
Unit - 5 □ Assessment of Family Needs

Structure

- 5.1 Introduction**
- 5.2 Objectives**
- 5.3 Significance of psycho-social need and its implication in family**
 - 5.3.1 Psychosocial needs: Significance**
 - 5.3.2 Assessment of psychosocial needs in the family**
- 5.4 Assessment of parental needs and its implication in planning IFSP**
 - 5.4.1 Need of the parent**
 - 5.4.2 Assessment of parental need**
 - 5.4.3 Implication in planning IFSP**
- 5.5 Assessment of sibling needs and its implication in planning IFSP**
 - 5.5.1 Sibling need**
 - 5.5.2 Assessment of sibling need**
 - 5.5.3 Implication in planning IFSP**
- 5.6 Assessment of extended family needs and its implication in planning IFSP**
 - 5.6.1 Need of grandparents**
 - 5.6.2 Assessment of grandparents need**
 - 5.6.3 Implication in planning IFSP**
- 5.7 Assessment of family and community resources for inclusion and strengthening of family**
 - 5.7.1 Assessment of family**
 - 5.7.2 Assessment of community resources**
 - Documentation, recording and reporting and assessment result**
 - a) Components of assessment report: Documentation and recording**
 - b) General Principles of reporting**

5.8 Check your progress

5.9 Let us Sum up

5.10 References

5.1. Introduction

Family is the smallest unit of the society in which members are held together by marriage of two person of opposite gender of all human groups, family is the most important primary group which consists of with or without children. The benefits of family centered interventions are being greatly recognized now more than before. Efforts are being directed towards involving parents and other family members in the training and rehabilitation of the individuals with intellectual disabilities precisely for the reasons that such approaches results positive in both parent, family and child outcomes. It helps in enhancing child development, reducing stress in the family, increasing family coping strategies and also leads to improve relationships within the family. For strengthening the family having children with intellectual disabled the intervention need to be directed towards meeting the needs of the index child ,of parents, siblings and extended family members as also recognize ,promote and utilize the existing strengths of the families.

What is needs ?

Needs can be defined as the gap between what is and what should be. A need can be felt by an individual, a group, or an entire community. It can be as concrete as the need for food and water or as abstract as improved community cohesiveness. An obvious example might be the need for public transportation in a community where older adults have no means of getting around town. More important to these same adults, however, might be a need to be valued for their knowledge and experience. Examining situations closely helps uncover what is truly needed, and leads toward future improvement.

What is Resouce?

Resources, or assets, can include individuals, organizations and institutions, buildings, landscapes, equipment — anything that can be used to improve the quality of life.

What is Family?

“Family is a group of persons united by the ties of marriage, blood or adoption, constituting a single household interacting and inter-communicating with each other

in their respective social roles of husband and wife, father and mother, son and daughter and hence creating a common culture.” (Buigess and Locke).

It is of different types like Joint, nuclear, extended.

What is extended family?

An **extended family** is a **family** that extends beyond the nuclear **family**, consisting of grandparents, aunts, uncles, and cousins all living nearby or in the same household. An **example** is a married couple that lives with either the husband or the wife’s parents.

To enhance the effectiveness of the family it is important to identify the needs of individual family members, locate resources for meeting those needs and help by guiding the family members in utilizing these identifying resources. Such a realization has already lead to the amendment of the U.S. Education of Handicapped Act of 1986(PL. 99-457)In the revised version of PL 99-457 necessitates by law to develop individualized family service plan(IFSP) for families who have children with developmental delays or those who are at risk for developmental delays. The law includes IFSP only for the families having children below 3 years, for reasons best known to the people involved in such decision making.

What is IFSP?

