

Children with Disabilities as Citizens or From Charity Towards Citizenship and Human Rights¹

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Children with Disabilities as Citizens or From Charity Towards Citizenship and Human Rights³. Article encourages research and new-fashioned projects focused on wider living conditions of children and young people with disabilities based on their human rights and promotes exchange of experience and good practices in this field. To stress importance of the mentioned effort author analyses selected facts about living conditions of children with disabilities. She develops psychology-based polemic to premises about special needs of children and young people with disabilities, and presents the demands-based approach to human needs based on social-right model of disability.

Second part of the study pays attention to situation in Slovakia – incidence of disability among children and some structural features of the Slovak disability research with emphasizing the research work focused on the field of education.

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Instead of introduction...

In our research carried out in 1999 we asked adult respondents with disabilities and the non-disabled to write their original first-time associations on term „disability“. A mother of a little girl with disability specified her association: „...*little belfry, Christine, excellent human being, interesting...*“. (Repková, K., 1999) Not all associations and facts relating to children and young people with disabilities are so positive and satisfied. G. Lansdown (2001, p. 4) announced that to have disability in child age means „... to cease to be valued as equal to other children; to be widely disregarded as both capable of, and needing love, affection, humour, friendship, cultural and artistic expression and intellectual stimulus; it means to be segregated, marginalized and isolated... The process dehumanises children and society...“. On the other hand author claims that „...the 21st century provides an unprecedented opportunity to bring about change“.

1. Some facts about children with disabilities

There is disunity concerning the disability incidence amongst children. That situation goes out from numerous and conflicting definitions of disability and from that fact goes out disunity about disability incidence amongst population in general. World Health Organization or World Bank present that about 10% (600

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million) of entire worldwide population is affected by the presence of disabilities. UNICEF estimates that 120 million of this number are children. G. Lansdown in a Report on the lives of disabled children worked out for the UN General Assembly, Special Session on Children (New York, 2001) offers some summarized facts concerning the lives of children with disabilities:

- There are up to 150 million disabled children globally.
- The numbers are rising.
- Disabled children are disproportionately likely to live in poverty.
- There are four times more likely by disabled children to be neglected and physically abused and over three times likely to be emotionally abused.
- The lives of disabled children are not treated as of equal value with others. Parents and medical professionals who murder disabled children often have reduced sentences and use mercy killing defences.
- In some countries 90% of disabled children will not survive beyond the age of 20.
- Only 20% disabled children across the developing world have access to education.
- Discrimination in relation to life saving treatments, to health care, to childcare services and education is endemic.
- Access to justice is routinely denied because disabled children are not considered credible witnesses.

(Lansdown, G., 2001, p.10)

Above mentioned statistics is supported by DAA's Human Rights Violation Database, according which 17% of all violations are against disabled children, but these children represent only 4% of the violated population with disabilities. All mentioned facts lead to acknowledgement that children with disabilities belong to the most vulnerable groups and need a support and legal protection based not on charity but rather than on their human and social rights rather on a charity.

2. Do have children with disabilities special needs?

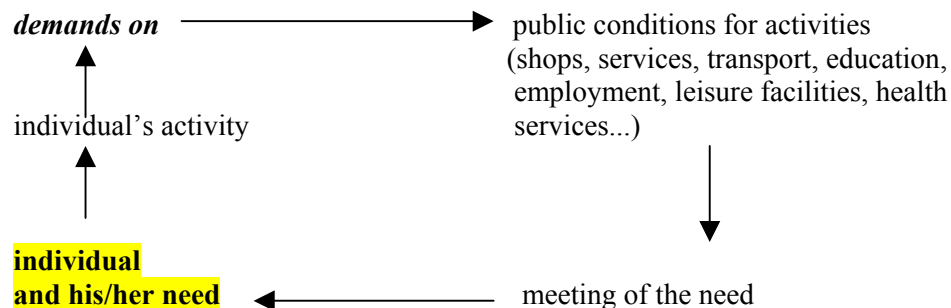
Understanding of human needs substance could be recognized as an essential point for implementation of human rights approach towards people with disabilities. There are more ways (definitions) how to describe situation when somebody has functional impairment and disability. One out of the newest approaches goes out from premise about *special needs of people/children with disabilities* and them being referred to as *people/children with special needs*. At different places (e.g. Repková, K., 1999; Repková, K. – Požár, L. – Šoltés, L., 2003) we have been coming with polemic to this premise going out from the psychological theory of human needs and motivation. In the modern motivation theory, a „need“ is specified as a “particular situation in organism empowering

individual's behaviour to meet his/her need". (Coon, D., 1989, p. 293) Even M. Nakonečný (1998) emphasises in his definition a "human need" as a situation of imbalance (caused by absence or over-supply), which leads individual to bring the situation away. So, it becomes a motive for his/her behaviour. That means, just through understanding of human needs we can analyse and understand a motivation of individual's behaviour.

