

Role of Parents in Training of Children with Intellectual Disability

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Abstract

This research paper identified the parents' multiple roles in the education of children with intellectual disabilities. The study was conducted with the purpose to identifying the role of parents in development of assessment tool, need assessment of functional skills, programing, implementation, and evaluation of training program by involving parents in all stages. Two children one male and one female and their parents who showed their written commitment to participate in the program were involved in the program. Need assessment of functional skills of each child was done through ecological inventories, functional skills training programs were developed of each child, implemented and evaluated by involving parents. Data showed that parents played multiple roles were observed in the whole study; their teaching style, use of different behavior modification technique and other were come forth and children performance was increased.

Key Words: Assessment, implementation, evaluation & intellectual disabilities.

INTRODUCTION

Parents can play a vital role in the training and development of children with intellectual disabilities. In training of functional skills among children with disabilities parents help a lot in achieving target goals. They are considered as leading mentors for children in their early life as well as later life. Parents can be involved in any part of education and training of their children. There is no boundary for parents' participation. The federal law (Public Law 94-142, the "Education For All Handicapped Children Act") indicate the need and importance of parent active participation in the development of the Individual Education Program (IEP) for each child. There are many researches available which indicate not only the better outcome of parents' participation in early intervention program and home learning environment but also in outreach programs for children (Newman, 2005). There are many processes in which parents can be involved, such as, identification, assessment, educational programming, training, teaching, and evaluation. The well informed parents can identify of early signs of a disability.

Parents can provide different information about the developmental characteristics of their children. There are many processes in which parents can be involved, such as, identification, assessment, educational programming, training, teaching, and evaluation. The well informed parents can identify of early signs of a disability. Parents can provide different information about the developmental characteristics of their children. Parents can also provide useful information in assessment of functional skills often otherwise inaccessible to the professional (Mohsin, 2009). Initial meetings with parents conducted to discuss the assessment results and findings also help to develop the management / teaching plan. To implement the management / teaching plan, parents' cooperation and involvement are very helpful. In Pakistan, 2.49 percent population is with disabilities (National Census Report, 1998). It seems that this estimate presented by national census report is not correct because the disability labels are not well defined. According to World Health Organization (WHO) as referred by Shahzadi (2001) about 10 per cent of the total population of developing countries is suffering from some sort of disabilities. Keeping in view, it seems necessary that there should be some program for development for this population and parents should be encouraged to participate in the education of their children.

This study is conducted with the purpose to identifying the role of parents in development of assessment tool, need assessment of functional skills, programing, implementation of training program, and evaluation of training program by involving parents in all stages. There are many researches available which advocate the role of parents in the education of children with disabilities and also in the education of mainstream children. The role of parents in all level was observed in this study for first time.

REVIEW OF LITERATURE ABOUT PARENTS' ROLE

There are a number of reasons for involving parents in assessment and education of their children with intellectual disability. Parents' involvement in the education of their children with intellectual disability causes improvement in child's outcome (Karnes and Taska, 1975). According to Bruner (1975) parents are the key teachers, socializing agents and caregivers for their children during early years. James (1986) highlighted the role of parents as they are well aware of many aspects of the their children's background and existing current conditions about which trainers and professionals know very little. Drew at al (1992) advocate that parents can assist by gathering data about the student's performance both before and after the treatment and provisions of special services. If parents are alerted to the critical areas being assessed, they can be more supportive and cooperative in instructional program. Home is the ideal setting to gather information about family concerns and priorities. Parent's involvement is very necessary in each stage of intervention.

