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Life of people with severe intellectual disability – from adulthood to old age

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Abstract
The psychology of development of human throughout his life developing worldwide after 1970 strongly emphasizes the interest in human in all phases of his life. The holistic attitude of the life-span psychology – manifested in the approach to human as a person – a multidimensional, but irreducible being, who functions in many areas, but always in a holistic way, and also a being that develops in a customized manner and without exception at every stage of life - helped to formulate many new detailed research problems. The scope of these research interests has also been extended to people with intellectual disabilities who increasingly take on social roles that are assigned to adults and perform developmental tasks assigned to a particular phase of life. Also, they increasingly reach late maturity, as the time of their dying gradually progresses.

The life of an adult is not homogeneous. It is created by the phases of life in which an adult functions, the life tasks that he or she undertakes, and the social roles that he or she performs. It is also difficult to clearly define the limits of adulthood, as it is not determined by the age, but the social and biological maturity. It manifests itself, first of all, in the ability to lead one's own life and to undertake and persistently strive for realizing development tasks, despite physical, social, and psychological obstacles encountered by every human being. Commitments, at this stage, are made in two spheres: family, which includes, in particular, procreation, choosing a life partner, setting up a family, birth and education of children, and professional, that mainly involves paid work of a fixed income, enabling to achieve financial independence (Gur-

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ba, 2000). The same situation applies to people with intellectual disabilities, although their life situation is slightly different. First of all, due to intellectual limitations, they are unable to carry out all the development tasks envisaged for this phase of life. This greatly limits their ability to achieve full autonomy and self-reliance. According to the DSM-V classification, *intellectual disability is a disorder beginning in the period of development and includes deficits in both intellectual and adaptive functioning in the areas of conceptual understanding, social functioning, and practical fields* (APA, 2015, p. 15). According to this definition, all three of the following criteria must be met, when it comes to intellectual disability:

– Criterion A concerning deficits in intellectual functioning, e.g. planning, problem solving, and abstract thinking. In the case of intellectual disability, there must be a decrease in intellectual efficiency by two or more standard deviations in the quotient of intelligence.

– Criterion B concerning overall deficits in adaptive behaviour by limits in one or more aspects of everyday life: participation in social life, communication, functioning at work and school, as well as home and community independence. Intellectual disability is characterized by significant disorders in adaptive functioning.

– Criterion C assuming that the onset of the disorder occurrence has been in the period of development.

The current classification distinguishes four types of disability: mild, moderate, significant, and profound (Morrison, 2016, pp. 26-27).

People with mild intellectual disabilities, entering adult life, take up most of the roles envisaged for this phase of life. On the other hand, preparing the more intellectually disabled for adulthood and its tasks requires work in the course of their whole life: at school, in the family home, or in rehabilitation centres for adults. Adulthood of people with intellectual disabilities, until recently, has not been of interest to researchers. Currently, there is a growing interest in the issue of adulthood of people with intellectual disabilities. This is due to an increase in the elderly population with disabilities (Cytowska, 2011). The environment should be maturely and appropriately treat them, properly select responsibilities and allow them to perform independently. Infantilisation of people with intellectual disabilities, lack of consent for their own actions or interference with their activity may lead to a slowdown in the development of their autonomy. Often, parents do not realize that their job is to help their child to become an adult, because the level of life skills he or she acquires will allow him or her to take up social roles envisaged for this phase of life. Jarosław Bąbka (2014, p. 14) points out that *people with disabilities are exposed to a variety of difficulties in functioning as adults due to poor education, not finding themselves on the labour market in times of intense social and economic change.*

After the period of early adulthood, there is a phase called middle adulthood. It involves the following tasks: getting a job, maintaining it and satisfaction with it, tak-

ing care of ageing parents, taking up the role of an uncle or aunt, and helping with housework. People with severe intellectual disability, properly prepared, are able to cope. In the middle adulthood phase, the first signs of ageing can be observed: first appearance of grey hair and wrinkles. These changes occur gradually and slowly, and often, for a long time, are not even noticeable. In addition, the moment of their start is dynamic and different. These first involutionary changes that occur in an adult human being are an indication of impending old age. They are proof that old age is an inevitable stage in every person's life. The changes are multidirectional, including both physical and mental changes.

They can lead to worsening of human functioning, which is often the cause of emotional crisis and lack of joy of life. The situation becomes even more difficult when people do not know that changes may occur, do not understand them, and often cannot deal with them by themselves. This is what the people with intellectual disabilities have to face. The dysfunctions resulting from the disability overlap with the person's individual pace of ageing, which complicates his or her already difficult life situation. Taking into account the way that people with intellectual disabilities function, there can be said that their ageing is slightly different. It is therefore very important to prepare people with severe intellectual disabilities for entering late adulthood. Parents, therapists and friends should take up this task earlier, as the changes may be incomprehensible for people with disabilities. They may cause irritation, annoyance, and even aggressive behaviour.