There are many classifications of human needs in psychology. Common principle for all of them is *universality of human needs*, what means that all people have in principle the same needs. They need to love, to be loved, to belong somewhere, to have satisfied their basic needs (food, water, sexual needs), they need cultural and artistic expression, intellectual and developmental stimulus. People are different, individualized not according to substance of their needs rather than according to an internal hierarchy and structure of their needs. With respect to the above mentioned there is no valid ground to understand needs of people with disabilities like „special“ ones.

The human needs are the ground for establishing and implementation of different public policies and legal provisions intended to meeting them. It could be pointed that human history is a history of seeking for and improving of ways how to meet and further develop human needs. Dialectic of human needs and demands in various public systems is illustrated in a Figure 1.

Figure 1: **The Demands – based approach to human needs**
(according Repková, K., 1999)



The *rights model of disability* goes out from premise that needs of all people are equal valued and important and there is no valid reason to exclude needs of some people (e.g. people with disabilities) from public awareness and interest to establish various systems accessible for all. On the other hand, in relating to people/children with disabilities, there exists a reason to consider their „specification/particularity“. This is related not to their needs rather than to

demands on public systems established to meet their human needs. (Lacan, J., In: Salecl, R., 1997; Repková, K., 1999)

In frame of the demands-based approach to human needs is the term „need“ considered not as a psychological category serving to describe individual's motivation to behaviour, to action, to activity. In that concept is need meant as a public social-political category serving to describe a commitment of society, its governmental and non-governmental structures, to create living conditions accessible for all based on their equally valued human rights. The demands-based approach is valid and suitable ground for a combination of *equal treatment strategy* (solutions built on universal design for all) with provisions based on *preferential treatment* (special support for people/children with disabilities to utilize general solutions).

Links between “needs” in the psychological and in the social-political perspective (due to above mentioned we prefer the term “demand”) can be observed in various important social-political documents or in approaches of various experts from psychology or sociology or from others social science fields. V. Dočkal (2004, p. 142) applied in his work a concept of the “special educational needs”. Author defines special educational needs of child as “demands (requirements) on special adaptation of conditions, organization and implementation of educational process to correspond with particular features of a pupil with physical, psychical or social development that is clearly different from a standard one”. As an essential point in the Dočkal's approach might be taken his broader understanding of children with special educational needs. Such “group” involves not only children with disabilities or chronic health conditions, but children coming from unfavourable social environment as well as high talented pupils.

Above-mentioned links between needs and demands on public services, correspond even with American Pediatrician Academy's approach to definition of children with disabilities. These children are characterized as children with special health care needs who “...have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”. (Who, 2001) The UN Convention on the Rights of the Child (1989) operates in Article 23 with „...recognizing the special needs of a disabled child...“, aimed to ensure assistance extended in accordance with Article 2 regulating rights of children irrespective of disability. The „particularity“ of the needs of children with disabilities does not mean they have special, different needs in comparison to their non-disabled peers rather than they need an effective support to develop their potential, ambitions and desires in all life spheres (education, family life, preparation for employment, leisure time, cultural and spiritual development).

Even one of the latest documents of European Commission "The social situation in the European Union/Overview 2004" operates with the denotation "disability: policy for people with special needs". Present EU-approach is based on a refusing of separate categories of people, but instead of that is based on individual needs. That implies a general shift from disability-specific programs towards a mainstreaming approach. (Equal, 2003)

Summary, with respect to above mentioned, the approach based on special needs of people/children with disabilities in a sense, which leads to special separated solution far from ordinary daily living circumstances, situations, human relations and social roles could damage their and our common real interests and restrict implementation of the approach based on human rights and equal valued human needs of all.

3. General principles in approach to rights of children with disabilities

A holistic framework of comprehensive and binding principles to establish children as subjects of rights is set forth in *The UN Convention on the Rights of the Child* (1989). According to G. Landsdown (2001) there are four general principles of the Convention which underpin all other rights:

- *Article 2: All the rights in Convention apply to all children without discrimination, including on ground of disability*

Applying of the non-discrimination principle does not prohibit legitimate differentiation between children; e.g. children with disabilities very often need additional educational assistance or facilities to help them fulfil their potential; on the other hand it does not allow to offer them lesser education simply because of their disability. On the principle of combination of equal treatment and preferential treatment/provisions is organized whole disability policy of Council of Europe and European Commission.