An Individualized Family Service Plan (IFSP) is a working document produced collaboratively by program staff and family members that contains the agreed upon Early Intervention services for an eligible child and family. Based on a multidisciplinary eligibility evaluation and any completed assessments, the plan includes services necessary to enhance the development of an eligible child, and the capacity of the family to meet the child’s needs

5.2. Objectives

After going through the unit you will be able to:

- Understand about significance of psychosocial needs and its assessment in the family.
- Describe IFSP
- Describe different types of parental, sibling, extended family needs.

- Distinguish between the various types of needs felt by the family members.
- Describe the implications of different needs and its implication in planning IFSP.
- Understand the assessment of family and community resources for inclusion.
- Describe the process of documentation, recording and reporting.
- Discuss the General principles of the interpretation and reporting of assessment results

5.3 Significance of Psychosocial Needs and its Assessment in Family

Learning is a very important phenomenon of human life and it occupies a central position in shaping human behaviour. A child begins his career as a learner at the time of birth and perhaps even before. Learning plays a crucial role in his development, it is through learning that he adopts the habits, customs and values the characteristics of the culture in which he is reared.

5.3.1. Psychosocial needs: Significance

Integration of any child with disability into the society, as far as practicable, is on of the basic objectives of any civilized country. In order to maximize his social integration the child has to be equipped with his potentials which will lead to societal gains by avoiding individual loss and avoiding living of a parasitic life on his family.

In order to achieve this objective it is of primary importance to

1. Understand different kinds of disabilities.
2. Different psycho-social aspects,i.e; self and social understanding ,thinking about the self, emergence of self-recognition and early emotional and social development involved in them.

5.3.2 –Assessment of psycho-social needs in family

It would, therefore, be appropriate to assess the different psycho-social aspects including cognitive, personality, emotional, motivational and other socio-cultural factors separately.

Other than these societal institutional level and group interaction level also can be assessed.

The assessment of

- Cognitive
- Personality
- Emotional
- Motivational and
- other socio-cultural factors will be done by using daily routine assessment schedule and environmental assessment format .These assessment will be done based on criterion referenced test.

5.4 Assessment of Parental Needs and its Implication in Planning IFSP

Parents having a child with intellectual disabilities experience a variety of stressors and stress reactions related to the child's disability. (*Orr et,al;1993*)

5.4.1. Need of the Parents –

Parents have various needs after getting impacted in may ways because of having a child with intellectual disability.

The needs are as follows –

1. Information Needs – It includes the various information condition such as the condition and level of the disability, information regarding assessment reports and outcomes, what will be expected achievement from the particular child, information needs regarding repetition of dangerous sequences and incidence like before. The parents should have proper information regarding materials related to the disability. There should also be a need of information regarding diet and nutrition.

2. Child Management – The parents should have the following need during and regarding the management and intervention of the child with disabilities:-

- Child rearing practice
- Discipline
- Problem behaviour management
- Make the child co-operative
- Training regarding the child i.e; Individualized Family Support Plan (IFSP)

and Individualized Educational Programme (IEP).

- Regular parent and teacher interactions
- All round development of a child irrespective of disability.

3. Service – This will include all the facilities, services and training procedures like:

- Services availability
- Making decision about school
- Training materials making and arrangement of ingredients.
- Home based training programme.
- Both positive and negative effect of regular and special school.

4. Facilitating Interaction – Parents are informed and counselled about the following daily interaction:

- Explaining about the child's condition
- Explain about the priority need of the family involvement.

5. Hostel – Parents find hostel or residential unit for their disabled child during their job time and after their life time .So there are following needs regarding hostel needs :

- Nature of hostel
- Making decision regarding staying and keeping at hostel.

6. Personal –Emotional - This need is most important for the parents having child with disability. This includes:

- Time to self both the parents.
- Talk about personal problems.
- Helping others and asking help when sad or depressed.
- Physical health problems.
- Planning and discussion about another child.

7. Personal –Social -

Due to having a child with disability the parents become rigid, sometime depressed and they become very contracted within themselves. For this reason the personal – social needs are aslo important for these parents.

