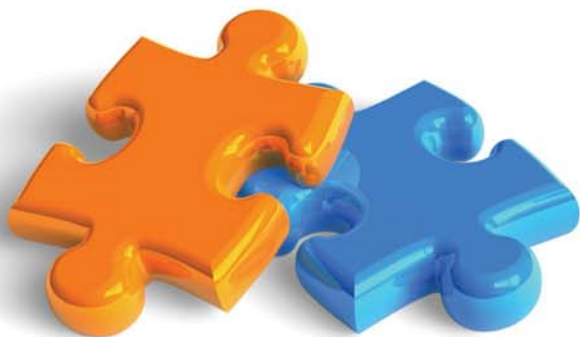


# Influence of the movement of parents of persons with intellectual disabilities on the development of science and social life

Research report



Warsaw 2014



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## Introduction

Polish Association for Persons with Mental Handicap (Polish acronym: PSOUU) solemnized in 2013 50th anniversary of the movement of parents of people with intellectual disabilities. PSOUU is a formal inheritor of the Committee for Support for Children with Special Needs, dealing from year 1963 in cooperation with Main Board of the Friends of Children Society. In 1991 PSOUU started as independent organization.

That beautiful jubilee was an excellent moment for remain beginning of activities, initiators and those friends who remarkably impacted for directions of activity of Association, but also was an occasion for summarizing and evaluation of possessions in different aspects and areas.

The desire of originators of international delves on influence of the movement of parents of people with intellectual disabilities on the development of science and social life - which result is this Report – was verification how in our country is seen PSOUU and how are seen such associations in other countries, in which parents are founders and impulsion of the movements.

Countries were chosen coincidentally:

- France, from its experiences Poland drew, during political changes, f.e. introducing in 1991 duty payments on PFRON for employers who aren't employing proper number of disabled people or found social and occupational centres,
- Lithuania, which gained independence and came through political transformation not long after Poland, had to face with soviet, highly dehumanized system of care of disabled persons,
- Italia, the only country in Europe, which in late 70's of 20'th century had inclusion education system for handicapped children,
- USA from which came the idea of self-advocacy and in which fight for civil rights of several groups is always inspiration for excluded in other countries in the world.

Invitation for taking part in Symposium, organized in frames of the project, despite the abroad researchers, were issued at the first place for the witness and perpetrator of the most achievements of polish parents movement, Honorary President of the Polish Association for Persons with Mental Handicap Krystyna Mrugalska. It was issued also for significant in polish environment representatives of world of science and practice. They were representing different kind of knowledge - sociology, psychology, medicine, rehabilitation, pedagogy and law. Their connection with the parents are dated on beginning of the movement in 60's of the last century sometimes.

They were:

- Professor Małgorzata Kościelska,
- Professor Anna Firkowska-Mankiewicz,
- Professor Antonina Ostrowska,
- Professor of Education Lidia Klaro-Celej,
- Professor of Medicine Jacek Zaremba,
- Professor Stanisław Kowalik,
- Justice Jerzy Stępień, former President of the Constitutional Tribunal in Poland.

Occurrences of most of invited precedents are in this report, just after the results of the researches in particular countries.

Historical material which were researched is very wide. Comparison of the movement in particular countries is for polish parents and intellectually handicapped significant and edifying. We received a message that we are not so different! Problems which have French, Italian, Lithuanian or American parents are the same. A bit different is only way of overcoming them. F.e. characteristic for American parents is folding lawsuits against state or federal administration. Comparison gave many information about this common threads, but there are differences also, f.e. in terminology.

In American report despite "self-advocacy" (intellectually handicapped speaking in their name) there is also used term "advocacy". This term define individual people acting for propagation the idea, public "speaking in the name of". In Poland term "spokesman" is associated more with formalized, placed in law, public function (Ombudsman or Ombudsman for Children) or with position of public relation officer for public or firm (spokesman is for Prime Minister, ministries, police and rail and so on). Among classic functions of non-governmental organizations there is advocacy, as action which "allows articulation of views and problems of groups which are not numerous to solicit their voices and are not rich and influential to win attention of public opinion. This organizations favors political and social integration of this groups with society". In Poland it concerns organizations (PSOUU has this role, as writes A. Wołowicz-Ruszkowska) not physic persons and parents (as wrote American researches in their study).

The second term rarely used in Poland, in context of environment acting for disabled persons, is present specially in Italian study, term "the culture of disability". Italian Report author titled even one of the chapters "The culture produced by the family associations in Italy". And the effect of cultural changes in Italy is that now „debate from care to of independent living, autonomy adult disability, non-discrimination and social inclusion – all of which characterize the activities of the organizations, the scientific community and the entire society". In Poland in 2008 was publicized translation of monograph of Colin Barnes and Geof Mercers titled "Disability" (edited by SIC!) with chapter "Culture of disability". This term is more often connected with taking part in culture and art of disabled people than used in such a wide context as in this monograph.

Hot encouraging Readers to introduce the report, I want to heartily thank to dr Agnieszka Wołowicz-Ruszkowska for inclusion the analysis of the activity of polish movement of the intellectually disabled persons parents in the scope of science interests and for active participation in foreign researches organization.



I want to remind also, enounced only during opening of XXXVII Science Symposium by President of the PSOUU Main Board, Joanna Janocha, thanks addressed to:

- Honorary President of the PSOUU Krystyna Mrugalska, for: "consequent, during few decades, care for PSOUU cooperation with world of science, also foreign, with huge own contribution",
- prof. Anna Firkowska-Mankiewicz, for: "many years of constant support the activities of our association through Polish Team for the Scientific Study of Intellectual Disabilities and specially support of Madame professor by herself".

Lecture of this report, same as presentations during Symposium, should leave in Your memory - as President Janocha said - "picture of the people determined to fight for better life and full rights of persons intellectually handicapped. People who their life experience transformed into readiness for help the others. Like says formed many years ago mission of the ourassociation".

*Barbara Ewa Abramowska*



*Agnieszka Wołowicz-Ruszkowska*

## Methodology of the study

In 2013 and 2014 the Polish Association for Persons with Mental Handicap (hereafter referred to as PSOUU) implemented an international research project co-financed by the Polish State Fund for Rehabilitation of Disabled Persons. The project's objective was to study the Influence of the movement of parents of people with intellectual disabilities on the development of science and social life (contract number BEA/000019/BF/D from 17 October, 2013).

The project was intended to diagnose and analyse the movement of parents of people with intellectual disabilities in Poland and other countries (France, Italy, Lithuania, and USA). This was achieved through a presentation of the functions fulfilled by the movements of parents in the countries under study and their positive impact on the beneficiaries, citizens, state institutions and science. After an analysis of the relevant reports, expert opinions and interview data, the project team described the current condition of the movement of parents of persons with intellectual disabilities in Poland (PSOUU: Agnieszka Wołowicz-Ruszkowska, Ewa Wapiennik-Kuczbajska), and in selected countries – Lithuania (Lithuanian Welfare Society for Persons with Mental Handicap “Viltis”: Natalija Olesova), Italy (National Council for Disability: Luisa Bosisio Fazzi), France (Poitiers University: Michel Billé), USA (Florida University: research team supervised by Diane Ryndak).

The project's key objective was to acquire knowledge on the role and potential of NGOs supporting people with intellectual disabilities in the creation of conditions, services, rehabilitation standards and inclusion based on equal rights, and to formulate and disseminate a register of best practices for the NGOs.

Through the development of model assumptions and standards for the NGOs and through suggestions for practical solutions resulting from the analyses, the project's outcomes may constitute a basis for the development of appropriate systemic solutions encompassing the areas of legislation, institutions and social life.

In recognition of a growing interest in NGOs and their immense contribution to the process of social inclusion and development of rehabilitation systems, the project team decided to analyse the functioning of the movements of parents of people with intellectual disabilities in Poland and the four partner countries.

The research area included a diagnosis and analysis of the impact of the movement on systemic changes and on the development of best practice in rehabilitation of people with intellectual disabilities. The team analysed the role of the movement of parents of people with intellectual disabilities as a catalyst of social change and change in the scientific approach to intellectual disabilities.

Project activities were implemented in two rounds. The first round was the already mentioned comparative study conducted in the 5 countries. The study included the following elements:

- desk research of the existing data sources documenting the achievements of the movement of parents in the fields of law, medical care, education, employment, accommodation, support for families, advocacy and social attitudes towards persons with intellectual disabilities;
- interviews with experts, representatives of public administration and/or representatives of parents' organisation, concerning the role of parents in the creation of support policies for people with intellectual disabilities in the above-mentioned areas. Moreover, interviews were conducted also with people with intellectual disabilities themselves; the interviews aimed at verifying their awareness of the existence and activities of parents' organisations.

The second round was an attempt to evaluate the role of the movement for the academia and science. It was performed by Polish scientists representing various fields: sociology, psychology, medicine, rehabilitation, pedagogy, and law.

The project was divided into three stages:

**The first stage** was the analysis of documents concerning the role of the movement of parents of people with intellectual disabilities for the shaping of social life (legal system, accommodation, education, social and vocational activation, advocacy, changing attitudes to intellectual disability, access to education and knowledge, support for families of people with intellectual disabilities, medical care) and science (knowledge creation: inspiration, joint research projects, study teams). The analyses were performed by experts from Poland, Lithuania, Italy, France and USA. In order to meet the objectives of the study, the team applied the qualitative method of desk research with the existing documents and other material, including the national acts of law concerning education and rehabilitation of disabled people, reports, studies, expert opinions and other documents drafted by national institutions.

**The second stage** consisted in interviewing people considered as significant actors in the process of shaping the system of support for people with intellectual disabilities. Each expert conducted in-depth individual interviews with 9 persons: three professionals who work with persons with intellectual disabilities or representatives of the academia (Panel 1), three representatives of state administration or representatives of parents' movement (Panel 2), three persons with intellectual disabilities (Panel 3). Interview analysis enabled the research team to answer the questions concerning the role of parents in the creation of support policies for people with intellectual disabilities.

In Panels 1&2, the experts asked the following key questions:

In what dimensions of social life have you observed an influence of the movement of parents of people with intellectual disabilities? Please provide examples of the impact on:

- acts of law/legal system concerning people intellectual disabilities;
- social and vocational activation of people with intellectual disabilities;
- access to knowledge and education for persons with intellectual disabilities;
- development of accommodation and living options people with intellectual disabilities;
- development of advocacy of people with intellectual disabilities;
- changing attitudes towards people with intellectual disabilities;

- development of support for the families of people with intellectual disabilities;
- development of medical care for people with intellectual disabilities;
- development of science concerning people with intellectual disabilities (in what dimensions and fields of science have observed an influence of the movement of parents of people with intellectual disabilities?)

The aim of the interviews with persons with intellectual disabilities (Panel 3) was to gather information about their awareness of the existence of parents' organisations and their activities. Due to the versatility of activities performed by the organisations, there was no single template for the interviews in Panel 3. Our suggestion was to start the interviews by asking the following questions: *Are you a member of ... organisation? Are your parents members of ... organisation? Do you know what organisation .... does?*

**The third stage** of the project was to draw up a study report and present its outcomes at 37. International Scientific Symposium entitled "The movement of parents of people with intellectual disabilities and scientific research and social practice: co-existence or co-operation?". The Symposium was organised on 28-29 November 2013 in Warsaw by the Polish Association for Persons with Mental Handicap in collaboration with the Polish Research Team for the Study of Intellectual Disabilities - a branch of International Association for the Scientific Study of Intellectual and Developmental Disabilities. IASSIDD's representatives sent their letter of support for our project's research initiative.



Michel Billé

University of Poitiers

## Intellectual disability - from disregard to civic mindness: the work of a parents' association

*Whatever you do for me but without me,  
you do against me*

*Nelson Mandela*

The second half of the 20th century and the beginning of the 21st century were a period of miraculous transformations in many areas. The world of disability was subject to these changes as well, including a deep transformation of the approach towards both old age and disability itself. It was largely the work of parents' associations that initiated the changes, which in turn made it possible to introduce transformations on social, professional and institutional levels.

We need to emphasize these changes, this superb improvement, even though there is still much to do on the way towards improving the fate of the disabled and their families. We now have bases to do it and the necessary experience. We have a better understanding of what should be avoided and what should not be repeated. We can therefore imagine a real future based on the dreams of our predecessors, often also precursors.

First of all, it has to be said that the dilemmas we have to face appeared for the first time just after the war. In the period when France was being completely rebuilt, the welfare state assigned means for solving the issues that no one had noticed, recognized or treated before.

In the period of time we decided that answers had to be found and a social, educational, socio-medical approach had to be created and appropriately adapted to the needs of the disabled and their families.

This process was to be slow (even today, we are justifiably still impatient) and was to have multiple stages, which we should not forget even today. Knowing where we came from and what has been our route so far is indispensable while building the future.

In order to lay down this route, we have to refer to our own personal and professional experience as well as to the conversations with three groups of people, all of whom in a way had been engaged in this process that took place recently or in the more distant past.

1. Panel 1: Members of administration or heads of institutions
2. Panel 2: Parents of adult people with intellectual disabilities
3. Panel 3: People with intellectual disabilities, members of institutions – among them one who had been working for 30 years in ESAT (*Etablissement et service d'aide par le travail* – Supported Employment Centre for the Disabled).

It is understandable, taking into consideration the small number of interviewed people, that these panels are rather a testimony than statistically valuable data. This testimony is, however, a special and important part of this history, and it concerns the engagement and the persistent work of associations uniting parents of intellectually disabled people. A synthesis of the interviews is provided at the end of this paper.

### **From disregard to isolation**

Everything started with deep disregard. After the end of the World War II, the French, experiencing a post-war trauma, ignored the existence of people with intellectual disability. There appeared disregard and rejection, which in turn generated the sense of living next to the “abnormal”, the carriers of “defects” which could only be a consequence of their parents’ or grandparents’ sins or a well-deserved punishment.

This disregard was accompanied by contempt for the disabled as well as for their families. It was believed that they should remain unseen, just like anything that brings shame. The families, therefore, tried to hide themselves and the persons with intellectual disability. Health services did not help families who suffered because of disability; they were unable to explain the disease; in order not to dash the parents’ hopes, it was said that “it will pass with time”. Of course, nothing passed with time and if the intellectually disabled survived, they stayed with their parents and had no other choice but to try to adapt, to be accepted, often in rural areas (but in cities as well), where people were sometimes tolerant and sometimes cruel. Those who did not succeed were regarded as “crazy” and put in asylums or psychiatric hospitals, unless they died beforehand because of lack of care, insufficient livelihood, material or moral poverty. It was the time of deep disregard – many believed that a problem ignored long enough would cease to exist, so it did not have to be solved.

In the face of this unacceptable and unbearable disregard, three groups: asylums, religious congregations and parents, who started to gather in associations, chose the same direction.

The only answer known back then was isolation. The asylums accepted new patients, but also isolated them; they had been isolating all “lunatics” for ages, and they simply continued their mission, establishing the common denominator that was the starting point of everything. Isolation might have passed as the best kind of hospitality, but often it was the worst possible way of living together and seclusion. When psychiatric help became a possibility, the level of care became acceptable, but was still very archaic.

Some religious congregations, whose mission is to take care of those in greatest need, practiced a ministry in the asylums or opened their own centres based on the same principle, but in complete poverty. Religious hospitality served as an answer to the misery of the most needy or those bearing the greatest mark of the war and the socio-economic life of those times. “The misery of those whom the world abandoned should touch you the most.”<sup>1</sup> And indeed, the ones “whom the world abandoned” were numerous, or at least visible.

Of course, the parents were not satisfied with such a complicated situation – they considered benevolence to be a Christian virtue and at the same time they were anxious about

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<sup>1</sup> “The misery of those whom the world abandoned should touch you the most” – the device of Saint Louis Grignon de Montfort, adopted by the Brothers of Christian Instruction of St. Gabriel and the Daughters of Wisdom as the basis of their work with the deaf, the blind and the deaf-mute, and the more or less important basis of the founding of such centres as the one in Larnay near Poitiers: the mental health hostel (Foyer de vie), the mental health and healthcare hostel (Foyer d'accueil médicalisé) and the residential care home for dependent elderly (EHPAD – Etablissement d'hébergement pour personnes âgées dépendants).



public health. In those times, everyone talked about “social plagues”, especially about tuberculosis, syphilis and alcoholism. (It would be of great importance when the representations of the disabled are created). Philosopher Michel Foucault (1976) was clear about the “great isolation” of everyone who posed or could pose a threat to the public order, including tramps, beggars, the poor, the homeless, and the elderly. It was a kind of “help through isolation” (Thomas 1996, p. 19) in an organised and disciplined asylum or hospital.

The parents, often left alone, living with the sense of injustice and sometimes revolt, started to mobilise and, in the 1950s, numerous parents’ associations were created all over France. Their aim was to change the situation and to acquire resources, especially funds, from the authorities in order to solve their problems.

We could therefore witness the centres sprouting to life, often in uncertain conditions, teetering on the brink of being illegal or against the administrative regulations of that time. The centres would soon be named Medical and Educational Institutes (*Instituts médico-éducatifs*) and would start admitting children to “dormitories”. It was still believed that in order for the treatment to be successful, the child should be separated from the family and the visits and vacation periods should be sparser. To isolate, and to isolate definitely – that was the prevailing approach.

This model survived until the 1960s, when pedagogy for special needs was born in France. The contribution of this field of pedagogy would be crucial for family absolution and the change in attitudes towards disability, especially intellectual.

It is worth emphasizing that while the parents’ associations opened resources and administered them, they also started to employ professionals, which of course improved their status significantly.

The parents still exerted social and political pressure; they were sometimes supported by great cultural and political figures. Philosopher Emmanuel Mounier, general de Gaulle, actor Lino Ventura – they all had children with Down syndrome and were all supported by high-rank officials, such as Simone Veil (the minister of health in 1975) and some innovative doctors who could hear the voice of the parents as well as of the intellectually disabled. Among the most active specialists were Stanisław Tomkiewicz (1999) and Elisabeth Zucman (2007, 2012, 2013). Great direct and indirect contributions were also made by well-known psychoanalysts such as Françoise Dolto (1971), Maud Manoni (1976) or Bruno Castets (1971). Each of them had their own way of influencing the consciousness and the approach towards intellectually disabled children and their families.

### **From isolation to acknowledgement**

The period of ignorance had passed. Of course, the means were insufficient, the activities did not meet our expectations, but the situation had already improved significantly. Thus, we entered the second stage, leading from isolation to acknowledgement.

The parents, naturally, did not lay down their arms. Isolation indeed started to be regarded as abuse causing everyone to suffer: the intellectually disabled as well as their parents. Those educated in the field started to acquire appropriate competences and could not imagine themselves as torturers who forced the intellectually disabled to adapt to the conditions of isolation, when they themselves felt that many other things could be done instead.

The organisations refined their structures and united on regional and national levels. The differences between associations resulted from their philosophical or political principles and caused the projects they conducted to be different and often complimentary. This model spread throughout France until the end of the 20th century. We can mention here:

French Association for the Paralysed (APF – Association des paralysés de France), created in 1933 thanks to the initiative of four young people suffering from cerebral palsy who stood against the isolation they had been subject to. More than 70 years later, the association is still fighting its battle for the full social inclusion of disabled people and their families ([www.apf.asso.fr](http://www.apf.asso.fr)).

National Union of Parents of Unadapted Children (UNAPEI – *Union nationale des associations de parents d'enfants inadaptés*), created in 1960 as a result of combining local centres called “Papillons blancs”<sup>2</sup> (“White Butterflies”) and other regional associations, ADAPEI (*Association départementale de parents et amis de personnes handicapées mentales* - Regional Association of Parents and Friends of Mentally Disabled People).

The Association for Disabled Adults and Children (APAJH<sup>3</sup> – *Association pour adultes et jeunes handicapés*), formerly the Association for Aid and Placement of Disabled Youth (*L'Association d'aide et de placement pour adolescents handicapés*) was created in 1962 thanks to an initiative started by teachers in reaction to the lack of support and shortcomings in national system of education concerning care for disabled youth ([www.apajh.org](http://www.apajh.org))

The country armed itself with organisations, the welfare state “naturally” financed socio-medical activities; one new centre entailed the creation of another, and thus we witnessed the rise of true “pillars of responsibility” for the disabled, especially intellectually. The problem of integration of such people would appear afterwards; as for the time being, only “places” were brought up. We can say that the “paradigm of isolation” was replaced by the “paradigm of placement”.

It was important to open hosting, educational, teaching, and treatment centres, which would accompany those who on the one hand were happy to have been admitted, but on the other hand had no other choice.

A dormitory replaced an asylum, “placement” replaced “isolation”. The logic and the paradigm of placement started to dictate and regulate the social and socio-medical activities. It concerned the world of the disabled, but in a few years it would also concern the world of the elderly.

The increasing professionalism (like the creation of a national title of pedagogue for special needs, *Educateur spécialisé*, in 1967 and the presentation of the first diploma with this

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2 We tend to forget that the expression was coined by Léonce Malécot, who created “Papillons blancs” in 1960. During the “Papillons Blancs” national assembly in 1954 in Nantes, he explained: “A butterfly is synonymous to friendliness, grace, lightness, journey, instability and vulnerability... White stands for purity and innocence... A white butterfly is therefore a symbol of our child!” Excerpt from: “Léonce MALÉCOT. Un pionnier de l'enfance inadaptée” (1964).

3 APAJH: In 1963, on the families’ request, the association extended its activities onto all kinds of disabilities and all children; this is the beginning of the Association for Aid and Placement of Disabled Youth. Firstly, the sole place of activity is Paris, but later on APAJH will extend into all the departments thanks to two powerful organisations: National Education Insurance Agency (MGEN – *Mutuelle générale de l'éducation nationale*) and National Teachers’ Trade Union (Syndicat national d'instituteurs) In 1964, the organisation consisted of 13 local committees and correspondents in 30 departments. Since its very beginning, APAJH has been acting in favour of the disabled people’s access to the right to education, social and professional life.

title in 1970), as well as the engagement of families were weakening the model of dormitories as the only possibility for treatment, and turning them into half-dormitories for children and foster homes for adults. A child, as most of its school peers, would spend part of its time with the family and the rest in the centre, and adults would be admitted, and not placed in foster homes – the difference was enormous.

The needs of persons with intellectual disability and the problems of their families were acknowledged. Much was happening in France. The acts of 1975 (Act on Orientation in Favour of the Disabled and Act on Social and Socio-medical Institutions) sealed the changes, turning the responsibility for the disabled into a “national responsibility”. The 30 years of battle were marked with the success of parents’ associations and other organisations – the success of acknowledgement.

### **From acknowledgement to opening**

It did not, however, end there. Equipment was insufficient, but it existed. The medical and paramedical world was becoming more and more interested in disabilities, including intellectual disabilities; child psychiatrics became a renowned discipline and made attempts to understand previously unknown phenomena. There was still much to do, but no one considered parents to be useless, to be a plague threatening their children and their development...

In this new context, the way of thinking changed – accompanying the child and the family was placed at the heart of the problem; therefore, there appeared a new type of assistance: assistance at home. This change was important for at least two reasons: firstly, the necessity of universal care and accompaniment was acknowledged; not a long time later, Centres of Early Socio-Medical Action (CAMSP – *Centres d’action médicosociale précoce*) appeared. Secondly, the parents’ competences were acknowledged and supported. The first Services for Education and Home Care (SESSAD – *Service d’éducation spéciale et de soins a domicile*) were created. It was a true revolution – the family was placed at the centre of educating an intellectually disabled child or a young person.

The logic of placement was replaced by the logic of aid, which was full of respect for freedom and the decisions of every human being. All the more so, the aid services became more diverse and in the case of adults, no one was thinking anymore about placing them in the centres or even foster homes, but they were thinking about helping them – for example, providing “aid in social life” or “aid in housework”, which then turned into “mediating aid in social life”, etc.

We understood at last that the status of the intellectually disabled changed and that different situations called for different answers. And this time, too, the fight initiated by the parents’ associations was key and led to victory.

New concerns appeared – employment and financing had to be maintained, personnel specialized in new kinds of work had to be trained and the work of expert groups, who in general did not know what it meant to work together, had to be coordinated. All this meant new challenges!

Every expert created an intervention project that was initiated by an association. This way, the activities were improved and more harmonized. It became easier to start cooperation

with child psychiatrists, and to gain access to diversified methods of treatment: physiotherapy, speech therapy, psychomotor skills training, psychotherapy for children, young people and adults.

Of course, the development of services made it possible to develop alternatives for the centres, especially for children. Some had an idea to adapt schools to the needs of children with intellectual disability. Since the 1980s, there were many attempts to integrate with the regular school environment. At the same time, adults who were admitted to the Employment Rehabilitation Centre (Centre d'Aide par le Travail) were being integrated in the work environment, in an office, with possible assistance in the adjustment.

In default of means and sometimes motivation, this field was then neglected and there remained much to do. The vocabulary describing the intellectually disabled developed in a spectacular way – at first, it went from disregard to isolation; we spoke of abnormal, retarded, underdeveloped, defective children. No wonder they had to be locked away! In the stage between isolation and acknowledgement, we spoke of a greater or lesser degree of mental underdevelopment or maladjustment. Therefore, an aim was set – to adapt, to educate, to straighten. In between acknowledgement and opening, we spoke of disability and started to differentiate, according to the international classification, intellectual disability, disability leading to capacity limitations and defaults.

- Disability: objective, probably measurable, evolving, relative or non-relative, perhaps reversible
- Incapacity: also relative, probably reversible
- Disadvantage, default: also partial, but most of all compensational, at least in what concerns the human aid or material or financial support

A change in the approach was extremely deep, and the parents undoubtedly had reasons to be glad.

### **From opening to social inclusion**

Who will we be talking about in the last stage? Here, the changes were spectacular as well. At first, we talked about the “handicapped”, which is important, because reintegration requires seeing a person not only through their handicap. Then, we started talking about a “situation of handicap” with all its components (Kristeva 2003). It was not about negating the existence of the handicap, but about seeing a person in their own relationship with the environment<sup>4</sup>. Since then we started noticing everything in a given environment – school, workplace, public transport, city, culture, sports, hospitals, shops, etc. – that could be an obstacle to integration, regardless of the kind of disability and the social situation.

“Handicap is (...) a function of the relationship between disabled persons and their environment. It occurs when they encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens. Thus, handicap is the loss or-limitation of opportunities to take part in the life of the community on an equal level with others.”<sup>5</sup>

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4 And this was the shift from the International Classification of Disability to the International Classification of Functioning adopted in 2001 by WHO

5 Standard Rules on Equalization of Opportunities for Persons with Disabilities adopted by the UN in 1993

We should not negate the necessity of a given person to adapt to their social environment, but we should emphasize the not less important changes in the environment aimed at eliminating obstacles to integration. Social integration on all levels and inclusion became essential to the new paradigm.

As a consequence, we started talking about “deinstitutionalisation”. We had created so many institutions and specialized centres and placed so many people in them, not always in accordance with their will, that it was high time we created an alternative, all the more so because we could expect that its costs would be lower. The risk was significant, because we could lose the cohesion of social and socio-medical activities. The benefits of such activities, especially the ones that resulted from placements of the disabled in centres, were not compensated for by high-quality support at home or in an open environment. For example, was school, as well as institutions, able to conduct special needs pedagogy adapted to children? Teachers would have to be trained and additional personnel would have to be employed; they would scrupulously assist the children at schools. If a teacher, regardless of the age of their pupils, had to deal with an overpopulated class, how could they spend time taking into consideration the special situation of students that were intellectually disabled?

The paradigm of inclusion also had its own limitations, especially as it omitted certain questions. Be included – right, but what for? Again, the parents’ associations spoke up and answered: it was to achieve a real social integration, not only by taking “place”, but finding one’s own place though the expression of individual abilities, self-development and participation in all the components of social, cultural, and political life of the country. Therefore, the paradigm of inclusion made sense only if we looked at it from the perspective of civic awareness.

The act of 2 January 2002 reformed social and socio-medical activities, laying the foundations for the act of 11 February 2005, called the Act on Equality of Rights, Opportunities, Participation and Civic Inclusion of the Disabled. The programme was political in nature, but behind it we could see, more or less, the participation of parents whose aim was to change the views on intellectually disabled people.

Equality of rights means also the equality in France’s motto. The citizens are all equal. Therefore, the society had to organise itself in order to be able to create equal opportunities for all citizens to find their place in society. The act specified: “participation” of the disabled! But participation in what? First of all, in the process of making decisions that concern their daily life (empowerment, self-advocacy). The act in a way put a final mark on the long-term process of changing the attitudes towards the disabled, as well as the work of parents and other activists. We would not make any decisions that concerned them without asking them first. We would have to find a way to integrate them, even if it’s hard. Numerous ethical questions arose at this point – and these questions pushed us forward.

The last term in the act was “civic inclusion” (social inclusion and all citizen’s rights). It meant participation in public life whenever possible. Guardianship courts could take measures in order to protect and maintain the right to vote, so as to avoid incapacitation whenever possible. This novelty in the French law had, naturally, a symbolic meaning. Civic inclusion,

however, was not limited to the right to vote, but covered all components of social life, especially in associations. Consequently, for several years we had been witnessing the creation of the so-called associations of “service users”, or associations of people with intellectual disability, who in their own way speak on behalf of those who they represent.

For example, in May, the president of “Us too” (*“Nous aussi”*), an association representing people with intellectual disability, became a member of UNAPEI.

### **More challenges**

Right now we are facing another challenge – the fact that intellectually disabled people are ageing. For a long time, we have been thinking that the disabled do not age or age slowly. However, they can age because they have been treated under the special needs pedagogy, they have received generally satisfying treatment and care. Ageing is good news, even if we have this horrible tendency to see in it only through the lens of questions, difficulties and problems.

The disabled are ageing in France and Europe, in the societies where the average life expectancy and the average age are going up.

They are ageing within or close to their families, but the families are also ageing (Billé 2004), and are not able to cope with the new situation on their own in the long run.

They are ageing in institutions and in conditions that have to be closely examined, as they give rise to phenomena influencing the quality of life – the ageing of the staff, the rise in the average age of their patients, the inevitable inappropriate administration and care, etc.

In order to accompany the disabled properly in this stage of life, we have to try and answer the questions that crop up and that we hear from them.

### **Disability does not retire**

First, we have to explain the legal and administrative status of the intellectually disabled people who are ageing, because this affects at least part of their financial resources. The law has to catch up. Nothing is foregone yet. We have to keep the hope that lawmakers will hear the parents and their associations, who have been repeating for a few years that disability does not have an age, does not retire at 70 or 75 and that the human, technical and financial resources that come with it cannot be subject to age limits.

We need to have numerous possible answers, adapted to every situation. It is unthinkable that the same solution is being forced even in one “family” of disabilities, regardless of the situation – the level of disability, financial and family means, psycho-emotional environment, individual history, institutional experience, etc.

The range of answers should include:

- personalised answers
- progressive decisions
- continued care or accompaniment
- adequate answers
- maintained family and emotional bonds
- respect of the person’s choices
- conscious consent obtained

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It is presumed that qualified staff will be capable of providing high-quality assistance in centres that will not be out of touch with reality – the disabled will be able to apply for everything the non-disabled can apply for, according to their age.

### **To recapitulate**

There have been so many changes in how we perceive people with intellectual disability. It has been a revolution of 60 years that has caused a shift from the fearful and contemptuous ignorance to the times where we notice the person, their situation and the situation of their family. I know that “we cannot change the society with a regulation”, but regulations accompany changes and give them momentum, which is of fundamental significance. However, there is still a lot of work to be done.

We have to closely observe the reinforcement of active and fruitful national solidarity. Without solidarity, the poorest, especially if they are disabled, cannot rejoice in their civic inclusion that we have been talking about.

We also have to support families, who are tired, sometimes even exhausted. Their situation is difficult and brings forth real traumas. The families have the right to a greater interest!

We have to take action together. It seems obvious, but only mobilization will let us change how we perceive the intellectually disabled, who are still being depreciated far too often.

We have to remain watchful – it is always possible that in the future, economic challenges will eclipse the ethical problems!

It is possible that the tricky differentiation that gradually seeps into our way of thinking and the consciousness of citizens, the differentiation between a human being and a person<sup>6</sup>, which lets us seemingly eliminate the former without touching the latter, will still be wreaking havoc.

It is still possible that the growing pressure that forces us to consider the value of life according to its usefulness will outweigh the conviction of inherent and inalienable value of every person and their constant and equal dignity (Fiat 2010), regardless of their physical or mental health conditions, the state of their body or mind.

Therefore, if we change the paradigm this way, we will undoubtedly enter not into the expected paradigm of civic inclusion, but into the paradigm of contempt and barbarism. The most abominable tyrants often act in the shadow. We have to remain watchful... But if we are aware of the perils, we can avoid them and create a world in which, as Elisabeth Zucman put it, “together, similar and different” (Zucman 2012), regardless of disability or lack of it, we will be able to create strong bonds within the society in favour of a common, free, equal life in human brother- and sisterhood.

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6 Reference to Australian “philosopher” Peter Singer, who attributes a certain quotient of humanity to each person.



## **Panel 1 – Results**

Guests: three representatives of public administration or special needs institutions

### **1. Changes in law and administration:**

The changes in law and administration introduced in France seem to be important, especially in the second half of the 20th century. In fact, after the war, there was no system of support for the disabled, particularly for the intellectually disabled.

Religious congregations accepted those capable of doing simple work into “asylums”. Public hospitals where religious nurses or social workers did their jobs admitted children, young people and adults with serious disabilities. The conditions were, however, appalling: no care, no hygiene, no leisure, no work.

Also “corrective houses” admitted juvenile delinquents and war orphans as well as disabled children and young people, whose behaviour was no more accepted by their families or schools.

The post-war mobilisation of parents called into question the state of affairs, which had become insufficient.

Parents’ associations mobilised at the end of the 1940s, and especially since the 1950s, started to put pressure on the authorities in order to obtain satisfying living conditions. The end of the 1940s brought about the term of “maladjusted childhood”.

1958 was the beginning of the Fifth Republic (even general de Gaulle had a daughter with the Down syndrome)... The changes in law reflecting the transitions were not numerous, but significant:

1967 introduction of the pedagogue for special needs diploma

1975 the Act on Orientation in Favour of the Disabled and the Act on Social and Socio-Medical Institutions

2002 act of 2 January introducing amendments to the Act on Social and Socio-Medical Actions Act of 11 February 2005 on Equality of Rights and Opportunities, Participation and Civic Inclusion of the Disabled

### **2. Access to social and professional life:**

Gradually, organisations, especially parents’ organisations, along with building legal and administrative foundations, started to create numerous support centres and institutions in France:

Medical and Educational Institutes (IME – Instituts Médico Éducatifs), Medical and Pedagogical Institute for Children, Medical Professional Institute (IMPro - Institut médico-professionnel) for young people, aiming at preparing them for work.

Employment Rehabilitation Centre (CAT – Centre d’Aide par le Travail) which then transformed into Centres of Assisted Employment for the Disabled (ESAT – Établissements et service d’aide par le travail). For those who could not start work, Houses of Occupational Stay or Houses of Medical Care were created (Foyer de vie occupationnelle, Foyer d’accueil médicalisée).



Much later, at the beginning of the 2000s, special houses for the elderly started to come into existence.

### **3. Access to education and schools:**

Disabled children were educated mostly in special needs establishments (Instituts médico-éducatifs). However, since the 1980s, a monstrous effort has been undertaken in order to adapt public schools to accept children with disabilities, especially intellectual disabilities. There would be talks of adaptive, integration classes...

### **4. Living conditions and housing:**

Some people can stay at Medical Care Houses and Occupational Stay Houses. However, people working in CAT do not have access to them, so they live with their families, or are independent enough to live alone, for example in a flat. Moreover, they can live full-time on only on weekdays in supported housing centres that were especially created for them. The centres provide support and companionship that allow for the best possible integration in internal and external social life.

