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Autonomy of adults with moderate and severe intellectual disabilities as perceived by their parents

Autonomia dorosłych osób z głębszą niepełnosprawnością intelektualną w percepcji ich rodziców

Abstract: The main aim of the study was to determine the level of autonomy among adults with moderate and severe intellectual disabilities living in family homes from the perspective of their parents. Additionally, it was examined whether the autonomy of individuals with intellectual disabilities is influenced by the severity of their disability and gender. To achieve the set objectives, the diagnostic survey method was employed. An author-designed questionnaire survey for parents living with their adult child with intellectual disabilities was utilized. The study covered the group of 68 parents aged 41 to 82 (M=59.66, SD=8.56). The age of adult children with intellectual disabilities (N=68) ranged from 18 to 63 (M=30.22, SD=8.98). The analysis of the results indicates that adult children with intellectual disabilities are perceived by their parents as having a moderately high level of autonomy in terms of making changes in their own room, deciding what to wear, and preparing meals. They have a moderately low level of autonomy in deciding on how to spend leisure time/vacations and a low level of autonomy in relation to

independent shopping. It was found that only certain areas of autonomy depend on the degree of disability and gender.

Keywords: autonomy, independence, adults with moderate and severe intellectual disabilities, parents, family home.

Introduction

In the humanities and social sciences, autonomy is often treated as synonymous with such concepts as sovereignty, independence, freedom, distinctiveness, self-determination, subjective agency, self-reliance, being oneself, maturity, self-management, neutrality – i.e. concepts referring to individuals, their actions, will, desires, principles, thoughts, ideas, values of territories, environments, structures, or institutions (Śliwerski, 2016). The process of educating children with intellectual disabilities to function independently in everyday life to the best of their abilities represents a particular challenge. As emphasized by Agnieszka Żyta (2011, p. 151), what is considered a normal path for the vast majority of adolescents – a gradual "departure" from the family through increasing the areas of autonomy, gaining financial independence, weakening bonds and building one's own life – is not so obvious in the case of adults with intellectual disabilities.

Among caregivers of children with moderate and severe intellectual disabilities, there is a shared belief in the need to allow some freedom for these individuals. Although the issue of autonomy is closely tied to the upbringing of a child, it remains one of the key concerns in adulthood as well, due to the fact that the consequences of upbringing mistakes affect one's functioning later in life (Zawiślak, 2008, p. 44).

Nurture for autonomy

The specificity of nurturing a child with intellectual disabilities mainly lies in striving for the child to be as autonomous as possible in satisfying their own needs, so that, to the best of their abilities, they can realize themselves in an individual way based on their own preferences in various social environments (Sidor-Piekarska, 2015, p. 130) by performing tasks typical of each developmental stage.

Nurture is a process in which, through the implementation of appropriate nurturing tasks, such as shaping the child's independence, shaping their system of values, shaping socially accepted principles of conduct, introducing the child to the world of culture and art, and developing the need for interpersonal contacts, the young person is prepared for their life in the society

(Kawula, Brągiel and Janke, 2007, pp. 53-54). The main goal of nurturing a child with intellectual disabilities is to shape autonomous behaviour in them and thus the parent should be the child's companion. In classical philosophy, autonomy is understood as the individual's ability to make rational choices, free from excessive interference from others (Dworkin, 1988, p. 48).

Catriona Mackenzie and Natalie Stoljar (2000, p. 127) argue that autonomy is not understood solely in terms of the independence and self-determination of the individual. The formation of desires, beliefs and attitudes of a person is influenced by social norms, social institutions, cultural practices and relationships. Laura Davy (2015, pp. 132-144), on the other hand, defines autonomy as relationships between individuals, where support and activation of autonomy capabilities are perceived as key elements of personal autonomy. This approach, referred to as relational autonomy, enables the assessment of external influences on personal autonomy, as it recognizes the importance of context in shaping our character and personal autonomy. This perspective enables more effective detection and definition of oppressive situations as well as identification of the responsibility of others for reinforcing one's personal autonomy. From the relational perspective, the development of the "self" is a process that occurs within relations with other people, and therefore autonomy is not understood solely in terms of independence and self-determination (Mackenzie and Stoljar, 2000, p. 130).

