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DISSERTATION

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Social Help for Disabled Children and their Families

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Declaration:

I declare to have elaborated my dissertation thesis on the topic of Social Help for Disabled Children and their Families independently, only under use of sources and references stated in the list of references quoted. I declare that, in accordance with § 47b of Act No. 111/1998 Coll., as amended, I agree that my Dissertation thesis is made public, in unabbreviated form, in electronic way in the publicly accessible part of the STAG database operated by the University of South Bohemia in České Budějovice at its websites.

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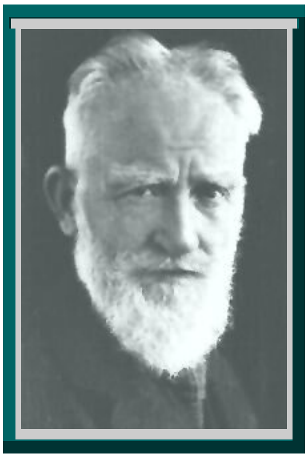
„You see, really and truly, apart from the things anyone can pick up (the dressing and the the proper way of speaking, and so on), the difference between a lady and a flower girl is not how she behaves, but how she's treated.”

George Bernard Shaw: Pygmalion (1912)



GEORGE BERNARD SHAW
(1856-1950)

Abstrakt

Narození postiženého dítěte staví rodinu před velký úkol, ale i společnost se musí podílet na pomoci a to plněním úloh zdravotnických, sociálních, vzdělávacích a jiných. Přístupy s moderním pohledem jsou předmětem mezinárodních dohod. Ve své disertaci zkoumám rodinné podmínky a vyslovuji taková zjištění, která vyhovují moderním paradigmatům. Vzhledem k modernímu ponětí postižení se musí k celému předmětu přistupovat s interdisciplinárním pohledem, tak jak to dělá celé mé pracoviště a také univerzita, která dává prostor mé disertaci. K postižení přistupuje komplexně nejen z pohledu zdravotnictví, ale i sociální péče a dalších oblastí. Na základě svého výzkumu formuluji i konkrétní návrhy pro praxi.

Cílem mého výzkumu bylo zjistit, kde dostane postižené dítě zdravotní a sociální péči, jestli v rámci rodiny, nebo v ústavu. Zjistit, jaké metody jsou nutné k tomu, aby se rodiny mohly zapojit do sociální a zdravotní péče jako partneři. Na základě výsledků výzkumu sestavit školící program pro odborníky, kteří se věnují postiženým dětem a jejich rodinám.

Metodika. Pro kvantitativní výzkum jsem si připravil dotazník s vlastní sestavou 34 otázek, kterou jsem pro lepší přehlednost rozdělil na šest hlavních částí. Zvláštní část je věnována osobě vyplňující dotazník, její domácnosti, postiženému dítěti, poskytnutým nebo žádaným službám, volnému času a budoucím plánům.

Získané odpovědi byly zpracovány pomocí SPSS analýzy a v první řadě byly podrobeny kvantitativnímu výkazu. Následně jsem pomocí křížových tabulek vybral údaje potřebné pro potvrzení nebo vyvrácení hypotézy, u kterých jsem provedl i jejich hodnocení a analýzu.

Stěžejní částí výzkumu byl literární rozbor. S tematikou postižení bylo vydáno mnoho studií, knih a mezinárodních dokumentů. Cílem literárního rozboru bylo prokázat vývoj idejí od poloviny 20. století.

Účastníci výzkumu. Dotazník byl věnován rodičům, kteří mají postižené dítě buď ve vlastní domácnosti, nebo v ústavu. Přirozeně dotazník byl dobrovolný, na základě vlastního přiznání s vyloučením identifikovatelnosti odpovídající osoby. Dotazníky vyplnili rodiče z 36 měst a obcí Maďarské republiky v roce 2009. Počet zúčastněných byl 339.

Výsledky

V rámci teoretického zpracování se podařilo získat domácí i mezinárodní literaturu věnující se moderním paradigmatům: normalizaci, integraci, přístupu k postiženým osobám z pohledu občanských práv. Výsledkem dotazníkového průzkumu je představení 339 dotázaných, jejich rodinných podmínek, postižených dětí a nouzových potřeb. Sjednotil jsem a zanalyzoval vzdělání rodičů, bydliště, pracoviště a jejich názory o vlastní situaci. Zaobíral jsem se časným odhalením postižení, úlohou odborníků z oblasti zdravotnictví, sociální péče a školství. Většinu mých hypotéz se mi podařilo potvrdit, jen některé ne.

Závěry

Na základě mého výzkumu jsem zformuloval návrhy pro praxi. Popsal jsem přístup s moderním pohledem, formy pomoci rodinám, nové úlohy ústavů. Jmenoval jsem takové nové služby, jejichž zavedení může vylepšit situaci postižených dětí a jejich rodin, dále jsem sestavil školící program pro odborné pracovníky.

Klíčová slova: postižení, rodina, dítě, občanská rovnost, sebeuvědomění schopností klienta.

Table of Contents

1.1 New Paradigms of Health and Social Care Provided for Disabled People

Introduction

I have chosen this topic since within the framework of the subject I teach at the University of Debrecen Faculty of Health, Hungary I deal with the quality of life of persons with disability. My students' interest shown in classes also inspired me to do researches into this topic. For me it is really important to promote the chances for children with disability to be brought up in a family setting. For families having children with disabilities and professionals dealing with them it is a high priority to bring them up in family settings, although the conditions to provide the optimum is a complex issue. The focus of this writing is to study the different layers of the above mentioned issue, basically how families with disabled children can be helped throughout the long and struggling way of bringing them up. Families caring for their children in a family setting should be provided with all the possible services and if the children live in a residential home, the family connection ought to be maintained. In order to fulfil the needs of both parties, some basic conditions should be created. Needs, services, surroundings are discussed in this writing. The modern definition of disability evokes that it should be approached with a disciplinary attitude. Disciplinary attitude has been applied at my place of work as well as at the university which made it possible to prepare this dissertation. Disability is being looked upon from health, social work and other fields' viewpoints.

Furthermore, within the framework of theoretical background we would like to present the new paradigms of health and social care for disabled people[1]. As a starting point we want to introduce the concepts of normalization and integration, then the International Classification of Functioning, Disability and Health, which created a new dimension in order to recognize and classify disability, however it is still to be answered what chances are and should be given for children with disability. Evaluating their trainability and describing the modern ways of help is of prime importance. These issues were discussed and several statements were concluded at Salamanca World Conference (1994.), which set up new paradigms on raising children with disability.

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[1] WOLINSKY S. *Violation of Human Rights of Disabled Persons.* Fulbright Commission, 1993. Budapest.

The United Nation's Declaration on Children's Right in 1989 and the 2006 Agreement on the Rights of Disabled People contain principles and obligations regarding the provision for disabled children. Since the foundation pillar of this writing is family care provided for disabled children, a whole chapter is devoted to the supporting role of a family, changes in family structure and to the tendency of number of children. Any situations stemming from either health or social problems, or related to bringing up a disabled child first should be tackled by helping the family itself. Thus a child with disability and his or her family should get help in their immediate surroundings. Only if it seems impossible, should the child be placed at a temporary or permanent residential home.

We made research into the family background of disabled children, accessible services and benefits given for them, as well as the available family resources. The questionnaires were filled in by parents either raising their disabled children in a family setting or in a residential home. By analysing their answers we try to clarify our hypothesis. Having analysed the questionnaires and studied many of the professional literature, we would like to present the most effective work forms, new services and suggestions that can render it possible to keep children in the family or help the family reunion[2].

In this dissertation I try to get an overall picture of social and health care addressing children with disability whether they are supported within the family or in the residential home.[3] As a matter of fact some questions need to be answered. Do these possibilities rule out each other? If children are placed in a residential home, what will be the family connection like? If they are brought up in a family setting, what type of

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[2] METZGER B. Integration in the Highlight. Changes in Public Education from the Point of View of Professional and Rehabilitacional Committees Examining Learning Abilities. In *Tamás M. (szerk.) Integration and Inclusion. Developmental Methods in Public Education.* Trefort Kiadó, 2006. Budapest. ISBN 963-446-406-8

[3] HORVATH L. Reasons of admissions of children with handicap in long-term facilities – reasons of dropping out of families. In *International Academic Conference, Health and Social Questions of Childhood in European Context II. Prevention of Health and Social Pathology.* University of Debrecen Faculty of Health, 2007. Nyíregyháza. 89-98.p. ISBN 978 963 473 108 5

help can be provided for the family? According to every day practice these possibilities are rather far from each other and in several cases they exclude each other on the long term, perhaps for good and all. A part of children placed at residential homes are not visited by their parents. We do think that the above mentioned possibilities should not rule out each other, however their proper linkage is to be reconsidered and worked out by professionals and decision makers. The questionnaires used in this research were filled in by parents raising their disabled children in a family setting or by those whose children had been placed in a residential home. I also deal with another relevant question that being entitled to one type of services really means a life-long provision or not. We are concerned that it should not be so, as the circumstances of the child change in time, so should the type of services. Their circumstances may get worse or improve, which means that services need to be flexible and respond in line with it by giving the appropriate provision for the child. I establish what methods are needed to involve families as active partners in health and social care services. Within the framework of helping process we must find a solution for each and every child and family. First a needs analyses is required which can be followed by working out a comprehensive help plan. My firm intention is to work out a post-qualifying training programme for social and health professionals so that they would be able to go on working according to the new paradigms. Thus, I can greatly contribute to the complex helping process.

1. Theory

1.1 The new paradigms of health and social care provided for persons with disability

In the next chapters the most important professional literature and studies will be cited and referred to which have proved to be relevant when describing disability and best practices of raising disabled children within the family.

1.1.1. The Normalization Principle

In Europe and North-America, the living conditions of persons with disability have developed to a great deal since the middle of the 20th century.[4] Paradigms and principles concerning persons with disability have also changed, bringing about the transformation of institutions supporting them and their social background. One of the most comprehensive principles is the Normalization Principle. The roots of the Principle lies in a Danish Act which came into the world in 1959 and provided the opportunity for people with learning disabilities to have living conditions as close to those of others in society as possible. The Swedish Bengt Nirje[5] is credited with forming the Normalization Principle. This new concept recognises and respects the identity of disabled people. The application of this Principle led to the transformation of care provided for disabled people, contributed to the recognition of dignity and to a movement aiming at the normalization of their living conditions. In the middle of the 20th century within the frame of civil rights movements, an idea was formed to treat disabled people as normal and provide them with the possibility to live a full life as far as possible. When the Soviet Army crushed the Hungarian Revolution in 1956, several people fled across the border to Austria. The 31-year-old Bengt Nirje was sent to a Red Cross Camp in Austria where he took up a post of Social Welfare Officer. His main responsibility was the morale of the camp.

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[4] KÖNCZEI GY., KÁLMÁN ZS. *A Tajgetosztól az esélyegyenlőségig. Interdiszciplináris tankönyv.* Osiris Kiadó, 2002. Budapest. ISBN 963 389 311 9

[5] NIRJE B., PERRIN B. *A normalizációs elv és félreértelmezései.* ÉFOÉSZ, 1998. Budapest. ISBN 963-03-5934-0

He realised that refugees in the refugee camp with 3,500 residents with 100-160 persons to one dormitory became depressed, mentally wounded and socially handicapped. When he returned to Sweden he started to work with disabled children. He realised that their lives could be characterized by dependence and powerlessness which were very similar to the feelings of Hungarian refugees. Bengt Nirje started using techniques and compared the normal days, weeks and vacation with that of the days, weeks and vacation of disabled people. Normal conditions led to normal outcomes whereas abnormal conditions led to abnormal outcomes. All that he had experienced helped him to work out his methods that he decided to call the Normalization Principle.

He was concerned that in order to execute the Normalization Principle, programmes, activities and new approaches must be found with following components:

1. Normal rhythm of the day
2. Normal weekly rhythm
3. Normal rhythm of the year
4. Normal developmental experiences of the life cycle
5. Choices, wishes, and desires of the mentally subnormal have to be respected
6. Living in a bisexual world
7. Normal economic standards
8. Standards of physical facilities

The principle was already known within Scandinavia in the early sixties. Gradually it became better known not only in Europe but in the USA as well. Bengt Nirje was invited to the USA to hold lectures and give a greater publicity to his theory. The seed fell on good ground, disabled people access to provision and education had already been ready to enact by the American legislation. It was in 1973 when the Rehabilitation Act passed which focused on the rights, advocacy and protections for individuals with disabilities. This Act orders the employer to employ people with disabilities. As a matter of fact the Principle of Normalization became the foundation stone of a new system dealing with disabled people. In Hungary, civil services started to apply the principle around 1990. As a first step they aimed to create adequate living conditions for disabled people. Even if people are not identical, and have different features, the same type and quality of care, preserving dignity and respecting identity, should be provided for all human beings regardless to the level of their disability. In conclusion, the Principle of Normalization has become a world-wide used principle which can be applied to people with disabilities at all ages and in all situations. It states that isolation and segregation foster ignorance and prejudice, whereas integration and normalisation improve human relationships and understanding. The application of the normalization principle could gradually decrease the majority's prejudice against disabled people. Whereas, it should serve as guiding thread in all types of medical, social, pedagogical, psychological and political issues. The regular, usual, annual, weekly and daily routines promote the principle to be put into practice. For disabled children it seems to be inevitable to have the rhythm and experience of a normal life cycle which may be provided at playgrounds, polyclinics, nurseries, kindergartens and schools. Services provided for children with disability and scenes of provision are the focal point where the main topic of this writing is actually connected to the normalization principle which aims to provide standards of living and facilities similar to those of others who are accustomed to live in a bisexual world where there is male and female staff, too.[6] [7] The denomination of the principle 'normalization' may be misunderstood and misused, which are not up to the new paradigms. If we have a closer look at the reason for misunderstanding, we might find that normalization is considered to be a process which makes people 'normal', makes any differences disappear. To the contrary, it should mean the provision of normal standard of living for everyone. Some might reach to the conclusion that the fulfilment of special needs is irreconcilable with the normalization principle. However, we are concerned that it is applicable in the surroundings of people with any type of disability not only mental or slight disability. International cooperation can promote to enforce the normalization principle.[8] If globalization and philanthropy develop in reconciliation, that will have a positive impact on disabled people's lives. However, further conflicts may stem from it. [9]

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[6] PORDÁN Á. Normalizált lakhatási lehetőségek útja értelmileg akadályozott emberek számára. In *Rehabilitáció,* 1996/3. ISSN 0866-479X

[7] CZEIZEL B., GALLAI M. A korai fejlesztés elméleti és gyakorlati tapasztalatai. In *Fejlesztő Pedagógia*, 2000/11. ISSN 0866-2495

[8] PAPP K., HORVATH L. Globalization and philanthrophy in nursing. In *Nové trendy v osetrovatelství V.* University of South Bohemia, 2006. Ceské Budejovice.

[9] BÁNFALVY CS. Fogyatékosság és szociális hátrány. In *Illyés Sándor (szerk.) Gyógypedagógiai alapismeretek.* BGGYTF, 2000. Budapest. ISBN 963-7155-28-7

1.1.2 The principle of integration

Concerning disabled people, the principle of integration can be derived from the normalization principle.[10] [11] In order to create integration in our society several conditions must be taken into consideration; an unprejudiced society, the economic development of the society, differential school system.[12] When talking about the issue of disability it is important to emphasize that integration, unlike segregation, do not separate people with disability. The significance of integration is that the community of healthy people will accept disabled people if, and only if, they have developed together, got to know each other since their early childhood. We can hear several discussions praising integrated education and criticising segregation.[13] [14] Fervent supporters and opponents voice their opinion despite the improper manner in which this question is phrased. The question seems improper because it suggests an obligatory choice between the two of them moreover, by being rather general it neglects the possibility of choosing the most suitable form of education for the individual, putting aside several components that can influence the success of integrated and/or segregated education. [15] [16] [17] The process of integration should involve an inclusive attitude,[18] [19] [20] [21] a supportive local

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[10] PAPP G. (szerk.) *Válogatás az integrált nevelés szakirodalmából.* Nemzeti Tankönyvkiadó, 1994. Budapest.

[11] CSÁNYI Y. (szerk.) Értelmileg és tanulásban akadályozott gyermekek integrált nevelése és oktatása (Útmutató szülőknek és szakértői bizottságoknak. ELTE GYFK, 2001. Budapest.

[12] PAPP G. Tanulásban akadályozott gyermekek a többségi általános iskolában. Comenius, 2004. Pécs. ISBN 963-214-529-1

[13] PAPP G. Tanulásban akadályozott gyermekek iskolai integrációja a szakemberek közötti kooperáció tükrében. In *Magyar Pedagógia,* 2002/2. ISSN 0025-0260

[14] ILLYÉS S. *Nevelhetőség és általános iskola. I. Eszközök és módszerek.* Oktatáskutató Intézet, 1984. Budapest. ISBN 963-404-005-5

[15] PERLUSZ A. (szerk) Fogyatékos gyermekek integrált nevelése hazai kísérletek tükrében. BGGYTF, 1995. Budapest.

[16] CSÁNYI Y. A speciális nevelési szükségletű gyermekek és fiatalok integrált nevelése-oktatása In: *Illyés S. (szerk.) Gyógypedagógiai alapismeretek.* BGGYTF, 2000. Budapest. ISBN 963-7155-28-7

[17] NAGY GY. Közoktatási intézmények és szolgáltatások a fogyatékos gyermekek számára In *Illyés Sándor (szerk.) Gyógypedagógiai alapismeretek.* BGGYTF, 2000. Budapest. ISBN 963-7155-28-7

[18] KOKAS K., KŐPATAKINÉ M., SINGER P. *Módszertani kaleidoszkóp az együttnevelés gyakorlatához.* OKI, 2005. Budapest. ISBN 963-682-560-2

community and rehabilitation services of high level. One of the most important scenes of integrated education is the school itself.[22] [23] The advantages and drawbacks of integrated schooling have been the subject of some fiery debates.[24] The importance of early identification and development, as well as the launching support services and forming partnerships can be regarded as the main principles.[25] Integrated education plays a significant part in the lives of disabled and healthy children alike since it is a process when disabled children can realize their handicaps, learn strategies to cope with conflicts, attain to fight for their positions and acquire a socially acceptable behaviour. Their ability to accommodate develops gradually and reaches a higher level of socialization. On the other hand, healthy children's personality enriches with the experience of accepting children who differ from them, and will be able to build moral values like empathy, helpfulness, tolerance and cooperation.[26] What is more, they are more likely to become tolerant, their self-esteem and self-evaluation strengthen, as well as their ability to accommodate.[27] Disabled people need to become an integral part of the society individually and as a social group, too because integration involves individual and interpersonal relationships and based on a common cultural ground. Specifics, concerning age and culture, as well as figures of scientific researches should be taken into consideration when creating the conditions for integration of any

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[19] CSAPÓ B. *A képességek fejlődése és iskolai fejlesztése.* Akadémiai Kiadó, 2003. Budapest. ISBN 963-05-8013-6

[20] GORDOSNÉ A. A gyógypedagógiai iskoláztatás fejlődése. In *Illyés Sándor (szerk.): Gyógypedagógiai alapismeretek.* BGGYTF, 2000. Budapest. ISBN 963-7155-28-7

[21] GORDOSNÉ A. A gyógypedagógiai iskoláztatás fejlődése. In *Illyés Sándor (szerk.): Gyógypedagógiai alapismeretek.* BGGYTF, 2000. Budapest. ISBN 963-7155-28-7

[22] SCHIFFER CS., BARDONÉ ZS., Türk M., KARDOSNÉ J. Együtt nevelünk. In *Fejlesztő Pedagógia*, 2005/4. ISSN 0866-2495

[23] GAÁL É. A tanulásban akadályozott gyermekek az óvodában és az iskolában In *Illyés Sándor (szerk) Gyógypedagógiai alapismeretek*. BGGYTF, 2000. Budapest. ISBN 963-7155-28-7

[24] TORDA Á. Az integrált iskoláztatás hatása a gyermek személyiségfejlődésére. In *Gordosné Sz. A. (szerk.): Gyógyító pedagógia.* Medicina Kiadó, 2004. Budapest. ISBN 963-242-757-2

[25] CSÁKVÁRI M. Az integrált óvodai nevelésről. In *Óvodai élet,* 1995/2. sz. ISSN 1216-6979

[26] ZSOLNAI A., NAGY J. *A szocialitás fejlesztése 4-8 éves életkorban.* Mozaik Kiadó, 2006. Szeged. ISBN 963-697-492-6

[27] RÉTHY E. Integrációs törekvések Európában az ép és sérült (fogyatékos) gyermek együttnevelésének elmélete és gyakorlata. In *Szociális Munka,* 12. évfolyam I. szám 9-22.p. ISSN 0865-347X

population group so that later they can become part of the society with success.[28] [29] From the healthy children's viewpoint, integration is a valuable process through which they experience the nature of disability, the joy and obstacles of living together and side by side. When healthy children have been brought up together with disabled ones they are not likely to judge or exclude them from the society when reaching adulthood. From disabled children's viewpoint, it is essential to get a daily positive model through which they can fully evolve their personality and abilities. From the adults' viewpoint, integration proves to be a valuable process by which they can experience the development of a specific network of emotional relationship, in line with it they also learn how take responsibility for either healthy or disabled children, let alone the feeling of doing good to them. The state, the society and the individuals should take the task of providing every possible aid for disabled people so that they could have an access to appropriate education, special care and development adjusted to their handicap. They should not live separately in institutions, but rather be able to get into shops, public buildings with wheelchairs, be able to use them in the street and public transport. As for children, the possibility of living with their family, going out and being with peer groups give them a chance to live a full live in dignity. If there is but one chance for disabled people to acquire skills by which they can be an integral part of the society, they do need to realise the importance of them and acquire those skills fulfilling the expectation of the society. In order to provide a smooth integration for them, all of our activities should be carried out with them rather than on their behalf. Further facts will be written about different ways of integration in a subchapter on Salamanca Conference[30].

Apart from integration the concept of self-determination, the rights and needs of disabled people to be free to make their own choices and decisions, should be taken into consideration.[31] Those around disabled people should appreciate and acknowledge these

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[28] KÖNCZEI GY. (szerk.) Sajátos nevelési igényű gyeremekek a többségi általános iskolában. Tanári-lét kérdések. 43. kiegészítő kötet. RAABE, 2003. Budapest. ISBN 963-85181-0-3

[29] ROSTA K. (szerk.) Add a kezed – a mentális fejlődés segítése sajátos nevelési igényű gyermekeknél. Logopédiai Kiadó, 2006. Budapest. ISBN 963-8659-03-3

[30] Salamancai nyilatkozat és Cselekvési Tervezet a sajátos nevelési igényű tanulók számára. UNESCO. Salamanca, 1994. június 7-10.

[31] ZALABAI P. Önálló életvitel és személyes segítés. In *Esély*, 1997/5. ISSN 0865-0810

rights and needs. Even in the case of children with disability it means the same; according to different age-specifics they need to have the right to make their own decisions. The concept of self-determination is promoted by a declaration of the United Nations.[32] Another terminology is self-sufficiency that should be shown and taught to them gradually from early childhood in line with socialization.[33]

1.1.3 Early identification

For the classification of disability, specialists need to know the cause of and developmental methods for certain disabilities. The earlier they can be identified, the better the chances are to prevent complications.[34] Early identification can be divided into three phases:

- In the first phase, scientific methods make it possible to make diagnostic prenatal testing and screening of the potential parents even before the conception to inform them in which cases and to what extent their child will be exposed to developmental disorders, if any. Several genetic examinations are applied.
- During the second phase the pregnant woman and her foetus is examined at intervals. Some of these examinations are to diagnose a wide range of disorders the foetus might have.
- The third phase is the birth itself, when further examinations are done to the new-born baby to diagnose any possible disorders that could not have been seen or foretold before.

The prevalence of congenital developmental disorders is about 3% in Hungary.[35] Unfortunately the reasons for occurring cannot be detected in all cases, and

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[32] ENSZ. Fogyatékossággal élő személyek jogairól szóló egyezmény és az ahhoz kapcsolódó fakultatív jegyzőkönyv. ENSZ, 2006. december 13.

[33] HORVÁTH L. Fogyatékos gyermekek és családjaik szociális segítése. In *A II. Nyíregyházi Doktorandusz (PhD/DLA) Konferencia Kiadványa.* Bessenyei Kiadó, 2009. Nyíregyháza. 87-94.p. ISBN 978 963 9909 19 9

[34] PÁLHEGYI F. (szerk.) *A gyógypedagógiai pszichológia elméleti problémái.* Nemzeti Tankönyvkiadó, 2006. Budapest.

[35] SZABÓ M. /szerk./ *Tájékoztató a szülészeti és nőgyógyászati szűrővizsgálatokról.* Debreceni Orvostudományi Egyetem, 1997. Debrecen.

approximately 20% of them stem from genetic defect. Furthermore, several disorders are triggered by circumstantial factors which are not revealed during pregnancy since mothers have no symptoms at all and it stays hidden that they are exposed to such danger. A part of congenital disorders is identified at the first examination of the new-born baby, but some of them, the so-called functional disorders appear later.[36] [37] Strictly speaking, early identification starts with genetic counselling. The aim of genetic counselling is to help families in family planning when there is a higher risk of birth defects or congenital disorders. These higher risks may involve diseases and disorders running in the family, the age and diseases of the mother. On the basis of diagnostic prenatal tests or screenings the parents get answers to their questions. If a prenatal screening or test is abnormal the specialist evaluates the risk of the affected pregnancy, educates the parents about these risks and informs them of their options. At this point another physician might be involved who is a specialist of the disease in question and can inform the parents on the seriousness, course, treatment and cure of the disease. The specialist also explains the recurrence risks in future children.