### **5. Self-advocacy:**

The term was coined slowly and has come into force in a limited way. The initiation of the project in institutions (act of 2 February 2002) caused the professionals to start paying heed to the disabled and take their opinions into consideration.

Associations of the intellectually disabled did not appear before the 1990s and were supported by parents' associations. Much time passed before the approach changed. The most beautiful example is the one of the "Us too" association ("Nous aussi"), which was created and developed at the UNAPEI.

### **6. Changes in the social approach towards disability and the disabled:**

Similarly, as with other changes, changes in social approach were happening very slowly, but brought about spectacular effects. The approach towards the disabled changed in their favour. They were not considered to be dangerous or guilty anymore; instead, they were treated with sympathy. The families of the disabled had started a battle back in the 1960s, and changed the way things were. The same act mentions rights, equality, equal access to education, culture, sports... However, there is still much to do in order for the full integration to be possible, which we all wish for. Accepting people with disabilities to schools has also contributed significantly to a change in the social approach to this issue.

### **7. Support for the families:**

The act envisages administrative and financial support, which is in fact provided to the families. However, the question of social and psychological support is much more sensitive, as it often remains a competence of the associations and individual initiatives.

## **8. Access to medical care:**

It is a sensitive issue. Medical services, such as neonatology, paediatrics and child psychiatrics have developed with great success in France. Support is provided to children and young people without any problems. However, the access to medical care for disabled and mentally disabled adults is problematic. Some medical care professionals are still not adequately prepared to take care of an intellectually disabled person and, thus, are reluctant to do it.

## **9. Development of research:**

The development of parents' associations has inspired many researchers to study the causes of intellectual disability. Mental diseases are no longer mistaken for disability, and intellectual disability for autism. Genetics has allowed for a better understanding of chromosomal disorders, such as trisomy 21. It has also become clear that abortion for medical reasons could, in certain cases, prevent the development of embryos with severe disabilities before birth.

Moreover, the development of neurology has created perspectives which were not long ago deemed impossible. Finally, communication technologies have enabled us to better adapt to the environment: for example GPS devices facilitating selection of optimal routes are very helpful. Parents' associations seem to closely observe such novelties.

## **Panel 2 – Results**

Guests: three parents of adults with intellectual disability

### **1. Changes in law and administration:**

The parents have much to say on this issue. Indeed, in a relatively short time (60 years) everything had to be built from scratch. It was necessary to create an institutional response, centres, services, to train staff, to find ways of funding, to adapt legal regulations. The battles were fought on all fronts. Sympathetic political partners were found.

Sometimes it was necessary to teeter on the edge of law in order to create structures that would meet the needs of disabled children and their families more and more efficiently.

Finally, structures had to be adapted and answers conforming with the needs of the adults had to be created. Our children are ageing, so we have to find a solution for the problems that will appear when we are no longer here for them.

For a long time, we have been anxious about the fate of the children after their parents die; now, we have become even more anxious and solutions have not been found yet.

Adaptation of law turned out to be fundamental (acts of 1975, 2002 and 2005). The status of our children was modified in their favour. The more regulations and recognition was in the public eye, the easier was the access to any kind of support. However, we still should exert pressure as there is still much to be done in order to fully integrate our children.

## **2. Access to social and professional life:**

If by social life we mean the bonds created in the structures into which our children are admitted, the access to it is assessed positively – it is important and it has improved significantly. However, if by social life we mean the life in the society as a whole, we have to admit that even though the access to it has improved, it is often problematic. The access to culture, sports, transports, even shops is still hindered. The schools made an attempt, in the 1980s and 1990s, to open up and admit our children. It had positive effects, but the scope of this initiative was limited and dependent on the good-will of teachers, who had to enable easier admission of children with disabilities.

A similar logic followed the access to work – if by work we mean activities in supported employment structures, much has changed since the 1970s. However, the economic crisis often makes it difficult for the supported employment enterprises to find customers. As far as the integration of the intellectually disabled into the labour market in ordinary enterprises is concerned, it is rare, not to say marginal. There is still a lot of work ahead of us if we want our adult children to be integrated into the labour market and find themselves jobs that will be appropriate for their status and guarantee decent wages.

## **3. Access to education and schools:**

The most important part has already been said, but there is one alarming reflection to be added: Since the 1960s, the schooling of our children, at least part of it, has been done in specialized centres such as Medical and Pedagogical Institutes (Instituts médico-pédagogiques). However, it excluded our children from the ordinary educational system and isolated them in special need establishments, which were eager to admit them, but at the same time were not very well-integrated and even less integrating. However, such a solution provides professional working methods and conditions adapted to the capacities of children: small groups, appropriate pace of work, activating and inclusive methods, etc.

The will to “deinstitutionalize” on noble (anti-isolational) and less noble (economical) grounds has caused our children to be included into the traditional schooling system without assuring pedagogical methods and high-quality professional support for those who need them. Schoolwork conditions are less favourable, the teachers are poorly prepared to introduce the activating methods that would facilitate teaching. Deinstitutionalisation should not harm those whom it ought to help.

## **4. Living conditions and housing:**

The parents are still anxious about the answers. What should be the quality of life? What solutions should be introduced when we are gone?

The issue of accommodation, living conditions, comfort, housing is, of course, essential. Another worry: will the already known solutions be lasting over the long term?

And finally: will the disabled always have to share a house with someone else? For this, they have to adapt and the effort exhausts them. There is still much to do in order to find forms of material and human support for a home worthy of its name and well-integrated with its surroundings.

## **5. Self-advocacy:**

Self-advocacy is an issue in which, according to parents, we have brought about tremendous progress. They have been considering their children, regardless of their age, to be valuable stakeholders, whose opinion is to be taken into consideration. However, the exclusion of the disabled is permanently rooted in the minds of today's people. From this point of view, physical disability is perceived as slightly better than intellectual disability. Associations representing the disabled, such as "Nous aussi", and the reform of means for caring for the adults have given power to the voice of persons with intellectual disability. For example, UNAPEI has accepted members of the "Nous aussi" association to its board.

## **6. Changes in the social approach towards disabilities and the disabled:**

Changes in the approach of the general society are slow and sometimes hard to detect. However, a change in the way we speak about disabilities, which has taken place recently, is significant. In fact, when we speak of "people in the situation of disability" we underline the whole situation, not only a given person. It entails the necessity to change the situation, and not to improve the person. The focus is on the situation, which should not be an additional burden. It is an important change in schools, workplaces, means of transport.

## **7. Support for families:**

Families receive financial support from authorities within the limits stipulated by law. At-home support, such as Service for Education and Home Care (SESSAD – Service d'éducation et de soin domicile), along with the support of Centres of Early Socio-Medical Action (CAMSP – Centres d'action médicosociale précoce), is provided to families, but this kind of activities is not always applicable. Material problems remain unsolved, too. As for the psychological problems of parents and siblings, the support is often insufficient. Parents are supported by the associations, solidarity is developed, and strong friendships are established between parents experiencing the same difficulties. We should undoubtedly create venues and facilities where parents could speak out, where they would be heard and their problems would be analyzed. Such places should be run by competent, well-trained, non-judgmental personnel, who would accompany the disabled with appropriate care.

## **8. Access to medical care:**

In June 2013, another UNAPEI National Congress took place in Marseilles. The topic was the access to medical care, which is left behind as a domain for numerous reasons:

- Difficulties in communication are not taken into consideration.
- Coordination of health paths is insufficient.
- The families are either isolated or summoned as a last resort.
- The offer of services is insufficient or ill-suited: there is little prevention or lack of it, insufficient dental health care, etc.
- Medical and para-medical staff are poorly trained and not sufficiently sensitive.
- Health centres are poorly or not at all adapted to admit intellectually disabled people.

- Funding is insufficient.
- Clinical research is insufficient.
- Analgesics are poorly applied, especially in the case of those people who speak little and, as a consequence, do not complain.
- Care for terminally ill persons and persons close to death is almost non-existent.

The above painful conclusions have been drawn also by other associations, especially APAJH.

## 9. Development of research:

Is it possible to create a branch of research concerned with intellectual disability? It is actually being created already as a result of an overlap of many complicated factors, organic and environmental causes, care and services. Tomorrow's neurobiology will allow us to better understand and better adapt our activities. Psychology and psychoanalysis have to aid the parents, who bear the bulk of the burden of the disability of their children. A human element should be present within the activities that have so far been purely medical.

Finally, we have to add that currently the parents' greatest distress is the ageing of their children with intellectual disability and a lack of satisfying answers. The parents' associations have started a battle to amend this situation. We are now facing, therefore, more challenges.

## Panel 3 – Results

Respondents: three people with intellectual disability, spokespersons of institutions, out of whom one has worked in ESAT for 30 years.

*“We wouldn't be here without our parents!”* This statement, expressed by one of the guests at the meeting, seems to be very strong. It emphasizes the power of family bonds and the dispersed but nonetheless real awareness of the parents' efforts to create appropriate living conditions for intellectually disabled adults.

Our respondents are fully aware that there are associations in which they participate regularly by organising events, meetings etc.

For our informants, the association's administrative structure remains incomprehensible – general assembly, board, etc. However, they feel great respect towards the president and are aware that this position requires responsibility and seriousness. *“The president can't fool around!”*

The respondents' opinions about associations and their work are closely linked to the issue of money and the way the centres are being managed financially. They are aware that huge amounts of money come into play, even if they cannot understand the particular components of financing.

The respondents feel that their voice is being heard and that their opinions are taken into consideration. *“When we really need something, we say so and we get it,”* says one of the interviewees and adds, *“But we need time, because it's difficult to work with the disabled.”*

*“The association is for the parents, because when they die, it will be necessary to find a solution...”*

The respondents therefore have a very realistic understanding of the challenges and the significance of the parents' association's role in finding solutions for the future.

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Lithuanian welfare society for persons with mental disability „Viltis“

## Influence of a civil society on quality of life of people with intellectual disabilities

*As long as I breathe, I hope.*

*Marcus Tullius Cicero*

### **Outline of the report:**

- History, main objectives of the Society “Viltis”
- Activities
- Priorities, membership
- Review of legal acts and laws of the Republic of Lithuania on persons with disabilities
- Review of results of interviewing

### **Parents movement - the main force in establishing of NGO**

In this article the influence of parents' movement on quality of life of persons with intellectual disability is viewed through the prism of the activities of Lithuanian welfare society for persons with mental disability „Viltis“ ( hereinafter referred as „the Society „Viltis“). It is one of non-government, voluntary, independent, public, seeking non-profit organisations of Lithuania. Lithuanian welfare society for persons with mental disability „Viltis“ has a long history. The date of foundation of organization is November 25, 1989. Next year „the Society „Viltis“ will celebrate the 25-th anniversary.

Parent movement of persons with disability in Lithuania has started before 25-30 years. Prerequisite for establishment of organisation was strong movement of parents and their endeavour to improve lives of their children. The parents understood that individually it is difficult to represent interests of their children with disability and their families. So the process of uniting parents into societies has started. Doctor Dainius Puras played especially active role in establishment of Lithuanian welfare society for persons with mental disability „Viltis“. At that time persons with developmental disorders were isolated from mainstream society in Lithuania. Persons with disabilities lived at stationary institutions or at home. Some of family members had to take care of them. Thus parents expressed their civil position. It was the chance for parents to achieve their goals through this organization – to make the life of their children better, to return disabled persons into mainstream society and create the opportunity for parents to work. For this purpose a network of community services for persons with disabilities have been created. Together it is always easier to promote ideas and get positive results. Activity of the society „Viltis“ is one of examples of parents movement. In 1990 German organization “Lebenshilfe” started to support “Viltis”. It gave an opportunity to the

members and specialists to enter the international arena, get financial support, visit foreign countries, take on best experience, get knowledge about positive practices and implement it in Lithuania.

Since the very start Society „Viltis“ worked in close cooperation with local municipalities and counties. A network of services for comprehensive integration of persons with disabilities has been initiated, supported and created by the society. Community based services have been available to all persons with disabilities and their family members at place of residence, not only to the members of society „Viltis“. In 2004 society „Viltis“ becomes the association. At present association „Viltis“ joins 53 associated members. They are located in various cities and regions of Lithuania. Total number of members makes about 11000: children, youngsters, adolescents with developmental disorders, family members and / or guardians and specialists.

At present population of Lithuania makes about 3 million people. Due to migration (especially of young people) the population decreased during the last 10 years from 3,460 mln. in 2001 to 3,054 mln. in 2011. About 263 000 people – are people with physical or mental health disabilities. It makes 7.5% of all population of Lithuania. It is the most vulnerable part of population and should be taken care of on all levels: legal, social, health care.

Main objectives of society „Viltis“:

- To seek that main provisions of International legal Acts and Laws of Lithuania determine liquidation of discrimination, social exclusion of persons with disabilities, ensure their equal rights to education, employment, social security and full integration into society.
- To rally children, young people and adults with intellectual disabilities of the Republic of Lithuania, their families, caregivers and other persons acting in their interests.
- To promote ecological, medical, social prevention of intellectual disorder, its identification at the earliest stage.
- To encourage development of rehabilitation methods of persons with intellectual disability and its practical implementation.
- To protect social and civil rights, freedoms and dignity of children, young people, adults with mental disability, their families.
- To meet social, cultural and other needs of persons with intellectual disability and their families.
- To create positive conditions for performance of obligations, choice, participation in public life of persons with disability.
- Setting up of new groups, classes in general education and special education institutions for pre-school children and school-age children with intellectual disabilities
- Establishment of day care centres, family support centres where social and labour skills of young persons with intellectual disability are trained
- Ongoing long-term legislative program seeking to create a new concept of disability based on principles of human rights and self- advocacy
- Extension of stationary and non-stationary community-based social services for persons with intellectual disability, their parents and guardians





Picture 1. Associated members

- Creation of parents mutual support groups in order to overcome crisis in the family after a child's disability has been confirmed
- Development of transport services network for those people with intellectual disability who are unable to use public transport services
- Give an opportunity to Families and people with intellectual disabilities to develop and relax in summer psychosocial rehabilitation camps on the sea shore
- Organize seminars, training courses for professionals and volunteers working with intellectually disabled people
- Organize training for parents. Issue of magazine "Viltis"
- Active work in international projects, share experience with Eastern, Central European, Asian and the Balkan countries

### **Cooperation with other institutions**

The Society "Viltis" cooperates with other NGOs, political parties, universities, local municipalities, education, health care, social service agencies, other international organizations, government organizations, with state and local authorities that are responsible for persons

with disabilities, individual supporters, people of good will, with foreign counterparts working in the field of persons with disability. The Society „Viltis“ organize occupation, social and professional rehabilitation, create conditions for independent living and ensure rendering of social services, provide legal consultations for members of society. It is a member of the Department for the affairs of disabled at the Ministry of Social Security and Labour of Lithuania, it closely cooperates with Ministry of Education and Science, Ministry of Health, Ministry of Justice, with municipalities and main committees of the Seimas of Republic of Lithuania. It was already noticed that successful results can be reached working together with other organizations. During meetings, discussions, oval tables it is easier to reach agreement between representatives of NGOs, municipal organizations, local authorities and representatives of state authorities. Therefore Viltis is often the initiator of such meetings in Vilnius and in the regions of Lithuania where its associated members work. Direct contact with representatives of authorities, possibility to talk about the most acute problems of persons with mental disabilities and to be heard usually gives positive results; it allows to overcome a lot of barriers in solving this or that problem.

### **Review of legal documents adopted in Lithuania on persons with disability**

The Society “Viltis” is actively implementing the Laws of Republic of Lithuania on persons with disabilities. The Seimas and the Government of the Republic of Lithuania adopted and approved through 70 various legal acts regulating rights of people with disability, type and form of assistance, accessibility of assistance and support, satisfaction of individual needs not only for a person with disability, but for his/her parents and trustees.

In the document “**Human rights in Lithuania**” (2005 yr.) issued under the UNDP (United Nations Development Programme) SUPPORT TO THE IMPLEMENTATION OF THE NATIONAL HUMAN RIGHTS ACTION PLAN (LIT/02/005) it is stated:

- The disabled have the same rights as other members of the society.
- They are provided with the same opportunities for education, work, spending the leisure time, participation in the public, political and community life.
- The special measures improving the situation of the disabled persons are provided only in cases when the mentioned conditions and measures are not met.

For the society “Viltis” as for other citizens of the country the **Constitution of the Republic of Lithuania** is a very important document in which such notions as freedom, the right to life, equality of citizens of Lithuania are determined. The Constitution was adopted by citizens of Lithuania on October 25, 1992 in the referendum. In Chapter II of the Constitution Article 18 it is stated that “Human rights and freedoms shall be innate“. In Article 19 it is clearly said that „The right to life of a human being shall be protected by law.“

Article 29 says that “All persons shall be equal before the law, the court, and other State institutions and officials. The rights of the human being may not be restricted, nor may he be granted any privileges on the ground of gender, race, nationality, language, origin, social status, belief, convictions or views.“

**Law on equal treatment** (18 November 2003 – No IX-1826)

The purpose of the law is to ensure implementation of Constitution of the Republic of Lithuania on equal rights. In Article 3 “Duty of State and Local Government Institutions and Agencies to Implement Equal Treatment” it is stated that: “State and local government institutions and agencies must within the scope of their competence: 1) ensure that in all the legal acts, drafted and passed by them, equal rights and treatment would be laid down without regard of age, sexual orientation, disability, racial or ethnic origin religion or beliefs”. This law provides the duties of the state, municipal institutions and agencies, educational and research establishments, educational providers, employers to implement equal treatment, also violation of equal treatment. Supervision of the implementation of the law shall be performed by the Equal Opportunities ombudsman.

**UN Convention on the Rights of Persons with Disabilities**

The Convention was ratified in Lithuania on May 27, 2010. The purpose of the 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. The Society „Viltis“ was actively participating in ratification of Convention. In 2009-2010 the organization together with Latvian Partner „Rupi Berns“ participated in the project “Ratified Convention is the guarantee of the rights of the disabled”. The date of the final conference of the project almost coincided with the date of ratification of Convention - May, 2010. Ratification of this document means serious international obligations Lithuania has undertaken. At the end of 2011 Viltis held a conference on implementation of the articles of UN Convention, which was attended by persons with mental disabilities, their parents, lawyers, representatives of local authorities, defenders of human rights and politicians. In 2013 European Union has to submit the first report on implementation of the articles of UN Convention. Therefore it is very important to not only to follow the articles of Convention, but also implement them into life. At present the society „Viltis“ is largely guided by this document in its activity as it provides general principles, general obligations of the parties and defines the rights of persons with disabilities. Every article of Convention is of highly importance, but at present we pay special attention to:

- Article 9 – Accessibility. It is stressed that persons with disability should live independently and fully participates in all aspects of life. They should get access to transportation, roads, buildings, information, communication, use services of assistants if necessary, etc. The States parties shall take all measures to implement this article.
- Article 25, - health and article 26 – habilitation and rehabilitation. It is said that „States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.“ The Society „Viltis“ actively works on implementation of this article. Each year social rehabilitation and training of life skills programme is performed for persons with intellectual disabilities and their families on the Baltic sea-shore. 2 sessions are arranged during summer – one for 300 persons and one for 50 persons with severe disability. Parents, specialists, Viltis staff and volunteers participate in the program. It's a good chance for families to have trainings, participate in mutual support groups and have though temporary leisure by the sea.

- Article 29 – living independently and being included into life. Persons with disability have the right to choose the place of residence, as other citizens, to have personal assistant necessary to support living and inclusion into community. Most parents are active in promoting the idea of independent living of their children, especially parents of persons older than 21 years old.
- Article 32 - international cooperation - It is said: „States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities.“ The society „Viltis“ has close relations with many foreign organizations from Eastern, West-European and Asian countries. The society „Viltis“ shares its experience and learns from their experience; it is an active member of Inclusion Europe and participates in events of this organization – projects, seminars, and conferences; the head of association Viltis is the member of the Council of Inclusion Europe.

Specialists of organization devote a lot of time to the problems of families raising children with disabilities. At present Society „Viltis“ participates in the project financed by EEA grants fund. The objective of the project „Temporary Respite Care Service – help and unfettered freedom for families raising children with mental disability“ – to create the possibility of temporary respite for parents of disabled persons. It is well known that parents need this service and it should be fixed on the legal level. In November 2013 the team of organization together with the head of association visited Iceland and studied the system of social care and the model of creation of respite care service. Similar model of respite care service will be developed in Lithuania. Of course, it is a scrupulous work requiring economic, legal and special knowledge; specialists of society „Viltis“ are ready to implement their ideas and use positive experience of Iceland and other countries.

Society „Viltis“ has long-term relations with Polish organizations; we participated in several projects, such as „Let's reconnaissance, Colourful sounds, Join adventures“, that took place not far from Zakopane and in Rybokarty, close to Grifce. We are very thankful to PSOUU in Grifce for invitation to participate in the project. A group from Poland together with persons with intellectual disabilities, assistants participated in the project „Exchange of the best practices. Promotion of persons with disabilities in the context of the program.“ Workshops and trainings have been arranged in Lithuania and Poland. Participation in international activity helps people to better understand each other, find new friends, get knowledge about traditions and habits, cultural life of another country. Experience gained during visits and mutual discussions, meetings is especially valuable.

**Law on social integration of People with intellectual disability** adopted in 1991 (new wording dd. 2010 yr.)

The aim of this law:

- to ensure equal rights and opportunities of the disabled people in society,
- to establish the principles of social integration, to define the system of social integration and its prerequisites and conditions,

- to define disability and incapacity level,
- to render vocational rehabilitation services,
- to set principles of evaluation of special needs and satisfaction of special needs..

The law is applied to persons with disability, who are recognized as persons with disability in accordance with this law. In the articles 2 of the law which sets principles of Social integration of the Disabled it is said that the state shall provide assistance and guarantees to disabled persons who cannot exercise their rights independently – protection of discrimination and abuse, life in family, all types of assistance in the place of residence, opportunity of development and education, get information and consultations on their rights and legitimate interests. It is also said that disabled person shall perform their duties according to their ability. The implementation of this law shall be controlled by the ministries, departments of LR, local governments and public organizations.

Integration of persons with disabilities into society is of highly importance and the society “Viltis” always pays attention to this issue. Now it is not surprising that the persons with intellectual disability, visitors of our day care centres, are frequent guests of café, shops, pizzerias, parks, public events arranged in the cities and villages.

#### **Law on social services** (January 19, 2006 yr.)

Purpose of the law: define the concept, objectives, types of social services, regulate the management, granting and provision of social services, licensing and financing of social care establishments, payment for social services, financing of social services and consideration of the disputes related to social services. The Law defines the notion of disabilities, community-based services, special services, and management of social services and subject of management, competences of ministry of social security and labour, municipalities, other institutions responsible for implementation of the Law. The Law provides the order of rendering services, suppliers of services, social workers, assistants of social workers, licensing of social welfare institutions, conditions on getting licence, way of implementation, requirements to social workers. The Society “Viltis” relies on this Law in its activity as there are important articles for proper functioning of organization and its associated members.

#### **The State Program of social integration of people with disability** (2012-2019 yr.)

The main task of the program is creation of harmonious environment, effectively promote social integration processes in Lithuania, ensure national legislation, integration of disabled people, equal opportunities for people with disabilities and implementation of UN Convention on the rights of persons with disabilities.

In this part there was taken an attempt to highlight the main documents concerning rights of persons with disability (including intellectual), services they get, responsibility of institutions in implementation of the Laws. It is impossible to review all legal documents as there are more than 70. It should be stressed that the Seimas of the Republic of Lithuania and the Government have adapted important laws in order people with disability could live:

- safely,
- with dignity,
- have the right to choose,

- have the right to live in families,
- have a possibility to learn and to live full-value life.

For parents and their children it is very important to have entire assistance arranged and rendered to a person with disability in the place of residence or closer to it; a child with disability or an adult person should be ensured to have the opportunity to live in a family; conditions, the environment should be created to use public services; families taking care of children or adults with intellectual disability have the right to get general and special social services from municipalities.

A lot has been done in Lithuania, but still there is a lot of work to do in order to make life of persons with intellectual disability better. At present Lithuania is in the process of deinstitutionalization. It is just the beginning and there are a lot of uncertainties, but one thing is very understandable and clear: a persons with intellectual disability is part of our society, he/she has the right live in the family and get qualified services. Life quality is important to every person; it also important for persons with intellectual disability. It is impossible to achieve this result without parents, their active position in social life of society.

## Results of interviewing

Before coming to review of results, it should be noted that parents are more concentrated on their needs, they want to talk about the problems, difficulties they come across, lack of services; they try to go forward, paying less attention to what has been already achieved.

During interviews 3 parents of persons with intellectual disability, 3 leaders of institutions and 3 persons with intellectual disability have been asked. The answers differ – sometimes the answers are subjective. However it is clear and evident – civil position of parents, their will and desire to improve the life of their children, seek for services of better qualities, attract their children into social life, integrate into society – all this can overcome a lot of barriers and solve the most acute problems.

### First group of interlocuters: parents

2 mothers of a person with down syndrom, 1 mother of a son with severe disability.

Does movement of parents influence:

### **1. Legal system concerning people with intellectual disability**

The parents replied that during 20 years a lot has been done in the country thanks to Viltis work as NGO, its cooperations with municipalities and government strutures. They said that services should be accessible. For example, persons with disabilities cannot use bank account, communication with physicians isn't satisfactory, lack of pedagogues with special education. Status of a guardian can be given only by court. Such a notion as "Partial legal capacity" doesn't exist. They noted, that meetings with authorities is important as some of parents' most urgent problems are heard and reaction is reached during meetings with authorities.

Comment: the society "Viltis" arranges meetings of chairmen of associated members, representatives of municipalitie take appropriate actions.



**2. Social and professional activation** – motivation of social workers is rather poor; this kind of work is very difficult, but low paid. Functioning of the system is necessary. There should be professional trainings, professional education of specialists. Parents themselves cannot arrange it, it should be done on a higher level. As lack of professionals is a great problem, there should be close cooperation between organizations and educational institutions.

**3. Access to knowledge for people with intellectual disability and their education** – the progress in education is evident; it has been arranged, but needs constant improvement. Opinion of one of mothers: at present education of children with intellectual disabilities is primitive. Sometimes they are educated as healthy pupils, but they need special approach; to her opinion they should have a good, specially trained assistant who could help them. She stressed that a lot of interesting and effective methods are developed. Ministry of education should work on implementation of these methods into practice. Parents can influence, but partially; sometimes parents are too passive because of psychological and / or physical tiredness, some parents cannot do so much; in this case the help of specialists and professionals is highly needed.

Comment: at present 2 lawyers, 4 program managers ( except specialist on public relations, chief accountant and economist) work for „Viltis“. They participate in meetings with Seimas representatives, department on the affairs for the disabled at the Ministry of social security and labor, in project activity. They work in close contact with parents.

**4. Development of housing for people with intellectual disability** – the mothers' opinion is that legal acts and laws exist, but in reality they are hardly fulfilled. This year the living house in one of the district of Vilnius has been opened.

It is the merit of movement of parents, their cooperation with authorities. It is the merit of NGOs which tried to promote the idea of establishment of a living house and respite care service. The respite care service for 15 places has been opened close to this living house. Not too many, but still it is a step forward in order to ease the life of parents who sometimes need to take free days for their needs. Another mother said that some parents do not trust that their child can be independent and can live independently. During meetings with authorities some parents face indifference, it influences negatively on activity of parents.

**5. Development of advocacy of people with intellectual disability** –

At present the rights of children in Lithuania are protected thanks to efforts of parents and their active work in NGOs . Parents say advocacy should be more accessible and exist on municipality level. The system of rights protection for adults with intellectual disability differ – it is not well developed. Now NGO can render legal advice if it finds financing for a lawyer via project or from other sources.

**6. Changes in attitudes towards people with intellectual disability and towards disability** – attitude of citizens and society towards persons with intellectual disability is changing to positive. Today the people are more tolerable than 10 years before, however parents want that their needs and demands be met. One of mothers said that it is difficult to get music lessons for persons with intellectual disability, not every music teacher is able to teach such

a pupil, special education of teachers is required. It means more financing should be allocated to non-formal education.

**7. Development of support for the families of people with intellectual disability**

– parents can influence via NGOs where they work. Support exists, though still insufficient. One mother says that there should be social workers at municipalities for persons with intellectual disability. Parents or guardians could apply there whenever they need. Respite Care services was created before several years by Vilnius municipality, but closed due to high costs. In September 2013 this service was rearranged in – it is also the merit of NGO cooperation with public institution and government. Mothers say that parents get more psychological help than material or professional. Parents should be more open, not to be reserved between 4 walls. Communication, inclusion into society make parents and persons with disability happier.

**8. Development of health care for people with intellectual disability** – for parents it is difficult to influence this field even through NGO. Mothers say that health care is poor, especially dentist service: no dentist cabinet for persons with intellectual disability, parents or guardians should be always next to the child during treatment. Another point: development of physical abilities of persons with intellectual disability: sport club with a swimming-pool for them would be a great help and would give a lot of pleasure. Rehabilitation for persons with severe disability needs to be improved. Now it depends mainly upon efforts of Parents and their financial wealth.

Comment: next year the State shall pay special attention to dentist services, especially dentist services for persons with disabilities. The lawyers of Society “Vilis” have actively participated in promotion of this resolution.

**9. Development of science regarding people with intellectual disability (according to your observations, what dimensions and areas of science are influenced by the movement of parents?)**

– Science exists and develops. But still there are few opportunities for lifelong learning of parents. One of mothers said that sometimes wishes of parents, needs are treated as criticism. Parents would make more influence, but there is a lack of interrelation between science and parents. Time is needed to make it on a higher level.

Second group of interlocuters: Leaders of institutions, member of the council of Department for the affairs of Disabled at the Ministry of social security and labor.

Question: Does movement of parents influence:

**1. The legal system concerning people with intellectual disability**

Long term experience prove that parents movement influences legal basis of persons with intellectual disability - the system is changing, social security of persons with disability becomes stronger, Parents activity enhances. Most of laws and legal acts on disability are adopted thanks to close cooperation with NGOs, proposals of NGOs and consultations with parents.



## **2. The social and professional activation of people with intellectual disability**

Now there is the opportunity to be involved into society, to be included into social life, to talk with persons with intellectual disability, not only about disability. One of the respondents underlines that parents movement influences social motivation, but as far as professional is concerned – it influences just partially. Professional motivation improves as those parents who want to work may bring their child to the day care centre or Day employment centre. Transport system for persons with disability is well arranged. It is the merit of NGO initiative.

Comment: Some years before the head of “Viltis” association Dana Migaliova visited Canada centers for the disabled and acknowledged with transport system for the disabled people. She brought this model to Lithuania and shared with the Department for the affairs of disabled at the Ministry of social security and labor. In 1999 this model was implemented in Lithuania and exists till now. It was good initiative of the mother and Lithuanian authorities helped to implement it.

One of the associated members “Vilties Akimirka” established by “Viltis”, runs this program. 11 specially equipped buses (with 1 driver and 1 assistant) transport 280 disabled persons every day to/from day centers and schools.

## **3. Access to knowledge for people with intellectual disability and their education**

The access exists; it can be proved by personal histories, personal experiences, at last theory is connected with practice. For example, Law on education – it was adopted thanks to efforts of parent organization; now children can go to school. Persons with disability may attend day employment centres; they can improve their skills and acquire knowledge. For any person, especially for a person with disability to be closed at home without friends and communication is a big punishment.

## **4. The development of housing for people with intellectual disability**

Development of small living houses /centres is going too slowly, payment issue does not satisfy parents. Legal basis is not created up to the end. A lot depends upon cooperation of municipality and NGO-s. There are some examples when this cooperation is successful and a disabled person gets a flat to live in – the head of associated member in Utena sought for apartment for a young girl with disability and had a success. The house for a person with movement disability should be fitted for him/her. Another successful example is cooperation of Kretinga Municipality with NGO that made possible for one of employees of Day employment centres to be integrated into employment market. They equipped entrance to the house of a young girl with movement disorders and she became able to use wheel-chair and go work using transport services.

## **5. The development of advocacy of people with intellectual disability**

Very often parents themselves influence negatively as they do not trust their children's decisions, professional competence of specialists. But there are some positive examples as well. Self socialisation of a person depends upon parents /guardians communicability and goals – parents should wish that their child could grow an independent person. As a rule parents, who are open to a dialogue and communication, are free and able to express their position,

find a way out of difficult situation. One of the chairwoman said that 50% of success in social work depend upon family members. Work with families is very important.

#### **6. Changes in attitudes towards people with intellectual disability and towards disability**

- Anonym histories, participation of parents in social life, inclusion into society make the society to learn more about the problems of persons with disabilities and treat them as a full-fledged part of society. Inclusion of persons into society will speed up recognition them as part of society. There are good examples when parents of the disabled persons work in Ministries or Departments. They have a lot of knowledge and experience in the filed of the disabled people and their experience is invaluable.

#### **7. The development of support for the families of people with intellectual disability.**

Parents participate in establishment of services, self-support groups, NGO-s activity, work in various institutions. Movement of parents helps to raise sensitive issues and submit them to the higher level institutions and legal institutions. Most acts and laws are adopted thanks to proposals of NGO-s. Example: Department on the affairs of the disabled of Lithuania informs NGOs, platforms and ask to submit their comments / proposals before making proposals to legislative authorities.

#### **8. The development of health care for people with intellectual disability**

Parents movement positively influences health care development. Before 20 years the talk was about treatment in general, now the talk is about quality of treatment and successful treatment.

#### **9. The development of science regarding people with intellectual disability**

New technologies, new fields of science which study problems of persons with disability are developing. The attitude towards science is changing. The society "Viltis" has long-term relations with Child's development centre. This cooperation helps to make the route of parents to high level medical care more quick.

### Third group of interlocuters: persons with intellectual disability

The goal of interviewing: to gain knowledge about awareness of persons with disability of the existence of parental organization and activities.

Three persons with intellectual disability have been interviewed (diagnosis - cerebral paralysis, all of them are in wheel-chairs). Questions have been asked taking into account complexity of ellness.

#### **1. Do you know the title of the centre you attend?**

All of them replied positively and named the title of the centre.

#### **2. Do your parents belong to organization?**

They could not reply at once. After mentioning the title of organization, they positively reacted and smiled saying that they do remember (the office of this oprganization is in the same building as the centre).

### **3. Do you prepare for holidays together with your parents?**

They positively reacted. After asking additional questions (do they help to make costumes, sing or dance together) they become more talkative and reply positively.

### **4. Do you celebrate holidays together with your friends /parents?**

Replies were ambiguous, additional questions were needed (do you participate in performance, do you come to Viltis hall for rehearsals, do your parents come to holiday to the centre? )

### **5. Do you go to the parks, shops from the centre?**

They started to smile and the answer was “yes”. We spoke about their favorite dishes, the talk continued about singers. One girl smiled and positively reacted when we asked her about the concert she visited recently and which one she plans to go to soon.

Comment: Usually in the morning at about 10 o'clock the group of persons with disability together with social workers go the city by bus. They like to celebrate birthday or events at café. It's a good sample of inclusion of persons with intellectual disability into society.

## **Conclusion**

Before 20 years one could rarely meet persons with severe disability in café or in the shops; nowadays it becomes a commonplace. Reaction and attitude of health persons also changes. People are more tolerant and understandable.

The Society “Viltis” was established thanks to strong parent movement. This movement is one of the main forces in implementation of UN Convention on the rights of persons with disabilities and laws of the Republic of Lithuania.

