

# THE AUTHORSHIP OF THEIR OWN LIVES IN PEOPLE WITH DISABILITIES: RESEARCH STRATEGY FRAMEWORK

---

**Abstract:** The article presents a basic strategic framework for research on the authorship of their own lives in people with disabilities (AOL-PwD). This issue corresponds to the humanistic approach to the exploration of the phenomenon of disability, which stresses subjectivity, agency, well-being, independence, and satisfaction with fulfilling age-appropriate tasks. Previous analyses resulted in the theoretical construct and the definition of the AOL-PwD. This article aims to present a research strategy framework for the construct. The following strategic assumptions are considered: (1) universalism, (2) affirmation, (3) interdisciplinarity, (4) comprehensiveness, (5) adaptation, (6) subjectivism, (7) objectivism, (8) participation, (9) individualism, (10) pragmatism, (11) contextuality, and (12) systemness. We think that the AOL-PwD concept creates an inspiring theoretical and empirical space and fosters valuable dialogue across various fields and between rehabilitation theory and practice. The ultimate goal will be to develop an assessment and rehabilitation model of the AOL-PwD concept. Following its recommendations will make it possible to provide people with individual support determined by their subjectivity, independence, and developmental satisfaction. That model will be made based on the identified personal resources and multidimensional determinants of the social environment.

**Keywords:** disability, authorship of their own lives in people with disabilities (AOL-PwD), subjectivity, wellbeing, independence, developmental tasks, social support, self-determination, quality of life, participatory paradigm

**Joanna Głodkowska, PhD**  
Full Professor at The Maria Grzegorzewska University (APS)  
Director of Institute of Special Education  
Head of Chair of Interdisciplinary Disability Studies  
40 Szczęśliwicka Street  
02-353 Warszawa  
Poland  
E-mail: jglodkowska@aps.edu.pl

**Urszula Gosk, PhD**  
Assistant Professor at The Maria Grzegorzewska University (APS)  
Institute of Special Education  
Chair of Educational Therapy  
40 Szczęśliwicka Street  
02-353 Warszawa  
Poland  
E-mail: ulagosk@aps.edu.pl

**Marta Pałowska, PhD**  
Assistant Professor at The Maria Grzegorzewska University (APS)  
Head of Institute of Special Education  
Chair of Interdisciplinary Disability Studies  
40 Szczęśliwicka Street  
02-353 Warszawa  
Poland  
E-mail: mpagowska@aps.edu.pl

---

## INTRODUCTION

Most frequently, the perception of human disability and attitudes toward people with disabilities result from individual experiences in interpersonal relationships as well as from mental patterns, prejudice, and stereotypes existing in the public consciousness. One of the ways to overcome them is to introduce new and important information into the public consciousness—information that will be powerful and valuable enough to change the old outlook and allow a different perception of people with disabilities and their lives. The special role of science in this regard should be pointed out: conceptual and empirical findings as well as explorations and reflection in science are important impulses penetrating the public consciousness. The ideas, concepts, or even visions of social sciences and the humanities make it possible to foster a public belief that people with disabilities—despite their limitations—have something important to offer to the world. A years-long exploration of such issues prompted devising the *authorship of their own lives in people with disabilities* concept (AOL-PwD) (Głodkowska 2015). The concept results from long-term studies that focused on aspects including the phenomenon, process, and social movement relating to the normalization of the lives of people with disabilities; the subjective rehabilitation model and the contemporary paradigm of support defining conditions for enabling people with disabilities to have independent lives; the positive image of people with disabilities; and the idea of well-being that fits in with the phenomenon of disability (e.g., Głodkowska 2003, 2005; 2012; 2013; 2014a,c,d; 2015; 2017).

We expect that the approach to people with disabilities from the perspective of their life authorship will allow building a comprehensive assessment and rehabilitation model. In this respect, we underline that the model will (1) highlight a person's potential above all and not his or her deficits; (2) provide an opportunity for a multifaceted assessment of a person's functioning instead of a fragmentary assessment; (3) probe into complex contexts and connections among various determinants; (4) provide a basis for devising a comprehensive research model; (5) explore a person's real life as subjectively perceived by him or her; (6) create a justified opportunity for people

with disabilities to participate in research as equal research partners; (7) provide important practical recommendations for designing support systems and rehabilitation programs; and (8) allow multi-layered analyses, interpretations, and designs of rehabilitation activities as well as a review of their effectiveness from the point of view of the wellness and resources of people with disabilities (Głodkowska and Gosk 2018).

The purpose of this article is to establish a strategic framework for research on the AOL-PwD. We believe that this work is an important link that leads to further stages of methodological and empirical procedures in AOL-PwD assessment, and ultimately to designing a rehabilitation and therapy model in this area. The research strategy framework formulated in this article is a crucial stage of methodological and empirical procedures in terms of further conceptualization and operationalization of the issue of AOL-PwD.

