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The analysis of the statements of nursing home workers on the perception and experience of adulthood by their charges

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Experiencing the institution by adults with intellectual disability still evokes controversy in source literature. The study presents the results of the research based on the analysis of narratives by nursing home workers. The reality they experience revealed the 'subjective truth' about the adulthood of intellectually disabled people. The analysis of the narratives showed personnel's work that can support, initiate and shape the lives of adults in the institution or can impair their functioning to such an extent that they become passive, withdrawn and isolated. Experiencing the institution, intellectually disabled adults more frequently face limitations that affect their lives and shape them according to a particular pattern. The adulthood of intellectually disabled people depends on the personnel's approach and attitude towards this group.

KEY WORDS: adulthood, intellectual disability, nursing home

Interdisciplinarity in the approach to disability

Man is a complex creature that has still not been fully explored and whose actions are unpredictable. Despite the continuous progress in the area of science and medicine as well as scientists' in-

volvement in revealing human secrets, it still poses a great challenge. The phenomenon of human being is underlined by B. Śliwerski, who writes that 'Man is not measurable, directly available to others, but only indirectly through their life expressions'¹. It happens, since, as pointed out by the author, 'Interpersonal influence and interactions undertaken consciously in relation to a person cannot be subjected to standardisation and empirical operationalisation processes'².

The above-mentioned complexity, especially when it comes to a disabled person and their functioning in various spheres of life, requires close interdisciplinary cooperation and the exchange of information by researches in various areas of science. A multifaceted approach to the issue of disability and disabled people allows 'for the confrontation of different points of view and, consequently, and the supplementation of disciplinary knowledge without lowering the awareness of the complexity of the examined issue. The intellectual roots of the interdisciplinary approach to disability should be placed in humanities and social sciences and the knowledge of rehabilitation'³.

A multifaceted approach to the improvement of the situation of disabled people will result not only in holism, but also broadly defined modernity and creativity in the methods and manners of influence. This innovative understanding of rehabilitation 'forces the necessity of obtaining knowledge from various sources, e.g. medicine, pedagogy, sociology, psychology, as the undertaken comprehensive rehabilitation is a multidimensional social process. The purpose of the efforts undertaken by the rehabilitation team is to restore to people in need the maximum ability to live independently

¹ B. Śliwerski 'Cóż po pedagogice w ponowoczesności?', *Annales. Etyka w życiu gospodarczym*, 2012, vol. 15, p. 321.

² B. Śliwerski, 'Cóż po pedagogice w ponowoczesności?', *Annales. Etyka w życiu gospodarczym*, 2012, vol. 15, p. 321.

³ Z. Urbanowicz, 'Od interdyscyplinarnego do transdyscyplinarnego spojrzenia na niepełnosprawność', *Ogrody nauk i sztuk*, 2012(2), p. 445 [after:] G. Albrecht, K. Seelman, M. Bury, 'Introduction. Formation of disability studies', [in:] *Handbook of disability studies*, G. Albrecht, K. Seelman, M. Bury (ed.), London 2001, p. 2.

in one's family, environment and society, but, most of all, to make them able to work and truth about create'⁴.

The functioning of disabled people – despite interdisciplinary research – still evokes controversy and implies numerous problems that cannot be solved. This may result from the fact that '(...) disability is not an explicit category. It can be recognised objectively (documented, certified); it can be noticed by the environment, attributed to an individual, without meeting the certification conditions'⁵. The complexity of this phenomenon also requires close cooperation and open dialogue in the field of science in order to not only define the existing problems, but also find the explanation to them that will facilitate the existence of disabled people in various areas of the social life. The cooperation of various disciplines related to disability and man is therefore recommended. Such joint efforts will enable appropriate support in the area of broadly defined rehabilitation, intensifying the participation of disabled people in social life. Moreover, it contributes to the greater awareness of deficiencies and shortcomings, which sets the directions of research activities.

Drawing on other sciences, such as psychology, cognitive science, social science, medicine, economics, law, IT, telecommunications or, recently, neurobiology, in pedagogical research is necessary⁶. The close cooperation between these areas contributes to the systemic and comprehensive exploration of the phenomena and issues covered by the research. Each discipline that cooperates with special education offers significant 'contribution of knowledge both in respect of theoretical solutions and practical applications. This is mainly true for broadly defined rehabilitation, therapy and resocialisation, which allows for their comprehensive and multicontextual presentation'⁷.

