

# Social protection of children with disabilities before the change of regime and at present

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**Abstract:** The integration of people with disabilities and the normalisation of their living conditions appear to be a key goal in today's social approach. However, it is not enough to change the social approach alone in order to achieve integration, we need instruments which are able to support the social participation, self-determination and normalisation of people with disabilities. Such instruments can be defined as follows: a wide range of social welfare support and social services ensured by the state. It is indispensable to help, support and strengthen families which raise a child with disabilities, consequently social policy instruments should be extended to families as well. The present study aims at providing an overview of how children with disabilities and their families were supported during the socialist regime and in the subsequent period. We used a qualitative case study, for the preparation of which secondary research and document analysis were conducted. Our analysis focused on the research question whether following the change of regime there was a change of attitude in the fields of social policy which could promote the improvement of the quality of life of children with disabilities and their families. On the other hand, do the benefits and services provided by the social care system support the integration, normalisation and self-determination of children with disabilities, as well as their upbringing in a family environment? The results of our analysis show that following the change of regime a slow change guided by the modern approach to disability began, which by continuously adding an element at a time attempts to help children with disabilities and their families. A Hungarian disability strategy which would thoroughly define a social policy adapted to the needs of those concerned is badly needed.

## Article History

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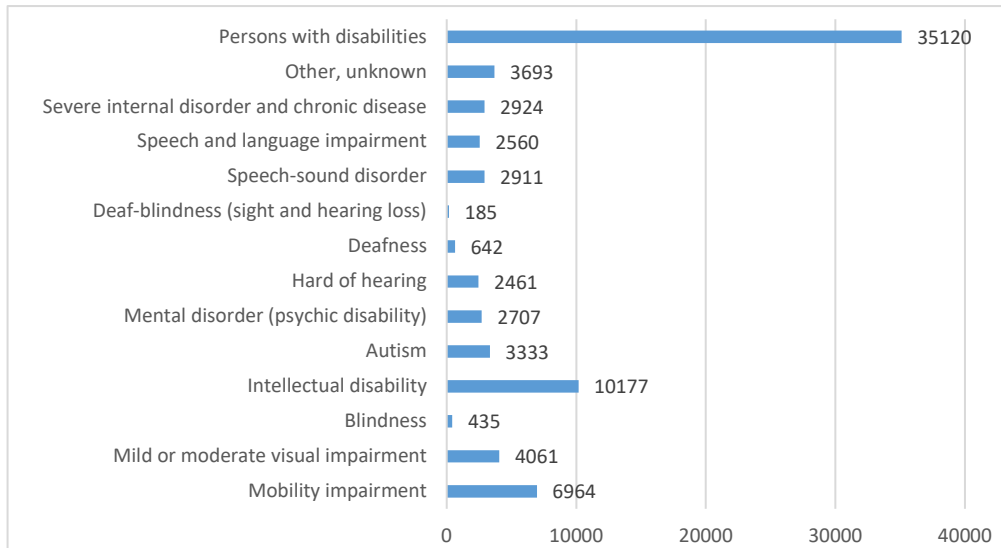
## Keywords

Social policy; Family; Social participation; Inclusion; Normalisation

## Introduction

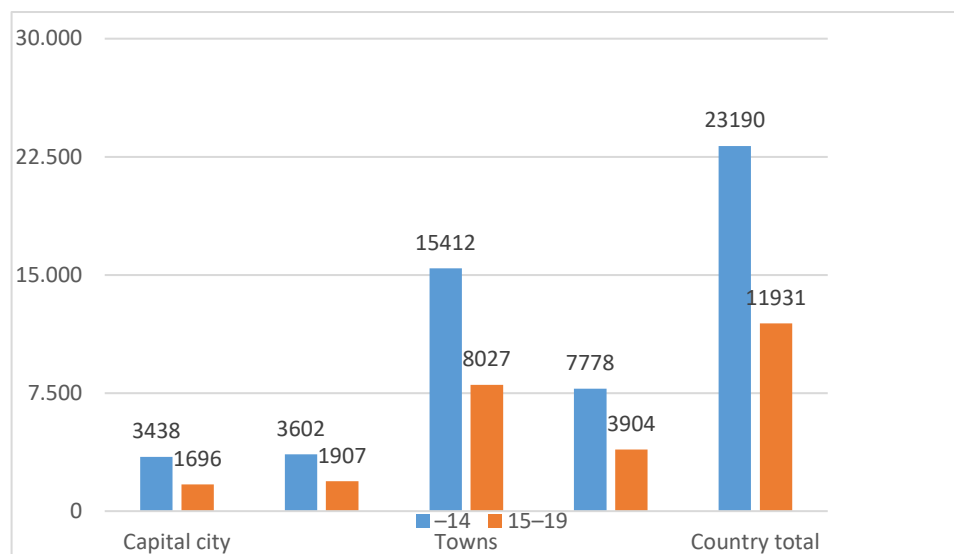
International research results (Ballesteros et al., 2013; Beresford, 1995; Brennan et al., 2016; Gordon et al., 2000; Pal, 2018) point out that children with disabilities and their families are one of the most disadvantaged social groups. Out of the nine and half million citizens living in Hungary more than four hundred thousand people have some sort of disability (Central Statistical Office [CSO], 2018), of which the number of people benefiting from social services is estimated at 35-40 thousand (Kozma et al., 2020). According to the data of the 2011 census, more than thirty-five thousand children with disabilities live in Hungary, accordingly 2.3 per cent of Hungarian families have a child with disabilities (Figure 1) (CSO, 2014a). The distribution by the type of disability among children with disabilities under the age of 19 shows the predominance of children with intellectual disabilities, almost a third of them are affected by this type of disability, followed by mobility impairment in the second place, which is followed by mild visual impairment and moderate visual impairment (Figure 1).