## DEFINITION, THEORETICAL CONSTRUCT, IMPORTANT ASPECTS

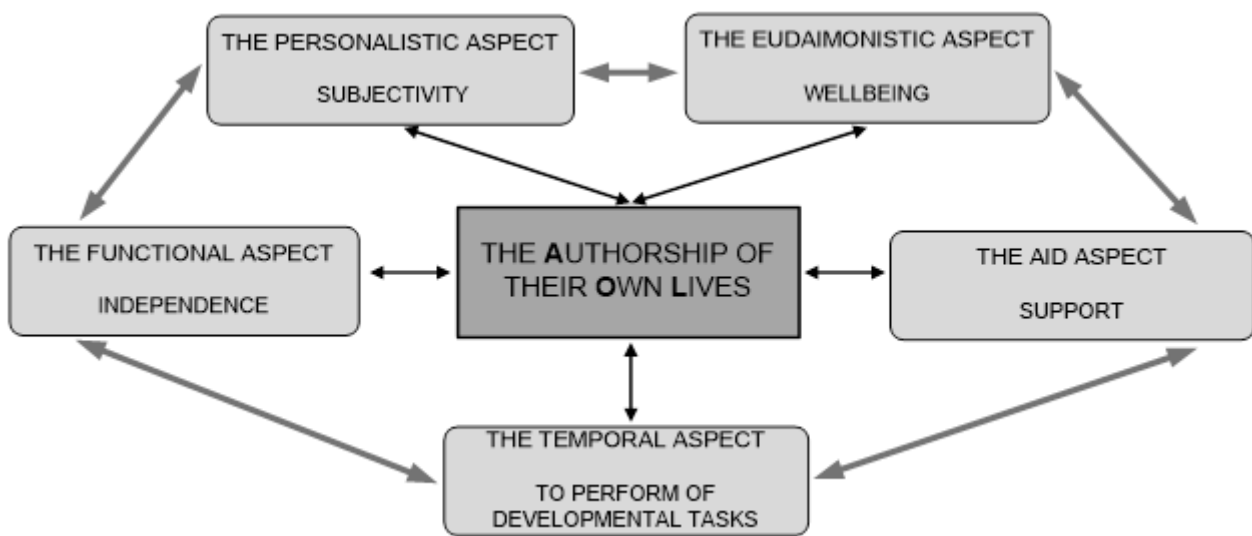
In previous papers, the AOL-PwD concept was presented, a definition was formulated, a theoretical construct was developed, and research stages and procedures were designed. According to the definition adopted:

The authorship of their own lives in people with disabilities (AOL-PwD) is a multidimensional construct that identifies their (1) subjective experiences, (2) wellbeing, (3) independence, (4) satisfying performance of developmental tasks, and (5) efficient use of social support (Głodkowska 2015, 116; Głodkowska and Gosk 2018).

The theoretical construct of the AOL-PwD includes five aspects (Diagram 1), which are interpreted in the light of appropriate theories. The personalistic aspect (to have a sense of subjectivity) clearly arises from pedagogical personalism. The eudaimonistic aspect (to have a sense of well-being) is oriented at the ideas of positive psychology. The functional aspect (to be independent) is presented from the point of view of optimal functioning theory. The temporal aspect (to perform developmental tasks) provides grounds

for interpretation based on developmental task theory. The aid aspect (to know how to use social support) allows explanation of the AOL-PwD in the light of social support theory. These aspects and meaning contexts of the construct as well as the theoretical horizons for their interpretation outline and emphasize those dimensions of the functioning of people with disabilities that explain affirmative and positive aspects of their lives (Głodkowska 2015).

Diagram 1. AOL-PwD theoretical construct  
Source: Głodkowska and Gosk 2018.



2006; Nota et al, 2007; Shogren et al. 2006; Miller and Chan 2008; Schalock et al. 2008; Schalock et al. 2010; Verdugo et al. 2011; Morisse et al. 2013; Shogren et al. 2014; Shogren et al. 2006; Niemiec et al. 2017).

A new interpretation of that paradigm is made within the cognitive area outlined by the AOL-PwD issue. The concept presented in this article clearly emphasizes the positive aspects of the lives of people with disabilities, including their subjectivity, well-being, independence, developmental task performance, and social support use (Głodkowska 2015; Głodkowska and Gosk, 2018).

The subject of this article consistently builds the next link in the development of the AOL-PwD concept. Previous analyses focused on its conceptualization, developing the theoretical construct, identifying meaning contexts, and defining and predesigning research stages and

We want to underline that the AOL-PwD theoretical construct relates to the paradigmatic change initiated by Robert Schalock (2004). The researcher developed an emerging disability paradigm in the perspective of personal well-being, which is the leading idea of positive psychology. Numerous authors have stressed the role of that paradigmatic change in the new approach to the phenomenon of disability (e.g., Dagnan and Sandhu 1999; Keith and Schalock 2000; Wehmeyer et al. 2003; Wehmeyer and Garner, 2003; Zekovic and Renwick, 2003; Lachapelle et al. 2005; Wehmeyer 2005; Dykens

procedures (Głodkowska 2014a; 2014d; 2015; Głodkowska and Gosk, 2018).

