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Communication of adults with moderate intellectual disability in the process of autonomisation – preliminary considerations

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The aim of this paper is to look into communication in adults with moderate intellectual disability in the process of their autonomisation. This matter has been investigated to shed some light on how people with intellectual disabilities communicate in their social realities in the context of their autonomy and independence. The paper presents a preliminary research using the interpretative paradigm. To deliver the intended goal, the author has used the problem-centered interview.

KEY WORDS: communication, intellectual disability, autonomy, independence, adulthood

Introduction

In this article, I will seek to analyze communication in adults with intellectual disabilities with respect to their self-reliance and independence in their daily lives. I will use the term ‘autonomy’

primarily from the perspective of one's autonomy being recognized and becoming self-reliant. Autonomy consists in the rights of those with moderate intellectual disability to make independent decisions about their external and internal affairs, that is to be self-reliant and independent in making decisions about themselves. In my view, the above are underpinned by socialisation processes, making essential contribution to social realities of those with moderate intellectual disabilities. In this light, it seems essential to look into the communication of individuals with intellectual disabilities, because it is words and the way they are understood and interpreted that create the reality.

The goal behind educating people with intellectual disabilities is to provide them with communication skills so they can express their needs and interests to the best of their ability. It is the learning and teaching processes that should support personal growth in this regard. Not only is the transmission and reception of messages an important element in the process of communication, but also the expression of thoughts, desires and needs to be able to fully participate in society. It is communication that gives some direction to our actions, gives us a sense of being understood, it is "an element that contributes to establishing, sustaining and shaping the entire cognitive system, as well as acquiring social skills (competence)".¹ In preparing those with moderate intellectual disabilities for adulthood, the process of acquiring communication skills should be oriented towards "one's building their own identity, developing autonomy and a sense of dignity, beginning to function socially, understanding and complying with social norms, in particular equipping oneself with skills and knowledge they need to enjoy freedoms and human rights, and to perceive themselves as an independent person, to the best of their ability".²

¹ J.J. Błeszyński, *Komunikacja osób ze spektrum autyzmu – w poszukiwaniu najlepszych rozwiązań*, [in:] *Autyzm i AAC. Alternatywne i wspomagające sposoby porozumiewania się w edukacji osób z autyzmem*, Ed. B.B. Kaczmarek, A. Wojciechowska, Kraków 2015, p. 34.

² A general education curriculum for pupils with moderate or severe intellectual disabilities in primary schools.

Undoubtedly, to deliver this educational goal, the process of (self-) communication shall be an integral part of the functioning of people with intellectual disabilities. One's becoming aware and expressing their needs, desires, expectations and hopes is a natural part of life for both non-disabled and disabled people.

Words create reality...

While observing daily lives of adults with moderate intellectual disabilities, I have always asked myself the question: how can we better learn, show and represent the social realities of those with moderate intellectual disabilities with respect to their communication with themselves and others. Their sense of independence, autonomy and being able to express their own needs is conditioned by their ability to communicate with themselves, but also, or even above all, with others. Everyone, disabled and non-disabled alike, needs to communicate with the world. There are no differences in this realm. The differences regard the forms of communication only. It is interesting how the calls for normalization, independence and social participation of people with moderate disabilities open up the space for full and valuable communication in those with some disability. This means a kind of communication that allows a person with intellectual deficiency to express themselves fully. One of interesting facts are the statements of disabled adults about themselves. These are statements about their independence, social roles, about their viewing themselves as mothers, fathers, wives, husbands and parents. The following question arises: Do these statements stem from their lived experiences, and provide their realities with some meaning and sense? Or are their declarations merely a copy of the words, beliefs of, for example, people significant to them? If the latter is the case, the words used are meaningless and pointless. Of course, this can be the result of people with intellectual disabilities' internalizing certain scripts and processing them

thoughtlessly as if they are their own. Therefore, in this article, I will highlight the ways in which adults with moderate intellectual disabilities communicate.

