

MONITORING THE ISSUE OF CHILDREN AT RISK IN THE CZECH REPUBLIC 2010:

DISABLED CHILDREN

The basic starting point of the project

“Children at risk” is defined as a child **whose natural development is threatened**. This natural mental development can be threatened by two – sometimes mutually overlapping – factors:

- the risk of organic (physical) damage;
- the risk from the social environment.

In the first stage the monitoring focussed on help during risks **stemming from the social environment (2008)**. In the second stage of the monitoring we focussed on **disabled children (2010)**.

Monitoring results

Research aim

Charting the problems encountered by disabled children focussed on the following areas:

- the most urgent problems regarding care for disabled children,
- the opinion of parents of disabled children who encounter problems in everyday life,
- the attitude of the specialist public to the problem of disabled children,
- the attitude of the state and state authorities to the problem of disabled children,
- the attitude of non-state non-profit organisations (NNO) to the problem of disabled children,
- how the entire problem is viewed by the public, i.e. the general population.

Basic starting point

Out of a total figure of more than 1 015 000 disabled people in the Czech Republic there are 46 208 disabled children up to the age of fourteen. 91 % of them are primarily looked after by their families. There are approximately 1.5 disabilities (combined disabilities) per child. Out of the total group of disabled children congenital disabilities account for 57 %, acquired disabilities 43 %. Both types of disability were taken into consideration in our research when selecting respondents so that the problems of both groups would be mapped out. The research looked at **common problems faced by disabled children** because there exist a number of very serious problems common to all disabled children regardless of diagnosis.

Definition: a disabled person is a person whose physical, sensory and/or mental abilities or mental health are different from the typical state for the corresponding age and it can justifiably be assumed that this state will last for longer than one year; the difference from the typical state for the corresponding age must be of a type or extent that usually causes the person to be restricted or actually prevented from taking part in social interaction.¹

¹ Selected survey of disabled people 2007. Czech Statistical Office, Prague 2008, page 5.

Methodology

A combination of several research methods:

- collection and analysis of available data on disabled children,
- charting of the non-profit sector whose activities focus on disabled children,
- in-depth, expert interviews with specialists in this particular area (a total of 31 specialists)
- in-depth, qualitative interviews with the parents of disabled children (a total of 8 families)
- quantitative questionnaire for the parents of disabled children (200 parents),
- quantitative questionnaire for representatives of the non-state non-profit sector (188 organisations),
- quantitative questionnaire for representatives of the state sector (200 respondents),
- quantitative questionnaire for the general population of the Czech Republic (1 200 respondents).

Results

The results of the entire survey show that there is a clear lack of method in the care for disabled children, in particular there is a lack of coordination in the services provided and insufficient or ineffective solution of problems. We consider the fact that in care for disabled children representatives of the state and non-state sector view the fundamental problems very similarly to be a very important finding. In addition, to a large extent these assessments are in accordance with the assessments given by the parents of disabled children.

The results of the survey contain two significant components:

- assessment of the main problems spontaneously mentioned;
- assessment of 77 specific problems regarding care for disabled children that were listed by respondents.

In order to assess the most serious problems that are spontaneously mentioned, respondents were asked an open question: what do they perceive to be the three main problems regarding care for disabled children?

Parents and representatives of the state and non-state sector consider lack of finances to be the most serious problem. Parents and representatives of the non-state sector put the public's negative attitude (indifference, prejudices and mockery) in second place. For state sector representatives the most serious problems are insufficient, unexplained legislation (16 %) and a lack of high-quality workers in education and assistants (15 %). It places the public's negative attitude as low down as eighth.

A summary of the opinions of all three groups of respondents which is depicted in the following graph showed the three most serious problem areas to be as follows:

- **finances,**
- **the public's attitude,**
- **state interest and the attitude of officials**

Figure 1: Problems in care for disabled children that were spontaneously mentioned

