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**FAMILIES WITH INTELLECTUALLY
DISABLED CHILDREN – PSYCHOSOCIAL PROBLEMS
AND SUPPORT IN THE REPUBLIC OF BULGARIA**

Abstract: Families with intellectually disabled children face many problems and difficulties in the process of care, which are influenced by their psychosocial functioning. The aim of the paper is to present *the current problems* of parents with a moderately intellectually disabled child, based on results of the study conducted with 80 families in the Bulgaria. The results show that *the main problems of the parents are connected with lack of adequate support and services for their children*. There is a discussion about *current changes and development of a policy for family support* for children with intellectual disability during the last ten years.

Key words: children with intellectual disabilities, psychosocial problems, family support

Introduction

Recently, the fast and large scale social and economical changes have created many stressful situations for the individual and the family. Adding to them the stress from upbringing a child with an intellectual disability puts strain on the proper functioning of the family as a whole as well as on its individual members. Meeting the needs of the disabled child, caring for the other, nondisabled siblings, maintaining satisfying marital relationships, and fulfilling professional commitments, as well as meeting the more mundane concerns of daily living can sometimes be overwhelming for the families (3, 4, 24). The children with intellectual disabilities have the limits in their intellectual and social functioning, as well as co-morbidity with somatic, neurological and sensorial disorders. This burdens families with great responsibilities and problems.

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Aim

The purpose of the study was to obtain a more comprehensive understanding of the current problems and needs of the families in the process of care for their intellectually disabled child.

Subjects

Eighty families were recruited to the study. Families were selected on the basis of having a child with moderate and severe intellectual disability, aged 3-7 years. Families were similar on SES and the location.

Measures

To study problems and needs of the parents of children with moderate and severe intellectual disability we develop a semi-structured questionnaire. This was made on the basis of literature review and questionnaires, most often used in this field (1, 21, 25, 28, 29, 31). The questionnaire includes 30 items grouped in following areas:

- 1) Satisfaction with the communication of the diagnosis,
- 2) Problems, connected with the intellectual disability of the child,
- 3) Worries for the future,
- 4) Division of the care for intellectually disabled child in the family,
 - ✓ Involvement of the fathers,
 - ✓ Participation of healthy children,
- 5) Family problems,
 - ✓ Limits of family opportunity,
 - ✓ Marital relationships,
- 6) Social support,
- 7) Satisfaction with the professional help received,
- 8) Expressed needs.

Procedure

The families were selected with the support of social services and general practitioners in the South-West region of Bulgaria. They were contacted by telephone and personal contact, with explanation and invitation to take part in the study. After the families consented, a questionnaire with a letter explaining the purpose of the study was mailed to them. After one week the questionnaires were sent back.

Results

Satisfaction with the communication of the diagnosis

Most parents (85%) are unsatisfied with the way the diagnosis was communicated. They reported for poor attitude of the professionals: most parents were informed in a hurry (75%), roughly (37.5%), without explanation about the disability (60%), without referral to other specialists (88.75%). Only a small proportion of the parents are satisfied with the way the diagnosis of their child was announced (15%).

Problems, connected with the intellectual disability of the child

The main problems are connected with lack of adequate equipment and services for children. Most parents report problems in the process of care for their intellectually disabled child (75%). The reported problems most, are connected with the difficulties in the communication, temper tantrums, problems in mobility, inability to be oriented in the neighborhood, inability to feed him/herself and care for personal hygiene.

Worries for the future

All parents are worried of their child for the future, as well as for the future of the family. The worries for the future of the child are mainly connected with the lack of progress in his/her development (75%), impossibility to take care of himself/herself (81.25%). Parents have concrete worries about the time when they cannot be able to take care for their child with intellectual disabilities (85%). Except difficulties mentioned above, most families (87.5%) prefer to provide the care for their intellectually disabled child at home.

Family problems

Limitation of family opportunity

Majority of mothers (60%) are limited in the choice of a well paid job, because of the necessity to subordinate professional and personal interests to the everyday requirements of care for the child with intellectual disabilities, as well as the requirements for the care of other family members. Some parents (40%) reported that the presence of an intellectually disabled child was a cause for the loss of a desired job. Most parents (80%) complain that the presence of the child with intellectual disabilities imposes limitation on their usual social activities: leaving for holidays and for weekends, engaging in personal activities. Few families (20%) reported no limitations on their social life.

Marital relationships

Nearly every other parent (48.75%) reported that the child with intellectual disability did not change their marital relationships. Some parents reported that the care for their intellectually disabled child has strengthened their relationships (36.25%). Even fewer parents reported that the birth of the child with intellectual disability was a reason for divorce (15%).

