

LIFE OF THE PERSONS WITH DISABILITIES IN THE REPUBLIC OF N. MACEDONIA - CHALLENGES THEY FACE FROM BIRTH TO OLD AGE

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Abstract

The theoretical framework for studying the life course of persons with disabilities through the prism of the social model is characterized by two basic approaches. On the one hand, we can conceptualize the life course in terms of individual biographies and unique life experiences. On the other hand, we can imagine the life course more generally, as a kind of generation system that functions on the macro level in societies, based on the common cultural rules and structural boundaries that define what a "normal life" should be. In this sense, the life course approach helps us understand how societies organize life transitions in an institutionalized or structured way. From the perspective of a social model, the value of this approach lies in the possibility of determining the existing challenges and barriers to determine the different impacts of disabling barriers and social meanings attributed to disability in different generational periods: childhood, youth, adulthood, and old age. The main goal of this study was to determine the most frequent challenges and obstacles faced by persons with disabilities and their families in their everyday lives in the Republic of North Macedonia. The research is analytical, retrospective, and qualitative, correlating the situation in our country with countries around the world through the analysis of documentation: strategic and political documents, laws, scientific research, and project activities. Although efforts have been made in the Republic of North Macedonia for decades to improve the quality of life of people with disabilities, the number of barriers they face from birth to old age is large in every domain. Collective work and cooperation among individuals are fundamental to the establishment of interpersonal relations and bonds, the creation and functioning of organizations, and the development of society.

Keywords: Life course, challenges, barriers, society, persons with disabilities.

1. Introduction

Humanity has been found to have six biologically distinct stages of life: infancy (from birth to 1 year); childhood (up to 5 to 6 years for boys and from 6 to 7 for girls); minors (lasting up to 10 years for girls and up to 11 years for boys); adolescence (up to 14 years for girls and 16 years for boys); adulthood (up to 24 years); and, finally, maturity. The division into stages of life developed in evolutionary terms for millions of years since the beginning of mankind. The stages of life, which were determined in the course of evolution, continue to change even now, at an accelerated rate (Balasundaram P, Avulakunta, 2022).

Each of the developmental stages is distinguished by certain characteristics and brings a series of challenges for the individual. Regardless of gender, race, ethnicity religion, degree of functional ability, or disability, life stages are equal for all. Nearly everyone faces hardships and difficulties at one time or another. However, for people with disabilities, barriers and challenges can be more frequent and have a greater impact.

The perception of disability varies among individuals based on their socioeconomic positions. Looking back over the years, efforts are constantly being made to improve the quality of life of people with disabilities and their equal inclusion in all areas of daily life. Today, society's understanding of disability is improving as we recognize "disability" as what occurs when a person's functional needs are not addressed in his or her physical and social environment. By not considering disability a personal deficit or shortcoming, and instead thinking

of it as a social responsibility in which all people can be supported to live independent and full lives, it becomes easier to recognize and address challenges that all people including those with disabilities experience. Modern societies in developed countries adopt various legal solutions, and legal documents, and create systems that will enable prevention, early detection, early stimulation, education, work training, and employment of persons with disabilities, creating persons who contribute to their personal development, but also to further development of society (Council of Europe, 2022).

2. Methods

The research is analytic and qualitative, trying to analyze the challenges that people with disabilities face in different stages of their life at the same time making a correlation to the quality of life of people with disabilities living in developed countries in the world. The research is also retrospective, looking back over the years to gain insight into the practices and steps taken so far.

3. Literature review

When we talk about the Republic of North Macedonia, there is a long tradition of working towards improving the lives of people with disabilities, the first institutions for the education of people with disabilities were opened in the fifties of the last century. Our country is also one of the signatories of the Convention on the Rights of Persons with Disabilities, advocating for the provision of all guaranteed rights. But despite all the efforts, the number of challenges and problems that people with disabilities and their families face during their lives in the Republic of N. Macedonia is huge.