Those who turn to a genetic counsellor might want to prevent potential disorders.[38] Unfortunately, primary prevention of them proves to be effective only in a few instances; when the development of a disorder can be prevented by treating the mother's problem persuading her to take vitamins right before the conception or during early pregnancy. Regarding the fact that in several cases these are preventive methods, it is advisable to turn to a genetic counsellor. On the other hand, for most of the cases only secondary prevention can be applied. With the help of intrauterine examination, certain diseases, disorders can be diagnosed in addition there are some diseases that can be treated intrauterine with great success. However, in case of incurable disorders procured abortion is offered for the mother to avoid giving birth to a seriously ill baby.

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[36] BALLA GY. A magyar intenzív neonatológiai ellátás jellemzői. In *Gyermekorvos Továbbképzés,* 2008/7. sz. 10-11. p. ISSN 1589-0309

[37] ÓVÁRI L., ARANYOSI J., BALLA G. Acute effect of cigarette smoking on placental circulation – a study by carbon-monoxide measurement and doppler assessment. In *Acta Physiologica Hungarica.* 2009/96. 243-250.p. ISSN 0231-424X

[38] HORVÁTH J., Horváthné J.: *Amit az óvónőnek észre kell venni.* Flaccus Kiadó, 2005. Budapest. ISBN 963-9412-41-4

The genetic specialist educates the parents on the choices but the decision is made by the parents. The genetic counsellor gives information about the ways of examinations by which the given disorder can be elicited or excluded. A part of these examinations are invasive that means the application of special devices to examine the uterus from inside, which might involve danger. The mother is informed about the medical intervention, risks, the possibility of eliciting or excluding other disorders, and the reliability of the applied examination. Having discussed all the questions, the mother decides whether she asks for the examination, if so she gives a written consent.

Besides genetic and invasive methods, a wide range of examinations are used, for example ultrasound, to follow the development of the foetus, to diagnose possible developmental disorders, to identify pathological conditions that can endanger either the mother or the baby. According to the Hungarian Obstetric and Gynaecological Ultrasound Association, for the sake of the mother and the baby it is advisable to have four ultrasound screenings during a normal pregnancy. First screening: in the 12th week of pregnancy, right after embryogenesis, they examine the condition and location of uterus and its surrounding, as well as the possibility of extra-uterine pregnancy. The ultrasound screening shows the foetus, its location, heartbeat, amnion and parameters that reveal the foetus' age. Early might it seems but some serious developmental disorders can already be seen, as well as some pathological conditions like bleeding or necrosis.Second screening: in between the 18th and 20th week of pregnancy, on the basis of blood sample taken from the mother on the 16th week and analysing AFP and HCG results, the ultrasound screens the uterus, records the condition, location and number of foetus, amnion and placenta. It measures the parameters of the skull, trunk, femur that reveal the pace of development. Its aim is to identify any developmental or chromosome disorders. Third screening: in the 32nd week of pregnancy basically the development of the foetus is checked and apart from it any developmental disorders are also sought for. Fourth screening: in the 38th week of pregnancy which helps to decide the way of delivery and besides the condition, location and growth of the foetus, the position of placenta the screening also shows the quantity of amniotic fluid.

Any abnormalities shown by the ultrasound screening require further steps, other types of examination.[39] As we have seen, early identification involves specialists who have experience of several years, although their work would not be complete without the contribution of the family.[40] [41] [42] [43] [44]

Educating potential parents is an essential part of prevention. The available brochures contain the tasks of parents: 'If forward planning plays an important part in their lives, so will family planning.' Furthermore, they emphasize the importance of conception and provide information about the range of professionals, obstetrics, gynaecologists, andrologists, health visitors, family support services and general practitioners. As for family planning, it is more likely to give birth to healthy babies if the parents undergo the accessible screening tests, as early as three months before the desired conception.

Certain developmental disorders can be avoided if the mother takes multi vitamins containing 0.8 mg folic acid on daily basis and continues taking them till the end of the third month of pregnancy. Since the organs of the foetus develop in the first eight week, the preventive protection of this period is of crucial importance.[45]

1.1.4 Social Charter

One of the relevant documents used world wide is the European Social Charter adopted in 1961, which includes the rights of persons with disabilities[46] to social integration and participation in the life of community. The protection of family and

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[39] HORVÁTH L. Fejlődési tendenciák a szociális képzésekben. In *Debreceni Orvostudományi Egyetem Egészségügyi Főiskolai Kar Tudományos Közleményei.* DOTE Egészségügyi Főiskolai Kar, 1998. Nyíregyháza. 329-342.p. ISSN 1418 88 72

[40] HORVATH L. Korai felismerés és szociális segítés című előadása a „Legyen jobb a gyermekeknek" című konferencián 2009. május 6. MTA – DE, 2009. Nyíregyháza.

[41] GORDOSNÉ A. Bevezető általános gyógypedagógiai ismeretek. 3. A gyógypedagógiai hatásrendszerről. Nemzeti Tankönyvkiadó, 2004. Budapest. ISBN 963-19-5351-3

[42] ILLYÉS S. Nevelés és fejlődés. In Mesterházi Zs. (szerk.) *Gyógypedagógiai Lexikon.* ELTE GYFK, 2001. Budapest. ISBN 963-463-511-3

[43] MILSON L. Balkezes a gyermek. Hogyan könnyítsük meg a dolgát a jobbkezesek világában? Gabó Kiadó, 2008. Budapest. ISBN 978-963-689-120-6

[44] SEKULER R., BLAKE R. *Észlelés.* Osiris Kiadó, 2000. Budapest. ISBN 963-379-654-7

[45] Családot, gyermeket szeretnénk. OTH és OEK, é.n. Budapest.

[46] The European Social Charter. Turin, 18.10.1961.

mother is also emphasized in this document. The aim of the European Council was to facilitate economic and social progress, in particular by the maintenance of human rights, so they created and adopted the European Social Charter which contains 38 Articles in five parts. Some articles worth examining in detail. Article 15 ensures the effective exercise of the right of the physically or mentally disabled to vocational training, rehabilitation and resettlement. In order to achieve this goal, adequate measures shall be taken for the provision of training facilities, including specialised public or private institutions. In addition, adequate measures shall be taken for the placing of disabled persons in employment, such as specialised placing services, facilities for sheltered employment in order to encourage employers to admit disabled persons to employment.

This document gives a definition for disability and the ways of help which are provided by institutions and workplaces. As a matter of fact, this view has been outdistanced by now, but at that time it could be regarded as a modern and progressive document, which undertook to outline the methods and ways of support provided for disabled persons. As it was mentioned before the European Social Charter also highlights the right of families, mothers and children to different services. In articles 16 and 17 the document declares families as a fundamental unit of society, therefore it is inevitable to ensure the necessary conditions for the full development of the family that involves economic, legal and social protection of family life by such means as social and family benefits, fiscal arrangements, provision of family housing, benefits for the newly married, and other appropriate means. Furthermore, appropriate and necessary measures shall be taken to establish and maintain the appropriate institutions or services that ensure social and economic protection for mother and children. We have cited these articles to reinforce the focus of this writing that is the importance of family during the long and struggling process of raising and developing children with disability. Even if the structure of family has considerably changed, its main task has remained the same; to ensure emotional, social and economic basis for the children.

1.1.5. The Salamanca Statement on Education

The participants of Salamanca World Conference[47] wanted to reaffirm their commitment to the 1993 UN Declaration on children with disability and special educational needs. The aim of this conference was to discuss the necessary policy shifts needed for the implementation of Education for All Programme, to promote inclusive education system, so that schools would be able to meet the needs of all children, particularly children with special educational needs. With the cooperation between the Spanish government and UNESCO the conference brought together senior education officials, administrators, policy-makers, specialists, representatives of the United Nations, specialized agencies, committees, other national governmental and non-governmental services and supporting services. The Conference adopted the Salamanca Statement on Principles, Policy and Practice in Special Needs Education and a Framework for Action. Its guiding principle is inclusion which stems from the recognition that adequate schooling and institutions should be established for everyone which can enrol and celebrate everyone regardless of differences, can help special education in regular schools and take into account the individual needs. By this they contribute to the implementation of Education for All Programme and make schools educationally more effective. Educating students with special educational needs – which is important for the northern and southern countries as well – cannot advance in isolation. Therefore, inclusive education should be part of a comprehensive educational strategy which is achievable by social and economic policy shifts and reforms of the education. The achievable goals of the consensus reached worldwide project the future of special needs education. Educational systems and programmes should be planned and adjusted to the students' unique characteristics and special learning needs. Children and youth whose needs arise from disabilities or learning difficulties should be given the chance to be included in educational arrangements made for the majority of children. In order to maintain an educationally effective inclusive school, a child-centred pedagogy should be developed that is capable of successfully educating all children. This can lead to inclusive orientation which is a crucial step in changing discriminative attitudes in

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[47] Salamancai nyilatkozat és Cselekvési Tervezet a sajátos nevelési igényű tanulók számára. UNESCO. Salamanca, 1994. június 7-10.

creating a welcoming society. Furthermore, by providing inclusive schooling for all children and youth, the whole educational system will be more effective and productive. It is desirable that governments adopt as a matter of law or policy the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise. The document encourages participants of the conference to exchange experience with countries that has gained experience in inclusive education. Governments should promote and facilitate the participation of parents, communities and organizations of persons with disabilities in the planning and decision making process. We have already written about the necessity of early identification, so has this document and urges governments to invest more effort into early identification and intervention, as well as into vocational aspects of inclusive education. Concerning the systematic change of the educational system, the teacher education programmes and post-qualifying courses should address the provision of children with special needs.

According to the guiding principle of the document, schools should accommodate all children, regardless to their physical, intellectual, social, emotional, linguistic or other conditions. This should include disabled and gifted children, street children and others from disadvantaged or marginalized areas or groups. These conditions create a range of challenges for the school system. By means of child-centred pedagogy inclusive school systems can rise to many of these challenges and can successfully educate children with serious disadvantages or disabilities. Apart from ensuring education of high level for all children, inclusive schools take crucial steps towards combating discriminatory attitudes and creating a welcoming society. The major role of inclusive schools is to respond to the needs of children and youth with disabilities or learning difficulties and provide them with all the support to be involved in an adequate education. Inclusive education is beneficial to the whole society since it can build solidarity between the majority of children and those of with special needs. Assignment of children to special schools or classes should be the exception but might be needed in some cases, especially where regular schools apparently cannot meet the children’s educational or social needs or when it is required for the welfare of the child or that of other children. There are countries with well established special school systems for children with specific needs. Such schools can represent a valuable resource for the development of inclusive schools. The staff of these special institutions possesses the expertise needed for early identification and development of disabilities. They can serve as a training and resource centre for the staff of regular schools. Finally, these special schools, or special classes within regular schools may continue to provide the child-centred education for a relatively small number of children whose impairments could not be developed in regular classes. The already existing special schools should be geared to a new role of providing professional support for regular schools, so that they could respond to special educational needs. An important contribution to regular schools is the matching of curricular content and method tailored to the individual needs of children.

Establishing inclusive schools that enrol a wide range of pupils in both rural and urban areas requires the following: the articulation of a clear and forceful definition of inclusion, together with adequate financial support; public information to combat prejudice and create a positive well-informed attitude; an extensive programme of orientation; and the provision of necessary support services. Changes of all the following areas are needed to contribute to the success of inclusive schools: curriculum, buildings, school organizations, pedagogy, assessment, staff, school ethics and extra-curricular activities. Most of these changes do not relate exclusively to the inclusion of children with special educational needs, but they are part of a wider education reform needed to improve both content and quality, so that pupils can reach a higher level of school achievement. The World Declaration for Education for All emphasizes the need for a child-centred approach which aims at successful schooling of all children. The adoption of more flexible and adaptive systems which are capable of fuller account of different needs of children will contribute both to educational success and inclusion. The success of inclusive education depends on early identification and development of children with special needs. Early childhood care and programmes for children up to 6 years should develop and promote physical, intellectual and social development as well as school readiness. These programmes have a major economic value on the individual, the family and the society in preventing the aggravation of disabling conditions. Programmes at this level should recognize the principle of inclusion and be developed in a comprehensive way by combining pre-school activities and early childhood health care. The principles described in the Education for All are milestones in the education provided for children and youth with disabilities, and are successfully applied worldwide. However, several countries need to take major steps towards inclusive education where one of the most important steps is integration, which seems to be a necessary pre-condition of inclusion. While integration means that young people with special educational needs are placed in regular provision with some adaptations and resources but on condition that the young person can fit in with pre-existing structures, attitudes and an unaltered environment, while inclusion is a kind of provision, where there is a commitment to removing all barriers to the full participation of each child as a valued, unique individual.

Within the mainstream of integrated education we can find five several types on the basis of how the integration process is being done. The first one is *local integration*, where the children with disability share the building with others but no other connection is possible between them. Although the shared building could be a good opportunity for joint programmes and extra-curricular activities, children remain excluded from the regular classes, groups and curricula. Sometimes so called speech therapy classes are run at schools where pupils with serious behaviour problems are also assigned to, even if a part of the lessons should be provided for them in regular classes.

Another type is called *spontaneous integration*, where children with special educational needs are accepted by a regular school, but the school is lacking in financial support, so no adaptations or resources can be reached. Without professional help, adequate information or guideline, the only component that can contribute to the development of children is the teacher and his or her conscientiousness. Possessing minor special educational needs and being taught by a conscientious teacher, the children can adopt with great success. In contrast at some institutions children are there on sufferance without being encouraged, promoted.

The third type is *social integration*, where children with special education needs are involved in the free-time activities of other groups or classes of the regular institution. It can be divided into two sub-types; temporary social integration where all children are together on the events of trips and festivals. In the case of permanent social integration the different groups or classes can meet in the court and can play together, in the canteen they can eat together or they can go for a walk together.

The last type is called *functional integration*, when all children are developed together. Partial functional integration means that children with special educational needs spend a specific time with the regular group or class when they have an art or P.E. lesson. If children can fully fit into the group or class, complete functional integration is provided for them. The whole time at the institution is spent without exclusion.

The process of integration is in a halfway house between being recipient and inclusion. In the phase of being recipient, children with special educational needs are accepted at regular institutions, although their special needs are not necessarily known and they are supposed to adjust to the system and perform well. As a matter of fact only a few children will be able to that while the rest of them, rather most of them, will fall behind the others. The recipient phase does not involve changing in attitude because teachers have not gained experience to find the solution themselves. Problem shooting is undertaken either by the parents or a specialist, the teacher of handicapped children. In the phase of inclusion, with all the resources at reach, children can be placed at a nearby institution, especially when the suggestions of the Salamanca Statement are applied. In this case the educational programmes are planned and adjusted to the students' unique characteristics and special learning needs. In order to maintain an educationally effective inclusive school, a child-centred pedagogy is applied that is capable of successfully educating all children. Inclusion is kind of an attitude, a shift in the attitude, that is the institution having accepted the children with special educational needs is committed to remove all the barriers, provides special training for the staff so that they would be able to carry out the individualizing teaching procedure to find the potentials of children. In sustaining integrated education certain conditions must be established. Objective factors consist of different medical equipment for disabled people, school equipment for differentiated instruction and creating an adequate classroom by reducing and differentiating pupils per class. Moreover, buildings that are handicapped accessible require significant reconstruction.Personal factors involve teachers with special training or additional qualification, adaptation of curricula and teaching programme and the application of proper teaching methods, like differentiation. The collaboration between parents and teachers is inevitable to reduce difficulties and ensure steady development. With the help of a teacher of handicapped children spontaneous integration will result in a purposeful education. The personality of children with special educational needs, as well as that of the others can facilitate or hinder the success of integration. Cooperative learning proves to be significant since the knowledge of children marginally differs. The composition of school groups tends to be heterogeneous, even the most homogeneous group consists of different personalities. Adequate learning methods are needed to ensure an effective and flowing education for mentally disabled children and/or children with special educational needs. These methods make independent, group and pair work possible for all of them. Cooperative work inspires children to build on their knowledge and use their potentials, develops their readiness to share tasks and respect others' opinions. Self-checking needs attention and self-control. The fundamental principle of the inclusive school is that all children should learn together, regardless of any difficulties or differences they may have. Children with special educational needs should receive extra and tailor made support they may require. Inclusive schooling is the most effective way of building solidarity, communication, interaction and cooperation among children with or without disabilities because instead of homogeneous groups or classes they can work and learn in heterogeneous groups or classes.

Establishing inclusive schooling was preceded by passing relating acts in those countries that have introduced inclusive institutions. These acts regulate the rights of parents, the utility of financial resource and the flexibility of curricula. The contemporary Hungarian legislation makes it possible to establish inclusive institutions. The education of children with disability is regulated in the Act on Public Education.[48] Instead of the terminology of compulsory education it uses the terminology of compulsory training. It contains the right for special care, handicapped care, early development, integrated education and developmental pre-activities. It also regulates the personnel and objective conditions.

1.1.6 Hungarian legislation

In Hungary, a separate act[49] regulates the right and equal opportunity for disabled persons, while another act[50] regulates the equal treatment of disabled people.

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[48] LAW. Az 1993.évi LXXIX. törvény a közoktatásról.

[49] LAW. Az 1998. évi XXVI. törvény a fogyatékos személyek jogairól és esélyegyenlőségük biztosításáról.

[50] LAW. 2003. évi CXXV. törvény az egyenlő bánásmódról és az esélyegyenlőség előmozdításáról.

Persons with disability are equal members of society who are less able or unable to exercise the rights and take the opportunities to which they are entitled. The aim of this act is to bring about a favourable change in social attitude and promote positive changes in ensuring their active participation in the life of society, in enabling their self-efficiency and social integration. The Act on equal rights for persons with disability defines the rights to which disabled persons are entitled concerning the environment, communication, transportation and support services. The Act also defines the target areas for the equalisation of opportunities that shall be provided for disabled persons. These target areas are: health care, education and training, employment, place of residence, cultural life and sport. The Act defines that children with disability can take part in kindergarten training and school education together with other children on the condition that it is advantageous for their development of capabilities. The kindergarten or school, where the conditions to accommodates children with disability must be provided by the local government, shall be chosen by the parents. The foundation documents of the institutions and the local educational programmes should contain the intention to accommodate children with disabilities and all the arrangements that will be done to build the conditions. This act defines rights for disabled persons in general, the rights for disabled children is not particularly regulated. The act gives a definition for person living with disability: anyone who is to a significant extent or entirely not in possession of sensory - particularly sight, hearing – loco motor or intellectual functions, or who is substantially restricted in communication and is thereby placed at a permanent disadvantage regarding active participation in the life of society. The act names two special services; supporting service: service aimed at promoting independent living for persons living with disability, at meeting their everyday needs and realised through personal participation. The other one is the residential home which is a form of residence for a small community, promoting independent living for persons living with disability. Two subsections are devoted to disabled children, both of them are connected with education, furthermore although the act entered into force on 1 January 1999, the objective and personnel conditions for the special education had to be created gradually, but had to be completed by 1 January 2005 at the latest.

It is the right of the person living with disability to take part in early development and care corresponding to his or her condition and depending on age, to kindergarten training, school training and education and development preparation for such education, in keeping with the provisions of the act on public education. If it is advantageous for development of the capabilities of the person living with disability – in keeping with the opinion of the expert and rehabilitation committee set up for this purpose – the person living with disability shall take part in kindergarten training and school education together with other children and pupils, in the same kindergarten group or school class. The act highlights the fact that accessibility – an environment without obstacles - has both figurative and abstract meanings. As for autistic and mentally disabled persons, and those with serious disadvantages, accessibility also means the possibility of access to information. Information is accessible if the person living with disability can perceive it and if it ensures for him or her the appropriate interpretation of it. For this reason the Hand in Hand Foundation published a book[51] which intends to explain the rules of law in an everyday language.

1.1.7 Madrid Declaration on Discrimination

The European Union wanted to bring about a favourable change in attitudes of the society concerning people with disabilities[52] in the European Congress on Disability in 2002, where 600 participants took part and welcomed the proclamation of 2003 as the European Year for People with Disabilities. The participants set down the declaration to provide a conceptual framework at European Community level, at national, regional and local level. In order to reach the goals of the new vision the old ones should be replaced. Disabled people are objects of charity although they should be considered as rights holders. People with disabilities are treated as patients although they are independent citizens and consumers. Usually the professionals take decisions on behalf of disabled people despite independent decision making and taking responsibilities by disabled people and their organisations on issues which concern them. At the moment the focus is on merely individual impairments although it should be put on removing barriers, revising social norms, policies, cultures and promoting a supportive and accessible environment. People with disabilities are labelled as dependants or unemployable despite emphasis on ability and the provision of active support measures. Instead of designing economic and social processes for the few designing a flexible world for the

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[51] Törvény az egyenlő bánásmódról. Könnyen érthető nyelven. Kézenfogva Alapítvány, 2008. Budapest.

[52] Madridi Nyilatkozat. EU, 2002. Madrid.

many should be promoted. Unnecessary segregation in education, employment and other spheres of life should be replaced by integration of disabled people into the mainstream. Now the disability policy is an issue that affects special ministries only although disability policy as an overall government responsibility should be included.

With the Madrid Declaration on Discrimination the European Union committed itself to an inclusive society where implementing their vision will benefit not only disabled people but also the society as a whole. A society that shuts out a number of its members is an impoverished society. Actions to improve conditions for disabled people will lead to the design of a flexible world for all. ‘What is done in the name of disability today will have meaning for all in the world's tomorrow’. The participants in the European Congress on Disability shared this vision and requested all stakeholders to consider the European Year of People with Disabilities in 2003 as the start of a process that will make this vision a reality. 50 million European disabled people are expected to get an impulse to the process to make this happen.[53]

The Hungarian government and professionals realized the necessity of change in attitudes defined in the Madrid Declaration therefore a National Action Plan for Social Togetherness[54] was brought about together with the relevant organizations of the European Union. The action plan describes the regulations facilitating the opportunities for disabled persons’ independent life conditions, and gives a picture of their circumstances. Regarding the whole population their circumstances are less favourable. The level of schooling has improved in the last few decades, though it significantly falls behind the national average. Their employment indicators are rather unfavourable, only 9% of persons with disability were employed in 2001, in addition more than half of this population lived in households without any adults being employed at all. The situation and statistical data described above gave occasion for passing and enacting the act on the rights and equal opportunities for persons with disability, and the adoption of the National Programmes for Persons with Disability[55] as early as December 1999. The Programme sets, in a comprehensive way, all the principles, strategic aims and tasks

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[53] Madridi Nyilatkozat. EU, 2002. Madrid.

[54] Nemzeti Cselekvési Terv a társadalmi összetartozásért. 2004. Budapest.

[55] Országos Fogyatékosügyi Program (100/1999. OGY határozat). In *Magyar Közlöny,* 1999. 111. szám, 7357-7368. p.

which require profound national actions in implementing the act, while it intends to rely on collaboration of municipals, institutions and civil organizations representing disabled people, and active participation of persons with disability. The Action Plan involves the following areas, where the main paths of development are to be indicated: physical accessibility to information, transportation, health care, employment, sport, culture, leisure time and social provision. On the basis of a comprehensive national implementation, the Programme aims to provide disabled persons with equal opportunity, social integration, conditions of independent way of live that is to ensure all the aspects of disability taking into account every possible mainstream.[56] [57] [58]

1.1.8. The United Nation's Convention on the Rights of Persons with Disabilities

One of the latest paradigms affecting disabled people is the Convention on the rights of persons with disabilities adopted by United Nations Assembly.[59] The Preamble of the Convention declares that 'children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalls obligations to that end undertaken by States Parties to the Convention on the Rights of the Child…' The Convention contains fifty articles starting from the aims and principles to the obligations and covers all essential areas that can be related to the life of persons with disability; independency, dignity, accessibility, equal opportunities, equal recognition before the law, discrimination, awareness-raising, justice, liberty, security, personal mobility, access to information, respect, education, health care,

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[56] FONYÓDI I. Az 1998. évi XXVI. törvény a fogyatékos személyek jogairól és esélyegyenlőségük biztosításáról In *Illyés S. (szerk.) Gyógypedagógiai alapismeretek.* BGGYTF, 2000. Budapest. ISBN 963-7155-28-7

[57] GYENE P. Az értelmi fogyatékossággal élő személyek emberi jogai: Nemzeti Jelentés Magyarország: Az Európai Bizottság "Az értelmi fogyatékossággal élő emberek emberi jogainak előmozdítása a civil társadalomban" című projectje keretében. Értelmi Fogyatékosok és Segítőik Országos Érdekvédelmi Szövetsége, 2002. Budapest.

[58] KISGYÖRGYNÉ A. /szerk./ Tájékoztató a fogyatékosokat ellátó intézményekben élők állapotának felülvizsgálatáról, rehabilitációs alkalmassági vizsgálatáról. Egészségügyi, Szociális és Családügyi Minisztérium, 2003. Budapest.

[59] ENSZ. *Fogyatékossággal élő személyek jogairól szóló egyezmény és az ahhoz kapcsolódó fakultatív jegyzőkönyv.* ENSZ, 2006. december 13.

rehabilitation, employment, recreation, leisure and sport. First we would like to present the general issues of the Convention then some points of greater importance in the view of children with disability will be described in detail. The Preamble contains several statements in which the State parties recognize the inherent dignity, worth and the equal and inalienable rights of all persons, that disability results from the interaction between persons with impairments and environmental barriers that hinders their full and effective participation in society. In an ideal case opportunities provided for them make them able to be actively involved in decision-making processes about policies and programmes, including those directly concerning them. It can be reached if the major of the society accepts their individual autonomy and independence, including the freedom to make their own choices. That is why they emphasize the importance of mainstreaming disability issues as an integral part of sustainable development. The State parties agree that discrimination against any person on the basis of disability is a violation of the inherent dignity. They are concerned about persons with disabilities who are subject to multiple forms of discrimination on the basis of race, colour, sex, language, religion and political or other opinion. Women and girls with disabilities are often at greater risk they might be subject to injury, abuse, neglect, maltreatment or exploitation. Thus there is a need to incorporate a gender perspective in all efforts.

