

Barriers in Optimizing Home Training Programs for Children with Developmental Disabilities

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Abstract

Given the contemporary emphasis on promoting “barrier-free” and “disability-friendly” social living conditions for persons with disabilities as ordained in the PWD Act (1995) and UNCRPD; the present study was undertaken to elicit information on the perceived “barriers” by caregivers/parents on a home training program for their kids with developmental disabilities. A 25-item “Family Barriers Identification Scale” exclusively developed for this study was used to determine perceived/reported impediments either as their own “self”, “in others” and/or in their “environment” that came in the way of optimizing the intervention programs for these children. The results show reported “barriers” for caregivers originate from their unfriendly “environments” rather than from “themselves” and/or “others”. Among the reported “environmental” barriers are “shortage of reading materials on child training/care”, followed by “lack of institutional facilities”, “inadequate teaching materials”, “lack of professional advice/guidance”, etc. The reported barrier from within “themselves” include defeatist attitudes that there are “no felt returns on their investment of efforts or energies” or that they “do not have the knowledge, skill or felt competence” to handle their own kids with developmental disabilities in their home settings. The “other” sources of barrier are “presence of problem behaviors in the child”, “ill health of the child”, “demands for child care from other kids”, “inadequate supports from spouse”, “inadequate supports from neighborhood”, etc. The results are discussed on the basis of available literature and their implications for further refinement/application with part three of International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The results are also discussed in relation to counseling caregivers on home based training programs for their kids with developmental disabilities.

Keywords: Barriers, Home Training, Developmental Disabilities, Parents/Caregivers

The difficulties experienced by persons with disabilities are increasingly being argued as the making of oneself or others; rather than, due to the primary condition. A facilitative, barrier-free and non-impeding mind-set in and around the affected person is likely to significantly shrink the struggles of their daily living. The contemporary thrust on “human rights model” against the traditional “medical/disease model” of understanding the disabled is a growing momentum in the right direction all the world over. The attempt is to diminish the barriers of their social existence (Venkatesan, 2002). The Persons with Disabilities (Equal) Opportunities, Protection of Rights & Full Participation) Act (1995) as well as Article 9 of United Nations Convention on Rights of Persons with Disabilities (UNCRPD) has an agenda in the same direction for removal of physical, social or environmental barriers impeding integration and mainstreaming of individuals with disabilities in our country. Beginning its initial proclamation on the

need for ‘creation of barrier free environment’ (under first chapter on ‘preliminary’), the PWD Act gives directives on ‘removal of architectural barriers from school, colleges or other institutions’ (section 30b in chapter five on ‘education’), and from ‘any/all places of public utility (that) shall be made barrier-free’ (with examples under sections 44-46 in chapter eight on ‘non-discrimination’). The UNCRPD clearly mandates ‘accessibility’ as responsibility of the State ‘to enable persons with disabilities to live independently and participate fully in all aspects of life...on an equal basis with others, to the physical environment, transportation, information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures shall include the identification and elimination of obstacles and barriers to accessibility’.

Home training programs for kids with

developmental disabilities through identified caregivers/parents in their own home settings is a recognized effective procedure for service delivery by rehabilitation professionals (Venkatesan, 2003; Kohli, 1989; Bubolz and Whiren, 1984; Bhuvsar, 1981). In this procedure, the professionals make themselves available at fixed timings for consultation by parents on what they "could do" or "ought to do" for management of their kids with developmental disabilities in their own home settings. Based on such professional dispensations, the parents may or may not follow some of their advice or suggestions (Peshawaria, 1989; Parikh and Yadav, 1979). While there is no denial on the need and importance of home based training programs for young kids with developmental disabilities; in actual clinical practice, it is seen that such programs are of help only to certain categories of caregivers/parents. In a previous and related study, it was found that more than half of the initial populations of parents on a home training program for their children dropped-out before the end of first month from their start-up (Venkatesan, 2003). Some of the possible reasons for this attrition identified by various investigators are related to difficulties in transportation of their child to the place of service delivery, behavior problems in the child, other demands of daily living, economic, physical or social burden, etc. (Venkatesan and Das, 1994; Mehta, Bhargava and Pandey, 1990; Mehta and Ochaney, 1984). In the background of these circumstances, it was considered useful to undertake a comprehensive investigation on the felt or reported "barriers" by caregivers/parents in optimization of home training programs for their kids with developmental disabilities.

