

BARBARA GRZYB¹, MONIKA BOŻENA MORGALA²

Activities of Institutions Supporting the Family of a Child with Disabilities: Selected Areas of Forecasting and Standardization

ABSTRACT

The article discusses institutions providing support and aid to people with disabilities and their families. The theoretical determinants of the aid process were discussed in the context of the possible forecasting of strategies for these interactions within the functioning of public, non-governmental and private institutions (without budgetary subsidies). The important area highlighted in the paper was not only disability and the family's needs but also the nature of a possible support which should depend on a forecast of actions resulting out of the nature and grade of person's disability. In turn, the scope of proposed solutions should comprise of a package of offers dependent on the grade and nature of person's disability and should lead to their life and economic independence. However, this requires a tripartite social dialogue, good will, and understanding of each person requiring a long-term support and aid. This article ends with a short conclusion highlighting the need for immediate actions for starting a social dialogue in order to establish a tri-sectoral aid, and within its scope, a reasonable forecast of the needs of the child with disabilities.

Keywords:

family, disability, support, aid, forecasting.

1 Silesian University of Technology, Institute of Education and Communication Research, Poland.

E-MAIL: Barbara.Grzyb@polsl.pl ORCID: 0000-0003-3649-4068

2 Silesian University of Technology, Institute of Education and Communication Research, Poland.

ORCID: 0000-0001-6856-9111

I am not there for them to love and admire me, but for me to act and love. It is not the duty of those around me to help me, but I have a duty to care for the world, for man...

Janusz Korczak (as cited in: Lewin, 1999, p. 54)

In the research literature, it has been established that institutional support aimed at families raising children at risk of disability is closely linked to the organisation of targeted aid. It is also believed that the scope of this impact, its continuity and legitimacy most often result from signalled needs and applicable standards of its granting. In turn, the mentioned standards are nothing else than criteria established – often by the legislator – which are more and more restrictive in the area of their implementation, often supported by a bureaucratic (Gąciarz, Kubicki, & Rudnicki, 2014, p. 114) form of applying for aid and support.

Meanwhile, the rationality of social action – as we can observe – is integrated with the direction of needs of the individual and the family, but also with its capacity in terms of the functions it performs. This means that granting social assistance will also involve a broad-profile analysis of the family’s existential area, taking into account the process of forecasting the aid provided and the proposed typology of interventions. Undoubtedly, the very process of diagnosis and planning is an important issue, because thanks to these activities, many “often hidden social problems, which however exist objectively and constitute an important element of prevention – primary and secondary prevention”, will be revealed (Kamieniarz, 2001, p. 83). Identification of the family’s problems and the tactic of supportive action sets a conceptual trend but according to B. Skałbania, “excessive focus on diagnosis distorts the idea of helping” (Skałbania, 2010, p. 192). In turn, “procedures called *providing aid* are frequently simplified, they are limited to necessary actions carried out in inadequate premises and organisational conditions, with poor diagnostic and therapeutic skills, in spite of professional preparation of helpers who are aware of the value of their own service” (Skałbania, 2010, p. 192).

The concept of “supporting families” finds its reference in several theoretical concepts, including social support, social capital, social exclusion by H. Silver (1994) or R. Szarfenberg (2005), or civil society by B.S. Turner (Turner & Rojek, 2001). On the basis of these theories, the concept of “supporting families” is defined in the context of the development and organization of various activities undertaken by government institutions and non-governmental organizations, especially in the local environment. Robert J. Chaskin defines them as “the interaction of human capital (resources and capabilities of an individual), organizational resources (institutions and organizations working for the environment), and social capital (relations that exist between the community and organizations acting for

its benefit), used to solve common problems, either to improve or to maintain the welfare of a given community” (Chaskin, 2009, p. 34). Małgorzata Ciczowska-Giedziun emphasizes the change in the perception of the paradigm of family support, ranging from

one-dimensional to holistic action, from equalization, correction to prevention and support, from deficits to resources (Saleebey, 1996), from hierarchy to partnership (Dolan et al., 2006), from a centralized and bureaucratic system to local solutions (Chaskin, 2006). The new view on supporting families is reflected in certain principles characterizing practical supporting activities: partnership of families and professionals (Mendel, 2002), responding to the real needs of families (Dolan et al., 2006), work based on the strengths of individuals, groups and communities (Saleebey, 1996), strengthening the support network (Kawula, 2008; Grotowska-Leder, 2008), shaping the skills of self-determination in families (Karoly, 1993), or inclusive activities (Dolan et al., 2006) (Ciczowska-Giedziun, 2017, p. 85)

However, looking from the perspective of the activities of many institutions³ involved in the assistance process, aimed at families experiencing a range of difficulties in life, each of them makes a specific diagnosis for itself, focused on the nature of the services provided.