The document highlights the fact that the majority of persons with disabilities live in poverty, so there is an urgent need to address the negative impact of poverty on persons with disabilities. Hopefully a comprehensive and integral international convention will make a significant contribution to changing the social disadvantage and will promote disabled people's participation in the civil, political, economic, social and cultural spheres providing them with equal opportunities, in both developing and developed countries. Expected changes, which presumably will happen not only in the countries' of the State parties, require several moves like reasonable accommodation. It is an umbrella term which means necessary and appropriate modifications and adjustments where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise of all human rights and fundamental freedoms. The major of the society tends to forget about these adjustments which should involve reconstruction of buildings to be suitable for accessibility, enough and adequate staffing resource for non-specialized institutions which try their best to provide inclusive education. As it was mentioned before, some cornerstones concerning the equalization of opportunities for children with disability involved in the Convention will be described in detail in the following section. These cornerstones are: education, health care, home and the family, and equal recognition before the law. States parties recognize the right of persons with disabilities to education. Without discrimination and on the basis of equal opportunity an inclusive education system should be included at all levels, furthermore life long learning should be directed to the full development of human potential, their personality, talents and creativity, as well as their mental and physical abilities. Governments should enable persons with disabilities to participate effectively in a free society. All these rights can be ensured if persons with disabilities are not excluded from the general education system, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education. The major of the society should realise how important it is that persons with disabilities can access an inclusive, quality and free primary education and secondary education others in the communities in which they live. At this point reasonable accommodation, like the adjustment of building to be suitable for accessibility, needs to be mentioned again where the individual's requirements are provided and their effective education is facilitated. Being included in the regular school system enables persons with disabilities to learn life and social development skills and be a member of the community. As a matter of fact appropriate measures shall be taken to support individual learning needs which involve the learning of Braille, alternative script, augmentative and alternative modes, the learning of sign language, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring. This way children who are blind, deaf or deaf and blind, are delivered in the most appropriate languages and means of communication in environments which maximise academic and social development.

In order to help ensure the realization if inclusive education and the development of children with disabilities to their fullest potentials appropriate measures should be taken to employ teachers who are qualified in sign language and/or Braille. It would be advisable for educational institutions to employ teachers with disabilities to show an example for children in the same shoes. The training of professionals should incorporate disability awareness and the use of appropriate augmentative and alternative modes, means of communication, educational techniques and materials to support children and youth with disabilities. Besides primary and secondary education there is a growing need to get into general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others.

Another cornerstone of the Convent is the adequate health care provided for children and youth with disabilities. States members recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health. Thus, the same range, quality and standard of free or affordable health care and programmes are provided for including in the area of sexual and reproductive health. In an earlier chapter we described the process of early identification and the Convent mentions it as the first step of ensuring the conception and development of a healthy baby. Early identification is followed by appropriate intervention and the designation of services to minimize and prevent further disabilities. Even though we live in a fairly small country, it seems to be impossible to provide these health services as close as possible to people's own communities especially in rural areas. In several cases the communication between persons with disabilities and health professionals proves to be difficult, quite understandably, although awareness of the human rights, dignity, autonomy and needs of disabled people could be raised through training, which could end in a successful cooperation. Ethical standards must be kept in both public and private health care, in taking out life and/or health insurance. The health care system also involves rehabilitation which proves to be crucially important for persons with disability so that they can attain and maintain maximum independence, full physical, mental, social and vocational ability. With some or all these potentials they can participate in all aspects of life such as employment. Rehabilitation should be started at the earliest possible stage after assessing the individual needs and strengths. Rural areas are usually at a disadvantageous situation, although rehabilitation in a wider sense than part of the health care system should be provided as close as possible to their own communities. For this different assistive devices and technologies, designed for persons with disabilities, are needed. The next cornerstone of the Convent highlights the respect for home and the family, described in Article 23. People belonging to the majority of society might think that it is not proper for a disabled person to have a relationship or get married. In order to eliminate discrimination against persons with disabilities relating to marriage, family, parenthood and relationships, the document wants to ensure that they have the right to marry and found a family with the mutual intention of the spouses. They can decide the number and spacing of their children. In the section about health care we have mentioned the access to reproductive and family planning education and age-appropriate information which enable them to exercise their rights such as retaining their fertility on an equal basis with others. Different national legislations can diverse in ensuring the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children but in all cases decision makers should focus on the best interests of the child. In line with it children with disabilities have equal rights to family life. State parties intend to ensure that children with disabilities have the right to express their views freely on all matters affecting them, and to be provided with disability and age-appropriate assistance to realize that right. In order to prevent concealment, abandonment, neglect and segregation it is inevitable to provide early and comprehensive information, services and support for children with disabilities and their families. It might happen that authorities determine to separate the child from his or her family because it seems to serve the child's interest. What really should be kept in mind that a child cannot be separated from parents on the basis of disability. Sometimes the wider family can give an alternative care or if it fails, the community can undertake this responsibility in a family setting. In addition family setting can build the best possible background for the child to acquire and start living independently and be included in the community on condition of the following:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Last but not least the final cornerstone that we would like to emphasize is the equal recognition before the law which is described in Article 12. States members reaffirm that persons with disabilities have the right to recognition before the law thus they can enjoy legal capacity on an equal basis with others in all aspects of life. Appropriate measures should be taken to provide access by persons with disabilities to the support they may require. It is important to ensure all measures that relate to the exercise of legal capacity which provides appropriate and effective safeguards to prevent abuse. It can be reached if measures relating to the exercise of legal capacity respect the rights and will and preferences of the person, are proportional and tailored to the person's circumstances, and are subject to regular review by a competent, independent and impartial authority or judicial body. As a matter of fact appropriate and effective measures must be taken to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit.

The Hungarian National Assembly adopted the modification of Civil Code on 21 September 2009 in which laws concerning capacity was also modified after the Convention entered into force.[60] The institution of trusteeship for incapacity shall be abolished and persons living with disabilities can make decisions as a 'supported decision' in matters related to them assisted by a family member or someone who is close to them. The abolition of trusteeship for incapacity and the restrictive possibility of application of the trusteeship for restricted capacity provide the right to autonomy for persons with disability, and respect their dignity. The institutions to be established – supported decision making and preliminary legal declaration – make it possible for persons with disability to get support tailored to their needs in case they would not be able to make decisions on their own because of their disability, psychiatric disease or old age. Within the meaning of the act we shall be given the chance to decide preliminary what the case should be if we found ourselves in a similar situation. The adoption of these modifications proves to be a significant advance to international human rights and especially to the United Nation's Convention on the Rights for People with Disability. Hungary joined the Convention in 2007. Since then advocacy services of persons with disability have worked to adjust the regulations to the international laws, and to prevent unnecessary and unproportional abridgement. The laws applied up till now marginally restricted the individual autonomy of persons with disability, made it possible to put them under guardianship, or to state their legal incapacity. Persons

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[60] LAW. Az 1959. évi IV. törvény a Polgári Törvénykönyvről. A törvény hatályba lépése körül még egyeztetések folynak.

with disabilities had no accessible help which could have substitute the severely restricted trusteeship with obligations with binding force related to their own life. Nowadays there are eighty thousand adults under trusteeship. About two third of them were not allowed to make any legally relevant decisions. The trusteeship of incapacity deprived them of any personal or political decisions, involving the right to choose the place of living. As a consequence many of them, against their will and preference, were placed in residential homes. Persons with disability stated to be legally incapable had no right to get married and found a family, and to be free to dispose of his or her properties.

Further regulations are needed to enforce the United Nation's Convent which ensures that disabled people can effectively and fully participate in social life on an equal basis with others. The Hungarian legislation interprets disability quite restrictively so some persons in questioned such as psychiatric patients are excluded from effective legal protection. Our Constitution, in contrast with Article 29 of the Convent, does not ensure that persons with disability can exercise their right to vote. For several persons with disability the opportunity to live in a family setting and be included in the community and society are not provided, they are obliged to live in a particular living arrangement although it violates their rights to live independently and be included in the community, described in Article 19. Furthermore the requirements of Article 33 are not fulfilled either, namely that the government should set up coordination centres for matters relating to the implementation of the Convention. In addition an impartial board should monitor the implementation of the Convent, while civil society should also be involved and participate fully in the monitoring system. The national assessment and checkup of persons with disabilities is done in accordance with the law[61] which describes the protocol in the case of children with disabilities. A committee of experts and rehabilitation examining the learning skills is responsible for the check-up of children with disability living in a family setting on the basis of the relevant law. The committee's check-up results are sent to the educational institution which should be taken into consideration in developing and caring for the child. At least once a year the leader of the educational institution informs the child's parents or legal representatives

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[61] LAW. A 92/2008. (IV. 23.) Korm. rendelet a fogyatékos személyek alapvizsgálatáról, a rehabilitációs alkalmassági vizsgálatról, továbbá a szociális intézményekben ellátott személyek állapotának felülvizsgálatáról.

about his or her condition, development and individual development plan. For parents or legal representatives the opportunity to visit workshops should be provided.

1.1.9 The new dimensions in classification disability

The identification and classification of disability and the definition of ground for comparison are inevitable for social workers.[62] [63] Identifying individual and social impact makes it possible to decide what kind of social support shall be ensured for the persons with disability or their family. Earlier, the restrictive and destructive definitions which were used during this process described disability as a disease, disorder or deficiency. The World Health Organization adopted the International Classification of Functioning, Disability and Health in 2001 abbreviated FNO[64] in Hungarian. It is in harmony with the National Classification of Diseases, abbreviated BNO in Hungarian, but is completed with functional aspect. After introducing this new concept, a new practice will become deeply rooted in the international assessment of disability as well as in its acceptance by the professionals. As we have mentioned before, ICF breaks the so-far used disease centred theory such as the International Classification of Impairments, Disabilities, and Handicaps, (ICIDH) so it proves to be absolutely useful for social workers. ICF places accent on attitude, interaction providing new opportunities for social work. However, its usability in practice cannot be foreseen especially in view of social participation and the recent opinion about the definition of disability.[65] ICF is a classification of health and health-related domains which are classified from body, individual and societal perspectives by means of lists: a list of body functions and structure, and a list of domains of activity and participation, plus a list of environmental factors. The list of body function and structure contains all the

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[62] HORVATH L. Új fogalmak és európai összefüggések a szociálpolitikában. In *Tudásalapú gazdaság és életminőség.* Szabolcs-Szatmár-Bereg Megyei Tudományos Közalapítvány, 2005. Nyíregyháza. 265-268.p. ISBN 963 218 743 1

[63] ILLYÉS S. A magyar gyógypedagógia hagyományai és alapfogalmai In *Illyés Sándor (szerk) Gyógypedagógiai alapismeretek.* BGGYTF, 2000. Budapest. ISBN 963-7155-28-7

[64] SEIDEL M. A funkcióképesség és egészség nemzetközi osztályozása (FNO). In *Szociális Munka,* 2004/2.sz. ISSN 0865-347X

[65] JUHÁSZ F. Irányelvek a funkcióképesség, a fogyatékosság és megváltozott munkaképesség véleményezéséhez. Medicina, 2004. Budapest. ISBN 963-242-838-2

functions, impairments, clinical knowledge and examine algorithm which are related to the systems and organs of the body. On the basis of them the nature, seriousness, and classification of a given disability can be identified and possible prevention can be suggested. Individual aspects are clustered around the list of activities and participation which involves learning and applying knowledge, general tasks and demand, communication, mobility, self-care, domestic life, interpersonal interactions and relationship, community, social and civic life. The list of environmental factors describes products and technology, natural environment and human-made changes to environment, support and relationship, attitudes, services, systems and policies. As it was stated before, the ICF puts the notions of 'health' and 'disability' in a new light. Every human being can experience a decrement in health and experience some degree of disability. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability.[66] Besides ICF, there exist audio-visual assistive devices which can improve dispensing information more effectively.[67] [68] They are essential for persons with disabilities and their families, as well. Disability awareness can help the majority of society to understand the difficulties of disabled people.

1.1.10 Contemporary models of the helping process

In order to tackle the problems rising from being disabled, both the person with disability and his or her surroundings should live an active life.[69] It is important to call their attention that solitude, depression and degradation are not necessarily involved in the disability existence. Personal and environmental integration is indispensable which can be influenced by the person himself, his family and his environment. When coping with the difficulties of disability the intensity of family cohesion can decrease or increase, this latter one is more favourable and serves the interest of persons with

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[66] BARON S., BOLTON P. *Autizmus*. Osiris, 2000. Budapest. ISBN 963-379-751-9

[67] Drama Therapy With Disabled Children. DVD. 2008. New York. 70AT6822

[68] The Diagnostic Process. 70AT6618. DVD. 2008. New York.

[69] KÁLMÁN ZS. *Bánatkő. Sérült gyermek a családban.* Bliss Alapítvány, Keraban Könyvkiadó, 1994. Budapest. ISBN 963-8146-26-5

disability, as well as their surroundings.[70] Having a supportive family both personal and social advantages can be multiplied.[71] A positive, welcoming attitude promotes reinforcing the coping strategies.[72] By acquiring if not all but most or some of them, persons with disability will be able to face physical, mental and environmental damages to a better degree.[73] Success, depending on the nature of handicap, can also be reached by disabled people, which has a great impact on their lives influencing their quality of life.[74] During the helping process civil services also play an important part both at individual and social levels. Their role in politics, public life, spare time and their self-support function is invaluable.[75] Persons with disability should be ready to respond to the opportunities for spending spare time in an active way.[76] As a matter of fact it can be promoted by it surroundings while the person with disability is expected to find his or her role in the family so both parties are to prepare for the tasks.[77] [78] [79] [80] [81] [82]

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[70] KOVÁCS K. *Nyújtsd a kezed! Tanácsadó kézikönyv látássérült kisgyermek szüleinek.* Látásvizsgáló Országos Szakértői és Rehabilitációs Bizottság, én. Budapest.

[71] KOSIKNÉ J. Fogyatékos gyermekek szüleinek elképzelései gyermekeik jövőjéről. BGGYTF, 1988. Budapest.

[72] KÖNCZEI GY. Fogyatékosok a társadalomban. Újabb adalékok a kirekesztettség anatómiájához. Gondolat Könyvkiadó, 1992. Budapest. ISBN 963-282-616-7

[73] HORVATH L. Fogyatékos gyermekek és családjaik szociális segítése. In *A II. Nyíregyházi Doktorandusz (PhD/DLA) Konferencia Kiadványa.* Bessenyei Kiadó, 2009. Nyíregyháza. 87-94.p. ISBN 978 963 9909 19 9

[74] KÖNCZEI GY., GYULAVÁRI T. *A szociális Európa.* Szociális és Családügyi Minisztérium, 1999. Budapest.

[75] TAUSZ K. A fogyatékos gyermekek helyzete és a civil társadalom az átmenet időszakában. In *Esély*, 1997/6.sz. ISSN 0865-0810

[76] FALVAY K. *Ritmikus mozgás-énekes játék.* OPI, 1990. Budapest. ISBN 963-682-366-9

[77] MITTLER P. A szülők és szakemberek közti kapcsolat újragondolása. In *Zászkaliczky-Lechta-Matuska (szerk.): A gyógypedagógia új útjai.* ELTEBGGYFK, 1999. Budapest. ISBN 963-7155-26-0

[78] BORBÉLY S., JÁSZBERÉNYI M., KEDL M. *Szülők könyve értelmileg sérült kisgyermek neveléséhez.* Medicina Kiadó, 2000. Budapest. ISBN 963-242-640-1

[79] FONYÓDI I. A konzultáció (counseling) és a gyógypedagógia. In *Gordosné Szabó Anna (szerk.): Gyógyító pedagógia.* Medicina Könyvkiadó, 2004. Budapest. ISBN 963-242-757-2

[80] HULLER GY. *A szülői hivatás.* Huller Gyula Kiadó, 2003. Budapest. ISBN 963-430-818-X

[81] KÁLMÁN ZS. A szülő és a szakember együttműködésének buktatói. In *Kálmán - Könczei: A Taigetosztól az esélyegyenlőségig.* Osiris Kiadó, 2002. Budapest. ISBN 963-389-311-9

[82] MAGÓ O., HEGYHÁTI E., GYÖNGY A. Van segítség. Kézikönyv értelmileg sérült gyermekeket nevelő szülők számára. ÉFOÉSZ, 1992. Budapest.

Distracting their thoughts from the difficulties can help in the short run but it would be better to teach and learn how they can turn reality into an active life. That is where education comes into the picture which provides them with training, not in the regular way which is basically for the majority of the society, but rather tailored to their personal needs. Furthermore, sport, music and art, which put a gloss on their lives, open up new possibilities.[83] It seems to be inseparable from human help that from time to time new paradigms are to be set up or reshaped and objectives need to be developed.[84] [85] [86] Partnership between the persons with disability, their family and the support services, which proves to be an efficient way of social care, should be built and sustain. Regarding the fact that all the three parties of this provision continuously change it is likely to be difficult to keep up a harmonious collaboration.[87] It is a real challenge.

The helping process starts with needs' assessment of the persons with disabilities and their surroundings which requires the help of professionals,[88] let alone good communication skills.[89] The previous sub-chapter dealt with the methods of the classification of disability which help professionals to assess the surroundings and resources of the persons with disabilities, and define the goals. When changing paradigms it can be dangerous to work out of mere habits. For the most part it is usually

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[83] KISS J. *Alternatív lehetőségek a zenepedagógiában*. Tárogató Kiadó, 1994. Budapest. ISBN 963-8491-52-3

[84] HORVATH L. Deficient Children in the Family. In *Kontakt,* 2007. ISSN 1212 4117

[85] SEIDEL M. A funkcióképesség és egészség nemzetközi osztályozása (FNO). In *Szociális Munka,* 2004/2.sz. ISSN 0865-347X

[86] BARKER L. *The Social Work Dictionary*. National Association of Social Workes, 2003. Washington. ISBN 087101355X

[87] HORVATH L. Fogyatékos gyermekek intézménybe kerülésének – családból való kikerülésének okai. In *Szociális munka az egészségügyben.* Debreceni Egyetem Egészségügyi Kar – Kent School of Social Work University of Louisville, 2009. Nyíregyháza. 104-114.p. ISBN 978 963 473 348 5

[88] HORVATH L. Szellemi erőforrásaink helyzete a szociális ágazatban. In *A vidékfejlesztés szellemi erőforrásainak hasznosítása.* Szabolcs-Szatmár-Bereg Megyei Tudományos Közalapítvány, 2000. Nyíregyháza. 126-128.p. ISBN 963 00 5229 6

[89] NEMES J. Hendicepes a mentálisan sérült betegek gyógyítása. In *Kórház,* 2009/12.sz. 15.p. ISSN 0230-3868

the family which tries to retrieve the handicaps.[90] [91]When the help delivered by family members is not possible for any longer or for any reason then in-home social service is accessible for the persons with disability. Thus the right way of helping is the development and priority of basic care which can accelerate the resources of the family and its immediate environment, utilize the services of civil organizations, and can induce community or group social work. If and only if any of these provisions proves to be impossible, should the person with disability be placed at a residential home. The connection with members of the new environment should be built at the very beginning of the placement, and family ties should be maintained for the well-being of the person with disability.[92] [93]

1.1.11 Definitions and disability

The definition of a person with disability is also described by the Hungarian laws[94]; anyone who is to a significant extent or entirely not in possession of sensory – particularly sight, hearing – loco motor or intellectual functions, or who is substantially restricted in communication and is thereby placed at a permanent disadvantage regarding active participation in the life of society. As we can see this definition meets the required standards of the international documents we have referred to in earlier sections. The Assembly of the United Nations adopted the 48/96 Resolution on 20 December 1993 which contains the required standards for equalizing opportunities for persons with disability and it gives the following definition for disability: 'the term "disability" summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical,

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[90] HORVATH L. Fogyatékos gyermekek és családjaik szociális segítése. In *II. Doktorandusz Konferencia kiadványa.* Bessenyei György Könyvkiadó, 2009. Nyíregyháza. ISBN 978-963-9909-19-9

[91] NAGY J. A kognitív kompetencia fejlesztése. Értelmi nevelés: értelmezésre nevelés. In *XXI. század és nevelés.* Osiris Kiadó, 2000. Budapest. ISBN 963 379 769 1

[92] HORVATH L. Az alap- és szakosított ellátás viszonya a szociális munkában. In *A humán erőforrás szerepe, fejlesztésének, hasznosításának lehetőségei az Európai Unióban.* Szabolcs-Szatmár-Bereg Megyei Tudományos Közalapítvány, 2004. Nyíregyháza. 212-215.p. ISBN 963 214 213 6

[93] LÁNYINÉ Á. Az értelmileg akadályozottak intézményes ellátási formáinak változása. BGGYTF, 1996. Budapest.

[94] LAW. Az 1998. évi XXVI. törvény a fogyatékos személyek jogairól és esélyegyenlőségük biztosításáról.

intellectual or sensory impairments, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.' Our reason for dealing with definitions is that workers of helping professions who care for persons with disability[95] often come across with expressions which are neither synonyms, nor equivalent, and are not in a whole and part logic connection but rather partially overlap one another. As a consequence the question of how to use them properly arises. Expressions like *children with special educational needs, legal incapacity, restricted capacity, person with supported decision making, person with changed ability to work* are on the list which can be expanded. Re-definition or re-adjustment of terminology is urged both by national and international professionals.[96]

A European study[97] has shown that definitions and the way they are used have an impression on governments and institutions in affecting their attitude towards and decisions on persons with disability. In the European Union the right to free movement is a basic principle which attracts attention of greater importance within the border of the extended European Union among national economy and excessive globalization. Comparing this principle to a simple obstacle removing we can understand a much broader sense of disability definition. The study has figured some delimitations of the 'social model' related to disability. This social model tackles disability in a more welcoming way than the previous medical model and recognizes the rights for disabled people in a wider sense. However, this social model is lacking in certain up-to-date information related to the latest events concerning disability, especially the attitude tailored to individual needs and mainstreaming. Public authorities – both at national and international levels - are expected to take responsibility to transform the society to a more welcoming one by articulating the open and welcoming definition of disability. In order to support persons with disability who need help on regular daily basis or have

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[95] HALMOS SZ., GAZSI A. Esetjogi tanulmányfüzet. Az értelmi fogyatékos, halmozottan fogyatékos és autista emberek számára működtetett antidiszkriminációs jelzőrendszer tapasztalatai. Kézenfogva Alapítvány, 2008. Budapest. ISBN 978-963-88082-0-2

[96] LAW. Az Európai Unió Tanácsa 2000. november 27-i 2000/78/EK Irányelve a foglalkoztatás és munkavégzés során alkalmazott egyenlő bánásmód általános kereteinek létrehozásáról. Foglalkoztatáspolitikai és Munkaügyi Minisztérium, 2005. Budapest ISBN 963-86523-4-9

[97] EURÓPAI BIZOTTSÁG. A fogyatékosság definíciói Európában összehasonlító elemzés. A Brunel Egyetem által készített tanulmány. Európai Bizottság. 2002.

extra expenses, member states of the European Union have introduced measures to ease their financial situation; long-term care, cash allocation, financial support for transportation and special diet and other needs, concession for persons with disability for free use of public transport or at reduced price, concession on device usage, TV subscription or phoning bills, and tax allowance. The needs to be met vary in nature, starting from different measures, medical care, personal care, in-home help, moving, social life, to the compensation of extra expenses. The helping staff include doctors, nurses, social workers, multidisciplinary team and officers of the social security system. Definitions and criteria determining disability set up in the international legislation may differ to a great extent in the state members of the European Union. Probably that is the main hindrance of the mutual acceptance of national decisions made on the subject of disability with special regard to the accessibility to special services and assist devices. As a result of if persons with disability who move to another country within the borders of the European Union may face difficulties they did not expect since different countries provide diverse social security for them.

The social attitude to disabled people in Hungary has changed for a few decades. The transformation year of 1989 brought some changes in several aspects like equalizing opportunities, though the society and institutions insisted on the moss-grown concept and regarded disability as deviance. Not many decades before part of the moss-grown concept was to protect the society from meeting and making connection with deviance. Several educational and health institutions made every effort to 'cure and care' persons with disability 'out of' their handicaps, but this aspiration made it even more difficult for disabled people to adapt themselves into the society. Their desire was acceptance and understanding rather than 'curing'. At the end of the 20th century attempts were made to loosen their isolation however the rigid school system could not include them. There were of wide range of methods for isolating them from the major of the pupils, and very often the intention to accept them at regular schools met a failure because of the teaching staff and the headmaster. Despite every good will for helping persons with disability the problems deepened. Unfortunately prejudice is being reproduced automatically, though the European Union's intention is to create welcoming societies.

Prejudice can be reduced or ceased with the help of integrated education at kindergartens and schools. We have written about the importance of training teaching staff and enabling them to tackle problems arising from disability. Thus children with disability could get a tailor made education. The Hungarian Academy of Sciences held a Conference[98] on Disability and the Contemporary Hungarian Society where the participants, among other things, discussed how TV programmes could contribute to a different mindset on disability and they warned of the lack and necessity of TV programmes on the same issue. They also pointed out that changes in attitude would take long.