Objectives

Develop and standardize a "Family Barriers Identification Scale" (FBIS) exclusively for the purpose of identifying impediments in the day-to-day home management of kids with developmental disabilities;

Administer the developed FBIS on samples of parents/caregivers of kids with developmental disabilities who are, both, on a regular home based behavior remediation program as well as those outside it;

Identify any specific patterns in the reported "barriers" by the parents/caregivers with respect to their experience in home management of their kids with developmental disabilities; and, evaluate the patterns of reported "barriers" in parents/caregivers in relation to variables like sex or diagnostic condition of the children with developmental disabilities.

Method

Sample

The study was undertaken by drawing respondents (parents/caregivers of preschool children with developmental disabilities) from 'Department of Clinical Services' at All India Institute of Speech and Hearing, Ministry of Health and Family Welfare, Government of India, located in Mysore, Karnataka (India). The following inclusion/ exclusion criteria were adopted for drawing a sample of 89 kids with developmental disabilities included in this study:

- i) Only cases of children with developmental disabilities below age range of six years of mental or chronological ages was included;
- ii) various categories of preschool children with developmental disabilities including delays in developmental milestones, sensory handicaps, cerebral palsy, learning disorders, specific speech delays, "at risk" cases, multiple handicaps, autistic disturbances, etc., were included;
- iii) preschool aged children with developmental disabilities having associated problems like attention deficit-hyperactivity disorders, autistic features, problem behaviors, seizure disorders, etc., were included; and,
- iv) preschool aged children with developmental disabilities on a regular home training program, and also, those outside were included as part of the sample in this study.

Procedure

The study was carried out on a sample of 89 children (Mean Age: 69.52 months; SD: 40.11) with identified diagnosis of developmental disabilities such as, specific or pervasive developmental delays, mental retardation, autistic disorders, emotional disturbances, cerebral palsy, etc. There were 62 males and 27 female kids with developmental disabilities. The sample included 31 cases with single diagnosis and 31 children with more than one diagnosis related to their developmental disabilities. Among the included cases, there were 32 children on a regular home training program and the remaining 57 cases were not on any such periodic program.

The "Family Barriers Identification Scale" (FBIS) is a 25-item scale to elicit possible reasons on why parents/caregivers are unable to implement or optimize their child's potential through home training programs. The scale lists various possible "barriers" or "deterrents" frequently reported as coming in the way of optimizing home training program for children with

developmental disabilities. Some of the items enlisted in the scale are “busy occupational schedule of caregivers”, “ill health of the child”, “lack of institutional facilities”, etc. The 25 items in the Scale are classified into three broad domains of reported barriers, viz., “self as barrier”, “and others as barrier” and/or “environment as barrier”. The respondents are free to choose any or all items in the Scale which best describe their predicament when it comes to handling their own children with developmental disabilities in their

own home settings. The Scale has also a provision to rank order the chosen reasons.

Scoring is done by simply counting the total number of “barriers” (N*) as reported by respondents as well the “weighted ranks” (WR) as the sum total of the rank weights designated by the respective respondents. The maximum score on this scale for any given respondent will be 25 A high score indicates more “barriers” felt by the respondents or caregivers of children with developmental disabilities.