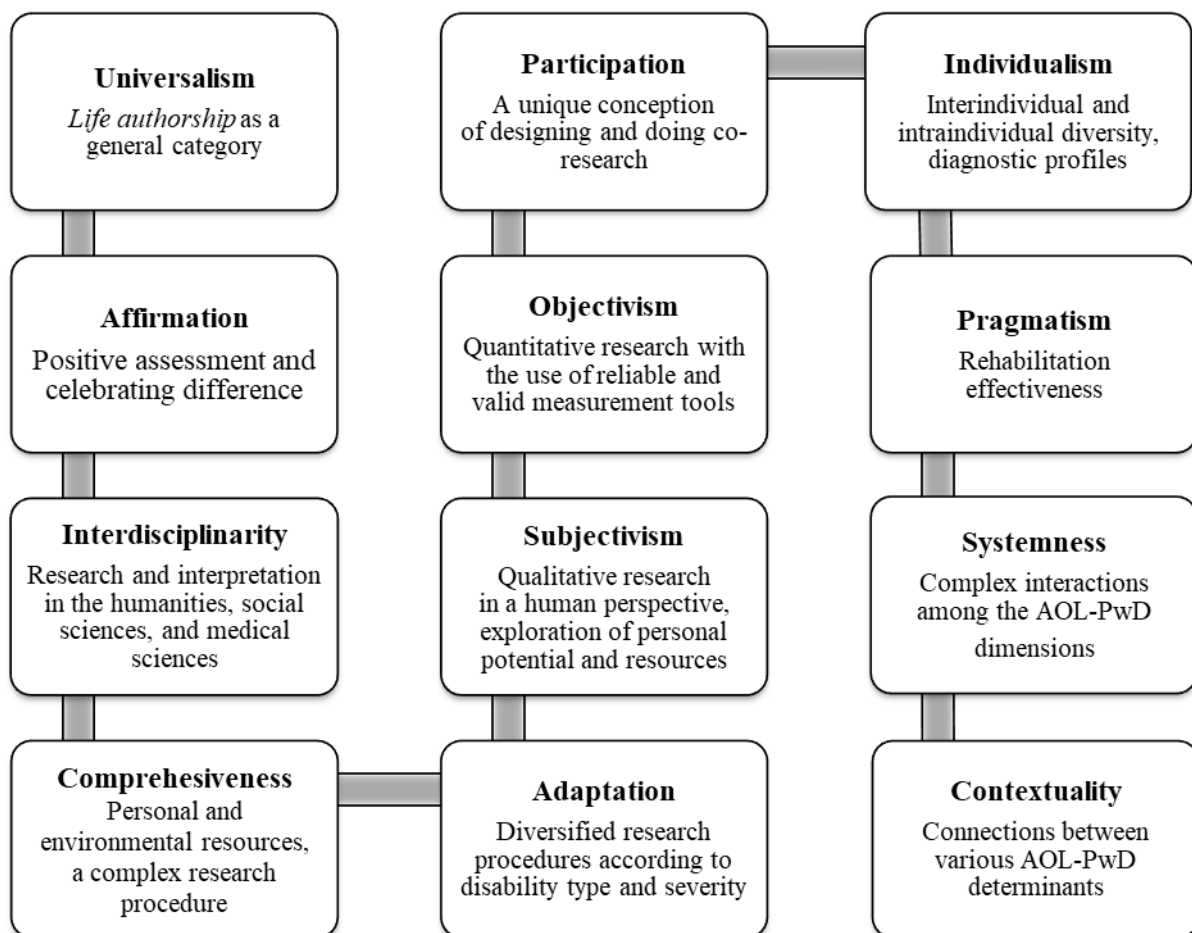
#### RESEARCH STRATEGY—METHODOLOGICAL BASIS

The research strategy development process needs to include formulating key methodological assumptions. The assumptions underline that *authorship of one's own life* is a category within which the experience of important human life dimensions is measured and described, including human subjectivity, well-being, optimal functioning, life task performance, and the ability to use social support. Measurement is performed with reference to a person's previous experiences and in the context of his or her living environment. It should be assumed that AOL-PwD assessment is important for rehabilitation in stimulating and improving a person's functioning, in stressing his

or her strengths in functioning, and in personal agency. It is important to point out that AOL-PwD measurement can be a source of significant findings regarding quality of life and self-determination.

The strategy for research on the AOL-PwD began with establishing a 12-stage research strategy framework: (1) universalism, (2) affirmation, (3) interdisciplinarity, (4) comprehensiveness, (5) adaptation, (6) subjectivism, (7) objectivism, (8) participation, (9) individualism, (10) pragmatism, (11) systemness, and (12) contextuality (Diagram 2).

Diagram 2. AOL-PwD research strategy framework.



(1) UNIVERSALISM: Life authorship as a general category

The concept starts from the assumption that authorship of one's life is a conceptual category that is characteristic of all people—both nondisabled ones and those with disabilities of various types and severity. Every person can demonstrate a specific state of life authorship, and this characteristic can be determined in relation to his or her abilities but also limitations resulting from a disability. Every person can, and has the right to, feel a sense of subjectivity, agency, and independence in his or her actions as well as feel satisfied and have hope for a good life. Therefore, assessing the AOL-PwD, we assume that all

people—nondisabled ones and those with disabilities—can experience a life authored by them, as life authorship is a universal value. It is interesting to quote here the concept of Nick Watson, who argued that people with disabilities can shape their self-identity based not so much on becoming aware of their disorders and

impairments but rather on reconstructing normality (Watson 2002, 519). In this respect, it is reasonable to assume that people with disabilities take on various life challenges to achieve what is socially considered normal. In such circumstances, people develop their self-identity by being aware of the purpose of their actions, which originate in their

social living conditions. Identity is formed not to show differences, emphasize diversity, or celebrate disability, but to define disability in one's own terms and according to one's own experiences and terms of reference in the social environment (Watson 2002, 521). Characteristics and values relating to identity formation are part of every person, and their essence is connected with life authorship, too.

(2) **AFFIRMATION:** Positive assessment and celebrating difference

Formulating strategic assumptions for research on the AOL-PwD, we want to emphasize the value of positive assessment. It orients activities as well as rehabilitation and therapy to strengths in a person's functioning, to his or her developmental powers or "Archimedean points," and not only to disorders, impairments, or disabilities (Głodkowska 2012). It is worth referring here to Swain and French's (2000) concept of an affirmation model of disability. The authors talked about celebrating differences among people and affirming people's individual functioning in social life. At the same time, they underlined that people with disabilities can be proud of the fact that they are different from the majority of society. Swain and French argued that people with disabilities not only need confirmation of how they are different from nondisabled people, but they also expect assurance of their personal nature and recognition of their lifestyle, quality of life, and identity (Swain and French 2000, 185).

(3) **INTERDISCIPLINARITY:** Life authorship in research and interpretations in the humanities, social sciences, and medical sciences

The aspects of the theoretical construct of the AOL-PwD (Diagram 1) and the theories in the light of which these aspect are interpreted use social sciences, the humanities, and medical sciences as sources. We think that the exploration of those multifaceted areas of the functioning of people with disabilities (i.e., personalistic, eudaimonistic, functional, temporal, and aid areas) requires reference to interdisciplinary theoretical analyses and research in various sciences. The AOL-PwD assessment framework assumes the need for cooperation among representatives from

many scientific disciplines, including psychology, sociology, special education, philosophy, family studies, and health sciences. For it is reasonable to think that limiting research to one point of view could result in reductionism and make AOL-PwD exploration fragmentary. It could be said—after Couser (2011)—that the interdisciplinary nature of the AOL-PwD research strategy emerges from the conviction that disability can be fully understood only if it is studied from many perspectives and with reference to the various areas of life it affects. Exploration of the AOL-PwD, who each experience their disabilities in their individual ways, live in different sociocultural and economic conditions, give unique meanings to their life experiences, and adopt specific strategies to cope with their disabilities, requires interdisciplinary research analyses. It is impossible—or even wrong—to study AOL-PwD in reference to selected conceptual assumptions and theories that are characteristic of only one specific field.