According to Ryszard Pichalski (2003), adulthood is a lifelong value, which means that a person is not fully mature, and therefore is not an adult, but constantly becomes adult, grows up to his or her own vision of the world and his or her place in it to his or her last moments of life. Almost every human being, as the years go by, more and more often thinks about his or her own old age, but also avoids this kind of thinking, fearing decrepitude, dependence on the family, loneliness, not wanting to accept the feeling of insecurity. He or she is frightened by the prospect of searching for support in social care. The author also points out that old age does not have to be a period of alienation, seclusion, total passivity. Old age - like childhood, youth, or maturity - takes something, but also gives something. The beginning of old age is not strictly defined, because it does not come overnight. There is a time to prepare for it. That is why everyone's job is to lead such a life so that old age is no surprise. One should take care of health condition and fitness better, which will translate into psychological well-being. The source of satisfaction for old age may be the feeling that life has not been wasted and it has not been squandered for trivial and unnecessary matters. Old age is characterized by a significant decrease in vital functions in terms of physical, mental, and social functioning. Old age also poses some challenges for the man, who, despite the difficulties, should tackle them. The most important tasks of this stage include accepting one's own life, taking up new roles and activities, and developing an attitude to death.

Expected life expectancy for the disabled is significantly lower than for the non-disabled. This is particularly true for people with severe disability and Down syndrome. Tadeusz Pietras, Andrzej Witusik, Marcin Panek, Piotr Kuna, Paweł Górski (2012, p. 377) cite research showing that the average life expectancy of people with Down syndrome is 55.8 years. In the 1930s, the average age of disabled people with intellectual disabilities increased to 15 for men and 22 for women. The mean median for the expected life expectancy of people with intellectual disability is 68.7 years. It is important to emphasize variety with regard to the degree of disability: for mild disability it is 74 years, moderate – 67.6 years, profound – 58.6 years. For people with a normal quotient of intelligence, the average life expectancy was 75.6 years for men and 81.2 years for women. The authors, analysing results of medical researches, indicate that the most common causes of death in people with intellectual disabilities are respiratory disorders, posture disorders' complications, gastrointestinal disorders, cardiovascular diseases, as well as oesophageal, stomach, and gall bladder tumours. The profile of the mortality structure differs from the population of healthy people, where cardiovascular diseases are the first, and on the second place there are tumours, with lung tumours as prevalent. In Down syndrome, the life-limiting factor is progressing stupor.

Effective adaptation to old age is the ability to cope with everyday problems by exercising personal control over one's own vision of ageing and quality of life under conditions of experiencing the loss of the most important values. Stanisława Steuden (2014, p. 8) emphasizes that *the complexity of human life, the richness of experience and the difference in the way of living is an individualized and person-specific manner of adjusting to old age.* Adapting to old age has a significant impact on the quality of life of people in this phase. Quality of life also depends on the course of previous stages, that is, from conception to old age. Old age is an inevitable and the most diverse phase of human life. *Disability has many names, but old age also has different faces* (Zych A.A., Kaleta-Witusiak, 2008).

According to Barbara Harwas-Napierała (2000), the support for development of adults with intellectual disabilities involves any (more or less conscious) measures manifested either by the individual (to himself or herself) or by other people to him or her in order to facilitate her developmental process. They should include:

– Assistance in accepting and adjusting to changes that occur in the social and family environment (retirement of parents, the need to support them in old age, preparation for passing away of the loved ones), and in oneself (involutionary changes, worsening of health).

– Consent of parents and therapists to make one's own decisions and to bear the consequences.

– Providing one's own activity related to family, professional, and social roles (Fornalik, 2008).

It depends to a great extent on the environment in which people with intellectual disabilities function whether they will have the opportunity to experience old age in all its aspects. It is the closest environment that should take care of their dignified old age.