The reason - people with disabilities themselves, their parents and guardians know better what kind of services they need, what kind of centre they want to attend, how often they would like to use temporary respite service, what kind of environment they need. The society, the government structures, legislative authorities should listen to the voices of parents, hear them and help to implement good laws, legal acts adopted in the country and provisions of UN Convention on the rights of persons with disabilities.

*I would like to express many thanks to participants of interviews – parents, leaders of institutions, persons with disability!*

Documents and material used

1. UN Convention on the rights of persons with disabilities, adopted in Lithuania in 2010.
2. "Human rights in Lithuania", 2005 yr.
3. the Constitution of the Republic of Lithuania, October 25, 1992.
4. Law on equal treatment, 18 November 2003 – No IX-1826.
5. Law on social integration of People with intellectual disability adopted in 1991 (new wording dd. 2010 yr.).
6. Law on social services (January 19, 2006 yr.).
7. The State Program of social integration of people with disability (2012-2019 yr.).
8. Material from the history of Lithuanian Welfare Society for Persons with Mental Disability "Viltis".

Luisa Bosisio Fazzi

Italian Disability Forum

## Parental associations in Italy. History, role and social function in assurance of rights and good quality of life for people with intellectual disabilities

### Introduction

*After his father's death in 1981, I had to deal with G., my brother. I took him to live with my family, instead of sending him to live in a care institution because I refused to accept that a boy who lived in the family for 28 years, left without both parents, was going to end up locked in an institution.*

*We are in February 1966.*

*Mr. G.T. in a letter to Corriere della Sera called for help and tips for his child who, again, was denied admission to the only special school of Milan, Treves De Sanctis via Colleoni, which hosted about 500 intellectually disabled children aged 6 to 14.*

*Mr. T. in his letter expressed the suffering of the continued refusal by all institutions in relation to the child.*

That's how all the stories start: stories of the associations that still deal with the protection of the rights of people with intellectual disabilities. Such associations were formed by parents, relatives and other family members who criticized the system of care and assistance whose only solution to the disability issue was separation and institutions. The associations' founders wanted, with a lot of courage and all their hearts, to end their children's isolation, challenging the approach to disability at the time when any impairment was still treated it as a penance to be served for God knows what sins of the parents.

Many of these associations, particularly those established in the 1950s, have become, in the course of modern Italian history, active and important players, innovating and inventing models of care and support for people with intellectual disabilities, promoting the respect of their dignity - for their children in the first place, and for all citizens with disabilities later. When there were no laws that identify the person with a disability as a citizen, the associations made possible services close to families and promoted a culture of social inclusion which was then called "integration and insertion".

This long political-organizational labour eventually led to the 1990s and results in terms of important laws that have improved the life of people with disabilities; and, together with associations composed exclusively of persons with disabilities, to the formation and growth of wider organizations that could represent the interests and rights of all persons with disabilities. This is how the association networks FISH and FAND (with different origins) have brought together in one voice their concerns to the national and international institutions. It was here that the disability movement was born, the unique movement that today uses around the world the same slogan “Nothing about us, without us”.

This long political and organizational labour eventually led to results in the 1990s in terms of important laws that have improved the life of people with disabilities; and, together with associations composed exclusively of persons with disabilities, to the formation and growth of wider organizations that could represent the interests and rights of all persons with disabilities. This is how the association networks FISH and FAND (with different origins) have brought together in one voice their concerns to the national and international institutions. It was here that the disability movement was born, the unique movement that today uses around the world the same slogan around the world “Nothing about us, without us”.

## 1. Family Associations in Italy: origins, development and efficacy

*“When you walk for a long time or when you are concentrated on the “MAKING”, you feel the need to pause and take stock of the situation: watch where you’re going, verify the path, evaluate the job done.”*

The history of associations of families of people with intellectual disabilities can be declared as belonging to the history of the associative movement of persons with disabilities. The movement has played a leading and active role in the community of people with disabilities.

The movement was aptly described by Matteo Schianchi in his book “History of disability”:

*The history of this movement is characterized by placing disabilities to the forefront through reflections, demands, and claims by many different actors and beyond divisions, thus creating an authentic, non-structured “movement”. And it is outside the traditional party and association alignments that the movement of the disability associations has gradually established itself as a socio-political entity.*

It shows that all the associations were originated from their founders’ desire to challenge and reject the model of care and treatment that was available in those days, in order to formulate new models of approach to the conditions of disability, and a new culture based on rights, participation and non-discrimination of persons with disabilities.

Today it is possible to associate the dates of establishment of associations of family members, the oldest in the years 1954 and 1958, with the legislative framework of the different historical periods, allowing us to understand, in the light of the changes just mentioned, the influence of their actions on the whole of society.

### **1.1 The history of Associations: the path and the historical evolution of the phenomenon.**

For the purpose of our research we think it useful to provide a general overview on associations working in the disability field, because it leads us to discover the roots of the associations. In this section we will also look at how the associations developed over the years and look at the founding fathers of parents' associations.

#### **The 1950s and 1960s: the associations by category**

A short description of the history of the associations can start from the 1950s (although *Opera Nazionale Invalidi di Guerra*, the national body for disabled war veterans, was set up in 1921). At that time the needs related to post-war reconstruction and to the social context, still affected by the outcome of World War Two, favoured the rise of the phenomenon of the so-called “*categorized*” associations. The organizations that were formed in this period take the shape of actual public bodies supporting those who could be claimed to have been disabled while “*servings the State*”, hence acronyms that have survived to this day like: UNMS (National Union for the Mutilated during Service, founded in 1950), ANMIL (National Association of the Mutilated and Invalids of Labor, 1945), ANMIG (National Association of War Invalids and Mutilated), ANVCG (National Association of Civilian Victims of War). Alongside these associations there were those which deal with particular diseases and conditions, such as UIC (Italian Union of the Blind, 1954), and ENS (National Body for the Deaf and Mute, 1950).

In the course of the 1950s and 1960s other associations for assistance and social security were established. Examples include ANMIC (National Association of the Mutilated and Disabled, 1956) or AIAS (Italian Association Assistance of Spastics, 1954), ANFFAS (National Association Families of Children and Subnormal Adults, 1958; in 1997, while maintaining the same acronym, the organization changed its name into National Association of Families of the Disabled with Intellectual and Developmental Impairments), ANIEP (National Association of Invalid Survivors of Polio, 1957 which, following the disappearance of polio due to the mass vaccination, also changed its name into National Association for the Promotion and Defense of Civil and Social Rights of the Disabled).

The work of these associations largely contributed to the enactment of the first specific laws in the fields of assistance, care, social security and health care. The associations also led to implementation of educational paths and professional training, still segregated but marking an important step forward in the history of the Italian disability movement.

#### **The 1970s and 1980s: the battle for integration**

During the 1960s there was evidence of progress in many areas (including research, medicine, health and science of rehabilitation) as well as a significant increase in the social and cultural sensitivity towards the issues of the exclusion of groups of citizens.

All this stimulated the creation of new associations, more attentive to the issues of “integration” with more specific reference to particular diseases when compared against the generalized approach of the 1950s and 1960s (for example: the already mentioned organizations AIAS and ANFFAS).

Muscular dystrophy, multiple sclerosis, epilepsy, Down syndrome, spinal cord injury – the sufferers of all these conditions and diseases finally had their specific associations such as

the UILDM (Italian Union for the Struggle against Muscular Dystrophy), the AISM (Italian Association Multiple Sclerosis, 1968), the AICE (Italian Association Against Epilepsy) and AIPD (Italian Association of Down's People). The latter was founded in 1979 with the name ABD (Association for Down's Children): the name change took place in the early 1990s, reflecting the birth of the issue of disability in adulthood.

It is in this period that the older and the newer associations met and clashed around a number of issues concerning social integration and education: Special schools or mainstream education? Institutions: yes or no? How to provide funding for disability? Should the disabled find work in sheltered workshops or on the open labour market? These were the themes around which often passionate debates were building up between the associations and the State with its local structures.

### **From the 1990s to today: an explosion of associations**

This period is characterized by a heated, almost violent, socio-political debate on disability (concerning the language used to describe disability, legislation, legal representation, etc.) and by the creation of numerous new associations.

In fact, the world of associations based on the medical model (each disease has its own medicine ... and its own association) refines itself further in 1990s. There are organizations for amyotrophic lateral sclerosis, osteogenesis imperfecta, autism, retinitis pigmentosa, spina bifida, dyslexia, Menkes syndrome, etc., intending to reflect the 5,000 rare diseases that medical science has defined.

In addition, in the 1990s many associations were created within the world of health care (hospital wards, specialized centers), perhaps with a certain amount of ambiguity, by parents of hospitalized children and by medical professionals with the aim of raising funds for scientific research and purchasing equipment for the relevant hospital departments.

Then there have also been the associations that arose, even in the same area and around the same pathology, because the "older" associations and the children they looked after became adults and, over the years, the "older" associations ceased to deal with most of the important topics for parents of young children.

And so many new associations were set up and had to start from scratch, additionally increasing fragmentation. And where there is fragmentation, competitiveness inevitably increases.

There have been many organizations that deemed relevant the technical approach to social issues and established themselves around famous people of sport or entertainment or figures of the medical field or health technologies (clinical, research, ITC, etc.). Some organizations acted around media events and aimed at raising funds, again, for research and for specific diseases.

In this struggle associations that deal with disability caused by disease are favored, as they can offer a message of healing and possible related medical research. Associations that deal with disability not related to disease are disadvantaged in that the message they must offer is to do with social and cultural integration. This approach is difficult to process for the general public and therefore results in a lower attention to the demands of such associations.



## The representation

Without doubt, this period sees the world of associations, including those that begin with families, characterized by fragmentation and competitiveness. This has brought to the attention of politicians and of civil society the issue of representation: who represents who?

The question of representation is at the center of the national debate provoked by the social and health care reforms introduced by the Italian government from the 1970s. These involved an active process of deinstitutionalization, health care reform and the launch of the National Health System. Moreover, the collection of important laws enacted in these areas has suddenly made the associations very visible for the general public, and fostered remarkable processes of identity and self-esteem growth. Today, facing the danger that the social security system might be dismantled, the associations and organizations are making use of this visibility and self-esteem to take the lead in the defense of the interests of people with disabilities in their areas of competence (solidarity, third sector, business, civil society, etc.).

### 1.2 Italian legislation in the field of disability

I have decided to include in this analysis of associations of parents / family members of people with intellectual disabilities an overview of the specific acts of law, because it seems good to provide the broadest possible framework of the path to full integration and social change regarding disability. It is also important and to look for a correspondence between the work of the lawmakers and the development of attention to the subject in question. However, it is worth pointing out that both the complexity and the number of regulations make it almost impossible to expect a full and complete reconstruction of social change.

The starting point is the Italian Constitution where we can find the fundamental rights guaranteed. It enshrines the state's duty to remove obstacles to the free exercise of these rights.

Article 3 states, for all citizens, equal dignity and equality before the law without regard to personal and social conditions. Its second half defines the role of the State which is obliged to: *"remove those obstacles of an economic and social nature that, by constraining the freedom and equality of citizens, prevent the full development of the human person and the effective participation of all workers in the political, economic and social development of the country"*. In practice, the State is the guarantor of inclusion.

In 1996, the Department of Social Affairs published a volume entitled *"Disability and Legislation"*. In this volume you can trace the evolution because it analyzes the regulatory framework in the field of social policy, starting from 1900, and showing that even until the 1970s the policy retained more or less the same features (Table1).

These features were centered around the culture of "categorization" which was favourable for the disabled or invalid war veterans (1917), plus a tendency to break the disabled up into categories defined by the causes of disability (disabled workers and disabled for service) or by the type of disability (e.g. the blind and deaf), financing the handicap and finally the start and intensification of the institutionalization process.

Table 1. The Italian legislation before the Constitution (from 1900 to 1948)

Before 1900	the person with disability is not entitled to have his/her individual rights
Year 1917	Rules in favor of "disabled or invalids of war"
Afterwards	<p>First legislative provisions (economic and health assistance, job placement)</p>
Year 1923	First rules on schooling (Gentile Reform)
Year 1928	Establishment of special schools and special classes
Years 30/40	Forms of assistance to numerous and specific categories
Year 1948	Promulgation of Constitution: civil rights for all, provisions for disabled
Years '50 – '70	Enactment of specific and sector-related measures

The following two decades (1970s and 1980s) were dominated by the impact of Framework Law 118/71 that, despite its limitations, can be considered the first step of the Italian society's difficult journey towards proper attention being paid to the world of disability.

Although the law only covered a marginal group of people with disabilities, the law contained for the first time general principles to promote the rehabilitation and integration of people with disabilities.

The act of law 118/71 was to remain the only point of reference of all legislation relating to disability until the Framework Law on Handicap no. 104/92. The 118/71 is directed to the people with disabilities excluded from measures adopted before inserting the definition of *citizens with disabilities congenital and acquired*..... Its contents provide economic assistance, health care and rehabilitation, prosthesis, social care, school placement, vocational training, job placement and removal of architectural barriers.

In her thesis for University Diploma in Social Service at the University of Milan, academic year 1998-99 Lorenza Longhini wrote:

*Starting from the early 1970s, individual provisions concerning specific areas and aspects of the issue of disability follow each other and help to build up a network of civil rights for the disabled. Even though no particular changes take place – categorization is still the standard approach – there is an increase in law-making at the national level, soon followed by detailed regional rule-making, encouraged by the tendency to decentralize and progressively delegate several functions of the State to the Regions. By the*

*end of the 1980s the legislation is complex, but impacts insufficiently on the real inclusion of persons with disabilities; this causes a debate that will lead to the formulation of the Framework Law 104/92.*

This law (No. 104/92) is still the only reference at the national level in the field of disability, and although it does not fully meet the expectations of homogeneity and easy application, it has the advantage of redirecting past trends towards social inclusion of people with disabilities.

Table 2 schematically brings together the areas of intervention described by the legislation relating to the first years of existence of the majority of parents' associations.

Table 2. Civil rights of persons with disabilities in the national Italian legislation

Economic Assistance	<ul style="list-style-type: none"> <li>- L. 66/62 (blind) L.406/68 (blind)</li> <li>- L. 381/70 (deaf-mute)</li> <li>- L. 118/71 (civil invalid)</li> <li>- L. 18/80 (civil invalid)</li> <li>- L. 508/88 (all categories)</li> <li>- <b>L. 104/92</b></li> </ul>
Social Assistance	<ul style="list-style-type: none"> <li>- L. 6972/1890 (Crispi Law)</li> <li>- DPR 616/77</li> <li>- <b>L. 104/92</b></li> </ul>
Health Assistance	<ul style="list-style-type: none"> <li>- L. 118/71</li> <li>- L. 833/78</li> <li>- Financial Laws</li> <li>- <b>L. 104/92</b></li> </ul>
Education	<ul style="list-style-type: none"> <li>- L. 118/71</li> <li>- L. 517/77 (compulsory education)</li> <li>- L. 270/82 (kindergarten)</li> <li>- <b>L. 104/92</b></li> </ul>
Vocational training	<ul style="list-style-type: none"> <li>- L. 845/78 (Framework Law)</li> <li>- <b>L. 104/92</b></li> </ul>
Employment	<ul style="list-style-type: none"> <li>- L. 482/68 (mandatory employment)</li> <li>- <b>L. 104/92</b></li> </ul>
Mobility	<ul style="list-style-type: none"> <li>- L. 118/71</li> <li>- DPR 384/78</li> <li>- L. 41/86</li> <li>- L. 13/89</li> <li>- <b>L. 104/92</b></li> </ul>

The criticism of the associations of parents and associations of people with disabilities regarding the existing regulatory framework (before 104/92) included the following points concerning persons with disability:

- He/she was not even considered as a person but according the status and the kind of disability that he/she has;
- He/she was the recipient of interventions related only to the sphere of health without synergy and integration with other spheres of life;
- He/she was covered by centralized support, not personalized support.

The enactment of the Framework Law 104/92 was of fundamental importance as it has provided a new point of reference in the form of the new concept of disability. Please note that during the same period (1990 - 1992) the national legislative production showed dynamism in broader political, institutional, and then social and cultural fields, shown by the following: F.L. 142/90 on local autonomy, the F.L. 381/91 on social cooperatives, the F.L. 266/91 on volunteering and Legislative Decree 502/92 on health care reform.

We can summarize that the key points present in the F.L. 104/92, are:

- The disabled person is placed at the center of the legislative intervention
- greater involvement of local authorities is desired
- Integration of the interventions within a single network of relationships
- Development of an evolutionary and dynamic vision of the condition of disability that focuses on removal of obstacles and prevention of marginalization

Again for the purpose of our research, certain changes made in the 104/92 with F.L. 17/99 must be highlighted. The most significant article is Article 41. concerning the "National Conference on disability policies". *The Minister for Social Solidarity [...] promotes statistical surveys and knowledge on disability and calls together every three years a National Conference on Disability Policies to which he/she invites such public, private and social-private bodies as exert their activities in the field of assistance and social integration of people with disabilities. The conclusions of this conference are forwarded to Parliament in order to identify any corrections to the existing legislation"*

This article introduced the involvement and the "equality" of the social and private entities (NGOs - associations and their networks) with the public and private sector, as well as the possibility that such involvement could affect any corrections to the law. This meant recognition of the active role of the civil society in Italy and a call for attention to the society's demands.

In general we can identify this Act (104/92) as bringing together the measures contained in the preceding laws, re-formulated and re-proposed, ending the fragmentation of the legislation. In fact, in its 44 articles, this law touches all aspects of the previous measures with simplicity and textual clarity, making it accessible to all. With this law and with the enumeration of the articles, the rights of persons with disabilities are legitimated.

Among the positive aspects of this measure there is undoubtedly the approach to the matter of school and education. In fact, this is the only matter proposed in a comprehensive way. The articles 12 to 17 cover the entire education path from the recognition of the right to education, through kindergartens and primary schools up to the preparation for the world of work and then moving to the matter of inclusion. Not only that, but the ways in which integration is to be implemented are also defined in the Act.

However, the obstacle to the implementation of the provisions of Law 104 within schools stems from subsequent regulations that are responsible for the allocation of funds for the whole school system, also including support teachers, qualified staff, aids and equipment needed as well as issues related the accessibility of school buildings.

In spite of these positive aspects it should also be noted that the law has some less valid features:

- The title "Law for the assistance, social integration, and the rights of disabled people" puts the emphasis on the word assistance, which precedes integration and equal rights.
- Total lack of innovation, except for the provisions regarding schools
- Lack of innovation: the whole legislative framework was rebuilt in line with the existing and decades-old regulations.

Finally, the world of associations, including associations of family members of people with intellectual disabilities, has unanimously recognized as the worst fault of the law:

- Insufficient allocation of funds and lack of deadlines

All this makes the 104, in practice, largely unapplied.

The perspective of the laws will only change in 2000, with the "Government Plan of action for disability policies 2000-2003" and the enactment of the "**Law no. 328/2000: Law for the implementation of an integrated system of interventions and social services**".

Article 1 of the Law states:

*The Republic guarantees to individuals and families an integrated system of interventions and social services, promotes measures ensuring the quality of life, equal opportunities, non-discrimination and citizenship rights, prevents, eliminates or reduces the conditions of disability, of personal and familiar poverty and suffering resulting from inadequacy of income, social difficulties and conditions of non-autonomy, in accordance with articles 2, 3 and 38 of the Constitution.*

The concept of welfare seems to be finally abandoned, and the legislation proposes a system in which *"the citizen is not only a user"*, and *"support is not just financial support."*

In order to respect the chronological order of the relevant legislative output in Italy we must go back to the year 1999 which saw the enactment of the "**Law no. 68/99: Measures for the right to work of persons with disabilities**", which reformed the system of work placement of people with disabilities, previously regulated by the Act of Law from 1968. Law 68/99 took the system from that of "mandatory employment", which forced the employer to keep special lists of disabled candidates for employment without regard for skill set, type of disability etc., to a system of "targeted employment" where "targeted" meant, again, special lists of "protected" prospective employees but including information sheets on professional and work skills, and with programming modes and timing of the inclusion in the workplace, all in line with the motto *"The right man in the right place."*

The year 2004 saw the publication of "**Law no. 6/2004: measures for the legal protection of persons with disabilities**" that reformed Title XII of Book I of the Italian Civil Code, introducing alongside the existing institutions of interdiction and incapacitation also the new role of the support administrator. Unlike the two previous protective measures, this measure set a "support tool" for the person, tailored to the specific needs of the individual case and the individual person.

In 2006 "**Law no. 67/2006: Measures for the legal protection of persons with disabilities who are victims of discrimination**" entered into force. This law provides the possibility for people with disabilities to refer to the Judicial Authority so that they can terminate discrimination, direct or indirect, suffered because of their personal condition of disability and in any social environment. It is also expected that the legal actions made possible by the law will be initiated by entities (associations, foundations) in the name and on behalf of the individual with a disability. Thanks to this, the law has ensured that the individual is not left alone with the burden of court proceedings.

Again in 2006, "**Law 80/2006**" allowed those who have already had check-ups to ascertain the condition of disability to be excluded from further check-ups if a permanent and irreversible condition of disability has been established.

In the health field three legislative documents are relevant:

**Ministerial Decree No. 33/1999** which identifies the method of delivery, by the National Health System, of aids and prostheses for people with disabilities.

**Decree of President of the Council of Ministers of February 14, 2001** that indicates which social and health services the NHS is in charge of and which are the responsibility of the municipalities. (for the temporary care in residential and semi-residential services the corresponding proportions are 60% - 40%, while for assistance in permanent residential structures the corresponding proportions are 70% - 30%).

**Decree of President of the Council of Ministers of 29 November 2001** fixing the Essential Levels of Health Care (LEA), i.e. the facilities and services that the NHS is required to guarantee to all citizens free of charge or against a reduced charge.

As mentioned at the beginning of this chapter, the presented list, albeit long, fails to highlight the complexity and number of regulations and is not exhaustive. However, we hope it will help our Readers identify and re-construct the social changes which have taken place in Italy. These changes have always been at the forefront of the political discussion among the associations including the associations of parents and relatives of people with intellectual disabilities.

## 2. The culture produced by the family associations in Italy

It is the parents of children with disability that naturally need to respond by acting as soon as the child is born, or an event triggering disability takes place which consequently puts a strain on the couple's bond. But it is not enough for the the couple to "keep going" and face and overcome the first difficulty: the nuclear family can and must confront the system of extended parental relationships and the system of external resources and relations, since the problems and needs of the child are almost always higher than the capacity of the couple or even the family.

It is precisely in the transition from the family to outside network of support that the greatest difficulties are triggered, because on the one hand, the family is not sufficient in itself,

on the other hand the external environment does not always adequately take into account the condition of the person with disability and the needs that the family has.

It is also well known that disability breeds questions that concern the life of the child (child, youth or adult) and his/her family in numerous areas, from school to work, from health and social services to urban planning, tourism and means of communication. This heterogeneity of issues results then, in fact, in a multiplicity of rules, organizations, paths, which makes navigation very complicated. But first of all the family needs a compass, a guide through the labyrinth, a map to avoid getting lost, and especially to be able to use all the resources to which it has the right.

This is where the family emerges as a powerhouse, capable of demanding that regulations be translated immediately into actions, to recognize and demand not merely formal observance of the law but real and practical impact. And what is decisive in such situations is the access to source of information and to cultural and relational assets surrounding each family and helping it to walk in the "labyrinth of services and interventions" and to allow the exercise of all human rights of the family member with disability.

The presence of strong and active movements of family associations has had a meaningful impact. The long history of associations that characterizes this sector has generated different phases of evolution (of family associations and of service providers, including the highly specialized ones), but above all it has guaranteed the ability to take the family with a disabled person out of isolation, loneliness, stigma. It has also led to social awareness of the problem.

Currently the mission of family associations, both with respect to the families and with respect to society at large, is to accompany families on their journey towards the society, and to fight together in the social, political, and cultural field, so that society is able to accept and include people with disability and their families.

## **2.1 The research: results obtained using the instrument interview**

What I set out in the previous chapters are the results of interpretation of documents and literature available. The outline has hopefully allowed us to detect a clear historical path of the associations and a significant specific regulatory framework for people with disability. We have also offered an analysis of the role of the associations of family members and the benefits they have brought for people with intellectual disabilities. The latter aspect has only been mentioned in point 2 because it is widely analyzed through the interview instrument that is described in this chapter.

The instrument of interview prepared by the project manager helps us to provide a very concrete analysis on the question that has arisen within the project: how have the associations of parents and relatives of people with intellectual disabilities affected and produced systems to support the quality of life and the rights of their members and all people with intellectual disabilities?

These interviews are considered as additional proof of the results of research and analytical activities described above.

Polish Association for Persons with Mental Handicap, the Project Manager, has prepared an interview grid that each country had to apply in interviews with three specific stakeholder groups:

- Group 1: three representatives of national government bodies
- Group 2: three representatives of the movement of parents
- Group 3: three people with intellectual disability

Interview questions and scenario (Panel 1 and 2):

*According to your observations, which fields of social life are influenced by the movement of parents of people with intellectual disability?*

*Please give real examples of the influence that the movement of parents has on: the legal system concerning people with intellectual disability; the social and professional activation of people with intellectual disability, access to knowledge for people with intellectual disability and their education, the development of housing for people with intellectual disability; the development of advocacy of people with intellectual disability; changes in attitudes towards people with intellectual disability and towards disability; the development of support for the families of people with intellectual disability; the development of health care for people with intellectual disability; the development of science regarding people with intellectual disability (according to your observations, what dimensions and areas of science are influenced by the movement of parents?).*

Regarding the interviews with people with intellectual disabilities (Panel 3), these were intended to understand if the persons interviewed were aware of the existence of family associations and their activities.

## **2.2 The outcomes from Panel 3 interviews (persons with intellectual disabilities)**

All three persons with intellectual disabilities interviewed as part of this study knew about the associations and all they were able to indicate the name of the specific associations (two respondents indicated more associations active in different areas).

One person declared to be member of an association, one declared not to be, while the third respondent was not able to answer.

With regard to the activities all people responded by clicking on the various options: the answers included working at the association; partaking in awareness-raising activities and in the organization of association's activities. One person also indicated all the cultural activities as well as the activities which prepare persons with disabilities for independent living and job placement.

Two out of the three know the laws related to disability, in particular the Framework Law 104/92, the Law on employment 68/99 and the UN Convention on the Rights of Persons with Disabilities. Only one respondent did not know the national regulations.

All three claimed to be up-to-date with news regarding available services and laws. They also stated that the associations known to them were known in their own area while two of them declared that the Associations were not fully heard by the society. They described services as available and all three respondents had experienced protest activities for the protection of their own rights.



These simple answers provide a good picture of efficacy of the association's actions on the quality of the personal lives of people with intellectual disabilities. The associations listed in the interviews are family associations formed in the past by parents and relatives - associations that belong to the history of the national disability movement, one of them is part of the regional network and other are smaller and local. The regional association (LEDHA) is interesting: it was founded in 1979 by parents of persons with severe disability. It is well known for its strong organizational structure that allows it to carry out an intense activity of political representation for the rights of persons with disabilities in the region of Lombardy. It offers an exceptionally good and famous, completely free-of-charge service of advisory and legal protection. Their legal center, after the entry into force of Law 67/2006, has successfully become a center of legal protection against discrimination of persons with disabilities.

### **2.3 The outcome of interviews from Group 1 (representatives of national government bodies) and Group 2 (representatives of the movement of parents)**

The interviews with Group 1 confirmed for us the picture of the regulatory framework described above. The short time available did not allow us to elaborate on the questions outside the strictly legal area with public officers. However, all respondents, when asked, agreed with the statements made by the respondents from Group 2.

The persons belonging to Panel 2 were representatives of the following Associations:

- Autismo Italia e Federazione Fantasia
- Associazione ANFFAS Onlus (Associazione Nazionale di Famiglie di persone con disabilità intellettiva e relazionale)
- Associazione AGPD (Associazione Genitori e Persone con Sindrome di Down)

Autismo Italia was established in 1998; its members are persons with autism, their families and local associations. The specific aim of the association is protection of the rights of persons with autism, with the specific aim of supporting only therapeutic treatments accepted and experienced by the international scientific community. It merged into the Federation Fantasia (National Federation of Associations for the Advocacy of Persons with Autism and Asperger Syndrome), joining in September 2008 the three major Italian non-profit organizations involved in the defense of the rights of individuals with Autism Spectrum Disorders:

Angsa (Associazione nazionale genitori soggetti autistici),  
 Autismo Italia,  
 Gruppo Asperger Onlus.

Now these associations act together, to protect the people affected and give voice to their families, to serve as a point of reference to local associations, to promote the guidelines of correct rehabilitative treatments – all inspired by the Charter of the Rights of Persons with Autism, adopted by the European Parliament.

Anffas Onlus - Associazione Nazionale Famiglie di Persone con Disabilità Intellettiva e/o Relazionale – was founded in Rome on 28 March 1958 by a group of parents. It is a large association of parents, relatives and friends of persons with intellectual disabilities.

It has more than 14,000 members distributed in 168 local Associations present across the national territory, 16 regional bodies and 45 autonomous groups; it ensures daily services and support to more than 30,000 persons with disabilities and their parents and relatives; in more than 1,000 centers (managed directly or through Anffas affiliated institutions) where 3,000 specialized staff and 2,000 volunteers and collaborators work. Anffas seeks to achieve solidarity and social inclusion in the field of: health, social, social health, assistance, education, sports - leisure, scientific research, charity, protection of civil and human rights, primarily for people with intellectual disabilities and their families, so that they are guaranteed the right to a free and supported life, as independent as possible, with respect for their dignity.

The AGPD Onlus Association of Parents and People with Down Syndrome is a support organization in Lombardy for people with Down syndrome and their families.

It and works for integration, respect, dignity and autonomy of people with Down Syndrome.

Founded in 1981 at the initiative of some parents, the association now has about 300 members and is managed by Board of Directors and President, chosen only from among parents, with the collaboration of a team of doctors and professionals in rehabilitation and education.

At the center of its actions is the person with Down Syndrome: first the child, then the adolescent, then the adult. AGPD focuses on their to their potential and capacity, helping them to achieve higher levels of social integration and autonomy. The association's slogan is *"Flying with your own wings"*: it obviously refers to the persons' independence and dignity which can be achieved if the right support is available.

For convenience I will repeat the list of the questions in order to make immediately understandable the context of the answer.

The general question was:

*According to your observations, which dimensions of social life are influenced by the movement of parents of people with intellectual disability?*

Please give real examples of the influence that the movement of parents has on:

### **1) the legal system concerning people with intellectual disability**

Since the 1970s no legislation has been made without some degree of involvement from the associations – first timid and acting each on its own, then with more and more awareness and determination, they created a conviction that no law on the subject can be prepared without hearing the point of view of families and their associations. Lobbying, support or protest in the early years, trying to overcome the grievous injustice suffered by people with intellectual disabilities, usually excluded from any form of participation – these actions with time have become more appropriate and targeted, focusing on equal rights for disabled persons. Those were the years of the struggle for social integration that led to the first law dedicated to persons with disabilities (118 /71) the Law 517/77, which established the principle of inclusion of students with disabilities in mainstream education; the historical ruling no. 215 issued by the Constitutional Court, after an administrative appeal made

by a family through the support of its association, that in 1987 recognized the full unconditional right of all disabled pupils, even those with severe disabilities, to attend secondary as well as primary schools; it also required all the authorities involved (school administration, local authorities, local health units) to provide the services in their field of competence to support general school integration.

The great political debate, stimulated by the associations, which led to the Framework Law 104/92, the removal of architectural barriers (Law 13/89), the work placement reform (Law 68/99), the integrated system of social services (Law 328/2000); the Law on the Support Administrator and the legal protection (Law 67/2006). Currently the Associations are at the forefront in defending the rights acquired with great effort in the previous years and now put at risk by the severe economic crisis in Italy and Europe.

With regard to the specific actions of the associations surveyed, the participation of the National network FISH (Italian Federation for Overcoming Handicaps) in the negotiations with the government authorities is worth mentioning. In particular, in the years 2012-2013 the network contributed to the definition of the new ISEE, which is the tool that assesses the economic conditions of the person with disability and determines access to social services and the contribution of family and/or user at their cost. At the regional level the network obtained an amendment in a resolution of the Tuscany Region, which excluded people with intellectual disabilities from access to the Services for Independent Living. The network also took part in the debate on the question of the definition of Essential Levels of Assistance; the battle for defining the severity of the disability condition and for the removal of continuous checks on the condition of permanent disability.

## **2) the social and professional activation of people with intellectual disability**

Respondents unanimously declare that participation is a strategic objective of their associations. All of them support and promote activities and services to facilitate the participation of people with intellectual disabilities in all spheres of social and professional life. Specifically, they brought up examples of collaboration with large international companies for the employment of people with disabilities (e.g. autism - L'Oreal Italy); the support activities for business companies during the recruitment process of workers with disabilities; conferences and seminars for families and service providers on the issue of social inclusion and autonomy; support activities for people with intellectual disabilities helping them to achieve higher levels of integration and autonomy. The older associations reported their interventions following inadequacies within public bodies in the services that promote the inclusion of people with intellectual disabilities in the field of professional life.

## **3) access to knowledge for people with intellectual disability and their education**

The school environment is heavily monitored by the associations at national, regional and local levels. The structure of the legislation itself allows for the participation of the Associations in the control bodies at the Ministry of Education and its local offices.

In addition, the national associations interviewed in this study are part of the National Observatory on the Conditions of Persons with Disabilities for the preparation of the State Report of the UN CRPD and the drafting of Governmental Action Plan every two years that includes the Working Group on Article 24 (Education).

In the areas of specific actions of each association, the work of support in schools at all levels is highlighted, with training of the person (rehabilitation) and collaboration with educational institutions (schools) through courses, training and internships. They promote life-long learning projects for students with intellectual disabilities and specific projects for teachers while stimulating the government to adopt specific regulations in this regard. This is for the purpose of improving the processes of inclusion of students with disabilities and satisfaction of families and teachers.

Finally, the associations are active in protecting the right to inclusive education and prevent or condemn any action that puts it at risk, standing side by side with people with disabilities and their families whenever this right is violated. Some specific local experiences were described in the answers: for instance, one association convinced its local authorities to launch traineeships for disabled persons on farms, guided by experienced educators.

#### **4) the development of housing for people with intellectual disability**

All associations indicated that they worked hard to ensure that access to the support services for independent living is available to persons with intellectual disabilities. Direct planning policies or lobbying and communication campaigns, both local and national, were emphasized. The practical experiences and actions reported include: paths of de-institutionalization of adults with intellectual disabilities and / or autism; protected apartments for small groups (3-4 people); houses for small groups (8 young adults); monitoring activities and organization of training of personnel; the work with families to accompany them in supporting their child with intellectual disabilities as a person capable of choices and opinions on his/her own life plan; assistance for families to overcome the moment of separation and to work together on the life project of their child; helping persons with intellectual disabilities recognize their own independent living skills.

#### **5) the development of advocacy of people with intellectual disability**

This is another area where the associations played a key role. They were at the forefront throughout the entire period of discussion on the reform of protective juridical institutions, and we can say that Law 6/2004 was the victory of the associations, especially those of family members of people with intellectual disabilities. Currently, the associations offer legal advice and assistance to families that have to seek legal remedies from competent courts. They also offer technical recommendations to lawyers, judges, etc. to improve the knowledge of the new legal protection instrument of Support Administrator. Additionally, they offer direct consultancy in some courts. Each association has set up numerous services of counseling via telephone call centers that are accessible to people with intellectual disabilities, their families as well as professionals (e.g. the previously mentioned service from LEDHA that provides legal protection, free of charge for person with disability and their families in the Lombardy Region. Lombardy outsourced to LEDHA and its experts the Regional Information Desk on all the issues concerning the lives of citizens with disabilities and their families. The Desk has been offering information about national and regional legislation, public and private transportation, social security, civil and economic rights, health, tourism and so on, for several years now.