Moreover, the AOL-PwD research strategy assumes exploration, analysis, and interpretation of multifaceted factors determining the sense of AOL-PwD. We assume that research will cover both personal factors and a broad social, cultural, and economic context of the functioning of people with disabilities. We refer here to aspects that include education, rehabilitation, and therapy; to the quantity and quality of interactions experienced by people with disabilities in their environment; to their socioeconomic status, cultural variables, and social support. We think that an interdisciplinary knowledge of the multifaceted functioning of people with disabilities is necessary to explore those determinants.

The practical dimension of AOL-PwD research that refers to the multilayered analysis, interpretation, and design of rehabilitation activities, as well as a review of their effectiveness from the point of view of the wellness and resources of people with disabilities, also fits in with the assumed interdisciplinarity of the AOL-PwD research strategy. We think that effective education, rehabilitation, and aid programs for people with disabilities must result from cooperation among representatives from various fields, including educators, psychologists, sociologists, social workers, physiotherapists, and therapists. Both the analysis and interpretation of previous interventions as well as working toward



new solutions need to be based on sound knowledge and practical experience of people from different sectors who provide services for people with disabilities.

(4) **COMPREHENSIVENESS:** Personal and environmental resources, a complex research procedure

According to the AOL-PwD conceptualization, the theoretical construct includes five aspects: (1) personalistic, (2) eudaimonistic, (3) functional, (4) temporal, and (5) aid (Diagram 1). As shown earlier, the aspects and meaning contexts of authorship of one's life are interpreted in the light of appropriate theories: pedagogical personalism, positive psychology, optimal functioning theory, developmental task theory, and social support theory. These aspects and meaning contexts of the construct as well as the theoretical horizons for their interpretation clearly outline the comprehensive, holistic approach to the functioning of people with disabilities. At the same time, they emphasize those dimensions that explain affirmative and positive aspects of disabled people's lives.

The AOL-PwD research strategy assumes that research will cover both participants' personal functioning and the characteristics of their environment, including peer relationships, family life, educational and vocational activity, and local community. The environmental context will be explored from the point of view of providing external conditions for the development of authorship of one's life. For it should be remembered that the living conditions of people with disabilities can be of causative significance for both reinforcing and decreasing their sense of AOL-PwD. At the same time, assessing a person with disability and his or her parents/caregivers and professionals will allow a more reliable design of support in terms of its type and intensity that will follow the needs, abilities, and expectations of the person himself or herself, and not only the predictions of people in his or her social environment.

The assumed comprehensiveness of AOL-PwD research also refers to the principles of life-span theory. That is why assessment will cover people of different ages and will be appropriately adapted to the participants' age brackets. The adoption of this perspective in AOL-PwD research

can be justified by making reference to the main conceptual assumptions of life-span psychology, according to which human development (1) continues throughout human life (from birth to death); (2) is marked by intraindividual plasticity of individual mental functions whose modification degree depends on the quantity and quality of a person's experiences and his or her personal way of coping with life events; (3) always takes place in changing sociocultural, economic, and natural conditions, which individualize its course; and (4) is determined by chronological age and factors of civilization as well as nonnormative factors, which include random incidents or choices made by an individual. It is also important that the changes taking place in a person's mental life do not have to be universal or necessary; neither are they fully predictable (Straś-Romanowska, 2001). Those principles of life-span theory fit in with the AOL-PwD concept. Firstly, the AOL-PwD concept involves assessment of people at different life stages and thus at different stages in terms of developing a sense of authoring their lives. Secondly, it takes into consideration the individually varied impact of disability on the multifaceted functioning of people with disabilities, which depends on their previous experiences and their specific ways of coping with them. We think that exploration of past experiences of people with disabilities will allow a better understanding of how they perceive life authorship at the moment. Thirdly, we are convinced that various social, cultural, and economic factors may have a different impact on the way specific people with disabilities perceive their life authorship. This impact is neither explicit nor direct. Its intensity and scope may change depending on the chronological age of a person with disability or the dimension of life authorship that is being analysed. Fourthly, taking into account the subjective nature of qualitative research, we also aim to identify important events in the lives of people with disabilities that determine the uniqueness of their life trajectories and consequently influence the way they perceive their life authorship.

Research comprehensiveness will also manifest in the use of a battery of AOL-PwD measurement tools, including subjective AOL-PwD assessment by a person with disability, objective AOL-PwD assessment by a professional

or a parent, and assessment of determining factors (personal, socioeconomic, and cultural). We plan to standardize the measurement tools by adapting them to people with disabilities of various types and severity. We also intend to evaluate the psychometric value of the individual AOL-PwD measurement tools.

Additionally, the comprehensiveness of the research strategy manifests in combining quantitative and qualitative research procedures. The use of both methodological orientations allows a more solid exploration of such a sensitive phenomenon as that of life authorship—not only through objective assessment, including showing existing relationships or the strength of these relationships in quantitative research, but also through detailed interpretation with the use of qualitative research.

(5) **ADAPTATION:** Diversified research procedures according to disability type and severity

Life authorship assessment will be carried out in groups of people with different disabilities. Each group needs to have the assessment procedure adapted to group members' perceptual abilities (visual disabilities, hearing disabilities), motor abilities (motor disabilities), and intellectual abilities (intellectual disabilities). Especially when a person has difficulty communicating with the social environment, it will also be necessary to introduce alternative, nonverbal communication. Moreover, adaptation will cover disability severity as well as important contexts of developmental tasks with reference to age groups. We anticipate that the type and severity of disability as well as chronological age might determine important aspects of a person's life authorship, including his or her sense of subjectivity and agency, independence and autonomy, awareness of personal resources, and developmental task performance or ability to use social support.

