NETAJI SUBHAS OPEN UNIVERSITY

B. Ed. Spl. Ed. (M.R./H.I./V.I.)-ODL

PSYCHO - SOCIAL AND FAMILY ISSUES

C-16 (M.R)

B. Ed. Spl. Ed. (M. R. / H. I. / V. I)-
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AREA - C

C - 16 (M.R) : PSYCHO-SOCIAL AND FAMILY ISSUES

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AREA - C
DISABILITY SPECIALIZATION
COURSE CODE - C-16 (M.R.)
PSYCHO-SOCIAL AND FAMILY ISSUES (M.R)

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The Self Instructional Material (SIM) is prepared keeping conformity with the B.Ed.Spl. Edn.(MR/HI/VI) Programme as prepared and circulated by the Rehabilitation Council of India, New Delhi and adopted by NSOU on and from the 2015-2017 academic session.

Mohan Kumar Chattopadhyay
Registrar

Netaji Subhas Open University

From the Vice-Chancellor's Desk

Dear Students, from this Academic Session (2015-17) the Curriculum and Course Structure of B. Ed.- Special Education have been thoroughly revised as per the stipulations which featured in the Memorandum of Understanding (MoU) between the Rehabilitation Council of India (RCI) and the National Council for Teacher Education (NCTE). The newly designed course structure and syllabus is comprehensive and futuristic has, therefore, been contextualized and adopted by NSOU from the present academic session, following the directives of the aforesaid national statutory authorities.

Consequent upon the introduction of new syllabus the revision of Self Instructional Material (SIM) becomes imperative. The new syllabus was circulated by RCI for introduction in the month of June, 2015 while the new session begins in the month of July. So the difficulties of preparing the SIMs within such a short time can easily be understood. However, the School of Education of NSOU took up the challenge and put the best minds together in preparing SIM without compromising the standard and quality of such an academic package. It required many rigorous steps before printing and circulation of the entire academic package to our dear learners. Every intervening step was meticulously and methodically followed for ensuring quality in such a time bound manner.

The SIMs are prepared by eminent subject experts and edited by the senior members of the faculty specializing in the discipline concerned. Printing of the SIMs has been done with utmost care and attention. Students are the primary beneficiaries of these materials so developed. Therefore, you must go through the contents seriously and take your queries, if any, to the Counselors during Personal Contact Programs (PCPs) for clarifications. In comparison to F2F mode, the onus is on the learners in the ODL mode. So please change your mind accordingly and shrug off your old mindset of teacher dependence and spoon feeding habits immediately.

I would further urge you to go for other Open Educational Resources (OERs) - available on websites, for better understanding and gaining comprehensive mastery over the subject. From this year NSOU is also providing ICT enabled support services to the students enrolled under this University. So, in addition to the printed SIMs, the e-contents are also provided to the students to facilitate the usage and ensure more flexibility at the user end. The other ICT based support systems will be there for the benefit of the learners.

So please make the most of it and do your best in the examinations. However, any suggestion or constructive criticism regarding the SIMs and its improvement is welcome. 1 must acknowledge the contribution of all the content writers, editors and background minds at the SoE, NSOU for their respective efforts, expertise and hard work in producing the SIMs within a very short time.

Professor (Dr.) Subha Sankar Sarkar
Vice-Chancellor, NSOU

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C-16 (M.R.) ❐ PSYCHO-SOCIAL AND FAMILY ISSUES

Unit 1 ▫ Psycho-Social and Family Issues

Structure :

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  1.3.7 Role of family in rehabilitation of PWID :

1.1 Introduction

Family is the smalled unit of the society in which members are held together by marriage of two persons of opposite sex. Of all human groups, family is the most important primary group which consists & with or without children who have set of obligations expectations towards each other. These sits of obligations are framed according to their cultural background.

In this unit learners will learn the concept, definition, characteristics of family including its types. They will learn also impact of disability, needs of family, counselling. The role of the family will be discussed in the view of disability rehabilitation.

1.2 Objective

On studying this unit students will be able to :

- Demonstrate understanding the concept, definition and Characteristics of family.
- Describe the types of family.
- Understand the reactions and impact of disability on family.

- Demonstrate sufficient knowledge about the needs of family and counselling of the family.
- Narrate the role of family in rehabilitation for persons with disabilities.

1.3.1 Concept :

Family exixts where people related to one another either by blood or sharing of a home, consider themselves resources for one another on a more comprehensive basis where the nature of relationship amongst members has no rigid rules or structures. It is non-pormal in nature. Structure of the family varies according to the cultural and sub-cultural patterns. There are forms and types of families. Types represent the structure and hierarchial mode in the family where as forms represents the role laid down for functional conveniences.

1.3.2. Definition

- ❖ "Family is a group of persons united by the ties of marriage blood or adoption, constituting a single house hold, interacting and inter communicating with each other in their respective social roles of husband & wife, father & mother, son & daughter, brother & sister and hence creating a common culture"

  —Buigess and Locke.

- ❖ "Family is a group, a group defined by sex relationship sufficiently precise and enduring to provide for procreations and up-bringing of children."

  —Mac-Jver

- ❖ The family is a group of individuals with a continuing legal, genetic and or emotional relationship. Society Relies on the family group to provide for economic and protective needs of individuals, especially children and the elderly.
- ❖ A family is social group organised or govered by a repeatable set of rules.

1.3.3 Characteristics

- ❖ Mating relationship : Family comes in to existence when a men and a woman establishes mating relationship between them. Thus family facilitates socially accepted sexual relationship between man and woman through an institution of marriage. It is the key factor that stabilizes the marriage entity.

- Form of marriage : The mating relationship takes place by the process called "Conduction of marriage."
- Nomenclature : Every family has its own name and descent.
- Common habitation : Family requires home/household for its living. Without a dwelling place, task of child bearing and childrawing cannot be adequately performed.
- Economic provision : Every family needs economic provisions for its maintenance, stability and balanced growth. The head of the family fulfills this need.
- Emotional basis : Family is a fundamental unit of human society which provides emotional and social security to the individual from birth to death.
- University : Family is globally present. It is recognized as the first social institutions in the life of person. No culture or society has even been existed in the absence of one or other form of family.
- Socialization and early formative influence : Family is the most powerful unit of society which helps an individual learn socially accepted behaviour.
- Social regulation : Family is particularly guarded by social customs & regulations which cannon be violated in an easy manner.

1.3.4 Types of family :

The early types of family found in primitive society and tribal communities are the maternal and paternal forms generally known as matriarchal and patriarchal families. Matriarchal family is a social unit in which the female or the mother is the head of the family the decent or lineage is traced through the female, the residence is in mother's abode and property is in heritage through female progeny. These features are characterised in terms of maternal authority, matrilined, matrilocal and matriarchal.' Mother has absolute control over all the other members, including her husband, who lives in her residence. Husband has a secondary position in matriarchal family. Women are the privileged persons.

Patriarchal family is characterised by the authority vested in father, decent through the male progeny, residence in fathers abode and in heritance of property in male lineage. It is characterised in term of paternal dominance, patrilineal, patrilocal and patriarchal.

In this type of family, father is a dominant member and wife is a sub ordinate. There is more privilege for male members.

Apart from these two forms there are two types of family–nuclear family and joint family.

Nuclear family : Marital partners with or without children living in a common house hold. Characteristics.

- Decrease control of marriage conduction by the elders.
- Decrease control of men in marital life.
- Economic independence of Women.
- Smaller in size.
- Decreasing religious control and increasing secularity.
- Exclusion of non-essential functions from the family responsibilities.
- Dominance of Children's views and decision over elders guidance and decisions. Joint family : Joint family is a group of small families usually father's brothers and their families live together under a common roof, sharing a common property, common kitchen and common culture. They pool their financial resources to meet the demands of the family. Father or elder brother in this system is the head of the family, or, cohem rests the responsibility to make decision for the family members.

Characteristics are :

- Large size of the family.
- Joint and undivided property.
- Common household and residence under one shelter.
- Common religious practices.
- Conduction of household business, economic production activity jointly.
- Bound by responsibilities towards weak and handicapped & member of family by mutual rights and responsibilities.

1.3.5 Reaction and impact of disability on family :

Every parents wishes to have healthy baby but some parents though not by choice are forced into a situation of having a child with disability. Parents having a child with disability. Parents having a child with intellectual disability experience variety of stress and strains. It is traumatic and painful specially when they learn/suspect disability in their child or at the time when their child entras for school or as they are growing old their worriedness also growing for the welfare of their child.

Evidence suggests that many parents of children with disabilities experience similar reachans and emotional responses and that most go through an adjustment process, trying to work through their feelings (Eden-Piercy, Blacher & Eyman, 1986, Frey, Fewell & Vadasy, 1989, Johnson 1993) 'Blacher (1984) found three consistent stages of adjustment. First, parents experience a period of emotional crisis characterised by sock, denial and disbelief. This initial reaction is followed by a period of emotional disorganization that includes alternating feelings of anger, guilt, depression, shame, lowered self esteem, rejection of the child and over protectiveness. Finally, parents reach a third stage in which they accept their child.

Poyadue (1993) suggests a stage beyond acceptance that involves approciation of the positive aspects of family life with a child with a disability as when, for example, example, patter son and Leonard (1994) interviewed couples whose children required intensive home care routines because of chronic and complex health care needs and found roughly equal numbers of positive and negetive responses. Among the positive responses was that care giving brought the couple closer together and created a stronger bond among family members. In another study, the majority of 1,262 parents children with disabilities agreed with the following statement about being the parent of child with disability : "The presence of my child is very uplifting. Because of my child. I have many unexpected pleasures. My child is the reason I am a more responsible person" (Behr, muphy & Summers, 1992, p. 26)

Sandler and Mistretta (1998) believe that the focus an positive family adaptation "represents an effort to both most accurately portray 'how it is' for families, and learn from the experience of successful families to better serve those families experiencing difficulty."

But emphasizing stages of adjustment as the basis for planning or delivering family services poses two potential problems. First, it is easy to assume that all parents must pass through a similar sequence of stages and that time is the most important variable in adjustment. In fact, parents react to the arrival of a child with disabilities in many ways. For some parents, years may pass but they still are not comfortable with their child. Others report that having a child with disability has strengthened their life or marriage. The sequence and time needed for adjustment are different for every parent.

The one common thread is that almost all parents and families can be helped during their adjustment by sensitive and supportive friends and professionals.

A second concern is that the various stages of adjustment have a distinct psychiatric flaxor, and professionals may mistakenly assume that parents must be maladjusted in some way. As Roos (1985) notes, some educators seem to assume that all parents of children with disabilities need counselling.

General impact of disability on the family :

Intellectual Disability can creat unique needs for the families as discussed above. Consequently the nature of needs and the resources required to meet the need can affect several areas of life of the parents. They are

- Physical area : It includes the demands placed an the family to meet the unique needs of physical care such as giving a bath, feeding, toileting etc. One might assume that these are commer needs met by any parent and wonder what is so special about in the case of intellectual disability. Imagine what skills parents need to have when the child is not expressing hunger or does not stay calm while beingfed.
- Health : In the process of parenting sometimes may involve themselves in too many activities which are physically taxing. Or, if the resources are scanty parents might ignose their children.
- Career : Sometimes parents may chenge their occupation or career to meet the child's need such as setting for low paid jobs or unable to take up a job as one might prefer to take care of the child than having a well paid job.
- Support : Prevalent misconceptions and attitude in the community may breech the support system otherwise usually available to the parents. People might distance themsolves for the fear of being asked for support.
- Financial : Parents may need financial support to meet the express towards transportation, arranging for thesapies, medication and training and all additional expenditure that the child's condition may demand.
- Social : Social domain may get affected when the parents choose not to take time out from child caring or when other people alienate them due to miscenceptions, or for the fear of having to share resources. You might have observed that gradually the parents become socially isolated nest taking part in social fanctions of family and friend because of the child with intellectual disability.

- Embarrassment/redicule : Community, and sometimes even the family members may redicule the parents for existence and condition of the child. Though these are variations, mothers are usually victims of this.
- Relationships : Relationships may get affected when the parents are too engrossed with the child-caring to maintain social interactions or when other people alienate them due to misconceptions, or for the fear of having to share resources. Studies indicate that relationship between the parents is more important then the external relationships when it comes to cope with the disability.
- Effect of sibling : When parents are too engrossed with the child with disability, or when these are no adequate resources to meet the need, sibling are affected.
- Specific worries : Some time parents may have specific worries about the future of the child. This may happen irrespective of the support system available.

1.3.6. Needs of family and counselling :

Primarity the family with having children with disabilities get upset slowly and gradually they adopt to real situation, start recognizing the fact by showing willingness to seek help and proper information. Besides this their inter personal relations also get affected. Now they need support from out side. To reduce the stress the most useful method is apply family intervention technique which enable the parent to cope up the stress having child with disability. Coping skill, coping strategy and family like, altering expectations, amelioration the problem, indentifying with the problem. Negative strategies are like with drawal and over protection.

The family intervention process practically use through three stages like, beginning stage, diagnstic stage and winding up stage. It is fact that present of a child with intellectual disability is unforeseen and new situation. Family members do not have alternatives to resolve the situation. The emerging crisis disorients them and lower their functional abilities. This situation can be prolonged if family members are not in hibited with coping skill. Through education, training, guidance and emotional support they can be helped to accept the problem in a realistic way. If family delays in recogniging it may lead to alienation. Preventing the family to react to this stage is not only the respons ibility of the society but that of the family as will. To prevent the situation some measures may be taken like.

1. Education to help society in learn all about the facts of intellectual disability.
2. Family members need to express the exchange their feelings with close ones frankly and honestly.

3. Establish a system of mental support and help between family and rest of the society.
4. Take an oppertunity to speak or discuss in religious, social or public gatherings to educate community members.
5. Publish article to share their thoughts and experiences or share the activities and efferts to others.

Needs of the Parents

Parents being the primary care gives in the family, understanding their needs in the context of care giving in the case of persons with intellectual disability are very importent. Knowledge about the needs of the parents will help the counsellor to evaluate the resources and support system to meet the needs. While it is difficult to specify the renge of needs, research indicate that following needs are commonly reported by the parent (Peshawaria et al. 1995)

- General information on the condition, availability of services, and child management including physical care.
- Educational and vocational planning.
- Ventrilation of feelings
- Facilitating interactions and family relationships.
- Issues related to adult living such a sexuality concerns, marriage, residential care and guardianship.
- Financial support and Other social benefits.

Counselling :

- The Process of helping lies is counselling. Contray to what people believe, advice, opinion giving, sympathizing and offering to assist are all ways of helping people, but there are no counselling. Conselling is also not a monologue of the professional; rather, it is an interactive process between the counsellor and counsellee. The first responsibility of any counsellor wishing to use counselling skills is to create a climate of warm acceptance and repport whese the individual feel safe enough to explore and understand their feelings and thoughts before considering action. This stage is known as stage setting or pre-counselling process. During this stage it is important that counsellor with an open posture and learning slightly forward while maintaining eye contact and stays relaxed. Perhaps the only exception to continuous eye contact is when the counsellee is in noticeable pain while sharing feelings. Just to give privacy to the person it is alrigtht to shift gaze from the person. In some places in our counting, eye contact is considered impolits and a counsellor has to be sensitive to such practices and suitably adapt himself.

Gerad Eagan's model of Counselling

There are several models of counselling. Gerad Eagan's Model (1986) is described have for its simplicity and specificity. This three stage model of helping is very solution-focused and enables the individual to work on certain issues and problem situations that are preventing them from moving forward and acheiving their goals. This approach is best used for short term contracts. Therefore this model works with individuals to focus on their problem situations, missed oppertunities and unused potential. There are three stages with in this model.

Stage 1 : This is known as exploration stage. At this stage, the counsellor explores the issues through listening and giving full attention. The main aim at this stage is to help the individual become aware of any lacunae which are affecting unused oppertunities, to help the individual gain leverage and start with issues that will make the biggest difference. This can help the indicidual cope initially and give them the incentive to move on. The counsellor's genuiness, acceptance and empathy are crucial to make the individual comfortable enough to share his or her problem with the counsellor. This is acheived through specific techniques such as paraphrasing, reflecting feelings, using unobtrusive open ended questions and summarizing. For some people, the change to explose their situation in an acceptiny atmosphese will be sufficient enable them to move on by themselves.

Stage 2 : This is also, known as understanding and 'Finding New Perspectives.' At this stage the persons is helped to look forward to the future by helping them find new perspectives of the problems. This can be a difficult and cumbersome process. Never the less, expressing what the individual implices, summarizing the main points, identifying themes, suggesting atternative ways of looking at the problems are some of the ways by which this task is acheived. The outcome of this stage is that individual will make choices, set acheivable goals, and get ready to make changes which will make a difference to their lives.

Stage 3 : This is known as Action Plan Stage as the individual is expected to implement the plan of action to reach their goals. For sustenance and durable results the action plan must be realistic and compatible individual’s lifes style. For some people exploring and understanding the problems are sufficient to mobilize their own resources and coping mechanisms while others will need specific help further. Therefore, in stage 3 the counsellor uses several skill like goal setting, providing support and resources, coaching and training, using learning theory to pursue action plans, probem solving, decision making and evaluating. There after the programme will be implemented and followed up for evaluation.

Although the model suggests that counselling is a sequential process, in practice the stages are not necessarily so cleared defined. The appropriate skills may be used at any stage in response to the individual needs. Never the less, the Key to counselling is to understand the real issues before action is decided.

Basic counselling goals :

While the general plan of guidance and counselling varies with the family needs, targets given below can be considered.

- **Provide information on the condition :** This comprises every thing related to mental retardation intellectual disability including the causes, management and progresis. Whele providing the information, it is important to clarifly misconception and faulty attitudes, if any. If the misconceptions embedded religious and cultural ideology it requeres a great deal of Caution while addressing them. At time breaking the information an disability could be painful and emotionally taxing. Never the less, it is important that the imformation provided is accurate and passed on with certains sensitivity. More importantly the information provided should preferably be devoid of any techinical jargon.
- Establishing a support system : The main purpose of this goal is to recognize the resources a establish a support system to meet the needs of disability. The resources can be both personal assets (such as education, training, financial, spiritual) and by others (such as resources of the spouse, family members). The support system can be formal (such as health and education system, local special school, social welfare programmes etc.) and informal (such as neighbours, self-help grops, friends). It is important that parents and families are aware of these resources and support system. So that they can meet the needs of the person with disability and self as adequately as possible.

- Guidance on training programme : This includes creating awareness about the training programme required to meet the diverse need of disability. Decisions related to home based and centre based programmes, scouting the services within the community come under this goal.
- Acceptance of the person with disability : It is important to develop consistant and stable relationship with the family members, and also help the family accept the person with disability.

1.3.7. Role of family in rehabilitation of PWID :

After acceptance of the child's condition, the first step towards rehabilitation would be exploring appropriate services required by the child. They move from professional to professional in search of better guidance. During school age, The parents find it defficult to get an appropriate school for education and training of their child. They change schools due to lack of appropriate resource or improvement in child. They keep comparing their child with other peers and undergo various stages of emotions. This process takes long time in which they lose the valuable period of child's life during which rapid development could have been facilated it appropriate intervention was rendered. Even after obtaining appropriate source of education and training, they need to spend extra time energy and financial resources which cause physical and psychological stress on parents.

Assistance and support extended to the families must be both enabling and empowering them creating oppertuntities for all family members to display and aquire competencies facilitates family's ability to meet the needs and realize asperiations in a way that promotes clear sense of control over the situation. The partnership between parents and professionals helps parents gain knowledge and skills necessary to utilize support systems to strengthen family's ability in its coping as well as meeting the need.

The major operations to enable and empower families.

- Be positive and protective in interactions with families.
- Offer help in response to needs identified by family.
- Permit the family to decide whether to accept or reject help.
- Offer help that is normative.
- Offer help that is congruent with the families appriasal of its needs.
- Promote acceptence of help by keeping the response costs low.

- Promote help to be reciprocated.
- The family's immediate steps in mobilizing resources.
- The use of informal support as the principal way of meeting needs.
- A sense of Co-operation and joint responsibility for meeting family needs.
- The family members acquisitions of effective behaviour or meeting needs.
- The family members ability to see themselves as an active agent responsible for behavioral change.

Source : Enabling and empowering families Dunst, Trivette and Deal (1988) PP 97.

Due to the changes in the life styles like increased member of working mothers, smaller family size, the lack of extended family and so on, families in modern society have diminished resources at their disposal to provide the care required by the person with disability in the family. This problem is compounded by poverty, lack of awarness and accessibility. Hence they are dire need to identify different service models parallel to existing services and suitable to resolve the emerging need of the family. Models of Parent Professional partnership.

The literature abounds with examples of professional support for parents of persons with intellectual disability. Once the parents reach the stage of acceptance they start searching for help beginning with family members, relatives, friends, neighbours and professionals.

As we are aware that parents have an important role to play in promoting welfare of the individuals with intellectual disability and also the family. Often it is observed that parents tend to use their own strategies in successfully handling their children with ID which may not be dervided from any theoretical foundation. Interaction of professionals with the parents many a time give suitable solutions to the problems in rehabilitation services. Rehabilitation professionals agree that families can be the "most powerful and enduring influence in the lives of persons with intellectual disability.

Today parents and professionals work together more comfortably to influence the service delivery system. Beginning in the year 1988, many advocacy efforts have coalesced around the theme of family support. The emphasis is on moving away from provider driver services to consumer driven ones, where families are given greater control of resources so that can responds to their self identified needs. Family involvement is imperative to acheive the goal of moving towards consumer driven services. Though parents are the best teachers, technically they need support and encouragement from the professionals to prove themselves as the best service fraviders. To boost parent professional partnership in rehabilitation services, the following models are currently in practice.

Parents training programme : A group of parents are trained in managing their children with ID. The training also focuses an empowering families having children with ID.

Parents as volunteers in service centre : Parents are encouraged to participate in supporting existing service divery system. For example, interested parents are taken in the Early Intervention centres, special schools and vocational training centres as volunteers to support the professionals.

Parents association : A group of parents join together with common objectives form an association and provide services based on their objection.

CBR Programmes : Family members mainly parents take part in several CBR programmes for the benefit of their children with Intellectual Disability.

Family support plan

With the improved medical facilities, many children with complicated medical conditions are now serving. The major goal of state family support programmes is to enhance care giving capacity and improve the quality of life for the family

Some salient points of Family support plan are;

- Financial support, cash subsidy, distribution of assistive devices, tax concessions, at trans portation allownances etc.
- Respite care, day care centre.
- Benefits of several schemes of Government of India and State Governments like DDRS, ADIP, NHFDC micro finances, schemes of National Trust etc.

Parents and sibling associations

Parents and siblings form a significant part of the natural family support system for both the children with intellectual disability and the family parents have an importent role to play in promoting welfare of the individuals with intellectual disability and also the family. They are permanent teachers, socializing agents and primary care givers for the child. The whole process of rehabilitation services for children with intellectual disability is through parents due to limitations in the cognitive ability of their wards. The parents are better aware of the strength and weakness of their children as "the wearer knows where the shoe pinches. Hence parents are the greatest stakeholders in the service delivery system available for these children. The effectiveness of the intervention programme usually depends on the improvement in child and parental satisfaction. Thus, to make the service programme a success, it is desirable to involve parents, sibling in the process of planning and implementation.

Practices to promote family participation in rehabilitation for the children with intellectual disability.

- Periodic parent teacher meetings; parents and teachers share and review the child's performance, future planning and various child related problems and its solutions.
- Siblings, grand parents and other significant members of the family can also participate in training programme.
- Family cottage service model is a viable model for promoting family participation in training of children with intellectual disability, has been introduced and succesfully being implemented by NIEPID (NIMH).
- Parents Meet at National and regional levels equip parents with the knowledge on Gvernment policies, latest trends and provisions in disability rehabilitation, which enable them to voice for establishing a right based society for persons with disabilities.

Unit Summary

Family is a group of person united by the ties of marriage, blood or adoption, constituting a single hense hold, interacting and inter communicating with each other. The characteristics of family are mating relationship, marriage as institution, common habilitation, nomenclature, economic, provisions, emotional basis, universality, socialization and social normsand regulation. There is mainly two types of family nuclear and joint family. Family members mainly parents face the variaus difficulties with their children is having disability. Parents experience the various emotional and psychological stage and adjust the crisis and prepare their children for independent living. It is under stand that intellectual disability would create various needs for the families in general and parents in particular. Meeting these needs requires defferent resources and both informal and formal supports. There are several models of counselling. Irrespective of the assumptions, counselling should start with in an at ambience where the counselle feel secure and cenfident to share the problems. Counselling should always proceed from exploration of the problems to understanding of the problem to action planning. Family plays an important role in rehabilitation of persons with intellectual disability. Families have various types of strengths and competenices that collectively define their unique family fanchoning style, and these styles reflect the ways, families cope and grow.

Question for critical reflection

1. Define family. Write different types of family with suitable examples.
2. Discuss the stages of family intervention.
3. Write a brief note on the problems of family having children with intellectual disability.
4. Discuss the role of family in rehabilitation of children with disabilities.
5. What is the impact of disability of intellectual disability on the family.
6. Why counselling parents is so important in the context of child with intellectual disability.
7. ‘‘Family functioning and stress is not just influenced by the child with disability alone.
8. Describe the role of parents siblinys associations in improving quality and quantity of disability rehabilitation services in our country.

Suggested readings

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Unit 2 ▫ Psycho-Social Issues

Structure :

2.1 Introduction

The phenomenon of intellectual disability has been known for millennia. It has been observed that the phenomenon has a complex nature and not understood completely by the various sections of the community such as parents, family, professionals, teachers peer groups etc. There have been a lot of miscenceptions and wrong practices seen across the society. Howeven in recent decades, serious attention has been paid to it. Considerable scientific information has been built up and published.

In the past, no defferentiation was made between mental illness and intellectual disability. However, currently the two conditions have been recognized as separate entities with distinguishing diagonstic criteria.

The present chapter focuses on various psycho social aspects and misconceptions regarding intellectual disability found in the community/society including exploitation, deling uency, child labour and child abuses etc.

In this unit, the rights of the persons with intellectual disability and advocacy to be dicussed.

2.2. Objectives

On studying this unit students will be able to :

- Understand the attitude of family, community, peer group, teachers, Co-workers.
- Describe the various myths, misconcephons, and social practices related with intellectual disability.
- Demonstrate understanding the difference between intellectual disability and mental illness.
- Illustrate the different psycho social issues, like exploitation, delinquency, child labour and child abouse.

- Discuss the various rights of the persons with intellectual disability and advocacy for them.

2.3.1 Attitude of the family

Various studies have focused on stressors associated with caring for children with disabilities, and the deleterians effective on parents well being. There is evidence that family attitude contributes to prognosis in these children. Limited financial resources, look of appropriate service, and in sufficient support systems are the family system risk factors that contribute to poor prognosis. Environmental risk factors such as lack of services and negetive attitude can also have adverse influence on the prognosis for the child with disability specially intellectual disability.

Children are the perfect extension and expression of a couple's love and caring. The emotional preparation for expectant parents is usually shaped by a glomourous image of the baby, kind of ego ideal. The discripancy between the perfect child of their fantasy and the real child may be the cause for negetive attitudes and parenting stress. Often a range of emotions, such as denial, guilt, blame, frustration, anger and despair, sweep through the parents as despair, sweep through the parents as they are confronted by their children with disability Loss of hope for the 'perfect child' causes grief, and over time the feeling is heightened by loneliness, isolation, and exhaustion. Parents frequently over profect their child and feel quilty that they are responsible for the child's disability.

The parents of children with disabilities develop 'Chronic sorrow' characterised by periodic recurrence of sadness, guilt, shock, and pain. They are plagued by feelings of pessimism, hostality and shame, Denial, projection of blame, guilt, grief, withdrawal, rejection and acceptance are some of the usual parental reactions. Some parents also experience helplessness, feelings of inadequacy, anger, shock and guilt, whereas other go through periods of disbelief, depression and self blame. The siblings also experience feelings of guit, shame and embarrassment.

2.3.2 Attitude of Community :

Historically, attitude of the society was totally negative and indifferent towards persons with intellectual disability. They were regarded as deviant, considered social evils, viewed as menance to the society, sub human, unspeakable objects and objects of redicule. Consequency the tendency to segregate them was motivated. Separate institution, hostels, care houses which would provide life long custodial care were established for them. Society did not rehabilitate them, on the contrary ware hense them from cradle to grave. The were considered as no good to the society.

Slowly and gradually these attitude have changed for the better management of these persons. People realized that these persons with intellectual disability can be trained to live and work in the community. What they needed was patterns and conditions at home as well as in school, which should be as close as possible to the norms and patterns of society. Keeping this view society adopted the policy of deinstitutionalization, that is to bring persons with intellectual disability back to the main stream.

Attitude of public play a very crucial role in bringing desirable change in society's out look. Programmes directed towards protection of rights, education and rehabilitation will only be successful if public has positive attitude towards such facilities or programmes. Besides this, how people feel about intellectual disability, what do they think about them and how do they estimate their abilities are important factors to know for people who work in the field of intellectual disability. Attitude of the family members, neighbourhood, are important factors to be studied considering the intervention programme. Besically three methods are commonly used for the study of attitudes i.e. interview method, questionarie method and vignettes methods.

2.3.3. Attitude of the peer group :

Young Children are expected to develop social skills through interactions with peers when they attend pre school programmes. In inclusive classrooms, the odds that children with disabilities will enhance their social skills increase when the children have opportunities to interact with typically developing peers.

However, children with disabilities do not interact frequently with typically development children, partly because they tend not to initiate social interactions. This implies that children with disabilities may be loss likely to interact with typically developing peers unless these peers those peers actively and positively initiate interactions cr unless adult intervene to facilitate such interactions. Therefore, typically developed children's attitudes towards children with disabalities may be crucial for premoting social interactions between children with and without disabilities in pre school settings.

Children as young as pre school ages, however, often display favouritism toward a group of peers who shares similar characteristics (e.g gender, ethnicity, and developmental status), displaying a negetively biased view and relative discrimination towards peers with characteristics they perceive as defferent from their own. On the other hand, young children's awareness of others or their playmates preferences, which usually begin forming at early ages (e.g four to five years of age), might be most malleable during this developmental period (i.e., the pre school years). We do have some ideas of what helps, such as children's prior contact with people with disabilities, but there is a lack of knowledge on what factors contribute to typically developing children's attitudes especially in early years, and some existing findings are equivocal.