⁴ S. Wrona, J. Rottermund (ed.), *Interdyscyplinarność w opiece i wsparciu osób niepełnosprawnych*, Wydawnictwo Uniwersytetu Śląskiego, Katowice 2015, p. 10 (from the introduction).

⁵ K. Parys, 'Zakres oddziaływań współczesnej pedagogiki specjalnej na tle dotychczasowych przemian', *Niepełnosprawność*, 2011, no. 5, p. 35.

⁶ J. Gnitecki, *Zarys pedagogiki ogólnej*, Zysk i Ska, Poznań 1994, p. 39.

⁷ J. Gnitecki, *Zarys pedagogiki ogólnej*, Zysk i Ska, Poznań 1994, p. 39.

Researchers' statements on the close cooperation are even more reasonable as disabled people '(...) not only face new challenges, but also become a new challenge themselves, both for sciences focused on supporting disabled people and for practical solutions in the area of education, rehabilitation and social support systems'⁸. Therefore, the functioning of a disabled person is closely associated with the cooperation between various environments and institutions that – as pointed out by W. Dykcik – integrate and coordinate their activities to ensure the greatest possible result of broadly defined rehabilitation⁹. The effective cooperation of professionals dealing with various academic disciplines as well as parents, teachers, carers, educators and therapists becomes the impetus for particular actions, both individual and collective ones.

Finding interdisciplinary solutions to the life problems of disabled persons results in giving them the right to lead a normal life. Solutions that enable them to participate in various spheres of social life and adopt different social roles, taking into account their dignity and subjectivity, have been worked out as a result of the efforts of various specialists to tackle these issues. For researches representing various fields of science, a disabled person poses a challenge not only here and now. Their future also implies numerous questions. Thus, as Z. Gajdzica writes, 'The permeation of various theories and concepts not only makes it possible to look at particular issues from various perspectives, but also favours the creation of new quality established on interdisciplinary knowledge. (...)'¹⁰, which becomes a basis for further considerations and reflections on disability.

⁸ K. Ćwirynkało, A. Żyta, 'Czy praktyka pedagogiczna dotrzymuje kroku zmianom w teorii pedagogiki osób z niepełnosprawnością intelektualną?', [in:] *Kierunki rozwoju pedagogiki specjalnej*, ed. K. Ćwirynkało, Cz. Kosakowski, A. Żywanowska, *Impuls*, Cracow 2013, p. 76.

⁹ W. Dykcik (ed.), *Pedagogika specjalna*, Wydawnictwo UAM, Poznań 2001 (from the introduction), p. 5.

¹⁰ Z. Gajdzica, *Sytuacje trudne w opinii nauczycieli klas integracyjnych*, *Impuls*, Cracow 2011, p. 7.

Applied methodology

The purpose of the paper is to present the results of research concerning the interpretation and construction of the lives of intellectually disabled people at a nursing home from the point of view of the employees of this institution. I was interested how this group of people experiences adulthood at a facility providing hospitality, care, aid and education services. I wanted to find out how nursery home workers experience the adulthood of their charges and how they construe this adulthood from the point of view of their experience.

The purpose of the research was to reconstruct the stories and get to the subjective meanings imposed by nursing home workers on the adulthood of their intellectually disabled charges within the confines of the institution. It covered subjective meanings, intentions and interpretations of nursing house workers in respect of the adulthood of intellectually disabled people living at this facility. I therefore examined how nursing house workers experience, through their speech, the adulthood of their charges and how they structure it.

The studies were embedded in the interpretative paradigm. This approach was selected on purpose, as the aim was to find the answer to questions that I found important in the fragments of reality presented by the nursing home workers. I was inspired by three perspectives: phenomenology, hermeneutics and symbolic interactionism. As a consequence of the applied interpretative perspective, it was possible to use the biographical method. It involved the analysis of a fragment of reality – created by nursing home workers – which makes it possible to observe the adulthood of intellectually disabled people living at a nursery home. An attempt to learn and understand this fragment of social reality, that is, the social world stored in the workers' memory, was possible based on the stories of their lives. The biographical method allowed me to obtain the 'real' knowledge on the adulthood of intellectually disabled residents. The reality structured by the workers resulted from their subjective

perspective and experiences related to their work at the nursing home.