Baine (1991) suggested following modes for parents' involvement in education of their children with intellectual disability; 1) It is necessary for parents to break down each activity into small steps. For example, drinking is an activity, which includes these steps: hold the mug, pour water in the glass, take mug to mouth and drink water. Parents should teach one step at a time with rewards, 2) Repetition and drill method is frequently used for children with intellectual disability. Parents have ample time opportunities to repeat the same activity every day for 2-3 times, 3) Demonstration of the task is very important in teaching the task to children with intellectual disability, 4) Parents can demonstrate different activities to their children during their daily interaction with children, 5) Learning through games is recommended for children with intellectual disability, 6) Parents can play different games with their children, 7) Reward helps to increase the possibility of desired behavior and parents are capable delivering rewards in their daily routines, and 8) It is necessary for parents to remain in touch with health professionals in rural areas for proper guidance and support about their children with intellectual disability .

METHODOLOGY

Participants

Two children one male and one female were selected whose parents showed motivation and commitment to participate in the program. The age of one female child is 12 years and male child is 14 years. The demographical information of participants children is available in table 1

Table 1 The demographical information of participants children

Name:	Age (in years)	Sex	Level of Functioning	Father Profession	Parents income (Rs.)	Parent education(Grade)	Geographical Situation
Amina	12	Female	Moderate	Govt. Servant	6000	12	Rural
Abdul Rehman	14	Male	Moderate	Private service	7000	12	Urban

Two parents of participants' children were involved in this study. The profile of parents is presented in table 2

Table 2 The profile of participants 'parents

Name:	Age (in years)	Sex	Relationship with child	Profession	Income (Rs.)	Parent education (Gra)	Geographical Situation
CC	45	Female	Mother	House wife	6000	12	Rural
DD	51	Male	Father	House wife	7000	12	Urban

Instrumentation

The following instruments were developed and used for collection of data.

1. Parents' Consent Form
2. Diaries for Parents to record tasks performed by their children with and without intellectual disability
3. Interview with parents and teachers for development of ecological inventories.
4. Goal Attainment Scale (GAS)
5. Weekly Evaluation Report

1. Parents' Consent Form

Parents' Consent Form (PCF) was used to gain the consent of parents for participation in the program. Original PCF was further modified and used in this study. On the form, the parents provided written consent and expressed strong commitment for cooperation with program staff. The Parents' Consent Form is provided in Annexure-1.

2. Diaries for Parents

Parents were given the specially designed diaries with instructions to complete them. In the diaries date and time were also mentioned. Parents were requested to record their observations, thrice a day i, e., morning, afternoon and evening. Parents were asked to identify different environments and sub-environments, where their children are required to function. An orientation session was conducted with parents regarding the use of diaries for identification of different environments and Sub- environments and their related tasks. Orientation was based on examples in real life and demonstration was given by filling the tasks in the diaries of one child. Follow up support was also provided to parents during task identification process. Parents filled the task performed by their children with and without intellectual disability with in fifteen days. The diaries for parents are provided in Annexure-2.

3. Interview with parents

Researcher conducted the series of interviews with the parents.

First Phase Interviews: In the first phase, interviews with parents were conducted with the purpose to supplement the information collected on diaries from parents. Baine, (1991) developed a list of questions for collecting such information through interviewing of parents and teachers. A modified form of this list was used as a guide for collecting the information. Some sample questions were as under:

1. What are daily tasks, your child frequently performed in the morning, afternoon, and evening in each sub environment?
2. What are the tasks performed by your child in common, special events such as marriage ceremony, birthday etc.?
3. Please, identify some of the seasonal functional tasks performed by child.
4. What are the daily tasks having low frequency but high importance?
5. What are the daily expected tasks needed to be learnt in the coming days, may be coming years in each sub environment?

On the basis of information collected from above mentioned sources, researcher consolidated the ecological inventory of each child and shared with parent.

Second Phase Interviews: Interview sessions were conducted with parents. Parents were asked: 1) to identify environment, sub environment and their related tasks, which their children are unable to perform, 2) draw a list of tasks according to their preferences to be learnt by their child.

Third Phase Interviews: The researcher conducted the interview sessions with parents. The purpose of interviews was designing educational program for the children. Parents were asked to tell their priorities for skill to be learned by their child. Lesson plans of identified tasks were developed on specific pattern discussed later in this chapter.