- Discussion with friends.
- Discussion with other parents.

8. Physical Support -

Support may be of physical, social, moral, financial matter. Physical support includes human resource support along with appropriate physical structure because these parents's own physical health is reported to be a greater risk. To overcome it following points is considered:

- Manual support for transportation
- Domestic support for child care.
- Transportation for child's training.

9. Marriage - Every parent have a dream about a new social and emotional life of their children. There is various misconceptions also exist regarding the cure of mental retardation just being married. Parents think about its solution through marriage of their children.

10. Sexuality - Sexual need and urge also include an important need of every human being according to Maslow's hierarchy (Physiological need which include sexual need).and it cannot be denied also. Parents also become tensed about the sexuality and sexual needs of their children. They become tensed about the non fulfillment or expression of those needs in any situation. There should be proper guidance about this matter to the parents having disabled child.

11. Financial - Financial burdens may mount on the parents having children with intellectual disabilities. This includes

- Financial help for services and service providers
- Financial help to buy and maintenance of training materials.
- Financial help for other intervention facilities and appointment of human resources.

12. Government Benefits - Parents should be aware about various central and state government policies regarding concessions and benefits i.e.; getting disability certificate, transportation facilities, educational, financial facilities, awareness about grievance readdresses. Parents should also have a need to know about various national acts and policies regarding disability. The main acts include PWD Act, 1995, National Trust Act, 1999, Right to Education Act, 2009 which will give them opportunity to avail all

types of facilities and concessions.

13. Vocational Planning- Vocational efficiency is one of the important aim of special education .To fulfill this aim the parents should know about the vocational rehabilitation, job survey, various employment models etc. Vocational rehabilitation makes a person with intellectual disability functionally independent in the community.

14. Future Planning- Irrespective of the disability as well as any human being every parents have a dream about their child and accordingly they plan for it.It becomes life long responsibility oriented programme for those parents who have a child with intellectual disability. For this future planning parents need to do:

- Financial Planning
- Prepare and mention the appropriate inheritance for their property.
- Financial and physical structure planning about social security of the child.

15. Family Relationship - The presence of a child with intellectual disability in the family calls for a lot of adjustment on the part of the parents and the family members. Interpersonal relationships with in and between the family members get affected. Marital harmony gets disturbed owing to various child related reasons such as meeting extra child-care responsibilities and burden, affecting sexual relationship between parents due to less privacy, more fatigue and fear of producing another child with disability.

5.4.2 Assessment of parental need

A semi-structured interview schedule NIMH-FAMNS (Parents) is used to elicit the needs of parents having children with intellectual disability. It consists of total 19 main area and 60 items /needs. The score of each item on the schedule ranged from (no need) ; 1 (Not sure) ; 2 (Little a need) and 3 (Very much a need).

5.4.3 Implications in planning IFSP

The IFSP is the written plan that lists services and supports to eligible children and families. At Early Intervention, we believe that no one knows the child as well as parents. Parents are a partner in developing the IFSP, and it is important for them to be part of the process. In this intervention programme parents will identify the assests, needs, choices of their children and also set the hope about their child which have a great implication in all over family life which are as follows:

- Individualized need based intervention programmes must be carried out with parents and goals for intervention should always be set in consultation with the parents.

