluate the role of RPWD Act.