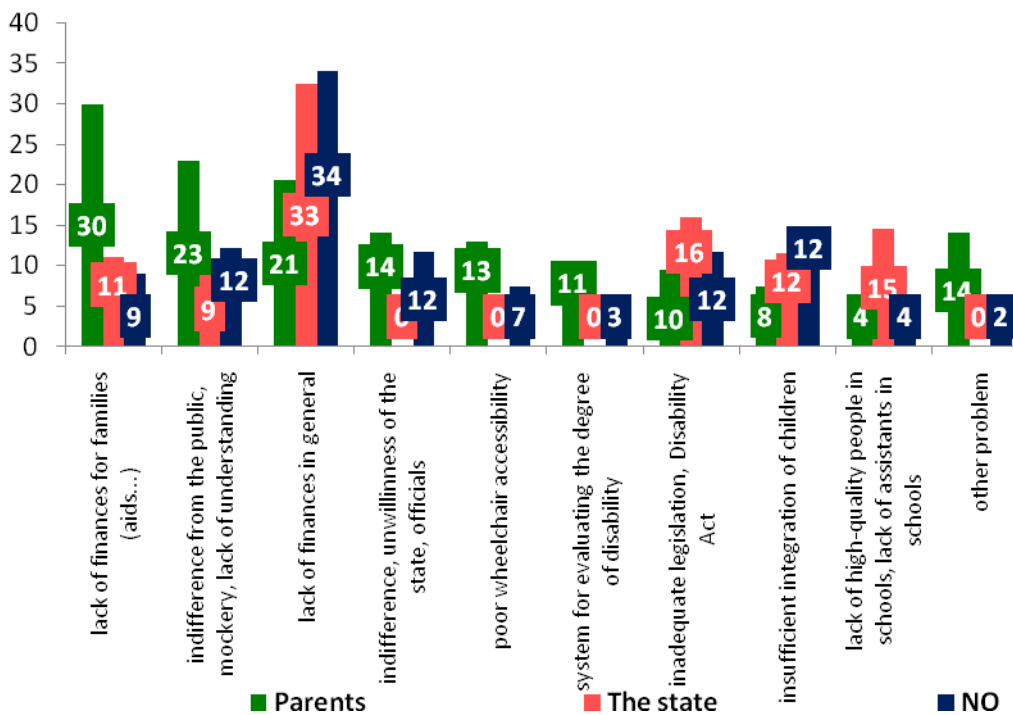
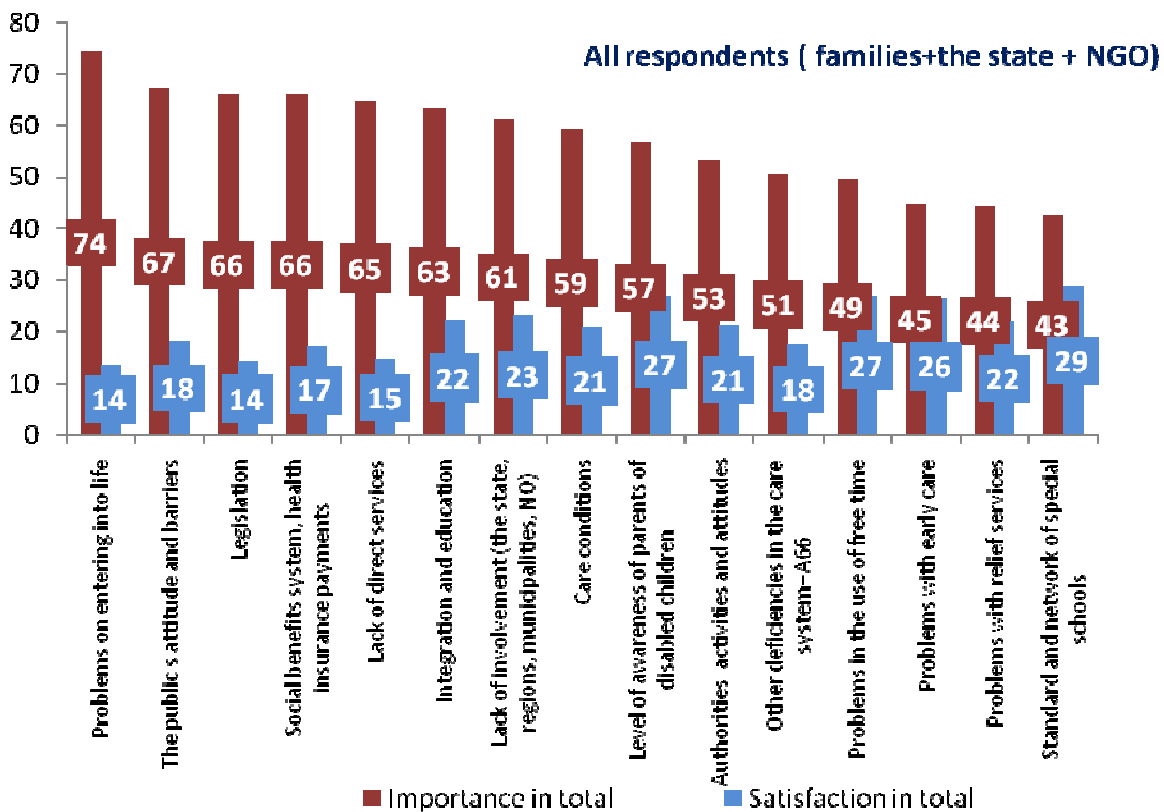


