

RESEARCH REPORT ON NEEDS OF PARENTS AND TEACHERS OF CHILDREN WITH CEREBRAL PALSY in ANKARA (03-18 AGES)

Researchers:

Ankara National Education Directorate

1. Banu Duman* and Rukiye Peker; project coordinators,
2. Ayfer Yıldırım Erişkin, Special Education Specialist,
3. Duygu Yörük, Measurement and Evaluation Specialist,
4. Gökhan Şengün, Psychologist,
5. Sülbiye Cebeci, Counselor from Guidance and Research Center,
6. Işık Akın, Teacher of Mentally Impaired Children,
7. Pınar Kahrıman, Teacher of Visually Impaired Children,

Hacettepe University Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation

8. Mintaze Kerem Günel, PT, PhD, Prof.,
9. Akmer Mutlu, PT, PhD, Assist. Prof.,
10. Özgün Kaya Kara,
11. Ayşe LİVANELİOĞLU, PT, PhD, Prof.

*Correspondence:

Banu Duman, Ankara National Education Directorate, Research&Development Center, Strategy Development Department, International Project Units.

E-mail:dumanbanu@gmail.com

Introduction:

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, by epilepsy and by secondary musculoskeletal problems. (Rosenbaum, Peter et al. 2006)

The prevalence of CP shows a variable rate ranging from 1.5 to 3 per 1000 live births. Each year 10000 children are diagnosed as cerebral palsy in EU countries. The reported rates are 2.5 per 1000 in Finland, 1.9 in England, 2.4 in Sweden, 2.1 in Norway, 2.4 in Malta, 1.6 in China, 4.4 in Turkey and 4.9 in Denmark (Serdaroğlu, A

et.Al. 2006). There are 1.5 million annual births in Turkey and the number of cerebral palsy is quite high. Considering the general population of Turkey is 75 million, we can say that the number of children with cerebral palsy between the ages 0-18 and their families can be expressed in large numbers.

As it is known participation is important for all children to become active member of the society. The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation 2001) define participation as involvement in life situations and environmental factors as the social, attitudinal and physical environments in which people live and conduct their lives. When there are positive aspects of environment; they are also called facilitators and when there are problems, they may be called as barriers.

Since many children with cerebral palsy have more than one disorder, they have serious hardness to participate into the society actively due to nature of this illness. Not only the children with CP but also the parents especially mothers have encountered participation problems since they have to spend quite much time with their children within a day. Meanwhile, their quality of life is also affected by several environmental factors such as mobility, transport, and support to and by parents, attitudes of individuals and institutions towards children, bureaucracy and access to information etc.

We couldn't find any study that analyzes the needs of parents and teachers of children with CP (03-18 ages) and that put remedies to cope with situation. However, a qualitative study using discussion groups was conducted by parents of 28 children with CP with a mean age of 7 years (range 5–14 years) and a range of severity and type of CP and associated impairments from five countries; Denmark, France, Italy, Ireland and Sweden. This study is designed to assist development of a relevant measure of environment. According to result of it, parents of CP children in many countries face some difficulties in a varying rate caused by bureaucracy, poor transport alternatives, less mobility, inadequate support resources, lack of information and difficulty to access, negative attitudes in the society.

Aim of the Research Report: It is aimed at determining needs of teachers working with children with Cerebral Palsy and parents having Cerebral Palsy children (03-18 ages) in Ankara.

Scope and Limitations: Although there are 226 schools that have children with CP in Ankara, the survey was restricted with 9 pilot schools (1 pre-school, 5 primary schools, and 3 vocational schools) which were taken into consideration according to socio-economic level of general population in Ankara for quantitative research. In the survey we carried out in Ankara, the parents and teachers of children with CP who continue to pre-school, primary school, high school and vocational school were chosen as target group.

Furthermore, focus group interviews were carried out with nine volunteer mothers and ten teachers of children with Cerebral Palsy (CP) who were attending to MEV Gökkuşığı EÇEM Kindergarten and Primary School. This school has the most children with cerebral palsy in Turkey so results of this study reflect needs of parents and teachers of children with CP in nationwide.