People are increasingly interested in the issues of the elderly, as a result of many social changes that we face today. These include changes related to the situation on the labour market, the demographic situation or social policy of the state (Wrótniak, 2015). The author believes that old age is a static term - it occurs after adulthood; while the ageing process is dynamic and progressive. Ageing of the body is a set of anatomical and physiological changes that progress over time. They lead to reduction in the reserves and limiting of the ability to maintain homoeostasis in stressful situations. These changes affect functioning of each cell, so they concern all tissues and systems. They are a natural stage of the body transformation, and therefore an inevitable part of every human life. Although they do not lead to illness or disability, they significantly increase their probability (Zasadzka, Wieczorowska-Tobis, 2014). The involuntary changes start around the age of 30 and deepen over time. Their progress is peculiar, which contributes to significant differences between people in old, the same, age. The ageing process is very fluid, it goes through stages (Wieczorowska-Tobis, Stogowski, 2014). Initially, there occurs social ageing, and then physical ageing. This process is also related to the conditions and the way of life, and is different depending on sex or place of residence. The process of ageing and old age are of interest to many sciences, including biology, geriatrics, medicine, philosophy, sociology, pedagogy, and psychology. Each of these areas has a different approach to ageing and old age. It is therefore very difficult to define these concepts in a way that would suit all researchers. The primary science related to ageing is gerontology. This is a field that involves the phenomena of late age. It seeks to understand the specificity of old people in the best possible way so that it can find ways to solve many of the problems faced by people in this age group. The goal of gerontology is to improve the quality of life for the elderly by rebuilding their authority, identifying their appropriate role in society and in the family, improving health, motivating for development, improving efficiency, and stimulating activity. (Krzysztofiak, 2016). To say that a human is already biologically, socially, and psychologically old, is, in fact, a question of convention that is ruling at a certain time, in a particular historical system, in a given culture and social sphere. In this view, in principle, it is the society who decides how old age is defined and perceived, because it is, in a certain way, a social destiny (Krzysztofiak, 2016). At present, ageing and old age appear in the field of pedagogy, whose aim is to raise to old age. This involves preparing people for old age by making them aware of the consequences of this stage in every sphere of life. The pedagogy of old age is to introduce the specificity of old age, and also to inspire and motivate older people to be active. Its purpose is to make that this group of people develop their interests and are socially active; as a result, it will enable these people to accept their age, to pass through this phase of life in a smoother way, as well as to avoid isolation and loneliness. The process of raising into old age should take place throughout the human life so that the desired habits can be appropriately established. The pedagogy of old age should also have an impact beyond seniors; it should also influence the people who help them, and even the whole society. It should develop an appropriate attitude, eliminate stereotypes

and prejudices against old people. On the other hand, help for people with intellectual disabilities entering adulthood and ageing should include:

– support of the family and providing financial help necessary for adults with intellectual disabilities to become independent,

– introduction of protected housing as a systematic solution contributing to the independence of people with intellectual disabilities,

– promoting universal health care programs and health programs,

–involving people with intellectual disabilities in social activities (Kijak, 2013).

It is important to assist people with intellectual disabilities in recognizing the positive aspects of ageing and eliminating the fear associated with arrival of this stage of life. It is also necessary to create a model of active ageing with a focus on development tasks. The positive reception of old age does not appear from nowhere – it is rather a result of good, wise preparation and raising to old age (Wolska, 2014). Good education to old age should be an essential element of modern education, free from prejudice and non-acceptance, and should be universal – referring to the needs and values, as well as preferences of the elderly *(*Kijak, 2013, p. 106).

Thanks to the *Scale of observation of involutionary changes in the development of mentally retarded people by Lambert* (in translating and modification by W. Pilecka, D. Wolska), I have obtained data concerning changes observed by parents or carers and occupational therapists in people with intellectual disabilities in the following areas: physical appearance, life activity, stereotyped and ritualistic behaviours, speaking and thinking, perception, memory, orientation in time and space, attention, nature and mood, and self-evaluation of changes (Wolska, 2014). The study included 300 adults living in a family of origin or in social care homes that were at least 40 years old.

Major regression changes were noted in the physical appearance of the subjects examined. They concern: *slowing the movements in the march, slowing the movements of the most important parts of the body,* and *manual difficulties*. Their intensity increased with the age of the subjects. The involutionary changes associated with life activity are: *lack of interest in external appearance, reluctance to engage in professional activity,* and *lack of interest in entertainment.* All stereotyped and ritual behaviours occur more frequently in the population of people over the age of 43 and concern: *the occurrence of stereotyped movements, stereotyped movements of hands,* and *ritual behaviours before falling asleep*. In the study group of adults with intellectual disabilities, the observed involutionary changes were also related to thinking: *slowing of train of thought, loss of thread during conversation,* as well as *reduced concentration* are the most common difficulties signalled by significant people. Rarely, there were difficulties with the severity of speech disorders: *less fluent language, difficulty in maintaining conversation,* and *loss of vocabulary*. All of the aforementioned changes had an upward trend in the group of over 43-year-olds. The change in perceptions observed by parents and therapists was mainly related to *wrong interpretation of events*. The *visual and auditory hallucinations* were minor. An involuntary change, which occurs most often in the population and is associated with