The journey begins with the very birth of a child with a disability. When a child is born, the life of the family changes significantly and each of its members must adapt to the new situation. When the child is born with a disability, in addition to regular adaptation, the family must cope with stress, grief, disappointments, and challenges, which may lead to a serious crisis or even disruption of family life (Chichevska-Jovanova & Rashikj-Canevska, 2015; Kandel & Merrick, 2003). The first obstacle that parents encounter is the lack of sufficient information about their child's condition, which further deepens fear and other emotional problems. If we were in one of the developed countries, we would say that this is not an obstacle considering the existence of multidisciplinary professional support for parents at the time of presenting the information. Supporting parents at the time of their child's disability diagnosis requires a multifaceted approach where parents, healthcare providers, and community organizations work together. Presenting information regarding the diagnostic process and prognosis in a way that can be understood is vital. It helps improve the outcome, avoids confusion and distress, and increases the satisfaction of speaking with other healthcare professionals. In developed countries, the healthcare providers have training in the specific skills required to communicate disability information to parents representing all the possibilities for the child, while connecting them with early childhood intervention providers, all to make timely and maximum use of all development potentials (Rahi et al., 2014). Unfortunately, the situation in our country is not even close, when faced with the information about their child's disability, parents receive the greatest support from their family. In our country, no systemically organized support would allow parents to get all the necessary information about their child's condition and prognosis, but also to face their feelings and get involved in the process of early childhood intervention as early as possible. Although developmental disorders in children are noticed already in the first 12 months, there is a delay in the process of determining the type and degree of disability and determining the types of stimulating treatment and interventions in which the child should be included. Often parents wander from one expert to another, until they find the information that will give them at least some hope for the future (Nechovska & Rashikj-Canevska, 2022). Should be mentioned that one center for supporting children with

disabilities and their families was opened in 2020 in the city of Skopje with the support of UNICEF and the European Union in cooperation with the National Association of Special Educators and Rehabilitators, but the method of operation and distribution of services is not precisely specified and presented to the general public. Families of children with disabilities receive the most active support from the Parent Resource Center, re-established with the help of UNICEF.

The second stumbling block for parents of children with developmental disabilities is involvement in the process of early childhood intervention (ECI). There are no laws, regulations, or policies for ECI, as well as the national strategy for ECI services, or an elaborate action plan. There is no national ECI organizational framework or intersectoral coordination system in N. Macedonia. Different centers provide an array of different services, ranging from basic rehabilitation and habilitation services to contemporary services, which is the result of the lack of guidelines, procedures, or regulations regarding the provision of ECI services in the Republic of N. Macedonia. The problem is even greater in smaller cities and rural areas, as early childhood intervention centers are located in only a few major cities across the country. In addition to the mentioned improvisation, another shortcoming is the lack of a family-oriented approach, which will include children from the earliest age, but in their natural environment. The largest number of services are implemented in the centers, which exposes the parents to additional costs for transportation and time organization, but also their implementation in the largest number of cases, considering the late confirmation of the disability starts after the completion of 12 or 18 months (UNICEF, 2022).

