NETAJI SUBHAS OPEN UNIVERSITY

STUDY MATERIAL

M. Ed. Special Education (Hearing Impairment / Intellectual Disability) - ODL

B 10 (I.D.)

ADULTHOOD AND FAMILY ISSUES

M. Ed. Spl. Ed. (H.I. / I.D.)
ODL Programme

AREA - B

B 10 (I.D.): ADULTHOOD AND FAMILY ISSUES

A COLLABORATIVE PROGRAMME OF
NETAJI SUBHAS OPEN UNIVERSITY
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AREA - B
DISABILITY SPECIALIZATION
COURSE CODE-B10 (I.D.)
ADULTHOOD AND FAMILY ISSUES

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The Self Learning Material (SLM) is prepared keeping conformity with the M.Ed.Spl. Edu.(MR/HI/VI) Programme as prepared and circulated by the Rehabilitation Council of India, New Delhi and adopted by NSOU on and from the 2020-2022 Academic Session.

Mohan Kumar Chattopadhyay

Registrar

Prologue

I am delighted to write this foreword for the Self Learning Materials (SLM) of M Ed in Special Education (ODL). The M Ed in Special Education in ODL mode is a new academic program to be introduced at this University as per NOC issued by the Rehabilitation Council of India, New Delhi and subject to approval of the program by the DEB-UGC.

I must admire the emulation taken by the colleagues from School of Education (SoE) of NSOU for developing the Course Structure, Unit wise details of contents, identifying the Content Writers, distribution of job of content writing, editing of the contents by the senior subject experts, making DTP work and also developing E-SLMs of all the 16 Papers of the M Ed program. I also extend my sincere thanks to each of the Content Writers and Editors for making it possible to prepare all the SLMs as necessary for the program. All of them helped the University enormously. My colleagues in SoE fulfilled a tremendous task of doing all the activities related to preparation of M Ed in Spl Edn SLMs in war footing within the given time line.

The conceptual gamut of Education and Special Education has been extended to a broad spectrum. Helen Keller has rightly discerned that *"Have you ever been at sea in a dense fog, when it seemed as if a tangible white darkness shut you in and the great ship, tense and anxious, groped her way toward the shore with plummet and sounding-line, and you waited with beating heart for something to happen? I was like that ship before my education began, only I was without compass or sounding line, and no way of knowing how near the harbour was. "Light! Give me light!" was the wordless cry of my soul, and the light of love shone on me in that very hour."* So education is the only tool to empower people to encounter his/her challenges and come over being champion. Thus the professional Teacher Education program in Special Education can only groom the personnel as required to run such academic institutions which cater to the needs of the discipline.

I am hopeful that the SLMs as developed by the eminent subject experts, from the national as well as local pools, will be of much help to the learners. Hope that the learners of the M Ed Spl Edn program will take advantage of using the SLMs and make most out of it to fulfil their academic goal. However, any suggestion for further improvement of the SLMs is most welcome.

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AREA - B

B 10 : ADULTHOOD AND FAMILY ISSUES

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Unit 1: Human Growth & Development in Adulthood

Structure

1.1 Introduction

Human development studies originally focused on the development of children from preschool. But later the research was extended to development during conception to development during adulthood. Now human development explains the changes that take place throughout the life span of an individual, spanning from conception to death. But still the focus of human development is child development. As children grow they display certain characteristics. It not only includes physical growth but also cognitive, social and emotional development.

The development of humans is sequential. According to stage theorists one cannot skip any stage of development. Every stage is important for the various aspects of human development. Many stage theorists such as Freud, Piaget and Erikson have contributed a lot in the study of human development. Freud's psychosexual theory emphasized the importance of psychological development while Piaget's theory explained about the cognitive development in a human being. Erikson's psychosocial theory spoke about personality development of an individual.

Human development looks at the holistic development of a human being, Paul Baltes articulated a set of principles to understand the nature of human development. The principles are as follows:

1. Development is life long as it encompasses all the changes from conception to death.
2. Development is multi dimensional as changes occur not only in one area but many areas. Development is the product of interaction between physical, socio-emotional, and cognitive areas.
3. Development is multidirectional. In other words, the increase ability in one area may lead to a decreased ability in the other for example, an adolescent may become more self regulated but may become less creative.
4. Development is plastic. It denotes the capacity of the human brain to compensate for the loss. For example, people with visual impairment develop their other senses to compensate for their loss of vision. Similarly, intervention can help improving the development or behaviour in a human being.
5. Development is influenced by contextual and socio-cultural influences. Every human being develops as an interaction between his heredity and environmental factors.
6. Development is multidisciplinary. Since human development cannot be perfectly explained by only one discipline other disciplines are not included for a holistic view.

A major portion of the theories in human development explain the changes that occur during childhood, since it's the most critical period of development. Learning and education becomes effective if one has the knowledge about child development. To understand the changes during developmental stages knowledge about developmental norms are very crucial.

Developmental norms represent the typical performance expected from a child at a particular age. Only when teachers are aware of what is to be expected normally from a child will it be possible to set off alarms when anything below or above normal is seen. Thus early intervention becomes possible when any anomaly or delays are detected at this age.

1.2 Objectives

- **To understand the developmental stages and principles**

- **To understand the factors influencing natural development of adults**
- **To understand the various aspects of human development**
- **To understand the problems in the areas of development**
- **To understand the challenges in Community Inclusion**

1.3 Developmental stages and principles

1.3.1 Meaning of development and growth

The best way to explain the differences that exists in behaviour and abilities in humans between different ages is through development. Development implies overall change in shape, form or structure resulting in improved working/functioning. Changes in the quality or character reflect development. There are two major views that describe development. One that views development as continuous, in which theorists believe that change, occurs gradually over time. For example changes in height. The other view views development as discontinuous, in which theorists believe new ways of responding to the world, emerges at particular time periods.

Theories that accept the discontinuous perspective include stage as a very important developmental concept. Stages are qualitative change in thinking, feeling and behaving that characterize particular time periods of development. Stage theories assume that development is universal and sudden. It also assumes that children not only undergo rapid changes as they go from one stage to another, but also plateaus during which there is no change.

Growth refers to changes in size and length. Changes in the quantitative aspects come into the domain of growth. Growth does not continue throughout life. It stops when maturity has been attained.

Growth and development are interlinked. Development encompasses growth.

1.3.2 Developmental stages

1. Infancy is the shortest stage of life that lasts from birth to two weeks. Once the child is born he is expected to adjust to the four major changes. They are changes in the temperature changes, sucking and swallowing, breathing and elimination.The infants depend on their parents to meet their basic needs. Whenever they are hungry or feel uncomfortable they need to be attended.

They need to feel this security in order to properly develop both physically and emotionally. They tend to trust others if their needs are met or else they tend to develop a feeling of mistrust towards others.

2. Babyhood extends from the end of two weeks to two years. It is the period when babies try to explore the physical world through their senses and motor movements. The foundation for social skills, emotional expression happens at this stage through the interactions between the child and the significant others. Language development at the end of this stage is noticeable.

3. Early Childhood starts from age 2 to age 6. The growth during childhood proceeds at a slow rate. The speech develops at a rapid rate. There is also a considerable amount of improvement seen in comprehension. Children develop morality by constraint. They learn through punishment and reinforcements. Happiness during this stage depends on the conducive environment at home.

4. Late childhood starts around six years of age and ends by the child attain puberty that is by thirteen years of age. Skills develop in four major areas that is self-help skills, school skills and play skills. The relationship with immediate family members may deteriorate. They tend to develop better relationships with peers. Increase in learning opportunities and intelligence leads to better understanding of concepts. Lot of attention is given to physical appearance. Belonging to a particular peer group is of utmost importance at this stage.

5. Adolescence begins once the child attains puberty by the age of thirteen and ends by the age of eighteen. It is called as the transitional period. An adolescent is expected to make mature decisions, failing which can lead to self rejection. This may further affect the personal and social adjustments .During this age an adolescent faces peer pressure and is influenced by peers to a large extent.

6. Adulthood is the longest period of the life span. It is divided into three periods. Early adulthood extends from eighteen to 40 years. It’s the period where one is expected to take up many new roles including the role of a spouse and parent. The career responsibility is of utmost importance. Middle adulthood extends from 40 to 60 years wherein lot of time is spent in the work field. Also family responsibilities are taken care of. Late adulthood extends from approximately sixty years to death. Here recreational activities play an important

role. The feeling of being able to contribute to the society is also important which leads to satisfaction.

1.3.3 Principles of development

1. Development follows a direction and pattern

a. Cephalocaudal-Development happens from head to toe. According to this principle, a child will gain physical control of their head first. After this, physical control will move downward to the arms and lastly to the legs.

b. Proximodistal-According to this principle development happens from centre to extremities. With this principle, the trunk of the body grows before the extremities of the arms and legs. Development of the ability to use various parts of the body also follows the proximodistal principle. For instance, effective use of the arms precedes the ability to use the hands.

2. Development proceeds from general to specific responses-gross to fine motor

- For example, the fetus moves its whole body but is incapable of making specific responses. With respect to emotional behaviour infants approach strange and unusual objects with some sort of general fear response.
- Later, their fears become more specific and elicit different kinds of behaviour, such as, crying, turning away and hiding etc.

3. Different body systems grow at different rates i.e. respiratory system, reproduction system, nervous system.

- The patterns of growth for body size, the nervous system, and sexual maturation are quite different.
- All system should be coordinated to function normally.

4. Development is a product of contribution of heredity and environment.

- The children carry with them several physiological and psychological peculiarities that are present in the parents. In fact it is the heredity that determines structure, complexion, structure of hair, height. Facial features nasal index etc. of the child. Thus different types of the genes help in the formation of a body.

- Environment is nothing but the sum total of the surroundings in which an individual has to live. Psychologically an individual's environment is related to all those stimuli which he faces from the moment of fertilization till death.

5. There is a wide individual difference in the growth pattern.

- It helps the teacher to know the principle of individual differences and arrange the educational experience accordingly.

6. Development is cumulative

- Development of one depends on the other. Experience helps build on.

7. Development is predictable

- The stages in development are predictable. Infancy-adolescence- adulthood-late adulthood and the changes are also almost universal.

8. Development has a critical period. For example some skills or areas of development happen within a certain age limit.

- Language acquisition: Native speaker up to age 5, proficiency up to puberty
- Cognitive skills: Birth up to age 8-10 Locus of Control: Puberty
- Height/health: Up to age 4-6

1.4 Factors influencing natural development of adults

14.1 Meaning of Adulthood

The word adult is derived from the latin verb "adultus" which means "grown to full size and strength" or 'Matured". Adulthood is a stage where the physical development of a human being is complete. They are expected to show maturity in their behaviour. The body stops growing but continues to show changes. Once a person becomes 20, he is called as an adult whether the adult behavior expected is displayed or not.

14.2 Factors influencing development

As an adult one is expected to carry out many responsibilities well. According to David Havinghurst there are certain developmental tasks expected at every stage of development. To complete the task there is a need for an active learner and an active environment. For example during infancy and early childhood children are expected to learn to walk, learn to talk, to take in solid foods, learn to control elimination of waste, learn about sexual differences (for example knowing that a girl's body is different from a boy)and sexual modesty (for example dressing according to the gender). Similarly at every stage of human development there are certain developmental tasks given by Havinghurst.

Adults have the following development tasks right from selecting a mate to learning to live with a marriage partner, starting a family, rearing children ,managing a home etc.

Adults have to fulfill the developmental tasks to be successful in life. During this stage the developmental tasks are related to family relationships, parenting and work environment. To achieve mastery of developmental tasks there are certain factors to that have to be considered.

1. Health: The adults are at the peak of physical health during early adulthood. Soif adults need to take care of their health. Health hazards affects work life and family life. Good diet and exercise is important during this stage to sustain good health. Only when the adults are healthy will they be able to concentrate on the other areas of development.
2. Good interpersonal relationships: is one of the important factors in adulthood. As there are many new roles as a partner, parent to be fulfilled. Relationship flourish if adults have good interpersonal relationships with their family members and peers. This leads to achieving the developmental tasks expected at the adult stage. When adults have a good home environment it helps in their psychological growth.
3. Work environment: At the adult stage, people are expected to make career choices. If the adults find their job interesting then they get motivated to work. Even the environment in which adults work should be motivating with good support from peers and seniors for the adults to grow.
4. Economic factors: If adults are employed and are paid well, then they are able to support themselves and their family members. This leads to having good interpersonal relationships with the family members. Unemployment leads to self doubt and low self esteem which is not good for development.

Thus it can be said that in the adulthood stage there are lot of changes happening due to the new roles and expectations from the society to perform each role well. So support and guidance from family and peers adults is a must at this stage of development.

1.5 Adulthood and Areas of development: Physical, Social, Cognitive, Language, Emotional & Moral

1.5.1 Changes in physical development

In early adulthood a person may continue to grow a bit in height and weight. But these changes are not noticeable as they are in the adolescent period. Once an adult moves to the middle adulthood stage there are more noticeable changes like the loss of skins elasticity. Some adults also face problems related to weight gain and or hair loss or grey hair. Women go through menopause. In late adulthood wrinkles start appearing on the face, skin becomes loose, eyesight deteriorates and many more health problems like arthritis, heart disease come into the picture. Though ,these changes are inevitable but can be managed through exercise, good diet and medicines.

1.5.2 Changes in social development

Social development involves getting along with people and to handle conflicts in a socially appropriate manner. In adulthood social development is very important because it's the stage where an adult has to deal with people and relations at home and work environment. Most of the adults at this stage have the knowledge about maintiaing good social relations.

1.5.3 Changes in cognitive development

Cognitive development is at its peak around 35 years of age. Research by Fischer, Yan and Stewart in 2003 suggested that adult cognitive development is a complex,ever changing process that may be even more active than cognitive development in infancy and early childhood. Although during late adulthood cognition may start deteriorating but engaging in mentally and physically stimulating activities leads to less cognitive decline and reduced incidence of dementia and mild cognitive impairment.(Hertzog, Kramer, Wilson, & Lindenberger, 2009; Larson et al., 2006; Podewils et al., 2005).

1.5.4 Changes in language development

Language is a system of communication. It involves phonemes, morphemes, syntax,context, grammar, semantics and pragmatics. To understand all these components of a language involves time. At adulthood humans are well equipped with at least their native language. They understand all the components of language. They further use language for effective communication with partneres, children, peers and co-workers.

1.5.5 Changes in emotional development

During this stage adults have to make decisions regarding their career and relationship formation. They are also expected to control their emotions in a socially appropriate manner. There are a lot of expectations stress as a partner, parent and as an employee that an adult has to fulfil. These expectations cause. People who have good interpersonal relationships and who can manage their emotions well inorder to sustain their relationships are able to develop emotionally.

1.5.6 Changes in moral development

Moral development helps to choose between right and wrong. Moral reasoning helps to make the choice. During childhood stage the fear of punishment or the approval of significant others leads children to choose what is right. As one grows into an adult the moral reasoning for choosing right and wrong depends on ones belief and core values. Moral judgement at the adult level requires higher moral reasoning. So for moral development cognitive development is a must.

1.6 Common adulthood problems in various areas of development

1.6.1 Problems in physical development

Along with the wrinkles and age spots that appear on the skin, there are other problems that affects the daily functioning of an adult. There is vision and hearing loss that tends to lower the pace of day to day activities. It also tends to affect the social relationships when hearing loss affects conversations. Other physical problems like BP, diabetes, heart problems, arthritis also come up which at times affects the mobility of an adult too.

Adults with Intellectual disability may have additional issues like seizures or any other comorbid condition which may need medication or else it may worsen their physical health.

1.6.1 Problems in social development

Social skills needed for sustaining a relationship is very important for a human being at all stages. But it becomes all the more important in adulthood as dealing with other people increases during this period. Be it the partner or colleagues, if maturity is not shown in these relationships then they tend to fail.

Persons with ID find it difficult to read non verbal cues which makes it difficult for them to have or sustain good social relations with others. This social skill deficit at times leads to loneliness

1.6.3 Problems in cognitive development

Crystallized intelligence is the knowledge and experience that one gathers throughout ones lifespan. It consists of all the information or strategies acquired during the development. This remains steady or may even increase slightly during adulthood. But fluid intelligence which depends on basic information processing skills declines during adulthood. The cognitive processing speed goes down along with the problem solving ability and divide attention.

Cognition is a problem area in persons with ID so as they develop into adults their cognition will still be that of a child.

1.6.4 Problems in language development

Adults use language to converse with peers and family members, to express needs and feelings, present ideas to others in educational or work setting and building new knowledge based on reading or listening. But in late adulthood as the memory fades some adults find it difficult to remember words during conversations or name of an object.

Compared to normal people, the person with ID might not have good vocabulary or the language needed to express. So adulthood problems add on to their language problems as well.

1.6.5 Problems in emotional development

There are many challenges that an adult comes across when it comes to sustaining relationships. Marriage and family formation leads to a lot of change in the adult's life. As these new roles bring in new responsibilities, it also brings along stress. As the roles are new, there is confusion as to what is expected. Only when there is good communication between the partners are they able to sort out things.

In some cases adults also go through midlife crises, if they are unable to find a job or if they are not able to sustain a relationship. They start doubting themselves and their choices. According to Erikson this is the stage of generativity v/s stagnation. If people do not think of themselves as contributing members of the society then they develop a feeling of stagnation. Some may even develop bad habits like drinking or smoking.

Persons with ID find it difficult to express themselves in a socially appropriate way and if there is no support or guidance given at the right age then it becomes difficult for them to behave in a matured manner.

1.6.6 Problems in moral development

As moral development requires higher cognitive skills, for individuals with ID moral judgement becomes difficult. They may do it superficially or because they fear punishment.

1.7 Implications of the above for Community Inclusion

1.7.1 Definition and meaning of Community Inclusion

Salzer defines community inclusion as "The opportunity to live in the community, and be valued for one's uniqueness and ability, like everyone else." So community inclusion aims at not only providing opportunities for participation but also welcoming that participation in the community. So community inclusion goes with the social model of disability. It believes that there is a gap between what a person with disability needs and what the environment offers. This gap leads to unemployment, unhappy relationships and many more issues. Community inclusion tries to bridge this gap and acts as fit between the person with disabilities and the environment. Members of the community includes not only parents and guardians their extended families, neighbours, school but also religious leaders (who are often considerably influential in changing attitudes),businessmen, shopkeepers, government workers and many others.

Communities can help build awareness and create positive attitudes towards child rights by conducting sensitization programs with active participation of people with disabilities. The community can be involved in monitoring the media for negative portrayal of people with disabilities.

1.7.2 Domains and Principles of Community Inclusion

The domains of community inclusion include the following areas which are required for leading a normal life. They are:

1. Employment
2. Education
3. Leisure/Recreation
4. Spirituality/Religion
5. Voting/Volunteering

   All the domains are equally important for ones physical, mental and cognitive development.

   Apart from these domains there are certain principles of Community-Based Inclusion which are as follows:

1. Community based inclusion instruction is individualized and focuses on those specific skills needed and wanted by the person for a desired life. Some of the questions addressed in this principle are what are the community places that the person desires to access? What are the resources available in the community? What are the dreams of the person related to community life? So this principle helps the people to decide the skill to be polished according to their interests.
2. The instructions are provided as far as possible in a natural setting where the person would apply the skill taught.
3. The instructions are looked at as a whole rather than as an isolated skill. So instructions focus on being a part of functional activities.

4. Varied instruction combined with supports natural to a setting are used to help individuals generalize skills.
5. Instruction takes place at the time of day at which the task is usually performed.
6. Whenever possible, instruction comes from the natural environment from those with the skills and experience who are in the setting where the skills will be utilized.

1.7.3 Implications of problems in human development in Community Inclusion

1. Non accessibility: For inclusion in mainstream activities, such as employment, education and recreation access to transport for people with disabilities is very important.

Accessibility to transport also improves social networks and connections among individuals. Hence accessibility indirectly helps in social development of adults with disability. If there is no access then it leads to loneliness. As per the study by Mc Villey et al. in 2006 it was noted that social exclusion, loneliness and lack of friends lead many people with ID with a health and well being problems. Social inclusion does not mean merely presence in the community but it also means to have social connections and being able to participate in the social activities (Cummins & Lau 2003; Hall 2005; Overmars Marx *et al*. 2013).In another study by Stancliffe et al. 2014 and Wilson et al. 2015 it was seen that there was a positive impact on loneliness for people with intellectual disability. Still, many people with intellectual disability remain socially isolated, and hence lonely, as they require support to access social opportunities and face added physical barriers. Lack of travel skills was noted to be one of the major hassles in people with ID to socialize with friends (Department of Health, 2011).

Thus in the light of the social and physical problems mentioned above, non accessibility sue to transport adds to further problems in the development and thus hiders community inclusion.

Although the association is not clear, Gilmore & Cuskelly (**2014**) suggested that the ramifications of loneliness and social exclusion could potentially contribute to the known mental and physical health inequalities that further exacerbate social exclusion.

2. Attitude: towards disability is also one of the barriers to community inclusion. People think that the people with disability would not be able to work in the normal setting; it may be too much for them to handle. If they employ PWDs then infrastructure may have to be adapted to their needs. The non accessibility of transport may result in absenteeism. Some of the employers do not want to take the responsibility. Since the cognitive development of PWDs is not high, they feel that they won't be able to fit in the job. Thus this leads to fewer opportunities for PWDs. Furthermore it leads to unemployment and hinders their overall development. If there is unemployment then payment of medical bills becomes a problem. Thus indirectly the attitudinal problems lead to problems in health as well along with further hindrance in cognitive and social development.

So community inclusion is very important not only for the concerned individual with disabilities, but also for the community. Only when they are part of the community will it lead to their holistic development. This will make them feel accepted in the community, as they become contributing members of the society.

1.8 Unit End Exercises :

1. What is the meaning of development?
2. What is the meaning of growth?
3. What is the difference between growth and development?
4. Explain the stages of development.
5. Discuss the principles of development
6. What is the meaning of adulthood?
7. What are developmental tasks?
8. What are the developmental tasks during childhood?
9. What are the developmental tasks during adulthood?
10. What are the factors influencing development?
11. What are the developmental changes during adulthood in the physical domain?
12. What are the developmental changes during adulthood in the social domain?

13. What are the developmental changes during adulthood in the cognitive domain?
14. What are the developmental changes during adulthood in the language domain?
15. What are the developmental changes during adulthood in the emotional domain?
16. What are the developmental changes during adulthood in the moral domain?
17. What are the developmental problems during adulthood in the physical domain?
18. What are the developmental problems during adulthood in the social domain?
19. What are the developmental problems during adulthood in the cognitive domain?
20. What are the developmental problems during adulthood in the language domain?
21. What are the developmental problems during adulthood in the emotional domain?
22. What are the developmental problems during adulthood in the moral domain?
23. Define community inclusion.
24. Discuss about the domains of community inclusion.
25. Discuss about the principles of community inclusion.
26. Discuss about the implications on community inclusion in the light of the problems in human development.

1.8 Let us Sum Up

Human development is an interdisciplinary approach which looks at the development of human beings from all domains across the life span. Human development is divided into stages starting from birth to old age. At each stage there are certain developmental tasks to be achieved. Developmental tasks are the expected level of performance. If humans achieve their age appropriate developmental tasks then individuals smoothly go from one to the other stage, or they get stuck. So when it comes to persons with ID their physical, emotional, cognitive, language, moral, social are not age appropriate. These problems in the domains of development may lead to problems in community inclusion. But if they are given good support by the community, then it enables them to become productive members of the community. This leads to feelings of satisfaction and happiness in the people with disability.

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Unit - 2 □ Family and Adult with Intellectual Disability

Structure

2.1 Introduction :

Savio De Gama born on October 17th 1981 a 38 year old gentleman settled in Goa in the family hospitality business is a very talented musician who has won several accolades as guitarist. He has won medals in Special Olympics as well in Shotput. He also has Downs Syndrome.

His mother Sybil has stood as a pillar by person, supporting every endeavour of his, understanding his talents and accordingly training him under different professionals in Dilkhush Special School in Mumbai.. The father Roy supported with all the finances required .His elder sister Liane undertook special training at SNDT University and later went abroad as a part of Residential volunteer program to return back and start Atmaviswas for young adults in Mumbai with 12 students. This institute shifted base in Goa fourteen years ago and has become the training centre and day boarding for people with Disabilities who are building their skills in gardening, home food productions, candle making. Recently a village cafe has been set up where services are rendered by PWID. Savio continues to charm everybody with his additional chromosome and cherishes opening his own musical band Savio Sunshine .

A Historical Perspective:these opportunities.

The birth of a child with a disability was seen as a tragedy for the family, without hope of resolution or adaptation, a view that stigmatized the child, the mother and the family. The permanent, day-by-day dependence of the child, the interminable frustrations resulting from the child's relative changelessness, the unaesthetic quality of mental defectiveness, the deep symbolism buried in the process of giving birth to a defective child, all these join together to produce the parent's chronic sorrow' (Olshansky, 1962).

In the 1970s, family research moved away from models of individual pathology with the development of family systems theory .The family was seen as an interacting set of relationships, both between the members of the family and with the wider society.

Research developed into areas such as stress, coping mechanisms, support networks, effects on siblings, other family members and the families of adults with a disability. Research has now moved away from looking at family dysfunction and increasingly recognizes the successful, resourceful ways in which families adapt and provide care. An almost monolithic conception of the inevitability of distress, crisis, and pathology has been replaced by a recognition of extreme variability of family response and an understanding of the importance of identifying the antecedent causes of that variability' (Glidden, 1993).

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2.2 Objectives:

To understand and apply in real life situations:

1. meaning of family, evolution of definition and concept of family.
2. different ways to classify family
3. affect of classification on attitude towardsPWID
4. family types and their approaches towards their PWID member

5. difference between the growth pattern and lifestyle of adult member and adult with ID in the family
6. concept of care and caregiver
7. impact of PWID on caregiver
8. relationship between caregiver, PWID and professional.
9. Need for family adjustment
10. Coping skills –from stress model to positive perception-strategies for coping to
11. human rights model.
12. Family support-need and kind
13. Government laws on Disabilities
14. Government schemes and benefits**.**

2.3 Meaning, Definition and concept of family

2.3.1 Family is the foundation stone of social life introducing the individual as a social animal. Family meaning can be interpreted in many ways. At the basic level Family is viewed as an instrument that helps in propagation of human species and perpetuation of human race. It is through the family that every family name is carried on from one generation to another. Functionally Family is responsible for the production and upbringing of children. Family provides an individual with a home, where the family is the basis of division of labour, where all members have their duties and obligations towards each other. Family also has a recreational function where family members out on holidays or for movies, plays, dinners, or parties, etc., perform the same function.

If one probes deeper into the meaning of family, one would understand that Family provides an individual with a social and cultural identity. Family being an important agent of socialization teaches all the basic rules and norms of social life to a child and the primary socialization of any individual takes place within the family. All the aspects of culture are learnt within the family as Culture is transmitted from one generation to another through family.

At the highest level Family is a great source of strength, emotional and psychological, for its members. All the members are aware that they can depend upon their family in the times of need.

2.3.2 Definition:

Family is a multidimensional unit performing various functions in a society.. Every society or social structure is characterized by the basic unit i.e. family. These are the building blocks of social structure. They have a common motto, culture, rules and values. ‘The family is the basic and important unit of society because of the role it plays in generation of human capital resources and the power that is vested in it to influence individual, households, and community behavior (Sriram, 1993).”The key function of family is to preserve, protect and promote its generation year after year. Elder members of the family are responsible for rearing their offsprings. They make sure the fulfillment of basic needs of family viz. food, shelter and clothes. Definitions of the word family generally fall into three categories: family structure, task orientation, and transactional process (Wamboldt & Reiss, (1989); Noller & Fitzpatrick, (1993)

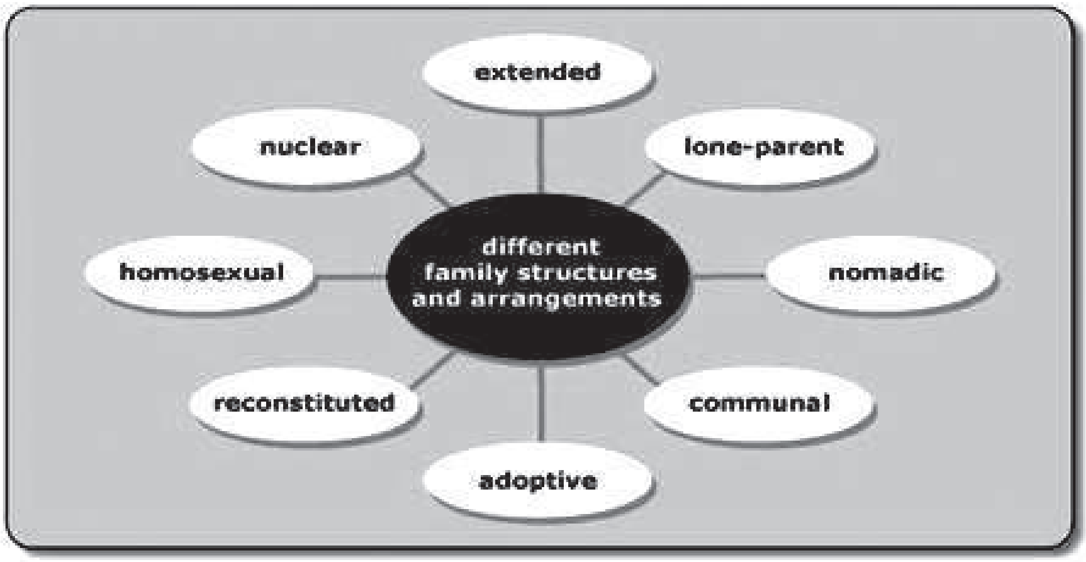
Family structure definitions are based on number of family members, their blood relations and the hierarchy followed. According to Wambldt & Reiss, (1989) – ¯Family structure definitions surround the family of procreation (partners and children), relatives by blood, or individuals that have established biological or legal legitimacy . Census, 2000) describes family as an example of households who are related to the householder by birth, marriage, or adoption. These definitions help to divide the families on the basis of size like small, nuclear, large, combined etc.

Task orientation definitions focus on whether certain tasks for family life are performed (Wambldt & Reiss, 1989). Families are described as a group working towards mutual need fulfillment. Lerner & Spanier, (1978) describe a family as working towards the socialization and nurturance of children. Thus the task oriented definition gives the impression of role and motto of family and its members. On this basis a family can be categorized under backgrounds like professional, educational, religious, economy based etc.According to Merriam-Webster Online Dictionary- ¯the basic unit in society traditionally consisting of parent(s) rearing their children where children refer to the young dependent member(s) and parent(s) refer to the adults taking care of the children. Even the traditional families whenever mentioned give us the impression of a bread winning father and a home making mother with two or more children. These meanings are created through a social process that reflects expectations about what an adult should do (e.g., marry and have children), that is, roles and behaviors in which adults should engage, and when these should take place
(Wapner & Craig-Bray, 1992).

Transactional process definitions view the family as a group of intimates who generate a group identity (Wambldt & Reiss, 1989). Families therefore have strong ties of loyalty and experience a history and a future together.Family may be broadly defined 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 (Desai, 1994). Family being a group of persons united by ties of marriage, blood or adoption constituting a single household interacting and inter-communicating with each other in their respective social roles of husband and wife, father and mother, son and daughter, brother and sister, begin to thus create a common culture. ‘Elements [people] in a family system are necessarily interdependent, contributing to the formation of patterns and organized in their behavior by their participation in those patterns’’ (Minuchin, 1988, p. 9)

2.3.3 Concept of Family

Pictorial representation of definition of family by structure:



The following may be considered the most commonly observed family variations in India: single parent families, female headed households, dual earner/career families, childless families, and adoptive families.(Sonawat.R,2001)

The Indian family is by and large patriarchal in structure (Kapadia, 1982). This patriarchal set up is changing slowly towards equalitarian interaction among the educated, urban middle classes, and also among some rural set ups (Mullatti, 1995)..

One of the few surviving bastions of women power are the Khasis of Meghalaya with a matrilineal system of family. The power, wealth, and rights of inheritance are vested in the women. Basaiawmoit (1987), however, found that with passage of time the matrilineal system has undergone dramatic change due to education, technology and politics. The younger generation is raising the issue to move towards some form of patrilineal system though the elders feel the existing matrilineal form should continue (Saiborne, 1995).

A significant aspect noted is the new economic order merging with the traditional pride in jointly owned property. Today's big business houses like the Tata and Birla are all family ventures. So instead of the breaking of joint families due to urbanization and industrialization, more joint families are found in urban business communities (Desai, 1980). Married brothers may have separate houses, but run a common business and meet regularly at a variety of family rituals. Hence, a large number of families in India are described as being functionally joint, with separate residence.In rural India, though agriculture is the main occupation, there are not many large land holdings. This, and modern education and other related factors, make it difficult to maintain joint families (Mullatti, 1995).In the Indian context, most family variations that are prevalent today are a result of such personal or socio-economic circumstance. Experimental or chosen life styles like living without marrying and being childless voluntarily are restricted to an extremely small group of people. The unwritten rule was, and still is, that all marriages must result in children and preferably male children (Gulati, 1995).

Thoughts for Discussion:

With the help of the following diagram explain your family structure tracing upto three generations.Deduce definitions of your family based on the three types of definition.

joint or extended family. Urbanization leads to households becoming less extended and more nuclear and that this trend is increasingly being observed in developing countries (Bongaarts, 2001).

But to survive , the family based on its type will have its own goals and strive to achieve them. A joint family structure in earlier years will have the goals of adjustment of PWID within the family system whereas the nuclear family as a byproduct of urbanisation will have the goals of fitting into the external world.

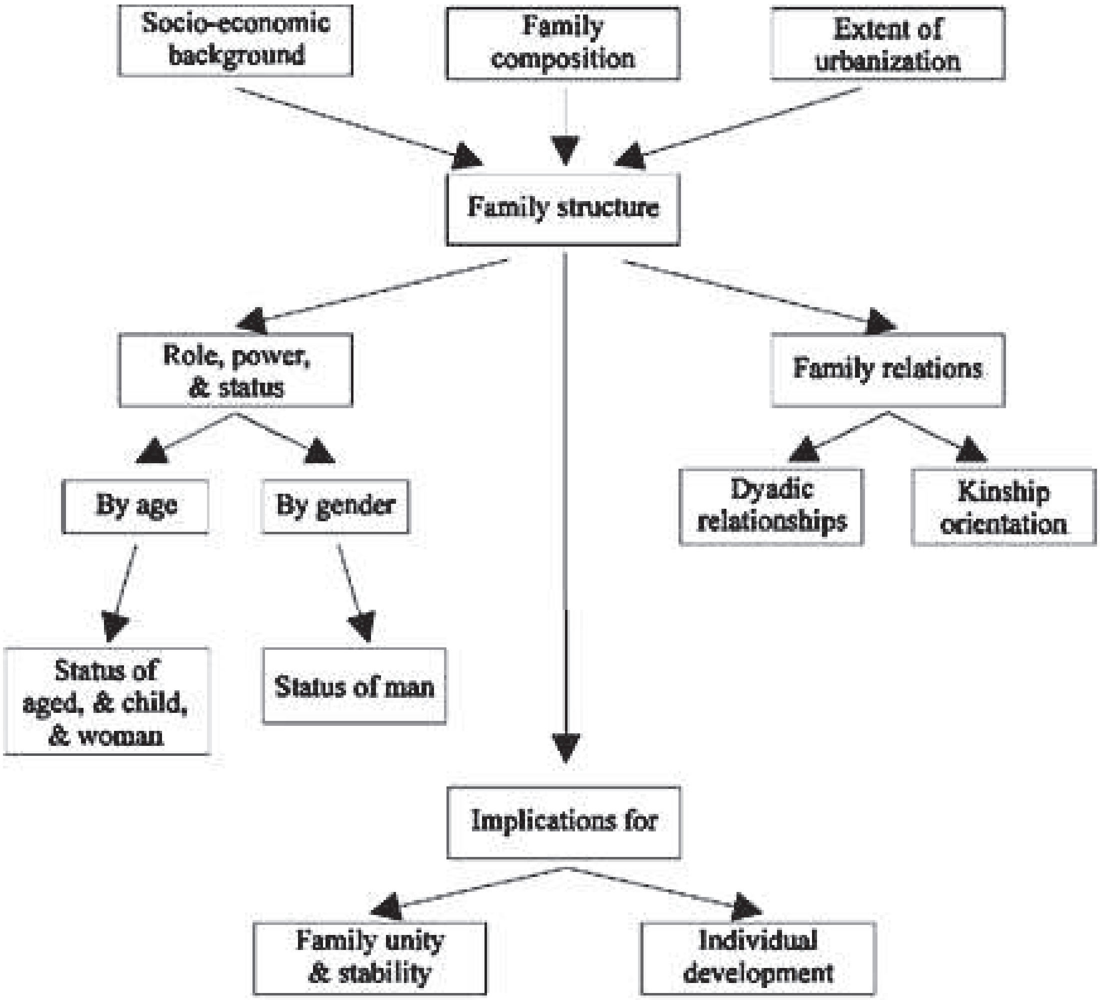


Figure 1. Diagram of the conceptual framework of family structure. From *Conceptual frameworks for understanding family. Enhancing the role of the family as an agency for social and economic development* (Unit for Family Studies Report, pp. 16-41), by Desai, 1994, Bombay, India: TISS. Copyright 1994 by Tata Institute of Social Sciences, Deonar, Bombay – 400 088, India. Adapted with permission.

If family can be visualised as an organized, relational transactional group, usually occupying a common living space over an extended time period, and possessing a confluence of interpersonal images that evolve through the exchange of meaning over time(Pearson, (1993))it is thus evident that family perceptions would largely vary with each different type of family and accordingly influence attitude towards PWID.As researches have shifted from the medical model to the social model, it is important to understand how family itself perceives the member with ID within its system

A classification that probes deeper into family interaction patterns other than mere number of family members is thus required to understand the varying attitude towards PwID within the family.This type of classification is based on communication between family members.

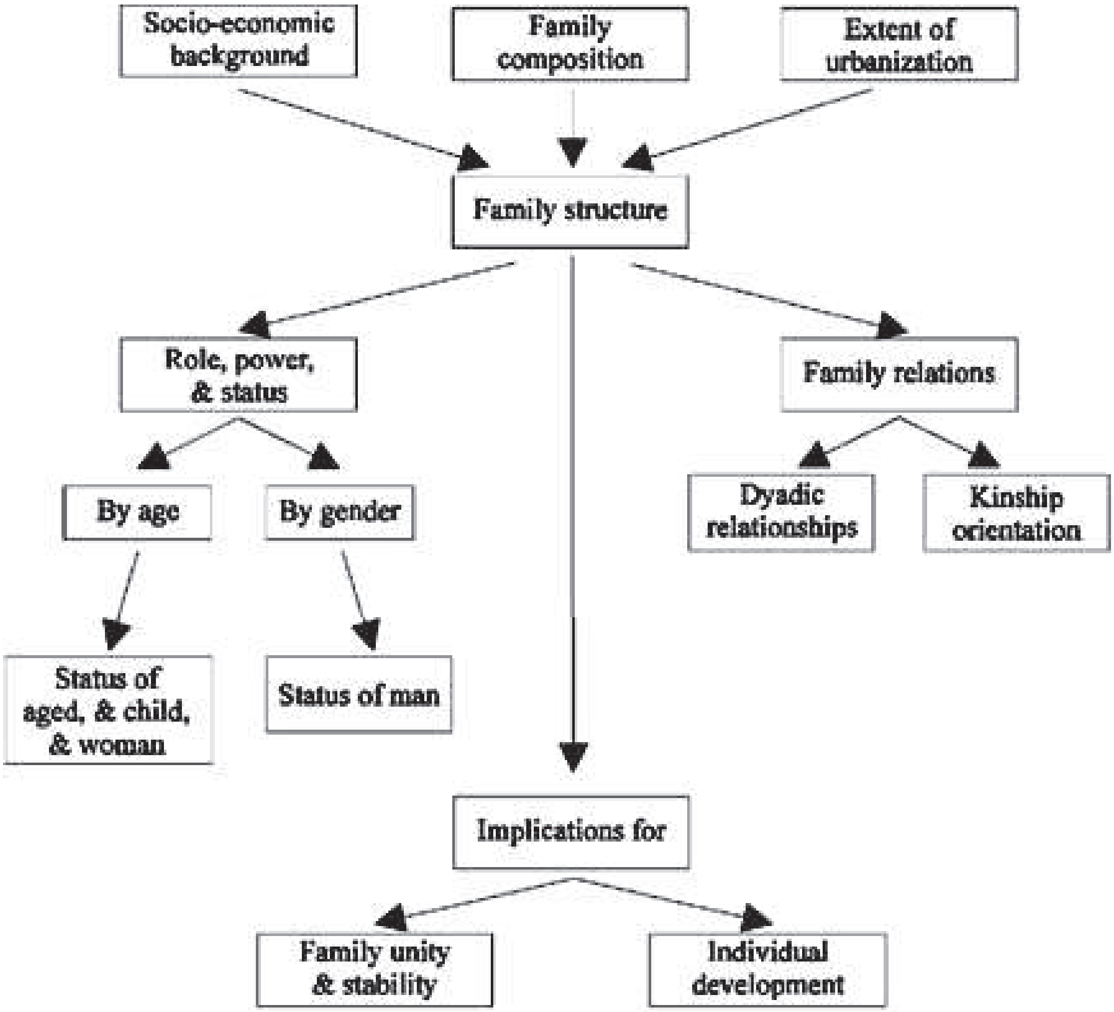
Communication can be determined by two factors, a.conversation orientation that is to what degree a family encourages members to interact and communicate (converse) about various topics; and b.Conformity orientation which is determined by the degree to which a family communication climate encourages conformity and agreement regarding beliefs, attitudes, values, and behaviors.(Ascan F. Koerner and Mary Anne Fitzpatrick, (2002):

Members within a family with a high conversation orientation communicate with each other freely and frequently about activities, thoughts, and feelings. This unrestricted communication style leads to all members, including children, participating in family decisions. Parents in high-conversation-orientation families believe that communicating with their children openly and frequently leads to a more rewarding family life and helps to educate and socialize children, preparing them for interactions outside the family.

Members of a family with a low conversation orientation do not interact with each other as often, and topics of conversation are more restricted, as some thoughts are considered private. For example, not everyone's input may be sought for decisions that affect everyone in the family, and open and frequent communication is not deemed important for family functioning or for a child's socialization.

. A family with a high conformity orientation fosters a climate of uniformity, and parents decide guidelines for what to conform to. Children are expected to be obedient, and conflict is often avoided to protect family harmony. This more traditional family model stresses interdependence among family members, which means space, money, and time are shared among immediate family, and family relationships take precedent over those outside the family.

A family with a low conformity orientation encourages diversity of beliefs, attitudes, values, and behaviors and assertion of individuality. Relationships outside the



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family are seen as important parts of growth and socialization, as they teach lessons about and build confidence for independence. Members of these families also value personal time and space.

2.4 Types of Family and Atitude towards PWID

2.4.1 Types of families:

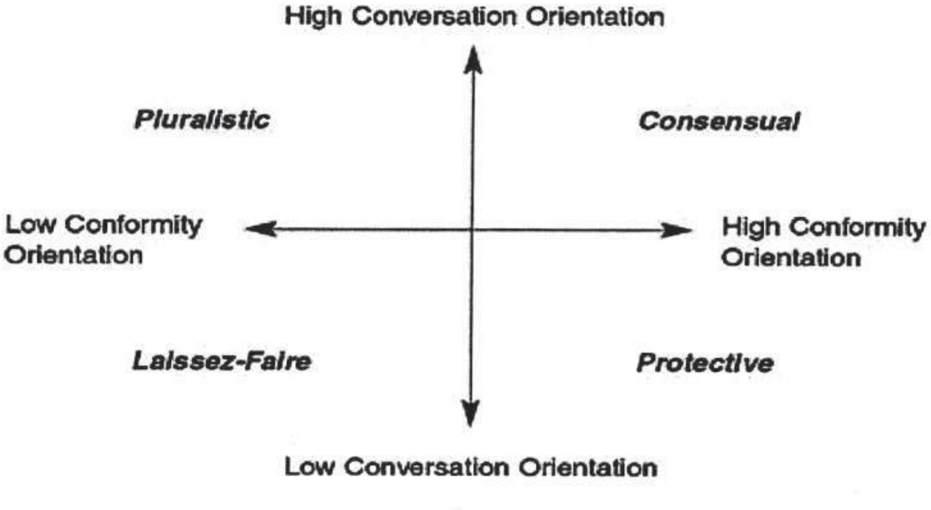
The types of families emerging from above discussions are as follows:

1.Pluralistic Families: The pluralistic family is high on conversation orientation but low on conformity orientation. Parents from these families allow their children to express opinions freely; younger members can make their own decisions without worry as to whether or not it could affect relations with their parents or other older members. Therefore, pluralistic parents and children engage in positive and successful conflict (Fitzpatrick et al., 1996). Children‘s decisions appear equal to parents‘ or other adults‘ (Koerner & Fitzpatrick, 2002 a, b; McLeod & Chaffee, 1972). There is open discussions between parents and siblings on the obstacles faced by the PwID member and members mutually decide post discussion on a smooth transition.

2.Protective Families: The protective family is low on conversation orientation but high on conformity orientation. Parents from these families believe in male domination in society. Fathers usually engage in masculine traits (assertion, competence, and rationality). Children should obey their parents and remain submissive. Because of the high authority of the parents, children from this type of family tend to get influenced and persuaded by others outside the family easily (Fitzpatrick, 2004).According to Fitzpatrick et al. (1996), ¯these parents expect boys to be less selfrestrained and expect girls to be both self-restrained and socially adept. It is difficult for the male head of the family and other significant male members to accept a PwID as the person grows and is unable to perform functions expected of him. The female member with ID often leads a. Protected life within the four walls of the family.

3.Consensual Families: The consensual family is high on both conversation orientation and conformity orientation. Parents believe in traditional gender role ideologies (Fitzpatrick, 1988, cited in Fitzpatrick et al., 1996). To illustrate, men emerge in leadership roles in society, while women ¯define themselves in relation to the feminine traits of expression, warmth, and nurturance. (Fitzpatrick et al., 1996) Overall, parents expect obedience from their children; however they also listen to their children‘s opinions. Also, parents try to explain why children should follow the family‘s rules and believe in the parents‘ decisions (Koerner & Fitzpatrick, 2002 a).Most boys tend to exhibit low level of self-restrain. Therefore, these boys may develop uncooperative behaviors (Fitzpatrick et al., 1996). Male members with ID may develop boisterous attitude and express difficult behavior in the society in their endeavor to imitate other male members of their family. The female members with ID stay in a more relaxed environment and may interact with members outside family within limits.

4.Laissez-Faire Families: The laissez-faire family is low on both conversation orientation and conformity orientation. Members in these families have low communication because both parents have little in common. (Fitzpatrick et al., 1996) The parents neither expect to hear their childrens‘ opinions nor to guide their actions because the parents believe that all family members can make their own decisions. Due to the lack of interactions in the family, the children tend to get influenced by social groups outside the family (Koerner & Fitzpatrick, 2002 a; McLeod & Chaffee, 1972).This kind of family may not realize the use of structured environment, varied levels of support required by PWIDand would require external community based support for the member to realize its true potential.