SNo.	Reported Barrier	NHT Cases (N: 57)		HT Cases (N:32)		Total (N:89)	
		N*	WR	N*	WR	N*	WR
	Self as Barrier						
1.	Busy occupational schedule	13	53	14	40	27	93
3.	Expecting natural/spontaneous improvements of my child	6	43	12	58	18	101
5.	Ill health of self	1	1	9	34	10	35
14	Multiple responsibilities in caregiver	5	17	14	82	19	99
15	No felt returns on my investment of effort or energies	11	27	21	95	32	122
16	No free time from domestic or household chores	8	17	12	45	20	62
17	No interest or motivation in self	3	14	2	7	5	21
18	No knowledge, skill or felt incompetence in self	12	34	20	80	32	114
20	Search for alternative or short cut therapies	3	18	3	11	6	29
25	Unrealistic appraisal of my child's capacities	5	40	7	39	12	79
	Subtotals (1)	67	264	114	491	181	755
	Percentages	34.0	32.5	30.2	31.7	31.5	32.0
	Others as Barrier:						
2.	Demands for child care from other kids	7	42	6	36	13	78
4.	Ill health of child	6	20	15	71	21	91
6.	Inadequate supports from in laws	3	17	6	29	9	46
7.	Inadequate supports from neighborhood	3	16	8	53	11	69
8.	Inadequate supports from siblings	-	-	2	14	2	14
9.	Inadequate supports from spouse	2	7	10	47	12	54
19	Presence of problem behaviors in the child	12	37	37	84	49	121
24	Uninvited interference by others	3	17	4	29	7	46
	Subtotals (2)	36	156	88	363	124	519
	Percentages:	18.3	19.2	23.3	23.5	21.6	22.0
	Environment as Barrier:						
10.	Inadequate teaching materials	20	75	31	113	51	188
11	Lack of institutional facilities	21	86	39	113	60	199
12	Lack of professional advice/guidance	15	62	29	116	44	178
13	Low priority for home training program	2	2	12	70	14	72
21	Shortage of money	6	26	14	71	20	97
22	Shortage of reading materials on child training/care	23	102	40	158	63	260
23	Too many or frequent visitors at home	7	39	11	53	18	92
	Subtotal (3)	94	392	176	694	270	1086
	Percentages:	47.7	48.3	46.6	44.8	47.0	46.0
	Grand Total (1+2+3)	197	812	378	1548	575	2360

(NHT: Non Home Training Cases; HT: Home Training Cases)(X²:2.1514; df: 2; p:0.3413; NS)

Table: 1 Distribution of Reported "Barriers" By Families In Relation To Home Training Variable

The informants were required to identify any or all those “barriers” (as given in the list) that come in their way of home training and also rank order them according to their evaluation of preferences. The results of major "barriers" reported by parents or caregivers in this sample in

relation to various variables like sex of the informant, cases attending home based training and those not attending such a program and cases with single or multiple diagnoses

Results and Discussion

The results indicates that the present sample of 89 parents/caregivers in this study have reported the presence of 575 (Mean: 6.46) "barriers" as interfering in smooth realization of individual rehabilitation objectives that they were guided to work in their home settings. The specific form, nature, number, type, locus or origin of the reported barriers varies. For the convenience of analysis, the types of 'barriers' or "deterrents" frequently reported as coming in the way of optimizing home training program for children with developmental disabilities were classified into three broad source domains, viz., "self as barrier", "and others as barrier" and/or "environment as barrier" respectively.

(a) Sources of Barrier

A greater percent of the reported "barriers" for caregivers appear to originate from their unfriendly "environments" (N: 270 out of 575; 47.0 %) rather than from "themselves" (N: 181 out of 575; 31.5 %) and/or "others" (N: 124 out of 575; 21.6 %). Among the reported "environmental" barriers are "shortage of reading materials on child training/care" (N: 63; WR: 260; 10.9 %), followed by "lack of institutional facilities" (N: 60; WR: 199; 10.4 %), "inadequate teaching materials" (N: 51; WR: 188; 8.9 %), "lack of professional advice/guidance" (N: 44; WR: 178; 7.7 %), etc.

