

**“DIFFERENTLY WITH DIGNITY” —
The Hungarian Ombudsman’s Disability Project**

**INVESTIGATION INTO THE PROBLEMS AFFECTING CHILDREN
LIVING WITH AUTISM**

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I. Introduction to the institution of the Ombudsman in Hungary

The main task of the Ombudsman (Parliamentary Commissioner for Civil Rights) is to investigate any abuses of constitutional rights he/she has become aware of and to initiate general or particular measures for their redress. The Ombudsman is solely accountable to Parliament. As for the legal status of the Ombudsman, in the course of proceedings he has to be independent and may take measures exclusively on the basis of the Constitution and law. The Ombudsman is elected for a six-year term by a majority of two-thirds of the votes of the Members of Parliament. The election is based on a proposal by the President of the Republic. The Ombudsman may be re-elected for a second term.

Act LIX of 1993, on the Parliamentary Commissioner for Civil Rights, states that anybody may apply to the Ombudsman, if they have suffered injury as a result of action of any authority or body performing a public service, or a decision taken in the course of action, or omission by an authority that has resulted in the infringement of their fundamental rights, or if a risk thereof exists.

The Act on the Ombudsman gives an exhaustive list of authorities. These are (1) Bodies or organisations fulfilling state administration (e.g. town officials, the Construction Authority, guardianship authorities, customs and excise); (2) Any other body acting as state administrative authority (e.g. the Land Registry, the Hungarian Energy Office); (3) The police, the armed forces and security services; (4) Local government, minority self-government, the office of the mayor; (5) Notaries public; (6) Court bailiffs; (7) Bodies performing public service (e.g. water, gas and electricity suppliers, social services and healthcare, educational institutions, parking companies, public service media).

The fundamental rights may be infringed by (1) Unreasonably long procedures; (2) Discrimination; (3) Provision of inaccurate or wrong information; (4) Unfair treatment; (5) Refusal to disseminate information on unreasonable grounds, and (6) Unlawful decision.

A very important aspect of the Ombudsman's role is that a complaint may be filed even if the complainant has already exhausted the available administrative remedies - except for judicial review of administrative decisions - or where no legal remedies are ensured. Cases where the Ombudsman cannot help (1) If the procedure has begun before 23 October 1989; (2) If the non-appealable decision was made more than one year ago; (3) If the legal proceeding is pending or is already *res judicata*; (4) With regard to acts of Parliament, the President of the Republic, the Constitutional Court, the State Audit Office or the public prosecutor's office (except for the investigation office of the public prosecutor), and (5) If the plaintiff seeks legal counsel.

The Ombudsman selects him/herself the course of action that is deemed to be more appropriate. Key measures are: (1) To make a request for remedy to the supervisory institution of the body that has infringed constitutional rights; (2) To initiate a remedy request at top management level; (3) To make a motion to the Constitutional Court for the examination of the unconstitutionality of a legal act; (4) To initiate (at the public prosecutor's office) the lodging of a public prosecutor's protest; (5) To propose that the Law Commission amends or repeals an existing legislative act or that a new legislative act is enacted, and (6) To submit the case to Parliament and request to be investigated by the Parliament.

II. Introduction to the projects of the Ombudsman

The Ombudsman *Prof. Dr. Máté Szabó* launched a new working method and a way of thinking after his election in September 2007. He determines every year what topics are especially important for the society and the enforcement of the rule of law and have a particular significance from the perspective of rights and freedoms.

Within these defined fields, he initiates special projects which have particular focus and consideration within the Ombudsman's Office (initiating particular investigations, etc), in the media and the public presentation of the Ombudsman. Since there is no independent parliamentary institution for the protection of the rights of the children, the Commissioner operates during his mandate as an ombudsperson for children's rights.

Projects in 2008 were: (i) Homelessness; (ii) Children's Rights (awareness-raising), and (iii) Freedom of Peaceful Assembly. Projects in 2009 were: (i) Rights of people living with disabilities; (ii) Children's rights (violence); (iii) Right to free movement and transport, and (iv) Right to strike. Projects in 2010 were: (i) Rights of elderly people; (ii) Children's rights (children in care), and (iii) Consequences of financial crisis.

II.1. "Differently with Dignity" — the Rights of People Living with Disabilities

The *basic thesis* of the prominent project launched in 2009 is that no one can suffer any disadvantage mainly because he/she lives with some kind of physical, communications or mental disability. The clumsiness of healthcare and social provision for people living with

disabilities is commonly known together with contradictions in their employment and training. First of all a real change of social attitude, their acceptance and inclusion would be needed to the solution, just as it is pressed for by the *Madrid Declaration* passed in 2002. People with disabilities would not need charity but a social environment which guarantees equal opportunities to everyone, and acknowledges their needs and their realisation.

It raises constitutional anxiety that the Hungarian legal system has still not properly adapted the UN Convention on the Rights of Persons with Disabilities recording the rights of people living with disabilities and has not practically acknowledged the fact that “the full and equal enjoyment of all human rights by persons with disabilities” includes their right to law and power of disposal. The Ombudsman is of the view that the assertion of basic rights is primarily not a financial issue, and the multiple disadvantageous situation of children with disabilities is particularly distressing.

