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Parents’ Responsibility for their Ageing Children with Intellectual Disabilities – Dilemmas and Concerns

Odpowiedzialność rodziców za swoje starzejące się dzieci z niepełnosprawnością intelektualną – dylematy i niepokoje

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Abstract

Introduction. Adulthood and the ageing process for people with intellectual disabilities raises many dilemmas and concerns for parents/legal guardians regarding their children’s future. Parents’ concerns revolve primarily around issues related to meeting their needs, providing appropriate care and support in everyday life. Parents wonder whether their adult child will have a social circle, whether they will experience social exclusion, whose care they will receive, and where they will live once the parents are gone. At the same time, the dilemmas surrounding growing up and ageing in children with intellectual disabilities prompt parents to take action to support their children’s development and future lives. It is important that, in this regard, caregivers receive appropriate forms of support, which will help them ensure the best possible adulthood and old age for their children.

Aim. This text attempts to draw attention to the need for systemic action to support adults

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and ageing individuals with intellectual disabilities. Current support systems require refinement and modification, as well as the introduction of innovative solutions that would ensure these individuals’ full participation in social life, and their security in old age. Furthermore, the text flags up actions taken by parents to ensure the best possible future for their children.

Methods and materials. Review and analysis of the literature on the subject, including models of old age for people with intellectual disabilities.

Results and conclusion. The analyses conducted demonstrate that there is currently a lack of appropriate solutions that would enable people with intellectual disabilities to live independently with appropriate support. Support provided by a therapist and assistant is crucial in helping these individuals prepare for life outside their homes without their parents, and gain self-confidence and independence. Developing a community support network, consistent with a needs analysis, may also be a good solution. A matter of great importance is the issue of assisted living, which, unlike training housing, is offered for both fixed and indefinite periods. This desirable housing model is developing very slowly in Poland though, and lacks sound legal regulations. Therefore, the most popular form of housing for this group of people in their old age still remains Social Welfare Homes (SWH).

Keywords**:** adulthood, person with intellectual disability, family, old age, social support

Abstrakt

Wprowadzenie. Dorosłość, etap starości osób z niepełnosprawnością intelektualną to tematy, które budzą u rodziców i opiekunów prawnych wiele dylematów i niepokojów dotyczących ich dzieci w przyszłości. Obawy rodziców oscylują przede wszystkim wokół problemów związanych z zaspokajaniem potrzeb, odpowiednią opieką, wsparciem w codziennym życiu. Rodzice zastanawiają się, czy ich dorosłe dziecko będzie miało swój krąg znajomych, czy nie doświadczy wykluczenia społecznego, pod czyją opiekę trafi, gdzie zamieszka w sytuacji gdy ich już zabraknie. Jednocześnie dylematy związane z dorastaniem i starzeniem się dzieci z niepełnosprawnością intelektualną stanowią dla rodziców asumpt do podejmowania działań na rzecz ich rozwoju i przyszłego życia. Ważne jest, aby w tym zakresie opiekunowie otrzymywali odpowiednie formy wsparcia, które pomogą im zapewnić swoim dzieciom jak najlepszą dorosłość i starość.

Cel. Tekst jest próbą zwrócenia uwagi na konieczność podjęcia działań systemowych na rzecz dorosłych i starzejących się osób z niepełnosprawnością intelektualną. Obecne systemy wsparcia wymagają dopracowania i modyfikacji oraz wprowadzenia takich rozwiązań, które byłyby w stanie zapewnić tym osobom pełne uczestnictwo w życiu społecznym oraz bezpieczną starość. Ponadto zasygnalizowano działania podejmowane przez rodziców mające na celu zapewnienie swoim dzieciom jak najlepszej przyszłości.

Metody i materiały. Przegląd i analiza literatury przedmiotu, m.in. na temat modeli starości osób z niepełnosprawnością intelektualną.

Wyniki i wnioski. Z przeprowadzonych analiz wynika, że obecnie brakuje rozwiązań, które umożliwiłyby osobom z niepełnosprawnością intelektualną samodzielne życie z odpowiednim wsparciem. Ważne jest wsparcie w postaci terapeuty oraz asystenta, którzy będą przygotowywali te osoby do funkcjonowania poza domem, bez rodziców, aby nabrały pewności siebie i samodzielności.