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**Figure 1.** Distribution of children with disabilities by type of disability (persons) Source: CSO, 2014a

The census results highlight the specific housing situation of minors with disabilities and their families, which aggravates their disadvantages (CSO, 2014a). Most of them live in smaller towns and villages, the number of those living in the capital city or in county towns, i.e. in bigger towns, is low. Kereki (2010) pointed out in his research that there are inequalities in access to education and social services based on the housing situation of the child with disabilities. Inequality in education and social services puts those living in smaller towns and villages at a disadvantage. According to the census data (CSO, 2014a) a more disadvantaged housing situation can be detected especially among children under 14 years of age (Figure 2).



**Figure 2.** Distribution of children with disabilities by age and place of residence (persons) Source: CSO, 2014a

Based on these demographic characteristics, it can be stated that the assistance in the supervision and the mobility of children is important for families raising a child with disabilities, and they especially need services provided at the place of their residence. Surely, the day care supervision and travel of a child with an intellectual disability or mobility impairment can be a significant financial and mental burden for the parents.

In Hungary, there have been three researches which explore the living conditions of children with disabilities and their families. These researches were conducted between 1990 and 2008, and since the 2010s no research has been aimed at exploring the problems of this specific social group.

The first research was conducted between 1994 and 1995. According to the results of this nationwide questionnaire survey (Béres, 1997) conducted among 3200 families, financial difficulties cause the biggest problem for more than the quarter (26.5%) of the respondents. The results of the survey suggest that 39% of the surveyed families can fully benefit from the available services, and 23% can only partially use them. The main hindrance to use the services is the transportation, as well as the distance from the services.

In 2003 László Bass (2004a, 2004b) conducted a nationwide representative research on the situation of children with severe and multiple disabilities and their families caring for them. He pointed out that the families struggle with a range of complex problems that make them particularly vulnerable to income poverty, loneliness and exclusion from services. In its background, there is a great amount of support and care that children with disabilities need, which, on the one hand, means significant additional costs for the families, on the other hand, mothers can only provide a permanent supervision for their children if they give up their work. Parents place their children in residential social care as a last resort, they try to preserve the family unit, but this may lead to impoverishment, the loss of social connections and the decrease in social participation. Bass (2008, 2009) repeated five years later his previous research among children with disabilities and their families. His results pointed out that there was no difference in the lives or social welfare of the families surveyed, and the employment of mothers remained low, therefore their income situation remained unchanged.

Fónai et al. in Hajdú-Bihar County in 2004 conducted a non-representative questionnaire survey asking persons with disabilities and their families which involved 387 persons (Fónai et al., 2007). The research was aimed at exploring the living conditions of people with disabilities, but it did not only comprise families caring for minor children with disabilities. The results of the study support the findings of the nationwide research of Bass (2004a, 2004b), according to which the person with disabilities affects the living conditions and income of the family caring for him / her. Their unfavourable income situation can be explained by multiple reasons, on the one hand, due to the care of the child at home the mother has no income from gainful activities, on the other hand the disability of the child accounts for extra expenses in the family budget. Families raising a child with disabilities are more affected by interdependence and isolation therefore they require benefits and services provided by social policy. According to the conclusion of the investigation, although families receive institutional assistance, further services and support would be needed in order to be able to care for their relatives in a family environment without the deterioration of their living conditions. People with intellectual disabilities are in a particularly disadvantaged situation and their independence and growing up into an adult is especially impeded in a family environment.

Based on the above mentioned research results, it can be concluded that the living conditions of families raising a child with disabilities are worse compared to those who care for a non-disabled child. In the background may be the lower income, higher expenses arising from care needs, disadvantageous housing situation, mobility and difficulties in accessing services. At present, we do not have current information on the living conditions of families raising a child with disabilities, as since the 2010s there has been no research into the living conditions of families caring for a child with disabilities.

The conclusion of the above mentioned research results is that social benefits and services are indispensable for the social group concerned in order to maintain their living conditions. One of the main objectives of social policy is, with the involvement of the state, to reduce inequality, poverty and exclusion in the society, as well as, to accomplish the social protection and security of citizens, the integration of marginalised and disadvantaged people. The state is conducive to the social protection of its citizens by using the tools of social policy, primarily by providing social services and benefits. If needed, social services help citizens to improve their everyday living conditions, solve difficulties occurring in their lives, which can be provided as basic care, e.g. by ensuring expert help, daycare supervision or in a more serious case residential institutional care such as in the framework of residential homes. More principles (prevention, integration, subsidiarity) have to prevail in order to achieve the proper functioning of social policy (Drake, 2001). In terms of the principle of prevention, the social system has to serve to prevent the development of social problems. The principle of integration furthers the reduction of social differences and inequalities

and the elimination of exclusion. In the sense of subsidiarity, support must be provided in the closest vicinity of the residence of the person concerned, and if possible through the immediate social system (family, local community) which surrounds him / her.