Method and Data Collection of the Survey:

Method: Both qualitative and quantitative research method were used in order to determine needs of children with CP (03-18 ages). As quantitative survey, questionnaire was implemented to the teachers and parents of children with CP at these schools through survey monkey. In addition to this, as qualitative research, focus groups were performed with 10 teachers and 9 mothers of children with CP. Focus groups are useful for reflecting the social realities of a cultural group, through direct access to the language and concepts that structure participants' experiences (McManus, V.2006).

1. Questionnaire survey

- **Sampling and Data Collection**

Official letter was sent to the national education directorates in 25 districts in Ankara to find out number of parents, teachers of children with CP, children with CP (03-18 ages) and type and number of schools. As a result, 609 children with CP between 3-18 years of age were detected in Ankara. There are 226 schools that have children with CP in Ankara. 7 of them are pre-schools, 197 of them are primary

schools, 15 of them are secondary schools and 7 of them are vocational schools. These schools were determined in 17 county in Ankara affiliated to Ankara Governorship. For quantitative research, 9 pilot schools (1 pre-school, 5 primary schools, and 3 vocational schools) were selected according to socio-economic level of general population in Ankara.

Many factors were considered to design appropriate way of implementation of survey such as; participant's education level, ability of using technology and possession level of technological equipment etc. Low skill and poor level education of parents in using technology/computer led us to apply questionnaires in school's lab under guidance and monitoring of project team. Teachers were instructed and participated in the survey by researchers. 97 teachers joined in the survey at school while 25 teachers participated in the survey from their home. Consequently, 93 parents and 122 teachers (Total 215 parents and teachers) replied to the questionnaire.

- **Analysis of Data**

Data, descriptive, statistics (mean, percentage, frequency etc.) were used in tables and graphics.

2. Focus group interviews

2.1 Focus group interview with parents

- **Sampling and Data Collection**

Focus group interview with parents included nine volunteer mothers of children with Cerebral Palsy (CP) who were attending to MEV Gökkuşığı EÇEM Kindergarten and Primary School. The participants were the mothers of children with CP which were at least one different affected type of CP. The mothers who had more than one child with CP answered the questions according to the most severely affected child. 4 of the mothers graduated from university, 4 from lycee/high school, 1 from primary school. 6 of mothers were housewives and 3 of them working mothers.

Focus group study was carried out in MEV Gökkuşığı EÇEM Kindergarten and Primary School. The questions including the “determined keywords” were asked

of mothers by the moderator of focus group respectively. The reporters kept the records that private. In addition, video and voice records were kept.

2.2 Focus group interview with teachers

- **Sampling and Data Collection**

Focus group interview with teachers included ten volunteer teachers of students with CP who were working in MEV Gökkuşığı EÇEM Kindergarten and Primary School. Teachers of focus group; five of them are class teachers, one is math teacher, one is guidance teacher, two are kindergarten teachers and one is vice-administrator. Work experiences of teachers with CP; three had one year, 2 had two or three years and two had four or five years. Three of them did not mention about their work experiences. Graduation of teacher; 2 were graduated from Mentally Impaired Class Teacher Department and 8 were graduated from different departments.

Focus group study was carried out in MEV Gökkuşığı EÇEM Kindergarten and Primary School. The questions including the “determined keywords” were asked to teachers by the moderator of focus group respectively. The reporters kept the records private and secure. In addition video and voice records were taken.

- **Analysis of Data**

Data was entered into the “hyper research programme” by giving special codes.

3. Findings and Comments

3.1 Comments on needs of parents’ of children with CP in accordance with results of analysis of questionnaire and focus group.

Children with CP

- Majority of the children walked with restrictions and supportive equipments,
- Majority of children used the body support devices and tools,
- Majority of children have problems of acceptance of their disability, making friends, focusing on tasks,

- Majority of children have difficulties in grasping the objects, and in regulating the activities,
- Majority of children had problems in sensory and social abilities; they were not at the same level with the peers,
- Majority of children did not receive any treatment except physiotherapy,
- Majority of children did not participate into the activities except the lessons,
- The children with CP are not accepted and treated equally except by the school and the close family environment (mother, father, sibling)
- Majority of children were effectively receptive and expressive in communication,
- Majority of children could use the communication devices,

Need of Children with CP

- Children with CP have to accept his/her disability and need acceptance in community.
- Children with CP need guidance for making hobbies.
- Children with CP need more leisure time to play with their peers.
- Children with CP need different therapies (speech therapy, occupational therapy and psychology).
- They need more physiotherapy opportunities.