Above is the diagrammatic representation of family types based on communication

2.4.2 Attitude towards PWID.

Let us study the following case studies:

1.Savio De Gama born on October 17th 1981, is a 38 year old gentleman settled in Goa, is in the family hospitality business, is a very talented musician who has won several accolades as guitarist.He has won medals in Special Olympics as well in Shotput.He also has Downs Syndrome.

His mother Sybil has stood as a pillar by person, supporting every endeavor of his, understanding his talents and accordingly training him under different professionals in Dilkhush Special School in Mumbai.She also started a school with similar adults as her son started growing up.The father Roy supported with all the finances required .His elder sister Liane undertook special training at SNDT University and later went abroad as a part of Residential volunteer program to return back and start Atmaviswas for young adults in Mumbai with 12 students.This shifted base in Goa fourteen years ago and has grown into an institute housing people with Disabilities who are building their skills in gardening, home food productions, candle making including setting up a village cafe where services are rendered by PWID.Savio continues to charm everybody with his additional chromosome and cherishes opening his own musical band Savio Sunshine

2.Mansi Puj, born in a conservative Gujrati family is the eldest of three sisters and comes from a highly educated business family .She is smiling ,eager to obey instructions of educators and is very determined girl who wants to be a high achiever probably like her younger sisters who are rank holders.She has mild intellectual Disability.who went to a regular school , repeated classes and discontinued school to appear for NIOS which she couldnot complete and finally cleared the practicum of a Montessori course .Mother refused to accept the diagnosis of mild ID and daughter was trained in all household chores under the guidance of mother and grandmother .Presently she is married with a two year old son .The husband has been financially established by the father.

3.Siddharth is twenty seven year old, parents hold high corporate jobs. He was going to a special school till he was eighteen.He has Moderate Intellectual Disability and is presently at home with his caregiver who supports all his activities of daily living.

Thus the attitude towards PWID cannot be generalised. If the family is treated like a system, having subsystems like parents, siblings and suprasyatems like friends, relatives, acquaintances, ,nation and culture;how they will respond to that system will actually depend on the family type.Therefore how the child with ID will grow and what impact it will have on the entire family system will largely depend on the type of family he or she comes from.

Thoughts for Discussion:

Create a questionairre to identify four types of family as discussed earlier.Analyse the family types of atleast four adults with Intellectual Disabilities using that questionairre……………………..

2.5 Impact of Adult with iD on the Family

2.5.1 When a child with Intellectal Disability enters the family, the family experiences the joy of welcoming a new member in the family.But the family pattern drastically undergoes a change as now after finding about the childs impairment parents and othe significant members start adjusting to a new way of life, find out about early intervention and support, followed by information about playgroups and nurseries and discovering educational needs along with the need to take a break

As an adolescent, life of people with Intellectual Disabilities is again different from the same age peers.Work by Baker(1991) indicates the reason behind the delay where he specifies a teenagers separation and rebellion is the main reason behind the development.Thomson, Ward and Wilson(1995) discuss similar themes where the achievement of adulthood is associated with getting employment and living away from parents.

Family is a dynamic process, as each member, ages, the roles of respective family member changes.Younger generations now take up more responsibilities in terms of functional as well as financial areas.The onus of parents being the dominant care giver shifts to the children now.Also many children move out of homes to establish themselves.Parents are relatively free with the day to day responsibilities but have an emotional void which they try and compensate with various other engaging activities.

The adult with Intellectual Disability needs some kind of care all the time depending on the severity as well as the kind of training imparted to him or her since childhood and adolescent years.Some may continue needing help in skills of bathing dressing and other personal areas.

Some may be independent in areas mentioned above but will need care in the areas of communication, shows adjustment difficulty has concerns of employability.

Therefore impact of having an adult with ID in the family will not show any homogeneous pattern but great deal of variability and will be an outcome of the combined factors of the type of family and the type of support needs.

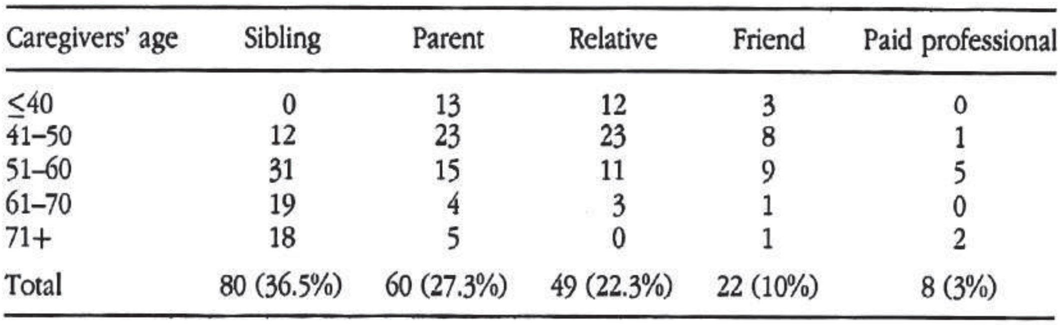
Peshawaria in an unpublished presentation in 2000 suggests that there are several domains of parenting a child with a disability. These include physical care, health, employment or career, support in the community, financial considerations, social embarrassment, relationships of the child and the family, and the effects of the disability on siblings

But the care families with an Adult with ID engage in is distinct from other familial caregiving relationships, such as adult children caring for aging parents. Family members can and do engage in instrumental or physical care activities, such as providing food, or helping their relative with Activities of Daily Living (e.g., getting dressed), there comes an additional requisite investment of emotional and organizational labor which is referred to as “invisible care” (Grant, 2007).This is perhaps the most prominent area of support provided by family members of aging adults with ID who live with relatives (e.g., parents) or in other community care facilities (e.g., group homes). Broadening the definition of what constitutes care highlights the management of such “hidden” care activities and the significant personal investment of the family members (Grant, 2007).As most of the times the adult with ID is unable to develop social relationships with the members outside his her family but feels the same emotional needs as any other person.

2.5.2 Research suggests that caring for an individual with ID is predicated on a complex mix of contextual and personal variables. If the parent has the belief system that becoming the parent of a child who has some disability in itself is a time of great stress and change the stress is very high.On the other hand if the birth of a child with disability and his or her gradual growing up has influenced the relationships of all the family members in a positive manner inculcating a reassessment of the family functioning , a care map is easily drawn, the member is repositioned within the system at every stage of transition.

A study found that the relative with IDs' care needs, coupled with the availability of informal supports, were associated with quality of life of family members. QOL as defined by the World Health Organization (WHO) is an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns.

Care that is given to a normal child itself is taxing for the parents many a times and to provide a higher level of life long care to a child suffering from long-term functional limitations may be strenuous for the parents and thereby may be affecting their QOL.



Caregivers' age	Sibling	Parent	Relative	Friend	Paid professional
≤40	0	13	12	3	0
41–50	12	23	23	8	1
51–60	31	15	11	9	5
61–70	19	4	3	1	0
71+	18	5	0	1	2
Total	80 (36.5%)	60 (27.3%)	49 (22.3%)	22 (10%)	8 (3%)

(Amy S Hewitt and Elizabeth B. Lightfoot and Matthew Bogenschutz and Katey McCormick and Lori Sedlezky and Robert F. Doljanac ,2010,in Parental Caregivers' Desires for Lifetime Assistance Planning for Future Supports for Their Children with Intellectual and Developmental Disabilities i)

Studies have also moved away from a unidirectional model of caregiving to highlight the dynamic and subtle interplay of caring relations between family members and adults with ID. Many parents, in particular, come to rely on their adult-child for support. Parents speak of reciprocal exchange as they depend on their adult-child with ID for practical tasks and emotional support (Bowey & McGlaughlin, 2007; Grant, 2007). There exist interpersonal rewards for these parents, such as a sense of gratification of seeing their adult-child happy and feeling a close emotional bond. Further, older parents, compared to new or younger family members, may be more certain of their expertise and experience and ability to handle situations, leading to satisfaction at an intrapersonal level (Grant, 2007).

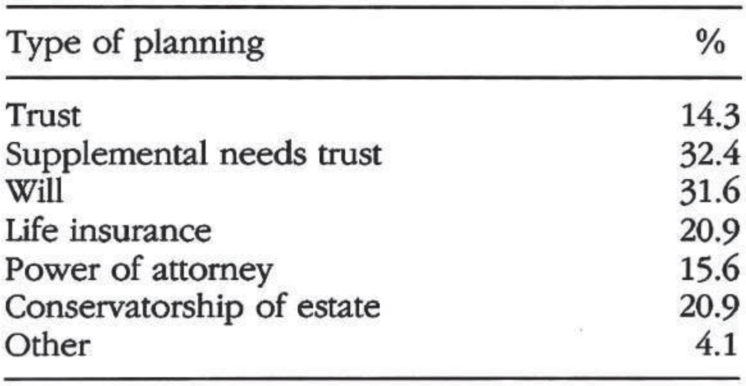
… Three key aspects of the caring relations that exist in families that include an adult with ID as family members age together in the community. These themes are illustrated below: (a) Recognizing the Changes of Aging:as parents it is necessary to make arrangements physically, spiritually and emotionally for the child. Further, parental appraisals of aging and stress associated with caring for an adult-child with ID was found to mediate the relationship between health and depression (Minnes, Woodford, & Passey, 2007).

(b) Strengthening Connections:It is important to establish network with community , relative and community homes who can extend a support chain as per the needs of the family and PWID. Parents have emphasized the importance of informal activities and supports, such as maintaining social connections, building networks, having a stable environment to live in, and being able to engage in the day-to-day activities that the individual enjoys, as key aspects of supporting aging adults with ID (Bowey & McGlaughlin, 2007; Hole et al., 2013; Weeks et al., 2009).

(c) Planning for the Future:This is one area that affects the parental concern as to who is going to look after the PWID once the parents are no longer there.It thus becomes imperative to care for the PWID and plan in advance.

In a study by Amy S Hewitt and Elizabeth B. Lightfoot and Matthew Bogenschutz and Katey McCormick and Lori Sedlezky and Robert F. Doljanac ,2010,titled as Parental Caregivers' Desires for Lifetime Assistance Planning for Future Supports for Their Children with Intellectual and Developmental Disabilities it was found that Future life planning is a growing concern among families with children with disabilities. This article presents a needs assessment evaluating feasibility of a new model for future life planning for family caregivers, Lifetime Assistance, which will provide ongoing planning and monitoring for individuals with intellectual and developmental disabilities. Using surveys informed by a series of focus groups, data were gathered from older and younger parents in one midwestern state regarding the potential program. Study results indicate that respondents did not feel the current system of support was adequate for planning for their child's future, nor sufficient for monitoring the quality of life for their children in the future. Although almost all families had identified a person to support their family members when they were no longer able to do so, parental caregivers overwhelmingly identified the need for the Lifetime Assistance program and many were willing to pay for this service themselves.

The table below identifies the extent of future planning that needed to be done



Type of planning	%
Trust	14.3
Supplemental needs trust	32.4
Will	31.6
Life insurance	20.9
Power of attorney	15.6
Conservatorship of estate	20.9
Other	4.1

Caregiving parents need support for future planning for their son/daughter to prepare them for transitions in life and for what will happen when they are too old to remain the primary caregiver (Minnes & Woodford, 2004; Kenny & McGilloway, 2007).

This worry about future transitions is not confined to parents. One of the review studies also found that siblings of children with complex behaviours have concerns about when their brother or sister moves from school to adult services, and what this will mean for them (Rawson, 2009).

In the same study the siblings indicated that to support them in arranging or providing care for their sibling in the future they felt a need for: training in legal/ fiscal issues, written information to guide them, having a named sibling support person within the organisation and a website for networking with other siblings (Rawson, 2009).

2.5.3 It is understood that the impact of a child , growing into an adolescent and finally to an adult is tremendous for any family.Studies reveal that this impact is multifold in a family having PWID.

Brehaut and colleagues(Brehaut, J.C., Kohen, D.E., Garner, R.E. et al ,2009) demonstrated that there are self-reported physical and mental differences between parents of children with disabilities and those of able-bodied children. They also found a relationship between their socioeconomic status and the increase in these health problems. They found higher levels of distress and chronicity of distress, increased depression, increased peptic ulcers, increased migraine headaches, increased back pain, increased hypertension and heart disease, and an increased cancer rate. The authors appreciated the limitations of their study was that these were self-reported symptoms, but they were drawn from a sample of over 9000 children with disabilities in Canada.

Hayes and Watson, in a meta-analysis found that parents of children who had the diagnosis of autism spectrum disorder had a much higher stress level, even more than those of children with severe physical disabilities. (Hayes, S.A. and Watson, S.L,2013) Although many patients with childhood disabilities also have a component of intellectual disability in addition to their physical limitations, Kishore(Kishore, M.T ,2011) found few differences in negative and positive coping skills in children who had physical disabilities and intellectual disabilities compared with those who just have intellectual disabilities.

Thus for the family with having a member with Intellectual Disabilities the words impact and care are intricately related.This family may be needing professional help right from the birth to the adulthood of the child.Hence the care model delivery should not be clinical.While respecting the right of being a person with disability and building a positive image of the person is essential, equally important is to see that the family doe not undergo undue pressure but accepts the child as he or she is, gradually imbibing her or his differences.Therefore principle of family centred care must be followed.

.The principles of family-centered care are:

1. Recognizing the family as a constant in the child’s life;
2. Facilitating parent–professional collaborations at all levels of health care;
3. Honoring the racial, ethnic, cultural, and socioeconomic diversity of families;
4. Recognizing family strengths and individuality and respecting different methods of coping;

5. Sharing complete and unbiased information with families on a continuous basis;
6. Encouraging and facilitating family-to-family support and networking;
7. Responding to child and family developmental needs as part of health care practices;
8. Adopting policies and practices that provide families with emotional and financial support; and
9. Designing health care that is flexible, culturally competent, and responsive to family needs.(MacKean, G.L., Thurston, W.E., and Scott, C.M. ,2005)

There are a multitude of new problems that are unique to the young adult with a disability. Most adults desire to have a job upon completion of school, and are cognizant of the many opportunities for independence, financial and otherwise, that follow. This becomes a significant challenge because factors like lack of job training, experience, employment support, and discrimination can severely limit chances for success. The unemployment rate among adults with cerebral palsy, for example, is near 75%. It is also to be kept in mind that as an adult, the person has many needs which range from bodily to emotional which the person is unable to fulfil owing to the disability.THIS MAY GIVE RISE TO DEPRESSION.Almost 75% of adults with Cerebral Palsy suffer from mental health issues..This again has a negative impact on the parents.In the Indian scenario, the concept of group homes, dating houses are not popular yet.So these adults have to spend time in their parent homes.

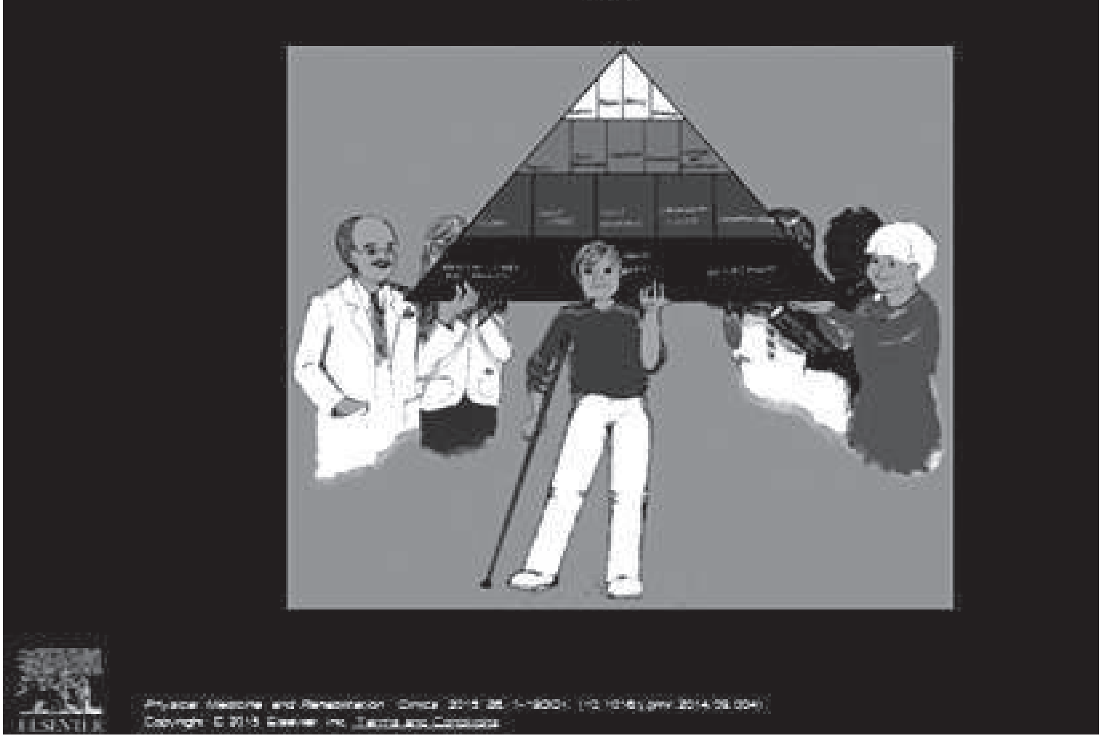
The kinds of living options for adults varies widely in terms of level of support (including full-time direct care in a residential setting or group home, supported living in one’s own apartment or home, assisted living, or independent living with limited services) as well as geographically, based on differing state, city, and county funding sources and services. Making a move from one’s family home to any one of a number of other options can be the most difficult and traumatic event in the life of the family with a special needs child. Often, families end up choosing "not to choose" for a variety of reasons, and the young adult remains at home until a crisis occurs (often because the parent is no longer able to care for them).

As the young adult is increasingly faced with choices and decisions regarding identity, independence, self-care and self-advocacy, this period of transition is likely to be a stressful time for parents, as they, like all parents, but with other complicating factors, are grappling on their own with how to "let go." Often because of the difficulty balancing issues regarding caregiving needs and promoting independence, as well as generally more limited living and working options in addition to financial concerns, families often find themselves continuing to live under on1e roof with the familiar patterns of parent–child interactions that have become less and less than ideal, healthy, and sustainable for all involved.

Parents can feel chronically exhausted, financially, physically and emotionally, from the years of direct caregiving and management of needs on multiple fronts with little time for self-care and adequate rest. They are also comparing their life pattern with their peers whose children have grown up , been employed and are married with children of their own.

It is important to consciously have parent support groups who through constant discussion can understand each other better.Look at the positive impact for example they can never be termed as empty nesters.Consider the attachment their son or daughter with disability have with them compared to others and finally the impact can be made positive if they begin self help groups, where these parents with their huge set of experience in handling people with disabilities start activities like sensitizing the regular population,making professionals aware of the humane aspects rather than clinical aspects and fiunally set up small training centres involving community besides continuing home and sheltered employment for the adults. A parent's ability to build new social networks and to have pride in dedicating one's life to their child's well-being is important, and parents can draw inspiration from their children.

Fig. 5



Finally in his “effects of caregiving of adults with disabilities “Dr.Henry G.Chambers M.D narrates his experience.It is pertinent to read this as it combines the professional and the parent.

Reid and colleagues[50] interviewed parents whose disabled children had grown up, and asked them to share lessons learned and tips for new parents of children with disabilities. The title of their article was “If I knew then what I know now.” Although it is not common to have the author of an article cite personal references, I am a pediatric orthopedic surgeon who is the father of a 32-year-old young man who has total body cerebral palsy GMFCS IV, as well as dystonia and bipolar disorder. As a physician and surgeon, I also have a very large cerebral palsy practice and see a significant number of adult patients with disabilities. Our family has lived a unique journey, forever transformed by the life of our son and, therefore, we are intimately familiar with many of the issues discussed in this article. Our son has had over 20 major surgeries, requires 24/7 care, receives supported living services while living in his home near us, with a friend, who also has cerebral palsy.

So, what follows is a bit of what have I learned in my 32 years as a parent and a physician caring for patients with cerebral palsy and other disabilities:

1. Parents are often focused on a cure for their child, including new and unproven treatments like hyperbaric oxygen, stem cells, and so on, but some families cannot wait for studies and evidence of efficacy. Many have been harmed physically and economically by seeking therapies that do not work.
2. Simple insights have led to great changes in care. For example, the gross motor classification system allowed researchers to stratify their subjects to determine all aspects of social, epidemiologic, and treatment methodology. Being able to more completely define and recognize dystonia (as opposed to spasticity) changed the way we understood its contribution and impact on the overall functioning of the more severely involved patients, and this has changed our management, treatment, and outcomes.
3. Parenting a child often means facing a series of losses and ongoing grief, and then moving forward to make adjustments. One has to change expectations about what a "normal" childhood is, having a "typical" family life, marriage, vacation, and so on. Many major milestones most parents and young adults anticipate may come and go unachieved but not unnoticed: Walking, first date, driving, sexual and romantic relationships, advanced education, and so on.
4. There is a huge disparity in health care options, treatment ,and outcomes between children and adults with disabilities.
5. For all childhood disabilities, treatment is important, but prevention is the real hope.
6. The ying to the yang is just as important; life with a son or daughter with a disability can enrich, expand, and educate us on many levels. When a family has a child with a chronic disability, there are many opportunities to make ourselves, our families, and our communities better, like:
7. Learning not to "sweat the small stuff" and distilling the essence of what really matters; prioritizing our values, and the many ways we can be more aware, sensitive, and inclusive to individual differences in our lives.

8. Experiencing exhilarating joy in some of the smallest, sweetest, most unexpected things.
9. Learning to stay open to possibility: Being creative and withholding judgment.
10. Meeting and including in your life a wider variety of different people who can teach you a lot about yourself and the world that you are creating.
11. Learning and relearning the value of compassion, patience, and a good sense of humor.
12. Until recently, you got to go to the head of the line at Disneyworld.

In conclusion, the rehabilitation specialist can and should understand their role in supporting the family as well as providing care for the child. The two are intertwined. My wife developed this "Parent Wish List" which can serve as tool to help providers serve both patients and their families with respect and dignity.

I wish you would

1. Treat our child as a whole person, not as parts; treat our child, not his disability.
2. Look at and talk to our child.
3. Notice and mention our child's abilities and strengths, not just his "deficits."
4. Not judge us, we are doing the best we can.
5. Not judge our child's behavior based solely on how he acts in your office; it usually does not bring out the best in him.
6. Remember that we may have had to drive or ride on a bus for 6 hours for this 15-minute appointment.
7. Watch your language: it is difficult to hear "impairment, deficit, abnormal, and defective" over and over again.
8. Ensure that your facility and office is prepared to handle our child's physical needs.
9. Imagine what life is like in our home for just 1 day.
10. Respect us as partners working together with a realistic goal of health and happiness for our child and our family.

11. It is imperative that all health professionals work together to not only help the child and young adult, but also understand the pressures and stresses that the family incurs

Thoughts for Discussion:

Based on the four case studies built, please enlist the factors that have influenced these families, the kind of support networks that they have and what are their future pland with regards to PWID.

Analyse the impact that the Adult with ID has had on the family in detail.

2.6 Family Adjustment and Coping skills

2.6.1 Family Adjustment –why the need

1.Behaviours that challenge in people with ID remains an issue to be addressed by services with respect to the individual, their family and service commissioners and providers (Bamford, DHSS, 2005).

Other studies found much higher rates of behaviours that challenge, for example in children with ID it has been reported that as many as 30-50% have behaviour problems or co-morbid mental health problems (Emerson, 2003; Kaptein, et al 2008).

In Northern Ireland based studies rates of behaviours that challenge in people with ID who accessed the hospitals that still exist here found as many as 70% of those admitted over an 18-month period had behavioural problems or mental health issues (McConkey et al, 2004).

2.The WHO (2000) indicated that older people with ID and their ageing family carers were two joint vulnerable groups that were at particular risk as housing was often inadequate, health provision neglected, there was a lack of co-ordinated supports and such individuals were not productive members of their societies.

McConkey (2006a) stressed that the demands for statutory support services for older people with ID and their ageing family carers will rise, particularly as these ‘double generation families’ are living longer. As the general population are ageing, with advances in medicine, nursing and technologies people with ID are also living longer, with many people living into their 70’ and 80’s now (WHO, 2000) McConkey et al. (2004) stated that ‘it may be more informative and meaningful to identify how this group are affected by ageing than to dwell unnecessarily on how old age is defined.'

There is a recognised co-morbidity between ID and mental health problems, and behaviours that challenge may be an expression of mental health problems in this population (Deb et al, 2001a; Ross and Oliver, 2002; Bouras, 2004; Myrbakk & von Tetzchner, 2008).

Many researchers from India have reported that people often find relief in religious propitiation and surrender to the will of God when faced with intractable disease and disability.[Dalal AK.. 2000)Parents' reactions may be affected due to economic status, personality traits, emotional maturity or immaturity, and marital stability or status. Due to poverty in the family; a child with a disability is regarded as a burden, an evil spirit, and an object of charity without rights, rather than as an unfortunate child.[Pal DK, Chaudhury G.. 1998;) Little support from informal family resources underscores the need for developing formal resources for supporting the parents.Parents of girl child and from low socio economic group repport more stress.

. Stress and Disability thus gets interwined.

The concept of 'stress' as the tension between an event or situation and the perceived ability to cope with or adapt to it has been developed to explore the effect on family functioning of a person with a disability.

This model of family stress developed from a simple stimulus-response model, in which the amount of stress related directly to the antecedent event. An early adaptation was the 'life events' model, in which the stress is seen as a result of a series of major life events, such as divorce or the birth of a child with a disability. The focus was on the event rather than the response and took little account of other factors that may affect the stress felt by the family.

(One model of stress that has been widely applied to families is the 'double ABCX' model (Figure 2). This provides a theoretical basis for examining the mediating variables contributing to family stress.Behavioral and developmental disability were associated with higher parenting stress than medical disability.[Gupta VB. 2007;)

Research indicates that a family has to respond to a complex array of protective and stress variables to fulfil its care-giving functions alongside its other family functions.

FIGURE 2: Double ABCX modelAa: Build-up of stressor events=birth of the child with ID,awareness given by professionals, comparison with other same age children (Bb: Resources build up to deal with situation=supports for growth of the child (Cc: Family perceptions of this and previous stressor events=family type and incidents that have occured to create stress (Xx: Outcome in terms of family adaptation=familyy type and perception of those eventsThe double ABCX model provides a theoretical framework for multivariate analysis, which could be used to understand the complex relation between having a child with handicaps and family adaptation. The model builds on Hill's (1958) ABCX model, but focuses on family events over time rather than single events.

A disabled child's family adjusts on several aspects in life to suit his needs. The physical and mental stress associated with raising such children could be multifold. Caring for such children can be a physically and mentally tasking job, depending on the type of disability resulting in compromised quality of life (QOL) of the carers too.

A substantive amount of evidence indicates that behaviours that challenge in people with ID create difficulties for clients, and challenges for their family and services. In addition the cost and resource implications for this population are considerable (Knapp, et al 2005; Allen, et al 2007; Hassiotis, et al 2008).At every stage of life, during each transition new set of behaviours may come in.These behaviours are the PWIDs way of expressing changes happening in his or her mind and body.

Transitions in life are important for everyone but even more so for ID people who have special needs or who challenge as they often face more transitions in life than others (Barron & Hassiotis, 2008 Myers, 2006). In addition although a person may be at the chronological age to receive adult services their disability and functioning may still require inputs that children's services provide and this is frequently overlooked (Beresford, 2004).

These transitions may involve among other changes: from home to school, school to work or day care, home to residential facility, institutional to community setting, the loss of a family member, children to adult services and between and across various agencies.

Transitions can create stress for both the client and their family e.g. when they leave school young people with ID have less opportunities for employment, to make friends, develop skills, have social networks and the loneliness the face can exacerbate their behavioural or mental health problems (Raghavan & Pawson, 2008, Heslop et al, 2002, Hanson et al, 2000).

It has also been reported that client's themselves and family carers are poorly understood, feel they are not kept fully involved in decisions about transition planning and successful transition from childhood to adult is rare with poorer post-school outcomes for ID people (Grigal et al, 2011, Unwin et al, 2008, Beresford, 2004, Ward et al, 2003, Heslop et al, 2002).

While treating and rehabilitating the disabled children, the needs of the carers are seldom thought about. It is quite possible that even the carers need help to cope with the physical, mental and emotional stress they bear while caring for their loved one. Complementary to the research on stress is the work that has been undertaken on coping mechanisms. These mechanisms take a number of forms but seem to cluster into two main areas.

2.6.2 Coping Skills:

A.The coping process is defined as 'cognitive and behav- ioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus andFolkman,1984).According to Lazarus and Folkman (1984), types of coping can be grouped into two categories: emotion-focused and problem- focused.

Emotion-focused coping entails efforts to regulate emotional distress, including avoidance, while problem -focused coping directs attention toward the problem and looks for ways of solving it. The type of coping chosen depends partly on an individual's appraisal of the situations and amen ability to change. ??Although both coping mechanisms may be required at times, families that predominantly use problem-focused coping have lower stress levels.

Problem-focused coping relates to conduct aimed at reducing the effect of the stressor event or changing it. It predominantly involves cognitive and behavioural strategies.Emotion-focused coping seeks to regulate the feelings aroused by a stress and aims to produce or maintain an emotional equilibrium.

Active avoidance coping and problem-focused coping appear to map quite clearly onto a typical emotion focused versus problem focused categorization prevalent in much stress and coping research.[Folkman S, Lazarus RS. 1980)

There can be many reasons for using problem focused and active emotional (both positive) coping in parents of children with developmental disabilities. The parents felt that Informal support from friends and relatives was regarded as essential for managing in everyday life.McCubbin HI, Patterson JM. ,1983)

Coping requires a cognitive reappraisal of the situation to manage it properly. A number of studies have concentrated on the degree to which families with disabled children feel stress, how they manage, what factors support them, and what coping strategies they use.

Majority of families cope with the situation relatively well and are able to continue their life normally.(Rimmerman A.. 1989)Social support and problem-focused coping strategies have been associated with decreased stress (. Factor et al. 1990; Miller et al. 1992).Social support has been associated with higher perceived efficacy (Stoneman & Crapps 1988), and distancing coping strategies have been associated with increased family hardiness (Judge 1998).

However, coping with a physically or intellectually disabled child is a highly individual process, and there is evidence to suggest that some families may never adjust fully to this event.(Koller H, Richardson SA, Katz M1992)])

B.Despite anecdotal data from parents and other family members reporting positive experiences and perceptions (e.g. Mullins 1987; Hornby 1992; Meyer 1993), research on families of children with intellectual disabilities has typically focused on stress and burden (Helff & Glidden 1998). The main limitation of the stress model is that it focuses on dysfunction rather than how families adapt to or function with complex demands and range of resources. This realization has stimulated research on the positive aspects for the family of a person with a intellectual disability, and the rewards and gratifications that it may bring.

At a theo- retical level, several authors within the disability field, and more generally within psychology have suggested that the positive perceptions may serve an adaptive coping function in the face of stress (Hastings & Taunt 2002).A number of research studies have explored the factors associated with various positive variables (Judge 1998), or have focused on positive adaptation (Flaherty & Glidden 2000).

Identifying family stress alone does not give a complete picture of the effects of disability on the family. Researchers have recognized that the care-giving role is associated with its own rewards as well as benefits for the beneficiary of care and the family as a whole. The rewards seem to be more than coping mechanisms to mitigate the stresses upon the family and are associated with positive benefits that the person with a disability has brought to the family. Researchers have attempted to identify core themes .?The concept of rewards does not mean that families do not experience stresses and there is some evidence that there is an association between the prevalence of stresses and rewards. The implication that overcoming adversity is a major source of reward is a recurrent theme in interviews with carers.

FIGURE 3 : Positive impact:

core themes

- Source of joy and happiness
- Increased sense of purpose and priorities
- Expanded personal and social networks?
- Increased spirituality
- Source of family unity and closeness?
- Increased tolerance and understanding?
- Personal growth and strength?o Positive impact on others/community (From Stainton, 1998)

C. Another model that drifts apart from the dysfunctional model and relies more on cooperation and social support is the eco cultural model.

The importance of this model, which is derived from the 'social ecology' model developed by Bonfenbrenner (1979), is that it proposes that individuals and families exist not in isolation but in the context of wider relationships within society. The functioning of an individual or family depends on how they relate to the wider context, which exerts influence upon them, and how they influence the wider context (Figure 4).

Examples of such relationships include workplace flexibility, which may facilitate the balancing of work and care-giving responsibilities, and how specialist intellectual disability services support a person with a intellectual disability living with his or her family.

Accommodations: the ecocultural model suggests that families create a meaningful and daily routine of family life. To create these routine families must respond in various ways to the often conflicting pressures placed upon them. These responses are referred to as 'accommodations'. The accommodations are not only within the family but within the wider social context, the family forming an ecocultural 'niche'.

The importance of the concept is that it regards families' behaviour as adaptive. By emphasizing extrafamilial aspects it allows the exploration of the effects of services and society on family adaptation.?The process of accommodation is common to all families, and particular accommodation variables have been identified in relation to families of a person with intellectual disability:

a. family subsistence and financial base

b. access to health or educational services

c. home and community safety and convenience

d. domestic tasks and chore workload for the family

e. caring tasks

f. socialization

g. marital role relationships

h. social support

i. father's role

j. sources of information and advice.

The parent of a child with a disability may change jobs and even move the family home to improve access to healthcare or schools. Siblings may take on domestic tasks and families may leave or develop new social-support networks, join advocacy groups or develop links with other carers. The accommodations they make depend on the ecocultural constraints/resources available to them.

- Research has shown that the nature and frequency of accommodation activity changes with the transition to adulthood. There are two complementary themes.

- Stable routines develop and the number of new accommodations reduces as other children of the family leave home and become independent.

● As carers age, their ability to provide care may be diminished by failing health. Siblings often share, either practically or emotionally, the support given to their parents and siblings with a disability.The family life-cycle changes may vary significantly in the timing and type of transitions needed.(R. Giallo S. Gavidia?Payne,2007)

?Families of people with intellectual disabilities usually make many accommodations, which alter in intensity and frequency over time, in order to maintain the family routine. This has important implications for services, which often increase the number and intensity of accommodations families will need to make; for example, behavioural interventions at home may involve a considerable amount of accommodation.?The ecocultural model also takes into account the other aspects of family life that have to be maintained in addition to the care-giving responsibilities. The overall impact of this research has been to show the sophistication of the accommodations that families make and also points to preparatory adaptations they make to prepare for future care-giving demands - often years in advance - that may be placed on them.

A study documenting family coping using a pretested self-administered questionnaire found that 74% families had adequately adapted to having a mentally retarded child in their family, as measured on the global adaptation scale. The remaining 26% families had inadequately adapted, of which 7% showed poor coping.[Farheen A, Dixit S, Bansal SB, Yesikar V. 2008)

Another study indicates 28% of the parents are extremely well adapted, whereas 8% of the parents show very poor coping or adaptation on global adaptation scale. [Pearson JE, Sternberg A.. 1986

Since the ecocultural model identifies factors / components required for adaptation even outside the family,it highlights the need for some policy to be formulated safeguarding the interest of the caregivers as well.The principles issued in the government department in North Ireland may be reviewed to understand how accomodations of families of PWID may be facilitated.

DHSSPS (NI) issued a Valuing Carers strategy in 2002 which identified five key principles:

1. Carers are real and equal partners in the provision of care. Carers must have equal status with other providers of care, e.g. access to training opportunities.
2. Carers need flexible and responsive support. This includes formal support - e.g. having a named contact person in social services - as well as informal support such as that provided by carer support groups.
3. Carers have a right to a life outside caring. Carers need rest, relaxation and a social life - hence the need for 'respite' breaks - and if they wish to work outside the home, they should have the opportunity to do so.
4. Caring should be freely chosen. Carers should be allowed to decide what level of caring support, if any, they can offer at any particular time. 'Shared care' arrangements may be necessary.
5. Government should invest in carers. This means addressing the personal needs of carers as well as those of the person for whom they care.

Family accomodations, specially for aging parents with a single child can only happen if the support services are looked into as there is no denial of the fact that lack of support would give rise to stress in the aging family members of PWID.

A report by an international panel of experts (IASSID, 2010) identified improvements in support services for ageing carers.

1. Services should combine expertise from different sectors, such as older people's services, advice services and/or voluntary organisations supporting older people or people with a ID;
2. Greater advocacy for older family members - both for the person with an ID and for the older family carer;
3. Information (in different formats) that explains the older families' options for support at the moment, in emergencies and in the longer term;
4. Training and improved awareness for people working in different sectors in older family issues, and fuller explanation of the options for supporting them (this is often most effectively delivered by older families themselves, either in person or through a DVD presentation).

Summarizing strategies that have been identified from several studies:

1. Social Support:The QOL of the parents who get social support is good because in Indian setting family plays an important role in providing support to the distressed members and the members stay together at the time of crisis.

   Using social support as a coping strategy and the helpfulness of informal social support resources were helpful to mothers in developing a sense of personal growth and maturity. However, although only of marginal significance, mobilizing the family to seek support within the com- unity reduced the positive effects reported by the mothers. This suggests that the nature of support that the families receive may be crucial in considering their adaptation.(Ganjiwale.D,Ganjiwale.J,Sharma.B,2016)

It has to be bourne in mind,that specifically in Urban India , family pattern is changing.Support within the family or extended family would become limited. Hence a new form of support must be kept in mind which is independent of the family pattern, could be a privatised or Government service but based on person centred planning approach.It is as follows:

1. Greater co-ordination between ID services and mainstream older people's services, as well as voluntary and private sectors should take place.
2. A key person should be identified to co-ordinate between the family home and statutory services including: transport, making appointments, domically care, financial support.
3. Succession planning should start early;
4. have clear communication and information strategies,
5. identified databases of ageing family carers and older people with ID,
6. identifying those people with ID not known to ID services early.
7. Statutory services should develop both proactive and reactive strategies (e.g. future planning, or emergency plans).
8. There needs to be regular annual health checks that include cognitive and behavioural assessments from as early as 35 years of age for ID people.l.
9. Development of high quality older person day-care, respite and recreational services for older people with ID within both ID services and mainstream older people's services should be put in place and used.

10. Development of specialist ID nursing facilities to manage older people should be introduced .

    (Slevin, E. Taggart, L. McConkey, R. Cousins, W. Truesdale-Kennedy, M. Dowling, L. (2011))

2. Family cooperation :The coping style mainly used by the caregivers was family cooperation.[Beavers J, Hampson RB, Hulgus YF, Beavers WR. 1986) Family cooperation helped them to cope with the situation in a better way.parents regarded family cohesion and co-operation as the factor most helpful for coping.[Barbarin OA, Hughes D, Chesler ,1985)]]

3. Spouse support:The spouse support in taking care of the child as well as supporting each other helped them in care taking. Some of the mothers had left their jobs and sit the whole day in the school with the child to see and repeat the same activities at home. It also helps the parent in the emotional release,[Burr WR, Klein SR, Burr RG, Doxey C, Harker B, Holman TB, et al. 1994)The fact that the spouses support each otherand share caretaking tasks and other housework equally is of major importance for their marital relationship.[Benson BA, Gross AM. T,1989).

4. Realistic Evaluation:A realistic outlook of the child's disability and acceptance of the situation had helped them to cope. After the information provided by the schools and other agencies about the supporting systems available, they were more optimistic about the future of the child.

5. Self Help Group Support:Putting the child in a special school helps the parents to find out other parents who are also facing the same problems and sharing of their concerns and problems helps them cope better. Research in India has indicated that receiving maximum social-emotional support from the spouse, family members, relatives, and friends are facilitators for effective coping. The physical support from within and outside the family is one of the greatest facilitators in coping.(Carver CS. ,1997)The social support or self-help groups have become increasingly popular forms of family support among families who have children with disabilities.

6. Parental positive perceptions:Parental positive perceptions about children with disabilities might also serve as an adaptive function by helping parents to cope with relatively high levels of stress. Because of the acceptance of their

child's status, parents had a realistic and optimistic attitude towards their own and their child's life and future. Since all the children were from special schools, this also indicates parents' positive approach to give a better platform to their child.

Mothers' positive perceptions is related to coping strategies, speci- finally positive reframing coping strategies..In the context of positive perceptions, it may be the contacts made with other parents, and with friends and family that are most effective. These sources of support are perhaps able to maintain a positive perspective when disability professionals and the community are generally more negative.

7. Right Knowledge :Adequate information about the child's disability is important and helps the parents to cope, whereas an ambiguity of diagnosis and expectations give rise to stress and isolation in the family.[Beavers J, Hampson RB, Hulgus YF, Beavers WR.1986)] Complete education and information about the child's disability seemed to be a very important factor for good parental coping.

   The parents who did not have adequate information seemed to have acquired an avoidant way of coping .They reported more of a fearful attitude and following a kind of escapism not to acknowledge the problem and think about it at all. They considered it as an extra burden on their shoulders which they have to carry somehow. They felt cheated and also felt a kind of social isolation where people looked at them in a different way. They also felt ashamed of their situation. Some of the parents perceived their physically challenged child as an extension of themselves and felt ashamed, socially rejected, ridiculed or embarrassed.In these cases, parents were mainly discussing the problems caused by the child and not emphasizing the efforts they are taking to cope with it. Thus not having right knowledge about disability may lead parents to suspect that something is wrong with their child.With uncertainty about what it is or unwillingness to admit it may give rise to insecurity and frustration in the family, which strains the relationship between the spouses and also affects the siblings.[Dyson L, Edgar E, Crnic K. 1989)

   It was found that families with better functioning actually searched for information about the disability and its treatment, worked to maintain family cohesion by sharing problems and seeking emotional support among family members, sought social support (both from formal health resources and by contacting other parents of children with disabilities and family and friends), expressed their emotions, looked for a space to be on their own and practice their hobbies and also had higher self-confidence and self-efficacy.Contact with a positive attitude helped parents to make their own positive attitude shift.

8. Parental Attitude:Parental attitudes influence the way parents treat their children and their treatment of the children, in turn, influences their children's (both with and without disability)attitudes toward them and the way they behave.(Gallimore R, Weisner T, Kaufman S, Fernheimer L. 1989]

   In another study with families of Adults with Disabilities,The results revealed that the family level of risk and resilience factors were better predictors of sibling adjustment than siblings' own experiences of stress and coping resources, highlighting the importance of familial and parental contributions to the sibling adjustment process. The implications of these results for the design of interventions and supports for siblings are tremendous as they throw a new insight into the coping skill model.(Dalal,A.K,2000)

Having a child with more severe disabilities may provide mothers with more opportunities to grow personally and to develop a mature outlook on the world because of the increased challenges posed. That is, rising to these challenges and dealing with them successfully may enhance feelings of efficacy, which contribute to personal growth and maturity. One of the key factors for success was a positive outlook on the part of the supporting parent (Singer et al. 1999).

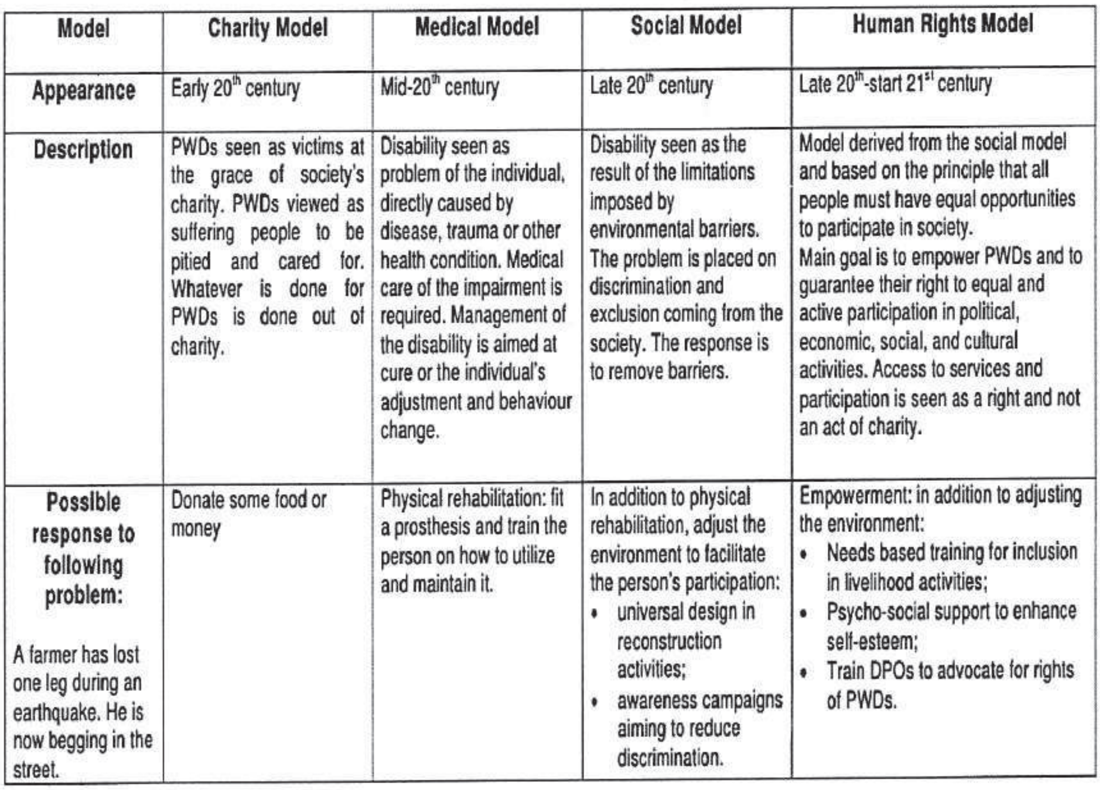
How well a family copes with the disability depends on multiple factors, including parental support, the parents' evaluation of the situation, their ability to function, and any additional stress they are experiencing.[McCubbin HI, Patterson JM,1983)

The emphasis is no longer on interventions that focus on a family's pathological reaction to the birth of a child with a disability but on supporting and augmenting the adaptive functioning of family care. The research increasingly reflects the complexity and variability of family life; although difficult, it is preferable to the former pathological models of family functioning.

2.6.3 Recent emphasis on Rights Model. .has dissipated the concept of coping.. The idea behind disability rights is that: A human rights approach to disability acknowledges that people with disabilities are rights holders and that social structures and policies restricting or ignoring the rights of people with disabilities often lead to discrimination and exclusion.So policies should change and not people.

Disability studies provide the theoretical background for what we call the shift from the medical to the social model of disability. The social model of disability was developed as a critique to the medical model of disability. However, within disability studies, the social model of disability has been almost as strongly criticized as the medical model of disability. Michael Oliver, one of the founding fathers of the social model of disability, has recently called for a halt to this criticism, unless someone can come up with a better alternative. The CRPD offers such an alternative: the human rights model of disability. It is by no means the only alternative to the social model of disability (many models have been developed, among them recently the capability approach model), but the human rights model is an improvement on the social model of disability, and it is a tool to implement the CRPD.

