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Challenges and Needs in Supporting Families of Individuals with Disabilities

Wyzwania i potrzeby we wsparciu rodzin osób z niepełnosprawnością

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Abstract
Aim. The aim of this article is to illustrate the functioning of a family having a person with a disability, highlighting its key role in the processes of care, support, and social integration. A definition of the family as the first, fundamental, and most important environment in a person’s life is provided. The concept of *disability* is explained with reference to the United Nations Convention on the Rights of Persons with Disabilities. The article also seeks to analyse the challenges and needs of families with a person with a disability and to identify the forms of support offered to them by institutions, including associations.
Methods and materials. The article is based on a subject literature review, which was complemented by insights gained from many years of professional experience in the field. Comparative analysis was applied to selected international examples of support systems for families raising children with disabilities. These examples include practices implemented in France, Great Britain, Sweden, and Australia, offering a broad perspective on diverse systemic solutions.

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Results. The analysis reveals that families of people with disabilities face significant burdens, both emotional and financial. While systemic forms of assistance exist, they often fail to correspond to the real needs of families. International examples demonstrate that, despite different organisational frameworks, the common objective is to ensure family stability, foster integration, and promote the active participation of people with disabilities in social life. Particular emphasis is placed on the role of the Polish Association for Persons with Intellectual Disability (PSONI) – the oldest non-governmental organisation in Poland serving this community. Its activities highlight the importance of non-institutional, grassroots initiatives in complementing state support systems.

Conclusion. Effective institutional support can significantly enhance the quality of life for both people with disabilities and their families. However, in practice, access to such support is often limited or inadequate. Families frequently report insufficient knowledge of their rights, available services, and strategies for managing everyday challenges. Education and counselling are therefore key elements of effective assistance. The article concludes with recommendations for strengthening support systems through interdisciplinary approaches and intersectoral cooperation. This would allow for more responsive and tailored solutions, ensuring that families receive the resources they need to thrive and to facilitate the full social integration of people with disabilities.

Keywords**:** family, child, person, disability, support, system, difficulties, challenges

Abstrakt

Cel. Celem artykułu jest ukazanie funkcjonowania rodziny z osobą z niepełnosprawnością, z podkreśleniem jej kluczowej roli w procesach opieki, wsparcia i integracji społecznej. Przedstawiono definicję rodziny jako pierwszego, podstawowego i najważniejszego środowiska w życiu człowieka. Pojęcie niepełnosprawności zostało wyjaśnione w odniesieniu do Konwencji Narodów Zjednoczonych o prawach osób z niepełnosprawnościami. Artykuł ma także na celu analizę wyzwań i potrzeb rodzin z osobą z niepełnosprawnością oraz wskazanie form wsparcia oferowanych im przez instytucje, w tym stowarzyszenia.

Metody i materiały. Artykuł opiera się na przeglądzie literatury, który został uzupełniony o wnioski wynikające z wieloletnich doświadczeń zawodowych autora w tej dziedzinie. Zastosowano analizę porównawczą wybranych międzynarodowych systemów wsparcia dla rodzin wychowujących dzieci z niepełnosprawnościami. Przykłady te obejmują rozwiązania funkcjonujące we Francji, Wielkiej Brytanii, Szwecji i Australii i ukazują szeroką perspektywę zróżnicowanych podejść systemowych.

Wyniki. Analiza ujawnia, że rodziny osób z niepełnosprawnościami mierzą się z istotnymi obciążeniami, zarówno emocjonalnymi, jak i finansowymi. Choć istnieją systemowe formy wsparcia, często nie odpowiadają one rzeczywistym potrzebom rodzin. Międzynarodowe przykłady dowodzą, że pomimo odmiennych ram organizacyjnych wspólnym celem jest zapewnienie stabilności rodziny, wspieranie integracji oraz promowanie aktywnego uczestnictwa osób z niepełnosprawnościami w życiu społecznym. Szczególną uwagę zwrócono na rolę Polskiego Stowarzyszenia na rzecz Osób z Niepełnosprawnością Intelektualną (PSONI) – najstarszej organizacji pozarządowej w Polsce działającej na rzecz tej społeczności. Jej działalność pokazuje, jak ważne są oddolne, pozainstytucjonalne inicjatywy uzupełniające wsparcie państwowe.

Wnioski. Skuteczne wsparcie instytucjonalne może znacząco poprawić jakość życia zarówno osób z niepełnosprawnościami, jak i ich rodzin. W praktyce jednak dostęp do takiej pomocy bywa ograniczony lub niewystarczający. Rodziny często zgłaszają brak wiedzy na temat przysługujących im praw, dostępnych usług oraz strategii radzenia sobie z codziennymi wyzwaniami. Dlatego edukacja i poradnictwo są kluczowymi elementami skutecznego wsparcia. Artykuł kończy się rekomendacjami dotyczącymi wzmocnienia systemów wsparcia poprzez podejście interdyscyplinarne i współpracę międzysektorową. Pozwoliłoby to na bardziej adekwatne i dostosowane rozwiązania zapewniające rodzinom dostęp do zasobów potrzebnych do prawidłowego funkcjonowania i wspierające pełną integrację społeczną osób z niepełnosprawnościami.