The project of the Ombudsman lasting for one year had three professional events (*Public life — differently; Private life — differently; and From residential institutions to venues of custody*) where the social and legal circumstances adversely affecting people with disabilities were discussed. Problems related to the *right to vote* are caused partly by the lack of the freedom from physical obstacles and by that in information and are partly due to the definition of the circle of people entitled to exercise their right to vote. It was stated that society had destroyed the self-assurance of people living with disabilities and made them believe that they were unable to represent their own interests. The decision makers of the political environment have so far not even intended to offer them such an opportunity, and the Hungarian Constitution does not permit people living under guardianship limiting or excluding disposing power to exercise their right to vote, one of the most important means of taking up a role in public life.

The Ombudsman called attention to the fact that the UN Convention on the Rights of People with Disabilities does not mention the institution of guardianship but deliberately uses the term of measures pertaining to the exercise of the power of disposal, which primarily means supported decision making. Upon the initiative of the Ombudsman a *memorandum* was signed laying down the principles of the realisation of equal opportunities and equality before the law of people with disabilities, the tasks of the state and of civil organisations in order not only to guarantee a life free of discrimination for people with disabilities but also that they may participate in decision making related to them and its implementation as well.

Among the conditions aggravating the daily and family life of people with disabilities such issues figured prominently in the discussions like their self-determination, support of autonomous decision making, the requirement of freedom of obstacles in information and communications, often available only in theory, as well as the social attitude as a consequence of which placement under guardianship sometimes would become a lifelong stigma. The institutional employment of people with disabilities, their healthcare provision, as well as the legality and professionalism of measures limiting the rights of people with psycho-social disabilities and the background of monetary allocations were also on the agenda.

The Ombudsman has also undertaken the role of sharing professional and practical knowledge and experience necessary to the interpretation of basic rights and making people conscious of law. For this purpose the working group consisting of his associates has been cooperating with several civil organisations. For instance, they have made a publication together with the *National Federation of the Deaf (SINOSZ)* entitled *Human Rights Yes* on the legal education of people living with disabilities. The *Mental Disability Advocacy Center* and the Ombudsman jointly study the situation of the child inhabitants of some psychiatric homes from the angle of human rights.

The Ombudsman has found by his investigation launched in early 2009 that the educational system was unable to react upon the *special needs of children living with autism*. According to the report published there are not enough schools capable of receiving children with autism in Hungary, and there is an insufficient number of properly trained experts. The often talented children who cannot be taught together with their non-impaired peers cannot develop due to the lack of special institutions, they may get into humiliating situations and as adults they would have fewer chances for autonomous life. The Ombudsman has pointed out that it means a great financial burden for parents of children with autism and it may even end in the disintegration of families if there is often no suitable institution near their residence. The state does not adequately perform its constitutional obligation concerning the promotion of equal opportunities.

The follow-up investigation after the *closing down of the National Institute for Psychiatry and Neurology (OPNI)* was completed in 2009, which explored the consequences of the structural change of psychiatric care, the grave and acute shortcomings of psychiatric care for adults and children, the financing difficulties of outpatient care, the territorial inequalities of active and chronic care and the structural disturbances of addictology and care for patients of endangering condition as well as half solutions resulting from a shortage of specialists. The violation of basic rights was also identified by the investigation into the situation and conditions of inmates in law enforcement institutes as well as of those ‘treated’ at the Institute of Observation and Mental Health (IMEI).

The Ombudsman has invited artists as well to raise the attention of the society. As part of the project *Differently with Dignity* creative artists have also presented themselves at the exhibition installed in the Office of the Parliamentary Commissioner.

II.2. Proactive legal protection

About 20% of the world population lives with some kind of disability. It means about 650 million people of whom 577,000 live in Hungary according to the data of the 2001 census. According to the fact sheet of the UN people with disabilities constitute the largest minority of the world.¹

¹ Ld.: <http://www.un.org/disabilities/documents/toolaction/pwdfs.pdf>

The stipulations of the UN Convention on the Rights of People with Disabilities can effectively help the realisation of the rights of the 577,000 Hungarians living with disabilities if the Accord and national law are harmonised as a consequence of the requirements of the Accord and if the processes of implementation of the Accord on national level and also the relevant control mechanisms are operating properly with adequate intensity. These preconditions are indispensable so that the vision defined below by the first Article of the Accord may be realised: *The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*

We have investigated the domestic situation of basic rights protected by the UN Accord in our project entitled *From residential institutions to venues of detention*; we have dealt with the conditions of institutional care for people living with disabilities within the various types of provisions. When studying the institutional care for people with disabilities we investigated into the possibilities of taking up public and private roles as well as anomalies of institutional structure and “the traps of total institutions”. In this context we have also analysed issues of institutional occupations, healthcare provision, measures limiting the rights of people living with psycho-social disabilities (binding down, locking up, sedatives) and the relationship between the guardian and the person under his/her care.

The Ombudsman and his working group has had extremely fruitful cooperation with several civil organisations, among others with the National Federation of the Deaf and Hard of Hearing (SINOSZ), the Mental Disability Advocacy Center (MDAC), the Hungarian Federation of the Blind and Partially Sighted (MVGYOSZ), the Regional Central Hungarian Association of the Blind and Partially Sighted, or with the Hungarian Autistic Society (AOSZ).