Parents and Families

Families are in need of information, support and opportunities for participation to social life. We found that the mothers mostly spent time with the children with CP, most of them were housewives and majority of mothers had the primary school educational level. Families and parents belonging higher socio-economic strata are much more aware of illness and greater opportunity both for following and using recent technological and curing developments.

Support System

- Majority of the families received the support from the first degree relatives (grandmother, grandfather, aunt, etc.),
- Majority of the families did not receive extended family or environment support,
- The families perceived insufficiency for the government or municipality support (economic, vehicle help, transportation, participation to activities, etc.)

Information Need

- Majority of families had limited knowledge about CP as an illness.
- The sources for acquisition of knowledge about CP were majorly restricted as health professionals and foundations (hospitals, medical doctors, physiotherapists),
- Families know little about assistive devices and tools and don't have knowledge about communication devices developed for the conditions of their children.
- Families need guidance for keeping themselves up to date in relation to technological advances that could make their life easier.
- Parents need training on therapy programme to be applied at home.
- Parents need to get information about the supportive devices used abroad and developments on CP.
- Parents did not get any information about home programme and home settings from health professionals.
- Parents need to learn possible ways of their child's behaviour and need training on how to cope with these behaviour problems.

Opportunities for Participation

- Parents are reluctant to accept their children's cognitive status and learning disabilities, on the other hand regular parents and children do not make life situation easier for families with CP. Families need acceptance of their children in society and community.
- Families have serious problems in creating and spending time for themselves and out of home. They need guidance for making hobbies.
- Parents obtained hardly their children's assistive devices.

- Outside home seems unsupportive to walk and move.

3.2 Comments about needs of teachers' of children with CP in accordance with results of analysis of questionnaire and focus group.

Information and Support Need for Teachers

- M
Most of the teachers are lack of information about CP.
- S
Sources of information about CP for the teachers are mostly other teachers and colleagues.
- Most of the teachers have no information about orhosis/devices/tools which their students with CP used so that only few of the teachers can help their students with CP regarding their orhosis, devices and tools.
- Most of the teachers have no information about supportive and communication devices.
- Teachers don't have enough information about fine and gross motor skills.
- Teachers have difficulty because of variable psychological status of students with CP.
- Teachers are in need of getting information and advice about behaviours of students with CP.
- T
Teachers can define learning disabilities of students with CP.
- M
Most of the teachers need on reaching information, legislations, rights and responsibilities.

Physical Setting

- Most of the teachers think that more physically suited settings are needed.
- M
Most of the teachers identified that student's chairs and classes are not compatible with the disability.
- Teachers complained about narrow classes.

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- Most of the teachers identified that there are no auxiliaries for students with CP.
- Teachers complained about negligence of parents towards their children.
- Teachers think that government do more and there are needed more schools for children with CP.

4. Conclusion

- Although the needs of an individual child with cerebral palsy vary, the complexity of their needs is something that many families have in common.
- Families have gone through very difficult physiological process first to accept that their children have some disabilities, second to get acceptance from the society. During this process they need to know that they are not alone. Therefore joining a parent support group allows parents to share and interact with others who have the same experiences and family stresses, and to become involved in advocacy work to improve services.
- Children's needs are often long-term and complex. Families should be empowered with adequate information to plan for their children's continuous needs.
- Remedies have to be tailor made according to degree and type of disability.
- Parents should not place too much emphasis on their children achieving normal function.
- Accommodative strategies and the use of assistive technology should be encouraged to enhance their social participation and quality of life.
- Families need to get information from different sources: they need a data base where they can follow recent developments in support devices and tools, communication vehicles, law and regulations, home setting and programme and so on.
- Government has to be more supportive (economic, tool support etc).
- Parents need information about all of their legal rights and responsibilities of local and central governments.
- Awareness of the society towards CP has to be increased through public spot or activities.

- Awareness in the school needs to be raised.
- There has to be seminars and programmes targeting families and in-service trainings that meet educational and teaching needs of children with CP for teachers.
- Parent- teacher dialogue has to be increased, meeting must be scheduled frequently.
- Physical setting and teaching technology at school should be improved and reviewed in line with the needs of children with CP.

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