In shaping one's independence, it is desirable to develop certain areas that play a particularly significant role in the development of autonomous behaviour in children with disabilities (Sidor-Piekarska, 2013, p. 45). Ewa Muszyńska (2008, p. 110) believes that the goals of nurturing children with disabilities should be: to ensure their optimal intellectual development, which will shape their worldview, moral education, preparation for vocational activation, cultural-aesthetic education and physical education. Achieving these goals is possible when children develop certain characteristics necessary for proper functioning. The author divides these attributes into two groups. The first concerns the child's relationship with themselves. Within this group, shaping independence, emotional resilience, optimism and self-acceptance are of particular importance. The second group of characteristics concerns the child's relationship with others and includes such traits as sociability, communicativeness, pro-social behaviour, the ability to cooperate and assertiveness (Table 1).

Table 1. Essential characteristics in shaping the autonomy of children with disabilities

Characteristics pertaining to the child's relationship with themselves	
Independence	There are two aspects to shaping independence. The first is related to the ability of the child to perform simple daily tasks (e.g., dressing up, eating, and toileting, moving around without assistance). The second aspect of independence pertains to the ability to control one's own actions. In the nurturing of a child with disabilities, it is important to create opportunities for making even small decisions. This can be achieved, for example, during playtime with the child (e.g., choosing from among available items). Limiting independence can hinder cognitive and social development (Batko, 2002, p. 18).
Emotional resilience	It is present in the so-called difficult situations and is expressed through the ability and willingness to overcome them. E. Muszyńska (2008, p. 112) believes that parents' reactions to everyday difficulties, their attitude towards the child and the family atmosphere play an important role in shaping this characteristic.
Optimism	It manifests itself in a person's tendency to perceive everything in line with their own desires and in the inclination to notice positive aspects of the surrounding world (Sidor-Piekarska, 2013, p. 41).
Self-acceptance	If a child with disabilities does not accept their own limitations, they will not be able to function properly in the society.
Characteristics pertaining to the child's relationship with others	
Sociability	A child who participates in various social situations will be able to learn social norms and gradually internalize them. Difficulties in shaping this characteristic may arise from the nature of the child's disability or from specific characteristics of the environment, such as reluctance and hostility.
Communicativeness	To shape children's readiness for communication, it is important for individuals who spend time with them to listen to the messages conveyed by the child through available means (augmentative communication, non-verbal communication). Learning to communicate occurs only in situations, where the child interacts with other people.
Pro-social behaviour, cooperative skills	Acquired by the child through the provision of behavioral models, thanks to daily observation of the immediate environment.
Assertiveness	It will be developed provided that respect is shown to the child with intellectual disabilities, dominance is avoided, their rights are respected, and relationships are established (Muszyńska, 2008, pp. 107-139).

Source: prepared by the authors based on: Muszyńska, 2008, pp. 107-139.

Nurturing a child with disabilities, especially intellectual disabilities, is a complex task, because shaping the child's life independence and preparing them for participation in social life (enabling them to achieve the highest level of life independence possible) sometimes becomes a particularly challenging goal to achieve and requires conscious and intensive nurturing work, the results of which are often neither quick nor obvious.

The limitations resulting from intellectual disabilities have an impact on a person's entire life. Adulthood is associated with autonomy and achieving social maturity, while being an adult with moderate or severe intellectual disabilities hinders both. As a consequence, it becomes impossible to fulfil developmental tasks characteristic of the adulthood (Tylewska-Nowak, 2011, pp. 40-41). In the studies conducted by Alice Nucifora, Sue Walker, and Areana Eivers (2024), the majority of parents interviewed (N = 8) felt that their children with an intellectual disability had reached adulthood or a similar stage. One of the consistently emerging themes was the importance of "independence" as an indicator of adulthood, both for their children and for the society as a whole. All but one parent were able to identify at least some signs of independence in their children, such as the ability to make decisions independently.

In this paper, it is assumed that autonomy in adulthood is manifested by the fulfilment of the need for independence in directing one's own actions and making decisions about oneself, which is achieved through a gradual expansion of autonomy in earlier developmental stages (Walkiewicz-Krutak 2015, p. 114). The focus was on activities such as deciding what to wear, how to spend free time/vacation and making changes to the decor of one's own room. The study examined the extent, to which adults with more profound intellectual disabilities, in their parents' perception, independently prepare meals, do shopping and have access to mass media.

Research problems

The main research problem is encapsulated in the following question: What is the level of autonomy of adult individuals with moderate and severe intellectual disabilities as perceived by their parents? Additionally, the authors decided to examine whether the autonomy, as perceived by the parents of adult children, depends on such factors as the degree of disability and gender. If so, in what way? Due to the exploratory nature of the research, hypotheses were not formulated (Rubacha, 2008, p. 102).