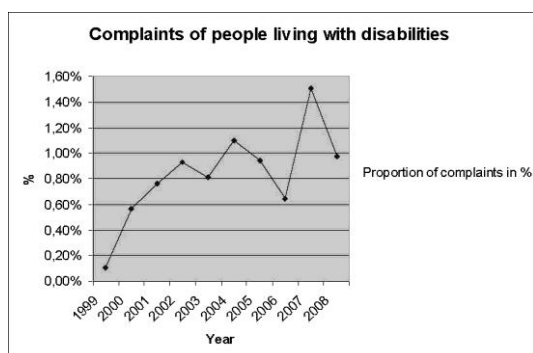
II.3. Distribution of Complaints Related to the Rights of People Living with Disabilities (1998-2008)

Provisions for disability, difficulties in parking, the situation of people living in residential care, the problems of freedom from obstacles, disputes related to employment, and generally the position of a child or adult with disabilities living in families raise several issues awaiting solution. During the past more than one decade (1998-2008) almost four hundred complaints of the fifty thousand submissions received by the Ombudsman’s Office were related to some kind of problems of disabilities. This is only 0.8 per cent of all the cases, and of those hardly one hundred contained some complaints related to working capability. Complaints were related to children living with disabilities in 30 cases, and parking by persons of impaired movement constituted 18 cases. The number of those complaints which were against some kind of monetary provision, contribution or fee was 113.

In the year 2009, during concentrated work the number of complaints varied as follows:

- *The rights of people living with autism* (each complaint affected children with autism!), such as the violation of the right to education, or other cases affecting children with autism: 51

- Cases related to residential institutions (to the functioning of the guardianship authority, and personal payment): 3
- Cases related to the operation of habilitating institution: 3
- Cases related to the right of persons living with other disabilities (disability support, parking): 13
- Issue related to sign language: 1
- Issue related to the rights of people of impaired hearing: 1
- Complaint against the language exam procedure (language lab) of a person with impaired hearing: 1
- Removal of obstacles (homepage, transport, flat): 3
- The rights of people with impaired mobility (parking, moped car, detained, transport subsidy): 9
- Ex officio investigation related to the project: 4



III. On Investigations related to Children with Disabilities: The right of children with autism to education

The Ombudsman has launched an investigation (followed by several dozens of complaints) into the realisation of the right of persons living with autism to education within the framework of the “Differently with Dignity” project focusing on the rights of people with disabilities. The investigation extended over access to educational and teaching institutions of children and the possibilities of young adults for participating in higher education with *special regard to the fact that autism is a complex disability recognisable in early childhood and lasting to the end of one's life. Education and development during their entire span of life is necessary to the achievement and maintenance of the greatest possible autonomy of persons living with autism*”² There are also highly talented people among those living with autism or the disturbances of the spectrum of autism, that succeed in adjusting to society, but a significant part of them require support to the end of their lives. According to indications of civil organisations however, children living with autism often have no access to an educational and teaching institution suited to their condition.

² Autism Foundation - www.autizmus.hu

The Ombudsman has requested information from heads of the relevant civil organisations, from the Minister of Social Affairs and Labour, from the Minister of Education and Culture, and from eight experts' and rehabilitation committees examining learning ability. When drawing conclusions from the investigation he paid attention also to the results of the Research into Autism conducted by the National Federation of People Living with Autism.

The Hungarian Autistic Society (henceforward: AOSZ) is the umbrella organisation in Hungary in respect of autism: it has 54 member organisations and more than 1300 private individuals. On 27 January 2009 AOSZ held a professional day discussing the National Research into Autism coordinated by them. The aim of the research was partly to map the family situation of children and young adults with autism, their healthcare provision and their participation in education, and partly, after summing up the results of the research, it initiated such legal norms and measures to be introduced by the National Programme of the Disability Affairs the implementation of which could promote the improvement of the living conditions of people living with autism. According to information received from AOSZ at least 7000 children with autism were supposed to appear in the 2007-2008 academic year, but the national statistics of the Ministry of Education and Culture indicate that only 1276 children and pupils appeared in the system.

The Acting Secretary and Chairperson of the National Federation of People Living with Autism pointed out in their submission to the Parliamentary Commissioner that there was no specialisation for autism at the Bárczi Gusztáv Faculty of Special Needs Education of Eötvös Loránd University. In 2009 "higher specialist extension training" was launched for diploma-holding special educationists of handicapped children, but the Federation is of the view that it cannot substitute the basic training in autism of specialist teachers. They also called the Ombudsman's attention to the fact that in *Act XXVI of 2008 on Ensuring the Rights and Equality of Opportunity of Persons with Disabilities* (Fot.) there has been basic training in the case of several branches of disability mentioned in the Act. In addition they have also underlined that there were such educational institutions which, referring to the fact that provision for children with autism did not figure in their constitution do not admit children with autism applying for admission. The AOSZ has also pointed out that it is the experts' and rehabilitation committees examining learning abilities that make recommendations as to the place and methods of education in the interest of realising the right of children of special educational requirements to education. Experts of those committees, however, are primarily prepared for the investigation of the various degrees of learning difficulties and the associated disturbances, and the diagnostic means used by them are suited for the investigation of those disabilities.