- *Article 3: In all actions concerning children, their best interests must be a primary consideration*

This principle applies to actions affecting both – individual children as well as children as a group. The principle means always to look for a solution with long-term positive impact on a child with disability. G. Lansdown (2001) presents situation, when decisions of parents and other adults affecting children with disabilities have contrary impact on them, mainly system of segregated education based on „special“ needs of children with disabilities. D. Werner (2004, p. 7) mentioned that „the reality of education for disabled children is that it is considered a „special needs“ rather than a right. Those disabled children who do have access to educational opportunities are often forced in to segregated schools

away from their families and friends, with no opportunity to interact with non-disabled peers“.

- *Article 6: The right to live, survival and development*

In accordance with the article children with disability alike non-disabled children have the equal right to the maximal support in their life to promote the fulfilment of their potential and the quality of their life. Records from DAA's Human Rights Violation Database show that 99% of cases affecting disabled children are against their protection from cruel, inhumane and degrading treatment and other cases of human rights violations include just areas of the right to life, right to education, right to privacy and family life. (Light, R., 2002; Werner, D., 2004)

- *Article 12: The right to be listened to and taken seriously*

All children, including children with disabilities, have the right to express their views on all matters of concern to them and to have those views taken seriously in accordance with their age and maturity. C. Bellamy (1996) expresses the view that applying of the mentioned approach is prevented by traditional perception of children, generally. In 19th century that was perception of the "innocent and sacred" child, after that period came so called „emergency-humanitarian approach to suffering child“ with its dominant goal to save children's lives and protect them against hunger, disease and other immediate suffering. Third approach is being described like a "developmental" one: children ought to be allowed to grow to their full potential both physically and emotionally. Children thereby would become, as adults, more mature, useful and "effective" citizens. Last one typical for over the last decade described C. Bellamy like a "combination of survival and developmental" approach to children. Thanks to available technologies and other means of development should be put maximum efforts to support children living in "silent" emergencies caused by poverty, disease and a hazardous environment. According to C. Bellamy all above mentioned perceptions have a tendency to put children in isolation, not to see them being embedded into society.

Empowerment of children status in society and exercising of their right to be listened to and taken seriously is, in accordance with C. Bellamy (1996, p. 15), always complicated by the question of parental rights and responsibilities. Therefore, the efforts of law-makers have been concentrated on finding the proper balance between the rights and responsibilities of parents, on the one hand, the rights and responsibilities of children, on the other hand, and the special obligation of the state to protect the children“. This matter have a very strong impact on design of various surveys or research projects concerning living conditions of children with disabilities, which is a main topic of the following part of this article.

4. Children with disabilities in research – some general points

At different places and in various occasions have specialists pointed out that it is difficult to gather accurate information and data about children with disabilities. At the same time valid, comprehensive statistics, access to information and data might be understood as a crucial point for research work. Several aspects contribute to such situation:

- *disunity in criteria to define a disability (disability as a legal construct)*

A critical point is related mostly to different purposes/approaches to what is the notion of “disability” applied for. Different purposes create different criteria for definitions, which leads to different incidence of disability. (Disability, 2003), at both, national and international level. O. Quintin (2003) mentioned there were only a few countries that explicitly have a standard term for disability in the sense of general, comprehensive description. According to D. Mont (2004, p. 5) “disability is multi-faceted, complex, and difficult to define”. Moreover, non-disabled people produced most of definitions of disability for the purposes to create statistics basis on cost effectiveness of service provisions rather than an attempt to address the barriers to inclusion and humanity. (Definitions, 2004)

- *imbalance in subject orientation of research*

Much of the research work has been done about the lives of disabled children focused on impairment issues, rehabilitation and health. There has been very little work done about daily lives of children with disabilities, their participation in communities. (Werner, D., 2004) This tendency has a direct connection to medical model of disability based on medical view on people with disabilities, their lives generally and reasons of their living troubles particularly. People with disabilities themselves started to realize that the traditional focus on impairment, rehabilitation and “special” services has been a fundamental cause of the segregation in institutions and in inaccessible homes and communities. (Definitions, 2004) Our research carried out in 1999 confirmed the mentioned tendency in public awareness. Adult respondents (with disabilities as well as non-disabled) discovered their first-time associations on term “disability”. Most, 38% of all individual associations had been related to health and individual-impairment matter (e.g. individual’s body, health conditions, health system, health services, compensatory aids). Other categories (e.g. handicaps, individual’s feeling, social relations, assistance) were represented in incomparable lower rate. In the research carried out by Páleník, L., Učėň, I. (2003) roughly 70% of basic schools pupils related the term “child with disability/disabled child” to “physically disabled child” what confirms a dominant orientation in the disability field on body aspect, particularly problems with moving.