A. Kanios (2010) notes that one of the most important actions is the diagnosis of the problem, planning/forecasting and implementation of support with outlining a detailed catalogue of activities, how they are to be carried out and how the whole process is to be documented. Apart from this, pursuant to a Social Welfare Act (Social Welfare Act of 12th March 2004..., 2017), the commune and the district also develop strategies for solving social problems, with the most important tasks being:

- diagnosis of a social situation,
- forecast of changes in the scope of the strategy,
- determination of:
 - a) strategic targets of developed changes,
 - b) directions of necessary changes,
 - c) means of carrying out the strategy and its financial frameworks,
 - d) performance indicators (Social Welfare Act of 12th March 2004..., 2017).

3 Social welfare institutions (Social Welfare Centres; District Family Support Centres, Regional Social Policy Centres; Crisis Intervention Centres; Support Centres; Family Welfare Homes, etc.), non-governmental organisations (including foundations and associations), specialist clinics (including psychological and pedagogical), re-socialisation entities (including Family Diagnostic and Consulting Centres) and educational institutions within the framework of psychological and pedagogical assistance.

Considering the forecasting activity of family support institutions, an important issue becomes the staging of aid activities, which can usually include:

- evaluation of the family's needs and problems,
- situational diagnosis,
- forecast and period of provided/possible support,
- implementation of aid program or temporary support,
- counselling,
- implementation of active, long-term aid.

In the course of the discussion so far, attention has been drawn to the theoretical conditions of the support process, strategy, and staging of interventions, in which a key role is often played by the process of forecasting support activities and the nature of the aid provided.

FAMILY WITH A CHILD WITH DISABILITIES IN THE PROCESS OF INSTITUTIONAL SUPPORT – FORECASTING INTERVENTIONS: SELECTED AREAS

From the perspective of the above-mentioned conditions, it should be noted that the above-mentioned support acquires specific significance when it directly concerns families bringing up children with disabilities. Unfortunately, the most important “problem is the fragmentation of actions (lack of cooperation and understanding) undertaken by state institutions and non-governmental organisations. Due to the complicated problem of support mechanisms, there is a need to ensure and facilitate access for this group of people to its various forms” (Szłuz, 2007, p. 207). In this situation, procedures of the support provided are extended, as it is more difficult to forecast the period of the support provided due to the unpredictability of the illness or disability, which often requires considerable financial resources. The next problem is a preclusion of the aid provided and the economic capacity of the family bringing up a child with disability. In most cases, the family's income indicates that it is able to overcome its problems on its own, but the cost-intensity of the rehabilitation and therapy process can significantly limit the existential capacity of such families. This raises the question of whether it is reasonable to forecast support/aid services based on economic/income discernment of the community/family raising children with disabilities? R. Bakalarczyk (2015) highlights that “in the question of justifying the introduction of an income criterion for granting support

entitlements, the dilemma is whether and what requirements should be applied. This is a very complex issue in the light of various economic and social rationales. In Western literature there is a dispute between the advocates of universal and selective social benefits” (Bakalarczyk, 2015, p. 73). Unfortunately, “the burden of care for dependent persons falls mainly on the family. It is difficult to estimate the costs of such care: they are borne mainly by women, erasing the omissions and gaps in the support system. This is evidenced by the findings of a number of studies carried out, for example, among families with children with disabilities” (Maciejasz & Kubicki, 2014, p. 20). Apart from that, the author emphasises that “the lack of a well-functioning system for informing concerned people about existing social policy instruments and its inadequacy to meet the needs of the support package for families with people with disabilities leads to many individual and social costs – the opportunities and potential of this group are not used. Focusing on monetary benefits, no development of services supporting families in carrying out care, mismatch of the social environment to the specific needs resulting from disability in many spheres of life (e.g., political – participation in elections, social – e.g., education, health care institutions, economic – labour market) shows that in Poland it is still difficult to realise the so-called social model of disability” (Kowalczyk, 2016a, p. 176). These criteria are an obvious signal to begin work on the social forecasting of support addressed to families bringing up children with disabilities. This contemporary dialogue cannot be postponed, as the problems of these families (economic, social, cultural, medical) grow from year to year, becoming one of the many ills of the contemporary social welfare system.