***Słowa kluczowe*:** dorosłość, osoba z niepełnosprawnością intelektualną, rodzina, starość, wsparcie społeczne

Introduction

The quality of life of older adults with intellectual disabilities, and optimal ageing, are the topics that are increasingly being addressed in today's scientific literature. However, they have not always been widely discussed. Experts focused on the issue of intellectual disability in children, adolescents, and middle-aged individuals, stemming from the fact that those individuals did not live to a ripe old age. Scientific literature from 15 or 20 years ago reported that people with intellectual disabilities (*e.g.*, with Down syndrome) lived to around 40 years of age (*cf*. Domagała-Zyśk, 2014). Today, we know that this life expectancy has significantly extended. Professor Wierzba, a paediatrician and clinical geneticist who has been treating patients with trisomy 21 for over 30 years, reports that over 70% of people with Down syndrome live to 50 or longer (Wierzba, 2022). Furthermore, it is emphasised that the average life expectancy of people with intellectual disabilities will soon match the average life expectancy of the general population (Perkins & Moran, 2010). This has been influenced, *inter alia*, by improvements in paediatric care. Nowadays, we are already witnessing people with intellectual disabilities ageing with their parents/guardians, and even outliving them. It is estimated that in the year 2030, people aged 65 and over with intellectual disabilities will constitute approximately 30% of the entire population of people with intellectual disabilities (Domagała-Zyśk, 2014).

The results of the latest National Census of Population and Housing in 2021 show that the total number of people with disabilities as of 31 March 2021 reached 5.4 million, which accounted for 14.3% of the country's population, compared to 12.2% in 2011 (GUS, 2023). Intellectual and mental disabilities affect a total of 25% of the population in Poland[1]. It is noteworthy that intellectual disability, alongside motor impair-

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[1] People with intellectual disabilities are more susceptible to mental disorders than those without disabilities, which is why these two types of disabilities are often combined in statistics. The co-occurrence of intellectual disability and mental disorders poses a serious challenge for caregivers and healthcare providers.

ment (45% of cases) and sensory impairment (30%), is the most common disability in Poland (Dąbrowska, 2024). The largest group of people with intellectual disabilities (approximately 90%) are those with mild disabilities (Śmigiel & Stembalska, 2007).

It must be acknowledged that in recent years, significant changes in views on intellectual disability have been observed. Such a state of affairs is undoubtedly related to the development of biomedical sciences as well as social sciences, including bioethics. Despite unquestionable scientific achievements in the field of intellectual disability, there are still many unresolved and neglected issues in both diagnostic and therapeutic/rehabilitation areas (Kościelska, 1995). Furthermore, many questions and controversies have arisen around the term *intellectual disability* itself. The search for optimal, stigmatisation-free terminology continues. However, not all terms are accurate; some can create a sense of ambiguity.

The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)[2] and American Association on Intellectual and Developmental Disabilities, (AAIDD)[3] recommend using the term *intellectual disability* or *a person with an intellectual disability* (Skowroński, 2006; *vide* Śmigiel & Stembalska, 2007).

In Poland, the term *a person with an intellectual disability* has been in use for several years. It is used formally (in administration), among activists, and among experts, who believe it more precisely defines this disorder and is less stigmatising. However, there are also opinions, such as that of Zakrzewska-Manterys (2021), that "[...] this term still carries a discriminatory note: disability is something undesirable, "attached" to a person as something unwanted"[4] (p. 24). Disability is a normal phenomenon of the modern world, a part of being human. Just like ageing, there is no reason to be ashamed of it or call people "with" a disability (Zakrzewska-Manterys, 2021).

The same applies to the term "old age." There are, in fact, two schools of thought on this issue. One opts for calling old age late adulthood or maturity, a position held primarily by psychologists, and the term is also used in social debates on senior policy and in journalistic practice. The other maintains that using other terms as substitutes for old age changes nothing (Sosnowska & Wieczorowska-Tobis, 2014). Wieczorowska-

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[2] The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) was founded in 1964 as the International Association for the Scientific Study of Mental Deficiency. It is the world's only association dedicated to the scientific study of intellectual and developmental disabilities.

[3] The American Association on Intellectual and Developmental Disabilities (AAIDD) was known as the American Association of Mental Retardation (AAMR) until 2006; the name was changed to move away from the stigmatising term *mental retardation* to the more rational term *intellectual and developmental disability*.

[4] Author's own translation.

Tobis emphasises that she dislikes the word *old age*, but nevertheless believes it would be more prudent to learn to accept the passage of time rather than fight something we have no control over.

Over a decade ago, during the *Małopolski Kongres Polityki Społecznej* [Małopolska Social Policy Congress], Staręga-Piasek stated that we fear old age, yet we should call a spade a spade. Old age should be elevated to the same status as youth. Being old is a value, so it should not be a pejorative term, but a descriptive one (Wójcik, 2012).