SNo.	Reported Barrier	Males (N: 62)		Females (N:27)		Total (N:89)	
		N*	WR	N*	WR	N*	WR
	Self as Barrier						
1.	Busy occupational schedule	18	47	9	46	27	93
3.	Expecting natural/spontaneous improvements of my child	13	67	5	34	18	101
5.	Ill health of self	7	26	3	9	10	35
14	Multiple responsibilities in caregiver	15	82	4	17	19	99
15	No felt returns on my investment of effort or energies	21	86	11	36	32	122
16	No free time from domestic or household chores	15	43	5	19	20	62
17	No interest or motivation in self	3	14	2	7	5	21
18	No knowledge, skill or felt incompetence in self	23	74	9	40	32	114
20	Search for alternative or short cut therapies	3	11	3	18	6	29
25	Unrealistic appraisal of my child's capacities	7	43	5	36	12	79
	Subtotal (1)	125	493	56	262	181	755
	Percentage:	30.2	29.6	34.8	37.8	31.5	32.0
	Others as Barrier:						
2.	Demands for child care from other kids	6	43	7	35	13	78
4.	Ill health of child	16	79	5	12	21	91
6.	Inadequate supports from in laws	9	46	-	-	9	46
7.	Inadequate supports from neighborhood	10	60	1	9	11	69
8.	Inadequate supports from siblings	1	6	1	8	2	14
9.	Inadequate supports from spouse	11	51	1	3	12	54
19	Presence of problem behaviors in the child	38	88	11	33	49	121
24	Uninvited interference by others	6	39	1	7	7	46
	Subtotal (2)	97	412	27	107	124	519
	Percentage:	23.4	24.7	16.8	15.4	21.6	22.0
	Environment as Barrier:						
10.	Inadequate teaching materials	36	135	15	53	51	188
11	Lack of institutional facilities	42	132	18	67	60	199
12	Lack of professional advice/guidance	33	121	11	57	44	178
13	Low priority for home training program	10	58	4	14	14	72
21	Shortage of money	13	62	7	35	20	97
22	Shortage of reading materials on child training/care	46	189	17	71	63	260
23	Too many or frequent visitors at home	12	64	6	28	18	92
	Subtotal (3)	192	761	78	325	270	1086
	Percentage:	46.4	45.7	48.4	46.8	47.0	46.0
	Grand Total (1+2+3)	414	1666	161	694	575	2360

(*X²: 3.2654; df: 2; p: 0.195; NS)

Table 2: Distribution of Reported "Barriers" By Families in relation to Gender Variable.

The parents perceive “themselves” also as “barrier” (N: 181; WR: 755; 31.5 %) with defeatist attitudes that there are “no felt returns on their investment of efforts or energies” (N: 32; WR: 114; 5.6 %) or that they “do not have the knowledge, skill or felt competence” (N: 32; WR: 114; 5.6 %) to handle their own kids with developmental disabilities in their home settings. There are also self-centric reported barriers like their own “busy occupational schedule”, “no free time from domestic or household chores”, “multiple responsibilities as caregivers”, etc.

The parents also perceive “other” sources of barrier (N: 124; WR: 519; 21.5 %), such as, “presence of problem behaviors in the child” (N: 49; WR: 121; 8.5%), “ill health of the child” (N: 21; WR: 91; 3.7 %), “demands for child care from other kids” (N: 13; WR: 78; 2.26 %), “inadequate supports from spouse” (N: 12; WR: 54; 2.09%), “inadequate supports from neighborhood” (N: 11; WR: 69; 1.91%), etc. (Table One). These findings are supported by available Indian literature on similar lines (Turnbull and Turnbull, 1986; Tangiri and Verma, 1992; Thressiakutty and Narayanan, 1992; Venkatesan and Das, 1994).

A comparative distribution of reported ‘barriers’ by caregivers on a home based training program (N: 32) as well as those not on such a program (N: 57) reveals no significant differences (p: 0.3413; NS). In other words, they all reportedly share similar patterns, or number of ‘barriers’ from their environments, others or themselves.

(b) Gender of Disability

The distribution of reported ‘barriers’ by families as coming in the way of optimizing home training program is seen to be similar irrespective of the gender of the child with disability. However, on closer inspection of the actual types of reported barriers, it is seen that parents of female kids with disabilities report slightly greater ‘environmental barriers’ (N: 48.4; WR: 46.8), and ‘self as barrier’ (N: 56; WR: 26.2) than ‘others as barrier’ (N: 16.8; WR: 15.4) in contrast to boys with disabilities-whose problem behaviors, greater ill health, or the lesser supports from others, come in the way of optimizing the benefits of home training for such children (Table Two). However, these differences are not statistically significant (p: 0.195; NS).

(c) Type of Disability

The type of disability in the child appears to be a significant variable in influencing the distribution of reported “barriers” by parents/caregivers. There are greater environmental barriers (N: 99; 54.1 %) for children with multiple handicaps as compared to kids with single handicaps (N: 171; 43.6 %). There are more

behavior problem in children with single handicaps (N: 33; WR: 83) than in children with multiple handicaps (N: 16; WR: 38). Caregivers of children with single handicaps reportedly feel greater ill health of self, lack motivation in self, find themselves more incompetent to handle their kids than parents of children with multiple handicaps. This could also be possibly because they expend greater energies and efforts than parents of children with multiple handicaps-who must have relatively given up hopes or aspirations about their child. Such findings are corroborated repeatedly by several earlier studies (Jain and Sathyavathi, 1969; Sequiera et al, 1990; Madhavan and Narayanan, 1992).