Figure 2: Assessment of 77 specific problems regarding care for disabled children that were listed by respondents



The problems that parents and representatives of the state and non-state non-profit sector encounter most frequently were summarised in the following seven areas:

- **finances;**
- **the attitude of the public and authorities;**
- **benefits, the size of payments for medical aids and medical care, the system for evaluating the level of dependence on care;**
- **children's future - employment, opportunities to study and live independently;**
- **support services for families;**
- **education for disabled children;**
- **legislation.**

It must be emphasised that ALL the problem areas listed are important to the respondents and that they are dissatisfied with how they are dealt with.

The problem of a **lack of finances** is closely linked to all the problem areas. It is viewed differently by the individual groups of respondents: for parents it is a lack of finances for families; from the point of view of the state and non-profit sector it is a general lack of finances. All the respondents expressed a high level of dissatisfaction with the current system of social benefits and the size of payments for medical aids.

The financing of care for disabled children in the Czech Republic is unclear and is not sufficiently systematic. Transparency in the way funds are used would not only help parents who would therefore be able to make better use of all available opportunities but would probably also help to change the public's attitude towards disabled people. Parents consider financial support to be the state's main task, both with regards to medical care and medical aids and also direct financial support. Only 46 % of respondents are satisfied with the current system for directing financial aid to families in order to purchase services and only 55 % of respondents say that they use these funds to purchase social services. Parents consider care benefits to be insufficient to buy services for their child.

81 % of state sector representatives who were asked consider the problem of low salaries in social services to be serious. NNO representatives (78 %) and parents (72 %) view this problem similarly.

The **public's attitude** was seen to be one of the most serious problems. Parents consider this problem to be particularly significant – 23 % of them spontaneously ranked this in second place behind lack of finances.

Almost 70 % of parents consider the public's attitude towards disabled people in general to be a serious problem. For the purposes of the survey several questions were created aimed at mapping out this attitude which were incorporated into the questionnaires for representatives of the public. Almost 70 % of those asked said that they were badly informed about the situation regarding disabled children. Almost half of them would sometimes follow an interesting story but they do not have any greater interest in the subject. The most frequent source of information is television. A very small percentage of respondents said that they had been informed in school. Professionals in the qualitative part of the research and conference participants expressed a need for information to be spread about particular subjects in the lives of disabled children.