- In order to seek greater co-operation from parents, it is essential to meet identified parental needs along with the child's specific training needs.
- Understanding and knowledge related to the functioning of the families, group dynamics and also skills in counselling, supportive psycho-therapy are essential for working effectively with families having individuals with disabilities.
- Service providers need to equip themselves with the necessary knowledge and basic counselling skills to communicate diagnosis and needful information to parents in an empathetic and sensitive way.
- Irrespective of the age of the child with intellectual disability, parents are concerned about the future planning for their child; they are eager to learn about his /her expected achievement and progress, vocational rehabilitation and issues related to sexuality and even marriage. Professionals need to counsel parents on such issues rather than postpone it for future consultations. It is important that professionals provide parents with honest and needful information before the parents shape their own thoughts and behavior toward meeting the needs of their child.
- Parent during the initial contact generally convey child related needs to professionals and are guarded to state needs related to personal –emotional aspect. However, a skillful professional through effective counselling skills should be able to tap the personal –emotional needs as well as also the needs related to family relationships, if required. Intervention programmes designed to meet family needs facilitate effective coping.
- Service providers need to have update information on state and central government benefits, legislation and the availability of services to meet this pressing need of many a parent.
- To strengthen the family unit and facilitate healthy interactions and relationships among family members, need based family counselling should be provided.
- Most of the available services resolve around child skill training, at the most involving the mother; the focus of intervention however continues to be the child. Efforts must be made to stretch the services to involve fathers and other family members to build support for the mother.
- Parent support groups need to be encouraged to help meet various needs for the parents such as sharing information and building parent to parent support.

- Indigenous and culture specific models of care which are acceptable to Indian parents need to be developed to meet physical support, needs of parents as also the financial needs.
- Efforts need to be made to set up need based services in non-urban areas. However need for expansion of services in urban areas cannot also be over-looked.
- Efforts should begin early to strengthen the families by meeting their identified needs. This will help retain children with intellectual disability with their families providing them with a better quality of life.
- Culturally relevant materials in print, audio or visual must be provided early to the parents and families for building awareness, right knowledge and correction of misconceptions, if present.
- Need based training workshops should be conducted for parents to empower them with the necessary knowledge and skills related to child management needs.
- Programmes for parents need to be conducted which could help clarify issues on sexuality, marriage and future planning related to financial and social securities of their child.

5.5 Assessment of Sibling Needs and its implication in Planning IFSP

5.5.1. Sibling Need

The presence of an individual with intellectual disability in the family call for a lot of adjustments on the part of the parents, siblings and other significant family members (Peshwaria & Menon,1991). Identifying and meeting individual needs of various members in the family is the only way to strengthen the family having a child with intellectual disability. Beyond the typical needs experienced by siblings with the birth of a brother or sister, increased stress and additional needs for support are experienced by siblings having brothers or sisters with disability. These unique needs may take the form of family support, assistance, information etc. Thus, to strengthen families having individuals with intellectual disabilities, interventions must recognize the feelings and needs of the siblings. (Turnbull & Turnbull,1990).

Although siblings may not always explicitly reveal their needs, the research does suggest that siblings of persons with handicaps do have a number of special needs related to

themselves, their families, and the community. However till date very few attempts have been made to empirically study the needs of siblings having brother or sister with intellectual disability. Anecdotal reports have been the main source of identifying needs expressed by siblings. Powell & Ogle (1985) contended that special concerns and unique needs will vary from sibling to sibling based on a number of individual characteristics of the family system. Broad interpretation of the research findings indicate that siblings of children with handicaps have a range of needs from knowing the cause of handicaps, how to get along with their handicapped sibling better, what to tell their friends about their handicapped sibling, future role, to dealing with parental expectations. Children are a source of strength for parents. This relationship assumes even greater significance when there is a handicapped member in the family and especially for a country like India where there are no special security systems and siblings naturally assume the role of guardianship of their brother/ sister with intellectual disabilities after the death of their parents. Within this context, to strengthen this natural resource of support i.e., the sibling by identifying and meeting their unique needs becomes imperative. The empirical understanding of these siblings having brothers/sisters with intellectual disability in Indian families in terms of their impact needs and involvement are far from adequate and hence need priority.

5.5.2 Assessment: The needs of siblings having a brother /sister with intellectual disability will be assessed by using a specifically developed semi-structured interview schedule NIMH FAMILY NEEDS SCHEDULE (Siblings) shortly known as NIMH-FAMNS(Siblings). The NIMH-FAMNS (Siblings) consisted of 16 different needs. The score of each item on the schedule ranged from 0 to 2 (0-no need, 1- Little, 2- Very much need) so that higher the score, greater is the intensity of the need expressed by the sibling.

