

Social workers' role in the provision of services for families with children and youth with disabilities in Latvia, Slovakia, and Portugal

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Abstract. The current qualitative case study aims at exploring the role of social workers in the provision of support services to families of children and youth with disabilities in Latvia, Slovakia, and Portugal. To get a deeper understanding of the knowledge and lived experiences of professionals, a qualitative research design was used. Using purposive sampling, fifteen participants were identified of which 11 were social workers and 4 other professions. Social workers work closely with other professions to support families of children and youth with disabilities. Even though most of the participants agreed to a face-to-face interview, there were a few who were not able to participate in person due to language and the nature of work; therefore, an online means of gathering the data was used for a few participants. A thematic analysis was used to identify themes in the study that explained the available support and social services to families, which come from both private and public institutions. The study also revealed community-based services (deinstitutionalization) process in these three European countries.

1 Introduction

A disability is defined as any either mental or physical ailment (disorder) that makes it harder or the individual with a disability to perform definitive tasks (movement restriction) or participate in social interactions with the others (engagement with others) [1]. Over the past few decades, disability policy in Europe has evolved from conventional social legislation to a contemporary policy formulation that includes not solely social security and labour market integration but also equal rights and non-discrimination [2]. The social work field has received adequate training to create and enhance support structures, which include support networks and delivering services that progress well for individuals, families, and societies because of its strengths-based, person-in-environment perspective [3]. The EU-28 has structures and social services with high involvement of social workers as professionals. Still the knowledge on how the social profession meet the needs of how to assist families of children and youth with disabilities is not completely evident. The purpose of choosing three countries—Latvia, Slovakia, and Portugal—was to see the similarities and differences in the provision of support services to families of children and youth with disabilities in within the selected country cases. Even though all three countries are part of the EU and are unified by similar legislation, such as the Convention on the Rights of Persons with

Disabilities (CRPD), the Declaration of Children's rights and the European Strategy 2020–2030 aimed at full participation and inclusion of persons with disabilities. Each country has adapted its own laws on how they work with families with children and youth with disabilities.

The overall aim is to study the role of social workers in the provision of support services for families of children and youth with disabilities.

The specific objectives:

- (1) To frame the support services for families of children and youth with disability within social and medical disability model, Ecological system theory, and Human rights (HR).
- (2) To map different support services available for families of children and youth with disability.
- (3) To analyse social work practice in provision of services for families with disabled children and youth in Latvia, Slovakia, and Portugal.

Research question:

1. What support services are available for families of children and youth with disabilities?
2. What is the social workers role in the provision of support services?

2 Theoretical framework

Under the Convention on the Rights of Persons with Disabilities (CRPD), persons with disabilities are provided with equal and full privilege of all human rights as well as liberty and protection of this group [4]. For disability rights, civil rights are defined in terms of anti-discrimination statutes and equality laws. Social protection policies have always viewed disability from the perspective of lost competence to generate earnings and requirements for care and rehabilitation treatment [5]. The ecological perspective in social work views this model as human interaction physical, cultural, and social [6]. Social workers play a wide range of roles in terms of helping persons with psychosocial disabilities. There has been a shift in approaches to how disability is perceived. The shift is more of an individual, or “personalization” approach in terms of the treatment. Since the shift is personalized, social workers are employed to work with psycho-social disabilities, which matches the skills needed to work with a person with a disability [7]. As previously mentioned, ecological, and Human Rights (HR) perspectives are equally important in disability studies. However, in the European context of disability, there are two basic models for determination or framing disability and services, which have developed in the past decades. They are the medical and social models of disability. Initially, in Western democratic society, disability was seen as an individual “medical” issue or “personal tragedy” rather than social [8].

The medical paradigm or model of disability aims at studying disease through “observation, description, and differentiation”. It does not emphasize the aspects of individual strength and abilities. In short, it emphasizes disability rather than the individual [9]. The Social Model of disability is a new paradigm that determines the relationship between individuals and society. This model explains how society hinders accessibility and creates social exclusion for people with disabilities. It is the right-based approach, which is at the core of the United Nations Convention on the Rights of Persons with Disabilities [10]. In the disability area, the above-mentioned models and perspectives are important as they allow an individual, especially children, and youth with a disability, to be well integrated into society. The human rights perspective and ecological model allow children and youth with disabilities to assimilate into society through their citizenry laws and rights to access education, healthcare, and overall community-based services. Social work is a profession whose values of advocacy and empowerment are essential in disability studies.