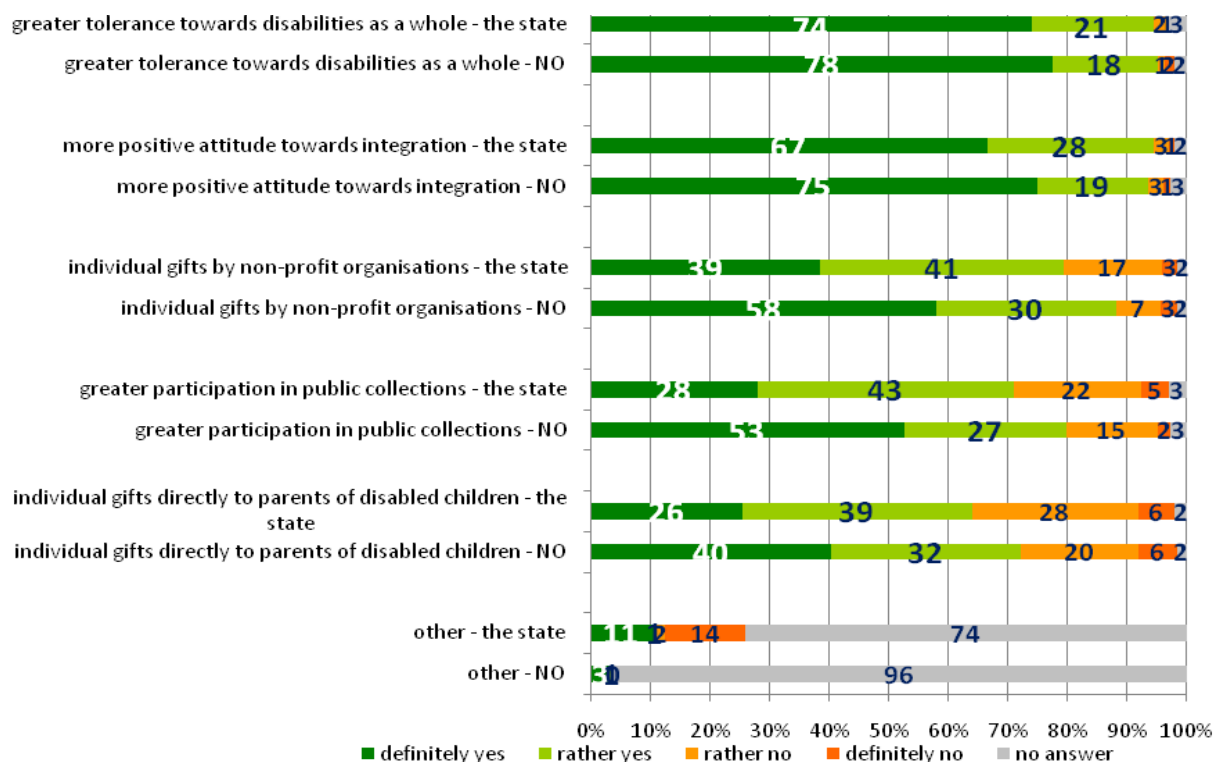
Part of the population believes that the problem lies in how to treat disabled children, uncertainty over how to act in particular situations, whether and how to offer help, how to communicate with disabled people. The vast majority of respondents have a tendency to help a disabled person in a particular situation, the answers differ only in the form that this help takes. "Fear of the unknown, of something different" causes a communication barrier. Men to a large extent believe that we should behave towards disabled people in the same way as towards other people and to not take excessive care of them which could make them feel detached from society. Women more often have a tendency to offer help immediately. In answer to the question "How would you describe what goes through your head when you see a disabled child?" 13 % of respondents said "I have a strange feeling of something unknown, something unpleasant".

According to non-state non-profit sector representatives, equally serious as the lack of interest shown by the public is the problem of a **indifference shown by the state and state authorities and the unwillingness of officials**. The parents of disabled children consider this problem to be even more significant. The state is represented in direct contact with parents by officials at municipal level and 37 % of parents consider the unwillingness of officials to be the greatest obstacle in the care for their child. A further 41 % of parents “rather agree” with this. The vast majority of parents believe that apart from financial aid and providing an easy-access environment the state’s main duty is to create a network of professional workers who would work directly in the field with children and their families. The unsatisfactory situation at present is underlined by the fact that for more than half of parents the authorities or the social worker is not a source of information.

Parents who took part in the survey emphasise the lack of help provided by state or other entities in ensuring care for their child and express a lot of fears regarding their child’s future after they have reached the age of majority. Parents who receive specialist care (medical institutions, social care facilities, specialist schools) view the effectiveness of the help provided by the state positively. On the other hand, state help regarding employment, housing and advice for parents is viewed most negatively.