Main Disability Models



Model	Charity Model	Medical Model	Social Model	Human Rights Model
Appearance	Early 20th century	Mid-20th century	Late 20th century	Late 20th-start 21st century
Description	PWDs seen as victims at the grace of society's charity. PWDs viewed as suffering people to be pitied and cared for. Whatever is done for PWDs is done out of charity.	Disability seen as problem of the individual, directly caused by disease, trauma or other health condition. Medical care of the impairment is required. Management of the disability is aimed at cure or the individual's adjustment and behaviour change.	Disability seen as the result of the limitations imposed by environmental barriers. The problem is placed on discrimination and exclusion coming from the society. The response is to remove barriers.	Model derived from the social model and based on the principle that all people must have equal opportunities to participate in society. Main goal is to empower PWDs and to guarantee their right to equal and active participation in political, economic, social, and cultural activities. Access to services and participation is seen as a right and not an act of charity.
Possible response to following problem: A farmer has lost one leg during an earthquake. He is now begging in the street.	Donate some food or money	Physical rehabilitation: fit a prosthesis and train the person on how to utilize and maintain it.	In addition to physical rehabilitation, adjust the environment to facilitate the person's participation: • universal design in reconstruction activities; • awareness campaigns aiming to reduce discrimination.	Empowerment: in addition to adjusting the environment: • Needs based training for inclusion in livelihood activities; • Psycho-social support to enhance self-esteem; • Train DPOs to advocate for rights of PWDs.

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Thus the concept of coping skills must be replaced with skills to empower.PwID are human beings in their own rights and their families together with the outside world are to endeavour to understand their capacities and empower them to the fullest.

Thought for Discussion:

Evaluate the adjustments made by the families of your case studies.Do you find any difference in pattern.Justify the difference.

What are the coping mechanisms adopted by these families.Enumerate with examples.

Human rights model is applicable for all these four persons with Intellectual Disabiliy.Validate this statement.

2.7 Family support, Government Schemes and benefits

2.7.1 Family Support:

The family always stands like a rock .Family values strengthen the individuals bonding and belief system. McConkey et al (2004b) in an Audit of ID services suggest the need for family support that for some needs to be intensive, should be person-centred and that there is a requirement to recognise that support needs to fit in with family dynamics and context.

Kenny & McGilloway (2007) also found significant dissatisfaction from formal care services in the RoI (Dublin area) and that parents found most satisfaction from informal support such as spouse, other parents or other children. Similar dissatisfaction by service users has been reported in other countries where it has been suggested direct care staff are not well equipped to provide behavioural support (Philips et al, 2010). This can have negative consequences as it has been found that caregivers with unmet needs are more liable to experience mental health problems (Caldwell, 2008; Herring, et al 2006).

Specifically for a family having PWID, it is important that the family extends into a community. Adults with severe disabilities will need life long care .Let us review a few studies to understand how the family needs to support this adult specially in the times of family centred planning and deinstitutionalisation.

Mansell et al (2001) evaluated the development of residential care in specialised staffed houses offering 'active support' for 35 individuals aged 13-39 with extreme behaviours that challenge, originally destined for institutional care in South East England. Placement outcomes were noted and residents' quality of life (QoL) was measured by direct observation with time-sampling and data collected using a hand-held computer. It was found that all participants showed an increase in the overall level of participation in meaningful activity after transfer to staffed houses. Nevertheless, average social interaction remained low and although average level of major and minor behaviour problems were lower after transfer, this was not statistically significant and showed great variability among individuals. Support from local managers and professionals' was however recognised as crucial to placement success although this was not always forthcoming. No major negative effects were recorded in co-tenants without behaviours that challenge and this was highlighted as a priority for future research. Finally, and 30 perhaps surprisingly, it was noted that the specialised residential care services had similar costs to specialised institutional care.

In a more recent study Perry et al, (2011) also found that resettlement of adults with severe behaviours that challenge from a traditional ID hospital to new purpose-built specialist settings resulted in quality of care and QoL outcomes superior to previous hospital levels. Two areas where improvements over time were demonstrated included greater family contact and reduction in staff-reported behavioural problems. However, the authors suggest a need for a longer-term follow-up study to identify whether improvements in the early stages of the move are maintained or enhanced. However, caution should be exercised with regard to grouping people with behaviours that challenge in specialised settings.

Robertson et al (2005) undertook a longitudinal study comparison of 25 people with ID living in noncongregate community settings where the minority of residents had behaviours that challenge, and 25 people with ID living in congregate community settings where the majority of residents had behaviours that challenge. They found that co-locating people with behaviour disorders in congregate community-based supported accommodation was associated with more physical restraint and reliance on medication to manage behaviour. The data regarding change over time suggest that these approaches do not appear to be effective in reducing behavioural challenges and the authors conclude that the specialist nature of congregate settings appears to be limited to more staff being trained in control and restraint with an increased reliance on this a means to control behaviour. In both types of settings, behaviour disorders were stable over a 10-month period and there were few ABA technologies in place to reduce behaviour .

Family support can often extend to day care centres.Here the adults can be meaningfully engaged with vocationalskill building activities.They could be assisting in all the areas like gardening , cooking, craft activities.Family could devote this time for rest or other activies. Less reliance on traditional day centre model and replacing this with more functional education, vocational training, work experience, paid employment, voluntary work, social and leisure activities.

A working group of professionals, students could be created who would increase their contact, reduce their social distance thereby reducing the negative perception by visiting theise day care centres and bring in their set of knowledge experience and skill to create a more socially inclusive environment.

The Challenging Behaviour Foundation (2010) in their Charter stress that: Challenging behaviour is often perceived as a 'problem' or 'illness' to be 'treated', 'cured' or 'stopped'. The problem is seen as being part of the person rather than the focussing on what needs to change around the person, such as their environment or how people support them. (cited in McConkey, 2010). This statement acknowledges that the environment has a key role to play in behaviours that challenge in people with ID.. International evidence indicates behaviours that challenge will improve or at least stay the same for most people who are deinstitutionalised (Kim et al, 2001) and other advantages such as improved QoL in terms of choice and inclusion have been reported (Young et al, 2000).

An expert panel who developed guidelines on interventions for people who challenge uniformly agreed that the most highly recommended interventions in almost every situation were ABA, managing the environment, and individual and/or family education (Rush and Frances, 2000). As noted this group included managing the environment as one of the core interventions for people who challenge. Clarke and Dunlap (2008) also noted that from 1999 to 2005, research articles published in the Journal of Positive Behavioural Interventions 63%–69% of the venues 53 described involved interventions in naturalistic, activity, and social contexts. Therefore the context and environment in which behaviours that challenge occur is an important variable. Preventative interventions that are 'proactive' and aim to promote alternatives or prevent behavioural challenges taking place will therefore frequently involve environmental and antecedent manipulation, skill building and reinforcement based approaches (Adams & Allen, 2001, p.335). Making changes to the environment is a powerful strategy in helping people who challenge.

A number of different approaches can be used in this strategy. One is what Fox (2003) referred to as 'accommodation' that is, to change the person's environment with the aim of reducing their behaviour problems, following having identified that antecedent environmental aspects are causing the behaviour.

Some of the other interventions identified in previous sections of this review are underpinning by environmental management e.g. TEACCH involves structuring the environment as an aid to education but it is also useful in reducing behaviours that challenge (Van Bourgondien et al, 2003; Panerai et al, 2002).

Active support approaches as detailed above and PBS may also involve environmental changes to support people who challenge.

Environment is not only concerned with buildings but also with people who support those with behaviours that challenge. The mind-set, attitudes and education of staff who work with ID people are vital components of the support needed by these clients. In staffed accommodations, or other community based services, staff education and training, good professional supervision, strong networking and communication systems, stress management and team building arrangements, effective monitoring systems.

All the above procedure can double up as excellent family support system.

In India the last decade has seen a number of parents coming together to form family support groups.These groups have worked towards understanding their childrens needs, working on rehabilitation services and training of individuals.At present there are 43 such organisations in India the first one being started in Gujrat in 1968.

They are extremely vocal about the rights of their child and into advocacy demanding facilities or them.They are also supporting professionals in their endeavour and establishing networks with various communities.

Along with this there are formation of sibiling groups, cottages where they can come to Secundrabad to avail of services and there are home based programmes as well.

2.7.2 Lawson et al, (2008, p.3) state that "Governments mediate, through their architecture of machinery and policy, access to rights and, by extension, to services."

Policy documents which aim to provide standardised guidelines have been developed. The Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists (2007) produced an inter-disciplinary report which aims to have relevance to all professionals who work with people with ID to inform and guide policy, service provision and commissioning. It places an emphasis on the design of effective environments and professional support for placements. It is recommended that assessment and treatment units should be used only for this purpose, mechanisms should be in place to ensure that out-of-area placements reflect individual choices and that an independent mental capacity advocate should be appointed if there is to be a change in the provision of accommodation to a service user. Consideration is also given to human rights issues and it is noted that services that are unnecessarily restrictive of an individual's freedom could be in breach of the European Convention on Human Rights

United Nations Conventions on the Rights of Persons with Disabilities (2009) The United Kingdom endorsed this Convention on Rights in 2010 which covers all persons with disabilities "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". Article 19, which relates to living independently and community inclusion, is particularly relevant to the two sub-groupings of persons covered by this Review as: 16 States party to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Other pertinent Articles in the Convention relate to Mobility (#20),

Respect for Home and Family (#23.2),

Education (#24),

Health (#25),

Habilitation (#26),

Work and employment (#27),

Adequate standard of living and social protection (#28) and

Participation in cultural life, recreation, sports and leisure (#30).

Within the Convention, there is scant mention of ageing as a specific issue facing persons with disabilities.

Two articles however stress the need to prevent age-related disabilities (#25)

and to promote the social inclusion of older persons (#28).

Many of the principles contained in the Convention find expression in international and national policies in relation to ageing and for persons with behaviours that challenge and mental health problems. These are summarised in turn. 2.2 Policies in relation to ageing.

The most comprehensive review of policy in relation to ageing was undertaken by the World Health Organisation (2001) in association with an 'expert' group of researchers drawn from the International Association for the Scientific Study of intellectual Disability (IASSID). Their report identified a number of policy guidelines which can be summarised as follows:

♣ Age related change appears to occur when people with ID are in their fifties although premature ageing can be present in persons with profound and multiple disabilities and frequently in those with Down Syndrome. Moreover life expectancy is shortened by poor health status and poverty. Hence planning and provision for people with ID cannot be based solely on chronological age cut-offs.

♣ Throughout the life span, public policies should be supportive of healthy ageing with opportunities for older persons to remain socially active and contributing to their wellbeing. This should reduce the burden on health and social care services resulting for higher levels of dependency over a prolonged period of old age.

- Ongoing research and evaluation is required to identify effective intervention programmes to promote healthy ageing within three broad domains: 1) maintaining functional abilities and extending competence in later life, 2) enhancing older 17 people's quality of life (notably in residential care) and 3) identifying the factors that promote increased inclusiveness with society.
- The needs of people with ID should not be cut-off from the wider field of ageing. This avoids duplication of services, encourages the sharing of expertise and in rural areas in particular, assists with maintaining people within their local communities. This policy objective requires the development of common infrastructures for accessing services, shared training for professionals and the wider public.
- However it was acknowledged that specialist resources should be available to which clinicians, families and carers can seek information, referral and training

With regard to the particular issue of dementia and people with ID, an international round-table drew up what has become known as the 'Edinburgh Principles' (Wilkinson & Janicki, 2001). These define internationally applicable working practices for community supports for adults with a learning disability who have Alzheimer disease based on the above policy guidelines. 2.2.1 Implementation of policy on ageing There is widespread agreement internationally as to the two core features underpinning a policy on ageing and ID in relation to accommodation options: 1) people should 'age in place' rather than leaving their home to live elsewhere, and 2) shared responsibility for this client group across aged-care services and disability provision.

Scenario in India:

The disabled and the constitution

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 the disabled have been guaranteed the following fundamental rights:

1. The Constitution secures to the citizens including the disabled, a right of justice, liberty of thought, expression, belief, faith and worship, equality of status and of opportunity and for the promotion of fraternity.

2. Article 15(1) enjoins on the Government not to discriminate against any citizen of India (including disabled) on the ground of religion, race, caste, sex or place of birth.
3. Article 15 (2) States that no citizen (including the disabled) shall be subjected to any disability, liability, restriction or condition on any of the above grounds in the matter of their access to shops, public restaurants, hotels and places of public entertainment or in the use of wells, tanks, bathing ghats, roads and places of public resort maintained wholly or partly out of government funds or dedicated to the use of the general public. Women and children and those belonging to any socially and educationally backward classes or the Scheduled Castes & Tribes can be given the benefit of special laws or special provisions made by the State.
4. There shall be equality of opportunity for all citizens (including the disabled) in matters relating to employment or appointment to any office under the State.
5. No person including the disabled irrespective of his belonging can be treated as an untouchable. It would be an offence punishable in accordance with law as provided by Article 17 of the Constitution.
6. Every person including the disabled has his life and liberty guaranteed under Article 21 of the Constitution.
7. There can be no traffic in human beings (including the disabled), and beggar and other forms of forced labour is prohibited and the same is made punishable in accordance with law (Article 23).
8. Article 24 prohibits employment of children (including the disabled) below the age of 14 years to work in any factory or mine or to be engaged in any other hazardous employment. Even a private contractor acting for the Government cannot engage children below 14 years of age in such employment.
9. Article 25 guarantees to every citizen (including the disabled) the right to freedom of religion. Every disabled person (like the non-disabled) has the freedom of conscience to practice and propagate his religion subject to proper order, morality and health.

10. No disabled person can be compelled to pay any taxes for the promotion and maintenance of any particular religion or religious group.
11. No Disabled person will be deprived of the right to the language, script or culture which he has or to which he belongs.
12. Every disabled person can move the Supreme Court of India to enforce his fundamental rights and the rights to move the Supreme Court is itself guaranteed by Article 32.
13. No disabled person owning property (like the non-disabled) can be deprived of his property except by authority of law though right to property is not a fundamental right. Any unauthorized deprivation of property can be challenged by suit and for relief by way of damages.
14. Every disabled person (like the non-disabled) on attainment of 18 years of age becomes eligible for inclusion of his name in the general electoral roll for the territorial constituency to which he belongs.

Law regarding marriage:

he rights and duties of the parties to a marriage whether in respect of disabled or non-disabled persons are governed by the specific provisions contained in different marriage Acts, such as the Hindu Marriage Act, 1955, the Christian Marriage Act, 1872 and the Parsi Marriage and Divorce Act, 1935. Other marriage Acts which exist include; the Special Marriage Act, 1954 (for spouses of differing religions) and the Foreign Marriage Act, 1959 (for marriage outside India). The Child Marriage Restraint Act, 1929 as amended in 1978 to prevent the solemnization of child marriages also applies to the disabled. A Disabled person cannot act as a guardian of a minor under the Guardian and

Wards Act, 1890 if the disability is of such a degree that one cannot act as a guardian of the minor. A similar position is taken by the Hindu Minority and Guardianship Act, 1956, as also under the Muslim Law

Succession Laws for the Disabled

Under the Hindu Succession Act, 1956 which applies to Hindus it has been specifically provided that physical disability or physical deformity would not disentitle a person from inheriting ancestral property. Similarly, in the Indian Succession Act, 1925 which applies in the case of intestate and testamentary succession, there is no provision which deprives the disabled from inheriting an ancestral property. The position with regard to Parsis and the Muslims is the same. In fact a disabled person can also dispose his property by writing a 'will' provided he understands the import and consequence of writing a will at the time when a will is written. For example, a person of unsound mind can make a Will during periods of sanity. Even blind persons or those who are deaf and dumb can make their Wills if they understand the import and consequence of doing it

Labour Laws for the Disabled

The rights of the disabled have not been spelt out so well in the labour legislations but provisions which cater to the disabled in their relationship with the employer are contained in delegated legislations such as rules, regulations and standing orders.

Judicial procedures for the disabled

Under the Designs Act, 1911 which deals with the law relating to the protection of designs any person having jurisdiction in respect of the property of a disabled person (who is incapable of making any statement or doing anything required to be done under this Act) may be appointed by the Court under Section 74, to make such statement or do such thing in the name and on behalf of the person subject to the disability. The disability may be lunacy or other disability.

(http://vikaspedia.in/education/parents-corner/guidelines-for-parents-of-children-with-disabilities/legal-rights-of-the-disabled-in-india#section-2)

2.7.3 Benefits:

UN Declaration on the Rights of Mentally Retarded Persons

This declaration on the rights of mentally retarded person's calls for national and international actions so as to ensure that it will be used as a common basis and frame of reference for the protection of their rights:

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as under human beings.
2. The mentally retarded person has a right to proper medical care, physical therapy and to such education, training, rehabilitation and guidance which will enable him to further develop his ability, and reach maximum potential in life.

3. The mentally retarded person has a right of economic security and of a decent standard of living. He/she has a right to perform productive work or to participate in any other meaningful occupation to the fullest possible extent of capabilities.
4. Whenever possible, the mentally retarded person should live with his own family or with his foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If an institutional care becomes necessary then it should be provided in surroundings and circumstances as much closer as possible to that of a normal lifestyle.
5. The mentally retarded person has a right to a qualified guardian when this is required in order to protect his personal well-being or interests.
6. The mentally retarded person has a right to get protection from exploitation, abuse and a degrading treatment. If prosecuted for any offence; he shall have right to the due process of law, with full recognition being given to his degree of mental responsibility.
7. Whenever mentally retarded persons are unable (because of the severity of their handicap) to exercise their rights in a meaningful way or it should become necessary to restrict or deny some or all of their rights then the procedure(s) used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure for the mentally retarded must be based on an evaluation of their social capability by qualified experts, and must be subject to periodic review and a right of appeal to the higher authorities.

Source: *A Handbook for Parents of Children with Disabilities*

Income Tax Concessions

Relief for Handicapped

- **Section 80 DD: Secti**on 80 DD provides for a deduction in respect of the expenditure incurred by an individual or Hindu Undivided Family resident in India on the medical treatment (including nursing) training and rehabilitation etc. of handicapped dependants. For officiating the increased cost of such maintenance, the limit of the deduction has been raised from Rs.12000/- to Rs.20000/-.

- **Section 80 V:** A new section 80V has been introduced to ensure that the parent in whose hands income of a permanently disabled minor has been clubbed under Section 64, is allowed to claim a deduction upto Rs.20000/- in terms of Section 80 V.
- **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).

The persons with disabilities (PWD) (equal opportunities, protection of rights and full participation) act, 1995

"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

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 vernment shall reserve at least 3% seats for people with disabilities.

No employee 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.

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 Centres
- Special Schools
- Research Schools
- Factories by Entrepreneurs with Disability,

Non-Discrimination

- Public building, rail compartments, buses, ships and air-crafts will be designed to give easy access to the disabled people.
- In all public places and in waiting rooms, the toilets shall be wheel chair 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.

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

Grievance Redressal

- 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

The national trust for welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities act, 1999

1. The Central Government has the obligation to set up, in accordance with this Act and for the purpose of the benefit of the disabled, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability at New Delhi.
2. 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.
3. 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 disabled.
4. Disabled persons 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 disabled person and their property and required to be accountable for the same.

5. A disabled person has the right to have his guardian removed under certain conditions. These include an abuse or neglect of the disabled, or neglect or misappropriation of the property under care.
6. Whenever the Board of Trustees are unable to perform or have persistently made default in their performance of duties, a registered organization for the disabled can complain to the central government to have the Board of Trustees superseded and/or reconstituted.
7. The National Trust shall be bound by the provisions of this Act regarding its accountability, monitoring finance, accounts and audit.
8. National Trust For Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability. Its objectives are to: (i) enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong; (ii) strengthen facilities to provide support to persons with disability to live within their own families; (iii) extend support to registered organizations to provide need based services during the period of crisis in the family of persons with disability; (iv) deal with problems of persons with disability who do not have family support; (v) promote measures for the care and protection of persons with disability in the event of death of their parent or guardian, including evolving procedures for appointment of guardians and trustees for persons with disability requiring such protection.

Benefits in Employment:

1. IF for any year the vacancies reserved for persons with disabilities are not filled, the vacancies are required to be carried forward for three consecutive years until a suitable candidate is found. If a suitable candidate is not found even after three years, the vacancies may be filled through interchanging between disabilities after which the reservation ceases to exist.
2. Persons with disabilities are given an age relaxation of up to ten years in the upper age limit for recruitment to government positions. They are also exempted from payment of application fees and examination fees.

3. The government provides that persons with disabilities should not be denied promotion in their employment on account of the disability / medical fitness if they are otherwise medically fit and can discharge their duties satisfactorily.
4. The government has identified positions in various departments and sections that are to be reserved for persons with disabilities based on their ability to perform the work of the position.
5. The government provides that persons with disabilities recruited to Group C and Group D employment on regional basis may be given postings, as far as possible under administrative constraints, nearest to their native places within the region. Requests from disabled employees for transfers to offices in or nearest to their native places may also be given priority.
6. The government has established special employment exchanges for persons with disabilities in all state capitals and special employment cells have been set up in all district headquarters for recruitment to government posts reserved for persons with disabilities. In places where special employment exchanges have not been established, special employment cells have been set up within regular employment exchanges. Persons with disabilities are required to register themselves with the special employment exchanges / cells to be eligible for government employment under reservation. Special employment registrations can also be done at the 17 vocational rehabilitation centres for persons with disabilities.
7. The government provides for employment of persons with disabilities in the private sector through incentives to employers. The government pays the employer's contribution of the disabled employee's provident fund and employee state insurance up to three years for employment of persons with disabilities with a minimum salary of Rs. 25,000 per month.
8. The Ministry of Petroleum and Natural Gas has reserved 7.5 per cent of all types of dealership agencies of public sector oil companies for persons with physical disabilities. This does not include defence personnel injured while on service. The dealership is advertised in one English daily and one regional language daily having maximum circulation in the district where the dealership is located. Applicants should be Indian citizens, aged between 21 years to 30 years, should have a minimum educational qualification of matriculation or

equivalent, should produce disability certificate with minimum 40 percent disability of either upper limb or lower limb or both limbs considered together. Persons with partial hearing impairment are also eligible to apply. Persons with total visual impairment are eligible to apply for retail outlets, kerosene / LDO dealerships but are not eligible to apply for LPG dealership. Total family income of applicant should not exceed Rs. 50,000 per annum.

9. The National Handicapped Finance and Development Corporation provides loans to persons with disabilities for self employment. The details of the schemes are given as under:

- For setting up small business in service / trading sector – loan of Rs. 3,00,000 (Three lakh)
- For setting up small business in sales / trading sector – Rs. 5,00,000 (five lakh)
- For agriculture / allied activities – Loan of up to Rs. 10,00,000 (ten lakh)
- Purchase of vehicle for commercial hiring – Loan of Rs. 10,00,000 (ten lakh)
- For setting up small industries unit – Loan of Rs. 25,00,000 (25 lakh)
- For professionally educated / trained persons with disabilities for self-employment – Rs. 25,00,000 (25 lakh)
- For building business premises on own land for employment – Rs. 3,00,000 (three lakh)

The business for which financial assistance is sought should be directly operated by the applicant. In case of persons with autism, cerebral palsy or mental retardation, the parent / spouse / legal guardian of the applicant is authorised to enter into contract with NHFDC on behalf of the applicant. Applicant should fulfil the following eligibility criteria:

- Should have disability of minimum 40 percent
- Should be an Indian citizen
- Should have required professional / technical qualification for the business undertaken
- Loans should be repaid by a maximum of 10 years.

Sl. No.	Notification / Scheme	Issuing Authority	Notification No. / Date
1	3% reservation in employment	Ministry of Personnel, Public Grievances and Pension	
2	Roster system for reservation	Ministry of Personnel, Public Grievances and Pension	
3	Carry forward of employment reservation	Ministry of Personnel, Public Grievances and Pension	O.M.No.14017/ 41/90
4	Age relaxation for direct recruitment	Ministry of Personnel, Public Grievances and Pension	
5	Non denial of promotion	Ministry of Personnel, Public Grievances and Pension	
6	Identification of jobs	Ministry of Personnel, Public Grievances and Pension	
7	Postings / Transfer of disabled employees	Ministry of Personnel, Public Grievances & Pensions -	2013
8	Special employment exchanges	Department of Personnel and Training	
9	Incentives for private employers	Ministry of Social Justice and Empowerment - Department of Disability Affairs	
10	Award of dealership / agency by oil companies	Department of Petroleum and Natural Gas	
11	Financial assistance from NHFDC	National Handicapped Finance & Development Corporation	

social Security, Health, Rehabilitation and Recreation

1. The Indira Gandhi National Disability Pension Scheme: This was inserted as a component of the National Social Assistance Programme on 17th February, 2009 by the Secretary, Ministry for Rural Development. Under IGNDPS, central assistance of Rs. 300 p.m. per beneficiary is provided to persons with severe or multiple disabilities in the age group of 18-79 years and belonging to a household living BPL as per criteria prescribed by Government of India. This scheme has been implemented in 8 districts of Manipur and a total of Rs 13.4 lakhs has been received by the State Government for this scheme in 2010-11.

2. Composite Regional Centres for Persons with Disabilities (CRCs): Due to lack of adequate facilities for rehabilitation of Persons with Disabilities, the Ministry has set up multiple Composite Regional Centres for Persons with Disabilities at Srinagar, Sundernagar (Himachal Pradesh), Lucknow, Bhopal, Kozhikode, Ahmedabad (No. 6-9/2009-NIs) and Guwahati to provide both preventive and promotional aspects of rehabilitation like education, health, employment and vocational training, research and manpower development, rehabilitation for persons with disabilities etc.
3. District Disability Rehabilitation Centres (DDRCs): The Ministry with active support of State Governments is facilitating setting up District Disability Rehabilitation Centres (DDRCs) to provide rehabilitation services to persons with disabilities. Centres are being set up in unreached and unserved districts of the country in a phased manner. These centres are to provide services for prevention and early detection, referral for medical intervention and surgical correction, fitment of artificial aids and appliances, therapeutical services such as physiotherapy, occupational and speech therapy, provision of training for acquisition of skills through vocational training, job placement in local industries etc. at district headquarters as well as through camp approach.
4. Assistance to Disabled Persons for Purchase /Fitting of Aids and Appliances (ADIP Scheme): The main objective of the scheme is to assist needy persons with disabilities in procuring durable sophisticated and scientifically manufactured, modern, standard aids and appliances that can promote their physical, social and psychological rehabilitation by reducing the effects of disabilities and enhance their economic potential. Aids and appliances which do not cost less than Rs. 50 and not more than Rs. 6,000 are covered under the scheme. Further travelling cost would be admissible and limited to a bus fare in the ordinary class or railway by second class sleeper subject to a limit of Rs. 250 for the beneficiary irrespective of the number of visits to a medical centre.[1]
5. Public Sector Banks: Under the ‘Scheme for Public Sector Banks for Orphanages, Women’s Homes and Physically Handicapped Persons’, the benefits of the differential rate of interest are available to physically handicapped persons as well as institutions working for the welfare of the handicapped. Rate of interest will be uniformly charged at 4% per annum keeping in view the social objectives.

Under the scheme of Financing Small Scale Industries, a special provision has been made in the rate of interest for the physically handicapped person (0.5% concession) for availing capital limit up to Rs.2,00,000/-.

6. The National Handicapped Finance and Development Corporation (NHFDC): This corporation has been set up by the Ministry of Social Justice & Empowerment, Government of India on 24th January 1997. The company is registered under Section 25 of the Companies Act, 1956 as a Company not for profit. It is wholly owned by Government of India and has an authorised share capital of Rs. 400 crores (Rupees Four Hundred Crore only). The NHFDC functions as an Apex institution for channelising the funds to persons with disabilities through the State Channelising Agencies (SCAs) nominated by the State Government(s). The schemes include loans for setting up small business in service/trading/industrial units, for higher studies/professional training, for manufacturing /production of assistive devices for disabled persons, for agricultural activities, for self employment amongst persons with mental retardation, Cerebral Palsy and Autism.

7. Deendayal Disabled Rehabilitation Scheme (DDRS): Replaced the earlier 'Scheme to Promote Voluntary Action for Persons with Disabilities' on 01.04.2009. Under this scheme financial assistance is provided through NGOs for various projects for providing education, vocational training and rehabilitation of persons with disabilities. It is a scheme to promote voluntary action for persons with disabilities. The maximum level of support could be up to 90% of the eligible amount of grant for the project. During the 10th Five Year Plan grant-in-aid to the extent of Rs. 335.4 cr. was released to NGOs under the revised DDRS.

8. Indira Awaas Yojana: It is a centrally sponsored housing scheme for providing dwelling units free of cost to the rural poor living below the poverty line at a unit cost of Rs. 20,000 in plain areas and Rs. 22, 000 in the hill/difficult areas. Three percent of its funds are reserved for the benefit of disabled persons living below the poverty line in rural areas.

9. Scheme of National Awards for the Empowerment of Persons with Disabilities: In order to recognise their effort and encourage others to strive to achieve excellence in this field, separate awards are being presented to the most efficient/ outstanding employees with disabilities, best employers, best placement agency/ officer, outstanding individuals, outstanding institutions, role models, outstanding creative disabled individuals and for outstanding technological innovation and

adaptation of innovation to provide cost effective technology. Awards are also given to Government Sector, Public Sector Undertakings and private enterprises for creating barrier free environment for the persons with disabilities, the best district in the field of disability rehabilitation, best Local Level Committee of the National Trust and to the best State Channelising Agency (SCA) of the National Handicapped Finance and Development Corporation (NHFDC). Preference is given to the placement of women with disabilities, particularly, from the rural areas and self-employed women.

10. Trust Fund for the Empowerment of Persons with Disabilities: The Supreme Court in its order dated 16th April, 2004 in the Civil Appeals No.4655 and 5218 of 2000 had directed that the banks, who had collected an estimated excess amount of Rs.723.79 crores annually from the borrowers through rounding off in collection of interest tax, should transfer it to a trust which would be used for welfare of persons with disabilities. The Court had constituted a Committee under the chairmanship of Comptroller and Auditor General of India with Finance Secretary and Law Secretary as members. The Ministry had sought directions of the Apex court for transfer of these funds to the National Trust for Welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities for purposeful utilization. The Supreme Court is yet to take a view on the request of the Ministry but in the meantime the trust has been set up and the banks have been advised by the Banking Division of the Ministry of Finance to deposit the due amount in the Trust account.

11. Technology Development Projects in Mission Mode: With a view to provide suitable and cost effective aids and appliances through the application of technology and to increase their employment opportunities and integration in society of the physically disabled, the above scheme was started during 1990-91. Under the scheme, suitable R&D projects are identified and funded for developing aids and appliances. The scheme is implemented through the IITs. Educational Institutes, Research Agencies and Voluntary Organisations etc. Financial assistance is provided on 100% basis. The four Technical Advisory Groups monitor the selection of the projects and also their progress at different stages in areas of disabilities, namely, Orthopaedic (including Cerebral Palsy), Visual, Speech and Hearing and Mental. All the projects those are recommended by the respective Technical Advisory Groups placed before the Apex Level Committee headed by Secretary, Ministry of Social Justice and Empowerment.

Sl. No.	Description	Issuing Authority	Date Issued
1	The Indira Gandhi National Disability Pension Scheme (IGNDP) D.O.J.-11013/2/2007-NSAP	Ministry of Rural Development	February, 2009
2	Composite Regional Centres for Persons with Disabilities (CRCs)	Ministry of Social Justice and Empowerment	
3	District Disability Rehabilitation Centres (DDRCs)	Ministry of Social Justice and Empowerment	1995
4	Assistance to Disabled Persons for Purchase / Fitting of Aids and Appliances (ADIP Scheme)	Ministry of Social Justice and Empowerment	01.04.2005
5	'Scheme of Public Sector Banks for Orphanages, Women's Home and Physically Handicapped persons' D.O.No.F.301/89-SCT (B) dated 8.9.89	Department of Economic Affairs & Ministry of Welfare	08.09.1989
6	The National Handicapped Finance and Development Corporation (NHFDC)	Ministry of Social Justice and Empowerment	24.01.1997
7	Deendayal Disabled Rehabilitation Scheme (DDRS)	Ministry of Social Justice and Empowerment	01.04.2009
8	Indira Awaas Yojana	Ministry of Rural Development	May, 1985
9	Scheme of National Awards for the Empowerment of Persons with Disabilities	Ministry of Social Justice and Empowerment	2012
10	Trust Fund for the Empowerment of Persons with Disabilities via Civil Appeals No.4655 and 5218 of 2000	Supreme Court of India	16.04.2004
11	Technology Development Projects in Mission Mode	Ministry of Social Justice and Empowerment	

Accessibility

Guidelines and Space Standards for Barrier Free Built Environment for Disabled and Elderly PersonsIn order to create a barrier free environment in consonance with the provisions of the Act, the Government of India (Ministry of Urban Affairs & Employment) is currently engaged in the process of amending/modifying the existing building bye-laws which would be applicable to all buildings and facilities used by the public. With this intention to ensure that everyone, including the physically disabled and elderly persons ,will have equal access in everyday life in the city, the Min. of UA&E has constituted a committee under the chairmanship of DG(W), CPWD with the following members for the purpose of developing comprehensive Guide lines and space Standards for barrier free built environment for disabled and elderly persons.

(https://cis-india.org/accessibility/blog/central-government-schemes)

Finally Right To Peersons With Disabilities Act has been passed in Loksabha in 2016 and has replaced PWD Act.

A glimpse into the act is as follows:

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 behavior which covers a range of every day social and practical skills including specific learning disabilities and autism spectrum disorders." 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, behavior, 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 subnormality 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, 2016 provides that "the appropriate Government shall ensure that the PWD enjoy the right to equality, life with dignity, and respect for his or her own integrity equally with others."

The Government is to take steps to utilize the capacity of the PWD by providing appropriate environment.

It is also stipulated in the section 3 that no PWD shall be discriminated on the ground of disability, unless it is shown that the impugned act or omission is a proportionate means of achieving a legitimate aim and no person shall be deprived of his personal liberty only on the ground of disability.

Living in the community for PWD is to be ensured and steps are to be taken by the Government to ensure reasonable accommodation for them.

Special measures are to be taken to ensure women and children with disabilities enjoy rights equally with others. Measures are to be taken to protect the PWD from being subjected to cruelty, inhuman, and degrading treatments and from all forms of abuse, violence, and exploitation. Under section 7(2) of the Act, any person or registered organization, who or which has reason to believe that an act of abuse, violence, or exploitation has been, is being or likely to be committed against any PWD, may give information to the local Executive Magistrate who shall take immediate steps to stop or prevent its occurrence and pass appropriate order to protect the PWD. Police officers, who receive a complaint or otherwise come to know of violence, abuse, or exploitation, shall inform the aggrieved PWD of his right to approach the Executive Magistrate. The police officer shall also inform about particulars of nearest organization working for the rehabilitation of the PWD, right to free legal aid, and right to file complaint under the provisions of this Act or any other law dealing with such offence.

For conducting any research, free and informed consent from the PWD as well as a prior permission from a Committee for Research on Disability to be constituted in the prescribed manner.

Equal protection and safety in situations of risk, armed conflict, humanitarian emergencies, and natural disasters are to be provided to PWD.

Children with disability are not to be separated from parents except on the order of a competent court and information about reproductive rights and family planning to the PWD is to be ensured.

Accessibility in voting and access to justice without discrimination to the PWD are to be ensured. Public documents are to be made available in accessible formats.

It is to be ensured that all PWD enjoy legal capacity on an equal basis with others in all aspects of life and has the right to equal recognition everywhere as any other person before the law and have the right, equally with others, to own and inherit movable and immovable property as well as control their financial affairs (Sec 13).

It is also provided that a PWD with benchmark disability who consider himself to be in need of high support, he/she or any other person or organization in his behalf may apply to the authority appointed by the Government for the same and the authority shall take steps to provide support accordingly (Sec 38).

However, the PWD would have the right to alter, modify, or dismantle the support system and in case of conflict of interest, the supporting person would withdraw from providing the support [sec 13(4&5)].

It has been provided in the section 14 of the Act that a District Court or any designated authority, as notified by the State Government, finds that a person with disability, who had been provided adequate and appropriate support but is unable to take legally binding decisions, may be provided further support of a limited guardian to take legally binding decisions on his behalf in consultation with such person, in such manner, as may be prescribed by the State Government.

It is also provided that the District Court or the designated authority, as the case may be, may grant total support to the person with disability requiring such support or where the limited guardianship is to be granted repeatedly. In these cases the decision regarding the support to be provided shall be reviewed by the Court or the designated authority, as the case may be, to determine the nature and manner of support to be provided. Limited guardianship has been explained to mean a system of joint decision which operates on mutual understanding and trust between the guardian and the person with disability, which shall be limited to a specific period and for specific decision and situation and shall operate in accordance to the will of the person with disability. It is also provided that on and from commencement of the Act, every guardian appointed under any other law for time being in force shall be deemed to function as a limited guardian.

The Bill provides for the access to inclusive education, vocational training, and self-employment of disabled persons without discrimination and buildings, campuses, and various facilities are to be made accessible to the PWD and their special needs are to be addressed. Necessary schemes and programs to safeguard and promote the PWD for living in the community are to be launched by the Government. Appropriate healthcare measures, insurance schemes, and rehabilitation programs for the PWD are also to be undertaken by the Government. Cultural life, recreation, and sporting activities are also to be taken care of.

All Government institutions of higher education and those getting aid from the Government are required to reserve at least 5% of seats for persons with benchmark disabilities. Four percent reservation for persons with benchmark disabilities is to be provided in posts of all Government establishments with differential quotas for different forms of disabilities. Incentives to employer in private sector are to be given who provide 5% reservation for persons with benchmark disability. Special employment exchanges for the PWD are to be set up. Awareness and sensitization programs are to be conducted and promoted regarding the PWD.

Standards of accessibility in physical environment, different modes of transports, public building and areas are to be laid down which are to be observed mandatorily and a 5-year time limit is provided to make existing public building accessible.

Access to information and communication technology is to be ensured. The Central and State Advisory Boards on disability are to be constituted to perform various functions assigned under the Act. District level Committees are also to be constituted by the State Government. Chief Commissioner and two Commissioners for PWD are to be appointed by the Central Government at the central level for the purposes of the Act. Similarly, State Commissioners for PWD are to be appointed by the State Governments. National Funds for PWD and State Funds for PWD are to be constituted at the central and state levels respectively by the appropriate Governments. Contraventions of the provisions of the Act have been made punishable by a fine of an amount up to ten thousand for first contravention and fifty thousand extendable up to five lakhs for subsequent contraventions. Atrocities on PWD have been made punishable with imprisonment of 6 months extendable to 5 years and with fine. Fraudulently availing of the benefits meant for PWD has also been made punishable.

Thoughts for Discussion:

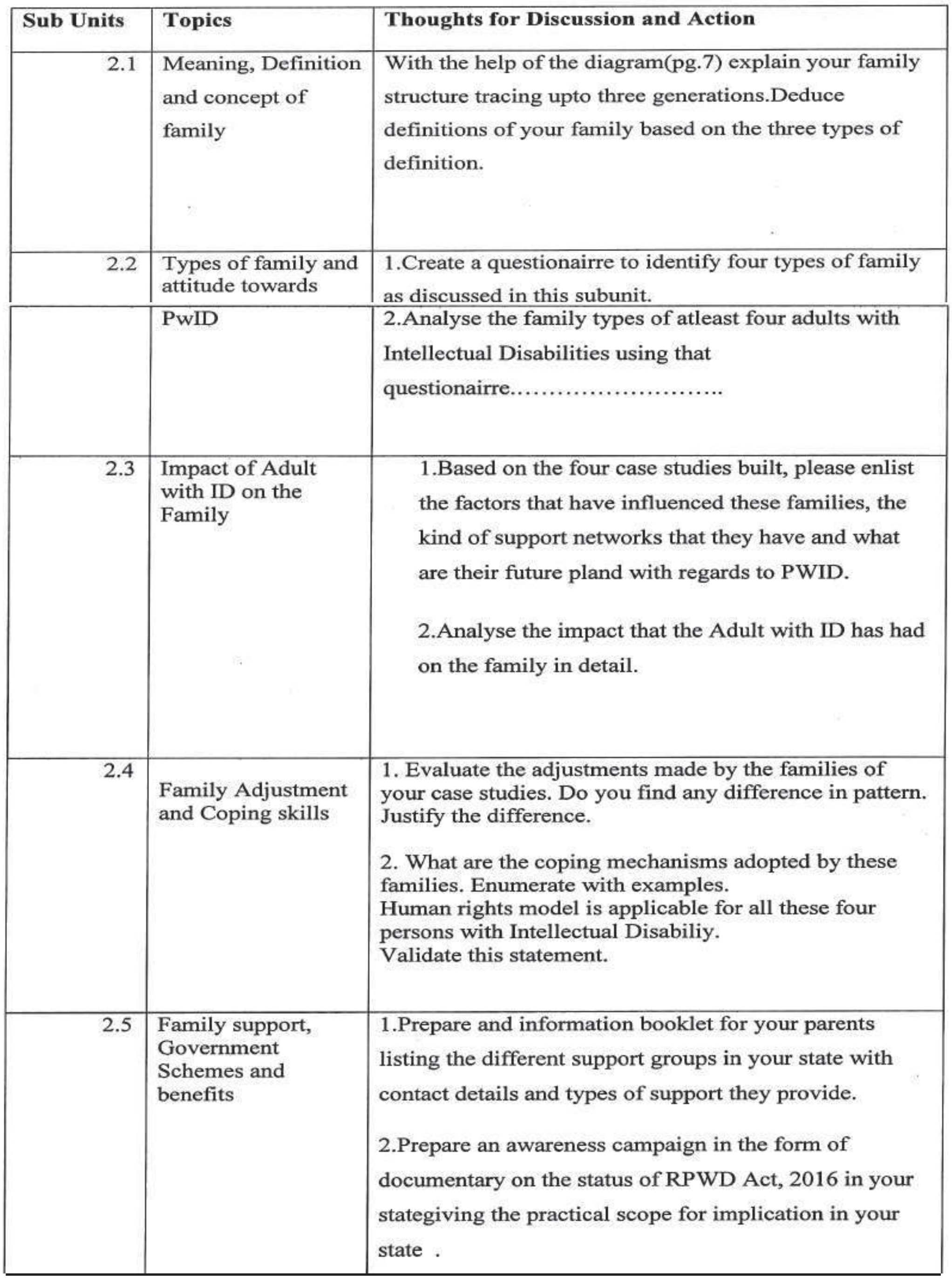
Prepare and information booklet for your parents listing the different support groups in your state with contact details and types of support they provide.

Prepare an awareness campaign in the form of documentary on the status of RPWD Act, 2016 in your stategiving the practical scope for implication in your state .

2.8 Let us sum up:

Having understood the meaning of a family, we have seen how different definitions of family have come into existence. We have read about the concept of family and how the changes have been brought about by urbanization. We have learnt different ways to classify family and have comprehended how the deeper modes of classification affect the attitude formation of the families. We have also learnt about the different types of families and the unique way each type approaches the existence of a PWID in its gambit. We have studied attitudes of different families through case study method. We have come to understand the difference between an child becoming an adult and a child with ID becoming an adult. The concept of caregiver and the factors affecting the caregiver himself or herself have been explained. The relationship between adult, caregiver and professional being enumerated have highlighted the need for family adjustment. The evolution of coping skills over the years has been analyzed and the strategies for coping have been enlisted. What is family support and why it required is have been established as well the support concept has been extended to Government Laws and schemes and benefits.

2.9 Unit End Exercises



Sub Units	Topics	Thoughts for Discussion and Action
2.1	Meaning, Definition and concept of family	With the help of the diagram(pg.7) explain your family structure tracing upto three generations.Deduce definitions of your family based on the three types of definition.
2.2	Types of family and attitude towards PwID	1.Create a questionairre to identify four types of family as discussed in this subunit. 2.Analyse the family types of atleast four adults with Intellectual Disabilities using that questionairre.……………………..
2.3	Impact of Adult with ID on the Family	1.Based on the four case studies built, please enlist the factors that have influenced these families, the kind of support networks that they have and what are their future pland with regards to PWID. 2.Analyse the impact that the Adult with ID has had on the family in detail.
2.4	Family Adjustment and Coping skills	1. Evaluate the adjustments made by the families of your case studies. Do you find any difference in pattern. Justify the difference. 2. What are the coping mechanisms adopted by these families. Enumerate with examples. Human rights model is applicable for all these four persons with Intellectual Disabiliy. Validate this statement.
2.5	Family support, Government Schemes and benefits	1.Prepare and information booklet for your parents listing the different support groups in your state with contact details and types of support they provide. 2.Prepare an awareness campaign in the form of documentary on the status of RPWD Act, 2016 in your stategiving the practical scope for implication in your state .

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Unit-3 : Gender, Sexuality and Marriage Related Issues

Structure

3.1 Introduction :

Walking back into the dusty corridors of history and mythology, we find a Razia Sultana who inspite of being a competent ruler was dethroned because she was a woman, we see the mighty Arjuna as a transgender Brihannala, we find Akbar marrying into Rajput clan to expand his kingdom and we see Kunti getting Draupadi married to five sons of her so that power does not getdivided.

It is a strange mixture of gender sexuality and marriage.

Lets enter into more recent times.

In 1971, Broverman and Broverman conducted a groundbreaking study on the traits mental health workers ascribed to males and females. When asked to name the characteristics of a female, the list featured words such as unaggressive, gentle, emotional, tactful, less logical, not ambitious, dependent, passive, and neat. The list of male characteristics featured words such as aggressive, rough, unemotional, blunt, logical, direct, active, and sloppy (Seem and Clark 2006). Later, when asked to describe the characteristics of a healthy person (not gender specific), the list was nearly identical to that of a male.

This study uncovered the general assumption that being female is associated with being somewhat unhealthy or not of sound mind. This concept seems extremely dated, but in 2006, Seem and Clark replicated the study and found similar results. Again, the characteristics associated with a healthy male were very similar to that of a healthy (genderless) adult. The list of characteristics associated with being female broadened somewhat but did not show significant change from the original study (Seem and Clark 2006).

According to critical sociology, society is structured by relations of power and domination. Social problems and contradictions are created when dominant groups exploit or oppress subordinate groups. Consider the women's suffrage movement or the debate over women's "right to choose" their reproductive futures. It is difficult for women to rise above men, as dominant group members create the rules for success and opportunity in society (Farrington and Chertok 1993)Feminist theory is a type of critical sociology that examines inequalities in gender-related issues. It uses the critical approach to examine the maintenance of gender roles and inequalities.Sanday's study of the Indonesian Minangkabau (2004) revealed that in societies that some consider to be matriarchies (where women are the dominant group), women and men tend to work cooperatively rather than competitively regardless of whether a job is considered feminine by North American standards. The men, however, do not experience the sense of bifurcated consciousness under this social structure that modern Canadian females encounter (Sanday 2004).

