

Research Paper

A study of coping strategies of parents in relation to child's level of intellectual disability

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Received: 05.01.2017; Revised: 15.03.2017; Accepted: 01.04.2017

■ ABSTRACT : The present research study was aimed at assessing and comparing the type and level of coping strategies among the parents of 150 intellectually disabled children, who were selected from 3 RCI (Rehabilitation Council of India) recognized special schools of Delhi across child's degree of intellectual disability. Sample was drawn randomly in equal proportions from three categories of intellectual disability namely mild, moderate and severe. The coping strategies of parents were assessed using Family Interview for Stress and Coping in Mental Retardation (Section-II) developed by NIMHANS. The findings of the present study revealed that parents having children with severe intellectual disability had low expectations, more negative attitudes towards child management and rearing practices as compare to parents with mildly and moderately disabled children. Coping strategies among these components were decreasing with the severity of child's intellectual disability. Overall it was observed that families of mildly challenged children were comparatively better coped up.

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KEY WORDS: Attitudes, Expectations, Low income and middle income families, Mental retardation, Mental challenge

■ HOW TO CITE THIS PAPER : Upreti, Rashmi and Singh, Ritu (2017). A study of coping strategies of parents in relation to child's level of intellectual disability. *Asian J. Home Sci.*, **12** (1) : 1-7, **DOI: 10.15740**/ HAS/AJHS/12.1/1-7.

To a parent, birth of a child is a very special and joyful event. But some children have special needs and demands that challenge parents to prepare these children for the future and to handle any problems that children may face, and such children are called as intellectually disabled children. Intellectual disability (ID), known as mental retardation (MR) formerly, sometimes also known as mental challenge. As per AAIDD (American Association on Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour,

which covers many everyday social and practical skills. The diagnosis of mental challenge or intellectual disability mainly requires low general intellectual functioning and age of onset before 18 years of age (Accordo and Capute, 1998). Intellectual functioning is also called intelligence, which refers to general mental capacity. One way to measure intellectual functioning is an IQ test. There are four different degrees of intellectual disability: mild, moderate, severe and profound. As per WHO guidelines, the IQ range 50 to 69 is indicative of mild mental retardation, 35 to 49 is moderate, 20 to 34 is severe and IQ under 20 is profound.

Having a child with developmental disabilities brings life changing implications and long-lasting effects in the life of the whole family (Simmerman *et al.*, 2001 and Martin and Colbert, 1997). Parents with a special need child experience life differently than others. Chronic conditions of disability, in both medical and emotional part, make extra demands on parents and finally results in stress (Tew and Laurence, 1975; Breslau *et al.*, 1982 and Miller *et al.*, 1992). For most parents, the birth of their child is a joyous time. But for some parents the time of mentally challenged child's birth may become mixed with stress and despair (Barnett *et al.*, 2003). In this way, becoming the parent of a child who has a disability is a time of great stress and change (Thompson, 2000).

Stress is a normal part of everyday life. However, there are some ways to cope with it that are more healthy and beneficial than others. Even if the child is intellectually disabled, coping strategies helps to eliminate, modify, or manage a stressful event. In this context, Lyons *et al.* (2010) found that while autism symptom severity was the strongest and most consistent predictor of the stress experienced by parents of autistic children, coping styles moderated the relationship between autism symptoms and parental stress.

In spite of enduring stress, one may find coping strategies to overcome the stress level. "Coping Strategies" refers to conscious efforts to adopt with/ solve stressful situation (Glidden and Natcher, 2009), they are practical active ways of responding to threatening situations. The goal of coping strategies is to bring continuous change in cognitive and behavioral efforts of family members to handle the increasing external and/or internal demands of caring the child with disability (Woodman and Hauser, 2013). Strategies directly aimed at coping with the source of stress, such as problem solving and seeking information are more adaptive strategies than those efforts to deny or minimize the situation (Bailey and Smith, 2000). The literature indicates that parental stress is associated with the type of disability present in the child (Gupta, 2007). In another study, child's degree of mental challenge found to have an impact on type and level of stress perceived by the mothers and fathers of mentally challenged children (Upreti and Singh, 2016). Schatz and Hamdan-Allen (1995) reported that IQ was positively related to each of the Vineland domains. A similar trend was present for daily living skills. Additionally, parent's expectations about future outcomes for children with severe mental challenge are much lower than those for children with mild or moderate mental challenge (Mutua and Dimitrov, 2001). However, Tucker and Fox (1995) and Grigal and Neubert (2004) also reported an influence of disability over parental expectations.

