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Information & Co-ordination Point for Persons with Disabilities (PIKON) as a form of information support aimed at improving the quality of life of persons with disabilities and their families

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This article presents, initiatives undertaken by social organizations and the office of the Capital City of Warsaw in order to improve the quality of life of persons with disabilities and their families. These initiatives concern, among others, continuation of activities of the education system in the field of equalling the chances of students with disabilities by institutions performing tasks in the field of various areas of social policy, including those supporting the professional and personal functioning of adults. One of the directions of fulfilment of this goal is the creation of an information and coordination point to support adults with disabilities in solving their problems, e.g., by providing information on possible participation in social rehabilitation and/or employment in an open, supported or protected labour market.

KEY WORDS: disability, needs, social policy, cooperation, providing support, informing about possibilities

Introduction

For many years, the structure of social populations has been subject to demographic changes. They result, for example, in the prolongation of the average length of human life and a drop in national population growth, which create challenges for each sphere of social life. Also the individual and social identity of the human being¹ has an impact on self-identification, the formation of relationships, the establishment of co-operation, acceptance and tolerance. According to theories being promoted by social and human sciences, the co-existence of various social groups according to the principle of equal rights and obligations should be treated as an indisputable value. In order to fulfil this condition, entities responsible for the implementation of social policy of our country² should implement preventive measures on the commune, county and province level. These measures may include:

- recognising the needs of inhabitants, including persons with special needs, according to the developmental age,
- elaborating a cohesive long-term and interministerial strategy considering the participation of all groups of inhabitants in social life (with special regard to groups of disadvantaged persons) and ensuring the co-ordination of these activities,

¹ The concept of identity occurs in the context of two relationships that are the most important for the human being: the attitude to himself/herself and the attitude to other people, which means both culture and tradition. It indicates a special type of relationship that connects an individual with himself – self-identity (his/her own psychophysical and moral condition) on the one hand and his/her relationship with others on the other hand. This relationship is based on (more or less) conscious attitudes towards himself and other persons, which means both culture and tradition. (on the basis of the book: Gałdowa Anna (ed.) *Psychology of personality. Human identity (Psychologia osobowości. Tożsamość człowieka*). Wydawnictwo UJp, Kraków 2000).

² The implementation of social policy of our country is the responsibility of both central and local government offices at each management level (which means also local government units acting in the role of authorities in charge of kindergartens, schools and institutions) and ministerial institutions having an impact on the support of human health and personal development.

- providing support to families having at least one person with disability by means of a family assistant³,
- creating conditions for the education of children and young people with disabilities in schools located closest to their place of residence,
- continuing systemic and interministerial multi-specialist activities addressed to persons with disabilities and their families (e.g., by supporting the development of a network of supported flats providing round-the-clock help to adults with disabilities and therapeutic flats allowing these persons to become more independent in friendly and adapted conditions, helping the family to establish social co-operatives, and providing easier access to lifelong learning for persons with disabilities and graduates of schools for young people).

Within the scope of systemic activities addressed to persons with disabilities, it is also necessary to ensure: a) health care and broad-range medical aid as indicated by their condition and the financing of these activities from the National Health Fund (deciding on the scope of preventive health care, treatment and rehabilitation), b) social rehabilitation and social aid to their family organised by social welfare centres acting under the ministry of social security, c) the liquidation of architectural barriers and the provision of access to a system of services compensating for functional limitations and enabling children, young people and adults with disabilities to live a fully independent life in their environment by the State Fund for the Rehabilitation of the Disabled.

³ The Resolution No. 160 of the Council of Ministers of 20 December 2016 regarding the comprehensive family support programme "Pro Life" is published in Monitor Polski item 1250. The introduction to programme assumptions reads: "The support of disabled persons and their families is a priority task of the state that requires multi-aspect activities to be undertaken. … Thus, support activities of the state should be addressed to the entire family. Disability affects many areas of family life, including the family's financial, social or health situation. Legal and organisational and financial solutions adopted under the programme are aimed at creating the possibility of real and full social integration of disabled persons and psychological, social, functional and economic support to their families".