The group of people with disabilities is one of the most disadvantaged social groups. Their disadvantages can be attributed to two factors, on the one hand, to the health damage of the individual, on the other hand, to the specific functioning of the society. The former aspect is the medical model, which derives the disadvantages of disability from the individual, while the latter one is the social model, according to which the barriers and hindrances originate from the external environment (Könczei & Hernádi, 2011). In the social model, the normalisation, integration and inclusion, independent living and self-determination, as well as the social inclusion play an important role (Oliver & Barnes, 1998). These principles shape the course of organising the community and social life of people with disabilities, whether it is about their lives in their homes or their participation in (educational, health, social) services. Based on the approach of the social model, the system of social policy must be created in a way that its operation may promote the normalisation, integration, independent living, self-determination, and social participation of people with disabilities (Wolfensberger, 1972).

Nirje defined the principle of normalisation in the sixties (Nirje, 1993). According to the concept of normalisation, people with disabilities should have the same living conditions and living circumstances as citizens of the given society. This means that their daily routine, lifestyle, and quality of life are the same as everyone else's in the given country. Social policy must promote that the daily life (daily routine, lifestyle, sexuality, etc.) of people with disabilities should be the same as that of non-disabled people, whether within their family or during their institutional care (Zászkaliczky, 1999). The fulfilment of the eight principles of normalisation is the basis of the integration, inclusion, and self-determination of people with disabilities. The integration means adaptation in which the emphasis is on the adaptation of the person with disabilities, whereas the principle of inclusion requires the other party's activity in the social inclusion of the person with disabilities, that is environmental factors must be changed e.g. by accessibility, by shaping the inclusive approach. The integration efforts have become generally accepted in the field of education in Hungary. In the context of disability, integration means that the housing and lifestyle of people with disabilities must be embedded in the society's life, i.e. for instance they have to receive social services in the same community as non-disabled people. Integration promotes the social participation of people with disabilities. Inclusion is a higher level of integration, it is rather an approach, in which the image of an inclusive community appears, where people with disabilities and the other members of the society are together active (work, study). The principle of self-determination is the freedom of decision-making and choice, i.e. similarly to others, people with disabilities can shape their lives according to their own ideas and plans. Supported decision-making is connected to this principle, according to which people with disabilities can determine the persons who support them in their decision-making. Living a self-determined life cannot be achieved without implementing the principles of normalisation, integration, and inclusion. The consumer principle should also be considered, which says that people with disabilities should be regarded as consumers, therefore the supply and quality of services have to be adapted to their needs (Andor, 2009).

The implementation of the above mentioned principles is highly important regarding the social participation of persons with disabilities. Social participation, already as part of the human rights model, means that persons with disabilities can exercise their human and civil rights in the same way as anyone else in the given society (Könczei & Hernádi, 2011).

Social policy has an important role, from the aspect of social participation, in compensating for the difficulties originating from health damage of people with disabilities. Social policy instruments include allowances, support in cash and in kind, as well as services. In the spirit of normalisation, allowances and subsidies supplement and compensate for additional costs arising from disability, while services facilitate the individual's daily life in his or her own living environment, on the other hand in an institutional framework they provide the individual with housing, meals or meet his or her other needs.

It is apparent that the previous studies revealed factors which determine the living conditions of families raising a child with disabilities and they did not examine the social policy possibilities which are available to support the members of the affected group. The present study examines the changes in the living situation of families caring for a child with disabilities in the light of the past thirty years from the perspective of social policy. The method of this study is a case study. Its aim is to explore what changes the social policy instruments (institutions providing long-term residential care or primary care, cash benefits) have undergone following the change of regime, whether these changes respond to problems which affect families or comply with principles of disability policy (social participation, normalisation, integration, self-determination). The present case study focuses on the examination of supports affecting children with disabilities under 18 years of age and their families. The 18-year-old age limit is relevant in the aspect of the investigation as the determination of the scope of entitlement of the social care system is linked to this age, and in Hungary those under the age of 18 are considered minors. In our study, we do not draw a distinction among children with disabilities based on the type of disability. In our analysis, we focus on cash benefits and social social services provided for children with disabilities and their families, due to the limitations of the length of the study, we do not examine the benefits in kind and reductions.

The research question at the centre of our investigation is whether, following the change of regime, there has been a change of attitudes in the areas of social policy which could promote the improvement of the quality of life of children with disabilities and their families. Do the benefits and services of the social care system support the disabled children's integration, normalisation, self-determination, as well as their upbringing in a family environment?

In the first part of the study, we present the research antecedents which explore the living situation of families raising a child with disabilities in Hungary. Following that, we review the fundamental principles of social policy and the principles of disability social policy, which must prevail in the field of social policy. Using secondary research and document analysis, through the history of the development of social policy, we explore the institutionalisation of services provided for children with disabilities and their families, the current social policy instruments and the proportion of minor claimants, pointing out the changes that have occurred in the past decades. Finally, we summarise the results of our analysis and draw conclusions from them.

## Method

The method of the study is case study, which according to Yin (2018) is a qualitative method that is suitable for a deeper, longitudinal investigation of a topic and for understanding a phenomenon. The case study was carried out by using secondary research and document analysis.