Let us in the course of the chapter unearth these seemingly unlinked terminologies and their influence on the world of Intellectual Disabilities

3.2 Objectives:

To gain knowledge and apply the following concepts:

a. Gender is a social decision
b. Gender ideology, identity and relationship with power
c. Sexuality and gender-interconvertibility
d. Sexuality-types and characteristics
e. Religion and its influence on sexual behavior
f. Different religion and marriage
g. Religion and culture-determining gender norms
h. Marriage of PWID-from past to present
i. Stereotypes regarding marriage and impact on PWID
j. Way ahead
k. Pre marital counseling-definition
l. Adjustment model of disability-requirement of counseling
m. Benefits of pre marital counseling
n. Counselor and Disability-what the counselor should keep in mind
o. PWID and sexuality-perception of society and parental attitude

p. Impact on PWID

q. Strategies for preventing STD and gender education.

3.3 Meaning & Concept of Gender & Sexuality and Marriage

3.3.1 Gender:

Gender is not something we are born with, and not something we have, but something we do (West and Zimmerman 1987) – something we perform (Butler 1990).

Sex is a biological categorization based primarily on reproductive potential, whereas gender is the social elaboration of biological sex. Not surprisingly, social norms for heterosexual coupling and care of any resulting children are closely intertwined with gender. Gender builds on biological sex which naturally leads to biological difference.

So sex is a biological component and gender is more associated with the roles that component is supposed to play and thus has social relevance.. People tend to think of gender as the result of nurture – as social and hence fluid – while sex is the result of nature, simply given by biology. However, nature and nurture intertwine, and there is no obvious point at which sex leaves off and gender begins.

But the sharp demarcation fails because there is no single objective biological criterion for male or female sex. Sex is based in a combination of anatomical, endocrinal and chromosomal features.

The criteria for sex assignment are based not on anatomical features but more on our conditioning which have given rise to cultural beliefs about what actually makes someone male or female. Thus the very definition of the biological categories male and female, and people's understanding of themselves and others as male or female, is ultimately social.

Across societies, the gendered division of labor involves differential power and status. Men's activities – those that are guarded the most closely as men's domain – involve greater societal power, through the disposition of goods and services and the control of ritual. Males in most cultures have more access to positions of public power and influence than females

The gendered division of labor in western society relies heavily on the allocation of women's function to the domestic, or private, realm and men's to the public realm. People often connect this division of labor to reproductive roles. Women, as bearers of children, are assigned not only to delivering them, but to raising them, and to the nurturing not only of children but of entire families, and to the care of the home in which families are based. If one were to imagine a division of labor based on sex alone, women would bear and nurse children and men would not. And women would likely be somewhat restricted in their other activities while engaged in childbearing and nursing.

Traditional women's jobs are in the service sector, and often involve nurturing, service, and support roles: teachers of small children, nurses, secretaries, flight attendants. There is also an emotional division of labor. Wherever they are, women are expected more than men to remember birthdays, soothe hurt children, offer intimate understanding

Anne Fausto-Sterling (2000) sums up the situation as follows: labeling someone a man or a woman is a social decision. We may use scientific knowledge to help us make the decision, but only our beliefs about gender – not science – can define our sex.

Biology offers up dichotomous male and female prototypes, but it also offers us many individuals who do not fit those prototypes in a variety of ways. Blackless et al. (2000) estimate that 1 in 100 babies are born with bodies that differ in some way from standard male or female. These bodies may have such conditions as unusual chromosomal makeup (e.g., 1 in 1,000 male babies are born with two X chromosomes as well as a Y, hormonal differences such as insensitivity to androgens (1 in 13,000 births), or a range of configurations and combinations of genitals and reproductive organs.

There are cultures where what we might think of as more than two adult gender categories are named and otherwise institutionally recognized as well: the berdache of the Plains Indians, the hijras in India. Transgender people may embrace the other of the two options standardly on offer or they may resist gender dichotomies altogether. Although details vary significantly, the members of such supernumerary categories are outside the "normal" order of things, and tend to be somewhat feared or devalued or otherwise socially disadvantaged.

The attribution of intersex does not end at birth – for example, 1 in 66 girls experience growth of the clitoris in childhood or adolescence (known as late onset adrenal hyperplasia).

Work on sex differences in the brain is very much in its early stages, and is far from conclusive (Fausto-Sterling 2000). Thus the causal relation between brain physiology and activity is completely unclear (Eliot 2009).

Deborah Cameron (2009) refers to the search for gender differences in biology as "the new biologism", and points out that the linguistic traits that scientists are trying to explain biologically (such as women's greater language ability) are not even themselves supported by serious linguistic study. An early discussion of social groups with more than two sex and/or gender categories is provided by Martin and Voorhies (1975), ch. 4, "Supernumerary sexes." biologically based explanations of sex differences ignore the fact that the very same linguistic differences that they see beetween the genders also correlate with race and social class, and many of the sex differences they cite as biologically based actually vary historically and crossculturally (e.g. Keenan 1974; Kulick 1993,1994).

It is commonly argued that biological differences between males and females determine gender by causing enduring differences in capabilities and dispositions. Higher levels of testosterone, for example, are said to lead men to be more aggressive than women; and left-brain dominance is said to lead men to be more rational while their relative lack of brain lateralization should lead women to be more emotional.

But the relation between physiology and behavior is not simple, and it is all too easy to leap for gender dichotomies. And the physiology itself is more complex than is usually acknowledged. It has been shown that hormonal levels, brain activity patterns, and even brain anatomy can be a result of different activity as well as a cause. For example research with species ranging from rhesus monkeys (Rose et al. 1972) to fish (Fox et al. 1997) has documented changes in hormone levels as a result of changes in social position.

Much of the popular work on gender differences in the brain are based on shaky evidence, and are commonly exaggerations and even distortions of what appears in the scientific literature. And the scientific literature itself is based on very small samples, often from sick or injured populations. In addition, not that much is known about the connections between brain physiology and behavior or cognition – hence about the consequences of any physiological differences scientists may be seeking or finding. And above all, the brain is very plastic, changing in response to experience. Thus the causal relation between brain physiology and activity is completely unclear (Eliot 2009)

In the famous words of Simone de Beauvoir, "Women are not born, they are made." The same is true of men. The making of a man or a woman is a never-ending process that begins before birth – from the moment someone begins to wonder if the pending child will be a boy or a girl. And the ritual announcement at birth that it is in fact one or the other instantly transforms an "it" into a "he" or a "she" (Butler 1993), standardly assigning it to a lifetime as a male or as a female. This attribution is further made public and lasting through the linguistic event of naming. In some times and places, the state or religious institutions disallow sex-ambiguous given names. Finland, for example, has lists of legitimate female and legitimate male names that must be consulted before the baby's name becomes official.

Thus the dichotomy of male and female is the ground upon which we build selves from the moment of birth. These early linguistic acts set up a baby for life, launching a gradual process of learning to be a boy or a girl, a man or a woman, and to see all others as boys or girls, men or women as well.

We do not know how to interact with another human being (or often members of other species), or how to judge them and talk about them, unless we can attribute a gender to them. Gender is so deeply engrained in our social practice, in our understanding of ourselves and of others, that we almost cannot put one foot in front of the other without taking gender into consideration. People even, it seems, apply gender stereotypes to computer-generated speech depending on whether they perceive the computer's voice as male or female (Nass et al 1997).

Although most of us rarely notice this overtly in everyday life, most of our interactions are colored by our performance of our own gender, and by our attribution of gender to others. From infancy, male and female children are interpreted differently, and interacted with differently. Experimental evidence suggests that adults' perceptions of babies are affected by their beliefs about the babies' sex.

Condry and Condry (1976) found that adults watching a film of a crying infant were more likely to hear the cry as angry if they believed the infant was a boy, and as plaintive or fearful if they believed the infant was a girl. In a similar experiment, adults judged a 24-hour-old baby as bigger if they believed it to be a boy, and finer-featured if they believed it to be a girl (Rubin, Provenzano and Luria 1974).

Such judgments then enter into the way people interact with infants and small children. People handle infants more gently when they believe them to be female, more playfully when they believe them to be male.

So we can infer that gender is made through belief systems, cultural practices as well as prejudices existing in the human society.It is through this the gender roles are assigned, behaviours of each gender is determined and laws and practices are followed to see the maintainance of those behaviours are established firmly to weave out a particular social fabric.

Gender development does not end with childhood or adolescence. Gender continues to be transformed as we move into the marketplace – as we learn to act like secretaries, lawyers, managers, janitors. And it continues to be transformed as our family status changes – as we learn to be wives and husbands, mothers and fathers, aunts and uncles, sisters and brothers, grandmothers and grandfathers. gender is collaborative.

Gender ideology is the set of beliefs that govern people's participation in the gender order, and by which they explain and justify that participation. Gender ideologies differ with respect to such things as the nature of male and female, and the justice, the naturalness, the origins, and the necessity of various aspects of the gender order. Ideologies differ on whether difference is fundamental, whether it should be maintained, and whether it can – or should – be maintained with or without inequality. Some accept difference as given, and as justifying, or as the necessary result of, inequality.

Gender identity is the extent to which one identifies as being either masculine or feminine (Diamond 2002). "The word gender has acquired the new and useful connotation of cultural or attitudinal characteristics (as opposed to physical characteristics) distinctive to the sexes. That is to say, gender is to sex as feminine is to female and masculine is to male" (J.E.B. v. Alabama, 144 S. Ct. 1436 [1994]).In his book Masculinities, Robert Connell (1995) counters the notion of "true masculinity," emphasizing that masculinity (like femininity) is not a coherent object, but part of a larger structure. Taking this structure as starting point, Connell locates, and elaborates on, two kinds of masculinities: the physical masculinity of the working class, and the upper-middle-class technical masculinity.

Connell points out that working-class masculinity is associated with physical power, while upper-middle-class masculinity is associated with technical (scientific, corporate, and political) power. This is not to say that physical power is unimportant for uppermiddle-class men – the masculine ideal throughout society involves physical power.

There is a similar class reversal for women. Women with social status are expected to be small and delicate, with a carefully maintained body down to the smallest detail. Just as physical strength is expected to some extent of all men, this delicacy is expected to some extent of all women. society often views riding a motorcycle as a masculine activity and, therefore, considers it to be part of the male gender role. Attitudes such as this are typically based on stereotypes, oversimplified notions about members of a group. Gender stereotyping involves overgeneralizing about the attitudes, traits, or behaviour patterns of women or men. For example, women may be thought of as too timid or weak to ride a motorcycle.

This gender identity gives rise to predetermined gender roles.The agents of socialisations eg,family, peers, school, community gradually through their role expectations and behaviours enforce these roles in an individual during his or her growing up .

Gender and power:

Agents for building up gender:

Family is the first agent of socialization. There is considerable evidence that parents socialize sons and daughters differently. Generally speaking, girls are given more latitude to step outside of their prescribed gender role (Coltrane and Adams 2004; Kimmel 2000; Raffaelli and Ontai 2004). However, differential socialization typically results in greater privileges afforded to boys. For instance, sons are allowed more autonomy and independence at an earlier age than daughters. They may be given fewer restrictions on appropriate clothing, dating habits, or curfew. Sons are also often free from performing domestic duties such as cleaning or cooking and other household tasks that are considered feminine. Daughters are limited by their expectation to be passive, nurturing, and generally obedient, and to assume many of the domestic responsibilities.

Even when parents set gender equality as a goal, there may be underlying indications of inequality. For example, when dividing up household chores, boys may be asked to take out the garbage or perform other tasks that require strength or toughness, while girls may be asked to fold laundry or perform duties that require neatness and care. It has been found that fathers are firmer in their expectations for gender conformity than are mothers, and their expectations are stronger for sons than they are for daughters (Kimmel 2000).

But at the same time it should be bourne in mind that parental socialization and normative expectations vary along lines of social class, race, and ethnicity. Research in the United States has shown that African American families, for instance, are more likely than Caucasians to model an egalitarian role structure for their children (Staples and Boulin Johnson 2004).

School is the next level of gender socialisation. Studies suggest that gender socialization still occurs in schools today, perhaps in less obvious forms (Lips 2004). Teachers may not even realize that they are acting in ways that reproduce gender-differentiated behaviour patterns. Yet, any time they ask students to arrange their seats or line up according to gender, teachers are asserting that boys and girls should be treated differently (Thorne 1993).

Peer interaction plays an important role in gender socialisation. When children do not conform to the appropriate gender role, they may face negative sanctions such as being criticized or marginalized by their peers. Though many of these sanctions are informal, they can be quite severe. For example, a girl who wishes to take karate class instead of dance lessons may be called a “tomboy” and face difficulty gaining acceptance from both male and female peer groups (Ready 2001). Boys, especially, are subject to intense ridicule for gender nonconformity (Coltrane and Adams 2008; Kimmel 2000).

Mass media serves as another significant agent of gender socialization. In television and movies, women tend to have less significant roles and are often portrayed as wives or mothers. When women are given a lead role, they are often one of two extremes: a wholesome, saint-like figure or a malevolent, hypersexual figure (Etaugh and Bridges 2003). This same inequality is pervasive in children’s movies (Smith

2008)Thus sexuality is an offshoot of gender again being guided by predetermined customs and belief system

3.3.2 Sexuality:

Sexuality is a multi-faceted and complex construct informed by sexual self-concept, behaviour, thoughts, values, emotions, physiology, interpersonal relationships, and diversity (McCammon, Knox & Schact, 1998:4). Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. (WHO, 2006a).

The first thing people want to know about a baby is its sex, and social convention provides a myriad of props to reduce the necessity of asking – and it becomes more and more important, as the child develops, not to have to ask. At birth, many hospital nurseries provide pink caps for girls and blue caps for boys, or in other ways provide some visual sign of the sex that has been assigned to the baby. While this may seem quite natural to members of the society, in fact this color coding points out no difference that has any bearing on the medical treatment of the infants.The kinder Joy that children have do not have any difference in taste but are packaged in blue or pink containining ‘gender Specific “ toys where blue is meant for boys and will have toy cars and pink is made for girls having dolls.This distinction is made even in the mid of twentifirst century where women are traversing every domain even the ones supposed to be male dominated.

Colors are so integral to our way of thinking about gender that gender attributions have bled into our view of the colors, so that people tend to believe that pink is a more “delicate” color than blue (and not just any blue, but baby blue). This is a prime example of the naturalization of what is in fact an arbitrary sign. In America in the late nineteenth and early twentieth centuries, Anne Fausto-Sterling (2000) reports, blue was favored for girls and bright pink for boys which is opposite the previous belief.

If gender flowed naturally from sex, one might expect the world to sit back and simply allow the baby to become male or female. But in fact, sex determination sets the stage for a lifelong process of gendering, as the child becomes, and learns how to be, male or female. Names and clothing are just a small part of the symbolic resources used to support a consistent ongoing gender attribution even when children are clothed.

That we can speak of a child growing up as a girl or as a boy suggests that initial sex attribution is far more than just a simple observation of a physical characteristic. Being a girl or being a boy is not a stable state but an ongoing accomplishment, something that is actively done both by the individual so categorized and by those who interact with it in the various communities to which it belongs. The newborn initially depends on others to do its gender, and they come through in many different ways, not just as individuals but as part of socially structured communities that link individuals to social institutions and cultural ideologies. It is perhaps at this early life stage that it is clearest that gender is a collaborative affair – that one must learn to perform as a male or a female, and that these performances require support from one's surroundings.

Parents use more diminutives (kitty, doggie) when speaking to girls than to boys (Gleason et al. 1994), they use more inner state words (happy, sad) when speaking to girls (Ely et al. 1995), and they use more direct prohibitives (don't do that!) and more emphatic prohibitives (no! no! no!) to boys than to girls (Bellinger and Gleason 1982).

Qualitative differences in behavior come about in the same way. A study of thirteen-month-old children in day care (Fagot et al. 1985) showed that teachers responded to girls when they talked, babbled, or gestured, while they responded to boys when they whined, screamed, or demanded physical attention. Nine to eleven months later, the same girls talked more than the boys, and the boys whined, screamed, and demanded attention more than the girls.

Eleanor Maccoby (2002) emphasizes that children have a very clear knowledge of their gender (that is, of whether they are classified as male or female) by the time they are three years old. It has become increasingly clear that children play a very active role in their own development. From the moment they see themselves as social beings, they begin to focus on the enterprise of growing up. And to some extent, they probably experience many of the gendered developmental dynamics we discuss here not so much as gender-appropriate, but as grown-up.

Until about the age of two, boys and girls exhibit the same play behaviors. After that age, play in boys' and girls' groups begins to diverge as they come to select different toys and engage in different activities, and children begin to monitor each other's play, imposing sanctions on gender-inappropriate play. Boys become more agonistic than girls, and many attribute this to hormonal and even evolutionary differences (Maccoby 2000). As children get older, their play habits are monitored and differentiated, first by adults, and eventually by peers. Parents of small children have been shown to reward their children's choice of genderappropriate toys (trucks for boys, dolls for girls) (Langlois and Downs 1980).

Asymmetry is partially a function of the cultural devaluation of women and of the feminine. One way or another, most boys and girls learn that boy things and boy activities are more highly valued than girl things and girl activities, and boys are strongly discouraged from having interests or activities that are associated with girls. Even where they do not encounter such views formulated explicitly or even find them denied explicitly, most boys and girls learn that it is primarily men and not women who do important things as adults, have opinions that 12 count, direct the course of events in the public world. It is hardly surprising then that pressures towards gender conformity are not symmetrical.This is where "boys don't cry" or " women gossip " terminologies start coming into existence.Even though in todays world gender differences are diffusing but a house husband enjoys less prestigious position when compared to a working wife.

Separation

To differing degrees from culture to culture and community to community, difference is reinforced by separation. Boys play more with boys; girls with girls. And this pattern repeats itself cross-culturally, in nonindustrial societies as well as in industrial societies (Whiting and Edwards 1988). American children begin to prefer same-sex playmates as they approach the age of three (Maccoby 1998), which is about the age at which they develop a clear sense of their own gender, and this preference increases rapidly as they age. Eleanor Maccoby notes that this preference emerges in institutional settings – day care, preschool, and elementary school – where children encounter large numbers of age peers. On the same theme, Barrie Thorne

(1993) points out that schools provide a population that's sufficiently large for boys and girls to be able to separate

Even though children lean towards same-sex groups in these settings, they often maintain prior cross-sex friendships formed outside the institution (Howes 1988). It is important to note that the preference for same-sex play groups is not absolute, and that in fact children often play in mixed groups. Maccoby and Jacklin's study (1987) of individual children's choice of playmates in a preschool setting shows four and a half year olds playing in same-sex groups 47 percent of the time, mixed groups 35 percent of the time and other-sex groups (i.e., where the child is the only representative of her or his own sex in the group) 18 percent of the time. While these figures show a good deal of mixing, the same-sex groups are far greater than random playmate selection would produce. And at age six and a half, children in the Maccoby and Jacklin study were playing in same-sex groups 67 percent of the time. Maccoby (1998,

Towards the end of elementary school, a highly visible activity of pairing up boys and girls into couples begins to dominate the scene. This activity is not one engaged in by individual children, and it is not an activity that simply arises in the midst of other childhood "business as usual." Rather, it is the beginning of a social market that forms the basis of an emerging peer social order (Eckert 1996).

Sexuality is then not just a physiological process determined by the physical characteristics.It is a combination of conditioning , culture handed down and belief system practised.Sexuality progresses to become gender development.

It is common to think of sexuality in terms of individual attributes – an individual is male or female, more or less masculine or feminine, is fulfilling male or female roles. This focus on the individual obscures the fact that we cannot accomplish gender on our own. Although gender includes individuals' sense of their own gender identity, it is not primarily an individual matter, but a practice connecting the individual to the social order.

The opposition larger–smaller, for example, does not only differentiate male from female, but it operates within the male and female categories as well. Men who are small with respect to other men are viewed as less masculine; women who are large with respect to other women are viewed as less feminine. Susan Gal and

Judith Irvine (1995) refer to this nesting of the overall opposition within each component of the opposition as fractal recursivity.

Recursivity provides a particularly powerful force in gender enforcement, as people tend to compare themselves not with people of the other gender, but with people of their own. Men deemed feminine (or effeminate) are seen as inferior men. While women deemed masculine may sometimes be seen as inferior women, they are also seen as striving for what is in fact a valued masculine persona. This is one reason that masculine behavior in women is often less stigmatized than feminine behavior in men

Masculinities and femininities :

that generalizations about gender can all too easily erase Male and female, masculinity and femininity, are not equally dimorphic everywhere. Nor are they experienced or defined in the same ways everywhere.

Types of sexual orientation:

According to current scientific understanding, individuals are usually aware of their sexual orientation between middle childhood and early adolescence (American Psychological Association 2008). They do not have to participate in sexual activity to be aware of these emotional, romantic, and physical attractions; people can be celibate and still recognize their sexual orientation. Homosexual women (also referred to as lesbians), homosexual men (also referred to as gays), and bisexuals of both genders may have very different experiences of discovering and accepting their sexual orientation. At the point of puberty, some may be able to claim their sexual orientations while others may be unready or unwilling to make their homosexuality or bisexuality known since it goes against North American society's historical norms (APA 2008). Transgendered males, for example, have such a strong emotional and psychological connection to the feminine aspects of society that they identify their gender as female. The parallel connection to masculinity exists for transgendered females. It is difficult to determine the prevalence of transgenderism in society. Transgendered individuals who wish to alter their bodies through medical interventions such as surgery and hormonal therapy—so that their physical being is better aligned with gender identity—are called **transsexuals**. They may also be known as male-to-female (MTF) or female-to-male (FTM) transsexuals.

Alfred Kinsey was among the first to conceptualize sexuality as a continuum rather than a strict dichotomy of gay or straight. To classify this continuum of heterosexuality and homosexuality, Kinsey created a six-point rating scale that ranges from exclusively heterosexual to exclusively homosexual (see Figure 12.4). In his 1948 work *Sexual Behavior in the Human Male*, Kinsey writes, “Males do not represent two discrete populations, heterosexual and homosexual. The world is not to be divided into sheep and goats … The living world is a continuum in each and every one of its aspects” (Kinsey et al 1948).

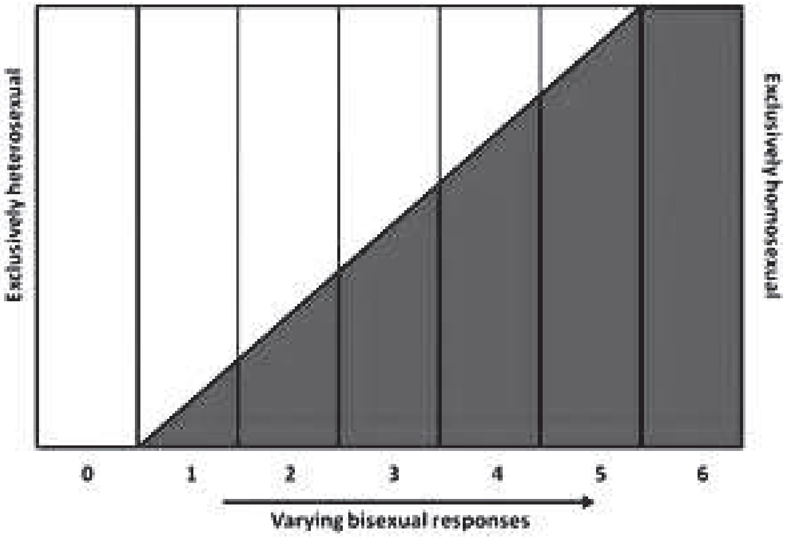


Figure 12.4. The Kinsey scale indicates that sexuality can be measured by more than just heterosexuality and homosexuality.

So Is sexuality an effect of sex or gender?

Gender refers to the widely shared set of expectations and norms linked to how women and men, and girls and boys, should behave. Unlike ‘sex’ which refers to the biological and physiological characteristics that define men and women, gender refers to the socially constructed roles, behaviours, activities, and attributes that are assigned to men and women in any given society. These expectations are are not fixed but are continually being constructed and reinforced through social relationships and economic and political power dynamics.(http://spl.ids.ac.uk/sexuality-and-social-justice-toolkit/1-issues-and-debates/what-link-between-sexuality-and-gender)

Gender and sexuality cannot be thought of as distinct and separate categories but as intimately related. The societies we live in construct the right and wrong way to behave as men and women and these are mapped onto ‘right’ and ‘wrong’ sexual practices, beliefs and behaviours:*”Ideologies claiming that women should be pure and chaste can lead to female genital mutilation, honour killings, and restrictions on women’s mobility and economic or political participation. Ideas that men should be macho can mean that sexual violence is expected rather than condemned. In many places, to be considered a ‘proper man’ or ‘proper woman’, you need to act one hundred per cent heterosexual, and stay in line with gender stereotypes.” (Ikkaracan and Jolly 2007: 3)*

Characteristics of Sexuality:

1. Sexuality is influenced by gender norms

Social expectations linked to gender influence how women and men behave and this includes their sexual behaviour, attitudes and feelings. These expectations tend to be based on the assumption that there are two categories of people, men and women and that they behave differently based on their biological sex. There is also a basic assumption in development policy and programming that gender is linked to biological sex and that the recipients of development interventions are heterosexual. The assumption that the normal and natural sexual relationship and basis for the family is a man and a woman in a heterosexual marriage is sometimes described as heteronormativity.

There is huge variation in the gendered norms and expectations relating to sexuality. The pressures to conform to the norms of any given society can have negative consequences for both women and men. In some contexts, women may be forced to enter marriages against their will and some may be subject to marital rape; or they may be compelled to undergo female circumcision in order to be perceived by society as an ‘adult woman’. Boys too are told how to behave as men, how to be taken seriously by their family and their community; this may entail being bullied or punished if boys are not ‘macho’ enough, or if they express same-sex desires.

2. Ideologies around sexuality work to control women

In many contexts, girls and women are seen as vulnerable and in need of ‘protection’ from men’s sexual advances. Virginity is often highly prized and is linked to a family's ability to arrange a marriage and maintain social status. Controlling girls' and women's sexuality is also linked to material resources such as education and whether or not girls are able to attend school. Where virginity is important, parents may fear the increased possibility of sexual encounters between boys and girls at school (as shown by the study undertaken by , Nirantar) or are concerned that, with education, girls may be more likely to challenge the *patriachal* structures that are reinforced through historic family customs, like arranged marriages.Sexuality is often used to control women who are seen to step outside of the norms of feminity:*…from the United States to Namibia to Poland, accusations around sexuality are used to attack women's organising. Women mobilising for gender equality are sometimes accused of being 'not proper women', lesbians, or promiscuous. Such attacks aim to undermine such women and curb their political power and impact, as well as reinforce ideas about what is proper behaviour for women. (Ikkaracan and Jolly, 2007: 5)*As IDS member Mariz Tadros demonstrates in her case study of politically motivated sexual assault in Egypt (2013), women who entered the public sphere of protest rather than remaining within the private sphere of the home were 'punished' through sexual assault.

As Tadros points out, men were also the victims of sexual assault but because of gendered assumptions about who is the victim and who is the perpetrator these cases were less likely to receive attention both domestically and internationally.

Of particular concern is the depiction of women in ways that are dehumanizing, especially in music videos. Even in mainstream advertising, however, themes intermingling violence and sexuality are quite common (Kilbourne 2000).

3. Gender norms related to sexuality can affect health and access to basic services

In many societies women are expected to remain silent around issues related to sex and sexuality. For this reason, it can be difficult for women to learn about risk reduction, or even if informed, it may be difficult for women to negotiate safe sex within their sexual relationships. Because of the strong norms that encourage women to remain virgins until they are married, studies have shown that it is difficult for unmarried women to access treatment services for sexually transmitted diseases as they may be subject to stigma within health care centres.

Research has shown, too, that in heterosexual relationships women's economic marginalisation can result in women entering sexual relationships where they have less economic power than their partner. This can impact on their ability to set the terms of their sexual relationship. Gendered expectations that young women cannot 'manage' or 'protect' their sexuality also has implications for women's access to education and employment. In their policy audit of the Rashtriya Madhyamik Shiksha Abhiyan (RMSA) education policy in India, Nirantar show the importance of considering the gendered dynamics of sexuality in relation to girls' ability to access education:

"the data indicate that fears related to girls' sexuality – namely that girls might express their desires or that they might experience sexual violence in the process of going to school – are a significant reason for pulling girls out of school. This is important in a context where girls' access to higher levels of school education is seen primarily as a gender issue. In the absence of evidence and without an acknowledgement of the key role of sexuality as a determinant, we are left with an incomplete understanding of this critical issue." (Nirantar, 2014: 2)

It is often assumed that gender applies only to women and girls but it is equally important to engage with the ways that men's health and access to services can be affected by expectations linked to masculinity. For example, in many parts of the world men are expected to have more experience and knowledge about sex than women; this discourages men from learning about safe sexual practices and may make them more vulnerable to contracting HIV or other sexually transmitted diseases.

Notions of 'macho' masculinities that emphasise men's domination over women – socially and sexually – not only contribute to high rates of violent crime against women (as we see in places like South Africa – link to Case Study) but also to the stigmatization of men who fail to conform to these gendered expectations, including those who have sex with other men. As men are generally positioned as the perpetrators of sexual violence and not the victims, men's vulnerability to and experience of sexual violence also tends to be ignored

Gendered norms around sexuality affect how sexual behaviour and sexual health issues are reported, researched and funded. Assumptions about women as the victims of sexual violence, for example, restrict our knowledge about how women negotiate risk and exert control in their sexual relationships. As men are considered to be strong and capable of managing sexual relationships, there is very little research into mens' experience of vulnerability, in both same-sex and heterosexual relationships. The lack of knowledge about the sexuality of transgender people often leads to the assumption that transgender men and women are homosexual. Gendered expectations of sexuality, therefore, also determine what we know about the sexuality of men and women, which in turn informs decisions about development programming, funding and research……………………………

3.3.2 Sexuality to Marriage:

If school leaving can be said to mark the end of childhood and the formal beginning of that journey to full adult status, then marriage, and even more so, parenthood, publicly announces its completion: historically, marriage was a strategic alliance between two families, more often than not orchestrated by the families to ensure long-term stability and prosperity for the maximum amount of people. Heterosexual marriage is deeply rooted in the idea of patriarchy with an attempt to legitimise bodily needs , proliferate progeny and has been a seat of control.

Marriage is a primary institutional context for the study of gender and gender inequality. Within this context, one way in which gender inequality is maintained is through gender norms, which are often upheld by hegemonic masculinity—the pattern of practices that legitimize men's dominance over women (Connell 1995; Connell and Messerschmidt 2005).

Power inequalities are shaped and structured in part by the division of labor within a relationship, which in turn affects marital quality. Division of labor in different-sex marriages often remains unequal even when couples believe that both spouses should share equal power (Hochschild 1989; Stevens, Kiger, and Riley 2001), and such inequality is associated with lower relationship quality, including less relationship satisfaction and intimacy (Carlson, Hanson, and Fitzroy 2016; Galovan et al. 2014; Holm et al. 2001; Kurdek 2007; Stevens, Kiger, and Riley 2001).

A rich literature on different-sex partnerships has focused on household labor as a measure of shared power in relationships to reveal substantial gender inequalities in the context of different-sex marriage, often through the maintenance of hegemonic masculinity. Men do less unpaid labor than their female partners, including less housework (Lachance-Grzela and Bouchard 2010), emotion work (Curran et al. 2015; Erickson 2005; Thomeer, Reczek, and Umberson 2015), and child care

(Hochschild 1989; Poortman and Lippe 2009). However, almost all prior research on power inequalities in different-sex relationships analyzes gender by comparing women to men (Davis 2010), which does not account for the degree to which women and men within these couples are gender conforming (i.e., women embody femininity and men embody masculinity). Hegemonic gender norms are often exaggerated forms of how women and men are expected to behave and interact in ways that perpetuate gender inequalities (Ferree 2010); however, few people fully enact and conform to these norms (Connell and Messerschmidt 2005). Past research on same-sex couples points to the importance of considering not just gender but also gender conformity in understanding relationship and marital processes. Lesbian, gay, and bisexual people are less likely to be gender conforming than are heterosexuals (Li, Pollitt, and Russell 2016), and same-sex couples share the household division of labor more equally than different-sex couples (Balsam et al. 2008; Gotta et al. 2011).

Gender norms and marriage:

The gender as relational perspective has been applied to different-sex partnerships to show how women and men structure gender in their relationships through an examination of the division of household labor. Within committed partnerships such as marriage, men do less unpaid labor—including emotion work, household work, and child care—than do women (Lachance-Grzela and Bouchard 2010), in part because this unpaid labor is associated with hegemonic gender norms expected of women. Women may do unpaid labor to conform to societal gender norms, and men may avoid unpaid labor in the home also to conform to gender norms (Civettini 2016; Curran et al. 2015; Pfeffer 2010). Thus, unpaid labor becomes a way in which adherence to gender conformity maintains power inequalities in relationships and reinforces hegemonic gender norms. For example, some wives who are not gender conforming because they earn more income than their husbands do more housework as a form of deviance neutralization, as a way to re-emphasize their femininity (Civettini 2016).

These subjective perceptions of shared power appear to have important implications for marital quality: both women and men report worse marital quality and increased likelihood of divorce when they perceive inequality in their relationship (Frisco and Williams 2003). One study found that, among middle-class, different-sex couples, perceived inequity in relationships was the strongest predictor of marital conflict (Perry-Jenkins and Folk 1994).

This finding supports prior research showing that women who hold more traditional views about gender roles (e.g., that men should be breadwinners and women should be caregivers) report less unfairness and gender inequality in their relationships than women who believe spouses should share divisions of labor more equally (Greenstein 1996; Lavee and Katz 2002)

Thought for Discussiom

a. What are the gender norms that you have grown up with.

b. Do you think gender norms have influenced your school, college or work place? Analyse citing atleast three situations

c. What are the positive and negative impacts of gender norms relating to sexuality for men and women?

d. How many different models of masculinity and femnity can you identify from the advertisements shown in television.

e. Does these gender norms influence marriage.

f. Give the criteria for a successful marriage ?

3.4 Religious and Cultural effect on Gender & Sexuality and Marriage

A growing body of research today indicates that religions play an important role in the economic, demographic, marital and sexual behavior of individuals and families, ranging from patterns of employment to fertility and marital stability [Waite LJ. 2000.) has been identified as a trait that is complementary in the context of marriage and for which positive assertive mating is optimal.[Becker GS. 1991.) Religion has also been found to effect one's choice of marital partner.[Oppenheimer VK. 1988) Religion is known to affect the pattern of sexual behavior one follows, attitudes towards pregnancy and premarital sex, desired fertility and the division of labor between partners across the life-cycle.[K ingsley D. ; 1985) Marriage is the voluntary sexual and public social union of one man and one woman from different families.(Priyanka, 2013).

The purpose of marriage remains, three fold.First and primarily it serves the concept of procreation, secondly it emphasises the human need for bonding and compassionate coexistence to create the innermost unit of society and thirdly to maintain public order , to generate control over overt sexual behaviour.

Religion and sexual behaviour:

Different cultures have shaped in India and the world owing to the adherence to different religion. Each religion comes with its own set of belief system, and rituals to give shape to that belief system. These rituals over the time crystalise to become cultures. Thus religion if not completely but was largely responsible for creating religion specific cultures before the era of Globalisation. India has seen religions like Islam, Hinduism, Christianity, Buddhism, and Judaism. In each of these religion, micro religious beliefs and macro religious cultures shape individuals' sexual behaviors. Cultural norms or personal religious beliefs are more powerful and they might work in conjunction with formal constraints to shape individuals' sexual behaviors.

Much research has been devoted to understanding religion's influence on sexual behaviors (Meier 2003; Rostosky et al. 2004). Researchers have found that individuals who believe religion is important and are religiously active are more likely to delay first sex (sometimes until marriage) (Chamratrithirong et al. 2010; Gilbert 2008; Holder et al. 2000; Meier 2003; Rostosky et al. 2004; Shirazi and Morowatisharifabad 2009; Zaleski and Schiaffino 2000).Some cross-national attitudinal studies find that Muslims and Hindus tend to have more conservative sex-related attitudes than do Christians (Finke and Adamczyk 2008). Likewise, in the few studies that survey people of different religions within the same nation, Muslims appear less likely than Christians to have premarital sex (Addai 2000; Agha 2009). Researchers have also found that Jews tend to have more liberal sex-related attitudes than do Christians (Regnerus and Uecker 2007). Finally, in the handful of studies that examine Buddhists, results are inconsistent (Adamczyk and Pitt 2009; de Visser et al. 2007; Finke and Adamczyk 2008; Lee et al. 2006).

3.4.1 Different Religions and concepts of marriage and pre marital sexual behaviour:

Buddhism and Marriage:

The Buddhist views on marriage are very liberal. In Buddhism, marriage is considered as personal and individual concern, and not as a religious duty. Buddhism does not compel a person to be married. It does not force somebody to remain as a bachelor. It is not laid down anywhere that Buddhists must produce children or regulate the number of children that they produce. Buddhism allows each individual the freedom to decide for himself all the issues pertaining to marriage. It might be asked why Buddhist monks do not marry, since there are no laws for or against marriage. The reason is obviously that to be of service to mankind, the monks have chosen a way of life, which includes celibaccy

Buddhist marriages have been considered as secular matters in Buddhist countries. The parties took a blessing from monks at the local temple after the civil registration formalities have been completed. Although Buddhist monks do not solemnize a marriage ceremony, they do perform religious services in order to bless the couples. From the Buddhist point of view, marriage is neither holy nor unholy. Buddhism does not regard marriage as a religious duty nor as a sacrament that is ordained in heaven.

Hinduism and Marriage:

Many Hindu communities discourage young men and women from regular private interaction (Caldwell et al. 1998). However, this may have more to do with cultural tradition and caste than with religious proscriptions regarding premarital sex. Some Hindu communities view social division by caste as religiously ordained. Additionally, in Asia, especially South Asia (Jensen and Thornton 2003), many Hindu families play a role in arranging their children's marriages (often with their children's permission) and a premarital pregnancy could be problematic for arranging a suitable match (Fuller and Narasimhan 2008; Ghimire et al. 2006). Stories from Mahabharata though legitimise premarital sex with Rishis(hermits) child out of wedlock is not accepted as seen in the case Kunti disowning her first child Karna.Family background is likely significant in selecting a spouse. If family members play a role in selecting their children's marriage partner, they may discourage their children from informally interacting with potential partners whom they do not know or prefer (Caldwell et al. 1998)

Early marriage (even before menarche) may be seen as protection against premarital sex (Makinwa-Adebusoye 1992). Consistent with these ideas, Agha (2009) examined two waves of data from the Nigerian Demographic and Health Surveys and found that 8 percent of Nigerian Christian women age 15 to 19 years were married in 2003, but 61 percent of Nigerian Muslim women of the same age were married.

Hindu parents may also marry their children at very young ages. Within middle-class and higher caste families, Hindu children are likely to marry after they complete their education (Fuller and Narasimhan 2008). For Hindus belonging to lower castes, however, marriage likely occurs much earlier, especially for girls, in part because of the group's lower socioeconomic status (Sheela and Audinarayana 2003). Indeed, according to the 2005 to 2006 Demographic and Health Survey, Hindus living in India and Nepal have an average age of first marriage of 17 years and 10 months. In contrast, Christians living in these countries have an average age of first marriage of 19 years and seven months.

Jainism and marriage:

Unlike the Hindus who look upon marriage as a sacrament, Jains treat the institution as a contract. Friendship and marriage is considered to be a worldly affair and marriage is recommended so that the children born to the couple would also follow the same dharma (religion). Its purpose is to make sex licit within a family. The role of sex between husband and wife is strictly procreational, so that its engagement is limited to the ovulation period(Zwilling L, Sweet MJ,1996)

Zoroastrianism and marriage:

Contrary to this is the Parsi belief that God revealed to Zarthustra, the prophet, that not only is a marriage a righteous act, but it is also a commitment which makes even the earth rejoice.(Priyanka , 2013). Some orthodox views of Zoroastrianism on sexual orientation are that homosexuality is considered evil.[Bhabha H; 1960)

Sikhism and Marriage:

Upholding the ideals propagated by Guru Nanak Dev, women have equal rights and are given as much respect as men, in Sikhism. In fact, Guru Nanak Dev fought fervently for women's rights during his life time and proclaimed them to be equal to men using the following argument:"In a woman, a man is conceived; from a woman, he is born. With a woman, he is betrothed and married; with a woman, he contracts friendship. Why say she is inferior, the one from who even kings are born? Without woman, there would be no one at all."[Singh NG. 2008)

Further, as per Sikh ideals, a woman is considered to be the other half of a man and the one who leads him to the doors of liberation. In accordance with his other teachings, Guru Nanak had also condemned various cultural practices, which were derogatory to the status of women and had proclaimed equality of both the sexes even within the wedlock.

Islam and Marriage:

For man to become eligible for taking a woman's hand in marriage, Islam has several recommendations. According to Islamic laws, when a boy attains the age of fifteen, or becomes sexually potent, he is *baligh*, and has attained puberty. But this is not enough for entering into a contract of marriage.

Apart from the laws related to puberty, there is a concept of *Rushd* 1 which can be translated as 'capability of a sensible conduct' or maturity. A husband has to be *Rashid* and a wife *Rashidah;* so that the responsibilities of married life are sensibly discharged.

n Islam, marriage is not restricted to a platonic relationship between husband and wife, nor is it solely for procreation. The Islamic term for marriage, "*nikah*" literally means sexual intercourse.5

So why has Islam provided extensive rules and regulation regarding sex? This was because Islam has fully understood that sexual instincts cannot and must not be repressed. They can only be regulated for the well being of human beings in this life and for their success in the hereafter.

Sex in married life has been openly recommended in Qur'an,

"…when they [i.e., the wives] have cleansed themselves [after menstruation], you go into them as Allah has commanded…" (Surah al-Baqarah, 2:222)

Islam also regards marriage as a way to acquire spiritual perfection.

The Prophet (S) said, *"One who marries, has already guarded half of his religion, therefore he should fear Allah for the other half."*

Christianity and Marriage:

Christians believe that marriage is a gift from God, one that should not be taken for granted. It is the right atmosphere to engage in sexual relations and to build a family life. Getting married in a church, in front of God, is very important.

A marriage is a public declaration of love and commitment. This declaration is made in front of friends and family in a church ceremony.

If you choose to get married in church, there is an added dimension - the assurance that God cares about your relationship and that His resources and strength are available to help you. Including God in your marriage doesn't mean that you will avoid all the usual ups and downs, but you will know that you can look to God for help and guidance and that His love will sustain you. You will also have the support of the Christian Church family.

3.4.2 Religion and culture-formation of gender norms:

India is a multicultural and multireligious country.Religion and culture most of the times are intricately related.Cross cultural influences are thus commonCertain relious practices become a representative of a culture and that itself becomes a norm. 'Norms are vital determinants of social stratification as they reflect and reproduce relations that empower some groups of people with material resources, authority, and entitlements while marginalizing and subordinating others by normalizing shame, inequality, indifference or invisibility. It is important to note that these norms reflect and reproduce underlying gendered relations of power, and that is fundamentally what makes them difficult to alter or transform.' (Sen et al., 2007: 28)

Cialdini et al. (1990) distinguishing between 'injunctive norms' (what people believe they and others are supposed to do) and 'descriptive norms' (what people actually do). The term 'norm' is often used to describe practices, such as early marriage or female genital mutilation/ cutting (FGM/C), (and can also be used as equivalent to 'cultural values') and this can lead to confusion. An ideal example would be from the Quran Surah an-Nisa' 4:1 states that men and women are created from a single soul (nafs wahidah). One person does not come before the other, one is not superior to the other, and one is not the derivative of the other. A woman is not created for the purpose of a man.(Haug F,1987)Rather, they are both created for the mutual benefit of each other (Quran 30:21).But practices like superiority of men over women in form of legitimised polygamy , wearing of Hijab or burkhah by women, non expression of sexual desires on the part of women are practised.

Because people are socialised into their community's gender ideologies which again has its root in religion and culture,and rules about how boys and girls are expected to think and behave from early childhood – often with limited exposure to other ideas or influences direct them to act and behave as they do. Gender ideologies and their associated norms can thus set the boundaries of what girls and boys and adult womenand men think as well as what they do; they can make inequalities of power and resources seem natural or Godgiven, and thus unchangeable. Values and norms about who can speak out or make decisions also directly affect how power is distributed in society – typically to the disadvantage of children and adolescents in general, and girls in particular (Sen et al., 2007; Marcus and Harper, 2014)

So, for example, for many young women, sexual harassment in public is a common experience. To understand the ways that different factors contribute to it, it is important to understand the Underlying values – such as ideologies of male superiority, of men's right to women's bodies, and of girls' and women's place being in the home.It is also resultant of age old beliefs that women should be appropriately clothed, follow certain norms of behaviour and if they deviate from the norms it becomes acceptable for men to leer, wolf-whistle, make sexually explicit remarks or to touch women (without their consent) .

However it would be pertinent to mention here that the western definition of gender is different from that of the Asian one. Western definitions of gender tend to group humans into two distinct static categories based upon the physical appearance of genitalia. However, this construction is not universal. South Asian gender definitions emphasize the different essences or humor attributed to men and women as opposed to the overt physical emphasis of the western world. Humors are present more or less strongly in every food or body tissue.(Lamb,S.2000)

It is interesting to note that women as per this definition are projected as having strong sexuality and power for destruction and specifically during youth can be subjected to pollution.Thus they need to be protected from their own power and bound within the norms of society. The changes in gender status throughout age are strongly linked to changes in her reproductive capacity and depiction as a sexualized being.[Caplan.P,1987)

This could be the foundation of practices like child marriage:

Child marriage is often thought of as an example of a discriminatory gender norm. A large number of factors contribute to the practice of child marriage, not all of which are relevant in any given circumstance. Cultural and/ or religious values emphasising virginity guides the principle of child marriage and thus encourages marriage in adolescence or before.

Hinduism as a religion started with the doctrine of equality which later through introduction of Manusamhita became more rigid with specific norms for specific gender and talked about the inferior status of girls.Child marriage is a mechanism of retaining that status of girls' future roles as wives and mothers only limiting girls' aspirations and parents' aspirations for the daughters.

The culture of male superiority as a part of gender ideology, assigns the majority of domestic work to girls, which can, in turn, impede their opportunities for study. Where resources are scarce this can lead to investments being concentrated on boys who have a lower burden of chores and are freer to fulfil their potential.

Son bias, which as well as affecting the resources invested in girls' education can lead to families viewing girls and their marriageability as an 'asset' to be traded at the appropriate time, and boys as worth investing in as they will stay in the parental home. Older women can also have a stake in upholding discriminatory gender norms if they have benefited from the prestige associated with having adult sons, or from having a daughter-in-law to share or take on the burden of domestic chores (Kandiyoti, 1988).

'Girls are expected to be submissive, docile and shy, and not to be outspoken, opinionated and mischievous. Similarly, girls' behaviour is closely linked to notions of honour, shame and prestige, with girls feeling they are under the close and continued scrutiny of society. This means girls are constantly under pressure to think about the family name and honour in their daily lives, ranging from the clothes they wear to the way they behave in public.