Parents were given written lesson plan of each task in their native language, where parents felt problem in understanding written tasks, they were given repeated demonstration.

4. Goal Attainment Scale (GAS)

Goal Attainment Scale (GAS) is a measurement procedure originally devised by Kiresuk and Sherman (1968). A modified form of GAS was used by Mohsin (2009) to determine goal attainment level of children with intellectual disabilities of Pakistan. The main purpose of the instrument was: 1) to know the performance of children on a certain task during functional skills training, and 2) to provide explicit role of parent's in specify targets, progress and outcome of training. Weekly performance of children during skill training was recorded through GAS by researcher. There were five levels in GAS (0-4): Backward step (regression score = 0), it means if the child shows negative performance, for example, a child failed to perform a step already learned, current observable behavior (baseline score = 1), which means what a child is doing now, smallest successful step (Score = 2), larger successful step (Score = 3), and greatest successful step / goal completed (Score = 4). Goal Attainment Scale is provided in annexure-3.

5. Weekly Evaluation Report

The Weekly Evaluation Report was developed by Garber (1977), The original Weekly Evaluation Report Document was modified and used by Uddin (1995) for monitoring Parents Outreach Program (POP) of Pakistan. The present Weekly Evaluation Report was further modified by Mohsin (2009) and this modified form was used in this study. There were two main purposes of weekly Evaluation Report: 1) to monitor the performance of child on each task at the time of each visit in the home, 2) to know parents teaching style.

The WER included the items such as: 1) opinion of parents about the task appropriateness and usefulness, 2) evaluation of task implementation and child performance, 3) type and frequency of behavior modification techniques used by parents, and 4) setting of new steps of task etc. The Weekly Evaluation Report is provided in annexure-4.

Procedure of the Study

This study comprised of four phases:

1. Development of ecological inventories of the functional skills
2. Educational programming with parental involvement.
3. Implementation of the program with help of parents.
4. Evaluation of functional skills training program through GAS and Weekly Evaluation Report.

Research Design

In this study, the participants were repeatedly pre-tested (the first A phase or baseline condition), then the experimental treatment condition was administered and the participants were repeatedly post-tested (the B phase or treatment phase).

Program evaluation

Success of the program was determined through: 1) Number of goals attained by each child as measured by GAS, 2) Effectiveness of program process as determined by WER, and 3) Reaction of parents and teachers to the program obtained through separate questionnaires.

RESULTS AND DISCUSSION

In this study the parents' roles were determined on four basis level; assessment, programing, implementation and evaluation of training program for disabilities.

Need assessment of functional among their children.

Three parents were approached and two parents provided their written consent and expressed strong commitment for cooperation with program staff. Research instruments were developed with the help of information provided by parents.

Identification of environment, sub environments and their related tasks by parents; Children spent most of their time with their parents in early years. Children have direct link with their parents. Parents are the best source of information of home and community. In this study, parents observed their child for fifteen days and recorded their performed tasks on specially designed diaries, which were used in developing their ecological inventories. Researcher conducted the series of interviews with parents, parents were asked to identify environment, sub environment and their related tasks, which their children are unable to perform. The information about environment and sub environment about each child from his/her parent is provided in table 3.

Table 3 Showing environment and sub environment identified by parents

Child	Environment	Sub Environment of home
Amina	Home	Kitchen, washroom area, family sleeping area, study area
Abdul Rehman	Community	preparation for school, market, managing money
	Home	Kitchen, washroom, study area,
	Community	visit to mosque, visit to market

The detail information of related tasks of each sub environment were also provided by parents such as one parent provided the following tasks of kitchen; eats food, takes pot from kitchen, uses utensils appropriately for eating, washes vegetables, drinks water in the glass, stores eatables things in fridge, puts on stove, cuts vegetables and fruits, makes tea, sweeps in the kitchen, and washes hands after meal. The detail information of each sub environment is provided in annexure.5. The above mentioned information is much cherished for need assessment of functional skills among children with intellectual disabilities and also for training of functional skills.