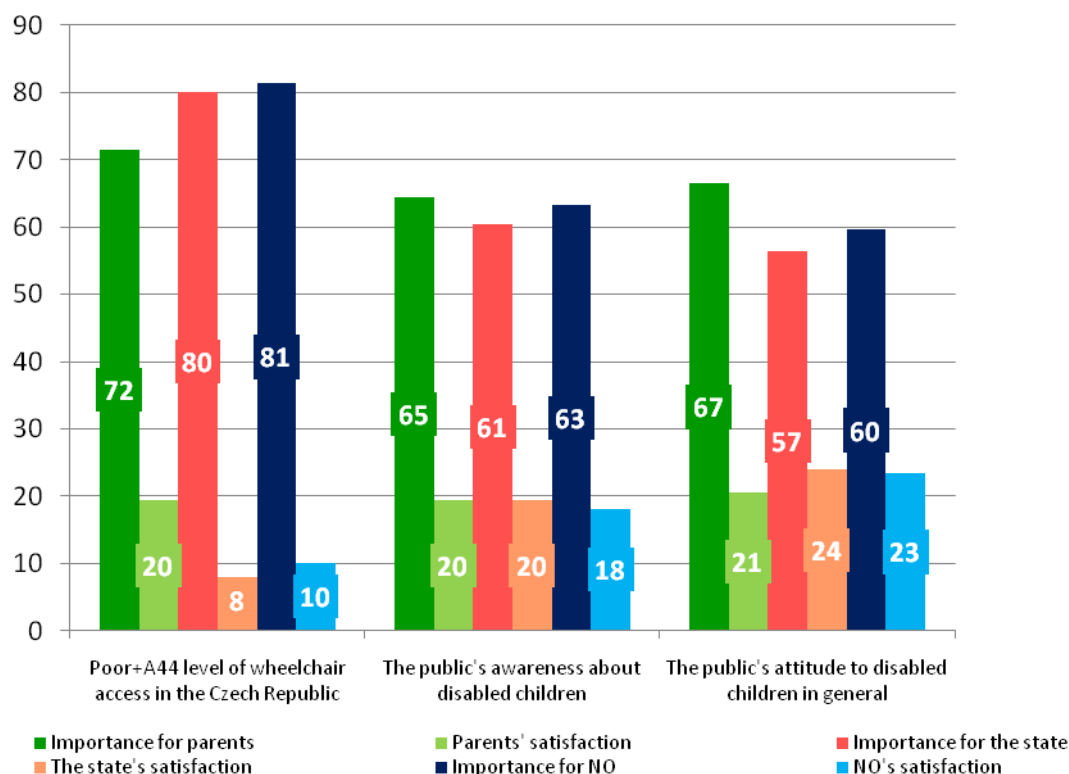
The survey focussing on how the needs of clients are ascertained by entities that provide care for disabled children showed that 37 % of state entities had never carried out similar research. The needs of their clients are not ascertained by 42 % of pedagogical-psychological centres, 41 % of special schools and special pedagogical centres, 33 % of authorities and 28 % of special institutions.

Figure 3: How should the public contribute to solving problems encountered by disabled children



For 13 % of parents a lack of **wheelchair accessibility** was one of the main problems that they spontaneously referred to. Providing an easy-access environment should be part of the support for integrating disabled children into normal society. The majority of parents view both these areas as another important role that the state should play. 48 % of parents wants their child to be integrated as much as possible and a further 44 % of parents “rather agree”.

Figure 4: Attitude of the public and barriers



Almost 80 % of respondents in all three groups said that **benefits, the size of payments for medical aids, and the system for evaluating the level of dependence on care** were important for the quality of disabled children’s lives and expressed a lot of dissatisfaction with the current system. In terms of dissatisfaction it came first. It is interesting that the system for evaluating the level of dependence on care is viewed more positively by parents than by state representatives themselves. Nevertheless 38 % of parents agreed that the evaluation system needs to be revised and a further 43 % “rather agreed”. The need to revise the evaluation system was also emphasised in the in-depth interviews with professionals in the qualitative part of the research.

The size of benefits and contributions often does not correspond to the current socio-economic situation in the Czech Republic and does not meet needs. The way amounts are spread around is often ineffective – some rates are overvalued, others are undervalued. There is a lack of balance in the contributions for care – what part should be directed to the family and what part to the service providers. Also developments in healthcare require a drastic change to the classification of disabilities and the related measures aimed at ensuring certain care and support services.

Some disabilities are not even on the lists of illnesses and so families are not entitled to benefits. The current method of assessment, for example, places children with a mental disability at a disadvantage – in principle the child meets the requirements to carry out a specific task (for example, getting dressed on his own) but the fact that he constantly needs the help of a carer to do so (he cannot judge what it is suitable to wear, i.e. somebody must get his clothes ready for him) is not taken into consideration. The assessment method is also inappropriate in the case of serious illnesses where a child may easily meet the criteria at a particular moment but the fact that a progressive illness can radically change the situation from day to day is not taken into consideration.