Early childhood development is a critically important period for the formation of a child's personality. In the last ten years, the essential has highlighted the significance of the period between three and five years of age for the overall development of the child, a period when the child's brain develops the most and exposure to different experiences and stimuli is key to optimal development. Research demonstrates that early childhood development programs are acknowledged to be of critical importance for young children's well-being and development, and they especially improve cognitive, motor, and socio-emotional skills and lead to higher levels of school readiness, and increase primary school enrolment (Rhoad-Drogalis, Justice, 2020). A large number of countries are creating strategies for more intensive and massive inclusion of children with disabilities in early educational programs, aiming at two main goals. One goal is to use the child's potential and prepare him in time for the transition to a school environment, while the other is to give space to parents to work through the organized care for children, thereby reducing the burden on the state by reducing the number of social endangered cases. To provide optimal child development on the one hand, and to provide support for parents of children with disabilities and expand work opportunities, the government in the United Kingdom provides early education and care for children aged 2 to 4 years on a charge of the state. This effectively means that all 2, 3, and 4-year-olds with a finding and opinion are entitled to 570 hours of government-funded early years provision per year. This is usually taken as 15 hours per week, over 38 weeks of the year (although fewer hours over multiple weeks are possible), and is referred to in these statistics as the 15-hour entitlement (Gov.UK, 2022). Despite the confirmed significance of the inclusion of all children in preschool institutions and programs for early childhood development, especially children with disabilities, as well as the positive examples in different countries, our experiences show a completely different practice. In a survey conducted by UNICEF in 2017/2018 on the territory of the Republic of N. Macedonia, out of the total number of children cared for in state preschool institutions, 35,286, only 415 children have developmental disabilities, i.e. from 58 kindergartens included in the research, from the entire territory of our country, 68% or 39 kindergartens included children with developmental disabilities. If only kindergartens that reported children with disabilities are taken into account, the average is 10.64 children per kindergarten, or from the total number of children enrolled and included in kindergartens, which is 34,700 children, the percentage of children with disabilities is 1.19%. The analysis of the data indicates that the people working in the kindergartens do not have enough information about the types of disabilities encountered in childhood and their classification, which leads to wrong information and statistical records about the numerical representation

of children with different types of disabilities. According to the records, most of the children with autism (104), followed by children with intellectual disabilities (101), consider children with Down syndrome and delayed psychomotor development as another separate group. Children with visual impairment are the least represented, 7 children. The lack of sufficient knowledge in the field of inclusive education and characteristics of the development of children with disabilities, which has been shown in a large number of researches conducted by the employees of the Institute for Special Education and Rehabilitation, leads to inadequate organization and way of working with children with disabilities included in preschools. One of the indicators of insufficient preparation is the fact that the detection and, consequently, the record of children with disabilities in kindergartens begins after the 18th month, i.e. the largest number of children with disabilities are detected in the older group, which covers the age of five to six years, which, on the other hand, can be partly due to the weak cooperation with the parents and the lack of appropriate documentation indicating the child's developmental characteristics and the need for special services. Another problem that stands out in preschool institutions is the lack of a professional team, especially special educators and rehabilitators who will organize and coordinate the work with children with developmental disabilities, in the UNICEF study, the employment of a special educator and rehabilitator is stated only in 22.8 % of kindergartens, i.e. in 13 kindergartens at the level of R. N. Macedonia (UNICEF, 2018). In the last few years, special educators and rehabilitators have been employed within several kindergartens, but as part of the professional team, serving all clones of the kindergartens, which does not meet the basic needs. In such conditions, the members of the professional team do not manage to get to know all the children, let alone assess them and determine their specific needs. According to the report of the Ministry of Education and Science, in the period 2019-2022, forty-nine (49) special educators and rehabilitators are employed, but only within regular schools and schools with a resource center, as support for the inclusion process, but they are not employed in pre-school institutions either (Javna administracija, 2022). Another indicator of the neglect of preschool education of children with disabilities is the lack of any national records on the number of children with developmental disabilities included in preschool upbringing and education, nor any reference to them in analyses conducted by state institutions.

Deficiencies in the field of preschool upbringing and education are directly reflected in the success of the process of primary education. Given that education is a continuous process that begins within the family from the very birth of the child, then continues institutionally organized, through preschools, primary and secondary schools, all the way to the university desks, we could not expect optimal outcomes and results if the chain process is carried out partially. The gap that exists in the period of early childhood development has a great negative impact on the speed of achieving success in the primary education process. In the Republic of N. Macedonia, the new law on primary education from 2019 foresees full inclusion, i.e. the inclusion of all children with developmental disabilities in the regular education system, regardless of their functional and academic ability. If we build on the previous analyses and information, it would be logical to ask how we expect to have success in inclusive education, if those same children were temporarily not included in a systematically organized educational process. Starting the school and moving from a less restrictive and playful environment to one with clearly defined rules of behavior, structured learning, and precisely determined goals and standards is stressful for any child, but this is especially true for children with developmental disabilities who spend most of their early childhood in a home environment. It is normal with such preconditions to have difficulty adjusting to the new environment, rules, social contacts, and learning process. Despite the relatively long tradition of organizing the educational process for students with disabilities in the Republic of N. Macedonia, the students themselves, parents, and even teachers are still faced with a large number of challenges and difficulties (Simikj–Ackovska, 2021). The new commitments and attempts to improve education seemed to have shaken the educational system, so many dilemmas and doubts appeared on the surface. In the previous setting of the education system in the country, parents of children with disabilities were hesitant about choosing the school, or the type of education for their child, on the one hand, fearing