Independent life

The concept of living an independent life refers to the functioning of people with disabilities in local communities. This concept has been developed in the Scandinavian countries in the 1960s and in the 1970s in the United States. It is “the ability to engage in self-care activities and to participate in the process of self-determination in the least restrictive community”.³ The respect for and recognition of the rights of people with intellectual disabilities is the basis of the concept of independent life. Communicating, expressing oneself, creating oneself, executing one’s plans for life, but also giving oneself the right to study, work, enjoy leisure time, housing and pursue relationships. All this rests on one’s ability to communicate with themselves and with the world. It is the ability to communicate and receive messages that is the foundation of an independent life. The way people with moderate intellectual disabilities communicate with themselves and with others determines their independent lives. By learning to communicate, people with disabilities can “become more independent of others [...]”.⁴ This is why it is so important to equip disabled adults as well as children and young people with communication skills and let them feel they belong in their communities. This is the responsibility of both schools and local communities.

Independence and self-reliance in adults with intellectual disabilities rests on the support for their communication within their communities. Communication facilitates individual agency and affiliation with a group and gives them an independent status. For

³ B. Borowska-Beszta, *Niepełnosprawność w kontekstach kulturowych i teoretycznych*. Kraków 2012, p. 171.

⁴ R. Kijak, *Dorośli z głębszą niepełnosprawnością intelektualną jako partnerzy, małżonkowie i rodzice*. Kraków 2017, p. 7.

people with intellectual disabilities, correct communication is a factor that contributes to their revalidation and rehabilitation. As Amadeus Krause argues: "the goals behind modern revalidation are much broader and apply to all types and degrees of disability. These goals are to:

- Neutralize developmental dysfunctions;
- Help to compensate for other dysfunctions;
- Improve the functioning of the whole organism;
- Prepare those with disabilities to pursue the processes of learning and upbringing;
- Preparation of the individuals to fulfill social roles and function in society;
- Take up employment"⁵ (Krause et al., 2010, p. 47).

How people with moderate intellectual disabilities will communicate, whether they will use facilitated communication or alternative communication, is subject to their fulfilling life or career goals. These are the manners, actions, meant to support their social functioning. After all, the essential objective is to use "all means available to enable people with complex communication needs to transmit and receive messages"⁶ and "all actions aimed at helping those who cannot speak or have limited use of speech and allow them to communicate".⁷

Adulthood

Everyone becomes an adult, regardless of their condition – whether we are disabled or non-disabled. In the case of people with

⁵ A. Krause, A. Żyta, S. Nosarzewska, *Normalizacja środowiska społecznego osób z niepełnosprawnością intelektualną*. Toruń 2010, p. 47.

⁶ M. Grycman, *Czym są wspomagające sposoby porozumiewania się*, "Biuletyn Stowarzyszenia Mówić bez Słów" 2003, No. 1, p. 3.

⁷ Tetzchner S. von, Martinsen H., *Wprowadzenie do wspomagających i alternatywnych sposobów porozumiewania się. Nauka znaków oraz używania pomocy komunikacyjnych przez dzieci, młodzież i dorosłych z zaburzeniami rozwojowymi*, Trans. A. Loebel-Wysocka, J. Gałka-Jadziwicz, Warsaw 2002, p. 7.

disabilities, the issue is obvious – adulthood means, among other things, living an independent life, finding a job and developing relationships. For those affected with moderate intellectual disabilities, this realm is more complex. The fact that a person with intellectual disability becomes an adult is obvious, as evidenced at least by their age. What is essential here is the ‘consent’ in those with moderate intellectual disabilities to their adulthood. Of course, in our reflection upon the support for people with moderate intellectual disabilities, “one should not become extremely optimistic and promote the view that every person with intellectual disabilities can play the role of a partner or parent if provided with adequate support”⁸, as pointed out by Remigiusz Kijak. This is to say: not all of them can communicate clearly. Thus: “adulthood in the social sense means the way an individual behaves that is characterized by a serious attitude to tasks, responsibility for oneself and others, care for one’s health and property, ability to earn a living and to support oneself”⁹. However, all this must be supported by clear and factual communication with the community. Among those with moderate disabilities (moderate intellectual disabilities), many do have communication skills, and, consequently, the ability to live an independent life.

As mentioned before, the socially acceptable functioning of adults with disabilities is determined by their fulfilment of tasks due to the adult stage of life, such as: building relationships, living an independent life and seeking for and keeping a job. The same factors apply to people with moderate intellectual disabilities. These are normalising aspects, showing that people with intellectual disabilities have the same right to work, live independently and establish relationships.