The range of problems associated with the **conditions for disabled children’s entry into life after leaving school and reaching adulthood**, termed “**children’s future**”, primarily includes employment opportunities and opportunities to study and live independently. Parents consider an education to be one of the priorities leading to a child’s personal happiness and his security in the future.

The importance of the range of problems included under the title **“support services for families”** underlines the fact that 91 % of the total number of 46 208 disabled children in the Czech Republic aged 0-14 (Czech Statistical Office 2007) are cared for primarily by their family. What is more, directing support to families is part of the ministries’ action plans and concepts aimed at ensuring that children and their families are provided with comprehensive care (for example, the National Action Plan for the Transformation and Harmonisation of the Care System for Children at Risk for the Period 2009-2011, Ministry of Labour and Social Affairs; the National Plan for the Creation of Equal Opportunities for Disabled People for the Period 2010-2014, Ministry of Labour and Social Affairs). Here the emphasis is put on the need to provide parents with advisory support.

The range of support services for caring families includes the following areas:

- urgent aid services,
- personal assistance services,
- social-legal advice for the parents of disabled children,
- psychological and special teaching support,
- high-quality long-term field work with the family after the completion of early care,
- early care,
- relief services,
- leisure activities for disabled children,
- an active approach by individual entities providing care for a disabled child,
- how well-informed the parents of disabled children are,
- a sufficient number of small, family-type establishments.

We have also included the problem of a lack of small, family-type establishments in this list. It belongs here because it is connected to the care of disabled children. The availability of these establishments – their abundance and quality – should accompany the directing of support to caring families so that these establishments can be used in cases of a most serious disability or in cases where a sudden change in a family’s situation requires a similar solution.

Unlike the list of most urgent problems respondents are reasonably satisfied with the provision of early care. They were mostly dissatisfied with the insufficient availability of the service – the number of centres and parents’ awareness of the possibility to use them.

Respondent’s rate relief services, respite care, with the least difference between their importance and the way the problem is currently handled – on average they are “neither satisfied nor dissatisfied”. The amount of relief services provided for parents is insufficient, even more so than is the case with early care. This fact was pointed out during the qualitative part of the research by both professionals from the academic sphere and also the parents of children with the most serious types of disability. This is probably one of the services that should be actively offered to parents, preferably by a specialist whom they trust and who can explain its importance and the risks of long-term care of a disabled child by a parent without the chance for relief.

