CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO

CNS nr 3(49) 2020
(lipiec–wrzesień)

Wydawnictwo Akademii Pedagogiki Specjalnej im. Marii Grzegorzewskiej

Wersja papierowa jest wersją pierwotną (referencyjną)

CNS jest indeksowany w: CEJSH, ERIH PLUS, ICI Journals Master List i WCOSJ

Czasopismo posiada punktację MNiSW – 20 pkt

Czasopismo znajduje się na wykazie czasopism objętych programem
„Wsparcie dla czasopism naukowych" (poz. 16)

ISSN 1734-5537

Nakład 150 egz.

SPIS TREŚCI
CNS numer 3(49) 2020

Artykuły i rozprawy

Studia nad niepełnosprawnością – nauka

Studia nad niepełnosprawnością – dydaktyka

TABLE OF CONTENTS
CNS No. 3(49) 2020

Articles and treaties

Disability Studies – science

Disability Studies – didactics

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO”
CNS nr 3(49) 2020, 5–33

ISSN 1734-5537
DOI: 10.5604/01.3001.0014.3573

ANTONIO M. AMOR GONZÁLEZ, MARIA FERNÁNDEZ SÁNCHEZ,
MIGUEL Á. VERDUGO ALONSO, ALBA AZA, ROBERT L. SCHALOCK*

SHAPING THE FACES OF THE PRISM: RIGHTS, SUPPORTS, AND QUALITY OF LIFE FOR ENHANCING INCLUSIVE EDUCATION OPPORTUNITIES IN STUDENTS WITH INTELLECTUAL DISABILITY[1)]

Introduction and Overview

Inclusive education (IE) is a key element in countries' education policy agenda (Amor, Hagiwara et al., 2018). In the last 40 years different documents have addressed IE. The most important among these are the Warnock's Report (1978), the World Declaration on Education for All (1990), the Salamanca Statement and Framework for Action on Special Needs Education (1994), the Dakar Framework for Action (2000), the United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006), the 48th International Conference on Education by UNESCO (2008), and the Incheon Declaration (UNESCO, 2015).

---

[*] Antonio M. Amor González (https://orcid.org/0000-0001-7757-1299); University of Salamanca, Avda. de la Merced, 109–131, 37005 Salamanca, Spain; tel. +34 923 294695; e-mail: aamor@usal.es

María Fernández Sánchez (https://orcid.org/0000-0002-3398-6086); University of Salamanca, Avda. de la Merced, 109–131, 37005 Salamanca, Spain; tel. +34 923 294695;
e-mail: mariafernandez@usal.es

Miguel Á. Verdugo Alonso (https://orcid.org/0000-0002-5802-8220); University of Salamanca, Avda. de la Merced, 109–131, 37005 Salamanca, Spain; tel. +34 923 294695; e-mail: verdugo@usal.es

Alba Aza (https://orcid.org/0000-0002-1460-1195); University of Salamanca, Avda. de la Merced, 109–131, 37005 Salamanca, Spain; tel. +34 923 294695; e-mail: azhernandez@usal.es

Robert L. Schalock; Hastings College. Nebraska, P.O. Box 285, Chewelah, WA 99109, USA; e-mail: rschalock@ultraplix.com

[1)] Financial disclosure: This work has been supported by the Erasmus+ program of the European Union under grant agreement No. 2017-3338/001-001 and by the Spanish Ministry of Economy and Competitiveness (R & D project PSI2015-65193-P and FPI grant number BES-2016-078252).

These documents have been accompanied by an increase in the effective and real inclusion of diverse learners, but the inclusion of students with intellectual disability (ID) is still a major challenge to be addressed (Amor, 2019). The inclusion necessitates creation of a comprehensive framework that systematically guides the efforts of education systems to improve learning experience of students with ID. To this end, the goal of this article is twofold: First, to offer a detailed view of the rights approach, the supports paradigm, and quality of life (QoL) model as keys to address the inclusion of students with ID; and, second, to present a framework which brings these three approaches together to direct them towards the improvement of personal outcomes in these students, thus offering them better opportunities for an effective and real inclusion.