Therefore, by keeping above discussion in mind, it can be concluded that the more severe the intellectual disability, the more help the child needs from parents to look after himself/herself and hence, make parents more stressed. Besides this, child's degree of intellectual disability affects the daily skills of an individual, parental expectations and attitude. So, it might be possible that coping strategies of the parents with intellectually disabled children can be affected by child's degree of disability. Therefore, the present study has been taken up with the following objectives to assess and compare the type and level of coping among parents across their child's degree of intellectual disability and to investigate statistical differences in the type and level of coping among parents across their child's degree of intellectual disability.

■ RESEARCH METHODS

Location:

Delhi was purposively selected as a locale for the present study, that has appropriate number of RCI (Rehabilitation Council of India) recognized special schools meant especially for intellectually disabled (ID) or mentally retarded children.

Sample:

The sample for the present study was selected by using a multistage purposive cum random sampling technique. Out of nine, three RCI recognized institutes (NIMH- National Institute for Mentally Handicapped, Manovikas and C.B.S Memorial) were randomly selected. Since, the population of ID children from high income group (HIG) was extensively low. Therefore, only those belonging to low income group (LIG) and middle income group (MIG) were considered for the present study. Out of the total population of LIG and MIG intellectually disabled children, 75 ID children were selected from each social/ economic class by randomly drawing 25 from each level of intellectual disability/ mental retardation. Thus, the sample for the present study comprised of 150 intellectually disabled children and their families.

Procedure:

The directors of the selected institutions were contacted, who provided all the necessary details related to the enrolled ID children and their families. The required samples were drawn and afterwards, first common meeting was organized. Assurance was given to the selected families that the information provided by them will be kept confidential and utilized only for the research purpose only. The selected parents of intellectually disabled children were then interviewed on the place of their choice-institute or their home and observations made by the researcher.

Measures:

Self-designed general questionnaire was used to study the socio-demographic and socio-economic characteristics of respondents. The type and level of coping strategies of the parents were assessed using Family Interview for Stress and Coping in Mental Retardation (Section-II) (Girimaji, 1999).

Analysis:

Data was analyzed by using statistical techniques like frequency, percentage and one way ANOVA.

■ RESEARCH FINDINGS AND DISCUSSION

The data presented in Table 1(a) clearly represents that among LIG, majority of parents irrespective of their child's degree of intellectual disability had slightly inadequate general awareness. In majority, mothers with mildly and moderately challenged children (84.00% and 80.00%) reported slightly inadequate general awareness. Whereas more numbers of fathers with severely challenged children (80.00%) had slightly inadequate general awareness. In middle income families, across child's level of intellectual disability more numbers of fathers with moderately challenged children (92.00%) and mothers with severely challenged children (76.00%) had slightly inadequate general awareness.

Among low income families, under the domain of misconceptions, majority of parents had no misconceptions about child's intellectual disability. Parents of moderately challenged children were comparatively less who had no misconception (84.00%). Similar kind of

patterns were observed among middle income families.

The findings on expectation from child depicted that in low income families, more percentage of mothers of moderately challenged children (76.00%) had mildly appropriate expectations. Whereas, fathers with severely challenged children who had mildly appropriate expectations were in less proportion (40.00%). Similar results were also drawn from middle income families, where, in majority both mothers and fathers with moderately challenged children (72.00% and 72.00%) reported mildly appropriate expectations from child.