In 2016, the Ministry of Family, Labour and Social Policy introduced new laws in which one of the leading tasks is to provide rehabilitation and supporting aid to families of persons with disabilities by providing them with time for rest (respite care) and, in the case of a fortuitous event, to help them in the handling of everyday issues or the participation of the given family member in professional activation organised by the county labour office and the taking-up of full-time or part-time employment by the given family member. The essence of aid addressed to persons with autism spectrum disorders and multiple disabilities is, among others, to enlarge access to institutional forms of support to a larger group of people and to develop a network of homes of mutual aid. An important part of the support system is also the establishment of county coordination & rehabilitation & care centres encompassing the early support of the development of children aged 0 to 7 years and persons with disabilities. The aim of this solution is to reinforce existing forms of help and to co-ordinate the activity of various institutions functioning in the county.

Another goal of theoreticians and practitioners specialising in education should be to elaborate consistent legal regulations guaranteeing the provisions of adequate support to small children and schoolchildren with diagnosed special educational needs due to their disability and to adults through co-operating systems of education, health and social policy. As a result of such an approach, local government authorities may notice and satisfy the needs of all inhabitants without ignoring any group and it may be easier to create conditions for equal opportunities of persons with disabilities. In this context, an important social task is also to enable persons with diagnosed disability or degree of disability⁴ and with diagnosed

⁴ Decisions on disability or a degree of disability are issued by a county assessment board acting pursuant to the Act of 27 August 1997 on professional and social rehabilitation and employment of disabled persons (i.e., Dz. U. from 2016, item 2046). Obtaining such a decision/diagnosis means the legal confirmation of the status of the given person as a disabled person and entitles him/her to receive benefits or privileges, such as tax discounts, disability benefits, discount travels, partici-

special educational needs⁵ to decide about their life and/or to authorise another person to help in solving their problems.

That was also, among others, the purpose of activities undertaken by non-governmental organisations associated with the Warsaw Forum of Initiatives for Persons with Intellectual Disability (WFIRONI), which proposed the continuation of activities conducted for schoolchildren with disability under the education system and the provision of support to school graduates in solving problems of adult life to the Project and Social Welfare Department. Initiatives undertaken by social organisations were recognised by the office and, in 2016, the Project and Social Welfare Department of the Municipal Office of the Capital City of Warsaw launched a competition for nongovernmental organisations for the implementation of a social task the context of which resulted from Priority I. Warsaw Programme of Activities for Disabled Persons for the years 2010-2020. The subjectmatter of the competition was: The use of an information system for the improvement of the quality of life of persons with disabilities and their families. This paper presents tasks being performed by a social organisation that won the competition and made an attempt to support adults with disability and to help them solve legal, organisational and social and professional rehabilitation problems.

pation in occupational therapy workshop activities, a daycare social welfare home or a round-the-clock social welfare home. Conclusion: the said decision/diagnosis may be issued at the request of the person concerned, his/her statutory representative or (subject to the consent of the person concerned or his/her representative) at the request of a social welfare centre. The recommendations included in the decision serve as guidelines for activities related to the ongoing therapy and rehabilitation of the person with disability.

⁵ A decision on special educational needs is issued by assessment boards functioning in public psychological and pedagogical counselling centres. The said statement is issued for educational purposes and determines needs for special organisation of the educational & upbringing process and adaptation of the educational programme and methods and recommends necessary rehabilitation activities adequate to the needs of children and young people with sensory or intellectual disability or social rehabilitation activities for the socially maladjusted and social & therapeutic activities for persons endangered by social maladjustment in the relevant document.