***Słowa kluczowe*:** rodzina, dziecko, osoba, niepełnosprawność, wsparcie, system, trudności, wyzwania

The Role of the Family in the Support System

The family provides a sense of security, surrounding its members with affection and care. It serves as the foundation for shaping an individual's character and values within society. Close bonds between family members allow individual personalities to merge, creating a cohesive whole. Each member's personality becomes a shared experience of the entire family, and its development becomes a collective goal (Ziemska, 1977). In pedagogy, the term *family* refers to the first, fundamental, and most important environment in a person's life (Izdebska, 2015).

For a child, the family constitutes a natural educational environment, distinct from institutional forms of upbringing, such as schools or extracurricular facilities (Matyjas, 2020). One of the family's greatest strengths—giving it an advantage over other environments—is the early onset of its influence. This influence begins not only earliest but also endures the longest. However, its strength depends not only on duration but also on continuity. Continuity is particularly important, as it is closely linked to a sense of closeness and security – conditions essential for the emergence and development of psychological, emotional, and social needs. These needs, in turn, support the child's healthy development across all domains (Ziemska, 1977).

The family thus proves to be the most important and irreplaceable environment in a person's life, playing a key role in the process of upbringing and personal development. It is within the family that a child first experiences love, care, and safety, and begins to shape their character and value system. Unlike institutional forms of education, the family's influence is both the earliest and the most enduring. The continuity of family relationships provides a sense of stability, supporting the fulfilment of emotional and social needs and fostering the child's harmonious development in multiple dimensions.

The family is also the place where individuals learn how to build relationships, take responsibility, and express love. Its forms and roles evolve across cultures, historical periods, and social contexts, reflecting the dynamic nature of human society. Matyjas (2024) characterises the contemporary Polish family in the following terms:

> The contemporary Polish family has been both the subject and object of pedagogical research since the inception of pedagogy as a science at the turn of the 19th and 20th centuries. It has always been, and continues to be, regarded as the primary environment for children's lives and upbringing, and more broadly, for their socialisation – that is, their preparation for social life and the various roles they will assume in adulthood. Scientific interest in the family thus has a specific focus within pedagogy: the upbringing of the younger generation. It should be noted, however, that this approach to the family is interdisciplinary, with pedagogy drawing on definitions and research from other social sciences, primarily sociology (of upbringing) and psychology (social, educational, and developmental). (Matyjas, 2024, p. 35)[1]

Parents fulfil multiple roles, acting as providers, caregivers, and educators. They make important decisions on behalf of the child and bear responsibility for the child's life path. However, the role of parents is not limited to caregiving. They play a decisive role in shaping the child's personality, their world of thoughts, emotions, aspirations, and in the formation of self-image and sense of personal identity (Ziemska, 1977).

Tyszka identified five key functions of the family: sexual, material-economic, regulatory, socialisation-educational, and emotional-expressive (as cited in Pilch & Lepalczyk, 1995). Today, parental roles are increasingly complementary, with parents alternating in performing caregiving and educational tasks.

The Concept of Disability in the Context of the UN Convention on the Rights of Persons with Disabilities

Disability is understood as a dynamic phenomenon – an interaction between the individual with a disability and their environment. It is subject to continuous transformation and is not regarded as a deficit inherent to the person (Oszustowicz & Lechta, 2009).

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[1] Author's own translation.

In the approach adopted in 2001, the term *disability* is used to describe "[…] a multidimensional phenomenon resulting from the mutual interactions between individuals and their physical and social environment"[2] (Kilian, 2007, p. 14).

There remains considerable ambiguity surrounding the concept of *disability*. Although the term appears in educational, healthcare, and social welfare regulations, its interpretation and understanding vary across contexts. Disability should be viewed not only as a characteristic of the individual but also as a function of the relationship between the person with a disability and their surroundings. It becomes apparent in situations where the individual encounters cultural, material, or social barriers. In this framework, disability signifies a limitation or lack of opportunity to fully participate in social life on equal terms with other members of the community. While the need for individuals to adapt to social conditions remains important, it is equally essential to pursue environmental transformation by eliminating barriers that hinder social integration. This integration — understood in a multidimensional way — forms the foundation of the modern paradigm of disability perception (Abramowska, 2014).

According to the United Nations Convention: "[…] disability is an evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, Preamble, § e, p. 1).

This document defines persons with disabilities as "[…] those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, Article 1, p. 4). The Convention complements previously adopted United Nations human rights treaties. It applies to approximately 650 million persons with disabilities worldwide. It is the first international document to frame the rights of persons with disabilities in terms of human rights, and to outline the obligations of States to ensure and uphold those rights (Leśniak, 2019).