Financial problems

All parents reported that the care for their intellectually disabled child is connected with many financial problems, due to many additional expenses (mainly for equipment, medicines, etc.).

Division of the care for intellectually disabled child in the family

Involvement of the fathers

Fathers of intellectually disabled children often take part in playing activities (47%), get up at night (40%), go walking with the child (60%). Every other mother (50%) reported that they receive emotional support from their spouses in the process of care for their intellectually disabled child.

Participation of healthy children

Most healthy children (75%) take part in the care of their disabled sibling. They participate in all activities in everyday life, except household duties. The majority (70%) of parents disclosed that they spent a little time with the healthy siblings.

Social support

Most parents receive help from their extended family (72.5%). Not many parents reported interrupting the contacts with the relatives (25%), neighbours (20%), and friends (40%) after the birth of their child with intellectual disability. Parents valued the moral support from their friends and colleagues (75%). Forty percent the families received help from the grandparents, and especially from the mother of the wife. Parents reported that they received inconsistent help (70%) from the friends and other relatives. Twenty percents of the families received valuable support in

activities conducted outside their homes: shopping, providing a transportation from their neighbours.

Satisfaction with the professional help received

Majority of parents (62.5%) do not receive help from psychologists, speech therapists or rehabilitators. Part of the parents (47.5%) reported that the help and information, received from professionals and social organizations is not enough. Some parents (40%) find it difficult to find a dentist for their child.

Evaluation of necessary help

The needs, expressed by parents are presented in table 1.

Table 1. Needs, expressed by parents in connection with the care for their child with intellectual disabilities

<i>Needs</i>	<i>I definitely need (in % number)</i>
Related to information	
Related to the disability of the child	40% (32)
Related to the development of the child	75% (60)
Related to coping with difficult behaviour of the child	47.5% (38)
Related to the education of the child	31.25% (25)
Related to appropriate services (existing services)	60% (48)
Help in connection with the care	45% (36)
Professional support	
Consultant for the child	60% (48)
Psychological counseling for coping with personal problems	50% (40)
Family and social support	
need of help in household	30% (24)
more support from the husband	56.25% (29)
More time for themselves	31.2% (25)
Somebody who could talk to me	52.5% (42)
More time for the healthier child	87.5% (70)
Meetings with parents with similar problems	77.5% (62)
More understanding from the society	80% (64)
Financial support	100% (80)

Discussion

The results of this study suggest that most parents are unsatisfied with the way of communicating of the diagnosis. A lack of satisfaction in the parents of intellectually disabled child from the way of passing the diagnosis is reported many authors (6, 7, 14, 15). The moment of diagnosis and its announcement to the parents is of great importance both for adaptation for the family and for the beginning of early rehabilitation and intervention with the child. The way of and approaches to telling the diagnosis are an issue with great importance for parents, who experience great difficulties in this period. Through appropriate communication and sufficient information, the professionals should support the parents at the initial stage of adaptation to the critical situation. The development of structural and applicable models for communication with the parents is of great importance. This will support parents in finding and using adequate coping strategies. There is an urgent need for new model of announcement of the diagnosis of the disability, for providing the proper and on-time information about the condition the child. For actualisation of new approaches, professionals should be involved in specialized training for building adequate skills to work with the parents.

The results from our study show that the child with intellectual disability creates some difficulties and requires changes in family life style, but in most families the child with intellectual disabilities is not a reason for aggravation of spousal relationships. In our social-cultural context, only very few families end in a divorce. This is consistent with the results obtained by other authors (12, 16, 25). The care for the child with intellectual disability is divided between family's members, but the main burden is put on the mothers. The participation of the fathers in the process of care is of great importance to lessen the physical burden of the care, as well as for the emotional support, especially for mothers. The fathers do not become disinvolved from families, the care is shared, especially in the case of everyday activities. Most healthy children take part in the care as well. This is consistent with the results from the other studies (13, 15, 19, 30). More parents of mentally retarded children reported that they do not spend enough time with their healthy children. The care for intellectually disabled child engages parents emotionally and rationally, and often, against their plans or preferences they cannot grant their healthy children proper attention. If there were possibilities for parents for alternative care of intellectually disabled child, parents would have more time for their own tasks and also more time for activities with their healthy children.

Because of the care for their intellectually disabled child, families are deprived of many recreational activities. The parents are limited in the choice of work, because of the continuous care for their intellectually disabled child. There are some limitations in the professional development of some family members, especially mothers. Support and close relationships with the extended families and friends are important factors countering social isolation. In psychosocial aspect, the isolation of the families is has a negative impact on both the child and parents.