stigmatization and labeling and choosing the regular education system, on the other hand, choosing the professional ones, access, the multitude of resources and alternatives in special schools. The new system arrangement overcomes the problem of hesitation, but does it mean that it curtails the choice and the right of parents to decide for the best of their children? The inclusion of students with disabilities (special educational needs) within regular schools reduces discrimination and segregation, and enables better socialization, mutual acquaintance, and acceptance, but does it also enable the satisfaction of all students' needs? Inclusive education is implemented in over 75% of the countries in the world, but success in implementation depends on the socioeconomic status of the country and educational and cultural traditions. Numerous analyses and research confirm that inclusive education in R. N. Macedonia is not even close to the level that was envisioned and foreseen in the strategic documents. A deficit of human and material resources is noted (such as insufficient professional preparation of the teaching staff, lack of special educators and rehabilitators, lack of visual aids and assistive technology, etc.), unsuitable infrastructure, uneven documentation, program discrepancies, etc. (Chichevska Jovanova, Rashikj-Canevska, Stankovska Kolevska, 2020). In the last two years, one of the essential problems within primary education is the determination of the need for educational and personal assistants and the method of obtaining them. The problem can be seen through several dimensions: differentiation of work responsibilities (which are the responsibilities of the educational and which of the personal assistant), the way of organizing the work (one assistant for one child or one assistant for several children), the principle of determining the need for an assistant and the type of assistant (academic abilities, functional ability, readiness of the teaching staff, etc.). Through the prism of parents, the problem is more complex, regardless of the type and degree of disability, parents are obliged to include their child in the regular education system, but they are limited in the services, support, and opportunities available to them, so they are often forced independently on personal initiative and expense to provide additional support and services for their child (Chichevska-Jovanova, Rashikj-Canevska, 2022; Rashikj-Canevska, Ajdinski, 2018).

Persons with disabilities and their families have no less stress and challenges when choosing secondary education. The inclusive practice in regular secondary schools since the adoption of the Strategy for the Development of Education in R. Macedonia 2018-2025 can boast of new curricula and programs adapted for students with visual impairment and hearing impairment, enabling students with a mild disability upon completion of the 4th year of education to take an adapted state matriculation exam and continue their education of higher education institutions in the country and abroad. What has been stated as the disadvantage is the weak physical (facilities, equipment for exercise and other equipment) and didactic-methodological approach in most secondary schools; and extremely limited conditions for inclusion of students with special educational needs, there is a lack of people to support both the teaching staff and the students with special needs and there is a complete lack of necessary means and tools in teaching (lack of assistive devices and technology). One of the basic problems that is not covered in the strategy, and is burning for parents of people with disabilities, is professional education and training of persons with disabilities for their application to the labor market. The main shortcoming in our country is professional counseling and choosing a profession that, on the one hand, will correspond to the functional abilities of the person, and on the other hand, will be competitive and in demand in the labor market (Rashikj-Canevska, Ajdinski, 2018). Adolescence is a period of transition from childhood to adulthood which implies many developmental changes and challenges. One of the most critical turning points in the lives of adolescents is the transition from schools to the world of post-secondary education, employment, and life in the general community as an adult. The transition literature suggests that students with special needs require self-advocacy training, employability skills training, systematic referral to adult agencies, life skills education, family involvement, and immediate and ongoing job support to obtain and maintain employment over time (Atasi, 2015; WHO, 1997). Hence, comprehensive transition skills, employability skills, and related social skills must be taught during the high school years to ensure student success in the adult world. During the elementary and middle school years, special education services tend to emphasize academic skills. As students with disabilities enter adolescence and young

adulthood, a greater emphasis is placed on vocational and general life skills. This is commonly referred to as career education.