Children with special needs encountered defficulty in social interactions with regular class peers. Most of the peer had little information abent their disabled peer i.e. children with special needs and this lack of knowledge could create fear and prejudice. Children with disability were often laughed at, or developed in many ways during interaction with peers.

2.3.4. Attitude of the teachers :

The mainstreaming education faced challenges such as negetive attitude of teachers to students with special needs; inadequate aids and services; unsupportive role of parents, lack of specialist teachers to provide important services that would assist regular teachers in managing the learners with special needs; inadequate personnel training programme lack of adequate and relevant educational materials; and unfriendly learning environment for students with special needs.

Children with special needs encountered defficulty in social interactions with regular class teaching. Children with disabilities were often laughed at, or devalued in many ways during interactions. One attitude that influenced teachers attitude was labeling, when students were indentified by negatively perceived label, for examples; intellectual disability. Compbell, Dodson and Boss (1985) opined that teachers were less able to objectively observe, rate and plan appropriate intervention for their behaviours. Another factor that could contribute to the rejection of children with disabilities by regular teachers and administrators was lack of special training. Many teachers were afraid that they did not have skills necessary for teaching special needs children. Others felt that working with these children was not gratifying as working with normal individuals.

Ottman (1981) reviewing the work of Allen (1978), indentified three pertient factors with regard to regular teachers attitude towards the special needs children.

1. That the classroom teachers wre generally not favour of accepting the handicapped in regular schools, because they were after afraid of the demands that may be placed on them.
2. The teachers have lower expectations for the handicapped students.

3. That the teachers tend to see their role as highly structured and group oriented, which runs counter to special education merxim of to individualized differences.

Elliot (2008) examined the relationship between teachers attitude towards mainstreeming of children with mild to moderate disabilityin physical education settings, and the level of success attained by these students compared to their peers without disability. The findings suggested a relation his between in clusion and teachers effectiveness, teachers with positive attitude to words inclusion provided their students with significantly more practice attempts, at a higher level of success.

2.3.5. Attitude of Co-workers :

Owing to attituders held by employers and Co-workers, PWD's face restricted access to employment. They are often disregarded and considered as "second class citizens" or objects of charity giving them a felling of inadequacy, dependence and insecurity. Such prevailing social attitudes not only determine the social expectation and treatment accorded to PWDs in the society but also their self image and function. Over the years perceptions towards PWDs varied and have changed from community to community. Some researchers observed that PWDs were completely rejected by the some cultures and in others they were outcasts while in some they were treated as liabilities. In other community settings, they were given respecte status and allowed to participate to the fullest extent of their capacity.

Philosophically, since the Greco-Roman Era (100 BC–300 AD), PWDs were given alms, such as money at certain designated dates. Besides this benevolence, disability was associated with idiocy and the evils of mankind. With changing philosophy in Europe people with disabilities were killed with obsession of creating a perfect human race (Fatalicism) the same applied in Africa, assuming that such an occurrance was a bad omen linked to witchcraft. Falalicism was soon replaced by religious philanthropic philosophy which was characterised by acts of patronage, sympathy, compassion, humanity, benevolence and charity. This soon led to philosophy of Humanism, whose premise was based on social welfare. The emergence of Social Philosophy brought about morality and humanistic ideas centred on the concepts "Social Justice, " "Affermative Action" and "Positive Discrimination" This accorded rights to PWD's such as right to education, right to employment and the right to movement. However, many researchers observed that the Co workers perceived PWDs as generally incompetent as they would need the assistance of fellow workers to accomplish tasks while employers were of the view that some of these PWDs scare away customers while some are dependent on fellow workers for the accomplishment of tasks. The some employers perceived most PWDs as lacking knowledge and having poor qualifications rendering them unemployable. Co workers felt that employees with disabilities need maximum supervision and needed to be assigned special tasks suitable to their conditions. From these findings, it was recommended that co-workers needed to change their attitude towards employees with disabilities.

2.4.1. Misconceptions

Misconceptions are incorrect ideas held in respect of the condition. Mental Retardation or intellectual disability is also a condition which is widely misunderstood not only by the by man but also among those who work for their welfare. It is not possible for everyone to know about everything specially in the country like areas. Often people give defferent explanation and conflicting advises without paying any attention to illness or disability. Intellectual disability is one such about which large number of people have misconceptions, wrong ideas and false believes. Some of these misconceptions are harmless but many a times it affects the person and families.

Measures taken by the parents in managing problems of their children with intellectual disability would depend upon ideas they hold about the condition, the amount of Co-operation they get from the professional in the process of training of their children with disability and the amount of correct knowledge they have about the condition.

Experiences show that majority of people don't have clear knowledge about the concept of intellectual disability. It causes, mismanagement. They still feel it is a result of their KARMA. They hold many misconceptions or have questions with regard to intellectual disability. Due to following reasons the condition of intellectual disability has been misperceived.

1. The deficit in intellectual disability can not be 'seen' as in case of other disabilities conditions.
2. Confusion between mental illness and intellectual disability :

In fact mental illness and intellectual disability are totally defferent. Intellectual disability is condition whese intellectual functioning is below average right from birth and adoptive behaviour abilities are impaired. It is a permanent condition, but they can be helped to over come their disability with right kind of training programme and community support.

Mental illness is due to the stress and problems with which people can no longer cope. It is a tempary condition and can be treated successfully. Intellectual disability is not a disease or therefore there is no treatment or cure.

3. Intellectual disability is due to fate or karma is due to karma helps parents to be free from feeling of guilt. But having this belief and making no effort to train child rather leaving him or her to fate is not correct. Parents must be told that what ever may be the cause, training will definitely improve.

4. Medicines only can cure intellectual disability ;

No medicine or any magic drug can cure the intellectual disability, but parents spend lots of money to bye some spurious medicine to cure their children with ID.

5. Marriage can cure intellectual disability :

Many people think that after marriage the persons with intellectual disability will become achive and responsible or sexual satisfaction will cure him. This is not correcrt. It will make problem more complicated as it is a known fact that persons with intellectual disability can not become totally independent. Therefore it is not possible for them to look after the interest of their families.

6. Persons with intellectual disability becomes normal as he grows.

Intellectual development of these persons is slower than that of normal persons. Where natural increase in chronological age and mental faculty do not develop at the some pace. Intensive training, however can improve their competence. Early identification and early training is very important.

7. Intellectual disability is infectionous :

Many people think that if normal poeple are allowed to mix up with intellectual disabled, they would also develop intellectual disability. This is wrong. Interactions between intellectual disabled and normal individual would rather help in bringing improvement and at the same time normals would understand problems and accept them in realistic way.

8. Persons with intellectual disability can be taught any thing :

They can be taught basic skills of daily life, depending upon their intellectual and functional abilities. They can be trained to do repetitive jobs that too under supervision.

Due to the misconceptions, people in general underestimate the capabilities of persons with intellectual disability, which in turn hampers the process of rehabiliting them. Hence, there is a need to eliminate these misconceptions mainly through awareness compaign in the society.

2.4.2. Social Practices :

In a developing country like ours, the existing societal system are generally influenced by the factors like religion and culture (multi-cultural society). These, along with other factors such as illiteracy, poverty and over population influence the community/ family to follow certain practices particularly in case of families having persons with intellectual disability. Some of the existing social practices are as follows.

1. Consangvinity : Since ages, in most of the communities marriage between close blood relatives is been practiced. This has the possibility of increasing the occurrance of disabilities including intellectual disability.
2. Most of the people in our society have strong belief in their religion without any other efforts, approaching religions places and faith healers for cure of any kind of illness/disease including intellectual has been the common practice. To certain extent, this practice may delay/hamper the actual process of management rehabilitation of the persons with intellectual disability.
3. Certain families in our society have the belief that marriage cures intellectual disability. In fact in certain cases the possibility of increase in the stressful and challenging situation following marriage are common in the life of a person with intellectual disability.
4. Since the older days, the practice of isolating the person with intellectual disability and putting them is asylams is a known fact. However, institutionalization is gradually transformed into normalization and integration, though, the segregation of these persons within the families still continues. Persons with intellectual disability are avoided in social functions and gatherings. This practice restricts the social growth of persons with intellectual disability.
5. Though less common, practice of punishing harshly the person with intellectual disability still continues in the community. This may lead to emotional disturbances and personality problems among them.

2.5. Difference between Intellectual disability and Mental Illness

The concept of Co morbidity of intellectual disability and mental illness is not only theoritical but also a practical issue. Some of the common questions posed to the therapist are the two conditions different or same? If different, can a person with intellectual disability have mental illness?

In recent decades the issue of mental illness in the persons who have also intellectual disability has been given increasing attention. This is because firstly, the general recognition of the right of person with intellectual disability to appropriate health care. Secondly, following the normalization principle, persons with intellectual disability are expected to live in the community and use community facilities.

As a result of recent works in the field, appropriate and canvincing answers and explanabans were given to the above mentioned questions and concepts.

Persons with intellectual disability due to can have mental illness, which will be manifested in the form of sudden, unpredictable change in the behaviour, mood and/or thinking. The nature and spectrem of the mental illness found in the persons with intellectual disability will be similar in comparison of general population. However, 'the incidence and prevalence of mental illness amengst the persens with intellectual disability is higher than that of general population.'

Why is incidence of mental illness high amongst persons with intellectual disability?

Because of the interaction of biological, psychological and social variable resulting in an atypical path of development for persons with intellectual disability. This may be manifested with the following deficits :

1. Poor integration of self.
2. Deficits in self regulation.
3. Lack of self confidence.
4. Inferiority complex.
5. Anxiety
6. Defficulty in living independently.

Due to the above mentioned of deficits, persons with intellectual disability are more vulnerable to psychopathology in comparison to the non-retarded individuals. Besides the above factors, stressful and competetive environment due to disparity between parental/family expectations to the individual capacity, adds to the problem.

The difference between mental illness and intellectual disability

In a country like India, most of the people feel that intellectual disability and mental illness are one and the same. This is mainly because of lack of information existing among the general public regarding the differences between mental illness and intellectual disability. Hence, it becomes essential to have clear guidelines to deffentiate these conditions for developing promising management strategies. The following table shows the distinguishing diagnostic criterial for mental illness and intellectual disability.

Intellectual disability	**Mental Illness**
1. It is an a condition, not disease	1. It is an illness/disease disorder.
2. Usually at childhood, can occur during the developmental period (up to 18 years)	2. Can occur at any age.
3. Below average general intellectual function originating during the developmental period and associated with impairment in adaptive behaviour.	3. It is a disease of brain or pscho producing significant behavioral or psychological disturbances associated with socio-occupational deteriotion.
4. Multifactorial but primarity biological (genetic, metabolic, perinatal injuries.	4. Causes : Multifactorial-Biological, Psychological, Social.
5. Usually developmental delay (motor, cognitive, speech, language & Communication, personal and social) is notel. IQ level is below 70. Behavioural problems may be there. Deticits in adaptive behaviour and learning are noted. Usually no normal pre morbid state.	5. Clinical features : No developmental delay. IQ level can be normal or below normal. It means mentally retourded/ intellecutual disabled can have mental illness in fact the rate of mental illness amongst mentally retarded is very high in comparison to the individual with normal IQ. Speech can be incoherent or irrelevant. Behavioural change is noted. Examples : Muttering to self, smiling or crying without reason, remaining aloof for a long period of times unproveked aggresiveness, extreme variason in mood and sleep disturbances etc. Will have normal premorbid State.

2.6. Psycho-social Issues : Exploitation, Delinquency, Child labour and Child abuse

2.6.1. Exploitation

People with intellectual disability experience more violence and exploitation in general when compared to then without disabilities. In 2008, The National Crime Victim Survey found that people with disabilities experience higher rates of violence them people without disabilities. (40 victimizations per 1000 persons with disabilities compared to about 20 per 1,000 without disabilities), and that rate of victimization is twice as high for people with disabilities. Another alarming finding was that people with cognitive disabilities (intellectual disability) experienced the highest risk of violent victimization. Any type of disability appears to contribute to higher risk of Victimization and exploitation but intellectual disabilities appear to contributs very high levels of risk, and having multiple disabilities (e.g. intellectual disability and behaviour disorders) result is even higher risk level.

People with severe intellectual disabilities may not understand what is happening or have a way to communicate the assoult to a trusted person. Others with a less severe disability may realize they are being assaulted, but don't know that it's illegal and that they have a right to say no. Due to threats to their well being or that of their loved ones by the abuser, they may never tell anyone about the abuse, especially if committed by an authority figure whom they learn not to question. In addition, they are rarely educated about sexuality issues or provided assertiveness training. Even when a report is attempted, they face barriers when making statements to police because they may not be viewed as credible due to having disability.

Some risk factors may include a feeling of powerlessness, communication skill deficits and in ability to protect one self due to lack of instruction and/or resources. Other factors include the care taken's failure to 1) request information on the background of all those involved in the person's life, such as professionals, para-professionals, ancillary and volunteers staff, 2) become familiar with the abuse reporting attitudes and practices of the agency, and 3) assure there is a plan in place for responding to reports of abouse when they occur. Also, affenders are typically not caught and/or held accountable for these crimes, which allows asure to continue.

2.6.2. Delinquency

Althouth for many years intellectual disability and delinquency were closely associated in the public mind, recent studies have tended to disprove a really close relationship. However, for wome intellectual disabled children delinquency may be the greater hazard than for their more fortunate others and sisters.

However some delinquent behaviours are found with mild and moderate children with intellectual disability. Particulary when those children are living in urban gheto or slum area. The subculture of these areas help to promote such delinquency like several antisocial activities, sextual offences, drug addition among some children with intellectual disability in lower socio economical status. Behaviour therapy, behaviour modification techniques can reduce such delinquent behaviours among the children with intellectual disability.

2.6.3. Child Labour

The International Labour Organization (ILO) estimates that around the world some 250 million children between ages 5 and 14 for a living. This number includes Children with disabilities, though their actual members have not been estimated. Some 200 million (10%) of the world's children are born with a disability or become disabled before age 19 (UNICEF, 2008). Intellectual disability is one of the most common form of disability; in fact one out of every (1/10) children who need special education has some form of intellectual disability. Those children with mild intellectual disability may be involved in child labour as they can follow instructions though a lot has not been done through empirical studies to establish their actual numbers.

It many countries, children with disabilities are 3-4 times more likely to maltreated then those without disabilities. They are bound to do work in underages. Many children with disabilities were reported being forced to do something against their will, which is a form of child labour.

2.6.4. Child Abuse

Peoples with intellectual disabilities (Particularly children) can be both victims and perpetrators of sexual violence (often termed sexual abuse). Prevalence rates of sexual abuse against children with intellectual disabilites are high when compared with experience of the general population. Whist people with intellectual disabilities experience sexual violence and abuse in many of the same ways as the general population, they may encounter additional ussues relating to their impairments and/or the social environments in which they live. These can include increased vulnerablity, questions around ability to consent to sexual activities, differential treatment before the law, social attitudes about intellectual disability and sexuality and restricted access to suitable support and recovery services.

A number of factors put children with intellectual disability an increased risk of sexual abuse.

- Lack of understanding.
- Lack of social awareness and training that would help identity and anticipate abusive situations.
- Ingrained reliance on the care given authority figure.
- Long term dependence on services and personal care.
- Lack of knowledge and training in sex education and life style skills.
- Powerless position.

Parents should be particularly careful to prevent a situation leading to the sexual abuse of their disabled children. It is very easy to take advantage of these youngsters, hence.

- be very careful with whom you leave your child.
- teach your child to discriminate between strongers and friends.
- teach him/her to scream when assulted.
- teach him/her that their bodies should be touched as little as possible by other people.
- encourage him/her to report unusual happenings.

2.7 Rights and Advocacy

2.7.1 Rights : Child Rights and Human Rights

Adopted by General Assembly resolution No A4/25 on 20 November 1989, the cenvention on the child was another step in the direction of recognizing human rights. The need to extend particular care to the child had been stated the Geneva Declaration of the Rights of the child in 1924, the Declaration of the Rights adopted by the General Assembly on 20 November 1989 and recognized in the Universal Declaration of Human Rights, the International Convention on Civil and Political Rights (Article 23 & 24) in the International Convenant on Economic, Social and Cultural Rights (Article 10) and also in other declarations the statutes and relevant instruments of significant agencies and organizations concerned with the welfare of children. Some of its article relevant to disabilities.

2.7.2. UN Declaration on the Rights of Disabled Persons

The UN General Assembly Pro-claims the Declaration on the Rights of Disabled Persons and Call for the national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights.

Realizing the need to intiate action at international and national level to guarantee these rights, two major initiatives were undertaken by the UN. Thse were the UN Decade for Disabled Persons (1983-92) and the Asian & Pacific Decade of the Disabled (1993-2002)

2.7.3 The Salamanca Statement and Frame Work for Action on Special Needs Education (1999)

The Salamanca Statement and the Frame Work of Action was adopted by the World Conference on Special Education in Salamanca. Spain in 1994 jointly organized by Government of Spain and UNESCO. Five regional seminars were held prior to this that prepared the basic ground for this conference Representatives of 92 Government and 25 international organizations participated in this World Conference on Special Needs Education. The framework stems fromework stems from the messages of the World Declaration on Education For All (1990) and was reaffirmed in the Dakar Frame Work of Action (2000).

The Statement begins with a commitment to education for all. The major approach reiterated in the conference was inclusive education, which is highlighted by the following statements. “School should accomodate all children regardless of their physical, intellectual, emotional, social conditions”. “Regular schools with inclusive orientation are the most effective means of combating discrimatory attitudes creating welcoming communities, building and inclusive society and ensuring education for all, more over, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system.”

2.7.4. Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995

This Act was passed by the Parliament on December 12, 1995 and notified February 7, 1996. The Act elaborated the responsibilities of the Central and State Governments, local bodies to provide services, facilities and equal oppertunities to the people with disabilities for participating as productive citizens of the country. The Act enlists the right and facilities persons with disabilities would be entitled to and which are enforceable.

This is an important land mark. The Act provides for both preventive and promotional aspects of rehabilitation. Chapter 1–Preliminary

The Disabilities covered in Act are blindness, lowvision, leprosy cured, hearing impairment, locomotor disability, mental retardation and mental illness.

A person with disability has to be certified by a medical authority that he or she is suffering from not less them 40% of the disability.

Chapter II–The Central Co-ordination Committee And Executive Comittee.

Chapter III–The State Co-ordination and Executive Committee.

Chapter IV–Prevention and Early Detection of Disabilities.

Chapter V–Education

Chapter VI–Employment

Chapter VII–Affirmative Action.

Chapter VIII–Non-Discrimination.

Chapter IX–Research and Man Power Development.

Chapter X–Recognition of Institutions for Persons with Disabilities.

Chapter XI–Institution for Persons with Service Disabilities.

Chapter XII–The Chief Commission and Commissioners for Persons with Disabilities.

Chapter XIII–Social Security.

2.7.5. Rehabilitation Council of India Act 1992 and it's relevance to education

This Act was passed in 1992 for the purpose of consifituing the Rehabilitation Council of India for regulating the training of Rehabilitation Professionals and for maintenance of a Central Rehabilitation Register. It was amended by Rehabilitation Council of India (Amendment) Act 2000 to provide for monitoring the training of rehabilitation professionals and personnel, prompting research in rehabilitation and special education as additional objectives of the Council.

Rights of the Disabled that emerge from the Rehabilitation Council of India Act, 1992.

1. To have right to be served by trained and qualified rehabilitation professionals whose names are borne on Register maintained by the Council.
2. To have the guarantee of maintenance of minimum standards of education required for recognition of rehabilitation qualification by Universities and other institutions in India.
3. To have the Guarantee of maintenance of standards of professional conduct and etiquettc by rehabilitation professionals through the provision of penalty of disciplinary action and removal from the register of the Council.
4. To have the guarantee of regulation of the profession of rehabilitation professionals by a statutory council under the control of the central Government and within the bounds prescribed by the state.

2.7.6 National Trust Act (For the welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities) Act, 1999

The National Trust is a statutory body under the Ministry of Social Justice and Empowerment, Government of India set up under the “National Trust for the welfare of persons with Antism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999.

The objectives of this trust are :

- To enable and empower persons with disabilities to live independently and as fully as possible with in and as class to the community to which they.
- To strengthen facilities to provide support to persons with disability.
- To strengthen facilities to provide support to persons with disability.
- To extend support to registered organizations to provide need based services during the period of crisis in the family of persons with disability.
- To deal with problems of persons with disability who do not have family support.
- To promote measures for the care and protection of persons. With disability in the event of death of their parent or guardian.
- To evolve procedure for the appointment of guardians and trustees for persons with disability requiring such protection.
- To facilitate the realization of equal appertunities, protection of rights and full participation of persons with disability and.
- To do any other act which is incident to afose said objects.

The National Trust is conducting several programme for the welfere of persons with disability like, registration of organizations, formation of Local Level Committee, appointment of guardians, support services, home visit, care givers programme, community participation programmes etc.

2.7.7 Rights of Persons with Disabilities Act 2016

After almost a decade's wait, the Rights of Persons with Disabilities Act 2016 came into effect on 30 December 2016 came into effect on 30 December 2016. The Lok Sabha passed it on 17 December and the Rajya Sabha an 14 December. The Act will replace the Persons with Disability (PWD) Act of 1995.

The passage of the Act took place amidst the logjam in Parliament over the issue of demonetization. Activists appreciated the Act, but many also raised concern over the language.

Salient features of the Act :

1. Reservation in vacancies in government establishments has been increased from 3% to 4% for certain persons or class of persons with bench mark disability.
2. Every child with benchmark disability the age group of 6 and 18 years shall have the right to free education.
3. District Level committees will be constituted by the State Governments to address local concern of PWDs.
4. Special Courts will be designated in each district to handle cases cencerning Violation of rights of PWDs.
5. Broad based Central & State advisary Board and disability are to be set up to serve as apex policy making bodies at Central and State level.
6. Office of the Chief Commissioner and these of the State Commissioners of Persons with Disabilities has been strengthened.
7. The Act says that any person who "intentionally insults or intimidates with intent to humiliate a person with disability in any play with public view" is punishable offences.

Categories of disabilities in Rights of persons with Disabilities Act 2016.

1. Blindness
2. Low vision
3. Leprosy Cured Persons.
4. Hearing Impairment (deaf and hand of hearing)
5. Locomotor Disability
6. Dwarfism
7. Intellectual Disability
8. Mental Illness
9. Autism Spectrum Disorder
10. Cerebral Palsy
11. Muscular Dystrophy

12. Chronic Neurological Conditions
13. Specific Learning Disabilities
14. Multiple Sclerosis
15. Speech and Language Disabilities
16. Thalassemia
17. Memophilia
18. Sickle Cell disease
19. Multiple Disabilities including deaf-blindness
20. Acid Attack victim
21. Parkinson's disease

2.7.8. Advocacy

Advocacy on the individual or systems level is acting with or on behalf of an individual or group to resolve an issue, obtain a needed support or service or promote a change in the practices, policies and for behaviours of third parties. Advocacy is essential for promoting and protecting the civil and human rights of people with intellectual and/or developmental disabilities and for establishing, maintaining or improving their quality of life.

Without strong advocacy at all levels people with intellectual and/or developmental disabilities may not have access to needed supports as well as opportunities to exercise inherent civil and human rights.

Additionally, strong advocacy may be required to prevent and/or address abuse neglect and exploitation that people intellectual and/or developmental disabilities may experience. Persons with intellectual and/or developmental disabilities may need the support of advocates to become effective self-advocates.

Advocacy is vital in improving and sustaining quality of life for persons with intellectual disability. To be effective advocacy must take place at both the individual and system Levels. Advocacy can be aimed at public officials, support systems and the general public.

Self Advocacy :

Self advocacy is about people with intellectual disability :

- Speaking up for themselves.
- Making their own decisions.
- Role of Self-advocates :
- They speak up for themselves.
- They speak up for others.
- They ask for support when they need it.
- They make sure they have a say in decision that affect them.
- They as questions and learn new skills.

People can support self advocates.

- Using information that makes sense to the self advocate.
- Making sure that self advocates get to have a say.
- In volve them in decisions and listen to what they have to say.
- Give self advocates time to make decisions.
- Understand that its okay for self advocates to make mistakes and support them to learn from them.

2.8. Unit Summary : Things to Remember

- Persons with intellectual disability live in an atmosphere created by the attitude held by the people and professionals they come in contact with in addition to those of their families. The change in their attitude is imperative for the complete growth of the child. People in cluding parents community teachers, Peer group, Co-workers around the world held a variety of attitudes, and perceptious towards persons with intellectual disability. The phenomenon of intellectual disability is complex and has been misperceived by various section of the community such as parents family, professional and other people. Person with intellectual disability with less IQ. Can have mental illness, which will be manifested in the form of sudden, unpredictable change in behaviour, mood and/or thinking. The defferences between intellectual disability and mental illness havebeen discussed.

The psycho social aspects including exploitation, sexual abuse, delinquency among same children with intellectual disabilities, effect of child labour and child abuse are discussed. Constitutional rights of the persons with disabilities specially for intellectual disability are described by informing various legal and constitutional provisions like PWD Act, RCI Act, NT Act and Rights of Persons with Disabilities Act etc. Explaination for advocacy and self advocacy for the persons with intellectual disability are given.

2.9 Check your progress/assignments :

1. What are the critical aspects of the plight of the persons with intellectual disability?
2. Discuss briefly the various misconceptions seen in our society regarding intellectual disability.
3. Write the defferences between intellectual disability and mental illness.
4. Discuss the attitude of family members towards the persons with intellectual disability.
5. What are the teacher's perceptions towards the children with intellectual disability?
6. Write a brief notes on exploitation and abuse of persons with intellectual disability.
7. Write the salient features of Rights of Persons with disability Act 2016.
8. What in the import ance of self-advocacy?

2.10 Suggested Readings :

1. Hewett. F.N. Fornees. SR (1988) Education of Exceptional learners (2nd edition). Boston Allyn, Bacon.
2. Goddard J.J (1912) The Kalli Kkak family, New York : Plenum Press.
3. Reading an mental retardatian prepared for DSE(MR) Course : Family and Community. Secunderabad : NIMH.
4. Mental Health in mental retardation : Recent advances and practices (1994) Cambridge University Press.

5. Sexuality and mentally handicapped : A manual for parents and teachers SCERT, FPAI.
6. Barbra. M & Mutswanga P. (2014) The Attitude of Employers and Co-Workers towards the Employment of Persons with Disabilities IJMSR Vol 2 Issue 3.
7. Reddy SHK. Narayan J and Menon DK (1990) Education in India : A Survey of facilities for Children with mental retardation. Mental Handicap Vol 8 pp 26-30.
8. PWD Act (1995) Government of India.
9. RCI Act (1992) Government of India.
10. NT Act (1999) Government of India.
11. RPD Act (2016) Government of India.

Unit 3 □ Involving Families

Structure :

3.1 Introduction:

The rehabilitation professional and parents need to see that, not the disability that hinders a child's adjustment, but how the child and others accept the disability. Moreover, a child with disability or special need becomes a victim of his own environment than the disability because of his limited capacity and dependency. There are various factors that determine effectiveness of rehabilitation of child with disability or special need. However, certain factors are more important than others in the initial phase of rehabilitation process.

Dealmg with the initial stress of experiencing the fact by the parents is very crucial aspect. Further, facilitating parental acceptatce of the realities of the child with disability helps in optimal involvement of parents in the process of rehabilitation. On the basis of this foundation, the process of rehabilitation can be enriched to provide further opportunities for the child with disability or special need.

The relationship between the parents of a child with disabilities and the professionals who serve and educate the child is one of the major factors which influence the child's development.

Self-help groups are informal groups of people who come together to address their common problems. While self-help might imply a focus on the individual, one important characteristic of self-help groups is the idea of mutual support - people helping each other.

The parent association is the structure through which parents in a school can work together for the best possible education for their children including children with intellectual disabilities. The parent association works with the principal, staff and the board of management to build effective partnership between the home and school.

Family empowerment has been defined as a family invested with authority. It is the process of a family acquiring the skills, resources, authority, opportunity, and motivation to meet the needs of their family. Family empowerment is the action associated with high self-efficacy. Empowering Families means to provide holistic support to parents and children.

Parent Empowerment: Parent empowerment includes the ability to meet the needs of one's family while feeling in control. Empowerment enables parents to achieve desired outcomes for their family and their children.

3.2 Objectives:

1. Understanding the techniques of family involvement in the rehabilitation process
2. Understanding the significance of Parent - professional relationship
3. Understanding the process of forming Self- Help Group and their activities
4. Understanding the necessity of Parent Associations
5. Understanding the process of empowering families

3.3. Training and Involving Families in the Rehabilitation Process:

Family is the primary unit in the life of an individual. Parents are the pillars of this unit. Parents and family need to fulfill certain responsibilities in order to function. A family must generate income to protect and maintain its members and home, nurture and love one another and see that children are taught social norms and educated.

No one plans to have a child with disabilities. The birth of a child with a disability is an unanticipated event. No family- regardless of race, ethnicity or socio economic status- is immune to childhood disability, yet almost all are poorly prepared to cope with its occurrence. (Selgiman & Darling)

The family is the first social unit of the child and its first center ofleaming. A professional may initiate, intervene or plan a rehabilitation programme but the child remains in the fold of its family. It is thus imperative that the family is involved in the comprehensive rehabilitation right from day one.

So, when a child is handicapped (child with special need), these responsibilities become more crucial. There is the expense, the time, the energy needed to care for this member having special need and his safety. Besides this there is the difficulty of helping this member to develop a good self-image and social skills, and even the problems of seeing that the disabled member receives an appropriate education. Every ordinary task becomes more difficult and more stressful.

Parent's reaction to the birth of a child with disabilities varies widely. While somewhat speculative, 3 to 7 emotional stages of parents are usually identified. They are as (a) feelings of shock and disbelief; (b) denial; (c) anger and guilt or depression; and (d) a shift from self-absorption to concentrating on now to deal with the child's needs. Whether all parents experience all these stages is still controversial, as is the exact sequence of stages.