Poland ratified the Convention on 6 September 2012, thereby committing to uphold all of its principles and values. As a result, the Convention became part of Polish law, and authorities at all levels — as well as society at large — were obligated to apply its provisions in everyday life. This document reflects a modern approach to disability, marking a shift from care and the medical model toward a holistic view of the individual. The text of the Convention was published in the *Journal of Laws* on 25 October 2012 (Konwencja [Convention], 2012). The Convention aims to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities, as well as to promote respect for their dignity.

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[2] Author's own translation.

As Abramowska writes, the Convention emphasises the importance of respecting the autonomy and independence of persons with disabilities, which includes the right to make choices and decisions independently – even in matters related to politics or support programs. However, their ability to live independently may be significantly limited not only by health-related impairments but also by external barriers – such as social prejudice, inadequate infrastructure (buildings, transportation, and communication), or ineffective systemic solutions in law, administration, and public services. Lack of access to these areas leads to the marginalisation of persons with disabilities and their families, and makes them dependent on the assistance of others (Abramowska, 2014). The Convention clearly emphasises that the independence and autonomy of persons with disabilities are not privileges, but fundamental human rights. It points out that obstacles to leading an independent life do not stem solely from the disability itself, but largely from social, infrastructural, and systemic barriers. This perspective shifts the responsibility for creating conditions conducive to social inclusion from the individual to society and public institutions. Ultimately, this means that addressing the exclusion of persons with disabilities requires not only medical or caregiving support but, more importantly, structural, legal, and attitudinal changes that guarantee equal participation in social life.

Participation in social life is closely linked to the realisation of numerous rights outlined in the Convention. As Abramowska (2014) summarises, these include: 1) The right to live in the community and to make choices on an equal basis with others (Article 19); 2) The right to education, which must be inclusive, lifelong, and adapted to individual needs, enabling persons with disabilities to acquire life and social skills through accessible means and formats (Article 24); 3) The right to enjoy the highest attainable standard of health without discrimination based on disability (Article 25); 4) The right to rehabilitation aimed at maximizing independence, physical, mental, social, and vocational abilities, and full participation in society (Article 26); 5) The right to work and employment on equal terms, including protection against discrimination in hiring, promotion, pay, and working conditions, as well as reasonable accommodation and protection from forced labour (Article 27); 6) The right to an adequate standard of living and social protection for persons with disabilities and their families, without discrimination (Article 28); 7) The right to participate in political and public life, including voting and forming organizations to represent their interests at national, regional, and local levels (Article 29); 8) The right to take part in cultural life, recreation, leisure, and sport (Article 30).

The Convention affirms that disability is a human rights issue. It is therefore the responsibility of every state to ensure broad support for persons with disabilities – support that reflects their rights and aspirations.

Family Caring for a Person with a Disability

Undoubtedly, the role and significance of the family become even more pronounced when considering the development and functioning of persons with disabilities. Rehabilitation concepts emphasise the importance of supporting individuals with disabilities within their natural family environment. They also highlight the need to move away from institutional rehabilitation models in favour of approaches that empower the families of persons with disabilities (Hulek, 1984). Implementing a comprehensive rehabilitation model is both complex and demanding. As the family's role in raising a child with a disability grows, so too do the challenges involved in putting such a model into practice. Families raising children with intellectual disabilities should receive systemic support that includes both emotional assistance and practical forms of help in daily care (Namysłowska, 2007).

A family with a member who has a disability may face challenges that affect multiple areas of life, including emotional, financial, social, and organisational aspects.

In the literature, numerous models describe the stages of family adaptation to the situation of having a child with a disability. One recognised approach is the model proposed by Popielecki and Zeman (2000), which distinguishes the following stages: 1) Uncertainty – surprise, shock; 2) Certainty – real suffering, "my world is changing," fear; 3) Aggression – rebellion, "why did this happen to me?," searching for someone to blame, anger; 4) Attempting – defensive in nature, seeking possibilities for help, sorrow; 5) Depression – helplessness in relation to the illness, decision-making ("am I with the child or against the child?"), powerlessness; 6) Acceptance – acquiring knowledge, learning about the illness, sensing one's importance to the child, friendship; 7) Activity – action, assistance, cooperation with the family, love; 8) Solidarity – acting with other parents, collaborating within a group of parents of children with disabilities, love.

From the perspective of the contemporary biopsychosocial model, disability is not solely an individual issue but becomes a phenomenon that affects the entire family system. Its consequences may include experiences of social exclusion not only for persons with disabilities but also for their close relatives (Kornas-Biela *et al*., 2016).

It is important that families receive support at every stage, as this can significantly influence their ability to adapt and provide appropriate care for their child.