The trend across countries in the world is to increase the participation of people with disabilities in higher education, which will improve their competitiveness in the labor market, and also increase the choice of professions. The European Union has shown success in supporting higher education in the direction of building an inclusive and integrated higher education system. All countries in the European Union in the field of higher education must develop a coherent set of policy measures related to the active participation of higher education in inclusion, identification of underrepresented groups in higher education, specifying concrete and measurable activities to improve access, participation, and completion of education for these groups (EHEA, 2015). In R. N. Macedonia, education for persons with first and second degrees of disability is free and covered by the Budget of the Republic of Macedonia. Also, the Law on Higher Education of Students with Special Needs provides them with a series of advantages and facilities for studying such as free participation, the right to regular studies, the use of all services determined according to the student standard, and many others, but despite these positive aspects, the number of people who are educated is still quite low, in 2015 year, only 49 persons with disabilities completed higher education, 5 became masters. In the interviews and surveys that have been conducted so far with people with disabilities, they point out that several main barriers make their daily functioning difficult, and all of this affects the decision to continue the educational process. The most frequently emphasized barriers are entry and use of public facilities (infrastructural barriers), public transport, the use of services and products, and accessibility to information. Problems highlighted by students with disabilities themselves are the lack of adapted teaching materials (audio books, braille books or braille printers, assistive devices, alternative models of communication, etc.), insufficient accessibility in all institutions and rooms, insufficient awareness and availability of information (Aliu, 2022). Research conducted by MOF (2017) shows that in terms of the readiness of teachers/professors to work with pupils or students with any disabilities, respondents with disabilities themselves consider that, to the greatest extent, their teachers/professors are insufficiently trained and competent to work with them. On the other hand, the professors themselves point out the need for additional training for working with people with disabilities, while taking into account the policies that will determine the criteria for admission and enrollment of candidates in higher education institutions. In the context of higher education, and related to European policies to increase the inclusiveness of universities and increase the number of students with disabilities, the questions arise: "Can all types of disabilities be included within higher education?" and "Is it justified and should professors make an individual educational plan for students?"

As previously stated, the level of education and work training has a direct impact on the employment and social status of persons with disabilities. Although in 2000 in the Republic of North Macedonia, the Law on Employment of Disabled Persons was passed, which provided for the establishment of protective companies as trading companies in which persons with disabilities will be employed, the number of employed persons with disabilities is significantly small. According to a study and statistical analysis conducted in R. Macedonia, 989 unemployed persons with disabilities have been recorded, who are without education and any qualification, 47 unemployed persons with disabilities with a university degree, 3 persons are Masters of Science of which 2 are women with disabilities (AVRSM, 2021). Looking back, we will notice that there is a constant growth in the number of unemployed persons with disabilities, and even more worrying is the fact that the number in the age group of the most productive age is growing. In 2018 there were 1,282 unemployed persons with disabilities, the majority, 182, were between the ages of 55 and 59. In 2021 the statistics showed 1482 people with disabilities unemployed: 30 with higher education (50% females) and 1 with a master's degree, 208 (14%) aged 35-39, and 221 (15%) aged 39-49. Regarding the type of disability most dominant are 677 (46%) persons with developmental disabilities and 335 (23%) persons with motor impairments (AVRSM, 2021).