(6) **SUBJECTIVISM:** Qualitative research in a human perspective; exploration of personal potential and resources

The research procedures include an assessment of the AOL-PwD based on the assessment carried out by the participants—authors—themselves in both quantitative research (measurement tool for

subjective AOL-PwD assessment) and qualitative research (structured interview). Recent changes in the scientific approach to people with disabilities allowed us to assume that the first stage of life authorship research would explore the potential and resources of people with disabilities and their immediate environment. Valuable information will relate to exploration of how people with different disabilities (visual, hearing, motor, and intellectual) as well as their parents, professional support network, and those without direct contact with them (nonprofessionals) understand the AOL-PwD concept. Identification of AOL-PwD determinants through interviews will also be of great importance (Głodkowska and Gosk 2018).

Additionally, it will be important here to explore the need for developmental reinforcement as well as to determine the effectiveness of rehabilitation interventions with which a specific person is provided. Doing research under a qualitative approach allows a fuller exploration of the phenomenon being studied and its whole context, as the researcher is not limited by presuppositions or hypotheses. Thanks to the use of qualitative research, it is possible to reach deep into the phenomenon and broaden the perspective from which it is viewed. Even though qualitative research does not allow generalization of results, it can still enable researchers to notice the AOL-PwD aspects that are indiscernible—hidden, in a way, in numerical data resulting from quantitative research. Qualitative information is especially valuable when research aims to use interviews to develop or expand the construct of a given phenomenon to include areas indicated by the participants, which might not have been covered by the theoretical assumptions.

(7) **OBJECTIVISM:** Quantitative research with the use of reliable and valid measurement tools

The research will be conducted under the quantitative approach with the use of reliable and valid measurement tools: the Subjective AOL-PwD Assessment Scale for people with disabilities and the Objective AOL-PwD Assessment Scale for professionals and parents. We plan to standardize the measurement tools by adapting them to people with disabilities of various types and severity. We also intend to evaluate the psychometric value of the individual AOL-PwD measurement tools. At

the same time, quantitative research will cover multidimensional AOL-PwD determinants and connections with personal, socioeconomic, and cultural factors (Głodkowska, Gosk, 2018). Measurement tools designed by other authors will be used in this area of research. Detailed information relating to this issue will be presented in a separate article.

It should be noted that quantitative research allows not only explanation of a phenomenon but also testing of hypotheses about relationships among variables. It enables the researcher to remain cognitively objective and thus to formulate objective truth. The research procedure, followed with quantitative research principles in mind as far as the standardization of the tool is concerned, will allow finding out about both the AOL-PwD phenomenon and its wider context—its multidimensional determinants, including personal factors (personality traits), demographic factors (age, gender, education, vocational activity), sociocultural factors (in microsocial, macrosocial, and mesosocial dimensions), and economic factors (e.g., financial situation, housing conditions, availability of specialist equipment).

(8) **PARTICIPATION:** A unique conception of designing and doing co-research

Research aiming to explore the AOL-PwD and its determinants defines the nature of the diagnostic process. It requires a general research approach—a unique methodological conception—that relates to participatory research. It is a conception of designing and doing research with the use of both quantitative and qualitative methods (Laws, Harper, Marcus, 2003).

At the beginning of the last century, Znaniecki put forward a thesis in humanistic sociology about researchers getting closer to the world of the subjects. According to Znaniecki, this ensures gaining the most accurate knowledge of the subject by using his or her experiences and interpretations. Research in the participatory paradigm has particularly developed over the last decades (Denzin and Lincoln 2009). It also covers issues relating to disabilities, e.g., inclusive research with people with intellectual disabilities, also called co-researching (French and Swain, 1997; Kiernan 1999; García-Iriarte et al. 2014; Bigby et al. 2014; Puyalto et al. 2016; Fullana et al. 2017). Co-

researching involves both university researchers, who share their research skills, and people with disabilities, who share what it is like living with a disability. Authors make attempts to use inclusive research: they develop a research strategy and identify the advisory nature, study course, and control over all stages as well as involvement of participants—academic researchers and people with disabilities (Bigby et al. 2014). The idea of inclusive research clearly changes the role of the participants; they become, in a way, authors exploring themselves and their lives. That is why to understand people with disabilities and to assess the authorship of their own lives—according to the principles of co-researching—an active, partnership - based research relationship needs to be used and the authoritarian role of the researcher as an expert need to be rejected. As Pushor (2008) stated research should be conducted with people rather than on people. The research process is at the same time a dialogical process, in which both the researcher and the participant contribute their knowledge and skills, and the research finding is the result of their cooperation (Głodkowska and Gosk 2018).

Following the participatory paradigm and dialogical principles of inclusive research, it can be assumed that it allows a thorough exploration of the meanings of the AOL-PwD phenomenon.

(9) **INDIVIDUALISM:** Interindividual and intraindividual diversity; diagnostic profiles

It should be remembered that research on the AOL-PwD is individually variable and diversified. That is why general aspects and individual categories can be at different levels in specific people in a given moment of their life. Moreover, assessment repeated at different times may show varied dynamics in acquiring these subjectivity- and identity-based areas of functioning: a sense of subjectivity, independence, well-being, developmental satisfaction, and the ability to use social support. It is reasonable to expect that the level of life authorship may be different depending on the type and severity of disability and may change depending on various factors that promote or hinder general development and life experiences. At the same time, it should be remembered that people can feel the need to author their lives to varying extents, which may result



from developmental conditions and the role of significant people in their lives (parents, siblings, other family members, peers, teachers, and other people). These issues, too, should be taken into account in the assessment of the AOL-PwD, thus emphasizing individualism in the research strategy.