Thus a girl cannot stay overnight at a friend's house; she cannot be seen to roam around/be mobile; she cannot be seen to be talking/interacting with boys. While boys can express their sexuality and sexual curiosity, girls face great pressure not to show interest in knowing about sex, sexual activity, or sexual appeal. Fear of being ostracised from society is the main reason girls do not challenge established norms, although this does not stop them from criticising and questioning both the norms and their own situation.' Source: Watson and Harper, 2013.

This leads to formation of a pattern of behaviour set for girls and her mode of interaction with the society.What happens when a girl is otherwise?We witness a series of violent acts on girls in the name of protection of family honour, the ultimate form of which is honour killing.When a girl expresses her sexual desires she is considered to be a fallen woman and when a girl expresses her opinion against she is retorted with violence.The ultimate form of it being rape which more than an act of lust is an attempt to reesablish male dominance and superiority over women.

The effect of religion on gender discrimination is echoed not only in India but other countries as well.

Following examples illustrate that:

1. 'God created us differently, the men and the women. That's why culture also treats us differently. It is government which is spoiling things. How can my son cook, bathe the children, wash my clothes, or fetch water when the women and the girls are there? How can my wife build the hut when I or her sons are there? Can I call my daughter to help to slaughter the cock when God blessed me with all these sons? God would curse me if I did.' Focus group with men and women, Uganda (Kyomuhendo Bantebya et al., 2013)

2. Son bias can reflect deep-seated perceptions (rooted in culture and religion) of the relative roles and values of boys and girls/men and women. Among Hmong communities in northern Viet Nam, for example, having a son to perform funeral rites and lead ancestor worship is perceived as essential to ensure wellbeing in the afterlife. Son bias is often exacerbated in communities where daughters are perceived as an economic drain on the family, because they will join another household upon marriage, or where it is not acceptable for parents to accept financial support from their daughters, as in some of the communities in Nepal.

3. For married girls, son bias can mean pressure to continue childbearing until a son is born (in this was particularly evident in Nepal and among the Hmong communities in northern Viet Nam).

Efforts to replace discriminatory gender norms with more equitable attitudes and practices therefore need to change how the norm is promoted and reinforced across all these institutions and settings (Marcus and Harper, 2014).

Thought for Discussiom :

1. Make a visit to the different religious institutions in your state.With the help of an open ended questionnaire gather information on the following:

a. practices essential for marriage

b. how religion is connected to marriage

c .dictates given in religion regarding marital practices in the sacred books

2. Review Literature on Indian marraiges .Estabish the influence of culture in the conduct of marital life.

3.5 Marriage & persons with intellectual disability: Misconceptions & Remediation.

3.5.1 Attitude of society towards Marriage, sexualityand intimate relationship of PWID:

A chronological account:

1. It is agreed,' asserted the Board of Control in 1949, with a spurious authority that in fact rested on little more than prejudice and anecdote, 'that mentally defective persons are generally unfit for the responsibility of marriage and parenthood' (quoted in Mattinson 1970, p.47).

2. Mabel Cooper describes some of the extraordinary strategies adopted by the authorities at St Lawrence's in the early 1950s to control social intercourse between the sexes and ensure that undesirable attachments did not form

3. Edgerton (1967), notes that for his sample of exhospital residents marriage and parenthood remained 'cherished goal, essential components of self-esteem, despite the fact that for many it was their sexuality– their proclivity, 'real or fancied', for sexual misconduct– that had prompted their removal from the community in the first place; a confinement from whichthey were only released by their agreement to sterilization.

4. Even with the adoption of community care and 'normalization' and the formal abandonment of the institution as the cornerstone of government policy, opposition to (perhaps one should more accurately say, incredulity with) the idea of people with intellectual disabilities marrying persisted, if perhaps in a less overt fashion. Like Normal People (Myers 1978) celebrates the marriage of two 'retarded' people inthe USA in the late 1970s as a major breakthrough (as it then surely was), achieved des

pite the reservations of support workers and family. The couple involved describe the obstacles they encountered to their burgeoning relationship from the staff in the residential home where they were both living before their marriage: 'They wouldn't let us be alone together, and if w e were in the same room, we had to leave the door open. It was as if they didn't trust us … Houseparents would criticize us if we held hands or if I put my arm around her' (p.148)

5. Craft and Craft (1979), pioneers in the field, were reporting on their failure, 'despite three years of staff counsellin g', to open up one UK institution to married residents. In this way, denied the opportunity to engage in meaningful adult relationships, the public image of people with intellectual disabilities as 'eternal children' was reinforced.

The shift:

The question posed at the very outset of Mattison's study–do the people with intellectual disabilities have a right to sexuality does not exist any more.(One of the earliest, and certainly most influential, studies of marriage is Mattinson's (1970) study of 36 couples discharged on licence from one large hospital in the south-west of England in the 1950s and 1960)

Has the situation changed now?

"Joymoti (name changed), was a very lovable young girl. She was under care at the Sanjivani Hostel. She was intellectually challenged. Joymoti loved to talk and when talking to boys, she would often propose them for marriage. As Joymoti kept pestering her guardians for a mobile phone, they gave her one on pretext, though it was not in working order. Most of the time, she was observed talking on that phone by herself where she would be proposing to the (imagined) person on the other side. Even while travelling, she would carry her mobile and was observed extending marriage proposals throughout the phone conversations. Sometimes, Joymoti would hug and kiss the person sitting next to her, out of the blue. These were all observations made by her caregivers but they were never considered a matter of concern.**(FST, 2016)**

The Bapu Trust works with individuals and family care providers dealing with intellectual and developmental disability. Bhargavi Davar speaks of a case where "the family wanted to get one such individual married. Initially, senior staff at

Bapu Trust were hostile to this idea. They did not grasp that IQ is not the same as EQ. Low IQ does not equal low EQ.

‘Is marriage a viable proposition for the subnormal and their children?’–

According to the WOHTRAC report, “In many cases, men with mild mental retardation are married off in the belief that marriage would cure them of their ‘problem’”. In such cases, the practice is to get a beautiful girl with a ‘defect’ for the man with mental disabilities. Similarly non-disabled women from lower socio-economic strata are often married to men with disabilities. who belong to a higher socio-economic class. This is often seen as a win-win situation as the poorer family of the woman does not need to worry about dowry for her and the man’s family is satisfied that they have found someone to care for their son with disabilities.. Prilleltensky (2004:41-53) notes that disabled women are no strangers to having their sexuality negated, with strong messages of motherhood and reproduction being off limits. Sex and disability continues to be approached as a clinical matter, written and talked about from a bio-medical viewpoint of regulating the fertility of the “dangerous female” (Fiduccia, 2000:167).

Prilleltensky (2004:35-37) refers to findings that many women are told by their families that they are not eligible for marriage and motherhood, and that parents of disabled girls have lower expectations for their daughters in terms of intimate relationships. Many well-meaning parents of disabled young men and women believe that discussing sexuality would raise false hopes, particularly in a society that places prime value on perfection and achievement (Milligan & Neufeldt, 2001:93-94).

The disabled woman as “tragedy”, that undermines their status as “eligible women”, is prevalent and still pervasive and mothers are legitimately doubtful about their disabled daughters entering into the social institution of marriage (Shakespeare, 1999; Karellou, 2003; Prilleltensky, 2004; Hassouneh-Phillips & McNeff, 2005).

So the sexual needs of a person with intellectual disability are not addressed, nor their emotional or relationship needs.

2.5.2 Support is required, to dissipate the myths

Very little studies have been conducted with Person with profoundIntellectual Disabilities.

There have been a number of myths associated with ID;

- **Myth 1:** People with intellectual disabilities are unable to think. Reality: People labelled intellectually disabled may take more time to come up with an answer. Some are challenged to engage abstract thinking. But they do think (WWILD, 2012). Nartey (2007) reckons that this myth has had much to do with professional disinterest in working with this population; the fear that the client would not be able to think, reasoned the psychoanalyst, meant that he would not be able to form transferences, the basis of psychoanalytic work (Nartey, 2007).
- **Myth 2:** People with intellectual disability cannot feel. **Reality:** People with disability have feelings and experience emotions in the same ways as people without intellectual disability.
- **Myth 3:** People with an intellectual disability do not feel hurt or trauma from exploitation or abuse like persons without disability do. **Reality:** People with intellectual disabilities feel these things as acutely as any other person.
- **Myth 4:** People with an intellectual disability are unable to communicate well in a therapeutic environment. **Reality:** The intellectually disabled can communicate in a number of different mediums if given the opportunity.
- **Myth 5:** So-called "challenging" behaviours by people with intellectual disabilities are displayed because of their disability. **Reality:**Although people with intellectual disabilities sometimes engage in unique behaviours, the behaviours labelled "challenging" usually occur because they do not know how to express frustration, anger, or other strong emotions engendered from abuse or trauma. They need help to deal with that (WWILD, 2012)

All the above myths have given rise to the notion that PWID cannot lead a normal life- a life consisting of getting married, having or adopting children and raising a family.

A no.of matrimony sites cater to that

Several commercial marriage bureaus in India play a role in connecting persons with disabilities to potential marriage partners. As Nidhi Goyal says, "Unfortunately, all of it is about the disabled marrying the disabled. Inevitably this is the only choice there is. Again, we return to the reductionist approach of society."Popular Indian matrimonial websites like Shaadi.com173 and Bharat Matrimony174 have special sections for people with disabilities on their websites. However, these are not immediately visible upon accessing the sites. In addition, it is quite often obvious that the communication from the marriage bureau is dictated by the saleability of the idea, the market need for the service. This has its positive and its dark side.(SHAADI.COM Indian Matrimonials. Retrieved from

BHARAT MATRIMONY. Indian Matrimonials. Retrieved from http://www.bharatmatrimony.com/)

Support is required from trained professionals as well,as is evident from the following study on parenting by PWID

the failure to adjust parenting styles to changes in their child's development, a lack of verbal interaction with the child, insufficient cognitive stimulation especially in the area of play, a tendency to overgeneralize instructions, inconsistent use of discipline (and, in particular, a reliance on punishment at the expense of praise), and a lack of expressed warmth, love and affection in relationships. (Booth and Booth 1993)

The harsh reality:

Gender Ideology and Marriage:

Eugenics is the practice or advocacy of improving the human species by selectively mating people with specific desirable hereditary traits. It aims to reduce human suffering by "breeding out" disease, disabilities and so-called undesirable characteristics from the human population. Eugenics societies mushroomed across the Western world and the pressure intensified on families of intellectually disabled people to encourage the disabled not to marry or to procreate.

Parmenter (2001) argues that it was Mendel's formulations of recessive and dominant genes that led to the over-simplification of interpretations in the inheritance of "feeblemindedness". In the context of Mendelian terms of heredity: if mental deficiency was transmissible from one generation to another, then it became of utmost importance that the "feebleminded" not be allowed to procreate (Carlson, 2001:127). Whitney's (1929) paper in the Journal Eugenics of May 1929, reproduced in Rosen, Clark and Kivitz (1976:199-200), asserts the views of the period unambiguously: "If we apply the principles of heredity to human beings, then we may evolve a superior race, and in so doing, eliminate the social menace of those who are feebleminded". Sloan and Stevens (1976:26) cite Walter Fernald, a superintendent of the Massachusetts School for the Feebleminded from 1887 to 1924, as asserting that the "feebleminded women are almost invariably immoral and if at large usually become carriers of venereal disease or give birth to children who are as defective as themselves. The feebleminded woman who marries is twice as prolific as the normal woman".Thus marriage for this community was out of question.

Carlson (2001:132) states that in the history of "mental retardation" the image of "bad mothers" played an important part in explaining feeblemindedness. The feebleminded woman was the quintessential "bad mother" in that she symbolized careless and immoral procreation and represented the danger of tainting the human race with defective hereditary material.

In her analysis of the role of women in disability history, Carlson (2001:128-146) explains how women were utilized in the "incarceration and eugenics industry". The women inmates were themselves paradoxically used to care for more severely feebleminded patients. Carlson (2001) argues that this happened within the two definitions of the feebleminded woman's nature – she was inherently morally defective, but her nurturing role was justified as long as it remained within the institution. The very same women who had perverted virtues of feminine purity were called upon to nurture others in the institutions. Carlson argues that it was the maternal, childlike, and asexual stereotypes of intellectually disabled women that were at work here, with the institution presiding over them.

Sayce and Perkins (2002:18-24) maintain that disabled women still live in the shadow of eugenics. The authors refer to Judge Holmes who in 1927 authorised the forced sterilization of Carey Buck, who was purportedly "feebleminded", saying that "it is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind" (Sayce & Perkin, 2002:19). Servias, Leach, Jaques and Roussaux (2004:428-432) report on their recent findings that the sterilization rate for intellectually disabled women in Belgium is three times that of the general population.

Servias et al. (2004) reveal that studies converge in their conclusions that although sterilization programmes have "disappeared", the policy of institutions and the families of intellectually disabled women are the agents authorising the sterilization of intellectually disabled women. A key feature of these studies is the rarity of consideration for the opinions of the women themselves (Passer, Rauh, Chamberlain, McGrath & Burket, 1984; Patterson-Keels, Quint, Brown, Larson & Elkins, 1994).

.A multi state socio ecomnomic study of India, 2007 revealed the harsh reality of low likelihood of marriage specially with ID , also spoke about hypergamy and widowhood

3.5.3 Impact on PWID:

The negative social, cultural, educational, political, and economic meanings that accrue and weigh in on the lives of intellectually disabled persons (Benjamin, 2002a:4-6, Mulvany, 2000:584-592) make it impossible to think on the normal events like marriage and family propagation taking place in the lives of PWID. Disabled people are routinely told by physicians and other health staff they would very likely never marry, never have a family, and certainly would not have a sex life (Milligan & Nuefeldt, 2001:95). So marital life remains in obscurity.

Disabled people find access very difficult, not only physical but social access, to the places where non-disabled people learn to express their sexuality and meet new people or prospective partners (Shakespeare et al., 1996; Milligan & Neufeldt, 2001; Thomas et al., 1989; Shuttleworth, 2000). Experiences and opportunities in dating enable adolescents to develop interactive skills and discover their needs and desires regarding relationships and intimacy (Wiegerink, Roebroeck, Donkervoort, Stam & Cohen-Kettenis, 2006:1023-1031). Drummond (2006:32-34) in her study of the attitudes of society to the sexuality of intellectually disabled people, asserts that intellectually disabled people remain socially excluded from wider society and remain powerless in accessing their rights with respect to intimate relationships and sexuality expression. Holomotz (2006:6) points out that intellectually disabled people generally lack information on sexuality, which may result in limited awareness of the social meanings of sexual behaviour and their right to refuse participation.

. The findings of Hassouneh-Phillips and McNeff (2005:227-240) support the argument that internalised oppression of disabled women increases their vulnerability to getting into and staying in abusive relationships. Some disabled women, due to rejection or overprotection, believe that they are not entitled to loving and intimate relationships and that if they are in abusive relationships, “fate proclaims they deserve what they get” (Nosek et al., 2001:179).

Changes in perspective from Medical to Social model:

The processes of assessment, diagnosis, and treatment are the focus areas for professionals working with disabled people. Slee (1997:411) gives a description of the “defective individual” being subjected to diagnostic classification, regulation and treatment.

Rowitz and Gunn (1984:157-159) argue that the medicalisation of disability diverts the focus away from sociological and political conditions that might need social reform. In the medical model, disability is conceived of as an objective attribute, not a social construct. The processes of assessment and diagnosis confer a label on the individual and this label precedes the person. The onus and responsibility for the cause and cure of disability is placed on the individual (Poplin, 1988:400). Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society” (UPIAS, 1976:14).

The social model of disability, as a social constructionist view of disability (Donoghue, 2003:206), Views about disability have changed and disability activists argue that “we have moved a long way in the past 30 years – away from the focus on physical conditions of disabled persons and towards a focus on tackling the oppression that disabled people experience in society” (Priestley, 2006:21).

the establishment of the journal Disability & Society in 1986 was crucial in generating an important body of literature that was more political and personal in style. This journal brought Disability Studies closer to disability culture and the disabled people’s movement.(Priestly (2006:27-28) The social model has been a major catalyst for the increasing politicization of disabled people and their allies throughout the world (Campbell & Oliver, 1996; Charlton, 1998; Hasler, 1993).

The social model redirects the focus from impairment on to disability and emphasises the disabling social, environmental and attitudinal barriers, rather than lack of ability by individuals. Thus, while impairment is the functional limitation which affects a person’s body, disability is the loss or limitation of opportunities resulting from direct and indirect discrimination (Abberly,1987; Bailey, 2004; Barnes, 1997a; Barton & Oliver, 2000; Dowling & Dolan, 2001; and Finkelstein, 2005). Oliver (1990:11; 1996:33) .

Disabilityis the disadvantage caused by contemporary social organization which takes little or no account of people with impairments. This disadvantage experienced by disabled people is considered to be institutionalised throughout society. “Impairment” in the social model of disability is not the focus; instead the focus is on the oppressive and exclusionary nature of society in response to impairment (Morris, 2000).Thus when the “defectiveness” of the individual is replaced by limitation of the society, the mindset can change and PWID can definitely get married and raise a family.

When a person with ID becomes a mother again has its effects.. Becoming a mother and thereby entering the discourse of motherhood, this young woman has in a way challenged and resisted widely held notions in relation to what kinds of statuses disabled women have in society (Grue & Lærum, 2002:674). At the same time, when combining motherhood and disability, disabled mothers come under close scrutiny and are in society’s critical gaze as they perform their roles as mothers (Booth & Booth, 2006:94-95; Reinikainen, 2008:26).Another study revealed that despite the formidable social pressures on these women to remain in a space of social devaluation, and for whom marriage is not a realistic option (Addlakha, 2007:113), they expressed their desire for marriage and having children, like most young adults do, a point also emphasised by Murphy (2005:640).

But the predominant concept guiding marriage and intimate relationship of PWID should be that despite the dominant perceptions that disabled people are less than sexual beings and therefore need to be protected, it is evident that disabled people are very sexually aware and are as capable of participating in and wanting relationships and intimacy as the non-disabled population (Browne & Russell, 2005; Potgieter & Khan, 2005; Timmers, Du Charme & Jacobs, 1981).

Following measures if taken timely and in a systematic manner right from the childhood may place persons with Disabilities aptly in social areana where just like their regular peers they would fall in and out of love, form intimate relationships , one of which may lead to marriage and then bear or adopt children to raise his or her own family.

Firstly , let the person since childhood interact freely with members of his or her community.It is important that people around are sensitised to understand his or her expression, language usage .The child also must be trained through cognitive behaviour modification how to interact appropriately.From a very early age sex education in the form of bad touch , good touch must be given in an appropriate manner like all other children. Tepper (2005:vi) urges parents to learn about and teach their young children about sexuality matters from an early age. Usually sexuality matters are difficult to speak about for some parents, and some parents of disabled children find it particularly difficult to speak about their disabled young adult's sexualities (Brown & Pirtle, 2008:60-61).

Secondly,timely sex education based on research based teaching strategies involving task analysis, use of visual cues should be given to fill the information gap.

Socialisation and relationship issues should form standard topics of sexuality programmes (Johns, 2005; Galea, Butler & Iacono, 2004; Leutar & Mihokovi, 2007). Di Giulio (2003:64) writes that sexuality 181 education should emphasize, among other things, social skills and relationship training. This includes informing disabled people of their rights and can assist with personal safety.

Thirdly, Closer co-operation and open discussions between parents and educators signify to disabled young people an acknowledgement of their sexuality and this is critical in assisting individuals with healthy sexual development (Gordon, Tschopp & Feldman, 2005:514-516). Schools can also provide a forum where parents can meet and discuss sexuality issues with other parents. Dating sessions could be orchestrated by parents with other adolescnts within a group setting so that they have increased social interactions.

Also there should be opportunities created for young adults to share their experiences, allow them to be "more normal" , to understand the feelings and frequent focus group interviews, talks to take place in an informal climate.Let each behaviour exhibited by them not be put unders scanner by the non disabled world.This constant communication will increase the level of consciousness not just from their part but also form an understanding in the non disabled community about their true capabilities.

Fourthly, PWID should be kept meaningfully occupied in sheltered , home or open employment as per their capabilities so that they establish themselves as meaningful contributing members of the society which would raise their self esteem .

Finally ,keeping their differences in mind, difficulties they face continuous knowledge dissemination using various media should be made for the public in the so called regular world to dissipate the misconceptions and firmly establish the right based approach towards disability.

3.6 Importance of Pre-marital Counselling, Gender Education

3.6.1 What is pre marital counselling?

Premarital counseling is a form of therapy that is provided to couples to prepare them for marriage. This counseling plays a vital role in this preparation. It is provided with the aim of helping couples have strong and healthy relationships, thereby giving them a greater chance of enjoying a stable as well as satisfying marriage.

Pre marital counselling when marriage is between two regular partners, in case of marriage of a PWID with a regular partner or a union between two adults with PWID.

In case of latter , it is first essential for the counsellor to understand have the people themselves adjusted to Disability .Unle.

Models of Adjustment to Disability:Two models of adjustment to disability that may be of particular interest to counselors are Wright's (1983) psychosocial model and Livneh and Antonak's (1997) stage model of adjustment.

According to Dembo, Leviton, and Wright (1956), and later by Wright (1983), the adjustment to disability process was believed to be affected by an individual's ability to: (a) enlarge or alter one's personal values following disability, (b) live a life that is not dictated by the disability, (c) focus on one's strengths and values rather than comparing oneself to others, and (d) live in a way that does not focus entirely on one's physical or personal appearance. Wright also helped counseling professionals understand that some people experience a sense of loss following their disability; thus, they may have a desire to make sense of it or to find meaning. Furthermore, through her work, Wright stressed that individuals must learn to view themselves as a whole person who has many attributes and abilities for successful adjustment to occur.

Disability scholars Livneh and Antonak (1997) developed a stage model to explain the process of adjustment to disability. Their model views adjustment to disability according to eight stages: (a) Shock, (b) Anxiety, (c) Denial, (d) Depression, (e) Internalized Anger, (f) Externalized Anger and Hostility, (g) Acknowledgement, and (h) Adjustment. Collectively, this model proposes that individuals may experience some or most of the first six stages, which comprises negative thoughts and feelings, before they reach a stage of acceptance and adjustment. However, they also stress the fact that adaptation may not take place in a linear fashion, adjustment phases may be skipped or later revisited, individuals' reactions will vary from one another, and each phase does not occur according to a pre-determined amount of time.

Regardless of the chosen model, counselors need to be aware that one model does not fit all experiences of disability or the needs of all individuals; therefore, the more knowledge counselors have about the adjustment to disability process, the better equipped they will be to select models they can use to explain the coping process of their clients.

Requirement of Pre marital COUNSELING:

Premarital counseling is provided in order to help couples enhance their relationships prior to marriage. Through this counseling, couples are advised to discuss numerous topics, including the following:

1. Intimacy, affection and sex-

This may require very sensitive , yet scientific way of explaining the concepts involved in above.The counsellor would have to have thorough knowledge off both counselling and disability.Its important for each partner to understand specific emotions, ways of expressing.Its important that PWID must be explained how certain behaviours be exhibited in private and others in public.

2. Communication skills-

It is important for each partner to understand the communication levels of the other.If the union is between a non disabled and a PWID, the former is already aware of the degree of communication existing.It is interesting to note that when both partners are with ID they have a unique way of communicating with each other.It is to be rememebered that pre marital counselling for such couple is not a one day process by a professional .rather this counselling needs to be done by a combined effort of the mother and the educators

3. Finances and money management-This is one area where lifelong support may be required for major financial decisions.If the couple reside in a group home then this responsibility is majorly taken up bythe community .but depending on the degree of ID day to day expenses within a set limit can be managed by a PWmild ID and training should be given on how the couple should not be expoited.Parents here play a big role .

4. Expectations, beliefs and values

A lot of information in a scientific and systematic manner must be given specifically to either partner.The onus falls greatly on the no n disab;led partner to gradually induct the other partner into the existing system.It is to be remembered person with ID does not ususally show deviant behaviour.He or she shows conformity if the concepts are given gradually, using a lot of real life examples and instread of abstraction of ideas , concete hands on training is offered on how beliefs and values are to be implemented in a measurable manner in the daily life.

5. Children and parenting

Woman with ID must be given prior information right from the onset of puberty on child bearing.Young mothers have shown tremendous resilience in bringing up children.Hence pre marital counsling should only focus on the area of functionality.Since PWID has certain limitations as far as cognitive capacity is concerned, information should be given keeping in mind their learning modalities.

There is a misconception that PWID will not be good parents.Women with ID are bad mothers and unable to take up responsibilities.On the other hand they can shower love and bring up children without stresss and without burdening their children with undue expextations.

6. Decision making and conflict resolution-This is one area which PWID definitely lack in.The have difficulty in problem solving behaviour, have difficulty in generalisations and do not apply previous life experiences to current scenario.They have lower level thinking skills.But they are excellent at hands on, concrete

level thinking.Therefore if certain situations typical of married life are explained, broken down into simpler sub events they would be able to comprehend and take decision .

Researches have shown the applicability of cognitive behaviour modification on PWID.They need systematic and continuous exposure to strategies to first identify the problem with

7. Dealing with anger and emotions

It is to be understood that regular couples have to live in this stressful world where thay are always running the rat race of career progress.This itself gives rise to anger a variety of emotions associated with that.Appropriate coping mechanisms have to be implemented more often to salvage he situation.It has been observed that in a heterosexual couple where thae female member is with ID has a more or less streamlined routine life .In case where the man is with ID, the woman takes the role of decision maker and manages the husbands emotion.Pre marital Counseling will help the couple to pre-empt the situations and deal with it.

8. Roles in marriage:

Getting premarital counseling is a great way for partners to enhance their ability to communicate and establish realistic expectations from one another. It’s also an excellent way to develop conflict-resolution skills.

It is important to not forget the fact that when each individual brings his/her opinions, values or history into a particular relationship, they do not always match with their partner’s. Often times, people get married believing that it will fulfill their emotional, financial, social, and sexual needs – and it does not turn out as they had expected.

When differences and expectations are discussed before marriage, the couple can develop ways to understand as well as support each other after they are married. Early intervention is crucial because the risk of divorce is normally at greatest early in marriage.

3.6.2 Benefits:

- **gain insight –** Let’s face the facts. When two people are in love, they often overlook those things that they ultimately have to face when married. Premarital counseling can shed light on these issues and help the couple solve them before it takes them by surprise.

- **Availability of outside professional guidance** – You benefit from having a licensed marriage and family therapist's wise and trained perspective that gives you an unbiased view on your relationship, and how to make it last.
- **Strengthening of communication skills –** Good communication is a fundamental part of a healthy relationship. Without communication, there's nothing to hold the relationship together and help it function smoothly. Counseling is a great way to help couples strengthen their communication skills.
- **Setting of realistic expectations** – Expectations within marriage can fall into different areas ranging from sexual intimacy to household chores. Discussing expectations with understanding and respect while being flexible is the attitude that leads to teamwork and resolution. It removes resentment and hurt and builds a peaceful home.
- **tips on financial planning** – One of the main reasons why marriages turn sour are financial and money issues. Many young couples do not have an idea of what it takes to manage finances together as a couple. Counseling explores the meaning of money each partner has and teaches the couples financial skills even before they face the issues in real life.
- **understanding each other's major triggers –** Identifying the "push buttons" you and your partner are most sensitive about is an important step toward avoiding and overcoming the personal triggers. Through premarital counseling, couples can identify each other's major stressors and learn how to support each other through thick and thin.
- **identifing potential conflicts –** No two people believe or have completely similar ideas regarding life in general. It is important to identify any potential conflicts before they even occur. This can be done through counseling to ensure stable relationships.
- **Learning de-escalation techniques** – Conflicting situations are some of the toughest things you'll face in your marriage. Given the destructive nature that escalation plays in relationships, it is important to develop tools and strategies

to limit and reverse this process. This is why when a potentially explosive situation occurs and negative emotions amplify, de-escalation is needed.

- **Establishing shared vision** – To have a successful marriage, you need to have a vision and a shared vision you and your partner both have expressed to each other. The vision is a conscious and deliberate way to create your relationship together towards your destination. It also gives couples a kind of roadmap to help them assess whether they are "on course" in their relationship, so that they can put in the necessary corrections.

3.6.3 Counselor and Disability-understanding Disability through social model:

Disability is an experience often perceived by persons without disabilities and society as a negative experience and as something undesired. Such attitudes are not necessarily the same as those held by individuals with disabilities and their families (Dunn & Brody, 2008; Wright, 1991); yet, it is the negative aspects of having and living with a disability that continues to be a primary focus and feature for people who do not understand disability (Smart, 2009).

PWID have been portrayed in a variety of manner from the relationship point of view. They have been projected as child-like, vulnerable innocents in constant need of care and protection on one hand, and on the other as possessing deviant sexual tendencies (Snyder & Mitchell, 2006:100-121). Clements, Clare and Ezelle (1995:426) argue that although the images vary, the outcome is the same – intellectually disabled are not real people, real men and real women. Shakespeare (1999:55) speaks of a third gender and Deepak (2005) in the title of his study "Male, Female or Disabled" implies a third gender. Shakespeare et al. (1996) provide personal accounts of disabled people in institutional settings and in families that were, due to dominant perceptions of disabled people, prohibited from having anything that resembled an intimate relationship.

This may in turn negatively impact the counseling relationship with persons with disabilities and their families (Hartley, 2012). Compounding this reality is the fact that many mental health, school, and clinical counseling and psychology programs do not offer much training or knowledge related to the specific needs and experiences of persons with disabilities and this may equate to the provision of inadequate care (Stuntzner, Hartley, & Ware, 2014).

Counseling a regular couple and a couple where either one or both are with Intellectual Disabilities are not the same.While in the former thorough knowledge and professional expertise are required, in the latteralong with those an insight into disability is mandatory.The counsellor must acquire a perspective in Disability and work with the team of caregivers along with professionals.With more and more people with Disabilities gaining access into social arena this may branch out as a separate field of counselling in future.

In an effort to help counselors improve their understanding, skill, and comfort level when addressing the diverse needs of persons with disabilities, Stuntzner and colleagues (2014) conducted a Pre-conference Learning Institute at the 2014 American Counseling Association Conference. Topics presented and discussed with session participants included the importance of

- <u>using proper language to describe the person and the disability;</u>

Language, regardless of intent, is very powerful. It can be used to uplift or degrade someone "depending on how it is used" (Stuntzner, 2012, p. 40) and to convey attitudes toward others (Smart, 2009) Outdated or inaccurate words can encourage and promote, even if unintentional, poor and negative perceptions and feelings about persons with disabilities; some of which include the words "invalid, suffering, afflicted, victim, handicapped, crippled, and wheelchair-bound (Titchkosky, 2001, p. 127). Counselors that work with individuals with disabilities and/or their families should be aware of the impact of historical and societal perceptions toward disability and how that affects societal beliefs (see Rubin & Roessler, 2008) More specifically, they need to be mindful of whether they view the person as an individual who has the same rights, needs, and desires as anyone else or if they perceive him as incapable, weak, less than, suffering, pitiful, handicapped, or physically/mentally challenged and so forth (Smart, 2009; Titchkosky, 2001). Counselors are encouraged to learn more about appropriate terminology including the use of "person-first" language. Although this is not a perfect system, it represents where the profession is at the moment. In most instances, persons with disabilities may be referred to as just that or as "individuals with disabilities" (Falvo, 2009). A final area worthy of consideration is that of personal sensitivity. Stuntzner and colleagues (2014) introduced a visualization exercise, which has been used previously in trainings, to enhance understanding of and sensitivity to disability.

- identifying personal and societal barriers encountered by individuals with disabilities;

Counselors can enhance their understanding and knowledge of issues relevant to the needs of persons with disabilities and their families by learning about the various forms of personal and societal barriers like attitudinal, architectural, environmental, medical, employment, access, and personal barriers that they often encounter. Of particular importance is for counselors to collaborate with their clients to (a) identify which barriers are most salient, (b) examine the ways the identified barriers inhibit their functioning or prevent them from coping more positively, (c) explore which ones are within their control to change, and (d) determine strategies they can use to cope with and move past them. This process is not always easy, nor is it particularly linear, and may require some time and effort to resolve.Counselors first must understand that these barriers even if they as human beings cannot perceive they exist. Once the most cumbersome and problematic barriers have been identified, counselors can assist individuals in uncovering the ways such barriers impact their life and in determining which ones they can change. Such a process requires counselors to work collaboratively with their clients to differentiate between self-imposed versus otherimposed barriers (Stuntzner, in press). Self-imposed barriers refer to those experienced by individuals with disabilities, partly in effect, because they are thinking or behaving in ways that contribute to their existence. For instance, individuals may have been told they are not capable of something and start to believe it. As a result, they feel disempowered, become consumed with negative feelings such as apathy or withdrawal, and end up feeling victimized. As a result, they do not behave in ways to help themselves address or move past these negative messages. Other-imposed barriers refer to those created or placed upon individuals with disabilities by other people, agencies, entities, or society. Examples of other-imposed barriers include: negative societal barriers, employers' resistance of hiring individuals with disabilities, and lack of access to public buildings due to non-accessible architectural structures.

- devising a theoretical framework from which to understand adjustment to disability;

Factors Influencing Adjustment to Disability Factors known to influence adjustment to disability are many and are used by counseling professionals to better understand "the probability of successful versus unsuccessful adjustment" (Stuntzner, 2008, p.

7). Some of the factors associated with adjustment to disability discussed throughout the rehabilitation literature include

(a) depression (Livneh & Antonak, 1997; Skinner, Armstrong, & Rich, 2003),PWID often experience deep seated depression owing to the gap between what they feel and what they can convey.

(b) locus of control (Livneh, 2000), PWID owing to limited cognitive capacity develop external locus of control.

(c) spirituality (Byrd, 1997; Longo & Peterson, 2002), negative perception based on discussions they have been exposed to since childhood that it was the hand of God that made them the wsay they are.A lot depends on the type of family they come from and how the family has perceived the situation.

(d) self-blame or unresolved feelings for cause of disability (Buckelew, Baumstark, Frank, & Hewett, 1990; Nielson & MacDonald, 1998),

(e) negative feelings and emotional distress (Lane, 1999), this again is a resultant of long lasting prolonged experience of segregation, the gap between wanting to belong and not being able to

(f) self-esteem (Wright, 1983), There is learned helplessness which is a key factor in producing low self esteem . Potgieter and Khan (2005:11-19) allude to the low self-esteem of disabled persons being a consequence of stereotypical social values about disabled people. The risk of psycho-emotional disablism (Reeve, 2004:89) increased with the concordant belief of deserving their lot. Nosek, Foley, Hughes and Howland (2001:186), in their study of abuse and disability, refer to the low self-esteem of disabled women as being a factor that increases the risk of vulnerability to sexual abuse

(g) coping strategies (Livneh, 2000), .Since the decision of marital conjugation is a big leap towards the mainstreaming process , it is likely that the individual has already some coping strategies which the counsellor has to unearth.

(h) social support, Hence premarital counselling techniques also involves taking the entire set of families in consideration rather than the two individuals only.

(i) gender (Nosek & Hughes, 2003),it is said that the otherbgender has two issues to deal with-firstly they are women and secondly they are women with Disabilities.

(j) age of onset (Crewe, 1999; Trieschmann, 1988),knowledge on the part of counsellor about ID

(k) familial support (Crewe, 1999), Counselors can enhance their understanding of the adjustment to disability process by becoming familiar with these models of adjustment with Disability and then counsellor could identify together with his or her client the support

Other factors discussed by Smart (2009) included the meaning one ascribes to the disability, severity of disability, visibility versus invisibility of the disability, and the amount of stigma experienced and associated with the disability along with socioeconomic status and financial health (Trieschmann, 1988), level of education and employment (Livneh & Antonak, 1997), andsocietal attitudes (Trieschmann, 1988).

- learning counseling techniques to enhance therapeutic effectiveness;

some approaches have been empirically studied and are known to reduce negative thoughts and emotions (i.e., forgiveness, self-compassion) or are discussed extensively throughout the literature as essential skills for living well with a disability (i.e., resiliency, self-advocacy, self-concept.It is important that both the partners are equipped with these.

Forgiveness, self-compassion, and resiliency are three constructs which have been empirically studied. More specifically, forgiveness and self-compassion have been shown to reduce negative emotions and improve overall functioning and well-being (Enright, 2001; Neff, 2011). Both constructs and approaches have much relevance to the lives of persons with disabilities due to the magnitude of negative experiences and treatment faced by persons with disabilities. Furthermore, resiliency is an identified skill which has been found to have much relevance to the needs and issues of persons with disabilities and may be taught to enhance functioning (White, Driver, & Warren, 2008).

- being mindful of general counseling tips when working with persons with disabilities(Stuntzner (2012)_

  These are simply based on common sense and related to the art of treating persons with disabilities with respect and as human beings the same as anyone else.

- being mindful that the expressed negative experiences related to disability are real;
- considering the effects that labels may have on your clients (Smart, 2009);
- treating persons with disabilities as human beings rather than as their disability;
- building awareness of your own attitudes and biases which may affect the counseling relationship;
- being aware of how persons with disabilities describe themselves;
- respecting the fact the persons with disabilities know their own bodies and experiences;
- getting the necessary training and supervision needed to effectively counsel persons with disabilities;
- paying attention to the abilities and strengths of persons with disabilities and incorporating them into the counseling relationship;
- recognizing that most persons with disabilities do not live their life "focusing" on their disability and limitations;
- identifying counseling topics which make you uncomfortable (i.e., sexuality and disability) so you can address these; and
- being willing to have an open mind to the shared experiences within the counseling relationship.

3.7 Sexuality related issues, HIV, STD

2.7.1 What is sexuality:

Sexuality is a word we use to talk about how we understand our bodies and how we understand our relationships. This understanding includes all aspects of who we are – our values and beliefs, bodies, desires, relationships, gender and our thoughts and feelings about all of these. Because our sexuality is made up of so many different components, our understanding of our own sexuality is ever-changing and unique to each person.

PWID and Sexuality:

Sexuality is an extensive term that covers a range of issues. It includes not only sexual behaviour but also sexual identity, gender identity, sexual orientation, roles, personality, relationship patterns, thoughts, feelings, attitudes etc. It also includes the social, ethical, moral, cultural and spiritual concerns of an individual. Multiple factors are influenced by and influence one's sexuality. Everyone does not experience sexuality in the same way. Being aware of these differences helps cater to individual needs and provide effective services to people. (Sexuality and Disability in Indian context, 2010)

"Sexuality is an area of distress, exclusion and selfdoubt for persons with disabilities.(ADDLAKHA, R. 2007. Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India. Occasional Paper No.46. Centre for Women's Development Studies, New Delhi.)

Historically, persons with disabilities have been regarded by society in two contradictory ways – either as nonsexual or as sexually threatening. Largely, their sexual desires are assumed to be non-existent. Most literature related to disability fails to mention sexuality, and sexual and reproductive health related issues. (ALBRECHT, G. L. 2005. Encyclopaedia of Disability. University of Chicago. Sage Publications.)

Stereotypical notions about disabled people have been "institutionalized throughout society" (Oliver 1996:33) and persons with intellectual disabilities are considered as lacking the capacity to responsibly and appropriately give expression to their sexuality needs (Milligan & Nuefeldt, 2001:92). Disabled people have had to contend with social, cultural, and medical denial of their sexuality (Wilkerson, 2002:33). generally, the lives and needs of disabled people are accounted and presented by others in particular ways for particular purposes, with little or no consultation with the people themselves (Atkinson & Walmsley, 1999:203; Shotter, 1993:48).

literature on sexuality with reference to 'milder' forms of intellectual disability does exist in relation to issues such as abuse, autonomy, consent, family planning, gender expectations, identity, inappropriate behaviour, parenthood, family and staff member views, sterilization, and vulnerability (for example, Abbott 2015; Banks 2016; Booth and Booth 2000; Desjardins 2012; Evans et al. 2009; Hamilton 2010; Hollomotz 2010; Lyden 2007; McCarthy 2014; Turner and Crane 2016; Wilson et al. 2011)

For women with intellectual disabilities, the reality is somewhat different; they are seen as sexually naïve, more vulnerable to sexual abuse than men and consequently in need of more protection (Young, Gore, and McCarthy 2012). This seems like a reasonable reaction to the fact that women with intellectual disabilities indeed are more likely to experience sexual abuse than men (for example, Cambridge et al. 2006; Gil-Llario et al. 2018). Especially in the case of individuals with profound intellectual disability, sensitivity to the significance of gender is undoubtedly appropriate considering the long history of sexual abuse of women with intellectual disabilities (McCarthy 2002).

Specifically if one talks about women with intellectual Disabilities the belief reflect the commonly that intellectually disabled women lack the requisite social judgements to behave in a socially responsible manner (Anderson & Kitchin, 2000:1164). This is entangled in the notion that they have excessive sex drives which they have very little control over (Tilley, 1998:97; Block, 2000:239; McDonagh, 2004:51). Meekosha (2004:5) states that women experience more extreme social categorisation than men, being more likely to be seen either as hypersexual and uncontrollable, or desexualised and inert.

Individual experiences and properties, such as impairments and their role in people's disablement, have been underplayed (Vehmas and Watson 2014). Profound intellectual disabilities have been at the margins of, or in fact virtually absent from, the disability studies scholarship probably because they involve the kinds of serious, all-inclusive impairment effects that cannot be explained merely by social arrangements (Boxall and Ralph 2011; Chappell 1998; Mietola, Miettinen, and Vehmas 2017).

Sexuality as an expression of love and a source of pleasure has not been extended to intellectually disabled people who have traditionally been marginalised by society (Tepper, 2000:285). Deepak (2002:5-6) cites Malaguti (1993:1) as stating that sexuality and disability are seen as antithetical to each other, negating each other. McCabe (1999:160) reports that in comparison to other disabilities, there is a stronger taboo on matters of sexuality, especially procreation, for intellectually disabled people.

According to Karellou (2003b:66) a commonly held notion is that intellectually disabled people have no sexual needs or desires; they are sexually dangerous or incapable of dealing with sex responsibly; they are not capable of falling in and out of love; they do not seek emotional satisfaction; and they are not interested in marriage or having children. "People with developmental disabilities have also been regarded as hypersexual, and in some cases as predators of children, or as inherently and inevitably victimized" (Wilkerson, 2002:43)

It is usually agreed, however, that it involves significant cognitive difficulties, with little or no apparent understanding of verbal language, little or no ability to care for oneself, and usually associated medical conditions (Pawlyn and Carnaby 2009, 6–7; WHO 1992, 230).., some prominent philosophers such as Jeff McMahan (2002) and Peter Singer (2010) portray such humans as psychologically comparable to pigs and dogs, and able to reach only the level of well-being of that of 'a contended dog' (McMahan 2002, 153). However, there are philosophers like Eva Feder Kittay (2010) who has a daughter with profound intellectual disability, and who uses her personal experience and knowledge about her daughter to refute the claims.

Professionals continue to speak on behalf of disabled women about sexuality matters and society continues to respond in ways that are negating and oppressive of disabled women's sexuality (Mgwili & Watermeyer, 2006; McDougall, 2006; Sayce & Perkins, 2002).

McClimens (2004) argues that sexual agency is considered as part of the rites of passage into adulthood; but due to the infantilisation of intellectually disabled people, they remain eternal children, denied the full status of adult citizenship and their sexuality obscured. What is socially valued and acceptable for others is greeted with fear, aversion and disapproval by society when it is intellectually disabled people who want to give expression to their sexuality (Brown, 1994:128).

Parental Attitude:

Aunos and Feldman (2002:288), in a Canadian study, found that parents of children with intellectual disabilities generally feel uneasy about their children's sexuality. In a Brazilian study, Block (2002:7-28) found that sexuality education was problematic in the parenting domain. Sait (2006) researched the complexities of mothering when nurturing the sexualities of their disabled daughters and highlighted the increasing difficulties that mothers experience in coping with sexuality matters of their disabled daughters.

Zdravka and Mihokovi (2007:108) report that their study showed that parents of intellectually disabled young persons do not fully acknowledge nor address their sons' and daughters' need for sexuality. Parents often keep the contact of their young intellectually disabled men and women limited, out of a fear of abuse and of unwanted pregnancy. Walcot (1997:96) reports that parents generally have a more conservative attitude towards matters of sexuality of their intellectually disabled sons and daughters. Cobblepot (1996:15-19) argues that parents often feel suspicious of 69 any intimate interest in their disabled sons and daughters, and that caring families can exert a powerful "possessive streak" when a disabled family member falls in love.

Gender Ideology regarding sexuality of PWID:

Gender stereotypes interact with disability stereotypes to constitute a deep matrix of gendered disability in every culture, developed within specific historical contexts, and affecting those contexts over time. Cultures sustain the social relations of gendered disability in constant reiterations of stereotypes and expectations (Meekosha, 2004a:9).

"The stereotype is that disability is always pathetic, that disability is dependent. It's represented, as disabled people are very innocent, and very much deserving of one's sympathy…" (McDougall, 2006:388). "Amedical model predominates whereby disabled people are defined by deficit, and sexuality either is not a problem, because it is not an issue, or it is an issue, because it is seen as a problem" (Shakespeare et al., 1996:3). Sexuality of disabled people is reduced to "erectile dysfunction, movement limitations and other incompetencies" (Shakespeare 2006:168).

The paucity of research relating to the sexuality of intellectually disabled women is partly a consequence of the ways in which their sexuality has been constructed within academic and professional discourse (Milligan & Nuefeldt, 2001; Shakespeare, 2000). Gender, disability and sexuality are areas of gross discrimination and exclusion (Mgwili & Watermeyer, 2006:261-272).

McDonagh (2000:50) asserts that in the literature of early and mid 19th century Britain, intellectually disabled men were represented as a debased form of masculinity and intellectually disabled women were represented as posing a threat to society because of their undisciplined sexuality. Block (2000:239), McDonagh (2000:51), and Carlson (2001:126) agree that disabled women and intellectually disabled women in particular were viewed paradoxically: as sexually vulnerable as well as sexually threatening, with a need for professional control and management. Sexuality in relation to disabled people is something pathological, to be treated, to be cured and controlled (Carey, 2003; Milligan & Nuefeldt, 2001; Shakespeare et al., 1996; Shakespeare, 2005, 2006; Block, 2002).

3.7.2 Impact on PWID

Impact on PWID :

A. lack of knowledge on sexuality:

Adults with ID may lack information about sexuality and sexual health [Galea J, Butler J, Iacono T, Leighton D. ,2004) and often lack both formal and informal opportunities for learning about sexuality [42. Isler A, Tas F, Beytut D, Conk Z. ,2009) In one study, adults with ID were more likely than both adults with physical disabilities and the general population to state that they did not have all the sexual knowledge that they would like to have [McCabe MP.,1999]. Additionally, adults with ID are more likely to get sexual information from questionable sources, such as television [uskelly M, Bryde R. ,2004)and to express misconceptions related to reproductive anatomy and physiology, sexuality and sexual health [Trent JW. *2000*) argues that the exclusion is not only at the level of disabled learners being left out of sexuality education, but that disabled youth feel excluded due to the omission of relevant disability-related sexuality information. "For instance, the educators… were more concerned with preventing pregnancy and 'keeping them busy' than with educating the girls appropriately on issues of sexuality" (Sait, 2006:112) Finkelstein (2001:4) argues that although it may be a personal tragedy to have an impairment, the focus should remain on the oppression that characterises the way in which society is organised so that disabled people are prevented from functioning like their chronologically same age peers. Not everybody learns in the same manner in the school and there are many ways to impart teaching on sexuality .This attitude starts at the school level itself where educators make a conscious effort to sieve information thinking it may be dangerous .