Cichocka (1995) is not in favour of "linguistic cosmetics," either; she takes a very transparent stance on this issue, according to which:

> It is a bit like we are ashamed of both old age itself and our attitude towards it. A manifestation of this shame can be, for example, reluctance to clearly name the phenomenon. We say seniority, the autumn of life, the elderly; we try, even verbally, to smooth over the problem, to embellish it, and thus convince ourselves that we are sensitive to its existence. (Cichocka, 1995, p. 81)[5]

The adopted terminology is not insignificant, as it strongly determines the attitudes of society toward ageing and intellectual disability. Furthermore, the way of talking and thinking about ageing and disability, and the attitudes assumed by society toward ageing individuals with intellectual disabilities have a secondary impact not only on the functioning of individuals with disabilities but also on their caregivers. Not only must caregivers grapple with the everyday challenges of disability and with the advancing age of those cared for, which translates into a more complex range of needs, but also with their own weaknesses, sometimes even illness. It is also important to consider that caregivers are also ageing and will eventually need support and assistance themselves.

People with intellectual disabilities are highly diverse, with needs and abilities varying significantly, and their ageing, like the ageing of the entire population, is an individual process.

Due to the individual pace of ageing, it is difficult to determine the beginning of old age and set universal criteria for the stages of old age.

Usually, the biological criterion is considered, defined by tangible changes in the physiological functions of the body, and the socioeconomic criterion, which results from the subordination of the living space of a modern man to sociological, institutional, and economic factors; and by the psychological criterion, considered the least precise, encompassing transformations in the spheres of mental processes, personality, and subjective experiences (Nowicka, 2008; Straś-Romanowska, 2000).

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[5] Author's own translation.

According to World Health Organization (WHO) experts, old age begins at the age of 60. They distinguished three periods: 1) ageing, defined as early old age (individuals aged 60 to 74); according to the Anglo-Saxon periodisation, this age range includes the so-called *young-old*; 2) old age, also called late old age (between 75 and 89 years of age), while in Anglo-Saxon literature it is the stage known as *old-old*; 3) longevity (90 years and more), this is the age of people called *the oldest old* (Zych, 2017).

Bromley, like the WHO, divides old age into three periods, albeit with different age thresholds. He identifies time prior to retirement from work (60–65), retirement (65–70) and old age (from 70 onwards – max. up to 110: late old age). Pikuła (2011) advocates a two-tier classification, encompassing early old age (65–74) and late old age (over 75).

Old age is a very difficult time for people with intellectual disabilities, for both practical and personal reasons. Generally, at this stage of life they can no longer count on their advanced in years parents, who have their own health problems and their vitality is in decline. Situations where parents are absent due to their death are not uncommon. In such cases, a change of living environment is the only option; it is usually moving to a social welfare home. It is important to remember that even if a person with intellectual disabilities has been well prepared for adulthood by their parents/guardians, he or she is not able to function independently. Support is an indispensable necessity in every stage of life, including old age (Zakrzewska-Manterys, 2021). Hence, a question regarding the future of such individuals arises. Responsible parents are confronted with numerous dilemmas, feel anxiety, and face a great unknown.

Specific Problems of Ageing People with Intellectual Disabilities – Parents' Dilemmas and Concerns

Health Issues

Numerous studies (*i.a.*, Horvath *et al.*, 2015) show that ageing begins earlier in people with intellectual disabilities than amongst the general population. For example, in the case of individuals with Down syndrome neuronal the onset of ageing is as early as around age 11, which is the result of abnormal DNA methylation levels. Changes of a biopsychosocial nature are also more dynamic and rapid, with signs of ageing occurring earlier. Ageing induces specific problems, primarily related to declining health. Caregivers of people with intellectual disabilities must face up to diseases characteristic of old age relatively early on (hypertension, diabetes, atherosclerosis and atherosclerotic diseases, osteoarthritis, senile dementia, depression, Alzheimer's disease, Parkinson's disease), as well as diseases to which older people with intellectual disabilities are susceptible, including early-onset dementia, and Alzheimer's disease. It is also noteworthy that the course of the same disease is quite often different in people with intellectual disabilities and in the general population. The disease progresses much quicker in people with disabilities and the symptoms are considerably more severe. Differences also apply to epidemiology, patient examination, and treatment. Diagnostic procedures also pose a challenge. Due to disabilities, there are limited opportunities to use diagnostic tests and observe behaviour; implementation of various therapies is restricted (Lennox, 2010). Therefore, treatment and care require collaboration between various specialists, *e.g.*, when establishing a general diagnosis, which in practice leaves much to be desired. A well-made diagnosis provides valuable information essential for determining the course of treatment and therapy, while an inaccurate diagnosis or a delay in intervention can result in serious health complications and limited treatment options.