Despite the fact that the multitude of child-care professionals with whom families typically have most frequent contacts the most contact tend to specially focus upon the needs of the child, majority of parents receive insufficient support or feel that professionals do not understand the practical difficulties they face (2, 10, 16, 17, 28). Seeking and receiving specialized help leads to losing important time for stimulation of the development of the child, as well as misunderstandings between parents and professionals. Most parents have difficulties in finding appropriate equipment proper for the handicapped child.

The recognition of the real state of the child with intellectual disabilities reflected in concrete worries for his or her and the family's future. All parents are worried about the future of their child, when they can no longer care for their disabled child. This confirms the results of other studies (2, 11, 20, 21).

Results of our study show that in the process of the care for their intellectually disabled child, parents need continuous help and support

Most studies have shown that parents are hungry for information about the child's condition, as well as information for development and education of the child (1, 10, 12, 22, 27). Similar issues apply to the provision of information about services. The parents need an adequate support and appropriate service that would ease the adaptation to the extra burden of upbringing an intellectually disabled child.

There is a need for improvement of communication between parents and professionals, as well as between different service providers and institutions, needed for the children with intellectual disability. Parents should be trained by professionals how to cope with the difficult behavior of the child, as well as in proper approaches, for stimulation of the development of the child. This might be done in specialized centers, and parents should be informed how to find this kind of support.

Most parents are needed for professional consultation about the state of the child, as well as for their personal problems. The need for psychological help that the parents are aware of defines the necessity to access programs for psychosocial interventions (23). The results obtained by other authors show the need to have access to information about existing and accessible services and programs for their intellectually disabled child (8, 9, 18, 29). Because in the last years the number of social and special services increased, there is a need for dissemination of information for existing services/possibilities.

Results from this study support the idea that parents need meeting other parents in similar situation, which is consistent with the results from other studies (1, 25, 27, 29). Very often parent organizations provide information and support, as well as lobbying for development of adequate services, consistent with the need of intellectually disabled children, and their parents.

Most parents reported need of better understanding of their problems on behalf of the society. This is connected with the existing stigma and little informa-

tion about the problems these families faced in our society. There is a need for a public social campaign, which would aim at better understanding of the problems of children with intellectual disabilities and their parents.

All parents have serious financial difficulties in connection with the care for a mentally retarded child. This on the one hand can be explained by the unstable social-economic situation in country, and with the limited financial support for the families, caring for a mentally retarded child on the other.

In the process of care for their intellectually disabled child, parents face many problems and difficulties, which are influenced their psychosocial functioning. Results of our study show that in the process of the care for their intellectually disabled child, parents need continuous help and support. The process of painful experiences and rambling of parents between different services and specialists will be shortened meaningfully with the creation of adequate programs and services. The professionals should be well trained, and build multidisciplinary teams for work with families with intellectually disabled children as well as with their families.

Conclusions

The questions referred to in this paper highlight only some of the numerous problems of parents who care for a child with intellectual disability. The present study reveals that parents with intellectually disabled child have many unfulfilled needs, except that in the recent years there have been many changes in legislation, as well as development of new kind of services.

The results from this study show that the main problems of the parents are connected with a lack of adequate support and services for their children with intellectual disability.

Basic needs of the parents are connected with the necessity for adequate information and specialized help for the child, for the educational possibilities, information for existing services and programs, financial support and counseling for coping with personal problems in the process of care

It is necessary for the policy for family support to be improved, in order to provide support and appropriate help for the child and his or her family at different stages of life cycle. This is connected with the development of a well coordinated system of care in medical, psychological, social and educational perspectives, as well as with the involvement of NGOs.

References

- Bailey, D., Blasco, P., Simenonsson, R. (1992), *Needs Expressed by Mothers and Fathers of Young Children With Disabilities*, "American Journal on Mental Retardation", Vol. 97, No 1, pp. 1-10.