1.1.12 Figures on disability

The issue of disability got involved in Census 1990 and 2001 in Hungary.[99] There are significant differences between them; the 1990 collection targeted only 20% of the population, while in Census 2001 the whole population was presented. Data survey based on personal questioning which defined the methods of population census, and the questioned ones had the opportunity to declare on disability. This method was likely to result in a certain inaccuracy concerning the number and distribution of persons with disability. Furthermore, disabled people's inadequate knowledge of the nature, cause and severity of their disability might diverse and is advisable to be taken into account. It cannot be decided whether elderly people declare themselves simply old or disabled due to their limitation of motion or sensory impairment like blindness and deafness. However, census figures give a comprehensive view of disabled people's circumstances and life style. The aim of the data survey, similarly to other issues, is not to count the number of persons with disability accurately which equals to that of registry offices but rather to evaluate and compare data with other information of the census such as circumstances and lifestyle of disabled people. On the other hand it seems quite obvious that certain types of disability, like mental disability, cannot be fully surveyed with personal questioning of the population since in most of the cases the

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[98] Fogyatékosság és a mai magyar társadalom. MTA konferencia. 2008. december 9. Budapest.

[99] KSH. *Népszámlálás. Magyarország*. KSH, 1990 és 2001. Budapest.

immediate surrounding of the questioned person is unwilling to reveal this information.[100] [101]

Several statistical tables were compiled after the censuses which prove to be relevant to the topic of this writing. Data from Census 2001[102] show that most of the population 9 million 711 thousand persons, 97.5 per cent, live in 3 million 863 thousand natural private households, while 249 thousand persons, 2.5 per cent, live in institutions. The majority of disabled people, 92 per cent, live in private households, though the prevalence of living in institutions is higher, 8 per cent among persons with disability than among those without disability. This rate is inconsistent with the Normalization Principle. At this point, figures showing the children population in the last 20 years in Hungary are relevant and informative data.

Table 1

Population of 0-29 age group between 1980 and 2009 per one thousand

Year	0-14 age group	15-29 age group
1980	2341	2356
1990	2131	2066
2000	1729	2278
2007	1530	2074
2008	1509	2030
2009	1493	1987

Source: *Yearbook of Social Statistics*. KHS-SZMM 2009 Budapest

The total population of Hungary has decreased and the figures above show decreasing tendency of the age group involved in the dissertation. Although there is a slight rise in the number of live birth the 0-14 age group has not been significantly influenced by this growth yet. The decreasing tendency in the 0-14 age group has slowed down, while the decreasing tendency is still deep in the 15-29 age group. Therefore the apparent increase in the number of disabled peopled has to be compared to this tendency.

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[100] LOVÁSZY L. A fogyatékos emberek helyzetéről - a filozófiától a demográfiáig. In *Kapocs,* 2006/1.sz. ISSN 1588-7227

[101] KSH. A fogyatékosság kérdése a magyar népszámlálások történetében (1869-1949). KSH, 1996. Budapest. ISBN 963-215-110-0

[102] KSH. *Népszámlálás. Magyarország*. KSH, 1990 és 2001. Budapest.

Census 1990 reported 368 thousand persons with disabilities, whereas this population consisted of 577 thousand persons in 2001, so their prevalence increased from 3.5% to 5.7%. Data from the Central Statistical Office might underestimate the number of persons with disabilities because other estimations show that it could be as high as 600 thousand. Their number is continuously increasing and it may reach 1 million by 2021. At the time of data taking the age structure of persons with disability and that of without disability was different. The prevalence of children among persons with disability was lower than the prevalence of persons over 60. The educational attainment proves to be an important differentiating factor. Even though the level of education among persons with disability increased in 2001, similarly to those without disability, it could not reach the educational level of persons without disability. The situation of persons with disability in the European Union has some significance over employment and it has become an issue of social policy and politics after designating social integration a main element of the goals. Any discrimination on the ground of sex, race, ethnic, religion or belief is prohibited in the Treaty of Amsterdam. The ground for a welcoming society can be reached by positive actions against discrimination. The disability policy of the new millennia does not consider the situation of disabled people exclusively an issue of health care, rehabilitation, social policy but the rights of disabled people are hoisted into the human rights. Discrimination and social exclusion caused by social barriers made this movement necessary. 'All communities should celebrate the diversity and disabled people form a very diverse group of people and only policies that respect this diversity will work' – says the Madrid Declaration. Disabled people need equal opportunities not pity or charity. To declare the rights for them is only the beginning and positive action as well as positive discrimination will prove useful and necessary methods against discrimination and social mechanism in order to diminish the social drawbacks of persons with disability stemming from social exclusion. The altered mindset can result in an open society where more people declare themselves disabled without fear.

As for the state of health, questions referred only to disability in the 1990 and 2001 Censuses. Comparison in the view of disability between the censuses is not reliable since in the 1990 census only 21% of the population was presented. However, the 2001 Census targeted the whole population and census-takers were prepared how to ask about disability and how to apply methods of empathy. The census-taking order called the census-takers' attention that due to the sensitive character of this issue to which some interrogated persons would be reluctant to give an answer, they need to be patient and attentive. The prevalence of males and females with disability was also different. Specifically, in 1990, the disability rate for males was higher, while in 2001 the rate for females became higher. It can be explained by the fact that in 2001 more elderly people declared themselves disabled than in 1990. It is also known from statistical data that the prevalence of females among elderly people is higher than the prevalence of males.

Table 2

Characteristics of the population by disability and gender in 1990 and 2001[103]

Percentage

Sex	1990		2001	
	With disability	Without disability	With disability	Without disability
Male	53.6	47.8	49.0	47.5
Female	46.4	52.2	51.0	52.5
Total	100.0	10.0	100.0	100.0

Source: *Census Hungary.* KSH 1990, 2001 Budapest

The data survey from 1990 and 2001 shows that the age pyramid of persons with disability and that of without disability diverse to a great extent. The prevalence of children among persons with disability was much lower than the prevalence of elderly people over 60. Significant changes can be seen in the rate of children among persons with disability which decreased by 4% and in the rate of adults over 40 among persons with disability which increased by 12%. It was 68.3% in 1990 and 80.4% in 2001.

Table 3

The population by disability and age group, in 1990 and 2001

Percentage

Age group	1990		2001	
	With disability	Without disability	With disability	Without disability
0-14	9.1	21.0	5.0	17.3
15-39	22.6	35.8	14.6	36.3
40-59	30,6	24.9	35.6	27.5
60-X	37.7	18.3	44.8	18.9
Total	100.0	100.0	100.0	10.0

Source: *Census Hungary.* KSH 1990, 2001 Budapest

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[103] The next Census in Hungary will be in 2011

The figures from 2001 show that the rate of single people among the population has increased whereas the rate of married couples has decreased. Both the rate of single men and single women among persons with disabilities has increased and the prevalence of single women more significantly, while the rate of married couples among persons with disability remained the same. The most significant difference can be seen among widows where more than one third of women with disability are widows, which doubles the rate of women without disability. The rate of divorced people among persons with disability has risen a bit more sharply than among persons without disability. The family relations also show that more persons with disability are single and live in institutions than persons without disability. The higher rate of single persons with disability correlates the higher rate of elderly disabled people. The prevalence of unmarried couples has increased among persons with disabilities, as well as among persons without disabilities, but the rate is still lower. The most important institutions for providing equal opportunities for disabled people are the schools. They provide the scene for socialization and have significant role in influencing the chances of the youth at the labour market. The potential employability of persons with disability is marginally determined by the lower rate of school attainment. Persons with disability and lower level of schooling are less likely to be employed. Comparing the figures of Census 1990 with that of 2001 the level of school attainment of persons with disability has risen but it is still much lower than those of without disability. Examining data on the basis of age group, it is true for disable people that their school attainment has risen expect for those with mental deficiency.

Table 4

The population aged 7 years and over by disability and highest education obtained in 1990 and 2001

Percentage

Highest education obtained	1990		2001	
	With disability	Without disability	With disability	Without disability
Primary school 1st-7th grade completed	50.1	30.6	31.6	19.3
Primary school 8th grade completed	30.6	31.8	38.8	30.2
Secondary school without general certificate	5.7	13.2	10.3	17.1
Secondary school with general certificate	9.7	17.0	14.3	23.3
University, higher education	4.0	7.4	5.0	10.2
Total	100.0	100.0	100.0	100.0

Source: *Census Hungary.* KSH 1990, 2001 Budapest

The geographic distribution of disability was significantly different in Hungary. The prevalence of persons with disability was much higher in the regions of Northern Hungary and the Southern Plain, which are disadvantageous regions from several other aspects, too. The distribution by settlements shows that the rate of persons with disability living in rural areas was higher than in the capital or other towns. Anyhow, this type of distribution adds to the problem of disparity between settlements.60% of the persons with mental deficiency did not even complete the 8th grade of primary school, although their school achievement basically depended on the nature and severity of mental deficiency. However, one third of them managed to complete the 8th grade and a small rate of them graduated from higher education. The school achievement of blind people differed to a great extent since a large percent of them successfully completed primary school and continued in secondary or tertiary schools. Their higher school attainment correlated their employability, mostly white collar jobs, and the rate of blind people in the labour market was higher among persons with disability.

The lifestyle of a family is absolutely determined by the number of children, especially if any of them is disabled. The rate of children with disability was 19% among families with disabled persons. In the case of married couples this rate was 15%, while among lone parent this rate was as high as 45%. Having two or three children with disability in a family implicates that families find themselves in extreme difficulties, 0.3% and 2.9% of families caring for disabled children belonged to this disadvantageous group. Looking at the same data from the viewpoint of age of children, the rate of families caring for children with disabilities younger than 15 among families in the same situation is about 6%. So there seems to be a large number of families caring for children with disabilities older than 15, whereas personal, social or financial difficulties stemming from disability may destabilize the future of a married couple.

Table 5

Families by family composition, number of children and disability

	Total	One-child family	Two-child family		Three-child family			Four-child family
			One child	Both children	One child	Both children	All the three children	At least one child
		disabled						
Number								
Married couples	41 802	15 858	15 370	1 198	5 376	576	120	3 304
Lone parent with child	24 150	15 570	5 606	706	1 346	199	52	671
Total	65 952	31 428	20 976	1 904	6 722	775	172	3 975
Of which: children with disability younger than 15 in the family	20 569	4 970	8 563	468	3 790	311	61	2 406
Percantage								
Married couples	100,00	37,39	36,8	2,9	12,9	1,4	0,3	7,9
Lone parent with child	100,00	64,5	23,2	2,9	5,6	0,8	0,2	2,8
Total	100,00	47,7	31,8	2,9	10,2	1,2	0,3	6,0
Of which: children with disability younger than 15 in the family	100,00	24,2	41,6	2,3	18,4	1,5	0,3	11,7

Source: *Census Hungary.* KSH 2001 Budapest

A great number of disabled people lived in institutions, in 1990 some 12% of them and in 2001 some 8% of them, due to their state of health or severity of the disability which might requires professional intervention and care. The demographic composition of persons with disability and those of without it and living in institutions was significantly different; concerning the first group the rate of children and elderly people was higher, while the prevalence of youth was the highest among persons without disability and living in institutions. Between 1990 and 2001 the rate of children among persons with disabilities and living in institutions decreased, whereas the number of elderly people with disabilities and living in institutions increased.

From the viewpoint of our topic the modern principles can be summarized as follows:

- The normalization principle. People live in families. Families having children with disabilities should be helped so that they can have a full live in their own environment.
- Helping families, especially those with disabled children, requires decisions and provisions from health care, social policy and social work
- The principle of integration. The aim is to build a social integration with the inclusion of families having children with disability. The exclusion of these families should be prevented by arrangements and regulations which can help them to preserve and enforce social connections.
- Early identification, classification of disability, as well as the determination of ground for comparison prove to be inevitable for the work of social workers. The allocation of social services for persons with disability and their families will surely have personal and social impact, too.
- Early identification. We have achieved good results in early identification although its efficiency may differ. However, the sooner the disorder is identified the more efficient preventive or adaptive methods can be applied. Early identification provides scientific ground for early development.
- The evaluation and types of trainability. In our contemporary world the question is not whether to integrate children with special needs into the regular school system, but rather how to. Integrated education is involved in the aims of schools’ teaching programme, however good practices need to be dispensed to implement inclusive education.
- Our priority is child care and child rare in family settings, so the main tasks of health and social services should be the support of family in their own surroundings.

1.2 Changing in family construction

1.2.1 Family, a support system

The family has a great influence on the development of children with or without disability alike.[104] [105] Family is a unit which collects and dispenses information. [106] Adaptation is basically defined on what principles this information is organized, how it is ranked, so the family plays a determining part in which the values of the children will identify themselves, what picture they will have on the world around them.[107] Besides deliberate intention of the family, these effects involuntarily filter and build into their personality, become their compass for the future in deciding what events of the world they will pay attention to, regard as important or disapprove.[108] The family is the source of identity, self-evaluation and self-image.[109] It performs as a special control function, its task is to give feedback and show direction concerning the family members' behaviour. Family members form opinion about the others' deeds, control and influence one and other. A further task of the family is to intensify the individual's emotional bearing capacity. It provides an appropriate basis to survive crises and cope with difficulties. Whether they will be constructive in problem solving or create further problems which he or she will not be able to control. It creates emotional balance, rehabilitation and a chance to respond to tensions coming from outside since the

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[104] HORVATH L. Reasons of admissions of children with handicap in long-term facilities – reasons of dropping out of families. In International Academic Conference, Health and Social Questions of Childhood in European Context II. Prevention of Health and Social Pathology. University of Debrecen Faculty of Health, 2007. Nyíregyháza. 89-98.p. ISBN 978 963 473 108 5

[105] BASS L. Szüljön másikat? Súlyosan-halmozottan fogyatékos gyermeket nevelő családok életkörülményei Magyarországon. In *Kapocs,* 2004/5.sz. 26-44.p. ISSN 1588-7227

[106] BARKER L. *The Social Work Dictionary*. National Association of Social Workes, 2003. Washington. ISBN 087101355X

[107] BÉRES CS. Halmozottan hátrányos helyzetben – fogyatékos gyeremekeket nevelő családok a társadalomban. In *Esély*, 1997/6. ISSN 0865-0810

[108] CSEPELI GY. *Szociálpszichológia. VII. A társas helyzetek.* Osiris Kiadó, 2002. Budapest. ISBN 963-379-563-X

[109] PÁLHEGYI F. A sérült gyermek családi helyzete. In Zászkaliczky P. (szerk.): „…Önmagában véve senki sem…" Tanulmányok a gyógypedagógiai pszichológia és határtudományainak köréből. ELTEBGGYFK, 2002. Budapest.

family's emotional acceptance is stronger, though it should not be extreme.[110] The family also supports family members and whenever a problem crops up it gives a hand.[111] Family members learn to listen to any ranking opinion supposing the underlying intention to help. We identify and evaluate ourselves in each other's reflection therefore the family provides referential points as well. Besides, it has legal and reproductive functions. These supportive functions will work efficiently if family members feel responsibility for the other members of the family, accept family control, lead an open communication and where relationships work by way of reciprocity. A further function of the family is to build and maintain a bridge between generations. If all conditions are fulfilled, the family is able to adapt and accommodate without giving up it distinctive features, characteristics.

Functions described by Caplan[112] still do not work properly. Even though the family as an organization changes from time to time in order to adapt to all circumstances coming from inside and outside, in case of disturbance it forms a united front. Families diverse, have their own distinctive features, rules and characters. Several factors like illness, unemployment, the arrival of a new born, the loss of a family member, divorce can disturb this delicate balance.

The structure of family developed in a fairly ambivalent way. Marriage and founding of a family were not based and did not depend exclusively on wealth, heritage and land property but also on the income of the head of the family. Besides traditional marriages, love marriages became accepted as well. By separating production and consumption family life became the scene of private life. The primary task of the head of the family was to earn a living and create financial security, whereas the wife stayed at home to preserve the harmony of home. The mother was the first to educate the child, at the same time the wife who actively participated in social life, represented the

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[110] MAGÓ O., HEGYHÁTI E., GYÖNGY A. Van segítség. Kézikönyv értelmileg sérült gyermekeket nevelő szülők számára. ÉFOÉSZ, 1992. Budapest.

[111] SCHWARZBACH B., WALTER U. *Mozgássérült gyermek a családban.* Medicina Kiadó, 1987. Budapest. ISBN 963-241-545-0

[112] Caplan G. The Family as a Support System. In Caplan, G. – Killiled, M.: Support System and Mutual Help, Grune and Stratton. 1976. New York.

cultural and economic level of the family. After World War Two a great number of women took up jobs which resulted in their financial and existential independency. The gradual advance towards equality between the two genders slowly transformed the structure of the family. The main problems of researches into sociology proved to be the terminology taken from the everyday usage. Concerning the family, the situation is almost the same since almost all of us were brought up in a family, spent several years in it, therefore formed a picture about it. The family is a small unit of the society, which can work as a separate structure by itself, though it keeps up tight relations of multiple directions with other structures of the society, in addition with members of the same family. From this viewpoint, that family is a group of people who are related by blood, and where grown-ups take the responsibility of reproduction and child care. Even this relation may undergo several changes like divorce, becoming lone parents, re-marriage, having a life-companion. The family undertakes tasks and functions partly for its own existence and partly for the society. Everything happening in the family reveals the system of relations inside the family and how it is embedded into the society, which determine the functions of the family.

Psychosocial function

One of the primary tasks of the family is to ensure a steady, mutual and mentally secured emotional system of relations and emotional network of relations. This function of the family is less and less likely to come to realization due to the weakening family cohesion.

Socializing function

The process when a biological being evolves into the member of society, a social being. The individuals acquire the knowledge, values, standards, behavioural rules, habits and traditions which enable them to live adequately in the society. During this process the family has a significant role. The first social impulses are given by the family and guiding values are formed here which later will determine the acts of the individual. Fostering for domestic life comprises values which are bound to the family and implemented in the family.[113]

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[113] TRINGER L. A család szerepe és a lelki egészség. In *Vigília,* 65 (8) 2000. ISSN 0042-6024

Spiritual and cultural function

It is the family which transfers and shapes cultural values, traditions, transmits up-to-date information (opinion forming, information process, information flow)

Caring-rearing function

The family is the most natural means for someone who is not self-efficient – still or any longer. The family is close to the family members in several meanings; both physically and mentally. The feudal family model fulfils the caring-rearing function. During the civic development several of these functions were taken over by the society, for instance kindergarten, elderly home. The reason for this is the change in dwelling, increasing employment of women and the transformation if family schedule.

Economic function

During the capitalism the production is no longer carried out in the family, although the consumption remains inside of it. This function is still changing rapidly.

Reproductive function

Child raring ensures the reproduction of the family itself. When a baby is born the family is accomplished, extra emotional charge becomes part of family life. Concerning the quantitative side, the reproductive task cannot be fulfilled. The number of children per family has been decreasing.

Function of public life and politics

The family is a unit which ties the individual into the society. The family plays an important role in becoming socially active, besides it can have an impact on how to form opinion about public and political activities.

Function of communication

The importance of communicative relations within the family is well known. Verbal and non-verbal communication can mobilize enormous forces in the family. The acquisition of mother tongue is a must for the child. Communication within family should be continuous. In absence of it needs are fulfilled too early and in absence of joint experiences communication will be restricted to topics stemming from the sharing the home. Experiences become more rich and colourful when not only one person of the family but someone else also passes through the same experience. Joint experiences have become restricted in number to a dangerous extent.

Emotional function

Emotional development of the child is basically ensured by the family. First of all, children need to have good connection with their environment so that their upbringing will become really efficient and successful. If adult family members can maintain good connection with children, they will trust us therefore we can encourage or restrict them thus ensuring the successful development of their personality. Nowadays the fulfilment of emotional needs is put in the highlight. People are social beings therefore they cannot exist on their own. For the fulfilment of this need the family proves to be the best micro-group. There exists a dominant and typically emotional relation between the members. Due to these relations the family is said to be ready to function. A warm, supportive and honest family relation may protect family members against tensions which are inseparable from their roles in the society. This function of the family, supposing it works effectively, creates emotional security, relaxation and harmony. The inner emotional power of the family and energy resources manifesting in it are able to filter all the threats coming from outside. Members of a good family belong to one another both physically and emotionally.

Being a family member the individual acquires problem solving strategies which are essential in the society. In almost every case there is solution to family conflicts and hopefully the family stays together. If no solution is applicable, the family might fall apart. Unfortunately nowadays this latter one is more likely to happen. Conflicts within the family do not conceal irresolvability. The basis of family cohesion is the ability to find solution. In acquiring conflict management children learn to tackle tension coming from outside. The lack of family can cause severe problems. However, having parents may not involve having a supportive family. It is still a question to be answered how could a person goes on living with all family connections broken. Even in the case of children's home, the family is regarded to be a basic union. Although cosy institutional environment is created for them which are suitable from every aspect, the family, specially their family cannot be substituted. Quite understandably, reunion with the family should be a prior task thus, before and while preparing for reunion the family connections of these children should be built or maintained. Concerning emotional development of children, family relations serve as a basis, therefore the aim to reunite always should be kept in mind.

1.2.2. The composition of households and changes in the number of children

The family, a founding stone of welfare societies, has gone through apparent transformation. Concerning the changes in family structure national and international tendencies seem to be congruent.[114] No one would ever deny that destabilization of traditional family structure lies behind demographic changes. In the member states of the European Union the number of marriages has decreased, whereas the number of divorces has increased since the beginning of the 90's. As a result of destabilization the number of birth has also decreased. As a matter of fact several other factors influence the number of children in a family; even changes in the labour market correlates with the decreasing child birth, since if employees are single, unmarried and have no children, the employer regards them as ideal labour force. There seems to be an obvious contradiction, which gains significance especially in the view of our topic.The number of married couples has decreased in Hungary, too. The decrease has been going on since the 80's although it started a bit later than in Western-Europe, as we called it then. On the other hand, the number of single parents has risen as well as that of other households. Other type of household involves being a widow or a widower or living with a life-partner. Concluded, the number of big families is on the decrease, furthermore less and less young people are planning to get married. In line with it the number of single persons is on the increase, less children are born and the age of parents at the time of birth increases.In line with the decreasing number of marriages the rate of live birth has decreased in Hungary and in the enlarged European Union. In EU-25 and EU-15 countries the decreasing tendency began at the beginning of the 60's, whereas in the new member states the same period shows rising tendency, the decrease started 10-20 years later, in the late 70's. As for fertility rate, there is a decreasing tendency in all European countries. The OECD average is slightly more than 1.6 child per family and permanently decreasing.

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[114] FÁBIÁN G. Őszülő társadalmak. In *Imre Sándor-Fábián Gergely (szerk.): Őszülő társadalmak.* DE-EFK, 2006. Nyíregyháza. ISBN 963-473-003-5

Table 6

Live birth in Hungary

Year	Live birth		
	Number	Thousand	
		inhabitants	15–49 women
1980	148 673	13.9	57.6
1990	125 679	12.1	49.4
2000	97 597	9.6	38.1
2001	97 047	9.5	38.1
2002	96 804	9.5	38.3
2003	94 647	9.3	378
2004	95 137	9.4	38.4
2005	97 496	9.7	39.8
2006	99 871	9.6	41.1
2007	97 613	9.7	40.5

Source: *Health Statistical Year Book* KSH, Budapest 2008

In Hungary, even the starting point is lower and then it sharply decreases, while in other countries, although the starting point is higher it decreases as sharply as in Hungary. We can say that significant change occurs in the 90’s. It seems that the desire to give birth to children has declined, furthermore the households children are born into are diverse: starting from the complete two-parent family, lone parent family to family composed of life-partners.

Table 7

Population 0-29 age 1960-2009. / 01. January/ thousand person

Year	0-14 age	15-29 age
1960	2529	2155
1970	2177	2437
1980	2341	2356
1990	2131	2066
2000	1729	2278
2007	1530	2074
2008	1509	2030
2009	1493	1987

Forrás: Szociális statisztikai évkönyv. KSH-SZMM, 2009. Budapest.

Concluded, we can tell about the families that the desire to have children has decreased, children are born into families of different structure: full family, single parent family and family of other type.

2. Aims and hypotheses

2.1. Aim of the research

- To establish whether health and social care for children with disability are provided within the family or in the institution.
- To establish what methods are needed to involve families as active partners in the services of health and social care.
- To work out a post-qualifying training programme, on the basis of the outcome of our research, for social and health professionals working with disabled children and their families.

In order to reach these aims I have clustered this writing around the following hypotheses

2.2. Hypotheses

1. There exist several international statements which aim to strengthen the relationship between the disabled children and their families.
2. The relationship between the disabled children and their families can be reinforced by providing social and health services.
3. The birth of a disabled child into a family has nothing to do with the level of education of the parents.
4. Families with disabled children are more likely to have more children, compared to the whole population.
5. Making diagnose of disability or disorder and uncovering any relevant damages seem to be delayed and seems incongruous in this modern scientific world.
6. National services created according to the law prove to be insufficient to fulfil all the needs of disabled children.
7. Families with disabled children are overburdened compared to other groups of the population.
8. Parents caring for their disabled children in family settings would not place them in a residential home even if their background went from bad to worse.
9. The geographical distance between the disabled children living in a residential home, and their parents' place of residence is larger than it is suggested in the normalization

3. Research methods

I have done quantitative research to reach the aims of this research work. We have compiled a questionnaire (vs. 10.1) divided into six main parts containing 34 questions in all. The six main parts cover the areas of:

- personal particulars of the respondent,
- the household of the respondent,
- the child with disability,
- the applied for and/or allocated services,
- spare time habits
- expectations for the future.

We tried to compile the questions in a varied form, they contained two-choice questions to be underlined which referred to the gender for instance, for some of the questions numerical answers could be given concerning the age of the respondent and the child, and the number of children with disability in the family. Multiple-choice questions were applied for more complicated questions. This version seemed to be user friendly for the respondents while made SPSS processing easier. Before compiling the questionnaire a pre-survey was carried out to see what alternatives the final version would contain. It was combined with the application of a table in question 24. Furthermore, the questionnaire contained an open question to provide the possibility for personal opinion in a longer form. As a matter of fact quite many types of answer were given therefore they were arranged in groups relevant to the topic of this research work. Those which proved to be irrelevant like thanking words or personal remarks were not evaluated. Attached to the questionnaire the parents could find a letter addressed to them with the unhidden intention to persuade them to cooperate with us, give answers to the questions and send back the questionnaires.

