



SOUTH-WEST
UNIVERSITY
·NEOFIT RILSKY·
BLAGOEVGRAD, BULGARIA

VOLUME 2
2004



SCIENTIFIC
Research

ELECTRONIC
ISSUE

COLABORATION BETWEEN PARENTS AND PROFESSIONALS IN THE FIELD OF INTELLECTUAL DISABILITIES

**VASKA STANCHEVA-POPKOSTADINOVA, M.D., PhD
DEPARTMENT OF MEDICAL-SOCIAL SCIENCES
SOUTH - WEST UNIVERSITY "NEOFIT RILSKI", BLAGOEVGRAD**

Abstract: Partnership between parents with intellectually disabled child and professionals is a vital for the effective work and benefits for the children

The paper presents results from the study the nature of the parents-professionals relationships in the field of children with intellectual disabilities in Bulgaria. The results show, that parents, as well as specialists working with them and their children experience various difficulties-parents are unsatisfied with the way specialists communicate with them; insufficient information, not refer to proper specialists. Recommendations for the improvement of collaboration between parents and professionals are mad, based on the results from the study, and finding in the current literature in this field.

Key words: children with intellectual disabilities, parents, professionals, collaboration

Introduction

During the last decade in Bulgaria , services and attitudes toward persons with disabilities and their families have changed dramatically. Institutions started to be reformed and closed; important legislative changes has been implemented (Children Act, 2001 Standards for care in the institutions for children, 2003, Program for deinstitutionalization,..), parents organizations become more and more strong and influence the important decisions concerning people with disabilities, day care centers for children and adults with intellectual disabilities are speeded in the whole country (Stancheva-Popkostadinoiva, V., G.Bogdanski, E.Kerankova, 2004), some trials for integration of children in school already made and show positive results on children development, many valuable technological advancements in education and services for persons with disabilities have taken place (Stancheva&Tuporova, 2002) .

Children with disabilities and their parents have varied difficulties and face diverse challenges throughout their lifespan. The systematic interactions between families and different professionals may have profound impacts on adjustment and maladjustment processes. The presence of a child with a severe disability in the family often means that parents need to obtain, understand, and use plenty of information.

In many cases professionals have made assumptions about the needs of parents and families of children with disabilities without obtaining solid empirical evidence or even bothering to confirm or refuse these assumptions by listening to parents themselves (Roos, 1977). As social services and professionals begin to realise the importance of meeting the needs of families, more productive networks of parent-professional alliances are being created. Although much progress in this area has bee achieved in recent years, parents and professionals alike realise that much more

remains to be accomplished. In the process of changing models of care for intellectual disabled persons, the partnership between parents and professionals become very important issue. Through the partnership families and professionals share valuable experiences and knowledge. The benefits for the families (A.Turnbull, 1992) are connected with obtaining sufficient information about child's disability and about specialists who could help them; receiving adequate information about parents' rights and responsibilities; receiving help in choosing appropriate schools; planning activities, which support development of the child. On the other side, there are benefits for professionals as well. Through the partnership with the parents, professionals receive much more information about the state of the child; better recognition of the needs and potential of the family as a whole, as well as feedback and planning proper activities which could be done at home. According to Dornberg (1991, p.240) there at least three important reasons why professionals need to collaborate with families. First, an adequate understanding of the home and family is necessary for designing and delivering services that are vitally important for the individual and the family. Second, if services provided to individual are to be effective, then parents and families need to be involved in and supportive of the specific programs of treatments. Educational, vocational, or health-related services must be delivered in a manner consistent and congruent with the ongoing structure, routines, and ecology of the family. Third, professionals should understand that families as unique and distinct units, have important needs of their own that extend beyond the immediate needs of their disabled family member.

The **aim** of the study is to examine the nature of the parents-professionals relationships in the field of children with intellectual disabilities in Bulgaria.

Subjects: 30 parents (mean age 37.0 ± 6.5) of children with intellectual disabilities (11.47 ± 4.51). The bigger part of the children was with unknowing diagnosis (33.3 %). The others were with cerebral palsy (26.7 %), Down Syndrome (23.3%), spine bifida (10 %), microcephaly (6.7 %).