- *unbalance in stakeholders' involvement in research*

Less research work has been organized to listen to what children with disabilities, themselves, have to say about their lives. (Werner, D., 2004) This situation goes out from general perception of childhood and children, moreover keeping children with disabilities traditionally in double patronizing status. According to G. Lansdown (2001) children with disabilities suffer a double jeopardy. Not only making them invisible, but even when action has been taken by relevant institution to highlight the issue of disability, it has generally been taken from the perspective of adults, not children. That is reflected by C. Bellamy (1996, p. 10) like a strong barrier towards a new vision of the child, when a child (regardless if disabled or non-disabled) is perceived “... not as a mini-adult or as a minor, but rather as a developing human being, endowed with all rights from the beginning, and growing to contribute to society”.

- *youth with disabilities in a “gap”*

According to N. E. Groce (2003), globally almost 180 million young people between the ages of 10-24 live with a physical, sensory, intellectual or mental health disabilities making their lives significantly different. There is no valid basis to expect that young people with disabilities do have some different needs in comparison to their non-disabled peers. On the other hand, their living situation is different mainly because of their being pushed to stay in the patronizing parental or residential relations schemes in contrast to non-disabled young people. N. E. Groce (2003, p. 12) notes that “a fundamental reason for this is that people with disabilities are often seen as being “childlike”. Programs concerning disability issues (particularly concerning disabled children) are aimed on family issues, educations and socialization, by adult disabled people on employment, housing and community integration. Unfortunately, adolescents and young people with disability are not “fit” for both, therefore they are frequently excluded from majority of community and research initiatives.

The Case of Slovakia

5. Incidence of children with disabilities in Slovakia

In the Slovak Republic live approximately 5.4 million residents. One fourth of them are children aged between 0-19 years of age. This share is continuously decreasing. For example in 1999 lived in Slovakia 28,1% of children in above mentioned age category, in 2003 it was only 25,5%. (Filadelfiová, J., 2004) Currently, we do not have general valid statistics concerning incidence of children with disabilities in Slovakia because of a non-existing common definition of disability. Rather we have more explanations/definitions developed in different

areas – health, social and educational fields – based upon a definition of disability as a legal construct. The definitions are summarized in the Table 1.

Table 1: “Child with disability” – a legal construct

Legal term	Legal purpose	Incidence
Child in the particular health care of medical specialists (health insurance system)	Children with deviations in their health conditions (mostly developmentally caused and likely developmentally corrected) in care of medical specialists. Only some of them need any particular social and educational interventions and they are recognized as children with severe disabilities	by 28% of entire child population, by 4% out of that with disabilities***
Child with unfavourable health conditions (system of family social state support)	Providing of parental allowance to parents caring about their children aged from 3-6 years with disabilities	No precise evidence
Citizen / including child with severe disability (system of social assistance)	Certification of person with severe disability; providing of various cash benefits or social services for citizens, including children with severe disabilities, to overcome negative social consequences due their severe disabilities in mobility, transport, communication, increased living costs and assistance-need areas.	Evidence based on: - certification as a person with severe disability (May 2005 – by 17 000 children holders, 1,5% of entire population aged from 5-19) - figure of benefits users aged from 0-17 (March 2004: by 3 600 users, March 2005: by 6 700 users, 0,6% of entire population aged from 5-19)*
Child/pupil with special educational needs (system of education)	Education of children with disabilities (in educational law as a pupil with mental, hearing, visual or physical disability, pupil with poor health conditions, with autism, with developmental learning difficulties) appropriate to their individual abilities and by methods relevant to their impairments.	Evidence based on arrangement of education (individual integration in mainstreaming school; special classes into mainstreaming schools; special schools (more further) by 4% of entire child population aged from 5-19**

Sources: * Statistics of The Central Office of Labour, Social Affairs and Family (2003, 2004)

** Statistics of The Institute of Information and Prognoses in Educational Affairs (2004)

*** Statistics of The Institute of Health Information and Statistics (2003)

6. Research on living conditions of children with disabilities

Generally we could state that in Slovakia the research is mainly focused on living conditions and human rights of children. Centre for Work and Family Studies regularly prepares a monitoring on how are in Slovakia exercised human rights of children and youth in accordance to the UN Convention on the Rights of the Child and to another international documents concerning of children's rights (last one was prepared by Bodnárová, B. – Filadelfiová, J. in July 2004). Another situation is in a research area concerning human rights and living conditions of

children and young people with disabilities. In the next part of this paper we try to characterize main features of previous and present situation in Slovakia concerning research in child-disability area.