We needed to be prepared for some special methodological cases since the questionnaire were sent to parents raring children with disabilities either in family setting or in long-term placement. It seemed to be obvious from the very beginning that answers to fairly personal and confidential questions would be difficult to obtain. Therefore, we acted circumspectly in selecting the interrogators and dispensing the questionnaires. We managed to rely on professionals of the social sphere, health care and educational institutions who had been in contact with these families through some service. Their personal credence and the trust of respondents were essential to get valuable answers. We made it possible for the respondents to answer the questions on their own, while in other cases the professionals filled them in with the parents in present. In several cases I was also there, which could help me to experience the parents' difficult as well as the significance of the reply.

Composition of the sample

The questonnaires were filled in in 2009, and compiled for parents. We contacted parents whose children have disability. Parents were contacted via social, educational, and health institutions. Those who volunteered for questioning, are included in the sample. There were no restrictions about the age of parents and children. Respondents were chosen from 36 locations of Hungary. In terms of size I tried to include every kind of settlement, the smallest with a few hundred, the largest with millions of people. Institutions included health, social, and educational institutions. Disabled children got several types of attendance in these institutions.

As a first step the questionnaires underwent a quantitative totalling with SPSS data processor. That cross-tables were selected to either justify or contradict our hypotheses. The analysis done to them will be presented in chapter four. All the conclusions we reached through the analysis and can be applicable in practice will be included in the next chapter. The analysis of literature is an important part of the research. Many studies, books, and international documents were published about the topic of disability. My aspect of literature review was to show the development of the attitude from the middle of the twentieth century. This method helps to prove the contents of the first hypothesis.

4. Results

The first area of questions enquired about the personal particulars of the respondent, which could help to draw a picture of their family and social background and system of relationship. Within this area there were questions about their local environment and place of living. The very first question asked about gender.

Table 8

Sex of respondents

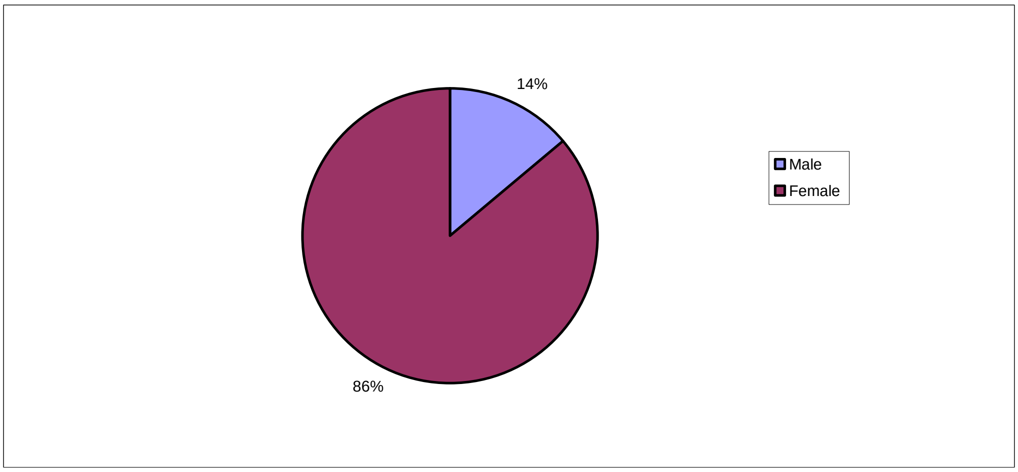
Sex of respondents	Number	Percentage
Male	47	13.9
Female	292	86.1
Total	339	100.0

Source: Own questionnaire

The respondents belonged to both sexes although female respondents were more prevalent with 86.1% that is 292 female respondents. The prevalence of male respondents was 47 that is 13.9%. The total number of elements here and during the research work was 339.

Fig. 1

Sex of respondents



The next question asked about the date of birth in a form of open question. During data process these data were grouped by approximately ten-year intervals thus the data store became well arranged. We inserted an extra column into Table 9 which shows the mean age of the age groups. So it was easy to survey the life-table of the respondents.

Table 9

Life-table of the respondents

Date of birth	Mean age	Number of people	Percentage
1981-1986	25	3	0.9
1971-1980	35	96	28.2
1961-1970	45	129	38.1
1951-1960	55	66	19.5
1941-1950	65	37	10.9
1931-1940	75	7	2.1
1929-1930	80	1	0.3
Total	-	339	100.0

Source: Own questionnaire

The age of respondents was not totalled since it had no significance. However, data showing the age of parents on an age scale is important and actually ranged from 25 to 80 years of age.

Fig. 2

Life of the respondents

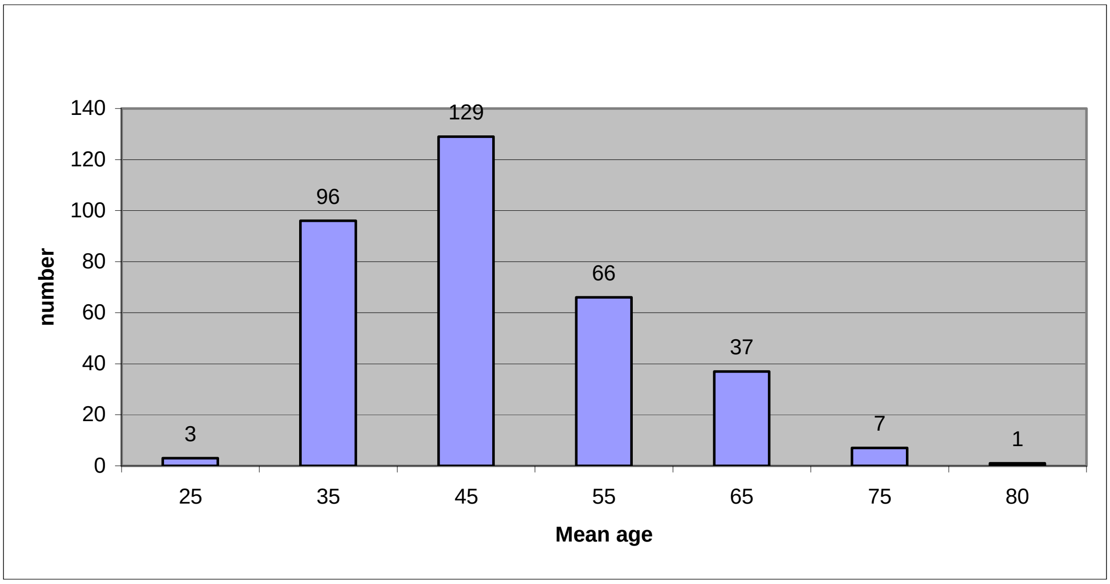


Table 9 shows that the 35-65 age group was presented in the largest number as it had been supposed to be at the beginning of the research work. Only 3 respondents were younger and 8 of them were older than that. 45 years of age could be regarded as the most prevalent age of the respondents with a rate of 38.1% of the whole. Another main group of respondents belonged to the 35 age group with 96 respondents which were 28.2% of the whole. Even the 55 age group was presented in a great number, 66, which was 19.5% of the respondents. The 65 age group was presented with 37 respondents, 10.9 % of the whole. The oldest respondent at the time of inquiry was 80 years old, 0.3% of the whole.

The next question asked about the respondents' marital status.

Table 10

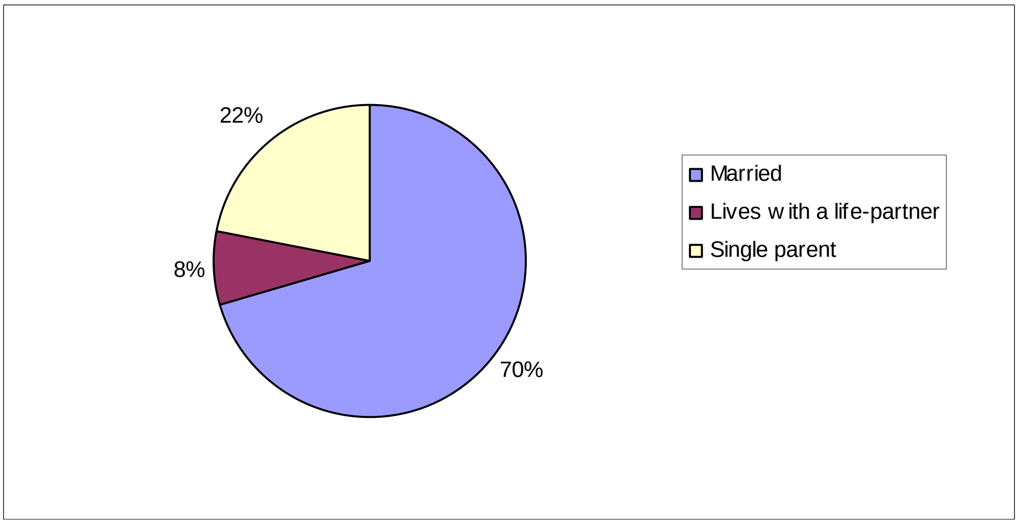
Marital status of the respondents

Marital status	Number of respondents	percentage
Married	239	70.5
Lives with a life-partner	26	7.7
Single parent	74	21.8
Total	339	100.0

Source: Own questionnaire

Fig. 3

Marital status of the respondents



An important data store of our questionnaire refers to families with disabled children. Response-giving was helped with multiple choice questions. Despite the wide range of family structures, families of lone parent or with more generations or life partner, we asked about three categories: the respondent lives with a life-partner, or is married, or is a lone parent. As a matter of fact other relatives could be around the children with disability but these relations were not relevant to our topic. As we can see 70,5 % of disabled children lived in a full family with a married couple.

The question about the highest level of school completed needed to be answered with a multiple-choice version. The wide range of possible types and levels of schooling was divided into five groups through which we could measure the number of school grades completed by the respondents. Table 11 shows how varied schools the respondents attended or/and completed.

Table 11

The highest level of school completed

The highest level of school completed	Number of respondents	Percentage
1-7 grades of elementary school	11	3.3
8th grade of elementary school	72	21.2
Vocational school	95	28.0
General certificate of secondary school	116	34.2
College or university diploma	45	13.3
Total	339	100.0

Source: Own questionnaire

The most prevalent answer to the question was the possession of general certificate of secondary school with a prevalence of 34.2 %, every third parent. The second most populous group, with a prevalence of 95 respondents and 28%, finished vocational school. Quite a large number of respondents, 72 that was 21.2%, finished the 8th grade of elementary school. A smaller scale of the respondents, 45 that was 13.3%, graduated from an institution of higher education, this rate correlates with the prevalence of graduated people in the whole population. The rate of those who did not finish elementary school was 3.3%, 11 respondents.

We raised a question on the number of children.

Table 12

Number of children

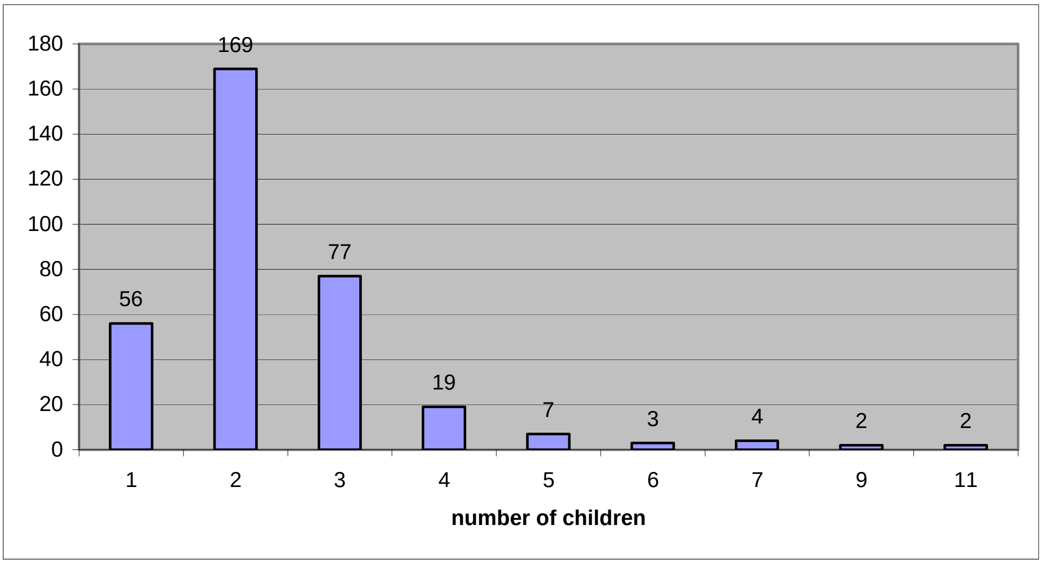
Number of children	Number of respondents	Percentage
1	56	16.5
2	169	49.8
3	77	22.7
4	19	5.6
5	7	2.1
6	3	0.9
7	4	1.2
9	2	0.6
11	2	0.6
Total	339	100.0

Source: Own questionnaire

The Table shows that most of the respondents had two children which was valid for 169 respondents with a prevalence of 49.8%.

Fig. 4

Number of children



Respondents belonging to the second most populous group had 3 children which was valid for 77 respondents with a prevalence of 22.7%. 56 respondents, 16.5%, had only one child. Some 19 respondents, 5.6%, had four children, while 7 of them, 2.1%, had 5 children. In four cases we could reach families with 7 children, 1.2 % of the whole and two-two families had 9 and 11 children with a prevalence of 0.6%-0.6%.

Caring for disabled children put a heavy emotional and financial burden on the family. Regarding the parents' chance to be able to provide a safe home it is essential for them to be employed and their work conditions are essential.

Table 13

Employment of the respondents

Employment	Number of respondents	Percentage
More than 36 hours a week	105	31.0
Short and occasional	33	9.7
Unemployed	22	6.5
Child care allowance	114	33.6
Pensioner	65	19.2
Total	339	100.0

Source: Own questionnaire

Table 13 shows that from the point of view of being employed, parents caring for disabled children basically belonged to two types. Most of the parents got child care allowances, the prevalence of them was 33.6%, 114 respondents. Similarly large was the number of those who were employed full time, over 36 hours a week, the prevalence of them was 31.0% with 105 respondents. Retired people belonged to the third group with a prevalence of 19.2%, 65 respondents. 33 respondents, 9.7% of the whole, had short or occasional jobs. 22 respondents, 6.5% of the whole declared themselves unemployed.

For families which care for disabled children the distance between their home and place of work proves to be an important factor. Not only does the distance but also the time spent on travelling matters.

Table 14

The distance between the parents' place of work and the place of living

Distance	Number of respondents	Percentage
Work at/from home	23	6.8
0-5 km	84	24.8
6-15 km	49	14.4
16-25 km	16	4.7
26-50 km	3	0.9
More than100 km	2	0.6
Does not work	162	47.8
Total	339	100.0

Source: Own questionnaire

This table shows that 47.8% of the parents, parents of every second child, do not work. Concerning the distance we got different answers. Most of the respondents' place of work was within 5 km which could be great if it was the parent's choice and met their expectations. The third most populous group with a prevalence of 14.4%, 49 of the respondents had workplaces within 6-15 km. The rate of respondents 6.8% working at home or from home was quite significant while 16 respondents, 4.7% had to travel 16-25 km to get to work. Three of the respondents go to work within the distance of 26-50 with a prevalence of 0.9%. With the questionnaire we could reach two respondents whose place of work was in a great distance, more than 100 km which counted for 0.6% of the whole. The next Table shows the size of the settlement where the respondents live.

Table 15

The size of the settlements where the respondents live

Size of the settlement	Number of respondents	percentage
Less than 2000 inhabitants	44	13.0
Inhabitants between 2001-5000	62	18.3
Inhabitants between 5001-10000	52	15.3
Inhabitants between 10001-50000	79	23.3
More than 50000	102	30.1
Total	339	100.0

Source: Own questionnaire

When compiling the categories of different settlements, groups were formed to cover all size of settlements typical to Hungary. Therefore special attention was devoted to the so called small settlements and as we can see 44 respondents were from places with a population less than 2000. Other settlements of much bigger population were also involved and counted for much. Most of the respondents, 102, lived in settlements where the number of inhabitants was over 50000 with a prevalence of 30.1%. 79 of the respondents lived in settlements where the population was between 10 001-50 000 their prevalence was 23.3%. In small settlements some 62 respondents lived with a prevalence of 18.3% while the rate of those who lived in middle-sized settlements was 15.3%, 52 of the whole respondents.

The next set of questions referred to the household of the respondents. We were interested in the number of family members living in the same household, as well as their dwelling circumstances.

Table 16

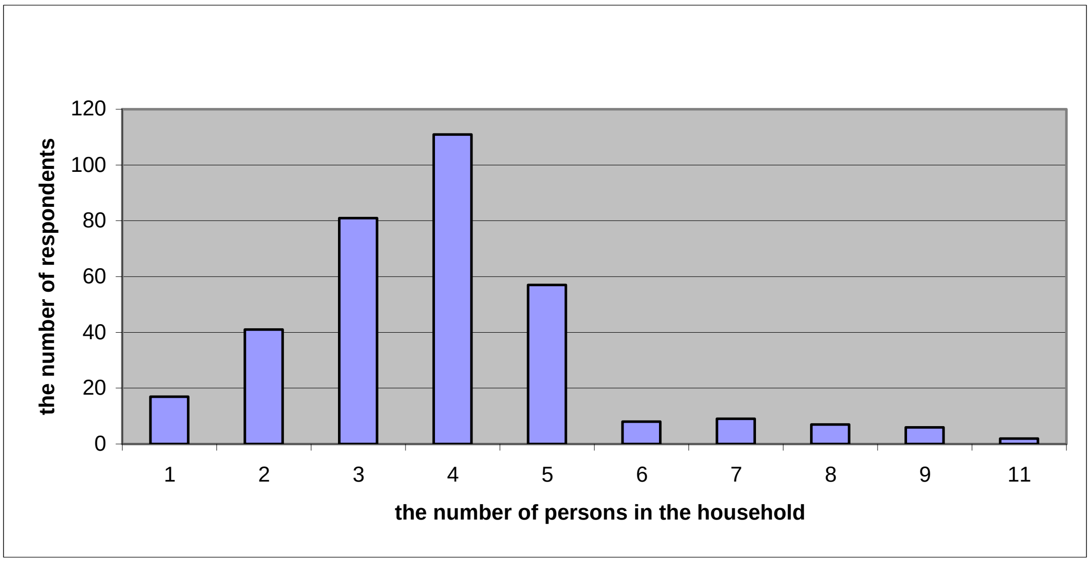
The number of persons living in the same household

The number of persons in the household	The number of respondents	percentage
1	17	5.0
2	41	12.1
3	81	23.9
4	111	32.7
5	57	16.8
6	8	2.4
7	9	2.6
8	7	2.1
9	6	1.8
11	2	0.6
Total	339	100.0

Source: Own questionnaire

Fig. 5

The number of persons living in the same household



The most prevalent number of persons living in the same household was 4 with 32.7% of the respondents. This rate shows that a significant part of children with disability lives in families which can be considered larger than average Hungarian families. There were a large number of households with 2 or 3 persons, with a prevalence of 36.0%. Whenever the circumstances of families with disabled children are evaluated the number of persons living together must be taken into consideration. The difference between a household with 2 or 3 persons might not seem too big but for a child with disability it might have consequences. Besides parents, the grandparents also live in some of the households. We got in touch with two really large families of 11 members furthermore we found 7 families with 8 members and 6 families with 9 members.

Table 17

The number of children younger than 18

Number of children younger than 18	Number of respondents	Percentage
0	113	33.3
1	85	25.1
2	90	26.5
3	39	11.5
4	2	0.6
5	3	0.9
6	7	2.1
Total	339	100.0

Source: Own questionnaire

Table 17 shows the internal structure of the households as we searched for the number of children younger than 18 years of age. The major share of numbers came from families where the number of children with disability was between 0 and 3. For the first sight the 113 respondents, parents of technically no children at all might seem astonishing, but they were the ones who lived in long-term facilities. The most prevalent numbers were between 1 and 3 involving 63.1% of the families. These figures confirm the data of Table 16 that large families were also included in this survey. Table 17 shows that in seven families the number of children under 18 years of age was 6, born in short intervals.

The families' standard of living is reflected in the size of their home. Therefore the next question asked about the number of rooms of the respondents' home from which we can arrive at further conclusion.

Table 18

The number of rooms

Number of rooms	Number of respondents	Percentage
1	8	2.3
2	136	40.1
3	142	41.9
4	29	8.6
5	18	5.3
6	3	0.9
7	2	0.6
8	1	0.3
Total	339	100.0

Source: Own questionnaire

The figures of Table 18 are quite different concerning the number of rooms, starting from 1 to as many as 8. We cannot draw a parallel between the number of rooms and the living of standard. Firstly, the number of rooms does not correlate with the quality of the flat or house. In some cases the interrogation took place in houses with many rooms which were in quite poor condition. The figures of Table 18 show that the prevalence of families living in houses or flats with 2 or 3 rooms was about 82.0%, 278 persons out of the 339 respondents. A further examination might follow this one in order to find out the quality and market value of these flats or houses. These details were not involved in this research work.

The next set of questions asked about disabled children in the family which is related to the main topic of the thesis. The very first question was about the number of them.

Table 19

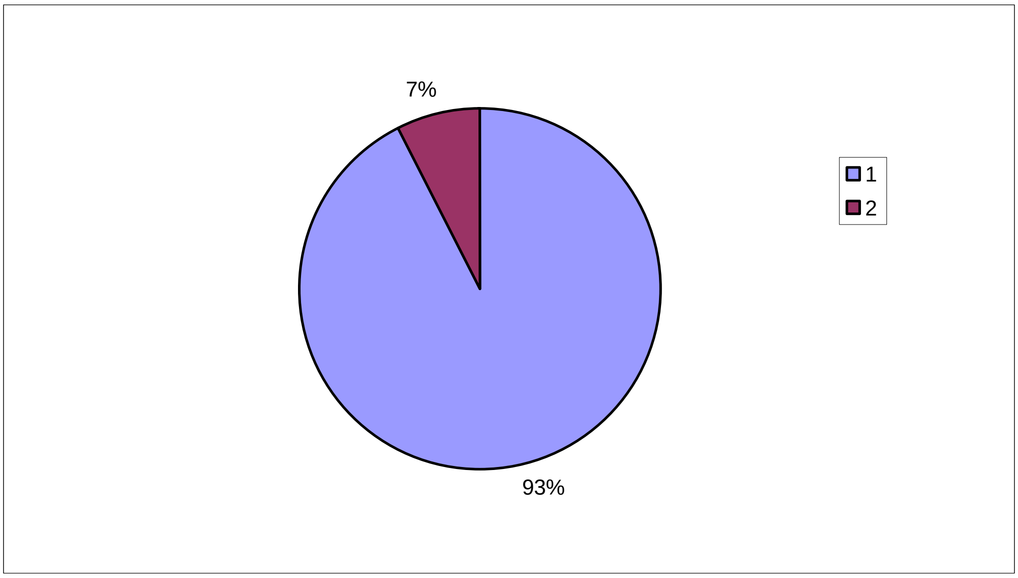
The number of disabled children per family

Number of disabled children	Number of respondents	Percentage
1	314	92.6
2	25	7.4
Total	339	100.0

Source: Own questionnaire

Fig. 6

The number of disabled children per family



Answers to the former question showed that the number of persons living in the same household was between 1 and 11. Therefore the basis of comparison is the number of children then the rate of disabled children. Table 19 clearly shows that the prevalence of families with one disabled children was 92.6%. In 7.4% of the families we found two children with disability which was a quarter of the whole.

The present age of disabled children serves as a basis to make some conclusions.

Table 20

Present age of the disabled children

Age	Number of respondents	Percentage
0-5	15	4.4
6-14	162	47.8
15-24	92	27.1
25-34	41	12.1
35-43	25	7.4
45-50	3	0.9
59	1	0.3
Total	339	100.0

Source: Own questionnaire

The age of the disabled children are given in full numbers. Some respondents had children younger than 1 year of age, but they were rounded off to 1 year old. We defined different age groups and from the viewpoint of our topic the 0-24 age group was the most important one, which was divided into three further sub-groups. The sub-group of 0-5 when early identification and development can be applied, the sub-group of 6-14 where special education is expected to apply then the 15-24 age-group when career may be started. As a matter of fact the age group of 25-59 was also presented in the table, although their rate was not significant. Those who belong to the 0-24 age group, 269 children in this survey, can be considered as children, and their prevalence was 79.3%. The rate of the 25-34 age group was 12.1% with 41 persons. According to the respondents the oldest 'child' with disability was reported to be 59 years old. This data correlates with the data of Table 9 which shows the age of the parents with a 80 years old parents. As it can be seen from Table 20 the majority of respondents were the parents of the 6-14 age-group. This fact is of great importance since the children's chance for schools and social integration can settle the outcome. The prevalence of parents of this age group was 47.8%.

Table 21

The nature of disability

The nature of disability	Number of respondents	Percentage
Blindness	50	14.7
Weak of hearing	34	10.0
Limitation of motion	125	36.9
Mental disability	224	66.1
Lack of communication /autistic child/	61	18.0
Total	494	145.7

Source: Own questionnaire

The definition of disability both in the international and national professional literature is a much debated question. During our survey we relied on the parents' judgement which was not necessarily consistent with the medical diagnosis. All together 494 disabilities were listed by the parents though only 339 respondents were presented, which indicates that some children live with multiple disabilities. That is the reason for the 145.7% rate. Among the population the most frequent disability is the limitation of motion, although this survey shows it as the second most frequent one. The prevalence of mental disability was higher among these children than among the whole population. As we can see 224 children were reported as mentally disabled. Other types of disability were also reported; 50 cases were reported as blind, 34 as deaf. Autism was also mentioned as a disability and respondents reported about 61 cases. So far autism has not been in the centre of surveys, although nowadays a growing number of studies are published on the issue.