The situation of families raising children with disabilities has been examined by analysing selected characteristics: "parental attitudes toward the child, the atmosphere of family life, the family's social structure, and the personality traits of the parents"[3] (Obuchowska, 1995, p. 19). Researchers assumed that the greater the irregularities within the family environment, the more pronounced the disruptions in the processes

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[3] Author's own translation.

of upbringing and caregiving for children with disabilities would be. However, the cause-and-effect model used to analyse the functioning of families with a disabled member does not fully capture the complexity of these families' situations. This model suggests a link between inappropriate parental attitudes and disturbances in the child's social development, attributing these outcomes to the use of inadequate parenting methods. It does not, however, explain why excessive protection of the child leads to difficulties in assuming social roles.

Greater insight into the psychological and social situation of families with members who have disabilities is offered by the interactional and systemic models of family functioning.

In the interactional approach, an individual's characteristics are viewed as derivative of the processes of their interaction with the social environment, particularly with close family members (Obuchowska, 1995). Behaviours are analysed in the context of mutual exchange between the individual and their social partners. The interactional approach is closely linked to the systemic view of intra-family relationships.

The systemic model assumes that there are interdependencies among the behaviours of family members. It also posits that the family is part of a broader social system, while simultaneously functioning as an autonomous unit whose purpose is to sustain its own existence and provide conditions for development (Obuchowska, 1995).

Adopting the interactional and systemic concepts of family functioning has made it possible to formulate certain assumptions about families with members who have disabilities. The difficulties faced by parents and other family members, as well as the relationships between the child and their close relatives, should be regarded as equally important as the child's developmental disorders themselves. It therefore becomes essential to strive for the optimal functioning of the entire family as a system. The emergence of a disability in a child affects the family's daily life, often modifying or completely altering its previous patterns of functioning. This may lead to increased tension and conflict among family members.

A full understanding of what occurs within the family following a diagnosis requires a longitudinal perspective. Only then can the interconnections between emerging phenomena be recognised, rather than being reduced to simple cause-and-effect relationships (Obuchowska, 1995). A child's disability affects not only their individual development but also significantly transforms the functioning of the entire family. It alters established patterns of daily life, which may lead to increased tension and conflict. Support should therefore extend not only to the child but also to their close relatives, treating the family as a cohesive system. Viewing the issue over time allows for a better understanding of the interconnections between various phenomena and emphasises that care for the child must go hand in hand with strengthening the entire family.

It is essential to recognise the psychological processes that arise both in the relationship between parents and their child and in interactions between parents and professionals. This approach is grounded in mutual listening, empathy, and the willingness to understand the other person, while also maintaining the ability to defend one's own beliefs and the readiness to modify them when the situation requires it (Żyta & Ćwirynkało, 2015).

No environment outside the family can fully satisfy the need for love. For a child to learn how to love and share that love with others, they must first be loved themselves and feel that they are needed by those closest to them. A child should be "needed and loved regardless of whether they are attractive or less so, more or less gifted, easy to raise or more challenging, healthy or prone to illness"[4] (Ziemska, 1977, p. 159). Acceptance is therefore essential for children — and later adolescents and adults — to be able to accept themselves and believe in their own strengths and capabilities.

Support and Examples of Good Practice in Poland – A Non-Governmental Organisation

Support refers to assistance offered to an individual or group experiencing a difficult or stressful situation. Many authors refer to the typology of social support developed by House (1981), which includes: 1) Emotional support – offering comfort, understanding, empathy, and presence; expressing care and fostering a sense of safety. This type of support is very common and most frequently expected; 2) Instrumental support – providing concrete guidance for the situation and the individual, including instruction; 3) Informational (cognitive) support – delivering reliable knowledge and information about the current situation and ways to cope effectively. This may include information about self-help groups or shared experiences from individuals who have faced similar circumstances; 4) Appraisal support – analysing personal actions and providing feedback.

Other authors propose a simplified classification, dividing support into emotional support (expressing care and interest, building a sense of safety, helping to reduce feelings of isolation, anxiety, and uncertainty) and practical support (concrete solutions; Sęk & Cieślak, 2004).

Support is critically important, as it enables individuals and groups to overcome difficulties, enhances their well-being, and fosters development. Despite the many challenges faced by families raising a child with a disability, often many draw strength and support through the work of non-governmental organisations. Contemporary society

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[4] Author's own translation.

shows increasing awareness and sensitivity to the needs of persons with disabilities, creating opportunities to improve the quality of life for these families. Assistance provided to individuals in difficult situations can be delivered by social groups functioning as organised relational systems, whose structures and mechanisms of operation can be analysed using a network-based approach (Szymanowska, 2019). Social support can thus be understood as all existing social networks that are accessible in times of hardship and capable of providing assistance.

Non-governmental organisations (NGOs) are a vital component of democracy and civil society, undertaking actions in the interest of both the state and the public.

