

Research Paper

Parental View on Problems Faced By Them with an Adult with Intellectual Disability- A Study

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ABSTRACT

Intellectual disability is a kind of disability which is lifelong. It has a major impact both on the children and their families. The learning characters of intellectual disability are that they learn very slow and forget very quickly. Naturally the school going intellectually disabled children also unable to perform daily essential works by own in adulthood which create many problems in the family. Parents of children with intellectual disability typically care for their child at home and then continue to provide care generally in the family home until they die or are no longer able to offer the support because of their own illness or frailty [Beange & Taplin 1996, Big by-2000] Based on this concept the study focused on the parental view on problems faced by them with an adult with intellectual disability.

The study was descriptive survey type. The sample consist of 50 parents (either mother or father) having an adult with intellectual disability selected by purposive sample technique of Bankura District. The age group of the parents was 40-65 years. Self constructed semi structured questionnaire consisting 30 (thirty) questions with the help of "Family Burden interview schedule developed by Pai, Kapoor 1981 was used for collecting data. The collected data were analysed by descriptive statistics and percentage count. The result showed that majority of the parents expressed positively about the problems faced by them like the child not entirely independence of activities in daily living (ADL), very slow in daily work, present of problem behaviour lack of proper socialization & sexual behaviour. The parental view also positively associated with family adjustment, suffering in stress, anxiety and depression hamper of marital relationship and relationship with other relatives.

Key words: - intellectual disability, problems, adult, ADL.

INTRODUCTION

From parental view every child is special in his or her own way. But some time some children needs special, which challenges parents to handle & prepare for the future to handle the problems that may surface. Intellectual disability is defined as a disability characterised by remarkably low intellectual functioning (I.Q <70) in conjunction with significant limitation in adaptive functioning (AAMR-2002) According to American Association on intellectual & Developmental Disabilities (AAIDD-2010) "intellectual Disabilities is a Disability characterised by significant limitation both in intellectual functioning

and adaptive behaviour, which covers many every day social & practical skill. This disability originates before the age of 18(Eighteen)

Clinical Definition of Intellectual Disability

The disability occurs in the development period of life (i.e. before age-18) and is characterised by bellow average intellectual functioning. Most people with intellectual disability are born with the disability.

Clinically intellectual disability is assessed as:-

- An I.Q. of 70 or under plus

- Deficit in at least 2 areas of adaptive behaviour i.e.
- Communication
 - Self care
 - Home living
 - Social skills
 - Self direction
 - Leisure & work
 - Learning

Based on the International classification of Diseases and Related Health problems, 10th Edition published by world Health organization.

| | |
|---------------------|----------|
| Mild – I.Q. Level | 50-69 |
| Moderate I.Q. Level | 35-49 |
| Severe I.Q. Level | 20-34 |
| Profound I.Q. Level | below 20 |

[Intelligence represented in numerical Index]

Several factors are identified that can cause intellectual disability but even though at least 30 to 40% of causes the aetiology remain unknown despite through evaluation (Armantas-2009)

The children with intellectual disability gradually become Adult. In adolescents the often display a number of Co-morbid problems with behaviours problems and make the situation more complex (DYkens -2000; Einfeld, Piccin, Mackinnon, 2006). Thus the present of an intellectual disabled adult may change the whole atmosphere of family including daily routine, emotional and financial aspect [Kaur &Arora-2010]. Here the study examined the parental view on problems faced by them with an adult with intellectual disability.

Review of Related Literature

The research literature indicates that there is a wide range of opinion amongst parents related to the problems faced by them.

Intellectual disability is a lifelong disability and has a major impact in the lives of the children & the families. While raising a child with chronic condition, parents experience psychological stress & disappoint when their child does not meet

their hopes and expectations (Barnett, Clements, Kaplan-Estrin and Fialka-2003).

Caring of those who are M.R. is often itself stressful as care giving affects several aspects of caregiver's life negatively including poor physical and emotional state (Pinquart & Sorensen-2003 vitiation, Zhang & Scalan;2003)

As a general agreement mental retardation can impose psychological problems, social issues & lifestyle restrictions them can affect quality of life of the caregivers & family members, who also bear the considerable indirect costs of patients disability. But this is only one side of the coin; there are examples where act of care giving is found to be associated with experiencing subjective gains & satisfaction (Kulhara, Kate, Grover, Nehra; 2012)

Parents may be devastated when they realize that their child is going to any a stigma that has been highly related to isolation, dependency and institutionalization in our socially (Fewell.1986).

Seligman & Myerson (1982) noted that the responsibilities associated with the care of disabled children may through an impact on parents, psychological financial, physical & social well being over time.

Wikler (1981) found that people often feel uncomfortable in the presence of Mentally Retarded people to strive to ignore them thus increasing the social isolation of the family.