But caregivers shouldn't feel alone in their situation. By working together with the rehabilitation team, the patient and family can help lessen the adverse effects of these changes and work toward finding realistic solutions.

First and foremost, families need to become educated about a loved one's condition and prognosis and involved in the development of the rehabilitation plan. The more caregivers learn—by communicating with the health care team and taking advantage of educational programs offered at the hospital- the better prepared they are to care for their loved one at home.

At Burke, for example, family members are encouraged to attend and participate in treatment and training sessions in order to become aware of their loved one's progress and learn safe and effective techniques to assist them. Families and caregivers have ongoing access to information about available services and resources that can help the patient successfully transition to the next phase of rehabil itation.

For the parents to be true partners in rehabilitation,it is essential that the professionals accept that:

- The parents have a right to be involved in the planning, as the child is their ultimate responsibility.
- That the home is the large canvas of the child's life as she he spends the major part of her his life there.
- That parents are aware of the problems of the child but not able to gauge the impact of disability.
- Parents have a major contribution to make in the life of the child.
- Professional efforts would not yield full results without family involvement.
- Parents have a right to know the various range of services and options available to the child and the right to choose the most practical one.

For the family to be successful in the rehabilitation process of the disabled person, it is essential that:

- There is demystification about disability. The family does not get confused and bogged down by labels and jargons but are told about the impact of the disability and the abilities of the child.
- The family as a whole decides to put its best foot forward to learn, to experiment, with ideas and understand, accept and love the family member with a disability.
- The disability is accepted by one and all and it is acknowledged.
- The family is open to ideas from the professionals.
- That the family is made aware of rehabilitation methods and avenues open to the child.
- The family members are present in decision-making process.
- The family members faithfully adhere to their part in the rehabilitation of the child.

With the above in view parents of the disabled take multiple roles which are neither separate and distinct from one another, nor do they fall into distinct chronological periods. Rather, they often overlap and share common elements.

Parents as Implementers of Professional Advice:

A widely ascepted assumption during 1970s was that parents should conscientiously implement decisions made by the professionals. If a child was not making satisfactory progress in the special education program, it was often assumed that the parents were not assuming their responsibility for implementing the program at home. The "myth of professional omnipotence" or the assumption that professionals, by virtue of their specialized training and technical expertise, have the ability to make wise decisions about other people's lives has slowly disintegrated. The recent age therapists and educators have accepted the potential of parents. Parents are now active partners in not only implementing of professional advice but also plan out and carry out the same at home.

Parents as Service Providers:

Parents' groups serve as a mechanism through which parents give each other mutual support and share information. Parents' initiated and supported efforts often at great personal expense has won the legal right to free and appropriate public education in the least restrictive environment, better conditions in residential facilities and integrated vocational, residential and recreational services in the community, provisions for better financial security.

Parents as Teachers:

As mentioned earlier since 1970s a great emphasis has been placed on the role of parents as teachers and members of the multidisciplinary team. Here parents are provided training to make them more resourceful and for better involvement.

Parents as Political Advocates:

The development of parents' organisations evolved from small, local support groups of parents to national professional organisations. The primary function of many parent organisations has changed from providing direct services to advocating for political, legal, economic and social change.

Parents as Family Members:

Professionals are becoming more aware of the necessity to consider the needs and roles played by all members of the family with a child with disabilities. It has been recognized that family has a value in developing and implementing programs for the disabled member. It is also realized that family members have much to offer professionals. They often have unique insights gleaned from their day-to-day experiences living with the member with disability.

Role of the Family

Throughout history and across culture the family has been the primary agency for survival. Although the forms of families vary, the tasks are universal. Parents or parent surrogates cross all cultures assured the responsibility for transmitting to their offspring their competencies required by the social, economic and political forces of their society or social group. The family constitutes the parents but also the siblings, grandparents, uncles and aunts and other extended family.

Hence, the major responsibilities of families can be listed as follows:

- The economic responsibilities to generate income and provide financial support for living costs and related payments.
- The domestic and health care responsibility, to meet the daily needs of food, clothes, health and medical care and safety.
- The recreational responsibility to provide leisure environment and activities.
- The responsibility for self-identity to increase each family member's sense of belonging.
- The affectionate responsibility to show and share love, care, emotional feelings and companionship.
- The responsibility for socialization to develop social skills and enhance interpersonal relationships.
- The educational and vocational responsibility to assist and support schooling and career & selection and preparation.

Adolescent mothers and single parent families

Traditional groups known to be at-risk of adolescent mothers were sometimes involved in social support and adolescent theories, as part of adolescent pregnancies and mothering research. At- risk families in intellectual disabilities also may be single mothers and early recommendations were for additional support options such as boarding nearby to family, modifying apartment programs to allow children, and increasing family support services in private homes. Critical are personal and family values, empowerment of families and home visitors, parent-child activities, and cluster groups (e.g., neighborhood improvement, natural child birth groups, toddler play groups, team group support), among others (e.g., Cochran, et al. , 1984).

Youth with disabilities

Youth with disabilities became an emerging "age group"in the late 1980s and 1990s as family approaches (often-parent-based) competed with approaches based more on the desires of youth with disabilities. For example, personal assistance approaches based on diverse lifestyles and hiring of aides by service users became a popular way of thinking about services.ln addition, major federal initiatives in transition planning in the US resulted in a variety of approaches to moving from child-centered to adult services, based in part, upon theories of adolescent development.Today, self-advocacy has grown worldwide and youth, in particular, have sought their own voices and futures.

Parents with intellectual disabilities

By the 2000s, internationally, the support of parents who themselves have intellectual disabilities moved to new prominence with extensive, multi-decade research' In addition, traditional parent training programs moved to community building and parents/mothers with physical disabilities also prominently advocated for better lifestyles for themselves and their children,inc1uded as part of a new National Resource Center for Parents with Disabilities.

The family-centered approach

The family-centered approach to early intervention is a way of thinking that leads to a set of practices in which families or parents are considered as the most important decision makers in a child's life (Sandall et al., 2005). It involves a process that acknowledges that early intervention programs and professionals must respect the unique values and priorities of families, encourage families' strengths, and support parents' sense of competence in order to foster a child's progress (Dunst, 2001; Keilty, 2010). During every interaction, professionals should express their belief in the capability of parents to support their own children. Trivette and Dunst (2004) found that a staffs strong beliefs about parents' abilities to support their child's learning were linked to more positive parental judgments about their parenting competence.

In other words, when professionals provide family-specific coaching and support, family members are better equipped to support their child's development. The family-centered approach is based on the belief that most parents of children with special needs possess the emotional investment necessary to encourage and motivate their child's development, particularly when given appropriate and individualized supports from professionals (Trivette & Dunst, 2004). Families who are not able to focus on the child's needs may have issues that are more pressing, such as when a family is facing homelessness or when a parent has substance abuse or mental health challenges. Other families may not feel that intervention is necessary, so they may be reluctant to participate, such as when a family is mandated to receive early intervention by the court system or when the family does not recognize the child's special needs. In any of these cases, the family-centered approach is individualized to meet families where they are, meaning that time is taken to build rapport with family members and ensure that supports revolve around their priorities and strengths. This approach acknowledges that children and their families possess strengths that are just as important as their needs. These beliefs lead to offering families positive helpgiving, which is a style of offering assistance to children or families with the intent that the help will have positive consequences for those receiving it (Sandall et aI., 2005). One way of achieving this is using family priorities for establishing outcomes and using multiple techniques to engage family members in discussions about how to develop their child's needed skills during the process of daily living. This kind of capacity-building, positive helpgiving (Dunst, Trivette, & Hamby, 2007) builds on the strengths the child and family displayed during the initial assessment and uses new strengths as they emerge, can improve parents' reported perceptions of their family's quality of life. Once again, professionals are reminded that they are not working with the child but rather with the entire family, which can lead to positive changes for both. When implementing this approach, professionals should ask parents what amount and type of involvement and services are best suited for their child and family, then attempt to provide services that match these priorities. This information is generally gathered through the process of collaborative consultation. Service providers should also use coaching-a collection of strategies such as listening, prompting, joint problem-solving, and planning-to promote changes in a child's outcomes by strengthening parent-child interactions and expanding parents' abilities to foster their children's learning.

Two common strategies are used in a family-centered approach.

First, supports are provided to families in their selected natural environments. Within these settings, service providers and caregivers brainstorm ways to embed goals for the child into natural learning opportunities within families' daily routines (Raver, 2005, 2009). When working with infants and toddlers, professionals do not remove a family from its regular environment; rather, they work in conjunction with a family to make established routines more responsive to the child's current needs

Second common strategy is attempting to support parents in their efforts to manage their own and their family's stress. Families of children with disabilities appear to be susceptible to increased stress. They report feeling isolated and may have smaller support networks than families of children without disabilities (Raver, Michalek, & Gillespie, 2011). All parents have to cope with family stress. However, parents of children with special needs tend to have additional daily stressors that may impede their child's development or negatively affect how the family functions (Hooste & Maes, 2003).

3.4 Parent- professional relationship

Parent Professionals often find themselves frustrated that parents don't follow through with recommendations; however, the problem is not with the parents, but with the relationship. Teachers and other professionals need to make an effort to understand the challenges that parents face in dealing with the negative messages about their child and the parents' own fears about making wrong decisions in the face of conflicting professional advice.

Starting in the earliest years, parents and professionals can work together to bring about the best possible education for the student, while keeping the student's long-term happiness and well-being at the center of the dialogue.

Importance of Family-Professional collaboration

A child's family spends the most time with a child and is the real constant in a child's life. Involving parents and other family members in the intervention process is more powerful than focusing exclusively on the child. When families are involved, trained, and supported, children are given the opportunity to receive interventions when professionals are not present because their parents or caregivers feel prepared to provide the intervention.

Encouraging family members to choose their level of involvement in intervention, program planning, decision making, and service delivery benefits both the child and the family (Sandall, Hemmeter, Smith, & McLean, 2005), and it also permits service providers to be more effective.

Interventionists must prepare parents or caregivers to understand how and why interventions can be used in their daily lives because parents are the ones who will be interacting with the child long after professionals leave. Formal early intervention accounts for less than 20% of an infant's or toddler's awake time (Bruder, 2001). For this reason, service providers need to develop outstanding communication skills to interact successfully with the range of adult personalities and styles they will encounter in families in order to reach the child (Turnbull et al., 2007). Basic effective interpersonal skills, such as building trust by following through on plans, actively showing attention during conversations, and pausing (Cheatham & Ostrosky, 2009), are courtesies viewed as critical to successful collaboration from a parent's point of view.

Because positive parent-professional collaboration is essential for meaningful services and outcomes, attempts are now being made to develop training and assessment instruments that evaluate the use of parent-professional collaboration in the field with families (Basu, Salisbury, & Thorkildsen, 2010).

The reality is that the field of early intervention is a relationship-based discipline. Without a sound relationship with the child, the child's family and extended family, and other important people in the family's life, it is impossible to make meaningful changes in a child's development. To achieve this, service providers must develop respectful, nonjudgmental reactions to families' values, beliefs, and lifestyles (Zhang & Bennett, 2001). This will lead to strong, lasting relationships with families that are undeniably strengthened by the amount of time that families and interventionists share.

The parent-professional relationship should not be confused with a friendship. Although collaborations with families are cordial and supportive, there is a necessary professional boundary established, which is not present in friendships. Time is a fundamental resource for any family (Brotherson & Goldstein, 1992). When time is not available, it can cause major stresses in a family's life. In the process of parent-professional collaboration, it is critical that service providers understand the importance of using their time with families efficiently and recognize time as a resource that is limited for many families. Time is always a key factor in the involvement level of a family with the early intervention team. Parents and caregivers are viewed as fully participating team members on the early intervention team. They are given the opportunity to be the primary decision makers regarding planning services, identifying the locations for the delivery of services (e.g., the child care provider' s home), identifying outcomes, and determining whether collaborative recommendations have benefited the child and family.

Parents also provide necessary information for evaluations and assessments. Although all decisions are team decisions, the family members have the final word on the services the child receives, and their commitment to the process is critical to the success of their child's intervention. Since the family is the primary change agent in the child's life and directly influences the child's development, family members are invited to participate in all aspects of the child's intervention. In addition, families should be encouraged to do so in a way that best suits them.

A number of best practices can be practiced to get a significant result and these are:

There needs to be a dialogue, a conversation between the parents and the professional that's truly safe and the uses of language should be commonly understood by both, that is without judgment, without hierarchy, but is free, allows for free interchange.

In case of a child with special need, in many incidences, it was observed that education and healthcare professionals interacting with parents in schools, hospitals and university clinics, in activities ranging from diagnostic evaluations and informal encounters, to meetings of all shapes and sizes from the preschool years through the transition to adult services. Many time disbelief to the "war stories" shared by parents about the additional stress they've experienced due to the behavior of professionals. Many "problems" addressed in school consultations are directly or indirectly grounded in less-than-harmonious parent-professional relationships. Also things can go so right in some situations and so wrong in others, right outcome is observed when time spent together engenders trust and builds positive and collaborative relationships; wrong, when encounters create mistrust, suspicion, and even anger (typically for the parents, but sometimes for professionals as well). Such polarization probably occurs because disability especially in severe level is a passionate affair, full of strong emotions for all involved, which may result in professionals and parents directing emotional energy in either positive ways, or in ways that interfere with the development oftrust. Well-intentioned and caring administrators, educators, and therapists stumble through the complex and intricate process of attempting to support parents. Other professionals allow their own judgmental attitudes, egos, and insecurities to dictate how they interact with parents.

On the other hand, some parents misdirect their anger by targeting professionals who have done little or nothing deserving of such extreme reactions. When things go right, parents are more willing to trust in the people and in the processes that are in place to support their child. Under such circumstances, there is a growing sense of mutual respect, collaboration, and a willingness to move forward as partners in the journey. Achievements and progress are celebrated, and the burdens and stresses of the difficult times are shared. Sadly, very few educators and therapists receive any comprehensive training in supporting parents from a "family centered" perspective, especially in school settings. Professionals may erroneously believe that being a "nice person", or having good intentions is all you need to work well with families, even those under great stress; however, without expertise in family support, when things go wrong, the consequences may include wasted time, energy, and resources, resulting in parents feeling that many professionals are simply not that helpful. Unfortunately, there may be even graver consequences. Parents may feel that school-based and other professionals are not qualified to provide the services that their child needs. This may occur even when a school district has quality services, if the parents' initial encounters with school staff did not create a foundation for trust. Clearly, the process of developing relationships and building trust rarely occurs with a few brief encounters. Establishing trust with parents is a delicate and intricate process, and demands far more than good intentions on the part of school personnel. The same may be said for professionals developing a sense oftrust in parents, even though there is an imbalance, since professionals are most often in a position of power and knowledge, whereas parents are often in uncharted territory. Despite these challenges there are clear steps that can be taken to build and maintain trust.

We may think of the following as a checklist of qualities we should all strive for in developing trusting relationship, Character and Competence traits that build Trust:

1. **Talk straight**—Most parents want to receive information clearly, directly, and with sensitivity, even if it involves a "difficult" conversation. The amount of information provided must be calibrated to parental understanding and emotional state, so that parents are able to process what is being said. We must understand that professional jargon, such as developmental delay may have different meanings for professionals (disability) than for parents (He'll catch up.). Vague information, or "sugar-coating" a child's difficulties is not helpful. Professionals need to be clear and descriptive, and when appropriate, they need to be honest by saying, "I just don't know". There is so much we are all learning together.
2. **Practice Active Listening Skills**— Parents want and need to be heard, and there are very few people who know the child as well as the parents. Trust flourishes when professionals acknowledge the parents' expertise about their child and demonstrate a willingness to listen to their concerns and constructive criticism. Paying full attention and providing opportunities for open communication build positive relationships. A defensive attitude that communicates, we know it all or an impatient demeanor that indicates, I do not have time to listen is insulting to parents. Active listening also involves suspending the impulse to attempt to "fix" all problems raised by parents. We must learn to distinguish between when parents just want to be heard, in contrast to their wanting tangible suggestions.
3. **Demonstrate Respect and Be Nonjudgmental**—Respectful and nonjudgmental language about a child and family go a long way toward developing trusts. By referring to a child by his or her name, we emphasize that we see the child as an individual. When we use the words he or she excessively, or refer to a child as a member of a category (ex - That's what children with autism do.), we are not communicating that we see the child as a unique person. Too frequently a child may be blamed for difficulties related to his or her disability when phrases such as she's being manipulative, or he's so noncompliant are used to explain behavior.

Parents may also feel that they are being blamed. We can also communicate respect by referring to parents by their first names, or by Mr. or Mrs. _____, not simply Mom or Dad, which implies a hierarchy of status (I'm the professional, and you're just the mom or dad.).

4. **Take Responsibility for, and Right Wrongs**—One of the most important trust-building behavior is to admit when we have done something wrong; state that we regret it; and whenever possible, take actions to make things right. When it occurs in a public forum, such as at a meeting, it is even more powerful. When this does not occur and blame becomes the overriding message, it can be one of the most devastating blows to developing trust.

5. **Demonstrate Loyalty**—Professionals should always communicate loyalty to the child and his or her family. Unfortunately, some professionals are given the message by superiors that their loyalty must be to the agency or their supervisors. If professionals think of their role as providing service, and realize that's what we get paid to do, the child and the well-being of the family is more likely to be at the heart of their efforts. That said, one must "walk the walk" and not just "talk the talk". Unfortunately, in some cases, parents may be told not to trust professionals (especially school personnel), and may be coached to seek legal remedy early in the process of developing relationships, causing professionals to be forced into abandoning any potential loyalty to the family due to legal constraints. Under such circumstances, communication breaks down and the potential for trust is almost always lost.

6. **Deliver Results**—When progress is documented and shared with parents on a regular basis, it supports trust in a tangible manner, but only when it is both meaningful (in terms of the difference it makes in family life) and valued by the family. There are situations where professionals highlight progress that they are excited about (the ability to learn academics, answer questions in a rote manner, and so forth), when parents are more focused on social communication, supporting a child's. emotional regulation, and establishing relationships. Being on the same page with families about priorities for a child is an essential ingredient for trust.

7. **Acknowledge and Confront Reality**—We all know that, at times, things may not be going well for a child or family. Unless service providers acknowledge

such difficulties, parents may feel that their concerns are being minimized. Even when uncomfortable issues are raised by parents (e.g., "James may be doing well at school, but he falls apart at home."), it is essential to join parents in their concerns, and solve problems together. Avoidance of challenges or concerns raised by parents violates trust, while acknowledgment and collaboration builds trust.

8. **Engage in Professional and Personal Growth Activities**—Professionals must demonstrate a willingness to grow and change, and communicate to parents how such efforts will have a positive impact on their services. Sharing information from such activities with parents also communicates our role as a resource, and our respect for parents as active learners. Following up on information that parents recommend for review also communicates respect for their knowledge and contributions.

9. **Clarify Expectations**—Trust is supported when expectations are clearly communicated-for example- expectations about the purpose of meetings, the role played by different professionals, and so forth. Trust is supported when we ask parents what their expectations are, and how activities may be designed to meet them. This also pertains to the more formal policies and procedures of schools and other agencies. When parents are given clear information about program policies (e.g., transition planning), and have the opportunity to be actively involved in formulating policies (when appropriate), they may feel a degree of ownership rather than powerlessness. Additionally, parental perspectives may provide invaluable contributions to quality improvement.

10. Practice Accountability and Keep Commitments-Trust is supported when professionals are punctual and well organized, and when meetings are run in a manner that respects the voices of all participants. Any information that requires extra emotional or informational processing time (e.g., suggestions about changes in a child's program) is best shared prior to meetings, since unexpected "surprises" about emotionally-laden issues cause anxiety and create strong negative emotional memories resulting in a lack of trust. Clear systems of communication between parents and professionals, the development of action plans, and specifying who is responsible for follow-through all contribute to trust. Concluding Comments

> In a field that has become so preoccupied with choosing the so-called "right" treatment, softer issues such as developing trust with families are often lost.

This is punctuated by the fact that most continuing education activities for professionals in special field focus on educational or biomedical approaches to the virtual exclusion of training in family support. If, however, we understand that schools and other agencies are first and foremost systems of support, it puts the priority of trust in a very different light that then must become a "front burner" concern.

3.5 Formation of Parent Selp-help Group

Self-help groups can serve many different purposes depending on the situation and the need. For example, within the development sector, self-help groups have been used as an effective strategy for poverty alleviation, human development and social empowerment, and are therefore often focused on microcredit programmes and income-generating activities.

Over the past 20 years, self-help groups have been used in various forms in the disability sector, and self-help groups of people with disabilities and their families are engaged in a whole range of activities including health care, rehabilitation, education, microcredit and campaigning. Most self- help groups consist members having different types of disabilities (cross-disability groups).

Self-help groups can facilitate empowerment; belonging to a group (or organization) is one of the principal means through which people with disabilities can participate in their communities and it is through the involvement in groups that they can begin to develop their awareness and the ability to organize and take action and bring about change.

While many eBR programmes focus their activities at the level of the individual, e.g. on providing direct assistance, such as basic therapy, they are encouraged to bring people with disabilities and their family members together to form self-help groups to address and resolve their own problems.

Self-help groups are a key element of the CBR matrix and can be a means to achieving the newly emerging CBR goals of inclusion of and ownership by people with disabilities, and to enhance their participation in development processes. This element mainly focuses on how CBR programmes can facilitate the formation of new self-help groups, but it also looks at the linking of eBR programmes with existing self-help groups of people with disabilities and their families, including mainstream self-help groups.

Goal: People with disabilities and their family members participate in groups to resolve common problems, enhance their individual strengths, and improve their quality of life.

The role of CBR : To provide support and assistance to people with disabilities and their families to form new self-help groups or sustain existing ones. Where mainstream groups exist within communities, e.g. women's groups and microcredit groups, the role of CBR is to promote the inclusion of people with disabilities and their family members in these groups.

Characteristics

Some common characteristics of self-help groups that are associated with CBR programmes include their:

- voluntary nature - they are run by and for group members, have regular meetings, and are open to new members;
- generally being formed in response to a particular issue, e.g. no access to education for children with disabilities, limited income-generating opportunities;
- clear goals, which originate from the needs of group members and are known and shared by all members;
- informal structure and basic rules, regulations and guidelines to show members how to work effectively together;
- participatory nature - involving getting help, sharing knowledge and experience, giving help, and learning to help oneself ;
- shared responsibility among group members - each member has a clear role and contributes his/her share of resources to the group;

democratic decision-making;

- governance by members, using an external facilitator only if necessary in the formation of the group ;

- evolution over time to address a broader range of issues;
- possibility of joining together to form a federation of groups across a wider area.

Challenges of organizing self-help groups

Rural vs. urban self-help groups: It is often easier to form self-help groups in rural areas.

Formation of self-help groups in urban settings can be particularly difficult because of frequent migration and difficulties in building trust and a sense of belonging among group members.

Although it should be noted that, in rural areas, geographical isolation and the long distances group members may need to travel, and the limited means of communication, may make it difficult to hold regular meetings.

Women and men

Women's groups are generally easier to form than groups for men. Women tend to have a stronger sense of solidarity towards one another and work more easily in a collaborative way.

Where groups have both male and female members, it is important to ensure that women are represented, their voices heard and their issues discussed.

Levels of education

Within self-help groups, members may have varying levels of education. It is likely that people with intellectual disabilities specifically will have lower levels of education and therefore may be disadvantaged. It is important that self-help meetings are not monopolized by those people who may have a higher level of education, and for those self-help groups that are based around microcredit, it is important that there is not an uneven distribution of benefits. To prevent inequalities from arising within groups, time needs to be dedicated in the early stages of group formation to building a sense of cohesion and empowerment among the less literate or vocal members.

Single-impairment groups

Many groups have been formed for and by individuals with similar impairments.

While single impairment groups have a clear and well defined purpose, often cross-disability groups are more practical in small communities where there are few people with one particular type of impairment. The basic needs of people with disabilities, irrespective of their impairments, are the same, e.g. food, shelter, health care, education. Single-impairment groups can often divide people with disabilities and set up competition for scarce resources.

Dependency

Disability is often associated with dependency, e.g. with doing things for people with disabilities rather than doing things with them. As a result, people with disabilities who are used to being recipients rather than contributors may lack the motivation and confidence to participate in self- help groups and activities.

Provide assistance to form new self-help groups

CBR programmes need to play an active role in creating self-help groups of people with disabilities and their family members. The process of forming a self-help group will vary according to the local situation, with different levels of support required for each group.

A general outline of suggested activities is provided below.

Getting started

CBR personnel usually start working with people with disabilities and their families in their homes, identifying their needs and providing basic information about disability and the types of support available. As trust and confidence strengthens over time, they can be encouraged to meet with others who share similar experiences.

At this stage CBR personnel can:

- provide information to people with disabilities and their family members about the concept of self-help groups and encourage them to form a group in their community - this may include talking about the advantages of being in a group and the types of concerns that can be addressed, e.g. concerns about forming a group when the primary focus is to generate income to sustain the family - people may want to know how the group can help them directly by providing regular work and income;

- encourage people with disabilities and their family members to identify and talk with other people in their communities who may be interested in joining;
- organize a formal planning meeting in an accessible location, if there is enough interest and motivation.

Planning

- Discuss what the shared concerns are and establish what the initial focus of the group will be, e.g. sharing feelings and experiences, raising awareness, exchanging information and resources.
- Ask people what resources they are willing to contribute for the benefit of the group.
- Identify a group leader or coordinator - it may be necessary to have more than one.
- Allocate tasks as early as possible to help promote ownership and responsibility.
- Establish a group identity by adopting a name for the group.
- Decide who can join the group - try to keep the group small to begin with as this will provide everyone with a chance to participate.
- Decide on how often to meet, setting a date and time for the first meetings. Ensure meetings are arranged in accessible locations and not too far from where the group members live. Consider holding meetings in community locations, e.g. schools, to ensure visibility of the group and the CBR programme.
- If necessary, decide how to publicize the group to encourage people to attend the first meeting. This might include talking to people, putting up a poster or advertising on the local radio station or in the newspaper.

Running the meetings

While CBR personnel are encouraged not to be in charge of running meetings, they need to be aware of the basic structure for a self-help group meeting so they can support and assist groups where necessary. The basic structure involves:

- welcoming people to the meeting as they arrive;
- opening the meeting and encouraging members to introduce themselves;

- establishing the rules for confidentiality - for keeping private what is discussed and what happens during a meeting - different cultures may interpret confidentiality in different ways, so it is important to decide what the group wishes to keep confidential;
- carrying out the main activities of the meeting;
- taking minutes of the meetings, making a record of attendance, key topics of discussion and decisions made;
- dealing with administrative matters, e.g. date and time of next meeting;
- closing the meeting.

Facilitating

CBR programmes should fulfil a facilitative role in self-help groups, enabling them to work cooperatively and effectively. For example, CBR programmes can:

- provide support and assistance for group leaders when requested;
- ensure meetings are run so that all members understand what is going on and are able to take part;
- encourage the rotation of roles and responsibilities within the group;
- assist the group to see how they can provide mutual support to one another, e.g. companionship, taking children to school, starting group saving activities;
- check to see that there are fair and transparent methods for sharing the benefits of group activities;
- assist with drafting group rules and regulations once the group is well established;
- provide financial contributions, e.g. seed money or matching grants to enable self-help groups to expand their activities, and to open bank accounts.

Building capacity

Groups often need considerable support and capacity-building before they can function effectively and independently. Important skills for group members include: preparing agendas, conducting meetings, speaking in public with confidence, writing minutes, resolving conflicts, problem-solving, democratic decision-making, delegation of tasks, monitoring progress. Sometimes self-help groups will benefit from the development of specific skills, and sometimes the skills may already exist within the group. Self-help group meetings in themselves provide a good opportunity for members to practice new skills.

New self-help groups can learn from already established groups in the community. New groups may benefit from inviting members from existing self-help groups within the community - a new self-help group will value most the experience of people in circumstances similar to their own. Early contact between self-help groups of people with disabilities is important for learning, future links and mutual help.

Groups may be hesitant about getting involved in social or political action at first because they feel they lack the know-how or ability. But with time, patience and encouragement, group members will begin to discover their ability to understand, plan and implement the activities needed to change their situation, e.g. mobilizing the community in the form of a petition to local authorities as a first step towards safe drinking water and improved sanitation.

Encourage inclusion of people with disabilities in mainstream self-help groups

While self-help groups specifically for people with disabilities and their families play an important role, CBR programmes should also encourage people with disabilities and their families to become members of mainstream self-help groups, e.g. women's groups, youth groups, microcredit groups, fanners' groups. The following activities are suggested:

- encourage mainstream self-help groups to include people with disabilities as regular members with equal rights, e.g. ensure they meet in accessible venues;
- highlight common issues faced by people both with and without disabilities, e.g. facilitate a discussion about gender discrimination with a women's group and highlight how this issue is shared by all women - this may provide an incentive for mainstream self-help groups to work in alliance with disability self-help groups and/or include people with disabilities in their groups;
- identify existing members of mainstream self-help groups who are either disabled or have a family member who is disabled and encourage them to talk about the issues and problems they face and to put disability on the agenda of their self-help group for discussion and debate;

- ensure people with disabilities and their families have the necessary skills and knowledge before linking them to mainstream self-help groups, as otherwise they may be vulnerable to discrimination.

Encourage self-help group members to participate in CBR programmes

Self-help group members (from both disability specific and mainstream self-help groups) have the potential to be important resources for CBR programmes, and thus need to be well informed about CBR. Self-help groups can play an important role in creating awareness about disability and promoting inclusive development. Self-help group members may also be able to volunteer their time and contribute to CBR activities, e.g. by identifying people with disabilities in the community, supporting people with rehabilitation activities, and providing follow-up. Disability- specific self-help groups should be particularly encouraged to gradually playa bigger role in CBR programmes. Their participation in the management (e.g. planning, implementing and monitoring) of CBR programmes can make programmes more appropriate, credible and sustainable.