According to NIMH-FAMNS (Sibling) the various sibling needs are as follows:

1. Information: condition
2. Expected achievement
3. Training regarding the sibling management.
4. Hostel placement provision and information.
5. Information explaining the condition.
6. More time: to self.
7. Help: Future Plan.

8. Information: Resources.
9. Information about the training programme.
10. Expecting equal attention.
11. Normal expect: Parents.
12. Help: mediate family.
13. Information: Motivate.
14. Awareness programme.
15. Information: Government Benefit.
16. Others

5.5.3 Implication in planning IFSP:

Unlike parents siblings also have a greater role in IFSP for the eligible child.

- Siblings do require information on the condition of their brother/sister with intellectual disability. They also require knowledge and skills to train and learn to manage behavior problems of their affected brother/sister effectively. To meet such needs of siblings, needs based intervention programmes such as Behaviour modification workshops could be conducted.
- Siblings do not only require help in meeting the needs of their brother. /sister with intellectual disability but they also require help for themselves in planning for their future.
- Sibling groups could be initiated to help siblings share their concerns with each other. Interactions between siblings could contribute immensely in resolving their emotional reactions and help learn from each other's experiences, the ways of coping with common situations encountered by them. Individual and group counselling programmes for siblings can be of great help.
- Parents and family members need to become aware of the special needs of siblings. Non-handicapped siblings i.e. brothers and sisters may also need to understand each others' needs and help share the extra responsibilities equally.
- Intervention programmes should emphasize and encourage involvement of non-handicapped siblings with their brother/sister with intellectual disability right from the beginning when a child with intellectual disability is identified in the

family. This would help shape up siblings to accept, adjust and also contribute constructively in strengthening the families.

- Parents are generally the decision makers for their children especially so when the children are still young. Hence, parental acceptance of siblings' involvement becomes one of the crucial factors in facilitating the initiation or conduct of intervention programmes with the siblings. Parents may need to be convinced on the merits of sibling involvement as also that, such an involvement will not adversely affect the non-handicapped sibling.

5.6 Assessment of Extended Family Needs and its implication in Planning IFSP

5.6.1 Need of grandparents:

Grandparents constitute important part of the environment that the index child must inevitably interact. Typically in India ,being elders in the family ,grandparents to a large extent influence the decision making related to child care ,nursing, nutrition and wide ranging matters in family life. Depending upon their resources, the availability of time, their age and physical health, most often the grandparents are drawn into the role of caregivers or supervisors of caregivers.

With rapid urbanization, even though the traditional joint family system is fast disintegrating, yet grandparents continue to play an important and significant role which has direct bearing on the child with intellectual disability and the family.

Following are the categories related to the needs reported by grandparents of children with intellectual disability:

1. Cure: Intellectual disability – Looking for a treatment or a therapy that will cure the condition of intellectual disability.
2. Guidance: Help family – Guidance from the therapists as to how they can help the family.
3. Information: Government Benefits – From where and what are the benefits available from the Government for such children.
4. Care: Future – Future social security of the grandchild.
5. Information: Child management – Availability of training programmes to help

them manage their grandchild.

6. Training Communication – Training programme in language and communication for the grandchild.
7. Cause: Intellectual Disability – Interested to know what caused the condition.
8. Sensitivity : Professionals – Want.
9. Information: resources – From whom and where to turn for help.

5.6.2 Assessment of grand parents need: The needs of grandparents having a grandchild with intellectual disability will be assessed by using a specifically developed semi-structured interview schedule NIMH FAMILY NEEDS SCHEDULE (Grandparents) shortly known as NIMH-FAMNS(Grandparents).The NIMH-FAMNS (Grandparents) consisted of 9 different needs. The score of each item on the schedule ranged from 0 to 2 (0-no need, 1- Little, 2- Very much need) so that higher the score, greater is the intensity of the need expressed by the sibling.