In our questionnaire there was a question about the person who first diagnosed the child with some type of disability. This answer was also given exclusively by the parents and no official or medical document was asked from them.

Table 22

The person who first diagnosed the disability of the child

Diagnosis	Number of respondents	Percentage
Doctor before birth	10	2.9
Doctor right after birth	53	15.6
A committee after birth	189	55.8
Other, exactly	87	25.7
Total	339	100.0

Source[115]: Own questionnaire

Making diagnosis of disability proves to be a difficult task. In order to identify it different professional fields are involved like genetics, gynaecology, obstetrics then later committees of specialists make decision on it.

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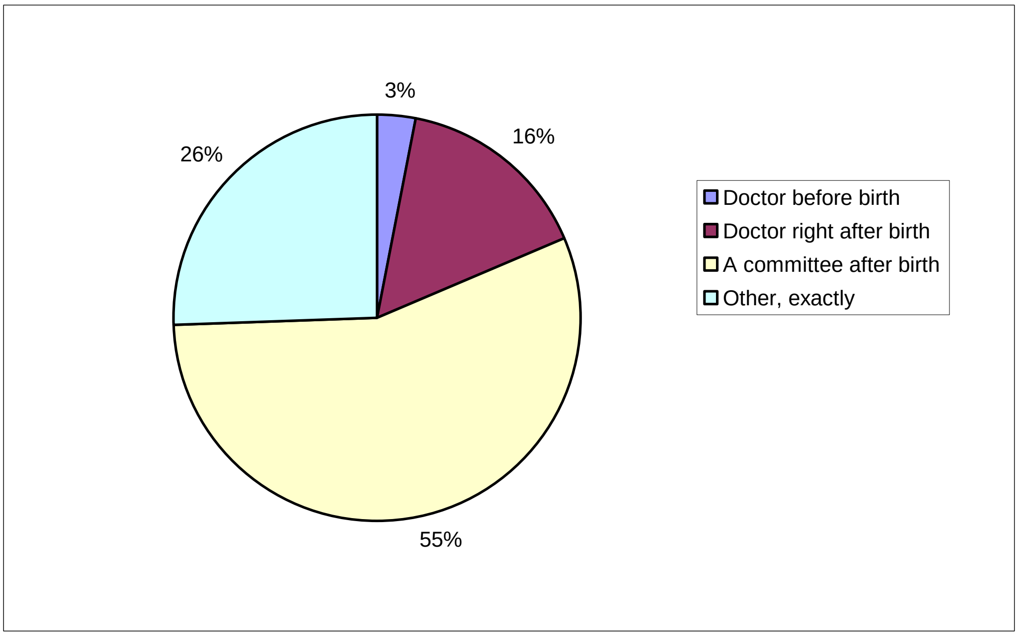
[115] HORVÁTH L. Fogyatékos gyermekek korai felismerése. In *20 éves a Debreceni Egyetem Egészségügyi Kara.* Debreceni Egyetem Egészségügyi Kar, Tervezett megjelenés 2010. Nyíregyháza.

Fig. 7

The person who first diagnosed the disability of the child



Some 252 cases, 74.3% indicated that a committee identified the nature of disability. The inner rate of this table seems to be surprising since only 2.9% of the respondents reported diagnosis of disability before birth. The modern science could identify more cases at an earlier stage and hopefully surveys which carried out after decades will prove this presumption. 25.7% of the respondents reported the lack of diagnosis by specialists which actually means that someone else, neighbours, relatives noticed it and called the parents' attention to the problem.

When identifying disability the age of the child is really important.

Table 23

The age of child when disability was diagnosed

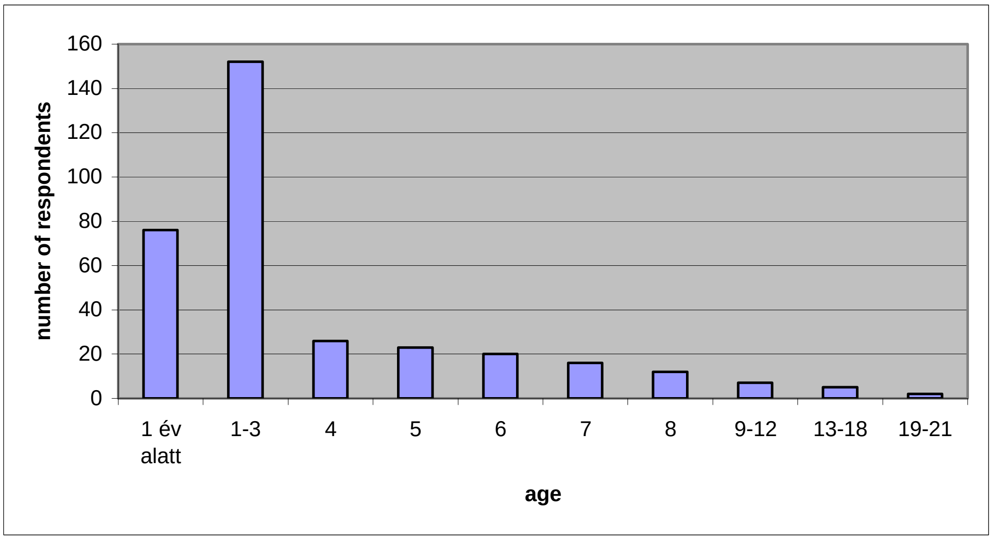
Age	Number of respondents	Percentage
Younger than 1 year old	76	22.4
1-3	152	44.8
4	26	7.7
5	23	6.8
6	20	5.9
7	16	4.7
8	12	3.5
9-12	7	2.1
13-18	5	1.5
19-21	2	0.6
Total	339	100.0

Source[116]: Own questionnaire

The answers to this question were given in years, in the case of fractured number we rounded them off and major age groups were used for children above 9 years of age.

Fig. 8

The age of child when disability was diagnosed



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[116] HORVÁTH L. Fogyatékos gyermekek korai felismerése. In *20 éves a Debreceni Egyetem Egészségügyi Kara.* Debreceni Egyetem Egészségügyi Kar, Tervezett megjelenés 2010. Nyíregyháza.

Concerning children from 0 to 8 years old, every year is of great importance so we did not reduce them into major age group. The prevalence of those under one year old was 22.4%, 76 children. At this age the priority is to fulfil different nursing and health care needs. If children 0 to 3 years old formed a major age group, 67.2% of them would belong to this group. It is essential since early identification ideally takes place at this stage. Some types of disability can be identified much earlier, while late identification can hinder early development of the child. According to the official documents early identification is performed and development starts when the child is around 5 years old. This statement was true for 81.7% of the respondents however, 18.3% of them were neglected; no early identification, no chance for early development. Hopefully a similar survey done in a few years' time will find similar cases of children younger than 6 years old since the aim of the contemporary social, health and educational services is to ensure early identification and early development. At the moment, as the Table 23 shows, the diagnosis of disability or disorder was performed at the age of six in 20 cases, in 16 cases at the age of seven and in 12 cases as late as at the age of eight. With the questionnaires we reached families where the diagnosis of disability was performed when the child was somewhere between 9-21 years of age. The prevalence of it was 2.1% with 14 respondents. The next question asked about primary services allocated to the family or the child.

Table 24

The services reached by the respondents

Name of the service	Number of respondents	percentage
Regular monthly payment in cash	128	37.8
Payment in kind	185	54.6
Village or farm caretaker service	5	1.5
Meal provision	67	19.8
Home service	11	3.2
Family support	29	8.6
Signalling system for home care	1	0.3
Supporting service	72	21.2
Day care	35	10.3
Placement in long-term facility	68	20.1
Child welfare primary care	8	2.4

Source: Own questionnaire

Table 24 contains the services which are accessible for disabled people and their families in Hungary. As we can see the two most frequently used services were the payment in kind in 185 cases with a prevalence of 54.6% and regular monthly payment in cash in 128 cases with a prevalence of 37.8%. 72 children got supporting service with a prevalence of 21.2%, which contains services provided within the family. As it was mentioned before 68 children lived in residential homes their prevalence was 20.1%. Quite a similar rate, 19.8%, was getting meal provision, all together 67 children. An important service is the day care since it makes possible for the children to spend the nights and weekends with the families. This kind of service was provided for 35 children, which was 10.3% of the whole.

Table 25

Problem solving potentials the services

The merit of solution	Number of respondents	Percentage
Absolutely	35	10.3
Partly	216	63.7
Not at all	88	26.0
Total	339	100.0

Source: Own questionnaire

The parents reported to be far from the solution and only a minority, 10.3%, reported that the solution to their problem was brought to them by the services. Among the respondents 216 reported that they were partly satisfied with the service, although these services could not fully solve their problems but at least they eased them. 63.7 % of the respondents wished to have more types of services. 89.7%, of respondents wanted to have further services.

A deeper answer can be found in the next part of the questionnaire with a direct question about the necessity of new services.

Table 26

Other necessary services

Other services	Number of respondents	Percentage
Allowances in cash	206	60.8
Allowances in kind	63	18.6
New services	70	20.6
Total	339	100.0

Source: Own questionnaire

As it can be seen from Table 26 most of the respondents, 60.8%, wanted to have allowances in cash. Some 70 persons expressed the necessity of new services, and this need can be understood fully after comparing it with question 34 since any possible new services are related to this question. The rest of the questionnaire deals with spare time and the way of spending it usefully.

Table 27

Number of hours the disabled child spent at home

Average of daily hours	Number of respondents	Percentage
0	85	25.0
1-15	21	6.2
16-20	186	54.9
21-24	47	13.9
Total	339	100.0

Source: Own questionnaire

The data store of this table is fairly varied. Children spending no time in the household are likely to live in long-term facilities, 68 children in Table 24, in addition 17 children with relatives, basically grandparents. The prevalence of them was 25.0%. Other children spent more or less time in the household, 54.9% of them were at home almost all day long that is 16-20 hours. They are likely to spend the rest of the day in an educational institution like crèche, kindergarten or school. The expectation of the normalization principle from the aspect of time be spend in an educational institution is met at this point. There are some services which accept children in a residential home during the week but they go home for the weekend. This form of placement also meets the requirements of the normalization principle. However, the case of children who spent 21-24 hours in the household of their parents implicates that hardly any services are provided for them, they are more likely to lack in peer relations. Table 27 shows that children with disability spent 1-15 hours together with the parents in 21 cases with a prevalence of 6.2% of the whole.

Table 28

Number of hours the child spent in creche, kindergarten or school

Hours	Number of respondents	Percentage
0	144	42.4
1-8	186	54.9
9-24	9	2.7
Total	339	100.0

Source: Own questionnaire

On the basis of Table 20, 70 children can be ruled out from this question, in contrast with it 138 children were reported to have no possibility to go to crèche, kindergarten or school. Practically it implicates that children with disability are ousted from these educational institutions. The picture was more favourable for 186 children who were reported to spend 1-8 hours in an educational institution. The minimum duration was one hour which would be worth examining to find out how efficient one hour could be. In all probability the 9-24 hours a week involved residential home.

Table 29

The number of days spent on travelling, holiday last year

Number of days	Number of respondents	Percentage
0	259	76.4
1-6	39	11.5
7-14	39	11.5
More than15	2	0.6
Total	339	100.0

Source: Own questionnaire

The figures of this Table show that 259 respondents with a prevalence of 76.4% did not spend a single day having a holiday. A holiday of shorter than one week was spent by 39 respondents, 11.5%. The rate for those who spent a 7-14-day-holiday was about the same while the rate of those who went on holiday for more the two weeks was only 0.6% of the respondents.

Table 30

The number of days spent on travelling and holiday in abroad

Number of days	Humber of respondents	Percentage
0	330	97.3
1-6	2	0.6
7-14	5	1.5
More than 15	2	0.6
Total	339	100.0

Source: Own questionnaire

The figures of Table 30 were quite similar to that of Table 29. Not a single day of holiday was spent abroad in 330 cases which was 97.3% of the whole. Respondents spent their 7-14-day-long holiday abroad with a prevalence of 1.5%. Two respondents reported on a shorter than one-week holiday and two respondents were reported on a longer than two-week holiday, their prevalence was 0.6% in both cases.

A similar question is asked within the same set of questions.

Table 31

The number of days spent on caring for the disabled child.

Number of days	Number of respondents	Percentage
0	130	38.3
1-10	4	1.2
11-299	60	17.7
300-364	26	7.7
365	119	35.1
Total	339	100.0

Source: Own questionnaire

It seems as if we saw the reflection of the former question. The prevalence of parents spending 365 days caring for their disabled children was 35.1%, 119 respondents. Practically it means that not a single day left for the parents to spend it by themselves. These answers also contributed to prove the seventh hypotheses. Among the 130 respondents whose answer was 0 are the parents whose children were in long-term facilities. Extremities can be seen in

Table 31 with 106 respondents spending no time with their children, whereas 120 respondents spent 365 days caring for the disabled child. We presume a kind of a normal case would be in a midway house between them, and the mean value was presented by only 60 parents with 11-299 days of caring. Among the reasons for extremities we can mention the rigid borderline between the accessible services, although a way of transition could protect both parties' interest. The table shows that there were 60 respondents between the two most extreme figures, 17.7% of the whole, who spent 11-299 days on caring for their children. 26 respondents a prevalence of 7.7% undertook more days that was between 300-364.

Table 32

The number of nights the disabled child spent away from home, in a camp for example.

Number of nights	Number of respondents	percentage
0	291	85.8
1-6	25	7.7
7-15	23	6.8
Total	339	100.0

Source: Own questionnaire

We would like to highlight the questions from the viewpoint of the disabled children. However, the statements will be very similar. As it can be seen from Table 31 the prevalence of children who were not in a camp was 85.8%, 291 persons. From this high number we can conclude that not only children who lived at home but also those who lived in long-term facilities had no possibility to go to a camp. Some 14.2% of disabled children were in a camp of some kind. Considering the fact that the term 'be in a camp' involves 1-day and 2-day long camps as well, this rate is really low. The rate of those who managed to go to a one-week camp was 6.8%.

Table 33

The number of nights spent away from home at relatives.

Number of nights	Number of respondents	Percentage
0	274	80.8
1-6	26	7.7
7-15	29	8.6
16-50	10	2.9
Total	339	100.0

Source: Own questionnaire

As a matter of fact going to the relatives for a couple of days is also a kind of change of scenery. It seems to be an achievable goal, though social integration and family support are still not up to the mark. Practically it means that the prevalence of children who did not spend a single night away from their home was 80.8%. Regarding the fact that the questionnaire recorded ‘children’ older than 18, the number of 274 children not spending a single night away from home seems depressing. The prevalence of children spending at least one week at the relatives was slightly higher, 11.5%, than that of spending days in a camp. The normalization principle requires a higher rate, although this rate was higher than the rate of the days spent in a camp. The Table also shows that children of 10 respondents spent 16-50 night away from the parents at relatives which was 2.9% of the whole.

Table 34

Frequency of family-child meeting

Last saw	Number of respondents	Percentage
With the parents right now	257	75.8
A day ago	28	8.3
A week ago	27	8.0
A month ago	13	3.8
A year ago	1	0.3
Others	13	3.8
Total	339	100.0

Source: Own questionnaire

Table 34 shows a data store of great diversity. The most prevalent answer to this question was that the disabled children were actually with the parents at the time of the interrogation either it took place in the institution or in the home of the respondents. It happened in 257 cases which was 75.8% of the whole. The rate of respondents who last saw their children within a day was 8.3%, with 28 respondents. 27 respondents, 8.0%, saw them the child a week. Quite a large number of respondents, 3.8%, saw the child within a month. There was one parent who had not seen the child for a month. The last four questions were asked to summarize some opinion.

Table 35

The respondents would find a place for the disabled child at a long-term facility, if his/her condition were getting worse.

Answer	Number of respondents	Percentage
Yes	14	4.2
No	234	69.0
Would think about it	11	3.2
Does not know	12	3.5
The child is in residential home	68	20.1
Total	339	100.0

Source: Own questionnaire

This question was posed to make the parents collect their mind what to do if the child's condition were getting worse. This question was relevant to the 271 respondents who cared for their children in their own home. The prevalence of rejection was 69.0%, thus 234 parents did not intend to change the situation even if the circumstance were worse. That is where we found the proof to our hypothesis. On the other hand the prevalence of parents answering with 'yes' was 4.2%, answers arrived measurably from those who were old enough to realize that their own death could turn the course of events. Uncertainty was presented in some of the answers: 11 respondents would think about it, 12 respondents did not know the answer.

Our next question aimed the parents of disabled children living in a long-term facility.

Table 36

The respondent would take the disabled child back into their household

Answer	Number of respondents	Percentage
Yes	12	3.6
No	38	11.2
With some help	18	5.3
The child lives with us	271	79.9
Total	339	100.0

Source: Own questionnaire

As we saw some Tables before, 68 children lived in long-term facilities. Table 36 shows that the most prevalent answer to this question was negative, with 38 respondents, so they did not intend to take them home. From this rate we might come to a conclusion that they were satisfied with the given long-term facility however, some of the respondents might have given up the opportunity to take their disabled children back to their home. It seems impossible to decide whether how many of the 38 respondents with a negative answer would take the children back to their home if they got significant help in their local environment. As we can see 18 respondents thought it would possible to change the course of events, while 12 respondents gave definitely positive answer.

The help they would need can be found in the next table in more details.

Table 37

Form of help they would need after taking the disabled children back to their home.

Form	Number of respondents	Percentage
Personal help	19	5.6
Technical aid, instrument	10	3.0
Cleaning of the home	15	4.4
Financial help	19	5.6
Other	5	1.5
The child lives with us	271	79.9
Total	339	100.0

Source: Own questionnaire

The answers to this question were very diverse. 19 respondents would ask for personal help which can stem from the overload of the parents, furthermore they would also need the help of professionals. Another 19 respondents would ask for financial help. The need for home reconstruction was mentioned by 15 respondents, 4.4% of the respondents. Technical help was asked by 10 respondents, 3.0% of the whole.

Table 38

The distance to get to the long-term facility from the place of living

Distance in km	Number of respondents	Percentage
The child lives with us	271	79.9
1-10	12	3.5
11-20	6	1.8
21-40	19	5.6
41-60	9	2.6
61-80	11	3.3
81-100	3	0.9
101-200	4	1.2
201-300	2	0.6
301-400	2	0.6
Total	339	100.0

Source: Own questionnaire

When disabled children live in long-term facilities, the frequency of visits and the way of keeping contact is measurably determined by the distance between the long-term facility and the family's place of living. This question was also asked from the parents of children living in long-term facility. We grouped the distances starting from 0-10 km to as far as 301-400 km. There was an old practice to place the disabled child in an institution far from the family, but now it is unacceptable. In a small country like ours the distance of 400 km is unimaginable as it practically implies living in the two farthest points of the country. Normally the distance of 60 km is acceptable, and taken the different ways of travelling into account we can say that regular visit within 60 km would not cause problems, as it happened in 46 cases, though the greater the distance the less frequent the visit was. Even if regular visit hardly seems accomplishable, some modern technical instrument like mobile phone or internet can help to keep in touch. However, it would be advisable to have a long-term facility within 60 km which would suit the parents' need and the expectations of the normalization principle.

The Table also shows that the most prevalent distance between the parents' place of living and the long-term facility was between 21 and 40 km, with a 5.6% rate, 19 respondents. In 12 cases the distance can be regarded quite short, 1-10 km, the rate of it was 3.5%. In 20 cases the distance was between 41 and 80 km, the rate if it was 5.9%. In 8 cases quite great distance, over 100 km, was indicated, the rate of this was 2.4%. The most extreme distance was between 301 and 400 km with two respondents, the rate of this was 0.6%.

The last question of the questionnaire was an open question to ask about the biggest problems around the disabled child. We got quite many different answers which we grouped so that we could evaluate them. We collected answers and opinions about overload into the first group. Only the most typical or frequent ones are listed:

- The child needs 24-hour care, the parent is tired, professional nurse or carer would be needed.
- Caring for the child all day long, the parent feels isolated.
- The mother has not been able to care for the child since the death of her husband.

The second group contains problems concerning financial help, financial difficulties.

- It is hard to make both ends meet, the child would need appropriate glasses.
- Because of the low income they cannot provide everything for the child.
- They cannot afford taking the child for developmental swimming.
- Lack of money makes it impossible to take the child to special school, the support service is also expensive.
- They need to run a car to be able to regularly visit the child with disability.
- Lack of money, lack of jobs.

The third group contains all the problems related to travelling. Travelling causes difficulties not only for physically disabled people but for persons without disability as well.

- In our settlement there is no opportunity to work or develop the child with disability.
- They need to run a car to be able to regularly visit the child with disability.
- The school is in a great distance from the place of living.
- Getting to school causes difficulties.

- No other ways of travelling is suitable except for their own car.
- Taking the child to school every day costs a lot.
- More possibilities for transportation and more developmental programmes would be good.

Into the fourth group we collected the parents' expectations concerning the services. They are basically qualitative and quantitative remarks.

- The waiting list for the day care is several years' long.
- For working parents it is impossible to collect the children at 4 pm., and it is difficult to arrange and get help for and during the school vacation.
- For working parents the working hours do not overlap the opening hours of the institution.
- If there was a day-care centre in the place where they live, the child would not have to live in a long-term facility
- There is no place to take the child when the parents want to go away for some days.
- With the help of a day-care centre the child could live at home.
- Children with disability are not accepted at the kindergarten, although developmental programmes are provided for them in the kindergarten.
- No psychologist at the school, lack of special physical education classes for the children.

The fifth group contains answers connected to family relations.

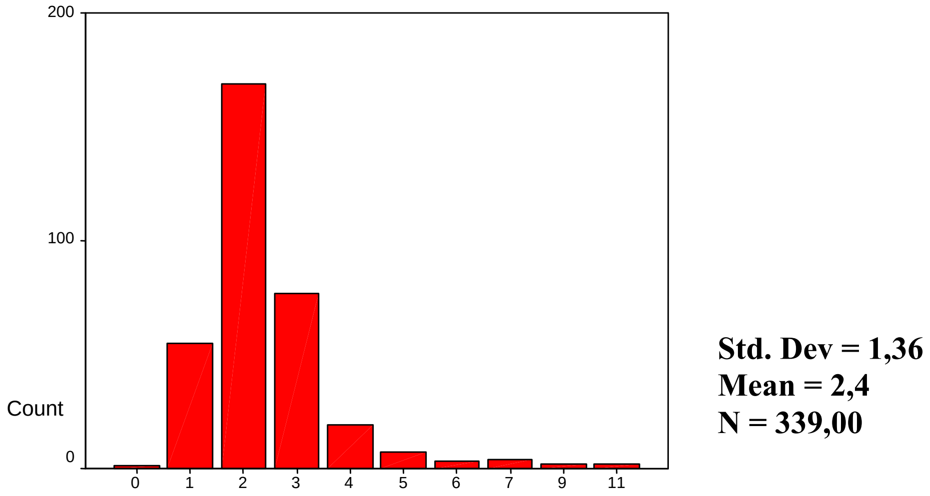
- The goal is to teach the child to conduct an independent life after the death of the parents.
- The partner in the second marriage cannot stand the disabled child from the first marriage.
- Lack of communication between the other members of the family and the relatives.
- Socialization and communication.

The figures above were calculated with SPSS cross tables and Chi square probe. I was examining whether the necessity of and the decision on placing the disabled child was influenced by the sex and family status of the parents. Those who hesitated were not taken into account, so we had 248 elements. I supposed that both the sex of the parents, especially that of the mother, and marital status, living in marriage, would significantly influence the decision making. The figures have shown that no significant difference could be stated either with sex (Chi square: 0.177; df: 1; p>0.05) or family status (Chi square: 3.458; df: 2; p>0.05).

The following histograms, made with SPSS programme, contain the most important figures of the research.

Fig. 9

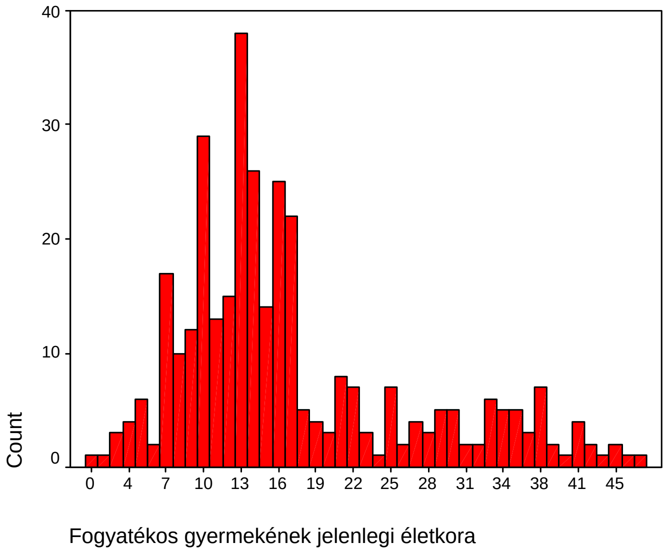
Number of children of the respondents



The histogram shows the total number of children of the respondents. As it can be seen, the most prevalent amount was 2 children per family, involving 169 respondents. The number of families having three was 77. The number of four, five or six children per family is decreasing. The histogram also shows that there were families with seven, eight and even more children among the respondents. The standard deviation is 1.36 the mean value is 2.4, while the number of elements was 339. The mean value of the number of children in families caring for a disabled child was 2.4 which is much higher than the national average.