1. Establishment of the Information & Co-ordination Point for Persons with Disability (PIKON)

The original plan of the Information & Co-ordination Point for Persons with Disability elaborated by WFIRONI concerned only the satisfaction of needs of graduates completing the education process in vocational schools, including special schools, in three-year job training schools for students with a moderate or significant degree of intellectual disability and persons with a deep degree of intellectual disability completing participation in remedial classes. In connection with the different scope of competition requirements, the first action plan was modified so that the consultation & information support of PIKON would include all groups of persons with disability residing in the Capital City of Warsaw, their families and legal guardians and so that representatives of public and non-public entities operating within the framework of social policy would be included in the provision of consultation, advice and help in solving problems. Thanks to information provided by PIKON, these entities can update and verify needs reported by interested persons, which is necessary for the satisfaction of needs of persons with disability. The main goals adopted for implementation by PIKON include:

- dissemination of the offer of the city regarding the social and professional activation of persons with disabilities and their families/guardians through access to full information about social institutions and non-governmental organisations providing support,
- 2) identification of material and legislative resources available in the city (public institutions and institutions run by NGOs) that create the possibility of social and professional activation of persons with disability and their families/guardians,
- 3) sending of collective information to the Project and Social Welfare Department of the Municipal Office of the Council City of Warsaw by PIKON in the form of intermediate reports and the preparation of a report at the end of the pilot period,

4) consolidation of co-operation and communication between local and central government and non-governmental organisations functioning in the field of social policy in the city.

By the decision of the competition board, the pilot running of information & co-ordination activities from 1 July 2016 till 30 November 2018 was entrusted to the Foundation for the Support of the Disabled. The co-ordinator of the Project on behalf of the foundation became Dorota Koman, the function of PIKON Office Manager was entrusted to Barbara Szostak, and questions are answered by experts: Iwona Grzesińska, Lidia Klaro-Celej, Zofia Pągowska, Teresa Serafin, Anna Witarzewska.

Anyone who would like to use PIKON's help to solve his/her problems may visit: www.pikon.um.warszawa.pl. The website publishes answers to questions asked by interested persons by e-mail or during visits to PIKON. Answers are given by experts. The website contains also an e-mail address: kontakt@pikon.org.pl.

2. Method of data collection and fulfilment of goals by PIKON

The implementation of tasks of the Information & Co-ordination Point for Persons with Disability is carried out by PIKON's office in co-operation with experts.

In order for the goals to be achieved, a data collection and storage model⁶ has been planned. Data are to be collected in an IT database in the following layout: a) a set of local government and nongovernmental entities; b) contact details (e-mail and phone number) of each entity, c) a description of activity having an impact on the solving of problems that are important from the user's viewpoint, in the following layout: type of institution, place of business, detailed address, district, superior institution, contact details, area,

 $^{^{\}rm 6}$ The draft database in the MS access 2016 was elaborated by an IT expert Anna Pogorzelec.

type of activity addressed to disabled persons, additional identification data of the target group covered by the activity of the entity concerned.

For the purpose of establishing co-operation with social policy institutions and NGOs, information about PIKON was sent along with an invitation to co-operation to 300 entities. On that basis, PIKON's experts elaborated a catalogue of institutions and entities providing support to persons with disabilities and implementing certain problem tasks (social rehabilitation in Occupational Therapy Workshops, the Home of Mutual Aid, etc.). It was assumed that information given to interested persons by employees of PIKON's office might contribute to a better recognition of material resources available in the city, an improvement of co-operation between local government and non-governmental entities and the social and professional activity of persons with disabilities.

Table 1. Categories of personal needs reported by interested persons from July 2017 till 7 November 2017 on the basis of PIKON's database

Determination of categories of needs	Specific problems marked as subpoints
1. Lack of information and knowledge about	 1.1 rights of persons with disabilities resulting from legal regulations or the neglectful approach of responsible institutions to the needs of these persons, 1.2 forms of support and rehabilitation to which persons with disabilities are entitled, 1.3 other forms of support, e.g. regarding the education system and the early support of development of small children, 1.4 PIKON's tasks and curiosity visit
2. Lack of employment, lack of help in looking for a job	2.1 lack of training courses adapted to the needs of persons with disabilities,2.2 rejection of a disabled person as an employee by an employer, mobbing,2.3 looking for a job relevant to the person's qualifications.