In the course of the investigation, we conducted search in the MATARKA (Hungarian Periodicals Table of Contents Database) database, as well as in the database called Digital Archives of Socialist Profession (Szociális Szakma Digitális Archívuma) where a collection of articles, studies, volumes written on the topic of disability between 1990 and 2008 is available under the link titled Care for people with disabilities. From the collection of studies, we reviewed scientific publications which met the above mentioned criteria. Using the Google search engine we explored further publications and study volumes. With a simple search in the database, entering the term disabled, we found 190 results. While examining the results, we gathered scientific publications on the social care, caretaking, social policy support provided for people with disabilities, keeping the aspect related to age and living conditions of families in view. Having narrowed down the results, we found four publications on the living conditions of children with disabilities and their families, and twelve specialised literature which helped to understand the historical background and changes undergone in the institutional system. The sources collected this way were subjected to analysis, their content covers the period before and after the 1990s. Legislation on the social care system also provided a point of reference to trace the changes. The main legislations are Act III of 1993 on Social Security and Social Services (Act III of 1993); Act XXVI of 1998 on the Rights and Equal Opportunities of Persons with Disabilities (Act XXVI of 1998); Act LXXXIV of 1998 on Family Support (Act LXXXIV of 1998).

After exploring the historical background, we examined the available official statistical results, in order to compare the results of secondary research with the results of the data collection of the CSO and to look for connection and explanation for the underlying reasons (Hunkár, 2013; Smith, 2008; Onwuegbuzie, 2012). In Hungary the CSO carries out quantitative data collection concerning the disabled population and social care system. For this reason, our analysis is based on the data source collected by the CSO, on the one hand we use data collection of the census in 1990, 2001 and 2011 and on the other hand, the data of the Social Statistical Yearbook 2012-2020. In addition to these, there is no statistical data on children with disabilities. In Hungary the statistical data collection on people with disabilities began only in the framework of the census in 1990, which was followed by data collection every 10 years. In 2021 due to the Covid-19 pandemic, the census was postponed to the year 2022, therefore the latest data source currently available is the 2011 census. In addition, the central statistical office annually collects data from social institutions, which the office publishes on its website or in the Social Statistical Yearbooks. The electronic databases of the CSO are relevant, the data is collected using the same methods, thus they are suitable for conducting comparative analysis.

The main topics of the case study are: the social care system supporting children with disabilities and their families, i.e. residential care, primary care and cash benefits. Subtopics: within primary care: day care institutions, support service, family support, infant nursery; within cash benefits: child care allowance, higher family allowance, home nursing allowance for children.

### **Results and Discussion**

After the Second World War in Hungary, similarly to other central-European countries, the communist ideology became prevailing, which was centred around the ideology of a paternalistic state. The authorities wished to resolve the situation of people with disabilities in the spirit of this ideology. From 1945 onwards, it was the state's task to provide social care for persons with disabilities (Csizmadia, 1977).

#### **Institutions Providing Residential Care**

The first residential institutions were typically in converted castles, mansions or barracks (Bencze & Pordán, 1999). So-called Residential Health Care Homes for Children were set up for children with disabilities. In this type of institution, care was provided for children with intellectual and multiple disabilities. The first Residential Health Care Home for Children which was not in a converted castle or mansion was built in 1963. In this modern institution, it was possible to segregate and look after the residents according to their gender, severity of their disability and diagnosis. In this period we cannot talk about the development or schooling of children with severe intellectual disabilities, they were said to be untrainable, therefore they were deprived of all kinds of educational services (Lányiné Engelmayer, 1996).

Act III of 1993 on Social Administration and Social Services established the institutional system which had been formed by the change of regime (Act III of 1993). The purpose of the law was to systematise and guarantee the forms and conditions of entitlement of social benefits and services which were provided by the state. The law established two types of social institutions for the housing of persons with disabilities: one type which provided nursing care and the other one which provided rehabilitation care (Bencze & Pordán, 1999). In the former one, people with severe intellectual and multiple disabilities were taken care of, while the latter one was for people with less severe disabilities who could be reintegrated in the society after a five-year rehabilitation. These institutions were named Nursing Home for People with Disabilities, whereas for minors the name of the institution remained Residential Health Care Home for Children. In her research, Mrs. Lányi tried to reveal the number of children with disabilities raised in Residential Health Care Homes for Children. She found that until 1990 the National Methodological Institute for Residential Nurseries collected data on children living in residential institutions, but the systematisation for handling and processing the reported data was not elaborate, therefore it is not suitable for determining the number of children taken care of. However, we can say with certainty that there were twenty-seven institutions for minors nationwide - one in each county and four in and around the capital city were available. Some of them also cared for adults with disabilities, especially since the person cared for as a child was provided

with accommodation after coming to age.

Following the change of regime, the principles of disability, normalisation and integration, which had already become generally accepted in Western Europe, gained ground in Hungary as well (Lovász, 2009). New ideological trends stimulated the need to create modern forms of care. The independent living movement, which originated from the USA and later gained ground in Europe too, inspired the development of new, family-based forms of housing which supported an independent way of life and self-determination (Bencze & Pordán, 1999). The deinstitutionalisation program envisaged the normalisation of the living conditions of people with disabilities by ensuring their housing, instead of large-scale residential social institutions, in small-scale residential care facilities - in the so-called residential homes - where there were fewer residents (Allard, 1996; Ericsson, 1996). The number of people living in residential homes could be a maximum of twelve, regardless of their age, gender and the severity of their disability (Zászkaliczky, 1998).

Hungary must implement the community-based lifestyle and living of persons with disabilities between 2011 and 2041, in a 30-year period. Its implementation allows people living in residential institutions to live a fulfilling and dignified life, it eliminates their institutional isolation, hospitalisation and stigmatisation. However, this form of care only provides residential care for adults with disabilities, for minors there are only large-scale residential institutions available, so the normalisation and social participation of children with disabilities in institutional care is severely limited.