The core values of social work emphasize improving individual quality of life focusing on interaction with other systems in society. While connecting these families to service providers, they also empower and educate them about the laws and their rights. Social workers adopt a humanistic approach in their profession, which is important from the human rights (HR) perspective.

3 Methodology

3.1 Research approach

The qualitative in-depth interviews aim at finding out the interaction and involvement of social workers with families of children and youth with disability. They also try to find their interaction with other disciplines in the provision of support services, as well as the social workers' subjective meaning to understand their role and experiences working with families with children and youth with a disability.

3.2 Sampling and selection of participants

In this research, the participants are social workers, school educators, special pedagogues, and special educators. Social work is a field where the profession demands that it collaborate with other professions regarding providing services and especially regarding disability, where various professions work together from the diagnosis stage to access services. Therefore, keeping in mind that disability is very broad and demands input from other professions besides social work, different professions such as pedagogical professions, school educators, and special educators were chosen. There was a total ($n = 15$) of participants, of which 5 informants were from Latvia: 4 social workers and 1 school educator. In Slovakia, there were 6 informants: 3 social workers, 1 special educator, and 2 special pedagogues. In Portugal, there were 4 social workers. The current study areas are Latvia, Slovakia, and Portugal. These three countries were chosen since they are part of the EU as well as because these countries adopted international laws and these countries have their own laws on how they work with people with disabilities. In all these three countries, the ratification of (CRPD) and UDHR has been implemented. However, there are variations in these support services. This small $N = 15$ case study covers the country cases from different regions in the EU. The methods and technologies used for data gathering, as well as data administration and analysis are covered in this section. In the current study, the research design is qualitative and the methods are: Interviews, documentary analysis, desk research, and descriptive statistics. Therefore, with the help of ATLAS.ti codes were identified, which helped to generate themes. For this research, thematic analysis is used. Findings are presented based on research objectives and summarized into themes and subthemes.

4 Social and support services for families of children and youth with disabilities

Findings are presented based on the research questions with reference to research objectives and summarized into themes and subthemes alongside professionals' statements that reflect each of these subthemes. Following themes have been found in the current study -Support services to families of children and youth with disabilities, Community based support (Deinstitutionalization), and social workers' roles. Four and 5 are findings based on research questions.

4.1 Social and support services for families of children and youth with disabilities

In Latvia and Slovakia, both public and private institutions provide support, while in Portugal, where the informants placed more emphasis on public support, public institutional support was crucial. The informants in the current research comprised of social workers, special pedagogues, and school educators had similar perceptions about formal support groups, which, according to them, consisted of professionals such as social workers, special educators, psychologists, doctors, etc. in all country cases.

“(..) we have to understand the whole course of the experience lived by families of children and youth with disabilities, perceiving their feelings, the difficulties expressed, and the needs felt, the support provided, the fears of the present and the future” (Interview with Social worker, Private Organization, Latvia).

Apart from municipality support, there are private organizations that provide services to families with children and youth with disability. Private organizations are also social service providers in cooperation with municipalities - Social work department, in providing services that are paid by the municipality, and in some cases, through charity organizations:

“We are a private organization, and our responsibility is just to cooperate with social services workers in the municipality when they send us their clients” (Interview with social worker, private organization, Latvia). *The organization provides ABA and speech therapy to patients who visit a centre away from the Riga region. “We have children who visit our centre twice a week, far away from Riga. Perhaps there is some cooperation with some municipalities. Some come for ABA therapy and speech therapy”* (Interview with social worker, private organization, Latvia).

The case study confirms the previous research that in Latvia role of the private or NGO sector in the provision of services for children and youth with disabilities and their families is substantial. Thus, reliance is both on parents (individual care - providers), and private and NGO sectors which are closely collaborating daily with social workers at municipalities and other stakeholders. The informants in Portugal emphasized the significance of institutions for support. Although it is possible that in this southern cluster, private support is equally important to public support, the informants from Portugal did not mention it in the current study.

However, in both the eastern countries, Latvia and Slovakia, the support came from both private and public institutions put rather high responsibility on individuals and families, compared to structures with higher relevance on state/ municipality institutions. Social work professionals emphasize the need to support those families in formal institutional settings– it is essential, as families are dependent on institutions for support needed for their children and youth with disability:

“Being a parent of a child with a disability requires health care, reformulation of intervention, as they become more dependent as they grow older. On the other hand, families who have been cared for throughout lifetime, need support from the institution to resolve daily family issues” (social worker, public organization, Portugal).