Ultimately, the AOL-PwD methodological procedure is to produce such assessment solutions that will allow effective use of profile assessment for every person with disability so that an appropriate, individualized, developmental support program can be designed for him or her.

#### (10) PRAGMATISM: Rehabilitation effectiveness

According to preliminary arrangements, research findings will be of diagnostic importance in terms of (1) exploring the understanding of the AOL-PwD concept in people with disabilities, in people working with individuals with disabilities, in people without direct contact with them, and in parents—people who deal with their child's disability on a daily basis; (2) exploring subjective life authorship assessments based on qualitative research; (3) exploring objective life authorship assessments based on quantitative research; and (4) identifying multidimensional life authorship determinants and connections with personal, socioeconomic, and cultural factors.

Based on the methodological tasks relating to the quantitative research, a battery of tools to measure the AOL-PwD will be developed. The tools will be evaluated for their psychometric value (reliability, validity, and normalization). Then it will be possible to use them in diagnostic tests. They will also be a valuable means to determine the effectiveness of rehabilitation and therapy, in terms of how they reinforce the sense of life authorship.

We stress again that the assessment of people with disabilities and their parents/caregivers as well as professional support network will allow a more reliable design of support that will be adapted to the needs, abilities, and expectations of people with disabilities themselves and not only to what their environment predicts.

#### (11) SYSTEMNESS: Complex interactions among the AOL-PwD dimensions

Systemness indicates multidimensional interactions among the individual aspects of the

AOL-PwD (subjectivity, well-being, independence, developmental tasks, and social support), which are then expanded within the research categories. The AOL-PwD aspects and categories constitute a specific system with its own individual and unique organization and network of relationships. This testifies to the unique way a specific person with disability perceives his or her life authorship. This manifests in the system of meanings people with disabilities give to their lives: What does it mean to them to author their lives? How do they understand their subjectivity? Are they satisfied with their lives? Where do they see their independence? Are they satisfied with their achievements? How effective is the support they are receiving? It could also be said that AOL-PwD systemness is a complex and unique ecosystem of a person with disability. Therefore, life authorship can be directly related to the micro-, macro-, or mesosystem, and the situation of a specific person can be analysed in that context.

#### (12) CONTEXTUALITY: Connections among various AOL-PwD determinants

It is important that research analyses take into account complex contexts and connections among various life authorship determinants. This set of references needs to be explored to understand the way a specific person perceives the aspects of his or her life authorship. The patterns of factors that reinforce but also weaken the sense of life authorship are important in this area. The family as well as experiences relating to education, therapy, support received within the immediate environment, availability of social and cultural resources, and peer relationships play a special role here. Additionally, the exploration of contexts and connections should take into consideration changes in developmental task performance, which may be significant for a sense of subjectivity, satisfaction with life and achievements, and independence as important AOL-PwD aspects.

Shogren (2013) emphasized that the research perspective—and the social perspective as well—requires that the interrelated contextual factors that have an impact on the findings of scientific research, social policies, and individual achievements of people with disabilities and their families be taken into account in the conceptualization of disability, diagnosis, and

classification. According to the definition of context proposed by the author, it is a construct that “integrates the totality of circumstances that comprise the milieu of human life and human functioning” (Shogren 2013, 4). In research, context can be perceived as an independent variable that includes personal and environmental characteristics that are not usually subject to modification (e.g., age, gender, culture, ethnic origin, and family). Among intervening contextual variables, Shogren (2013) listed organizations, social policies, and social practices that can be influenced and properly managed to improve the functioning of people with disabilities and their families. As an integrative construct, context constitutes a certain framework for describing, analysing, and interpreting various aspects of human functioning relating to personal and environmental factors as well as social policy planning, implementation, and improvement.

From the point of view of this AOL-PwD characteristic, it is also important to consider the degree of acceptance of one’s disability. Due to different experiences or developmental tasks that change with age, a given person may be in different places on the continuum between full acceptance and lack of acceptance of his or her disability. Assessing the level of this variable will be of scientific importance—not only in terms of defining where a given person is at the moment, but also as a relevant factor that explains his or her sense of life authorship.

It should be pointed out that identifying multifaceted life authorship determinants corresponds to the principles of disability studies, in which researchers clearly stress the diagnostic and rehabilitative value of life contexts of people with disabilities (e.g., Campbell & Oliver 2013; Swain et al. 2013). Therefore, the theoretical, methodological, and empirical development of the AOL-PwD concept requires that contextual references be identified, which is necessary to understand how a specific person perceives the aspects of his or her life authorship.

## CONCLUSION

The issue of the authorship of their own lives in people with disabilities (AOL-PwD) is a humanistic concept of assessment and rehabilitation. It fits in with the trend in disability

exploration that participates in creating a positive, causative image of people with disabilities in society. We think that the idea of disability perception from the point of view of AOL-PwD attains another important goal, too. It enables people with disabilities to view themselves and their lives in a different way, not only from the angle of limitations, disorders, or deficits but mainly through the lens of subjectivity, agency, personal resources, independence, and satisfaction with fulfilling age-appropriate tasks, which are essential aspects of authoring oneself and one’s life.

The theoretical analyses performed to date substantiated the AOL-PwD concept, developed the construct, pointed to the meaning contexts of the AOL-PwD aspects, and planned research stages and procedures. This article discussed methodological issues—formulating important assumptions for the AOL-PwD research strategy. The following strategic assumptions have been made: (1) universalism (AOL as a general category); (2) affirmation (positive assessment and celebrating difference); (3) interdisciplinarity (AOL in research in the humanities, social sciences, and medical sciences); (4) comprehensiveness (personal and environmental resources); (5) adaptation (diversified research procedures); (6) subjectivism (qualitative research); (7) objectivism (quantitative research); (8) participation (co-research); (9) individualism (diagnostic profiles); (10) pragmatism (rehabilitation effectiveness); (11) systemness (complex interactions among the AOL-PwD dimensions); and (12) contextuality (connections among various AOL-PwD determinants). We think that the concept of the AOL-PwD creates an inspiring theoretical and empirical space and fosters valuable dialogue across various fields and between theory and practice of therapy and rehabilitation.