5.6.3 Implication in planning IFSP:

Any work on the families would be incomplete without taking into account the role of grandparents. Grandparents are one of the significant natural support providers to a family having a child with intellectual disability, helpful for developing IFSP

- Grandparents are a great natural resource/support for the families having persons with intellectual disability and hence their role needs to be strengthened. It has been reported by parents that acceptance and support by grandparents’ especially parental grandparents is considered as an important facilitator in coping.
- Grandparents are involved in many ways in providing support to the family yet they have expressed the need for further help and guidance from professionals’ as to how they can contribute better which must be meet.
- Grandparents do get affected in many ways because of having a grandchild with intellectual disability. Help in mitigating such effects must start early with grandparents and strategies for help included in the family intervention programmes.
- Grandparents though have emotional reactions as the strongest impact, yet, while expressing needs they did not seek any help for the same. The need to

resolve or understand these emotional reactions could be explored if necessary during counselling programme.

- Grandparents too have several needs because of having grandchild with intellectual disability in the family. These needs require to be identified and individualized intervention programmes have to be worked out to meet such needs.
- All the family members including the parents and siblings of the child with intellectual disability must become aware of the grandparents needs and involve themselves in meeting the grandparents' needs. When professionals work towards mitigating the impact and help meeting the needs of grandparents, it would help strengthen grandparents to involve more constructively to the wellbeing of the grandchild with mental retardation and the whole family. Family counselling would go a long way in meeting some of the needs.
- Grandparents could be brought together in a group to share their concern with each other. Interactions amongst affected grandparents could contribute immensely in resolving emotional reactions and learning from each other's experience in coping with certain common situations.
- Professionals working and interacting with the families do need to equip themselves with effective counselling skills to communicate the child's condition and also to have better relationships with all the family members.
- Training programmes for the grandparents could be conducted as per identified needs of grandparents. This would equip them with the knowledge and skills and enable grandparents to spend time with their grandchild more usefully and effectively.

Other than the grandparents there are little need for cousin brothers and other uncle, aunts those who are continuously living with the family which include the entire family member's need are discussing throughout this chapter. Acceptance of these children and involve with them will have greater implication in planning IFSP.

5.7 Assessment of Family and Community Resources for Inclusion and Strengthening of Family

5.7.1. Assessment of family –

In this point we explore the context and process of family assessment with in early intervention programme for children with disabilities or developmental delays. Family

assessments are now a routine, indeed mandated, practice in early intervention programmes. Three primary reasons can be advanced with disabilities.

1. Family assessment recognizes explicitly the need to examine the children's development within their most powerful context, that of the family.
2. Family assessment is grounded in the belief that parents can benefit from focused attention on their capacities for providing a nurturing, informed and attentive environment for their children with disabilities.
3. There is an increasing recognition that the intensity and specificity of early intervention programme need to be tailored to the characteristics and functioning of the family in light of the child's disability or risk status. (Guralnick, 1998)

5.7.2 Assessment of Community Resources

Resource assessment is central to economic development planning since local resources are the primary means through which communities can effect economic development outcomes.

Resource Assessment Goals:

- Identify critical resources and assets
- Evaluate their potential and current contribution to development goals
- Define ways to more effectively apply them

Five resource areas to evaluate:

- (1) Land, facilities and infrastructure that supply (and sustain) the physical assets and systems that support economic activity
- (2) Human capital and labour force resources, including the education and training system, that provide the skills and talent to form, manage and operate enterprises.
- (3) Capital resources that finance businesses, community facilities and other community needs.
- (4) Technology resources that contribute new products and processes, technical know-how, and best practices to the economy.
- (5) Organizational capacity and relationships to undertake economic development activities.