functioning of memory, is *forgetting where they leave their belongings*, *forgetting the names of known people,* and *losing memories of recent events*. In over 43-year-olds, there is a growing group of people *who do not remember from day to day*. Regression in terms of time and space orientation in the examined group of disabled people is not very serious and concerns: *confusing weekdays and hours of day*, as well as *forgetting the date and time*. The involutionary changes related to attention are evident when playing a *well-known game, the need to repeat well one routine that has been "mastered" so far* and *loss of the ability to track TV programs*, even though that before, watching TV filled almost all of the free time of the subjects. The involutionary changes in nature and humour are intensive in the study group. These include: *irritability, global changes of humour without cause, suspicion of people, feeling of persecution* and depressive symptoms: *no interest in the environment, general apathy* and *lack of cooperation.* A relatively small number of people with intellectual disabilities are unaware that their functioning has changed due to involutionary changes that have occurred in their lives. This is confirmed by the fact that self-assessments of people with intellectual disabilities who function well in the environment and are aware of their strengths and weaknesses – are right.

The above analysis clearly indicates that with age, the skills of people with intellectual disabilities developed during education and in activity centres change under the influence of emerging involutional changes. Therefore, these changes need to be taken into account when planning professional or social activity of adults with intellectual disability. The study enables to state that involution changes occurs more frequently when a person with disability lives in a social welfare home. Also, the lack of professional activity promotes intensification of involutionary changes.

At the end of the discussion on the most frequent involution changes in people with intellectual disabilities, I would like to propose a model of good old age that takes into account the independent variables influencing involutionary changes.

In the interest of good old age for people with intellectual disabilities, it is necessary to introduce systemic aid solutions. Older people emphasize the importance of the fact that the social worker is interested in their needs, views, and health. They appreciate the fact that they are still important members of society and that the state is taking action in support of people in old age. Employees who provide preventive home help should assist in small household chores. Sometimes it is enough to walk with the worker, to do shopping or to have a tea or a conversation together. Susan Gustafsson, Kajsa Eklund, Katarin Wilhelmson, Anna Karina Edberg, Boo Johansson, Greta Kronlof, Gunilla Gosman-Hedstrom, Synneve Dahlin-Ivanoff (2012) research indicates that in the elderly who have systematically benefited from this type of support, involutionary changes have considerably slowed. I think that in families with intellectually disabled, the workers would have to be prepared to talk about the possibilities and limitations of the disability. In Poland, families and people with intellectual disabilities can benefit from the services provided by social welfare facilities, but in order to make them available, there must be met a number of conditions. The preventive home visits would require only one criterion – of age.

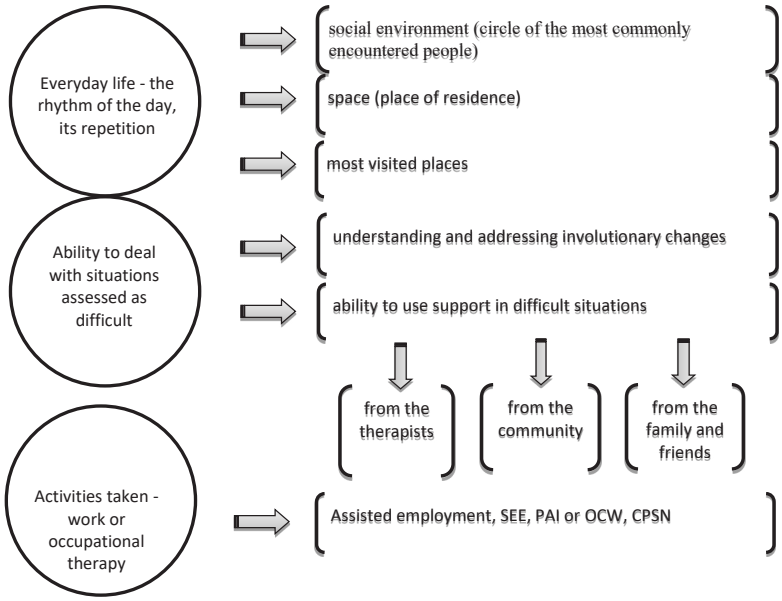

Chart 1. Model of good old age of a person with intellectual disability

I would like my considerations to help people with intellectual disabilities, their parents, therapists, and friends to consider old age as a phase of human life, with its tasks, difficulties and joys. I would like to convince them that it is worth trying to make it possible for them to experience full adulthood and old age. A person with intellectual disability at this time will need family and professional support to understand involutionary changes, to try to delay them and then, to accept it.

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