Gyrne &Cunningham (1985) provided a conceptual review of literature specific to children with mental retardation. Out of three approaches the first approach, the pathological orientation has focused on inevitability of stress. Although this approach has predominated the literature, a modified approach that attempts to identify families more at risk for dressed caused by the child has developed.

Singh et.al (2008) found a negative impact (25.26%) which includes difficulties in meeting extra demands for physical care of the child experiencing health related problems, making career adjustment, experiencing loss of support from the

spouses Gyrne &Cunningham (1985) provided a conceptual review of literature specific to children with mental retardation. Out of three approaches the first approach, the pathological orientation has focused on inevitability of stress. Although this approach has predominated the literature, a modified approach that attempts to identify families more at risk for distress caused by the child has developed. Further they found that parents were having a maximum negative impact on the domains like physical care & financial areas. It means that the funds in the care and training of their retarded children as well as in other necessary domestic requirements.

Narayan J, Madhavan T, Prakasam BS(1993) studied the factors influencing the expectations of parents for their Mentally Retarded Children. In terms of treatment for cure, education, training and general information, parental expectations for their Mentally Retarded Children are influenced by various factors such as the age and sex of the retarded children, the level of Mental Retardation, the education and occupation of the parents and the Socio-Economic status and area of living.

Hemant Chandorkar and Brig. P.K. Chakraborty (2000) studied Psychological problems of parents of Mentally Retarded Children compared to that of parents of normal children. The result of the study proved that the parents of Mentally Retarded Children have a higher prevalence of psychological morbidity than the parents of normal children.

Montes G, Halferman Js(2008) reported that parents of children with Mentally Retarded have Significant out of pocket expenditures related their child's care. This likely places a significant burden on families in the face of additional out of pocket expenditure.

There is a growing literature on the confusion, embarrassment, anger, helplessness and feelings of depression to having Mentally Retarded child (Bristol & Schopler 1983, DeMyer(1979), Konstantareas & Homatidis (1988).

Gallagher (2008) reported that the parents of children with mental disabilities registered high depression and anxiety scores and the majority met the criteria for possible clinical depression and anxiety.

Green berg (1983) found that strong personal faith and religious affiliation were important to the adjustment in the family having mentally retarded child.

Mugno D, Ruta L, D arrigo VG, Mazzone L(2007) Viewed the impairment of quality of life in parents of children and adolescents with mental Retardation. They had seen to display a higher burden probably for a combination of environmental and genetic factors.

Statement of Problem

Intellectual disability is a lifelong disability with a major impact on the lives of children & their families. Parents of an adult with intellectual disability typically care for their child at home and then continue to provide care until they die or are no longer able to offer the support because of their own illness or frailty. So several problems generally faced by the parents in family and social adjustment, emotional and health adjustment & economic adjustment. So this study sought to find out the parental view on problems faced by them with an adult with intellectual disability.

Purpose of the Study

- To review the parental view towards problems faced by them with an adult with intellectual disability.
- To study the level of adjustment, depression anxiety and stress, experienced by parents of adult with intellectual disability.

METHODOLOGY

Research Design – The study was descriptive survey type.

Sample and Sampling Technique

The sample consisted of 50 percents (either mother or father) having an adult with intellectual disability selected by purposive sample technique of Bankura District. The age group of the parents was 40-65 years. Self constructed semi

structured questionnaire consisting 30 questions with the help of “Family Burden interview schedule developed by Pai, Kapoor 1981 was used for collecting data.

Data Collection and Analysis

For the collection of the data the researcher administered the questionnaires on the participant.

The collected data were analysed with descriptive statistics and percentage.

RESULT

Percentage of response of all parents (N=50)