80 specialists working with children with disability and their families: paediatricians (10), psychiatrists (10), neurologists (5), physiotherapists, psychologists (10), special educators (20), social workers (20).

Instruments: Two semi-structured questionnaires, especially designed for the purpose of the study were used for collection of opinions of parents and professionals. Parent's questionnaire included 8 open questions and focused in parent's point of view of their communication with different professionals - satisfaction with the provided information and evaluation of help, received from them. The second questionnaire was designed to professionals for assessment of their views about the difficulties in the process of working with the parents and approaches for building collaboration and improving the current practise. The questionnaire consists of 9 open questions. The questions facilitate answering in a structured way.

After the previous selection of the parents and agreement for the participation in the study, we sent 100 questionnaires. The 80 of them were return. The questionnaires for the professionals also been send by post.

Results and discussion

Results from the study of parents

Most of the parents (70 %) expressed the need for more information. The type of information needed by parents is for the nature of their child's disability (50 %), characteristic patterns of normal development (30 %), methods of parenting and management with mentally retarded child (36.7 %). In providing parents with information, care should be taken to avoid the use of technical, professional jargon or of communicating proper with them. The results support the findings from other studies that have stressed parents' wishes to be given as much information as early as possible and to be treated as people primarily responsible for their child (Tarran, 1981; Quinne and Pahl, 1987; McKay, M., Hansen, O. 1990; Cunningham et al., 1984; SCOVO, 1988).

The bigger part of parents (60 %) had difficulties with the paediatrics and feel that their needs are not specifically addressed by these professionals. 63.3 % of studied parents share difficulties in finding appropriate equipment in connection with the accompanying symptoms of their child's disability. One of the most important need reported by the parents is for professionals and others to attempt better understanding their problems and provide emotional support in a way, that is not blame them..

One of the most important needs for all families of children with severe disabilities in our study is to obtain the necessary services for their children . This is consistent with the results from other studies (Quinne L.&Pahl, J. 1985,Taanila, A. et al., 1996;Tarran, E.C.1981; Turnbull, A.P.&Turnbull, H.R.,1986). Many families (70 %) need direct home care and assistance. There is a current need for changes in models of care for persons with mental retardation.

The wishes of the parents in accordance with interactions with the professionals in summary are:

- to tell them the diagnosis on time and in understandable words;
- to refer them to the respective specialists and services timely;
- to hear their opinion when they take a decision concerning treatment or moving to a social care home;
- to help more competently and accurately

This is the comment of one parent: "Some of them added to our grief their misunderstanding and lack of humanity. It's good there weren't many of them".

4. Results from study of professionals

On the other side-professionals who work with children with intellectual disabilities and their families also reported some problems and needs.

A permanent problem for them is the lack of appropriate context that might promote the integration of their efforts. Most of the physicians share that they were target of the verbal aggression of the parents who often want even the impossible. The isolation and lack of support and co-ordination in their efforts' leads to the feelings of helplessness and exhaustion . By many of them were finding Burnout syndrome

The professionals in our study think that the parents:

- Are capricious (50 %)
- Do not understand and appreciate the efforts of the specialists (63.3%)
- Do not participate in the process of rehabilitation, because of lack of stubbornness and argumentation (66.7%)

- Are unwilling to share the difficulties they have with the upbringing the child at home (36.7 %), often hiding the truth about the state of the child as well as their own methods of treating him/her (46.7 %).
- Do not take and follow the professionals' advises (63.3 %)
- Do not know basic things about upbringing (23.3 %)
- Some parents do not accept the reality (23.3)

How can the relationship with the parents improve according to the professionals?

Social workers and pedagogues point out that the following are necessary:

- more frequent meetings with the parents;
- building of understanding and respect in the parents to the professionals
- To find an appropriate systematic approach for work with the parents of mentally retarded children, to give the parents specialised help for improving the relationship between them
- psychological counselling for solving the conflicts and personal problems

The physicians point out that specialised areas in the education should be created dealing with the problems of families with mentally retarded member.

Most professionals involved in providing services to persons with moderate and severe disabilities agree that working effectively with parents and families is a vital aspect of service provision.