Role of parents in ranking of tasks; The role of parents in ranking of tasks about each child was also observed. The interviews with parents were conducted for ranking of tasks. The tasks were rated on four levels by parents: High, medium, low and none. The importance of each task was judged during interview sessions with parents by its contribution through indicators given by Baine (1991) such as: a) learning functional skills, b) increasing the social acceptability, c) appropriateness for the chronological age of the child, d) increasing opportunity to learn additional skills, e) learning survival skills, f) improving performance in a variety of environments, g) increasing opportunity of interaction without handicapped children, h) increasing ability to fulfill frequent opportunities to perform, i) increasing ability to perform in less restricted environment, j) improving health, k) improving safety, l) increasing opportunity to understand/ express thoughts, and feeling, m) increasing opportunities to enjoy social emotional recreation life.

Role of parents in need assessment of functional skills; The developed ecological inventories were shared with parents and they were asked to provide help in need assessment. Parents provided information about each tasks on three level 0 to 2 such as 0=Unable to perform the task, 1 = Able to Perform task with assistance, and 2 = Able to Perform task without assistance.

Role of parents in programing of functional tasks

Interview sessions were conducted with the purpose of educational programming of each child with intellectual disability. Parents' determined their preferences for functional skills task. Task Importance Rating Scale guided parents to select suitable functional tasks for their children. Table 3 is showing the information about parents' preferences for functional skills of each child for first six months treatment phase.

Table 4 Parents' preferences for functional skills

Parents	Identified tasks	Parents' preferences	Detail of Parents' preferences tasks
AA's parents	45	5	Puts the laces in shoe holes Runs independently Cuts a paper with scissors and pastes on a paper Indicates toilet need Shares toys with other children.
BB's parents	32	5	Counting from 1 up to 10 Managing money Identifies the shapes of circle and square Repeats rhymes Carries out simple instructions.

Role of parents in implementation of the program

Intervention program was implemented for four months by researcher. Parents were given lesson plans with directions and guidelines. The task were also explained, demonstrated and if necessary role played with parents. The whole program was implemented under the supervision of researcher. The analysis of developed and achieved training goals of both children is presented in table 5

Table 5 Goals achieved by both children

	Goals determined by parents	Goals achieved at the end of intervention period
Amina	5	2
Abdul Rehman	5	2

The above table showed that at the end of 4 month intervention phase, Amina achieved two goals, first goal "Indicate the need of toilet use" was achieved in 9 weeks and second goal "cuts a paper with scissors and pastes on paper" was achieved in 5 weeks. Abdul Rehman also achieved 2 goals, first goal "Managing Money" in 8 weeks and second goal "Carries out simple instructions" in 4 weeks.

Parents' role in Evaluation

Parents also become the part of evaluation process in this study. In the first week, tasks were given to parent in written form in their local language. The steps in the task were explained, demonstrated and role played to parents. During second week, children weekly performance was recorded individually on Goal Attainment Scale (GAS) and through Weekly Evaluation Report (WER). In each visit, researcher filled the Weekly Evaluation Report with the help of parents. Weekly Evaluation Reports for the program period were analyzed regarding opinion of parents about task, weekly performance of child, teaching style of parent, type and frequency of behavior modification techniques used by parent and setting of new goal.

Setting of new tasks goals;

Task analysis technique was used in developing the training program. While during training, researcher was busy in setting new goals of the new task, parents provided their feedback in setting new goals of their child.

Adaptation in tasks;

In this study, parent's involvement in adapting the steps of task of their children was also observed. In the whole study 34% time parents adapted the developed task of their children according to the strengths and situation. This situation also encourages parents to get involve more in the training of their children.

Report regarding progress of the child;

Success of any program depends upon real feedback. Role of parents as reporter regarding the progress of their child was observed through analysis of Weekly Evaluation Report (WER). During home visits, 66% of instances children's performance was explained by their parents, and in 33 % instances child's performance was recorded by observing the parents while teaching.