- Beresford, B. & Lawton, D. (1993), *Coping with the care of a severely disabled child: Final Report on the Joseph Rowntree Foundation (No JRF 1078)*, Social Policy Research Unit, University of York.
- Brodin, J. & Molosiwa, S. (2000), *Support for families with children with mental retardation in Botswana, Southern Africa*, "International Journal of Rehabilitation Research", No 23, pp. 163-167.
- Brodin, J., Stancheva-Popkostadinova, V. (2002), *A reflection of varieties in support for families of children with severe intellectual disabilities in Sweden and Bulgaria*, Euro-Rehab, No 1, pp. 9-20.
- Cobb, S. (1976), *Social support as a moderator of life stress*, "Psychosomatic Medicine", No 38, pp. 300-314.
- Cooke, K., Bradshaw, J., Glendinning, C., Baldwin, S., Lawton, D. and Staden, F. (1982), *10 Year Follow-Up Study. Interim Report to the DHSS 108/6*, 82. Social Policy Research Unit, University of York.
- Cunningham, C. (1994), *Telling Parents their Child has a Disability*, [in:] P. Mittler and H. Mittler (eds), *Innovations in Family Support for People with Learning Disabilities*, Lancashire.
- Darling, R. B. (1987), *The economic and psychosocial consequences of disability: Family-society relationships*, "Childhood Disability & Family Systems", No 11 (1/2), p. 45.
- Davis, H., Buchan, L. & Choudhury, P. (1994), *Supporting Families of Children with Chronic Illness or Disability: Multi-cultural Issues*, [in:] P. Mittler and H. Mittler (eds.), *Innovations in Family Support for People with Learning Disabilities*, Lancashire.
- Grunland, M., Roll-Pettersson, L. (2001), *The perceived needs of support of parents and classroom teachers – a comparison of needs in two Microsystems*, [in:] L. Roll-Pettersson, *Between open systems and closed doors. The needs and perceptions of parents of children with cognitive disabilities in educational settings*, Stockholm Institute of Education Press, Studies in Educational Sciences 45.
- Kazak, A. E., & Marvin, R. S. (1984), *Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child*, "Family Relations", No 33, pp. 67-77.
- Lamb, M. E., Meyer, D. J. (1991), *Fathers of Children With Special Needs*, [in:] M. Seligman (ed.), *The family with a handicapped child*, London, pp. 151-179.
- Lindstrand, P., J. Brodin, L. Lind (2002), *Parental expectations from three different perspectives: What are they based on?*, "International Journal of Rehabilitation Research", No 25 (4), pp. 261-269.
- Llewellyn, G., Dunn, P. & Fante, M., Turnbull, L., Grace, R. (1996), *Families with Young Children with Disabilities and High Support Needs. Report to Ageing and Disability Department*, University of Sidney.
- Longo, D. C. and Bond, L. (1984), *Families of the handicapped child: research and practice*, "Family Relations", No 33, pp. 57-65.

- McKay, M. & Hensey, O. (1990), *From the other side: parents' views of their early contacts with health professionals*. "Child: care, health and development", No 16, pp. 373-381.
- Parker, G. (1990), *With Due Care and Attention* (2nd Edition), London.
- Philp, M. and Duckworth, D. (1982), *Children with Disabilities and their Families: A Review of Research*, Windsor.
- Powell, T. and Ogle, P. (1985), *Brothers and sisters-exceptional families*, Baltimore.
- Quinne, L. & Pahl, J. (1989), *Stress and Coping in Families Caring for a Child with Severe Mental Handicap: A Longitudinal Study. Final Report*, Canterbury.
- Roll-Peterson, L. (2001), *Parents talk how it feels to have a child with a cognitive disability*, "European Journal of Special Needs Education", No 16, pp. 1-14.
- Schulman, S. (1988), *The Family of the Severely Handicapped Child: The Sibling Perspective*, "Journal of Family Therapy", No 10, pp. 125-134.
- Stancheva, V. (1996), *Parent-Professionals Partnership-Reality and Perspectives. Selected abstracts from 10th World Congress of the International Association for the Scientific Study of Intellectual Disabilities. 8-13 July, 1996, Helsinki*, "The British Journal of Developmental Disabilities", vol. XLII, Supplement, p. 23.
- Stancheva-Popkostadinova, V. (1999), *Psycho-social Functioning in Families of Children with Mental Retardation*, Doctoral dissertation, Sofia.
- Taanila, A., Kokkonen, J., Jarvelin, M. R. (1996), *The long-term effects of children's early-onset disability on marital relationships*, "Developmental Medicine and Child Neurology", No 38, pp. 567-577.
- The Law for Protection, Rehabilitation and Social Integration of Disabled Persons* (1995), Sofia.
- Upshur, C. C. (1991), *Families and the Community Service Maze*, [in:] M. Seligman (ed.). *The family with a handicapped child*, London, pp. 91-116.
- Walsh, P., Conliffe, C., Birkbeck, G. (1994), *Assessing the Needs of Family Carers*, [in:] P. Mitler and H. Mitler (eds), *Innovations in Family Support for People with Learning Disabilities*.
- Willoughby, J. C. & Glidden, L. M. (1995), *Fathers helping out: Shared child care and marital satisfaction of parents of children with disabilities*, "American Journal on Mental Retardation", No 99, pp. 399-406.
- Wilson, J., Blacher, J. & Baker, B. L. (1989), *Siblings of children with severe handicaps*, "Mental Retardation", No 27 (3), pp. 167-173.
- Wing, L. (1985), *Services for Severely Retarded Children and Adolescents*, [in:] M. Rutter and L. Hersov, *Child and Adolescent Psychiatry. Modern Approaches*, pp. 753-465.