According to Mustafovska's research (2021), a significant part of the families in which people with disabilities live have a "bad" socio-economic situation and the monthly income is below the average monthly net salary in R. N. Macedonia, or something above that amount (28,642 denars according to (MAKSTAT, 2021) which is even less than the minimum union basket for 08.2021, which is 34,342 denars. This indicates that people with disabilities will likely not have enough funds for basic subsistence needs, not taking them considering the needs for medical examinations, medical aids, and other specific needs. Another problem that Mustafovska highlights about the employment of persons with disabilities, which directly affects the quality of their life, is the lack of regulations or norms for the employment of persons with reduced working ability. Companies only have regulations, norms, and codes for typical people, so if employ a person with a disability, they apply the same to them. Human services resources in companies, that are responsible for employing people from the general population and persons with disabilities, do not have educated employment managers for employment of persons with disabilities. This directly leads to problems with the organization and adjustment of the working area and conditions.

The mentioned problems and difficulties faced by people with disabilities and their families are only one of their everyday lives. If a correlation is made between daily functioning and satisfaction of basic needs, we will encounter a huge number of obstacles that people with disabilities have to overcome. A simple example is the procurement and use of orthopedic or assistive aids. Persons who are health insured in the Republic of Macedonia can exercise the right to orthopedic and other aids at the expense of the funds of Health Insurance Fund of Macedonia. According to the Rules for the allocation of orthopedic aids, the insured person is entitled to only one hand-powered room cart. An exception to this rule is made in a situation when the insured person who is employed or performs an activity based on which is insured, as well as children who are in regular schooling until 18, that is 26 years old, in addition to an indoor wheelchair, he has the right to an off-road one manual wheelchair. The problem arises at the moment when the need for additional aid is detected, necessary for the functioning of the person with a disability (e.g. dubak, scooter, belt, tricycle, etc.) in as many as 87.5% of people with disabilities. The additional aid is entirely at the expense of the family and on average amounts to 79,336 denars, which, considering the previously mentioned incomes, represents a problem whose solution requires many sacrifices and cancellations (Helsinki Committee for Human Rights of the Republic of Macedonia, 2021). Another example is the purchase of medicines which, among other things, are necessary for the prevention of deterioration of the condition. Although, a certain part of the costs of medicines are covered by the Fund, however, a significant part of the families participate with additional own means of procuring therapy. The results show that 70.6 percent of households had an additional cost in whole or in part borne by the family budget for the purchase of medicines.

In general, analyses of the quality of life of people with disabilities and their fellow citizens point out that people with disabilities have a lower quality of life in several segments. The results indicate poor accessibility to health services, to public institutions (bad infrastructure, inaccessible information), poor participation in social and cultural events, participation in political elections and consideration of their needs and demands, bad transport conditions (lack of suitable public transport), poorly accessible and unorganized public areas and spaces, architectural barriers, lack of sound signaling for visually impaired people, etc. (Dimitrova-Radojichikj, Chichevska-Jovanova, 2016). Families of people with disabilities highlight concerns about their children's housing, independent living, and survival after the death of their parents. Although R. N. Macedonia has had an option for housing with support since 2008, this system is still not sufficiently developed and cannot include a larger number of users, not only people who are deinstitutionalized but also people who want to live independently outside of the family. People with disabilities and their families highlight the lack of centers and organizations for recreational activities and socialization of young people, adults, and elderly people with disabilities, not counting daycare centers, as a special shortcoming in the social organization.

Conclusion

People with disabilities are entitled to the same human rights as people without disabilities, yet they are subject to direct and indirect discrimination and exclusion in almost every area of life. Non-discrimination includes the concept of reasonable accommodation that must be made for people with disabilities. Reasonable accommodation means carrying out, when necessary, appropriate modifications and adjustments, which do not impose a disproportionate or undue burden so that people with disabilities can enjoy their human rights and fundamental freedoms on an equal basis with others. Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. The rights-based approach to disability aims to empower disabled persons and to ensure their active participation in political, economic, social, and cultural life in a way that is respectful and accommodating of their differences.

What we should pay attention to in our country is the way of implementing world trends and practices aimed at improving the quality of life of people with disabilities and their active inclusion in every segment of society. The raw adoption of other people's practices and policies without analyzing them and adapting them to our context is the same as not taking any action at all.

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