Data on the institutional placement of minor children with disabilities have been available since 2012 onwards in the statistical data collection of the Central Statistical Office. Based on this, it can be stated that the number and proportion of children with disabilities raised in large-scale residential homes show a slow but steady decrease (CSO, 2013, 2014b, 2015, 2016, 2017, 2018a, 2019, 2020). While the proportion of children with disabilities raised in residential institutions was around 6% in 2010, it was only 4.8% in 2019.

**Table 1.** Total number of persons with disabilities receiving social residential care and the number and proportion of children with disabilities in residential social care between 2012 and 2019 (persons, %) Source: CSO, 2013, 2014b, 2015, 2016, 2017, 2018a, 2019, 2020, compiled by the author.

	2012	2013	2014	2015	2016	2017	2018	2019
<b>Total number of persons in care</b>	15 921	15 810	15 581	15 510	14 999	14 743	14 464	14 243
<b>Number and proportion of 0-17 year olds</b>	953 5.9%	880 5.6%	849 5.4%	826 5.3%	829 5.5%	798 5.4%	774 5.3%	691 4.8%

From the declining numbers, we can conclude that families are making less and less use of the residential form as a social service, they try to take care of their children with disabilities in their own homes. This suggests that families of children with disabilities try to rely on their own resources, and locally available primary social care services play a greater role in their lives.

### Primary Care Institutions

In Hungary primary care services are provided to support persons living in their own home but seeking help for their daily lives. A further aim is to help service users to be able to maintain their independent life in their own homes, relying on and exploiting the client's existing resources (nuclear and distant family relationships, breadwinning ability, self-sufficiency). Social institutions providing primary care can effectively contribute to discharge residential care facilities, and to enable the person to live as long as possible in his/her own environment among people supporting him/her. At present, services to assist people with disabilities include day care institutions, support services, family support and infant nursery care. Prior to the change of regime, only day care services and the infant nursery services were available.

#### *Institutions Providing Day Care*

In the period following World War II, there were no day care services available for children, until

the 1980s. The first day care facility for children with disabilities opened its doors in Debrecen in 1980, relatively late. Later, additional facilities were established in bigger towns, mainly in county towns, but actual care needs could not be fulfilled, the service was not available for people living in the countryside, so they continued to rely on the residential institutions. In this period, similarly to residential homes, nurses took care of the clients and they also fulfilled educational tasks, although they did not have any qualifications.

Day care services provided supervision, meals, and if necessary, care for children with disability daily in an eight-to-nine-hour interval. It enabled children with disabilities during the day to keep busy, be in company, expand their social relationships and develop their skills. It enabled mothers to get a job and it discharged the family for a few hours.

From the 1990s onwards, although several day care institutions were founded e.g. by Churches, the service was still not countrywide - while in larger towns there were several day care homes, smaller settlements had none. After 1993 social legislation defined the welfare obligations of the state and the settlements. Social tasks of the settlements are differentiated by the number of inhabitants, currently it is obligatory to provide day care in settlements with more than ten thousand inhabitants. The goal is to enable persons with disability, in accordance with the principle of subsidiarity, to have access to services in the close vicinity of their home and so they are not forced to live in a residential home.

According to the legislation, day care can be used by persons with disabilities over the age of three, in case of minors compulsory education must be fulfilled as well. There is a growing demand for this service, the number of people with disabilities benefiting from day care services was 1.053 persons in 1993, 1.899 persons in 2000, 6.116 in 2010 and 7.755 persons in 2020 (Komáromi & Lendvai, 2016; CSO, 2021a) (Table 2). The reason behind this radical increase is, on the one hand, that the number of residential places has not risen, therefore people with disabilities choose day care, on the other hand, the need of families to care for their relatives with disabilities in a home environment has also increased. However, in case of minors, it can be stated that in spite of the increase in the number of users, the number and proportion of children in care is constantly decreasing, while 8.1% of children with disabilities use day care services in 2012 and only 4.6% in 2019 (Table2).

**Table 2.** Total number of persons with disabilities who use daycare and the number and proportion of children with disabilities receiving day care (persons, %) Source: CSO, 2013, 2014b, 2015, 2016, 2017, 2018a, 2019, 2020, compiled by the author

	2012	2013	2014	2015	2016	2017	2018	2019
<b>Total number of persons in care</b>	7125	7353	7450	7468	7732	7722	7613	7742
<b>Number and proportion of 0-17 year olds</b>	580 8.1%	643 8.7%	529 7.1%	483 6.5%	462 6%	446 5.8%	411 5.4%	359 4.6%

The possible reason for this is that children with disabilities complete their compulsory education in the public education system and not in day care, where development education and the organisation of appropriate special education care appear as a separate additional task. It is likely that children with disabilities attend day care facilities only during school breaks, when, due to the work of parents, the day care supervision for children becomes necessary. On the other hand, it is presumed that minors aged between 16 and 18 who reach the compulsory education age use it in greater numbers. However, detailed statistics are not available to further investigate it.

### *Support Service*

The primary goal of the support service is to facilitate the independent lifestyle of people with severe disabilities. The need to introduce a support service was stated by § 11 Act XXVI of 1998, i.e. this type of care was not available to those in need before the change of regime. It was introduced in the social legislation in 2003, as a form of basic care provided by the municipality (Act III of 1993 § 65 / C). The municipalities, however, mostly entrusted the implementation of this activity to civilian maintainers in the



framework of supply agreement. The demand for this service increased, but there were significant differences in the territorial coverage: the support service in Eastern Hungary was more available, whereas it was less available in Western-Hungary (Farkasné Farkas et al., 2016).