Also any kind of sexual behaviour that would be normally expressed by a person entering puberty is held in close scrutiny in case an adolescent with ID .This additional attention often interrupts the natural development of the person.

B.Propensity for sexual abuse:

Though very little evidence is available as Kliewer and Drake (1998) make claims that disability history of the disabled themselves, who were outside of the disability professions but inside the stereotype and discrimination, are dismissed as anecdotal and seen as “non-scientific”. The authors make it clear that the absence of documented experiences of disabled people themselves is an opportunity missed, whereby rich descriptions of experiences of disability have been lost to disability history .But it can be definitely said that lack of biological and health knowledge may correlate to a lack of practical knowledge , that may put adults with ID at increased risk of negative sequelae of sexual activity.

Though problems with tracking, reporting, and definition make it difficult to determine the exact prevalence, adults with intellectual disabilities are thought to be at high risk for abuse, including sexual abuse, with rates estimated as high as over half of all women with ID [Horner-Johnson W, Drum CE,2006)In one Australian study, almost 6% of police reports related to sexual assault involved an adult with ID, though these adults comprise just 0.8% of the Australian population [Wilson C. *,1990)*This finding is especially significant considering research suggesting that women with ID are less likely than other women to report abuse [Wilson C, Brewer N. ,1992) In addition, certain aspects of the disability experience, such as the need for paid personal caregivers, who are often alone with their clients, potentially increased dependency on family and support staff (creating a power differential that can create a barrier to reporting abuse) and decreased economic status can increase vulnerability to abuse [Saxton M, Curry MA, Powers LE, Maley S, Eckels K,2001) The danger of sexually transmitted diseases also thus becomes high.The population may report prevalence of HIV and STD.

Thus it is evident that PWID need proper knowledge which is to be disseminated in a systematic manner. Any sexuality programme for intellectually disabled learners must cover topics such as body parts, as well as physical and physiological changes (Isler, Tas, Beytut & Conk, 2009:32-33). Johns (2005:xiv)

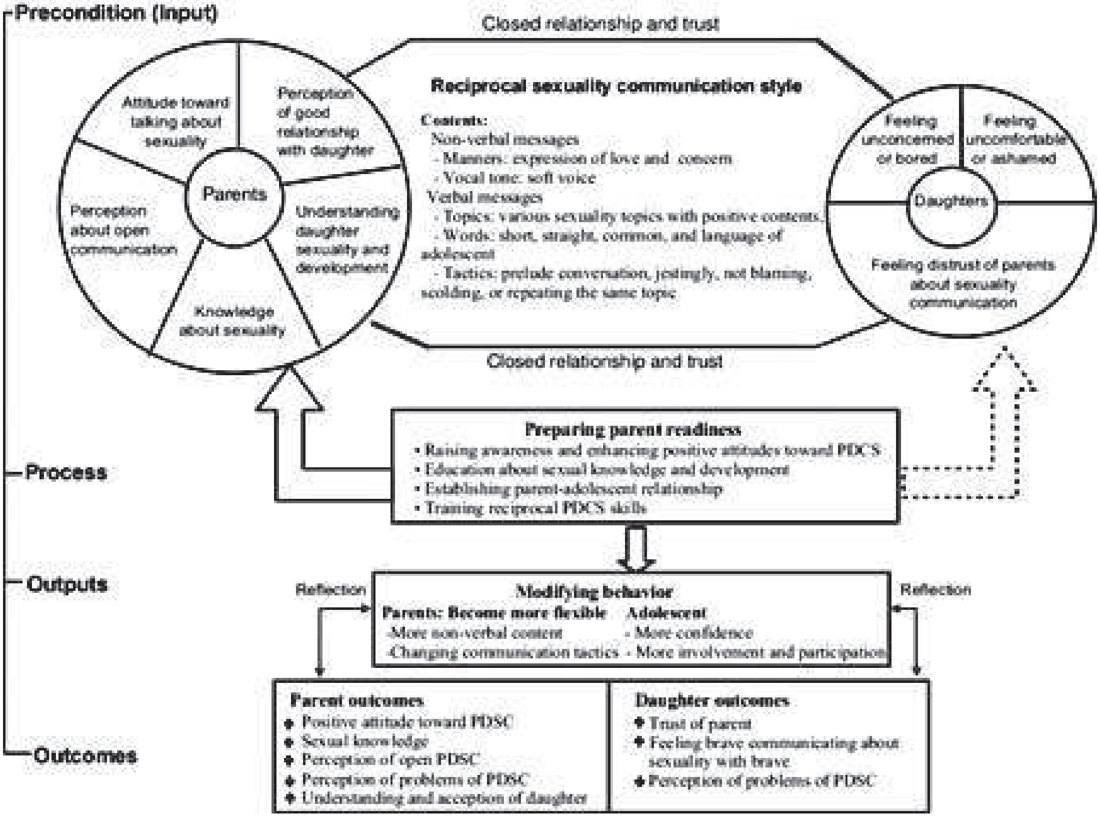
A study conducted in South Africa with 20 young adolescent girls with ID revealed that there was much happening in their romantic and personal lives and that these young women were far from the “eternal children” they are often thought of .

3.7.3 Strategies for preventing STD in PWID:

A.Cole (1991:232) asserts that disabled people ‘‘must be taught personal safety lessons, including sexual abuse, and protecting the right and dignity of their well-being’’. Doyle (2008:27) and Brown and Pirtle (2008:59-75) state that sexuality education should encompass comprehensive personal, social, and sexual education to provide young people with the knowledge and skills they need to clarify their values and attitudes, develop self-esteem and self-awareness, develop healthy relationships, and recognise and prevent unsafe situations. This view is supported by Johns (2005:xiv), where the author states that sexuality education is much more than giving information about sex; and that it should teach people how to make healthy sexual choices, build self-esteem, and promote an awareness of rights and responsibilities.

For example knowledge of sexuality and the aspects it encompasses can be given by educators themselves through the use of visuals , role play and a questionnaire.It is very important that any kind of sexual abuse must be prevented by proper knowledge disseminationP.It is important that young girls with ID be given systematic knowledge on menarche, taking care during menstruration, effect of it so that they are well informed.Rogers and Lipscombe (2005:51) point out that intellectually disabled women are seldom encouraged to manage their own menstrualcare.

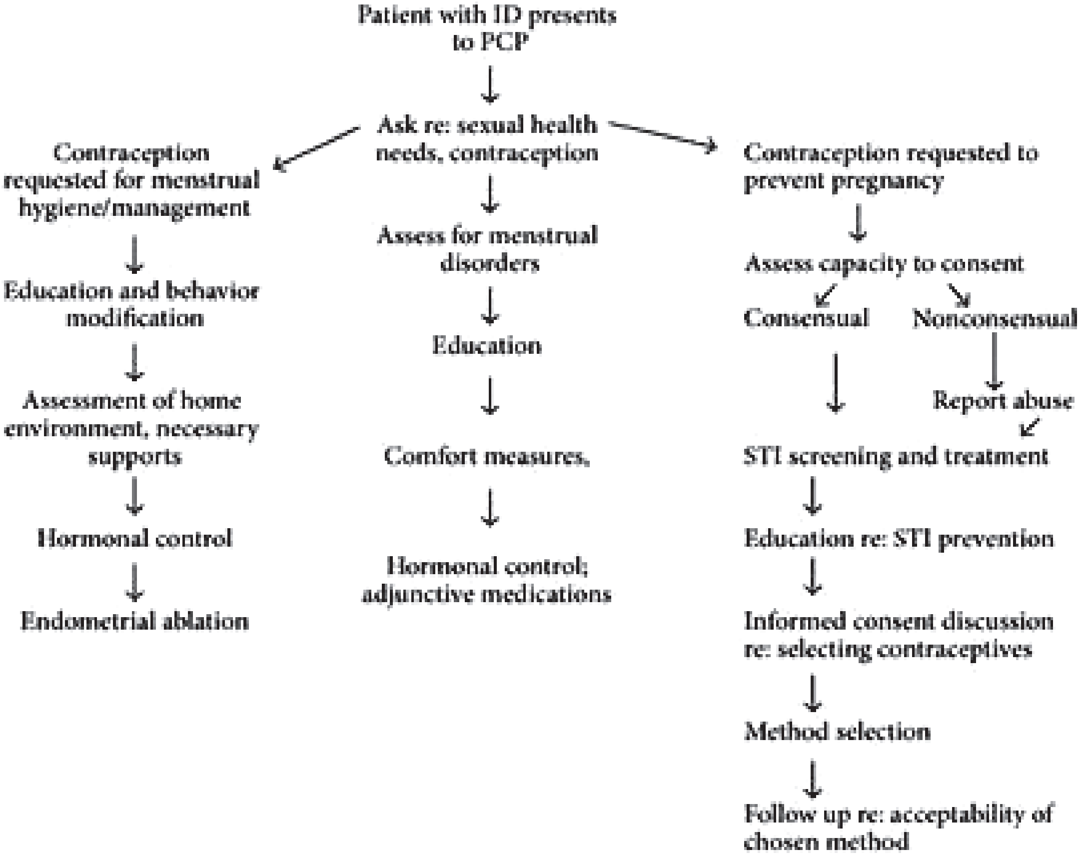
Sex education is thought to be beneficial in combating sexual exploitation, as it may increase participants' abilities to recognize and report abuse [McCabe MP, Cummins RA, Reid SB. ,1994). Education about basic reproductive physiology, communication about sexuality and intimacy, gender differences, and safer sex has been theorized to increase the ability of women with ID to recognize and report abuses perpetrated against them [Dukes E, Mcguire BE. 2009) Thus parents specifically mothers play a very important role as information provider and assessing how much has been actually comprehended.The diagram below details on the procedure that mothers could follow to give inputs to their daughters



(Arpaporn Powwattana

It has been hypothesized that effective sex education for people with ID should include decision making skills, as adults with ID may have less opportunities to practice decision making than their peers without disabilities [E. Dukes and B. E.

Mcguire, 2009)and should include practical and person-centered planning [V. A. Lumley and J. R. Scotti, 2001) Adults with ID may need support in multiple areas of their lives, including their sexuality, and may need assistance with sexual expression, such as help undressing before intimacy [V. A. Lumley and J. R. Scotti, 2001) However, direct support workers who assist people with ID often lack training in supporting positive sexuality or even providing basic information to their clients Paransky and Zurawin have developed a decision tree model for use by health care provides when a patient with ID and/or her caregivers request contraception or



Thus Adults with disabilities are adults first with all the needs, desires and aspirations of an adult.The disability factor must be viewed only from the support point of view. The self-advocacy movement has asserted that adults with ID have the same right to sexual expression as their peers without disabilities, and many regard sexuality as a human right This movement uses a rights-based framework that suggests suggests that adults with ID be supported in accessing opportunities for consensual sexual expression if they desire to do so.and focuses on the human rights, rather than the limitations, of people with ID.

In fact it is the right of the individual with disability to choose which of the models of disability he or she would be benefited.

According to Janet Price, a feminist, disability rights campaigner who works on disability, sexuality and social justice mainly in India and the UK, Western research on sexuality and disabilities has been conducted from different approaches:

a the medical approach, as seen in research on physical medicine and rehabilitation where techniques have been adopted that have been found, for example, to help men with spinal cord injuries to have erections

b the historical approach that looks at how people with disabilities have been treated and sexuality has been regarded in past

c the rights based approach that addresses, for example, sexual violence and/or abuse faced by people with disabilities

d the feminist approach that analyses information about sexuality and disability to understand how the two interact in the context of social structures.(Janet Price. 2009)

The socio-cultural model sees disability as a pervasive system that, through its stigmatisation of certain bodily variations, informs our notions of self, structures institutions and identities, informs cultural and political practices and constitutes sexuality. Feminist disabilities studies theorist Rosemary Garland-Thomson summarises it when she speaks of four aspects of disability, “First, it is a system for interpreting and disciplining bodily variations; second, it is a relationship between bodies and their environments; third, it is a set of practices that produce both the able-bodied and the disabled; fourth, it is a way of describing the inherent instability of the embodied self.”Sexual emancipation can only happen if each of these components and the bias associated with each are tackled with sensitivity.

A study on sexual behaviours of PPID was carried out The fieldwork was carried out in three phases, in which altogether six research participants with profound intellectual disability were followed, one at a time, individually by one researcher. The fieldwork took place in five group homes, two day activity centres, and one vocational school. The participants were also followed in rehabilitation and leisure activities on a regular basis. Each participant was observed for a period of three to four months for two days a week, four to eight hours a day during different times of the day (approximately 100 hours of observation per participant). In addition, altogether 19 interviews were carried out with family members and caring staff of the participants.It was found that each expressed the desire of intimacy. since many of them have such interests, the minimal threshold for a life with dignity for them is one in which this capability is acknowledged and facilitated rather than denied and prevented (Boni-Saenz 2015; Kulick and Rydström 2015, 286-287). intimacy exposes us to a vulnerable position in relation to the other person and also to the possibility of exploitation (LaFollette 1996, 108–114; Popovic 2005; Umberson, Thomeer, and Lodge 2015). It is therefore that trust is a necessary condition of intimacy: 'trust and sensitivity heighten intimacy; their absence diminishes it' (LaFollette 1996, 111). Intimacy can be seen as an essential element of one's security, subjectivity, and sense of self (Jamieson 2011).

To conclude one needs to understand just like any other individual sexuality and the need to satisfy and be satisfied is there in individual with disabilities.The words of Malini Chib, a disability rights activist and author who has cerebral palsy brings out the anguish experienced by such people.

in an online article:"The word sex and disability don't go together. Can disabled people have sex? Tauba tauba! A topic best not mentioned. Even though I have been brought up in a westernised, liberated family and social strata – the topic has rarely been brought up with me. Most people think that if they start the conversation, they will hurt my feelings. Why does the topic sex frighten everyone when it comes to disabled people?(2011, Malini Chib)"

Thought for discussion:

Based on the criteria given below, set by WHO Prepare a rating scale for an online survey to measure the sexual rights enjoyed PWID in your state .

WORLD HEALTH ORGANISATION. 2006. Defining Sexual Health.

: Sexual rights include the right of all persons, free of coercion, discrimination and violence, to: • The highest attainable standard of sexual health, including access to sexual and reproductive health care services • Seek, receive and impart information related to sexuality • Sexuality education • Respect for bodily integrity • Choose their partner • Decide to be sexually active or not • Consensual sexual relations • Consensual marriage • Decide whether or not, and when, to have children, and • Pursue a satisfying, safe and pleasurable sexual life.

3.8 Let us sum up

We learn that gender is a social decision and understand the relationship beteween gender and sex.We comprehend and apply meanings of terms like gender identity,gender ideology and how gender is linked to ppower.We also come to know the agents for gender development.We check what is sexuality and how gender and sexuality are linkedWe also come to know the characteristic of sexuality.

Religion and sexuality and impact on several religions on sexuality along with gender norms being dictated by culture and religion are understood by us.We understand the historical perspective of marriage of PWID and how situations have changed or not over the years.We know about the parental attitudes, the stereotypes that circumscribe marriage and how reality should be spun around right based approach.With regards to marriage the requirement and benefits of premarital counseling is studied and approaches of the counselor is also studied in detail.In Sexuality related issues we again study the perception of society, the impact on persons with Disabilities and finally strategies to prevent STD

NO.	Subunits	Thoughts for Discussion
3.1	Meaning & Concept of Gender & Sexuality and Marriage	: What are the gender norms that you have grown up with. Do you think gender norms have influenced your school, college or work place? Analyse citing atleast three situations What are the positive and negative impacts of gender norms relating to sexuality for men and women? How many different models of masculinity and femnity can you identify from the advertisements shown in television. Does these gender norms influence marriage. Give the criteria for a successful marriage ?
3.2	Religious and Cultural effect on Gender & Sexuality and Marriage	1.Make a visit to the different religious institutions in your state.With the help of an open ended questionnaire gather information on the following: a.practices essential for marriage b.how religion is connected to marriage c.dictates given in religion regarding marital

		practices in the sacred books 2.Review Literature on Indian marraiges .Estabish the influence of culture in the conduct of marital life
3.3	Marriage & persons with intellectual disability: Misconceptions & Remediation	Create a handbook for parents giving information of marriage sites, stories , strategies for preparing for married life, support structure post marriage, directory of support services
3.4	Importance of Pre-marital Counseling, Gender Education	**Prepare four counseling reports of pre marital counseling for the four case studies**
3.5,	Sexuality related issues, HIV,	Based on the criteria given below, set by WHO Prepare a rating scale for an online survey to measure the sexual rights enjoyed PWID in your state . WORLD HEALTH ORGANISATION. 2006. Defining Sexual Health. : Sexual rights include the right of all persons, free of coercion, discrimination and violence, to: • The highest attainable standard of sexual health, including access to sexual and reproductive health care services • Seek, receive and impart information related to sexuality • Sexuality education • Respect for bodily integrity • Choose their partner • Decide to be sexually active or not • Consensual sexual relations • Consensual marriage • Decide whether or not, and when, to have children, and • Pursue a satisfying, safe and pleasurable sexual life.

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Unit - 4 : Disability Issues – Community

Structure

4.1 Introduction :

4.2 Objectives:

4.3 Attitude of Community towards Adults with I.D.

4.4 Community related Issues - Aggression, Antisocial behaviour, Abuse and Social discrimination of PwID

4.5 Creating awarness related to community Issues

4.6 Community Involvement and Resource Mobilization

4.7 Impact of technological developments on disability issues

4.8 Let us sum up

4.9 Unit End Exercises

4.10 References

4.1 Introduction :

Community based Rehabilitation to community involvement-disability to discovering ability, blame –shame to rights of PWID.The history of understanding community and PWID goes a long way.Let us unearth the pebbles that formed the path of this journey.

4.2 Objectives:

1. various attitude formation.,
2. the stereotypes in the Indian scenario
3. how they have been formed.
4. various studies on aggressive behavior noticed in PWID.

5. aggression as a social construct
6. develop a new way of looking at aggression and antisocial behavior.
7. A thorough study of various disability model
8. Changes in approach to community issues shall be dealt with.and an enabling model would be comprehended of disability.
9. The status of CBR programmes,
10. The degree of community involvement
11. Concept of resource mobilization
12. Concept of technology , bettering life,
13. Universal design
14. Some illustrations of enabling technology shall be studied.

4.3 Attitude of community towards Adults with ID

The fight for equal rights and inclusion of people with intellectual disabilities has led to considerable changes to policy and service provision over the last 30 years. The most notable changes consist of the closure of long stay institutions in favour of community based care and the move away from segregated learning environments to inclusive education in many countries globally. Internationally, social policy has been designed to promote the acceptance, integration and inclusion of people with disability into the mainstream of society (United Nations, 1975; United Nations, 1993; International Association for the Scientific Study of Intellectual Disabilities, 2001), creating a community in which people with disability are 'able and allowed to be themselves among others' (Nirje, 1985). This trend has been advanced on the premise that people want, and have a right to an identity and a role in society defined by their humanity, not their disparate abilities (Banks-Mikkelson, 1980; Henry, Keys, Jopp, & Balcazar, 1996a; Nirje, 1985; Parmenter, 2001; Wolfensberger, 2000;). However, as Priestly (1998) pointed out, while people of difference have existed in all societies, the degree to which they are integrated or excluded varies according to predominant cultural perceptions, such as social attitudes.

Attitudes refer to the extent of an individual's favour or disfavour towards a particular attitude object (Eagly AH, Chaiken S. 1998) Two distinct types of attitude (explicit and implicit) have been identified. Explicit attitudes are evaluations which are consciously accessible and controllable, whereas implicit attitudes are evaluations which are automatically activated and occur without effort or intention (Prestwich A, Kenworthy J, Wilson M, Kwan-tat N. 2008; Theorists have suggested various dual-processing models to try and explain how these different types of attitudes influence individuals in different circumstances (e.g. [Chaiken S. 1980 Brewer MB. 1988, Trope Y. ,1993)

A dual-process type model for understanding the influence of attitudes on behaviour (Strack and Deutsch,2004) suggests there are two information processing systems: a reflective processing system (which allows for conscious consideration of relevant information) and an impulsive processing system (which is always activated and does not require very much cognitive capacity). Deliberate behaviour is a reflection of explicit attitude and impulsive behaviour is an expression of implicit attitude.

Implicit attitudes are formed by unintentional or automatically activated processes which require limited cognitive resources; whereas explicit attitudes are formed by processes controlled by the individual and consume cognitive resources. information stored in memory relating to a particular attitude object is consciously accessed and considered alongside new information (if available), to produce an average evaluation / judgement of the attitude object (Betsch T, Plessner H, Schallies E. 2004.).

Participants may well support the inclusion of individuals with intellectual disabilities and that their implicit attitudes reflect “aversive disablism” [Deal M. 2007) that is widespread negative stereotypes that prevail because people behave in subtly prejudiced ways which actually reinforce negative stereotypes, even though at face level they may believe that this population should be treated equally. An example of aversive disablism would be advocating the empowerment and inclusion of individuals with intellectual disabilities within society, but choosing not to use shared leisure facilities.

Over the last few decades considerable effort has been made to tackle negative stereotypes and attitudes held towards people with intellectual disabilities. This study highlights that, despite all these efforts, negative attitudes, in the form of implicit attitudes, appear to prevail.

positive explicit attitudes observed may predict fairly positive deliberate behaviour towards individuals with intellectual disabilities, the negative implicit attitudes observed may drive subtly prejudiced non-verbal behaviours, interfering with the formation of positive social relations.(Wilson.M.C.SCIOR.k. 2015)

A slightly brighter side is revealed in one of the studies (Yazbeck, M., McVilly, K. & Parmenter, T.R. (2004).) Students and disability services professionals exhibited similar attitudes, with both groups reporting significantly more positive attitudes than members of the general population.

Makas, Finnerty-Fried, Sugafoos and Rees, (1988) suggested that for a non-disabled person a positive attitude is usually conceptualised as being 'nice' and 'helpful', while for a person with disability, positive attitude means dispensing with the category of disability entirely. Meyer, Agar, Kerr and Miles (1998) identify three types of attitude that influence how non-disabled people interact with and include or exclude people with disability: a preparedness to engage with people as consumers, neighbours or as friends; a lack of awareness about people with intellectual disability; and finally, a wariness or even hostility towards the idea of community integration. Regrettably, it is the latter, negative, non-accepting attitude that is commonly observed (Gething, 1994; Novac, 1993; Yuker, 1988; Yuker & Hurley, 1987), and has been ascribed as the fundamental source of disablement in our society (Gleeson, 1995; Shakespeare & Watson, 1997). The effects of negative attitudes in a society are to be observed in areas as diverse as political agendas that present people with disability as a burden on the welfare system, social agendas that question the fitness of people with disability to be parents and subsequently argue for their sterilisation, and medical agendas that promote the termination of human life where atypical foetal development is identified (Hume, 1996).

previous research on attitudes towards people with disability has identified, gender, age, personal contact and cultural factors as important correlates (Antonak, 1982; Florian, *et al.*, 1989; Garske & Thomas, 1990; Gething & Wheeler, 1992; Henry, Keys & Balcazar Jopp 1996b; Lynveh, 1982; Rees, Spreen, & Harnadek, 1991;).

to date many studies of attitudes toward people with disability have focussed on the acceptance of children in the integrated school system. There have been a limited number of studies focusing on attitudes towards adults with intellectual disabilities and their integration into the wider society. Also, many studies have reported the attitudes of undergraduate students, particularly in the area of special education. This group, due to a combination of their chosen career and training are likely to express attitudes towards people with disability different from those of the general population (Gilmore *et al* 2003).

Factors affecting attitude:

Social distance refers to the willingness an individual has to engage with a member of another group in situations of varying degrees of intimacy [Bogardus ES. 1959)Researchers have used social distance as a measure of external stigma towards various stigmatised populations, including individuals with mental health problems ([Jorm AF, Oh E. 2009and people with intellectual disabilities [18. Ouellette-Kuntz H, Burge P, Brown HK, Arsenault E. 2010)

The contact hypothesis [Allport G. 1954) suggests that contact between members of different social groups can help reduce prejudice. Support for the association between contact and attitudes has been reported in numerous studies, with researchers finding that contact in various forms (e.g. voluntary, intimate, direct, and indirect) can help to improve prejudiced attitudes [1. Corrigan PW, Morris SB, Michaels PJ, Rafacz JD, Rüsch N. 2012)

This extends to individuals with intellectual disabilities, with research suggesting that those who have more contact with individuals with intellectual disabilities hold more positive explicit attitudes towards them than those with less frequent contact [Gill F, Stenfert Kroese B, Rose J. . 2002)

Similarly, it has been reported that contact can reduce the desire for social distance from members of out-groups (Ouellette-Kuntz H, Burge P, Brown HK, Arsenault E. . 2010;]

Researchers have reported there is less discrimination toward people with intellectual disability when there has been interaction with them over the preceding six months. However, causal direction regarding the effect of personal interaction on discriminatory attitudes is not conclusive (Tak-fai Lau & Cheung, 1999). Some researchers reported that contact produces positive attitudes (Ashman & Pendrid, 1983; Kinfune, 1986; Parsons, *et al*, 2000) while others reported that contact gives rise to, or reinforces negative attitudes (Goodman, Gottlieb & Budoff, 1973; Gottlieb, & Harrison, 1972). A third group reported that contact produces no significant change (Begab, 1970; Cleland & Cochran, 1961; Graffi & Minnes, 1988; Hagen, Powell, & Adams, 1983).

Given contradictory findings, it might be the type of contact that is the critical factor. For example, it has been demonstrated that if contact is structured and direct, it can promote a shift to a more positive attitude (Acton & Zarbatany, 1988; Esposito & Peach, 1983). This implies that it is not enough to have exposure to people with intellectual disability, but that contact must be structured and organised along a meaningful dimension (Rees *et al.*, 1991) and it is the quality of the contact that influences attitudes (Eigenbroad & Retish, 1988; McConkey & McCormack, 1983).

Emotions are thought of as one of the three key components of attitudes [Swain J, Lawrence P. Learning about disability: Changing attitudes or challenging understanding? In: French S, editor. On equal terms: Working with disabled people. Oxford: Butterworth-Heinemann Ltd; 1994. pp. 87–102. [Google Schola]. Numerous studies have identified the important influence of emotions on attitudes towards a variety of social groups and situations, and interactions between individuals with and without disabilities within a school context [Sirlopú D, González R, Bohner G, Siebler F, OrdóÆez G, Millar A, et al. 2008;)

Studies investigating emotional reactions towards individuals with intellectual disabilities have mostly focused on emotional reactions of care staff to challenging behaviours [35–37]. Research that either investigates emotional reactions not specifically related to episodes of challenging behaviour or that explores the emotional reactions of members of the general public towards this population is lacking

Tak-fai Lau and Cheung, (1999) found that people with higher levels of education reported being more willing to talk to people with intellectual disability. In a related finding, Henry, Keys, Jopp and Balcazar (1996b) found that managers and senior administrative staff expressed a stronger belief in the philosophy of community living and in promoting independence and empowerment of people with disability, than ‘hands-on’ staff in community based support services

Posner (1968) found that executives with lower educational attainment placed less emphasis on educational background and were more favourable to employing people with intellectual disability. However, Hartlage (1974) found that executives with higher educational attainment were more receptive to employing people with intellectual disability

Younger people with prior knowledhe of disabilities and high level of education showed the most positive attitude.They showed their belief in community inclusion and not in the theory of eugenicsThey also spoke from rights point of view, put less stress on social distance and associated their belief system with very few negative stereotypes of Intellectual Disabilities.. . Their attitude towards PWID was not of sympathy or over protectiveness but including them within the community keeping in mind their differences.. Also, attitudes giving rise to discrimination against people with disability have been noted as less prevalent among younger people than older people (Tak-fai Lau & Cheung, 1999).

Cultural factors have been reported as a significant influence on prevailing attitudes towards people with intellectual disability. Berry and Dalal (1996), in a study spanning India and Asia, noted significant contrasts in attitudes towards *integration* and *assimilation*, *segregation* and *marginalization*. One explanation was the varying religious beliefs across these cultures (Hinduism, Buddhism and Islam).

Attitude in India:

Historically, disabilities have been considered punishments for sins committed in a previous life by an individual or their family members (Schlossar, 2004), Director of the World Institute on Disability (WID), points out in an article on the definition of disability:

The moral model is historically the oldest and is less prevalent today. However, there are still many cultures that associate disability with sin, shame and guilt even if these are not overtly based on religious doctrine. For the individual with a disability, this way of thinking is particularly burdensome. This model has been associated with shame on the entire family of a person with a disability. Families have hidden away disabled family members, keeping them out of school and excluded them from any chance at playing a meaningful role in society. Even in less extreme circumstances, this model has resulted in general social ostracism and self-hatred.

Even though the Government of India has several policies and acts geared towards inclusion of people with Intellectual Disabilities their visibility in the community is still very faint.

There are certainly many vulnerable groups present in India, but one of the easiest to forget are the 31 million individuals with intellectual disabilities (ID) in India (WHO, 2004) 1 . The regular world still maintains social distance , has implicit negative attitude and hesitant to increase contact with PWID. Historically, disabilities have been considered punishments for sins committed in a previous life by an individual or their family members (Schlossar, 2004).It is very important to understand the prevalence of the kind of attitude within a community inorder to bring about a social change.Attitudinal barriers can be the greatest enemy of inclusion of Adults with Intellectual disabilities.

Given negative attitudes about people with intellectual disability can seriously impede the progress of their inclusion in schools, the workplace and in the wider community (Gilmore *et al* 2003), particular care must be taken to monitor changing social attitudes toward people with intellectual disability, to identify and circumvent any return to segregation and eugenics as the norm in society (Henry, *et al* 1996a).

4.4 Community related Issues - Aggression, Antisocial behaviour, Abuse and Social discrimination of PwID

4.4.1 General principles of Article 3 of UNCRPD comprises of

- Respect for inherent dignity,
- individual autonomy including the freedom to make one's own choices, and
- independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and
- acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity
- Accessibility;
- Equality between men and women..

These principles leave no room for aggression, antisocial behaviour , abuse and social discrimination for PWID.

The report of the UN Secretary General for the seventy second session of the UN General Assembly, observing that "Grave issues have been flagged in 'Sexual and reproductive health and rights of girls and young women with disabilities'. The report points out that the inability of women to take autonomous decisions exposes them to multiple forms of rights violations, abuse and violence, including forced sterilization and abortion." (UNITED NATIONS. 2017.)

After India signed and ratified the UNCRPD in 2007, the process of enacting a new legislation in place of the Persons with Disabilities Act, 1995 (PWD Act, 1995) began in 2010 to make it compliant with the UNCRPD. After series of consultation meetings and drafting process, the Rights of PWD Act, 2016 (RPWD Act, 2016) was passed by both the houses of the Parliament. It was notified on December 28, 2016 after receiving the presidential assentPrinciples stated to be implemented for empowerment of persons with disabilities (PWD) are respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.

The Act lays stress on nondiscrimination, full and effective participation and inclusion in society, respect for difference and acceptance of disabilities as part of human diversity and humanity,The National Policy recognizes that Persons with Disabilities are valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society.

The question that raises isIs the society ready for the change:

In the words of Dr.Anita Ghai, Disability in the Indian context is often understood as a 'lack' or 'deficit' as well as a 'difference'. Very few people accept the fact that disability is as much a social construct as, say, gender. Since the normative culture in India and the world over carries existential and aesthetic anxieties about differences of any kind, be it caste, class, gender, race or disability, people who are impaired in any way have to live with markers such as 'disabled', 'handicapped', 'crippled', 'differently-abled' and 'special'. This results in an existence marked by acute marginalisation, discrimination and stigmatisation, and disability appears more as a personal quest and tragedy to be borne alone. Even those of us who have lived and studied in apparently inclusive educational institutions, have felt the intolerant attitude of Indian society towards disability.(GHAI, A. 2009.)

In the two most popular epics Mahabharata and Ramayana, negative characters were attributed some form of deformity, for example, Manthara the 'hunchback' in the Ramayana and Shakuni, the ‘lame’ man in the Mahabharata. But, as she says: At the same time, historically there are also narratives to highlight the belief that people with disabilities are children of God. This positioning provided spaces, in spheres of religion and knowledge, where the ability to transcend the body was a distinct possibility. Even though the implicit meaning of such possibilities may be disturbing within our present understanding of disability, it does indicate a dignified negotiation of difference. Thus, the renowned scholar Ashtavakra who had eight deformities, and the great poet Surdas, who was visually impaired, are illustrations of strength and ability to fight oppression. However within these constructions, disability is something that can be overcome. All the same, the predominant cultural construction of disability is largely negative.Ghai.A.,2003)

In some cases, families regard their children as “cursed” and a burden that they must deal with, which at times leads to the neglect and rejection of the child; the child might even be hidden from the community as the family fears they might be rejected by the community (Girimaji, et al. 2001).

In India, disability is often seen as bad karma. As Renu Addlakha says: Indeed the law of karma decreed that being disabled was the just retribution for past misdeeds. Pity, segregation, discrimination and stigmatisation became normalised in the management of persons with disabilities. Such constructions of the disabled by the non-disabled have the dual effect of not only justifying the complete marginalisation and disempowerment of a whole population group but also leading to the internalisation of such negative stereotypes by disabled persons themselves.

At present, individuals with ID are seen by the majority of people in India as fundamentally “flawed” and perceived to have diminished capabilities, thereby placing them at the bottom of the social structure regardless of their caste identity (Ghai, 2002).

In countries with high levels of illiteracy and predominantly rural/agrarian communities, individuals with mild ID are not easily recognizable because they seem to function like everyone else in the community (Girimaji, et al. 2001)

In a study conducted in 10 cities in urban middle class India by The Gallup Organization which conducted face-to-face interviews using the Multinational Survey of Public Attitudes (2003) with a final sample of 1,011 adults in India, 18 years or older. The survey included questions about perceptions of people with ID, knowledge of Special Olympics, and beliefs about inclusion.

23% of the sample said they have no contact a PWID, 54% have never heard about special Olympics. Overall, the respondents significantly underestimated what individuals with ID can do, and seemed to view individuals with ID as being more moderately to severely impaired. That is, those surveyed from India see individuals with ID as being limited in their ability to perform not only complex independent living skills, but also the more simple self-help skills. These findings further illustrate the stereotype that exists among the Indian public that individuals with ID are less capable than their non-disabled peers and are more comparable to children (Ghai, 2002)

In comparison to other countries, Indians perceived the capabilities of people with ID to be much lower than the respondents from all other countries with the exception of Egypt. In countries like the US, Ireland, Russia, and Germany, more than 80% of the public believes that people with ID are capable of tasks such as engaging in simple conversations, washing and dressing themselves and even sustaining friendships and It is also important to consider the predominantly held belief in India that care for individuals with ID should be conducted by the family, including their educational needs (Peshawaria, 1991).

With regard to employment, approximately 51% of those surveyed believe that individuals with ID should work in special workshops. Further, 11% indicated that individuals with ID should not work at all. This belief that people with ID should work in sheltered workshops could be a reflection of the government's current practices, in which they encourage individuals with ID to 11 work in protected work environments (International Labor Organization, 2003). It also could be an indication that people are not comfortable working alongside an individual with ID. The remaining third of the respondents believe that people with ID are best employed in integrated environments, doing either unskilled or skilled labor. In comparison to the other countries surveyed, India is most comparable to South Africa in terms of where they believe individuals with ID should work (see Figure 9). However, the attitudes of those surveyed in India towards including individuals with ID in the work environment were generally more negative than other countries surveyed. Over 50% of those surveyed believe that having a person with ID on the job would lower the productivity of other workers and create safety problems for individuals and the others.The negative attitude towards inclusion as cited by 61%was largely due to the belief that the lack of job training programs as a major obstacle to inclusion in the work force. It may be rooted in the cultural belief of bad karma leading to production of such peole but attitudinal barrier reains the biggest source of hindrance to inclusion. Public's underestimation is the result of the strongly held stereotype that exists among the Indian public that individuals with ID are less capable than their non-disabled peers (Ghai, 2002).

A description of above Scenario in India would analyse why aggression, antisocial behaviour and abuse is common with people with Intellectual Disabilities leading to social discrimination.

On searching for review of Literature concerning aggression towards Intellectual Disabilities , a number of Literature evidenced studies conducted on challenging behaviour shown by PWID. A joint report by the Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists (2007) defined behavior as challenging when: …it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion

Aggressive behavior is defined as any verbal, nonverbal, or physical behavior that was threatening, or physical behavior that actually did harm (in Morrison, 1990). Aggressive behavior is a common phenomenon in the care of people with intellectual disability (ID), especially in inpatient settings (Crocker et al., 2006; Tyrer et al., 2006). People with intellectual disabilities frequently have some forms of behavioral disorders that may manifest as stereotypies, difficult or disruptive behavior, aggressive behaviors toward other people, behaviors that lead to injury of the self or others, and destruction of property (Lowe et al., 2007; Smith & Matson, 2010a). A large study conducted in South Wales (United Kingdom) found that 10% of the intellectual disability population manifested some form of serious challenging behavior, with disruptive behavior being the most prevalent. Multiple forms of challenging behavior in the same person were common (Lowe et al., 2007). These figures were convergent with earlier studies that also found selfinjury, destructiveness, aggression, and disruptive behavior to be prevalent in 10% of the intellectual disability population (Emerson et al., 2001). Earlier studies of a broader range of behavioral problems, including problems such as verbal aggression and temper tantrums, in the intellectual disability population have suggested prevalence between 22.5% and 55% (Deb & Joyce, 1999; Cooper et al., 2007)

These lead to difficulties for the individual themselves and are often problematic for those who work with and care for them.Physical injury, interference with social activities, and abuse are some of the detrimental consequences of aggressive behavior for the aggressors (e.g., Cooper et al., 2009; Emerson & Einfeld, 2011; Matson & Kozlowski, 2012) and that persons with ID often display multiple forms of aggressive behavior at the same time (e.g., physical, verbal, and/or auto-aggressive behavior; Cooper et al., 2009; Crocker et al., 2006; Nijman & à Campo, 2002; Tenneij & Koot, 2008).. Staff and family members can experience negative emotions, stress, physical injuries, and fear of assault or burnout (e.g., Allen, Hawkins, & Cooper, 2006; Hensel, Lunsky, & Dewa, 2014; Mills & Rose, 2011). it is shown that people with mild ID or borderline intellectual functioning are at a clearly increased risk of developing mental health problems. These mental health problems, as known from the *Diagnostic Manual–Intellectual Disability* (*DM-ID;* Fletcher, Loschen, Stavrakaki, & First, 2007)

There are studies that show they are confronted with the use of coercive measures, such as seclusion, much more often, even up to four times as often compared to clients without ID (Nieuwenhuis et al., 2017). Tenneij and Koot (2008) found that aggressive behaviour of people with ID was aimed at staff members in most cases.The above studies clearly establishes aggression as a form of communication and an attempt shown by the people with ID that they are not in favour of the prevailing situation.

In some studies, the prevalence of behavioral disorders in this population has not been found to be higher than that found in individuals with an intellectual disability alone (Deb & Joyce, 1999; Espie et al., 2003). Research shows that aggressive behavior in persons with ID, as is the case in other populations, generally tends to persist over time (Einfeld et al., 2006.

Both the studies cited above shows aggression not as a characteristic typical to ID but as a response to the environment.Thus assessment of behavioral disorders should take into account person factors such as the physical health and mental state of the person and environmental factors such as the quality of their interactions with carers and their living conditions(Kerr , et al,2013)

The joint report by the Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists (2007) considers challenging behavior to be a social construct. They suggest that challenging behavior represents the interaction between person factors, (e.g., degree of intellectual functioning, sensory,motor, or communication difficulties, or underlying mental health problems) and environmental factors (e.g., staff numbers and training, quality of material environment, opportunities for social engagement). According to this perspective, challenging behavior can result from a mismatch between the person's individual needs and the environment. This view posits challenging behavior as a response to a poor environment and as such suggests a role for approaches such as functional analysis with appropriate environmental changes in managing behavioral problems.

What could be the reason behind such negative attitude that has developed over the years.Why are adultswith Intellectual Disabilities often held in suspiscion?Why are they considered"safe" in a sheltered environment?

Researches made earlier looked at Adults with Intellectual Disabilities from a clinical point of view. Researcher speak of aggression and anti social behaviour being reported in Adults with ID.Aggression and related disruptive acts represent the most frequently occurring behavioral challenges of persons with intellectual disabilities (ID) (Eyman & Call, 1977; Jacobson, 1982; Schroeder, Rojahn, & Olenquist, 1991). Even though aggression occurs in a social context and is maintained to a major extent by social contingencies, medical, genetic, psychiatric, neuropsychiatric, and psychological conditions also are reported to represent significant contributing influences (Barnhill, 1999; Gardner, 2002a; Sheard, 1984).

In a recent study , 2013 of aggression in Adults with Disabilities, it was reported that

Again If we look into the characteristics of people with Intellectual Disabilities the main aspect that surfaces is that they have difficulty in adaptive behaviour.if we probe into adaptive behaviour we would see that it is from the point of view of us, the non disabled people that they have difficulty in adapting. Is that because they have less knowledge , or are denied knowledge or are given knowledge in such a manner that they don't understand?

It is time that we look into aggression, anti social behaviour abuse from a sociological point of view rathen than taking up individual cases and going into remediation mode.With self advocacy gaining importance just like womens studies changed with the advent of feminism, the perspective of looking at the world of disability is changing with disability studies which is largely based on social model.This speaks of the society being at fault, where the control of disabling society is in the hands of disabled people.There are structural barriers, environmental barriers and above all attitudinal barriers.

Again it should be bourne in mind that social model itself is debatable.Can the model alone encompass so many varied types with varying degree of disabilities fitting in personal experiences of each.Does the oppressor oppressed model work or is it the lack of knowledge on the part of non disabled world that is making the members apprehensive towards all challenging behaviour exhibited by PWID?Since the right based model stresses on right to be with disability it is time that the non disabled world expand their vista of knowledge.

Are these challenging bewhaviour exhibited as a sign of expression where PWID wanted to communicate their discomfort, anguish , dislike towards events, people or occurances?

Recently, a fourteen year old learner in an inclusive school in India exhibited antisocial behaviour. He entered the 'Mains" room which has all electrical connection and switched off the mains. The entire scenario was reported through CCTV.After few minutes he resumed the connection. Before taking any disciplinary action, the committee decided to "talk" to the learner. Since he has Downs Syndrome compounded with speech difficulty, it was decided that the special educator would have a dialogue .The communication revealed that as the learner's regular peers had interrupted academic sessions due to the frequent power cuts and this specific learner based on his previous knowledge(given by the same special educator in a session on technology) switched off and on the mains to provide uninterrupted sessions ..

It is time we take cognisance of both the worlds.

While we have almost removed the structural barriers that talk about disempowerment of people with disabilities, denial of human rights through our policy and laws, it is time to focus on the environmental barriers where we still use disabilist language, where the disability comes first and then the person, where even though we build inclusive schools and talk about inclusive workplace, attitudinal barriers in the form of cognitive prejudice , assumptions regarding abilities, emotions , needs are continuously made and an element of fear remains associated with PWID.

While we speak of aggression, antisocial behaviour , abuse and discrimination we need to understand that these behaviours exist in human race and time and again have been shown towards people who are considered weaker and have no voice to express.It has essentially been a power struggle and we need to experience a social change . Thus, as a Black feminist writer, Lorde (1984), has stated:

> Somewhere on the edge of consciousness, there is what I call a mythical norm…this norm is usually defined as white, thin, male, young, hetero sexual, Christian and financially secure. It is with this myt hical norm that the trappings of power reside within this society. Those of us who stand outside that power often identify on e way in which we are different, andwe assume that to be the primary cause of all oppression, forgetting other distortions around difference, some of which we ourselves may be prac-tising.

From concept of victory of the people in the seats of power, from the concept of the control of the weak over the strong the concept of abuse comes.

Disabled women's experience of sexism is often exacerbated by the intersection of gender and disabily (Lonsdale 1990; Lloyd 1992). There seems to be a proliferation of additive approaches, such as' double disadvantage' and ' triple burden', to capture the experience of disabled people encountering a number of forms of oppression. However, additive approaches are far from ad equate, particularly because no one experience of oppression is uniform or fixed. Dis abled people who have multiple identities experience both multiple a nd 'simultaneous oppression' because oppression occurs singularly,multiply and simultaneously in their lives, the dynamics of which vary from day to day and fromcontext to context.

There is very little research in India on abuse of people with disabilities. Between 1998 and 2000, CY Gopinath and Shilpa Patil conducted a research programme – Project Signpost – to explore deaf adults' sexual behaviour and vulnerability to HIV involving three groups of deaf people, two schools for deaf children and one workshop of deaf women in Delhi, Mumbai and Chennai. Their report Exploring the Sexual Vulnerability of Urban Deaf Indians (2000) revealed above average (compared with the general population) levels of sexual abuse of deaf women and children, average levels of sexual activity, and well below average levels of knowledge about the body, anatomy, functions, sexual and reproductive health.**196**

A small 2004 survey in Odisha, India, found that virtually all of the women and girls with disabilities were beaten at home, 25% of women with intellectual disabilities had been raped and 6% of women with disabilities had been forcibly sterilised.

.About twenty years before in one of the special schools in Mumbai there was a beautiful girl with sharp features and a perfect torso.She also had Cerebral Palsy with Moderate Mental Retardation as was the term used in those years and was wheelchair bound.She was seventeen and on the verge of adulthood.A young B.Ed Spl Ed trainee encountered strange exhibition of sexual behaviours during her home visits which was one of the requirement of course .Since the girl had no speech, puppet therapy sessions with five puppets representing her family of three sisters and parents were conducted. During one of the sessions, the girl insisted on making the puppet touch her private parts and then burst into tears. It was the father puppet that she had in her hands. When this information was shared by the trainee with the mother, the mother replied:"atleast the father is not spending money outside in a brothel,instead saving it for the marriage of the other two daughters.This one is as it is a vegetable and can never be married off."

The story is about abuse , extreme oppression. But it is also about gaining an insight into the dark pathological world of the disabled .The story that tells us we are in the presence of thinking feeling human beings who can differentiate right from wrong.This girl felt humiliated,was angry and showed frustration like any other victim of incest.She just needed a different medium to express.This is the torchbearer of change. The Rights model of disability thus is the vision of the liberation and emancipation of the people with disability.

4.5 Creating Awareness related to community issue

According to The World Bank:

"One billion people, or 15% of the world's population, experience some form of disability, and disability prevalence is higher for developing countries. One-fifth of the estimated global total, or between 110 million and 190 million people, experience significant disabilities". It is also stated that people with disabilities are more likely to experience a discriminatory attitude in the prevailing fields of education, health, social economy, employment and justice.