The Acting Secretary of AOSZ also informed the Ombudsman that the greatest difficulty in the field of educating children with autism was that the education and teaching of children with autism did not figure in the constitution of every institution of special curriculum. A great deal depends on the parent's proper information and endurance because it is very difficult to find the proper educational and teaching institution for a child with autism. Therefore in 2008 AOSZ, involving the leading experts of autism and of specialist politics drew up the development plan of institutions related to people with autism (diagnostic places,

schools, care for adults, and training of experts) upon the commission of the Ministry of Social Affairs and Labour. The National Autism Strategy³ (henceforward: Strategy) phases those tasks and proposals for the modification of law for 5 years, up to 2013, that are to be implemented by the government of the day so that the current national deficiency of provisions should be reduced.

According to the Strategy the services of the current domestic system of care should be developed quantitatively as well as qualitatively in order to ensure the impairment-specific development, training and education of children and adults with autism to be tailored to individual needs. Keeping in view that the current supply of experts is inadequate in numbers as well as in quality and the per head payment after pupils with autism is also not in proportion to the needs, ultimately the institutions do not get either financial or professional support to an adequate extent.

The aim of the Strategy is to take such long-term measures which simultaneously assist and make the institutions interested in providing professional care but also expectations are set against them. As surveying, planning and development as well as the prevention and treatment of grave behavioural problems often associated with autism are all totally tailored to the individual, autism-specific education and training is extremely expert demanding. Therefore the Strategy has targeted the increase of the expert-child and pupil ratio so that it may gradually approximate the proportion specified by international recommendations up to 2013. In addition the Strategy also emphasizes that the elaboration of the common criteria of a quality autism-specific education is necessary because the unevenness among regions and types of institutions could be mitigated by them and children living with autism may receive a more uniform and better controlled provision.

The Strategy also stands for the setting up of a professional orienting and consulting organisation, the Autism Professional Workshop (henceforward Workshop) of temporary nature for five years (for the time span of the Strategy) to coordinate issues affecting several professional areas and the large number of developmental tasks. The Strategy has specified 31 May 2009 as the ultimate date for the setting up of the Workshop. According to the Strategy the AOSZ, in the interest of identifying the need for experts has undertaken to map what kind of and how many experts would be needed by region and field of specialisation. The Acting Secretary has emphasized that the approval of the Strategy in a government resolution would ensure the implementation of its contents. The associates of AOSZ have handed over the elaborated Strategy to the Ministry of Social Affairs and Labour in the middle of 2008, but so far the government resolution has not been passed.

Experts of the Autistic Society have stressed above all that the number of diagnostic places equipped properly with trained staff and a standard set of diagnostic tools is very little. Long waiting lists are frequent in those places. It may happen that children receive different diagnoses at various diagnostic places or the drawing up of the diagnosis is protracted for long. It is also quite frequent that after the setting up of the diagnosis there is no impairment-specific provision. Associates of the Society have also informed the Ombudsman that

³ "Medium-term concept of institutional system for the rehabilitation of persons living with autism"

committees investigating learning ability often do not have experts trained in the field of autism. In addition part of children with autism often wander from institution to institution because no proper school can be recommended to them. Parents are often recommended to look for an institution admitting their child that would be subsequently recommended by the committee in its expert opinion.

The associates of the Society have stressed that the realisation of the educational rights of people with autism is also often impeded by the lack of information. For instance, it is a problem that in many cases it is not clear to the school management at what learning disability a given specialist teacher of handicapped children can be employed. Such teachers of the Society have also said that private studies do not mean real provision for children with autism. It can be regarded as a kind of excuse by the institution. Educational institutions often exercise pressure on parents to force the child into a status of private pupil. In such cases the institution is legally obliged to give ten lessons a week only which is absolutely not sufficient for a child with autism. Parents have repeatedly indicated it to the Society that the educational institution often requests the parents to try and have a different diagnosis written in the expert opinion or should "keep it a secret" that the child is of a specific educational demand so that the institution may admit him/her.

In his answer the Minister of Social Affairs and Labour informed the Ombudsman that the aim of elaborating the concept of the complex rehabilitation of persons living with autism and of the institution suited for diagnosing autism was set by the medium-term action plan of the National Programme for the Disability Affairs for 2007-2010. The realisation of the task was started by the Ministry, involving AOSZ, in early 2008.

The concept prepared by AOSZ, the Strategy has been discussed professionally, and even its inter-portfolio adjustment with the Ministry of Education and Culture and the Ministry of Health has been completed and as a result the Strategy has been reworked. According to the Minister's information a draft government resolution is planned to be submitted to government in 2009 on the basis of the final concept, which is expected in the near future and will contain specific tasks related to complex rehabilitation and diagnosis. Further on, he has also indicated that some elements of the concept were already considered when the earmarked budget and special programmes of 2009 were drawn up. This year's tasks include the setting up and operation of the Autism Professional Workshop specified by AOSZ as a requirement, which would do the coordination of developmental tasks pertaining to several specialisations. The Ministry also wishes to launch the model programme of autism crisis institution recommended by AOSZ for the temporary care of persons with autism in a crisis situation. The Ministry also wishes to support the special extension training of persons in autism out of its budget.