The main task of the support service is to facilitate the access of the affected users to basic services or public services, mainly by using personal transport. Public services include healthcare, social or educational institutions. Besides, the transport service helps the person with disabilities to access his/her workplace or any other services that ensures his/her social integration (e.g. leisure, cultural programs). In addition to transportation, the support service can provide care, counselling, information, personal assistance, home help, skill development, special education assistance, supervision and case management. The highest demand is for transportation, personal help and assistance, although the latter two service elements are less available among the support services.

Analysing the statistical results of the CSO, we can state that the number of the users of support services is declining. Although the support service met the needs of more than twelve thousand people in 2019, the number of those receiving care is decreasing. In 2012 nearly fifteen thousand people benefited from the service, by 2019 the number of users had decreased by more than two thousand (Table 3).

**Table 3.** Total number of persons with disabilities and the number and proportion of children with disabilities using support services between 2012 and 2019 (persons, %) Source: CSO, 2013, 2014b, 2015, 2016, 2017, 2018a, 2019, 2020 compiled by the author

	2012	2013	2014	2015	2016	2017	2018	2019
<b>Total number of persons in care</b>	14 844	14 844	13 639	13 356	13 186	13 306	13 100	12 718
<b>Number and proportion of 0-17 year olds</b>	2904 19.5%	2749 18.5%	2601 19%	2437 18.2%	2309 17.5%	2256 17%	2220 17%	1967 15.5%

Children with disabilities under the age of 18 use the service less and less in direct proportion to the decrease in the number of users, but there is also a significant decrease in the proportions. In 2012, 19.5% of the users were minors, whereas in 2019, only 15.5% (CSO, 2013, 2014b, 2015, 2016, 2017, 2018a, 2019, 2020). From this we can draw the conclusion that on the one hand, families are able to solve the transportation of their children from their own resources and they do not need institutional assistance, on the other hand, the children have the opportunity to use healthcare, education or other services in the close vicinity of their living environment and therefore they do not require support.

### *Family Support*

The first family support centres were established in 1985 on experimental basis, primarily to address the consequences of deviations in the society that affected families and children (Gosztonyi, 1993). In this period family support mainly involved preventive and anti-crises tasks. Since the 1990s it has been supporting families and children through complex activities and with the extensive toolbox and methodology of social work. At present, the institutional system of the Family and Child Welfare Services plays an important role in social care, it has nationwide coverage, i.e. its services are available in every settlement (Rákó, 2017). In addition to services provided to families and children, they offer professional help to the members of other social groups, such as persons with disabilities or families taking care of them. In the framework of various social work, family support provides social, life and mental health counselling, information on benefits in cash and kind, the organisation of access to services, dysfunctional family management, skill development, conflict and crisis management.

The tasks of family support include the case management of persons with disabilities using supported living in order to facilitate their new lifestyle and integration in a supporting way. In addition to these, the Information and Coordination Points, which were introduced in 2022, provide additional assistance to the members of the social group concerned. Disability counsellors who work at the Information and Coordination Points provide information and advice not only to people with disabilities and their families, but also to professionals who work in family support, they also ensure the accessibility

of people with disabilities to services. It is not their task to take over the responsibilities of the family support staff, not even in the case of people with disabilities and their families who care for them, their assistance is limited to solving special problems arising from disability. The service is available in twenty-two places in Hungary, in the capital city and in bigger towns countrywide and it is intended to improve the quality of life, autonomy and independent living of people with disabilities.

### *Infant Nurseries*

Infant nurseries provide day care and education for children aged between 20 weeks and 3 years. Infant nursery care for toddlers has existed in the Hungarian care system since 1852, but until 1945 it operated only in some bigger towns. Following World War II, the establishment of infant nurseries became a state duty, as due to the efforts to promote women's equality, children of working mothers needed supervision. In 1955 more than seventeen thousand children were in infant nursery care. From the 1970s onwards as the number of infant nurseries started to increase, more and more attention was paid to the qualification of infant nursery school teachers and the increase of the care quality (Vokony, 2002). The activity of infant nursery workers got professionalised and in addition to the caretaking duties, professional expectations relating to the education of children became more emphasised. However, from the 1980s onwards, the need for infant nursery care started to decrease, partly due to the declining number of children and partly because of the widening range of cash benefits given to families raising children as this allowed mothers to stay at home with their children until the age of three. In 1980 the number of children attending an infant nursery was around seventy thousand, but in 1990 it hardly reached forty thousand (CSO, 2012).

Following the change of regime, it became part of the social care system in 1997, as an institution which helps families and provides day care for children (Vokony, 2002). The function of infant nurseries is to provide professional caretaking for children, supplement the upbringing tasks of families, educate and develop children at their early stage of life. Infant nurseries have always cared for children with disabilities, mainly in special groups (CSO, 2012). Integration efforts which appeared in public education had an impact on infant nursery care. Since 2008 statistical data on the number of children with disabilities enrolled in nurseries have been collected, based on which it can be stated that the number and proportion of children with disabilities who are educated in an integrated framework is constantly on the rise (CSO, 2012, 2020). While 289 children with disabilities were enrolled in infant nurseries in 2010, 575 children with disabilities were enrolled in 2019 (Table 4) (CSO, 2013, 2019, 2020). It is likely that these children will continue their kindergarten education in an integrated way, following their infant nursery care.