In attitudes towards child, from low income families maximum number of mothers of severely challenged children (84.00%) showed favourable attitude. It was pleasurable to note that fathers of moderately challenged children (88.00%) reported most favourable attitude. From the analysis of middle income families it was revealed that more numbers of fathers with moderately challenged children (96.00%) had favourable attitude. While, in majority mothers with moderately and severely challenged children also showed favourable attitude.

In attitudes towards child management from low income families, majority of mothers of mildly challenged children (92.00%) presented favourable attitude. However, only 56.00 per cent of fathers with mildly challenged children also showed favourable attitude. Besides this, in middle income families percentage of mothers of mildly challenged children were more (80.00%) in favourable attitude. On the other side, fathers of children with moderately challenged children were more (76.00%) who presented favourable attitude.

Under the dimension general rearing practices, in low income families more number of mothers (96.00%) and fathers (80.00%) of mildly challenged children had somewhat favourable rearing practices. Whereas, among middle class families all the mothers of severely challenged children and 72.00 per cent of fathers of mildly challenged children showed somewhat favourable rearing practices.

In rearing practice specific to training, more percentage of mothers of mildly and severely challenged children (92.00% and 92.00%) presented somewhat favourable rearing practices. Likewise, fathers of mildly and severely challenged children (96.00% and 100.00%) also showed somewhat favourable rearing practices. In middle income families, at somewhat favourable level, percentages of mothers with severely challenged children were found to be more (92.00%). However, all the fathers of moderately and severely challenged children reported somewhat favourable rearing practices.

By the overview of Table 1(a) it can be clearly seen that, in low income families more number of parents having moderately challenged children received somewhat inadequate social support. Among middle income families parents with moderately and severely challenged children in majority shared exactly equal proportion (88.00%) and reported somewhat inadequate support.

Under global rating of family adaptation, in majority, 76 per cent of mothers and 72 per cent of fathers found adequately adapted. While, more percentage of mothers