The application of the biographical method implied the use of the narration analysis. Narration based on people's history – points out Dorota Klus-Stańska – is 'one of the ways people understand the world'. The author stresses out that narration is a 'natural way required to understand life'.¹¹ Selecting a research method, I was guided by Bruner's words, quoted by E. Kos: '(...) the life of an individual is not what it is, but how it is described and interpreted by them¹². In other words, a narrative reveals the way the reality is understood by an individual'¹³. Narrative conversations were conducted with 4 workers of nursing homes for intellectually disabled adults in Warmińsko-Mazurskie Voivodeship with 10 years of experience. Two persons requested anonymity and the change of their names.

Research material analysis

Facilities for persons requiring 24-hour care have various obligations resulting not only from applicable regulations, but also the fact that they work with people having an absolute right to respect and dignity. Personnel working at such facilities has the greatest experience related to disabled people and the implications of their disability. The reconstruction of these experiences reveals the subjective truth about the functioning of intellectually disabled adults at such an institution. Each story is exceptional and shows a range

¹¹ D. Klus-Stańska, 'Narracja w badaniu i kształceniu nauczycieli', *Forum Oświatowe*, 2002, p. 111.

¹² E. Kos, 'Wywiad narracyjny jako metoda badań empirycznych', [in:] *Badania jakościowe w pedagogice*, D. Urbaniak-Zajac, E. Kos, Wydawnictwo Naukowe PWN, Warsaw 2013, p. 95.

¹³ E. Kos, 'Wywiad narracyjny jako metoda badań empirycznych', [in:] *Badania jakościowe w pedagogice*, D. Urbaniak-Zajac, E. Kos, Wydawnictwo Naukowe PWN, Warsaw 2013, p. 95.

of individual senses, meanings and interpretations. The narratives reflect the truth about the reality experienced by facility workers.

In the analysed fragments of the workers' stories, certain threads common for the narratives as well as totally different ones start to emerge. They cover **subjective definitions of the adulthood of intellectually disabled people** of the workers, who understand the sense of it and define it in their own way. This is exemplified by the words of Dorota, for whom:

'(...) adulthood is when a person thinks and decides independently and is self-reliant in everything they do. Unfortunately, there is no such self-reliance among our charges; if they were self-reliant, they wouldn't be here'.

Marek shares this view, but adds that residents need their support and the organisation of life in which they are not able to adapt to the rules and standards. The narrator underlines that in the case of persons with intellectual disability, adulthood occurs only in terms of age:

'despite their age, they display no other signs of adulthood. The residents have problems with basic things, not to mention taking the responsibility for their actions'.

Jowita also thinks that intellectually disabled people, due to their deficits related to their disability, do not enter the phase of adulthood. They are not able to function independently, both individually and socially:

'We all know what adulthood is, as we all go through it, but we also know that we cannot expect these people to behave like adults, as it is impossible. They will never function like adults both emotionally, mentally and socially'.

Agnieszka also mentions the fact that her charges are not self-reliant, which – according to the narrator – blights their chance to become adults:

'First of all, can we talk about adulthood in the case of such people? I think we can't, as most of them don't know that they should wash themselves or clean their room if you don't tell them to do so. They will, of course, do it perfectly, but only under our supervision'.

The analysis of the narrative shows that the adulthood of disabled people **is achieved to a limited extent**. This may result from the specific nature of the institution as well as the consequences of intellectual disability:

Dorota: 'Our residents can have their personal belongings and arrange their rooms as they wish (...) they invite us to show it to us (...) they are very satisfied if they can do something themselves'.

Marek: '(...) they can do the gardening, plant flowers if they want to; they do it at our house even at their own initiative (...) and even if they will later root them, because they will mistake them for weeds, they feel that they do something on their own'.

The analysis of these narratives shows the workers' happiness with any activity of their charges that involves self-determination, which gives them the sense of authorship, decisiveness and independence. Although the decisions they take are related to trivial things and matters, one can conclude from the narratives that they are extremely important to intellectually disabled people and treated by them with priority, as this is how they express themselves and their adulthood.

However, I have a different impression analysing other narratives, which imply that the workers do not initiate any activity among the residents and do not observe signs of adulthood in them:

Jowita: 'When they have money, they want to go to the shop, but when we are at the shop, they buy sweets, coke and other such things (...) it is natural that if they live like 16-year-olds, their decisions will be the same'.

Agnieszka: '(...) they can watch TV or listen to the music all the time (...) they rarely have any ideas (...) we have a resident who messes up all the time (...) we don't do much, as there is no time for it'.