| Sl. No | Question | Yes N% | No N % | Not sure N % |
|--------|--|-----------|-----------|--------------|
| 1. | Do you aware about the disability of your child? | 30 60% | 15 30% | 5 10% |
| 2. | Did you send your child to school? | 23 46% | 27 54% | NA |
| 3. | Any improvement observed after school going? | 24 48% | 16 32% | 10 20% |
| 4. | Presently is your child school going? | 40 80% | 10 20% | NA |
| 5. | Do your child independent in activities in daily living? | 24 48% | 18 36% | 8 16% |
| 6. | Do you forced to spend more time for your child? | 40 80% | 10 20% | NA |
| 7. | Have any effect in your work place for your child? | 28 56% | 12 24% | 10 20% |
| 8. | Is your financial condition affected for your child? | 30 60% | 15 30% | 5 10% |
| 9. | Has your family adjustment been disrupted for your child? | 27 54% | 14 28% | 9 18% |
| 10. | Does the child prevent you from having satisfying relationship with the rest of your family? | 26 52% | 17 34% | 7 14% |
| 11. | Has the quality of your marital relationship declined for your child? | 25 50% | 18 36% | 7 14% |
| 12. | Do you think that your health has been affected because of your child? | 30 60% | 12 24% | 8 16% |
| 13. | Do you find time to look after your health? | 28 56% | 8 16% | 14 28% |
| 14. | Do you become emotional for the condition of your child? | 35 70% | 8 16% | 7 14% |
| 15. | Are you able to relax for some time during the day? | 7 14% | 29 58% | 14 28% |
| 16. | Do you feel depressed and anxious because of your child? | 27 54% | 12 24% | 11 22% |
| 17. | Do you some time feel that it is lifelong problem and there is no solution? | 32 64% | 10 20% | 8 16% |
| 18. | Does the Childs unpredictable behaviour disturb you? | 30 60% | 12 24% | 8 16% |
| 19. | Have you take your child in social function? | 24 48% | 26 52% | NA |
| 20. | Does the child shows any behaviour related to sexuality which is unpredictable? | 26 52% | 18 36% | 6 12% |
| 21. | Do you think the child create problem in social adjustment? | 31 62% | 12 24% | 7 14% |
| 22. | Do you feel lonely & for your child? | 29 58% | 14 28% | 7 14% |
| 23. | Do you want to share the problems with other? | 18 36% | 25 50% | 7 14% |
| 24. | Do you feel that society appreciate you for caring of your child? | 20 40% | 18 36% | 12 24% |
| 25. | Do you want to send your child in a residential institution? | 27 54% | 14 28% | 9 18% |
| 26. | Do you think that caring of other children hampered due to your child? | 30 60% | 12 24% | 8 16% |
| 27. | Do you anxious about the condition of your child in your absence? | 29 58% | 13 26% | 8 16% |
| 28. | Do you wishes to die your child before your dead? | 22 44% | 16 32% | 12 24% |
| 29. | Do you think that you should plan some special savings for your Childs future? | 31 62% | 8 16% | 11 22% |
| 30. | Do you think Govt. Should pay stipend for this type of child. | 34 68% | 6 12% | 10 20% |

DISCUSSION

The study was designed to examine the parental view on problems faced by them with an adult with intellectual disability. After data collection the result of study are:-

Majority of the parents are (60%) quite aware about the disability of their child. Only 10 % (Ten) of parents are now still in confusion about the disability. 54% parents said that they were sent their child in school regular basis. But the important finding is 48% parents expressed their positive attitude regarding the improvement of the child after school going. 60% parents expressed that presently their child is not going to school. 48% parents expressed that their child is dependent in activities in daily living. 80% parents said that they are compelled to spend more time for the child for caring. Regarding financial condition of the family 60% parents responded positively that financial condition affected for the child. 54% also commented positively about disruption of family adjustment for the child. Relation with the rest of the family also hampered for the child, 52% parents agreed with this fact. 50% parents stated that quality of marital relationship decline for the child. 60% parents expressed that their health has been affected because of the child. 70% parents commented positively that the condition of the child always remain a cause of becoming emotional. 58% parents also said that they have unable to find time for relaxation for the child. Feeling depressed & anxious because of the child, 54% parents commented positively. 64% parents thought that the problem is lifelong and there is no solution. 60% parents commented that Childs unpredictable behaviour always remain a matter of disturbance. 52% parents showed negative attitude regarding accompanied the child in social function. 52% parents said that the child shows behaviour related to sexuality which is unpredictable. 60% parents commented that the child create problem in social adjustment. 58% parents expressed their loneliness due to their child.

50% parents do not want to share their problems with others. 40% parents demanded that society appreciate for caring such type of children. 54% parents are willing to send their child into residential institution. 60% parents associated with positive attitude that caring of other children hampered due to this child. 58% parents expressed that it would be better if the child passed before their death. 62% parents said that some special savings plan must be done for such type of child for future. 68% parents expressed their opinion positively that Govt. Should pay stipend for this type of child.

CONCLUSION

These findings of the study reveal that most of the parents of adult intellectually disabled are quite aware about the disability of their child. They also agreed that improvement observed after school going. But according to majority of parents their child is not totally independent in daily living skill and they are forced to spend more time for their child for this purpose. Personal as well as social life also disturbed due to presence of the child. Suffering from stress and anxiety for the future of the child and consider the intellectually disabled child as a burden of the family and escaping tendency from the situation remain major concern. Parents also want financial help from the part of the Govt. and positively associated with the attitude to plan for some special saving for this type of child for future.

Limitation

The main limitation of the study is less sample size, so it cannot be generalised. Moreover the researcher investigated only the problems faced by the parents with an adult with intellectual disability. Future research with larger sample with the parents of children with all kind of disabilities will be a further attempt.

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