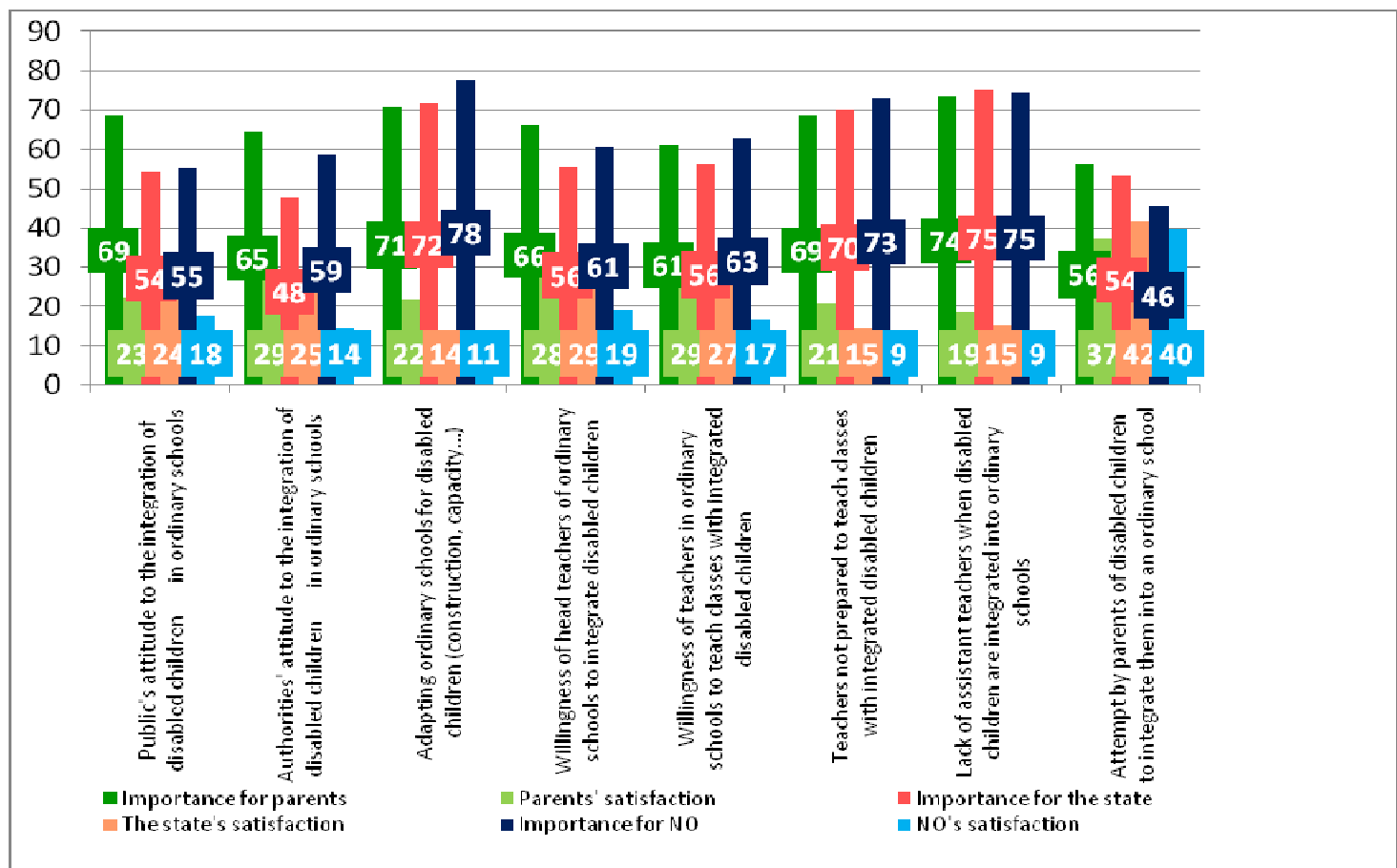
Parents are slightly more satisfied with the leisure time opportunities for disabled children. Nevertheless, here too state and non-state sector representatives express their dissatisfaction with the number of centres providing these services.

Also a lack of involvement by entities providing care for disabled children with regards to parents was mentioned during the qualitative part of the project. Respondents feel that there is the same urgent need to resolve this group of problems as there is regarding the conditions for the education of disabled children. A joint aspect of the following items which we have included on this list is parents being actively contacted by assisting entities offering help.

With regards to parents' awareness there was not much difference between the seriousness of the problem and the satisfaction with how it is being dealt with. Nevertheless on average only 24 % of parents are satisfied or "rather satisfied" with the amount of information and their assessment differs from the assessment given by state representatives who express greater satisfaction. We think it is important to emphasise that for a significant proportion of the families of disabled children a lack of information has a direct effect on the difficult situation that the family finds itself in. Parents named doctors (37 %), friends and acquaintances (24 %) and the internet (18 %) as the most common sources of information.

With regards to the **education of disabled children** the survey focussed on two components: a) the quality and availability of special schools and b) the possibility of ordinary schools educating disabled children. Whereas in the assessment of the first of these two components there was general satisfaction with the quality of the services provided, the assessment of the second component showed that there were insufficient conditions for the education of disabled children, accompanied by the problems that we come up against throughout the research – a lack of finances, the attitude of the public and the authorities, a lack of wheelchair accessibility.