Providing appropriate healthcare for ageing individuals with intellectual disabilities is crucial not only because of increasingly poor mobility and sensory dysfunctions, but also because of increasing emotional and cognitive problems. Emotional and cognitive dysfunctions are a consequence of early-onset dementia, as noted above. The lack of appropriate medical support worsens the quality of life for those requiring being taken care of and their parents/guardians. Healthcare for older individuals with intellectual disabilities is still not of high quality. Medical services for children and adolescents with intellectual disabilities function much better. Therefore, adulthood and old age pose a significant challenge in this context. Telling in that respect are the words quoted by the mother of a 17-year-old son with Down syndrome. She heard two doctors say:

> Treat him as best you can, because when your son turns 18, he will be taken care of by doctors for adults, and they have less experience in treating people with Down syndrome, and it is more difficult to obtain access to specific medical procedures. (Konstantyn's mother; Martyniak, 2025, p. 25)[6]

The limited access to healthcare was noted by the UN Committee on the Rights of Persons with Disabilities, which submitted recommendations for Poland in 2018. The recommendations were issued after analysing the first report on the implementation of the provisions of the Convention on the Rights of Persons with Disabilities. The issue of accessibility of healthcare facilities and medical offices is also addressed in petitions submitted by citizens to the Commissioner for Human Rights (Rzecznik Praw Obywatelskich, 2020).

The fact that people with intellectual disabilities, compared to the general population, have limited access to preventive healthcare can also be found in foreign literature on the subject concerned (*vide*, *i.a.*, Backer *et al.*, 2009; Scholte, 2008). Such a situ-

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[6] Author's own translation.

ation is utterly incomprehensible, considering that those people are usually in poor health due to somatic and mental disorders. Furthermore, they are at an increased risk of secondary complications resulting from their disability. Therefore, difficult and insufficient access to healthcare and rehabilitation can be considered a manifestation of indirect discrimination[7] against people with disabilities.

Communication, Mental, and Competency Barriers

Communication, mental, and competency barriers are a separate issue. Communication barriers prevent effective information exchange between patients with intellectual disabilities and healthcare professionals, who do not always consider the fact that their patients use alternative communication methods, especially at this stage of life. Mental barriers, in turn, include a lack of willingness to take action to effectively communicate with a disabled patient, as well as a reluctance to treat them as autonomous individuals. Competency barriers are related, although not always, to mental barriers. They concern the medical staff's lack of basic knowledge about disability, the needs of people with disabilities, lack of experience in treatment and lack of soft skills related to the proper interaction with an ageing person with intellectual disabilities.

In the booklet published by the *Fundacja Wielkie Serce* [Big Heart Association] and edited by Martyniak (2025), *W dorosłość z zespołem* [Into adulthood with the syndrome], the mother of an adult daughter with Down syndrome confides:

> She still lives at home with us, her parents. She functions well within established patterns. However, as she says, she feels more confident when she receives confirmation that her actions are correct. Despite her independence, she expects support. There are times when she feels lost and seeks help. New situations and spaces, as well as questions or behaviours that are incomprehensible to her worry her. Banking transactions to be made on her own, large purchases of goods, technical issues related to household maintenance, and administrative matters cause her trouble and require supervision. Although her medical examiner has not indicated such a need exists, as a mother, I know she needs an assistant. (Dominika's mother; Martyniak, 2025, p. 15)[8]

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[7] Indirect discrimination is a situation in which, for a natural person, due to, among other things, disability, as a result of an apparently neutral provision, criterion applied, or action taken, unfavourable disproportions or a particularly unfavourable situation occurs or could occur, unless the provision, criterion or action is objectively justified by a legitimate aim to be achieved, and the means of achieving that aim are appropriate and necessary; *vide* Rzecznik Praw Obywatelskich, 2020.

[8] Author's own translation.

The "Personal Assistant for Persons with Disabilities" Programme and a Bill on Personal Assistance for Persons with Disabilities – (not) Perfect Support

Caring for ageing individuals with intellectual disabilities is arduous and demanding. Taking advantage of the "Personal Assistant for Persons with Disabilities" programme for Local Government Units, developed by the Minister of Family and Social Policy, would undoubtedly be a significant support for families. The programme has been in operation since 2019, and the 2025 edition is currently underway. Although the main goal of the programme is to introduce personal assistance services as a form of generally accessible support in performing daily activities and functioning in society, this service is still unavailable to many individuals with disabilities. The programme is addressed to children who turned two years old and lasts until they are sixteen and who hold a disability assessment certificate as well as appropriate medical indications, and to people with a moderate or severe disability assessment certificate. The programme is not without its flaws, though. Concerns raised specifically relate to limitations in the scope of services, for example: assistants cannot perform nursing and medical services; there is no continuity of assistance services – the support period is limited to one year; shortage of qualified assistants; poor accessibility in rural or urban-rural municipalities. Personal assistance services are more available in large cities, thereby access to support is unequal. Furthermore, there is no option to employ family members, which, in some cases, can create an obstacle.