The narrators do not notice that their charges verbalise their needs and show initiative, for example, in relation to the organisation of their free time. These ideas are ignored by the personnel due to the excess of duties related, in particular, to the completion of documentation.

Another important issue that is present in every narrative is **the atmosphere at the facility**. The workers' stories show that it affects the residents' mood and their activity at the facility.

Dorota: 'our facility is small (...). There are, of course, certain advantages of this fact, as we know our residents very well, (...) But the drawback is that you must get involved in various matters. (...) but the atmosphere is good, as our boss wants to make the residents feel like home (...) we get them involved in various duties and activities, like at home'

The analysis of the narratives shows that a small facility is characterised by pleasant and friendly atmosphere between residents and personnel. According to the author, it results in greater involvement in the residents' affairs. It is expressed by taking into account their opinions and involvement in their everyday duties. The narrative of another worker of the same nursing home has similar overtones:

Marek: 'we are lucky to work with people who treat disabled people normally, that is, they take into account their needs and expectations. People do not laughs at each other. We try to create a place where we all feel well. And we manage to do so, I guess (...) I think our residents feel comfortable here'.

The narrator's statement is very uplifting, as it underlines the significance of the competencies of other facility workers for whom intellectually disabled people are not only objects of their care, rehabilitation and social influence.

The stories told by another interlocutor have a different character, as they do not mention good atmosphere. Working conditions are harsh, which makes them tired, stressed and discouraged from

the work they perform. The relations between the workers are tense, which affects the working atmosphere. As a result, people living at the facility are treated like objects and they get involved in hardly any activity. The residents' lives at the facility are limited – as the author points out – to basic living activities:

Jowita: 'The atmosphere here is not positive. Everything is performed in a rush and everything must be done yesterday. What is more, we have difficult charges and it is hard to spend time with them in a nice atmosphere when they are aggressive. Besides, it is hard to treat someone seriously if they behave like a child or worse. This is the truth and there is no point hiding it, as it is obvious how such people live'.

Agnieszka: 'When I started to work here, I had a different vision about this job, but life rapidly proved the truth. The work here is hard, as there are both ambulant and bedridden residents and we just can't cope with everything. People don't cooperate with each other; but I can't give up this job'.

Another thread that was highlighted in the narratives was **the social life / loneliness of the residents**. The stories show that the charges feel lonely, as they do not have families, they are rarely visited by anyone or taken home for Christmas. The residents miss their relatives – mainly persons that stay at the facility due to their parents' or carers' death:

Dorota: 'Not all of them have families, some of them were left by their relatives and forgotten (...) every situation is different, (...) you can see sadness and a kind of disappointment that they are not taken home or visited (...) they are very envious when someone else is visited by an aunt or someone else (...) they are even proud when they are visited by a neighbour or a member of their family (...). There are parents who don't want to take their children even for Christmas (...) and we know they can afford it; dysfunctional families is a different story'.

This loneliness stems from the fact that some adult charges do not have parents any more. However, those that are visited are very satisfied with this fact, which means that any relationship outside

the facility is of great importance to the residents. However, one should point out that the contacts of the charges with their families are incidental:

Marek: 'I'm aware of the fact that people who live here do not have parents or their families cannot take care of them, and I understand that this place is supposed to be their home. But they sometimes seem to feel lonely and abandoned, some of them even say it'.

My interlocutors' statements reveal that the adulthood of the residents involves social life that is limited to contacts and relationships within the confines of the facility. The facility is located in a small place, where the local community no longer stigmatises, but still treats the residents with reserve. Another problem that limits the residents' social life is the lack of time and willingness of the personnel to organise their free time in a constructive and interesting way that would favour the establishment and tightening of the relationships:

Jowita: '(...) the charges talk to each other, do something together, but they rarely go to meet people or are visited by anyone. Besides, people in our village used to protest, but it has already subsided. There is no time to go out for ice-cream or for a walk, only somewhere in the vicinity (...) but they sometimes don't even want to go out of their rooms, and I won't drag them by force after all'.

The following fragments of the story reveal a very sad reality, as the narrators mention not only **the infantile treatment of adult people by the personnel, but also the task-oriented attitude towards them**. The residents do not show any initiative – as one of the interlocutors points out – but it may result from the personnel's excessive control or treating the residents like objects:

Agnieszka: '(...) one can see that these adult people are treated like children here, they are given everything, nobody asks them about anything, everything is done for themselves, but without themselves (...) it is also us who select room-mates for them, decide what they are to do, I have an impression that everything is mechanical (...) they do not

display any initiative; as I said before, they behave like children who needs to be guided'.