In Poland, standards for supporting people with disabilities within local communities have been implemented for over 60 years. One such network through which families can access support is the Polish Association for Persons with Intellectual Disabilities [*Polskie Stowarzyszenie na rzecz Osób z Niepełnosprawnością Intelektualną*, PSONI]. This is a parent-led movement that has organised itself into an association advocating for individuals with intellectual disabilities and their families. PSONI is the oldest and largest non-governmental organisation in Poland working on behalf of people with intellectual disabilities.

The association brings together thousands of parents, professionals, and individuals with intellectual disabilities who work collaboratively, actively, and creatively to promote the full inclusion of people with intellectual disabilities in society. PSONI pursues its statutory goals across several key areas: 1) Advocacy and legal reform – initiating changes in legislation to ensure the protection of human rights for persons with intellectual disabilities and to meet their needs; 2) Expert activity and research – inspiring and collaborating on scientific research related to various aspects of intellectual disability; 3) Information and education – conducting informational, advisory, outreach, educational, training, and publishing activities; 4) Service provision – offering a wide range of services, including comprehensive, multidisciplinary support centres for individuals with intellectual disabilities of all ages, from birth to end of life, while also supporting their families.

Currently, PSONI operates 312 facilities across Poland, providing support to 28,316 individuals – children, adolescents, and adults. It employs over 8,000 staff members and collaborates with approximately 1,000 volunteers. Families can access support through a nationwide network that includes 83 occupational therapy workshops, 69 rehabilitation and educational centres, 25 early intervention clinics, 54 community support centres, 14 vocational activity establishments, 14 life skills schools, 27 day care and therapy centres, 18 training apartments, 16 supported housing units, 2 community organizing centres, 20 kindergartens, 6 early development support clinics, 7 special schools, 6 employment support centres, 6 residential care homes, and 49 other types of facilities (PSONI, n. d.).

PSONI is a pioneer of innovative approaches to disability, a representative of the interests of people with intellectual disabilities, and an effective advocate for changing societal attitudes toward this group in Poland.

The association's social initiatives, developed and refined over the years, have been permanently incorporated into Poland's social policy (Leśniak, 2017). PSONI collaborates with a wide range of partners, including other non-governmental organisations, educational institutions, universities, municipal authorities, training centres, healthcare and social care facilities, international and governmental organisations, national and local authorities responsible for supporting persons with disabilities, as well as individual supporters and relevant organisations working on behalf of persons with disabilities in other countries. PSONI undertakes actions to promote equal opportunities for persons with intellectual disabilities, to create conditions that ensure respect for their human rights, to guide them toward active participation in social life, and to support their families (PSONI, 2023). Members of the Association include parents and legal guardians, persons with intellectual disabilities, their family members, and friends.

As Abramowska observed, engaged parents have played a key role in supporting families and persons with disabilities at every stage of social transformation in Poland. Their activities — initially spontaneous, informal, and driven by enthusiasm, goodwill, and altruism — gradually evolved into more organised forms, gaining effectiveness and influence. Through their consistent efforts — both within international organisations such as the European Disability Forum and national associations — changes were achieved in local and international legislation, as well as in social policy toward persons with disabilities. The system of institutions and services providing support to this group was also transformed, public awareness of their needs and capabilities grew, and persons with disabilities themselves gained greater influence over shaping their own life circumstances (Abramowska, 2014).

Abramowska (2014) provides a detailed account of the systemic barriers faced by persons with disabilities and their families in Poland. Her critique highlights the fragmentation of services, the dominance of outdated models, and the urgent need for coordinated policy reform. Families of persons with disabilities in Poland face a wide range of systemic challenges. These include a lack of professional guidance regarding available support, inconsistent service standards across regions, and limited access to high-quality assistance. Early childhood support is often dominated by a medical model, with delayed referrals to non-medical specialists and an absence of interdisciplinary teams capable of assessing and addressing the needs of both the child and the family. There is no coordinated system for monitoring individuals with intellectual disabilities or ensuring continuity of support as they transition through education and into adulthood. Teachers receive insufficient assistance when working with children with disabilities, and institutional cooperation remains fragmented, leading to duplicated and scattered services. Adults with disabilities encounter a lack of structured pathways into adulthood, including few opportunities for supported or protected employment in the open labour market, and a shortage of training apartments, protected housing, and emergency accommodation. Support for adults with complex and profound disabilities — and their families — is especially inadequate. As Abramowska (2014) emphasises:

> It is therefore necessary to organise and coordinate actions around the person with a disability, their family, and the institutions they engage with. Efforts should be directed toward the creation of a government programme for persons with disabilities — especially intellectual disabilities — that integrates the activities of the ministries of social policy, health, and education. (p. 136)[5]

An analysis of the social, cultural, political, and economic conditions of life for Polish families raising children with disabilities makes it possible to better capture their experiences in relation to social policy, the health care system, and prevailing societal attitudes. Despite noticeable progress in this area, it is still difficult to regard the situation of families caring for children with special developmental and educational needs as fully satisfactory (Cytowska, 2017).