6. 1. “Disability - blindness” of a child - focused research

The Slovak Republic ratified the UN Convention on the Rights of the Child in 1991. Since then a monitoring concerning the protection and exercise of children and youth's human rights has been regularly prepared. Research carried out in the previous phase had been aimed on different topics: demographical development in Slovakia; economical and social situation of families with small children, impact of unfavourable economical situation of families on meeting of children's developmental needs; awareness and acknowledgement of children's rights (by parents and children themselves); involvement of children and youth by governance of public affairs; children brought up out of a family and so on (more in Bodnárová, B. – Filadelfiová, J., 2004). Unfortunately, none from the above mentioned research has been disability-mainstreamed. Child as an “object” of the above-mentioned research has been considered as ability-neutral. Issues concerning disability in the child's life have not been included, which contradicts the disability-mainstreaming paradigm.

6. 2. Preference of pupil status (living position)

Our experience corresponds with N. E. Groce (2003) who notes that the programs and advocacy for children with disabilities are usually focused on family, education and socialization issues. We recognize a meeting of educational needs of all children, including children with disabilities, as their basic human and developmental right and as a basic topic for their citizenship and future welfare. On the other hand, we have to admit that in Slovakia is the research concerning the living conditions of children with disabilities mostly focused (we could say reduced) on their school, educational and pupil status. Research projects focused on other aspects of their lives (e.g. family life, leisure, emancipation, sexual development, friendships) are rather very rare.

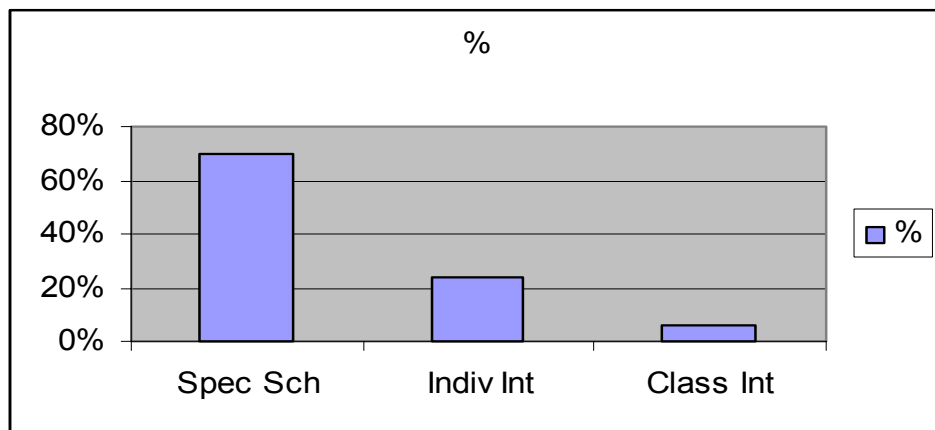
The Research Institute of Child Psychology and Pathological Psychology has carried out for a longer period several research projects concerned with integrative, mainstreamed education of pupils with disabilities and their non-disabled peers. According to current legal situation exist in Slovakia three following schemes (arrangements) of children with disabilities education:

1. education in special schools
2. individual integration in mainstreamed schools (individuals with disabilities attend a mainstreamed school and are educated according curriculum common for all pupils/students)

3. integrated classrooms in mainstreamed schools (individuals mostly with intellectual disabilities attend “special classes” involved into structure of mainstreamed schools and they are educated according individual curriculum).

The following Graph 1 illustrates current situation in education of children with disabilities in above-mentioned schemes in Slovakia how it has been developed during 15 years of effort to support the new-fashioned arrangement of children and young people with disabilities education.

Graph1: Arrangements of children with disabilities education in Slovakia (situation to September 2004*)



Legend: Spec Sch – special schools
Indiv Int – individual integration
Class Int – integrated classes

*Source: Statistics of The Institute of Information and Prognoses in Educational Affairs (2004)

From the graph is clear that in Slovakia, in spite of developed effort, are being currently children and young people with disabilities (meant children of preschool facilities, basic schools and secondary schools) educated mostly in “special” arrangement (70%) – schools specialized for children with different type of disabilities (physical, visual, hearing, mental).

Various international sources give evidence that among disabled people’s movements there is not an accord in attitudes to and support for the important role of inclusive education (e.g. Disabled, 2004). Even in Slovakian research findings in this area are not unified. Specialists (mostly psychologists) from The Research Institute of Child Psychology and Pathological Psychology in their research projects and discussions have been trying to explain advantages and disadvantages of both of the above-mentioned educational arrangements. Based on their

experience and research findings we can give some selected summarized information on actual situation in Slovakia (chosen from Učeň, I., 2002a; 2002b; Bronišová, S. – Učeň, I., 2002; Páleník, Ľ. – Učeň, I., 2003; 2004; Dočkal, V., 2004; Zborťeková, K., 2004).