			Coord												
			Score range		LIG (n=75) Children with mild Children with moderate Children w								with severe		
Domains of coping	0 1 1	Levels of coping	runge	intellectual disability				intellectual disability $(n_2=25)$				Children with severe intellectual disability (n ₃ =25)			
	Subscales			(n ₁ =25)											
				Fathers		Mothers			thers	Mothers		Fathers n %		Mothers	
Child an arise a	Commentaria		12.00	<u>n</u>	<u>%</u> 0.00	<u>n</u>	<u>%</u>	<u>n</u>	%	<u>n</u>	%	n 2	·	n 2	<u>%</u>
Child rearing	General rearing	Most favourable	13-22	0		1	4.00	2	8.00	1	4.00	2	8.00	2	8.00
practices	practices	Somewhat favourable	23-32	20	80.00	24	96.00	14	56.00	21	84.00	18	72.00	19	76.00
		Somewhat unfavourable	33-42	5	20.00	0	0.00	9	36.00	3	12.00	5	20.00	4	16.00
		Most unfavourable	43+	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Rearing practice	Most favourable	7-12	1	4.00	2	8.00	0	0.00	1	4.00	0	0.00	2	8.00
	specific to training	Somewhat favourable	13-18	24	96.00	23	92.00	22	88.00	21	84.00	25	100.00	23	92.00
		Somewhat unfavourable	19-24	0	0.00	0	0.00	3	12.00	3	12.00	0	0.00	0	0.00
		Most unfavourable	25+	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Awareness	General awareness	Largely Adequate	9-15	0	0.00	0	0.00	0	0.00	0	0.00	2	8.00	2	8.00
		Adequate	16-22	8	32.00	4	16.00	3	12.00	2	8.00	3	12.00	3	12.00
		Slightly inadequate	23-29	17	68.00	21	84.00	19	76.00	20	80.00	20	80.00	18	72.00
		Highly inadequate	30 +	0	0.00	0	0.00	3	12.00	3	12.00	0	0.00	2	8.00
	Misconceptions	No	4-6	23	92.00	23	92.00	21	84.00	21	84.00	23	92.00	25	100.0
		Almost Absent	7-9	2	8.00	2	8.00	4	16.00	4	16.00	2	8.00	0	0.00
		Present	10-12	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
		Present to a large extent	13 +	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Expectations	Expectations from	Largely appropriate	10-17	6	24.00	5	20.00	0	0.00	1	4.00	1	4.00	1	4.00
and	child	Mildly appropriate	18-25	14	56.00	18	72.00	14	56.00	19	76.00	10	40.00	12	48.0
attitudes		Moderately inappropriate	26-33	5	20.00	2	8.00	11	44.00	5	20.00	14	56.00	12	48.0
		Highly inappropriate	34 +	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Attitudes towards	Most favourable	15-26	5	20.00	5	20.00	22	88.00	3	12.00	5	20.00	4	16.0
	child	Favourable	27-38	20	80.00	20	80.00	3	12.00	19	76.00	20	80.00	21	84.0
		Unfavourable	39-50	0	0.00	0	0.00	0	0.00	3	12.00	0	0.00	0	0.00
		Most unfavourable	51 +	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Attitudes towards	Most favourable	17-29	0	0.00	1	4.00	2	8.00	0	0.00	0	0.00	0	0.00
	child management	Favourable	30-42	14	56.00	23	92.00	13	52.00	19	76.00	11	44.00	17	68.0
		Moderately unfavourable	43-55	11	44.00	1	4.00	10	40.00	3	12.00	14	56.00	8	32.0
		Most unfavourable	56 +	0	0.00	0	0.00	0	0.00	3	12.00	0	0.00	0	0.00
Social support		Best social support	3-5	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Social support		Adequate	6-8	4	16.00	4	16.00	1	4.00	1	4.00	0	0.00	0	0.00
		Somewhat inadequately	9-11	17	68.00	17	68.00	21	84.00	21	84.00	19	76.00	19	76.0
		No support	12 +	4	16.00	4	16.00	3	12.00	3	12.00	6	24.00	6	24.0
Global rating		Extremely well adapted	1	0	0.00	0	0.00	0	0.00	0	0.00	2	8.00	0	0.00
of family		Adequately adapted	2	18	72.00	19	76.00	0	0.00	13	52.00	12	48.00	14	56.0
adaptation		Inadequately adapted	2	7	28.00	5	20.00	15	60.00	9	36.00	6	24.00	8	32.0
adaptation		Very poor coping/	4	0	28.00	3 1	4.00	10	40.00	3	12.00	5	20.00	о З	
		adaptation	4	0	0.00	1	4.00	10	40.00	3	12.00	3	20.00	3	12.00

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(68.00%) and fathers (72.00%) of moderately challenged children found adequately adapted.

With regards to the child's characteristics, severity of disability attributed to greater stress and poor coping

in both parents (Sethi et al., 2007). Table 2 (a and b) clearly represents that among parents significant differences exist in their coping strategies across child's degree of intellectual disability. Parents having children