Thus, it can be said that the institutional support “should lead to the use of the entire ‘range’ of assistance elements from medical care, through financial measures (reliefs and subsidies), to the use of strictly specialised instruments within the framework of social policy in the broad sense” (Kowalewska, Goździalska, & Jaśkiewicz, 2012, p. 64). In turn, the areas of possible support, which should be emphasised, “must be diagnosed and should remain relevant in strengthening [the process of] coping with disability. The scope of such support is classified depending on type (content) and function it has in the course of supporting interaction” (Rutkowska, 2012, p. 44). Please note that “not every family in which disability occurs requires support pursuant to the Family Benefits Act. First of all, not every disability necessarily generates care needs, and especially needs so intensive that the disabled person requires constant and long-term care from third parties. For persons for whom support in day-to-day activities could be merely a supplement to daily functioning, it would not even be advisable to set them in the context of long-term care” (Bakalarczyk, 2015, p. 68). The author’s findings are proved by

M. Olcoń-Kubicka and P. Kubicki (2012). The authors emphasise that a lot of costs borne by the families bringing up children with disabilities could be avoided if there was a coherent and effective system of support. A lot of costs are entirely unnecessary and result from the lack of knowledge and parents' experimenting with various forms of support, but also from too late or too limited therapy. The costs incurred often bear no relation to the actual needs of the child or the results achieved, which in addition to the parents, causes losses to all taxpayers who support an inefficient and incoherent support system" (Olcoń-Kubicka & Kubicki, 2012, p. 56). This is why it is essential to forecast specific forms of individual aid for families bringing up children with disabilities. Complex support actions are differentiated by the disease or disability itself, and the scope of their implementation should be carried out from the earliest period of a child's life. In addition, excessive bureaucracy causes many people to give up on claiming a range of benefits to which they are entitled, perceiving in these convoluted procedures a concern as to whether it is worthwhile taking action at all.

Moreover, a contemporary family with a child with disabilities is a beneficiary of many institutions, including non-governmental organisations. Unfortunately, these actions are not permanent, but quite often temporary, which, without a rational policy, cannot claim the right to fully secure the care of a child with disabilities without the supervision of the state social institutions. Therefore, forecasting support in the institutional system of social welfare should be one of the many classical activities aimed at exercising control over the process of functioning of such specific families. Not only they are unique, but above all, burdened with an excess of responsibilities which often co-determine that many of them do not seek the help and support they deserve.

TRI-SECTORALITY OF SUPPORT INSTITUTIONS: SELECTED ISSUES

Social support of the family of a child with disability is indispensable in a holistic view of processes related to the equalisation of opportunities for persons with disabilities. It results not only from the egalitarian features of the society in which the child with disability and their family lives, but also from an actual need to provide support. The mere information about the child's disability is a tremendous experience for their family members, with which they need to deal in a diverse and individual way. However, it is indisputable that without an appropriate support structure, a family left alone with the problem of disability will not be able to overcome many of the problems and difficulties in everyday life. Unfortunately,

a child's disability is a traumatic experience for the entire family, it disrupts its functioning, requires a lot of sacrifice and self-denial, a reorganisation of work schedules, a change in goals, and often the abandonment of development and career. [...] Without any support and necessary economic and social assistance, it is pushed to the margins to the point of total exclusion" (Janocha, 2009, p. 15).

Hence, a targeted and effective support system is such an important element in the lives of these families.

Basing on many analyses of the institutional support provided, social welfare is the most often indicated by the persons in need. According to the definition, "social welfare is an institution of state social policy aimed at enabling persons and families to overcome difficult life situations which they are unable to overcome using their own entitlements, resources and possibilities" (Terms and Conditions of Social Welfare, 2018). Such a presentation of social welfare implemented in Poland can be found on the website of the Ministry of Family, Labour and Social Policy. Besides, the directions of the state social policy consist mainly of proposals for social assistance or professional activation of adults with disabilities. In the case of children with disabilities, the activities of educational institutions are mainly directed towards inclusive education. The comprehensive efforts of support institutions thus aim to improve the lives of both the disabled person and their family. They also aim to include the family in an active participation in society, which is very important from the point of view of the state apparatus itself.

It should be underlined that a family learning about the disability of their child receives their first support from public institutions (National Health Fund, Disability Evaluation Board, District Family Support Centre, Psychological-Pedagogical Clinic, etc.). Apart from that, a parent raising a child with disability is also entitled to free health care and specialist care and has the possibility to apply for purpose-specific benefits or another form of institutional support. Undoubtedly, financial assistance is among the most frequently granted by state support institutions (Table 1).

As can be seen from the above statement, the number of families covered by temporary financial assistance due to disability occurring in the family is very high. In the first half of 2017 alone, such assistance was granted to a total of 37,455 families for a total amount of PLN 26,135,119, while the number of temporary benefits alone accounts for about 45% of the total number of such assistance granted. Based on the comparison of data from 2016 and the first half of 2017, it can be forecasted that the annual report for 2017 will show higher values, in terms of granting temporary benefits due to disability, compared to the previous year (MRPiPS-03-P Report for 1–6 of 2017).