Legal and organizational conditions for inclusive education:

- a legal framework for school integration of children with disabilities is actually finished (prepared),
- according to teachers’ view, the critical point of integrative approach is an insufficient financial and material arrangement of schools,
- according to psychologists' view, the critical point of integrative approach is an insufficient teachers' preparation for educational work with children with disabilities,
- daily-living process of integrative education is complicated by the lack of individual educational plans for pupils with disabilities,
- initial enthusiasm of teachers to integrative approach (according to the research from beginning of 1990s) is in these days away. Presently more than a half of them perceive an integrative approach as a burden due to unsuitable conditions for this approach,
- successful integration (inclusion) requires professional cooperation with school psychologists or special pedagogues. Unfortunately, presently only one fifth of basic schools with integrative arrangement cooperate with those specialists or facilities.

Semantic associations on term “child with disability”:

- 70% of semantic associations of non-disabled pupils on notion of “child with disability” are related to physical (body) side,
- there are differences between semantic associations on term “child with disability” by adults and non-disabled children. Adults have presented more associations related to physical features, while children associated the term more with intellectual qualities.

Attitudes to inclusive education:

- non-disabled pupils are more radical to pupils with disabilities in the situations, in which they have no experience with integration,
- children with disabilities belong in a class environment among the “overlooked”,
- pupils with higher social status (so called “class-stars”) used to refuse inclusive education and negatively assess its benefits,
- pupils of the basic schools often disagree, in comparison to their parents, with inclusive education of peers with physical disabilities,

- teachers of the basic schools more frequently disagree with inclusive education of pupils with mental (intellectual) disabilities and visual and hearing disabilities.

Gender-based differences:

- non-disabled girls are more protectively directed towards schoolmates with disabilities and they assess integration more positively than non-disabled boys,
- non-disabled boys with a higher social status in classroom more often refuse an inclusive education in common class,
- boys with disabilities with a higher social status do not perceive as being correct to educate disabled and non-disabled pupils in the common class,
- non-disabled boys prefer a cognitive substance of integration (general mentioned benefit for children with disabilities), non-disabled girls prefer general ethical values.

Some challenges for future research:

- from one-side integrative approach towards both-side inclusive approach (up to the present time had been approach based on a one-side acceptance of non-disabled population (pupils, their parents, and teachers) with “entering” of children with disabilities into “non-disabled” educational environment. It is inevitable to understand a pupil with disability as a “starting-point (inclusive) feature” of educational arrangement. The mentioned request and approach should be applied even in a whole research conception in form of higher involvement of children with disabilities and their parents into research projects),
- inclusive school environment and education in the preparing for life (findings of research projects have confirmed common value of inclusive education in minds of various types of respondents (pupils, teachers, parents): inclusive education is very important to promote abilities of all children for creative approach to daily living situations, activities and tasks. The above-mentioned conclusion should be a basis argument to opponents of inclusive education),
- there is a lack of studies concerning gender-based differences in attitudes to inclusive education according to different sociometric parameters.

The situation in a meeting of educational needs of children with disabilities had been searched even in monitoring of implementation of the UN – Standard rules on equal opportunities for people with disabilities in Slovakia. (Pavliková, E. – Kondášová, A., 2000) The educational area monitored by adult respondents' perception belonged to relatively well satisfied (34% of respondents expressed

positive assessment) in comparison, for example, to employment area, accessibility of public buildings or places and ensuring of an adequate income.

6. 3. Wider living conditions of children with disabilities

The situation of families with disabled children in Slovakia has been researched in framework of various projects. (e.g. Šuterová, V., 1992; Prevendárová, J., 1998) The finding indicated that these families have been in higher risk due to:

- child disability-related increased costs (mainly for transport, nutrition and dressing),
- disadvantaged work status of disabled children's parents on labour market,
- increasing of a “passive” income (income based on social benefits) in comparison to an “active” income (income based on employment),
- preference of cash benefits by parents instead of social services helping them by caring about child and supporting their active lives and citizenship (own job, leisure).