The ultimate target is to develop an assessment and rehabilitation model of the AOL-PwD. Following its recommendations will make it possible to provide people with individual support determined by their subjectivity, independence, and developmental satisfaction. That model will be made based on the identified personal resources and multidimensional determinants of the social environment. We point out a special situation here that is cognitively and methodologically inspiring.

The development of the life authorship assessment and rehabilitation model offers a unique circumstance: a person with disability is not only the recipient and executor of the support program designed for him or her, but actually participates in its development, providing important diagnostic information about himself or herself and his or her life and also becoming the author of subsequent planned activities.

#### REFERENCES:

- Bigby, Christine, Patsie Frawley, and Paul Ramcharan. 2014. "Conceptualizing inclusive research with people with intellectual disability." *Journal of Applied Research in Intellectual Disabilities* 27(1): 3–12.
- Campbell, Jane, and Mike Oliver. 2013. *Disability politics: Understanding our past, changing our future*. Abingdon-Thames: Routledge.
- Couser, Thomas. 2011. "What disability studies has to offer medical education." *Journal of Medical Humanities* 32: 21–30.
- Dagnan, Dave, and Sandhu, Satinder. 1999. "Social comparison, self-esteem and depression in people with intellectual disability." *Journal of Intellectual Disability Research* 43: 373–379.
- Denzin, Norman, and Yvonna Lincoln. 2009. *Metody badań jakościowych*. Warszawa: Wydawnictwo Naukowe PWN.
- Dykens, Elisabeth. 2006. "Toward a positive psychology of mental retardation." *American Journal of Orthopsychiatry* 76(2): 185–193.
- French, Sally, and John Swain. 1997. "Changing disability research: Participating and emancipatory research with disabled people." *Physiotherapy* 83(1): 26–32.
- Fullana, Judit, Maria Pallisera, Elena Català, and Carolina Puyalto. 2017. "Evaluating a research training programme for people with intellectual disabilities participating in inclusive research: The views of participants." *Journal of Applied Research in Intellectual Disabilities* 30(4): 684–695.
- García Iriarte, Edurne, Patricia O'Brien, and Darren Chadwick. 2014. "Involving people with intellectual disabilities within research teams: Lessons learned from an Irish experience." *Journal of Policy and Practice in Intellectual Disabilities* 11: 149–157.
- Głodkowska, Joanna. 2003. „Przestrzeń rehabilitacyjna w otoczeniu osób z niepełnosprawnością intelektualną – ujęcie koncepcyjne." *Ruch Pedagogiczny* 5–6: 7–23.
- Głodkowska, Joanna. 2005. „Optymizm czy pesymizm w stylu wyjaśniania stosowanym przez młodzież z lekką niepełnosprawnością intelektualną." *Człowiek – Niepełnosprawność – Społeczeństwo* 1: 153–179.
- Głodkowska, Joanna. 2012. *Konstruowanie umysłowej reprezentacji świata. Diagnoza, możliwości rozwojowe i edukacyjne dzieci z lekką niepełnosprawnością intelektualną w aspekcie stałości i zmienności w pedagogice specjalnej*. Kraków: Wydawnictwo Naukowe Akapit.
- Głodkowska, Joanna. 2013. „Przełamywanie stereotypu niepełnosprawności intelektualnej." *Ruch Pedagogiczny* 3: 31–69.
- Głodkowska, Joanna. 2014a. „Autorstwo życia a niepełnosprawność – ponawiane odczytywanie idei normalizacji." *Człowiek – Niepełnosprawność – Społeczeństwo* 1: 75–97.
- Głodkowska, Joanna. 2014b. „Rozważania o podmiotowości a niepełnosprawność-u źródeł współczesnego ujęcia i w perspektywie interdyscyplinarnej." *Człowiek – Niepełnosprawność – Społeczeństwo* 2: 91–110.
- Głodkowska, Joanna. 2014c. „Podmiotowość a doświadczenie zależności przez osoby z niepełnosprawnością – normalizacja jako narzędzie ideowe rehabilitacji podmiotowej." *Człowiek – Niepełnosprawność – Społeczeństwo* 3: 87–106.
- Głodkowska, Joanna. 2014d. „Być podmiotem i stawać się autorem własnego życia - paradygmat wsparcia w przygotowaniu osób z niepełnosprawnością do egzystencji podmiotowej." *Człowiek – Niepełnosprawność – Społeczeństwo* 4: 29–44.
- Głodkowska, Joanna. 2015. „Autorstwo własnego życia osoby z niepełnosprawnością – konceptualizacji w perspektywie dobrostanu, podmiotowości, optymalnego funkcjonowania i wsparcia." In *Personalistyczne ujęcie fenomenu niepełnosprawności*, edited by Joanna Głodkowska, 110–134. Warszawa: Wydawnictwo Akademii Pedagogiki Specjalnej.
- Głodkowska, Joanna. 2017. „Dziecko Osobą: personalistyczne odczytywanie kanonów wczesnego wspomaganie rozwoju dziecka." In *Interdyscyplinarne konteksty wczesnej interwencji, wczesnego wspomaganie rozwoju dziecka*, edited by Joanna Głodkowska, Grażyna Walczak, Radosław Piotrowicz, and Iwona Konieczna, 17–32. Warszawa: Wydawnictwo APS.
- Głodkowska, Joanna, and Urszula Gosk. 2018. *The authorship of their own lives in people with disabilities (AOL-PwD) - From the sources and theoretical construct to the design of research stages and procedures* (in press).
- Keith, Kenneth, and Robert L. Schalock, eds. 2000. *Cross-cultural perspectives on quality of life*. Washington, DC: American Association on Mental Retardation.
- Kiernan, Chris. 1999. "Participation in research by people with learning disability: Origins and issues." *British Journal of Learning Disabilities* 27(2): 43–47.
- Lachapelle, Yves, Michael L. Wehmeyer, Marie-Claire Haelewyck, Yannick Courbois, Kenneth Keith, Robert Schalock, Miguel Angel Verdugo, and Patricia Noonan Walsh. 2005. "The relationship between quality of life and self-determination: An international study." *Journal of Intellectual Disability Research* 49: 740–744.
- Laws, Sophie, Caroline Harper, Nicola Jones, and Rachel Marcus. 2013. *Research for development: A practical guide*. Los Angeles: Sage.
- Miller, Susan, and Fong Chan. 2008. "Predictors of life satisfaction in individuals with intellectual disabilities." *Journal of Intellectual Disability Research* 52(12): 1039–1047.