4.2 Deinstitutionalization and community - based services

In the current research, most informants were well informed about the national strategy for inclusion. All three countries have taken steps to integrate people with disabilities into society; however, there is variation in the process of inclusion. For example, in Latvia, a social worker stated that the deinstitutionalization process started in 2017, but few municipalities took part in this process. In Slovakia, the informants mentioned the process being slow. Portugal implemented the process before Latvia and Slovakia; however,

through this process, it was found out that most informants in all three countries felt that there was a lack of societal acceptance and limited support services, especially access and mobility, home-based care services, and day-care centres, which were lacking in all three countries. The process of integration and inclusion is moving at a slow pace. Social workers from social services and private organizations stated that, “*In Latvia, the deinstitutionalization process started in 2017, and all municipalities need to send information about the number of children and youth with disabilities in their municipality*”. (Interview with the Social worker, Social services, Latvia). In Slovakia, early intervention was established to provide guidance to families of children and youth with disabilities, to give them hope, and to give advice about services—medical services, therapies, financial support, or compensation, support from the government. One of the informants, a social worker in Slovakia, stated: “*Children are not required to stay in institutions. They can grow at home for a while before being able to integrate into kindergarten or school, and we support them while they go through this process with all institutions.*” (Interview with Social worker, private organization, Slovakia). A few social workers in the interview stated that they help parents solve problems after an earlier diagnosis. They stated that parents get support from us through early intervention, which works in the child’s natural environment, which is home. According to the informants, deinstitutionalization was declared in Latvia in 2017, but the process is taking a long time. Deinstitutionalization in Slovakia meant interacting with children and youth with disabilities in their own homes, which is their natural habitat. Early intervention was crucial in Slovakia because it helped families of children and young people with disabilities integrate more successfully into educational institutions. By working at home rather than looking for professions, the early intervention tries to address issues at an earlier stage of diagnosis and promote social integration for these children and youth. In Portugal, the constitution of Portuguese Republic aims at full inclusion of persons with disabilities, allowing them to be integrated well into society.

Community support means the assistance or services needed to promote independent living and integration in the society, as well as to prevent segregation or isolation from society. Most social workers in all three countries felt that society was not ready to accept these children and youth. Schools are not willing to take these children even though the DI (deinstitutionalization process) is implemented in these countries. There was a lack of day care and home-based care in all three countries. Most informants in the interview stated that there was a lack of inclusion of children and youth with disabilities into mainstream schools due to a lack of capacity and the unavailability of small classes. Each country has its own laws on how they provide support through integration to families of children and youth with disabilities. Similar research also indicated that nations have their own structures and methods for achieving this ideal goal by addressing their unique contextual obstacles and issues, despite the UN Convention on the Rights of People with Disabilities with Equal Rights for Inclusion in the Learning Process [11].

Social workers in Latvia stated that educational institutions are not well motivated to take children and youth with disabilities. In Latvia, to be able to enter a mainstream school or kindergarten, children must pass pedagogical medical commission to access the educational programs needed for individual child. “*Educational institutions are not very motivated to take children with disabilities. you must pass pedagogical medical commission which decides the type of educational program*” (Interview with social worker Latvia). Moreover, the school educator expressed that there is lack of inclusion in schools due to absence of small classes. “*There are many kids, and the problem is that, if there are 30 kids in class how can you see inclusion. We don’t have small classes in Riga*”. (Interview with School Educator, private organization, Latvia).

In Slovakia, majority of the interview informants felt that there is a greater need to develop integration and inclusion because there is lack of day-care centres. “*There is the*

lack of great number of day-care centres which hinders the possibility of developing integration and inclusion within mainstream schools". (Interview with Social worker, private organization, Slovakia). However, social workers along with other professions help families with their children transition from early education to kindergarten, which is essential in guiding families for better understanding of the child. "We also try to help with transition from early intervention to kindergarten. We also help by transitions when the child is changing his environment. We try to guide the family to help them understand things better". (Interview with Special educator, private organization, Slovakia).