cont. tab. 1

Determination of categories of needs	Specific problems marked as subpoints
3. Lack of help in	 3.1 daily functioning, shopping, 3.2 social functioning, e.g., by creating a support circle, 3.3 substantive support in solving current problems, 3.4 social security of persons with disabilities aged more than 25 years by aid institutions.
4. Adaptation of the nearest environment (building), (flat)	 4.1 lack of knowledge about the possibility of getting help in the adaptation of the flat and/or building (lift, broad entrance) or the neglectful approach of responsible institutions to the ensuring of these rights, 4.2 lack of substantive aid in the settlement of problems of the housing community and other entities acting in the housing industry, 4.3 failure to remove architectural barriers by PFRON and to mark parking places for persons with disabilities.
5. Services and equipment for daily use:	5.1 rehabilitation equipment, artificial limbs,5.2 rehabilitation services aimed at the improvement and maintenance of health.
6. Transport:	6.1 ensuring of permanent transport for rehabilitation, treatment,6.2 provision of transport in emergency and occasional cases.
7. Lack of access to medical specialists:	7.1 very distant dates of appointments,7.2 refusal to make an appointment, limited access to certain specialists (gynaecologist, dentist) or hospitals (only with a parent).
8. Financial difficulties:	8.1 lack of funds, medicines, 8.2 lack of funds for rehabilitation.
9. Deficiencies or gaps in decisions:	9.1 appeal periods as a limitation,9.2 deficiencies in recommendations concerning social rehabilitation (e.g. occupational therapy workshops),9.3 renewal or change of a decision (e.g. change in the assessment of the degree of disability).

cont. tab. 1

Determination of categories of needs	Specific problems marked as subpoints
10. Insufficient exercise of rights of persons with disabilities by relevant institutions:	securing the fulfilment of needs of persons with
11. Lack of solutions and support tools:	11.1 referring to the functioning of persons with a significant degree of disability after guardians' death,11.2 determination of a permanent compulsory methodology of working with a pupil with disability.

Source: own work on the basis of PIKON's database.

Activities supporting persons with disabilities and/or their families in solving problems are entered into the database according to the following criteria: age, sex, reported problems, method of intervention, type of information provided and/or the best method of solving the reported issue⁷. This allows these persons to talk about their problems honestly and openly. The type of advice and information and the method of consultation is covered by the regular documentation procedure.

On the basis of problems reported by persons with disabilities and collected in the database during the annual activity of PIKON, it became possible to identify the needs that are most often experienced by persons visiting the office and/or asking question by telephone or by e-mail. Categories of identified needs are presented in the table below.

⁷ Data are anonymised to protect the privacy of interested persons.

For the needs of data analysis and the transparency of its results, the categorisation of reasons and types of disability and recorded according to codes used in making assessments⁸. The following categories of disability have been adopted:

- 1) intellectual disability, defined by codes 01-U,12-C,
- 2) sensory (visual) disability, defined by codes 04-O,
- 3) sensory (auditory) disability, defined by codes O3-L,
- 4) motor disability, defined by codes 05-R,
- 5) mental disability, disorders on the level of the central nervous system, defined by codes 02-P, O6E,
- 6) disability connected with a fortuitous event (accident or disease in persons aged under 55 years), defined by codes 08-T, 09-M, 11-I, 09-M,
- 7) disability connected with the loss of health in persons aged more than 55 years, defined by codes 10-N, 07-S.

3. Description of persons seeking help from PIKON

In the period from July 2017 till 7 November 2017, 409 persons made use of PIKON's services (100%). Most of the persons from this group were more than 50 years' old. This means that the aforementioned group of persons is not aware of types of support and rehabilitation to which they are entitled, does not receive help in dealing with their life problems and comes across mental and architectural barriers. The picture of age groups of PIKON's Customers is presented on Chart 1.

The largest group of persons seeking help from PIKON were women – 221 (~54%), 180 persons (~44%) were men, and 8 persons (~2%) sending questions by e-mail did not specify their sex. The following Chart 2 shows the division of customers according to sex.