Table 1. Temporary Benefits Granted due to Disability

Analysis period	Total temporary benefits				Periodical benefits granted due to a disability			
	Number of benefits	Benefits amount in PLN	Number of families	Number of family members	Number of benefits	Benefits amount in PLN	Number of families	Number of family members
	1	2	3	4	5	6	7	8
1-12.2016	2415206	838613140	408075	1 008 943	270312	55 817 071	51742	125281
1-6.2017	1115252	372631986	277 653	621 782	139 842	26 135 119	37 455	80 016

Source: MRPiPS-03 Report for 1–12 of 2016 and MRPiPS-03-P Report for 1–6 of 2017.

The reality in which everything necessary for the proper functioning of a disabled child and their family is easily accessible and free of charge is often insufficient. The family is then forced to look for help in other places – from relatives, friends, associations, foundations, private clinics, or therapy and rehabilitation centres.

As the website of the Ministry of Family, Labour and Social Policy states, “the activities in the field of social welfare pursuant to the act are performed by the government and local government administration bodies. In this scope they cooperate with social organisations, the Catholic Church, other churches, religious associations, foundations, associations, employers and natural and legal persons” (Social Welfare Institutions, Organisational Units, 2017). Thus, it can be said that the Ministry also notes the need to link family support and assistance activities with institutions outside the public sector.

However, looking from the perspective of support activities, it should be underlined that one of the tasks carried out for the benefit of families in need of help is granting purpose-specific benefits, which most often assume a three-sectorial nature of interactions (public, non-governmental, private sector). In many cases, it is precisely this type of support arrangement that is most often observed, as it is the result not only of the involvement of the above-mentioned entities, but above all – of the family itself (Table 2).

The above-mentioned institutions (public, non-governmental, private) provide assistance to families bringing up children with disabilities in their own specific way. It results mainly from the nature of the support provided, but also from their statutory capabilities and means.

Table 2. Tri-sectorality of Support Institutions

Support institutions		
Public	Non-governmental	Private (without budgetary subsidies)
<ul style="list-style-type: none"> • Social Welfare Centre (MOPS, GOPS) • District Family Support Centres • Regional Social Policy Centres • Crisis Intervention Centres • Support Centres • Family Welfare Homes • State Fund for the Rehabilitation of the Disabled (PFRON) • Social Insurance Fund (ZUS) • Agricultural Social Insurance Fund (KRUS) • National Health Fund (NFZ) • Patients' Ombudsman of NFZ • Patients' Ombudsman of the Ministry of Health • Government Plenipotentiary for the Disabled • Office of the Government Plenipotentiary for the Disabled (BON) • The Polish Ombudsman (RPO) • Psychological and Pedagogical Clinics • District Disability Evaluation Board • Education facilities (kindergartens and schools) • Care facilities 	<ul style="list-style-type: none"> • Foundations: - e.g., "Zdążyć z Pomocą" - "Słoneczko", etc. • Associations: - e.g., "Tęcza" - "Stowarzyszenie Osób Niepełnosprawnych SON", etc. • Polish Association of the Blind • Polish Association of the Deaf, etc. • Social religious entities • Parish organisations of the Catholic Church 	<ul style="list-style-type: none"> • Psychological and Pedagogical Clinics • Specialist practices • Rehabilitation practices • Care facilities • Education facilities (kindergartens and schools)

Source: Authors' own study.

It should be also emphasised that the main organisational units of social assistance include:

- regional social policy centres
- district family support centres
- social welfare centres
- nursing homes
- specialist counselling centres, including family counselling centres
- support centres
- crisis intervention centres (*Terms and Conditions of Sociat Welfare*, 2018).

Due to the multiplicity of different support entities, the table presents most of the public institutions that are intended to support all those in need, including families with a child with disabilities.

The aid provided by public support institutions is to be primarily based on “granting and payment of benefits, social work, running and development of necessary social infrastructure, analysis and evaluation of phenomena generating demand for social welfare benefits, implementation of tasks resulting from identified social needs, development of new forms of social welfare and self-help within the framework of identified needs” (*Terms...*, 2018). Social welfare, understood in this way, is designed to support “persons and families in their efforts to meet their basic needs and to enable them to live in conditions compatible with human dignity” (*Terms...*, 2018). It is not without significance that, according to the assumptions of support institutions, “persons and families benefiting from social welfare are obliged to cooperate in solving their difficult life situation” (*Terms...*, 2018). In practice, this means that aid from the state cannot be based only on a passive expectation to obtain it, as the other party is expected to at least attempt to take an initiative aimed at improving its own living conditions. On the other hand, the organisation of social welfare is the responsibility of administrative bodies at each level – from government administration, through local government, to commune heads and mayors. The level of aid provided at each of these levels is different, but the criteria and procedures for providing aid are the same for all. According to the Ministry of Family, Labour and Social Policy, “a person or a family may apply for aid to the social welfare centre in the place of residence (there are centres in every commune). Decisions on granting or refusing to grant aid require a prior family environmental interview to be conducted by a social worker. Decisions on social welfare benefits are issued in writing. Every decision may be appealed against” (*Terms...*, 2018).