Work is currently underway on a government bill on personal assistance for people with disabilities. The bill aims to implement systemic solutions to these issues. The assistant service is scheduled for implementation on 1 September 2026. However, the bill has sparked some controversy within both the *Polskie Forum Osób z Niepełnosprawnościami* [Polish Forum of Persons with Disabilities (PFON)] and the *Rządowe Centrum Legislacji* [Government Legislation Centre], which, like PFON, fears that instead of the expected systemic solution, an "assistant-like product" will emerge (*vide* Dązbłaż, 2025a; Sadziński, 2025).

The Commissioner for Human Rights also submitted comments on the bill (Dązbłaż, 2025b). These concern, in particular, the insufficient number of hours of support provided by assistants to persons with disabilities, differentiation of access to the service for children and adults, and age-restricted eligibility to personal assistance. People over 65 were excluded from that form of assistance. It is worth noting that President Andrzej Duda submitted his bill on personal assistance to the Sejm (the lower house of the bicameral parliament of Poland) in March 2024. The bill assumes that the assistance service is to be available in every district and is to be financed from the state budget. Furthermore, the bill is to cover also people over 65 years of age (*Prezydencki projekt ustawy*..., 2024).

De facto, it is currently unclear what the final outcome of the bill on personal assistance for persons with disabilities will be, hence, it remains the great unknown for parents/guardians of persons with disabilities.

Practice clearly shows that the issue of old age, including the old age of people with disabilities, is not among the key strengths of social policy in Poland. Everyone deserves a decent life, a dignified old age, and a sense of security. Systemic solutions in Poland are therefore essential. Particular care and attention should be devoted to those whose financial situation is difficult and who, for various reasons, cannot, or will not, be able to rely on their family (Zawada, 2018). Loneliness and a lack of family support in the immediate surroundings are problems that arise when parents plan the future for their adolescent and growing old children. The statement below may serve as an example:

> My family is small and scattered across the globe. It's not a multigenerational tribe that will naturally care for the weakest. Ania is unlikely to leave the family nest, live independently, or manage her budget, diet, and chronic illness. However, the fact that we'll be living together doesn't mean we'll manage without outside help. If my health declined, I can't count on a role reversal, on Ania taking care of me in my old age. [...] Will my child be happy? I'd still like to see her future bright [...]. (Anna's mother; Martyniak, 2025, p. 11)[9]

Social Barriers, Ethical Obligation

The attitude of society towards adults and ageing people with intellectual disabilities is also essential. It could seem that much has already been achieved in terms of social integration and dispelling stereotypes and myths about the said social group. Nevertheless, the attitude of society towards intellectual disabilities can still be considered a social problem. Situations where this group of people face misunderstanding and social exclusion are not uncommon. They are usually treated like children throughout their whole lives, so forms of activities are quite often age-inappropriate, and opportunities for cultural pursuits are often beyond their reach. Adopting an ill-suited attitude toward people with intellectual disabilities — either excessive care or its lack — makes it difficult for them to transition through consecutive stages of life. They often do not even realise they are already in their twilight years. Such a situation is not unfamiliar to parents with adult children:

> In Poland, systemic changes are necessary to allow parents of children with disabilities to look to the future with confidence [...]. Human beings are by nature social creatures;

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[9] Author's own translation.

> they are born and develop within families. Over time, they "leave" the family home to venture out into the world and live independently [...]. Unfortunately, in most cases, a person with an intellectual disability will need the support of others. Even in such obvious matters as making friends [...]. Spaces are being created to facilitate development, but there are far too few of them. There are no clubs, and generally accessible activities in community centres do not always welcome people with disabilities [...]. If changes do not occur, what is the point of our efforts and dedicated lives, when the end of the road is still a social welfare home? (Zofia's mother; Martyniak, 2025, pp. 29–30)[10]

Ethical issues in a broad sense are an integral part of caring for ageing individuals with intellectual disabilities. Not only is ethics in healthcare addressed here but also specific ethical challenges surrounding intellectual disability and the problems it creates (Salvador-Carulla *et al*., 2008).