All the associations through their networks participate in the monitoring mechanism of the UN Agencies (Alternative report CRC, CEDAW, CRPD, UPR) for the drafting of the Alternative Reports.

## **6) changes in attitudes towards people with intellectual disability and towards disability**

The Associations have run countless communication and awareness campaigns against prejudice, aimed at changing perceptions about people with intellectual disabilities. The subject area of the campaign included: effective use of national law to protect against discrimination based on disability in the media (TV, newspapers, advertising), attention to the correct language in communication campaigns; also on general themes that appear not in relation to disability; severe criticism when the languages are not respectful of the dignity of the person with intellectual disabilities; communication campaigns in schools and for the general public; courses, conferences, training seminars on the rights of persons with disabilities and the impact of UN-CRPD on the rights of people with intellectual disabilities and autism. All the associations also publish newsletters for members, followers and society in general.

## **7) the development of support for the families of people with intellectual disability**

All associations offer training for parents, helping them to understand the capabilities of their children with disabilities. These courses include awareness-raising and training of parents on the rights of people with intellectual disabilities and autism; meetings with specialists, with teachers, rehabilitation professionals. The support is also expressed through the legal assistance outlined above whenever the family has to start legal action to defend the rights of their child.

## **8) the development of health care for people with intellectual disability;**

This field of activity has always been part of the movement of the associations of relatives of people with intellectual disabilities and is reflected by the associations' intense and tireless struggle for recognition of the right to access health and rehabilitation care. The associations have always claimed the right to treatment while rejecting the purely medical approach to disability and have treated persons with intellectual disability not as patients but as citizens deserving availability of appropriate health care and services as well as equal opportunities and full participation in social and civic life. The associations are initiators of many awareness-raising endeavors and urge the scientific community to ensure standards of respect for dignity of disabled persons in scientific research. Another important type of activity that the associations direct to the scientific community is monitoring of treatments and therapies offered: the associations report intense collaborative activities with centers of excellence, and hospitals, aimed at improving the quality of access to hospital facilities and access to health care for children, adolescents and adults with intellectual disabilities (e.g. Autism Italy cooperates with Hospital Bambino Gesù in Rome; project DAMA is another relevant example). Moreover, training courses for healthcare professionals are often organized where the representatives of the associations act as trainers. The associations are also involved in collaborative preparation of regional Health Plans and are represented in the Scientific and Health Committees of local authorities.

## **9) The development of science regarding people with intellectual disability (according to your observations, what dimensions and areas of science are influenced by the movement of parents?).**

None of the associations surveyed position scientific research as their official purpose. Nevertheless, the associations recognize and inspire relevant research, possibly leading to beneficial application. As for the Autism Association of Italy, it delivered the draft of guidelines on the treatment of Autistic Spectrum Disorders in Children and Adolescents, created in 2011 under the coordination of the Istituto Superiore di Sanità. The draft was later used by the Ministry of Health. The guidelines were based on the analysis of scientific literature and real-life cases and recommended evidence-based interventions.

### 3. Conclusions

For the purposes of the whole project and of the analysis presented in Chapter 1 entitled "The Family Associations in Italy: the origins, development and efficacy", we can say that it was thanks to the strong work of the associations, and in particular the associations of family members of people with intellectual disabilities, that the first laws in the fields of assistance, social security and health care were approved, followed by the implementation of education, vocational training (at that time separate and special) and rehabilitation.

We must recognize the limitations and problems of the early days, partially still experienced today, linked for example to the protective mentality, the preservation of the differences between disabled and non-disabled people, and rooted in the categorization of disability (as caused by military service, labour and physical, sensory, intellectual ...).

At the same time we must recognize that the associations of family members have always worked to promote the rights of persons with disabilities by stimulating solidarity and participation. Without doubt we can identify among their activities not only political pressure but also study and research, family support groups, organization of community living and / or workshops - all understood not only as services for people with intellectual disabilities but also, from a more general perspective, as forms of inclusive social policy based on equal rights.

The dual nature of the activities, positioned somewhere between the role of management and the role of promotion and defense of human rights, has significantly influenced the culture of disability in Italy. Thanks to the associations' efforts, the perception of persons with disabilities by the scientific community and by the society at large has evolved from that of a sufferer / patient / user to a citizen with full rights and a unique life plan. The evolution has shifted the core of the disability debate from care to of independent living, autonomy, adult disability, non-discrimination and social inclusion – all of which characterize the activities of the organizations, the scientific community and the entire society.

With regard to the question of representation, understood as representation of the citizen's rights that the person with intellectual disability is not able to fully use and defend, there undoubtedly have been strenuous battles of the associations of family members leading to recognition of persons with intellectual disability full citizens. They also fiercely argued against the previous concept of legal protection, in favour of protection that would support the persons without ignoring their desires and aspirations. In line with Article 12 of the CRPD, Italy produced legislation in this regard thanks to the political pressure of the associations of family members along with the whole disability movement even before the United Nations adopted the CRPD in full.

Although this historical and political analysis on the movement of associations of family members of people with intellectual disability is relatively brief and certainly far from complete, we can use this paper to reflect and try to identify the demands that the world of disability has to face.

It is important to start from reading the mission statements of and short descriptions of the associations that deal with disability as it gives us a broader perspective on what has changed over the recent decades, on what the present is like and on what developments in the field of disability can await us in the near future.

The first conclusion concerns the organizational characteristics of the associations – especially those of small size. They usually have a top-down structure, usually headed by a President or Founder and, frequently, hierarchical dependencies. A brief analysis of the associations shows that the structure and leadership are often composed of parents of disabled persons who often perceive disability of their children as unwanted drama and traumatic experience. This may sometimes interfere, despite the best intentions of the parents, with realistic managing capacity of the organizations that would relativize both the objectives and the "raison d'être" of the association. This risk cannot be totally eliminated but being aware of it may help turn limitations into resources.

Presently, a move seems to be noticeable towards an even wider diffusion of small associations, because the centralist model of the big ones (with national headquarters and local offices) clashes with the dynamics related to the various forms of federalism and subsidiarity. This must be taken into account so that we can confront the complexity of the time in which we live and the rapidity of the changes we need to face.

Although the challenges listed above are certainly important, our analysis of associations of family members of persons with intellectual disabilities brings out several positive aspects briefly listed below:

- a) the political commitment: confronting and assessing public policies and strategies;
- b) the education function: information, training and documentation;
- c) the economic function: services, employment, funding and the "rationalization" of resources, reflection on the ethical dimension of the economy;
- d) the relational function: supporting services and research in the field of disability: provision of care and support, helping relationships, sexuality, adolescence in families, the first information on disability given to parents at the time of birth, the impact of chronic diseases and adult disability, the question of what will happen "after we are gone" (i.e. the life situation of people with disabilities, especially severe and/or intellectual, after the death of their parents), the situation of women with intellectual disabilities;
- e) the social function of the public and private domains: the role of the third sector, the relationship with local government and politics, civil society and the element of participation/inclusion;
- f) the creation of networks: between the various NGOs, with associations active in other areas with common goals (home, work, mobility), with other social actors, with the world of culture, research and communication.



At last and finally we can declare that the history of the associations of families of people with intellectual disabilities is a valuable part of the history of humanity and society of the last one hundred years. It is the history of active organizations which fight for respect for diversity as added value, dignity and human rights for all; the history where respect for inherent dignity, monitoring and defence of human rights, transformation of policies, mainstreaming of disability, are key aspects of a new economic, social and cultural approach to persons with disabilities.

Throughout the years, all the associations have been guided by the inclusive and equality-centered principles of the CRPD pertaining to all persons with disabilities, including the ones with intellectual disabilities.

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## The Role of Advocacy and Not-For-Profit Organizations in the Development and Implementation of Services for Individuals with Mental Retardation in the United States of America

Exploring the dynamics of how a society creates strong inclusive practices for all people, including those with disabilities, is a complex task that involves a review of all systems within that society including, but not limited to, systems of education, housing, health care, law, and medicine. In this chapter we explore the critical role of advocacy and not-for-profit organizations in the development and implementation of effective services in the United States of America (USA). To do so we reviewed current literature and interviewed national leaders in inclusive services for people with intellectual disabilities, including self-advocates, parents who have advocated for their children and other persons with intellectual disabilities, and advocates with a long history of leading national not-for-profit organizations. We present preliminary findings of these activities, comprising a cycle of societal activities that has been resulting in services that are ever-increasingly more equitable and excellent for persons with intellectual disabilities.

Reporting on a review of the full set of services and supports for persons with intellectual disabilities and how those services and supports have evolved to date in the USA is beyond the scope of one chapter in one book. Indeed, it would take multiple books to fully cover the dynamics of a society involved in creating change in just one area (e.g., education, medicine). Instead, we present an over-arching framework to describe societal activities that have led to inclusive practices being developed and improved cyclically over decades. We use specific examples from education within a larger historical context, and use experiences reported by self-advocates and advocates as illustrations of societal activities.

The phrase “inclusive practices” is a broad term that might be interpreted differently by different individuals and societies. We did not explicitly investigate the individual meanings of this term with each person we interviewed. Instead, we used their bodies of work and on-going struggles for overall societal inclusion to determine the following working definition of inclusive practices: (a) each person has the same rights to make decisions that impact their lives, regardless of whether or not they have an intellectual disability; and (b) each person has opportunities to be actively and meaningfully involved in all aspects of the society in which they would live if they did not have an intellectual disability.

We reviewed the literature related to the civil rights movement for people with intellectual disabilities and examined how societal activities related to that movement informed the field of education. From there, we identified seven advocates and self-advocates who had extensive experience working to promote more inclusive practices for persons with intellectual disabilities on a national level.

The purpose of these interviews was to learn what self-advocates, parents, and advocates do to advocate for the development and implementation of inclusive services for persons with intellectual disabilities. We chose our participants in an attempt to obtain perspectives of (a) self-advocates who have been advocating on local and national levels for inclusive services for themselves and other persons with intellectual disabilities; (b) parents who have been advocating on local and national levels for services for their child and other persons with intellectual disabilities; (c) people with extensive experiences working with or for national organizations charged with developing or implementing services for persons with intellectual disabilities. We asked these individuals about their advocacy activities and approaches to determine the intent to which their activities and approaches have resulted in changes to services (e.g., education, employment, living options) for persons with intellectual disabilities.

### **Equity and Excellence**

During our review of the literature and interviews we found a cycle of societal activities rooted in the belief that services for persons with intellectual disabilities should result in lives that are comparable to the lives of persons who do not have disabilities in relation to equity and excellence. This cycle reflects a process that has been resulting in changes in services for persons with intellectual disabilities that are increasingly more equitable and excellent. We contend that this cycle could be perceived to be a model for supporting ever-improving movement toward equity and excellence in services and quality of life for persons with and without disabilities. This cycle is based in the belief that all people deserve equity and excellence in the services provided for them. Equity and excellence provide both the impetus for and the goal of change. Current systems of service delivery and the quality of the services provided, therefore, are evaluated through this lens. If there are service components or outcomes that are not considered to be equitable, or that do not provide excellent service, those components become the focus for change.

Equity and excellence are ever-evolving concepts that are tied to current conceptualizations of individual rights, advances in research, and understandings around persons with intellectual disabilities (e.g., how they learn; where and when they need supports to maximize independence; re-evaluations of our own biases and prejudices). Equity and excellence refer not only to the service quality but also to the outcomes of those services. For instance, having equity in services has led to a better quality of life for people with disabilities; and improving the quality of those services has led to better outcomes. The first part of this chapter examines inclusive practices in education and the changing expectations of service delivery related to these practices. While a comprehensive examination of the whole history of education for students with intellectual disabilities in the USA is not the purview of this chapter, it is helpful to understand the changing understandings of inclusive education since the 1970s.

Prior to the 1970s, there was no concept of inclusive education because most students with intellectual disabilities either were living in institutions or remaining at home with their families. Education for students with disabilities was not yet mandated by federal law, therefore it was not even a consideration in most states. Hence, the first construct of equity and excellence was to provide an education for persons with intellectual disabilities, similar to the provision of education for persons who did not have disabilities. When federally-mandated special education first began in the USA in the mid-1970s, it was based on developmental constructs; that is, the hypothesis that persons with intellectual disabilities had missed an important developmental milestone that currently was hindering their development. Initially, therefore, the educational approach focused on providing students with opportunities to re-experience the developmental stages and meet each developmental milestone.

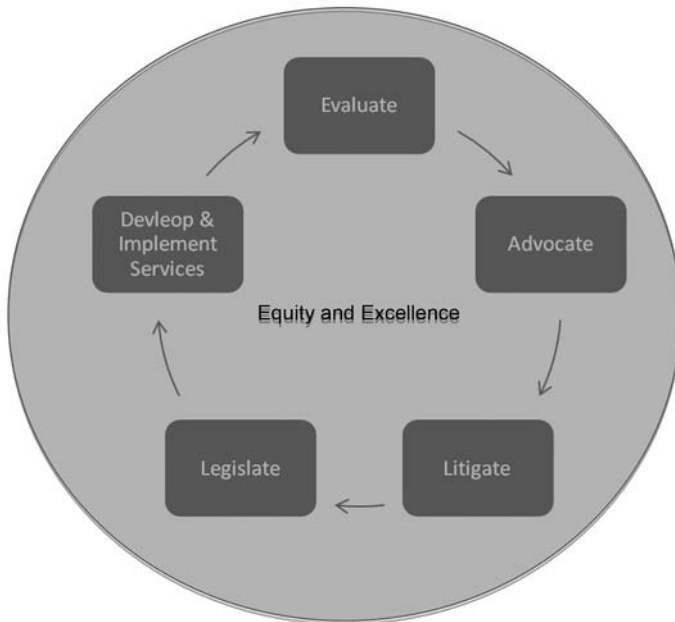
However, in the late 1970s and 1980s, educators began to realize that the student outcomes from this approach to curriculum and instruction were not preparing students for life in their home communities or life after school, and some educators and researchers began to advocate for a “functional” curriculum aimed at preparing students for routine tasks that could be used both during their school experiences and in post-school settings (e.g., work, home). The curriculum and instruction focused on daily living skills (e.g., getting dressed, cooking, shopping) and requirements for adult life. In the early 1980s though, the idea of excellence and equity again evolved as advocates reviewed student outcomes and found that they were not being included socially in their communities. Now concepts of equity and excellence in educational services had an added component of social inclusion, where students received services alongside their same-aged peers in order to promote their acquisition and use of social skills and build natural support networks. In the late 1990s and early 2000s concepts of equity and excellence in educational services maintained the social focus but evolved to incorporate an academic component. Students with intellectual disabilities now were expected to have opportunities to learn and progress in the same grade-level curriculum content provided for their same-age peers who do not have disabilities. When evaluating educational systems today, the concept of “appropriate services” includes additional dimensions: (a) positive post-school outcomes, (b) social inclusion, and (c) equal access to the same content as same aged peers. The following sections will explore how these ideas of equity and excellence influenced and set the stage for new models of service delivery.

### **The Cycle of Societal Activities**

The concept of a cycle of societal activities which emerged from the literature review and interviews provides a credible model for describing types of events that have led to change in services for individuals with intellectual disabilities in the USA. In addition, evidence of this model can be found today in societal activities. In this cycle, individuals or organizations evaluate current services to determine whether those services are adequate or lack the level of quality desired. If the latter is found, the individuals or organization advocate for change in those services. In the USA, this process often results in litigation, which has the potential to eventually lead to new laws that outline new policies and procedures that increase the quality (i.e., equity and excellence) of mandated services. Service providers then either revise their system of services or develop new services to reflect the mandated change. After these new or revised services have been provided for a period of time, advocates then evaluate

those services and, again, determine whether those services are adequate or lack the level of quality desired. Thus, the cycle of societal activities begins again, if needed. Picture 2 presents a visual representation of this cycle of societal activities.

Picture 2. The cycle of societal activities



The cycle of societal activities outlined here presents a model for change. In this chapter we explore each component of this cycle and provide examples from advocates who strive for inclusive educational practices that reflect equity and excellence in the USA. Each evolution of society’s understanding of inclusive practices that reflect equity and excellence outlined above has influenced the evaluation of existing services and has led to a new iteration of the cycle of societal activities, in efforts to improve the system of educational services.

Our findings address how self-advocates, parents who are advocates, and not-for-profit organizations have assisted in changing services so that the lives of persons with intellectual disabilities are of a higher quality and embedded more fully in their involvement in their home communities. In the first section of this chapter we address our preliminary findings about the cycle of societal activities and how it is reflected in the changing landscape of education for students with intellectual disabilities in the USA. In the second section of this chapter we present a case study of one person’s lived experience in moving to contexts and services that were increasingly more inclusive. We contend this case study illustrates the potential power of the cycle of societal activities.

## Preliminary Findings

### **Equity and Excellence**

Equity and excellence are both the bar for measuring the quality of current services and the goal for changes in services for which advocacy occurs. In the field of education, our understanding of equity and excellence are informed by larger social movements; thus, concepts of equity and excellence in education continuously evolve.

In the USA the 1960s and 1970s were characterized by both political and racial upheaval. Politically, the country was engaged in a controversial war, and almost daily protests and riots occurred. During this same time, the civil rights movement swept the country, and numerous nonviolent protests occurred across the country in support of racial equality for all. As a result of these advocacy activities and related litigation, such as *Brown v. Board of Education* (1954), African-American students were integrated into schools that formerly provided services only for white students (Keogh, 2007). By overturning a previous court ruling (i.e., *Plessy v. Ferguson*, 1896) which allowed racial segregation, the unanimous court ruling in *Brown v. Board of Education* declared that “separate educational facilities are inherently unequal.”

Although the educational ruling that separate facilities and services are inherently unequal was related to race, for disabilities advocates this ruling also changed the understanding of equity and excellence in services for students with intellectual disabilities. With the civil rights movement as the backdrop, the disability rights movement took shape in the late 1960s with a demand for equal rights and equal access to high quality services for every student, regardless of the presence of a disability. These two social justice movements (i.e., related to racial and disabilities issues), our changing understanding of civil rights, and society’s increased awareness that all people should have the same rights, set the stage for a new conceptualization of equity and excellence in education. This conceptualization continues to evolve and this evolution continues to inform our understandings of inclusive education.

### **Evaluate**

With this new conceptualization of equity and excellence, education in the USA changed significantly from the 1970s until now. In the 1960s and early 1970s educational services for students with intellectual disabilities was not mandated; such services existed only if a state (e.g., Wisconsin) chose to provide them. Students with intellectual disabilities, therefore, were rarely present in schools.

One of the advocates we interviewed described starting her own school to meet her child’s needs because at that time no school was providing educational services for students with disabilities. This is a clear example of advocates evaluating the current landscape of educational services and finding it lacking. Similar evaluations have occurred in the USA for other areas of services for people with intellectual disabilities (e.g., medicine, housing, employment). Advocates have evaluated practices provided in one type of service using current perceptions of both the needs of persons with disabilities, and best practices that address equity and excellence. If during the evaluation process advocates have found aspects of services that either do not match their conceptualization of equity and excellence, or meet the needs of persons with disabilities, they then have advocated for changes in those services.

**Advocate**

Advocates have played a vital role in shaping educational services for students with intellectual disabilities so that they reflect equity and excellence at their current level. In the early 1970s schools and districts could refuse to educate students with disabilities, public buildings did not have to be accessible for persons with disabilities, and employers could refuse to hire applicants who were qualified for jobs, but also had disabilities. Persons with disabilities began staging protests to advocate for all persons to have access to education, community facilities, and the same opportunities that were open to persons who did not have disabilities. The public was ill-prepared to see persons with disabilities as self-advocates, and the self-advocates' message was both strong and credible (Barnett, Schriener, Scotch, 2001).

As one interviewed advocate stated, "A single voice is pretty easy to ignore whereas a group voice is more powerful." As advocates worked together and presented a unified call for action, their power increased. Successful advocacy requires both a group movement and individual acts of activism; however, the individual acts of activism must be consistent with and connected to the group movement. To accomplish this, it has been critical for advocates to consider the skill sets that make advocacy activities powerful. The information we gathered from the self-advocates, parents who had children with intellectual disabilities, and advocates who worked with national not-for-profit organizations we interviewed revealed some strong commonalities related to the skills required to advocate successfully. These skills included:

- Perseverance and skills to consistently follow-up
- Gaining knowledge about
  - policies, laws, and key issues
  - the beliefs and positions demonstrated by key individuals (e.g., politicians, school administrators)
  - reasons provided for having those beliefs and positions
  - activities that might influence or change those beliefs and positions
- Being able to explain things simply
- Learning from everyone across their roles
- Being resourceful
- Negotiating and being strategic
- Building relationships

While some of these skills initially might seem more pertinent to those advocates who work on a national level, these areas also can be viewed from a micro (i.e., single person) and macro (i.e., national) level. If a parent advocate is working on building inclusive practices for his/her child, that parent needs to be able to understand the policy, law, and key issues relevant to the placement of the child in general education classes and the services that will support the child in those classes. It also is important for the parent to understand why school and district personnel demonstrate their current beliefs and positions and what the parent can do to change those beliefs and positions to support inclusive education. Activities that influence beliefs and positions can take many forms. For instance, some of the interviewed advocates reported having to know which people they should partner with and strategies to build a stronger set of partners that could apply more pressure on the decision

makers. Other advocates we interviewed built personal relationships that engaged others in relevant activities, demonstrating a sense of camaraderie. Although the advocates used many pathways to successful advocacy, most of the advocates we interviewed began with a non-threatening approach that helped them build relationships. This is not to say that these advocates did not stand up for their beliefs; rather they worked on ways to bring people “over to their side,” to negotiate, and to think strategically about how to make the desired changes in educational services.

The advocates we interviewed knew how difficult it is to create change. They spoke of the need to take action, rather than waiting for others to take action for you. In addition, they recognized the fact that change takes time. As one advocate stated: “If you’re right it should be a part of your life. If you are going to do it [i.e., advocate], do it for the long haul.”

### **Litigate**

Negotiation and relationships do not always lead to change. In the USA there have been times when litigation (i.e., law suits; court cases) was necessary to create change. The civil rights movement of the 1960s and 1970s gave way to a number of court cases that demanded educational equality. Prior to the 1950s public institutions in the United States were racially segregated. This was permitted based on the doctrine that it is possible to provide separate services that are equal to each other, which was legally permitted by the 1896 Supreme Court case *Plessy v. Ferguson*. This doctrine was upheld for more than 50 years and public buildings and services, including schools and educational services, were segregated based on race. The landmark case *Brown v. Board of Education* (1954) outlawed segregation in public schools. Unlike the previous policy, the judge declared “separate is inherently unequal.” This ruling paved the way not only for racial integration, but also for the inclusion of all persons, including those with disabilities, in the same buildings and services.

In 1967 civil rights activist Julius Hobson went before the Circuit Court and argued that tracking students (i.e., predetermining a student’s curriculum and desired outcomes of services) based on academic testing was unfair to low-income, minority students. Hobson contended that placing students in predetermined classes, or tracks, based on an intelligence score unfairly determined a student’s future. The judge agreed with Hobson, ruling that tracking students violated both the due process and equal protection guarantees of the 14th amendment of the United States Constitution. While this case again explicitly referred to racial inequalities, the implication was that students could not be segregated based on their academic performance.

In the early 1970s two cases were brought before the District and Supreme Courts targeting the inequalities faced specifically by children with disabilities. In 1971, the Pennsylvania Association for Retarded Citizens (PARC) brought before the District Court the first right-to-education lawsuit in the USA. In this seminal case (*Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania*) the judge ruled that children with intellectual disabilities were afforded equal protection and due process under the law. The case pronounced that schools could not turn away students, even those with the most significant intellectual disabilities, and that preference should be given to the placement of all students in general education settings. Prior to the PARC (1971) case, most states had legislation that

excluded children with intellectual disabilities from the public education system. While this case never moved past the District Court, and only referenced students with intellectual disabilities, it was the first piece of litigation to challenge the existing exclusionary legislation.

Shortly after the PARC case, a parallel court case was brought before the Supreme Court in 1972. *Mills v. Board of Education of the District of Columbia* expanded the educational rights of all students with disabilities, not just those with intellectual disabilities (1972). In this case, a 12-year-old boy with emotional and behavioral disabilities was denied an education by the Washington D.C. School District. The Board of Education argued that educating this one student would cost millions of dollars and would, therefore, be an undue burden to the local government that funded the education system. The court disagreed, and ruled that no school-aged child could be denied an education based on having a disability.

These court cases paved the way for the passage of Public Law 94-142, the Education for All Handicapped Children Act in 1975. Prior to the law, a state could choose to provide educational services to school-age children, but those services were not mandated by federal law. Because of this, it was common for school-age children with disabilities to be excluded from schools and denied their right to a free and appropriate education. The court cases discussed above set the Congress of the United States into action, and they passed legislation to address the inequities faced by school-age children with disabilities in the educational system. Public Law 94-142 was the first piece of legislation in a line of many to address these issues. A list of court cases with subsequent legislation can be found in Table 1.

Table 3. Litigation and legislation (shaded)

YEAR	LITIGATION /LEGISLATION	RULING
1954	Brown v. Topeka Board of Education	"Separate educational facilities are inherently unequal."
1967	Hobson v. Hansen	Tracking violates both the due process and equal protection guarantees of the 14th amendment.
1970	Diana v. State Board of Education	Assessment must be in a child's native language and be free of cultural bias.
1972	PARC v. Commonwealth of Pennsylvania	Applied the equal protection & due process guarantees to children with intellectual disabilities (a) regular education placement preferred (b) beginning of parents' rights.
1972	Mills v. DC Board of Education	Extended equal protection and due process guarantees to children with any type of disability. Court ruled that the board was not able to deny based on inadequate resources.



1973	Vocational Rehabilitation Act (Section 504)	Banned discrimination in programs that received federal funds.
1975	Education for All Handicapped Children Act/Public Law 94-142	Six key components for all students include: (a) free and appropriate education (b) special education and related services in the least restrictive environment (c) nondiscriminatory assessment (d) individualized education programs (e) parental due process rights (f) parent involvement in their child's educational process.
1982	Board of Education v. Rowley	Children with disabilities" must have reasonable opportunity to learn."
1983	Roncker v. Walter	The presumption must be in favor of placement in the regular education environment.
1984	Irving Independent School District v. Tatro	Provided guidelines for whether a medical service is a related service, based on who provides the service.
1989	Daniel R. R. v. State Board of Education	Upheld the right of children with severe cognitive disabilities to attend regular education classes  Students with disabilities have a right to both academic and extracurricular school activities.
1990	Individuals with Disabilities Education Act (IDEA)	New key provisions include: (a) classification of the disabilities traumatic brain injury and autism (b) services to assist students 16 years and older to transition from school to adult life (c) further clarification of the concept "least restrictive environment."
1990	Americans with Disabilities Act (ADA)	Strengthen Section 504 of the Vocational Rehabilitation Act. ADA banned discrimination based regardless of funding.
1992	Oberti v. Board of Education of New Jersey	"A student does not have to earn his way into an integrated school setting by first functioning successfully in segregated settings. Inclusion is a right, not a privilege for a select few."
1994	Board of Education, Sacramento City Unified School District v. Holland	A child should be educated inside the regular education classroom above all other setting.
1997	Individuals with Disabilities Education Act (IDEA)- Reauthorization	A key focus was including students with disabilities into the general curriculum. The reauthorization of IDEA made reference to the following for students with disabilities: (a) access to the general education curriculum, (b) involvement in the general education curriculum, (c) progress in the general education curriculum.
2001	No Child Left Behind	The key focus was accountability for all students (as measured by annual state assessments).
2004	Individuals with Education Disabilities Improvement Act (IDEIA)	Availability of accessibly materials in a timely manner.

In the years following the passage of Public Law 94-142 the cycle of societal activities leading to services that are ever-increasingly more equitable and excellent continued. This resulted in more litigation as advocates worked to lessen the inequalities faced by students with disabilities. In *Board of Education v. Rowley* (1982) the Supreme Court ruled that students with disabilities “must have reasonable opportunity to learn.” A year later a judge declared that schools must presume that a student would best be served by placement in general education settings. In the 1984 Supreme Court case *Irving Independent School District v. Tatro* the judge stated that medical services were a necessary part of the education for a student with disabilities, and therefore the relevant medical services must be provided by the student’s school district. Illustrative of the changing understanding of equity and excellence, by the end of the 1980s litigation had shifted away from merely providing an education to all students with disabilities, requiring that education services be provided in general education classes, so students with disabilities were taught alongside students who did not have disabilities. In 1989 *Daniel R. R. v. State Board of Education* upheld the rights of students with severe intellectual disabilities to attend general education classes. This case defended the students’ right to participate in both academic and extracurricular activities, services, and contexts supported by a school for students who did not have disabilities.

This trend of litigation continued throughout the 1990s with two famed pieces of litigation - *Oberti v. Board of Education of New Jersey* (1992), and the *Board of Education Sacramento City Unified School District v. Holland* (1994). In both court cases, when compared to self-contained/segregated settings, general education classes were found to be a more appropriate placement for students with severe disabilities. These court cases ruled that “a student does not have to earn his way into an integrated school setting by first functioning successfully in a segregated setting.” Furthermore, the judges stated that “Inclusion is a right, not a privilege for a select few.” These court cases helped pave the way for the reauthorization of federal legislation (i.e., Individuals with Disabilities Education Act) in both 1997 and 2004.

### **Legislate**

Mounting litigation and increased advocacy efforts led to two monumental pieces of federal legislation in the early and mid-1970s. After being rejected twice, the Vocational Rehabilitation Act of 1973 was passed, banning discrimination in programs that received federal funds.

Two years later Public Law 94-142 (i.e., the Education for All Handicapped Children Act) was passed, mandating six components for all students, regardless of disability:

- (a) free and appropriate public education,
- (b) special education and related services in the least restrictive environment,
- (c) nondiscriminatory assessment,
- (d) individualized education programs,
- (e) parental due process rights,
- (f) parent involvement in their child’s educational process. The language calling for services in the “least restrictive environment” is first used in this legislation, and is defined as the following:

*States must have procedures to ensure that, to the maximum extent appropriate, children with disabilities, including those in public/private institutions, are educated with non-disa-*

*bled children and that removal from the regular education environment only occurs when education in that setting, with supplementary aids and services, cannot be achieved satisfactorily (Public Law 94-142, 1975, Sec. 612, 5).*

Public Law 94-142 was a seminal piece of legislation for students with disabilities. For the first time in the history of the USA the local government was mandated to provide access to a free appropriate public education for all students with disabilities, and to do so in the least restrictive environment. This law laid the groundwork for the context in which the education should occur.

The cycle of societal activities is in constant motion. While Public Law 94-142 was a major victory for advocates for the educational rights of students with disabilities, the advocates continued to work vigorously to further advance the rights of persons with disabilities. With this advancement came new understandings of equity and excellence followed by additional evaluations of services, advocacy to increase the degree to which equity and excellence were reflected in services, and litigation. Fifteen years after Public Law 94-142 was introduced, the law was reauthorized by the US Congress and renamed the Individuals with Disabilities Education Act (IDEA) of 1990. New key provisions of IDEA included the addition of two new disability categories (i.e., traumatic brain injury, autism), services to assist students 16 years and older to transition from school to adult life, and further clarification of the concept “least restrictive environment.”

Due to the changed understandings of excellence and equity, litigation in the 1990s focused on the placement of students with disabilities in general education settings and the provision of equal opportunities for the students to access general education curriculum and experiences. Two court cases previously discussed (i.e., *Oberti v. Board of Education of New Jersey*, 1992; *Board of Education Sacramento City Unified School District v. Holland*, 1994) are examples of this trend in court cases. These court cases laid the foundation for the 1997 reauthorization of IDEA and its clarification of the concept “least restrictive environment” and statements that students with disabilities must (a) have access to the general education curriculum, (b) be involved in the general education curriculum, and (c) make progress in the general education curriculum.

Building on this trend of focusing on equity for all students, in 2001, the No Child Left Behind (NCLB) Act was introduced as a reauthorization of the Elementary and Secondary Education Act (ESEA) of 1965. While this legislation mandates general education services, it had a major impact on education services for students with disabilities. A key component of NCLB was the inclusion of all students in state accountability programs; that is, it was mandated that schools must demonstrate that all students, including students with disabilities, were making progress on the general education curriculum across school years. Schools with consistently low test scores were given a short window of time to make improvements or risk closure.

Each piece of legislation has furthered the support for inclusive education in the USA. Yet, how states and schools enacted policies to meet the federal mandates for best practices, social and academic inclusion, and accountability has played a vital role in whether the vision of equity and excellence was achieved.

**Develop and Implement Services**

Through advocacy, litigation, and legislation, public educational services have been mandated for all children, including those with disabilities. After the passage of Public Law 94-142, educational services focused on providing students with intellectual disabilities instruction on developmental content, usually in segregated special education settings. After another cycle of societal activities the passage of IDEA opened the door for social inclusion in schools, and students who had intellectual disabilities increasingly were placed in the same general education classes as their same-age peers who did not have disabilities. Typically, however, this social inclusion occurred only in non-academic classes (e.g., music, art, physical education). At the time the curriculum standard for students with intellectual disabilities was “functional” skills; that is, skills that would prepare them for adult life. For example, students might be taught sight words they could use in the community (e.g., stop, danger), skills for using money in the community, and life skills (e.g., making a bed, cooking, shopping). This was considered best practice, and the educational services provided for students with intellectual disabilities reflected this.

As the cycle of societal activities continued, advocates recognized that providing students with intellectual disabilities services comprised of different content and provided in segregated contexts was no longer acceptable. Advocates then fought for equity in educational content and contexts. Court cases in the 1980s and 1990s focused on including students in general education classes and providing them instruction on the same content as their same-age classmates who did not have disabilities. These court cases were supported by legislation (e.g., Public Law 94-142, 1975; IDEA, 1990) that increasingly clarified and strengthened the concept of “least restrictive environment,” and required that all students be involved and make progress in the general education curriculum. Despite such legislation, however, school districts were not held accountable for the performance of most students with disabilities, and their educational services reflected this flaw. For example, some schools continued to place students with intellectual disabilities in segregated special education programs that provided instruction on an alternate curriculum (i.e., not the general education curriculum), thus denying those students opportunities to be involved and make progress in the general education curriculum. Instruction on this alternate curriculum was inconsistent with inclusive educational practices because students were not given opportunities to learn the social or academic skills being taught to their same age peers who did not have disabilities.

Upon realizing this lack of opportunities, the definition of equity and excellence again began to shift, leading to the passage of the No Child Left Behind (NCLB) Act of 2001. With this legislation school districts became accountable for the academic success of all its students, including students with intellectual disabilities. For the first time schools were required to measure the progress of all students on the general education curriculum, and for school districts to be considered successful they had to demonstrate that all groups of students were making progress, including students with intellectual disabilities. Advocates could use this legislation to support the development of inclusive educational services that increasingly reflected equity and excellence comparable to services provided for students who did not have disabilities.

## **Perceptions of Participants**

Our interviews with self-advocates provided information on how persons with intellectual disabilities perceived the services they had received and the challenges they had experienced. Through the interviews we learned about the power of self-advocacy. In the following section we explore one self-advocate's experiences in relation to the cycle of societal activities that has been resulting in services that increasingly are more equitable and excellent. We examine how this self-advocate's life changed due to changes in services for persons with disabilities in the USA in response to advocacy efforts. Through this case study we can critically examine the gaps in services through the perspective of one self-advocate with an intellectual disability.

Katherine was born with fetal alcohol syndrome in the late 1950s. She tested positive for a variety of illegal street drugs and was classified as having an intellectual disability. At a young age she was placed in a state institution, where she remained for over two and a half decades. In the institution Katherine endured abuse and neglect. For example, when she was two years old she was set on fire by her caregivers.