Encourage self-help groups to join together

While self-help groups for people with disabilities and their family members may be able to make a difference at the local level, their members may be limited in capacity to make changes at higher levels. Greater numbers of people can bring about change and therefore the next step is to encourage self-help groups (both those which have been started by CBR programmes and those which exist independently) to come together under one "umbrella" - this is commonly known as a federation. CBR programmes can facilitate the formation of a self-help group federation by bringing together one or two elected representatives from each self-help group. Self-help group federations need to ensure that people of different groups (e.g. of different age, impairment, gender, socioeconomic status) are equally represented. A self-help group federation can also take on greater responsibilities and one day may become a formal organization in its own right.

3.6 Parent Association

The parent association is the structure through which parents in a school can work together for the best possible education for their children. The parent association works with the principal, staff and the board of management to build effective partnership between the home and school. Partnership between the home and school is important because with positive and active partnership the child gets the best that education can offer.

The purpose of the Parents Association is to build a strong school community by providing support for the parents, students, faculty and staff. Parents Association hopes that everyone can become involved by finding a way to participate and feel included in the community.

Although the Parent Association may organise many activities, these activities should all assist the association to achieve its two main roles within the school:

A) To work in partnership with the Principal, Board of Management and the whole school community for the betterment of the children in the school

B) To support and empower parents to be active in the best interests of their children's educational lives

6 What is the Special Needs Parents Association?

Special Needs Parents Association exists to support all parents of children with special needs irrespective of age or diagnosis, by advocating at all levels for improved treatment, education, welfare and acceptance for their children.

Why do they exist?

To give parents a voice by bringing them together.

The Special Needs Parents Association generally set up by likeminded parents who realized that there was a need for a organisation to represent the views of all parents who had children with special needs, regardless of their diagnosis or age.

The intention is not to distinguish between parents who had children with physical disabilities; intellectual disabilities, sensory disabilities, autistic spectrum disorders, learning difficulties and non-diagnosed conditions, but for all parents of these children had one thing in common. They are parents of children with special needs.

Their activities

They do not seek to compete with other local groups, but to help point parents in the right direction who may be looking for a local group or service and to provide parent to parent support in the areas where there is none.

On a national level the Association aims to represent parents who feel strongly about their children's access to the education system as well as to society in general.

What are the most common issues raised by parents?

Reductions in educational resources and supports in primary, second and third level education.

Lack of services such as Occupational, Speech & Language and Physiotherapy.

Lack of appropriate services, respite and options for further education for over 18' s in particular areas.

Why is partnership between home and school important?

Partnership between home and school is important because with positive and active partnership the child gets the best that primary education can offer. We know from research that: Children do better, behave better and are happier at school when parents and teachers work closely together and when parents are able to give their children support at home Teachers can do a better job when they are supported by and work closely with parents Parents can do a better job when they have the support of other parents The Parent Association is the key mechanism in a school that can support the home/school partnership. Partnership in action Introduction The school is a learning community. This community is made up of pupils, staff, the Board of Management and the parents of children in the school; they all have a strong interest in the school and are commonly known as stakeholders. The linkages and connections between all of these partners must be clear and effective, if they are to work well together for the benefit of the children. It is important that collaborative work in the school occurs. Good relationships between the partners depend on good communication between them. Schools work best when everyone is working together. The Parent Association committee, on behalf of parents, must ensure that it has good connections with all the other partners in the school community, so that there are: Shared goals and expectations for children and the school Shared understandings of one another's work and responsibilities Partnership between the Parent Association and the Principal The Principal has a central role in the school. S/he is responsible for the day to day management of the school and plays a key leadership role. The Principal is also likely to best know the needs of the school; s/he has responsibility for encouraging the involvement of parents of students in the school, in line with the Education Act, 1998. It is imperative therefore that the Parent Association and Principal develop a good working relationship and develop a good system for communicating with each other.

When a system of communication has been planned it will be important to review it together from time to time to make sure that it is working for both parties.

Ways the Parent Association may communicate with the Principal:

- Inviting the Principal to relevant meetings throughout the year to update the Principal on activities of the Parent Association and share information about school developments
- The Chairperson (and Secretary) of the Parent Association may meet with the Principal (and Deputy Principal) before and after each meeting that is not attended by the Principal
- The Principal attending an agreed relevant portion of the Parent Association meetings by invitation
- The Principal attending all of the Parent Association meetings by invitation from the Parent Association and in agreement with the Principal
- Giving written or verbal feedback of parents' views on aspects of school policy which the Parent Association committee has gathered for example, code of behaviour, anti-bullying, homework, school uniform
- Sharing information, such as the Parent Association calendar of events, with the Principal
- Joint working groups for particular projects,for example,sports days,Christmas fairs, sales of work
- Joint working groups for the development and review of particular school policies, for example: the code of behaviour, anti-bullying and relationships and sexuality education policies

Supporting and Empowering Parents

The Parent Association should be a structure that actively supports parents to ensure the best interests of their children. Parents value opportunities to meet other parents and share experiences about bringing up children and helping them to learn.

The Parent Association will be stronger and will help networking if it fully represents all parents. Therefore efforts should be made to:

- Produce materials using straightforward and simple language, that is, avoid abbreviations and the use of jargon and make all communication respectful, unambiguous and clear

- Choose times for meetings that will suit the majority of parents
- Ensure where possible that Parent Association meetings are always held in accessible locations
- Specifically reach out to under-represented parents of children in the school, for example parents from the Traveller and migrant communities, and invite them to become involved with the Parent Association committee

The Parent Association can actively support the involvement of parents by:

- Arranging opportunities for parents to meet informally
- Running a social event (such as a coffee morning) for parents of a particular school class.
- Getting together with parents from neighbouring schools for an occasional event such as a talk or workshop.
- Helping to run a parents' room, where this is available, where parents can meet and information can be displayed.
- Having a parents' page on the school website.
- Welcoming new parents and making sure to include parents from different cultural and ethnic backgrounds.
- Providing a Parent Association notice board in the school.
- Linking with local organisations to promote positive communication and parental partnership, for example, health boards, county councils.
- Organising after-school activities with the agreement of the Board of Management, such as dance classes, sports activities, social events etc.
- Finding out what information parents would like or need.
- Preparing a newsletter or contributing to the school newsletter.
- Helping teachers set up an information meeting for parents of particular class groups.

- Contributing to the preparation of a school handbook in cooperation with staff
- Providing access for parents to leaflets and books on topics of interest.
- Identifying parents who have certain skills for curricular and after-school activities e.g.painting, Information and Communications Technology, music.
- Providing information for parents about how to help their children.
- Providing opportunities for parents to network Inviting speakers to address the parents on issues which are topical or relevant e.g. homework or the curriculum

Supporting and empowering parents to deal with an issue relating to their child

It is important to note that a Parent Association is not a forum for complaint against an individual teacher, parent or child, nor does it have a role in pursuing individual complaints. However, it may be appropriate for a Parent Association to have an involvement in complaints in two ways:

1) Where a complaint raises a whole-school issue such as a school policy For example, a parent may have a concern about a child's experience of bullying. The parent should be advised to bring their concern through the proper channels (see below). However, the Parent Association might want to consider whether there is a need to raise the question of the school's anti-bullying policy with the Principal or the Board of Management. Is there a policy in place? How is it working? Does it need to be revised and updated? If a policy is reviewed this should be done without reference to any individual complaint.
2) In supporting and empowering parents In the situation of a parental complaint regarding a specific issue the Parent Association can:

- Help a parent to find good ways of approaching a teacher about a problem with a view to having the problem sorted out
- Let a parent know that if they need to make a formal complaint there is a complaints procedure available through the school and encourage the parent to use the procedure.

Parent Associations need to be non discriminatory in the way they deal with issues of concern from parents and treat all concerns objectively and equally. A Parent Association must treat all parents with respect and dignity and provide all parents with the same guidelines and advice.

Establishing a Parent Association - A step by step approach

Step 1: Where to begin

There are three main ways to establish a Parent Association in the child's school;

- A group of parents with an interest in setting up a Parent Association can hold a meeting at which they can do some initial planning with the support of the Principal/Board of Management
- The Principal and/or the Chairperson of the Board of Management might write to parents asking for volunteers to establish a working group to organise a meeting of all parents
- The Principal, the Chairperson of the Board of Management or the parents' representatives on the Board of Management may invite all parents of children in the school to a meeting

Step 2: Establishing a Planning Group

Through one of the above activities a planning group should be established which then organises a meeting to which all parents are invited. At this meeting a parent association committee is elected. For this meeting a Chairperson needs to be chosen; this could be a parent, the Chairperson of the Board of Management, one of the parents' representatives on the Board of Management or the Principal.

Step 3: Establishing a Parent Association committee

While all parents are members of the Parent Association, not all can, or need to, be involved in the day-to-day business of organising the work. It is for this reason that parents in a school elect a committee.

The committee is the team of people who manage the tasks ofthe Parent Association on behalf of all the parents. The Parent Association committee needs to work as a team in order to be effective.

In establishing or electing the Parent Association committee it is vital that all members of the Parent Association understand the role and work of the committee.

The role of the Parent Association committee

The Parent Association must:

- Communicate with the entire parent body
- Represent the entire parent body

The work of the committee/team

The team has shared responsibility for:

- Planning for the future and developing a vision for the Parent Association
- Planning and managing the annual programme of activities for the Parent Association
- Communicating, consulting with and involving as many parents as possible in the activities of the Parent Association
- Communicating and consulting with the Principal and Board of Management
- Planning agendas and keeping records of meetings
- Managing the Parent Association finances
- Drawing up the rules (constitution) by which the Parent Association operates in collaboration with the entire parent body
- Valuing diversity and intercultural ism and making sure parents who might find it hard to get involved are encouraged and supported to do so

Remember - there may be many parents who do not want to be on a committee but who may want to help with particular activities. It is important to gather this information; this can be done at the annual general meeting or by sending out a questionnaire to parents.

Subcommittees can be created for specific activities or events, members of subcommittees may be sought from the local community to avail of various skills and expertise. It is important to note, however, that subcommittees may not make decisions, they remain at all times accountable to the main committee. The Terms of Reference of any subcommittee should be clearly stated in writing and agreed by the Parent Association committee.

Step 4: Electing the Parent Association committee

If electing a committee for the first time the planning group, as established under step 2, are usually the group that organise the election. It is important that these elections are run fairly and efficiently

With an established Parent Association, the committee is elected at the Annual General Meeting, to which all parents of children in the school are invited. It is the responsibility of the outgoing committee to ensure that the elections are run efficiently and in line with the provisions in the Parent Association rules (constitution).

In both situations it is good practice to ask an independent third party to chair the election.

Step 5: Electing the Officers of the Parent Association committee

Before parents are elected as officers of the committee the roles of the officers should be clarified.

The Chairperson

The role of the Chairperson of the Parent Association committee depends on the committee structure; some committees prefer to have a more flexible approach to working together. This role may be shared/rotated among the members which allows for committee members to gain experience of different roles and responsibilities. Other committees however have a more formal structure, where each officer serves for a full year and has a very defined role and set of responsibilities.

The Chairperson should:

- Lead and guide the committee in planning and delivering on their activities.

  This should involve:

  -Chairing meetings

  - Helping the committee to have a clear vision and clear goals

  - Keeping the work of the Parent Association to agreed targets

  - Ensuring all members are respected, listened to and are encouraged to have their say

  - Facilitating people to work well together ensuring that the work ofthe committee is shared

  - Reviewing the work of the committee
- Ensure that everyone has a clear understanding of their roles within the committee
- Delegate the work of the committee to ensure all work is not the responsibility of one or two people

- Work closely with the Secretary to plan the agendas and meetings
- Ensure that the minutes are signed, dated and kept safely
- Encourage the committee members to be prepared for the meetings
- Ensure meetings start and finish at the agreed times
- Make sure that, as each item is finished, the group is clear about what has been decided

The Secretary

The role ofthe Secretary of the Parent Association committee is to:

- Take minutes at each meeting
- File all correspondence and minutes safely

  - Minutes should be brief and should be a record of decisions made and actions to be taken; they may also record a brief outline of issues discussed
- Agree the agenda for committee meetings with the Chairperson. It is important that all committee members have a right to have items included on the agenda, therefore they must be given adequate time to pass these items on to the Secretary
- Make sure all committee members have the agenda prior to the meetings so they can be adequately prepared
- Make sure all committee members receive a copy of the minutes of meetings, including committee members who had been unable to attend
- Appropriately administer incoming and outgoing correspondence
- Ensure the minutes are approved at each meeting. It is important at committee meetings that the minutes are agreed by those that attended to be a true and accurate record of what happened. Once this has been agreed by the committee the Chairperson should sign the minutes for the committee's records. This process is especially useful if there is any confusion in the future regarding any decisions made.
- Assist the Chairperson with clarification of decisions made at meetings
- Ensure that at the end of term of office all relevant documentation is passed on to the incoming Secretary

The Treasurer

The role of the Treasurer of the Parent Association committee is to:

- Lodge and record all financial transactions
- Manage and maintain books/record of income and expenditure
- Give monthly reports on the Parent Association finances to the Parent Association committee
- Issue receipts for all financial transactions
- Ensure that the committee has the necessary information to understand the Parent Association's financial needs
- Advise on how the resources can best be used to fulfill the aims and work plan of the committee
- Liaise with a bank or other financial institutions on behalf of the Parent Association
- Present a full account of the year's income and expenditure at the Parent Association AGM. National Parents Council Primary (NPC) recommends that a copy of these records should also be submitted to the Board of Management for their information
- Ensure that at the end of term of office all relevant documentation is passed on to the incoming Treasurer

3.7 Empowering Families

Empowerment is the ability to seek control over one's life by taking action to get what one wants and needs. Empowerment involves increasing one's knowledge and skills and boosting motivation to achieve a desirable outcome, and it refers to a continuum of experiences that offer the individual opportunities to utilize his or her own competencies to learn new information and skills Self-efficacy, one of the strongest measures of success, is the belief in one's ability to organize and carry out an action or task. In order for the process of empowerment to be effective, it must allow the individual time to practice new skills in a supportive environment to work toward new goals. Family empowerment has been defined as a family invested with authority. It is the process of a family acquiring the skills, resources, authority, opportunity, and motivation to meet the needs of their family. Family empowerment is the action associated with high self- efficacy

Family-centered support services have been defined as "those practices that (a) include families in decision- making, planning, assessment, and service delivery at family, agency, and systems levels; (b) develop services for the whole family and not just the child; (c) are guided by families' priorities for goals and services; and (d) offer and respect families' choices regarding the level of their participation" (Murphy, Lee, Turnbull, & Turbiville, 1995, p. 25).

Parent Empowerment: Parent empowerment includes the ability to meet the needs of one's family while feeling in control. Empowerment enables parents to achieve desired outcomes for their family and their children (Zhang & Bennett, 2003). A parent's role in the education of a child with a disability is a unique one. In fact, Dunst and Dempsey (2007) propose that "the role of parents with a child with a disability shows a level of complexity and intensity not generally found in the general population" (p. 305). Due to the multifaceted role required of parents raising a child with a disability, educators should work to empower parents in these efforts (Blue- Banning, Summers, Frankland, Nelson, & Beegle, 2004; Green et al., 2007; Ice & Hoover- Dempsey, 2011; Pinkus, 2005; Van Haren & Fiedler, 2008).

Empowering Families means to provide holistic support to parents and children which include:

- Helping parents who are feeling lonely and isolated
- Improving the health and well being of parents and children
- Developing parents' self confidence
- Managing children's behaviour
- Coping with several pre-school children
- Improving parents' ability to manage their household

Empowerment principles promote family strength, competence, and decision making. Empowered families strive for control over their lives and take action to get what they want and need (Turnbull, Turnbull, Erwin, & Soodak, 2006).

The following strategies and suggestions can serve special education professionals in their attempts to support and empower families of children with disabilities.

Family Support

1. **Display empathy for families.** Some special education professionals approach families from a judgmental perspective critical of family actions or lifestyles that conflict with their own values or lifestyle choices. Effective family support must be built upon a foundation of empathy, that is, understanding and compassion for a family's situation. Without empathy for families, professionals will lack the motivation to engage in family support and empowerment activities.

2. **Individualize family participation.** Although active family participation is beneficial to a chikfs educational progress, professionals must be careful to recognize that more family educational participation is not necessarily better for the family as a unit. Due to the demands of simply being a parent of a child with a disability, many parents are unable or unwilling to serve as their child's teacher, therapist, or case manager in following school recommendations for "active participation" with the school program. A supportive professional approach with families would assist them in identifying a level of educational participation that is realistic, given their time and energy resources.

3. **Recognize families as experts and build on family strengths.** On a regular basis, special education professionals must step away from their "expert's role" and actively seek to learn from families by acknowledging that families are experts when it comes to their child. When professionals recognize family expertise, families are supported, their functioning is enhanced, and family strengths begin to emerge. Family strengths can be any characteristic that contributes to a family's sense of well-being or balances individual needs with the needs of the entire family. For example, one family's sense of humor became a principal coping mechanism for the stress associated with raising a son with multiple disabilities.

4. **Value and support family decision making**. In developing educational services for children with disabilities, dIsagreements between families and special education professionals will sometimes occur. In those instances, support is offered when professionals suspend their own opinions and attempt to reflect on the issue from the family's perspective. If the family's perspective and decision is not clearly contrary to the child's best interests, whenever possible, professionals should attempt to abide by the family's decision and thus promote family self-determination.

5. **Be a professional dally of families.** Families feel tangible support when special education professionals act as allies. Professionals can communicate this ally

perspective in a variety of ways: by demonstrating an understanding of the child's uniqueness and individualized needs, showing a willingness to listen to and respect family concerns, being actively involved in professional organizations devoted to protecting rights and improving services for individuals with disabilities, and being willing to express concerns to administrators when families' and special education professionals' educational services are perceived as inappropriate or inadequate.

6. **Engage families in open communication.** Pugach and Johnson (2002) identified communication asthe cornerstone of any collaborative partnership. Communication between families and school professionals, as well as among family members, provides an open, supportive environment and ultimately enhances educational involvement. With today's technological advances, communication tools have increased in availability and accessibility. Examples to engage in continual dialogue with families include communication via e-mail, teleconferences, cell phones, and pagers. More traditional examples include face-to-face conferencing, telephone calls, handbooks, and newsletters.

7. **Enhance family access.** Families are more apt to feel supported in an educational environment that is flexible, responsive to their needs, and readily accessible to them. For example, the concept of the neighborhood school-the school the child would be educated in if the child did not have a disability-has long been encouraged as a means for the delivery of special education services. One of the key advantages of the neighborhood school for families is accessibility to educational services. If the child with a disability is placed in the neighborhood school, family members can attend parentteacher conferences, open houses, and other school activities at the same site for the child with a disability as for other children in the family. It also allows children with disabilities to establish relationships with the same individuals they will come in contact with throughout the community. Another example of enhancing educational access is providing a flexible contractual workday for school professionals to be available to meet with families at more convenient times.

8. **Offer family networking.** Support for families can come from a number of avenues. A critical suppo system can exist between families with common ground. Family connections can result in very transformational experiences and long-lasting relationships. Seeking new information, asking questions, and simply soliciting support can be significantly more comfortable with a peer than with school professionals. Schools should offer parents networking opportunities or

a list of potential parental contacts as a resource and support system for those having new experiences in the special education system. For example, many communities have parent-to-parent programs. In these programs, one-to-one matches are made between a trained veteran parent and a referred parent who is experiencing special education or related issues for the first time.

9. **Extend support systems.** Vital members of the family unit include siblings and other extended family members. Often, caregivers include siblings, grandparents, aunts, uncles, and other extended family members or close friends. It is critical that schools open their doors and provide a welcoming atmosphere to all those involved in a child's care. It is also imperative to provide support to these family members. One example of this is Sib Shop, a unique learning and recreational opportunity for brothers and sisters of individuals with disabilities
10. **Embrace and celebrate families' successes**. It is critical for special education professionals to recognize the successes experienced by families as they support their child with a disability, regardless of how small the successes may seem. Family members' efforts and ideas should be appreciated and applauded and, thus, serve as a bridge for future success.
11. **Enhance families' sense of self-efficiency**. Turnbull, Turnbull, Erwin, and Soodak (2006) proposed an empowerment model that views families as empowered when they possess a high degree of motivation and have sufficient knowledge and skills. Families are highly motivated when they believe in their own capabilities to solve their problems. This is a sense of self efficacy. Anytime a special education professional provides a family with information, knowledge, or a skill that can address a current problem, the family's sense of self-efficacy is fostered. For example, one special education professional showed a parent how to incorporate letter recognition into the family's daily routine with their first- grade son, who was struggling with beginning reading skills. When the family started to see marked improvement in their son's reading ability over the course of a year, their confidence rose and they became more motivated to tackle other problems.
12. **Model effective problem solving for families**. Effective problem solving is an essential empowerment skill. Empowered families possess the ability to execute a plan of action to resolve problems or barriers to meeting their child's goals or needs. Special education professionals can teach families effective problem solving steps and look for every opportunity to model those steps in

real-life situations with families. The problem-solving process involves the following steps: (a) defining the problem, (b) generating possible solutions, (c) choosing a solution, (d) implementing the chosen solution, and (e) evaluating the solution.

13. **Increase family coping skills**. Another important component of the empowerment model is the use of coping ;kiils to handle stress in a family's life. Professionals can enhance family coping skills by offering information about and referrals to various community support organizations, such as respite care agencies or parent support groups like United Cerebral Palsy or The Arc. Professionals can also increase family coping skills by encouraging families to focus more on their child's positive characteristics or strengths than on the child's weaknesses. Another example of a coping skill is to help families identify what they can or cannot control in their lives. These last two coping skills are examples of cognitive strategies.

14. **Build family competencies and capacity.** Information is very powerful and essential in a lamily's movement toward gaining knowledge and achieving empowerment. As suggested by Smith (2001), families can gain valuable insight into their child's education as well as into the school system as a whole. School professionals can encourage this by providing information on educational issues and concerns as well as on processes for educational decision making. Families should also be given the opportunity to observe the child in school environments and to share the information gained as educational partners.

15. **Offer training and professional development to families.** Family members should have opportunities to participate in training and professional development. Such participation offers accurate information and skill-building opportunities, which are cornerstones of empowerment. Families should be vital partners in the development and provision of training. This process should start with a needs assessment, as family members have important insight into their unique needs. Parents should also assist in setting agendas, establishing priorities, and evaluating the effectiveness of professional development opportunities. The ultimate level of empowerment for family members in professional development initiatives is to be encouraged in their own leadership as trainers of others.

16. **Engage family members in all stages of the Individualized Education Program (IEP) process.** Several recommendations for doing so are offered (Lytle & Bordin, 2001; MilesBonart, 2002; Smith, 2001) and include providing

IEP training for parents and other IEP team participants; minimizing educational jargon to enhance understanding of the process; affording opportunities to increase educators' understanding of the child and home environment as well the parents' understanding of the child's educational setting; ensuring that all appropriate personnel are present at the meeting; and ensuring appropriate follow-through of IEP decisions. A positive parent-educator partnership is most effective when a common goal is established. This is best expressed as follows: "The common denominator for the IEP is the team's concern for a particular child" (Lytle & Bordin, 2001, p. 44).

17. **Encoura e student articipation in the IEP meeting.** An IEP team meeting can be an intimidating environment, particularly for students with disabilities. Students, as appropriate, should be encouraged to develop and participate in their own IEP process as an initial step in self-advocacy and empowerment. Key steps in a student-led IEP program (McGahee, Mason, Wallace, & Jones, 2001) include (a) assisting students to understand their IEPs, (b) engaging students in developing an IEP, (c) helping students assess and write sections of their IEPs, (d) preparing students to participate in or lead their IEP meetings, and (e) providing support during the meeting.
18. **Involve families in community collaborIDion.** Families' lives can be greatly enhanced through community resources and services that are available for assistance. Schools can serve as conduits between families and the numerous services offered. Making family members aware of resources and services and assisting them in the navigation of the systems in their communities will involve them in self-advocacy and empowerment. Though school personnel can and should make family members aware of community supports, they should recognize that families have insight into what will best meet their unique needs.
19. **Foster hope.** Families are typically concerned about their child's future, and large issues loom both hlilie nt;;r and distant landscapes. Will my child attend a post-secondary educational institution? Will my child be able to live independently? What supports will be needed to assist my child in securing full-time employment? Will my child have a full and rich life in the community with friends to provide socialization and enrichment? Although special education professionals must be careful not to paint an unrealistic future scenario for any family, optimism and hope about continued progress and increased independence for their child must dominate family-professional interactions. For one family who was especially worried about their daughter's employment possibilities

after high school, hope was instilled when a special education professional developed several job placements during the last 2 years of school. Through those diverse job experiences, a clear picture emerged of the kind of work environment and supports necessary to ensure a successful employment experience for this student.

20. **Assist families in articulating their vision for their child's future.** Families are empowered when they know what they want for their children. Professionals can help families to be realistic and optimistic about the services their children need and to recognize what is appropriate for their children. One process that assists families in clearly articulating their children's future vision is the Making Action Plans (MAPS) process (Falvey, Forest, Pearpoint, & Rosenberg, 1997). With MAPS, a facilitator leads a group of school professionals and family members in discussing the following questions: What is the child's history? What are your dreams for your child? What are your nightmares? Who is your child (brief descriptions)? What are your child's strengths, gifts, and talents? What are your child's needs? What would your child's ideal school day look like?

Benefits abound when families of children with disabilities are supported and empowered through the educational system. The 20 ways described here can prove to be fruitful efforts in enhancing family feelings of support and empowerment.

For proper empowerment the knowledge of **self advocacy** can be regarded as one of the most essential element.

SELF -ADVOCACY

Self-advocacy is one of the most important ways in which people with intellectual disabilities have a voice of their own. The words of Jackie Downer, a self-advocate, encapsulate all that self-advocacy has the potential to be. Her words emphasize that having a voice of your own is immensely personal and therefore is important to different people for different reasons. Through her words, the importance of people with intellectual disabilities having a voice of their own is emphasized.

In explaining self-advocacy, Jackie says, "Broken down it means 'speaking for yourself, 'communicating in other ways', but it's personal. For me it means that I can speak for myself. It means I've got a voice and even without a voice I can communicate in other ways. It means yes and no-most important- 'No, I don't want tea, I want coffee, I don't want sugar'- all the things we take for granted. It means people must listen to me, I can take a risk, I can have a relationship, that can be hard. I can think for myself, I can go to the shop with support and if I need help, people can help me.... " (Jackie Downer in Goodley 2000:81).

Self-advocacy refers to the civil rights movement for people with developmental disabilities, also called cognitive or intellectual disabilities, and other disabilities. It is also an important term in the disability rights movement, referring to people with disabilities taking control of their own lives, including being in charge of their own care in the medical system. The self-advocacy movement is (in basic terms) about people with disabilities speaking up for themselves. It means that although a person with a disability may call upon the support of others, the individual is entitled to be in control of their own resources and how they are directed. It is about having the right to m"Self-advocacy training: Preparing students with disabilities to request classroom accommodations", students could experience more positive outcomes based on when and how they approach professors (Roessler, Brown & Rumrill, 1998). This research which was conducted on the topic twenty years ago remains relevant even today

According to an article titled "Self-advocacy training: Preparing students with disabilities to request classroom accommodations", students could experience more positive outcomes based on when and how they approach professors (Roessler, Brown & Rumrill, 1998). This research which was conducted on the topic twenty years ago remains relevant even today. Below are a few tips for requesting accommodations and self-advocating compiled from different sources mentioned at the end of this story:

- Timing is everything! Students must find the appropriate time to ask for accommodations, preferably toward the beginning of the semester or prior to the start of their class. Asking in the middle of a lecture or a few days before the exam may appear inconsiderate ofa professor's time on the part of the student.
- Disposition can take students far.
- Everyone is human. Professors can at times get distracted by what is going on within their classrooms or research and may forget to sign a student's accommodation letter or fill out their testing request form. Jfthis happens, students should keep their cool and simply reinforce their need for assistance via a kindly worded email or quick conversation before the start of class.
- When self-advocating, students must ensure that they understand their accommodation letter and know their rights along with the professor's responsibilities of upholding those rights.

3.8 Let us sum up:

Family is the primary unit in the life of an individual. Parents of the special child take on multiple roles, which are not separate and distinct from one another, nor do they fall into distinct chronological periods. Rather, they often overlap and share common elements. These are: Parents as Implementers of Professional Advice, Parents as Service Providers, Parents as Teachers, Parents as Political Advocates, Parents as Family Members.

Throughout history and across culture the family has been the primary agency for survival. Although the forms of families vary, the tasks are universal. Parents or parent surrogates cross all cultures assured the responsibility for transmitting to their offspring their competencies required by the social, economic and political forces of their society or social group. The family constitutes the parents but also the siblings, grandparents, uncles and aunts and other extended family.

Traditional groups known to be at-risk of adolescent mothers were sometimes involved in social support and adolescent theories, as part of adolescent pregnancies and mothering research. At-risk families in intellectual disabilities also may be single mothers and early recommendations were for additional support options such as boarding nearby to family, modifying apartment programs to allow children, and increasing family support services in private homes.

Youth with disabilities became an emerging "age group"in the late 1980s and 1990s as family approaches (often-parent-based) competed with approaches based more on the desires of youth with disabilities. For example, personal assistance approaches based on diverse lifestyles and hiring of aides by service users became a popular way of thinking about services.

By the 2000s, internationally, the support of parents who themselves have intellectual disabilities moved to new prominence with extensive, multi-decade research In addition, traditional parent training programs moved to community building and parents/mothers with physical disabilities also prominently advocated for better lifestyles for themselves and their children.

The family-centered approach to early intervention is a way of thinking that leads to a set of practices in which families or parents are considered as the most important decision makers in a child's life (Sandall et al., 2005). It involves a process that acknowledges that early intervention programs and professionals must respect the unique values and priorities of families, encourage families' strengths, and support parents' sense of competence in order to foster a child's progress (Dunst, 2001; Keilty, 2010).

Parent Professionals often find themselves frustrated that parents don't follow through with recommendations; however, the problem is not with the parents, but with the relationship. Teachers and other professionals need to make an effort to understand the challenges that parents face in dealing with the negative messages about their child and the parents' own fears about making wrong decisions in the face of conflicting professional advice.

A child's family spends the most time with a child and is the real constant in a child's life. Involving parents and other family members in the intervention process is more powerful than focusing exclusively on the child. When families are involved, trained, and supported, children are given the opportunity to receive interventions when professionals are not present because their parents or caregivers feel prepared to provide the intervention. Encouraging family members to choose their level of involvement in intervention, program planning, decision making, and service delivery benefits both the child and the family (Sandall, Hemmeter, Smith, & McLean, 2005), and it also permits service providers to be more effective.