Examples of Solutions in Selected Countries

In various countries, families raising children with disabilities benefit from different forms of support, including financial, institutional, and educational-social assistance. Financial benefits aim to compensate for the costs associated with care and rehabilitation – for example, *France's Allocation d'Éducation de l'Enfant Handicapé* [Disabled Child Education Allowance, AEEH] and the United Kingdom's Disability Living Allowance [DLA]. Institutional support ensures access to specialised facilities, personal assistance services, and local structures that coordinate aid, such as *France's Maisons Départementales des Personnes Handicapées* [Departmental Homes for Disabled People, MDPH]. The socio-educational dimension is also of key importance, with an increasing role played by inclusive education, support teachers, and networks of family and peer support (Gardou, 2012; McCrossin *et al.*, 2025).

Sweden is renowned for its extensive system of social support. Families can access a care allowance (*vårdbidrag*), assistance from personal aides for children, and a wide network of psychological counselling and support groups organised by municipalities. The Swedish model offers not only financial assistance but also fosters conditions

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[5] Author's own translation.

for the integration and active participation of the entire family. Support for families of children with disabilities in Sweden is based on both institutional solutions and informal assistance provided by the immediate community. This includes financial benefits, rehabilitation services, temporary respite for caregivers, and a well-developed network of social initiatives.

An important component of support is habilitation (*habiliteringstjänster*) – a multidisciplinary form of assistance for children with developmental disorders and their families. Recent research by Täljedal has shown that the lack of adequate formal and informal support significantly increases parental stress (Täljedal, 2024). Despite a well-developed social policy system, support provided within the family and close social networks remains highly significant. As Grassman and colleagues observe, even in a welfare state such as Sweden, the role of family-based support continues to be crucial to the quality of life of children and their caregivers (Grassman *et al*., 2009).

An important tool of Swedish social policy is respite care – short-term substitute care designed to relieve parents. As Engwall (2021) describes, respite care may be provided by institutions, supporting families, or during camps, and is offered free of charge, with families only required to cover food expenses. This solution allows families to recuperate and helps reduce the psychological burden associated with daily caregiving.

By contrast, the support system for families raising children with disabilities in Australia is among the most extensive and complex in the world. It is based on a combination of government instruments, the activities of non-governmental organisations, and grassroots initiatives such as support groups. A key element of this policy is the National Disability Insurance Scheme (NDIS), complemented by a range of therapeutic, educational, and social programmes.

The introduction of the NDIs in 2013 marked a new phase in social policy for persons with disabilities in Australia. The programme was designed to enhance independence and promote active participation in society for individuals with permanent and significant health-related limitations. As Lai and colleagues emphasise, the NDIs was developed to support the process of building autonomy among persons with disabilities and to expand their opportunities for engagement across various areas of social life in Australia (Lai *et al*., 2025).

The NDIs is based on individual support plans developed in collaboration with families and service recipients themselves. According to the analysis by multiple researchers, including Smith-Merry and colleagues, the programme remains "[…] the largest social policy experiment in Australia's history" after a decade of operation, yet it continues to struggle with inequitable access and administrative challenges (Smith-Merry *et al*., 2023).

In addition to government forms of assistance, non-profit organisations such as Lifestart play a significant role by offering services in early intervention, therapy, and family counselling. Their work is based on the key worker model, which assigns a single specialist to each family to coordinate therapeutic and educational activities. The key worker model helps improve relationships with institutions, reduces the number of unmet needs, and increases parental satisfaction and engagement in the support process (Young *et al.*, 2021). Additionally, this model is recommended as best practice by Early Childhood Intervention Australia due to its capacity to reduce family stress (Alexander *et al.*, 2019).

A comparison of support systems for families raising children with disabilities across different countries reveals significant variation in institutional, financial, and social solutions, while also highlighting shared goals in social policy. France offers extensive material and organisational instruments. The United Kingdom, like Poland, focuses primarily on financial benefits, while simultaneously developing inclusive education, whose core aim is to increase the integration of students with disabilities into mainstream schools.

Sweden, by contrast, represents an approach in which formal social and rehabilitative instruments are complemented by informal support provided within families and local social networks. Particularly important in this context are habilitation and respite care, which not only foster development but also reduce the psychological burden on caregivers and enhance their sense of security.

The Australian support system is highly complex, with the NDIs at its core. Although innovative, the NDIs is hindered by unequal access and an intricate administrative framework. The system is further shaped by the significant contributions of the non-governmental sector.

In light of the above analyses, it can be concluded that the most effective support system should combine stable state mechanisms with the flexibility of non-governmental organisations and the role of informal support. Only such an integration of diverse forms of assistance enables families of persons with disabilities to not only cope with everyday burdens but also to achieve long-term emotional, social, and educational well-being.