The presented study is part of a broader research project (Architects of Change, n.d.), within which interviews were also conducted with adult

individuals with moderate and severe intellectual disabilities residing in various environments (with parents, in social care homes and in L'Arche homes) in order to compare the quality of their lives. The research results presented in this article pertain to adults with moderate and severe intellectual disabilities who still live with their parents.

Research methods and tools

The study involved 68 parents of adult children with moderate and severe intellectual disabilities, including 39 (57.4%) from Opole and 29 (42.6%) from the Opole County. The participants were aged between 41 and 82 (M=59.66, SD=8.56), predominantly mothers (95.5%). The sample selection was non-probabilistic. The study included only parents of individuals with moderate and severe intellectual disabilities. Parents of adult children with mild or profound levels of disability were excluded from the research. These criteria were adopted due to the fact that, under the Polish law, supported housing is primarily targeted at individuals with moderate and severe levels of disability. The aim of the study was to assess the level of autonomy of people who could potentially benefit from such housing.

Participation in the study was voluntary. The questionnaires were distributed among parents with normal intellectual capacity, whose adult children receive support from the Family Rehabilitation Home for Children with Cerebral Palsy Foundation in Opole, the L'Arche Poland Foundation, the "Magnolia" Community Self-Help Center in Opole and the Special Education School Complex in Opole. Most parents completed the questionnaire and submitted it within the agreed time frame. A few were not included in the analysis due to missing data.The diagnostic survey method was used. To collect data, a questionnaire survey for parents living with their adult child with intellectual disabilities was utilized. The tool consisted of 32 questions covering areas of life such as daily routine, safety, relationships, autonomy, development and perspectives. In the development of the tool, the competent judges procedure was applied. These included specialists who work with people with intellectual disabilities, representatives of institutions in the city of Opole that support individuals at risk of social exclusion, as well as academic staff. A total of 15 people were involved.

Most questions were closed-ended and accompanied by a four-point scale with responses: Yes, Mostly yes, Mostly no, No. In addition, each question featured open-ended supplementary questions with space for respondents to provide their answers.

To identify the autonomy scale, a factor analysis was conducted, which included 17 questions that respondents could answer using a four-point scale. The results of the analysis showed that the autonomy scale consists of 6 questions. The Cronbach's Alpha reliability coefficient for the scale is 0.68.

The empirical data obtained was statistically analysed with Statistica 13.3 software (StatSoft Polska). The non-parametric Mann-Whitney U test was used. To indicate statistically significant differences between groups, a significance level of $p<0.05$ was adopted.

Results

Based on the survey conducted among the parents, data regarding 68 adult children with moderate and severe intellectual disabilities living in family homes was obtained. Their age ranged from 18 to 63 (M=30.22, SD=8.98). The discussed group consisted of 27 (39.7%) females and 41 (60.3%) males. Individuals with severe intellectual disabilities accounted for 63.2%, while those with moderate disabilities accounted for the remaining 36.8%. The vast majority of them (88.2%) regularly participated in educational activities, including 51.5% attending Occupational Therapy Workshops, 25% participating in activities at a community self-help center and 11.8% engaging in other activities, including rehabilitation.

Autonomy of adult individuals with intellectual disabilities as perceived by their parents and the degree of disability

The surveyed parents responded to questions regarding their children's autonomy in daily life using a four-point scale, where 4 represented "Yes", 3 - "Mostly yes", 2 - "Mostly no" and 1 - "No".

Table 2. Mean values and standard deviations regarding autonomy of adult children with intellectual disabilities considering the degree of intellectual disability

Items	Degree of Intellectual Disability				Total (N=68)	
	Moderate (n=25)		Severe (n=43)			
	M	*SD*	*M*	*SD*	*M*	*SD*
Is the son/daughter allowed to change the decor in the room they live in?	3.35	0.88	3.05	1.06	3.15	1.00
Do household members knock before entering the son/daughter's room?	2.55	1.26	1.71	1.09	2.00	1.21
Does the son/daughter decide what to wear?	3.08	0.86	2.95	0.95	3.00	0.91

Does the son/daughter decide how to spend their free time/holidays?	2.00	0.91	1.91	0.97	1.94	0.94
Does the son/daughter participate in the preparation of his/her meals?	3.40	0.76	2.65	1.07	2.93	1.03
Does the son/daughter shop independently?	1.88	1.24	1.30	0.77	1.51	1.00

M - mean, *SD* - standard deviation
Source: Authors' own research.