Parental teaching style;

Parental teaching style was also observed during training of functional skills. While training 65 % of instances parents introduced the task to their children. In 22 % of instances parents demonstrated the task their children and 13 % of instances role playing technique was used.

Parents' role in use of behavior modification techniques;

Parents were observed to use of different types of modification techniques during training. Physical prompts, verbal prompts, shaping, chaining, demonstration and rewards. Most of the time parents used verbal prompt and very a few time, shaping techniques was used. Following rewards were frequently used by parents; parental hugs, sweets, verbal praise, toys, and tapping on shoulders.

Discussion

Parents' role in the teaching and training of children with intellectual disabilities was observed in this study in different types. Parents are considered as equal partner with teacher for teaching of children with intellectual disabilities. The role of parents in development of instrument "ecological inventories" for need assessment of functional skills tasks, need assessment, development of training tasks, implementation of training program and evaluation of training program was observed. During implementation of the training program, different parents teaching style come forth such as introduction of new task through demonstration, this will encourage parents to learn more and more from their parents, parents become aware about the hidden qualities of their children which encourage them and change their attitude toward effectiveness of training program. During home visit, most of the time parents explained the performance of their children. This increased the confidence among them regarding training of their children. In the beginning of training, most of the time parents introduced the task to child through demonstration which helped parents in achieving goals rapidly for their children.

While training use of rewards played a vital role in achieving desire goals of training. Most of the parents helped in adapting steps of the task during training. Parents learned task analysis and used it for teaching and developing new tasks. They also learned the use of different rewards and their effectiveness. By involving parents many changes occurred among parents for example, at the end of program parents expressed confidence in their ability to teach their children and their children's ability to learn, while at the beginning these parents were doubtful about the ability of their children. Regular, consistent and predictable daily routine and activities helps in achieving desired outcomes. Parents are the best teachers for learning of functional and community living skills. Training of parents is also necessary for successful implementation of the program. Parents should be involved in education of their children with disabilities.

For this kind of program gentle and conducive teaching approach is vital. Parents and others involved in training and education of children with disabilities should avoid any kind of punishment. Parent's satisfaction also plays vital role in training of children with intellectual disability, Parents should repeat the same activity/task every day for 2-3 weeks. Each activity should perform with the child rather than instructing him to do it on his own.

Further Research

There is need of follow up studies of cohorts of children with the similar disabilities and socio economics condition. In Pakistan many children with disabilities are not attending any kind of school. It is strongly recommended that home based program involving parents should be initiated by the Government and NGOs.

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Annexures

Annexure-1

Parents Consent Form

Name: _____

Address: _____

Date: _____

Dear Parents

A program is going to be implemented in the area for children with intellectual disabilities. For this purpose, I want to select you and your child for this program. I need your consent and cooperation for data collection. This program entails you setting objectives for your child to help set up objectives and to evaluate their success. If you agree to participate you will be contacted and trained about the whole process. I assure you, your child information will only be used your research study. Your cooperation will help me to complete my research well in time.

Thanks

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Please tear off and return after tick marking in the appropriate row.

- 1) I wish to join and allow my child to join ()
2) I do not wish to join and not allow my child to join ()

Signature/Thumb of witness

Signature/Thumb of parents

Annexure-2

Diary For Parents

Child with intellectual disability / Child without intellectual disability

Instructions for writing the diary:

Please read the instruction carefully and fill in separate forms for child with intellectual disability and child without intellectual disability .

1. Observe your child with intellectual disability and child without intellectual disability for 15 days and write main functional tasks he/she performs in home, community and school.
2. Complete the given diary daily
3. Write those tasks which your children perform frequently.
4. Identify environments and sub environments in which the child is required to function
5. Identify the task your child has to do in different environment and sub environment.