Katherine's life in the institution is a classic example of what life was like for persons with intellectual disabilities in the USA prior to the 1970s. At that time, few persons with disabilities were present in American society. Under the recommendation of doctors, most parents abandoned their children who had disabilities, placing them in state institutions; when doing so, parents believed they were doing what was best for their child by following the doctors' recommendations. Conditions in the institutions were deplorable and the residents with disabilities received minimal care or attention. It was common for the residents to be abused and neglected on a daily basis (e.g., not clothed; not cleaned or groomed; left with no activities or persons with whom they could interact) (Blatt & Kaplan, 1974; Kugel & Wolfensberger, 1969). Persons with disabilities living in institutions were denied education, as well as any opportunity to be members of and to be involved in the community outside of the institution.

## **Advocating for, Litigation and Ensuing Legislation**

In part because of the civil rights movement, advocates began to evaluate the services provided to persons with disabilities living both in the institutions and in the community at-large. Researchers and the media began to illustrate how these services did not reflect the same understandings of equity and excellence reflected in society's services for persons who did not have disabilities. American society was outraged by the conditions in which persons with disabilities were living and the lack of equal rights afforded to them. They demanded change and equal rights for persons with disabilities, and the ensuing societal activities were similar to those of advocates who were seeking equal rights for other persons (e.g., persons of differing races) who, at the time, were also devalued in American society. Advocates sought deinstitutionalization and the return of persons with disabilities to their home communities. Between 1955 and 1980 the number of residents living in hospitals and institutions decreased from 559,000 to 154,000 (Koyanagi, 2007; Kovanagi & Bazelon, 2007). Consistent with this decrease, in the early 1980s Katherine was appointed an advocate and was allowed to leave the institution when she was 26 years old.

The deinstitutionalization movement required the development of multiple systems of services. For instance, for persons moving out of the institutions and back to their home

communities to be close to family members, services were needed to support them where they lived, worked or spent their daytime hours, and where and how they spent their leisure hours. In addition, services were needed to prevent persons with disabilities from being placed in institutions to begin with, upon being identified as having a disability. Thus legislation was passed and new services were developed. Table 2 outlines some of the most influential advocacy, litigation, and legislation that led to significant changes in services for people with intellectual disabilities.

Table 4. History of deinstitutionalization

1961	Joint Commission report Action for Mental Health
1963	John F. Kennedy's Message to Congress
1963	Mental Retardation Facilities and Community Mental Health Center Construction Act enacted
1965	Community Mental Health Centers Construction Amendments authorizing staffing funds for Community Mental Health Centers
1965	Medicaid and Medicare enacted
1971	Wyatt v. Stickney case decided regarding obligations for treatment of those involuntarily hospitalized
1972	Supplemental Security Income program enacted
1975	Community Support Program established by the National Institute for Mental Health
1977	Commission on Mental Health establish by President Jimmy Carter
1980	Mental Health Systems Act enacted
1980	Publication of National Plan for the Chronically Mentally Ill
1981	Mental Health Systems Act repealed and community mental health centers program replaced by block grant Supreme Court rules Social Security Income/Social Security Disability Income benefit rules must be revises
1988	Fair Housing Act amended to include persons with disabilities
1990	Americans with Disabilities Act enacted
1999	Surgeon General's Report on Mental Health
2003	President's New Freedom Commission on Mental Health Report

(Koyanagi & Bazelon, 2007).

It is important to note that the legislation that supported the deinstitutionalization movement addressed multiple fields, including housing, mental health, medical services, and supplemental income programs. Part of the advocacy by and for Katherine involved making her wishes known, identifying her strengths and needs, learning which services would accentuate her strengths and support her needs, and securing her enrollment in those services.

Upon leaving the institution Katherine first moved into a group home where she lived for three years with several other persons who had disabilities with support for their participation in life in the community. When she was living in the institution, Katherine had no choices. Although this move allowed her to be in a normal society, Katherine did not perceive living in the group home as much of an improvement. She and her housemates still were told what to eat, when to eat, when to bathe, when to sleep, when to get up, and what to do during her hours awake. These daily decisions that most persons take for granted, were freedoms that remained outside of Katherine's control.

### **Evolving into a Self-Advocate**

It was during this time period that Katherine began to see herself as a self-advocate. One of her friends suggested that she enroll in a leadership program for people with intellectual disabilities. She did so, and through this program Katherine met numerous advocates and self-advocates. She also developed skills (e.g., public speaking) that were essential to advocacy efforts and, as an athlete in Special Olympics, she was invited to tell the story of her life to an international audience. At the end of that talk Katherine received a standing ovation, and described for us how she felt she had a voice for the first time in her life. Finding her voice and being heard was the turning point in Katherine's life. From that day on, Katherine advocated not only for her own rights, but also for the rights of other persons who had intellectual disabilities. She worked to ensure that all persons, especially those with intellectual disabilities, had the power to make their own choices.

### **Focusing on Equity and Excellence**

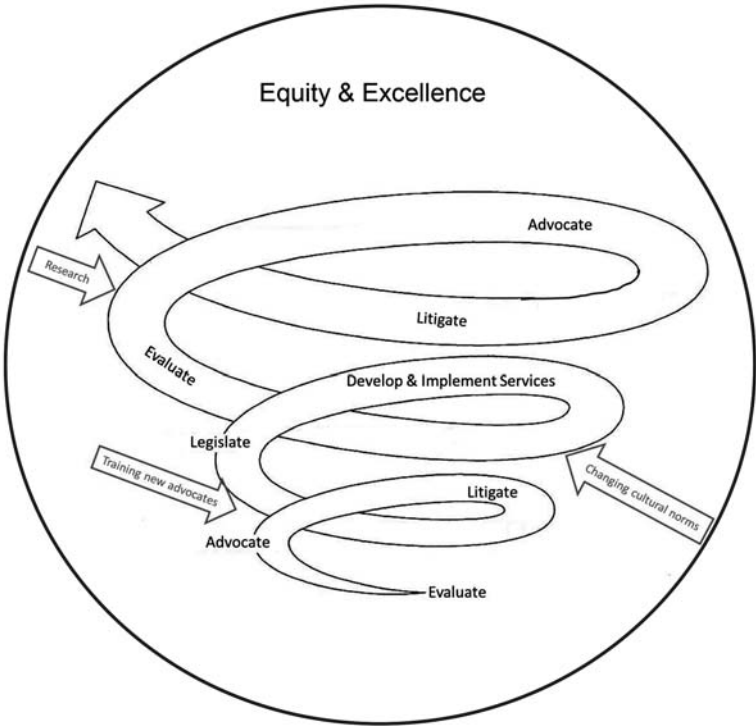
Katherine continued to use the standard of equity and excellence to evaluate the services she received, finding that there remained a need for continued advocacy to improve her own living situation. She worked with her appointed advocate, with whom she had become very close, and used her still-developing skills to find services she needed and ways to move out of the group home first to an apartment she shared with a roommate, and then to a one-bedroom apartment she shared only with her cat. Katherine's moves to increasingly less restrictive and more normalized settings (i.e., institution to a group home, to a shared apartment, to her own apartment) occurred because of her self-advocacy efforts, supplemented by the efforts of other advocates, to:

- (a) evaluate the services she received and comparing them with current understandings of equity and excellence;
- (b) pursue through litigation changes in those services to more closely reflected current understandings of equity and excellence; and
- (c) support changes in legislation, policies, and procedures that would improve services.

Katherine's story is also an example of how the cycle of societal activities can become a spiral of changes in services that increasingly reflect society's understandings of equity and

excellence for persons with intellectual disabilities. As illustrated in Picture 3, as the cycle of societal activities progresses, the shape appears less as a two-dimensional circle and more as a three-dimensional spiral as more advocates are added to the cycle. Katherine used her own journey to empower other persons with intellectual disabilities, urging them to enter into this spiral. Through her work at an advocacy center Katherine is a staunch supporter of equal rights for persons with intellectual disabilities in all areas of life (e.g., education, employment, housing, voting, healthcare). To support these efforts Katherine speaks with several constituencies (e.g., parents, pre-service teachers, administrators) and urges them to assist in the realization of equal right for persons with intellectual disabilities, including equal rights to make mistakes.

Picture 3. The spiral of change



Katherine is a firm believer that students with disabilities should be educated alongside same-age classmates who do not have disabilities in general education classes. For example, she supported the efforts of a high school student with Down syndrome to become a member of the school's swim team. Katherine collaborated with the student, her family, and school district personnel to modify the workout so the student could participate at her own level, thus ensuring the student's success with the team.



Katherine and the organization for which she works provide professional development for local medical personnel to assist in the development of services that are more equitable and excellent for patients who have disabilities. She might assist by speaking directly to a patient who has disabilities, using language that matches the patient's skills and knowledge base, and using her own experiences as a cancer patient to cultivate the changes she hopes to see within the medical profession.

When asked about her goals as a self-advocate and advocate, Katherine replied:

*I would like to see people with disabilities treated equal [sic]. [That they have] meaningful jobs in their community; not sheltered workshops. That they have a voice to speak up for what they need - health care or whatever. That they have the same rights, [that they are] not [in] a separate category from regular people. That is my dream for America, that everyone is on the same playing field, from education, to jobs to healthcare. That is all I really want, I really do.*

Katherine's goals are simple, to level the playing field so that persons with disabilities can live in a world where they have the same rights as persons who do not have disabilities.

Katherine has overcome much hardship and adversity in her life, however, the residual effects of living in an institution are difficult to ignore. While Katherine joked about shopping too much, she confessed to having too much stuff to fit inside her one-bedroom apartment. Now that she is able to buy and own material objects, she acknowledges that she has difficulty parting with any possessions. Katherine is, however, in control of everything and everyone that is allowed into her apartment. This sense of empowerment and choice was a theme throughout her interview, and is a stark contrast to the sense of powerlessness Katherine had for the first half of her life.

## Summary

Katherine's life covered the time span from pre-civil rights era until the present day. She lived in institutions, group homes, shared apartments, and independent apartment living. She lived through times when society almost guaranteed she would live an isolated and controlled life in an institution, to times when she developed a powerful voice that changed both her own life and the lives of other persons with disabilities. She has witnessed the shift in educational services provided to students with disabilities. She has seen education be denied to students with disabilities, but has also seen educational services that equal those which are provided to students without disabilities. Upon finding her own voice, Katherine made it her own life's work to use her voice to help persons with disabilities that have been silenced. Her life represents a model of how powerful the cycle of societal activities can be, and how it can develop into a spiral.

## Conclusion

The power of advocacy is clear. Fifty years ago "special education" did not exist in the USA. Now, there legislation mandates that all students have access to a free and appropriate education program; that universities prepare new teachers to facilitate each student's involvement

in the general education curriculum, including all students with disabilities; that teachers and schools be held accountable for the progress, or lack of progress, demonstrated by all students, including students with intellectual disabilities, in the general education curriculum; that teachers and schools implement research-based practices for all students; that universities conduct research to determine the most efficacious way of meeting the educational goals of students with intellectual disabilities; and that all teachers be highly qualified and collaborate to meet the needs of all students. As one advocate stated, "Advocacy is the only thing that created services [in the USA]. It keeps [those services] going."

We have presented a cycle of societal activities that illustrate the process advocacy took in the USA to create and improve services for persons with intellectual disabilities. In the first part of this chapter we outlined how this cycle worked across time, and illustrated changes that were made in special education services in the USA. While our portrait of special education is only one small part of a larger set of changes that occurred in services for persons with intellectual disabilities, it exemplifies similar changes that occurred in other aspects of life (e.g., employment, housing, medicine).

Special education in the United States has come quite a distance since the 1950s. Now schools must provide a free and appropriate education to all students, including those with intellectual disabilities and our understanding of what "appropriate" means has changed dramatically from the early years of special education. Through ongoing changes in our understandings of what it means to be equitable and have excellence in services, advocates have sought ever-improving models of services for persons with intellectual disabilities. We have moved from full segregation to social inclusion and now to academic inclusion where all students are expected to be involved and make progress in the general education curriculum. This change was difficult and required hard work and decades of change. The evolution of society's understanding of equity and excellence in educational services has led to evaluation of services, advocacy and litigation, revised legislation, and changes in our service models. Yet, our work is ongoing; it continues.

In the second section of this chapter we focused on a case study of one woman's experiences, first in an institution, and eventually in her own apartment. Her experiences illustrate how the cycle of societal activities can be seen in changes at the individual level, as well as at the national level. However, this case study also presents a powerful indication of how this cycle of societal activities can evolve into a spiral, thus becoming a powerful movement that extends into services for all persons, assisting persons whose voices were ignored and marginalized to having voices that are heard and valued.

The foundation and steps of the cycle of societal activities are built on the premise that services for persons with disabilities should be based on current concepts of equity and excellence. In turn, equity and excellence in services then becomes both the catalyst for and the goal of advocacy efforts. As advocates evaluate current services and find inconsistencies with desired services that are equitable and excellent, they advocate for change at both the local and national levels for individuals, as well as for all persons with disabilities. This advocacy might lead to litigation that might in turn lead to revised or new legislation. This legislation then generates new or improved services that more closely reflect society's understandings

of equity and excellence. This cycle continues, with the new or improved services evaluated against society's new understandings of equity and excellence.

If, however, we add a few additional influences to this cycle of societal activities it has the potential to develop into a spiral of powerful proportions. This could become evident when advocates

- (a) assist others in developing advocacy skills,
- (b) turn potential adversaries into allies, or
- (c) teach others in the same field to use their advocacy skills as they work for services that increasingly reflect equity and excellence with services for persons who do not have disabilities.

Such acts can develop additional advocates and strengthen a movement for change. In addition, the support of society is critical to make change that lasts. In the USA litigation and legislation built off the societal support of the civil rights movement created change in special education services. In other countries, however, other catalysts might be needed for change to occur. Whatever form the public support takes, it is critical for the development of this cycle, and potentially a spiral, that leads to change that lasts.

Finally, change that lasts also relies on rigorous research that supports and informs society's understandings of equity and excellence. Such research must help society understand the impact of current service delivery models, and determine where improvements are needed. Without these additional factors, the cycle of societal activities runs the risk of being an endless merry-go-round of rehashing the same struggles over and over again.

Developing advocates is key to creating and sustaining change. When a parent advocate was asked of the advice she had for other parent advocates, she said: "Involve your children in everything. Give them opportunities to speak for themselves and to make friends who will speak up for them. Raise them in a culture of speaking up for what is right." Advocacy has the power to change the world, especially when one advocate becomes two, and two advocates become four, and so on. Katherine's evolution from being a child abandoned in an institution to a vital woman supporting others on their journeys to self-advocacy is a powerful testament to the potential of this process.

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## Polish Association for Persons with Mental Handicap as the vanguard in the Polish system of support for people with intellectual disabilities

The aim of this report is to analyse the activities of one of the largest and most complex organisational structures from the Polish NGO sector, the Polish Association for Persons with Mental Handicap (hereafter referred to as PSOUU) and to show PSOUU's forefront character. The Association has been working to be recognized as the leader of change for 50 years now. Currently, PSOUU is one of the few organisations which can be referred to as being an element of a systemic solution to the problems of people with intellectual disability in Poland.

Since the 1990s, after the political shift in Poland, we have been observing an increase in the number of NGOs that deal with disability. The emergence of a large number of self-help NGOs results from the formalisation of self-help group structure (with the new one characterised by a broader influence on the environment, more effective cooperation with other public and private institutions, capacity to undertake business activity, with profits channelled into statutory activities). However, the most significant benefit associated with the establishment of the NGOs has been the creation of a sense of shared responsibility for the problems of the disabled within local communities (Sokolowska 1981, pp. 8-9). The services offered by the NGOs fill a gap, i.e. the area of activity not covered by the public formal care system, or are complementary to the existing range of services.

Polish Association for Persons with Mental Handicap (and its predecessors, the Committee for Support for Children with Special Needs and the Committee for Support of Persons with Mental Handicap at the Friends of Children Society - TPD) carries out activities aimed at achieving equal opportunities, human rights and active participation in social life for persons with intellectual disability, as well as supporting their families (Article 4 of the organisation's Articles of Association). The Association's members are: parents and legal guardians of persons with intellectual disability, other family members, friends and professionals involved in work for the benefit of persons with intellectual disability.

PSOUU is active in fulfilling its mission and participates in co-creating and implementing the principles of social policy towards persons with intellectual disability. The Association helps them to adopt an active civic attitude concerning the local affairs that must be taken care of in the spirit of common interest, pluralism and versatility of social life. Moreover, the

Association enables them to carry out their individual and social plans, alternative or complementary to government support, and creates the mechanisms of social inclusion in the process of decision-making concerning various problems and levels of functioning in the contemporary society.

NGOs constitute a significant element of democracy and civil society. Therefore, they can be defined as civic organisations which integrate people willing to take actions in public and social interest (Firkowska – Mankiewicz, Wapiennik, 2007). In democratic countries, disability NGOs play a range of significant roles:

- **The Vanguard Role:** they introduce innovative solutions and experiment by adopting pioneering approaches to problems, procedures, programmes and to service provision. They are the change drivers in their areas of activity. When innovations prove successful, after being tested and developed by NGOs, the remaining actors, major state service providers in particular, can implement them.
- **The role of Guardians of Values:** they become the basic mechanism of promoting and safeguarding particular values which enable social groups to express and disseminate, among others, cultural and social ideas, preferences and interests.
- **The role of Advocates:** In the political process determining the design and shape of social policy, the needs of under-represented or discriminated groups are not always taken into account. Non-profit organisations fill the gap by giving voice to minorities and by amplifying their interests.
- Not-for-profit organisations are also non-profit **watchdogs** scrutinising government activities, so their role is to monitor and validate government practice in the area of ethics and social responsibility.
- **The role of Service Providers:** Government programmes are usually large-scale and do not match individual needs sufficiently. This is one of the reasons why non-profit organisations play a vital role in the process of provision of public goods and services. Service providers from the NGO sector are therefore the basic service providers in the niches within which neither the state nor business want to act or can act. They may deliver services complementary to the services provided by other sectors, but of different quality (Wygnański, 2006).

### **Non-Governmental Organisations in Poland**

(according to Klon/Jawor organisation, 2013)<sup>1</sup>

In 1988, there were just above 2,000 associations and foundations in Poland. After the political shift in 1989, the third sector began to grow intensively: already in 1989 nearly 600 NGOs were established, followed by over 1,000 in 1990, more than 2,000 in 1991 and more than 3,000 in 1992. Throughout the 1990s we observed a consistent upward trend, with associations as the most popular form of third-sector organisation. The rising curve peaked just

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<sup>1</sup> The data quoted in my analysis excludes Voluntary Fire fighters organisation.

after the year 2000, after which the annual amount of newly-established NGOs became stable. Currently, approximately 4,000 new NGOs are established each year<sup>2</sup>. As far as foundations are concerned, the increase in their number was not as dynamic. After the initial four years of growth, following 1995 the number of new foundations became stable for some time at the level of about 300 new foundations each year. After 2000 there was renewed interest in foundations and the number of newly-established ones has been growing ever since. In recent years, more than 1,000 new foundations have appeared each year.

Currently, nearly 25 years after the re-birth of the NGO sector in Poland (according to official registers: REGON, as of 30 November 2011, the National Court Register and the data from the website [bazy.ngo.pl](http://bazy.ngo.pl)) there are 11,000 foundations and 72,000 associations officially registered in Poland. About 60,000 organisations are actually active, more than a quarter of which (27%) have been active for more than 15 years.

The highest NGO-to-population ratio is in the following regions of Poland: mazowieckie, dolnośląskie, warmińsko – mazurskie, pomorskie, lubuskie and zachodniopomorskie, while the lowest NGO-to-population ration is observed in świętokrzyskie, podlaskie and śląskie regions. Mazowsze, Poland's central region, has nearly 15,000 registered NGOs. The region's leading position is due to the capital city, Warsaw, where two-thirds of all the region's NGOs are registered (9,500). This, however, does not result from high civic activity in the region, but rather in from the number of headquarters of nationwide NGOs.

The most important fields of activity of Polish NGOs are: sports, tourism and recreation, hobbies, with 55% organisation active in the fields (with 38% indicating the fields as their key areas of activity). The respective numbers for education and upbringing are 42% (14%), for culture and arts - 33% (17%), social services and care - 16% (6%), local development - 16% (5%) and health care 15% (6%). We are currently observing a decrease in the number of support organisation active in the area of social services, social support and health care. The changes are taking place slowly yet systematically: just a few years ago the areas of activity jointly made up 18% - 19% of the sector, while in 2012 their share dropped to only 12%.

Within the area of social services, social, humanitarian support and emergency, support for children and youth is the dominant core activity, implemented by 54% of the organisations i.e. 8% of the entire NGO sector. The following fields are support for disadvantaged families (the respective percentage share is 49% and 8%) and support for disabled persons (45% and 7%) as well as support for people suffering from extreme poverty (42% and 7%). Almost one-third of the organisations from the social support area (29%, i.e. 5% of the entire sector) help the elderly and just above one quarter (27% - 4%, respectively) organise distribution of the donated food, clothing and other items. Over one-fifth (23%, 4% of the entire

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2 However, the rapid growth must be approached with reservations; the factual increase has most probably been less spectacular. This is because the data presented in the graph are based on the information from the REGON (statistical data) register. Although the register is the most complete source of data with number of organisations, the recently introduced changes in regulations may have caused certain deviations within the trend. The graph's peak at the turn of the centuries may have been associated with the changes to the obligation of registration in the National Court Register, introduced in 2001. The consequence of the changes was a rapid growth in the number of organisations reported to REGON register, with a lot of organisations indicating 2000 or late 1990s as their year of foundation. . We can assume that a proportion of the organisations had been created earlier and they had been active even though they had not registered with REGON.

sector) of the social-profile associations help addicts of their families, with a very similar number (21% and 3%, respectively) supporting children's homes and foster families.

Among the NGOs under analysis, as much as 87% act for the benefit of individuals, while two-fifths also indicate organisations or institutions as their beneficiaries. Sixty-four per cent of the organisations are active within one region or a smaller area (with 41% limited to their own municipalities or poviats), and 37% are active across Poland or internationally.

The organisations act for the benefit of their members, beneficiaries or clients (66%). They take actions aimed at reaching wider audiences and increasing awareness of the issues they deal with (54%). One third cooperate with other organisations or support them non-financially, and a quarter provides material assistance to individuals, organisations or institutions.

## A list of the most important Polish acts of law concerning persons with intellectual disabilities in Poland.

### **Convention on the Rights of Persons with Disabilities**

(Official Journal 2012 item 1169)

The Convention is complementary to the previously adopted UN human rights conventions. It refers to approximately 650 million disabled persons worldwide. The Convention is the first international act of law which comprehensively refers to persons with disabilities. Its aim is to contribute to improving the situation of the disabled by facilitating a real and equal exercise of all fundamental rights and freedoms.

On September 6, 2012 Poland ratified the Convention and thus made a commitment to respect all its values and principles. Thanks to the ratification, the document has been incorporated into our national law and authorities at all levels as well as the society have been obliged to implement the stipulations of the Convention in everyday life. The Convention is also the first international act of law than comprehensively talks about disability.

It defines what must be done in order to make the universal human rights and fundamental freedoms really accessible to all, including persons with disability. The Convention recognises the modern model of disability i.e. the shift from care and charity to creation of society and environment open to all, inclusive and based on equal opportunities and human rights.

The aim of the document is to ensure respect for the dignity of people with disability and to support, protect and ensure a full and equal exercise of all human rights and fundamental freedoms by such people. The most important stipulations of the convention refer to the necessity of safeguarding the exercise of human rights by disabled persons without any discrimination. The provisions also describe discrimination on the grounds of disability as violation of inborn dignity and human rights. The Convention emphasises the importance of individual self-reliance and independence of the disabled, which includes the freedom of choice and the freedom to make effective decisions regarding policies or participation in various programmes directed to such persons. Independent living for the disabled may be hampered or even made impossible not only due to body impairment but most of all due to attitudes of other people and due to ill-adapted environments (infrastructure, transport, communications etc.) and organisation of social life (legislation, administration, support system,



services etc.) Lack of access to these fields leads to isolation, exclusion, disorientation, helplessness, inactivity and dependence on other persons and their services.

Participation in social life is associated with implementation of many rights. The Convention enumerates the following rights:

1. the right to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community (Article 19),
2. the right to education: with a view to realizing this right without discrimination and on the basis of equal opportunity, it must ensure an inclusive education system and the necessary, individually tailored support. Inclusive education should span the person's entire life, matching the particular person's needs. Education systems must enable disabled persons to learn life and social development skills to facilitate their participation in education by taking all appropriate measures tailored to the type of disability (Article 24),
3. the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (Article 25),
4. the right to rehabilitation enabling persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full social inclusion with participation in all aspects of life (Article 26),
5. the right to work and employment on an equal basis with others, with prohibition of discrimination in recruitment, hiring and all forms of employment, continuance of employment, career advancement and safe and healthy working conditions; the right to reasonable accommodation in the workplace. as well as the right to protection from forced or compulsory labour (Article 27),
6. the right of persons with disabilities and their families to an adequate standard of living and social protection without discrimination on the basis of disability (Article 28),
7. the right to participate in political and public life, including the right to vote,
  - the right to participate in non-governmental organisation, the right to form and join organisations of persons with disabilities in order to represent disabled persons at international, national, regional and local levels (Article 29),
  - the right to take part in cultural life, recreation, leisure and sport (Article 30).

According to the Convention, the state must ensure adequate support for persons with disability but the support must not consist in institutionalised care and exclusion from social life. Therefore, the support should respect the rights, decisions and preferences of persons with disability. It must also be appropriate and match the particular person's situation; be applied for a shortest period of time possible and be constantly monitored by the appropriate authorities. The Convention also introduces the model of supported decision-making instead of the model of substitute decision-making (Zima-Parjaszewska 2012). The model of supported decision making means that the disabled person is not represented by a statutory representative in his or her legal actions (as the Convention also prohibits incapacitation) but, instead, is supported to make decisions where and when appropriate.

**The Constitution of the Republic of Poland, binding from April 2, 1997.**

(Official Journal 1997 No. 78 item 483)

Article 32 of the Polish Constitution expresses the principle of equality. The article stipulates that all persons shall be equal before the law and have the right to equal treatment by public authorities. Moreover, no one shall be discriminated against in political, social or economic life for any reason whatsoever. The principle of equality is one of the fundamental principles of democracy and rule of law. Many experts claim it overlaps with the principle of justice which belongs to the core concept of law in general. The principle of equal treatment of all persons by the norms of law and the consequent prohibition of discrimination must be referred to, predominantly, persons with disability. According to another article of the Constitution (Article 30) the inherent and inalienable dignity of the person, regardless of the person's individual physical and psychological features, is a source of all rights and freedoms. In Article 68 item 3, the Constitution stipulates that public authorities shall ensure special health care to disabled persons. Finally, Article 69 imposes on public authorities the obligation to provide, in accordance with the statute, aid to disabled persons to ensure their subsistence, adaptation to work and social communication.

**The Charter of Persons with Disability** (Ministry of Labour 1997 No. 50 item 475)

According to the document, disabled persons (i.e. persons whose physical, mental or intellectual abilities and capacities permanently or temporarily hamper, limit or prevent everyday life, education, work or fulfilling social roles in accordance with law and custom), shall have the right to an independent, self-directed and active life and must not be discriminated against.

**The Act on Social and Occupational Rehabilitation and Employment of Persons with Disabilities of August 27, 1997** (Journal of Laws 1997, No. 123, item 776)

The Act, along with implementing regulations, concerns social and occupational rehabilitation of persons with disabilities. It defines disability (differentiating between mild, moderate and severe disability – Article 4) and contains provisions on disability evaluation, the rights of persons with disabilities (Article 14) as well as on the rights and obligations of employers with respect to the employment of persons with disabilities (e.g. Article 23a). The Act also implements provisions of the Directive on Equal Treatment in Employment and Occupation concerning reasonable accommodation for disabled persons and “appropriate measures” (Directive on Equal Treatment in Employment and Occupation, Article 5).

The Act determines what services and forms of services should be provided for disabled persons in order to respond to their social and occupational needs. Public administration in Poland is obliged to address collective and individual needs of the citizens according to the principles of equal rights, equal opportunities and non-discrimination. The Government Plenipotentiary for Disabled People supervises and coordinates the implementation of the provisions of the Act. Other tasks of the Government Plenipotentiary for Disabled People include: drafting and evaluating bills concerning employment, rehabilitation and living conditions of persons with disabilities, drawing up drafts of government programmes regarding persons with disabilities, initiating measures designed to limit the effects of disability and remove barriers for persons with disabilities, as well as cooperation with NGOs and foundations supporting disabled persons (Article 6).

With few exceptions, regulations concerning social and occupational rehabilitation and employment of persons with disabilities do not discriminate between physical and mental disability, while differentiating between the situation of persons with mild, moderate and severe disability.

### **The Education System Act of September 7, 1991**

(Journal of Laws 2004, No. 256, item 2572, as amended)

The Act regulates the most important principles of education in Poland, including education of persons with disabilities. Pursuant to the Act, all children with disability are entitled to education (Article 1(1) of the Education System Act of September 7, 1991 (Journal of Laws 2004, No. 256, item 2572, as amended) and Article 70 of the Constitution of the Republic of Poland) and to:

- early childhood development support: Article 71b(2a) of the Education System Act of September 7, 1991 (Journal of Laws 2004, No. 256, item 2572, as amended), the Ordinance of the Minister of Education and Sport of April 4, 2005 on Early Childhood Development Support (Journal of Laws, No. 68, item 587);
- postponement of compulsory schooling until the end of the calendar year in which the child turns ten: Article 14(1a) of the Education System Act of September 7, 1991 (Journal of Laws 2004, No. 256, item 2572, as amended);
- education in all types of schools, according to individual capabilities as well as developmental and education needs: Article 1, point 5 of the Education System Act of September 7, 1991 (Journal of Laws 2004, No. 256, item 2572, as amended);
- adaptation of content, methods and structure of education to their physical and mental capabilities, also in mainstream schools: Article 1(4) of the Education System Act of September 7, 1991 (Journal of Laws 2004, No. 256, item 2572, as amended); Article 4(1), point 3 the Ordinance of the Minister of Education and Sport of January 18, 2005 on Providing Education and Care for Children and Adolescents with Disability and Social Maladjustment in Mainstream Kindergartens, Schools and Forms (Journal of Laws No. 19, item 167);
- extension of each stage of education by at least one year (the Ordinance of the Minister of National Education of February 12, 2002 on Curriculum Frameworks in State Schools (Journal of Laws No. 15, item 142, as amended);
- psychological and educational support and care as well as special forms of teaching, including individual education activities: Article 1 points 4 and 5a of the Education System Act of September 7, 1991 (Journal of Laws 2004, No. 256, item 2572, as amended), the Ordinance of the Minister of National Education of February 12, 2002 on Curriculum Frameworks in State Schools (Journal of Laws No. 15, item 142, as amended), the Ordinance of the Minister of Education and Sport of January 18, 2005 on Providing Education and Care for Children and Adolescents with Disability and Social Maladjustment in Mainstream Kindergartens, Schools and Forms (Journal of Laws No. 19, item 167), the Ordinance of the Minister of Education and Sport of January 7, 2003 on the Rules of Providing and Organising Psychological and Educational Support in State Kindergartens, Schools and Institutions (Journal of Laws No. 11, item 114).

**The Social Welfare Act of March 12, 2004** (Journal of Laws 2004, No. 64, item 593)

The Act determines: the tasks of the social welfare system, the kinds of social welfare services, the principles of provision of social welfare services, the organisation of social welfare as well as the principles concerning supervision of the execution of social welfare services. The Act states that the social welfare system, as a part of the social policy of the state, aims at enabling persons with disabilities and their families to overcome difficult living situations which they could not overcome by means of their own qualifications, resources and capabilities.

**The Act on Family Support and Foster Care System of June 9, 2011**

(Journal of Laws 2011, No. 149, item 887)

The Act determines: the principles and forms of support for families who have difficulties providing care for their children, the principles and forms of foster care and support for foster children who become independent, the tasks of public administration with respect to family support and foster care system, the financing of family support and foster care system, as well as the principles of adoption proceedings.

## The wide array of activities of the Polish Association for Persons with Mental Handicap (PSOUU)

Disability NGOs have to adopt a variety of perspectives and they often deal with a wide array of issues at the same time. The scope of activities of PSOUU is also extremely broad, which makes it possible to provide people with intellectual disabilities and their families with complex support that takes into account the diversity of their needs. The multidimensionality and the tendency to recognise the current needs of the society illustrate the innovative role of PSOUU.

In the social dimension, PSOUU responds to systemic needs, whereas in the personal dimension it aims at meeting the individual needs of people with intellectual disabilities and their families.

The activities of PSOUU exemplify the idea of normalisation, understood as giving access to experiences related to the life-cycle, places, forms of activities and social relations which are considered important and valuable in a given cultural circle.

*Throughout the years, we have been doing all the things that human beings do and we have been looking for ways to make these things available for people with disabilities. The normalisation of life of people with disabilities requires understanding that diversity is an inherent characteristic of the human kind.*

The normalisation does not concern only people with disabilities but also their families. For years PSOUU has been thinking how to enable families to live “normal” and harmonious lives in their local communities.

PSOUU has a two-stage structure: the main board and 124 local branches.

According to the reports delivered by local branches of PSOUU on December 31, 2012 the Association had 11,976 members, including 8,774 parents, 1,711 persons with disabilities as well as 1,486 employees and others.

Picture 4. PSOUU's local branches



On the basis of the reports on the activities of PSOUU in 2013, delivered by the local branches and sent to the management board, a table presenting the main facilities run by the association and the number of persons using their services was compiled (Table 5). Moreover, the Honorary President of the association Krystyna Mrugalska outlined the contribution of PSOUU to the creation of the system of rehabilitation, education, care, preparation for work and support in independent life and in the labour market (Table 6). As of the end of 2013, PSOUU run over 400 facilities, providing services for 27,672 people.

Table 1. The main facilities run by PSOUU and the number of persons using their services

FACILITY	NUMBER OF MEMBERS	NUMBER OF FACILITIES
Modern complex rehabilitation and educational facility (OREW)	6,744	67
Early intervention centre/early intervention station (OWI/PWI)	8,285	30
Kindergarten	40	6
Community centre	114	5
Community self-help centre (ŚDS)	1,181	38
Occupational therapy workshop (WTZ)	3,407	80
Vocational activation centre (ZAZ)	277	8
Day activity centre, rehabilitation and therapy team	664	13
Sheltered, supported and training accommodation, nursing home (DPS)	678	34
IN TOTAL:	21,390	281

The abovementioned activities have undeniably contributed to the development of support methods for persons with intellectual disability. PSOUU's activities constitute a significant instruction support when training special pedagogues, psychologists and social services staff.

### **Education for persons with severe intellectual disability**

*What I did is I wrote about the new elements we were introducing... I was also the one to write our regulations, and in the regulations I said how a handicapped person was to be treated, what methods were to be applied, how it all was to be organised, what kind of classes, what material the classes ought to cover etc. Then it was circulated all around Poland, in carbon-copies, and that is how we disseminated the method. And later, other milieus, including the academia, began to adopt our perspective.*

For many years, persons with severe intellectual disability remained beyond the area of interest of education authorities. Instead, such persons were assisted by the ministry of Health and Social Policy and the support was usually limited to ensuring care at an institution. The Polish Association for Persons with Mental Handicap created the first centre for such persons in 1964, thus forming a foundation for the methodology of work with persons with severe intellectual disability.