Fig. 10

The present age of the disabled child

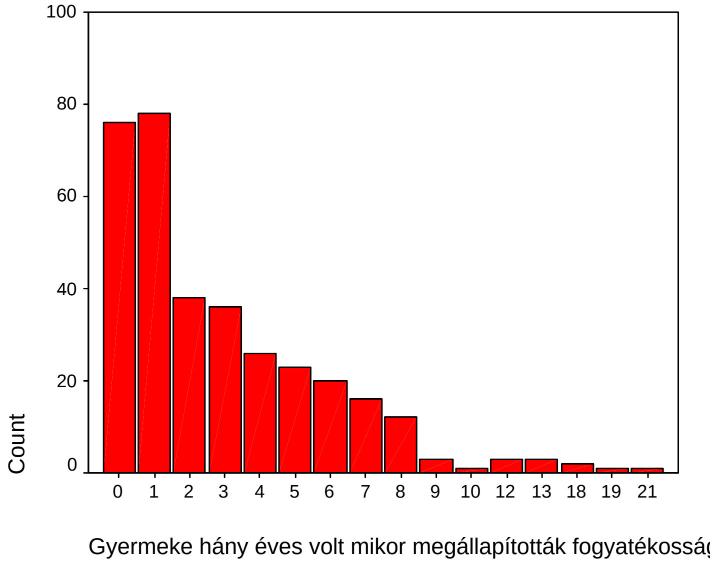


Std. Dev = 9,81
Mean = 17,2
N = 339,00

The histogram shows the age of the disabled children of the respondents at the time of enquiry. Most of them were between 10 and 17 years of age, this data tallies with the most important data of Table 20. The standard deviation is 9.81, the mean value is 17.2 and the number of elements was 339. The wide range of ages of the histogram shows disabled young adults who are cared for by their parents, because the 20-40 age group was also present in our research.

Fig. 11

The age of child when the disability was diagnosed

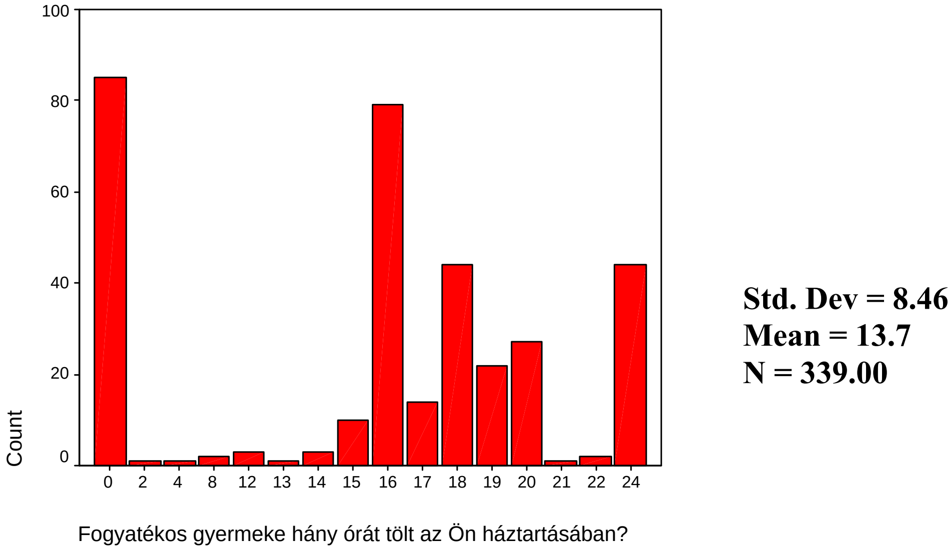


Std. Dev = 3.27
Mean = 2.9
N = 339.00

The histogram shows the age of child when the disability was diagnosed. In this research we took the 1-5 years of age as an optimum and as it can be seen it was valid for most of the children involved in the research. However, the histogram also shows a several cases were diagnosed at the beginning of school age, around 6-7. What is more diagnosis on disability was performed even at a later stage. The standard deviation is 3.27 while the mean value is 2.9. Throughout the study the number of elements was 339.

Fig. 12

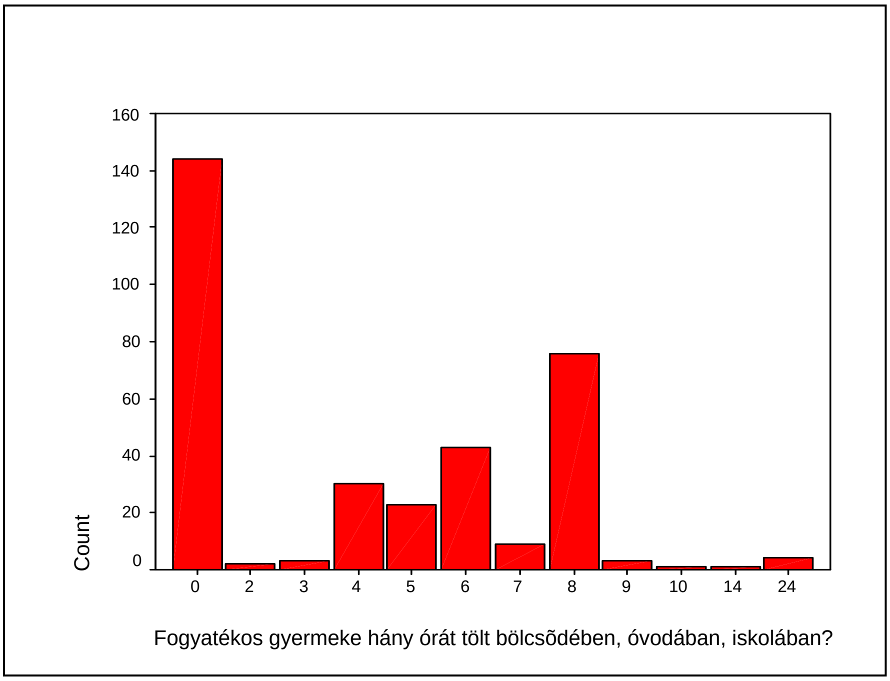
The number of hours the child spent at home



The histogram shows the number of hours the disabled child of the respondent spent at home. As it can be seen the two extreme values are the most prevalent. While a great number of answers indicated the number of hours between 0 and 1 hour, other answers indicated the amount between 16 and 20 hours. Between the two extremes hardly any answers were given. The third most significant column shows a 24-hour amount indicating children who spent the whole day with their parents at home.

Fig. 13

The number of hours the child spent in creche, kindergarten or school



Std. Dev = 4.08
Mean = 3.9
N = 339.00

The histogram shows the number of hours the disabled child of the respondents spent in crèche, kindergarten or school. The most prevalent answer is 0 hour and the amount decreases. A slight increase appears at the amount of 8 hours. The standard deviation is 4.08 while the mean value is 3.9. Throughout the study the number of elements was 339.

5. Discussion

The figures of our survey has supported what was written in 1.1.1 about the Principle of Normalization. According to Nirje Bengt[117], the regular daily, weekly and yearly activities are very important for children with disability. The answers we obtained have shown the regularity of the disabled children of the respondent greatly alters from the Principle of Normalization. The time spent on holiday either in our country or abroad is absolutely less than among the population without disabled children.

The theoretical approach is possible from several points of view. First of all, let us summarize the principles of the Madrid Declaration /Madrid Declaration, 2002./ which is considered to be the most important in the European Union. The European Union declares new aspects in the case of deficiency.

There should be:

- A change in regarding deficient people as subjects of charity, deficient people should be regarded as possessors of rights.
- A change in the practice according to which decisions are made on behalf of deficient people, they should bring their own decisions and take their own responsibility in the questions they are concerned.
- A change in the point of view of focusing on individual damages. Re-examination of unimpediment, social norms, occupational policy and cultures are important, as well as creating supportive and accessible environment.
- A change in regarding people dependent and disabled. Their abilities should be emphasized and supportive measures should be brought.
- A change in the planning of economic and social processes involving few people, creating a flexible world involving many.
- A change in education, occupational policy and segregation in other areas of life, deficient people should be integrated.

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[117] NIRJE B., PERRIN B. *A normalizációs elv és félreértelmezései.* ÉFOÉSZ, 1998. Budapest. ISBN 963-03-5934-0

- A change in ranking deficiency policy to the competency of certain ministries, deficiency policy should belong to governmental responsibilities.

With the Madrid Declaration the European Union committed itself to recommending a recipient society to everybody.[118]

On the basis of the UN Declaration[119], the State members ensure equal rights for people with disability within the family. Several services are used to enforce these rights.

In Hungary the state and occupational policy have recognized the importance of this new approach. In co-operation with the appropriate organizations of the European Union, the National Activity Plan was born for the social affinity. Within this framework we can read about measures taken to assist deficient people's individual way of life, as well as analysis of the situation. „Their life circumstances are much more unfavourable than those of the average population in many respects. Although their level of education improved in the last decade, they are far behind the national average. Their employment figures are very bad, according to data from 2001, only 9% of them were employed, and half of them lived in households where there were no employed members at all. In order to improve the disadvantageous situation of deficient people, a law was passed about their rights and about guaranteeing their equal opportunities. In order to realize the principles set in this law, the National Deficiency Policy Programme was accepted in December 1999. The Programme determines the principles, strategic goals and tasks, which need coordinated state measures in order to put the law into effect, but it also builds on the local governments and their institutions, the civil organizations and the active participation of deficient people. This programme aims to determine the most important developmental directions in the following areas: physical and information accessibility, transport, health care, education, employment, sports, culture and free time, social provisions. The target of this programme is to realize equal opportunities, social integration and to guarantee the fundamental conditions for the individual way of life for

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[118] HORVATH L. Fogyatékos gyermekek intézménybe kerülésének – családból való kikerülésének okai. In *Szociális munka az egészségügyben.* Debreceni Egyetem Egészségügyi Kar – Kent School of Social Work University of Louisville, 2009. Nyíregyháza. 104-114.p. ISBN 978 963 473 348 5

[119] ENSZ. *Fogyatékossággal élő személyek jogairól szóló egyezmény és az ahhoz kapcsolódó fakultatív jegyzőkönyv.* ENSZ, 2006. december 13.

deficient people through coordinated state measures, namely the interest of the deficients should be taken into account in all areas of the occupational policy.[120]

The 1.1.10 sub-chapter contains the contemporary process of social help which require a wider range of services[121].

The basic approaching method of the supporting services is exposing and fortifying the ability of self-sufficiency, and the respect of autonomy. We can summarize this process in the following flow chart.

THE PROCESS OF THE ABILITY OF SELF-SUFFICIENCY

Creating a supportive relationship /trust/

↓

Assessment

↓

Individual developmental, keeping the level programmes

↓

Social rehabilitation

↓

Autonomy, end of supportive relationship

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[120] HORVATH L. Reasons why Handicapped Children are taken out of the Family and Placed into Residential Institutions. In *Szociális munka az egészségügyben.* Debreceni Egyetem Egészségügyi Kar – Kent School of Social Work University of Louisville, 2009. Nyíregyháza. 214-224.p. ISBN 978 963 473 348 5

[121] HORVATH L. Fogyatékos gyermekek és családjaik szociális segítése. In *A II. Nyíregyházi Doktorandusz (PhD/DLA) Konferencia Kiadványa.* Bessenyei Kiadó, 2009. Nyíregyháza. 87-94.p. ISBN 978 963 9909 19 9

This process cannot be static, because assessment can be done again, depending on the outcome of rehabilitation. If needed, new rehabilitation services must be planned and realized.[122]

It is inevitable to launch more day care and support services. These are the most important ones so that the children could access to the necessary services in their immediate surroundings. However the inner programme of long-term facilities also should be reformed so that they could pay attention to peer and family connections. Therefore I have compiled the outline of a post-qualifying training programme for social and health professional which will enable them improve the quality of the services, and will introduce a new approach of interdisciplinary.

Priority of assistance given in the family is our basic principle. Assistance should be given first in the deficient's own environment. Residential institutions are also needed, but the services provided there, should be connected to the client's own family. I am going to write about the possible processes of this connection in the following part.

Services Built On One Another

I deal with the complete process in six steps. The order of steps is important, but the duration of each step can significantly vary depending on the individuals. All these steps should be supported by a detailed and renewed assessment of necessities now and then.

1. Early recognition. The first step of the process is the early recognition of deficiency. In many cases it can be stated before the birth with the help of modern scientific instruments.
2. Assistance services should be brought to the family. Health care and social services should be improved, so that they could be brought to the client's own environment, therefore the deficient does not have to be taken out from the family.
3. In case of serious, but temporary problems, temporary care should be provided. In the life of families such temporary problems may come up, which make the upbringing of the deficient child difficult /e.g. an illness, unemployment, a journey abroad, taking a

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[122] HORVATH L. Deficient Children in the Family. In *Kontakt,* 2007. ISSN 1212 4117

job/. In such cases the child should not be taken out from the family permanently, only for the time needed.

4. Only in case of emergency should the child be taken out from the family. Only if the child cannot be helped within his/her environment, should he/she be taken to a residential institution. In today’s practice providing assistance begins at this point in many cases. We should break the tradition as much as we can.
5. Preparing the child’s setting back into the family should be an important task of residential institutions. It means that the child should keep in touch with his/her family, the institution should strengthen their relationship as well. This demand requires new and up-to-date forms of work.
6. Setting back into the family. After the deficient child and his/her family had been strengthened, in some cases this lucky turn can be achieved. It is not pure chance, but it is due to conscious assistance work.[123]

For the survey we selected parents who were in close connection with the institution from which the professional reached the potential respondents. In many cases the questionnaires were answered at the respondents’ home, furthermore a double meeting between the professional and the respondent was also possible so the respondent could discuss the answer with the family members. The respondents belonged to both sexes. We selected those parents who were in close connection with the institution from which the professional reached the potential respondents. In many cases the questionnaires were answered at the respondents’ home, furthermore a double meeting between the professional and the respondent was also possible so the respondent could discuss the answer with the family members. Chart shows that most of the answers 86.1% were given by women thus we can conclude that basically mothers keep contact between their disabled child and the institution. However, the rate of males answering was 13.9% which implicates that the contact person differs from family to family. Even if this 13.9% was not much of the whole, it means that the father was the contact person in every tenth case. Great importance can be attached to this data if he was a single or lone parent. The following pie chart illustrates the gender rate of the respondents.

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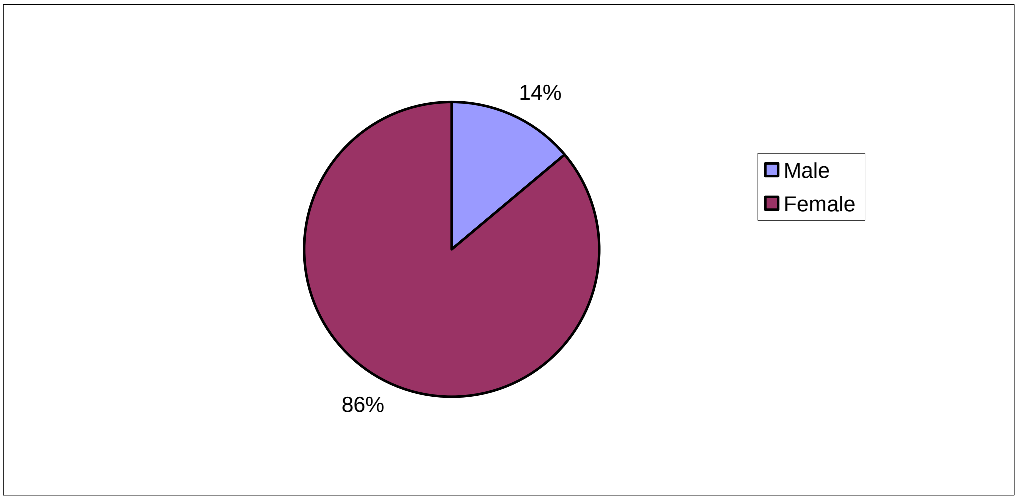
[123] HORVATH L. Deficient Children in the Family. In *Kontakt,* 2007. ISSN 1212 4117

Fig. 14

Sex of respondents



At the beginning of this research work we presumed that the highest age of parents caring for a child with disability would be around 40 or 50. In contrast with it, a large number of the respondents were 60, 70 or even 80 years old. The data is in relation to the possible definition for 'child'. The Hungarian legislation considers someone a child under 14, although they come of age over 18. Therefore we presumed that the mean age of parents would be between 20 and 50. On the other hand, parents of disabled persons who still care for them interpret 'child' as a relation which last till the end of life and feel responsibility for them even if they are as old as 80. This walk of life does not contradict what is written in the professional literature[124] [125] so questionnaires filled in by them remained in our survey. Later it proved to be a good choice since persons with disability cared for by elderly parents usually lived in the same household and needed 24-hour care because of the nature and severity of their disability. Several studies have been published on this topic.[126] [127] [128]

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[124] HULLER GY. *A szülői hivatás.* Huller Gyula Kiadó, 2003. Budapest. ISBN 963-430-818-X

[125] HORVÁTH L. Fogyatékos gyermekek és családjaik szociális segítése. In *II. Doktorandusz Konferencia kiadványa.* Bessenyei György Könyvkiadó, 2009. Nyíregyháza. ISBN 978-963-9909-19-9

[126] KÁLMÁN ZS. A szülő és a szakember együttműködésének buktatói. In *Kálmán - Könczei: A Taigetosztól az esélyegyenlőségig.* Osiris Kiadó, 2002. Budapest. ISBN 963-389-311-9

[127] KOSIKNÉ J. Fogyatékos gyermekek szüleinek elképzelései gyermekeik jövőjéről. BGGYTF, 1988. Budapest.

[128] KOVÁCS K. *Nyújtsd a kezed! Tanácsadó kézikönyv látássérült kisgyermek szüleinek.* Látásvizsgáló Országos Szakértői és Rehabilitációs Bizottság, én. Budapest.

Table 10 has shown the family status of the respondents and that of living in marriages. The rate of married couples exceeded the rate of married couples without disabled children. Fundamentally this data reflects a positive picture of families with disabled children though a further survey would be needed to find out to what extent married couples are forced to stay together. However, the joint responsibility taken for the child could be revealed in 239 cases. The prevalence of parents living in life-partnership was 7.7 %, which was lower than the national average of the same data store.
It might be in close connection with the fact that the mean age of the respondents was high enough no to break up with traditional family constructions in contrast with a younger generation. The prevalence of lone parent was 21.8% and concerning their social and financial background they must face difficulties.

Table 11 has shown the level of education obtained. The most prevalent answer to the question was the possession of general certificate of secondary school with a prevalence of 34.2 % that was every third parent. This rate correlates with that of the national average moreover it was slightly higher than that, with special regard to the mean age of the respondents. Concerning other type of school completed, the prevalence of those with college or university diploma was 13.3%, 45 persons, which contradicts a typical stereotype of the general public that poorly educated families are more likely to have disabled children. The second most prevalent answer to that question, with 95 respondents, was the possession of certificate of vocational school. 72 of the respondents completed elementary school which may project difficulties at the labour force market, in addition the chance for those who did not complete elementary school, 3.3% of the respondents, is much worse.

Table 12 shows the number of children because we were curious to know who were in the family of the disabled children. For disabled children it is important to be surrounded by family members and grow up with the siblings like any other children. The normalization principle emphasizes this practice. As our survey shows the number of children in the same family was quite different: starting from 1 to as many as 11. The total number of children of the respondents was 822. The total number of respondents was 339 so the average number of children per family was 2.42. This rate is much higher than the national average which is under 2. As a matter of fact the average counted on the basis of the different age groups may differ, since younger parents can decide on having another child therefore the number of children per family can increase. The most prevalent number of children was between 2 and 3, their rate was 72.5%. Since the number of children per family was higher than that of families without disabled children we can presume that after the birth of the disabled child the family wanted to and hoped to have a healthy child as well. On the other hand, 16.5% of the families had one child only. Later, with a deep interview parents could be interrogated whether they plan to have another child. Table 12 shows that the prevalence of families with 4 children was quite significant with 5.6%.

The answers we got concerning employment definitely show that the rate of employment among persons with disabled children was low and it does not fulfil the expectations of the normalization principle. The multiple-choice question made it possible to map the different labour relations therefore we have a synoptical table. Being employed 36-hour-work per week, one of the most important data, could ensure the safe and satisfactory standard of living and care provided for children with disability by the parents, which could also meet the expectations of the normalization principle. The prevalence of employed parents was 31%. The most prevalent answer to this question, 33.6%, was the childcare allowance designated as family income. Although it is a significant financial support for the family, the parent is not an active shareholder of the labour market, gains no experience in and has no contact with workplace environment, his or her role as a parent is restricted to a child carer. We will see it from some answers further on that these parents are overloaded since caring for a child with disability is much more demanding than the challenges of families without disabled children. Only 6.5% of the respondents were unemployed, this rate is lower than the national average. The age of the respondents, presented in Table 9, was quite different, probably that was the reason for having a great prevalence of pensioners, 19.2%, among the respondents.

Making diagnosis of disability proves to be a difficult task.[129] In order to identify it different professional fields are involved like genetics, gynaecology,[130] obstetrics then later

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[129] KÁLMÁN ZS. *Bánatkő. Sérült gyermek a családban.* Bliss Alapítvány, Keraban Könyvkiadó, 1994. Budapest. ISBN 963-8146-26-5

[130] BALLA GY. A magyar intenzív neonatológiai ellátás jellemzői. In *Gyermekorvos Továbbképzés,* 2008/7. sz. 10-11. p. ISSN 1589-0309

committees[131] of specialists make decision on it. Some 189 cases, 55.8% indicated that a committee identified the nature of disability. The inner rate of this table shows that only 2.9% of the respondents reported that the diagnosis was performed before birth. The modern science could identify more cases at an earlier stage and hopefully surveys which carried out after decades will prove this presumption. Some 25.7% of the respondents reported the lack of diagnosis by specialists which actually means that someone else, neighbours, relatives noticed it and called the parents' attention to the problem. This statement is of crucial importance concerning our second hypothesis which urges new type of health and social services for families with disabled children. Identifying disability and allocating adequate social help require collaboration of professionals from different fields and services of a wider range.

Table 24 has shown figures on services the respondents were getting. It was mentioned earlier that the prevalence of children placed in long-term facilities was 20.1%. We also wanted to get a view of these children so the analysis contains data collected from their parents. On the other hand, a respectively high number of children with disability, 68, were placed in long-term facilities. This rate is definitely higher than among children without disability. Obviously this procedure is against the normalization principle. Among other services we find payments in kind or cash as accessible services in 313 cases. The third most frequent service is the supporting service provided for 72 families. It would be advisable to use meal provision and day care services more frequently. Inadequate number of these services proves our second hypothesis. In order to meet the expectations of the normalization principle, it is not enough to have the above mentioned services but a wider range of them with more frequent services could serve children with disability more efficiently. Other services seem to be accidental, although any of them could be useful for disabled children. It is another question to find out to what extent the problems of these families can be solved with the help of these services.

Table 27 has shown how overload the parents of disabled children were.[132] Presumably the most overloaded respondents are the parents of these children since they need

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[131] GÖLLESZ V. (szerk.) *Gyógypedagógiai kórtan.* Nemzeti Tankönyvkiadó, 1998. Budapest. ISBN 963-18-8412-0

[132] KÁLMÁN ZS. A szülő és a szakember együttműködésének buktatói. In *Kálmán - Könczei: A Taigetosztól az esélyegyenlőségig.* Osiris Kiadó, 2002. Budapest. ISBN 963-389-311-9

to arrange an almost 24-hour long care for the children. According to normalization principle 16-21 hours a day is unfavourable both for the child and the carer, but the 21-24 care totally contradict the principle. The data store of the Table 29 has shown that 76.4% of the respondents did not spend any days on travelling or holiday. The figures themselves are enough to prove our seventh hypothesis that families with disabled children are much more overloaded than families without disabled children. We are convinced that normally one week a year would be good for every family though data shows that only 12.1% of the respondents had the chance for that. On the other hand a week away from home would be ideal for the disabled children, too. In conclusion, more services would be needed to provide placement for a short term for the sake of parents and children as well. A similar question was asked about travelling abroad Having seen the data in Table 29 we were not surprised that data in Table 30 were even less favourable. Not a single day was spent abroad by 97.3%, 330 families, of the respondents. Only 2.1% of the respondents reported one-two week holiday, although it would be ideal for all of them. Presumably the data of Table 29 and 30 are overlapping, therefore families which could not spend a one-week holiday in Hungary, could not go abroad either. Concluded, caring for a disabled child involves extra burden on the families.

I have also examines the connection between the content of my hypotheses. My experiences have confirmed the figures in several studies and facts in the professional literature.[133] [134] The very first hypothesis is of great importance and I managed to compare several international documents and statements[135] [136] which will be referred to later. At the end of the 20th century, the theoretical approach of disability involved the helping process, societal participation and the significance of civic rights. Concerning these umbrella terms new terminology was created in the international documents, which were fully described in 1.1. A comprehensive principle is the equalization of opportunities for disabled people, which

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[133] HALMOS SZ., GAZSI A. Esetjogi tanulmányfüzet. Az értelmi fogyatékos, halmozottan fogyatékos és autista emberek számára működtetett antidiszkriminációs jelzőrendszer tapasztalatai. Kézenfogva Alapítvány, 2008. Budapest. ISBN 978-963-88082-0-2

[134] LOVÁSZY L. A fogyatékos emberek helyzetéről - a filozófiától a demográfiáig. In *Kapocs,* 2006/1.sz. ISSN 1588-7227

[135] HALMOS SZ., GAZSI A. Esetjogi tanulmányfüzet. Az értelmi fogyatékos, halmozottan fogyatékos és autista emberek számára működtetett antidiszkriminációs jelzőrendszer tapasztalatai. Kézenfogva Alapítvány, 2008. Budapest. ISBN 978-963-88082-0-2

[136] LOVÁSZY L. A fogyatékos emberek helyzetéről - a filozófiától a demográfiáig. In *Kapocs,* 2006/1.sz. ISSN 1588-7227

means that disabled people can experience their rights and become an active participant of the society both from social and economy aspects. They also contribute to the sustainable development and their reception by the major of the society can enforce solidarity. The definition for disability is continuously changing and developing and involves modern approaches. Persons with disability are not only physically impaired people, a term used in medical sense, but persons whom the environmental barriers deprive of their full and effective participation in the society. Within the general and international framework there might be differences from nation to nation, and even the nature of environmental barriers depends on the public opinion about disability. The quotation on the cover is worth mentioning here; "treat and being treated". Disability is a wide term, though an accurate internal classification is inevitable to describe the varied life positions. One of them is the reasonable accommodation of the society which can be ensured by universal planning process which makes it possible for the disabled people to have access to specific services, in addition to be able to participate in and be part of the system. Mainstreaming is of vital importance for persons with disability since it is a key issue for them to attend the same school, to work at the same place as the major of the society[137]. This way adults and children with disability can live a full life. All in all, having read the international documents dealing with disability we can prove the first hypothesis that there are international declarations, conventions, resolutions which aim to enforce the family relations between disabled persons and their families. Due to these documents the attitude towards disabled children has undergone a permanent and positive change.