**Table 4.** Number and proportion of children with disabilities enrolled in infant nurseries between 2010 and 2019 (persons, %) Source: CSO, 2013, 2019, 2020, compiled by the author

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
<b>Number and proportion of children with disabilities</b>	289 0.8%	252 0.6%	271 0.7%	394 1.0%	457 1.2%	468 1.2%	542 1.4%	528 1.4%	583 1.5%	575 1.5%
<b>Total number</b>	35 782	36 685	37 163	36 819	37 269	37 906	38 123	37 977	38 223	38 611

For children with disabilities personalised developmental plans are needed and special education tailored to their abilities must be provided for them, in a group their number must be multiplied by two. As of 2010, the government has been devoting significant resources to increase the number of nursery places in order to further women's return to work before the age of three of their children. By 2020 there had been more than fifty thousand places available (CSO, 2012). In order to raise the standard of their professional work and due to the complexity of their activity, nursery teachers are trained in higher education.

## **Types of Family Benefits**

Prior to the 1990s, families taking care of their child with disabilities were not entitled to special cash benefits which could have compensated the extra costs of caring for their child. Two most common types of family benefits are the childcare allowance and the family allowance.

### ***Childcare Allowance***

The childcare allowance, formerly known as childcare benefit, was introduced in 1927. The childcare allowance provided a financial resource for mothers for the period when they couldn't engage in gainful employment in order to raise their children. The change in 1967 brought a breakthrough, as the duration of the childcare allowance was extended until the child reached two and a half years of age (Göndör, 2012). Mothers who had been employed at least for twelve months were entitled, so the allowance was linked to an insured status. It was also extended to mothers raising a disabled child, but the duration and the amount of the childcare allowance did not differ from other families'. From 1969 onwards, the allowance was paid until the child reached 3 years of age and mothers who pursued a gainful activity of no more than 6 hours a day could also apply for it. As of 1982, families raising a seriously disabled or chronically ill child were entitled to the allowance up to the child's 6 years of age and its amount doubled. In addition to the cash benefit, the mother was allowed to work up to four hours a day (Göndör, 2012).

From 1998, the parent can benefit from the allowance to look after a child living in his/her own household until the age of three, in case of a disabled or chronically ill child until the age of ten. In addition to receiving the allowance, the parent may also engage in a paid employment after the child has reached six months of age, but the parent is entitled to the allowance even if he/she does not pursue a gainful activity (Göndör, 2012).

### ***Higher Family Allowance***

The family allowance as a cash benefit appeared in Hungary in 1912 (Kristó, 2015). The family allowance provides support to families with children from the birth of the child in order to reduce the expenses of raising a child and promote the social security of families.

As of 1990, the family allowance became a universal benefit, i.e. those raising a child could apply for it based on their civil rights, regardless of their wealth and income. Thus, no prior employment based insured status was needed. From 1998 onwards, parents raising a chronically ill or disabled child are entitled to a higher amount of family allowance until the child has reached 18 years of age, adults with severe disabilities can receive it until the end of their life. This type of differentiation of the family allowance supports the fact that disability means a significant additional burden to families and to the person concerned, which should be compensated in accordance with the principle of normalisation. The higher amount of family allowance is almost the double of the amount of family allowance given after one child (Act LXXXIV of 1998 § 10 (1) (g) (h)). The higher amount of family allowance entitles the person concerned to a travel discount as well. According to the statistics of the CSO for the period between 2005 and 2019, the number of minors receiving higher family allowance is around 80,000 persons per month, but this also includes chronically ill children (e.g. children with diabetes, asthma), therefore it is not possible to say exactly how many families raising a child with disabilities are entitled to it (CSO, 2020).

### ***Nursing Fee (Home nursing allowance for children)***

The nursing fee is a form of cash benefit which is paid to a person who provides care for his/her relative with severe disabilities living in his/her home and therefore he/she cannot pursue a gainful activity. Since 1990, support provided by local governments has been available. Pursuant to Act III of 1993 § 40-41, a close relative is eligible to the nursing fee if he/she provides care for a person with severe disabilities (regardless his/her age) who is in need of permanent and long-term care or for a permanently ill child under the age of 18. It entitles the claimant to a pension.

As of 1st January 2019 significant changes have been made, the state introduced the home nursing allowance for children for parents looking after their children reliant on care in their home (Act III of 1993

§ 38-39). This income replacement benefit can be claimed by the parents until the age of eighteen of their child and pension contribution is deducted from it. In addition to this allowance, the parent is allowed to work four hours a day. The amount of the benefit has considerably increased and equals to the current amount of the minimum wage. Due to the January introduction of the home nursing allowance for children, there are currently limited statistical data available on the number of users to make comparisons. Based on the date from 31 December, 2019, 6605 parents raising a severely disabled child under the age of 18 received this benefit that year.

**Table 5.** Social services and benefits in Hungary for children with disabilities and their families. Source: compiled by the author

Social Services		Cash Benefits
<i>Long-term residential care</i>	<i>Primary care</i>	
	Infant nursery	Higher family allowance
Nursing Home for People with Disabilities	Family support: Information and Coordination Points (providing advice on disability)	Home nursing allowance for children
	Day care	
	Support service	Child care allowance

As a summary of the above, Table 5 provides an overview of the services and cash benefits which are provided by the current social care system for families to raise their child with disabilities.