Another narrative also reveals that adult residents are treated like objects and there is no understanding of their specific way of functioning:

Jowita: 'It is often me who is the bad one, I say something and there is no response; I understand that they are disabled, but I'm alone here and everyone wants something (...) Bedridden residents also must be taken care of, fed and washed'.

The narrators' stories often refer to the **passiveness of the residents**. It may result from the personnel's attitude, which does not motivate or initiate any forms of activity:

Agnieszka: '(...) they do not show any initiative, as I said before, they behave like children who need to be guided'.

Jowita: '(...) but they sometimes don't even want to go out of their rooms, and I won't drag them by force after all'.

In order to provide the context, it is worth mentioning those narratives that prove not only great activity of the charges, but also their creativity and artistic activity. The subjective and individual approach of the charges as well as their open attitude towards the residents and treating them seriously bring positive effects:

Dorota: '(...) I am in charge of the arts workshop, and we have a resident called Adam who wants to sleep all the time and nobody does anything with him. I took a brush and showed him that he can use various colours, and now he keeps coming to the workshop and wants to paint'

Dorota: '(...) but the residents are mostly interested in sports and recreation as well as cultural classes, as this is when they are in their element and integrate not only with each other, but also with the residents of the village and other facilities. Sometimes they come and ask: 'Dorota, when can we organise a disco?' or 'It is soon Christmas and we must prepare cards'. So they show great initiative, you only need to let them do it'.

One of the fragments refers to the activity of the house residents, who are supported by the personnel. Moreover, one can see great openness among the residents to any integration activity both at the facility and outside. This openness may result from the attitude of the personnel towards the residents and their respect for them, great involvement in their affairs and outstanding sensitivity to their needs. Treating the residents and their needs seriously leads to a relation based on attention and trust.

Conclusion

Institutional support is very important for intellectually disabled people, especially if they do not have families or relatives that could take care of them. Life at the institution is very specific and thus the adulthood within its confines has a different meaning than outside it. The stories told illustrate maturity experienced at nursing homes by intellectually disabled people. The workers of these facilities presented 'their own' truth about this group of people and their lives by reconstructing their own experiences. It is only a fragment of knowledge concerning intellectually disabled people, presented from the point of view of the subjective experience of workers.

The analysis of the narratives reveals two different worlds of the same institution. The first one proves that most services performed at nursing homes not only does not satisfy the needs of the residents, but even limits and impairs their functioning. Disabled adults do not take part in the life of the facility, they are left on their own and are only the objects of the personnel's care, which has a negative impact on their functioning. Work at the facility and too much burden related to the completion of documentation, or maybe the lack of will and initiative of the personnel, isolate the residents from the environment, limit their independence and self-reliance and, consequently, violate their human rights. Not all workers of nursing homes notice that these people want to decide for themselves, take

decisions concerning their 'existence' at the facility, perform their social roles, meet other people and integrate with other residents.

The narratives I have analysed have proven that experiencing institutions, intellectually disabled people experience also limitations that influence their lives and shape it in accordance with a certain pattern. The residents do not have much freedom to decide about their adulthood or prospects for their own life at the facility. However, if there are workers who are open to the needs of this group of people, there is hope that their needs associated with their age and condition will be verbalised and taken into account. There is a chance that these persons will be able to express their adulthood. Otherwise, the needs of the charges are ignored, as they cannot decide about their lives in such a situation.

The consequences of disability and random events cause that intellectually disabled adults can only count on the support of the facility workers. The narratives prove that the other face of a nursing house are workers for whom a charge is, above all, a human. The narrators notice not only the needs, but also the potential of these people. They focus on the self-reliance of residents, create situations in which the residents can show their initiative and creativity. The narratives show that most intellectually disabled people want to spend time actively. These people want to help in the kitchen, garden or other works, but are also willing to take part in integration meetings both at the nursing home and outside it. They like spending time together and listening to the music, watching TV, but are also eager to participate in recreational and sports, artistic as well as other activities offered to them.

The conducted studies were mainly supposed to show how intellectually disabled adults experience adulthood within the confines of a nursing home. The necessity for the cooperation between specialists in various areas in a pursuit to standardise the living conditions of the facility residents was a secondary consequence of my deliberations. Such an approach makes it possible to take into account all the needs, possibilities and limitations of disabled adults based on the respect, dignity and subjectivity of these people.

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