The most common dilemmas concern the right to autonomy and self-determination, confidentiality, privacy, or the ability of people with disabilities to pursue their chosen lifestyle. Actions aimed at people with intellectual disabilities should respect their rights, dignity, and preferences. Therefore, if they are conscious of their surroundings, they should be given the opportunity to make choices in all areas that concern them, including those related to their place of residence. It should not be forgotten that they should always have a support person nearby to ensure that the decision they have make is the best possible decision for them.

Housing is undoubtedly one of the most challenging areas of state social policy. For parents caring for an ageing child with intellectual disabilities, housing, alongside health, is a priority.

Models of Ageing for People with Intellectual Disabilities

Fornalik (2006) lists three models of ageing for people with intellectual disabilities: the community model, the model of living in a social welfare home (SWH), and the model of living in a 24-hour institution for people with profound intellectual disabilities. The models mentioned by Fornalik should also be supplemented with ageing in assisted living or training facilities.

Community Model – Ageing at Home

The model of ageing at home might seem like the best solution. A person with disabilities is cared for by their parents until their death, or as long as they are strong

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[10] Author's own translation.

and healthy enough to care for them. This ensures a sense of privacy and security. Furthermore, having their own home is a vital asset and the centre of life values. Organising home care is relatively easy if there is an extensive family support network, which means that support provided by able-bodied children and relatives can be relied on. However, there are situations when support from relatives is unavailable, the family is incomplete, or the disabled child is an only child, siblings have started their own families and live elsewhere or abroad, or due to work and limited availability, they must choose between caring for ageing siblings and their parents who require care. In such situations, informal caregiving potential is significantly compromised.

To relieve the burden on parents and siblings, who are often the sole caregivers, to improve their quality of life and functioning, and at the same time enable them to perform their professional duties, it would be advisable to recommend: 1) the development of Community Self-Help Centres (CSC)/Day Self-Help Centres (DSC), where people with intellectual disabilities could actively spend several hours a day (at least eight). Currently, in line with the Social Assistance Act of 12 March 2004 (Ustawa, 2004), they are more of a form of support for people with mental health disorders (CSC) and for elderly people, primarily those who are lonely but intellectually able (DSC – Day Care Senior Centre). Although there are already individual facilities of this type operating in Poland (*e.g.*, the *Środowiskowy Ośrodek Samopomocy* [Community Self-Help Centre] "Chatka" in Nowy Targ, established on October 1, 2003), they operate upon the initiative of self-help groups, various associations, foundations and, of course, interested parents of people with intellectual disabilities; 2) organising senior clubs only for people with intellectual disabilities; activities conducted in such clubs would enable seniors to further develop and maintain previously acquired skills, including self-care skills, to keep them in good physical condition and facilitate interpersonal contacts, which are essential for ensuring good mental health.

The functioning of the said facilities is justified due to their role in activation and integration, and, as mentioned before, in the context of combining work and care for an elderly person with intellectual disabilities. Engagement in caregiving and professional work at the same time is difficult to combine due to limitations of time and physical capacity.

The Model of Living in a Social Welfare Home

Another model involves living in a social welfare home for adults with intellectual disabilities. However, this option is unacceptable to many parents and as long as they are able to care for their disabled child, they do not consider this option at all. The stereotype still persists that social welfare homes (SWHs) are a cruel last resort, a form of "social isolation," a "waiting room" where one awaits death. As a rule, an SWH is not perceived as a place which can be described as "your home," where one can also lead a normal lifestyle appropriate for this age group and level of intellectual disability (Zawada, 2013). It is therefore not surprising that parents find this form of care difficult to accept. A mother of a son with autism spectrum disorder and severe intellectual disability, is not alone in this attitude.

> If nothing changes in Poland, after my death, my 39-year-old son, Antoni, on the autism spectrum and with a severe intellectual disability, will end up in a social welfare home. I am saying this, but at the same time I know it cannot happen. And I will do everything to prevent it. There, he will be unhappy and withdrawn. He will live in a room with two strangers, perhaps with a drunkard who will beat him. He will not receive the personalised care he needs; on the contrary, he will spend his days in a group of ten. No one will understand his slurred speech, so his requests and needs will not be considered. No one will care that he likes playing the saxophone and riding a bike. (Wilczyński, 2023)[11]

Sometimes, however, it is worth considering the option of placing a disabled adult "child" in a social welfare home. Do not wait until you reach a point when, due to your age or illness, you begin to have difficulties with daily functioning and caring for your ageing child. Such a situation, in most cases, reduces the quality of life and excludes both parents from participating in social life.