⁸ Ordinance of the Minister of Economy, Labour and Social Policy of 15 July 2003 on the assessment of disability and a degree of disability (Dz. U. 2015, item 110).

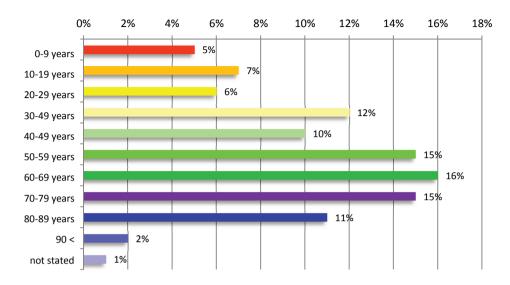


Chart 1. Persons who contact PIKON's office in order to seek help in solving their problems according to age groups

Source: own work on the basis of PIKON's database.

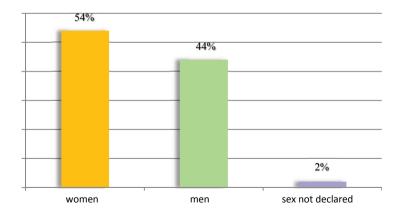


Chart 2. Division of customers according to sex

Source: work based on PIKON's database.

The largest group of persons (139) has obtained decisions from the county motor disability assessment board. The most frequently reported types of disability of PIKON's customers are shown on Chart 3.

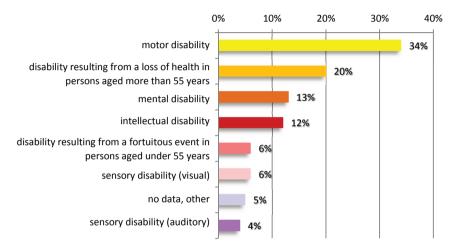


Chart 3. Types of disability reported by PIKON's Customers Source: work based on the database.

Each type of disability presented on the chart generates a different scope of needs. The problems indicated most often by Customers are shown on Chart 4, where definitions marked with numbers from 1.2 to 9.1 refer to categories of persons identified in Table 1 of this work that were reported by PIKON's customers in the period from July 2017 till 7 November 2017.

The above chart shows that the most frequently reported problems indicated by more than 282 (69%) persons with disabilities were those from the scope of categories 1.1–1.3. This means that PIKON's customers are not aware of the rights of persons with disabilities to use various types of support and social and professional rehabilitation that are specified in applicable legal provisions.

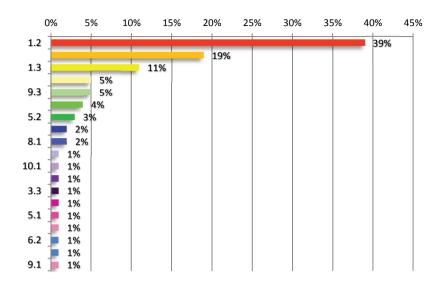


Chart 4. Problems indicated by PIKON's customers; the left axis presents categories of needs

Source: work based on PIKON's database.

4. Analysis of needs reported by selected groups of persons with disabilities

The largest group of PIKON's customers is formed by persons with motor disability (34% out of 409 persons), who reported problems presented on Chart 5.

Altogether, 71% of persons with disabilities reported problems in obtaining knowledge and information about rights resulting from legal regulations, forms of support and rehabilitation and other forms of support, including the early support of children's development (presented in reference 9). The problems reported by 5 persons (1%) in each category included: finding permanent transport for rehabilitation and treatment (Category 6.1), finding a new job because of rejection of this person as an employee by an employer

(Category 2.3), getting support in solving current problems (Category 3.3), removing architectural barriers and creating parking places (Category 4.3), overcoming formal errors of assessments contained in decisions concerning social rehabilitation (Category 9.2), obtaining new decisions or a change of previous decisions (Category 9.3) and help in negotiations with institutions that do not comply with legal provisions concerning the support of persons with disabilities (Category 10.1).