Character and Competence Traits that Build Trust: Talk straight, Practice Active Listening Skills, Demonstrate Respect and Be Nonjudgmental, Take Responsibility for Right and Wrongs, Demonstrate Loyalty, Deliver Results, Acknowledge and Confront Reality, . Engage in Professional and Personal Growth Activities, Clarify Expectations, Practice Accountability and Keep Commitments.

Self-help groups can serve many different purposes depending on the situation and the need. For example, within the development sector, self-help groups have been used as an effective strategy for poverty alleviation, human development and social empowerment, and are therefore often focused on microcredit programmes and income-generating activities.

Self-help groups are a key element of the CBR matrix and can be a means to achieving the newly emerging CBR goals of inclusion of and ownership by people with disabilities, and to enhance their participation in development processes. This element mainly focuses on how CBR programmes can facilitate the formation of new self-help groups, but it also looks at the linking of CBR programmes with existing self-help groups of people with disabilities and their families, including mainstream self-help groups.

Characteristics

Some common characteristics of self-help groups that are associated with CBR programmes include their:

- voluntary nature - they are run by and for group members, have regular meetings, and are open to new members;
- generally being formed in response to a particular issue, e.g. no access to education for children with disabilities, limited income-generating opportunities;
- clear goals, which originate from the needs of group members and are known and shared by all members;
- informal structure and basic rules, regulations and guidelines to show members how to work effectively together;
- participatory nature - involving getting help, sharing knowledge and experience, giving help, and learning to help oneself
- shared responsibility among group members - each member has a clear role and contributes his/her share of resources to the group;
- democratic decision-making;
- governance by members, using an external facilitator only if necessary in the formation of the group;
- evolution over time to address a broader range of issues;
- possibility of joining together to form a federation of groups across a wider area.

Empowerment is the ability to seek control over one's life by taking action to get what one wants and needs. Empowerment involves increasing one's knowledge and skills and boosting motivation to achieve a desirable outcome, and it refers to a continuum of experiences that offer the individual opportunities to utilize his or her own competencies to learn new information and skills Self-efficacy, one of the strongest measures of success, is the belief in one's ability to organize and carry out an action or task. In order for the process of empowerment to be effective, it must allow the individual time to practice new skills in a supportive environment to work toward new goals.

Empowering Families means to provide holistic support to parents and children which include:

- Helping parents who are feeling lonely and isolated
- Improving the health and well being of parents and children
- Developing parents' self confidence
- Managing children's behaviour
- Coping with several pre-school children
- Improving parents' ability to manage their household

3.9 Check your progress

Parents of the special child take on multiple roles - justify this statement

What are the two common strategies are used in a family-centered approach.

What is importance of family-professional collaboration

Explain how Self-help groups may serve many different purposes depending on the situation and the need.

What is the purpose of the Parents Association?

Empowering Families means to provide holistic support to parents and children - justify this statement.

What is Self- advocacy?

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Unit 4 ❒ Adolescent Issues

Structure :

4.1 Introduction:

Adolescence is a time of great emotional and psychological change, of emerging sexuality and important life choices about employment and education. During this period of transition, adolescents, and especially those with disabilities, may be vulnerable in society.

Adolescence is a complex and dynamic process characterized by simultaneous but asynchronous development within several development streams. These streams include physical development (puberty), cognitive and psychological development, and social development. Although puberty is only one component of adolescent development, it generally is considered to define the onset of adolescence and certainly is the most visible and tangible of all of the developmental changes occurring during this period.

Adolescence is a time that represents profound physical, cognitive, emotional, and social change. For some adolescents, this period in their development is exciting and happy; for others, it is a roller-coaster ride of ups and downs; and yet for others, it is tumultuous and confusing.

Families today can take many forms-single parent, shared custody, adoptive, blended, foster, traditional dual parent, to name a few. Regardless of family form, a strong sense of bonding, closeness, and attachment to family have been found to be associated with better emotional development, better school performance, and engagement of adult with Intellectual Disabilities.

The majority of adults with intellectual and developmental disabilities (I/DD) are either unemployed or underemployed, despite their ability, desire, and willingness to work in the community.

Sexuality is a key part of human nature. People with intellectual disability experience the same range of sexual thoughts, attitudes, feelings, desires, fantasies and activities as anyone else.

People who are intellectually or mentally disabled have many disadvantages. They may have an associated impairment, such as paralysis, blindness, or a psychiatric disorder, that reduces their ability to do things that other disabled or nondisabled people do and may interfere with their fulfillment of socially valued roles. Also, intellectually disabled people often are subjected to various degrees of exclusion from the social and economic life of their communities.

While all adolescents and young adults face the challenge of acquiring the skills and experiences they will need in order to become successful adults, the transition to adulthood for disabled young people is particularly complex. A fundamental reason for this is that people with disabilities are often seen as being "childlike." Disabled children, particularly those with more visible disabilities, are frequently assumed to be in frail health and unlikely to survive into adulthood.

4.2 Objectives

- To understand the physiological changes: Implication in Emotional and Social development during adolescence.
- To find out the interpersonal relationship with Parents, siblings, single child, peer group, extended family
- To understand several important issues : Employment, Sexuality, Marriage, Alternative options, pre-marital counselling

- To understand ethical issues
- To understand the challenges and implications of adolescents

4.3 Physiological Changes: Implication in Emotional and Social Development

Adolescents with disabilities are among the most marginalized and poorest of all of the world's youth. According to the United Nations, almost a third of the world's disabled population is youth and over 80% live in developing countries. Like people with disabilities generally, adolescents with disabilities often experience social exclusion and discrimination and do not have the same access to human rights as their non-disabled peers.

Adolescence is a time of great emotional and psychological change, of emerging sexuality and important life choices about employment and education. During this period of transition, adolescents, and especially those with disabilities, may be vulnerable in society.

Adolescence is a complex and dynamic process characterized by simultaneous but asynchronous development within several development streams. These streams include physical development (puberty), cognitive and psychological development, and social development. Although puberty is only one component of adolescent development, it generally is considered to define the onset of adolescence and certainly is the most visible and tangible of all of the developmental changes occurring during this period.

One of the hallmarks of puberty is its variability. The onset, timing, tempo, and magnitude of pubertal changes are influenced significantly by genetic factors as well as by general health and nutritional, environmental, and socioeconomic factors. The timing of pubertal milestones approximates a normal distribution. Studies correlating the timing of puberty between mothers and children or between twins support a strong genetic influence that has been estimated to account for 50% to 80% of the variance in the timing of pubertal onset. Racial and ethnic variations also are seen. All these conditions and situations are fully applicable for adult with Intellectual Disabilities. In this period of life most of them face various unexpected situation

PHYSICAL DEVELOPMENT IN ADOLESCENT

Adolescence is a time that represents profound physical, cognitive, emotional, and social change. For some adolescents, this period in their development is exciting and happy; for others, it is a roller-coaster ride of ups and downs; and yet for others, it is tumultuous and confusing. One thing is certain: As adolescents move through this developmental period, the adults in their lives are often caught in the wind of their sails, making it necessary for both adolescents and adults to change the way in which they relate to each other. During this time, adolescents prepare and practice for the coming role of young adulthood. Teachers might spend more time with adolescents than do even their own parents. For persons with Intellectual Disabilities it is a crucial period because of the imparity of their physical development and cognitive or intellectual development.

The Anatomical Development of the Adolescent

Adolescent growth first centers on the extremities-the legs and arms during the early stages of adolescence. Changes also occur in the facial configurations of both sexes. The lower portion of the head begins to grow because the chin lengthens and the nose grows in width and/or length. Additional changes in proportion of the face are accredited to changes in tissue distribution. Even though both sexes undergo this change, within females a layer of subcutaneous fat develops which causes the rounding and softening of contours of the face and body. Whereas, the male subcutaneous fat development is much less pronounced, but the development of muscles and bones in the face is clearly seen. This gives the males a leaner and more angular face than the females.

Changes also occur on the surface of the body in both sexes. The most observable change is the growth on body hair, both pubic and auxiliary (armpit). The development of pubic hair is the first sign of a child ending the prepubescent stage and entering the pubescent stage. This process begins about the same time as the growth spurt begins. In males, the growth of facial and chest hair may be pronounced, and tends to represent virility in the eyes of the adolescent. Noticeable chest hair, with a thickness in texture does not usually appear until the post pubescent stage and continues to grow during manhood. Facial hair usually appears in the form of a dark shadow above the lip. Then it appears on the chin, along the jaw line, and then develops along the neck. Females may also find small amounts of facial and chest hair.

Both male and female skin undergoes other changes, such as becoming coarser with the sebaceous glands becoming more active, producing oily secretions which usually help cause acne or blackheads. Sweat usually causes an odor in adolescents because the chemistry and composition of sweat is altered by the oils that the sebaceous glands emit. Adolescents also show an increase in their blood pressure, and a decrease in both basal metabolic rate-the rate at which the body in a resting state (basal) consumes oxygen-and in pulse rate.

IMPLICATIONS OF PHYSICAL CHANGES ON ADULT WITH INTELLECTUAL DISABILITY REGARDING SOCIAL AND EMOTIONAL DEVELOPMENT

For non-disabled young people, the transition from childhood to adulthood is a period that prepares the individual for successful adulthood. Yet for young people with disability, there is an almost universal lack of inclusion in activities that build fundamental social, educational and economic skills. This exclusion is often formally sanctioned, with adolescents and youth with disabilities being barred from participating in formal cultural and religious ceremonies that help define an individual's changing status in the eyes of the community. Disabled young people are also often left out of the less formal 'rites of passage': joining a sports team, courting, learning to drive the family truck. This exclusion distinguishes young people with disability from all other groups of young people in every society and this exclusion has profound implications for their personal lives.(UNICEF:1999) A major issue in the lives of all disabled young people is the growing physical maturation and changing social role that prepares them for marriage and children. In reality, young people with disability often have little or no say over where they will live, whom they will live with and what role they will play within their families or communities. Moreover disabled young people are often denied the right to build families of their own. Social and family constraints make it unlikely that many young people with disabilities will marry. Indeed, in some countries, individuals with some types of disability are unable to legally obtain a marriage license. This is particularly true for disabled young women. (ESCAP:1995) Without the prospect of marriage, in many societies, these young people cannot hope to be accepted as full adult members of their communities. This does not mean that young men and women with disability do not become involved in relationships, or that they do not engage in sexual activities, only that there is often no social acknowledgement (and often no sex education) provided to them. (Wallace:1990; Cheng and Udry:2002) This places adolescent girls and young women with disabilities in particular, at increased risk for pregnancy and sexually transmitted diseases. In one of the few studies of its kind, the United States National Longitudinal Study (1993) found that three to five years after completion of high school, females with disability were significantly more likely to be mothers than were either non-disabled females or disabled males. Although 23.7% of all youth in this demographic pool had had children, only 16.5% of disabled males had become fathers. In contrast, 40.6% of all disabled females in this age range had given birth to one or more children. For young women with emotional disturbances, learning disabilities or those with hearing impairments, almost 50% had become pregnant in the years immediately following high school. For disabled females who had dropped out of school, 54% had become mothers. (US Department of Education: 1993) The majority of these pregnancies occurred outside of marriage. Already struggling to earn a living comparable to that of their non-disabled peers, the necessity of providing for a child, particularly in those cases where they are not married, places yet an additional burden on these young disabled mothers. (ILO: 1989; Crawford et al:2002) In those societies where men are allowed to take more than one wife or routinely take a mistress, a teenage girl or young woman with a disability is more likely to become second or third wives within a larger household or a mistress, than to become a first or primary wife. In these types of arrangements, the young women with disability, and their children, often will have less right to play a key role in family decision making and significantly less claim to both household resources and inheritance. Not only do expectations for what is an appropriate role for young men and women with disability vary from one country to the next, within countries, expectations often vary from one ethnic or minority community to the next. (Groce and Zola: 1993)

4.4 Interpersonal Relationship

Families today can take many forms-single parent, shared custody, adoptive, blended, foster, traditional dual parent, to name a few. Regardless of family form, a strong sense of bonding, closeness, and attachment to family have been found to be associated with better emotional development, better school performance, and engagement of adult with Intellectual Disabilities.

RELATIONSHIP BETWEEN ADULT WITH ID AND THEIR PARENT

Relationships matter - When they work well, they are a vital source of support and protection against life's stresses and strains. All relationships go through periods of change and challenge. Parents caring for a disabled child have to adjust to new roles, and may have different expectations about their child. They also have to cope with significant emotional, social, physical and financial pressures.

In India prevalence of Intellectual Disabilities/Mental Retardation varies from 0.22- 32.7 per thousand populations. ID children are more and more dependent on their family caregivers and particularly on parents. Therefore, they required more support and help for various needs as per their requirement. Needs has been defined as the basic requirement expressed by an individual for survival. Basic needs are food, shelter and clothes. However, for survival in society needs expressed by an individual or families are social support, informative needs, financial needs, childcare needs, and professional support and community services. Informative needs are about intellectually disabled children's condition, about handling their behavior, about how to teach such children, how to play or talk with them and their development (Bailey and Simeonsson, 1988). Supportive needs include support required by other family members and support of doctors, dentist, babysitters and day care centre. A financial need is about paying for basic expenses, paying for special equipment, paying for the therapy / daycare centre, paying for a baby sitter, etc. Family functioning is about discussing problems or reaching solutions, supporting each other, deciding on household tasks, etc.

Needs express by families of children with Intellectual Disabilities vary from person to person and from family to family. Rao (2008) also admitted the various needs of the parents of mentally challenged children. Some of them need supportive services, some of them need money, some of them require information, etc. Mentally challenged children in families show negative and positive impact on family and family's demand for some specific needs. Singh et al., (2008) found a negative impact (25.26%) which included difficulties in meeting extra demands for physical care of the child, experiencing health-related problems, making career adjustments, experiencing loss of support from the spouses, etc. Further, they found that parents' were having a maximum negative impact on the domains like 'physical care and financial areas'. It means that the parents' are having problems in the allocation of funds in the care and training of their retarded children as well as in other necessary domestic requirements. Becoming a parent of a mentally challenged child is not a choice of parents but it is forced upon them. Therefore, the birth of a mentally challenged child is a shock for them and they undergo hostile stage like shock, denial and anger before accepting the child. Therefore, they need special needs and extra requirement for child and family for the complete development of the child. The most pertinent areas where parents need to have support and guidance are relieving them from a stressful situation, ensuring family stability, managing child's maladaptive behavior, placement options and future planning for their mentally handicapped child. Some other important needs expressed by families of mentally challenged individual are: information about the condition of the child, management of child's condition, seeking for the available services for present life and future of child with special needs, educational and vocational rehabilitation, marriage of the child, emotional needs expressed by the child and the parents themselves, societal acceptance of the child, government benefits and legislation, relief of burden (financial and respite) etc. The needs of the families having a mentally challenged child are very complex and call for developing support programs for these families. Bailey et al., (1992) concluded in their study that the factor structure for fathers was significantly different from that obtained for mothers. Mothers expressed significantly more needs than did fathers, mother expressed needs primarily in family and social support, explaining to other and childcare. They mainly expressed financial needs. Bailey and Simeonsson (1988) suggested group of needs expressed by families for program planning in early intervention.

TRANSITION IN RELATIONSHIPS WITH PARENTS

One of the hallmarks of adolescence is a reconfiguration of relationships with parents from one of dependency toward one of greater mutuality. Although such reconfiguration often involves struggles on the part of both the adolescent and the parent, national data indicate that most adolescent-parent relationships are positive (Moore, Guzman, Hair, Lippman, & Garrett, 2004). Such close and positive adolescent-parent relationships are related to a wide range of benefits for adolescents, including better academic outcomes and fewer problem behaviors (Moore et at., 2004).

Most adolescents with disabilities also report having strong and positive relationships with their parents (Wagner et aI., 2006). They differ from other adolescents, however, in that they report receiving a great deal of attention from their families, more so than that reported by other adolescents (Wagner et aI., 2006). Although such attention may indicate high levels of protection, resulting in less development of autonomy, it may also be a response to the adolescent's need for support from a trusted adult. Collins and Laursen (2004) propose that adolescent-parent relationships often serve to modify the impact of deleterious sources of influence, such as difficulties at school or destructive peer relationships. Although this proposition has not been tested explicitly in relation to adolescents with disabilities, survey data from parents of adolescents or young adults with disabilities leaving high school indicate that parents are well aware of the dilemmas they face regarding their dual role in the promotion of independence and the protection from harm of their child (Thorin, Yovanoff, & levin. 1996). Protection may limit immediate opportunities for independence but may serve an intermediate function that, in turn, promotes autonomy. For example, Dixon and Reddacliff (2001) found that parental behaviors aimed at protecting their adolescent with developmental disabilities from difficulties and exploitation also led to more successful employment outcomes.

In contrast to returning to the family home for brief periods of time, many adolescents with developmental disabilities live with their parents consistently for many years (Fujiura & Braddock, 1992; Seltzer & Krauss, 1984).

Researchers have found that the majority resided with their parents, although over 75% of those individuals said they would prefer to live independently. Kraemer and Blacher (2001) investigated the living situations of young adults with low levels of intellectual functioning and found that the majority lived at home; furthermore, their parents did not identify leaving home as a primary goal for their child. Thus, the reasons that the young adult with developmental disabilities most likely continues to live at home.

Parents and other family members serve as a potentially strong support network for individuals with intellectual and developmental disabilities but may also substitute for friends. In a study of young adults with mild to severe disabilities, McGrew, Johnson, and Bruininks (1994) reported that an inverse relation occurs between the number of family and non-family members in their social networks. Therefore, the parent-child relationship, although always complex, becomes increasingly so for adolescents with developmental disabilities, especially those who rely on parents for many aspects of their daily living and social activities.

RELATIONSHIP OF ADULT WITH ID WITH SIBLINGS

There has been limited exploration of the experience of siblings who live in family situations where their sister or brother has an intellectual disability (ID) or an autistic spectrum disorder (ASD). Little is known about how adult siblings understand their relationship with their brother or sister, and what understandings they may have about the roles they expect to play in the life of their brother or sister in the future.

Understanding sibling relationships:

- Adult siblings maintain high levels of involvement and emotional connection with their brothers and sisters with ID across the life course. Adult sibling roles take many forms and frequently change over time.
- Siblings feel a sense of responsibility for the future of their brother/sister with ID and expect to be involved in supporting them or caring for them in the future.
- Siblings' wishes to provide support for their brother or sister with ID can sometimes clash with responsibilities they have to spouses, partners, children, their work etc. This can cause tension and guilt for the adult siblings. The future roles that adult siblings might play in the lives of their brothers or sisters are rarely formulated into concrete future care plans. There is reluctance among parents to discuss or engage in futures planning.
- Adult siblings do not systematically consult with their brothers or sisters with regard to what future living or care arrangement the latter might prefer.

SIBLING SUPPORT NEEDS

- There are serious gaps in the supports available to siblings throughout the life course. Key supports required include; information about disability entitlements and service provision, support with engaging in family discussion of future and transition planning and access to high standard day, respite and residential services for brothers and sisters with ID/ASD.

- Initiatives to promote greater public awareness of ID and forum that provide ongoing information and support for siblings are also required.
- Siblings are not a homogenous group and their different family configurations, personal circumstances and personality types will influence their perceptions of what supports might be of use to them and their willing and capacity to engage with same.

INFORMATION AND SUPPORT NEEDS

- Young siblings need to be supported by parents and service providers from an early age. They need age appropriate information about the impairment experienced by their brother or sister and about how this might impact on their brother or sister's behaviour, appearance and development.
- Siblings need to receive information about their brother or sister's disability throughout their childhood. The information needs to be age appropriate and should keep siblings informed about changes in their brother of sister's behaviour, health or impairment and changes in the therapies or medication they are receiving.
- Consideration should be given to the best way to provide information. It" needs to be age appropriate, provided in a way that is easily accessed and that recognises the level of digital engagement of young people.
- As many students with ID/ASD are now integrated in mainstream schools, there is a need for disability awareness education to be integrated into primary and secondary school curricula. Awareness programmes would assist in educating students from families who do not have the experiences of living with special needs and make it easier for siblings to explain their own personal situations to their peers.
- Information products such as short films or animations would be a useful resource in school settings. The provision of age related fact sheets which could be shared

with parents would extend the potential of such school based awareness initiatives.

- As siblings transition from young childhood into adolescence, there is an increased need for more information regarding the brother/sister's disability. Many participants had searched for information on the Internet Page 16 and there is a need to provide easy access to online forum in the Irish context.

WITHOUT SIBLINGS

Without siblings the only child does get all the attention, care, and resources that parents have to offer. The opportunity to experience normal conflict, competition, comparison, and cooperation with other children in the family is absent. The push and shove, give and take, speak up and shut up, divide and share of peer relationships must be learned outside the home, and often later on.

PEER RELATIONSHIPS

At the heart of the negative portrayal of disability's impact on interpersonal relationships is the presumed inequality imposed on the relationship when one participant has a disability but others do not. The type of inequality and its explanation are not always made explicit. Does it result from the (perceived) inability of people with disabilities to participate in activities that are important to some, most, or all friendships? or does it arise from the (perceived) need on the part of the person with a disability for technological or human assistance to manage typical life tasks? Does it stem from a belief that the person with a disability does not possess the social or psychological resources to prove a stimulating and rewarding friend?

The influence of a dichotomous conception of disability, that is, of a conception of disability as a personal attribute one either has or lacks, is evident even in the way questions about disability and personal relationships are framed. in asking questions like "are relationships between disabled and nondisabled people necessarily unequal?" we tend to assume that disability is a categorical characteristic: that there is a distinct subset of the population that is disabled and everyone else is nondisabled. if, instead, we adopted the human variation model of disability we could reframe such questions. that model conceives of an impairment as an arbitrary range on the continuum of variation for a human attribute. Moreover, the model sees disability as an interaction between atypical functioning or embodiment and an unaccommodating environment. Consequently, it emphasizes that most people are "disabled" in some particular physical or social context, insofar as they have some atypical characteristic which fits poorly in that context. the model also suggests that a disability, like an impairment, ought to be considered as a graduated characteristic: just as there are degrees of functioning, there are degrees of fit between functioning-embodiment and social environment.

On this view, the question "Are relationships between disabled and nondisabled people problematically unequal?" would be better reformulated as—

“Is there a positive correlation between the degree to which the parties to a relationship differ in overall level of disability, on the one hand, and the degree of problematic interpersonal inequality, on the other?”

Although this is largely an empirical question and cannot be answered by philosophical reflection alone, philosophy can clarify the concepts that figure in the question: what is it to have a disability, what sorts of equality matter in valuable interpersonal relationships, and is there a reason, given what disability is and what sorts of equality matter, to think ex ante that such a correlation would exist?

One reason having or acquiring a physical, intellectual, or emotional disability lessens the chances that relationships will move beyond acquaintanceship is that the disability looms so large in the minds of the nondisabled person (and perhaps the disabled person as well) that it obscures or eclipses other features on which an intimate relationship can be solidly grounded. most people do not yet see disability as one among many characteristics with respect to which humans can vary. in this way, one aspect of a person comes to dominate the whole, an aspect of stigmatization that elsewhere we have described as "synecdoche" (asch and wasserman 2005).

PEER SUPPORT STRATEGY

Peer support is a strategy that involves placing students in pairs or in small groups to participate in learning activities that support academic instruction and social skills. This instructional approach does not require additional staff or extra funding. It is a research-based methodology that yields positive results related to student achievement and a sense of "belonging" over the course of time. Peer supports provide teachers with a learning tool to enhance instruction for students with and without disabilities.

The following are three innovative ways that peer supports can be used to meet the instructional and social needs of students with disabilities in the general education setting. However, each of these models require upfront planning that includes selecting the right type of strategy, utilizing it at the right time with perhaps individualized outcomes all aligned with the lesson goals.

- Collaborative Learning - An instructional strategy used to reinforce skills taught by the teacher. This teaching method allows time for practice, review, and opportunities for students to use higher-level thinking skills.
- Cross-Age Peer Support is another strategy that assists with the learning in the general education setting. This approach typically involves older students, usually high school age, who provide instructional support for elementary or secondary students.
- Peer modeling is another support that can be used to help students learn academic, processes and classroom routines. It also provides the classroom teacher opportunities to use peers to assist with instruction, clarifying directions and give social reminders with little or no disruption to the lesson cycle. It is an excellent way for peers to provide appropriate behavioral models of students who need to improve their social skills.

Research has clearly defined the benefits of inclusion and peer supports for the student with a disability.

Benefits for Students With Disabilities

- Friendships
- Increased social initiations, relationships and networks
- Peer role models for academic, social and behavior skills
- Increased achievement of IEP goals
- Greater access to general curriculum
- Enhanced skill acquisition and generalization
- Increased inclusion in future environments

- Greater opportunities for interactions
- Higher expectations
- Increased school staff collaboration
- Increased parent participation
- Families are more integrated into community

Benefits of Inclusion for Students Without Disabilities

- Meaningful friendships
- Increased appreciation and acceptance of individual differences
- Increased understanding and acceptance of diversity
- Respect for all people
- Prepares all students for adult life in an inclusive society
- Opportunities to master activities by practicing and teaching others
- Greater academic outcomes
- All students needs are better met, greater resources for everyone

The power of peers as shown here has a cumulative effect, which makes issues such a bullying incompatible. Rather, we have peers helping peers become more integrated into the school culture.

EXTENDED FAMILY

Despite increasing extended family involvement in child rearing, particularly in minority families, few studies investigate their role in talking with teens about sex or how this relates to teens' sexual behavior. This mixed-methods study assesses extended family sexuality communication through a survey of 1,492 diverse middle school students and interviews with 32 students. Logistic regression shows that participants who report having had sex are more likely to report talking with extended family than those who report not having had sex. Interview themes explored reasons for and content of teen sexuality conversations with extended family. More sexually active teens' reporting communication with extended family is interpreted as extended family members gaining importance in sexuality communication as teens become sexually active.

4.5 Employment, Sexuality, Marriage, Alternative Options, Pre-marital Counselling

Employment

The majority of adults with intellectual and developmental disabilities (I/DD) are either unemployed or underemployed, despite their ability, desire, and willingness to work in the community.

Employees with disability are not likely to have all the listed disability features OR affects at work! Most people have just a few of those listed; you'll only know by asking the person directly.

Here are some examples of how an employee with an intellectual disability may be affected at work. They may have difficulties with:

- Learning new tasks and processes.
- Sorting out arising problems, without help to think through the issue and possible solutions.
- Understanding others and expressing themselves.
- Having a concept or firm understanding of time and time management.
- Travelling to and from work independently.

Possible workplace adjustments for people with intellectual disability

The following examples of workplace adjustments are only examples! These examples will not suit everybody.

In each case the best supports in the workplace can only be discovered through conversations between employer, employee and, if needed, a disability specific employment specialist.

Some examples of workplace adjustments that have been used for people with an intellectual disability include:

- Work with a specialised disability employment service who will provide on-the-job and, if needed, ongoing workplace support to the employee and the workplace.

- Employees with an intellectual disability often learn in small steps through repetition. This means that their work activities may need to be structured this way.
- Develop a 'work buddy' system where a co-worker is identified, based on their personal qualities and experience in the work environment, to provide learning support and guidance.
- Use pictures and other prompts in the person's work space to help them remember their daily work tasks and processes.
- Provide disability awareness training to all staff to help them be confident and respectful of employees with disability.

Requirements related to employment include:

- Opportunities for post-secondary education, including college and vocational training, to gain knowledge and skills to allow people to get better jobs.
- Ongoing planning to promote job advancement and career development.
- Fair and reasonable wages and benefits.
- Opportunities for self-employment and business ownership.
- Opportunities to work with and, in the case of people with I/DD who own small businesses, employ people without disabilities.
- The ability to explore new directions over time and, at the appropriate time, retire.
- Opportunities to work and increase earnings and assets without losing eligibility for needed public benefits.

Tips for communicating with people with intellectual disability

- Speak clearly using uncomplicated language and sentences; avoid jargon
- Allow time to explain work requirements and information to the employee
- Explain any changes to the job or routines in advance
- Allow time for the employee to respond to your requests and also ask questions
- A non-response from the employee may mean that they are having difficulty understanding what you have said or are unsure of what they need to do next

- Check understanding by asking the person to repeat what you have said in their own words
- Rephrase information if it is not understood, or present it differently
- Ask short questions to gather information
- Use multiple communication strategies to explain concepts, requests or information; for example pictures, physically demonstrate the activity a couple of times; or break down the activity to create small achievable goals.

Sexuality, Alternative options for people with intellectual disability

Sexuality is a key part of human nature. People with intellectual disability experience the same range of sexual thoughts, attitudes, feelings, desires, fantasies and activities as anyone else. To understand and enjoy sexuality, everyone needs adequate information and support from a young age.

Sexuality has psychological, biological and social aspects, and is influenced by individual values and attitudes. A person's sexuality develops throughout childhood and adolescence, and is a key part of their identity. The way each person understands and interprets their sexuality varies significantly, and often changes over time. Healthy self-esteem and respect for self and others are important factors in developing positive sexuality.

Most people with intellectual disability can have rewarding personal relationships. However, some may need additional support to develop relationships, explore and express their sexuality, and access sexual health information and services

Sex Education for people with intellectual disability

A child's sex education comes from a range of sources, including their parents, teachers and friends. People with intellectual disability also require sexuality education that:

- teaches them that people with disability can have fulfilling sex lives
- covers age-appropriate sexual issues that may be associated with their particular disability
- explains social rules, such as telling the difference between private and public behaviours
- is delivered in a way that a person with intellectual disability can understand.

It is important for parents to have access to the information they need to support their child in dealing with particular challenges they may face.

Some adults with intellectual disability may have received adequate sexuality education at school, while others may have missed out. Those who have received adequate education may need follow-up information that is suitable for an adult of their level of ability and literacy. For those who have missed out, it is important to start at the beginning, no matter how old they are.