Based on the data analysis (Table 2), it can be concluded that adult children with intellectual disabilities, as perceived by their parents, have a moderately high level of autonomy in terms of making changes in their own room (M=3.15, SD=1), deciding what to wear (M=3, SD=0.91) and preparing their meals (M=2.93, SD=1.03). They have a moderately low level of autonomy in deciding how to spend their free time/holidays (M=1.94, SD=0.9). Shopping is the activity, which was least frequently performed independently by the children (M=1.51, SD=1).

During the analysis, it was also checked whether there is a difference in the autonomy between individuals with moderate and severe intellectual disability. For this purpose, the non-parametric Mann-Whitney U test was used. Table 3 includes only those items for which statistically significant differences were found.

Table 3. Results of the Mann-Whitney U test regarding the autonomy of individuals with moderate and severe degrees of intellectual disability

Items	Degree of Intellectual Disability						*Z*	*p*
	Moderate (n=25)			Severe (n=43)				
	M	*SD*	Me	M	SD	Me		
Do household members knock before entering the son/daughter's room?	2.55	1.26	3	1.71	1.09	1	-2.617	0.01
Does the son/daughter participate in the preparation of his/her meals?	3.40	0.76	4	2.65	1.07	3	-2.835	0.005
Does the son/daughter shop independently?	1.88	1.24	1	1.30	0.77	1	-2.254	0.02

M - mean, *SD* - standard deviation, *Me* - median
Source: Authors' own research.

The analysis of the results of the difference test (Table 3) indicates that parents of individuals with severe intellectual disabilities significantly less frequently knock before entering their child's room as compared to parents of individuals with moderate intellectual disabilities ($z=-2.62$, $p<0.01$). Additionally, adults with severe intellectual disabilities, as compared to those with moderate disabilities, significantly less frequently participate in meal preparation ($z=2.83$, $p<0.005$) and less frequently shop independently ($z=2.25$, $p<0.02$).

Table 4 presents the percentage of affirmative responses to questions regarding various areas of autonomy considering the degree of intellectual disability.

Table 4. Autonomy of adult children with intellectual disabilities considering the degree of intellectual disability

Items	Degree of Intellectual Disability				Total (N=68)	
	Moderate (n=25)		Severe (n=43)			
	Affirmative responses					
	N	%	N	%	N	%
Does the son/daughter have their own room?	21	84.0	37	86.0	58	85.3
Does the son/daughter have access to the Internet?	19	76.0	25	58.1	44	64.7
Does the son/daughter have their own phone?	16	64.0	18	41.9	34	50.0
Does the son/daughter have their own computer (laptop, tablet)?	13	52.0	28	65.1	41	60.3
Does the son/daughter have a girlfriend/boyfriend?	0	0.0	2	4.7	2	2.9

Source: Authors' own research.

One of the elements of independence is having one's own room. According to the research, the vast majority of adult children with intellectual disabilities (85.3%) have a room to themselves. Over half of them also have access to the modern "window on the world", i.e. the Internet (64.7%). In response to the additional question, i.e. "What does your child do on the Internet?", parents most commonly mentioned: listening to music, watching cartoons, watching YouTube, playing games, watching movies, series and, much less frequently, reading news. Half of the participants (50%) have their

own phone, which they use to communicate with their loved ones, but also for listening to music and watching videos. The majority of them (60.3%) also have their own computer.

In the group of adult children with a moderate degree of intellectual disability, there are 17.9% more individuals who have access to the Internet and 22.1% more who have their own phone, as compared to the group of adults with severe intellectual disabilities. A significant manifestation of life autonomy is the possibility of being in a romantic relationship, in other words, having a girlfriend or a boyfriend. This applies to only two individuals (2.9%) from the discussed group.

Autonomy of adult individuals with intellectual disabilities, as perceived by their parents, and gender

An attempt was made to determine, if there is a difference in autonomy between women and men with profound intellectual disabilities. For this purpose, the non-parametric Mann-Whitney U test was used. Table 5 includes only those items, for which statistically significant differences were found.

Table 5. Results of the Mann-Whitney U test for differences in autonomy between women and men with intellectual disabilities

Items	Gender						*Z*	*p*
	Women (n=27)			Men (n=41)				
	M	*SD*	*Me*	*M*	*SD*	*Me*		
Is the son/daughter allowed to change the decor in their room?	3.56	0.64	4.00	2.87	1.12	3.00	-2.485	0.01
Does the son/daughter decide what to wear?	3.30	0.78	3.00	2.80	0.95	3.00	-2.164	0.03

Source: Authors' own research.