The Ministry has also defined in detail the scope of lower-level administrative proceedings in determining and implementing recommendations resulting from the state social policy, stating that it is

the social welfare centre, while granting care services, that determines their scope, period and place of provision. The commune council defines, by way of a resolution, detailed conditions for granting and payment for care services and specialist care services, except for specialist care services for people with mental disorders, and detailed conditions for partial or full exemption from fees, as well as the mode of collecting them (*Forms of Assistance...*, 2018).

Table 3. Forms of Assistance Provided in Public Social Welfare Institutions

Forms of assistance provided	
Public support institution	<ul style="list-style-type: none"> • Permanent benefit • Temporary benefit • Purpose-specific benefits • Aid for becoming economically independent • Grant for becoming independent • Social work • Specialist counselling • Crisis intervention • Aid in the form of shelter, food, clothing • Giving a funeral • Care services and specialised care services • Support centre • Family Welfare Home • Sheltered housing • Nursing Home

Source: Ministry of Family, Labour and Social Policy, Department of Social Assistance and Integration (*Forms of Assistance...*, 2018)

As emphasised earlier, public institutions have to cooperate with other entities outside the public sector. State aid alone is insufficient. In the process of providing direct aid, non-governmental organisations (NGOs) are of considerable importance (Cf. Non-governmental organization, 2018). These organisations are, by definition, “acting in the interest of the chosen cause and not for profit” (*Organizacja pozarządowa...*, 2018). Non-governmental organisations are situated between public and private structures – unlike public ones, they are set up on the initiative of their founders (i.e., private persons), but unlike private ones and analogously to public ones, they operate not in the private but in the public interest (*Organizacja pozarządowa...*, 2018). “The cooperation between local government administration and non-governmental organisations can be financial as well as non-financial and should be based on the principles of subsidiarity, sovereignty of the parties, partnership, effectiveness, fair competition and openness. They play the role of innovators introducing alternative methods of activity, they enliven social life. They have greater freedom of action and a greater degree of independence than local government bodies” (County Family Support Center in Tarnów, 2018). The official website of the NGO database lists approximately 141,000 profiles of associations and foundations, including 5480 aimed at supporting children with disabilities and 2805 aimed at families with sick or disabled people, and 6330 in which whole families are targeted (Database of non-governmental organizations, offices and institutions, 2018).

According to the three-sector division proposed by the authors of this article, in the area of support for the family of a child with disabilities, the third is the private sector (without budgetary subsidies). These organisations are created by private persons, however, their activities are to a greater extent profit oriented. In reality this means that the services provided by such entities are paid for. One can ask here about the purpose of creating such institutions, since there are organizations supporting people with disabilities and their families, both in the public and in the non-governmental sphere. The answer is simple – the main advantage of private care is definitely shorter waiting time for the service (support/assistance) as well as wide range of services provided. This includes private psychological-educational clinics, specialist clinics, therapy and rehabilitation centres. In the case of therapeutic or rehabilitation services, it is possible to pay the fees from funds obtained by non-governmental public benefit organisations with which the child in question has a sub-account. All rules related to the settlement of accounts between the recipient (parent/legal guardian of the child) and the service provider (owner) are set out in contracts concluded between the entities.

Table 4. Support Institutions – Assessment of Actions

Type of sector	Pros	Cons
Public sector	<ul style="list-style-type: none"> • free access • fixed terms and conditions, and overarching regulations • relatively easy access • multi-faceted nature of the assistance provided 	<ul style="list-style-type: none"> • long waiting times/queues • complex procedures • bureaucracy • incomprehensible official decisions • no individualisation • failure to disclose all opportunities arising from the rights of persons supported
Public sector		<ul style="list-style-type: none"> • overburdened employees • lack of knowledge of social workers on the functioning of people with disabilities • lack of clear and specific treatment for “applicants” depending on the problem they are experiencing • limits

Type of sector	Pros	Cons
Non-governmental sector	<ul style="list-style-type: none"> • fixed procedures of support provision • possibility of volunteering • free access • multiplicity and variety of support programmes • reimbursement of costs incurred 	<ul style="list-style-type: none"> • often complex procedures • long waiting time for settlements (sub-account) • programmes addressed to narrow group of recipients • limits
Private sector	<ul style="list-style-type: none"> • short waiting times • wide range • flexible schedule • no limits • responding to the needs of supported persons • searching for recipients 	<ul style="list-style-type: none"> • high fees • paying with private funds • employees' lack of professionalism and qualifications • a business approach to the activities carried out • no uniform standards

Source: Authors' own study.