Conclusion and Recommendations

Support for families raising a child or caring for a person with a disability is a key element in improving their quality of life, fostering social integration, and building a system based on solidarity and inclusion. This text clearly indicates that comprehensive assistance — encompassing emotional, social, environmental, legal, and material aspects — has a direct impact on the functioning of the entire family, not only the person with a disability.

Long-term support requires collaboration among multiple institutions – from educational and medical facilities, through non-governmental organisations, to public administration. Equally crucial is the inclusion of families' perspectives in the development of social policies and support programmes – only then is it possible to genuinely respond to their needs.

An analysis of international examples reveals numerous sources of inspiration that may contribute to improving support systems for families raising children and individuals with disabilities. Particularly important is the integration of various forms of assistance — financial, institutional, and socio-educational — in order to respond comprehensively to the complex needs of families. The Swedish model highlights the significance of habilitation and respite care, which simultaneously promote development and alleviate the psychological burden on caregivers. Australia offers inspiration through individual support plans and the key worker model, both of which enhance service coordination and provide parents and caregivers with a greater sense of security. Meanwhile, the French and British approaches demonstrate the value of combining material benefits with inclusive education, enabling both the compensation of care-related costs and fuller social participation. These findings suggest that an effective support system should be characterised by flexibility, collaborative partnerships between the state, non-governmental organisations, and families, and the provision of long-term, coherent assistance. Only in this way can a society be built in which every family — regardless of its circumstances — can live with dignity, hope, and a sense of security.

References

Abramowska, B. E. (Ed.). (2014). *Wpływ ruchu rodziców osób z niepełnosprawnością intelektualną na rozwój nauki i życie społeczne: Raport z badań* [The impact of the movement "Parents of People with Intellectual Disabilities" on the development of science and social life: Research Report]. Polskie Stowarzyszenie na Rzecz Osób z Upośledzeniem Umysłowym.

Alexander, S. L., Frederico, M., & Long, M. (2019). Attachment security, early childhood intervention and the National Disability Insurance Scheme: A risk and rights analysis. *Children Australia*, *44*(4), 187–193. https://doi.org/10.1017/cha.2019.39

Cytowska, B. (2017). Ojcowie wobec opieki nad dziećmi z głęboką niepełnosprawnością intelektualną i ich edukacji – studium etnograficzne [Fathers' attitudes towards the care and education of children with profound intellectual disabilities – an ethnographic study]. *Człowiek – Niepełnosprawność – Społeczeństwo*, *2*(36), 89–112.

Engwall, K. (2021). *The assessment of respite care for children with disabilities and its processes in Sweden*. Uppsala University.

Gardou, C. (2012). *La société inclusive, parlons-en! Il n'y a pas de vie minuscule* [Let's talk about an inclusive society! There is no such thing as a tiny life]. Érès.

Grassman, E. J., Whitaker, A., & Taghizadeh Larsson, A. (2009). Family as failure? The role of informal help-givers to disabled people in Sweden. *Scandinavian Journal of Disability Research*, *11*(1), 35–49. https://doi.org/10.1080/15017410802253518

House, J. S. (1981). *Work stress and social support*. Addison-Wesley.

Hulek, A. (1984). *Rewalidacja dzieci i młodzieży niepełnosprawnej w rodzinie* [Rehabilitation of disabled children and youth in the family]. Wydawnictwo Naukowe PWN.

Izdebska, J. (2015). *Dziecko – dzieciństwo – rodzina – wychowanie rodzinne: Kategorie pedagogiki rodziny w perspektywie pedagogiki personalistycznej* [Child – childhood – family – family upbringing: Categories of family pedagogy in the perspective of personalistic pedagogy]. Niepaństwowa Wyższa Szkoła Pedagogiczna.

Kilian, M. (2007). Niepełnosprawni w społeczeństwie [Disabled people in society]. *Polityka Społeczna*, *6*, 14–16.

Konwencja o prawach osób niepełnosprawnych, sporządzona w Nowym Jorku dnia 13 grudnia 2006 r. [Convention on the Rights of Persons with Disabilities, prepared at New York on 13 December 2006]. (2012, October 25). Dz.U.2012.1169.

Kornas-Biela, D., Domagała-Zyśk, E., & Smołka, E. (2016). Preventing social exclusion of people with disabilities and their families. *Rozprawy Społeczne*, *10*(1), 7–15.

Lai, J. H. J., Ireland, P., Nguyen, D., Woodbury, A., & Pacey, V. (2025). The use and experience of the National Disability Insurance Scheme for Australians with skeletal dysplasia: A mixed-methods study. *Orphanet Journal of Rare Diseases*, *20*, Article 105. https://doi.org/10.1186/s13023-025-03630-6

Leśniak, J. (2017). Mieszkam sam! Niezależne życie osób z niepełnosprawnością intelektualną [I live alone! Independent life for people with intellectual disabilities]. In K. Barłóg (Ed.), *Metody i formy pracy z osobami o specjalnych potrzebach edukacyjnych i społecznych – perspektywa life-span* (pp. 45–60). Wydawnictwo Uniwersytetu Rzeszowskiego.