(d) Psychometric Properties

A two week test retest reliability exercise was attempted on a sub sample of 35 respondents. The pretest score (N: 35; Mean: 6.23; SD: 1.08) on number of reported barriers as against the re-test score (N: 35; Mean: 6.27; SD: 1.05) is not found to be statistically significant (p: > 0.05). There is also a very high correlation coefficient between the repeat measures is 0.9965. In sum, this study highlights the feasibility of developing a “Family Barriers Identification Scale” (FBIS). It demonstrates the reliability and validity of the tool to offer itself as an useful device for planning, pre-counseling and programming home based interventional therapies for children with developmental disabilities.

In sum, there is a demonstrable need and possibility for development of an objective measure to elicit the family barriers in implementation of home based training programs for children with developmental disabilities. These trends are promising and futuristic in view of the ongoing emphasis by International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) as ‘a universal human experience’ by shifting the focus of disability from ‘cause’ to ‘impact’ that it has upon an individual’s functioning in the familial, social, or environmental context. Thereby, the FBIS shows an potential for further refinement and application in consonance with part three of ICF dealing on ‘environmental factors’, especially the formats on ‘support and relationships’ (e3) and ‘attitudes’ (e4). Such investigations are likely to evolve as objective functional assessment scales for national/international disability reporting, clinical and epidemiological use and studies for social policy in the disability sector. Such measures can help throw light on specific patterns in the needs of affected families as well that must be addressed by professionals for creating a ‘barrier-free’ environment and optimization of habilitation

programs for these children within their home settings.

SNo	Reported Barrier	Single (N: 58)		Multiple (N:31)		Total (N:89)	
		N*	WR	N*	WR	N*	WR
Self as Barrier							
1.	Busy occupational schedule	18	77	9	16	27	93
3.	Expecting natural/spontaneous improvements of my child	13	74	5	27	18	101
5.	Ill health of self	9	35	1	-	10	35
14	Multiple responsibilities in caregiver	15	86	4	13	19	99
15	No felt returns on my investment of effort or energies	23	103	9	19	32	122
16	No free time from domestic or household chores	14	45	6	17	20	62
17	No interest or motivation in self	5	21	-	-	5	21
18	No knowledge, skill or felt incompetence in self	24	87	8	27	32	114
20	Search for alternative or short cut therapies	5	26	1	3	6	29
25	Unrealistic appraisal of my child's capacities	10	68	2	11	12	79
	Subtotal (1)	136	622	45	133	181	755
	Percentage:	34.7	36.5	24.6	20.3	31.5	32.0
Others as Barrier:							
2.	Demands for child care from other kids	10	58	3	20	13	78
4.	Ill health of child	14	69	7	22	21	91
6.	Inadequate supports from in laws	6	23	3	23	9	46
7.	Inadequate supports from neighborhood	8	48	3	21	11	69
8.	Inadequate supports from siblings	1	8	1	6	2	14
9.	Inadequate supports from spouse	8	38	4	16	12	54
19	Presence of problem behaviors in the child	33	83	16	38	49	121
24	Uninvited interference by others	5	36	2	10	7	46
	Subtotal (2)	85	363	39	156	124	519
	Percentage:	21.7	21.3	21.3	23.9	21.6	22.0
Environment as Barrier:							
10.	Inadequate teaching materials	32	113	19	75	51	188
11	Lack of institutional facilities	38	126	22	73	60	199
12	Lack of professional advice/guidance	29	130	15	48	44	178
13	Low priority for home training program	9	55	5	17	14	72
21	Shortage of money	15	86	5	11	20	97
22	Shortage of reading materials on child training/care	37	150	26	110	63	260
23	Too many or frequent visitors at home	11	61	7	31	18	92
	Subtotal (3)	171	721	99	365	270	1086
	Percentage	43.6	42.3	54.1	55.8	47.0	46.0
	Grand Total (!+2+3)	392	1706	183	654	575	2360

(X²:6.97; df: 2; p: 0.03; S)

Table 3: Distribution of Reported "Barriers" By Families in relation to Type of Disability

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