It was as late as August 19, 1994, that the Act on Mental Health (Official Journal of Laws 1994 No. 111 item 535) that the Polish Ministry of Education became obliged to provide education and revalidation for children and youth with severe intellectual disability. The real change took place when the Ministry, by issuing the relevant regulation on January 30, 1997 (Official Journal 1997 No. 14 item 76) defined the principles of organisation of revalidation and education classes for children and youth with severe intellectual disability. This opened the road to further education for the group of disabled. Until then, the education system in Poland did not offer anything to such children and youth: the specificity of their disability had not been reflected in any didactic activities.

Another important endeavour contributing to the system of support for persons with severe intellectual disability was the project *“Support for persons with intellectual disability - persons with Down syndrome and severe intellectual disability”*, implemented in 2012. One of its key aims was to support social and vocational activation of persons with severe intellectual disability. The project’s brevity and innovative nature consisted in setting vocational activation as its goal. This meant a significant change in the functioning of persons with the most severe forms of disability: such persons were usually perceived as passive, non-trainable, dependent and affected by multiple health issues making employment impossible (Mrugałska 2010, p.8). The project’s objective was to create special and favourable conditions for 100 persons with severe intellectual disability to be able to perform (systematically and with support from their mentor or job coach) simple, meaningful and useful activities in a continuous way for a certain period of time. Detailed scenarios were developed for the beneficiaries, training was organised for staff and the whole programme was implemented.

The results are astounding and highly motivating, inspiring us to continue such endeavours, develop them further and introduce their outcomes to the care centres for beneficiaries with severe intellectual disability. The project’s success undermined the popular stereotype, according to which persons with intellectual disability are unable to learn and acquire new skills. The stereotype is very often the reason why no conditions for meaningful, simple activities for persons with severe disability are created - and such activities could lead to more dynamism, inspiration and motivation to make an effort in the lives of such persons. This, in turn, could lead to better functioning and the joy of being in control. An important outcome of the project is also a manual for parents and therapy professionals who organise employment for adults with severe intellectual disability entitled *“Crossing the borders, rejecting the stereotypes”* (2012) written by Zofia Pakuła. The manual complements the existing (scanty) literature on the methods of activating the capacities of persons with severe intellectual disability.



### **Early intervention**

*Following the meetings, I have compiled a list of parents' expectations. The experiences of parents of young children show that it is usually too late when they learn that they can do something. They need the first instructions as early as possible, even if there is no complete diagnosis yet. Parents need to be told what they can do, they need instructions. The second important expectation is as follows: why don't physicians inform parents that they should consult other specialists such as psychologists, physiotherapists or speech therapists? I have written down all these expectations. Parents have also complained about the fact that each time they have a medical appointment they see a different doctor or psychologist who does not know anything about the child and the appointment ends with nothing. We need one place and one team. They have also asked why specialists think the only role of parents is to carry their children. Following the meetings, I have organised the first early intervention camps for young parents with small children.*

PSOUU's early intervention centres offer children and their parents early specialist support, including early diagnosis of psychophysical functioning of the child, individual therapy and various forms of stimulation of development. Specialist teams deal with diagnosis, programming, therapy and evaluation in a complex and coordinated way, taking into account all the areas of child development and the needs of the family.

An important role of early intervention centres is to give psychological support to families, who also should be provided with help. They are offered psycho-education and – when necessary – psychotherapy, access to information, trainings on rehabilitation and parenting, especially with respect to rehabilitation at home, life and legal counselling, and contact with other parents who face similar problems. Families are also offered support in contacting medical and educational facilities and encouraged to lead active lives.

### **Self-advocacy**

In Poland, it was initiated in 1990s, partly by PSOUU. In September 1995, the management board of PSOUU, along with the Dutch Parent Federation, held an international conference "Human rights and people with mental handicap in Central Eastern Europe" in Warsaw under the auspices of the International League of Societies for the Mentally Handicapped. During the conference, for the first time in Poland, persons with severe disability took part in a self-advocacy panel (source: PSOUU's milestones).

However, a more dynamic development of the self-advocacy movement occurred only several years later, following trainings for persons with disabilities and those who support them and a change of the attitudes of health care professionals and families. Moreover, it took time to encourage persons with disabilities to speak up for themselves and present their opinions and to make them heard as well as to organise events so that they had a chance to speak in public (PSOUU, 2006). In 2006, PSOUU successfully participated in an international Inclusion Europe project entitled "Mainstreaming Mental Disability Policy", which enabled 50 persons with disabilities to take a self-advocacy training course. Additionally, four workshops for self-advocates were conducted in Łuczniczka. They examined civil and human rights, legal protection, including court protection, and various legal issues. Persons with disabilities learned how to speak in public and how to behave during public debates. The



workshops, attended by 80 persons with disability, were conducted by 20 instructors and 40 volunteer law students of the University of Warsaw. Moreover, seven booklets were published, all of them written in plain language that can be understood by persons with intellectual disabilities (e.g. “Discrimination hurts,” “The European Union against exclusion,” “Your civil rights – persons with intellectual disabilities and the law,” “Your civil rights – access to rights and justice for persons with intellectual disability,” “I know what I want!,” “I have the right to... Persons with intellectual disabilities in public offices” (PSOUU 2006).

Legal workshops is a unique initiative targeted at persons with intellectual disability. They enable persons with intellectual disability to gain legal knowledge necessary to function in the society. We had the opportunity to learn about the outcomes of the workshops during panel 3 (persons with intellectual disability): *We learned there what rights and duties people with disabilities have. We got to know what constitution is and how courts function; we talked to important people and learned how to speak in public. Education was not the only thing we did in Lucznica: we had bonfires, parties, games and plays aimed at integrating people; we worked with clay and wicker and, most importantly, we got to know amazing people and made true friends. What was very important for us was the possibility to meet student volunteers. We learned from one another how to be tolerant, how to talk to one another and how to socialise. We felt we were all equal and, deep down at heart, the same. We need more such meetings!*

### **Incapacitation**

PSOUU for years has been taking actions aimed at changing the Polish regulations concerning incapacitation. In 2002, PSOUU and the Legal Advice Centre of the University of Warsaw compiled a report entitled “The Polish courts and incapacitation of persons with intellectual disability” (Firkowska–Mankiewicz, Szeroczyńska, 2005). It was based on case files concerning the incapacitation of persons with intellectual disability by six regional courts in Poland from 1998 to 2000.

In recent years, representatives of PSOUU have cooperated actively with the Government Plenipotentiary for Disabled People with respect to the regulations on incapacitation. They have participated in the Expert Committee on People with Disabilities at the Human Rights Defender. The management board of PSOUU has had impact on legislation by taking part in the sessions of the Sejm committees and presenting its positions and opinions. For instance, the management board of PSOUU has expressed its opinion concerning „the analyses of conformity of the Polish legislation to the Convention on the Rights of Persons with Disabilities carried out by the Ministry of Labour and Social Policy”, including Article 12 of the Convention, which regards legal capacity. The management board participated actively in a joint session of the Social and Family Policy Committee and the Justice and Human Rights Committee on 11 November 2013, which discussed incapacitation.

### **Social and vocational activation of people with intellectual disability**

*In the Polish public sphere, too little space is given to the real work of persons with intellectual disabilities; work which is personally and socially meaningful.*

The experiences of PSOUU suggest that the efforts related to rehabilitation, education, therapy and the provision of support pay off when taking up a job becomes the next stage

of life and the main objective. If one cannot work, it is impossible to enhance their development and improve social functioning. PSOUU consistently supports the inclusion of persons with disabilities in active life and has developed the idea of supported employment for persons with intellectual disability in Poland. One of such initiatives is the centre for vocational counselling and support for the disabled (DZWONI). It is a combination of a day care centre and workplace, providing complex, multidisciplinary support and vocational counselling for persons who have difficulties starting and maintaining a job (Mrugalska, 2008). DZWONI is an innovative solution aimed at providing persons with intellectual disabilities with complex and specialist employment support. The initiative facilitates the transition from care centres to work, integrating separate services into a complex system which responds to the needs of persons with intellectual disability. The objective of DZWONI is to fill in the gaps which make persons with disabilities unable to take up vocational activation. The centre evaluates the predisposition, preferences and vocational skills as well as the necessary social competences (functional diagnosis), prepares individual action plans, evaluates the training needs and helps to satisfy them, offers internships, searches for employers and supports the creation of jobs, organises induction trainings, supports the employee, employer and co-workers, provides monitoring and legal counselling, cooperates with institutions in the labour market, as well as provides rehabilitation, social welfare services and education in local environment.

### **Sheltered, supported and training accommodation**

Enabling persons with intellectual disability to live independently gives them a chance to lead autonomous lives according to their needs and capabilities. People with intellectual disability want to live independently as much as their peers without disability. However, they often have no experience doing everyday activities. If they are provided with necessary support, they can live in accordance with their desires and needs.

The training accommodation programme run by PSOUU gives persons with disabilities a chance to experience independence, to learn how to do everyday activities, to socialise and to develop relations with other people. Training accommodation enables persons with disabilities to live for a certain period of time in facilities where they can gain more independence.

Sheltered accommodation gives persons with disabilities a chance to function independently in the society and integrate with local communities. It enables people to achieve their goals and improve the quality of life as well as allows them to get to know what independence means, which is a valuable experience.

### **PSOUU – a supporter of democracy and development**

When analysing the activities of PSOUU, it turns out that on the one hand the association facilitates “top down” changes, i.e. influences the system and promotes human rights (through lobbying and trainings), and on the other it adopts a bottom-up approach, targeted directly at those who need changes to occur (persons with intellectual disability and their families), and aimed at enhancing their development capacities in order to make sure that they enjoy the right to dignity.

From this perspective, PSOUU pursues the basic objectives of an NGO (Toczyski, 1998, pp. 14-15): it satisfies individual and social needs of those who are exposed to discrimination and social exclusion, adopts a civic attitude with respect to human and local problems

that need to be solved for the good of all, promotes plurality and diversity of social life, is part of the sector providing individual and social services, alternative to the public sector, as well as contributes to the creation of mechanisms of participation in decision-making processes related to various problems and levels of functioning of modern society.

## Conclusion

Arnold Mindell, psychotherapist, Jungian analyst and founder of process oriented psychology, developed a concept according to which communities develop when they are able to learn from groups which are believed to make their functioning more difficult<sup>4</sup>. This regards various social minorities and groups which are marginalised, rejected and stigmatised. According to process oriented psychology, if members of different groups assimilate and marginalise certain experiences from one another, they will have to react and start to exhibit the same behaviours.

This attitude emphasises the interdependence of phenomena existing within one system and the two-level thinking which is based on the responsibility a group takes for an individual and the responsibility an individual takes for their group. The group can learn more about itself and become more aware by studying the patterns of behaviour followed by the subgroups it rejects. The phenomena which cause anxiety in social life can become the source of transformation and the starting point for the development of a given community. This means that societies create city shadows, as Mindell calls them, to learn more about themselves. They are our potential teachers and the secondary process of the society, which in turn needs to integrate all the elements in order to fully develop. As a result, the analysis of city shadows indicates the things that are marginalised by a given community (with prejudice to this community) and the things we should pay more attention to.

The level of social development can be measured against the level of tolerance towards mental, physical or spiritual differences. Improving this level by using the experiences of minority groups as information as to how to become a more complete society is not the easiest method. But is there any other solution?

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Table 6. PSOUU's contribution to the system of rehabilitation, education, care, vocational preparation and support in independent life and on the labour market

*Between 1963 and 1984: as the Committee and Branches for Children with Needs of the Children's Friends Society (TPD); Between 1984 and 1991: as the Committee and Branches for Persons with Mental Handicap of the Children's Friends Society (TPD); Since 1991: as the Polish Association for Persons with Mental Handicap (PSOUU).*

Ideas developed and put into practice by the association of parents	Solutions included in the public system thanks to parents' efforts
summer camps	schools for children with moderate and severe disability
rehabilitation, education and other teams (later on day activity centres)	special kindergartens for children with moderate and severe disability
rehabilitation and educational centres, offering complex activities for persons with severe and multiple disability	
teams preparing for work	jobs in sheltered workshops in disability cooperatives; creating a system of outwork teams
various forms of leisure	
special concerts in the Warsaw Philharmonic (for the first time access to culture)	
in-home services for families with a bed-ridden family member	
support groups for families	
family camps and early intervention centres	
modern complex rehabilitation and educational facilities (OREW) for children with severe disability	introducing the right to education for children with mental handicap irrespective of the level of disability (Mental Health Protection Act); introducing the right to mandatory education for children with severe disability (rehabilitation and educational activities) and introducing regulations on non-public rehabilitation and educational facilities (OREW) and their funding (Education System Act)
self-care community centres (ŚDS)	self-care community centres (Mental Health Protection Act)
occupational therapy workshops (WTZ)	occupational therapy workshops (Act on Vocational Rehabilitation and Employment of Persons with Disabilities)
rehabilitation camps	
group sheltered and supported accommodation as well foster family homes	securing social welfare services: care allowance, extended post-maternity leave, early retirement for mothers/fathers, social pension (at first, small allowance); increasing the maximum amount of social pension, salary and family pension for a family
training accommodation	
diverse forms of participation in cultural and leisure activities (clubs, orchestras, theatres and others)	
personal assistants	

vocational activation centres (ZAZ)	developing the concept of vocational activation centres and including them in the Rehabilitation Act
examining the situation in the open labour market	including a new type of post-secondary school („special school preparing for work”) for persons with moderate and severe disability in the Education System Act
centres for vocational counselling and support for the disabled (nationwide projects financed from EU funds)	
supported employment in the open labour market (key role of job coaches)	
investigating incapacitation cases, delivering a report, cooperation with the Human Rights Defender	Constitutional Tribunal finds some regulations on incapacitation unconstitutional
starting legal and civic education	introducing human rights as an instrument of life quality assessment for persons with disabilities (Standard Rules on the Equalisation of Opportunities for Persons with Disabilities – 1993 and the UN Convention on the Rights of Persons with Disabilities – 2006, ratified in Poland in 2012)
„easy to read” texts	
self-advocacy (workshops on legal and civic issues and support)	
supporting decision-making processes	
freetime for employed persons	
legal counselling	
change of social attitudes (media, publishers, campaigns)	
Training courses	
production of training films	
proclamation and annual observance of the Day of Dignity of Persons with Intellectual Disabilities all over Poland	
putting into practice: individual curricula based on the strengths of an individual; learning by practice, observation and interpretation of behaviour in connection with living conditions and experiences	

Made by: Krystyna Mrugalska





*Krzyszyna Mrugalska*

Honorary President of the Polish Association for Persons with Mental Handicap

## From the world of barriers to the world of horizons. PSOUU's contribution to the creation of the system of support for persons with intellectual disability

It is good to be able to look back to evaluate what is behind you. Fifty years is a very long period of time: let us see what we have managed to do and what we have managed to change. Let me begin my presentation by describing a few situations which will set a clear background for the path we have travelled.

Let us first take a look at the years 1963 - 64: it was the time when parents organised themselves by communicating via the press and the radio. A single appeal from Ewa and Roman Garilcki, parents from Warsaw, followed by a press article by a famous writer published in a popular weekly magazine was enough to produce the first spark. The first meetings were attended by 200 - 300 people who very emotionally described their lives with a disabled person and the lives of disabled persons themselves. They talked about loneliness, isolation, deep alienation, poverty, absence of any forms of support for their children. An elderly father from Warsaw said: "It is a shame, but I take my son for walks at night only. This is because people turn their heads and keep pointing fingers at us, they accuse us of all kinds of sins for which the child is, in their opinion, a punishment. We are frightened." At the time it often happened that doctors refused to treat our children when they had common illnesses, they would send them to psychiatrists. Parents also reported very negative experiences from care institutions which were supposed to look after their children. After visiting such facilities, they said: "Never again". At the same time they stated: "It is not true that our children are unable to learn anything, that they do not need contacts with their peers, that elementary care at an isolated institution suffices for them. What they need is rehabilitation, psychological support, speech therapy, education and joy of life". Slowly, a feeling of solidarity and awareness of rights appeared, coupled with the awareness of their children's needs and goals, and the willingness, the energy to introduce changes. Hope was being born.

Now let us consider today's situation: almost all children with intellectual disability have access to public education provided by the state - including the ones suffering from multiple and severe disabilities, recipients of multi-specialist, comprehensive educational and rehabilitation services, care and transportation services at PSOUU centres. The majority of the youth can benefit from vocational preparation and enjoy an active lifestyle by participating in various forms of recreation and cultural life. They can also develop their interests and talents. The lucky ones work at vocational activity workshops. Others, yet still too few, benefit from supported employment schemes. Training in independent living and coping skills, supported accommodation schemes in different organisational forms are also accessible, though not

to very many persons with intellectual disability. However, the biggest success of empowerment of persons with intellectual disability and the result of many years of education and development of social competencies coupled with attitudinal changes in the society is the movement of self-advocacy, i.e. public representation of the interests of the disabled by the disabled themselves in contacts with the decision makers regarding the lives of the disabled (who used to decide without consulting the persons with intellectual disability). Self-advocate represent themselves in contacts with their families, professionals, local authorities, central government and parliament. They speak out for their rights.

I mentioned the beginnings of the movement of parents at the beginning of my presentation. The movement soon transformed in to an organisation. It took place in 1963. The most interesting feature of the movement was the fact that it was in reality an entirely grass-roots initiative, which was rather unusual at the time. Parents wanted to start their own organisation and they wanted to copy the structure of existing organisations: the Polish Association of the Blind and the Polish Association of the Deaf. Unfortunately, the authorities did not approve of this plan. What we heard in response to our idea was: "Such pathologies must not be represented formally". However, as a group of parents, we were granted permission to join one of the existing organisations. Our choice was the Society of the Friends of Children (TPD), whose articles of association enabled us to support disabled children in various ways. Just after we joined the Society we were able to organise summer camps, education, rehabilitation and care centres as well as integration meetings for our children and families. And this, after all, was what we had been aiming for. The name we came up with was the Committee (at the Mangement Board of TPD) and local Support Centres for Children with Special Needs<sup>1</sup>. We adopted a motto that was revolutionary at the time: "Let us open life for them" and the logotype which we have been using until today (designed by a famous graphic designer Henryk Zwolakiewicz from Lublin).

Why was our motto so appealing at the time?

- (1) It promoted the courage of parents to come out despite the stigma – and to become socially visible
- (2) It formulated the needs of our children from the point of view of development, equal rights and inclusion, not merely care
- (3) It treated and presented persons with intellectual disability as persons with capacities and social personalities, i.e. as valuable members of the society,
- (4) to show determination of the parents in creating their own (non-public) forms of ensuring equal opportunities, support for life in open communities and strengthening of families.

The mission of our organisation, formulated in the final stage of "special care approach" and then adopted by PSOUU, contained all the most important values from the point of view of parents: "*Safeguarding the human dignity, the place within the family and among other people as well as the happiness of persons with intellectual disability*"<sup>2</sup> and supporting the per-

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<sup>1</sup> In 1984 we changed our name into the Committee and Local Support Centres for Persons with Mental Handicap ("Komitet i Kola Pomocy Osobom z Upośledzeniem Umysłowym").

*sons' families so that they can cope with the situations resulting from the birth and life of a child with mental handicap"*

The aim of the Association is *to act in favour of equal opportunities for persons with intellectual disability, creation of conditions for respecting human rights of such persons and guiding persons with intellectual disability towards active participation in social life, supplemented by support for their families* (Article 4 of PSOUU's Articles of Association).

Both happiness as a personal category and respect for human rights are associated with quality of life, the true metric for observance of values in the implementation of the Association's mission.

The Committee and its local branches were active until 1991 (28 years in total). It is then, just after the political shift in Poland, that a new law on associations was passed and we were able to register a new independent and self-governed organisation under the name: Polish Association for Persons with Mental Handicap (PSOUU). PSOUU was created as a result of democratic decisions by the Committee and local branches to move away from Friends of Children Society (TPD) to the new Association, along with the local centres we managed. This is why a newly-established organisation already had its rich history, its system of values, its mission, goals and achievements. Last but not least, it also had the people with their dedication and extensive experience. We were also well-known, both at the central and local levels, thanks to the 28 years of our active contacts with the ministries, the parliament, the media and local communities where local branches operated. A characteristic feature of our organisation, both in its previous form and as later PSOUU, was the continuity of representation: the leaders of particular structures of the organisation changed very infrequently<sup>3</sup>.

The contribution of parents and friends, including the professionals employed at PSOUU centres, to the creation of a new environment and new opportunities for persons with intellectual disability spanned many areas. I will now present some of these areas.

1. At the very beginning we concluded that the basic needs of persons with intellectual disability should be satisfied despite the numerous barriers - just like the needs of non-disabled citizens. This contributed to a creative search for appropriate methods, techniques and forms of support.

We adopted a few methodological assumptions which we tried to apply across all PSOUU centres and for all beneficiaries. The assumptions were verbalised in the standards contained in our Articles of Association and in training curricula for our staff. The standards were as follows: (1) individual treatment based on respect for dignity, (2) focusing on the person's strengths, (3) positive motivation, (4) individual action plans and taking into account the outcomes in planning further action, (5) cross-disciplinary team of professionals facilitating a comprehensive approach, (6) learning by doing, (7) work in small groups and individual support, (8) different treatment of children and adults, (9) using observation of behaviours in the diagnosis, planning, therapy and evaluation.

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2 At the time, the plan surfaced to change the term "mental handicap" into "intellectual disability", in accordance with the suggestions contained in the UN Convention on the Rights of Disabled Persons.

3 Krystyna Mrugalska held the following positions within the Committee since 1964: Secretary, Vice-President, President; in PSOUU, she held the position of the President of the Management Board until retirement in 2008.

2. The support programmes of our centres reflected the systemic goals, such as: rehabilitation, education, therapy, vocational preparation, development of social skills, work, participation in cultural events (handicraft and artisan activities, musical expression workshops, theatrical workshops etc.), visiting plays, concerts and exhibitions, tourism, sport, recreation, supported living in local communities and independent living with appropriate support. A characteristic feature of PSOUU centres established across Poland was their consistency, which translated into a network of centres guided by a common set of principles. In other words, we managed to implement a unified organisational and practical solution across the country. This also enabled us to apply for accumulated and unified funding for our activities.
3. Examples of support services and centres we launched and which were later introduced into the Polish system of support for persons with intellectual disability were as follows: rehabilitation and education centres for children with severe and multiple disability, early intervention centres, occupational therapy workshops, community self-help homes, vocational activity workshops, vocational advisory and support centres DZWONI (specialised employment agencies), pilot runs of supported employment on the open labour market, independent living with support as a community-based alternative to institutions, training and support for self-advocates, publication of easy-to-read texts, managing clubs, active life groups (orchestras, theatres, sports teams, socialising) holiday excursions, summer camps and many more.

PSOUU has also been offering support, assistance and advice to parents and adults with intellectual disability in the form of life skills training (part of lifelong learning educational programmes).

The parents' way of establishing local centres is also worth mentioning. The following two examples can depict it well:

1. An early intervention centre concept was created on the basis of complaints from parents (in 1976). The parents complained about the following:
  - (1) too late diagnosis,
  - (2) diagnosis limited to medical issues,
  - (3) lack of information on the necessity to include other professionals,
  - (4) lack of comprehensive support,
  - (5) lack of a centre where all relevant professionals could cooperate when diagnosing, programming therapy and evaluating its outcomes i.e. lack of multidisciplinary teams,
  - (6) lack of guidance for the child and its parents from the moment of diagnosis until the age of 7,
  - (7) lack of coordinated, comprehensive and cross-disciplinary programmes developed for each individual child,
  - (8) focusing on weaknesses,
  - (9) focusing on the child and not taking into account the needs of the family, informational/ support/training/therapeutic development needs in particular.

A pilot programme which took into account all the above-mentioned complaints was tested during a 2-week-long early intervention camps in 1976-77 and then implemented by the establishment of Poland's first (and one of the world's first) Early Interven-

tion Centre in 1978 at the Committee for Support for Children with Special Needs in Warsaw. The Centre still operates and is now managed by PSOUU, with funding provided by the National Health Fund (NFZ)<sup>4</sup>. The parents from beyond the capital city who used early intervention services in Warsaw would then go back to their towns and establish similar centres based on the methods, programmes and staff training curricula we had developed in Warsaw. At PSOUU's initiative and in collaboration with the Ombudsman, we also launched a pilot government programme for the main-streaming of early development support.

2. The concept of supported employment for persons with intellectual disability based on the results of analysis of root causes of vocational inactivity within the group: (1) lack of motivation and support from the family, (2) lack of the necessary social and practical work skills, (3) lack of vocational preparation forms, (4) lack of functional diagnosis, (5) lack of individual action plans, (6) lack of guidance for disabled persons in the process of vocational activation and implementation of individual action plans, (7) lack of support in finding and maintaining employment, (8) lack of support from the family, co-workers and employers, (9) leading role of the job coach, (10) lack of structures for realisation of all the above-mentioned elements.

All the deficiencies were taken into account in the concept and the programme of Vocational Advisory and Support Centres for Persons with Intellectual Disability (DZWONI). The programme was then implemented in PSOUU's projects co-financed by the Polish State Fund for Rehabilitation of Disabled Persons and in two EU-funded projects, in a few Polish cities. As a result of the projects, many persons with intellectual disability were employed on the open labour market and managed to maintain their jobs. We are continuing our efforts to officially introduce DZWONI centres into Polish legislation.

The 1980s there was a favourable climate for parents organisations to secure various kinds of social benefits. We were able to secure the care allowance (for all disabled persons, including the intellectually disabled), a permanent disability benefit for persons disabled since their childhood and unable to work (later referred to as a social allowance), a longer maternity leave for mothers with a disabled child etc.

Among PSOUU's achievements from the last five decades there are also two very significant areas. The first area concerns the relevant changes in legislation, most importantly: the right to education provided by the state for children with moderate and severe intellectual disability and creation of appropriate schools for such students; the right to education for children with very severe and multiple disability, which we saw enacted after many years of efforts and lobbying. We also managed to introduce the provisions on non-public education centres for such children, and the financing of such centres from the general budget for education. Moreover, we were able to complement the education of youth with moderate and severe intellectual disability thanks to the introduction of the new "special vocational secondary schools" into the relevant legislation. We also developed vocational activity workshops and we were successful in convincing the lawmakers to include the workshops in the

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<sup>4</sup> The Centre's activity was widely recognised by professionals and we can now say that it contributes to the change in the approach to the development of small children with developmental impairments and in the therapeutic practice across the country.

act on vocational rehabilitation - as a form of employment which matches the needs of persons with severe disability. A favourable ruling of the Constitutional Court concerning unconstitutionality of some regulations and incapacitation of persons with intellectual disability was difficult to acquire but we finally succeeded in securing it, also thanks to our cooperation with the Ombudsman.

The second area of change are the effects of the “side” activities of the Association: these activities were of crucial importance for persons with intellectual disability in families and local communities, and for social policy in general. This area concerns changes in social awareness and attitudes to the problem of intellectual disability and to the individuals affected by the problem as well as their families, and even the professionals working with such persons. The fact that PSOUU developed various services at the local level led to disabled persons coming out of their family homes and facilitated contacts with the neighbours and getting to know “the others” within the local communities. This alone meant that the people became closer to one another, some barriers were overcome and some stereotypes broken. PSOUU’s headquarters and many local branches organised Days of Dignity of Persons with Intellectual Disability each year, an annual celebration launched in Poland by PSOUU. These took the form of festive marches through main streets with representatives of the authorities and posters. Usually, our marches also end with open air celebration and events. The point behind the marches is to demonstrate for dignity and inclusion in the society replacing the model based on care and rehabilitation.

The media have a particularly powerful position, capable of bringing about a change of awareness. All structures within PSOUU cooperated with the media and provided them with positive input (both written information and visuals or videos) showing what the disabled can do, what they are like, how they learn, work and how they can enjoy their lives and overcome their weaknesses. The material we have supplied has also taught the media to use positive language conveying positive emotions instead of stigmatisation.

The awareness and attitude of many professionals and students has shaped the style of work with disabled persons during traineeships, study visits and practical training sessions held at our centres. Our Centres have always been open for that kind of cooperation and contacts. PSOUU’s head office and regional branches have been publishing leaflets, brochures and other material including the quarterly “Society for All” which presents disabled persons, their lives and their support needs in an interesting way. For many years we have been publishing publications by Polish authors and translated from foreign languages. They present the difficult legal issues surrounding disability, social policies, methods of work with the disabled. We have also edited and disseminated videos showing different aspects of lives of the disabled. The more positive information and impressions there are resulting from PSOUU’s activities, the more extensive the understanding of the general public is, followed by the acceptance and readiness to build closer relationships and to support persons with disability in their functioning and inclusion in mainstream social life. We can therefore say that since the Association’s very beginnings, PSOUU has been changing social awareness: we have vigilantly and carefully recognised the needs of disabled persons and their families; we have created new support forms within local communities in order to create equal opportunities for persons with intellectual disability and to facilitate inclusion. We have stri-

ved for more friendly legislation and we have looked after the dignity and human rights of persons with intellectual disability and their families.

### Time for a summary

Fifty years have passed, it is 2013 now. We have brought up new generations of persons with intellectual disability who now can benefit from public education and who can experience inclusion, relationships with other people and different social roles, including the role of an employee and citizen (self-advocacy). More frequently, they are expected to be more independent, to cope and to function more autonomously and more responsibly. We have overcome many barriers, but is our over-protectiveness not another barrier we have to look at?

What new horizons are there ahead of the persons who we refer to as the intellectually disabled? What horizons do they see for themselves? What new responsibilities are they becoming ready to accept? What do they need in order to be able to accept them? What do they demand for themselves? What support do they need, depending on their individual choices? How do they want to live their lives? Are we listening to them?

There remains a lot to be done both in terms of discovering and overcoming the still-existing and well-rooted barriers, but also in terms of preventing the creation of new barriers. A lot needs to be done to enable them to reach their new horizons. Without civic organisations of parents and friends, we will not be able to reach many ambitious goals associated with the implementation of the UN Convention.

It still is a challenge - even though we had been implementing many values now explicitly stated in the Convention not only many years prior to the ratification of the document by Poland, but even before the Convention was written.





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## Movement of parents as a stimulus for social change

We would like to put our considerations on the significance of the movement of parents for research and social practice into a wider perspective of the sociological notion of social change. This perspective seems to be the most comprehensive and adequate to analyse the unprecedented role that the movement of parents struggling for a decent life for their children with intellectual disabilities has played in Central and Eastern Europe since its very beginnings.

To begin with, the notion of “social change” will be defined. According to Piotr Sztompka (2002, p. 437), social change is the difference between the state of a social system (a group or organisation) at a given point of time and the state of the same system at another point of time. The two states can obviously differ in many respects. From the point of view of the transformation of the system of support for people with disabilities in the society that we have seen in recent years, one should take into account elements such as changes in the composition of “actors” active in the system (the emergence of active organisations of parents), the change of functions and patterns of interaction between particular elements of the system, changes in the structure of interests of particular institutions and organisations that make up the system as well as changes of normative structures. As a result of these changes, people begin to hold other, new values, e.g. they start to consider people with disabilities as citizens with full rights and not just patients or a burden to the society. They also gain new information concerning the world, the situation of people with disabilities in other countries and their opportunities to live independently and enjoy autonomy. Thus, they develop a new idea of the place of people with intellectual disability in the society. This new perception as well as the contribution of the activities of parents to social change are the main focus of the present thesis.

Social change can occur quite harmoniously, evolving from less desired to more desired states. Such transition is called social progress. If the change is planned and is supposed to have a reformatory character, Jan Szczepański (1999) defines it as an attempt which makes it possible for the humanity to continue the work of the creator of the world. Szczepański claims that the ability of human beings to change the created world is tantamount to their ability to improve the world, as changing can also mean improving. However, if social change is sudden, violent and unexpected, and if it pertains to various areas of life and has a radical and deep character that violates the values which are particularly important to people, it can also turn into a traumatic experience.

In our view, in order to analyse the phenomenon of disability, the notion of trauma should be applied. Despite the fact that disability has accompanied human beings and their communities from the very beginning of their existence, both at the individual and collective

level, it used to be (and often still is) perceived as a traumatic experience, a “personal catastrophe” fraught with consequences for the individual and the society they live in (Finkelstein 1980, Oliver 1990).

The strategies to cope with the trauma resulting from disability can assume different forms, both individual and collective ones. As for the former, people tend to isolate themselves, hide their or their relatives’ disability, do not accept it or look for remedial measures on their own. Collective strategies encompass common, organised and targeted actions which aim at changing and improving the situation of people with disabilities.

Considered from this perspective, in the last fifty years the movement of parents seems to have become a powerful impulse, stimulus and driving force behind social change concerning people with disabilities, their families, the functioning of the state and its institutions as well as social awareness of the whole society.

To begin with, the most fundamental change related to the perception of the disabled will be outlined. It can be succinctly described as a transition “from patients to citizens”. At this point, a table should be presented which illustrates the most typical elements of the medical, consumer and political model of disability. The model refers to intellectual disability, apart from mental illness the most stigmatizing form of disability and the focus of this paper (cf. Firkowska-Mankiewicz 2010).

Table 7. From patients to citizens

	The age of institutionalisation	The age of deinstitutionalisation	The age of participation
The type of the model	Medical and institutional model	Development, rehabilitation and consumer model	Model of individual support based on civil rights
Who is at the centre of attention?	Patient	Client – consumer	Citizen – member of the community
The place of stay	Institution	Hostel Special school Occupational therapy workshops	Home State school Workplace
What kind of help is provided?	Providing care	Implementing the programme	Individual support
Who supervises the implementation of the programme?	Professional (usually physician)	Cross-disciplinary team	Individual
What is the priority?	Basic needs	Developing abilities, control of behaviour	Self-determination and relations with others
What is the goal?	Protection and/or treatment	The change of behaviour of an individual	The change of societal attitudes

Source: J. Knoll, 1992, V.J. Bradley, 1994

Until the end of the 1960s the medical model of disability prevailed (and it still makes its presence felt). It focuses on defects or injuries to the body of a given person, in a way blaming them for their state and committing them to special institutions: mental hospitals, residential care homes and special schools, or trying to make them adapt to the conditions that other, fully-fit members of the society live in. Growing criticism towards solutions based on segregation and paternalism, expressed mainly by parents, has resulted in a paradigm change towards a social, or even a broader socio-political model.

In the social model, what constitutes the problem are not physical or mental limitations of an individual but the limitations of the environment that creates various barriers. In practice, according to the assumptions of the model one should not only help individuals adapt to the society but also consider whether and to what extent the society is ready to adapt its solutions and patterns of behaviour to the capabilities of the disabled. Hence, the social model rejects considering disability from the perspective of individual limitations and dysfunctions and suggests identifying barriers and correcting deficits of the physical and social environment instead. It points at the stigmatisation of people with disabilities resulting from the organisation of social life and social control. The social model also emphasises the role of prevailing attitudes and stereotypes concerning the disabled as it should be noted that the barriers created by the society are not only physical but also mental (Ostrowska 2009).

When analysing the social model of disability and social changes leading to its implementation, it is crucial to refer to an important concept of social capital (Bourdieu 1986), which in sociology is the sum of the resources, actual and/or virtual, that accrue to an individual or a group by virtue of possessing a durable network of more or less institutionalised relationships (e.g. NGOs) of mutual acquaintance and recognition. Social capital is an important tool of the Polish Association for Persons with Mental Handicap, which has been the driving force behind the mechanisms of social change in Poland.

Social interactions can be considered as capital if they can be used to achieve goals that would be difficult or costly to achieve otherwise. Common capital means mutual understanding, developing action strategies and raising funds. In the micro scale, such resources constitute the social capital of individual families. In the macro scale, understood as an organisation linking families, the capital is multiplied. Robert Putnam, a theorist of democracy, developed the concept of social capital (1995), i.e. supportive networks which increase the efficiency of the society by facilitating engagement and improve the effectiveness of the actions taken. Within the concept, it is the networks of people who jointly head towards common goals that create the potential for democratic change.