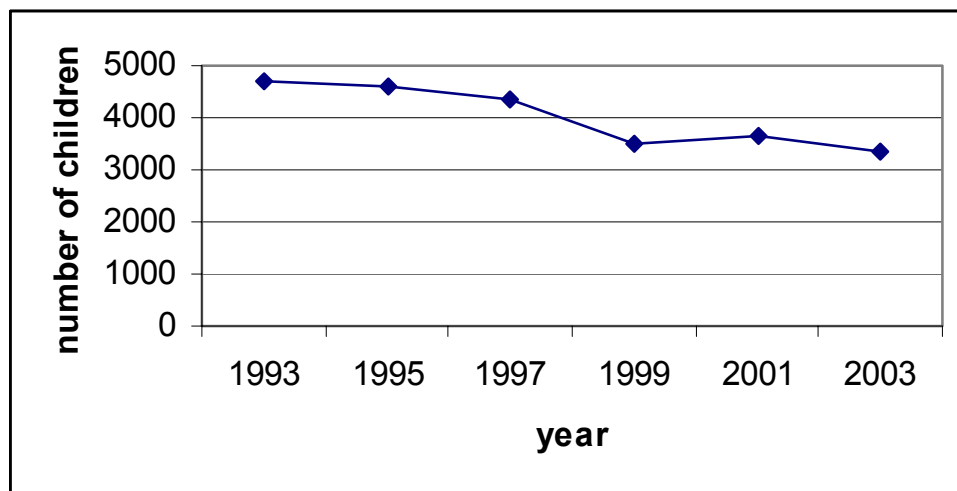
Unfortunately, other research projects have not been precisely focused on the living situation of children with disabilities. The works have been operating with “citizens” with disabilities, mostly understood as adult people with disabilities. In spite of that, these research projects indicated very similar findings in comparison to previous ones. Ten years after Šuterová's analysis monitored E. Pavliková, A. Kondášová (2000, 2001) an exercising of The UN Standard rules in Slovakia and social-economical situation of families with disabled member. Respondents of mentioned surveys were adult people with severe disabilities and their family members caring about them. As a most problematic were identified three following areas: unsatisfied financial situation of families with respect to disability-related increased living costs, transport with members with disabilities and technical devices helping them moving and self-service as independent as possible.

Since the 1990s Slovakia has adopted more legal provisions focused on improving of the situation in families with disabled member/-s to enable them to stay in family setting with suitable social support as their social right. The effort has been manifested in a gradual decreasing of a long-term residential child-care (about children and young people with physical, combined physical and mental disabilities). Developmental trend in the long-term residential childcare illustrates graph 2.

The gradual decreasing of the long-term residential child care out of the family and community (not as fast as we would wish) is being possible only thanks to the maximal support of children in their natural family setting. In 1999 came in Slovakia into a force a new system of social assistance for people in need,

including people/children with severe disabilities. The system is focused on *compensation of social consequences related to severe disability* (physical, visual, hearing, mental, developmental disabilities or chronic health conditions) in various living areas, as following: mobility and transport (moving in and accessibility of housing, mobility and transport outside), communication and orientation, different types of increased costs (e.g. nutrition or dressing, care about special trained dog, operating of personal car) and finally, support by need of personal care. All instruments (direct payments or social services) can be even affordable by children and young people with disabilities.

Graph2: Long-term residential care for children with disabilities in Slovakia



Source: Základné ukazovatele z oblasti sociálneho zabezpečenia vo vývojových radoch 1957-2001. Ministerstvo práce, sociálnych vecí a rodiny SR, 2002 (Basic developmental indicators in social security areas 1957-2001, Ministry of Labour, Social Affairs and Family, 2002)

6. 4. Lack of children's reflection and participation

We have above admitted that in Slovakia had been in previous time done not much in a research work concerning living conditions of children and young people with disabilities. This situation had strong impact on their involvement into research projects as active respondents. Practically during the period of last 10 years we have not carried out research about wider living conditions of children and young people with disabilities aimed at the reflection of their own living situation. Some research projects involving them in the active respondent's role had been related to educational setting and affairs. In the case of the wider living conditions research projects, the adults had been usually recruited as respondents

(medical doctors, teachers, parents, other adult relatives or adult caregivers, personal assistants).

6. 5. Lack of cooperation

Finally, I would like to remind an importance of cooperative approach of various public legal and unofficial authorities and stakeholders to support disabled children's welfare. Until 1999 existed in Slovakia a system of so called "the coordinated care about children and young people with disabilities". That presented a platform for coordination of supported provisions aimed at children in higher health risk and their families in health, educational and social field. After that period the system had been cancelled and up to now has not been established any further. Therefore the newest development in Slovakia clearly points out to the need to establish some legal point coordinating all measures affecting children and young people, particularly children and young people in higher risk, among whom stand out particularly children and young people with disabilities.