The 3, 4, 6, 7 and 8 hypotheses deal with the disabled persons and their families. In order to verify them we have lots of information concerning the respondents' gender, age, level of education and dwelling circumstances. According to our third hypothesis the existence of a disabled child in a family did not depend on the level of education of the parents. Disability could also appear in a family where parents possessed or lacked high level of education. Table 11 showed all the figures concerning the level of education obtained, where the highest level was university degree and the lowest was the unfinished elementary school somewhere between 1 and 7 grades. Table 11 serves as a proof to the hypothesis.

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[137] HORVATH L. Reasons why Handicapped Children are taken out of the Family and Placed into Residential Institutions. In *Szociális munka az egészségügyben.* Debreceni Egyetem Egészségügyi Kar – Kent School of Social Work University of Louisville, 2009. Nyíregyháza. 214-224.p. ISBN 978 963 473 348 5

In the fourth hypothesis we presumed that families with disabled children were more likely to have more children, compared to the whole population. We presumed that these families wanted to have a healthy baby as well, and decided on giving birth to another child. However, even the opposite of it could have been true; because of having a disabled child the family was not averse to having another one. Table 12 showed that the mean value of the number of children per family was 2.42 which was measurably higher than the national average, under 2 children per family for a long time.

In our sixth hypothesis we stated that services created according to Hungarian legislation proved to be insufficient to fulfil all the needs of the disabled children or to stop the gap. Furthermore, services were less accessible for them than children without disability. As it can be seen in Table 25 the prevalence of those who required further services was very high, which could be regarded as a direct proof of the hypothesis. A more detailed manifestation of the problem could be found among the answers of the questionnaire asking about the necessity of services. The figures concerning these questions can be found in Tables 26 and 37. Among the answers given to question 34 we found the most typical problems concerning travelling. Not enough services were provided in the settlements of the respondents therefore they spent a lot of time and money on travelling. Difficulties in travelling and transportation did not only concern physically disabled children but children with other disabilities as well.

According to the seventh hypothesis families raring and caring for disabled children were overloaded compared to other groups of the population. We could see astonishing figures in Table 29 showing that the prevalence of respondents who did not spend a single day travelling or on holiday was 76.4%. The rate itself proved our hypothesis on the heavy load on parents with disabled children. Only 12.1% of the respondents could go on a one-week holiday, although this duration could be regarded as normal for any parents. Two extreme figures can be seen in Table 31 showing that a large number of parents did not spend a single day away from their children on the other hand, there were parents who hardly ever met them. The ideal rate would be in a halfway house between them supposing the situation be changed by more flexible and traverse services. More figures proving the seventh hypothesis can be seen in Tables 29 and 33.

In our eight hypothesis we presumed that parents caring for their disabled children in their own household would not place them in a long-term facility even if the condition of the children went bad to worse[138]. The prevalence of those who would not so was 69.0%, with 234 respondents. We think this high rate proves the eighth hypothesis. Only a small rate of the respondents, 4.2%, would place the child in a long-term facility in case of deterioration. Presumably they were old parents who needed to face the possibility of oncoming death. Three groups of the respondents expressed uncertainty and the rate of those who needed extra help was 6.7%. These figures also proved our second and sixth hypothesis that it would be advisable to improve and launch services.

The second and sixth hypotheses deal with services about which, as well as the gaps in services, we managed to collect information from the parents.[139] Concerning our second hypothesis the relationship between the family and the disabled child can be enforced by appropriate social and health care services. In order to prove this hypothesis we applied a questionnaire to find out what gaps needed to be stopped with the help of improving the already existing services or launching new ones. On the basis of the figures of the survey we summarized our suggestions under the chapter of Conclusion. At the same time we managed to prove the second hypothesis.

According to the fifth hypothesis identifying the disability or disorder and uncovering any relevant damages seemed to be delayed and seemed incongruous in this modern scientific world, moreover several facts could slip outside the scope of examination even at the age of three or five. The figures of Table 23 have shown that the prevalence of early identification until the age of 3 was 67.2%, whereas the prevalence of early identification until the age of 5 was 81.7%. Even at the age of 5, the rate of those whose disability still had not been identified was 18.3% compared to the number of respondents. With this rate we managed to prove the sixth hypothesis.

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[138] HORVATH L. Fogyatékos gyermekek intézménybe kerülésének – családból való kikerülésének okai. In *Szociális munka az egészségügyben.* Debreceni Egyetem Egészségügyi Kar – Kent School of Social Work University of Louisville, 2009. Nyíregyháza. 104-114.p. ISBN 978 963 473 348 5

[139] HORVATH L. Az alap- és szakosított ellátás viszonya a szociális munkában. In *A humán erőforrás szerepe, fejlesztésének, hasznosításának lehetőségei az Európai Unióban.* Szabolcs-Szatmár-Bereg Megyei Tudományos Közalapítvány, 2004. Nyíregyháza. 212-215.p. ISBN 963 214 213 6

According to the ninth hypothesis the geographical distance between disabled children living in a residential home and their parents' place of residence was larger than suggested in the normalization principles. We think a distance of 60 km is acceptable and institutions within this distance, supposing average travelling conditions, can be regularly visited. The prevalence of disabled children who were regularly visited was 93.4%. So the hypothesis is not justified. In other cases the distance measurable became longer, even as long as 300 or 400 km. As a matter of fact no regular visit was possible in these cases, although the application of modern information technology like internet and mobile phone made it possible for parents and children to be in touch. And still, regarding the normalization principle an institution providing the necessary services and being much closer to the family should be found for these children.

6. Conclusion

On the basis of studying the theoretical background and international documents of this field and analysing the figures of the survey I have managed to reach the aims of this research work. I established in what ways the social and health care are provided for persons with disability or their family either living in family settings or institutions.

Furthermore, I established what methods are needed to actively involve families with disabled persons into the services of social and health care. On the basis of the figures I have compiled the outline of a post-qualifying training programme for professional dealing with disabled people and their families. The outline of the training programme will be introduce at the end of this chapter.

The summary and verification of the hypotheses of the dissertation is the following:

1. There exist several international statements which aim to strengthen the relationship between the disabled children and their families. – Verified.
2. The relationship between the disabled children and their families can be reinforced by providing social and health services. – Verified
3. The birth of a disabled child into a family has nothing to do with the level of education of the parents. – Verified
4. Families with disabled children are more likely to have more children, compared to the whole population. – Verified
5. Making diagnose of disability or disorder and uncovering any relevant damages seem to be delayed and seems incongruous in this modern scientific world. – Verified
6. National services created according to the law prove to be insufficient to fulfil all the needs of disabled children. – Verified
7. Families with disabled children are overburdened compared to other groups of the population. – Verified
8. Parents caring for their disabled children in family settings would not place them in a residential home even if their background went from bad to worse. – Verified
9. The geographical distance between the disabled children living in a residential home, and their parents' place of residence is larger than it is suggested in the normalization- Not verified.

6.1 Offering to the implementation of practice

In this chapter we would like to make suggestions, adjusted to the applied principles, on the basis of the figures and conclusions of our survey and the opinion articulated by the respondents of the questionnaire. As we have seen certain elements of the system do not work properly therefore we feel it necessary to extend the system, either by improving or launching new services, in order to ensure social provision for each and every child, family and institution.

We are concerned that most of our suggestions are accomplishable both in family settings and in long-term facilities. According to the normalization principle only a slight difference is acceptable between the two settings, therefore long-term facilities require structural and content based transformation.

1. Disorders which can be identified before pregnancy need to be handled separately from those which are identified till the 20th week of the pregnancy. With the help of modern scientific methods early identification could take place in more cases, still they are not as spread as they could and should be. Our survey has proved that early identification is not complete between 0-5 years of age, although in accordance with the legislation it would be very advisable. Professionals working as genetic counsellors could lend a hand in prevention, while other specialists in early identification and early development. It is never too early to carry out the early identification. In line with the development of medical science early identification is shifted to prevent disorders and is carried out before the conception with diagnostic prenatal tests and screening.
2. Early identification and development should be family centred where information flow is a two-way process between the family and the specialist. Family connection can be enforced in tying up different services.
3. Injuries during pregnancy should be handled separately from injuries during labour. The reason for injuries during pregnancy can stem from inadequate life style, although it should be of great importance. Domestic violence can affect pregnant women as well, which may result in the injury of the baby. Further injuries can happen during the

4. Persons with disability should be treated according to the characteristics of the age group. Older disabled children require different treatment. The major of the society should learn to treat disabled adults the way they do with any other persons.
5. Following the expectations of the normalization principle children with disability should have a room of their own, which provides privacy and stimulus rich environment.
6. Autonomy of disabled children should include spiritual life. Their surrounding is responsible for introducing religion and ensuring the conditions to practice it, which should take place in compliance with the children's age, at the right pace within the framework of autonomy.
7. Freedom provided for disabled children should become universal. With appropriate supervision tailored to their needs and characteristics, they can go on trips and stay in camps without their parents. This opportunity should refer to children living in long-term facility as well, let alone the opportunity to go home or for vacation.
8. Children should be familiar with different ways of transportation. We know it from first hand experience that children with disability are not aware of the usage of public transport because it is not shown to them. It would be important for them to know the way of travelling by train, bus, tram or other type of vehicles. They should be prepared for and helped with it.
9. Varied and social environment should be created around the disabled children. In family settings we can witness family relations restricted to the disabled person and the carer, while relations in institutions involve fellow sufferers and the carers. It would be advisable to form social relations with the wider environment like family members, distant relatives, school mates, neighbours.
10. Communication is inevitable among family members. It refers to children brought up in family settings as well as for children living in long-term facilities. Institutional placement does not necessarily mean the end of the family's roles. To the contrary, this type of placement involves regular visit, joint activities which maintain the family relations. This way the anxiousness of the disabled person can be reduced, whereas the burden on the family can be relieved.
11. For the sake of reasonable utilization and accessibility of contemporary services, they should be found close to one another. Long-term facilities possess special knowledge

12. The biggest problem of parents with disabled children seems to be the travelling and transportation, which does not exclusively concern physically disabled children. A solution should be found which could cover all disabled children. In Hungary, the support services should be transformed to meet this requirement. The support service provides opportunities which can promote the independent way of life of the disabled persons, through which they will be able to reach and get personal assist to fulfil their needs. The aim of the support service is to give provision for the disabled persons in their own environment, to help to reach other general services like health care, social care, education, to help them to preserve their self-efficiency and provide special help they might need at home. Concerning all activities of support services they stop the gap existing in the social care system. They aim to meet the needs for which the contemporary social system is totally or partly incapable. These support services aim to keep disabled people's self-efficiency by helping with their every day life and needs, which will result in the improvement of the life quality of disabled people.

13. For deaf and blind people the sign-language interpreter is accessible. Some of the deaf people do not use sign-language since they were not blind in their childhood, so they use Braille writing. For those who are deaf and blind the general sing-language is not applicable. A special interpreter with assisting tasks can help them to communicate. This special interpretation involves signs from one hand to another, Braille writing into the hand, or touching the speaking lips.

14. The identification of autistic children and services related to this disorder need to be developed. Parents, health visitors, nurses in children's institution should be prepared

15. According to the modern definition for disability it is open and ready to involve new terms and phenomenon. An example could be the term of psycho-social disability which refers to the legal incapacity that should be replace with supported decision making. This task should be integrated into the helping responsibilities. Constant research work and needs analysis and recognition are needed to ensure the development in this field.

I have compiled the outline of a post-qualifying training programme for professional dealing with disabled people and their families.

POST-QUALIFYING TRAINING PROGRAMME

Length of training: 40 lessons

Requirements: professional qualification and one year of experience

Syllabus:

Topic	Method	Group
Principle of normalization in the society, family and institutions	Lecture	Large group
Social and educational integration	Lecture	Large group
Specific groups of disability, classification and new possibilities	Lecture and seminar	Large group and workshop
Health care and early identification	Lecture and seminar	Large group and workshop
Social care and early identification	Lecture and seminar	Large group and workshop
Education and early identification	Lecture and seminar	Large group
Early development and collaboration of related professions	Lecture and seminar	Large group and workshop
Communication with the family	Communication training	Workshop
Workplan to promote institutional normalization	Seminar and individual work	Workshop and individual work
Workplan presentation, final exam, feed-back	Final discussion	Workshop

The outline of the training programme also contains the sketches of the lectures so that the theme of the different subjects so that lecturer would have the same information on the content of the subject. The international documents and declarations serve as the basis for the content of the subjects. When working out the training programme I could utilize the figures of my research work and all the information I have obtained by analysing the professional literature.

Module One: Principle of normalization in the society, family and institutions

- In order to implement the Normalization Principle, programmes, activities, new approaches must be found, which need the following components:
  1. Normal rhythm of the day
  2. Normal weekly rhythm
  3. Normal rhythm of the year
  4. Normal developmental experiences of the life cycle
  5. Choices, wishes, and desires of the mentally subnormal have to be respected
  6. Living in a bisexual world
  7. Normal economic standards
  8. Standards of physical facilities
- The Principle of Normalization is a broad principle that can be applied to people with disabilities at all ages and in all situations. It states that isolation and segregation foster ignorance and prejudice, whereas integration and normalisation improve human relationships and understanding.
- The principle of normalization is considered to a process that makes people ’normal’, makes any differences disappear. To the contrary, it means the acceptance of persons with disability, which gradually leads to overcome prejudice in every sphere of the society; health and social care, education and in policy.
- The denomination of the principle ’normalization’ may be misunderstood and misused, which are not up to the new paradigms. In all circumstances it should mean improving standard of living of disabled people.
- The principle of normalization is applicable in the surroundings of people with any type of disability not only mental or slight disability

Module Two: Social and educational integration

  - As for disabled people integration can be derived from the Principle of Normalization. Integration can be promoted by a differentiated school system, which can be triggered by financial support. A reformed school system could enrol disabled people and

- The significance of integration is that the community of healthy people will accept disabled people if, and only if, they have developed together, got to know each other since their early childhood. Therefore it should be started as early as possible even in the kindergartens.
- More and more can be heard about integration and segregation at panel discussions on education. Fervent supporters and opponents voice their opinion despite the incorrect manner in which this question is put. It is incorrect because it suggests an obligatory choice between the of them, on the other hand it seems too general neglecting the possibility of choosing the form of education most proper for the individual, as well as putting aside several components that can influence the success of integrated and/or segregated education.
- The process of integration should involve an inclusive attitude with a welcoming society and high level of rehabilitation services.

Module Three: Specific groups of disability, classification and new possibilities

- The definition of a person with disability is also described by the Hungarian laws; anyone who is to a significant extent or entirely not in possession of sensory – particularly sight, hearing – loco motor or intellectual functions, or who is substantially restricted in communication and is thereby placed at a permanent disadvantage regarding active participation in the life of society. As we can see this definition meets the required standards of the international documents we have referred to in earlier sections.

- The Assembly of the United Nations adopted the 48/96 resolution on 20 December 1993 which contains the required standards for equalizing opportunities for persons with disability and it gives the following definition for disability: 'the term "disability" summarizes a great number of different functional limitations occurring in any population in any country of the world.
- Workers of helping professions who care for persons with disability often come across with expressions which are neither synonyms, nor equivalent, and are not in a whole and part logic connection but rather partially overlap one another. As a consequence the question of how to use them properly arises. Expressions like *children with special*

Module Four: Health care and early identification

For the classification of disability, specialists need to know the cause and development of a certain disability. The earlier they can identify it, the better they can reduce complications.[140] Early identification can be divided into three phases:

- In the first phase, scientific methods make it possible to make diagnostic prenatal testing and screening of the potential parents even before the conception to tell in which cases and to what extent their child will be exposed to developmental disorders, if any. Several genetic examinations are applied.
- During the second phase the pregnant woman and her foetus is examined at intervals. Some of these examinations are to diagnose a wide range of disorders the foetus might have.
- The third phase is the birth itself, when further examinations are done to the new-born baby to diagnose any possible disorders that could not have been seen or foretold before.

- ➢ A part of the congenital disorders is identified at the first examination of the new-born baby, but some of them, the so-called functional disorders appear later.
- ➢ Strictly speaking, early recognition starts with genetic counselling. The aim of genetic counselling is to help families in family planning when there is a higher risk of birth defects or congenital disorders. These higher risks may involve diseases and disorders running in the family, the age and diseases of the mother. On the basis of the diagnostic prenatal test or screening the parents get answers to their questions. If a prenatal screening or test is abnormal the specialist evaluates the risk of the affected pregnancy, educates the parents about these risks and informs them of their options. At this point another

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[140] PÁLHEGYI F. (szerk.) *A gyógypedagógiai pszichológia elméleti problémái.* Nemzeti Tankönyvkiadó, 2006. Budapest.

physician might be involved who is a specialist of the disease in question and can inform the parents on the seriousness, course, treatment and cure of the disease. The specialist also explains the recurrence risks in future children.

Module Five: Social care and early identification

- Early identification utilizes the result of several scientific fields. Besides the representatives of health science other professional can also contribute to the success of early identification.
- District nurses, nurses in creches and kindergartens, as well as teacher can be involved and educated. When the child is within sight of the social worker, appropriate supporting help is arranged for him or her and the parents. These supporting help promotes the work of the doctors, teachers of handicapped children and other professionals as well.
- Early identification is followed by early development. The sooner it is started the better the results will be.
- Parents, the immediate surrounding can rise to the challenge to identify disability early and to refer the child to specialists.

Module Six: Education and early identification

- The task of kindergarten and school in early identification.
- Early identification and pre-school exam of skills.
- Educating parents about schooling.
- Educating teachers about children with special education needs.

Module Seven: Early development and collaboration of related professions.

- The possibilities of collaboration among health professionals and experts of education.
- The possibilities of collaboration among social professionals and experts of education.
- The possibilities of collaboration among health and social professional and experts of education.
- Applied team work and its conditions.

Module Eight: Communication with the family

- The importance of communication, different approaches.
- About the importance of communication training.
- Communication workshop with specialists.
- Pair work.
- Personal report on situations, emotions.

Module Nine: Workplan to promote institutional normalization

- Normalization in theory
- Normalization in practice.
- Disseminating information on different aspect in health care, social care and education

Module Ten: Workplan presentation, final exam, feed-back

- Presentation of the participants' workplans in workshops
- Discussion of the workplan
- Summarizing best practices
- Evaluation of the programme

Location: in institutions of education, in social or health institution. Different practices will be shown during the workshops.

Requirements: to compile a workplan which can promote integration and normalization and can be executed either in the participant's place of work

Evaluation: After executing the workplans, experiences and result will be discussed in the framework of the final module.

Quality assurance: The participants fill in a questionnaire assessing the training, which will be evaluated. On the basis of it an action plan will be carried out.

Documentation: Similarly to any accredited trainings held in social or health institutions.

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In my opinion the interrelation of theory and practice will contribute to the improvement of living circumstances of disabled people.

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8. Key words

Disabled
Children
Family
Mainstream
Empowerment

9. Abbreviations

BNO	Betegségek Nemzetközi Osztályozása /Hungarian/
ENSZ	United Nations
EU	European Union
FNO	Fogyatékosság Nemzetközi Osztályozása /Hungarian/
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Desabilities, and Handicaps
KSH	Hungarian Central Statistical Office
MTA	Hungarian Academy of Sciences
OECD	Organisation for Economic Co-operation and Development
SPSS	Statistical Package for the Social Sciences
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organization

10. Annex

10.1 Questionnaire

Dear Parents,

Annex 1.

Family relations of a child are of crucial importance. Relations between disabled children and their family members are no exception. In 2009, the University of Debrecen Faculty of Health is making a research into surveying the living circumstances and social provision of disabled children. With this research we would like to reinforce family relations and collect applicable forms of help.

By answering the questions you can assist in our work. The questionnaire is anonymous and voluntary. Data will be summarized, analyzed and used exclusively for scientific purpose.

This questionnaire will be forwarded to you by social, health and pedagogical professionals. We would like you to trust them and help our work by fulfilling the questionnaire, which will be collected by our colleagues when you have finished answering the questions.

Thank you for your cooperation.

QUESTIONNAIRE

1. Sex: male - female

2. Year of birth: …….

3. Family status
    - a/ Married
    - b/ Living with a partner
    - c/ Single parent

4. Highest level of schooling completed:
    - a/ 1-7 grades
    - b/ 8 grades
    - c/ vocation
    - d/ general certificate of secondary school
    - e/ college or university diploma

5. Number of your children: ……

6. How many of your children live
    - a/ in your own household ……
    - b/ in a long-term facility ……
    - c/ with relatives …....
    - d/ at other places ..….

7. Employment:
    - a/ more than 36 hours a week
    - b/ short and occasional
    - c/ unemployed
    - d/ getting child care benefit
    - e/ old-age pensioner
    - f/ student

8. How far is it from your place of work to your home?
    - a/ works at home
    - b/ 0-5 km
    - c/ 6-15 km
    - d/ 16-25 km
    - e/ 26-50 km
    - f/ 51 -100 km
    - g/ more than 100 km
    - h/ I don’t work.

9. The size of the settlement you live in:

a/ less than 2000 inhabitants
b/ between 2001 - 5000 inhabitants
c/ between 5001 - 10000 inhabitants
d/ between 10001 - 50000 inhabitants
e/ more than 50000 inhabitants

Household

10. How many people live in the household, together with your? …….

11. How many of the household members is under 18? …….

12. Who else live in the household?:

a/ husband/wife
b/ spouse
c/ grandparents
d/ child above 18
e/ other relatives
f/ other

13. Number of rooms in your home: ……..

Disabled children:

14. Number of your disabled children: ......
If you have more than one disabled child, please multiple the answers.

15. How old is your disabled child? ….. years old

16.The type of disability /you can sign more than one/

a/ seeing
b/ hearing
c/ movement
d/ mental disability
e/ lack of communication /autism/

17. Who diagnosed the disability of your child for the first time?

a/ the doctor before birth
b/ the doctor right after the birth
c/ special committee right after birth
d/ someone else, namely: …………………………

18. How old was your child then? …... years old

Services

19. Sign the service you or child is getting.

a/ regular monthly payment in cash
b/ payment in kind /eg. food, school books, fuel, both public utility charges and children's institution fee for free, free national health service/
c/ village or farm caretaker service,
d/ meals,
e/ home service,
f/ family support,
g/ home support for call,
h/ community services,
i/ supporting services,
j/ street social work,
k/ day care service
l/ placement at long-term facility,
m/ other specific service
n/ child welfare service

20. Do the services you are getting solve your problems?

- a/ absolutely
- b/ partly
- c/ not at all

21. What other services would you apply for relating to the disability of your child?

- a/ payment in cash
- b/ payment in kind
- c/ new services
  such as: ………………………………………………………………...

22. How are the tasks around your child shared? Try to express it per cents.

a/	You and your family	…. %
b/	health services /doctors, health visitors, hospital, etc./	…. %
c/	social services and institutions	…. %
d/	school, kindergarten	…. %
e/	remedial education teaching	…. %
d/	neighbours	…. %
e/	others, such as: …………………………………….	…. %

23.How much did you spend on babysitting, if any? ……… HUF

Free time

24.How many hours does your child spend on average at the following places?

at home	hours
creche, kindergarten, school	hours
long-term facility	hours
other places such as:	hours

25. How many paid holidays did you have last year?

- a/ …… days
- b/ I didn’t work
- c/ I don’t know

26. How many days have you used up? ……. days

27. How many days did spend doing the following activities? Only the most typical activities should be answered.

a/ holiday in your country, travelling …. days
b/ holiday abroad, travelling …. days
c/ holiday in your home town: going to the beach, outings, sports …. days
d/ patient care …. days
e/ caring for your child …. days
f/ learning …. days
g/ house building …. days
h/ farm work …. days
i/ other part-time paid jobs …. days
j/ household chores, administration, etc / …. days

28. How many nights/days did your disabled child spent outside your home, away from you?

a/ in a camp …. days
b/ at relatives …. days
c/ in long-term facilities …. days
d/ in hospital …. days
e/ at other place, namely: ……………………………….. …. days

29. When did you last see your disabled child?

a/ she/he is with me
b/ in a day
c/ in a week
d/ a month ago
e/ a year ago
f/ several years ago
g/ other, such as……………………….

Future

A/

30. If your child lives at home at the moment, would you place him/her at a long-term facility, if your circumstances were getting worse?

a/ yes
b/ no
c/ I would think about it
d/ I don’t know

B/

31. If your child stays at a long-term facility, will you take him/her home, into your own household?

a/ yes
b/ no
c/ yes, if I get some help

32. What kind of help would you need in the above mentioned cases?

a/ personal help from someone
b/ technical aid, instrument
c/ rebuilding our home
d/ financial support
e/ other: ……………………….

33. How far is to get to the log-term facility, where your child is living, from your workplace? ……. km

34. What are your biggest problems related to having and caring for a disabled child?

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

Thank you for answering the question.