- Morisse, Filip, Eleonore Vandemaele, Claudia Claes, Lien Claes, and Stijn Vandeveld. 2013. "Quality of life in persons with intellectual disabilities and mental health problems: An explorative study." *The Scientific World Journal* ID491918.
- Niemiec, Ryan M., Karrie A. Shogren, and Michael L. Wehmeyer. 2017. "Character strengths and intellectual and developmental disability: A strengths-based approach from positive psychology." *Education and Training in Autism and Developmental Disabilities* 52(1): 13-25.
- Nota, Laura, Lea Ferrari, Salvatore Soresi, and Micheal L. Wehmeyer. 2007. "Self-determination, social abilities, and the quality of life of people with intellectual disabilities." *Journal of Intellectual Disability Research* 51(11): 850-865.
- O'Brien, Patricia, Roy McConkey, and Eburne Garcia-Iriarte. 2014. "Co-researching with people who have intellectual disabilities: Insights from a national survey." *Journal of Applied Research in Intellectual Disabilities* 27:65-75.
- Pushor, Debbie. 2008. "Collaborative Research." In *The Sage encyclopedia of qualitative research methods*, edited by Lisa M. Given, 91-94. London: Sage.
- Puyalto, Carol, Maria Pallisera, Judit Fullana, and Montserrat Vilà. 2016. "Doing research together: A study on the views of advisors with intellectual disabilities and non-disabled researchers collaborating in research." *Journal of Applied Research in Intellectual Disabilities* 29: 146-159.
- Schalock, Robert L. 2004. "The emerging disability paradigm and its implications for policy and practice." *Journal of Disability Policy Studies*. 14(4): 204-215. Washington, DC: American Association on Mental Retardation.
- Schalock, Robert L., Miquel A. Verdugo, Gordon S. Bonham, Fernando Fantova, and Jos Van Loon. 2008. "Enhancing personal outcomes: Organizational strategies, guidelines, and examples." *Journal of Policy and Practice in Intellectual Disabilities* 5(4): 276-285.
- Schalock, Robert et al. 2010. *Intellectual disability. Definition, classification, and systems of support. 11<sup>th</sup> Edition*. Washington DC: American Association on Intellectual and Developmental Disabilities.
- Shogren, Karrie A. 2013. "Considering context: An integrative concept for promoting outcomes in the intellectual disability field." *Intellectual and developmental disabilities* 51(2): 132-137.
- Shogren, Karrie A., Michael L. Wehmeyer, Cindy L. Buchanan, and Shane J. Lopez. 2006. "The application of positive psychology and self-determination to research in intellectual disability: A content analysis of 30 years of literature." *Research and Practice for Persons with Severe Disabilities* 31: 338-345.
- Shogren, Karrie A., William Kennedy, Chantelle Dowsett, and Todd D. Little. 2014. "Autonomy, psychological empowerment, and self-realization: Exploring data on self-determination from NLTS2." *Exceptional Children* 80(2): 221-235.
- Strnadová, Iva, Therese M. Cumming, Marie Knox, and Trevor Parmenter. 2014. "Building an inclusive research team: The importance of team building and skills training." *Journal of Applied Research in Intellectual Disabilities* 27: 13-22.
- Straś-Romanowska, Maria. 2001. „I Konferencja Psychologów Life-Span: między psychologią rozwojową a psychologią rozwoju.” *Przegląd Psychologiczny* 44(1): 93-103.
- Swain, John, and Sally French. 2000. "Towards an affirmation model of disability." *Disability and Society* 15(4): 569-582.
- Swain, John, Sally French, Colin Barnes, and Carol Thomas eds. 2013. *Disabling barriers-Enabling environments*. Thousand Oaks, CA: Sage.
- Verdugo, Miguel Angel, Laura E. Gómez, Benito Arias, Robert Schalock. 2011. "The integral quality of life scale: Development, validation, and use." In *Enhancing the quality of life of people with intellectual disabilities*, edited by Ralph Kober, 47-60. Dordrecht: Springer.
- Watson, Nick. 2002. "Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability." *Disability & Society* 17(5): 509-527.
- Wehmeyer, Michael L. 2005. "Self-determination and individuals with severe disabilities: Reexamining meanings and misinterpretations." *Research and Practice in Severe Disabilities* 30: 113-120.
- Wehmeyer, Michael L., Brian H. Abery, Dennis E. Mithaug, Roger J. Stancliffe. 2003. *Theory in self-determination: Foundations for educational practice*. Springfield, IL: Charles C Thomas.
- Wehmeyer, Michael L., and Nancy Garner. 2003. "The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning." *Journal of Applied Research in Intellectual Disabilities* 16(4): 255-265.
- Zekovic, Buga, and Rebecca Renwick. 2003. "Quality of life for children and adolescents with developmental disabilities: Review of conceptual and methodological issues relevant to public policy." *Disability & Society* 18 (1):19-34.