The Minister of Education and Culture has informed the Ombudsman that as a first step so-called "experimental groups" were launched from 1990 on with a view to elaborate professional frameworks and those of content that would successfully develop children living with autism. The Autism Research Group has been doing the examination and diagnosis of

children, assisted and directed the work of the experimental groups with the financial assistance of the Ministry.

The competence-based programme packages have been published in the framework of the Human Resources Development Operative Programme of the National Development Plan (henceforward: HRDOP), as an outcome of development work serving the creation of opportunities in public education for pupils of special demands which are also suited for supporting education together with others. Recommendations considering the specificities of every type of disability including autism spectrum disturbance have been made for each programme package. The recommendations contain among others the description of special features necessary to the identification of disability causing special educational needs, the underlined areas of abilities and expectations linked to the area of competency, as well as forms of the organisation of knowledge, further on, forms of behaviour which can be expected from the teachers and the non-impaired members of the learners' group in the receiving educational and teaching institution. Methodological institutional guidelines, documentary guidelines as well as sets of tools promoting life and learning by the different types of disabilities promoting daily pedagogical work for every field of disability were also elaborated within the framework of the HRDOP programme. The elaboration and publication of all this has created the legal and professional foundations ensuring the development of a network that safeguards care.

According to the Minister's stand the growth of the number of institutions providing care is an encouraging trend, but in the interest of developing a network ensuring an equal level of and all round care he considers that it is necessary to take further steps. In his answer the Minister agreed with the suggestion that one of the major problems has been and is still the lack of relevant experts and their training in the care provision system of people with autism. Some years ago the Autism Research Group has joined the Bárczi Gusztáv Faculty of Special Needs Education of Eötvös Loránd University (ELTE BGGYK) as an External Departmental Working Group on Autism in theoretical and practical training, and practicing educationists can obtain basic skills necessary in their work in two accredited extension training courses⁴ as part of the extension training of educationists.

The educational portfolio closely cooperates with the Ministry of Social Affairs and Labour in the elaboration of the concept of the complex (occupational, social and pedagogical) rehabilitation of people living with autism as well as of the set of institutions suited for diagnosing autism (Strategy) as the latter one coordinates this work. The professional discussion of the Strategy has been completed and a draft of a government resolution, also containing the definition of tasks as well as the cooperation of ministries can be expected in the near future. The Ministry has taken the concept under preparation into consideration when the professional tasks of 2009 were planned, and would analyse the professional work of institutions performing well, their personnel and objective conditions during the year. Keeping in view the results the Ministry would have indicators elaborated that could measure the quality of special provisions for autism in a form and content so that they may be

⁴ "Pedagogical development of people with autism" is a basic course, and "Development of the social and communications abilities of children living with autism" is an advanced course of communications and social skills.

incorporated into the institutional programmes of institutions providing care for children and pupils with autism.

Based on the written answers of the Ministries the Ombudsman has contacted the heads of eight experts' and rehabilitation committees, asking them to give information on the placement of children with autism in kindergartens and schools, as well as about current problems related to their education and teaching, and also requested them to present their professional views.

Based on the reports of the experts' committees contacted the Ombudsman has found that conditions of provision are highly different among various counties in Hungary, but the head of each committee contacted has stressed that there was a lack of a sufficient number of experts and adequate kindergartens, and in settlements outside the county headquarters provision for children with autism was not available in their place of residence, there were few experts and special educational and teaching institutions, and there would be great need for the development of a network of travelling specialist educationists in each county.

According to information given by the head of AOSZ a significant part of the results was based on surveys by questionnaire and interviews made with 700 families bringing up family members with autism. The questionnaires were filled by members of AOSZ and those availing themselves of the services of member organisations; therefore they do not represent the 'total' population consisting of families bringing up family members with autism.

Specific questions put by the Ombudsman were answered by the Chairman of AOSZ on the basis of the quick reports⁵ drawn up by the researchers up to early August 2009. According to the findings of the research there were 9.1 pupils with autism for every 10,000 in public education in the academic year 2008-2009. The number of such pupils has been steeply and continuously growing in absolute numbers as well as per 10,000 pupils participating in public education. About one-third of those pupils, 35% of them participated in integrated education. Pupils with autism participate in integrated education in different proportions at the various levels of public education. Their proportion is the highest in kindergartens, where it is 80% compared to all children with autism attending kindergarten. In comparison only 47% of the pupils attend integrated classes in primary schools, and this proportion is the lowest in vocational and secondary schools. In other words a large part of pupils still learning in integration in kindergartens would later on get into special education, presumably also because a proper integrating school is not available.

Based on regional data great unevenness can be experienced. The number of pupils with autism is the lowest in South Transdanubia, and the largest number of pupils with autism was in the Central Transdanubian and South Plain regions. Between 2002 and 2008 the regional distribution of institutions receiving pupils with autism seems to get balanced with the exception of the South Transdanubian region.