Social opportunities, sexual relationships and intellectual disability

The opportunity to mix with other people of both sexes, whether socially, at school or at work, is important in developing confidence and social skills. However, some people with intellectual disability may have fewer opportunities to form social and sexual relationships for a number of reasons, including:

- a lack of privacy
- being dependent on others for daily living
- a lack of confidence about their physical appearance and ability
- less knowledge of how to negotiate relationships and express their sexuality
- a limited social circle and a lack of social experience
- physical or cognitive limitations
- cares who wrongly think of them as childlike or asexual
- Cares who view their sexuality as something to be feared and controlled.
- A person with intellectual disability may need additional support to explore sexuality and relationships. This can be particularly relevant to people with high support needs, for example, those who live with their parents or in supported housing, or those who need help with communication or personal care, such as toileting.

People in these situations may want sexual relationships, but wrongly, this may not be permitted by their parents or caregivers. They may lack the privacy needed for sexual activity. Restrictions at home may lead some people into unsafe or illegal activity, such as sex in parks or other public places.

Sexual sensation and function and intellectual disability

- There are many different types of disability. Intellectual or cognitive disability may be caused by a genetic (inherited) condition, difficulties that occurred during childbirth, an illness or an accident.

- Sometimes, a person with intellectual disability may be less able to enjoy sex, which may be due to:
- the disability itself or its physical or emotional consequences
- a physical injury
- prescribed medication
- ageing
- psychological illnesses, including depression.
- A person with intellectual disability who is experiencing problems with sexual sensation or function can talk to a doctor, sex therapist or support group for suggestions on how to overcome these challenges.

Body image, intellectual disability and sexuality

In some ways, society presents a narrow view of how men and women should look, particularly through the media. A person with intellectual disability may feel less worthy of a healthy sexual relationship because they do not match this idealized image. Talking with other people who have overcome body image concerns or a counselor may help.

Appropriate sexual behaviour and intellectual disability

Sometimes, a person with intellectual disability may exhibit inappropriate sexual behaviour, such as public masturbation, or soliciting sex from minors or in public. This is more likely to occur when the person lacks more appropriate sexual outlets, or has not been provided with appropriate education about the complicated social etiquette and legal issues around sexual behaviour and relationships.

Sometimes, police may charge the person with a sexual offence. The person may also be restricted in unreasonable ways, such as a man being prescribed medication by a doctor to suppress androgens (male hormones). However, appropriate education and behavioural training are, in most cases, better ways of addressing issues such as these.

Unfortunately, some people with intellectual disability may have received the message that any sexual expression is unacceptable. This may need to be addressed before the person can learn more acceptable behaviours.

Contraception for people with intellectual disability

- All women and men, including those with disability, have the right to make their own informed choices about which method of contraception they use. To make these choices, people need adequate, accurate and accessible information about reproduction, the purpose of contraception and their contraceptive options.
- Some people with intellectual disability may find it difficult to access contraception and other sexual health products and services, especially if they cannot be open with their family or care givers about their sexual activity.
- The contraceptive choices available to a person with intellectual disability may be limited for a number of reasons, including:
- Certain medication can interfere with oral contraception, the contraceptive vaginal ring, the contraceptive implant or emergency contraception (EC, also known as 'the morning after pill').
- The contraceptive injection (depot medroxyprogesterone acetate, known as Depo-Provera) and contraceptive implant (Implanon NXT) may cause unpredictable bleeding that can be difficult for some women with an intellectual disability to manage.
- There can be difficulties with insertion of the contraceptive implant or an intrauterine device, which can be overcome by having the procedure while sedated or under anesthetic.
- Some women have difficulty remembering to take tablets such as the contraceptive pill regularly. This can be overcome by supervised use.
- Some people with intellectual disability may have difficulty negotiating the use of condoms.
- It is important to remember that EC can prevent pregnancy after having unprotected sex, for example, if a pill is missed, a condom breaks, or a woman is sexually assaulted. EC is available from pharmacists without a doctor's prescription. It should be taken as soon as possible, ideally within 24 hours of having sex, but it still works well within 96 hours (four days). It can be taken within 96 to 120 hours (five days), but it will not be very effective.
- It is legal in Victoria for any woman to seek to terminate a pregnancy. All people

are entitled to access support and counseling about issues relating to abortion.

Reproductive rights for people with intellectual disability

According to Chapter II article 10 of RPWD. 2016-

(1) The appropriate Government shall ensure that persons with disabilities have access to appropriate information regarding reproductive and family planning.

(2) No person with disability shall be subject to any medical procedure which leads to infertility without his or her free and informed consent. So reproduction of disabled became a legal right for persons with Intellectual Disability. However, people sometimes misunderstand these laws to mean that it is illegal for a person with intellectual disability to have sex. This may make families and support organisations wary of supporting sexual relationships.

While the question of understanding and giving informed consent to sexual activity may sometimes be more complex for people with intellectual disability, they still have the same right to consensual sexual relationships as others in the community.

Genetic services for people with intellectual disability

Some people with intellectual disability who are pregnant or are considering having a child may want to use genetic services such as diagnosis, screening and testing, counseling, education, clinical research and information on the management of individuals and families with a history of particular health conditions. Access to services such as these will help people to make the best decisions for themselves and their children.

Pregnancy, parenthood and intellectual disability

- Some people with intellectual disability, such as men and women with Down syndrome, have lower fertility, but many others are as fertile as the general community. Many people with intellectual disability want to have children. However, their own family or carers may oppose this, making it difficult for the couple to plan for pregnancy and parenting, and to access the necessary services for themselves and their baby.
- Many people with intellectual disability can be loving partners and parents, maintain strong relationships and care for a child. Parents with intellectual

disability usually need additional support, as do many other groups in our community, such as parents who are very young or who are experiencing mental health issues.

Sexual health and people with intellectual disability

- People with intellectual disability should have the same choice regarding preventive health measures for sexually transmissible infections (STIs) and other conditions as people without disability, including:
- Condoms should be used to prevent the transmission of STIs. The person with disability may need to be provided with appropriate and accurate education about STIs and condoms, including the opportunity to practice how to put condoms on correctly.
- Nearly all women with intellectual disability can learn menstrual hygiene, just like any other woman. A woman's menstrual cycle should not be suppressed just because of her intellectual disability.
- People with disability should participate in immunisation programs, including the HPV (human papillomavirus) vaccine and immunisation program, which helps prevent cervical cancer.
- Women need to understand the importance of being aware of how their breasts normally look and feel and should be encouraged to see a doctor if they notice anything unusual.
- Women aged over 50 year's needs to consider having a mammogram for the early detection of breast cancer. A doctor can provide more information about this.
- Men need to understand the importance of seeing a doctor if they notice a lump or anything unusual with their testicles.
- When providing health services to people with intellectual disability, doctors and other healthcare professionals need to take into account the particular disability and circumstances of their client. For example, some women with intellectual disability can find a gynecological examination or procedure such as a pap test overwhelming. It is important for people with intellectual disability

to provide informed consent before these procedures are carried out, unless in the case of medical emergency.

Sexual abuse or exploitation of people with intellectual disability

- All people, including those with intellectual disability, have the right to enjoy relationships and sexuality without being abused or exploited. Unfortunately, statistics show that people with disability experience all forms of abuse at much higher rates than people without disability.

Reasons for this include:

- inadequate sexuality education on where and when it is acceptable to be touched by other people
- inability to resist, protest against or stop abusive behaviour from happening
- not knowing that a person has the right to decide what happens to their body, especially if they are used to other people constantly attending to their physical needs
- being raised in situations where they are used to being told what to do and therefore going along with requests or demands made by an abuser
- agreeing to engage in sexual activity to fulfill unsatisfied cravings for attention, affection or rewards
- Consenting to initial sexual activity, but not to sexual activity that follows, this amounts to abuse.
- Just as in the wider population, assaults against people with disability are more likely to be perpetrated by somebody they know, such as a family member, carer, work colleague or someone they live with. Research also shows that sexual assaults on people with disability are less likely to be reported.

Reasons for this include:

- Some people with disability find it difficult to communicate with others.
- A person may tell someone of the assault, but that person may not understand them.

- A person may have limited knowledge or ability to report what happened to them.
- Some people wrongly think the effect of sexual assault on a person with disability is not as serious as an assault on someone without disability.
- A person may not be believed.
- Any sexual assault is a very serious matter and should be referred to police and sexual assault support agencies.
- The carers of a person with intellectual disability can help by modeling assertive behaviour, making referrals if the person needs further training or support, and explaining the basics of protective behaviours, including:
- Every person has the right to say what happens to their body.
- Everyone has the right to feel safe.
- There are laws that protect a person's right to live safely without being harmed or exploited.
- There are many people who can be trusted, but also some who cannot be trusted.
- Some types of behaviour are appropriate for yourself and others, but some types are not.
- You can communicate assertively and say 'no' to unwanted behaviour.
- It is okay to change your mind about sexual behaviour or activity, even if you have already agreed to something.
- There are people who can help if you are being abused or exploited in any way.

Premarital counseling

Teenagers and adults with intellectual disabilities often dream about finding love, moving in together, getting married, and having children. Yet, historically, there has been resistance to people with intellectual disabilities becoming companions, living together or marrying, due in large part to fears about them procreating and "contaminating the gene pool." This resistance took the form of legal restrictions on marriage, eugenic laws leading to forced sterilizations, and at one time, many admissions to institutions (Kempton & Kahn, 1991). However, throughout history, many individuals married, raised children and did not come to the attention of service providers, because they were able to manage their lives (Koller, Richardson & Katz, 1988).

- In the early 1960's, attitudes started to change. Society began to more openly discuss the topic of sexual expression, love and marriage concerning people with intellectual disabilities. The "sexual revolution," along with advances in birth control methods, had the effect of decoupling sex from procreation. This removed one of the principle objections to love relationships and marriage for people with intellectual disabilities (May & Simpson, 2003). Unfortunately, even today, many of these couples have problems accessing counseling services because therapists often assume that "they are not good counseling candidates."
- Based on 36 years of work as a couple and family therapist, the author believes that no clinical work is as exciting and rewarding, or as potentially challenging, as counseling and trying to improve the emotional functioning and relationships of couples with intellectual disabilities.
- Intervening with Couples, Extended Family and Service Systems
- Because people with intellectual disabilities often have very involved families upon whom they can be very dependent, separate sessions with concerned relatives may be a significant part of the therapeutic process to help the couple. The couple's parents, siblings or grandparents may have many strong (sometimes misguided) opinions about the couple and their suitability for each other; whether they should go out, move in together, marry, or have children. Families may also be concerned about wills and estate planning; budgeting and money management; housekeeping, hygiene, proper food preparation and refrigeration; the partner's physical health; or the partner's propensity for genetic problems (e.g., Down Syndrome leading to early onset dementia). Families may worry that one of the partners is sexually promiscuous or shows other high-risk behaviour (e.g., hanging out a strip clubs, unprotected sex), or have criminal or abusive tendencies.
- Therapists should view the strategic use of (well-timed and appropriate) humor, frankness, cheerleading, and brief inspirational or motivational talks as important tools for reducing anxiety and defensiveness when working with couples, their families or service system representatives. Also, it is likely that family representatives will need honest feedback and reassurance from therapists and agencies around five critical questions concerning the couple: (a) Is my adult child/relative physically and emotionally safe in this relationship, (b) Is my

adult child/relative really happy with this partner, (c) Are money management, daily living and health needs going to be properly met, (d) Is reliable birth control in place to prevent pregnancy, and (e) Are they receiving enough agency support.

- At the same time, if a couple is experiencing serious service system difficulties, the therapist and co-therapists may combine forces with the couple and other significant people including family and local agencies, to organize special "couple-centered planning" meetings. These meetings are held regularly (e.g., every 4-8 weeks) for a several months or longer if needed, to address practical problems. Planning meetings can help to improve networking, information sharing and communication among key people, and encourage creative problem-solving; while permitting the expression of deeply held concerns. Advocacy for improving "instrumental supports" for the couple also may be suggested (e.g., housing, daycare, transportation, employment, budgeting, a disability pension and health services).
- To Parent or Not to Parent? That is the Question!
- For couples seriously considering pregnancy, the PSCT Model neither encourages nor discourages this possibility. Parenthood, as a personal right, has been gaining ground over the past two decades (May & Simpson, 2003) and it is assumed that there are competent and inadequate parents in both the disabled and the general populations. Research has demonstrated that many parents with intellectual disabilities can learn parenting skills and provide acceptable child-care, if given appropriate training and support (Aunos & Feldman, 2007).
- It is not unusual for couples with intellectual disabilities requesting premarital or marriage counseling to have already decided that they do not want children (Craft & Craft, 1979). However, couples seeking counseling around this issue should be fully informed about the responsibilities, challenges and skills required to be adequate parents. Birth control and family planning options should also be presented - and the couple's physician or a public health worker may be of assistance. For couples needing considerable support to ensure proper parenting, it is both ethical and necessary (with the couple's permission) for therapists to interview the couple's parents (potential grandparents), other involved family and agency representatives, to realistically determine how much support might

be available and needed. Too often, families (especially potential grandparents) are already overwhelmed by responsibilities involved in supporting one or both of the partners. Facing the possibility of having to nurture a small child (along with the child's parents) can create a formidable challenge (Parr-Paulson, 1998).

- In situations where there is suspicion that a child may be neglected or abused, it is imperative that professionals inform child protection authorities. The couple should know that this is a possibility prior to conception, if possible. Couples who unrelentingly want children will probably have them regardless of the views of others. In the end, if the couple unilaterally moves ahead with pregnancy, professionals and agencies should do everything possible to ensure proper parenting and child-care.
- Private Sessions: What Couple Therapists Need to Know!
- There appears to be systemic biases among many experienced therapists against working with couples with intellectual disabilities. It is not uncommon to hear therapists make erroneous statements that these couples are "too low functioning" or "lack the insight to be good counseling candidates." Yet, nothing could be further from the truth, especially for many adults functioning in the moderate or mild range of intellectual disability.
- Private couple sessions are an important part of the PSCT Model. Therapy usually involves a short-term, action-oriented, contracted approach of six to twelve sessions; spaced out every two to four weeks, later augmented by occasional "booster sessions" if needed. Biased therapists may assume that these individuals are incapable of "insight" (i.e., affecting action through understanding). In fact, many adults have some capacity to consciously change behavioural and cognitive patterns as a result of psychodynamic and behavioural insight, at least on a basic and practical level. Some have wisdom, intuition, verbal and memory skills well beyond assessed intellectual functioning; and these couples are often refreshingly honest, and motivated to accept help.
- Private Sessions, along with "active listening" and clinical note-taking, can reinforce for couples the notion that their relationship is special and significant. Being really listened to is a powerful therapeutic tool, since individuals with intellectual disabilities often have a history of being ignored, put off or not being taken seriously by others. Couples can improve communication, self-

assertion, problem-solving and coping skills; develop better teamwork with their partner; resolve deep hurts and misunderstandings; and with extra practice can become more skilled at clarifying, labeling and channeling intense feelings.

- Couples with intellectual disabilities tend to distrust clinicians who are too formal, pedantic, patronizing and serious. A therapist axiom for "hooking" couples into the counseling process might be: "Make sessions positive and fun, and half the work is done!" Most individuals with intellectual disabilities have a great sense of humor and love to learn; but on their terms, and often at a slower pace. With this in mind, the following strategies (sometimes skillfully modified from traditional counseling methods) are noted as being helpful.
- First, interviews usually should be held in the privacy of a therapist's office. Because these individuals may have memory and scheduling difficulties, it is usually wise to call the couple ahead of time, to remind them of the next session. Sometimes, couples ask the therapist to come to their apartment or home for sessions, since many support agencies provide service in this manner. The therapist may do this, if the couple presents serious physical and mobility challenges. However, showing a willingness to come to the therapist's office can provide a general clue as to the couple's motivation for accepting help; can nudge them away from the rigidity of their daily routines; and avoids in-home distractions.
- Second, when interviewing people with cognitive limitations, frequent repetition of clinical impressions and advice is often necessary, followed by a request that the couple repeat what has been said to ensure they understand. If individuals still seem confused, therapists should speak in a slower, clearer, more succinct manner, and request eye contact. Because generalization of learning for these individuals can disappear between sessions (especially at first), it is helpful to review the content of previous sessions at the start of each interview. Over time, as the information is repeated again and again, messages usually are retained.
- Third, the structured, specific, more directive nature of cognitive-behavioral counseling strategies (Burns, 1980; Jacobson & Christensen, 1996) seem particularly well suited for
- working with couples with intellectual disabilities. "Cognitive distortions" (e.g., "catastrophizing") can be explained simply as "ways your thoughts are playing

tricks on you.". Behavioral rehearsal or role-play, used in conjunction with relaxation training, can be a particularly effective and often enjoyable learning tool. Couples can rehearse ways of improving interactional skills with partners (e.g., appropriate sexual advances); learn to deal with anxiety-producing situations (e.g., meeting the in laws); or practice self-assertion strategies for coping with domineering relatives or friends.

- Fourth, better management of anger, jealousy and conflict is a therapy outcome frequently requested by one or both partners, or their extended families. The PSCT Model supports the feminist belief that couple therapy not continue, when one partner presents extreme abuse or battering. Yet, with "low -level violence" (e.g., threats, pushing and other physical aggression without battering), there is often value in treating the couple together (Jacobson & Christensen, 1996; Nichols & Swartz, 2004). Partners can be taught simple but effective strategies, such as the "Stoplight: STOP/THINK/GO method" of anger management. To illustrate, when angry, the partner is taught to use a visual or pictorial prompt (e.g., stoplight picture), and imagine a Red Light (STOP anger is escalating), Amber Light (THINK about what unpleasant consequences might occur) and Green light (GO). GO is a '"time-out" command to immediately "disengage" (Wolf, 2006), walk away or redirect oneself into other vigorous activities. At the same time, couples can be taught concrete "rules for fair fighting" (Bach & Wynden, 1968), such as no physical violence, focus on the "here and now" (not old hurts), and avoid global terms (e.g., "bitch", "jerk").
- Fifth, reframing can be used to teach couples to re-think, change their perception and reinterpret people or situations, in a less emotional, more constructive and rational manner. For instance, a man became uncharacteristically hostile towards his "stupid, retarded wife", after she was diagnosed with diabetes. During counseling, the therapist reframed this concern by suggesting the diabetes was "actually an advantage", because now for the first time, they both would have to exercise, watch their diet and take better care of themselves. After several reframing repetitions, the couple accepted this explanation, lost weight, tension disappeared and their love returned.
- Sixth, Koller, Richardson and Katz (1988) reported that sexual difficulties are more common in couples with intellectual disabilities. Educating couples about

sexuality, related health and hygiene issues, or ways of dealing with sexual dysfunction can be helpful in reducing tension and increasing intimacy. Couples can be taught to make behavioural requests of each other, to increase demonstrations of affection (e.g., "Give me a hug, you big lug!"). Masturbation can be prescribed as sexual insurance for either partner, if intercourse is not an option.

- Seventh, Mattinson (1973) noted that most couples with intellectual disabilities function on a complementary basis (ie, the skill of one partner supplements a weakness in the other).
- Therapists can help couples to identify specific ways to better complement each other's weaknesses or stated desires, keeping in mind emotional and physical limitations. For instance, a man with severe speech difficulties was encouraged to use his wife as his interpreter, since she had an uncanny ability to understand him. In return, she asked him to accompany her for frequent doctors' appointments, which she found very anxiety-producing. In another case, the illiterate husband of a woman with physical challenges was able to run errands, feed, and bath her; while she agreed to read and write for him.
- Eighth, healthy boundary-setting (Minuchin, 1974) is an approach that can be easily understood by most couples with intellectual disabilities. Strengthening boundaries may involve establishing conversational rules (e.g. only one person speaks at a time); insisting on less interference from in-laws (e.g., refusing visits with relatives who demean them); or encouraging more distance between a passive woman and her dominating partner (e.g., an evening out each week with her friends). On the other hand, relaxing boundaries may involve "giving permission" to isolated couples to get out more (e.g., cheap dates or vacations, join a fitness club) or increase their social network (e.g., joining Special Olympics bowling, People First advocacy meetings).
- Ninth, for couples unable to read and write, therapists must be flexible in coming up with creative, practical approaches. For instance, one couple created (with therapists' help) a song with pragmatic coping strategies outlined in the lyrics. Near the end of each session, the therapists and the couple sang the song together (with much enjoyment), to remind the couple of specific coping strategies, updating and improving the strategies/song, when needed. For people with

serious communication deficits, augmentative communication devices or visual tools (e.g., picture or symbol systems) can be used to improve specific skills (e.g., hygiene, basic cooking, manners and politeness, anger management, understanding public transportation schedules). The key is to be inventive and have fun with it!

- Tenth, and finally, when appropriate, therapists can suggest that one or both partners might benefit from a psychiatric assessment, or should speak with their physician regarding psychotropic medication, to help treat mental health concerns. This, ultimately, can greatly improve couple relations (Carver, Waring, Chamberlaine, McCrank, Stalker, & Fry, 1987).

4.6 Ethical Issues

According to the BBC, ethics is a branch of philosophy that deals with the ways in which people should live their lives. Ethical issues must be dealt with when examining these philosophies. Ethical issues often deal with what is right and what is wrong, what is good and what is bad, and what rights and responsibilities people should have. The general goal of ethics is to enable people to live good lives.

The problem with ethical issues, such as whether capital punishment should be allowed or the morality of euthanasia, is that there generally is no single accepted answer. These ethical issues are hotly debated because the answer generally comes down to personal opinion or philosophy. Ethics can give more than one answer, and sometimes that answer is not universally correct.

Ethical issues are often at the center of the debate when it comes to social issues. Groups argue that things are moral or immoral, and they create an ethical debate to support their argument. Ethical guidelines can come from personal philosophy, religion and government.

ETHICAL ISSUES ON SOCIETAL AND SEXUAL PERSPECTIVES OF PERSONS WITH INTELLECTUAL DISABILITIES

People who are intellectually or mentally disabled have many disadvantages. They may have an associated impairment, such as paralysis, blindness, or a psychiatric disorder, that reduces their ability to do things that other disabled or nondisabled people do and may interfere with their fulfillment of socially valued roles. Also, intellectually disabled people often are subjected to various degrees of exclusion from the social and economic life of their communities. Political movements by disabled people to remove barriers and overcome discrimination, and protective legislation in several countries, have focused attention on the controversial concept of disability and on what constitutes just and compassionate behavior toward the disabled by individuals and institutions, including private employers, providers of public services, and schools. These ethical issues are pressing for all people because everyone can be disabled by trauma and because in societies in which life expectancy is long everyone may expect some impairment in old age.

This entry analyzes the concept of disability and its links to certain other concepts (impairment, handicap, health, and disease), explains the two competing explanatory models of disability, and surveys some of the ethical controversies that pertain to the nature of disability and the relationship between a disabled person and the rest of society.

In recent decades, people with intellectual disability have moved from institutional to community living, with a resultant increase in the use of mainstream housing and social and health services including general practitioners. General practitioners recognise that people with intellectual disability have specific needs and face particular problems, but may experience difficulty addressing these needs.

Many people with intellectual disability live in supported accommodation, or with family, and many lack jobs, meaningful activities or close relationships in their life. Unrecognized health problems, mental illness and psychotropic prescribing are more frequent in people with intellectual disability than in the general population, and challenging behaviours can also be a problem for some.

Sexual relationships in people with intellectual disability present a particular challenge. Attitudes have shifted from viewing people with intellectual disability as asexual 'innocents' or 'oversexed' potential sex offenders to recognition of their sexual needs and rights. However, attitudes toward sexual expression may remain restrictive. People with intellectual disability express desires for intimate relationships but report limited opportunities and difficulty negotiating relationships. Sexual knowledge in people with intellectual disability has been shown to be poor and access to education limited despite the development of appropriate programs. Capacity to consent to sex may be limited or difficult to assess, and social and legal rules regarding sexual behaviour may be confusing. Laws addressing sexual exploitation may be interpreted as prohibition of relationships.

People with intellectual disability are prone to physical, psychological and sexual abuse. These problems may present to GPs as mental illness and/or challenging behaviours. Perpetrators may include family members, support workers, intimate partners and co-residents. People with intellectual disability may lack the assertiveness to report abuse or the verbal skills to describe it. When abuse is reported, responses may be inadequate. Lack of sexual knowledge, relationship experience and protection skills may increase the risk of abuse and impair the ability to recognise an experience as abusive. Innovative and successful support programs have been developed, such as the Australian 'Living Safer Sexual Lives' initiative, but availability of these programs is often limited.

We have previously interviewed women with intellectual disability about sex, relationships and sexual abuse. This study aims to add the perspective of those involved in the care of people with intellectual disability.

4.7 Adolescents and Youth with Intellectual Disability Issues, Challenges and Implications

Globally, almost 180 million young people between the ages of 10-24 live with a physical, sensory, intellectual or mental health disability significant enough to make a difference in their daily lives. The vast majority of these young people, some 150 million (80%) live in the Developing world. Routinely excluded from most educational, economic, social and cultural opportunities, they are among the poorest and most marginalized of the entire world's young people. Recent World Bank estimates suggest that individuals with disability may account for as many as one in five of the world's poorest. Because of this, disability is now increasingly recognized as a key development issue and its importance in relation to poverty, human rights and the achievement of internationally agreed upon development goals is receiving mounting recognition.

The Cycle of Disability, Poverty and Isolation among Young People

Young people with disabilities have needs very similar to the needs of all other young people, as clearly stated in various Articles of the United Nations' Convention on the Rights of Persons with Disabilities ld. (UNCRPD, 2007). They need to live in a safe and supportive environment; they need education, health services and access to sport and recreation. They also need to develop skills that will serve them well in the community and the workplace. In many cultures however, the traditional approach to a young person with a disability is to acknowledge that they are no longer children but to assume that they will never be accepted or able to function, as adults. This is often true no matter what the nature of their disability. The problem of where they should exist is often dealt with poorly.

While all adolescents and young adults face the challenge of acquiring the skills and experiences they will need in order to become successful adults, the transition to adulthood for disabled young people is particularly complex. A fundamental reason for this is that people with disabilities are often seen as being "childlike." Disabled children, particularly those with more visible disabilities, are frequently assumed to be in frail health and unlikely to survive into adulthood. Indeed, in many countries, a significantly disabled child is referred to as "an innocent" or a "little angel." (UNICEF:1999) Sending such children to school, including them in social interactions or preparing them for participation in the adult world seems unnecessary. Families with significantly disabled children have often anticipated their early deaths, but not their possible survival. Bjarnason (2002) discussing the transition to adulthood of young disabled people in Iceland describes this as "eternal youth" - a limbo in which young disabled people are not expected to reach adulthood, but remain enmeshed in segregated services. Where no services exist, such young people usually must either continue to live as "children" in their parents' households, or find themselves on the street. In many countries, particularly where extended family units are still the norm, it is considered appropriate for all young people to remain at home, including those with a disability. Personal assistance, if needed, is provided by immediate family members, (most commonly the mother), which means that these young people with disability often have little or no say over even the most basic aspects of their lives. Such arrangements can also preclude a young person's ability to establish a sense of autonomy or gain experience in making independent decisions about immediate or long-term plans. Elsewhere, rapid moves towards modernization have lead to the expectation that young non-disabled adults will eventually want a live independently of their parents. Young disabled adults however, are often expected to continue living at home - making their lived experiences as young adults increasingly different from that of their non-disabled peers. Of even greater concern is the reality that in many cases, poverty and lack of viable options will force many young adults, particularly young males, to leave home for a life without family supports or a life on the streets.

Following are the common challenges faced by persons with Intellectual Disability and other disabled persons.

EDUCATION

For the vast majority of young people who have been born with a disability, their initiation into their own cycle of poverty begins early when they are unable to access needed medical and rehabilitation services, and when they are denied admission to school. For those who acquire a disability later in childhood, this initiation often begins after they acquire a disability, when they find themselves dismissed from school. Lack of education is a key concern for most disabled young people in the Developing world. In many countries, children with disabilities are considered to be incapable of learning, no matter what their disability. Often a disabled child is considered a distraction to other students and simply sent home. Lack of schooling may reflect the belief that such children cannot learn, that such children should not be put through the stress of learning or such children are an embarrassment (evidence of bad blood, incest or divine disfavor) and should not regularly be seen in public. School buildings are routinely built with stairs, or far from community centers, making them inaccessible to those with mobility impairments. Lack of trained teachers, appropriate teaching materials and an unwillingness to include disabled children in the regular classroom limits access to education for millions of blind and intellectually disabled children as well as those with mental health difficulties. Perhaps the primary reason these children are so rarely in school however, is because there is little perception by their families or their societies that they will have need of an education. (UNICEF:1999) This general lack of access to education is cumulative and by the time children with disability reach early adolescence, the vast majority find themselves far behind the educational levels and skills of their non-disabled peers. Gender further compounds inequities found in education available to young people with disability. As Russo (2003) notes, cultural bias again women in general, makes many families and educational systems less willing to allocate resources and opportunities to all female students. Reduced expectations for 14 disabled females further limits what funds families and schools are willing to spend on academic and vocational training. Although, as is true of many other aspects of adolescents with disability globally, little information exits, it is clear that the educational resources and opportunities available to adolescent girls and young women is significantly less than even the already limited resources available to comparably disabled young males. Compounding this issue is the fact that in where school fees and barriers make universal education unavailable, anecdotal reports indicate that some parents choose to put all the family resources into educating non-disabled siblings, with the expectation that more education will guarantee a higher paying job, thus allowing the educated children to support their disabled sibling into adulthood and old age. (Unfortunately, the option of educating the child with a disability to ensure his or her ability to be self-supporting is often not considered as an alternative). A few studies have found some inclusion of disabled adolescents and youth in general classrooms without special consideration being given to their disabled status. Miles for example (1995) in a study in rural Pakistan, found 22% of all disabled children had received some schooling within the general classroom setting and reports similar observations from Sri Lanka. This "casual integration" is hard to track, but represents an important area for further study, not only for its implications for education, but also because it might provide functioning models of inclusion that have relevance to subsequent job training and economic development schemes. Additionally, there has been growing interest in "inclusive schooling practices" with UNESCO and UNICEF promoting greater integration into the general classroom setting. However, most of these efforts have been directed towards younger children, not towards disabled adolescents. In fact, by adolescence worldwide, the vast majority of young people with disabilities are no longer in school. The social isolation, poverty and discrimination faced by children with disabilities also sets up an interconnected pattern of problems. (Neueldt 1984; Helander:1995; Harriss-White:1996) Many children with disabilities either do not attend school or leave school early. Millions of these young people end up on the street, unemployed and often involved in crime, sex work and drugs, frequently at 15 the behest of others who see them as easy prey. It is estimated that at least one-third of all street children have a disability. (UNICEF:1999) There are some exceptions. In Western Europe, North America, Japan, Australia and New Zealand there exists extensive educational systems for most children with disabilities from early childhood through late adolescence. Some nations integrate these adolescents into general classrooms. Others provide specialized classes and offer sophisticated training in social and job skills to help in the transition to adulthood. These programs have varying degrees of success. An extensive body of research has documented this process of transition in some detail, although there is still comparably little information on the effects of this process on the social integration of the individual and the implications for the family unit over the course of time. Comparable data from the Developing world is hard to come by. However, presence in a classroom alone does not guarantee education. For example, the average reading level for deaf American high school graduates is at a third grade level. (Peinkoff:1994) Students with disability are often formally restricted in what course of study they are allowed to pursue. In a recent study from Ireland, Shevlin (2002) has found that disabled high school students were not allowed to enroll in the full range of academic courses that other students, of comparable abilities, were allowed to take. In China, disabled university students are not allowed to major in most sciences, as it is felt that the degree would be 'wasted' on an individual who would never be able to find a position in the field. This systematic lack of education comparable to that of non-disabled peers has immediate relevance to disabled young people as they begin to anticipate entering the workforce. At an age when non-disabled individuals are beginning to define themselves through their anticipated careers, most disabled young people enter the workforce strikingly unprepared.