Name of the child: _____ Age: _____

Name of parents: _____ Relationship with child: _____

Date and day	Task performed			
	Morning	After noon	Evening	Others
Week-1				
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				
Week-II				
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				

Annexure-3

GOAL ATTAINMENT SCALE

Name: _____

Date Set: _____

Date Started: _____

Date Completed: _____

Goal/ Objective: _____

Weekly Reviews

- Backward step (regression score = 0) Date: _____
- Current observable behavior (baseline score = 1) Date: _____
- Smallest successful step (Score = 2) Date: _____
- Larger successful step (Score = 3) Date: _____
- Greatest successful step (Goal completed - Score = 4) Date: _____

Annexure-4

Weekly Evaluation Report

Name of the child: _____ Age: _____

Visit Date: _____ Respondent Name: _____

Task Objective: _____

1- Opinion of parents about appropriateness and usefulness of the task and instructions of task implementation:

Yes / No /To Some Extent

2- Method of evaluation:

Observation of child’s performance. ()

Asking parents to explain the performance of their child. ()

Observing the parents when teaching of their child. ()

3- Observation Checklist (when parents’ were busy in training of their child):

Sr. No	Statement	Yes	No
1	Introduction of the task to child by parents.		
2	Demonstration of task to child in the beginning of training.		
3	Use of reward during task by parents.		
4	Compliance of parents’ directions by child.		
5	Parents’ satisfaction with their child’s performance.		
6	Repetition of the task at the end of training session.		

4- Type and frequency of Behavior Modification Techniques used by parents:

- 1) Physical Prompt
- 2) Verbal prompt
- 3) Shaping
- 4) Chaining
- 5) Reward

5- New Steps of Task:

I Did parents’ help in adapting the steps of task Yes / No

II New step of task presented through:

- Verbally explanation
- Demonstration
- Role playing
- All above

Annexure 5**Ecological Inventory of Amina****1-Environment: Home**

1A	Sub environment: kitchen (D)
1Aa	Eats food (D).
1Ab	Takes pot from kitchen.
1Ac	Uses utensils appropriately for eating (D).
1Ad	Washes vegetables (D).
1Ae	Drinks water in the glass.
1Af	Stores eatables things in fridge (D)
1Ag	Puts on Stove (D).
1Ah	Cuts vegetables and fruits.
1Ai	Makes tea (D).
1Aj	Sweeps in the kitchen (D).
1Ak	Washes hands after meal (D).
1B	Sub Environment: Washroom Area
1Ba	Indicates the need of toilet use
1Bb	Showers as per need.
1Bc	Combs hair (D).
1Bd	Cleans teeth (D).
1Be	Communicates to others (D).
1Bf	Wash the toilet area (D).
1C	Sub Environment: Family sleeping area
1Ca	Cleans the home (W).
1Cb	Passes urine before going to bed (D).
1Cc	Sleeps at proper place according to weather
1Cd	Sleeps independently (D).
1Ce	Cleans the bed before sleeping (D).
1Cf	Dresses the bed (D).
1Cg	Uses over cloth according to weather (D).
1D	Sub Environment: Study Area
1Da	Studies quietly (D).
1Db	Completes home work properly (D).
1Dc	Shares learning material (D).
1E	Sub Environment: Preparation for School
1Ea	Puts on uniform (D).
1Eb	Puts on shoes (D).
1Ec	Puts laces in shoe laces (D).
1Ed	Ties shoes (D).
1Ee	Brushes her shoes (D).
2	Environment: Community
2A	Sub Environment: Go to Market
2Aa	Manages money (D).
2Ab	Locates market nearby (W).
2Ac	Follows the instructions properly (D).
2Ad	Purchases things according to instructions (D).
2Ae	Crosses the road safely (D).
2Af	Returns home from market (D).
2Aa	Functional Skill Task: Managing Money (D)
1	Uses money to buy things.
2	Identifies the currency note.
3	Knows the value of 1,2 5 coins..
4	Identifies the currency note of 10, 20, 50, 100.
5	Adds money from 1-10.