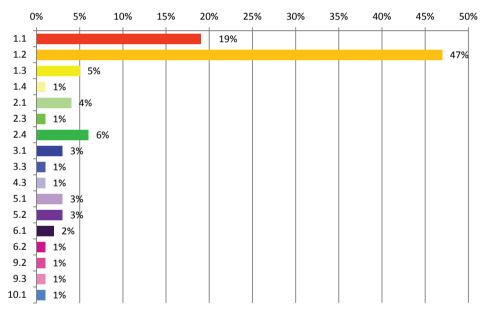


Chart 5. Needs reported by persons with motor disability

Source: work based on PIKON's database9.

⁹ Key: the left axis of the chart presents categories of needs presented in Table 1. As a reminder, I will give an example of selected categories of needs reported by customers indicated on the vertical axis:

[–] Category 1.1 – 19% (78 persons) lack of knowledge about rights resulting from legal regulations,

The needs resulting from the unawareness of or the lack of knowledge about legal standards by persons with various disabilities specified in Category 1.1 were reported by persons from various disability groups, which is illustrated by Chart 6.

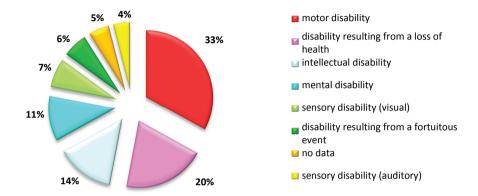


Chart 6. Types of disabilities of persons reporting the needs resulting from their lack of knowledge about legal provisions, on the basis of which they can obtain social support

Source: work based on PIKON's database.

⁻ Category 1.2 - 47% (192 persons) lack of information and knowledge about forms of support and rehabilitation,

⁻ Category 1.3 - 6% (25 persons) problems related to seeking forms of support in the education system, the early support of development of small children,

[–] Category 2.3 – 6% (25 persons) problems related to looking for a job relevant to the person's qualifications,

[–] Category 2.1 – 4% (29 persons) lack of training courses for persons with disabilities,

⁻ Category 3.1 - 3% (12 persons) lack of help in daily functioning,

[–] Category 5.1 – 3% (12 persons) lack of help in the provision of rehabilitation equipment and artificial limbs,

⁻ Category 5.2 - 3% (12 persons) lack of access to rehabilitation services,

[–] Category 6.2 – 2% (8 persons) lack of help in the obtaining of transport in emergency cases.

A prevailing number of persons report the need for help in the clarification of legal provisions and support options resulting from them. Such needs were reported by 135 persons with motor disability (~ 33%), around 82 persons with disability resulting from the loss of health after 55 years of age (20%), around 57 persons with intellectual disability (~14%) and 45 persons with disability resulting from mental illness (~11%). The above needs were reported also by persons with sensory (visual and auditory) disabilities, including those who have become disabled because of a fortuitous event (less than 10%) and around 21 persons (~5%) did not disclose the type of their disability when asking questions by telephone.

Persons with intellectual disability reported the following problems most frequently:

- lack of knowledge about forms of support and rehabilitation available to them,
- lack of information about rights to receive social rehabilitation and various forms of support and problems in understanding recommendations contained in decisions and/or the need for change or issue of a new document confirming their disability. The problems indicated less frequently included: the lack of help in providing social security to persons under 25 years of age, the need to provide rehabilitation equipment, difficulties in the co-operation with institutions resulting from the inconsistency of legal provisions or the lack of good will on the part of institutions, in obtaining permanent transport for rehabilitation/treatment, the lack of money for a living or the purchase of medicines.

The analysis of categories of needs shows that the lack of knowledge about available rights specified in legal regulations is reported by 74% of persons with intellectual disability, 17% of persons with auditory disability and motor disability and 33% of persons who have become disabled as a result of a fortuitous event; (non-)compliance with legal provisions specifying the rules of issuing decisions on disability and/or unwillingness to provide support

by employees of family support centres are reported by 74% of persons with intellectual disability; the non-adaptation of the nearest environment is reported by 75% of persons with motor disability and 25% of persons with disability resulting from mental illness. The lack of legally established solutions providing support to persons who have become disabled after 55 years of age was reported by 100% of persons.