7. Support of children's with disabilities autonomy – a good practice from Slovakia

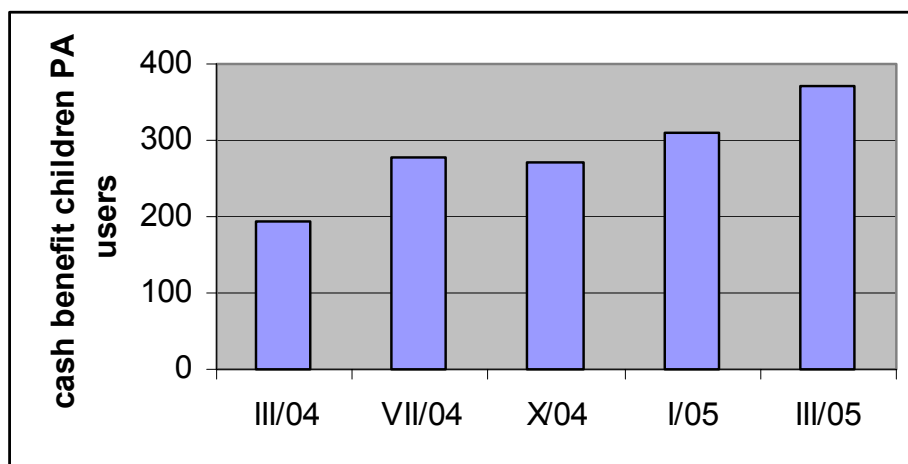
Since July 1999 Slovakia employed a new legal system of social assistance for people with disabilities. In framework of the system has been working a *personal assistance* focused on support of social inclusion of people with severe disabilities thanks to assistance provided for them by various daily living activities. The main goal is to encourage, as much as possible, self-determination /independency (more in psychological meaning, Repková, K., 2004) of individuals with severe disabilities in their daily lives, to recognize their right to make decisions in matters affecting them. That is reachable by a self-management of the whole personal assistance system carried out by individual with disability:

- he/she is choosing personal assistant/-s according of his/her own criterions,
- he/she is making contract with personal assistant/-s according to necessary assistance demand,
- he/she makes decision about a place, demand, form and time of provided assistance (tailored-made and individual-oriented service),
- personal assistants are not primarily people recruited from he/she with disability's relatives in the intention to support independency (oft emotionally based) on them (that is one of the most important difference from the traditional care system based on care work provided by relatives),
- he/she with severe disability can receive from social office monthly a cash benefit (personal assistance budget) to cover costs related to performed personal assistance,

- based on the cash benefit and subscribed contract he/she rewards the personal assistant/-s (personal assistance as a service paid by client in a role of a consumer, not traditional social service paid by institution and “given” to client based on the principle “about client – without client”).

In comparison to other states in Europe, Slovak legal provisions accept only that individualized personal assistance budget as legitimate, which is provided for adult people with disabilities and children with disabilities above 6 years of age. Additionally, more legal performances related to personal assistance system must be made on behalf of the age-dependent children by their parents. In spite of that, first experience on individual level have shown that this arrangement of assistance is much effective to support developing of independency and autonomy of children with severe disabilities. Increase in the number of children with severe disabilities – as personal assistance users in the course March 2004 – March 2005 is illustrated in the Graph 2.

Graph 2: **Children users of cash benefit for personal assistance – development in the course of March 2004 - March 2005***



* we have not been able to use statistical data from earlier period because of non-existing age-related data

In spite of the above mentioned positive development the families with severe disabled children in Slovakia stably more prefer a traditional form of care (care provided by parents or other adult relatives) rather than new-fashioned one (personal assistance provided by the “foreign” adult).

When we come back to research perspective we have to admit that current projects have been reflecting on the changing situation in care work towards children with disabilities and on their forming new chances to promote their

independency on relatives only minimal. The carried out projects have been focused on perception of adult people with severe disabilities, how arrangement of personal assistance has changed their lives, what are there advantages and disadvantages of that form of assistance. (e.g. Dudková, L., 2004; Repková, K., 2004; Večereková, M., 2004) There have been some surveys (not many) focused on impact of personal assistance on families with children with severe disabilities. (e.g. Behunová, A., 2001) But, those projects have been based on perception of adult (parents) rather than on perception of their children, what is critical point of research work done in this field and has been stressed at the beginning of this paper.

Conclusions

Author intended to encourage research and new-fashioned projects concerning living conditions of children and young people with disabilities based on their human rights and promote exchange of experience and good practices in this field. Common national and international experience suggests that for the close future a crucial point in a research work will be an improvement of situation in statistical field (accessibility of various statistical data for research institutions, as comprehensive, unified, as possible). Essential aspect seems to be the empowerment of children and youth with disabilities to take active part in various research projects concerning their living conditions based on recognizing their right to be listened to and having impact on their own lives.

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