Figure 5: Attitudes with regard to integration into ordinary schools



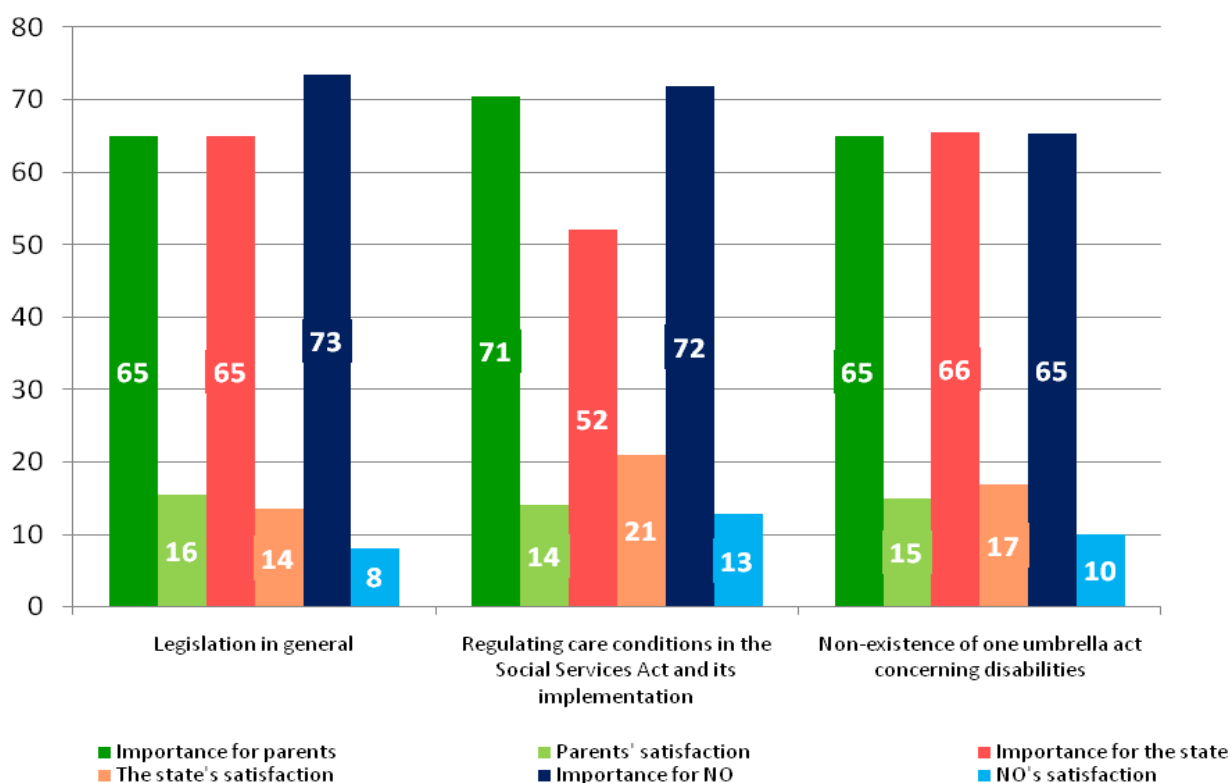
The assessment of the possibility for ordinary schools to educate disabled children confirms the fears expressed by professionals – especially psychologists and special teachers – in the qualitative part of the research. They pointed out the risks to the successful integration of a disabled child into an ordinary school when neither the teachers and the school nor the children, their fellow pupils and parents are prepared and so for some children the integration process can actually do them more harm than good. One of the most serious deficiencies was considered to be the lack of assistant teachers for disabled pupils. As a result the majority of specialists and parents agreed in the in-depth

interviews that they consider integration into ordinary schools to be beneficial and desirable, nevertheless it must be assessed individually whether all the necessary conditions are provided in a particular case.

The problematic situation regarding the conditions for the education of disabled children in ordinary schools is probably part of the reason why there are not considered to be enough special schools (only 14 % of parents are satisfied with their availability) because when a child cannot be integrated into an ordinary school the only option is a special school and far from all types of disability require this solution and parents consider it important for their children to be taught in ordinary schools (56 %).

We see a lot of contradictions regarding **legislation**. Measures aimed at resolving the problems regarding care for disabled children are incorporated into individual laws and decrees and when they are put into practice this often leads to complicated situations where measures contradict each other or are not compatible. This applies, for example, to the contradictions between the Schools Act and the Social Services Act, the various definitions given by individual departments (early care, prompt care, etc.). This problem is tied up with the fact that no comprehensive system of care for disabled children exists, there is a problem in communication between the individual ministries and a lack of systematic cooperation between them.

Figure 6: Legislation



Reports on individual parts of the research are available at: www.nadacesirius.cz.