Undoubtedly, the most trusted institutions in society are those which have clearly defined rules and regulations for their activities. However, in the age of individualisation actions, each “case” is considered individually, often expecting a degree of flexibility that may be lacking in the public sector. Procedures, strictly defined financial limits, overburdening of public sector employees, as well as non-disclosure of all rights and possibilities given to the recipients by the legislator cause parents/legal guardians of a child with disabilities to reach for other sources. Therefore, they look for support in non-governmental organisations, which also operate according to certain principles, and the number and variety of aid programmes do not require a special search for recipients. Here, however, there is a long period of settling payments, e.g., from the campaign to transfer 1% of the tax (PIT). It should be borne in mind that the reimbursement of the costs incurred, on the basis of accounting bills, covers the scope indicated in the regulations of the respective organisation.

For the private sector, short waiting times for appointments or a very flexible schedule of activities are certainly a plus. The parent can schedule specialist tests or rehabilitation services without long waiting periods, and the only condition is that the service is paid for. However, there is a risk that the owner of such an institution is profit-oriented to the extent that the amounts for services provided are very high and may change at any time, and that people with incomplete or no qualifications are employed to reduce the costs of maintaining the activity. Parents of children with disabilities, however, have many options both in choosing

the institution to which they will turn for help and in checking the organisation in question in terms of its reliability and professional approach to the activities undertaken.

However, it should be noted that there is a degree of dependence between the public, non-governmental and private sector institutions identified in the article. Public institutions operate according to strictly defined procedural rules/standards as well as specific “financial discipline”. Non-governmental institutions have an invaluable opportunity to raise funds for the implementation of their statutory activities. Private institutions are undoubtedly the most rapidly developing of the support sectors, and this is due to the real need for immediate response in matters related to rehabilitation, therapy or simply treatment of children with disabilities.

The laws of the free market, on a competitive basis, regulate the activities of institutions in the non-governmental or commercial sphere. In this situation, public institutions are on the losing end, because they cannot offer such a range of activities, and often using their services is a “thorny path”. Public units with a number of restrictions and procedures are not always fully accessible to people with disabilities, as their parents and carers repeatedly confirm. Therefore, an important solution would be to forecast and differentiate support, for example, according to the degree and nature of a person’s disability. It results from the fact that definitely more assistance is required by a person who is totally incapable of independent existence (e.g., lying, with associated developmental disorders) than by a disabled person with uniform disability, e.g., visual or hearing impairment, etc. Hence there is a signalled need to forecast the support provided and to increase justified financial outlays for those most in need.

INSTEAD OF A CONCLUSION

The overview of activities and entities involved shows the very high dynamics of the discussed area of public policy, both in the objective and subjective dimension. At the same time, many issues have not been properly addressed in the social dialogue, e.g., combining care and employment, targeting support to actual carers, including those outside the circle of closest relatives or the prospects of differentiating support according to the scope of care needs (Bakalarczyk, 2015, p. 79). It seems indisputable, however, that the prognosis of the assistance provided, as well as the interdisciplinary support of the family, are not slogans but real needs, the implementation of which requires a much higher economic valuation. Unfortunately, the reality shows that low financial outlays for rehabilitation, therapy,

rehabilitation equipment, basic hygiene products and pensions for the disabled lead to social marginalisation of these people.

The aim of this study is to review the activities of institutions supporting the family of a disabled child in the context of selected areas of forecasting this support and its standardization. The indication in the article for specific support institutions, especially regarding the scope of their possibilities, is to provide an overview of relevant information on current and applicable today forms of support, which in all their forms should be centralized and provided to families at the time of diagnosing a child's disability. Well-established theoretical and practical knowledge allows the authors of the article to submit a postulate, which is precisely this centralization of support for the family of a child who is not fully able, aimed at creating a model of support for a family raising a child with a specific disability, by specialists. We suggest that this model should be based on the integrated operation of the system, which automatically indicates a specific family to aid institutions. This would result not only in forecasting individualized support, tailored to the needs of a given family, but also in defining the standardization of this support not only through targeted benefits and respite care, but most of all by implementing the established rules in the field of specific services, allowing for the improvement of the quality of life of families raising a disabled child. It appears that the change in the current system, based mainly on the constant search for information and help by parents or legal guardians on their own, allows for the adjustment of the support in such a way that it would be specific, targeted, effective, and long-term.