⁸ R. Kijak, *Dorośli z głębszą niepełnosprawnością intelektualną jako partnerzy, małżonkowie i rodzice*. Oficyna Wydawnicza “Impuls”, Kraków 2017, p. 23.

⁹ M. Kościelska, *Przeżywanie własnej i cudzej dorosłości przez osoby z niepełnosprawnością*, [in:] R.J. Kijak Ed., *Niepełnosprawność – w zwierciadle dorosłości*. Kraków, 2012, p. 16.

One's being prepared to play social roles, function in a society and take up gainful employment demonstrates the features of adulthood, and allows them to fully function in a community as an independent person, fulfilling the tasks due to their role and functioning properly as a member of society. It should be stressed that people with moderate intellectual disabilities need to have their adulthood recognized by the society to be able to fully and autonomously participate in their communities. Adulthood in people with disabilities varies as much as intellectual disability itself. This state is characterized by different levels of functioning, so it should be reflected upon in individual rather than global terms. As Małgorzata Kościelska argues, "adulthood is a multidimensional process, involving different mental functions and different life roles. The process can also take place harmoniously and at a pace similar to that of the whole social group, or can be more individual, inhibited, uneven, for example accelerated or partially slowed down".¹⁰

Methodological framework

In connection with my interest in the issue of communication among adults with intellectual disabilities, I have chosen a method of problem-focused interview and participatory observation. As the data was collected primarily to learn about "the context of the phenomena described by a given individual"¹¹, the statements made by adults with disabilities were concentrated on the importance of communicating from the perspective of living an independent life, self-reliance and autonomy. It was important to "obtain contextualized data that shows a bigger picture (...)"¹², in this case, the context of communication.

¹⁰ M. Kościelska, *Przeżywanie własnej i cudzej dorosłości przez osoby z niepełnosprawnościami*, [in:] R.J. Kijak Ed., *Niepełnosprawność – w zwierciadle dorosłości*. Kraków 2012, p. 18.

¹¹ K. Rubacha, *Metodologia badań nad edukacją*. Warsaw 2008, p. 140.

¹² *Ibid.*, p. 140.

My aim was to focus on the issue of communication rather than respondents' experiences, and so the problem-focused interview was adopted instead of a narrative interview; as a result, respondents' statements help us focus on the problem. The choice of a method was also dictated by the fact that I knew what information I wanted to obtain from the very beginning of my research project, while at the same time bearing in mind that 'it is the respondent that makes up the dominant features of one's theoretical concept'.¹³ It is obvious that relevant literature (Konarzewski, 2000; Rubacha, 2008; Kruger, 2007; Juszczuk, 2013; Silverman, 2009) clearly points out that the problem-focused interview stems from the typology of semi-guided interviews. They are "receptive to the context and respondent's free narrative, and allow specific questions to be asked in the course of the interview. Such interviews are always focused on something. Interviews can be focused on:

- A problem;
- Material;
- Subjective theories;
- information (ethnographic interview)".¹⁴

A problem-focused interview and participatory observation have been adopted in this article. Participatory observation consists in the researcher, the observer, 'entering' the environment of the observed persons. The researcher gains greater insight into the culture of the community under observation and is closer to the events within the group. This method is often used with "closed communities" of individuals subject to research projects. Thanks to participatory observation, the researcher can participate in the life of a given social environment to conduct scientific research. They are focused on gathering empirical material to be used in analyses later on. The researcher must be aware that they play the role of a scientist, although "they can never stand completely outside of the social reality

¹³ S. Juszczuk, *Badania jakościowe w naukach społecznych. Szkice metodologiczne*, Katowice 2013, p. 154.

¹⁴ K. Rubacha, *Metodologia badań nad edukacją*. Warsaw 2008, p. 140.

and the situation under inquiry”.¹⁵ When starting their observation, the researcher shall find out about the area under investigation as much as possible. It is therefore important, in the initial research phase, to “take into account the nine dimensions of each social situation that come into contact with each other in a complex manner:

1. Space – Physical place or places.
2. Actors – People involved in a situation.
3. Action – A set of activities done by people.
4. The object – Physical things present in a given situation.
5. Activity – Single human activities.
6. Event – A set of interrelated activities.
7. Time – Temporal sequencing, the pace of events.
8. Objectives – What people are trying to achieve.
9. Emotions – Feeling and expressing”.¹⁶

The observation took place in an integrated flat. It has furnished data that was then subjected to empirical analysis, and the observed reality was interpreted from the perspective of previously adopted assumptions.