Let us understand how the people's way of treating people with disability have changed over the years by looking into the various disability models:

1.A 2007 World Bank report on disability in India describes the charity or welfare model of disability that "views the person with disabilities as the problem and dependent on the sympathy of others to provide assistance." (O'KEEFE, P. 2007)

The medical model looks at disability as a defect or sickness which has to be cured through medical intervention. It regards disabled people as bodies that are damaged, broken and being unable to match or fit the norm or 'ideal' body type. Thus, the medical model regards the body of a person with disabilities as pathological. It also looks at disability as a personal tragedy of the person affected by it, which if at all, can only be cured by medicines)Medical interventions focus on repairing the body to make it fit the prevalent notion of the body in society, often disregarding what disabled persons themselves feel or want. .(KHANNA, R., et al. 2004

The rehabilitation model is highly influenced by the medical model and believes that disability is a deficiency that must be fixed by rehabilitation professionals or other helping professionals. It focuses on therapies, exercises and special care to help people with disabilities overcome their constraints and approximate the ideal body. (KAPLAN, D. ,2004)

The social model makes a distinction between 'impairment' and 'disability'. Impairment is lacking part or all of a limb or having a defective limb, organism or mechanism of the body. On the other hand, disability is the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities.(The DEMOS project. 2003.)The present social structures – predominantly shaped by people's attitudes and understanding of disability – deny access to resources and information which disables an individual. The social model argues that people with disabilities are people who are challenging oppressive social norms and structures; they are resisting the exclusion, discrimination and abuse that they have faced from society.(SHAKESPEARE, T. 2000.)

Rights-based model of disability builds on the insights of the social model to promote creation of communities which accept diversities and differences, and have a non-discriminating environment in terms of inclusion in all aspects of the life of society.(O'KEEFE, P. 2007.)According to this model all human beings irrespective of their disabilities have rights, which are unchallengeable. This is in alignment with international human rights laws and instruments that invoke the rights of all human beings, everywhere, to certain basic, fundamental, freedoms, opportunities and legal protection of these. Therefore this model promotes the dignity, self, entitlement and agency of the individual human being, as a holder of rights, not the recipient of such resources and aid as another may deem fit to apportion out. Importantly, as Bhanushali emphasises in a paper, "This model emphasises viewing persons with disabilities as subjects and not as objects thus locating the problem outside disabled persons and addresses the manner in which the economic and social processes accommodate the differences of disability or not, as the case may be".(BHANUSHALI, K. 2007)

It is very important to understand what is the model of disability or the combination of which approaches are being followed by the community.Awareness can be created only after ascertaining the perspective and belief system of the community.Discriminatory attitude can dissipate by creating awareness, building a bond of mutual trust and sharing experiences. The uprooting of discrimation towards PWID is not an overnight process, nor can it happen by bringing in laws.

In many communities there are barriers which impact on the quality of life of people with disabilities and their family members. These include physical/ environmental, attitudinal, cultural, and services, system and policy barriers. More detailed accounts of the different types of barriers that people with disabilities and their family members may encounter. Communities consist of different people, groups and organizations, many of whom are important stakeholders for CBR programmes. These include people with disabilities and their family members and neighbours and friends, schoolteachers, self-help groups, disabled people's organizations and local authorities.

A thorough understanding of the society tell us that a child is a product of his or her system. This system is not an isolated family but a combination of the immediate family, school, neighbours , peer groups, their interaction as well as the social and cultural values that each family carries within and with itself.Removal of prejudices and stereotypes can only happen if the entire system is geared towards it.

Awareness about disability issues cannot come in isolation to the community till the time the seed of change is not sown in childhood. The society for a long time have got used to seeing people with disability as someone out of the social arena, who needs to be segregated not for the sake of oppression but for the well being of the person himself so that he can be nurtured in a safe environment as his capacities are too limited to allow him to venture outside.

Labeling is a very common phenomenon that has always happened to the marginalised.With the emphasis on right based approach with regards to disability one must not think that the labelling will be removed or the sympathy will be replaced by empathy.

Laws and policies can give the society a direction to move forward but it is only an attitudinal shift that can change the society as a whole .Any change is a slow process and is met with resistence.Any change also comes with the “why”

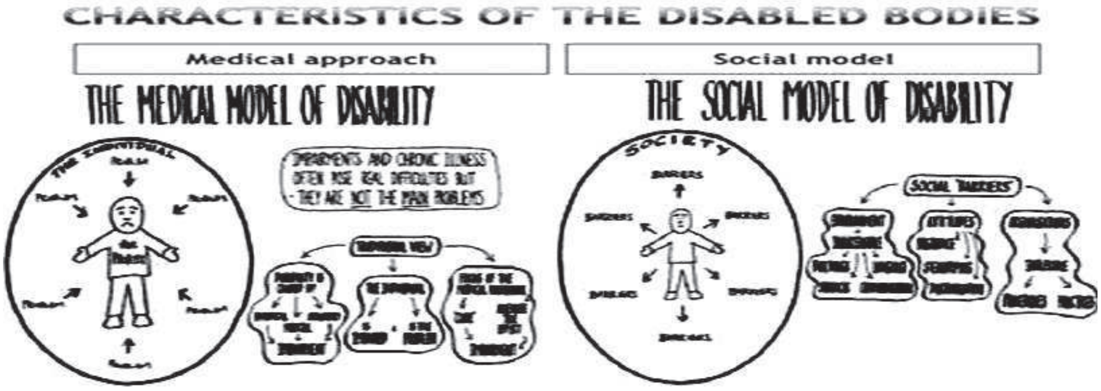
To understand the ‘why” the only way is accessibility-the marginalised must come in contact with the non marginalised. Everyday interactions must increase at everyplace starting from school to neighbourhood, to marketplace, recreational area and definitely workplace. Professionals, mothers, fathers, sibilings must come forward creating niche communities who will take the message forward of hope, togetherness .

The burning issues that connect community to marginalised are as follows:

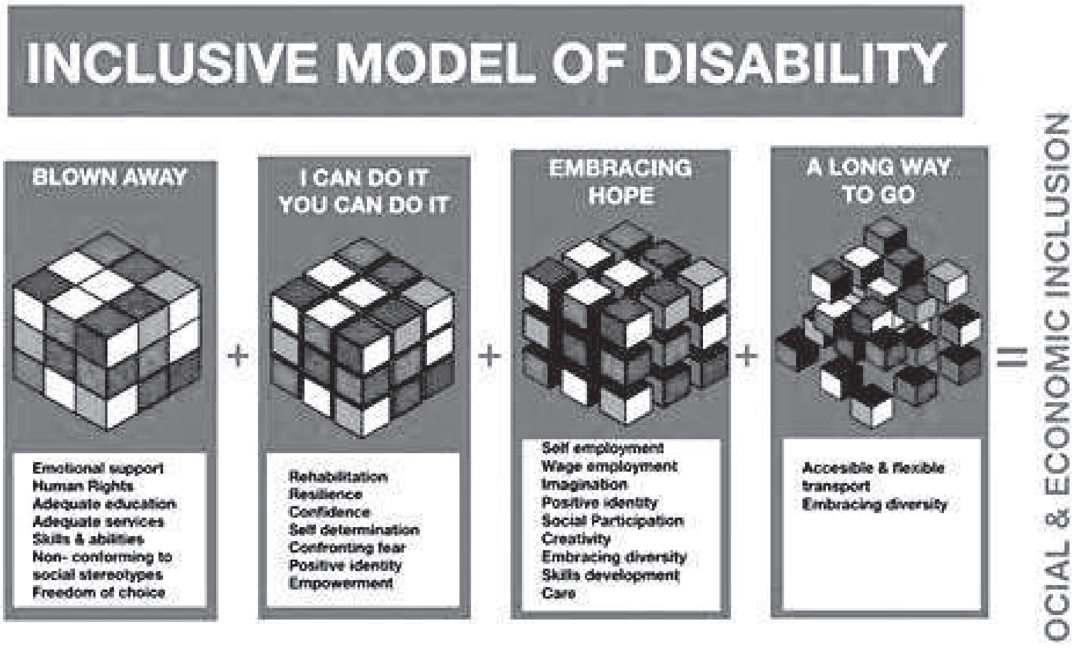
- Language being a social action must changeto accommodate People into the concept of Disabilities.
- People with Disabilities must get a right to meaningful education
- Disability and poverty are closely linked.They should gain access to proper health care
- There are laws and policies but the community must disallow employment discrimination
- Time to sit up and take cognisance of the cases of sexual violence and abuse
- To make aware of parents with disabilities that their adult children have a right to dignified life and can no longer be treated as objects of pity and or fear.It is

a structural racism that is practised right from childhood where PWID are subject to implicit attitude of negative stereotypes .

It is time to focus the community issues towards rechanging the environment rather than focusing on the problem of the individual.

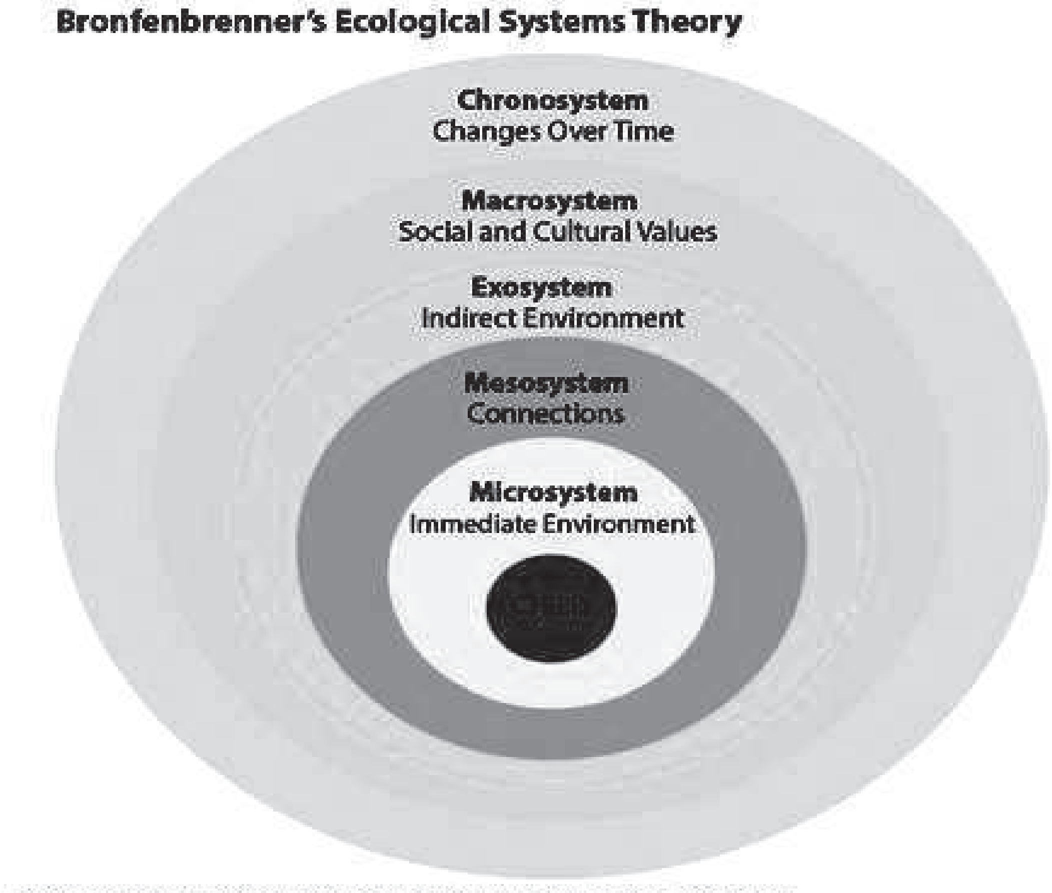


And the community issues start focusing on enabling model of inclusion rather than disabling model of inclusion as is evident from the following diagram.



https://weareunlimited.org.uk/whats-changed-marlene-le-roux-two-of-three/inclusive-model-of-dissability/

2.5.3 A model is presented below to understand the various systems and their interactions to promote the enabling model of inclusion.These factors when taken into considerations the minor issues in community shall be looked into.



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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 interact with and influence 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.

The first and the best place to start creating awareness is in the schools.The schools house citizens of tomorrow.If they understand disability as a condition or just a way of life and can segregate impairment from Disability while the former belongs to the individual and the latter belons to the society a community of disabled and non disabled shall coexist in future.

Schools can have disability awareness programmes in a variety of ways:

1. Being inclusive and giving admission to children who"look different, behave differently"-placing them in same age group peers would give rise to everyday interactions.Through these interactions children will devise mechanisms for communication and resolving conflict.
2. Connecting topics with Disability.for example if there is a topic on "different ways of speaking"a session could be taken with learners where through hands on activities they are sensitised to undersatand that people can have different ways of expression.
3. Monthly interaction programmes could be arranged with special schools for these children to understand the functioning of their peers
4. School event slike special Olympics , draw with your feet , sing a song of two lines can be arranged where regular exposure can be made
5. Even at the pre-primary level ,regular learners may have paired sessions with Children with multiple disabilities to understand their modalities of learning.

Researchers have found that disability awareness programs at schools have led young children to gain empathy and have positive attitudes. This particular attitude then further grows on an individual, making them better citizens as they mature. Another great aspect of disability awareness at school is that the classrooms are more inclusive and diverse which allows a student to learn more from his/her peers."Many outside influences shape a child's attitude. They may develop ideas about diversity, life and people from home, peers, and life experiences but school plays an important role in developing attitude. School is the place where students learn surrounded by other people with many differences. At school, students should learn to be accepting, understanding and friendly". (Rillotta & Nettlebeck, 2007)

The next place to start is the home.When we say home it does not mean a place where a child with disability has already been welcomed .A lot of new learning continues to take place within the home periphery and discovery of the child takes place.Home means the residence of the regular peers of the specific learner.Often these are the hot beds of negative perceptions.and stereotypes.With the policiesbeing there even though the explicit attitude is pro disability, implicit attitude speaks of fear and rejection and singling out the child on every occasion.

This process can be done as follows:

1. Parental interaction sessions
2. Sensitisation workshops organised by the school.
3. Videos of class events to understand that the learner is not a potential harm
4. Working as volunteer within school during activity to decrease social distance and increase contact.
5. Carrying back the concept of empathy, accessibility and diversity to other family members
6. Attending party meets as arranged by parents of the specific child.

In todays digital world, a system forming the part of the community can also be virtual in nature.

Communities can be formed both virtually and non-virtually. A disabled individual can have access to an online community where he/she feels comfortable in finding their voice and the ability to spread their knowledge across the globe. There are plenty of platforms on the internet that provides great virtual services for the disabled individuals. Some of these include: DisabledUnited, Special Bridge, Able Here, Disabilities-R-Us, to name a few. The common ideology of all these platforms is to provide a sense of belonging for the disabled individuals where they can share their real life experiences online in a safe, comforting and friendly environment. Furthermore, thanks to social media platforms like Facebook, more individuals dealing with a disability have become part of communities as it provides direct contact with the peers and raising their voices for various social causes such as in communities like Disability Support Group and Diversability.(https://medium.com/arise-impact/the-role-of-a-community-empowering-the-disabled-individuals-collaborating-and-creating-30941a388858)

Workplace:

1. Coworkers before the person joins in should be given inputs on exact nature and degree of difficulties and how they can be met with.
2. Coworkers should be sensitised on Language usage

3. Coworkers should refrain from a patronising attitude.
4. All staff should focus on the PWID as a person and not an expression of all the characteristics of Disabilities.

In a letter published in one of the journals sums up the community issues and its importance.

A diagram shall illustrate the relationship between trainer and community.

The following image is an illustration of how Community based support have been given to people with profound Intellectual Disabilities

Figure 1. The *active support system*
Adapted from Jones and Lowe (2005)

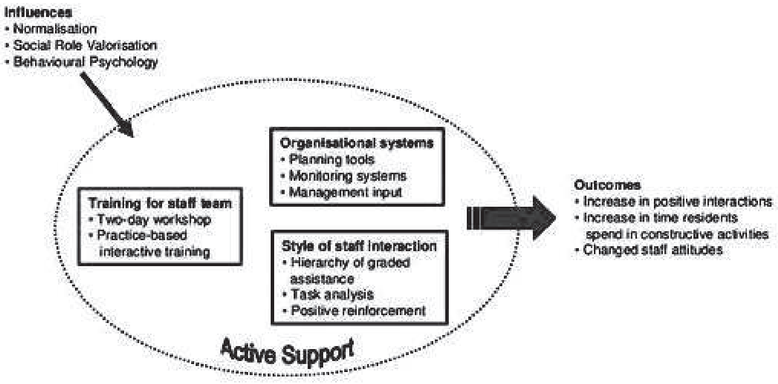


Figure 1. The active support system Adapted from Jones and Lowe (2005)

Published in 2008

Making life good in the community. Implementing person-centred active support in a group home for people with profound intellectual disabilities : Issues for house supervisors and their managers.

Tim Clement, Christine Bigby

4.6 Community involvement & Resource Mobilization

24Throughout history and in most cultures disabled people have been viewed as inferior, dangerous, tragic, pathetic and not quite human. They have been kept apart from other people by the practice of institutionalization and by hostile attitudes and an inaccessible environment (Hughes 1998). Such are the negative presumptions held about impairment and disability, that the abortion of impairedfoetuses is barely challenged (Parens and Asch 2000) and compulsory sterilization of people with learning difficulties has been widely practised in many parts of the world (Park and Radford 1999).The erroneous idea that disabled people cannot contribute to society, or enjoy an adequate quality of life, lies at the heart of this response.

In 2015, Nipun Malhotra a disability activist and self-advocate challenged exclusion by working to have an online restaurant listing company, zomato.com, list restaurants that are wheelchair and disabled friendly.168 Nipun himself was in the news for having been denied entry into a Delhi restaurant with his friends. The group was told that as a policy the restaurant does not allow entry to 'disabled people'. He says, "It was a struggle to find disabled-friendly restaurants in Delhi and other Indian cities before Zomato agreed to my request. Not many places advertised themselves as disabled friendly and that was disheartening. Most disabled people in India do not visit restaurants very often and that severely restricts their social life."

4.6.2 The problems that disabled people experience are seen to result from impairment rather than the failure of society to meet that person's needs in terms of appropriate human help and accessibility. Furthermore people who acquire an impairment are assumed to suffer feelings of loss from which there will be no gain and from which they will never completely recover. (Swainne.J., 2003) Many disabled people have internalized these ideas resulting in a negative self-image for, as Linton (1998b: 152) points out, 'Disabled people and non disabled people have both been schooled in the same ableist discourse/ Similarly Morris (1991) states: Most of the people we have dealings with, including our most intimate relationships, are not like us. It is therefore very difficult for us to recognise and challenge the values and judgements that are applied to us and our lives. Our ideas about disability and about ourselves are generallyformed by those who are not disabled.Disabled people who view their impairments as positive or neutral have found it difficult or impossible to convince nondisabled people that this is the case (Linton 1998a). Talking of Helen Keller, Crow (2000: 854) states that ' It seemed that she could never fully satisfy people's curiosity for details nor could she reassure them entirely that she was content herself. When the nondisabled world feted her courage, for Helen, her impairments were a natural, largely neutral condition.' People with disabilities are finding a voice and have downright rejected the tragic model of Disability.

Therefore the onus lies on the non disabled to remove barriers and include PWID in the mainstream society. How and who can do that?The government, trained professionals or the community itself?

This is in reference to the article by Kumar SG, Roy G, Kar SS. entitled "Disability and rehabilitation services in India: Issues and challenges" published in Disability and rehabilitation services in India. J Family Med Prim Care. 2012;1:69–73.

- People with disabilities in developing nations face a number of social, medical, educational, employment, and political challenges due to the scarcity of services and resources. In many cases, such services are confined to the citiesA large percentage of people with disabilities live in poverty and in rural areas.
- They face manifold challenges. This population deserves services, but what are the options? Social implications of disabilities are more disadvantageous for people with disabilities; where these institutions are merely reaching. So far, the CBR approach has been viewed as an option. Presently, the CBR approach has been practiced in around 90 countries
- Many studies found that the CBR is a cost-effective, accessible, sensitive to the community needs, flexible, and an applicable approach in resource-poor settings. It has evidences of enabling and empowering people with disabilities and their communities.[World Health Organisation,Geneva)] Usually, the CBR program/s are conducted by nongovernmental organizations (NGOs) in India. The CBR programs in India mainly focus on four major components: Medical, educational, economic, and social. The NGOs further choose their focus area within four components depending upon the resources and capacity they have. Current literature on the CBR advocates several benefits as well as many challenges. The government should promote funding for the CBR programs, trainings, and research to make this model more effective and comprehensive

Initiative towards employment:

People with an ID are amongst those in society with the lowest employment rate. The most recent statement of general policy towards people with ID estimates that less than 10 percent of this population in the UK are in employment (DoH, 2001a).

This is supported by the work of McConkey and Mezza (2001) who estimate the rate to be 9 percent. Valuing People (DoH, 2001a) noted that 8800 people with ID were employed in supported employment schemes run by the Department for Education and Skills in the UK. Beyer (2001) estimated that a further 7000 are assisted by independent agencies.

It has been well documented that people with ID often experience employment difficulties and a great deal of research has been conducted on this issue (Stephens, et al., 2005; Capella, Roessler & Hemmeria, 2002; McConkey & Mezza, 2001). However, employment figures are not available for those people with an ID that challenge and they have limited employment opportunities. The limited opportunities for employment for this population may be attributed to the lack of understanding of the reasons for behaviours that challenge as well as a lack of expertise regarding behaviour management and autism (McGill et al. 2006b). Rose et al. (2005a) in a study aimed to identify factors that may affect the likelihood that people with intellectual disabilities will find employment through a supported employment agency found staff motivation to be the only significant predictor of employment outcome.

Cole et al. (2007) brought together key themes and issues emerging from a review of UK literature and a survey of best practice of community-based day activities for people with ID. It identified that sufficient time and resources are needed to explore gaps around the provision of community-based day opportunities for people from ethnic communities, people with profound and multiple learning difficulties, people who present behaviours that challenge, and people in older and younger age categories

Community based care:

The development of community-based services as alternatives to institutional care for people with ID first originated in the 1950s and this has been probably the most important change in policy and the pattern of service provision in ID in the last 50 years. Supported staffed homes are now the most common form of living support in Britain, North America and Australia (Braddock et al. 2001).The evaluation of community-based models of care for people with ID in comparison to institutionalised care generally shows a relatively clear picture highlighting the superiority of community-based services (Mansell, 2006).

Within the development sector there is a strong focus on communities taking a lead role in development activities rather than just being the receivers of grants and services. The community is seen as the best judge of its own problems, and to have the ability to undertake appropriate action to solve these problems. CBR is a strategy for community-based inclusive development so the importance of community participation is acknowledged, e.g. communities are listened to and directly involved in decision-making and activities that affect their lives

Community mobilization is the process of bringing together as many stakeholders as possible to raise people's awareness of and demand for a particular programme, to assist in the delivery of resources and services, and to strengthen community participation for sustainability and self-reliance. A lot can be achieved when people from different parts of the community share a common goal and actively participate in both identifying needs and being part of the solution. Community mobilization helps to empower communities and enable them to initiate and control their own development.(Khasnabis C, Heinicke Motsch K, Achu K, et al., editors.

The different strata of the society needs to be actively involved to bring in a change and provide a meaningful life for all the members.

CBR programmes to identify and remove barriers within the community and ensure the successful inclusion of people with disabilities in their communities with equal rights and opportunities can use community mobilization to bring together stakeholders in the community, e.g:

- community members,
- local authorities,
- local leaders,
- decision- and policy-makers,.

The four steps of community mobilisation are as follows:

1. Bringing people together:

It is a mandatory requirement for people from all walks of lifew in the community should meet on a common forum to discuss issues The meetings can happen by forming a committee of members from each section who can then motivate the others to be present for the meeting.If a non governmental organisation takes the initiative it is important for it to understand the nuances, the seats of power and accordingly tread.

2. To raise peoples awareness:

It is to be remembered that not every member would have prior knowledge of disability.Members actually would be of three categories-one who are proactive and believe in disability rights and issues.second one may have no exposure and be neutral and the third may harbour misconceptions and be victim of negative stereotype and prejudices.There may be a fourth type who himself or herself is a PWID.

Awareness could be raised by sensitisation programmes, street plays, exposure to movies related to disability. Presentation and lectures or giving hands on experience in an organisation.It has been seen that lecture and presentation create least impact on mmembersbut greater impact is created when actual persons come and narrate their story.

3. Assist in the delivery of resources and services:

It is important that a planned schedule be created .The NGO may require to do handholding in the beginning of the programme but ultimately the onus must rest on the community itself. It is important that the people who will be ultimately offering suppor and services to PWID should be adequately trained and have a positive attitude towards this population.They should be trained in research based teaching and intervention strategies as well.

Grey et al, (2007) summarises barriers to staff implementing effective behavioural interventions:

- Absence of an organisational ethos supporting behavioural supports, combined with disparity in belief systems on the causes of behaviours that challenge (Ager & O’May, 2001)
- The absence of adequate performance management systems for the implementation of behavioural interventions (Reid et al., 2005)
- Poor competency-based training (Murray et al., 2000)
- Negative staff perceptions of behavioural interventions and
- poor understanding of such interventions (Ager & O’May, 2001).

Grey et al., (2007) suggested that perhaps it's time for a reappraisal of the research agenda for staff training and behaviours that challenge.Often labelling some behaviours that are challenging results from stereotyping and negative perceptions.

4. Facilitate and strengthen community participation This is the most important aspect where roles and responsibilities of each member must be specified.community members who are otherwise not economically independent can be selected for training to give services independently later.

The hand holding should continue till it becomes a self reliant and self sustainable programme.

About 80% of people with disabilities live in developing countries. The majority are poor and experience difficulties in accessing basic health services, including rehabilitation services. This causes immobility, isolation, dependency, inequality, often premature death and increased poverty. With proper health care and rehabilitation services, this picture could be significantly changed and people with disabilities would become important contributors to society. Indeed, people with disabilities are equal members of society and it is their fundamental right to access health care, rehabilitation and support services as mentioned in the United Nations' Standard Rules on the Equalization of Opportunities for Persons with Disabilities (December 1993).

(Geneva: World Health Organization; 2010) Community-Based Rehabilitation:Guidelines

An analysis of the above reveals the following:

There is a goal which principally means removing structural, environmental and attitudinal barriers.It also entails identification of strength areas for that goal to be achieved.

The role of any community mobilisation programme will be to motivate the community itself to remove barriers from within, create a sustainable system that is beneficial for all community members and finally impart training in such a manner that mentors within the community become trainer themselves.

What are the desirable outcomes:

1. Communities are aware about the needs, and motivated to improve the quality of life, of people with disabilities and their family members.
2. Barriers in the community are reduced or removed for people with disabilities and their family members.
3. Communities are knowledgeable about CBR and how community resources can be used to develop and sustain CBR programmes.
4. Communities participate in planning, implementing and managing CBR programmes. Some illustrations:

Colombia

Empowerment through leadership roles

In Colombia, many municipalities run CBR programmes which are funded and managed by local government. In 2002, after a few years of experience, one local government, realizing that many of its programmes were not sustainable and lacked community ownership, helped to establish a pilot project, FUNDISCA (Foundation of the Disabled – Caucasian), in the municipality of Caucasia, north of Colombia.

The key objective of FUNDISCA was to facilitate the empowerment of people with disabilities by allowing them to assume leadership roles within the CBR programme and to play an active role in planning and controlling their own lives. FUNDISCA mobilized many people in the community to come together and support the programme, including people with disabilities, parents, caregivers, displaced individuals, indigenous people, community members and community leaders.

FUNDISCA now has 218 members and has engaged 20 volunteers who work as CBR personnel. These CBR personnel are primarily responsible for identifying people with disabilities and providing them and their families with the necessary support. They work to promote self-esteem, family inclusion, and access to services in the health, education, labour and employment sectors.

FUNDISCA has experienced several setbacks, e.g. some members putting their own interests before the group's interests, limited availability of resources for addressing disability issues at municipality level, and institution/service providers often demonstrating limited sensitivity regarding disability issues.

However, with time and effort FUNDISCA has overcome these difficulties and has become a dynamic and well-established foundation. Because of its continuous community mobilization strategy, FUNDISCA has stimulated the community to become interested and involved in disability activities. It has brought people with disabilities and their communities closer together, and encouraged community leaders to become advocates for disability issues with the local authorities

Activity:

Using the above model analyse any CBR programme undertaken in India.

Since any community involvement requires large funds , it is important to understand the concept of resource mobilisation.

According to A Practical Guide for Research and Community Based Organizations report 2009,(Creating and SWE/SWFD/TRM/M25 by Ms. Easter Subha Jasmine)

Resource mobilization may be defined as a management process that involves identifying people who share the same values as your organization, and taking steps to manage that relationship. Looking closely at this definition, one can see that resource mobilization is a process that involves three integrated concepts as follows

Organizational Management and Development: It involves establishing and strengthening organizations for the resource mobilization process. It also involves identifying the organization's vision, mission, and goals, and putting in place internal systems and processes that enable the resources mobilization efforts, such as identifying the roles of board and staff and efficiently managing human, material, and financial resources. implementing a strategic plan that addresses the proper use of existing funds on one hand, and seek out diversified sources of future funding on the other. This concept covers the following principles

a) Resource mobilization is just a means to the end, the end being the fulfilment of the organization's vision

b) Resource mobilization is a team effort, and involves the institution's commitment to resource mobilization, acceptance for the need to raise resources and institutionalizing resource mobilization priorities, policies and budget allocation

c) The responsibility for the resource mobilization effort is shared by the board, the president or the executive director, and the resource mobilization unit

d) An organization needs money in order to raise money

e) There are no quick fixes in resource mobilization

Communicating and Prospecting Once an organization gets ready for resource mobilization, it must ensure long term sustainability through acquiring new donors and maintaining a constituency base. Resource mobilization entails learning how to connect with prospective and finding common ground through shared values and interests. It also entails discerning the right prospect to approach, and matching the appropriate resource mobilization strategy to the prospect. This concept is governed by two principles:

a) Resource mobilization is really friend-raising. Financial support comes as a result of a relationship and not as the goal in and of itself.

b) People do not give money to causes, they give to people with causes. People give to organizations to which they have personal affiliation, in some form.

Relationship Building Once donors are identified, get closer, get to know them better, same way as developing an acquaintance. Initiating new relationships, nurturing existing ones and building an ever expanding network is an on-going activity. The following principles are important in this process.

a) Donor cultivation means bringing the prospect to a closer relationship with the organization, increasing interest and involvement

b) Start at the bottom of the resource mobilization pyramid to get to the top

Strategic Networking Guidelines

a) Begin with the end in mind.

b) Know your audience.

c) Keep the interests of the donor in mind.

d) Listen and be prepared to explain elements of your organization to the donor

e) Prepare your talking points in advance.

f) Leave critical information behind.

g) Follow up.

Concept of resource mobilization: Resource mobilisation is commonly used in similar meaning with fund raising. Fundraising is just a part of it or only an outcome of resource mobilisation efforts. Resource mobilisation includes building valuable contacts and networks, and garnering the interest, support, and contributions of people important to the organisation.) 2.2.1 Importance of resource mobilization: The importance of resource mobilization can be stated for the following reasons.

a) It diversifies, expand its resources base and develop new thinking and challenge the old traditions in supporting the achievement of integration agenda.

b) It identifies and analyse the resources available for her program priorities, policies and efficient budget allocation as stipulated in the Development Strategy.

c) It understands current donor funding landscape, resource availability and support commitment.

d) It help to maximize use of domestic capital and skills to expand deep relations with stakeholder and

e) It provides continuity and stability to the organization and its work

Important point's donors look for: Advocating for a good cause is not enough to gain local funding. Legitimacy, transparency and accountability are the key factors the donors look for.

Do's and don'ts when meeting with the donors: According to Resource mobilisation and proposal writing by Lisa Thomson,

a) Remember to always speak on equal terms with funders b) Treat donors with respect and curiosity c) Follow through on everything that you say you will do d) Meet all donor deadlines e) Listen well to know who you are talking to. f) Learn their name and position and learn how to communicate with people from different backgrounds. g) Do not use too much flattery h) Do not speak in a 'poor us' way i) Do not act desperate or complain about having no money j) Do not call a potential resource provider too often or talk for too long k) Do not hurry or rush the funder

Tips for starting conversation: According to Resource mobilisation and proposal writing by Lisa Thomson, a. Use questions to get started b. Listen well and patiently c. Do not deny objections but find a positive way to answer them d. Do not ask until you feel the time is right – then ask for the specific amount e. Always base your appeal on facts rather than emotion f. Mention if you have support from other donors g. Offer a written proposal if necessary h. Be flexible and understanding i. If the answer is no, try to find out what the reasons were and if there are ways that this can be changed to yes. j. Suggest a follow up meeting if necessary. 2.2.5 Information that can be shared during meeting: According to Resource mobilisation and proposal writing by Lisa Thomson, a. Annual reports (which would include financial reports) b. Stories / Case Studies / Photos c. Testimonials / Letters of support d. A standard short description of your project. e. Newspaper articles / press coverage about your organization f. Business cards

Levels of Participation of donors a) Passive Participation b) Participation by giving information about other sources of donations c) Participation by

Consultation d) Participation by sharing Material Incentives e) Functional Participation f) Interactive Participation g) Self-Mobilization

Donor performance indicators a. Return on investment b. Donor acquisition cost c. Response rate of donors and average donation d. Attrition rate of both donors and volunteers 2.3 Situational analysis It helps organizations to identify their positions before planning for an action. Development organizations plan methodologies that contribute to the viability and sustainability of the communities with which they work. Situational analysis is conducted for various reasons, like assessing organizational performance, various skills and knowledge areas, motivation and environmental influences on its performance and so. This involves a SWOT Analysis for assessing resource mobilization capacities of the organization.

Internal factors a situational analysis can give a. Affirm resource mobilization successes to date b. Provide a sense of history and present the organization's evolution in its responses to changes in the funding environment c. Present a "reality check" on where the organization is at currently going on achieving its vision, mission and existing strategic plan goals d. Validate funding targets over a set period of time, identify available funding and resource gaps e. Indicate gaps in administrative systems such as Finance and Accounting f. Indicate gaps specific to resource mobilization skills and systems such as proposal writing, implementation of other strategies, donor acquisition and upgrade g. Establish ownership of resource mobilization functions h. Open new doors or widen perspectives on prospective resourceproviders i. Determine buy in, or lack thereof, of various stakeholders to organization's funding priorities and resource mobilization strategies j. Establish resource mobilization policies and code of ethics anchored to the organization's core values k. Review the relevance of the organization's existing key messages l. Determine the organization's capacity to invest in a resource mobilization program

External factors a situational analysis can give a. Funders' priorities and changing trends b. Demand for your organization's services c. Technological innovations related to your area of work d. Legislative and regulatory changes e. Competing grantees f. Prevailing political, social and economic conditions (Chaim 2011)

Methods of resource mobilization: The principal methods of resource mobilization are: 2.4.1. Government grants: Resource mobilization can be done through availing the various Government grants. There are grants available for supporting various types of disabilities. It is important to have sufficient knowledge of these provisions when working in the field of disabilities. Some of the grants are disbursed at DDRO levels, like self-employment assistance while some other grants are available with the Health Department. (Chawla 1996)

Public revenue raising efforts : This is also called finance campaigns. Organisations working in various fields engage in fund raising efforts. The do’s and don’ts when meeting the donors is already mentioning the details of fund raising. (Chawla 1996)

Usage fees : There are several steps in the design of a user-fee system. Step 1: Set targets for cost recovery. Step 2: Determine the structure of user charges. Step 3: Set user fees. Step 4: Formulate a policy on exemption and waivers. Step 5: Design and operationalize a system for managing fee-collection

Contributions from private donors, and Non-monetary contributions from private donors sometimes play an important role in the process of resource mobilization. Here also, the do’s and don’ts of practice when meeting with the donors need to be kept in mind. (Chawla 1996)

Foreign assistance. (Chawla 1996) there are funding agencies of various types, funding for various types of developmental needs. Many of these are funding in the field of disability also. Availing funding from them requires preparation of a detailed write up called project proposal, stating things in detail. (Chawla 1996)

Successful Proposal Writing: A proposal must convince the prospective donor of two things such as the significance and magnitude of the problem and measures for its solution. There are three major types of proposals such as, unsolicited, a response to a specific program within a specific donor agency, a response to a Request for Proposals (RFP).

Rules for proposal writing are as follows (Resource mobilisation and proposal writing Lisa Thomson) a. Be concise b. Be passionate and positive c. Write separately for each funder Proposals should include chapters as follows a) Title/ Cover Page

– the name of the organisation, contact details, name of the programme etc b) Letter of Intent c) Proposal summary (executive summary) d) Statement of need (also called a problem statement) e) Programme Description - describes goals, objectives, method, etc… f) Project plan for funding period - milestones over a certain delivery period, with costs g) Monitoring and evaluation plan h) Organisational information - history, structure, board of trustees etc. i) Budget 3.

Conclusion: Resource mobilization is an emerging area of Social work interventions. A skill similar to closing skills necessary in marketing and sales is significant here too. The client group being a regularly changing one, the work environment is very dynamic and challenging with the highest level of opportunities for those with desired skills. The right utilization of skills is essential in resource mobilizing effort for the persons with disabilities since nobody contributes something easily. India being a developing nation has no full-fledged healthcare system to support persons with disabilities and the number of persons with disabilities is increasing alarmingly. It requires more committed professionals to enter in to the field of working with persons having disabilities.(SWE/SWFD/TRM/M25 by Ms. Easter Subha Jasmine)

4.7 Impact of technological developments on disability issues

4.7.1 Technology advances have changed the way people live. But not all people have benefitted equally, due to limited accessibility, social and economic barriers

Throughout human history, new and changing technologies have impacted on the way people live. Today, it is built in to nearly every part of daily living, from work, consumer goods, to recreational activities and social interactions. Information and communications technologies have also dramatically increased connectivity between people and their access to information, further helping to raise living standards.

For the 1 billion people living with some form of disability around the world, technological advances that could enhance inclusion, such as Apps on smart phones, interactive whiteboards in the classroom and 3-dimensional films can be a challenge to access. In spite of being the world's largest minority group, persons with disabilities have remained largely invisible in mainstream development frameworks and its processes. The UN General Assembly continues to reiterate accessibility as a means and a goal for inclusive, sustainable development and as key for empowering and including all persons in the future development efforts.

What do we mean by accessibility? Accessibility is best defined as flexibility to accommodate each user's needs and preferences. While the design of accessible technologies ought to cater for all individuals in society, it is important to note that the accessibility of such information and communications technologies does not automatically diminish the opportunities for others to enjoy the ease and flexibility of using such goods or services. Accessibility should therefore be identified as a set of global public goods, which are not a defined to benefit a particular group in society, but rather, to be accessible to all on a local, national and global level.

Realizing the rights of persons with disabilities often requires policy interventions and the implementation of measures to remove barriers and provide reasonable accommodation in order to ensure their equal access and full participation In recent years, there has been increasing recognition that development paths would not exclude the participation of persons with disabilities in economic, social or political life. This is key for an inclusive, equitable and sustainable future for all, and the repositioning of accessibility as an integral development goal would secure such inclusion.

The concept of universal design is not a matter of style, but rather an orientation to design. It is based on the premise that design processes must be inclusive, produce equitable benefits and be appropriate to all groups in society, regardless of economical, social, cultural or physical feature. With this in mind, performance standards and technical requirements for accessibility should produce results for persons with disabilities and non-disabled persons alike.

UN Member States have recognized increasingly that ensuring accessibility for, and inclusion of, persons with disabilities is important for achieving internationally agreed development goals, such as the Millennium Development Goals.

Indeed, technology can be used as a tool to impact on the achievement and outcome of the post-2015 development agenda for persons with disabilities, and for people everywhere. The post-2015 development agenda can be used to promote the impact and benefits of assistive technology, accessible information and communications technology, technological adaptations and other policy and programmatic measures to improve the well-being and inclusion of persons with disabilities in society and development.

During the High-Level meeting on Disability and Development in 2013, UN DESA's Under-Secretary-General Mr. Wu Hongbo made a call for all stakeholders to implement more disability-inclusive national development strategies, to ensure that development takes into account the needs of persons with disabilities.

(Paul Carter, 2018)

4.7.2 Universal Design

A report from a conference by Australian Human Rights commission, 2014 highlights the concept of universal design.

people with disability don't need to be told what they want or need, they simply needed to be provided with the environment and tools to grow and be independent.

"We need to make sure the system is better at supporting people with disabilities to make systemic change," McEwin said.

With that in mind, the panel explored co-designing technology with people with disability, saying it was critical if accessible technology was to become widespread.

Co-design could encompass different principles depending on context, and referred to the involvement and engagement of the users, in this case people with disability, to actively understand, explore and ultimately change the system together.

A significant advantage of the approach was it had the potential to benefit everyone, not just those with disability.

The approach was often referred to as "universal design" or "inclusive design" – making products and services that could be used by all people, without the need for specialised or adapted features.

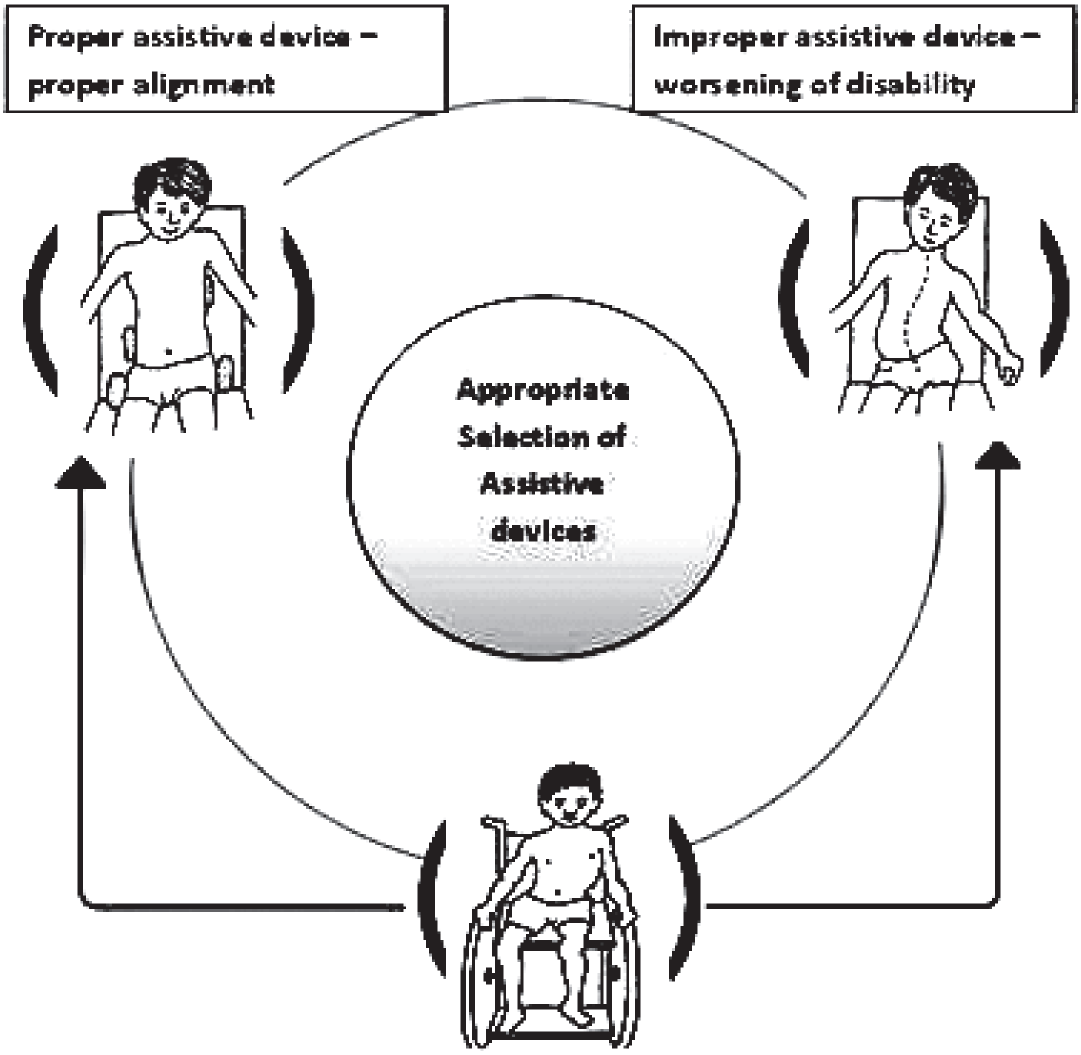
Mobile phones were originally designed for hearing people; text messaging became widespread and popular because deaf people discovered the functionality in the 90s, proving inclusive design helped everyone.

One area McEwin was particularly monitoring was the employment space.

Innovation and technology could play a key role in challenging traditional ways of work, removing barriers to equality and participation for people with disability in the workplace.

Machine learning, artificial intelligence and human computer interaction were examples of opportunities that had challenged traditional ways of working and enabled accessibility – as demonstrated by IBM's Content Clarifier.

McEwin said technological advancements, innovation and a "digital revolution" were already transforming the lives of people with disability, "and therefore when I think of the future I envisage a world with unlimited possibilities and opportunities". It was equally important, however, to monitor these advancements to ensure people with disability were included, rather than widening a gap in the innovation cycle where disability is forgotten and not thought about from the beginning.



Illustrations of technology enabling disab led :

What is switch access?

Switch access refers to a specialist way of accessing a computer, smartphone, tablet, or communication aid using a simple switch, in the place of the more varied a complex interfaces such as keyboards and touch screens which most people use every day.

What is a switch?

AbleNet Jelly Bean Switch

A switch is a simple device that has two states – on and off – just like a light switch. They come in a variety of different shapes and sizes and are operated in different ways. Often this is through a push motion but you can also buy switches that you grasp, pull, sip, puff or even blink to activate. The most common type of switch is the buddy button or jelly bean switch (pictured). You can check out a selection of switches and some video examples of them in use.

Who uses switches?

Switches are used by people with physical and/or intellectual disabilities. Switches are used by people who have a degree of physical impairments that means that they are unable to access a keyboard or any type of pointer control. Sometimes a single switch is used, or sometimes a combination of multiple switches working together. Such set-ups are used by people with motor neurone disease (MND/ALS), cerebral palsy, traumatic brain injury and so forth. Switches are also suitable for people with intellectual disabilities as they are a simple method of accessing games and other activities.