A solution to the problems would be to outline a three-sectorial forecast of needs, focused on the family and the child with disabilities. In turn, the scope of the proposed solutions should be a package of offers depending on the degree and nature of the disability. However, this requires tripartite social dialogue, good will and an understanding that time is the most unfavourable condition for many people awaiting this most humane support and assistance.

References

- Bakalarczyk, R. (2015). Polityka wsparcia rodzin z osobami niepełnosprawnymi. W cieniu wyroków Trybunału Konstytucyjnego RP i protestów społecznych. *Studia z Polityki Publicznej*, 2(1), 63–80. DOI: 10.33119/KSzPP.2015.1.4.
- Chaskin, R.J. (2009). Building Community Capacity for Children, Youth and Families. *Children Australia*, 34(1), 31–38. DOI: 10.1017/S1035077200000511.
- Ciczowska-Giedziun, M. (2017). (Nie)odkryte możliwości wspierania rodziny w środowisku lokalnym. *Pedagogika Społeczna*, 16(1), 83–96.

- Dolan, P., Pinkerton, J., & Canavan, J., (2006), Family support. From description to reflection. In: P. Dolan, J. Pinkerton & J. Canavan (Eds.), *Family support as reflective practice* (pp. 11–26). London and Philadelphia: Jessica Kingsley Publishers.
- Gąciarz, B., Kubicki, P., & Rudnicki, S. (2014). System instytucjonalnego wsparcia osób niepełnosprawnych w Polsce – diagnoza dysfunkcji. In: B. Gąciarz, & S. Rudnicki (Eds.), *Polscy (Nie)pełnosprawni. Od kompleksowej diagnozy do nowego modelu polityki społecznej* (pp. 105–126). Kraków: Wydawnictwa AGH.
- Grotowska-Leder, J., (2008). Wsparcie społeczne w perspektywie teorii socjologicznych – kontekst więzi społecznej, sieci społecznych, sieci wymiany. In: J. Grotowska-Leder (Eds.), *Sieci wsparcia społecznego jako przejaw integracji i dezintegracji społecznej* (pp. 9–27). Łódź: Wydawnictwo Uniwersytetu Łódzkiego.
- Janocha, W. (2009). *Rodzina z osobą niepełnosprawną w społecznym systemie wsparcia*. Kielce: Wydawnictwo JEDNOŚĆ.
- Kamieniarz, K. (2001). Dylematy instytucjonalnego wspierania procesu wychowania w rodzinie. In: Z. Gawlina (Ed.), *Kształtowanie postaw czynnych i więzi środowiskowych* (pp. 77–92). Kraków: Wydawnictwo UJ.
- Kanios, A. (2010). Partnerstwo lokalne na rzecz osób wykluczonych społecznie w opinii pracowników socjalnych. In: A. Kanios, & M. Czechowska-Bieluga (Eds.), *Praca socjalna. Kształcenie – działanie – konteksty* (pp. 139–154). Kraków: Oficyna Wydawnicza „Impuls”.
- Karoly, P., (1993), Mechanism of self-regulation. A system view. *Annal Review of Psychology*, 44, 23–52.
- Kawula, S., (2008), “Spirala życzliwości” jako cel społecznego wsparcia i forma skutecznej pracy środowiskowej – wymiar psychopedagogiczny. In: B. Kromolicka (Eds.), *Pedagog społeczny w meandrach środowiska lokalnego* (183–196). Szczecin: Wydawnictwo Ars Atelier.
- Kowalczyk, O. (2016a). Jaka polityka społeczna wobec rodzin z osobami niepełnosprawnymi w Polsce? *Prace Naukowe Uniwersytetu Ekonomicznego we Wrocławiu*, 38, 166–179. DOI: 10.15611/pn.2016.438.10.
- Kowalczyk, O. (2016b). Sytuacja społeczno-ekonomiczna rodzin z osobami niepełnosprawnymi w województwie dolnośląskim. Wybrane aspekty. In: O. Kowalczyk, A. Kubów, & W. Wątroba (Eds.), *Spółczesność i zmiana* (pp. 54–69). Wrocław: Wydawnictwo Uniwersytetu Ekonomicznego we Wrocławiu.
- Kowalewska, M., Goździalska, A., & Jaśkiewicz, J. (2012). Wsparcie społeczne jako element instytucjonalnej pomocy rodzinie z osobą zależną. In: G. Dębska, A. Goździalska, & J. Jaśkiewicz (Eds.), *Rodzina w zdrowiu i chorobie. Uwarunkowania środowiskowe zdrowia* (pp. 61–68). Kraków: Krakowskie Towarzystwo Edukacyjne sp. z o.o. – Oficyna Wydawnicza AFM.
- Lewin, A. (1999). *Korczak znany i niezany*. Warszawa: Ezop.
- Maciejasz, M., & Kubicki, P. (2014). Niepełnosprawność i długotrwała choroba – definiowanie, koszty i zadania dla lokalnej polityki społecznej. *Polityka Społeczna*, 3, 16–21.
- Mendel, M., (2002). Animacja współpracy środowiskowej. In: M. Mendel (Eds.), *Animacja współpracy środowiskowej* (17–26). Toruń: Wydawnictwo Adam Marszałek.
- Olcoń-Kubicka, M., & Kubicki, P. (2012). Analiza kosztów ponoszonych przez rodziców dzieci z orzeczoną niepełnosprawnością. *Polityka Społeczna*, 2, 52–56.