⁵ *Virág BOGNÁR: Az autizmussal diagnosztizált népesség az egészségügyi és a közoktatási rendszerben Összefoglaló kutatási jelentés, Budapest, 2009. június Kézirat (Population of diagnosed autism in the systems of healthcare and public education. Summary research report. Budapest, June 2009. Manuscript). Kiss Márta: Országos Autizmus Kutatás Kutatási Jelentés, Budapest, 2009. augusztus 4. Kézirat (National Autism Research Report. Budapest, 4 August 2009. Manuscript.)*

The proportion of pupils participating in integrated education also differs by region; the largest part of pupils with autism registered in 2008 received integrated education in the Northern Plain, and its smallest proportion was in the territory of Central Hungary. According to the results of the research altogether 11.5% of all persons living with autism below the age of 20 did not receive any level of educational provision. The reason of the lack of provision was the lack of proper opportunity or expert in 19 cases, and the condition of the child and behavioural problems in 8 cases.

Finding the proper school is a difficult task for parents, and this is supported by the figure according to which 26% of parents questioned during the research had tried admission at several institutions by the time they could place their children in a proper institution. The reason for rejection in most cases was that “there was no training for persons with autism in the institution”, or “the child did not belong to the institution by territorial distribution”, and several institutions mentioned the lack of experts and places. Every third family said during the course of the survey that they were forced to change school at least once, and 38% had to do so for more than once due to dissatisfaction with the school, to the teacher’s attitude, lack of qualifications or to problems of adjustment. According to the research travel also meant a major problem for families bringing up children with autism, together with the additional costs, and also because the condition of most children did not allow for the use of community transport.

According to the data of the research two adults with autism had upper level diplomas in the full sample, and there are several data on higher studies in progress or without completion, but as the research shows about 70 to 75% of adults living with autism had primary school education or even less. In summary it can be stated that the largest part of people living with autism participates in such forms of education which do not give basic qualifications.

According to AOSZ the experiences of the research show that the greatest problem in relation to access to education by children with autism is caused by the inflexible and fragmented educational system. Autism is a ‘new’ branch of disability, even if its diagnosis began in Hungary two decades ago. The educational system according to AOSZ, is unable to react upon the special needs. It tries to include children with autism in its own system, unfortunately often shaping them according to its own expectations instead of trying to satisfy the special needs of people living with autism.

Only 40 to 50% of children with autism, receiving special outpatient care appeared in integrated or special education between 2002 and 2007. According to AOSZ the explanation is that though the other, ‘missing’ part of children with autism presumably receives some kind of education, the school does not know about them that they live with autism. This is possible either because the experts’ and rehabilitation committee, examining learning ability does not accept the diagnosis set up by the child psychiatrist, or the parents, in the interest of ensuring proper education and hoping admission to the institution deliberately keep silent about the existing medical diagnosis. The educational institution, however, does not know about the problem in these cases, therefore it is unable to ensure professional care and development based on needs for the child.

The AOSZ is of the view that in most cases these children are included in the educational system as mentally retarded which is risky because measuring the intelligence of people with autism is rather uncertain according to the current practice. Thus it may happen that a child of sound intellect would be sent to the school of children with mild learning difficulties because the symptoms are misunderstood (for instance a non-cooperating child at the test of verbal intelligence) and a diagnosis of mentally retarded is issued. At this point the basic problem is that though there are such standard intelligence tests by which children with autism can also be examined, the experts' committees are not trained to use them.

Keeping in view the above information the Ombudsman has underlined that based on the relevant legal norms it is the duty of the state just as much to assert the right to education of children living with autism or autism spectrum disturbance as well as of young adults past 18 as in the case of other children. Children with autism just as much need experts of proper specialisation and educational and teaching institutions that are integrated or special ones depending on their condition, namely they need smaller or bigger communities in the interest of unfolding their talent, of developing their personality and expanding their knowledge in order to develop into adulthood capable of caring for themselves and of independence.

As stipulated by legal norms the experts' and rehabilitation committee, examining learning capability decides if the child is of special learning requirement that is living with autism. The committees contacted have supported the assumption of AOSZ and of the Autism Foundation that experts of the committees are not prepared professionally for the expert diagnosis of autism, nor do they possess the necessary tools of examination. Therefore the lack of examination tools constitutes an obstacle in the way of providing proper care for the capabilities and circumstances of children with autism or autism spectrum disturbance, hence the Ombudsman has stated that *the inadequate training of the experts of experts' and rehabilitation committees examining learning capability and the lack of examination tools cause an adverse situation related to the right of children with autism to human dignity and to the principle of equal opportunities.*

The Act on Higher Education rules that the direction of the branch of higher education is to be done by the Minister of Education and Culture. The Minister participates in the preparations of the state decisions on the policy and development of higher education and shapes them, further on he/she governs the science policy of the branch and its implementation, and he/she coordinates the development of the national concept of science policy and makes the relevant submissions. The Minister avails him/herself of the opinion of the Hungarian Accreditation Committee for Higher Education as well as of the Council of Higher Education and Science to his/her decisions. Within the competency of the Minister of Education and Culture responsible for higher education he makes recommendations to the government for the number of students to be admitted to higher education financed by the state, he/she decides on the number of students to be admitted to Master courses and for PhD financed by the state as well as on the distribution of seats in special further training among the institutions.