JOB-TRAINING AND EMPLOYMENT

Globally, employment is a problem for all adolescents and youth. Formal education for most of the world's young people ends by mid-adolescence after which most males and many females are expected 16 to work outside the home. The ILO has termed the pattern of present and growing global youth unemployment as "stark" (ILO:2002) Young people worldwide are at higher risk for unemployment, partial employment or full employment at lower wages than adult workers. Adolescents with disabilities are at even greater risk. Coming on to the job market with little education and few or no skills, they have difficulty competing. (UNICEF:1995) For some, specific physical or intellectual impairments may further limit their job options. For most, social prejudice makes employers unwilling or hesitant to hire them. Yet, as the United Nation's report Disabled Youth and Employment states, "the aims of transition (into the work place) are the same for all ... the needs of those with disabilities are not different in kind, only in degree." (UN:1998) Employment rates of disabled youth are rarely tracked in

Developing countries. However, if the general pattern of unemployment and underemployment for the rest of the disabled population holds true, it can be anticipated that unemployment rates among disabled adolescents and youth will be the higher than for all other young people. Rates of unemployment among the general adult disabled population vary from country to country but on average, tend to be at some 40-60% higher than for the general nondisabled population. (Elwan:1999) This is true even in developed countries with sophisticated skills training programs to help in the transition from school to work and reserved employment schemes. (Elwan:1999; Metts:1999). Overall, the ILO estimates the unemployment rate among people with disabilities in the Developing world is an overwhelming problem - up to 80% in some countries. (ILO:2003) Furthermore, even when they enter the work place, adolescents with disabilities often find they have little margin for error. Unlike non-disabled adolescents who frequently fail at a first job or apprenticeship, adolescents with disabilities are rarely allowed to explore their options. Should they not succeed in an initial apprenticeship or be fired from their first job, those around them are quick to label them unemployable and refuse to let them try again. Unemployment among disabled young women, in all societies, averages 50% higher than unemployment among comparably educated disabled young men, (itself double that of their non-disabled male peers). 17 Disabled young people who are members of ethnic and minority communities also are routinely found to have an unemployment rate significantly higher than that of their non-minority disabled peers. For all these reasons, young people with disabilities are more likely to be unemployed, more likely to be underemployed (i.e.: working fewer hours, working at seasonal jobs) and more likely to be employed at a lower wage, than their non-disabled peers. Moreover they are often the last to be hired and the first to be laid off or fired should time become hard. Not only is their employment status in a continual state of flux, but individuals with disability are also more likely to be hired for jobs that require little training and have few opportunities for advancement. Even when they have received a solid education, they take a longer time to find a position, have less job security and less prospect of advancement with that job than do their non-disabled peers with comparable levels of education. This is true even in industrialized countries for individuals with disability who have received a college education and particularly true for college educated women with disability. (Fine and Asch:1988; Ficke:1991) Citing formal employment figures however, may be misleading. Presumably, only those whose disabilities are too severe or those whose families are wealthy enough to provide for their needs, do not contribute in some way. The vast majority of young people with disabilities worldwide do in fact work, although they usually are officially listed as unemployed. Millions work outside the home, doing menial tasks or working as street beggars. Millions more work long hours within the family home or on the family farm. They cook, clean, baby-sit, care for ailing and aged relatives, or tend gardens, fields and flocks. (UNICEF:1999) For the non-disabled young adult, taking on an increasing number of chores within the family unit is often seen as a way of building skills that will eventually lead to more independent, adult status. Identical work is frequently viewed as an end in itself for those with disabilities or as a way of helping to cover the costs of their food and housing. Such types of work by disabled young adults, even when they are of 18 great financial significance to the household, may go unnoticed by economists, local communities and even by their own families. Moreover, many young people with disabilities working on the family farm or assembling piece work in the kitchen may have their work brought to the marketplace by others who receive the credit and collect the wages for that work. As is the case with so many other aspects of disabled youth, we simply know very little about young people living in these types of household arrangements. Overall however, the situation continues to be dire. Millions of adolescents and young adults with disabilities find themselves in the position of being unable to support themselves for the present or to plan for the future. Moreover, not only do they routinely earn far less than their peers, but in many cases, society and their families allow them little or no control of what income they do manage to bring in.

SOCIAL IMPLICATIONS

For non-disabled young people, the transition from childhood to adulthood is a period that prepares the individual for successful adulthood. Yet for young people with disability, there is an almost universal lack of inclusion in activities that build fundamental social, educational and economic skills. This exclusion is often formally sanctioned, with adolescents and youth with disabilities being barred from participating in formal cultural and religious ceremonies that help define an individual's changing status in the eyes of the community. Disabled young people are also often left out of the less formal 'rites of passage': joining a sports team, courting, learning to drive the family truck. This exclusion distinguishes young people with disability from ALL other groups of young people in every society and this exclusion has profound implications for their personal lives..(UNICEF:1999) A major issue in the lives of all disabled young people is the growing physical maturation and changing social role that prepares them for marriage and children. In reality, young people with disability often have little or no say over where they will live, whom they will live with and what role they will play within their families or communities. Moreover disabled young people are often denied the right to build 19 families of their own. Social and family constraints make it unlikely that many young people with disabilities will marry. Indeed, in some countries, individuals with some types of disability are unable to legally obtain a marriage license. This is particularly true for disabled young women. (ESCAP:1995) Without the prospect of marriage, in many societies, these young people can not hope to be accepted as full adult members of their communities. This does not mean that young men and women with disability do not become involved in relationships, or that they do not engage in sexual activities, only that there is often no social acknowledgement (and often no sex education) provided them. (Wallace:1990; Cheng and Udry:2002) This places adolescent girls and young women with disabilities in particular, at increased risk for pregnancy and sexually transmitted diseases. In one of the few studies of its kind, the United States National Longitudinal Study (1993) found those three to five years after completion of high school, females with disability were significantly more likely to be mothers than were either non-disabled females or disabled males. Although 23.7% of all youth in this demographic pool had had children, only 16.5% of disabled males had become fathers. In contrast, 40.6% of all disabled females in this age range had given birth to one or more children. For young women with emotional disturbances, learning disabilities or those with hearing impairments, almost 50% had become pregnant in the years immediately following high school. For disabled females who had dropped out of school, 54% had become mothers. (US Department of Education: 1993) The majority of these pregnancies occurred outside of marriage. Already struggling to earn a living comparable to that of their non-disabled peers, the necessity of providing for a child, particularly in those cases where they are not married, places yet an additional burden on these young disabled mothers. (ILO: 1989; Crawford et al:2002) In those societies where men are allowed to take more than one wife or routinely take a mistress, a teenage girl or young woman with a disability is more likely to become a second or third wives within a larger household or a mistress, than to become a first or primary wife. In these types of arrangements, the young women with disability, and their children, often will have less right to play a key role in family decision making and significantly less claim to both household resources and inheritance. 20 Not only do expectations for what is an appropriate role for young men and women with disability vary from one country to the next, within countries, expectations often vary from one ethnic or minority community to the next. (Groce and Zola: 1993)

HEALTH AND MEDICAL ISSUES

Globally, social, economic and educational issues are far more pressing issues for many young people with disabilities than are medical issues. However, the availability of rehabilitative care, prosthetic devices and age appropriate health care need to be singled out both because of a significant lack of such services and because all too often, socio-economic discussions about disabled young people are side tracked by the presumed medical or rehabilitative needs of the population. (SIDA 1995) There are two areas of medical concern that must be noted: unmet rehabilitative needs for some young people may lessen their ability to fully participate in society; and lack of access to general health and health promotion services may lessen a young person's ability to maintain good health and productivity. The United Nations estimates that worldwide only 3% of all individuals with disability who need rehabilitation receive any sort of care. (Helander:1999) Moreover, rehabilitative services tend to be concentrated in urban areas and are prohibitively expensive. Programs that require long-term care are unavailable to many. This is particularly true for young women in societies where females not allowed to travel or live away from home unescorted once they enter puberty. (ILO:1989) Globally women and children receive less than 20% of all rehabilitation services. (ESCAP:1995:10) Prosthetic devices, (artificial limbs, wheelchairs, hearing aids, eyeglasses, etc.) are often difficult and expensive to acquire, and a rapidly growing adolescent will need a replacement every year or two. (Werner:1987) The issue is not simply cosmetic. A poorly fitting artificial limb has profound psychological and social implications for an already marginalized young person. A wheelchair that has become too small limits the ability of a 21 young person to leave the house to attend school, work or establish any measure of autonomy. Community Based Rehabilitation efforts (CBR), while often offering significant interventions and programs, usually concentrates either on younger children or on adults, again missing the opportunity to reach out specifically to address the specific needs of young people with disability. Decreased productivity for disabled young people is not attributable solely to lack of access to rehabilitative care and technologies. Lack of access to general medical care is also reported widely. (Altman:1999) In many cases, health care facilities are simply inaccessible - stairs block access for wheelchair users or there is a lack of Sign Language interpreters, making medical consultation virtually meaningless for deaf individuals. Additionally, health care workers often refuse to provide basic vaccinations or reproductive health information to disabled young people because it is felt that these people do not have the need for such information or do not have the right to utilize scarce resources. (Groce:2003) All of this has significant implications for potential productivity of individuals with disability and can lessen their ability to contribute to their communities. An additional issue that is often overlooked, but a key concern to the health and well being of young people with disability is their increased risk of being victims of violence. Many young people are initially disabled as a result of violence, either through interpersonal violence within the household or community, or as a result of warfare, child soldiering, through landmines or other forms of civic strife. Once disabled, these individuals are at increase risk of being victims of physical and psychological abuse, domestic and sexual violence and rape. Again, few statistics are available, but what statistics do exist indicate that individuals with disability are at up to three times as likely to be the victims of domestic violence, violence in the community and rape as their non-disabled peers. (Sobsey:1991, 1996; Chenoweth:1996; Nosek et al:2001) These young people are at risk in the home and in the community. They also face a profound lack of legal protection. In many countries, police and prosecutors will not even take complaints from disabled individuals or will not allow them to give testimony in courts - which means that such violence can continue unchecked. Indeed, in both Developing and industrialized countries, there has been a growing number of accounts of disabled young 22 people being targeted by sexual predators specifically because they either cannot report the abuse or will not be believed when such abuse is reported. (Groce:2003) Violence and sexual abuse is also of great concern for the significant number of young people who continue to be institutionalized in schools, hospitals and asylums. Some young people have been consigned to such institutions as young children, however, many are sent to institutions and asylums during adolescents by families who feel they have grown to big or are now too old, to be able too live at home. Reports of violence in such institutions, as well as a number of other significant human rights violations, are of particular concern. (Crossmaker:1991; MDRI:2002)

Programs for Young People with Disability

There are an increasing number of programs that address the specific needs of young people with disabilities organized by government agencies, private voluntary organizations, religious organizations and community groups. However, globally the number of such programs remains small. In an international survey on the status of disabled adolescents (UNICEF:1999) only 12% of all the disability experts and organizations contacted were able to identify specific programs that targeted disabled young people as a distinct group. Almost all the programs identified were very small, serving fewer than 100 young people in nations where millions are disabled. Such programs furthermore, are more likely to be urban based and only available to more affluent young people. These small programs can provide models, but have not yet been taken to scale or systematically evaluated. Also in recent years, a number of disability organizations have begun to address the needs of young 23 people with disabilities as a distinct subgroup. Some, such as the World Blind Union have established a Committee on Youth to improve outreach. In several cases, organization has been formed to focus wholly on adolescents or young adults with disabilities. For example, in Russia, the new National Federation of Hard of Hearing Young People, is bringing together adolescents for mutual support and social interactions. In the United States, there is now a National Center on Youth with Disabilities in Minnesota. In several communities in both the United States and Canada, adolescents are paired with older adults with similar disabling conditions, who serve as mentors. Because there is such a diversity of the types of programs for young people with disabilities worldwide, it is difficult to establish universal criteria for why certain programs are judged to be successful. However, programs identified as successful in the UNICEF study (1999) seem to share the following attributes: whether serving young people with disabilities separately from or alongside of their nondisabled peers, such programs encourage them to engage in activities that build the skills and confidence they will need to function effectively in society. These programs have well thought out outcomes, sufficient organization structure and funding for on-going support. They include an evaluative component to ensure that programs and services provided meet the actual needs of young people as well as their long-term goals. Finally, and of great importance, such programs were felt to be particularly effective when young people with disabilities themselves help design, oversee and evaluate them. Such programs also appear to be more successful when they help to foster leadership, advocacy and self-sufficiency skills in young people with disability through the mentorship of older disability advocates. (Crawford, et al 2002) The need for more gender sensitive programs that ensure that the unique programmatic needs of girls and young women are considered and addressed has also been reported. Russo (2003) notes that adolescent girls and young women are less likely to participate in programs than are their disabled male peers and are more likely to leave such programs if their specific needs are not meet. Of additional concern is the fact that in a number of countries and regions, the leadership of disability advocacy groups remains predominantly male. Where females are included, they are often assigned to oversee and advocate in arenas traditionally defined as 'female' - for example, the welfare of disabled children or of education. A similar pattern has been noted for individuals with disability who come from ethnic or minority communities: they are often asked to oversee disability advocacy efforts or outreach programs targeted to their particular ethnic or minority populations. Broader leadership and policy roles in organizations are often denied these women and members of minority populations - no matter what their specific individual interests and aspirations might be

Inclusive Programs

Separate programs for disabled young people are not alone the answer. All too often, young people with disabilities are not included in broader international development programs; for example, village wide, regional, and national programs that targeted to all young people in the general community. Given the prevalence of disability in the community, some 10% of any group of young people in any community should be young people with disability. If young people with disability are missing from a skills building initiative or local development project, then the question for whomever is organizing the program is: where are they?, why are they missing from a program designed to benefit the general population? Innovative examples are beginning to appear, such as the World Bank's recently initiated Velugu project which is intended to systematically integrate disabled people into the mainstream of rural poverty alleviation programs. It has been suggested that the fundamental measure of inclusion cross-culturally is, 'does a disabled young person have the same rights to participate and to make decisions on their own behalf as do their non-disabled peers'. Answering this question offers a starting point for assessing economic and social inclusion in a broader cross-cultural framework.

Development of an Advocacy

Base while the past decade has seen a blossoming of disability-directed advocacy groups throughout much of the Developing world, in fact, only in a small percentage of these groups do young people with disability play a significant role. However, there are examples of such programs that already focus on the development of specific skills or provide unique experiences for young people with disability. For example, Mobility International USA, (MIUSA) brings disabled adolescents from around the world to leadership training programs at its home base in Eugene, Oregon; specifically targeting young disabled women for leadership training. (Crawford et al, 2002) The Japanese Society for Rehabilitation has an international Fellows Program that identifies and brings to Japan a select group of disabled young people from Developing countries who have shown great promise as future leaders. Such leadership among disabled young people at the local, national and international level, must be fostered as part of overall advocacy, both to strengthen the present and to guarantee the future. Of particular note are Centers for Independent Living, both in industrialized countries and increasingly in the Developing world, where in addition to broader advocacy issues, increasing attention has been paid to issues of mentoring young people by older individuals with disability. In countries where the norm is for young people to establish households independent of those of their parents, develop job skills, enter the workforce and establish social networks separate from those of their families, such centers have been instrumental in reaching out to many young people in transition. They provide young people with disability access to information, choices and supports that allow them new options and ideas. Most importantly, such Centers often put young people with disability in touch - (sometimes for the first time in their lives) with other disabled young people and with disabled adults, who can provide them with crucial support networks and mentoring relationships. Currently, such Centers tend to be poorly funded and urban based. How they can be better adapted to reach young people with disability in rural areas, those living within more traditional family and traditional community structures, still needs to be more systematically examined.

4.8 Check Your Progress`

- What is Anatomical Development of the Adolescent?
- Illustrate Sexuality, Alternative options for people with intellectual disability.

- What is peer support strategy?
- What is premarital counseling?
- Illustrate the ethical issues on societal and sexual perspectives of persons with intellectual disabilities.
- What are the common challenges faced by persons with Intellectual Disability and other disabled persons?

4.9 Let Us Sum Up

Adolescents with disabilities are among the most marginalized and poorest of all of the world's youth. According to the United Nations, almost a third of the world's disabled population is youth and over 80% live in developing countries. Like people with disabilities generally, adolescents with disabilities often experience social exclusion and discrimination and do not have the same access to human rights as their non-disabled peers.

As adolescents move through this developmental period, the adults in their lives are often caught in the wind of their sails, making it necessary for both adolescents and adults to change the way in which they relate to each other. During this time, adolescents prepare and practice for the coming role of young adulthood. Teachers might spend more time with adolescents than do even their own parents. For persons with Intellectual Disabilities it is a crucial period because of the imparity of their physical development and cognitive or intellectual development.

Families today can take many forms-single parent, shared custody, adoptive, blended, foster, traditional dual parent, to name a few. Regardless of family form, a Strong sense of bonding, closeness, and attachment to family have been found to be associated with better emotional development, better school performance, and engagement of adult with Intellectual Disabilities.

The majority of adults with intellectual and developmental disabilities (I/DD) are either unemployed or underemployed, despite their ability, desire, and willingness to work in the community.

Sexuality is a key part of human nature. People with intellectual disability experience the same range of sexual thoughts, attitudes, feelings, desires, fantasies and activities as anyone else. To understand and enjoy sexuality, everyone needs adequate information and support from a young age.

Ethical issues are often at the center of the debate when it comes to social issues. Groups argue that things are moral or immoral, and they create an ethical debate to support their argument. Ethical guidelines can come from personal philosophy, religion and government.

Millions of young people between the ages of 10 and 24 are disabled and few currently have lives or will have futures a rich as those of their non-disabled peers. These individuals' physical, intellectual or mental health impairments are not what will hold them back. At issue are common social, economic and cultural prejudices against disability that are particularly pronounced when viewed in conjunction with the widely held social discomfort with the needs of adolescents and young adults.

In too many countries, disability is seen as a transient state. The expectation that a child with a disability will either recover or die does not fit the realities of those young people who will survive, often for decades to come. These young people will survive whether or not they receive an education, are provided medical and rehabilitative care or are included in the social, religious and economic life of their communities. Their existence and our own however, will be much richer if they are allowed to develop to their full potential.

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Unit 5 ❑ CBR (Community Based Rehabilitation) and CPP (Community People Participation) Curriculam Evaluation

Structure :

5.1 Introduction:

CBR is an inclusive development strategy deployed to eliminate barriers to development; it aims to address the causes of disability; and to deliver quality services and programs. **Community-Based Rehabilitation (CBR)** strives for a better life for everyone in the community, including people with disabilities. It is a right-based approach that aims to bring persons with disabilities and the community together on an equal basis.CBR is concerned with community action, which guarantees the same rights and opportunities for everyone, including persons with disabilities, in order to maximize the full potential of everyone in the community. It believes in the ability, potential and right of persons with disabilities to contribute to progress.

The components of a CBR programme should include: creating a positive attitude towards people with disabilities, provision of functional rehabilitation services, provision of education and training opportunities, creation of micro and macro income-generation opportunities, provision of care facilities, prevention of the causes of disabilities, management, monitoring and evaluation.

A community asset (or community resource, a very similar term) is anything that can be used to improve the quality of community life. Hence community resources are the people and places that members of a given community can turn to for assistance in filling an unmet need.

Community assets should be reviewed on a regular basis. Asset identification should be a regular part of community life, so that community assets can be taken advantage of when they're needed.

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.

Parents' potential contribution to CBR development is enormous, Parents have a very powerful role to play in the promotion of the inclusion of disabled children within mainstream educational settings, as well as working towards the development of special provisions of that children, both, within mainstream settings and in special settings as required.

Throughout the world, people with disabilities have united in organizations as advocates for their own rights to influence decision-makers in governments and all sectors of society. These organizations are known as disabled people's organizations.

Disabled people's organizations usually exist at the regional and national levels e.g. in major cities. They may be "single-disability" organizations and represent individuals with a particular type of impairment, such as an intellectual or visual impairment or they may be "cross-disability" organizations and inclusive of all people with disabilities.

Historically CBR programmes and disabled people's organizations have not worked closely together. Disabled people's organizations may be hesitant about working with CBR programmes for a number of reasons, including the fact that, in the past, most CBR programmes were based on a medical model of disability and were run by nondisabled people and professionals, without the active participation of people with disabilities. Also, many CBR programmes have failed to include people with particular impairments, e.g. people with intellectual or hearing impairments who are priority groups for many disabled people's organizations.

While disabled people's organizations and CBR programmes have differences in their origins and strategies- they do share similar goals, e.g. ensuring equal opportunities and social inclusion of disabled people. It is important that both disabled people's organizations and CBR have mutual respect for each other and work towards developing successful partnerships to meet these common goals.

Little progress will be made towards mainstreaming disability until community support is built up and the different sectors of society become actively involved in the process of change. CBR programmes can use community mobilization to bring together stakeholders in the community, e.g. people with disabilities, family members, self-help groups, disabled people's organizations, community members, local authorities, local leaders, decision- and policy-makers, to address barriers within the community and ensure the successful inclusion of people with disabilities in their communities with equal rights and opportunities.

5.2 Objectives:

1. Developing concept regarding CBR
2. Understanding the significance and several elements of CBR
3. Understanding the types of community resources along with process of their mobilization
4. Understanding the process of organizing services for disabled including PwIDs in the community
5. Developing a clear concept about the roles of several service providers involved in CBR

5.3 Concept, Definition and Scope of CBR:

Before discussing Community Based Rehabilitation we should understand what rehabilitation is.

REHABILITATION:

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self - actualization. Rehabilitation can no longer be seen as a product to be dispensed; rather rehabilitation should be offered as a process in which all participants are actively and closely involved.

COMMUNITY BASED REHABILITATION (CBR):

It is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. The primary objective of CBR is the improvement of the quality of life of people with disability / marginalized persons.

In simple terms, CBR refers to the delivery of basic services to disabled people within their community, including all services necessary to improve the participation and functioning in daily activity. More broadly, the UNESCO and WHO define CBR, as:

A strategy within community development for rehabilitation, equalization of opportunities, and social inclusion for all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and appropriate health, education, vocation and social services.

Key principles relating to CBR are

- equality,
- social justice,
- solidarity,
- integration
- dignity.

CBR is not an approach that only focuses on the physical or medical needs of a person or delivering care to disabled people as passive recipients. It is not outreach from a centre. It is not determined by the needs of an institution or groups of professionals, neither is it segregated and separate from services for other people.

It involves capacity building of disabled people and their families, in the context of their community and culture. It is a holistic approach encompassing physical, social, employment, educational, economic and other needs. It promotes the social inclusion of disabled people in existing mainstream services. It is a system based in the community, using district and national level services.

While initially a strategy to increase access to rehabilitation services in resource-constrained settings, CBR is now a multi sectorial approach working to improve the equalization of opportunities and social inclusion of people with disabilities while combating the perpetual cycle of poverty and disability. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services.

Hence, CBR is an inclusive development strategy deployed to eliminate barriers to development; it aims to address the causes of disability; and to deliver quality services and programs.

Community-based rehabilitation (CBR) strives for a better life for everyone in the community, including people with disabilities. It is a rights-based approach that aims to bring persons with disabilities and the community together on an equal basis.

CBR is concerned with community action, which guarantees the same rights and opportunities for everyone, including persons with disabilities, in order to maximize the full potential of everyone in the community. It believes in the ability, potential and right of persons with disabilities to contribute to progress. CBR also believes in the inherent capacities of any community and begins by living, listening, learning and sharing with the community. CBR is an approach which aims to deliver specialized services and access mainstream services, builds on what is already happening in any community, utilizes local resources and break down barriers so that people with disabilities have the same rights, the same opportunities as their fellow citizens.

Why CBR?

The aim of community-based rehabilitation (CBR) is to help people with disabilities, by establishing community-based programs for social integration, equalization of opportunities, and Physical therapy rehabilitation programs for the disabled.

The majority of persons with disabilities live in low-income countries, where they may experience poverty and marginalization.

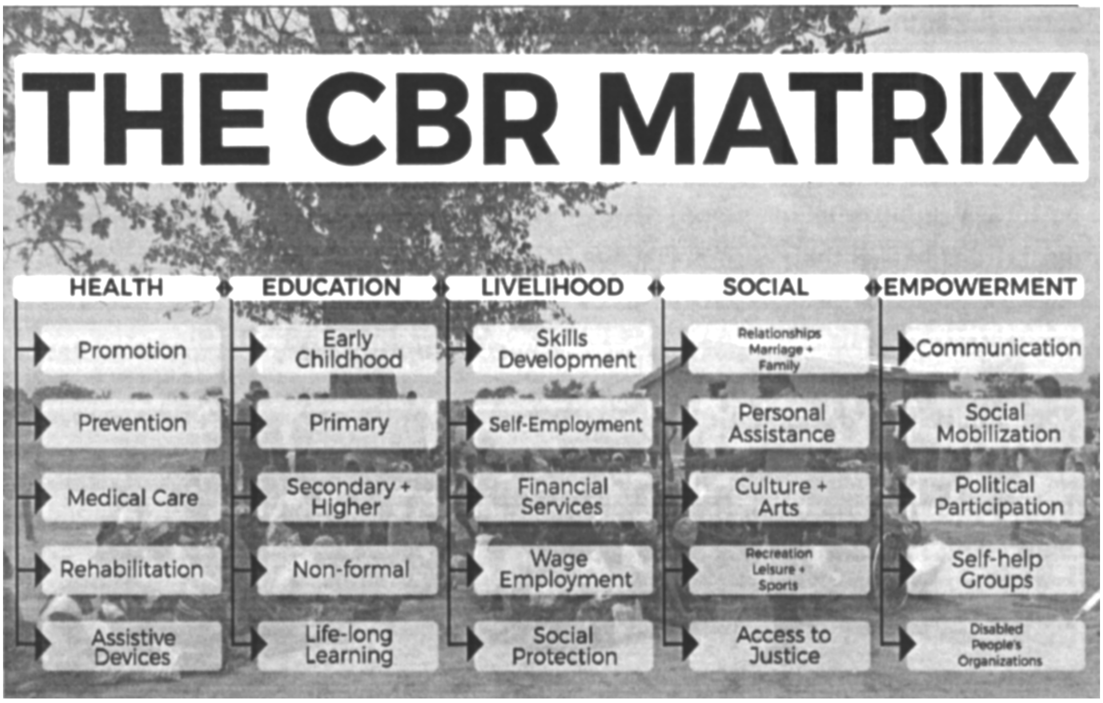
Poverty has been shown to lead to exclusion (from services and community activities) and increases the chances of disability; in turn, disability usually means exclusion from these same services and increases the chances of poverty. Health care, education and livelihood services may be scarce, costly and not conducive for persons with disabilities to access due to various barriers.

A cost-effective strategy that makes use of existing community services and promotes inclusion in place of exclusion is needed to reach persons with disabilities within their communities.

5.4 Models of CBR - Advantages and Limitations:

Community Based Rehabilitation, or CBR, is becoming increasingly recognized as an appropriate model of service delivery to provide effective rehabilitation and therapy services to rural and remote communities, with particular relevance for remote and rural Indigenous communities.

The basic concept of CBR centers on decentralizing responsibility and resources, both human and financial, to community level organizations. CBR models are based on a collaborative relationship between the Allied Health Professional, Community Based Workers and the broader community.



THE CBR MATRIX

HEALTH	EDUCATION	LIVELIHOOD	SOCIAL	EMPOWERMENT
Promotion	Early Childhood	Skills Development	Relationships Marriage + Family	Communication
Prevention	Primary	Self-Employment	Personal Assistance	Social Mobilization
Medical Care	Secondary + Higher	Financial Services	Culture + Arts	Political Participation
Rehabilitation	Non-formal	Wage Employment	Recreation Leisure + Sports	Self-help Groups
Assistive Devices	Life-long Learning	Social Protection	Access to Justice	Disabled People's Organizations

Community-based rehabilitation (CBR) was initiated by WHO following the Declaration of Alma-Ata in 1978 in an effort to enhance the quality of life for people with disabilities and their families; meet their basic needs; and ensure their inclusion and participation. While initially a strategy to increase access to rehabilitation services in resource-constrained settings, CBR is now a multi sectorial approach working to improve the equalization of opportunities and social inclusion of people with disabilities while combating the perpetual cycle of poverty and disability. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services.