- Rutkowska, E. (2012). Wsparcie jako element rehabilitacji kompleksowej osób z niepełnosprawnością. *Niepełnosprawność – zagadnienia, problemy, rozwiązania*, 3, 39–52.
- Saleeb, D., (1996). The strengths perspective in social work practice. Extensions and cautions. *Social work*, 41(3), 296–305.
- Silver, H., (1994). Social exclusion and social solidarity: Three paradigms. *International Labour Review*, 133, 5–6
- Skałbani, B. (2010). Dyskusje wokół tożsamości poradnictwa pedagogicznego. *Edukacja Dorosłych*, 1, 189–197.
- Szarfenberg, R., (2005). Słabość trzeciego sektora i partnerstwa publiczno-prywatnego. *Trzeci Sektor*, 4.
- Szluz, B. (2007). Wsparcie społeczne rodziny osoby niepełnosprawnej. *Roczniki Teologiczne*, 54(10), 201–214.
- Turner, B.S. & Rojek, C., (2001). *Society and Culture: Principles of scarcity and solidarity*. London: SAGE Publications.

Reports

- MRPiPS-03-R Report for 1–12 of 2016, Summary by Province, Ministry of the Family, Labour and Social Policy, Department of Social Assistance and Integration. Retrieved April 23, 2018 from: <https://www.mpips.gov.pl/download/gfx/mpips/pl/defaultopisy/10397/1/1/MPiPS-03%20za%202016.xls>.
- MRPiPS-03-P Report for 1–6 of 2017, Summary by Province, Ministry of the Family, Labour and Social Policy, Department of Social Assistance and Integration. Retrieved April 16, 2018 from: <https://www.mpips.gov.pl/download/gfx/mpips/pl/defaultopisy/10610/1/1/Sprawozdanie%20MRPiPS-03styczen-czer%202017korekta.xls>.

Legal Acts

- Social Welfare Act of 12th March 2004 (as amended), Chapter 2, Social Welfare Tasks, Art. 16b. Journal of Laws of 2017, item 1769.

Internet Sources

- Organization databases; <http://bazy.ngo.pl/lista-baz>, [accessed on: 15.04.2018].
- Social policy: https://www.ipiss.com.pl/wp-content/uploads/dowlands/2013/06/ps_2-10t_2012,pdf#page=55 [accessed on: 05.04.2018].
- County Support Family Center in Tarnów: <http://www.pcpirtarnow.pl/organizacje-pozarządowe/> [accessed on: 06.04.2018].
- Questionnaire Family Environmental Interview: <https://www.mpips.gov.pl/dowland/gfx/mpips/pl/defaultopisy/10397/1/1/MPiPS-03%20za%202016.xls> [accessed on 23.04.2018].
- The forms of assistance provided by Ministry of Family, Labor and Social Policy: <https://www.mpips.gov.pl/pomoc-spoeczna/formy-udzielanej-pomocy/> [accessed on 16.04.2018].

- Forms of Assistance Provided, Care Services and Specilaised Care Services: <https://www.wpips.gov.pl/pomoc-spoleczna/formy-udzielanej-pomocy/uslugi-opiekuncze-i-specjalistyczne-uslugi-opiekuncze/> [accessed on 16.04.2018]
- Social Welfare Institutions, Organisational Units: <https://www.mpips.gov.pl/pomoc-spoleczna/instytucje-pomocy-spolecznej/jednostki-organizacyjne/> [accessed on 16.04.2018]
- Terms and Conditions of Social Welfare: <https://mpips.gov.pl/pomoc-spoleczna/system-pomocy-spolecznej-w-polsce/zasady-pomocy-spolecznej/> [accessed on 16.04.2018]
- Non-government organization (NGO)-definition: https://pl.wikipedia.org/wiki/Organizacja_pozarz%C4%85dowa [accessed on 17.04.2018]
- Google Books: Skałbana, B., *Diagnoza pedagogiczna*: <http://books.google.pl/books?isbn=8375876445> [accessed on 19.04.2018]