In Portugal social workers stated that there is legal regime for inclusive education, which also aims at employability of person with disabilities. *"In this context, a set of initiatives and specific measures that sought to promote the autonomy, participation and self-determination of people with disabilities stand out: the Social Benefit for Inclusion, the Legal Regime for Inclusive Education, the creation of the "Modelo de Apoio à Vida Independente" (MAVI) Program, the approval of the new Legal Regime of the Accompanied Minor, the Promotion of the Employability of People with Disabilities and the Promotion of Physical and Digital Accessibility". (Social worker, public organization, Portugal).*

Apart from support services such as individual plans and family-centred approaches, in all three countries, most informants mentioned the availability of home-care support services. In Latvia, the municipality in collaboration with private organizations provide home care services for families of children and youth with disabilities. *"We have home-care, and I am in charge of signing the agreement with the care provider and receiving a report at the end of each month on how many hours they work, socialization activities, care, and reporting" (Social worker, private organization, Latvia). Informants from a private organization in Slovakia mentioned that there is a lack of homecare services for families of children and youth with disabilities. In one of the organizations in Slovakia, a few informants mentioned that youth with intellectual disabilities don't have the opportunity to integrate into society as there is a lack of home treatments, which leaves them in institutions. "There is a lack of homecare facility and availability of treatments as well as lack of inclusive education, which leaves youth with intellectual disabilities in institutions" (Interview with social worker, private organization Slovakia).*

In Portugal, social workers from public organization stated that the service exists but due to inaccessible finance, parents of children and youth with disabilities cannot avail it easily as there is big gap in access. *"The services mentioned exist, but they are not made available in sufficient numbers as needed, nor are they easily accessible financially". (Social worker, Public organization, Portugal.) Majority of social workers in all three countries felt that there is a greater need for access to transportation and mobility so that children and youth with disabilities can easily be included into society. "More structural accessibility such as ramps, adequate sidewalks, accessible transportation, which allow effective inclusion in society, allowing independent access to goods and services" (Social worker, Public organization, Portugal).*

Majority of the informants in the current research stated that community is informal support network and parents of children and youth with disabilities rely on communal support, but they don't receive the support from the community.

Other social workers also mentioned that often families report that they face difficulties in taking their children to social gathering. *"Families studied are aware of the importance of their children's socialisation for a more efficient integration in the different circles to which they belong. Most of them report difficulties in taking them to social gatherings outside the home". Social worker, public organization, Portugal*

Similar situation of low communal acceptance was also found in Slovakia, where majority of the informants stated that people with disabilities are not accepted into society.

“People in Slovakia will take time to accept people with disabilities as these people are not well integrated.”

There are still stigmas attached to disability, few informants mentioned that the process of acceptance is slow, but there are many campaigns being held to give awareness and educate people about disabilities in society. *“Last few years we have lot of campaigns because we have very good paralympic sports. Earlier people were afraid of speaking about disability.”* (Interview with social worker, private organization, Latvia).

5 Social worker’s role in the provision of support services

Social workers are professionals who help families with a family-centred approach through support and assistance. Social workers described how they create conditions that strengthen the resources needed by parents. Their role is to support and assist the families of children and youth with disabilities. *“From a family-centred intervention perspective, the social worker creates conditions to strengthen and expand the parents’ resources in order to help them perform their roles better through support and assistance.”* (Social worker, Public organization, Portugal).

5.1 Advocacy, empowerment and guaranteeing rights

Few informants in the interview expressed that they are in the position to advocate for families with difficulties. *“I always presented the children’s family difficulties to the Supervisors, in order to be helped to overcome their problems and avoid family breakdowns, but to contribute to the good and healthy development of the child and his family”* Social worker, social services, Latvia. Besides advocacy, social workers play an important role in empowering families and encouraging them to enhance their potential. *“To give visibility to disability and to people with disabilities, emphasising what they can do, to enhance their voice. To achieve this paradigm, it will be necessary to support and empower families, which are a key vector in the development and life path of people with disabilities”.* (Social worker, Social services, Latvia).