The analysis of the results of the difference test (Table 5) indicates that women with intellectual disabilities have significantly higher autonomy in terms of being allowed to change the decor in their own room as compared to men ($z=-2.49$, $p<0.01$), as well as in deciding what to wear ($z=-2.16$, $p<0.03$). There were no statistically significant differences observed in relation to the remaining items.

Table 6 presents the percentage of affirmative responses to questions regarding various areas of autonomy with consideration of gender.

Table 6. The autonomy of adult children with intellectual disabilities with consideration of gender

Items	Gender				Total (N=68)	
	Women (n=27)		Men (n=41)			
	Affirmative responses					
	N	%	N	%	N	%
Does the son/daughter have their own room?	26	96.3	32	78.0	58	85.3
Does the son/daughter have access to the Internet?	18	66.7	26	63.4	44	64.7
Does the son/daughter have their own phone?	17	63.0	17	41.5	34	50.0
Does the son/daughter have their own computer (laptop, tablet)?	16	59.3	25	61.0	41	60.3
Does the son/daughter have a girlfriend/boyfriend?	0	0	2	4.9	2	2.9

Source: Authors' own research.

The analysis of the results (Table 6) indicates that almost all women with intellectual disabilities have their own room in the family home (96.3%), while among men, the percentage is 78%. There were no significant differences between women and men in terms of having Internet access or one's own computer. However, when it comes to having one's own phone, 21.5% more women have it than men.

Summary

The study sought to answer the following question: What is the level of autonomy of adults with moderate and severe intellectual disabilities as perceived by their parents? Based on the data analysis, it was established that adult children with intellectual disabilities, as perceived by their parents, have a moderately high level of autonomy in terms of making changes in their own room, deciding what to wear and preparing their meals. However, they have a moderately low level of autonomy in deciding how to spend their leisure time or vacations and a low level of autonomy in terms of shopping independently. From the research conducted by Natalia Marciniak-Madejska (2014) among adult individuals with intellectual disabilities living with their parents (N=204), it appears that nearly half of the respondents do not buy selected products independently, i.e. they usually do shopping with

their parents. Beata Gumienny (2016), based on her research conducted among parents, found that they try to encourage their adult children with disabilities to be active, but most of them admit that constant supervision is necessary. Moreover, over half of the caregivers admitted that they assist their children with household chores. The researcher concluded that parents typically adopt a controlling-planning attitude and avoid involving their children in decision-making.

In the course of our own research, we also examined whether autonomy of adult children, as perceived by their parents, is influenced by such factors as the degree of their disability and gender. The analysis of the results indicates that parents of individuals with significant intellectual disabilities significantly less often knock before entering their child's room as compared to parents of individuals with moderate intellectual disabilities. Additionally, adults with significant intellectual disabilities, as compared to those with moderate disabilities, significantly less often participate in meal preparation and less frequently do their own shopping. This is likely due to the need for the parents to ensure the safety of their adult children with significant disabilities as well as their belief that their child needs to be closely monitored. Whereas the fact that only 41.5% of adult children in this group have their own phone and only 63.4% have access to the Internet may result from their actual difficulties in communication and reading.

As far as the effect of gender is concerned, it turns out that women with intellectual disabilities enjoy significantly higher autonomy than men in terms of being allowed to make changes in their own room and deciding what to wear. This is likely due to societal stereotypes regarding differences in preferences between men and women. Taking care of aesthetics and appearance is considered to be more typical of females.

However, the presented results do not allow for generalizations which would apply to the entire population of parents and their adult children with intellectual disabilities but only to the studied group. Nevertheless, the following recommendations have been formulated:

– It is worthwhile to educate parents of children with intellectual disabilities in terms of fostering autonomy. Workshops should address issues such as: developing the child's belief in their own abilities, motivating the child to undertake increasingly ambitious tasks within the limits of their capabilities, supporting independence and developing skills which are necessary for cooperation with others (Mumbardó-Adam, Guàrdia-Olmos and Giné Giné, 2020, p. 48).

- It is essential to organize workshops for adult individuals with intellectual disabilities on autonomy, which would promote the development of their imagination, causal thinking, self-confidence and decision-making skills. During the workshops, attention should be paid to the extent to which an adult with an intellectual disability copes with difficult situations and whether they can use support. It is important for them to maintain a balance between relative independence and the need for assistance (Żyta, 2018, p. 62).
- It is important to educate parents on family-type supported housing, which, to a large extent, allows adults with intellectual disabilities to exercise their autonomy with discreet support from assistants.

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