Many countries have undergone significant transformations in institutional care. For example, in Sweden, where community-based care is preferred, 24-hour facilities also operate, most of which house around 10 people in single or double rooms with private bathrooms (Bakalarczyk, 2019). Therefore, a process of deinstitutionalisation of long-term care is necessary in Poland, which should involve moving away from large institutions towards smaller, friendly settings that resemble home life.

An alternative to a residential care is to limit the number of places in support centres and social welfare homes to 30 residents and to create family care homes (Łuczak, 2021). Care institutions should be professionalised, specialised, and subsidised to the highest possible level.

Therefore, 24-hour care should not be eliminated, but rather improved. This issue is crucial because the community-based support and alternative care options (supported housing, family care homes) are still relatively underdeveloped.

Negating the entire sector is not conducive to improvement, as such an attitude can further stigmatise and isolate residents, employees of these institutions, and close relatives of ageing disabled people (Bakalarczyk, 2019). Social welfare homes are not always places of human suffering. They also employ friendly and helpful staff, but there are often too few of them, and some lack qualifications.

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[11] Author's own translation.

Model – Old Age of People with Profound Intellectual Disabilities in a 24-hour Institution

The third model identified by Fornalik involves elderly people with profound intellectual disabilities in 24-hour institutions. That group was treated separately because it constitutes the smallest percentage of people with intellectual disabilities who are unable to live independently. Therefore, people in that group require the greatest stimulation from the environment. Their functioning also features considerable differences. Thus, an attempt is made to draw attention to the fact that too little time is allocated to rehabilitation and therapeutic activities with those individuals. To a degree, such a situation is the result of a shortage of staff who focus on meeting only basic needs.

As with the previous model, changes are needed to ensure a comfortable stay for seniors with disabilities. Therefore, an open discussion about the real problems in such facilities is crucial, thanks to which it will be possible to develop effective solutions (Zawada, 2017).

Ageing in Assisted Living and Training Homes as a Universal Strategy for Social Policy Transformation

Ageing in assisted living and training homes are among the most wished-for housing options for parents of adult children with disabilities. Usually, parents who are deeply involved in the development and care of their disabled children do not plan to organise their children's lives in old age in social welfare homes. They would rather see their ageing children in small, cosy settings, surrounded by friends, acquaintances and a supportive assistant.

Below are excerpts of personal reflections on this issue shared by three parents of children with intellectual disabilities.

> What would I like my child's adult life to be like? I dream of Dominika living among good and empathetic people in the future, surrounded by her dearest and nearest, friends and acquaintances [...]. I dream of her not being uprooted from her surroundings without her will or prior preparation. I dream of her always being able to count on someone who will respect her, support her, and allow her to pursue her passions and interests. I wish that her family, friends, and acquaintances won't let her down in this regard; I wish she could be supported by associations and foundations she knows. Perhaps she will find refuge in a private or foundation-run home, or in a flat with the support of an assistant in a sheltered community? I want her to have a choice and the ability to decide where and with whom she would like to be. (Dominika's mother; Martyniak, 2025, pp. 15–16)[12]

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[12] Author's own translation.

> Kacper and his friends are wonderful, but they will always need help and care of another person. Unfortunately, they are not capable of living independently. I would very much like Kacper to be healthy, have kind people around him, do what he loves, and be accepted in society [...]. Training flats are also needed, as well as places where they can live after we are gone. (Kacper's mother; Martyniak, 2025, pp. 21–22)[13]

> Marek copes very well with everyday activities, such as getting dressed and preparing simple meals [...]. At the same time, I realise that in some respects Marek will always need our support. I dream of Marek finding his place in society [...]. I imagine Marek living in a sheltered flat where he can lead an independent life, but with access to support whenever he needs it. I would like him to have the opportunity to participate in cultural and social life, to develop his interests [...]. My dream is for Marek to feel accepted and respected in his community [...]. It would be wonderful to know that at some point Marek will have the opportunity to find a place in a sheltered flat in the immediate neighbourhood. (Marek's father; Martyniak, 2025, pp. 26–27)[14]

Supported and training housing, which is highly important for parents, is a service provided in the local community in the form of a flat or house. Under the supervision of specialists, residents learn to lead independent lives, improve their self-care skills, participate in various forms of occupational therapy, and organise their free time. They are active in the local community, they participate in outings to cultural institutions, or attend local events.