Adults with moderate intellectual disabilities were invited to take part in the study. They live in integrated flats. These people have occupied their flats for 3 years. They are learning to live independent and self-reliant lives. This comes handy in investigating their communication methods within the realm of gaining independence and self-reliance.

I’m independent and self-reliant – words create reality

The examined individuals declare their own independence. This can be thought of as a dream, a desire they are striving for. They communicate their independence in a directive way, as if someone

¹⁵ K. Konecki, *Studia z metodologii badań jakościowych. Teoria ugruntowana*, Warsaw 2000, p. 144.

¹⁶ M. Ciesielska, K. Wolanik-Boström, M. Öhlander, *Obserwacja*, [in:] *Badania jakościowe. Metody i narzędzia*. Vol. 2, Ed. D. Jemielniak, Wydawnictwo PWN, Warsaw 2012, p. 44.

could take it away from them or put it in question. Their attitude to reality is manifested in the interviews.

W:1 *"I can take care of myself. Upon graduation, I will find a job. I will earn money and move out of the flat. [author's note: the integrated flat]"* [K. L: 19]

It is a declaration on how he/she wants to achieve his/her goals:

W:2 *"My aunt Monika will help me, she will come with me and help me with important matters"* [K. L: 19]

When asked about difficulties in expressing their expectations

W:3 *"because they don't understand us, they know better than we do" [P., l: 30], "and I know everything, I can sort out with everything".*

W:4 *"Why can't I do what I want?" [N:l:25] "I want to meet whomever I want and yet I cannot"*

The way the residents communicate between each other flows naturally. They express their needs, desires and negotiate. During the daily 'community meet up', the inhabitants express difficulties they have faced but also their success stories and share about their daily lives. Below are some of the observational categories.

Image 1

"I cannot be the only one to clean the bathroom. I do not want to keep cleaning up the bathroom after everybody. Girls don't clean up after themselves, it's not fair."

This is a fairly clear-cut statement, and it shows the ability to use "I" messages: It also shows some kind of assertiveness and one's exerting their rights.

Image 2

"A new carer started working in the flat. She is a young girl. One of the residents became very committed to 'onboarding' her. They state at

a community meeting: I will be her mentor, I will tell her everything, how to work with us. After all, it is easy, she should just talk to us about life”.

This shows the willingness to be in touch, as well as the willingness to help and to communicate one's needs.

The quoted examples are only an excerpt from the broader research on disability. Of course, it cannot be claimed that everyone with moderate disabilities communicates in a clear way with their community. This is a manifestation of the cooperation built between residents and carers. The way in which this group of respondents communicate is the result of training, workshops with specialists in the field of communication, but also, or perhaps above all, building and maintaining relationships. The kind of relationships that give residents the right to self-determination and self-expression. It is the open communication between carers and the disabled residents that makes them feel accepted the way they are. This helps them build their self-esteem. Visible is also the theme of relational autonomy, which, as Dorota Podgórska-Jachnik argues, “(...) may be used to seek for and address various social relational dilemmas, different areas of support for people with disabilities and their families, to define the scope and conditions of social responsibility and solidarity, to build competences supporting personal independence”.¹⁷

Conclusion

Communication is everyone's need, whether they have any deficits or not. It is not the disability that defines a person, but their preparation to communicate with themselves and with other people. With people with moderate disabilities, this is all the more important because it is subject to the vetting of their social participation. Therapists, teachers and parents of people with disabilities

¹⁷ D. Podgórska-Jachnik, *(Nie)pełnosprawność a (nie)samodzielność w kontekście autonomii relacyjnej, Niepełnosprawność. Dyskursy pedagogiki specjalnej*. No. 32/2018.

themselves should think of those individuals' capacity to communicate as their drive to express themselves, their rights and live their lives as independently as possible. These are the lives in which people with moderate disabilities can create their own reality with words. A reality that is, after all, available to all of us. In this article, I would like to point out that whether people with moderate disabilities can express themselves, their needs and desires or not largely depends on us therapists, the individuals who play a significant role in the lives of those with disabilities. Of course, I am aware that the community that I have presented herein is provided with comprehensive support and the process behind the acquisition of their skills has been long and complex.

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