			Score						LIG (r	n=75)					
	Subscales	Levels of coping	range		Children	with	nild	Ch	ildren wit			(Children v	vith s	evere
Domains of				intellectual disability			ir	intellectual disability			intellectual disability				
coping			•	(n ₁ =25) Fathers M			others	F	(n ₂ = Fathers		others	Fathers		Mothers	
				n	%	n	%	n	%	n	%	n	%	n	%
Child rearing	General rearing	Most favourable	13-22	3	12.00	7	28.00	1	4.00	3	12.00	1	4.00	0	0.00
practices	practices	Somewhat favourable	23-32	18	72.00	18	72.00	17	68.00	22	88.00	13	52.00	25	100.00
L	1	Somewhat unfavourable	33-42	4	16.00	0	0.00	7	28.00	0	0.00	11	44.00	0	0.00
		Most unfavourable	43+	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Rearing practice	Most favourable	7-12	5	20.00	7	28.00	0	0.00	4	16.00	0	0.00	1	4.00
	specific to	Somewhat favourable	13-18	20	80.00	18	72.00	25	100.00	21	84.00	25	100.00	23	92.00
	training	Somewhat unfavourable	19-24	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	1	4.00
	-	Most unfavourable	25+	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Awareness	General	Largely adequate	9-15	2	8.00	2	8.00	0	0.00	0	0.00	1	4.00	1	4.00
	awareness	Adequate	16-22	10	40.00	8	32.00	2	8.00	7	28.00	5	20.00	4	16.00
		Slightly inadequate	23-29	13	52.00	15	60.00	23	92.00	18	72.00	18	72.00	19	76.00
		Highly inadequate	30 +	0	0.00	0	0.00	0	0.00	0	0.00	1	4.00	1	4.00
	Misconceptions	No	4-6	25	100.00	25	100.00	24	96.00	24	96.00	24	96.00	25	100.00
		Almost absent	7-9	0	0.00	0	0.00	1	4.00	1	4.00	1	4.00	0	0.00
		Present	10-12	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
		Present to a large extent	13 +	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Expectations	Expectations	Largely appropriate	10-17	8	32.00	7	28.00	0	0.00	0	0.00	2	8.00	2	8.00
and	from child	Mildly appropriate	18-25	12	48.00	15	60.00	18	72.00	18	72.00	6	24.00	14	56.00
attitudes		Moderately	26-33	5	20.00	3	12.00	7	28.00	7	28.00	17	68.00	9	36.00
		inappropriate													
		Highly inappropriate	34 +	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Attitudes towards	Most favourable	15-26	10	40.00	10	40.00	1	4.00	2	8.00	3	12.00	2	8.00
	child	Favourable	27-38	15	60.00	15	60.00	24	96.00	23	92.00	22	88.00	23	92.00
		Unfavourable	39-50	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
		Most unfavourable	51 +	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Attitudes towards	Most favourable	17-29	1	4.00	1	4.00	0	0.00	0	0.00	0	0.00	0	0.00
	child	Favourable	30-42	18	72.00	20	80.00	19	76.00	18	72.00	9	36.00	17	68.00
	management	Moderately unfavourable	43-55	6	24.00	4	16.00	6	24.00	7	28.00	16	64.00	8	32.00
			56	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Social		Most unfavourable Best social support	56 + 3-5	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	1	4.00
support		Adequate	5-5 6-8	5	20.00	5	20.00	2	8.00	2	8.00	2	8.00	2	4.00 8.00
support		Somewhat inadequately	9-11	19	20.00 76.00	19	20.00 76.00	22	88.00	22	88.00	22	88.00	22	88.00
		No support	9-11 12 +	19	4.00	19	4.00	1	4.00	1	4.00	1	4.00	1	4.00
Global rating		Extremely well adapted	12 +	4	16.00	2	4.00 8.00	0	0.00	0	0.00	1	4.00	0	4.00 0.00
of family		Adequately adapted	2	12	48.00	16	64.00	18	72.00	17	68.00	10	40.00	9	36.00
adaptation		Inadequately adapted	2	9	36.00	5	20.00	6	24.00	8	32.00	14	40.00 56.00	15	60.00
adaptation		Very poor coping/	4	0	0.00	2	8.00	1	4.00	0	0.00	0	0.00	1	4.00
		adaptation	-7	0	0.00	4	0.00	1	4.00	0	0.00	0	0.00	1	4.00

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with severe intellectual disability had low expectations, more negative attitudes towards child management and specific rearing practices as compare to parents with mildly and moderately disabled children. Coping strategies among these components were decreasing with the severity of child's intellectual disability. This finding is supported by Narayan et al. (1993), who reported that parental expectations for their mentally retarded children were influenced by level of mental retardation.

Parental attitude towards child management varies with the child's level of mental challenge/ intellectual disability. It might be because of the variation in the child's ability to perform a task. It has been observed that severely challenged children were not able to perform, learn a task as mildly or moderately challenged children. Hence, parents of both the gender irrespective of their income class reported unfavourable attitude towards child's abilities and also had low expectations. The more severe the mental retardation, the more help the child needs to look after himself/ herself.