While training flats are not intended for final housing, as here support is provided only for a specified period of time, in assisted living residence support is granted for both a specified and indefinite period. Housing for an indefinite period is granted for individuals holding a certificate confirming severe or moderate disability, as well as in particularly justified cases. Training and assisted living facilities are defined in the Social Assistance Act of 12 March 2004, and pursuant to Article 53, Section 11 of the said Act (Ustawa, 2004), the basis for their eligibility is a decision issued after arrangements have been made between the entity referring the applicant to this form of support, the entity operating the training or assisted living facility, and the person applying for residence in such a facility or their legal representative, hereinafter referred to as the "housing contract." The register of training and assisted living facilities operated by a municipality, poviat [district], or upon order of the said units of local government and administration is maintained by the voivode [governor] with jurisdiction over the location of the facility (Ustawa, 2004).

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[13] Author's own translation.

[14] Author's own translation.

However, the model, which is already operating successfully in European countries such as the United Kingdom, France, and Germany, is still developing in Poland and requires good legal regulations, which are currently absent. Rymsza (Suchodolska, 2024) emphasises that legal regulations are essential to stabilise the system. He also notes that now there are two programmes in Poland supporting the development of this form of support: Care and Housing Centres, which are primarily run by local governments, and Supported Housing Communities, managed primarily by non-governmental organisations. However, programme- and project-related activities are ephemeral, they do not guarantee long-term operation, and their future remains uncertain. Questions also arise about future funding and operational capacity. Lack of funds for the operation of various supported housing facilities could pose a risk of their commercialisation, *e.g.*, conversion into retirement homes for affluent seniors (Suchodolska, 2024).

Since this issue has not yet been resolved by authorities, parents of disabled children have decided to take matters into their own hands. The leader of the bottom-up initiative for the bill on assisted housing for people with disabilities is Dudzińska, a sociologist who specialises in the sociology of law and politics, and she is also the mother of a man with a disability. The initiative to develop a social draft law on supported housing was initiated by a group of parents of people with cognitive disabilities, as a result of their determination, concern, fear for the future of their children, and the will to change the existing situation.

A two-day diagnostic debate among practicians, held on 5–6 September 2024, organised by the *Stowarzyszenie Wspierające Inicjatywę „Nasz Rzecznik”* [Association Supporting the "Our Ombudsman" Initiative] in cooperation with the Institute of Social Prevention at the University of Warsaw, entitled *Prawne, instytucjonalne i społeczne uwarunkowania mieszkalnictwa wspomaganego dla osób z niepełnosprawnościami* [Legal, institutional, and social conditions of supported housing for people with disabilities] was the first, key element of this initiative *Mieszkania i domy ze wsparciem: Jak/Dla kogo/Jakie/Ile/Kiedy...? Debata diagnostyczna praktyków* [Flats and houses with support: How/For whom/what/how much/when...? Diagnostic debate among practicians] (*Mieszkania i domy…*, 2024).

The tangible outcome of the debate was the development of a series of partial diagnoses, which identified institutional, legal, and social barriers to supported housing. Desirable legislative directions were also identified. The text that has already been published is entitled *Ustawa o mieszkalnictwie ze wsparciem dla osób z niepełnosprawnościami. Podstawowe założenia opracowane przez zespół Inicjatywy "Nasz Rzecznik" i ruchu społecznego "Godność i Wsparcie Drogą i Nadzieją"* [The Act on supported housing for people with disabilities, basic assumptions developed by the "Our Ombudsman" initiative team and by the social movement "Dignity and support is our path and hope"] (*Ustawa o mieszkalnictwie…*, 2025). Expert consultations on this issue are still ongoing.

Conclusion

Old age and the ageing process for people with intellectual disabilities is difficult and specific, both for them and for their parents/guardians. It is difficult because people with intellectual disabilities in their old age stage are a social group whose needs are commonly overlooked or neglected at the time when various programmes aimed at improving the quality of life for people with disabilities are being developed. No coherent and satisfactory system of community and institutional care and support exists, either. Therefore, this particular social group is more likely than other people with disabilities to be exposed to social exclusion. The situation of people with intellectual disabilities is particularly tragic when, due to natural causes, they can no longer rely on their parents' care. Adults with intellectual disabilities usually find care and support in social welfare homes after their parents' death, which contradicts the concept of independent living.

Given the lack of government action, it is hardly surprising, though, that parents responsible for their children initiate many projects themselves, establish associations and foundations that are of paramount importance for social progress.

Principally, people with intellectual disabilities need systemic solutions, including those in the field of assisted housing with support services, thanks to which they will be able to live in their local community for as long as possible. Systemic solutions should currently be a priority in social policy in this regard. People with intellectual disabilities are part of society and should enjoy the same right as everyone else to smooth transition to the consecutive life stages, including old age. Old age is the final stage of life deserving proper respect and in which a sense of security should be maintained. Let us hope that the path to improving the quality of life of people with intellectual disabilities will not be hampered, as usual, by a financial barrier.

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