Health

The Constitution of the World Health Organization (WHO) states that "enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" Unfortunately, evidence shows that people with disabilities often experience poorer levels of health than the general population and face various challenges to the enjoyment of their right to health. Community-based rehabilitation (CBR) programmes support people with disabilities in attaining their highest possible level of health, working across five key areas: health promotion, prevention, medical care, rehabilitation and assistive devices. CBR facilitates inclusive health by working with the health sector to ensure access for all people with disabilities, advocating for health services to accommodate the rights of people with disabilities and be responsive, community-based and participatory. Specific services include;

- Advisory services in blindness prevention and sight restoration by way of referrals, medical treatment or surgery
- Organizing health promotion talks through community durbars and radio programmes
- Orthopedic and Physiotherapy services
- Audio logical services
- Mental health services (Management of epileptic seizures and other mentally related disorders)
- Prevention of childhood disability activities through a multi-sectorial collaboration
- Provision of rehabilitation services to persons with disabilities
- Provision of basic assistive devices to persons with disabilities
- Prevention of childhood disabilities using a multi-disciplinary team screening approach

Education

Education is about all people being able to learn what they need and want throughout their lives, according to their potential. It includes "learning to know, to do, to live together and to be". Education takes place in the family, the community, schools and institutions, and in society as a whole. The role of CBR is to work with the education sector to help make education inclusive at all levels, and to facilitate access to education and lifelong learning for people with disabilities. This include;

- Referrals of Children with disabilities to special Schools from primary, secondary and tertiary
- Provision of lifelong learning activities for the severely disabled persons
- Early Childhood intervention
- Integration of Children with mild disabilities into the regular school system

Livelihood

People with disabilities in low-income countries are affected by the same factors which cause poverty for others, but also face added disadvantages. Children with disabilities face barriers to education; youth with disabilities face barriers to training; adults with disabilities face barriers to decent work. Most damaging of all, families and communities may think that people with disabilities are incapable of learning skills and working. By encouraging and facilitating work by women and men with disabilities, community-based rehabilitation (CBR) programmes can help individuals and their families to secure the necessities of life and improve their economic and social situations. By taking into consideration the needs and views of people with disabilities and making provision for their inclusion in national poverty reduction and other development programmes, opportunities for education, skills acquisition and work can be provided for people with disabilities and their families, enabling them to emerge from poverty. Accessing livelihood opportunities is one of the key factors in eliminating poverty.

Under this component CBR is to facilitate access for people with disabilities and their families to acquiring skills, livelihood opportunities, enhance participation in community life and self-fulfillment.

- Engaging vulnerable groups/individuals in economic activities (PWD's and mental health clients in productive income generating ventures)

- Micro - credit for the vulnerable groups
- Vocational skill training/ skill development for young disabled adults/persons with mental illness
- Linking persons with disabilities/individuals to financial institutions for credit
- Animal rearing/Credit in-Kind system(cashless system)
- Handicrafts

Social

Being actively included in the social life of one's family and community is important for personal development. The opportunity to participate in social activities has a strong impact on a person's identity, self-esteem, quality of life, and ultimately his/her social status. Because people with disabilities face many barriers in society they often have fewer opportunities to participate in social activities. The role of CBR is to work with all relevant stakeholders to ensure full participation of people with disabilities in the social life of their families and communities. CBR programmes provide support and assistance to people with disabilities to enable them to access social opportunities, and can challenge stigma and discrimination to bring about positive social change.

Under this component CBR seeks to work with all stakeholders to ensure the full participation of persons with disabilities in the social life of their families and communities. The program provide support and assistance to persons with disabilities to enable them access social opportunities and challenge stigma and discrimination to bring about positive change.

- Ensuring that the vulnerable groups that we work with/ for have good relationship/marriages with the family/community members
- Ensuring culture/religious participation of the vulnerable groups
- Ensuring that persons with disabilities have access to justice

Advocacy and Empowerment

While the first four components of the matrix relate to key development sectors (i.e. health, education, livelihood, and social sectors), the empowerment component focuses on the importance of empowering people with disabilities, their family members and communities to facilitate the mainstreaming of disability across each sector and to ensure that everybody is able to access their rights and entitlements. Empowerment begins to happen when individuals or groups of people recognize that they can change their situation, and begin to do so. It is a process that involves things like awareness and capacity-building leading to greater participation, to greater decision-making power and control, and to action for change Having a say and being listened to promotes a self-power to make decisions which allows people with disabilities to live free and independent with the ability to fight for their own rights and gain recognition as equals.

Under this component CBR seeks to assist persons with disabilities to develop advocacy and communication skills and, to ensure that their environment provides appropriate opportunities and support to allow them to make decisions and express their needs and desires effectively.

Currently the CBR programme has established forty five (45) Disable People Organizations (DPOs) and twenty three (23) Self-Help-Groups of persons with mental illness.

- Awareness creation on rights based issues on disabilities
- Establishment of Disable People Organizations (DPOs)
- Establishment of Self-Help-Groups in working communities
- Establishment of community Development Committees to spear head development at the community level.
- Social mobilization at the community level for development.
- Provision of training on group dynamics

Advantages of CBR Programmes

CBR has many benefits for both the clients and the clinician, particularly in remote and rural practice settings. For communities, CBR increases the accessibility of rehabilitation and therapy services for clients. These models increase the services available to people living in rural and remote areas and allow clients to stay in their communities when receiving therapy services.

Additionally, the community development orientation of CBR builds on community capacity and both the individual and community level. At the individual level, CBR models facilitate the training and employment of Community Based Workers, increasing the skills, income, and employability of local community members. At a community level the collaborative relationship between communities and health services empowers communities and develops leadership.

For the clinician, CBR increases the service coverage that can be achieved. It also reduces the frequency of travel to communities, and as a consequence saves time and money.

- Home based
- Less expensive
- Existing community responses and resources
- Focus on quality rather than quantity
- Multiple approaches based on community needs

Limitations of CBR Programmes

- Different priorities in poor- Survival needs has more priorities than solving problems of disabled. CBR programme should therefore be focusing on essential needs.
- Complex Organization
- Low field activity- Educated workers rarely go to field and also find hard to communicate with low educated disabled people.
- Low Social status to CBR worker- Frontline CBR is low profile job so less educated workers may influence quality of services provided
- Lack of community ownership- Breakdown of traditional social structure that contribute to several problems
- Expensive approach- as focus on quality (few hardcore patients)

5.5 Types of Community Resources and Their Mobilization:

A community asset (or community resource, a very similar term) is anything that can be used to improve the quality of community life.

Hence community resources are the people and places- members of a given community can turn to for assistance in filling an unmet need.

And this means:

- It can be a person -- Residents can be empowered to realize and use their abilities to build and transform the community. The stay-at-home mom or dad who organizes a playgroup. The informal neighborhood leader. The firefighter who risks his life to keep the community safe. These are all community assets.
- It can be a physical structure or place -- a school, hospital, church, library, recreation center, and social club. It could be a town landmark or symbol. It might also be an unused building that could house a community hospice, or a second floor room ideal for community meetings. Or it might be a public place that already belongs to the community -- a park, a wetland, or other open space.
- It can be a community service that makes life better for some or all community members - public transportation, early childhood education center, community recycling facilities, cultural organization.
- It can be a business that provides jobs and supports the local economy.
- Everyone in the community are potential community assets. Everyone has some skills or talents, and everyone can provide knowledge about the community, connections to the people they know, and the kind of support that every effort needs - making phone calls, stuffing envelopes, giving people information, moving equipment or supplies - whatever needs doing. This suggests that everyone in the community can be a force for community improvement if only we knew what their assets were, and could put them to use.

WHY SHOULD ONE IDENTIFY COMMUNITY ASSETS?

- They can be used as a foundation for community improvement.
- External resources (e.g., federal and state money) or grants may not be available. Therefore, the resources for change must come from within each community.
- Identifying and mobilizing community assets enables community residents to gain control over their lives.
- Improvement efforts are more effective, and longer-lasting, when community members dedicate their time and talents to changes they desire.
- One can't fully understand the community without identifying its assets. Knowing the community's strengths makes it easier to understand what kinds of programs or initiatives might be possible to address the community's needs.

When efforts are planned on the strengths of the community, people are likely to feel more positive about them, and to believe they can succeed. It's a lot easier to gain community support for an effort that emphasizes positive-view - like"We have the resources within our community to deal with this, and we can do it!" - Than one that stresses how large a problem is and how difficult it is to solve.

MAPPING COMMUNITY ASSETS

Once one has collected asset information, it's often especially helpful to put it on a map. Maps are good visual aids: seeing the data right in front of one often increases his/her insight and understanding. There are several ways to go about this:

One mapping method is to find a large street map of one's community, with few other markings. (Local Planning Department may help here, or one can probably print one out from Google Maps or some other similar site.) Then just mark with a dot, tag, or push-pin (maybe color-coded by type) the geographic location of the groups and organizations he/she has found. Certain locations have different numbers or types of associations. Those areas where few associations exist may be good targets for community development later on.

This type of mapping can also be done by computer. Software programs are available to help one to do this.

USING THE IDENTIFIED COMMUNITY ASSETS

The next and most important step is to make sure the assets identified get used.

The real value and payoff of identifying assets is in actions that will improve one's community. If one has personal assets, such as savings, he/she probably don't want to hide them under a mattress. The same applies to the assets in his/her community. How one can maximize their return?

We'll itemize just a few possibilities below. Think about which might fit best for you, and what your own next steps might be:

- Community assets can be the basis for asset-based planning. Planning for community development and interventions can be based on what the community has to work with, and can include strengthening current assets and developing new ones as well as addressing problems. (John McKnight and John "Jody" Kretzmann, known as the founders of the asset-based planning movement, are also the founders and Co-Directors of the Asset-Based Community Development Institute at Northwestern University, one of the Chicago area's community assets.)

- You can publish the assets identified - on a town or separate website, in a community newsletter, in a community service section in the local newspaper, to name just three possibilities - and make them available to all community members. In doing so, you will stimulate public asset knowledge and use.
- You can target a particular neighborhood or other area for development, on the basis of the asset patterns you have found.
- You can use your knowledge of assets to tackle a new community project -- because now you may have more resources to work on that project than you originally thought.
- You can find new ways to bring groups and organizations together, to learn about each other's assets -- and perhaps to work collaboratively on projects such as the one above.
- You can publicize these assets, and attract new businesses and other opportunities to your community. In both this example and the ones just above, you are using existing assets to create new ones. (This is what makes community work exciting!)
- You can create a school curriculum to teach local students about these assets, thus enriching their knowledge of the community and building community pride.
- You can consider creating a "community coordinator," (or some other title), someone who would deal with assets every day. The coordinator's new job would be to find the right assets in the community to respond to any request or community concern. Would this position pay for itself?
- You (or the new coordinator) can keep records how assets are used in the community, and use those records to generate ideas for improving asset exchange.
- You can set up structured programs for asset exchange, which can range from individual skill swaps to institutional cost-sharing.
- Community assets keep getting reviewed, perhaps on a regular basis. New assets are always coming on the scene; it's good to keep up to date on them. By so doing, the whole asset-identification process can become a regular part of community life.

Community assets should be reviewed on a regular basis. Asset identification should be a regular part of community life, so that community assets can be taken advantage of when they're needed.

Social mobilization- Social mobilization means to bring people and resources together to achieve a particular task. It is necessary to promote the inclusion of people with disability into all aspects of society. The purpose of social mobilization is to get disability into the social consciousness of the community and integrate the disability issue into all development programs Political & economic approach is most powerful, it influences local economic and cultural life. Every decision made by political leaders affects local people. Society is to be involved in problem solving by understanding 'cause and effect'. Changing the policies which causes the pattern of exclusion may result in a wider and longer term effect. The behaviors of people reveal their values and attitudes. Behaviors include how people treat each other. Understanding what motivates people is critical to bring about a change in behavior.

Advocacy and Negotiation skill is required to mobilize community. To advocate means to ask and persuade.

The steps of advocacy are:

i Ask the basic questions:

- What is the problem?
- Where and when does it occur?
- Is it a one-off or does it recur?
- How does it all come about?
- Does it connect to any other problems?
- Who can do something about it?

ii. Set out what you want to achieve - a clear goal.

iii. Collect information - policy documents, legal documents, reports of seminars and conferences, information from professionals and the community, and stories from people with disabilities and their families

iv. Collect similar examples of social injustice from newsletters, TV, the community, people with disabilities, etc.

v. Identify the best point at which to make an intervention - at village, district, provincial or state level.

vi. Look at how decisions were made :

- What is the process?
- What is the decisive moment
- Whose opinion carries most weight and why?
- Build a good working relationships with decision-makers, agencies,media and allies.
- Make sure the interests of people with different impairments and multiple disabilities are included.
- Follow-up, review, change the plan.
- Document the process - the successes and failures

5.6 Organizing Services for PWID in the Community:

The development and implementation of CBR programmes should be based on the following criteria:

1. People with disabilities including PwID must be included in CBR programmes at all stages and levels, including initial programme design and implementation. In order to give significance to their involvement, they must have distinct decision-making roles.
2. The primary objective of CBR programme activities is the improvement of the quality of life of people with disabilities.
3. One focus of CBR programme activities is working with the community to create positive attitudes towards people with disabilities and to motivate community members to support and participate in CBR activities.
4. The other focus of CBR programmes is providing assistance for people with all types of disabilities (physical, sensory, psychological and mental); for people of all ages who may be identified by the community as needing special assistance.
5. All activities in CBR programmes must be sensitive to the situation of girls and women. This is because in many communities throughout the Asian and Pacific

region women are not treated equally. When they are disabled, the problems that they face in life are doubled. Furthermore, women are usually the primary family care-givers for all people with disabilities.

6. CBR programmes must be flexible so that they can operate at the local level and within the context of local conditions. There should not be only one model of CBR because different social and economic contexts and different needs of individual communities will require different solutions. Flexible, local programmes will ensure community involvement and result in a variety of programme models which are appropriate for different places.
7. 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.

CBR programme should include:

1. Creating a positive attitude towards people with disabilities:

This component of CBR programmes is essential to ensure equalization of opportunities for people with disabilities within their own community. Positive attitudes among community members can be created by involving them in the process of programme design and implementation, and by transferring knowledge about disability issues to community members.

2. Provision of functional rehabilitation services:

Often people with disabilities require assistance to overcome or minimize the effects of their functional limitations (disabilities). In communities where professional services are not accessible or available, CBR workers should be trained to provide primary rehabilitation therapy in the following areas of rehabilitation:

- Medical
- Eye care service

- Hearing services
- Physiotherapy
- Occupational therapy
- Orientation and mobility training
- Speech therapy
- Psychological counselling
- Orthotics and prosthetics
- Other devices

3. Provision of education and training opportunities:

People with disabilities must have equal access to educational opportunities and to training that will enable them to make the best use of the opportunities that occur in their lives. In communities where professional services are not accessible or available, CBR workers should be trained to provide basic levels of service in the following areas:

- Early childhood intervention and referral, especially to medical rehabilitation services
- Education in regular schools
- Non-formal education where regular schooling is not available
- Special education in regular or special schools
- Sign language training
- Braille training
- Training in daily living skills

4. Creation of micro and macro income-generation opportunities:

People with disabilities need access to micro and macro income-generation activities, including obtaining financial credit through existing systems, wherever possible. In slums and rural areas, income-generation activities should focus on locally appropriate vocational skills. Training in these skills is best conducted by community members who, with minimal assistance, can easily transfer their skills and knowledge to people with disabilities.

5. Provision of care facilities:

Often, people with extensive disabilities are in need of assistance. When they have no families or their families are incapable of caring for them, in order for them to survive, long-term care facilities must be provided in the community where they can get the assistance that they need. Moreover, day-care facilities may be needed to provide respite for families who either work or need time off for other activities.

6. Prevention of the causes of disabilities:

Many types of disability can be prevented by relatively simple measures. Proper nutrition is one of the more significant ways of preventing disabilities. Another important area of disability prevention is the detection of disability in young children and intervention early in their development, to minimize the effect of impairment. There are many other areas of disability prevention that are also important. These include activities to decrease the number of accidents in the home, on the road and at work, as well as other initiatives to encourage people to pursue healthy lifestyles over the course of their lives.

7. Management, monitoring and evaluation:

The effectiveness and efficiency of all CBR programme components, both in the community and in the area of service delivery outside the community, depend on effective management practices. The impact of programme activities must be measured on a regular basis. People must be trained in effective management practices. Data must be collected, reviewed and evaluated to ensure that programme objectives are met. In this way, the success or failure of a CBR programme can be honestly measured.

8. Empowerment component - The essence of empowerment is that people with disabilities and their families take responsibility for their development within the context of general community development. The outcome of CBR is expected to be a change in their mindsetfrom passive receiver to active contributor in learning, playing, working, and household activities; in politics and cultural activities.

Empowerment of community to assume responsibility for ensuring that all its members, including those with disabilities, achieve equal access to all of the resources that are available to that community, and that they are enabled to participate fully in the social , economic and political life of the community.

Approaches for empowering may be social mobilization, political participation, communication, Self Help Groups (SHGs) and Disabled People's Organization (DPOs). People come together in groups to pursue common interests. A DPO is a bigger than a SHG. It is more formally structured, with office bearers and with systematic ways of conducting its work. Providing information and choices about rehabilitation, education and livelihood, and laying out choices and opening up opportunities for decision making enhances the process of empowerment.

For empowerment to happen five approaches can be used - 1. Social mobilization. 2. Political participation. 3. Language & communication. 4. Self Help Groups (SHGs). 5. Disabled People's Organizations. (DPOs)

About Adult Services

Adult Services are provided to impaired adults age 18 or older, and to their families when appropriate. Services are designed to allow the individual to remain in the least restrictive setting and function as independently as possible by establishing or strengthening appropriate family and social support systems, or by supporting the individual's self-determination. Services may include:

- Case management
- Home-based care
- Access to transportation
- Adult day services
- Nutrition services
- If staying at home is no longer possible, social workers assist clients with finding the most independent setting that meets their needs.

The Philosophy of Adult Services

Adult Services adheres to these principles:

- The worker is an advocate for the adult.

- The adult is the focus of service delivery, and the worker shall preserve and protect the adult's right to self-determination even when there is a community or family request to intervene.
- The least restrictive and least intrusive intervention necessary to stabilize the situation is the most appropriate.
- The adult has the right to make decisions on his or her own behalf until he or she delegates that responsibility voluntarily or the court grants that responsibility to another individual.
- A family-based approach to service delivery enhances services which support and strengthen the adult's informal support system.
- Coordination and combination of formal and informal support systems provide the most effective delivery system

5.7 Roles of Several Service Providers Involved in CBR:

5.7.1 Families and Parents' contribution to CBR development:

Families have the primary responsibility for caring for all of their members. They are the first line of support and assistance for people with disabilities at the local level. As such, families must be included in CBR programme activities. Where the individual with a disability is not able, for whatever reason, to speak for himself or herself, a family member should represent him or her and should be considered a legitimate member of disabled people's organizations. Members of families with experience in caring for people with disabilities are the people who most often initiate CBR programmes and are, or prove to be, the most effective contributors at all levels.CBR programmes can work with families to encourage family members to become advocates for changing negative attitudes within the community; support people with disabilities to effectively communicate and self-advocate for their own needs and wants.

Parents' and families ` potential contribution to CBR development is enormous, but in this topic, five possible areas will be explored, where their efforts could make a significant difference.

1. Overcoming ignorance

We all know that CBR has a major role to play in the education of the community, about disability. Ignorance is a big obstacle; many people with disabilities are in their present situation because they did not know what to do at the time when, the 'enemy' attacked them. Community members need to know how to prevent disabilities. They need to know how to care for, respect and communicate appropriately, with people with disabilities. Parents can make a major contribution towards sensitising families in these areas, by sharing their own experiences. They can encourage other parents to include their children in everyday activities, by providing a sympathetic, listening ear to the families' difficulties. They can also facilitate referrals to medical and social services. Their contribution in these areas can strengthen these aspects of a CBR programme considerably.

2. Promoting sustainability

The sustainability of an individual's independence relies heavily upon setting up the structures and support, which will enable him/her to acquire daily living skills and provide the opportunity for education and employment. Parents can facilitate this process by establishing NGOs, finding ways of sustaining individual PWDs, and making relevant connections between PWDs and prospective educational opportunities and employers. People tend to underestimate the capacity and capability of PWDs to carry out productive activities, for which they can be financially rewarded. They need the opportunity to practice any newly acquired skills and this is where parents can also be very supportive.

3. Promoting the validity and relevance of CBR activities

Essentially, PWDs and their families are the customers and consumers of CBR programmes and one of the objectives of any organization is to satisfy its customers. In order to do this, the customers need to be involved in the identification of what is required and how it can be best achieved. In practice, this means that PWDs and their families need to be involved from the very beginning in any initiative so that their perspectives, wants, hopes, needs, fears and deep seated knowledge of the barriers, can form the design of an initiative, from the very beginning. Their participation is then required throughout the project, to keep the monitoring process relevant and to ensure that the project develops in a way, which will continue to benefit the 'customers'.

4. Parents' role in promoting education

Parents have a very powerful role to play in the promotion of the inclusion of disabled children within mainstream educational settings, as well as working towards the development of special provisions that children, both, within mainstream settings and in special settings, require. Their role is again one of raising awareness and providing the drive and inspiration needed, to initiate and sustain programmes with a lifetime of interest and commitment.

5. Raising gender awareness

Disabled girls, appear to be at a double disadvantage in many societies and India is no exception. CBR programmes need to be very sensitive to the situation faced by disabled girls and women, which includes facing both physical and mental abuse, rape and exploitation. It is difficult for others to imagine what they have to learn to face, such as the problems that arise from menstruation, pregnancy and labour. Culturally, girls are expected to get married, have children and create their own homes. In Indian societies, it is very painful (for parents and PWDs) to know that marriage is almost completely out of question. The worry is also that if you do get married, will you (or your child) be able to live up to the expectations required, and if you do not, what will happen to you?

5.7.2 People with Intellectual disabilities:

People with Intellectual disabilities can and should contribute to all levels of CBR programmes in every position within a programme.

- They know what the effects of local conditions are on themselves. They are likely to have a good understanding of those effects on their peers with disabilities.
- They also know what impairment really means in the context of their family, community and nation. This knowledge enables them to be very effective members of a CBR team.
- They can be more effective than non-disabled people as role models for and counsellors of other people with disabilities.
- People with disabilities have an important role in community education. As community educators, they serve as living examples of people with disabilities who make a significant contribution, provided that they are given the opportunity and the right type of assistance.
- CBR programmes should also facilitate the development of self-help organizations of people with disabilities at the community level.
- They can organize self advocacy group by which they can demand their right. According to RPWD 2016 and UNCRPD 07 they have every right by which they can leave a descent life.

5.7.3 Role of communities and its members in CBR:

Community members should be involved in CBR programmes at all levels because they already know the local environmental conditions, the local economy, the local political situation and how to work with them. They also know about the accessibility, availability and effectiveness of locally available rehabilitation services; who in the community cares enough about other people to become a programme leader or worker; and, which community members have the knowledge and skills for training others in micro-economic activities. They are the people most likely to want to live, work and stay in the community. Community involvement usually requires the agreement and approval, both formal and informal, of the community leaders.

- **Governments (local, regional, national):**

Governments have the most important role in the development and sustainability of CBR programmes. Their cooperation, support and involvement are essential if CBR is to cover the total population and be sustainable. They should implement and coordinate the development of the entire programme structure, including the development of the referral system, as well as the activities within the community. They also should provide resources for non-governmental organizations (NGOs) and community activities. Finally, they should ensure that discriminatory legislation is changed and that the rights of people with disabilities are guaranteed and protected.

- **Non-governmental organizations, local, regional:**

NGOs, including organizations of people with disabilities, are often able to provide resources and skills to facilitate the development of new programmes, especially in areas where none exist. They can develop new approaches to CBR and provide training programmes for government employees, CBR workers, and people with disabilities, families, and community members. NGOs are effective in facilitating the development of community members as CBR programme leaders. They are often best able to provide long-term care facilities for those people with extensive disabilities whose families cannot or will not look after them.

- **Medical professionals, allied health science professionals, social scientists and other professionals:**

Professionals are often in a position where they can, as trainers and educators, facilitate the development of new programmes by making their knowledge and skills accessible to community members and CBR programme workers. They can also ensure that they support community efforts by making themselves available and accessible on a referral basis. When they are in government service, they can advocate and promote the development of CBR programmes as an effective way to provide local-level services quickly.

- **The private sector (business and industry):**

The private sector has a social obligation to return some of the benefits of its operations to the communities that support it. In the past, this support has largely taken the form of charity. Charity occurs when donors "give" whatever they feel are needed or appropriate to people with disabilities. This approach to assisting people with disabilities is no longer appropriate and needs to be changed. Supporting CBR programme activities eliminates the need for charity. CBR support is a much more appropriate way of directing resources to communities and people with disabilities. By supporting CBR programmes, the private sector receives credit for its social involvement while being guaranteed that its support is put to effective and efficient use. Who but trained, knowledgeable community members would know what is most needed by the people of their own community?

5.7.4 Role of Special Educators in Community Based Rehabilitation

The roles and responsibilities of special education professionals are varied. They are responsible for complying with many laws and regulations regarding the treatment and well-being of people with disabilities. Their roles involve every aspect of the educational process.

- Provide direct and indirect instructional support to students in a positive environment.
- Employ special educational strategies and techniques during instruction to improve the development of sensory- and perceptual-motor skills, language, cognition, and memory.
- Instruct students in academic subjects using a variety of techniques such as phonetics, multi-sensory learning, and repetition to reinforce learning and to meet students' varying needs and interests.
- Teach socially acceptable behavior, as determined by the students' individualized education programs (IEPs) by employing techniques in an overall positive behavioral support system.
- Modify the general education curriculum for students with disabilities based upon a variety of instructional techniques and technologies.
- Plan and conduct activities for a balanced program of instruction, demonstration,

and work time that provides students with opportunities to observe, question, and investigate. o Establish and enforce rules for behavior and procedures for maintaining an environment conducive to learning for all students.

- Meet with parents to discuss their children's progress and to determine priorities for their children and their individualized educational needs.
- Confer with parents, administrators, testing specialists, social workers, and other professionals to develop individualized education programs (IEPs) designed to promote students' educational, physical, and social/emotional development.
- Maintain accurate and complete student records and prepare reports on children and activities, as required by laws, district policies, and administrative regulations.
- Establish clear objectives for all lessons, units, and projects and communicate those objectives to students.
- Develop plans for effective communication, monitoring, and follow-up of students in inclusive classroom settings.
- Provide crisis intervention, as needed, for students and those in inclusive classrooms.
- Assist in collection of data for providing appropriate classroom interventions.
- Serve as a member of a multidisciplinary team as appropriate.
- Assist in preparation of data for local, state, and federal reports.
- Maintain professional competence by participating in staff development activities, curriculum development meetings, and other professional opportunities.

5.8 Check Your Progress:

Define Rehabilitation.

Define CBR.

Why CBR is essential?

What are the aims of CBR?

Illustrate the models of CBR.

What is CBR matrix?

What are the advantages and limitations of CBR programmes?

What are the criteria for development and implementation of CBR programmes?

What is Parents' contribution to CBR development?

Explain how People with Intellectual disabilities can contribute to all levels of CBR programmes.

Illustrate the Role of communities and its members in CBR.

Illustrate the Role of Special Educators in CBR.

5.9 Let Us Sum Up:

- Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self - actualization. Rehabilitation can no longer be seen as a product to be dispensed; rather rehabilitation should be offered as a process in which all participants are actively and closely involved
- Community Based Rehabilitation (CBR) is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. The primary objective of CBR is the improvement of the quality of life of people with disability / marginalized persons.
- CBR is an inclusive development strategy deployed to eliminate barriers to development; it aims to address the causes of disability; and to deliver quality services and programs.
- The aim of community-based rehabilitation (CBR) is to help people with disabilities, by establishing community-based programs for social integration, equalization of opportunities, and Physical therapy rehabilitation programs for the disabled.
- Community Based Rehabilitation, or CBR, is becoming increasingly recognized as an appropriate model of service delivery to provide effective rehabilitation

and therapy services to rural and remote communities, with particular relevance for remote and rural Indigenous communities.

- The basic concept of CBR centers on decentralizing responsibility and resources, both human and financial, to community level organizations. CBR models are based on a collaborative relationship between the Allied Health Professional, Community Based Workers and the broader community.
- CBR has many benefits for both the clients and the clinician, particularly in remote and rural practice settings. For communities, CBR increases the accessibility of rehabilitation and therapy services for clients. These models increase the services available to people living in rural and remote areas and allow clients to stay in their communities when receiving therapy services.
- A community asset (or community resource, a very similar term) is anything that can be used to improve the quality of community life. Hence community resources are the people and places - members of a given community can turn to for assistance in filling an unmet need.
- When efforts are planned on the strengths of the community, people are likely to feel more positive about them, and to believe they can succeed. It's a lot easier to gain community support for an effort that emphasizes positive - view - like "We have the resources within our community to deal with this, and we can do it!" - Than one that stresses how large a problem is and how difficult it is to solve.
- Mapping Community Assets: once one has collected asset information, it's often especially helpful to put it on a map. Maps are good visual aids: seeing the data right in front of one often increases his/her insight and understanding.
- Community assets should be reviewed on a regular basis. Asset identification should be a regular part of community life, so that community assets can be taken advantage of when they're needed.
- Social mobilization- Social mobilization means to bring people and resources together to achieve a particular task. It is necessary to promote the inclusion of people with disability into all aspects of society. The purpose of social mobilization is to get disability into the social consciousness of the community and integrate the disability issue into all development programs.
- Advocacy and Negotiation skill is required to mobilize community. To advocate means to ask and persuade.

9. CBR programme should include: creating a positive attitude towards people with disabilities,provision of functional rehabilitation services,provision of education and training opportunities,creation of micro and macro income-

generation opportunities,provision of care facilities,prevention of the causes of disabilities, management, monitoring and evaluation and empowerment component

- People with Intellectual disabilities can and should contribute to all levels of CBR programmes in every position within a programme.
- CBR programmes can work with families to encourage family members to become advocates for changing negative attitudes within the community; support people with disabilities to effectively communicate and self-advocate for their own needs and wants.
- The roles and responsibilities of special education professionals are varied. They are responsible for complying with many laws and regulations regarding the treatment and well-being of people with disabilities. T
- Community members should be involved in CBR programmes at all levels because they already know the local environmental conditions, the local economy, the local political situation and how to work with them.

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— 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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