Documentation, Recording and Reporting Assessment Result

a) Components of assessment report: Documentation and Recording -

The major components of assessment report which are needed to record for documentation are as follows:

1. *Identification Data:* All essential demographic information about the student: full name, address, date of birth, and so forth.
2. *Reason for referral:* The basis for and source of the referral.
3. *Relevant background:* Significant information about the student's medical, developmental, educational and socio cultural background.
4. *Behavioural Observations:* Descriptions of the student's behaviour during assessment.
5. *Assessment result and discussion:* Scores and other results in pertinent areas, such as reading, mathematics, and so forth.
6. *Summary and conclusions:* A brief statement of the level of performance and strength and weakness in the areas assessed.
7. *Recommendations:* The goals and objectives, special services, and service delivery models appropriate for the student's educational needs.
8. *Data Sheet:* All the formal and informal results for independent analysis and reference.

b) General principle of reporting—

The interpretation and reporting of assessment results are guided by a set of general principles —

- a) Follow a structured format.
- b) Report only relevant data
- c) Report information once and then mention it only as needed.
- d) Avoid making recommendations or giving ideas for solutions throughout the report.
- e) Report facts and data accurately and in a simple way.
- f) Insert sensitive information tactfully.
- g) Note the source of any information and report the data accurately.

- h) During reporting data from previous assessment, do so briefly and with full reference to the source.
- i) Mention the absence of critical data, such as recent visual and hearing assessments.
- j) Report any test administration errors or problems and reservations about the findings.
- k) Consider information about instructional factors in the classroom and non-instructional correlates (medical, social, and cultural).
- l) Address discrepancies between data and present possible explanations.
- m) Statistical and clinical analysis should be done during interpreting test results.
- n) Selectively use of theoretical constructs.
- o) Keep a variety of stylistic points in mind. Interpretation and reporting the results require both an excellent understanding of data as well as a good grasp of communication skills.

5.8 “Check Your Progress”

1. What do you mean by family?
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2. What are the various needs faced by parents?
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3. What is IFSP?Mention the various implication of sibling needs assessment in planning IFSP.
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4. What are the guiding principles of report writing?

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5. How will you assess the needs of grandparents needs in planning IFSP?

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5.9 Let us Sum up

- Families are critical agents in the care, management and habilitation of individuals with intellectual disability. Parents, sibling and other significant family members are increasingly, being involved in the training and habilitation of the individuals with intellectual disability. The underlying concept of family centered intervention is that children’s functioning can be maximized by providing services that are designed to enhance the effectiveness of their families. Families are interactive, interdependent systems with individual members reciprocally affecting each other.
- Consequently, any events or changes that affect one member of the family will directly or indirectly affect all other members and therefore affect the family as a whole. Family needs are identified by analyzing the needs of every family members need i.e; parental needs, sibling need and grandparent’s need. NIMH Family Needs Schedule (NIMH-FAMNS) are used to assess the needs of various family member according to the relationship which are available in three separate checklists.
- Individual Family service Plan (IFSP) plan required by PL 99-457 that includes the related needs of the family of the child with disabilities. The regulation require that an IFSP or Individual Family service Plan, be developed for each infant or toddler and its family. Family members are taught and trained about

the identification of the assets of the child, need of their child with disabilities, their involvement with them, choice of those children, hope with these children.

- Intervention should be individualized for parents and families as per their individual needs.
- Community is also plays a major role to develop a child. So there is a need of assessing the community resources i.e.; physical, financial, human, technical and organizational resources.
- A community needs assessment identifies the strengths and resources available in the community to meet the needs of children, youth, and families. The assessment focuses on the capabilities of the community, including its citizens, agencies, and organizations. It provides a framework for developing and identifying services and solutions and building communities that support and nurture children and families.
- It's important to have a plan in writing, which shows the work families and staff will do together .Every work with the child should be well documented, and properly reported.

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