Leśniak, J. (2019). *Uwarunkowania zachowania o charakterze niedostosowania społecznego młodzieży z niepełnosprawnością intelektualną* [Determinants of social maladjustment behavior in youth with intellectual disabilities]. Oficyna Wydawnicza AFM.

Matyjas, B. (2020). Pedagogika rodziny: Aktualna problematyka i nowe obszary badawcze [Family pedagogy: Current issues and new research areas]. *Studia z Teorii Wychowania*, *11*/2(31), 81–98. https://doi.org/10.5604/01.3001.0014.3650

Matyjas, B. (2024). Badania nad rodziną: Perspektywa pedagogiki społecznej [Family research: The perspective of social pedagogy]. *Pedagogika Społeczna Nova*, *4*(7), 23–45. https://doi.org/10.14746/psn.2024.4.7.2

McCrossin, J., Lach, L., Biette, S., & Cappe, É. (2025). Caregiver peer support for families of autistic children in France. *Child: Care, Health and Development*, *51*(4), 70–123. https://doi.org/10.1111/cch.70123

Namysłowska, I., (Ed.). (2007). *Psychiatria dzieci i młodzieży* [Child and adolescent psychiatry]. Wydawnictwo Lekarskie PZWL.

Obuchowska, I. (1995). *Dziecko niepełnosprawne w rodzinie* [A disabled child in the family]. WSiP.

Oszustowicz, B., & Lechta, V. (Eds.). (2009). *Teoretyczne i praktyczne aspekty terapii pedagogicznej osób z niepełnosprawnością* [Theoretical and practical aspects of educational therapy for people with disabilities]. Wydawnictwo Naukowe Uniwersytetu Pedagogicznego.

Pilch, T., & Lepalczyk, I. (Eds.). (1995). *Pedagogika społeczna* [Social pedagogy]. Wydawnictwo Akademickie „Żak”.

Popielecki, M., & Zeman, I. (2000). Kryzys psychiczny rodziców w związku z pojawieniem się w rodzinie dziecka niepełnosprawnego [Parents’ psychological crisis in connection with the arrival of a disabled child in the family]. *Szkoła Specjalna*, *1*, 15–19.

PSONI. (2023). *Statut Polskiego Stowarzyszenia na rzecz Osób z Niepełnosprawnością Intelektualną* [Statute of the Polish Association for People with Intellectual Disabilities]. https://psoni.org.pl/statut/

PSONI. (n.d.). *O nas* [About us]. https://psoni.org.pl/o-nas/

Sęk, H., & Cieślak, R. (2004). Wsparcie społeczne – sposoby definiowania, rodzaje i źródła wsparcia, wybrane koncepcje teoretyczne [Social support – ways of defining, types and sources of support, selected theoretical concepts]. In H. Sęk & R. Cieślak (Eds.), *Wsparcie społeczne, stres i zdrowie* (pp. 45–67). Wydawnictwo Naukowe PWN.

Smith-Merry, J., Gilroy, J., & Watharow, A. (2023). *The NDIs at ten years: Designing an equitable scheme for the next decade. Medical Journal of Australia*, 218(7), 291–294. https://doi.org/10.5694/mja2.51899

Szymanowska, J. (2019). *Jakość życia rodziny z dzieckiem z niepełnosprawnością w kontekście wsparcia społecznego i kultury działań pomocowych: Studium pedagogiczne* [The quality of life of families with children with disabilities in the context of social support and the culture of support activities: Pedagogical study]. Wydawnictwo Uniwersytetu w Białymstoku.

Täljedal, T., Granlund, M., Osman, F., Norén Selinus, E., & Fängström, K. (2024). Parenting children with disabilities in Sweden: a cluster-analysis of parenting stress and sufficiency of informal and formal support. *Frontiers in Psychology*, *15*, Article 1389995. https://doi.org/10.3389/fpsyg.2024.1389995

United Nations. (2006). *Convention on the Rights of Persons with Disabilities: Optional Protocol*. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

Young, D., Gibbs, L., Gilson, K. M., Williams, K., Reddihough, D., Tracy, J., Tonmukayakul, U., & Carter, R. (2021). Understanding key worker experiences at an Australian Early Childhood Intervention Service. *Health & Social Care in the Community*, *29*(6), e269–e278. https://doi.org/10.1111/hsc.13350

Ziemska, M. (1977). *Rodzina a osobowość* [Family and personality]. Wiedza Powszechna.

Żyta, A., & Ćwirynkało, K. (2015). Wspieranie rodzin dzieci z niepełnosprawnością – perspektywa zmiany [Supporting families of children with disabilities – a perspective on change]. *Wychowanie w Rodzinie*, *11*(1), 377–396. https://doi.org/10.23734/wwr20151.377.396