### Conclusion

The study aims at exploring the changes which the Hungarian social care system has undergone compared to the period prior to the change of regime and whether these changes meet the aspirations of the current disability policy: the principles of integration, normalisation, self-determination and social participation. The results of the research are presented in the form of a case study, which was carried out by performing, on the one hand, document analysis with a qualitative method, on the other hand, statistical result analysis in the framework of secondary research.

In the first part of the study, we presented the research results revealing the living situation of children with disabilities and the families raising them. The research results have suggested that they are in disadvantaged situations for multiple reasons. Firstly, they struggle with a lack of income, as it is only the fathers who work in families raising a disabled child, and they have extra expenses due to the disability of the child. Furthermore, they have a particular housing situation, as most of them live in small provincial towns or villages, from which educational, healthcare and other services are only reachable using transportation. In order to compensate for their disadvantages, the support and services provided by social policy are indispensable for them, as they promote the normalisation, integration, self-determination and social participation of the affected social group.

In the second part of the study, we explored the cash benefits and services of the Hungarian social care system which intend to support children with disabilities and their families, as well as the history of the development of these tools. In order to carry out this case study, we conducted a secondary research method and document analysis, and analysed statistical results. Based on the results of the research, it can be stated that in Hungary the system of social policy services provided for children with disabilities has undergone significant changes compared to the period before the 1990s. Based on this, two well-separable periods can be identified. On the one hand, the period before the change of regime, and on the other hand, the period after the change of regime. In the period before the change of regime, only residential care provided help for families raising a child with disabilities, therefore those concerned relied on their own support system and scarce resources. That is why, the life of children with disabilities and their families probably narrowed down, they had a limited network of contacts and their everyday life was featured by isolation and impoverishment. The results of our analysis have pointed out that following the change of regime, such primary care and cash benefits appeared that helped those concerned in their home environment and supplemented their income. It can support the normalisation, integration, self-

determination and social participation of the affected social group. It can also be stated that as of the 2010s the number of services and the amount of income replacement benefits have increased, and this may result in improvement of the living condition of children with disabilities and their families and the child's upbringing in a family.

Based on these, we can state that the period before and after the change of regime interpret the social situation of people with disabilities differently, and this different approach considers different solutions to be adequate, therefore other sets of social policy instruments are created. The period following the change of regime, probably due to the effects of disability policy coming from the west, can be interpreted as a process that adds more and more elements to the social system in order to provide support for families caring for their child with disabilities. Social policy measures were clearly aimed at improving the living conditions and life situation of families raising a child with disabilities. Income supplement and replacement subsidies support the costs related to the care of a disabled child to a greater extent. The longer duration of the child care allowance and the increase in the family allowance and in the home nursing allowance for children, introduced in 2019, embody the principle of normalisation, according to which it is necessary to compensate for the disadvantages and costs related to disability. The measures which have been introduced in the area of cash benefits since 2010 may not only contribute to the normalisation, but also to the equal opportunities, integration and social participation of the affected social group because parents are not forced to place their children in residential social care due to lack of income. It also supports the fact that the number of disabled children raised in residential care is decreasing. This promotes the upbringing and socialisation of the child with disabilities in the family or local communities and enables him/her to have active contact with the members of the society, all of which can contribute to the elimination of discrimination, stigmatisation and prejudices. This can certainly improve the society's inclusive approach and sensitivity towards the population with disabilities.

It can be stated in case of all primary care that the number of children with disabilities who make use of these services is decreasing. The only exception to this is the infant nursery service, where a slow, but steady increase can be detected. It is presumable that families provide for their child's needs using their own resources, and probably the public education system (kindergarten, school) offers more possibilities for the education and development of children with disabilities in the close vicinity of the family's place of residence, which eliminates the need for social primary care services (e.g. transportation, day care services). In support of this, it would be advisable, as further research, to investigate the number and proportion of children with disabilities studying in Hungarian public education.

It is also evident that in case of minors with disabilities the social policy impacts of cash benefits prevail more than those of social services. Presumably, the services of primary social care play a more significant role in the lives of adults with disabilities. The results show correlation with the efforts of the public education system to ensure integration and full territorial coverage, i.e. children with disabilities could access special education services locally within an integrated framework.

In summary, based on the results of the research, it can be stated that social policy services and benefits have changed significantly since the 1990s. New ideological trends coming from the western countries have resulted in a new approach concerning disability, in which the image of an able disabled person with abilities is shown. The implementation of the principles of integration, inclusion, autonomy and normalisation has resulted in a slow, but steady shaping of attitudes towards people with disabilities. The currently prevailing individualistic, person-centred perspective has an impact on the social policy approach, which results in the introduction of new services and benefits supporting children with disabilities and their families.

The results of the study highlight the fact that instead of a contingently forming disability policy, a conceptually thought-out strategy which is created with the involvement of various stakeholders (parents, professionals, politicians specialised in this field) would be needed so that people with disabilities could get the adequate support for their independent life from early childhood till the end of their lives. For this, it would be necessary to carry out research from a social policy aspect in order to find out whether,

according to those concerned, the applied social policy tools effectively and efficiently support their living conditions. In the framework of the research, it would also be important to examine what kind of services would be needed in addition to the present social policy tools and whether these service elements could be integrated into the operation of the current institutional system or whether further institutions would be necessary. It is recommended to involve service providers in the investigation who could evaluate with expertise both the families' lack of needs and the demands for the expansion of services.

## Declarations

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