Currently it is only the ELTE BGGYK which offers higher specialist training for teachers of handicapped children under the title "pedagogy of autism spectrum disturbances", which is,

however, against tuition fee. This year about 25 specialist teachers participate in this training. Students of special education have an opportunity to acquire specialist skills free of charge from the second year as part of basic training for seven branches of disabilities, but this is not ensured in the case of autism. It can be stated on the basis of civil organisations, the reports of the experts' committees and data of the National Autism Research that there is need for a far greater number of experts than the cadre currently available in Hungary. Therefore, in the interest of ensuring experts of adequate expertise in the field of autism the extension of training in autism specialisation as part of the basic education of specialist teachers is indispensable.

As a first step towards extending basic training the College has started to elaborate the curriculum of specialisation in autism. The Dean of the College, however, has indicated that there is need for increasing the number of students, for ensuring personal and objective conditions such as teachers and teaching aids are necessary to the inclusion of autism specialisation in undergraduate education. According to the Dean's information the ELTE BGGYK is not only open to launching undergraduate and master's courses (BA, MA) in the field of autism, but the professional conditions of such training are also available due to the professional contacts of the College.

The experts' committees, civil organisations contacted during the investigation as well as data of the National Autism Research have pointed out that the number of properly trained experts helping children living with autism spectrum disturbance is insufficient, therefore the provision of adequate educational and teaching institution in the residence of such children is not solved in the majority of the counties. In the interest of increasing the number of experts there is need for the training of more specialist educationists so that children living with autism spectrum disturbance may be educated and taught in an educational and teaching institution in the place of their residence.

Keeping in view the above situation the Ombudsman has found that the lack of specialist teachers of adequate training causes an adverse situation in respect of the right to human dignity of children living with autism, of the requirement of equal treatment as well as their right to education and culture.

It is also clear from the written answers of the experts' committees that in many cases the committees are unable to find a suitable educational and teaching institution for children having the diagnosis of autism because the available list of institutions does not contain any. With the exception of the Experts' Committee of the Hajdù-Bihar County Special and Pedagogical Professional Services Institute all committees contacted have indicated that they did not find the number of kindergartens and schools dealing with children with autism sufficient. Kindergartens and schools do not include the provision for children with autism in their constitution because they do not have expert teachers properly qualified in the field of autism. In an unprepared educational institution the condition of pupils who can otherwise be integrated and excellently developed would deteriorate and later on as adults they would have less chance to conduct their life independently, and to become useful members of the society. Children who may be less integrated cannot develop because of the lack of special

educational and teaching institutions, they may get into humiliating situations hurting their human dignity, and as a result of rejection due to the lack of understanding they would be pushed out of their environment even more.

Based on the data of the investigation it can also be stated that even if there is such an educational and teaching institution in a county which can receive children with autism, in many cases it is located rather far away from their residence. Additional cost of transport is often a major burden on parents, in addition it takes up additional time as a result one of the parents can take up only a four-hour job or is forced to give up employment, and ultimately the existence of the family may be endangered.

On the above basis the Ombudsman has found that the lack of a system of institutions capable of providing for the complex development of children living with autism spectrum disturbance causes adverse situations in respect to the right of children with autism to human dignity, to their right to protection and care, to the requirement of equal treatment as well as to the right of children with autism to education and culture.

In the interest of eliminating and avoiding the malpractices related to constitutional rights in the future the Ombudsman has recommended the following:

- To the Minister responsible for healthcare and to the Minister of Social Affairs and Labour to see to it that the medium-term action plan for the years 2007-2010 of the new National Programme of the Disability Affairs is implemented, with special regard to the deadlines⁶;
- To the Minister responsible for education to see to it that that the medium-term action plan for the years 2007-2010 of the new National Programme of the Disability Affairs is implemented, with special regard to the deadlines⁷;
- To the Minister responsible for education as well as to the Minister of Social Affairs and Labour to regulate the training requirements of undergraduate training of specialist teachers in autism specialisation as well as the personal and objective conditions of such training in a legal norm.⁸

⁶ 2 April. "The rules of operation based on the coordination of the existing provision systems of early childhood diagnostics and development as well as a phased plan of the setting up of the system should be created."

³ April. "The concept of an institutional system suited for the complex (employment, social and pedagogical) rehabilitation of persons living with autism as well as for the diagnosis of autism should be created."

⁷ 3 January. "The sphere of institutions receiving pupils of special educational needs+of public education should be expanded. The implementation of methods better adjusted to individual learning needs should be ensured. Schools participating in special education and teaching should be prepared for performing methodological tasks related to the teaching of children of special educational needs."

⁸ 5 January. "In institutions training primary school and other teachers the possibility of learning the communications and teaching methods to be used in integrated educational forms and in dealing with children of disabilities should be created."

SUMMARY

“Differently with Dignity” – The Hungarian Ombudsman’s Disability Project

Investigation into the problems affecting children living with autism

MÁTÉ SZABÓ

The Hungarian educational system cannot handle the special needs of children living with autism appropriately. Civil society organizations have blown the whistle because in many cases such children do not have access to the educational institutions they need. More and more parents have turned to Máté Szabó, Parliamentary Commissioner for Human Rights, to help them find the right institution for their children. Some of the people living with autism spectrum disorders are highly talented and manage to fit in; others need support throughout their lives even though their disability was recognized in early childhood. In early 2009 the Ombudsman began an investigation into the access to the appropriate educational institutions of children living with autism and into the opportunities of young adults with autism to enter higher education. Having analysed reports by experts on learning abilities and rehabilitation committees, the Ombudsman concluded that today Hungary does not have enough schools that can admit children living with autism, neither are there enough experts with the required training. Relying on statistics issued by Hungarian Autistic Society, the Ombudsman’s report says that Hungarian schools cannot satisfy the special needs of children living with autism. Efforts are made to oblige the children living with autism to adjust to the school requirements and not the other way round.