An extension of the social model is the political model, which focuses on the rights of people with disabilities and attempts to grant them the same civil status as any other citizen, thus guaranteeing them an equal position in the society. This marks another milestone as far as the change of the situation of people with disabilities is concerned. They are no longer helpless patients or clients of more or less successful support institutions present (or absent) in various societies and become citizens of their countries which are obliged, under threat of sanctions, to comply with and carry out the rights the disabled have been granted by the international community.

So far, the most complete expression of social change with respect to disability is the Convention on the Rights of Persons with Disabilities adopted by the UN and ratified in numerous countries all over the world (Poland ratified the Convention in 2012). The implementation of the Convention is an epoch-making event that has permanently changed and raised the status of people with disabilities in the society as well as triggered positive changes in the functioning of institutions which support the disabled.

There is no denying the fact that it is the determination of parents that has driven the social change in the field of disability. Their movement, at first spontaneous, loosely organised and based on enthusiasm, good will and selflessness, over the course of time has become more institutionalised and gained strength and effectiveness. The pressure it has consistently exerted (especially through large international organisations for the disabled associated in the European Disability Forum but also through local and national associations) has translated into the change of the local and international legal framework and social policies regarding people with disabilities as well as of the system of institutions and services supporting them. Moreover, the knowledge and social awareness concerning the needs and capabilities of the disabled have improved and people with disabilities have changed as well.

The historical review of the achievements of the Polish movement of parents of children with intellectual disabilities included a film and a speech delivered by Krystyna Mrugalska. Taking into account the central theme of our conference, we in turn will try to focus on research related to different dimensions of the situation of people with various disabilities, especially intellectual disability, inspired more or less clearly, directly or indirectly, by the movement of parents. As we are both sociologists and students of Magdalena Sokolowska, the forerunner of sociology of medicine and disability in Poland, we will obviously focus on research conducted according to the principles of sociology or with participation of a number of sociologists. Our choice is necessarily selective and in general includes only the research we have been involved in as authors, co-researchers, consultants or reviewers. Our description pertains to different dimensions and areas of functioning of people with disabilities and is motivated by the intention to capture changes that have occurred in their lives in recent years.

The starting point is the earliest research examining the epidemiology of disability (its distribution in the population) and personal circumstances, i.e. the financial, educational, professional and family situation of people with disabilities. The first study on this subject in post-war Poland concerned the prevalence of severe intellectual disability and was conducted between 1964 and 1965 in what was then the Institute of Psychoneurology under the supervision of two physicians: neurologist and geneticist Ignacy Wald and neurologist Danuta Stomma (1965). The subject of the research comes as no surprise because, as already mentioned, Ignacy Wald from the very beginning supported the movement of parents of children with intellectual disabilities that emerged in 1963. The study was carried out on a representative sample of 260 children at the age of 5-14, with IQ between 0-50, and then repeated on the same group twice: after 10 years (Wald et al. 1978) and after 23 years (Wald et al. 1995). The researchers, in cooperation with sociologists, demonstrated educational neglect and the difficult financial and social situation of adolescents and their families, the lack of services providing support in natural environment and, most of all, the negative

impact of institutionalisation (committing an individual to an institution) on the intellectual and social functioning of people with severe mental disabilities.

Another study which turned out to have a long-term character was initiated in 1970 by Magdalena Sokołowska and her team (including both authors of this paper). The research was called Warsaw Study and it investigated the bio-psycho-socio-cultural determinants of the intellectual level of teenagers in Warsaw (Sokołowska et al. 1977, Firkowska-Mankiewicz 1993, 1999). In the end, the study pertained to the whole spectrum of intellectual functioning of eleven- and then thirteen- and thirty-year-old people, but initially it was supposed to focus on the problem of mild intellectual disability. One of the initiators and consultants of the research (along with American colleagues) was Ignacy Wald.

The findings of research investigating children and then adults with reduced IQ clearly proved (though long before the emergence of inclusive education which is supported nowadays) the negative impact of special schools on professional achievements and social adaptation of former pupils (Firkowska-Mankiewicz 2000). The skepticism over the effectiveness of teaching children with mild intellectual disability in special schools (the first three grades) when compared to the effectiveness of teaching them in ordinary schools was reinforced by recent studies by Grzegorz Szumski conducted with our participation between 2008 and 2009 and published in a book *“Wokół edukacji włączającej – efekty kształcenia uczniów z niepełnosprawnością w stopniu lekkim w klasach specjalnych, integracyjnych i ogólnodostępnych”* (2010).

We should go back to the 1980s in order to outline major and pioneering research conducted by the Committee of Rehabilitation and Re-adaptation of People of the Polish Academy of Sciences PAN (1978). It was a comprehensive evaluation of the situation of people with disabilities and rehabilitation in Poland. The team of researchers analysing different aspects of this situation was led by sociologists Jan Szczepański and Magdalena Sokołowska. There is no doubt that the form and content of the study could not have been directly inspired by the movement of parents of children with intellectual disabilities as the movement was in its infancy at that time. Although the evaluation did not become a significant tool of social policy and did not contribute to solving numerous problems of people with disabilities, it managed to attract attention to a range of issues such as the need to change the legal system and judicature, the functioning of institutions supporting people with disabilities as well as societal attitudes towards these people (Ostrowska 1994). Importantly, the evaluation called for the development of objective scientific research diagnosing the situation and needs of people with disabilities.

This demand was met by the next large evaluation that summarised a series of studies conducted in 1993 under the direction of Antonina Ostrowska (Ostrowska et al. 1994). The studies took place during the first years of economic transformation in Poland, at the time when new social rules, a new institutional order and new principles of cooperation between the state and society were being shaped. The political changes that occurred at the beginning of 1990s placed people with disabilities in a difficult position. The fact that the state started to give up its welfare function and especially the collapse of the system of cooperative movement of the disabled at first undermined their social security. At the same time, that

period saw a sharp increase in the number of associations of people with disabilities. They attempted to create interest groups which would protect the rights of the disabled in the new, emerging social order (Ostrowska, Sikorska, Gąciarz 2001). It is thanks to these organisations (including associations of parents) that a number of changes to the legal and institutional system of supporting people with disabilities were introduced.

The research conducted at that time aimed at presenting the conditions people with disabilities lived in as well as their scale of needs. It attempted to depict whether and to what extent they could cope with the new socio-economic situation and whether they were involved in solving their own problems. The research focused also on the diagnosis of societal attitudes towards people with disabilities. It revealed mental barriers present in the society which hinder social integration of the disabled. A comparative analysis of the attitude of our society towards people with different kinds of disabilities showed that the tendency of the society to keep its distance is relatively strongest in the case of people with intellectual disabilities (Ostrowska 1994). This indicated the need for large-scale educational activities targeted at the society which would depict the real image and capabilities of people with intellectual disabilities and, as a result, break the negative stereotypes. Such actions were taken, among other, by the Polish Association for Persons with Mental Handicap and groups of active parents. They initiated numerous persuasive media events (celebration of the Day of Dignity), educational activities (conferences, symposia and publications) as well as political and lobbying campaigns (parliamentary sessions, struggle for changes in legislation concerning education and incapacitation).

It should be mentioned that the preliminary findings of the study on societal attitudes towards the disabled conducted by Ostrowska 20 years later, in 2013, indicate that the society is more open towards people with intellectual disabilities, which is certainly linked to social campaigns of the Association and the fact that inclusion is promoted and the civil rights of the disabled are recognised.

The studies conducted under the project "Disability in Poland in 1993" analysed also the functioning of a number of institutions and systems supporting people with disabilities, the legal framework concerning the disabled, the functioning of families of people with disabilities and the ways their interests are voiced. In fact, they pointed to the weaknesses of the system of institutional support and shortcomings of the cooperation between organisations of the disabled and public institutions (social welfare, jobcentres). Organisations of people with disabilities used the findings of these studies as an argument and support for their efforts to implement new regulations such as the Law on Professional and Social Rehabilitation and the Charter of Rights of the Disabled, which helped to raise the awareness of the society of the situation of people with disabilities.

Apart from studies that were conducted simultaneously with the activities of the movement of parents or were loosely-linked to their actions, several research initiatives should be mentioned that were inspired directly or indirectly by the Polish Association for Persons with Mental Handicap, and especially its long time president, Krystyna Mrugalska. To begin with, we would like to present the subjects of our conferences which have been organised since 1975.

They have dealt with innovative topics and rebelled against stereotypes concerning people with intellectual disabilities in Poland, which can be documented by the names of conferences:

- I. "Situation of juveniles and adults with mental handicap in the society", 1975
- II. "Preventing mental handicap", 1976
- III. "Early intervention versus mental handicap", 1977
- IV. "Social welfare and its position within the system of services for people with mental handicap", 1978
- V. "Conditions of employment and rehabilitation of people with mental handicap at the workplace", 1979
- VI. "Mild mental handicap" 1980
- VII. "Mental handicap in the countryside", 1981
- VIII. "The role of families in the rehabilitation of people with mental handicap and family counselling", 1982
- IX. "Education of people with mental handicap: its functioning, shortcomings and perspectives", 1983
- X. "Mental handicap accompanied by sense defects as well as somatic and psychological impairments", 1984
- XI. "Education of staff working with people with mental handicap: its functioning and needs", 1985
- XII. "Severe mental handicap", 1986
- XIII. "Genetic counselling and mental handicap", 1987
- XIV. "Achievements and problems of social integration of people with mental handicap", 1988
- XV. "Nursing homes for people with mental handicap and contemporary tendencies", 1989
- XVI. "Methods of teaching and upbringing of people with mental handicap", 1990
- XVII. "Advances in biological research on mental handicap", 1991
- XVIII. "Participation of people with mental handicap in social life", 1992
- XIX. *The conference was cancelled, 1993*
- XX. "Developing the system of support for families", 1994
- XXI. "The rights of people with mental handicap in Poland", 1995
- XXII. "Society for Everyone versus people with mental handicap – experience from Norway", 1996
- XXIII. "Independent life of people with intellectual disabilities - a pipe-dream or a challenge?", 1997
- XXIV. "Problems of elderly people with intellectual disabilities", 1998
- XXV. "People with intellectual disabilities and their right to full humanity", 1999



- XXVI. "The quality of life of people with intellectual disabilities", 2000
- XXVII. "Legal position of people with intellectual disabilities under the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities", 2001
- XXVIII. "Emotional and family life of people with intellectual disabilities from the point of view of their sexuality", 2002
- XXIX. A jubilee conference: "From non-being to inclusion: forty years of existence of the movement of parents of people with intellectual disabilities", 2003
- XXX. "Included in the society", 2005
- XXXI. "New tendencies in education and the development of services for people with intellectual disabilities", 2006
- XXXII. Inclusion Europe conference – "Europe in Action 2007: Civil rights for everyone. Full civil rights and legal protection for people with intellectual disabilities", 2007
- XXXIII. "Lifelong learning for people with intellectual disabilities as the key to self-determination and independence", 2008
- XXXIV. "For a better quality of life of people with intellectual disabilities", 2009
- XXXV. "People with intellectual disabilities and their families in the face of death and dying", 2011
- XXXVI. "UN Convention on the Rights of Persons with Disabilities", 2012
- XXXVII. "The movement of Parents of people with intellectual disabilities versus scientific research and social practice", 2013.

We invite to the conferences not only research workers and professionals but also practitioners and, recently, self-advocates. Unfortunately, only three conference papers were published: "Situation of juveniles and adults with mental handicap in the society" (1977), "People with intellectual disabilities and their right to full humanity" (2000) and "Emotional and family life of people with intellectual disabilities from the point of view of their sexuality" (2003).

In this part, a number of strictly scientific studies will be presented. The first of them brought about a significant change in the legislation concerning people with intellectual disabilities. This sociological and legal study on the incapacitation of people with intellectual disabilities decided on by Polish courts was conducted on the initiative of the Association on almost 400 incapacitated persons in six regional courts all over Poland (Firkowska-Mankiewicz, Szeroczyńska 2005). The findings of the study were so shocking that they triggered an intervention of the Ombudsman, a series of inspections ordered by the Ministry of Justice and, finally, a significant change of certain regulations introduced upon the request of the Constitutional Tribunal (Firkowska-Mankiewicz, Szeroczyńska 2009). It also encouraged other studies and sparked off a serious debate over the forms of legal protection of people with intellectual disabilities other than incapacitation (If not incapacitation, then what? 2012).

The next research worth mentioning is a little known but very interesting study on the effectiveness of genetic counselling in families with a child with Down syndrome ("Effectiveness of genetic counselling," 1983). The study was carried out by, among others, a team



of sociologists of medicine from the Polish Academy of Sciences and initiated by a geneticist and a member of the Polish Research Team on Intellectual Disability, Tadeusz Mazurczak. The study investigates the complex psychological, sociological and cultural context of reproductive decisions taken by people who face the risk of disability of the next child and is related to the last aspect of social change inspired by the movement of parents that we would like to outline.

The change mentioned concerns recognition and self-determination of people with disabilities and their families as well as the quality of their life. In fact, the research on this important issue appeared as late as in the last decade and, to a large extent, was initiated by the consistency of the movement of parents. It showed the capabilities, development, creative and social possibilities as well as the desire for self-determination and the will of people with disabilities to live just like the rest of the society, to learn, work, live independently, make friends, love, start families and enjoy full civil and social rights.

This was presented in a spectacular but, at the same time, scientifically reliable way by the last two studies. The first of them was carried out by a research team of the Academy of Special Education and concerned the quality of life of people with intellectual disabilities (Zasępa, Wołowicz 2010). The other one was conducted by the Polish Disability Forum research team and was published in a book on the so-called Stargard model of rehabilitation and social inclusion entitled *"Życie w integracji – stargardzki model lokalnego systemu rehabilitacji i wsparcia społeczno-zawodowego osób z niepełnosprawnością intelektualną"* (2012). The book demonstrates that the opportunities for a good quality of life, self-reliance, recognition and autonomy of people with disabilities to a large extent depend on the existing system of support institutions, wise regulations and social policy as well as a friendly social climate. At the same time, it indicates that social change has occurred in all the mentioned dimensions: the legal system, social policy, support institutions and services as well as the recognition and quality of life of the disabled, which can be attributed to long-term professional activities of parents associated in the branch of the Polish Associations for Persons with Mental Handicap in Stargard.

**It turns out that social change is possible. It has been inspired and driven by the movement of parents.** However, it cannot be stated that its activities, though successful, are enough to ensure the integration of people with disabilities in our country. What is still needed are new action plans which could help remove social barriers the disabled have to deal with. The NGOs and associations of people with disabilities as well as their families and friends, though full of positive energy to struggle for a decent life, still have to face numerous challenges. What we also need is a serious debate over the role of the state and NGOs in supporting people with disabilities as well as over their mutual relationships.

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## The dialogue between psychologists and parents over the last 50 years

The fiftieth anniversary of the movement of parents of children with intellectual disability coincides with the fiftieth anniversary of clinical child psychology for children in Poland. In 1963, the Committee for Support for Children with Special Care Needs was established at the management board of the Friends of Children Society. The Committee was managed by Ewa and Roman Garlicki and supported by professor Ignacy Wald, head of the Institute of Genetics, as well as by the members of the Institute of Rehabilitation and the Child Psychiatry Clinics at the Institute of Psycho-Neurology in Warsaw. The Committee later transformed into management board of the Polish Association for Persons with Mental Handicap (PSOUU) - a large nationwide association of parents and friends of children with disabilities.

Also in 1963, a separate scientific entity in the form of Chair of Clinical and Developmental Psychology was created at Warsaw University, headed by Professor Halina Spionek. An outstanding psychologist and physician by education, Professor Spionek invited practitioners and students to cooperate with her. This is how the University began to educate MA and PhD students in this field of specialism and introduced research in the area.

I was then in my third year of studies. I was starting to learn the practical side of the job so I can treat the 50th Anniversary also as the anniversary of my personal involvement in psychology. It also enables me to describe the changes which have taken place in the relationship between psychologists and parents – both from the perspective of an “eye witness” but also, to some extent, from the perspective of a participant.

The relationship I wish to analyse here will be broadened to include multiple stakeholders: more than one type of psychologists who take part in the process (researchers/scientists and practitioners) and parents with their children. Moreover, all the stakeholders have contacts with institutions such as : kindergartens, schools, rehabilitation centres, universities etc. Their activities also influence social policies, and social policies feed back to offer various opportunities for parents, professionals and children. The basis for such contacts is provided by direct conversations, research, study programmes as well as conferences, publications, and staff training taking place both at universities and at various centres where knowledge is applied in practice.

Professor I. Wald was the initiator and the first President of the Polish Research Team for Intellectual Disability which formed the scientific basis for the parents' movement. The most recent 37th Symposium, of which this paper is an outcome, was also a result of combined effort of scientists and parents. Both these major groups of stakeholders are members of the relevant international associations: International Association for the Scientific Study of Intel-

lectual and Developmental Disabilities and the International League of Societies for Persons with Mental Handicap (now: Inclusion International).

I would like to divide the 50 years of contacts between the stakeholders into a number of phases.

### **The First Phase: the Era of Unconsciousness**

Except for the small Department of Defectology at the Jagiellonian University headed by Anna Dzierżanka-Wyszyńska, universities did not really conduct any research on intellectual disability. Scant knowledge in this field was passed on to students during psychiatry classes, but it was limited to description of levels of intellectual disability as well as presentation of contributory organic factors and the irreversible consequences of the condition. The subject lay then within the domain of medicine or special pedagogy. The latter was included by Professor Maria Grzegorzewska, the founder of the Institute of Special Pedagogy, in the teaching programme already during the interwar period, but achievements in this field were not significant. Children with more severe levels of intellectual disability were perceived as uneducable and un-trainable. Only mildly or moderately disabled children could attend special schools.

Psychologists in clinics gave certificates and conducted selections, i.e. they referred children on basis of their IQ to special schools or mental health institutions. The institutions were terrible and did not provide rehabilitation. Children there were treated impersonally and their living conditions did not meet any standards, not even as far as hygiene was concerned. Parents were perceived by psychologists as a source of information on the state of their children. Sometimes they were treated even as the ones responsible for the child's mental disability due to the widespread belief that the condition was caused by inborn disorders, alcoholism and child neglect. The media and the Church did not publicize the problem since it was perceived as embarrassing at the time, which contributed to the atmosphere of dislike that surrounded the parents.

The described state of affairs began to change in the 1970s.

I can define the following change factors: As far as the parents' movement is concerned, the factors were: the establishment of the first schools of life which proved that children with moderate and more severe forms of disability could and should learn. As far as the academia is concerned, a very significant factor was the existing research into psychosomatic diseases in orphans by Izabella Bielicka and Hanna Olechnowicz (dating back to 1959). The research showed the impact of broken emotional bonds and the deprivation of little children in institutions and hospitals, leading to severe developmental pathology. It also sent a clear message: the overall picture of disability is largely influenced by its environment. The research programme, managed by Danuta Stomma, showed significant improvements in the health of the children after introduction of higher activation levels into the care institutions under study.

Halina Spionek (1969) proved in her research that developmental delays in children were not only "horizontal" (i.e. enabling us to divide them into degrees of disability based on generalized impairments), but were also characterised by disharmony and irregularity within the stages of development of different functional capabilities. Although Halina Spionek did not deal with children with intellectual disability herself, her claims opened an opportunity

to seek developmental strengths in children with lowered IQ levels - possibly, a basis for their achievements - and discover deficits which could be subject of rehabilitation and equalization.

In 1972, PZWL, a major Polish medical publishing house, published a book authored by I. Wald, D. Stomma, E. R. Garlicki et al., entitled "How to prepare a disabled child for life?", (original title: "*Jak przygotować do życia dziecko upośledzone?*"). The publication was a breakthrough in the mode of thinking of parents and professionals who recognized the developmental opportunities of children with disabilities.

### **Phase Two: Stimulation and Development**

Having recognized disabled children as capable of learning and developing, researchers (psychologists mainly) adopted the subject area as an interesting field of study. A number of studies were launched into activation of disabled children. Credit must be given to the work of Hanna Olechnowicz in 1979, 1983 and 1986. She and other researchers were looking for optimal and early forms of stimulation of development of such children. At the same time, best practice from abroad became known and was, at times, followed (including the concepts proposed by Carr, 1984; Clarke, Clarke, 1969).

In the middle of the 1970s important workshops for the disabled were established, combining practical and creative endeavours. An example is the Early Intervention Centre at the Friends of Children Society, first located in the more than modest facility of the Institute of Psychiatry and Neurology and later, thanks to efforts by PSOUU, in the beautiful headquarters of the Association at Pilicka St., Warsaw. The centre was skilfully managed by Zofia Pakuła who built a cross-functional team of professionals, volunteers, consultants and students to try out new methods of cooperation with children and parents. Cooperation with parents must be underlined here: they were no longer passive recipients of advice; instead they became active participants of the early intervention process.

The 1970s also saw the opening of the first Academic Centre for Therapy for Children and Parents at Warsaw University, managed by Małgorzata Kościelska. The centre was unprecedented in the history of Polish applied psychology: its young researchers, independently and without support nor directives from anywhere, developed new forms of contact with children and parents as well as new forms of diagnosis and therapy. Responding to the overwhelming helplessness and suffering, they created support and psycho-education groups for parents of children with autism and developmental impairments. The so-called "Stawki" (the name of the street where the Institute was located) was the first point of contact for parents. They could share their problems in small groups, listen to advice from others, pour their hearts out, and receive support. Meanwhile, their children benefited from non-directive therapy in a specially adapted room. This was the time of leaving the era of stimulation and we were slowly beginning to move in the direction of discovering the children's own activity and capacity.

Further changes took place, and news arrived from the West concerning the inclusion and normalization movement. M. Kościelska's book (1984) on social development of special school students indicated the similarities in the creation of social behaviours between children with normal and lowered IQ levels. This created a scientific basis for the creation of shared living, playing and learning conditions for children with different degrees of intellectual development.

**Phase Three: Integration**

In the 1980s, thanks to pressure exerted predominantly by parents, the first integrated groups of children with both normal and lower than normal development levels were launched in kindergartens and later in primary schools. Along with psychologist at the Centre for Children with Cerebral Palsy, Jadwiga Bogucka, we monitored the beginnings of the integration process and organized conferences and training courses for teachers. The first experience was enthusiastic, as evidenced by the books we edited in 1994 and 1996. Thanks to the support from the Ministry of Education we were able to publish a whole series of brochures entitled *"They are among us"* (in the years 1997-2004) describing the problems of children with different disabilities for teachers, parents and students at mainstream schools. With time, integration reached the level of secondary education. Sadly, after the initial enthusiasm showed by teachers, parents, school principals, education and welfare officers as well as communities, complex obstacles to the process became visible. On the one hand, integration handbooks became available (e.g. Hundertmarck, 1993), but on the other hand more numerous publications appeared on the negative developments in school integration and on more frequent internal segregation and persecution of weaker students (e.g. Ostrowska, Sikorska, 1996; Maciarz, 1992; Bąbka, 2001). Although some parents began to take their children back to special schools (perceiving such schools as peaceful enclaves of care and professional didactics), in general there was no going back from integration. However, even today successful integration must be the result of a long process with multiple stakeholders. Most of all, it depends on promoting the change in social awareness.

The change is taking place. It is partially imposed by EU directives, UN declarations and intergovernmental agreements. The concept of people with disability enjoying all equal citizen's rights is slowly beginning to filter through to social practice.

M. Kościelska's book *„Oblicza upośledzenia"* (1995) ("The Faces of Disability") caused a breakthrough by posing the claim that intellectual disability is not inborn but a result of an inappropriately travelled developmental path - a path one can sometimes go back and travel once again. Her research showed that the generally perceivable picture of disability is created by, most of all, the experience of suffering, helplessness and anxiety. According to her, intellectual functioning is greatly influenced by the structure of "I" which, in the case of children with intellectual disability, is often not created or only created rudimentarily, as a result of treatment of such children as objects or, at best, objects of rehabilitation and integration, not as independently developing subjects.

**Phase Four: Dignity and Empowerment**

Contemporary parents' movements which are associated in different organizations demand from governments rights for their children and respect for their dignity.

Studies suggest that an upbringing and capacity-building which takes into account disabled persons as individuals takes such persons to a totally different level of functional capability. In this phase we can observe the so-called self-advocates i.e. persons with disability who speak in public and present their own problems, demanding a real share in social life. Disability is becoming a widely publicised topic. A large number of films and TV series are being produced in which persons with visible disability show how normal their perception of the world and how amazingly original their thinking processes are. Paralympic Games are

held, orchestras and theatrical groups are being established, and international exchange is being developed. However, new problems are also surfacing.

The change which has taken place is mostly about recognizing the adulthood of the disabled: we no longer call them the “children forever”. Among other issues, we have started to notice their sexuality. This problem was well described in the post-conference publication by Anna Firkowska-Mankiewicz (2003) and then by Kościelska (2004) in her book entitled “Unwanted Sexuality”. Other books and research followed, including Kijak (2012 and 2013). It has turned out that our legislation does not allow marriage of people with intellectual disability and mental health problems without court consent, so the path to shared life in a relationship has been closed for many. The question has arisen of sexual education and preparation for adult life of persons with intellectual disability. Recognition of adulthood in disability has also led to independence-related issues surrounding work, accommodation and the relevant support services.

### **Phase Five: social debate on possible solutions**

The problem of normal life and inclusion in social life has to be translatable into real-life practice. Currently, young people with intellectual disability can develop their skills in occupational therapy workshops, vocational activation centres and in some cases may be employed at sheltered workshops which are more and more reluctant to hire people with disabilities due to the existing competition on the market. Care institutions are not an optimal solution either, despite the recently improved conditions in such facilities, as they are still enclaves of disability. Currently we are witnessing various debates on how we can aid inclusion in normal social life for persons with disabilities in a way which is beneficial to all stakeholders.

For a long time I have been a proponent of the idea that we are all, in one way or another, disabled; we all sometimes need the assistance of others and we are able to give ourselves to others to some extent. In my understanding, a multitude of forms of life of people with diagnosed disability with accessible support services would be optimal. I believe that the basis for all solutions should be the social bonds. Such bonds are naturally created within families but when there is no family, they must be replaced with other forms of close bonds with other people thanks to: living in hostels, supported accommodation, accommodation at church parishes, on farms and at workshops. The list of opportunities is extensive and I can only mention a few here. The essence of disability is and will always be dependence... Let us try to reduce the dependence to a minimum.



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## Contribution of the Polish Association for Persons with Mental Handicap to the Polish system of education of persons with intellectual disabilities

The integrated parents' movement has played a very significant role in shaping the Polish system of education for persons with intellectual disability. Parents were initially grouped within the Friends of Children Society (TPD) and later they formed an independent organisation: the Polish Association for Persons with Mental Handicap (PSOUU), in order to break further barriers. Huge commitment of the parents who were active in a growing number of PSOUU's regional circles and their centres has resulted in many positive changes for students with intellectual disability. The Association's charismatic leader, President Krystyna Mrugalska, has consistently worked towards the defined goals and at the same time has been able to turn many people into allies of the cause. Her work, therefore, deserves immense respect and praise.

President Mrugalska is a role model for us and her attitude is the engine to drive further changes. Personally, I wish to thank her through this paper for shaping me as a special pedagogue.

When discussing the achievements of the Association we must not forget the following activities and dates:

- In 1963, thanks to the involvement of Ewa and Roman Garlicki, parents of a child with Down syndrome, Warsaw's first Special School for Persons with Severe Intellectual Disability was established. In November 2013 we celebrated 50th anniversary of the school and Eunice Kennedy Shriver, the initiator of Special Olympics, became the patron of the Special Schools Complex No. 85 at Elektoralna Street in Warsaw.
- PSOUU was Poland's first organisation to initiate international conferences on various aspects of life of persons with intellectual disability. Participation in the conferences has opened the "window to the world" for the teachers and has been an incentive to introduce changes to Polish schools. The conferences have enabled us to become more independent and organise study trips to other European Countries, which have totally changed the approach of school principals, teachers and also representatives of local governments to education and support for persons with intellectual disability.

A few years ago conferences also helped us find the courage to fight for a different model of education for students with moderate and severe disability, a model that would include:

- more subjects and different subjects,

- different teaching curricula,
  - different organisational model of schools and lessons,
  - separate basic curriculum for primary and secondary schools where students with moderate and severe intellectual disability learn,
  - a basic curriculum for Vocational Preparation Schools for students with moderate, severe and multiple intellectual disability.
- After seeing what PSOUU's local branches were able to achieve over the last 20 years in the Association's Rehabilitation and Education Centres (OREW) in terms of equipment, didactic aids and the applied methods, finally state-run special schools began to change as well. The teachers began to follow the examples and ideas employed at OREW centres, often modifying them and creating their own solutions.
  - In 1997, after many years, we won the struggle for inclusive education for persons with severe intellectual disability. Thanks to the great involvement of PSOUU and President Mrugalska, such persons finally found their space within the public education system. In 1997, a regulation of the Minister of Education was published on the conditions of organisation of revalidation and education classes for students with intellectual disability. The document was further amended (in a positive way) on April 23, 2013. For a period of time, many revalidation and education units existed in schools and kindergartens, offering only 4 hours of care per day. However, currently more and more revalidation and education centres are being created, where children can spend up to 10 hours per day. This has finally enabled many parents to go to work.
  - Thanks to the experience gathered by the Early Intervention Centres run by PSOUU's circles, since 2005 disabled children have been able to receive assistance from Early Development Support Teams for Children established in schools, kindergartens and psychological advisory centres. In 2009, a regulation concerning the organisation of early development support for children was issued by the Ministry of Education. It guarantees free-of-charge professional support and stimulation tailored to the child's psychological and physical capacity to each child who has received a relevant opinion from his or her psychological support centre. The support is also meant for families of children with disability. In the academic year 2013/2014 we already have 29 early development support teams for children. State kindergartens and schools have learnt how to help little children with disabilities from PSOUU's early intervention centres.
  - With PSOUU's immense support during the reforms of education system at the beginning of 21st century we were able to establish Special Schools for Vocational Preparation for the students with moderate or severe intellectual disability who have completed secondary education. Since 2005 such schools have had their separate basic curriculum. It was PSOUU that first started being vocal about supported employment for persons with intellectual disability on the open labour market. The Association initiated a number of conferences with speakers from abroad and has published many publications on the topic. Thanks to EU-financed projects managed by PSOUU and the Association's Vocational Activity Workshops cropping up across the country, persons with

intellectual disability have been introduced to supported employment and we, the teachers, have been able to look at the education at our Vocational Preparation Schools from an entirely new perspective. In the years 2010-2013, five Warsaw-based Vocational Preparation Schools and PSOUU jointly and successfully implemented an EU project entitled "Through Education to Independence: modernising vocational preparation". In September 2013, eight Warsaw-based Vocational Preparation Schools decided to change their mode of teaching of persons with moderate and severe disability and to apply the curriculum developed by the project. Currently I am trying to promote a new, different model of Vocational Preparation for students with moderate, severe and multiple intellectual disability across the country.

- Another important activity that the Association organises and manages is translation and publication of conference papers as well as editing many other publications, including the „Społeczeństwo dla Wszystkich“ (“Society for All”) magazine. The published material is perceived as highly valuable by Polish pedagogues and students. Moreover, numerous easy-to-read publications provide great methodological support.

### **What do we still need to do together?**

It is high time we started, along with other non-governmental organisations and institutions to fight for an integrated cross-departmental and cross-institutional system of support for persons with intellectual disability, from birth until death. We can do so based on the rich body of experience gathered by PSOUU's regional centres which have created excellent lifetime support systems for persons with intellectual disability.

The current system of education, care and assistance unfortunately still does not ensure appropriate development conditions for children, teenagers and adults with intellectual disability.

The most frequently enumerated gaps include:

- lack of a reliable system to inform the parents about the necessity and possibility of comprehensive support for the child and the family, from the moment of disability diagnosis,
- lack of a consistent support offer and standards for disabled children, youth and families in particular regions,
- a narrow scope and low quality of services across the country's regions: the main issue is that the medical model of support for pre-school children still dominates; moreover, the children acquire support from non-medical professionals too late, there are not enough professional teams which could comprehensively define the needs of the children and their families and design appropriate support,
- low accessibility of support, in particular for children from rural locations and small towns,
- lack of monitoring of persons with intellectual disability and their history, lack of consistency and continuity - especially when transgressing from one stage of education to another, and when transgressing from education to adult life,
- lack of assistance and support for kindergarten and school teachers who are supposed to educate children with intellectual disability,

- lack of sufficient cooperation of support institutions which often results in overlapping services, dispersed services or service abuse and misuse. Moreover, the consequence is often that the system makes the lives of families more difficult instead of making them easier by fossilized procedures which are harmful to the child's development (e.g. many different therapies in different locations, parents having to travel with their child to visit professionals, non-coordinated support, chaotic and inconsistent therapy).
- lack of consistent and well-designed social and health care assistance
- lack of a well-designed adulthood path for persons with intellectual disability, including a lack of lifelong learning programmes, few jobs on the open labour market, too few sheltered jobs, lack of training/supported/respite accommodation, lack of insurance system for the group of disabled
- lack of planned support activities for persons with multiple and severe disability and their families

Therefore, it is necessary to organise and integrate support activities for the disabled undertaken by their families and the relevant support institutions. We must strive towards creating a government programme for disabled persons, in particular – for persons with intellectual disability. Moreover, the activities of the Ministries of Social Policy, Health and Education must be integrated.

One year ago, the Warsaw Forum for Initiatives for Persons with Intellectual disability was launched at the initiative of PSOUU's Warsaw Branch. The Forum has so far been joined by 16 NGOs and friends as well as experts from an array of different Warsaw-based institutions. We are currently working on a Warsaw model of lifetime support for persons with intellectual disability: from their birth to death.

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## Life arranging in case of families with a child with intellectual disabilities

### **1. Introduction**

The time when an intellectually disabled child was treated in Poland as a private matter of his or her parents has already passed. I can still remember, how parents asked in various offices and institutions for more kindness for their children and themselves but suffered humiliations instead. 'How can you,' said the official representatives of the Polish society, 'even show such children in public – if they are in such a state, you should keep them at home.' They explained that in that way the parents should be at least able to avoid the shame, and the society's spirits would not be dampened. I remember that whenever I asked journalists working for one of the local TV stations to prepare a film about intellectually disabled people who have been put into care I received the same answer: 'We must not bother the society with such things, it would spoil the optimism, with which we build socialism.' I remember parents from Koło Pomocy Dzieciom Specjalnej Troski (Branch for Support for Children with Special Needs) who participated in meetings held in a basement, which was a dark, dirty, room that smelt faintly of mould. I remember helpless mothers and fathers losing hope of any help for their children. And yet they wanted so little: the right for their children to attend a nursery school and a kindergarten, special school classes for more severely disabled children, jobs in co-operatives for the disabled or sheltered workshops, and enabling them to open a hostel, where their grown-up children could live after their parents' death. And I also remember that when I led a group of more severely disabled youth and we tried to dine in a restaurant, other customers frequently left or we were shown the door by the staff.

The examples above show that it was a time not only of indifference but also of blatant discrimination against families with more severely disabled children. At that time, more than forty years ago, the majority of parents who tried to improve the lives of their children called for social kindness, for help with this difficult family problem. The matter was not considered then in terms of lack of social justice or social solidarity, the values assuming that individuals should not be left alone with very difficult problems and that taking care of severely disabled children is not only their parents' duty. This injustice was twofold. Using I. Prilleltensky and G. Nelson's typology (1997) we may call the first one the distributive injustice. The enormous organizational, financial and informative effort the parents made did not have almost any effect. It was wasted because the institutions that should have helped them blocked the solutions to this difficult social problem. The second type is the procedural inju-

stice – inaccessibility of the institutions that should have helped children with severe intellectual disability. There were no legal regulations that would provide those people with education, rehabilitation, health care and job opportunities. At the time when other social groups – more or less successfully – secured their needs, the efforts of intellectually disabled children lacked sufficient social resonance.