5. Establishment of co-operation with social policy institutions

496 entities (100%) operating in various areas of social policy, including NGOs (54%), public entities (44%) and private entities (2%) were invited to co-operate in providing information & co-ordination support and to help solve problems of persons seeking support from PIKON. Among these entities:

42% support persons with intellectual disability,

22% support persons with mental disability,

16% support persons with visual disability,

14% support persons with auditory disability,

6% support persons with motor disability.

The areas of social policy where entities co-operating with PIKON operate are shown on Chart 7.

The above chart shows that the most difficult thing for PIKON was to establish co-operation for the purpose of supporting person with disability with institutions operating in the field of information, social activation, care, rehabilitation and diagnosis. The easiest thing was to obtain support from entities operating in the education system.

During the period concerned (from July 2016 till 7 November 2017), PIKON's website was visited by 1,135 (100%) users with a Polish-language operating system, who created 1,663 sessions and viewed pages 5,930 times.

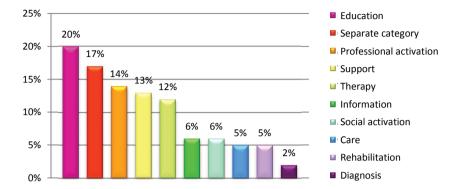


Chart 7. Areas of operation of institutions co-operating with PIKON in providing support to persons with disability

Source: elaboration based on PIKON's database.

New users accounted for 33.1%, and repeat visitors accounted for 66.9%. The website was visited, among others, by inhabitants of Poland (Warsaw, Toruń and Poznań) – 1,471 sessions (88.45%), inhabitants of the USA (Austin) – 69 sessions (4.15%) and inhabitants of Brazil (Parauapeba) – 58 sessions (3.49%).

Summary

The legal standards that have been valid in Poland for many years authorise local government authorities to make decisions on forms of activity aimed at the development of local communities. This area of competence includes also the provision of the following services to all inhabitants by communes, counties and provinces:

- education adapted to revalidation, social rehabilitation and other therapeutic activities as close as possible to the place of residence,
- provision of health care along with therapeutic and social rehabilitation,

 jobs on the open, supported and protected labour market and professional rehabilitation for persons completing school education,

- liquidation of architectural and other barriers,
- support of the development of children/pupils/students from kindergarten to primary and secondary education and the support of higher education,
- continued provision of benefits, including the provision of detailed information and professional support to families of persons with disabilities (e.g., with regard to social welfare, social benefits, special housing and, possibly, specialised care services to children and young people upon completion of school education and to adults who cannot live without another person's support).

The information about PIKON's activity presented in the paper shows that applicable legal provisions do not guarantee the commitment of authorities to their practical use and are not sufficient to obtain:

- knowledge about available forms of support by persons with disabilities, particularly because they are specified in various laws and ordinances,
- information about institutions helping persons with disabilities to solve their life problems,
- help in arrangement of transport, a medical visit or employment,
- information about social rehabilitation and other institutions.

The activity of the Information & Co-ordination Point for Persons with Disabilities (PIKON) shows that information support and the co-ordination of activities aimed at solving problems of persons reporting them can improve the quality of their life.

Even after this short period of functioning of PIKON (from July 2017 till 7 November 2017), we can notice that 11 categories of needs having a negative impact on the life of adults with disabilities have been separated (Table 1). These needs are also indicated by entities co-operating with PIKON who are interested in giving support to

selected groups of persons with disability. On this basis, we can conclude that these activities must be developed and continued. The interest in PIKON's website among inhabitants of the USA and Brazil shows that they can also find it difficult to obtain support in solving their life problems and look for hints about initiatives undertaken in other countries.

After the implementation of this programme is finished, a detailed report will be made; it will describe decisions concerning potential modifications of legal standards and recommendations for the compulsory support of adults with disabilities by all entities operating within the framework of social policy.

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