Since, with the increase in disability involvement of disabled children in daily living activities were found to be low. So, parents irrespective of their income level put more efforts to train the child. Although intellectually disabled children requires more parental efforts than normal children. But when compared across their level of intellectual disability/ mental challenge it was revealed that lesser parental efforts were found to be associated with mild and moderately challenged children. Therefore, child rearing practices specific to training were found to be significantly differ across child's level of intellectual disability/ mental challenge. Overall it was observed that parents of children with mild intellectual disability were comparatively better coped up.

Conclusion :

It has been obtained from the study that parents having children with severe intellectual disability had low expectations, more negative attitudes towards child management and rearing practices as compare to parents with mildly and moderately disabled children. Overall it was observed that parents of children with mild intellectual disability were comparatively better coped up. To bring about positive change in the condition of

		L	IG fathers $(n_1=7)$	5)	LIG mothers $(n_2=75)$				
Domains of coping	Subscales	Mildly challenged children n _{1a} =25	Moderately challenged children n _{1b} =25	Severely challenged children $n_{1c}=25$	Mildly challenged children n _{2a} =25	Moderately challenged children $n_{2b}=25$	Severely challenged children n _{2c} =25		
Child rearing	General rearing practices	21.85	22.36	22.48	23.44	23.58	24.28		
practices	Rearing practices specific to training	8.76 ^a	10.98 ^b	12.16 ^c	10.68 ^a	12.03 ^a	14.84 ^b		
Awareness	General awareness	23.00	23.97	24.79	23.94	24.89	25.44		
	Misconceptions	3.83	3.97	4.12	3.95	4.02	4.36		
Expectations and	Expectations from child	23.98 ^a	25.59 ^b	27.56 ^c	24.87 ^a	26.43 ^a	28.28 ^b		
attitudes	Attitudes towards child	26.96	27.68	28.55	27.88	28.37	29.23		
	Attitudes towards child mgt	36.89 ^a	39.97 ^b	42.78 ^c	37.28 ^a	40.52 ^b	42.25°		
Social support		9.61	9.98	10.08	9.80	10.02	10.64		

		M	IG fathers $(n_1 = 2)$	75)	MIG mothers $(n_2=75)$			
		Mildly	Moderately	Severely	Mildly	Moderately	Severely	
Domains of coping	Subscales	challenged	challenged	challenged	challenged	challenged	challenged	
		children	children	children	children	children	children	
	,	n _{1a} =25	n _{1b} =25	$n_{1c}=25$	n _{2a} =25	n _{2b} =25	n _{2c} =25	
Child rearing	General rearing practices	20.66	20.97	21.12	22.14	22.37	22.86	
practices	Rearing practices specific to training	7.12 ^a	9.14 ^b	10.75 ^c	9.52 ^a	10.86^{ab}	13.26 ^b	
Awareness	General awareness	21.16	22.09	23.00	21.64	22.32	23.12	
	Misconceptions	1.07	1.86	2.63	1.20	2.08	2.75	
Expectations and	Expectations from child	22.60 ^a	24.17 ^{ab}	26.78 ^b	23.12 ^a	25.09 ^a	26.94 ^b	
attitudes	Attitudes towards child	25.65	26.31	27.19	26.24	27.12	28.04	
	Attitudes towards child mgt	35.71 ^a	38.64 ^b	41.56 ^c	36.08 ^a	39.42 ^b	41.11 ^c	
Social support		9.50	9.56	10.01	9.70	9.98	10.32	

Note: 1. Higher the score, lower the coping 2. Means with different superscripts differ significantly at 0.05 level of significance

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children with intellectual disabilities and their families parental training by government, NGOs, educational or research services may proves helpful. Intervention programmes can be developed for the parents to enhance their coping strategies. Parents with intellectually disabled children can get a much better quality of life with the right support, love from their friends and relatives, and respect from the society. This may not completely heal their wounds but it will at least make their journey of raising a special need child easier.

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