Accessing computers, smartphones and tablets

Primary Switch Access

Primary Access Switching involves the use of a switch to operate a computer, communication aid, environmental control or a wheelchair. In Primary Access

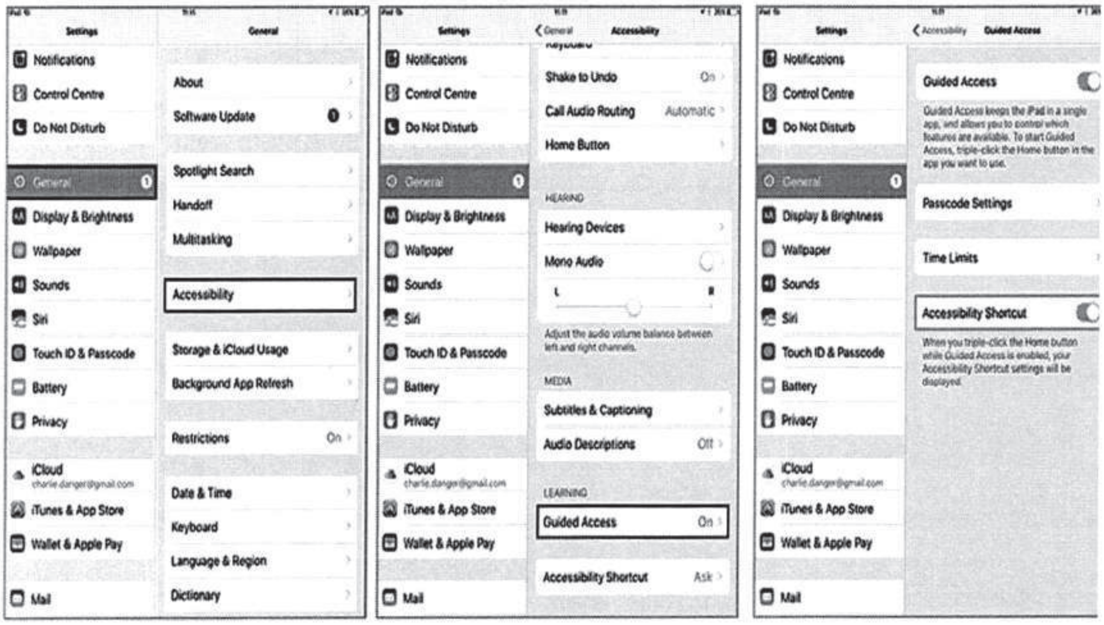
Switching, the user relies entirely on a switch or a combination of switches to control this device. Use of switches ranges from single-switch 'hit-and-happen' games for early users and those with severe cognitive difficulties, up to multiple-switch 'scanning' for those who want to use a computer to write emails, documents, surf the Internet, and for AAC. Modern Apple Mac computers have switch access built-in to the system, which works to a lesser or greater extent. Microsft Windows users will need to invest in software such as The Grid which can control the computer using a switch. Both the iOS (Apple iPads etc.) and Android platforms have switch access built-in and ready to go, although the iOS option is far more sophisticated.

There are many iPad and Android apps that can be used as tools to help parents interact with children with challenging communication, attention and behaviour needs that may be associated with conditions such as ADHD or Autism. This interaction can help develop appropriate social skills and can be leveraged to include academic skills such as reading and writing, maths, and shapes and colours. iPads can even be used to encourage improvements in hand-eye coordination.

Identifying an activity that involves a single app, and sticking to it for the duration of an activity, is an important to ensure that your activity has beneficial outcomes. When using the iPad it is easy to purposefully or accidentally switch apps, return to the home screen, or open up system menus and other features which distract from the planned activity. Attention for the intended activity is easily lost. Guided Access fixes this problem and has been part of the Apple iPad and iPhone operating system (iOS) since version 6, released in 2012.

Guided Access is also an important consideration if an iPad has been designated as an AAC device. In some instances it is better that only the AAC app should be available to the user, and Guided Access can be used to lock the iPad to a single app.

How to configure an iPad or iPhone for people with attention difficulties



Restrictions On

Shake to Undo On

Call Audio Routing Automatic

Mono Audio

Adjust the audio volume balance between left and right channels.

Audio Descriptions Off

Guided Access On

Accessibility Shortcut Ask

Guided Access

Guided Access keeps the iPad in a single app, and allows you to control which features are available. To start Guided Access, triple-click the Home button in the app you want to use.

Accessibility Shortcut

When you triple-click the Home button while Guided Access is enabled, your Accessibility Shortcut settings will be displayed.

Configuring Guided Access on the iPad (iOS 10). Photo by Screenshot by Charlie Danger/BLTT

1. Launch the **Settings** app on your iPad or iPhone
2. Scroll down and select the **General** option
3. In the General page select the **Accessibility** option
4. At the bottom of the the Accessibility page select the **Guided Access** option
5. Slide the Guided Access switch to the **On** position
6. Also slide the **Accessibility Shortcut** switch to the On position

Using Guided Access

You can launch Guided Access any time by pressing the Home button three times in quick succession. This triple-click can be quite difficult and may need some practice – you'll need to press the button three times in less than a second for it to work!

1. Launch whichever **activity app** you want to use

2. Triple-click the **Home button** to enable guided access
3. Press the **Start** button
4. You may be asked to **set a new passcode**. Choose one you'll remember but that the user won't guess!
5. To finish Guided Access triple-click the home button again and enter your passcode
6. Press the **End** button
7. Press the Home button to return to the home screen.

Touch ID

The Touch ID fingerprint sensor is available on iPhone 5S and newer s iPads since iPad Air 2. The advantage of using Touch ID is that you will not have to enter a passcode to end the Guided Access and therefore you reduce the chances of the user seeing the code and taking control of the system.

1. Launch the **Settings** app on your iPad or iPhone
2. Scroll down and select the **General** option
3. In the General page select the **Accessibility** option
4. At the bottom of the the Accessibility page select the **Guided Access** option
5. Select the **Passcode Settings** option
6. Slide the Touch ID switch to the **On** position

Finishing an Activity – Time Limits

Many caregivers experience difficulties in ending the activity session if the person using the iPad has become fixated on their activity. This is common for young people with ADHD and Autism. While it is good that they are engaged in the activity for practical reasons it does need to end at some point. Learning to stop an activity can be part of the learning outcomes for which we are applying the iPad as a tool. To make this easier it is possible to set the iPad to automatically end the activity and lock itself after however many minutes we feel is best for this activity. **Touch ID does not work when time limit has been reached but will work if the caregiver wishes to interrupt the activity.**

1. Launch whichever **activity app** you want to use
2. Triple-click the **Home button** to enable guided access
3. Select **Time Limit Options***
4. Slide the Time Limit switch to **On**
5. Select the amount of time required for the session
6. Tap on **Time Limit Options**
7. Press the **Start** or **Resume** button

These settings are stored automatically for each app on the iPad. Once you have set the settings for each app Guided Access will bypass the options screen. * If the app launches without displaying the options screen then you will first need to **end Guided Access** (triple-click Home screen)

Adding Sounds or Speech to the Timer

An automated sound can be added to the iPad to prepare for user that the session is coming to an end soon. Either an alert tone or speech can be used to indicate the time left.

1. Launch the **Settings** app on your iPad or iPhone
2. Scroll down and select the **General** option
3. In the General page select the **Accessibility** option
4. At the bottom of the the Accessibility page select the **Guided Access** option
5. Select the **Time Limits** option
6. Tap on the **Sound** option to select an **Alert Tone**
7. Slide the Speak switch to the **On** position for spoken alerts

What about Android?

Android tablets from Lollipop (version 5.0) onward have a Pin Screen option which allows apps to be locked in a similar manner as Guided Access, but without any of the additional features.

ACCESSIBILITY

Find the mouse pointer by pressing the Ctrl key

by charliebltt-org|Published June 11, 2013

It is easy to lose the mouse pointer on modern computer screens. This handy trick allows you to use the CONTROL key to quickly locate the pointer on the screen.

If you're finding it difficult to find see the pointer you might want to investigate changing the pointer size or colour, download my high-viz cursor set or enable Windows pointer trails.

In all versions of Microsoft Windows press and hold the Windows Key and press R. Type **main.cpl** and press ENTER. Click on the **Pointer Options** tab at the top of the Mouse Options dialog that appears.

4.8 Let us sum up:

The unit will give us an insight into the various attitude formation., the stereotypes in the Indian scenario and how they have been formed.It would also make us understand the various studies on aggressive behavior noticed in PWID.We shall understand aggression as a social construct and thus develop a new way of looking at aggression and antisocial behavior.A thorough study of various disability model would be done to understand the various community issues.Changes in approach to community issues shall be dealt with.and an enabling model would be comprehended of disability.The status of CBR programmes, and the degree of community involvement with the concept of resource mobilization would be studied.Finally the concept of technology , bettering life, universal design and some illustrations of enabling technology shall be studied.

4.9 Unit End Exercise

1. **Write a street play and enact it on community attitude, stereotypes, how community issues to change from deficit finding to capacity building for persons with Disability**
2. **Develop a proposal for resource mobilization from the Government towards a community based rehabilitation project.**

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Unit - 5 □ Adulthood And Family Training

Structure

5.1 Introduction

Adulthood is a period in the human lifespan in which a person attains full physical and intellectual maturity. The stage of adulthood begins at the age of 20 years and has three distinct stages: early, middle, and late adulthood. A person passes through various transition phases to reach to the stage of adulthood which is called the process of aging. In this natural phenomenon of aging, each stage brings its own set of rewards, challenges and unique experiences whose impact reflects at the late stage of life. In the light of it, a positive aging is believed to have social connectedness and social support. Studies evident that a positive relationships with significant others in adulthood years have been found to contribute to a state of well-being. Most adults identify themselves through their relationships with family particularly with spouses, children, and parents. Due to various developmental challenges, the transition process can have multiple and complex impacts on individual with intellectual disability and their families. Issues may arise concerning conceptual, social, practical life skills, occupational roles and leisure activities which may affect youths' self-esteem, self-concept, and sense of hope. They may experience difficulty in independent living, establishing and fulfilling responsibilities and relationships with others. In this regards, family members are the key source of services and supports for people with intellectual disabilities across the life course, helping people to remain living at home. With the aging of their parents and caretakers, several health issues starts reflecting which majorly affects the system of protection and supports extended to individuals with intellectual disability. The family dynamics change as spouses or siblings becomes the key person to extend the care and protection to adult with intellectual disability. The transition brings lots of adjustment issues from the side of care taker and the adult with disability. The present section gives an insight of the need of understanding the issues and challenges of person with intellectual disability at adulthood stage and the need of family training for the effective transition of services.

5.2 Objectives

- To understand the family experiences of disability in the context of ageing.
- To understand the need of training of Adults with intellectual disability.
- To develop knowledge about the services for PwID in urban and rural areas

- Understand the need of Independent living within family, group home & institution.
- To understand the parental attitude and the need of counselling

5.3 Family experiences of disability in the context of ageing

5.3.1 Family experiences having children with disability

Having a family member with intellectual disability can have major impact on the entire family including the parents, siblings, and extended family members. Disability places a set of extra demands or challenges on the family system; most of these demands last for a long time. It is a unique shared experience for families and can affect all aspects of family functioning. The impact is very much depends on the level of severity, their age and the type of family in which the person with disability lives.

On the positive side it can broaden horizons of the system of support, increase family members' awareness of their inner strength, enhance family cooperation, increase positive interdependence, promote emotional bounding and sense of belongingness, share responsibilities and encourage connections to community. On the other hand, the negative impact comes in a light more rather than positive experiences such as it may increase stress, guilt; blame; anger; conflicts; worry or reduced self-esteem among parents and family members, difficult to find appropriate and affordable child care services, time and financial costs, demands of physical and emotional support, affect decisions about work, logistical complexities associated with caring of a disabled child/adult, lack of coordination among different service providers may act as a burden, leads to exhaustion and fatigue, may lead towards the separation among the family members, family's dreams and plans for the future may be given up, social roles may disrupted, negative attitude of the community and neighbors.

A child with ID in a family is usually a serious stress factor for the parents. It often requires a reorientation and reevaluation of family goals, responsibilities and relationships. At the same time also it has been reported that a child with a cognitive disability may have anxiety, fear, shame or other negative feelings. These reactions usually reflect the relationship between child and the family members, parents, teachers or community as a whole.

The intensity with which a family of child with disability gets affected depends upon the internal coping skill of parents and other family members. The negative way of interaction within family members may also generate numerous problems within family. Hence, there is necessity to involve all family members to provide needs based family intervention and there is a high need to understand the family dynamics in order to understand the disability at large.

5.3.2 Experiences of family in context of aging of disabled individuals

Changes in practices and policies for adults with ID have evolved over recent decades leading to a shift from segregated residential or institutional care to a person cantered approach with an emphasis on inclusion and community living. This shift has been instrumental in improving the quality of life of people with ID, providing them with greater choice and control over their lives. A large number of adults with ID who live in a community setting are cared primarily by parents and other family members. A research conducted in United States evident that approximately 2.79 million of the 4.56 million people with ID live with family caregivers and more than 25% of the adults with ID lives with parents aged 60 or older. In Canada, family members are the main source of support for almost 80% of adults with ID and approximately 50-60% lives with family members. In context of significant improvements in social and health conditions leading to a drastic increase in life expectancy over the past decade, aging with ID has emerged as an important area of research. The care responsibilities lead to increasing stress over the lifetime of a family member. While family members can and do engage in instrumental or physical care activities, such as providing food, or helping their relative with activities of daily living there is an additional requisite investment of emotional and organizational labour which is less obviously discernable. It is perhaps the most prominent area of support provided by family members of aging adults with ID.

As parents age, they may be less able to provide the type and amount of care needed by their adult-child with ID. Factors contributing to this situation include: being physically unable to provide a high level of personal care, needing to care for an ageing spouse, being older than 75 years; having greater stress levels, having limited income, and/or the death of the caregiver and the other side of the fact is that children with ID are themselves aging. Though families may acknowledge that there will be a lifetime of exchanging care, many have not engaged in formal future planning activities. A lack of future planning can contribute to inappropriate and rushed care when a parent or family member is no longer available. As a result, some adults with ID are placed in nursing homes designed for the frail elderly people, even though they are poorly matched to these settings. Caring relations between aging family members and their relative with ID are markedly different from "typical" care giving relationships. Despite the ongoing shift from institutionalization to community living, there are little evidences available exploring the unique caring relations in aging families that include adults with ID. Aging family members are acutely aware of their own aging process, and the potential consequences of the care work they undertook with their relative with ID.

As families aged together, there is an emphasis on fostering connections that could supplement or replace their care activities, particularly for aging parents facing their own physical decline and mortality. These connections focused on helping their relative with ID strengthen relationships with siblings and develop peer friendships, while also shifting care responsibilities to formal care providers and other community-based supports. Aging family members viewed the creation and maintenance of informal connections, particularly with siblings, as an important source of care. With increasing life expectancy of individuals with ID, policy and practice reform and development is required in order to support families as they navigate new ground in the aging process.

5.4 Training of Adults- Personal Care, Social, Domestic, Community and Leisure

5.4.1 Training of adults with Intellectual Disability: need and significance

The ultimate goal of any education and training is to develop the potentialities of individuals up to an extant so that they can live their life independently or with the least possible supports. It is equally applicable on individual with disabilities too. Children with ID generally experience numerous developmental challenges which greatly affect their overall life functioning and if not intervened at the right time the limitations become more critical as they grow to the older age. Each stage of development puts a new set of demands with which CwID are expected to deal with their own and so they need to be prepared for all those life experiences to minimise the level of dependency with the aging process. It is evident that children with ID due to restricted social participation spend much time in their home along with their family and as they grow older the level of dependency increases in order to fulfil their daily needs. The supports are extended to them from their family members mostly by parents but with the process of aging of both the CwID and his/her parents as well, the responsibilities gets transferred from parents to siblings or spouse. On the other side, various physical and psychological concerns also emerge with the age for which the new support system may not be ready to bear the new roles and responsibilities for a long. This unfavourably affect to both. Ironically, in developing countries, many families do not make plans for the future care of the adults with ID, and social services are usually inadequate to cover these individuals' needs. All these barriers significantly affect the adulthood experiences of PwID and their family. The risk of challenging adulthood experiences can be reduced only when AwID will be prepared well in advance to participate in fulfilling their day to day needs and the needs of family as well through which the future responsibilities could be shared and meaningful participation can be promoted further.

5.4.2 Training in personal care, Domestic, Community and Leisure

In recent years, with the growing awareness about disability at national and international level, the service systems for the disabled individuals are improving gradually. Multiple scopes are getting open now to access the need based services and educational intervention is the major one among them. With modern training procedures, PwID can engage in some occupations and achieve at least partial economic independence. Vocational training is therefore of great importance for which NIEPID (formally known as NIMH) has identified a number of simple occupations that can be undertaken by PwID. Ironically, quite a lot number of PwID may not get benefit from all those services therefore; they are dependent largely on their family members to fulfil their basic day to day requirements. In order to reduce the level of support, it is a major responsibility to train them in some basic life functioning skills so that they can survive in their family and community with minimum helps.

Training in personal care

Personal care training is given to the person with ID in which they learn to perform their day to day personal tasks such as maintaining physical cleanliness, taking care of their toilet needs, maintaining their physical appearance such as selecting, wearing and maintaining cloth appropriately, grooming self according to the occasion, maintaining personal hygiene, basic first aid, maintaining meal time etiquettes and so on. Functional independence in these skills helps an individual to better adjust in their immediate environment and also the additional responsibilities of the caretakers gets reduced which further helps in maintaining better and healthy relationships. Maximum opportunities need to be given to PwID so that they can experience the real life situations and learn how of adjust in that by performing the tasks by themselves.

Training in social skills

Social skills are very much essential for everyone to take a part in social functioning. These skills generally help a person to maintain interpersonal relationships with the other family and community members. Skills such as maintaining respectful relations, listening to others, taking permission, waiting for the turn, asking for permission, avoid conflict based situations, asking for help or extending helps to others, maintaining healthy communications and so on.

Training in all those skills is necessary to enhance their social understanding which is very much restricted due to their cognitive limitations. Social skills can be developed only in a situation when they are allowed to be a part of society. PwID must be trained and sensitized towards various social- behavioural issues and with those experiences they must relate the learned behaviour. Behavioural sensitisation and behavioural restructuring is the key learning for social skill development and later on the learnt skills must be generalized in to a various situations.

Training in Domestic activities

Domestic activities include all those tasks which a person is expected to do to maintain the household works such as preparing or helping in preparing meal, cleaning the home, maintaining the household belongings at proper place and so on. An adult with ID generally kept separate from these tasks because of the limited exposure of learning and performing it in their daily routine. These tasks can be taught to them in order to keep them engage meaningfully and making them realizes their belongingness with their family. It has been often experienced that due to inappropriate way of functioning; taking comparatively much more time to complete the task; need multiple instructions to understand and follow the task, these individuals generally left isolated and deprived with the sufficient exposure of learning and doing the tasks which at later stage of life increase their level of dependence and further leads to various physical and behavioural challenges. PwID need to be allowed to be a part of all those household works which happens at home. They must get freedom to execute the activities at their own pace and should be promoted and appreciated to move to the next level of proficiencies in the learned tasks.

Training in community living

Being a part of community, a person must know about the available community resources and their utility. AwID need to get the opportunity to know and explore their community resources such as health care centres, transportation services, services for our safety and protection, recreational places and other public places. They also need to understand that how these resources do serves in our life and further how we can avail those services for our own purpose. Along with the community orientation, the safety measures must be introduced to them. If the orientation is provided from the right time onwards, the person with disabilities can enhance their community life and avail it independently or with the minimum supports.

Training in Leisure time activities

Access to free time and utilizing that time effectively is the basic right for all human beings regardless of their abilities and disabilities. Leisure time activities are planned in a structured way considering one's own interest. These activities include dance, music, drama, art, craft, indoor-outdoor games, watching T.V and so on. Persons with ID due to limited and restricted participating in family and community generally spent much of their time ideally which may further cause for various behavioural problems. Due to the lack of understanding to utilize their time in a productive way or to make self busy in fun filed activities or doing interest based activities, they generate undesirable behaviours in their free time. Leisure time activities are not just help us to get engaged in free time but also it has a deep significance in our life as it helps us to get released from all the physical, mental stress and revive our energy to work in more productive way.

5.5 Services for PwID in urban and rural areas

5.5.1. Services for PwID

Persons with disabilities make 15% of the world population. Currently, most of them rely on informal means of support, from families and personal networks, which are insufficient to meet their personal needs. The lack of options and appropriate support services puts persons with disabilities at risk. It has negative consequences on the way they live their life. Lack of formal support systems puts more pressure on persons with disabilities, their families and communities. It also increases the risk of institutionalisation and segregation. Support should be based on persons with disabilities having choice and control over their own lives. In India, a majority of the disabled individuals resides in rural areas where accessibility, availability, and utilization of rehabilitation services and its cost-effectiveness are the major issues to be considered.

The various services available for persons with disabilities in community are-assessment; identification and diagnosis services, personal care services including all the activities which are needed for an individual to perform their day to day life. It also includes medical facilities, educational and training services; therapeutic services home based and centre based services, guidance and counselling services, rehabilitation services, vocational training and employment services including self-employment; sheltered employment; supported employment and open employment. Group home facility day care facility, residential facility, sports and recreation, government benefits and provisions for PwD and government and non-governments agencies.

5.5.2 Services for PwID Urban Areas

National Institutes

Various National Institutes have been established by government of India to execute their services to the respective areas of disabilities. Such as NIHH Mumbai, NIVH Deharadun, MIEPMD; Chennai, SVNIRTAR; Cuttack, NIOH, Kolkata, IPH; New Delhi, ISLRTC; New Delhi and NIEPID, Secundarabad.

National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID, formerly named as NIMH)

The NIEPID is an autonomous body under the Ministry of Social Justice & Empowerment. It was established in the year 1984 as registered society. It has four regional centres in Secunderabad, Navi Mumbai, Noida and Kolkatta. The objectives of NIEPID are-

- To develop appropriate models of care and rehabilitation for the persons with intellectual disability appropriate to Indian constitutions.
- To develop manpower for delivery of services to the person with intellectual disability.
- To identify, conduct and coordinate research in the area of intellectual disability and to assist them wherever necessary.
- To serve as a documentation and information centre in the area of intellectual disability.
- To acquire relevant data to assess the cause, magnitude, socio-economic factors of intellectual disability.
- To promote and stimulate growth of various kinds of quality services in the country of the persons with intellectual disability throughout the country.

Vocational Rehabilitation Centres

The Ministry of Labour & Employment has set up 21 Vocational Rehabilitation Centres for Handicapped (VRCs) at different parts of the country. The main objective of these centres is to impart non formal vocational training and extend vocational rehabilitation assistance to PwDs as per their residual capacities with a view to assist them to lead an independent and productive life in society.

Composite Regional Centre

To overcome the lack of adequate facilities for rehabilitation of Persons with Disabilities, the Ministry of Social Justice & Empowerment has set up seven Composite Regional Centres for Persons with Disabilities at Srinagar (J&K), Sundernagar (Himachal Pradesh), Lucknow (U.P.), Bhopal (M.P.), Guwahati (Assam), Patna (Bihar), Ahmedabad (Gujarat) and Kozhikode (Kerala) to provide both preventive and promotional aspects of rehabilitation like education, health, employment and vocational training, research and manpower development, rehabilitation for persons with disabilities.

Health care services

People with disability report seeking more health care than people without disability and have greater unmet needs. For example, a recent survey of people with serious mental disorders, showed that between 35% and 50% of people in developed countries, and between 76% and 85% in developing countries, received no treatment in the year prior to the study. Health promotion and prevention activities seldom target people with disability. In recent initiatives taken by government, health care services are given priority. In urban areas, the facilities for health care services are very much accessible. Government and non-government health care centres are in quite a good number and well equipped with all kind of diagnosis, treatment and referral services for PwDs.

Educational and therapeutic Services

Special education, inclusive education and therapeutic services are given much emphasis during the recent legislative changes. Many special schools are running in urban areas with the objective not only to educate PwD but also to spread knowledge and awareness in the communities. There overall educational and therapeutic needs are taken care by the respective schools. The inclusive education practices also taking shapes much faster in the urban areas where as even in rural areas, the enrolment and retention of children with disabilities in nearby primary schools are major practices.

Home Training Services

With the belief that no child should be deprived from the educational services, home based education is well practiced not only in urban but in rural areas as well. All those children who cannot reach to the educational centres due to severity of disability, lack of transportation,

residing in remote areas and so on can avail educational services at home itself through the trained professionals. Parents also play a very essential role in this process.

5.5.3 Services for PwID in Rural Areas

District Disability Rehabilitation Centres (DDRC)

District Disability Rehabilitation Centres (DDRCs) is an initiative by the Ministry of Social Justice and Empowerment, Govt. of India, to facilitate comprehensive services to Persons with Disabilities in the rural areas. These units have a group of rehabilitation professions for providing services like identification of Persons with Disabilities, Awareness Generation, Early Detection and Intervention, Provision / Fitment, Follow-up and repairing of Assistive Devices, Therapeutic Services like Physiotherapy, Speech Therapy etc., and facilitation of Disability Certificates, Buss Passes and other concessions/ facilities for Persons with Disabilities. The District Disability Rehabilitation Centres are now set up and funded under the Plan Scheme "Scheme for Implementation of Rights of Persons with Disabilities Act, 2016 (SIPDA)" - an umbrella scheme under which grants-in-aid are provided to State Governments and various other bodies, set up by the Central and State Governments, including Autonomous Bodies and Universities, to support activities.

Integrated Child Development Service (ICDS)

Integrated Child Development Services (**ICDS**) is a government programme in India which provides food, preschool education, primary healthcare, immunization, health check-up and referral services to children under 6 years of age and their mothers. The scheme was launched in 1975, discontinued in 1978 by the government of Morarji Desai, and then re-launched by the Tenth Five Year Plan. Tenth five year plan also linked ICDS to Anganwadi centres established mainly in rural areas and staffed with frontline workers. In addition to fighting malnutrition and ill health, the programme is also intended to combat gender inequality by providing girls the same resources as boys.

Anganwadi centres are considered as rural child centres in India which was started by Indian government in 1975 as a part of ICDS to combine child hunger and malnutrition. It also provides basic health care, nutrition and preschool activities to all children regardless of their abilities and disabilities.

Community Based Rehabilitation (CBR)

The services are being extended to persons with disability at community level through Community-based rehabilitation (CBR) program. It is widely being implemented not only in rural but in urban areas as well. The well trained professionals screen out persons with disabilities in the community, conduct the need based assessment and helps them and their family to rehabilitate in their community itself. Through CBR, the priority is given to strengthen the individual with disability, family and the community as well.

CBR programmes must coordinate service delivery at the local level. Community members seldom understand the different roles and specializations that are part of providing assistance to people with disabilities. They tend only to see the problem of disability and only to want access to “one window” for help. They may focus only on where to go and who to see about a specific “problem”, rather than understanding the totality of what constitutes a fulfilling life for a community member who has a disability.

Integrated Education for the Disabled Child (IEDC) under Department of Education

IEDC is a centrally sponsored scheme and was launched in 1974 by the Department of Social Welfare. The scheme has however been transferred to the Department of Education since 1982. Under the scheme, disabled children are sought to be integrated in regular school system. Hundred percent assistant is provided to the state/UTs for education of the children.

Department of Rural development- MGNREGA

National Rural Employment Guarantee Act 2005 (or, NREGA later renamed as the “Mahatma Gandhi National Rural Employment Guarantee Act”, MGNREGA), is an Indian Labour Law and social security measure that aims to guarantee the ‘right to work’. This act was passed in September 2005. It aims to enhance livelihood security in rural areas by providing at least 100 days of wage employment in a financial year to every household whose adult members volunteer to do unskilled manual work. MGNREGA is to be implemented mainly by gram panchayat (GPs). The involvement of contractors is banned. Labour-intensive tasks like creating infrastructure for water harvesting, drought relief and flood control are preferred. Under the scheme, it is stated that if a rural person with disability apply for work, work suitable to his/her ability and qualifications, will have to be given to them. For this, provision of PwD Act will 1995 be kept in view and implemented.

National Rural Health Mission – NRHM

Government of India has launched the National Rural Health Mission (NRHM) in the year 2005 to strengthen the rural public health system throughout the country with special focus on the States and Union Territories (UTs), which have weak public health indicators and/or weak infrastructure. It provides effective health care to the rural population, especially the disadvantaged groups including disabled, women and children, by improving access, enabling community ownership and demand for services, strengthening public health systems for efficient service delivery, enhancing equity and accountability and promoting decentralisation. Indian Public Health Standards (IPHS) for Sub-centres, Primary Health Centres (PHCs), Community Health Centres (CHCs), Sub-District and District Hospitals have been used as the reference point for public health care infrastructure planning and up-gradation in the States and UTs. Primary Health Care Centres are available in rural areas to provide health related services to persons with disabilities. The major challenges still remains with the health care centres are accessibility in terms of transportation, access to health insurance services, health literacy, affordability and quality as compared to the urban areas.

Self help group

For persons with disabilities and many others too, it is not enough to be merely independent, but it is also necessary to have a group that supports and provides an empathetic relationship. Such a group acts as a forum to meet, to discuss and to represent their interests and needs to the outside world. Now that the state administration has begun to recognise the special needs of disabled people, such a group can also work collectively to seek the support services from those in authority, more as a right than a benefit, to improve on their existing situation. Organising people in self help groups serves different purposes, depending on the situation and the need. Such a forum can help people to be visible members in the larger community. Members can support one another through sharing information on referral services and other available resources, help make decisions on family and individual matters etc. Self help groups with the support of other such groups, can advocate jointly to obtain services, aids and equipment, and for integration in the larger community.

Schemes for Persons with Disabilities

NHFDC: In 1997, the Government set up a Corporation named National Handicapped Finance and Development Corporation (NHFDC) under the administrative control of the Ministry of Social Justice & Empowerment for providing financial assistance at concessional rate of interest to Persons with Disabilities (PwD) for self employment. This Corporation also gives skill training grant for Skill Training and Entrepreneurship of PwDs wherein it provides 100% of the total recurring cost of the training programme to the training institutes/organisations. NHFDC also provides stipend @Rs.2000/- per month to the disabled trainees during the training. The training duration ranges from one month to six months. The funds for training programmes of NHFDC are provided through the DDRS and SIPDA schemes and also by internal resources of the Corporation.

Deendayal Disabled Rehabilitation Scheme (DDRS): Under Deendayal Disabled Rehabilitation Scheme (DDRS) Vocational Training Centre projects are given financial assistance (up to 90% of the project cost) for skill up gradation of PwDs. These are meant for the age group of 15-35 years to provide skills to enable such persons to move towards economic independence.

Skill training through the National Institutes: The seven National Institutes (NIs) under the administrative control of Department of Disability Affairs also organise Vocational Training Programmes for the PwDs in their respective field of disability for appropriate trades.

SIPDA (Scheme for Implementation of Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995): Under this scheme, financial assistance is provided to State Governments and to autonomous organizations/Institutions under Central or State Governments, for various activities relating to implementation of Persons with Disabilities Act, 1995. Under this scheme grant-in-aid is provided for the skill development programmes for PwDs with effect from the year 2013-14.

National Trust (1999) Schemes

- **DISHA** (Early Intervention and School Readiness Scheme)
- **BADHTE KADAM** (Awareness and Community Interaction)
- **GHARAUNDA** (Group Home for Adults)
- **NIRAMAYA** (Health Insurance Scheme)
- **SAMBHAV** (Aids and Assisted Devices)
- **SAHYOGI** (Caregiver training scheme)
- **GYAN PRABHA** (Educational support)
- **PRERNA** (Marketing Assistance)

- **SAMARTH** (Respite Care)
- **VIKAAS** (Day Care)

5.6 Independent living: Within family, Group home & Institution.

5.6.1 Independent Living

The term Independent living has both a generic meaning and a symbolic meaning. The generic meaning of independent living may be thought of as the opportunity and ability to participate actively in the community through home and family life, and civic and recreational involvement. Symbolically, however, independent living implies much more than that. Independent living is defined as Control over one's life based on the choices of acceptable options that minimize dependence on others in making decisions and in performing everyday activities. This includes managing one's own affairs; participating in day to day activities in the community; fulfilling a range of social roles; and making decisions that lead to self determination and the minimization of psychological or physical dependence upon others. Independence is a relative concept, which may be defined personally by each individual. The trends for people with intellectual disability have experienced significant change over the past twenty-five years. This shift was not only in social, but in professional attitudes which supported the idea that people with the most challenging needs could live successfully in the community.

Independent Living is a philosophy, a way of looking at disability and society, and a worldwide movement of disabled people who work for self-determination, self-respect and equal opportunities. Independent Living is the foundation of the disability rights movement which is a global movement to secure equal opportunity and equal rights for all people with disabilities. It is made up of organisations of disability activists around the world working together with similar goals and demands, such as: accessibility and safety in architecture, transportation, and the physical environment; equal opportunities in independent living, employment equity, education, and housing; and freedom from discrimination, abuse, neglect, and from other rights violations. Disability activists are working to break institutional, physical, and societal barriers that prevent people with disabilities from living their lives like other citizens.

Independent Living does not mean that we want to do everything by ourselves, do not need anybody or like to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same transportation services as our neighbours, and work in jobs that are in line with our education and interests, and raise families of our own.

Need of independent living

Services for adult persons with ID in India are still in a state of evolution. Presently, majority of the adults in India remain un-served. Services for the adults with ID are generally restricted to sheltered workshop in special schools. These services provide limited opportunities for training towards earning and independent living. Studies also revealed that unacceptable personal appearance, inappropriate social interaction with others, behavior problems are some of the major reasons for job loss among ID adults. Further, vocational/ independent living assessment is used for different purposes and may differ according to a country's culture and social system. It may be used to determine a person's potential, the content of a vocational training programme, his or her employability or ability to adapt to different work environments.

Independent Living Programs provide services to adults with developmental disabilities that offer functional skills training necessary to secure a self-sustaining, independent living situation in the community and/or may provide the support necessary to maintain those skills. The Independent Living Movement grew out of the Disability Rights Movement, which began in the 1960s. The IL Movement works at replacing the special education and rehabilitation experts' concepts of integration, normalization and rehabilitation with a new paradigm developed by people with disabilities themselves.

It claims that people with disabilities are the best experts on their needs, and therefore they must take the initiative, individually and collectively, in designing and promoting better solutions and must organize themselves for political power. Besides de-professionalization and self-representation, the Independent Living ideology comprises de-medicalization of disability, de-institutionalization and cross- disability. People with disabilities are primarily seen as citizens and secondarily as consumers of healthcare, rehabilitation or social services. As citizens in democratic societies, the IL Movement claims, persons with disabilities have the same right to participation, to the same range of options, degree of freedom, control and self-determination in everyday life and life projects that other citizens take for granted.

Thus, IL activists demand the removal of infrastructural, institutional and attitudinal barriers and the adoption of the universal design principle. Depending on the individual's disability, support services such as assistive technology, income supplements or personal assistance are seen as necessary to achieve equal opportunities. As emphasized by the IL Movement, needs assessment and service delivery must enable users to control their services, to freely choose among competing service providers and to live with dignity in the community.

2.6.1 Independent living within family

Disabled persons can be converted from beneficiaries to benefactors only when given the opportunity for self-development and provided with equal opportunities for education, vocational training and employment. In this process, a family plays a very significant role in order to help a child with disability to learn the life skills and enhance their functional capacity. It is the family who creates all these opportunities for a child with disability who at later stage grows as an independent adult. Each member of the family contributes their time and efforts to work with the child and facilitate with numerous learning experiences. With this, they develop their understanding about the child and build a strong bounding with him. Along with the functional skills, it is equally important to develop the self confidence, development of choices, decision making skills and problem solving skills. These all abilities can be developed by giving daily life situations such as allowing them to express their choices and follow it further, taking part in different activities and building their self confidence. It is also important to appreciate them for their efforts that they take to get in to the tasks. They must be allowed to be a part to family related personal, social and financial decisions. Independent living in a family is a human right regardless of what disabilities a person have. PwID is also an integral part of the family as similar as the other typically developing members are. A little support can make a bigger change in the life of the child with ID and create a better opportunities for him to become an independent adult to contribute in the family functioning in a productive way.

5.6.3 Independent living within group homes and institutions

A **group home** is a private residence for children, young people, adults or people with chronic disabilities who cannot live with their families due to various reasons. It is a residential setup or a separate to home where there is at least one trained caregiver with 24 hours of service in a day, a house manager, weekend activity coordinator, and 4 part-time skill teachers are needed. It can accommodate 8 to 16 individuals at a time, residential nursing facilities also included. Group homes functions in local communities and it may be self financed or government funded. Group homes are services systems plan for residential community services or Long-Term Services and Supports (LTSS). Society may prevent people with significant needs from living in local communities with social acceptance key to community development. The residents sometimes need continual or supported assistance in order to complete daily tasks, such as taking medication or bathing, making dinners, having conversations, making appointments, and getting to work or a day service.

Group homes were revolutionary in that they offered individuals life experiences as they get in their homes such as engage themselves in earning money, taking care of all households i.e. learn to cook and prepare meals, budget their personal allowance, maintaining home, maintaining relationships, connecting with their neighbours and utilizing all the community resources i.e. go grocery shopping, eat in restaurants, make emergency calls or inquiries, taking care of their personal needs fulfilling all job related responsibilities, carry out civic duties and living together as a family.

The community living movement has been very successful in the US and other countries, and is supported in 2015 by the UN Convention on the Rights of Persons with Disabilities (UN, 2006). Yet, in 2015, the homes and personnel continue to meet the challenges of a changing multicultural society, and changing and norms in areas such as gender expectations. It is also evident that the opening of group homes in neighbourhoods is occasionally opposed by residents who fear that it will lead to a rise in crime and/or a drop in property values.

Group homes for children with disabilities provide an alternative to traditional foster care, though family support to the birth, adoptive, and foster families have been first recommended. In comparison to other placement alternatives, this form of care is the most restrictive for youth in the foster care system. Unrelated children live in a home-like setting with either a set of house parents or a rotating staff of trained caregivers. Specialized therapeutic or treatment group homes are available to meet the needs of children with emotional, intellectual, physical, medical and/or behavioural difficulties.

5.7 Parental Attitude and Counselling

5.7.1 Parental attitude towards children with Intellectual Disability

Attitude of parents play a very crucial role in the overall development of a child's life. It is generally seen that due to the increased demands for energy, time, and financial resources which last for a long, the level of stress raised among parents may adversely affect the attitude towards their children with ID. Additionally, the social stigma and ridicule attached to any form of disability leads to social isolation. If negative emotions among parents and caregivers are high, it may lead to family disharmony which may have a negative impact in the development and rehabilitation of these children. So, the reaction of parents towards their children with ID depends on their perception and understanding about disability and also that how much it has impacted on their life. This in turn determines the attitude, level of stress and negative emotional increases among parents. It is also affected by the severity of the disability among their children. It was evident in many researches that the attitude of parents having children with mild ID is significantly varies with the attitude of parents having children with severe to profound ID.

The parental attitude may also get adversely affected due to various factors such as negative interaction between family members and child with ID, low socio-economic status and heavy financial burden, low level of motivation, lack of awareness of services, lack of physical social and emotional support system, stigma about disability, wrong beliefs or misconception about the birth of disabled child in family and inappropriate expectation for children with ID and so on.

The parent-child relationship is dependent on the parents' attitude towards their children. If parental attitudes are favorable, the relationship of parents and children will be far better than when parental attitudes are unfavorable. People with ID continue to report hostile attitudes and discrimination, experience social exclusion, limited social relationships, lower rates of employment, and a reduced likelihood of participating in community based activities . Available literature suggests that most of the researches on parental attitudes towards their children with ID have been conducted in the past and there is a paucity of literature on the subject in Indian context considering the nature of social complexities and cultural diversity of the country. A study conducted by subhash D Wagh

and Showkar A. Ganaic (2014) concluded the fact that there is an association between the need of the parents related to the management, facilities, services, social and emotional needs, physical and financial support, family relationship and further planning and needs related to the legal benefits as well and their attitude towards children with ID.

Disability in children gives rise to various needs among parents which may vary according to the nature and severity of disability. When the needs are not address in appropriate way, then it may leads towards the dissatisfaction, low self-steam, low level of acceptance, indifferent interaction towards children with ID as the attitudes and needs are generally interdependent. A negative attitude of parents adversely impacts the overall life experiences of children with ID.

5.7.2 Need of counseling for parents of adults with Intellectual Disability

Parenting of child with disability is challenging task and it has a major psychological impact on the life of whole family. Due to low acceptance, sympathetic and negative attitude and stigma, parents feel embraced and limit their involvement in society. The majority of literature has highlighted the stresses and the subsequent negative consequences in caring for a child with a disability. Family members of children with disabilities are often perceived to experience harmful psychological effects. These extreme stress levels heighten negative health outcomes like depression and marital dissatisfaction. Parents are found with unstable emotionality, constant grief, psychological ill health and unsatisfactory social health. It has been well documented that the parents of children with disabilities experience chronic stress. The recent research evidence has evaluated the types, degree and determinants of the stress faced by the families in caring for their disabled members. The literature is uniform in reporting that families do experience high levels of stress. It is also noted that having a child with disabilities affects not only the parents, but also siblings and the relationships among the family members. In this regard, counseling plays a major role and helps the parents and other family members to overcome form the negative and hopeless believes and can develop good relation with children. It helps parents gain a better understanding of themselves and their own personalities much harmony could be affected. Parental counselling deals with the dimension of parent-child interaction and interdependence. Parental counseling, thus, is one of the important services that can help and foster a healthy home atmosphere. The focus of counselling depends upon the needs of the disabled child and his parents.

Points to be considered in counseling of parents of CwID:

- Give parent proper space to express themselves. Do not intercept in between and do not impose your believes on them. Maintain confidentiality, use language and tone wisely and develop the level of comfort with them.
- Parents should be given proper and true information about the capability and incapability of the child and should be motivated to behave as normal as they do with other children of the family.
- Parents must be educated about the disability condition and motivated regarding their active role in screening and planning of the entire life of their child with ID.
- Parents must be encouraged to play an active role in the life of child with ID and further seek support from the immediate environment such as family and community.
- Further, parents must be sensitized towards the problem of future care such as understanding the child's strengths and limitations, extending quality time with the child, motivate the child, use positive language and appropriately set the expectations and accept the way child is.

Barriers in Counselling

There are various challenges faced by the counsellor during the counselling of parents of CwID. Barriers such as emotional imbalances of the parents i.e., stress and anxiety, rigid religious and cultural beliefs of the parents, misconceptions and false beliefs of the disorder, their personality characteristics of the parents, low level of positive hope and motivation, attitude and awareness among the parents are few of them. These barriers need to be minimized in counselling sessions.

Changing the attitude of parents is the hallmark of counselling program. Counsellors need to deal with a broad spectrum of issues while counselling to the parents of the CwID. Sometimes parents have trouble bonding i.e., establishing a close and loving relationship with a child. The main role of the counsellor should be for the removal of misconceptions and false beliefs about the disability and to provide social support to the parents at the initial and subsequent counselling stages. Parental adjustment with CwID requires a good foundation in basic problem solving skills. Moreover, the counselling should be directed toward the problems of future care.

5.8 Let us sum up

A large number of adults with ID who live in a community setting are cared for primarily by parents and other family members. The care responsibilities lead to increasing stress over the lifetime of a family member. As parents age, they may be less able to provide the type and amount of care needed by their adult-child with ID. Though families may acknowledge that there will be a lifetime of exchanging care, many have not engaged in formal future planning activities. A lack of future planning can contribute to inappropriate and rushed care when a parent or family member is no longer available.

The risk of challenging adulthood experiences can be reduced only when AwID will be prepared well in advance to participate in fulfilling their day to day needs and the needs of family as well through which the future responsibilities could be shared and meaningful participation can be promoted further. Ironically, quite a lot number of PwID may not get benefit from all those services therefore; they are dependent largely on their family members to fulfil their basic day to day requirements. In order to reduce the level of support, it is a major responsibility to train them in some basic life functioning skills so that they can survive in their family and community with minimum helps. The various services available for persons with disabilities in community are- assessment; identification and diagnosis services, personal care services including all the activities which are needed for an individual to perform their day to day life. It also includes medical facilities, educational and training services; therapeutic services home based and centre based services, guidance and counselling services, rehabilitation services, vocational training and employment services including self-employment; sheltered employment; supported employment and open employment. Group home facility day care facility, residential facility, sports and recreation, government benefits and provisions for PwD and government and non-governments agencies Nis, VRC, CRC, DDRC, IEDS, CBR, IEDC, MGNREGA, National Rural Health Mission – NRHM, self help group, Independent Living Programs provide services to adults with developmental disabilities that offer functional skills training necessary to secure a self-sustaining, independent living situation in the community and/or may provide the support necessary to maintain those skills. The Independent Living Movement grew out of the Disability Rights Movement, which began in the 1960s. The IL Movement works at replacing the special education and rehabilitation experts' concepts of integration, normalization and rehabilitation with a new paradigm developed by people with disabilities themselves.

Disability in children gives rise to various needs among parents which may vary according to the nature and severity of disability. When the needs are not address in appropriate way, then it may leads towards the dissatisfaction, low self-steam, low level of acceptance, indifferent interaction towards children with ID as the attitudes and needs are generally interdependent. A negative attitude of parents adversely impacts the overall life experiences of children with ID.

Family members of children with disabilities are often perceived to experience harmful psychological effects. These extreme stress levels heighten negative health outcomes like depression and marital dissatisfaction. Parents are found with unstable emotionality, constant grief, psychological ill health and unsatisfactory social health. It has been well documented that the parents of children with disabilities experience chronic stress. Parental counseling, thus, is one of the important services that can help and foster a healthy home atmosphere. The focus of counseling depends upon the needs of the disabled child and his parents.

5.9 Unit End Exercises

1. Discuss about the experiences of a family having disabled individuals in context of aging.
2. Justify why training is essential for an adult with ID in different areas of life skills?
3. Enlist various services available for PwID in rural and urban areas.
4. Write a short note on group homes for PwID.
5. What is the significance of independent living for PwID?
6. Justify the need of counselling for parents of AwID.

7. Discuss how the attitude of parents impact on the life of PwID?

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মানুষের জ্ঞান ও ভাবকে বইয়ের মধ্যে সঞ্চিত করিবার যে একটা প্রচুর সুবিধা আছে, সে কথা কেহই অস্বীকার করিতে পারে না। কিন্তু সেই সুবিধার দ্বারা মনের স্বাভাবিক শক্তিকে একেবারে আচ্ছন্ন করিয়া ফেলিলে বুদ্ধিকে বাবু করিয়া তোলা হয়।

— রবীন্দ্রনাথ ঠাকুর

ভারতের একটা mission আছে, একটা গৌরবময় ভবিষ্যৎ আছে, সেই ভবিষ্যৎ ভারতের উত্তরাধিকারী আমরাই। নূতন ভারতের মুক্তির ইতিহাস আমরাই রচনা করছি এবং করব। এই বিশ্বাস আছে বলেই আমরা সব দুঃখ কষ্ট সহ্য করতে পারি, অন্ধকারময় বর্তমানকে অগ্রাহ্য করতে পারি, বাস্তবের নিষ্ঠুর সত্যগুলি আদর্শের কঠিন আঘাতে ধূলিসাৎ করতে পারি।

— সুভাষচন্দ্র বসু

Any system of education which ignores Indian conditions, requirements, history and sociology is too unscientific to commend itself to any rational support.

— Subhas Chandra Bose

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