Apart from connecting families with service providers, a few social workers in the interview stated that social work is a profession that has the competence to guarantee rights to families and to look after their wellbeing. *“Social work is a professional category that possesses enough competence to carry out a work that aims at the well-being of families from the perspective of guaranteeing rights, since it is qualified to deal with families that are in social vulnerability”.* (Social worker, public organization, Portugal). Few social workers stated that they are in position of guaranteeing rights, however, sometimes they may not be able to bring in change at policy level due to limited resources. The research relates to [12] where it was mentioned that social workers play an important role in disability in accessing services, but they are limited to bringing social change and change in policy due to a lack of resources. Social workers at the municipal level stated that they are able to connect families to service providers, but their role is limited when it comes to bringing about social change. *“I can’t make big changes because I feel these changes start from the top and come down”.* (Social worker, Social services, Latvia).

Informants from social services in Latvia stated that their role is to connect families with service providers, guide families about available services, and help the families with paperwork, as sometimes it is a complicated procedure to avail services for families of children and youth with disabilities. *“We connect parents with service providers, and of course agreement, paperwork are main activities and goals”.* (Social worker, Social services, Latvia).

5.2 Consultation, education and connecting families to service providers

According to social workers in Latvia, many parents are unaware of the services that are available to them because there are not many pages or websites where they may learn about them. The social workers assist families by teaching them with the necessary paperwork and papers to access support services within their designated social service territory. *“I try to help family who get through consultation, who send email, or some colleagues ask me to help them. When they come to this organization, I explain them the required forms and documents needed to require services for their child from social services, as there is limited pages or website where parents can see available services”* (Social worker, private organization, Latvia).

In Slovakia, the informants from private organizations mentioned the importance of educating parents to manage the family situation better. *“We prepare some internal education for parents to get enough information that will help them manage the situation better in the family. We plan some educational workshops on the topic of communication and the prevention of burnout in parents.”* (Social worker, private organization, Slovakia).

In Portugal, informants from public organizations also expressed that social workers inform families and caregivers about the legislation as well as the documents needed to receive social benefits. *“The social workers inform families and caregivers about the legislation and benefits of the children and youth with disabilities, indispensable documents to receive social benefits, apply for support services, and contact institutions for the best development and growth of their children throughout their lives.”* (Social worker, Public organization, Portugal).

5.3 Multidisciplinary approach in support services to families

Most of the informants showed a great appreciation for multidisciplinary cooperation in giving support to families with children and youth with disabilities. *“You know there is always cooperation between me, my co-workers, and the family. So, if the problem is feasible, we are constantly in contact with colleagues from our work, from our team”* (Social worker, Social services, Latvia).

In Slovakia, few informants expressed that cooperation with other organizations, such as the law and protection for children, is an essential part of their role and responsibility. Social workers communicate with these organizations to overcome obstacles related to children. *“When we notice some family-related problems, we invite other experts from different organizations, and the workers in the fields of law and social protection for children ask for collaboration. Together, we discuss what they can do, what we can do, and how to inspire the parents”.* (Social worker, private organization, Slovakia).

Social workers from the public sector in Portugal described that it is very essential to work as a team that needs cooperation and coordination to provide support to families of children and youth with disability. *“Working as a team in the rehabilitation process, which has as its goal the social inclusion of the person with disabilities and support for their family, presupposes a multidisciplinary methodology. It is understood that the whole team needs coordination, and I emphasize the importance of the team coordinator’s role and the need to train the different technicians for this objective.”* (Social worker, Rehabilitation centre, Portugal).

6 Conclusion

The current qualitative case study focused on the similarities and differences in the provision of support services to families of children and youth with disabilities in Latvia,

Slovakia, and Portugal. Even though all three countries are part of the European Union (EU) and are unified by similar legislation, such as the Convention on the Rights of Persons with Disabilities (CRPD), each country has its own laws on how they work with families with children and youth with disabilities. Disability policy in Europe has evolved over the past few decades from a previously underutilized area that comprises conventional social legislation to a contemporary policy formulation that includes not solely social security and labour market integration but also equal rights and non-discrimination.

There are various support services available in each country for families with children and youth with disabilities. Support includes formal, which comes from municipalities, non-government organizations, and private organizations. Informal support includes extended family, charity organizations peer groups, parental clubs etc. Both formal and informal support services are essential for families. In recent times, the process of deinstitutionalization has allowed national-level legislation for integration and assimilation into society, but it was found in the present study that the process of deinstitutionalization is slow and there is a lack of communal support in the assimilation of children and youth with disabilities. The social worker's role is very essential in the disability area. They contribute skills and expertise to help communities, families, and persons with disabilities with strategy formulation and administration, as well as individual case management, planning, consulting, and coordination.

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