The current situation is different. Families with intellectually disabled children are no longer socially excluded. Should such a family come across a callous official or an incompetent “expert”, it can always count on an NGO helping such families. As S. B. Sarason (1959) once put it: “Organized parents have done more for the happiness of their disabled children and for their families than any professional institution” (p. 5). It does not mean that all what is possible has been done in order to solve the problems and make up for the negligence in that area. In this paper I would like to show a few problems that families with intellectually disabled children need to deal with and which unexpectedly arose when professional care and rehabilitation was developing. I will discuss them within the theoretical framework proposed here since I am convinced that it will both prevent me from growing overly emotional about the matter and help me present the problems in a completely different manner.

## **2. Theoretical Framework for Analyzing the Situation of Families with an Intellectually Disabled Child**

No child with intellectual disability should be alone –it belongs to a family after all. Also, no family with such a child should be alone as it is a part of a society. In order to improve the life of the child we must improve the social situation of the family. This can be achieved only by ensuring social care for people in a difficult life situation (Birenbaum 1971, Weingold, Hormuth 1953). Only then can a family, without the unnecessary emotional losses resulting from a sense of social isolation, care for their own disabled child. It is a crucial factor for at least some more severely disabled people in developing self-care, i.e. actions aiming at improvement of the quality of one’s own life (McGregor 1994). But since I am placing so much importance on care, we should clarify what it really is.

The notion must be considered as significant in the social life because a number of philosophers, sociologists and psychologists have tried to define it. It is advisable therefore that we present here ideas of some of them. M. Heidegger (1994) considers care one of the most fundamental ways in which we can approach our existence. Realization of its finiteness causes fear, which in turn makes one start caring for one’s existence. Care for oneself means here creating oneself, one’s own identity, one’s Self as an antidote for the emptiness of human life. Care in this perspective should be treated, therefore, as a state of mind, which focuses on tackling a situation that is hostile and unacceptable for an individual. Fear of the future is always a source of care and although it will never be thoroughly eliminated, it can at least partially secure us for the times ahead. Other philosophers treat care in a more precise manner. For B. N. Waller (1997) it means voluntarily taking responsibility not only for oneself but also for others. In other words, it is an established duty to do something good for oneself or for others. Care protects us from worrying if something is not happening as intended. However, care must not be perceived as passive suffering because striving to

improve the existing situation is also its part. Care always creates the hope of overcoming one's own or other people's difficulties. The opposite of care is carelessness, which consists in living irresponsibly, not caring for anything and avoiding commitments. For A. Grzegorzczak (1989), in turn, care means kindness: "We care above all for the loved ones. If they are inadequate, we cater for all their needs. [...] We are motivated by kindness when we bestow our care on someone only for their own good, and without comparing their situation with that of other people. Care may also be a result of justice. If a misfortune befell someone, we may wish to level their chances by caring for them even more" (pp. 222-223). Care is understood here as attention for other people who are in a difficult situation. However, the possibly most universal definition of care was given by R. May (1991), who writes: "Care is an ability of people to sympathize, to communicate on deeper levels and to love" (p. 111). What is emphasized in this approach to care is a strong emotional relationship with someone in a difficult situation. Carelessness, in turn, is a lack of consideration for others, indifference towards them; it is caring for one's own independence, freedom and a life that is not restrained by considering other people's needs. Carelessness towards others is caused by a special kind of care for oneself. Based on the definitions of care, we may try to provide the most important characteristics of this notion. In this paper I will assume that:

- a) care is a special state of mind, a sense of responsibility for one's own and other people's lives,
- b) care arises when something bad happens in life or there are signs that something like that may happen,
- c) the course of this process indicates that it may end in a more or less undesirable manner,
- d) the measures taken may lead to the best end possible,
- e) these measures may be aimed at oneself, others (including animals) or their communities (family, local community, nation or the whole of human kind). Caring for oneself will be labelled here as self-care (Kowalik 2005).

A specific social manner of expressing care is governmentality. The term was first introduced to social studies by M. Foucault (2010). The outstanding French philosopher assumed that the entire social life is organized by government by imposing certain legal rules of conduct on members of a given community. The consequence of such governing is, on the one hand, ensuring the survival of the community and, on the other hand, governing the lives of citizens in a manner imposed from the top and not chosen by the citizens themselves. One may assume then that establishing the institutions of social life results from the government's care for the state and its citizens. It does not mean, however, that it also cares for people. Governing the lives of community members consists in a systematic limitation of their sphere of privacy by constantly expanding the extent to which they are supposed to participate in public life.

In this paper I will use M. Foucault's term, but I will give it a completely different meaning. First of all, I distinguish between the process of arranging and the state of arrangement in life. I treat governmentality as a fairly autonomous way of organizing one's surroundings, so that they meet one's expectations to the fullest extent, and consequently satisfy one's needs. We may use a simple example to illustrate this thesis: furnishing the flat in a way one has dreamt it or planned it. Normally, each of us does it differently, because we

have different aesthetical needs, financial means, and some of us have a more precise picture of what they want to achieve. We usually furnish our flat gradually, and perfect it only when the achieved effect does not meet our expectations. In extreme cases we may even change our plans and start everything from scratch. In a similar manner we plan our garden, free time, birthday parties, social circle or workplace. Arranging is then a sequence of actions that should prepare us for the ultimate organization of our lives in the best external conditions possible. By arranging we express our self-care, we simply want to live more comfortably, safely and even more rationally. The effort put into the process is supposed to result later in a greater stability of life and satisfaction from the achievements. It should also secure our future life and make it easier thanks to the lack of constant care.

Arranging the lives of others also results from care. Sympathizing with their problems and difficulties, we try to help others solve them and, more importantly, we help them secure their future. Authentic care is therefore not just a kind of social support. It consists in taking responsibility for another person or a social group. However, this may easily evolve into governing someone in a way described by M. Foucault (2010). We take decisions for other people, control and judge their conduct, introduce serious limitations in their private lives, we impose our own point of view on the way private problems should be tackled. We do all this in conviction that we know better how to arrange the life of another person. We treat our way of arranging life as more rational. By constantly and increasingly arranging another person's life we may easily make this objectified treatment of the person we care for permanent. However, we must not forget about social carelessness towards a serious problem, i.e. resignation from helping a group of people arrange their lives.

Whenever care or self-care appear, the probability of the following increases: a) a positive change of living conditions, b) more stability in life, c) safety from unexpected events that could threaten our efforts put into arranging our lives. Arrangement of one's life is a period of rest after the process of arranging, i.e. the sequence of actions leading to stability. Sometimes it is a time of the ultimate "parting" with care or self-care. More often, however, new events make us re-arrange our life after a period of stability.

Concluding the theoretical part, which can be treated as an introduction before we return to discussing problems of families with intellectually disabled children, I would like to briefly mention two issues. Firstly, we must not forget the possibility of a careless attitude towards oneself and others which causes stagnation, passivity and resignation instead of stability, which in turn helps gain energy necessary to move to the next stage of life (arrangement of life). Needless to say, careless attitude to life is tantamount to a gradual developmental regression. Secondly, care and carelessness are closely connected. Excessive care expressed by other people can weaken self-care and consequently discourage from arranging one's own life. A lack of any care shown by others can also weaken self-care – people feel alone and lose all hope of overcoming difficulties which seem overwhelming.

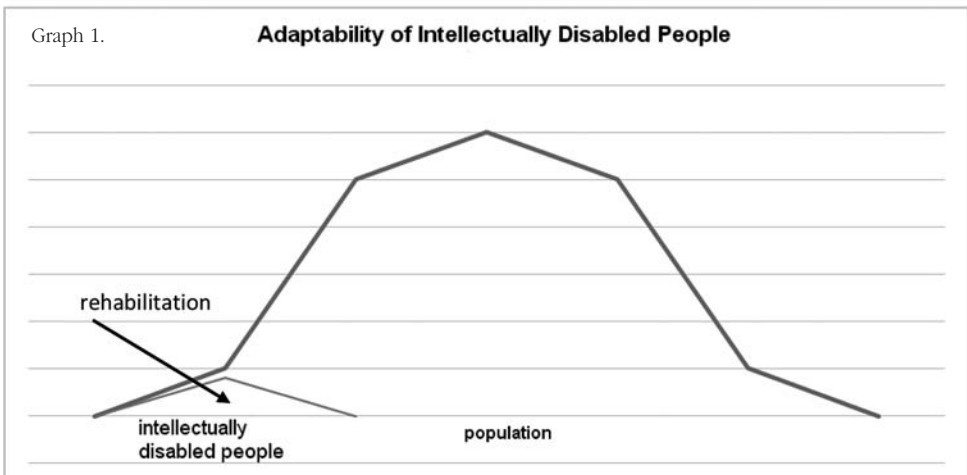
### **3. Between the Process of Arranging and the State of Arrangement in Life of a Family with an Intellectually Disabled Child**

Let me remind the Readers that when the first association of parents with children suffering from moderate and severe intellectual disability was founded in Poland in 1963 it was called *Koło Pomocy Dzieciom Specjalnej Troski* (*Branch for Support for Children with Special*



*Needs*). The name was not chosen at random. The founders wanted to avoid the term “mental retardation”, which already then had a derogatory meaning, so using it in the name of the association could have led to the society disliking the undertaking. Emphasizing the word “needs” in turn, reflected best the parents’ situation and showed their aims when acting as an organized community. In the meantime the association changed its name, which now does not include the word “needs” any longer. However, this does not mean that all problems have been solved. What are then the problems that parents of an intellectually disabled child must face?

In brief, children with intellectual disability are less adaptive than healthy children. It means that when external conditions change, such children is not able to adapt as quickly and successfully to the new challenges (Catania 2013). Lower adaptability consists, among others, in a slower pace of acquiring skills, hindered development of increasingly well organized mental representation of the surroundings, and maybe even in a decreased ability to plan one’s actions, lower sensitivity to changes occurring in the surroundings, and sometimes also in a slower pace of biological development (Ha, Hong, Seltzer, Greenberg 2008; Matson et al. 2010; Szczerbakowa, Szemanow 2010). The fundamental reason for the developmental inhibitions mentioned above are changes in the central nervous system. It means that the adaptability of the disabled children will never improve to an extent which could make their pace of development match that of the healthy ones. This can be illustrated graphically (graph 1).



Since most of human characteristics can be described with the Gaussian curve, we may assume that adaptability is represented in the population in the way shown on the chart. The subpopulation formed by people with intellectual disability is located in its extreme left-hand part. It is discussable whether this curve also reminds the Gaussian curve or looks differently. If we assume that disability is connected with organic brain damage, we may consider the situation shown as real. However, something else is important in this analysis. The location of the intellectually disabled under the Gaussian curve means that due to their adapta-

bility it is impossible for them to participate in social life in the way healthy people do. What is more, people with intellectual disability have special needs and therefore they require special care. Thus, the whole family is in the same area under the Gaussian curve as the disabled child. We may call this area the area of special care. Of course, if the child is in the extreme left-hand side under the Gaussian curve, the involvement of parents in taking care of their child is bigger. If the child is severely disabled, at least one parent needs to focus on his or her needs twenty four hours a day (Faerstein 1981).

I will not describe here all problems parents face as a result of their child's low adaptability as they are well-known. Something different is much more important. Relatively quickly parents have to make a very important decision, namely how they are going to arrange the life of their family in future. Until recently the choice was between putting the child into care, and taking care of him or her directly and getting involved in the child's rehabilitation (Cuskelly 2006). The first option means that the parents resign from any attempts to include the disabled person into a normal social life. The second option, in turn, means that the parents want to try to prepare their child for full integration with the rest of the society by changing his or her position under the Gaussian curve (marked on the graph with an arrow).

The decision is not an easy one and it is frequently postponed. Parents usually do not realize what happened. This time is often described as a period of various life crises (Kowalik 1989). There is the emotional crisis caused by the gap between parents' expectations and the reality of having a child with special needs (which may end in rejecting the child); the emotional crisis that may cause a marriage breakup; we should also mention the financial crisis connected with a sudden deterioration of the financial status (resulting from rehabilitation costs and limiting parents' professional activity). Each of those crises can make parents more anxious not only about their child but also about the whole family (Farber 1968).

It appears that at least at that time the people closest to the family and specialists can play a significant role. Their approach to the disabled child can either deepen the crises mentioned above or encourage parents to secure conditions facilitating complete development of their child (McDermott et al. 1997).

The most important factor determining whether parents will arrange the family life including the disabled child is the hope that they will be able to improve the child's adaptability (Cuskelly 2006). The belief that their efforts and support of various specialists will make further development of the child possible encourages parents to participate in rehabilitation. Of course, this decision depends also on other factors. A.G. Moskavkina, E.V. Palehomova and A.V. Abramowa (2001) emphasize the role of such factors as the co-occurrence of behavioural disorders (stereotypic movement disorder, self-destructive behaviour, problems with communication, poor condition of physical health, atypical appearance). M.M. Burke, M.H. Fisher, R.M. Hodapp (2012) underline in turn that the decisive factor can be the type of disability. Parents who have children with Down Syndrome are more likely to keep the children at home rather than put them into care. However, as the abovementioned authors notice, the decision does not depend only on the characteristic way, in which people with Down Syndrome function, but also on the age, financial situation and the social status of the parents (we must remember that older couples are more likely to have children with Down Syndrome). Research conducted by W.H. Miller and W.C. Keim (1978) indicate other factors important for the decision: optimism, level of depression, education and stability of marriage.

Even after the children reach the school age and enter into adolescence, parents still feel responsible for perfecting their adaptive skills (although various institutions take care of the children). Sometimes they get intensively involved in the rehabilitation and spend significant amounts of money to ensure their children comprehensive help. Broadly speaking, they try to include the children into the institutional system of rehabilitation (special or integrative education, the Special Olympics movement, occupational therapy, health summer camps, and rehabilitation holidays). They still believe that their efforts can get their children out of the unfortunate special care area on the left-hand side under the Gaussian curve. They do not realize, however, that such an arrangement of life is permanent. When I study different rehabilitation systems I often have the impression that it is they that make leaving that area more difficult. It is so despite the effectiveness of the rehabilitation, which contributes to the improvement in the adaptive skills. It can be said that the more severely disabled youth is kept in the “socially unfortunate area” due to superfluous care. People involved in helping intellectually disabled children usually assume that there is always room for improvement as far as preparation for living in the society is concerned. They focus therefore on constant rehabilitation and neglect arranging a new area (in the middle part under the Gaussian curve) that could receive a person with a more severe disability.

Leaving such children at home means that their parents decide to spend the rest of their lives with them. Studies show that such a decision can be beneficial for the child but, as I have already mentioned, is not always good for the family (Boutin et al. 1997). However, recent studies indicate that in some conditions the development of such a family can be beneficial for all its members. Living together under the same roof makes parents gradually grow used to such a situation, which leads to a smaller number of conflicts between spouses, and even a slight improvement in the child’s adaptive skills is a reason for great satisfaction for the parents (Dermott et al. 1997). Grown-up disabled children can also be helpful for their aging parents. They can help with routine everyday activities (preparing meals, doing shopping, tidying), the family can use together social benefits and they can support each other in stressful situations (illness, marriage crisis, death of a loved one). Monica Cuskelly (2006) writes that after the healthy children have left home, the parents together with their disabled child create their own “small, intimate world”. Arranging such a world consists in limiting contacts with other people, taking care of one another and observing the established rhythm of life, which additionally enhances the inner stability of the family. The characteristic feature of this stage of family life is the avoidance of contact with social care and health service. In Australia, for instance, even up to 50% of parents with a more severely disabled child do not seek any outside assistance (Cuskelly 2006). It creates an impression that the families are disappointed with the professional rehabilitation services. Their child has not after all changed his or her position in the social life despite the long-standing efforts. It is not how they imagined his or her life. It may well be that the unfulfilled hopes make them cease doing anything that could improve the adaptive skills of their grown-up offspring. They also give up their own aspirations and enter thus the social area determined by the adaptive skills of their child. After the parents die, the disabled family member is usually put into care.

I realize that my criticism of the rehabilitation of people with intellectual disability can be ill-founded. However, my long professional experience induces me to formulate the follo-

wing supposition: the rehabilitation as it is today is usually about allocating a separate social area where the adaptive skill can be perfected. Even the integrative part of the rehabilitation only seemingly makes it possible for the disabled to move into other social areas. In reality they cannot arrange their lives freely or permanently and the specialists keep control over them demanding full submission in the name of a successful rehabilitation. Paradoxically, the institutional support of the development consists in constantly postponing the moment when one can leave the "miserable" area of special care. The ideological justification for this arrangement/disarrangement (one should say: seeming arrangement) of life of the disabled people is the principle of rationality. According to it, the disabled person and his or her family should submit to the rehabilitation specialists because they are the only people who know what is best for the intellectually disabled (Pusta et al. 2008).

#### **4. Arranging Life by an Intellectually Disabled Person**

Let me emphasize that the two ways in which a family with an intellectually disabled child can arrange their life do not give the disabled person a chance to move beyond the area of special care. Putting the child into care makes the lives of other family members easier. However, the costs of such a decision are serious. The disabled person is in fact forced to spend the rest of his or her life in social isolation. Even if the person receives intensive rehabilitation, its effects will never enable him or her to arrange life in a different way. Leaving the child at home also does not fulfil the initial hopes of the parents. Instead of the child growing self-reliant and finally achieving full autonomy, the parents have to leave their current social area and enter the area of social care. Tightening bonds with the child at the expense of limiting other social contacts excludes the chance of the disabled child to use those relations in order to enter the world of healthy people and settle oneself there permanently. Consequently, a question arises: do the people with a more severe intellectual disability have a chance of building their lives outside the family home or an institution?

The legal regulations have introduced in recent years increasingly successful rehabilitation, and, above all, consistent actions of parents' associations, have increased the probability of people with intellectual disabilities arranging their lives independently (Hayman 1990). The effects of the rehabilitation, consisting in a significant improvement of adaptive skills, should be properly used by moving the person rightwards under the Gaussian curve. A new arrangement of life should lead to a similar autonomy which healthy people enjoy.

Access to the job market for people with moderate (and, possibly, severe) disability is of key importance here. Do not understand me wrong. I do not mean sheltered workshops or even social enterprises, but normal companies, which offer remuneration adequate to the work. Once I personally managed to help fifteen people with moderate intellectual disability find a job. Thirteen of them managed to keep the job until retirement. I would like to emphasize that they had been treated as special care workers only for the first two years. Later, their healthy colleagues stopped considering them different from the rest of the staff. The success of this experiment was the result of a prior preparation of all employees of the company to receive the untypical group of people. The understanding attitude of the management towards production norms and productivity during the first months of their employment was also helpful. The most important, however, was the family. Parents are best at

motivating their sons and daughters to work hard by emphasizing the importance of the money earned and allowing their offspring to decide about the way to spend a part of it, and appreciating their position in the family. A number of publications confirm my experiences (Cytowska 2012; Skibska 2012).

A far more difficult matter is allowing the moderately disabled to marry. The Polish law makes it significantly more difficult for them to arrange their lives in this respect. The Polish society is not ready to accept it either. However, some countries have had some experiences in that area. According to certain studies, some opinions widespread in Poland should be discarded. The following notions turn out to be false: a) children of intellectually disabled parents will also be disabled, b) such couples always have numerous offspring, c) intellectually disabled parents cannot raise children properly, d) such marriages do not last long, e) social pathology (prostitution, alcoholism, domestic violence) is a frequent phenomenon in such families (Bloomfield, Kendall 2010; Espe-Sherwindt, Crable 1993; Tymchuk, Feldman 1991). Intensive research allows us to show a number of factors, which condition the success of marriages or even of parenting. The family of the spouses is of utmost importance here. More precisely, it is the acceptance as well as the emotional and educational support from parents of the people willing to get married that is crucial. The support of appropriate institutions, which need to monitor the situation of the family, also plays a significant role. It is of particular importance when the couple has children (Darbyshire, Kroese 2012).

I also have my personal opinion on this matter. For a number of years I had the opportunity to observe various kinds of couples (two intellectually disabled people, one healthy person and one with a severe disability, one intellectually disabled person and one with a physical disability, homosexual couples). I do not doubt that: a) strong emotional bonds between partners have a very positive influence on the general development of the more severely disabled people – they experience a “fast forward” improvement of their adaptive skills, b) having children is not beneficial since ensuring them proper conditions for development is impossible without grandparents’ help, c) the decision about forming a lasting relationship requires prior consultations with very experienced specialists as well as a thorough preparation for living in a family. I also think that establishing a stable and intimate relationship favours a true arrangement of life, provided that the partners have sufficient funds allowing them to support a family which in practice means having a regular job.

The easiest way to leave the special care area and settle beyond it is involvement in the normal public life. In order to achieve this goal one may use housing, cultural and sport associations or social institutions which are beyond the special care area. The openness of those organizations for new, disabled members is a necessary but insufficient condition to start settling in a natural environment. I am not optimistic enough to believe that good intentions and kindness of healthy people will be sufficient to compensate for the inadequate adaptive skills of the intellectually disabled. Entering such organizations can be effective if the disabled people are accompanied by their parents. It is their task to support their children, who are only beginning the process leading to the maximal autonomy, with their love and knowledge.

So far two organizations have decided to act in the manner indicated, which shows their true care for the intellectually disabled people. Polskie Stowarzyszenie na Rzecz Osób z Upośledzeniem Umysłowym (Polish Association for Persons with Mental Handicap) allows intel-

lectually disabled people to become its members provided that they realize the importance of their membership. Positive effects of this decision are easily noticeable. Numerous disabled members express their needs and seek help in fulfilling them actively and without their parents' assistance. The other organization is Olimpiady Specjalne – Polska (*Special Olympics Poland*) where a reversed phenomenon occurred. The organization of disabled athletes started granting memberships to their parents and volunteers. Thus the organization has managed to get out of the vicious circle of the special care area, it is becoming one of the biggest sport associations in Poland, and its members have a realistic perspective of arranging their lives in their own way.

### 5. Closing remarks

I have tried, within the limits of my possibilities, to show the situation of families with intellectually disabled children. In order to achieve it I have used a few terms that – in my opinion – allow us to depict the problems caused by having a more severely disabled child, and, above all, facilitate orientation in the possible solutions to these problems. The analysis has enabled me also to outline the ways of further improving the support provided to people with severe intellectual disability. Polskie Stowarzyszenie na Rzecz Osób z Upośledzeniem Umysłowym (*Polish Association for Persons with Mental Handicap*) seems to act in the way I am proposing here, but I realize that some experts in this field can be sceptical about my solutions. I obviously lack sufficient empirical arguments to fully substantiate the way of thinking about mental disability which I have proposed in this paper. Moreover, the described concept of co-operation with families who have disabled children is still only an outline. It can be used for the families which understand the care for disabled children as assistance in arranging his or her life in a way that ensures maximal autonomy.

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## Summary of research results

At present, there exist few studies on the role the NGOs play in the process of social change (Delisle, Roberts, Munro, Jones, Gyorkos, 2005). There are no comparative studies on the implementation of solutions that have been worked out, on the activities they run or on introduction of possible modifications. There is no information on the activity of Polish NGOs in comparison with the selected countries. Therefore, the goal set before the planned research project was to close this gap, at least partially, by gathering important information on the impact the movement of parents of persons with intellectual disability exerts on science and society as well as defining the areas where this impact is most significant.

Discussion on the role that the community of parents of persons with intellectual disability plays in initiating social change should begin with the definition of what the relevant social policy is, what its goals are, and with naming the persons who execute these goals. The most comprehensive definition seems to be the one formulated by Kurzynowski (2003), which defines “social policy” as “activities by the State, local authorities and NGOs that shape the general working and living conditions for the society, that aim at establishing social structures that favor progress as well as at establishing social relationships based on equality and social justice so that they facilitate the satisfaction of existing social needs at an attainable level”. This definition encompasses all crucial elements of a social policy, i.e. its role in protecting the living conditions in a broad sense as well as establishing social structures and social relationships that support development. According to this definition, activities undertaken by the State, local authorities and NGOs must aim at attaining the main social goals.

Considering the growing interest in NGOs as well as their input into the process of social integration and the present shape of the whole rehabilitation system, the necessity to analyze how the community of parents of persons with intellectual disability functions in Poland and four selected countries was recognized and acted upon. The area researched under the project encompasses, as has already been said, the diagnostics and analysis of the community of parents’ impact on systemic changes and development of good practices in the field of rehabilitation of persons with intellectual disability. The scope of research under the project also includes definition of existing knowledge about the movement of parents of persons with intellectual disability as a catalyst of changes in both society and science.

Persons with intellectual disability, as well as people with mental disorders, are the most susceptible to discrimination and social exclusion as a group. In many societies, they encounter great difficulties, also when compared to other groups of people with disabilities (Quinn, Degener et al., 2002). The fact that these people do not form a homogenous group is often disregarded. It is therefore necessary to implement policies that respect the diversity and pay special attention to people with complex, multifaceted needs that make them

dependent on their family's and other people's help. This important principle has found its expression in the Madrid Declaration (2002) as well as in the UN Convention on the rights of persons with disabilities (ratified by Poland in 2012, Lithuania and France in 2010, Italy in 2009; not ratified by the USA).

Country	Convention signed	Protocol signed	Convention ratified	Protocol ratified
France	30-3-2007	23-9-2008	18-2-2010	18-2-2010
Lithuania	30-3-2007	30-3-2007	18-8-2010	18-8-2010
Poland	30-3-2007	--	25-9-2012	--
Italy	30-3-2007	30-3-2007	15-5-2009	15-5-2009
USA	30-7-2009	--	--	--

Table 1. Convention and Optional Protocol signature and ratification dates for the countries participating in the project

Source: <http://www.un.org/disabilities/countries.asp?navid=12&pid=166#1>

UN Convention on the rights of persons with disabilities introduces a new, evolving definition of disability into the legal system. According to the Convention, the category of "persons with disabilities" comprises persons who suffer from a long-term impairment in their physical, intellectual or sensory capacity, which might, combined with various other barriers, hinder their full and effective social inclusion on equal footing with others."

Persons with intellectual disability are hardly ever "heard" in the society and, therefore, their needs are often ignored or disregarded when programmes that aim at improving standing of the disabled are being developed (Wapiennik, 2006). In the light of the legal acts in force, public administration organs have specific obligations with regards to implementation of social policies pertaining to persons with disabilities. When characterizing the society in the era of globalization, Zygmunt Bauman wrote about a system that fails to provide security and stability (Bauman, 2000, p. 144-145). When we examine some modern models of the ideal society including its building blocks of market economy, democracy, civil society institutions (Karwińska, 2010) as well as social expectations towards justice, security, equal treatment, acceptance, participation, right to vote, equal access to resources and services (Wnuk – Lipiński, 2004, p. 187), the importance of social integration and re-integration becomes apparent. There can be no doubt that the existence of areas of exclusion poses a real threat to a smooth functioning of the society.

The results of the research conducted show that at present it is the NGOs that secure and safeguard the rights of groups that are not included in the mainstream social order. Evolution of the traditional role played by the State as the key institution that stabilizes the internal social processes and mitigates conflicts might find itself counterbalanced by other options and mechanisms that allow exerting an impact on social coherence by mobilization of various

social actors and resources (Jessop, 1997). The efficiency of a democratic State has been becoming increasingly dependent on the State's ability to initiate and sustain various kinds of policies facilitating integration of different groups and communities as well as attentive listening to groups that have for many years been deprived of their right to speak and be heard (Karwińska, 2010). Therefore, NGOs constitute a significant element of democracy and civil society. Cooperation between public administration and NGOs is defined by, among others, the principle of subsidiarity inscribed in the Constitution, the partnership principle as well as the principle of social and civil dialogue. Such cooperation is not an option but a legal responsibility that public administration and NGOs bear. (see: the Constitution of the Republic of Poland or Public Benefit and Volunteer Work Act, Article 5)

NGOs in the selected countries that took part in the research project provide various services to persons with intellectual disability, i.e. services related to education, welfare and social services. They also fulfill a whole range of functions - among others, economic functions (employment, provision of services, incl. education and welfare, development of innovative solutions in the area, lowering the costs of social support services) as well as social and political functions (impact on public opinion, social integration, initiating social change in the approach towards disability, recommending systemic solutions and supplementing actions undertaken by the State). All experts have put great emphasis on the fact that regardless of the type of services provided, it is crucial that NGOs guarantee the disabled a living standard comparable with the standard enjoyed by the people without disabilities and, therefore, that they respond to claims of social solidarity and perfection (see: Megan Foster, Deborah Taub, Diane Ryndak, this volume). Claims of solidarity and perfection remain a point of reference for the evaluation of the quality of services provided. They also set the direction for future, proposed changes.

According to the experts participating in the research, NGOs frequently replace public administration entities in fulfilling their obligations. The range of services they offer to the persons with intellectual disability is constantly growing: starting with education services, through changes in social attitudes towards the question of disability, legal changes, initiation of social dialogue, organization of employment to advocacy. For example, in the countries participating in the research project, NGOs create licensed recruitment agencies and professional advisory centres and organize professional training courses or job placement services. At present, NGOs also exert significant influence on most legal acts pertaining to persons with intellectual disability. They conduct activities ranging from exerting political pressure, to conducting scientific research that initiates a change in social attitudes towards such persons and leads to introduction of modifications to the systemic solutions and procedures. These activities cannot be regarded simply as services provided to persons with disabilities but must be seen in a broader context as a policy of social inclusion based on the principle of equal rights.

In established democracies, the importance of actions undertaken by the community of parents is not to be underestimated since from the State's and any minority's perspective such actions are often crucial. Research results show that public institutions are not always capable of tackling the problem of social exclusion and marginalization. The third pillar of

democracy, devoted to solving problems of a specific group of individuals and minorities, guarantees social cohesion on a local level and facilitates the creation of a whole range of bonds, links and interactions. In order to create a sense of community and togetherness, it is particularly important to boost the chances for mutual understanding and inspire a real public debate with the participation of self-advocates, a group widely described and recognized by international experts. Involvement of persons with intellectual disability in the decision-making process regarding their daily lives increases their self-confidence. Therefore, involvement and participation remain strategic goals of the communities researched, their actions being based on the following assumptions:

- (a) every person has equal rights when it comes to making decisions regarding their own life, regardless of their intellectual disability;
- (b) every person has an opportunity to actively and meaningfully participate in all of the aspects of social life that would be accessible to them if it wasn't for their intellectual disability (see: the American report, this volume).

The results of our research prove that the movement of parents of persons with intellectual disability impacts the process of de-institutionalization in that the actions undertaken by the community of parents help promote the support model for persons with intellectual disability outside the public institutions. According to Luisa Bosisio Fazzi (report from Italy, this volume): "All associations have stemmed from their founders' desire to question and reject the support and treatment model established in the past as well as implementing a new approach to disabilities based on rights, active participation and non-discrimination". The Authors of the reports have learned from their own experience in working with the institutions that support the disabled that the movement of parents is characterised by its ability to form a coherent political movement, without losing any of its humility and attentiveness to the delicate matter of intellectual disability. Such an approach leaves a lot of space for personal experience and genuine, deeply personal encounters.

The experts participating in the research indicate the movement's role in shaping the "citizenship" of the persons with intellectual disability. It is extremely important to remember that the category of "citizenship" is multi-level. This is best explained by the difference between "being a citizen" and "being a citizen with full capacity". It is also necessary to define the conditions that will have to be met in order to decide about the possibility of inclusion of persons with intellectual disability who do not enjoy full civil rights. Being a citizen with full capacity seems to be possible only through real inclusion and not assimilation. Assimilation is a one-sided process that works under the assumption that the disabled will become full members of a given society, gaining over time more and more resemblance to its other members and sharing the same civil values. In contrast with assimilation, integration works on the assumption that the process of adaptation of the disabled to the society is mutual, as both groups bring their own input into the social change process while keeping their particularities and characteristics. Seen from this perspective, integration redefines both sides of the relationship.

The double nature of the activities by NGOs, whose role is to try to reconcile the questions of management, promotion as well as protection of human rights, has exerted great impact on the disability culture in the researched countries. Thanks to efforts made by

the NGOs over the years, the scientific community and the society in general have ceased to consider persons with intellectual disability only as the impaired i.e. patients to be treated and recipients of medical services (see: article by Anna Firkowska-Mankiewicz and Antonina Ostrowska, this volume). Instead, they have begun to regard them as citizens with their own, individual outlooks and plans for life. Such a change in attitudes has resulted in shifting the focus of the public debate away from the question of caring for the disabled to the question of support that such persons require to lead independent lives, their acquisition of autonomy, and adulthood of the disabled, non-discrimination and social inclusion. There is no doubt that in all the countries participating in the project, the credit for this great success which consists in bringing about the change in attitudes from ignorance to citizenship (see: report from France by Michele Bille, this volume) goes to the movement of parents.

Parents' organisations in Poland, Lithuania, Italy, France and USA first identified and then overcame a whole series of barriers and obstacles on the way to social inclusion of persons with intellectual disability. These obstacles appeared on different levels and ranged from micro-social ones (families of persons with intellectual disability), through mezzo-social ones (institutions, in particular schools as well as medical services and NGOs) to macro-social ones, i.e. the law, social policies, public awareness as well as social attitudes.

According to the experts who took part in the project, the movement of parents responds to the social need and general yearning to belong and be together, which has become particularly strong in the era of advanced globalization. The civil society formula encompasses general principles and values whose absence makes it impossible to create the foundation or the environment required for such a society to develop. In democracies, on individual and group levels, and on local community and global society levels, particular importance is attached to the fundamental principles and values that influence the following elements: the attitudes and social behaviours, the functioning of public institutions, the actions taken by businesses, stimulation of various forms of civil activity, including the NGOs. Their importance is graded according to the nature of the social phenomena and processes in question. These principles and values include, above all, freedom and responsibility, autonomy and partnership, subsidiarity and participation, solidarity and social justice. One of the respondents interviewed by the experts stated that when a voice or an opinion comes from the whole group, it can no longer be ignored. In this context, the movement understood as organisations, groups of representatives, self-advocates etc. gained considerable strength when it began to cooperate and formulate joint demands.

Results of the research conducted within the framework of the project clearly show that the activity of organizations bringing together families of persons with intellectual disability constitute an important element of social development. Aside from the regular activities centred around provision of services, establishment of support centres and other forms of support for the disabled and their families, the organizations actively promote respect for diversity and struggle intensely to widen the "mainstream" and counterbalance the "tyranny of normalcy" present in the modern world (Kristeva, Vanier, 2012). It seems that in order for the organizations, communities and nations to succeed today and continue their legacy far into the future, they must be deeply democratic. This means that each individual and emotion

must be properly considered (Mindell, 2002). Such is the definition of genuine democracy by an internationally recognized psychotherapist, Arnold Mindell. His definition is based on a conviction that all members and parts of the society, as well as all perspectives, are equally valid and valuable. When it comes to social groups, every voice should be heard, regardless of the presented position: opinions need to be acknowledged in some way. This is not an easy process as it requires great involvement, attentiveness and openness. We are used to the democratic force that rests with the majority. However, the problem with the majority rule is that it may lead to many kinds of abuse, often inadvertent. Conflicts often arise as a result of frustration resulting from not being heard and acknowledged. The communities of parents in the selected countries are developing social awareness and contributing to a vision of the future that facilitates openness to all the people who are making an effort to be acknowledged. Genuine democracy makes it possible to steer away from the rule of majority for the sake of free expression of needs by various groups, thus providing space for every individual to express themselves and become a party to a real dialogue.

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