It has been found that the state of children living with autism - who could be integrated into society and whose skills could be greatly improved - is bound to deteriorate if the teachers who treat them are not appropriately trained. In the absence of adequate schools, the children living with autism - who cannot be taught in the same class with their nondisabled peers - do not get the required opportunity for development; occasionally they are even caught in humiliating situations and when they grow up, they will have less chance to live unattended.

The report of the Ombudsman says that when there is no appropriate school nearby, that is bound to strain the budget of the family and can even ruin the marriage of the parents. If appropriate nursery schools and primary schools are missing in the neighbourhood, the children living with autism face an unjustified disadvantage. Affirmative action is needed if children living with autism are to receive equal treatment with their non-disabled peers. In the absence of such measures, the state fails to honour its constitutional obligation to ensure equal opportunities for all, writes Máté Szabó, Parliamentary Commissioner for Human Rights.

RESÜMEE

„Mit Würde anders“ —

Untersuchung des Parlamentsbeauftragten der Staatsbürgerrechte

Untersuchung der Situation der Kinder mit Autismus-Spektrum-Störung

MÁTÉ SZABÓ

Das Bildungssystem kann nicht auf die besonderen Bedürfnisse der mit Autismus lebenden Kinder reagieren. Den Berichten der Zivilorganisationen zufolge haben sie in vielen Fällen keinen Zugang zu Erziehungs- und Lehranstalten, die ihrem Zustand entsprechen. Immer mehr Eltern wenden sich an Ombudsmann Máté Szabó und bitten ihn um Hilfe, um für ihre Kinder eine entsprechende Institution zu finden. Unter den mit einer Autismus-Spektrum-Störung Lebenden gibt es sehr begabte Menschen, denen es gelingt, sich in die Gesellschaft zu integrieren. Ein bedeutender Teil dieser Menschen ist jedoch - obwohl ihre Behinderung bereits im frühen Kindesalter erkannt wird - bis zum Lebensende auf Unterstützung angewiesen. Der Ombudsmann untersuchte ab Anfang 2009, wie diese Kinder in die entsprechenden Erziehungs- und Lehranstalten aufgenommen werden können, welche Möglichkeiten junge Erwachsene haben, um an der Hochschulausbildung teilnehmen zu können. Der Ombudsmann stellte auf Grund der Erfahrungen der Experten- und Rehabilitationskommissionen, die die Lernfähigkeit untersuchen, fest, dass heute in Ungarn nicht genügend Schulen existieren, die Kinder mit Autismus aufnehmen würden, und dass auch ein Mangel an entsprechend geschulten Fachleuten besteht. Der Parlamentsbeauftragte betonte auf Grund der Forschungsergebnisse des Nationalen Verbandes der Autisten (Autisták Országos Szövetsége) in seinem Bericht, dass das heutige Bildungssystem den besonderen Bedürfnissen der mit Autismus lebenden

Kinder nicht entsprechen könne. Stattdessen versuche es, diese Kinder in sein eigenes System zu integrieren, sie auf Grund seiner eigenen Erwartungen zu formen, anstatt die speziellen Bedürfnisse der mit Autismus Lebenden zu befriedigen.

Infolge des mangelnden Fachwissens der Pädagogen und Heilpädagogen verschlechtert sich auch der Zustand der Schüler, die ansonsten integriert und deren Fähigkeiten hervorragend geschult werden können. Kinder, die nicht zusammen mit ihren gesunden Mitschülern unterrichtet werden können, haben mangels einer entsprechenden, speziellen Erziehungs- und Lehranstalt nicht die Möglichkeit, sich zu entwickeln. Sie können in demütigende, ihre Menschenwürde verletzende Situationen geraten und werden später als Erwachsene weniger Chancen für ein selbständiges Leben haben.

Der Ombudsmann wies auch darauf hin, dass es für die Eltern der mit Autismus lebenden Kinder finanziell gesehen eine große Last bedeute und auch zum Zerfall der Familien führen könne, dass es in der Nähe des Wohnortes oft keine Institution gibt, die die Kinder aufnehmen könnte. Im Vergleich zu ihren gleichaltrigen, gesunden Mitschülern erleiden diejenigen mit

Autismus lebenden Kinder unbegründeter Weise einen Nachteil, denen der Staat in ihrem Umfeld nicht den ihrem Zustand, ihren Fähigkeiten entsprechenden Kindergarten, bzw. solch eine Schule gewährleistet. Im Interesse der wahren Gleichheit sind positive Maßnahmen notwendig. Der Staat erfülle mangels dieser seine in der Verfassung vorgeschriebene, sich auf die Verbesserung der Chancengleichheit beziehende Verpflichtung nicht, stellte der Parlamentsbeauftragte der Staatsbürgerrechte, Máté Szabó, fest.