5. Conclusion

The results from our study clearly indicate that parents, as well as specialists working with them experience many difficulties. There are some misunderstandings between them, connected mainly with difficulties in the early stages in the communication with the specialists, lack of adequate structure for serving children with intellectual disabilities, lack of specialized training for the professionals. Training must be provided to the many different professionals who are expected to work effectively with children with intellectual disabilities and their families. Professionals must adopt an ecologically valid approach toward these families as well as to their own particular roles. The child and the family must be viewed within the context of one another (Lyon and Lyon, 1991).

Professionals are needed to remember and to understand the family as a system, with its own unique structure, functions, and life cycle.

Parents and specialists should work together on behalf of the children. Working together, parents and professionals can minimise the difficulties and maximise the opportunities for both the severely disabled children and their families. The contacts with the colleagues should be more frequent and close.

Better understanding the problems and needs of persons with disabilities and their families will prepare professionals to communicate and collaborate effectively with them. There are some factors that impede physician-parent communication. According to Seligman (1991) they are:

- the physician's inadequate knowledge of developmental disabilities
- physician's negative attitude toward disabled children
- the physician's inept skills in communicating with parents.

All these factors are interrelated: That is, deficiencies in one area affect the physician's abilities in other areas. The professionals cannot be expected to be an expert on every disabling condition or even on all of the ramifications of any condition. It is necessary to refer parents to written materials, other knowledgeable professionals, and organisations with specialised information about disabilities.

Attempts must be made to develop co-ordinated and permanent services so that the lifelong needs of these persons and their families can be met. Professionals in a wide variety of education, health, and human service fields must become knowledgeable and skilful in working with persons with severe disabilities and in understanding and working with their families.

For useful partnership, or partnership in action professionals must realise several important principals when attempting to collaborate with the families with intellectually disabled children:

- Children with disability and their families' characteristics, needs, and preferences differ widely. Never forget that what may be important or appropriate for one family may not be for another
- Families are complex units with varying and unique interaction styles
- The focus of the intervention should not be narrowly defined

Services and professionals should be more family oriented than individually oriented and should direct more of their efforts toward positively affecting the social system of the family.

Effective collaboration with families of persons with severe disabilities may require professionals to do many things, ranging from providing simple encouragement and support to assisting in providing and interpreting information and assisting in special problems to help parents clarify goals and needs for themselves, their severely disabled child, and their family.

It is necessary to create multidisciplinary teams in the system of care to persons with intellectual disabilities. By gaining a clearer understanding of the dynamics of collaborative efforts with fellow workers and with consumers, human service workers can increase their own effectiveness in the field (O'Connor, B., 1997) Usually the team is composed by physicians, psychologists, social workers, special educators working in active co-operation with the families. The main goal is to ensure, through early diagnosis and intervention, the necessary support and optimal social adaptation for the intellectually disabled persons according to their individual abilities. For the effective collaboration between parents and professionals it is important the realistic goals to be put, as well as division of responsibilities, good communication, adequate ways for parents' participation.). To work effectively with persons with severe disabilities and their families, it is important that professionals develop a basic understanding of the common needs of these families as well as the ability to identify specific needs that are unique to individual families (Lyon and Lyon, 1991). The best model in collaboration is this in which specialists are experts in their work and parents are experts according to their parents.

Bibliography:

- Cunningham Cl. Telling Parents their Child has a Disability. In P. Mittler and H.Mittler(Eds). Innovations in Family Support for People with Learning Disabilities, Liseux Hall, 1984, 85-105.
- Dornberg N.L. (1978). Some strategic effects on family integration of health and educational services for young handicapped children. American Journal of Orthopsychiatry, 39, pp 107-110
- Lyon,S.R.&Lyon,G.A. (1993). Collaboration with Families of Persons with Severe Disabilities. In: Seligman,M.(Ed.), , pp.237-267
- McKay M.&Hensey, O. (1990). From the other side: parents' views of their early contacts with health professionals. Child: care, health and development,. 16. 373-381.
- O'Connor,B., (1997). A team approach to service provision. In P.O'Brien&R.Murray (Eds.).Human Services:Toward partnership and support , NZ:The Dunmore Press, pp.215-228
- Quinne L.&Pahl, J. (1985). Examining the causes of stress in families with severely mentally handicapped children. British Journal of Social Work, 15, 501-517.
- Quinne L.&Pahl, J. (1989).Stress and Coping in Families Caring for a Child with Severe Mental Handicap: A Longitudinal Study. Final Report. Canterbury: Institute of Social and Applied Psychology, University of Kent.
- Roos, P. (1977). A parent's view of what public education should accomplish. In E.Sontag (Ed.)Educational programming for the severely and profoundly handicapped. Reston, VA:Council for Exceptional Children, Division on Mental Retardation, pp.72-83
- SCOVO. Parents Deserve Better. A Review Report on Early Counselling in Wales. SCOVO, 32 Cowbridge Road East, Cardiff (2nd ed.), 1992.
- Seligman,M. (1991). The Family with Handicapped Child. 2nd ed. Allyn and BACON,
- Stancheva, V. (1997). Models of care for mentally retarded persons and their families in Bulgaria. Proceedings of International Conference for human rights for mental handicaps. 7-12 September, Prague 1996, 226-229.
- Stancheva,V. Understanding and helping Families with Moderate Intellectually disabled child. Asklepios, XII , 1999/2000, 75-78
- Stancheva-Popkostadinova, V., G.Bogdanski, E.Kerankova (2004). Day care centers for children and youth with intellectual and physical disabilities. Proceedings of International conference "Societal support and social work in Bulgaria-history, institutions, ideologies, names, Blagoevgrad, 2004 (in press)
- Stancheva-Popkostadinova, V., D.Tuparova (2002). Possibilities of the informational technologies for the education of children with mental retardation, S. Asclepius, pp.143-147 (in Bulgarian Станчева-Попкостадинова, В., Д.Тупарова. Възможности на информационните технологии за обучение на деца с умствена изостаналост. . Асклепий, XV, 2002)
- 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, 38, 567-577.
- Tarran, E.C.(1981). Parents' Views of Medical and Social-Work Services for Families with young Cerebral-Palsied Children. Developmental Medicine and Child Neurology. 38 (7), 567-577.

- Turnbull A.P. (1983). Parent-professional interactions. In M.E. Snell(Ed.), Systematic instruction of the moderately and severely handicapped (2nd ed.) Columbus, OH:Merrill.
- Turnbull, A.P.&Turnbull, H.R. (1986). Families, professionals, and exceptionality: A special partnership. Columbus, OH:Charles E. Merrill.
- Turnbull, A.P., Summers, J.A., & Brotherson, M.J.(1984). Working with disabled members:A family systems approach. Kansas University Affiliated aculty, Lawrence.
- Turnbull, A.P.,Summers, J.A.&Brotherson, M.J. (1986). Family life cycle:Theoretical and empirical implications and future directions for families with mentally retrded members. In J.Gallagher&P.M.Vietze(Eds.)Families Of handicapped persons:Research, programs, and policy issue. Baltimore:Paul H. Brookes Publishing Co.
- Turnbull, H.R., Guess, D., & Turnbull, A.P. (1988). Vox populi and Baby Doe. *Mental Retardation*, 26, 4, 261-272
- Turnbull,H.R., Turnbull, A.P.,Bronicki, G.J., Summers, J.A.,&Roeder-Gordon, C.(1989). Disability and the family:A guide to decisions for adulthood. Baltimore:Paule H. Brookes Publishing Co.
- TurnbullH.R., Garlow, J.E.,&Barber, P. A.(1991).A policy analysis of family support for families with members with disabilities. *Kansas Law Review*, 39(3), 739-782.
- Turnbull, A.P.&Ruef, M. (1996). Family perspectives on Problem Behavior. *Mental Retardation*, 34, 5, 280-293.
- Turner, S., Sloper, P., Knussen, C. And Cunningham, C.C.(1991). Factors relating to self-sufficiency in children with Down's Syndrome. *Journal of Mental Deficiency Research*.
- Upshur, C.C.(1991). Families and the Community Service Maze. In M. Seligman(Ed.). *The family with a handicap child* (91-116). Allyn and Bacon, London.