Article 24: The Right to Inclusive Education

The great change in educational trends regarding the inclusion of students with disabilities occurred in 2006, when the UNCRPD was passed (United Nations, 2006). Since this milestone, IE evolved from a principle guiding education toward a right to be guaranteed for all students, regardless of their personal or social conditions. The UNCRPD includes 50 articles: Social and Civil Rights are embodied from article 5 to article 30, and the general principles, which are common – and transversal – to all the rights, are detailed in article 3. These principles are: (a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (b) non-discrimination; (c) full and effective participation and inclusion in society; (d) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (e) equality of opportunity; (f) accessibility; (g) equality between men and women; and (h) respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (United Nations, 2006).

Concerning IE, Article 24 stipulates that State's Party must ensure an "inclusive education system" at all levels and lifelong learning for all students directed to: (a) the full development of human potential; (b) the development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential; and (c) enabling persons with disabilities to participate effectively in a free society. To fulfill this right, signatories must ensure that: (a) students with disabilities are not excluded from the general education system on the basis of disability; (b) persons with disabilities can access an inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live; (c) reasonable accommodation of the person's requirements is provided; (d) persons with disabilities receive the support required, within the general education system, to facilitate their effective education; and (e) effective personalized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion (United Nations, 2006). This article highlights two main implications regarding the meaning of IE. First, IE involves providing education within a general education context, where all children establish relationships and learn (i.e., regular schools and communities of reference). Second, IE must ensure that all children access regular education and contexts, and have the opportunity to participate, learn, and develop to their fullest potential, both academic and social (Amor, Verdugo et al., 2018).

Having documents signed that recognize the right to IE give us a view of the future we want, concerning the education of students with ID. However, the process of paving the road towards this goal is a complex issue, and it is necessary to offer different approaches that help in this task. The following section presents the supports paradigm, which offers a conceptual model to understand how supports can be provided to a student with ID and which is closely linked to the proposals contained in Article 24 of the UNCRPD (Amor, 2019).

1. Supports Paradigm and Inclusive Education

Overview of the Supports Paradigm and its Relevance to Students with Intellectual Disability

Decades of research in the field of ID indicate that education systems can include students with ID. One of the approaches which has brought more attention to improve the inclusion opportunities of these students is the supports paradigm (Amor, 2019). Specifically, the importance given to the supports paradigm is that it provides: (a) a renewed view of ID and of the students who have the condition (Amor, Verdugo et al., 2018); (b) tools (e.g., Thompson et al., 2016); and (c) a framework for action that makes possible a holistic support needs assessment and planning strategy aimed at improving opportunities for students with ID regarding their access, participation, and learning from the general education curriculum (Thompson et al., 2018). The supports paradigm is also focused on improving the development of students with ID to their fullest potential, because it creates bridges between the classroom, the school, and the communities where all children (with and without disabilities) live, grow, and develop, thus generating opportunities for a real participation in the school and society, and putting the accent in a whole approach to education (Amor, Verdugo, 2017; Verdugo, Amor et al., 2018).

The supports paradigm is embedded in a social-ecological model of disability and in strengths-based perspective. As a social-ecological approach, the supports paradigm approaches ID as a state of functioning characterized by a mismatch between personal competences and environmental demands, defined by the contexts of participation, and age- and culturally-appropriated activities within these contexts (Schalock et al., 2010). This mismatch originates the support needs, which are "a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning" (Thompson et al., 2009, p. 135). Focusing on the interaction between the *person and his/her environment* and not on intrinsic personal characteristics is the most salient feature of the supports paradigm. Thus, from this perspective, the main difference between persons with and without ID is their support needs, in the sense that the former have extraordinary support needs that go beyond the supports required by the latter (Verdugo, Amor, Arias et al., 2019).

Several implications for the IE of students with ID emerge from this social-ecological perspective. First, the supports paradigm is an inclusive approach as it highlights the need to understand the support needs of students with ID for the same contexts – and activities – where all students, regardless of their personal and social conditions, learn; that is, in general education contexts (Amor, 2019). Second, through the lens of the supports paradigm, students with ID are seen as learners who experience a mismatch between their personal competence and the environmental demands posed by general education context and activities. These demands are defined by what the students with ID are expected to do in the classrooms (i.e., in relation to access and learning from activities linked to age-related curricular content), in the school, and in the community where the school is located (Amor, Verdugo et al., 2018). And third, given that the contexts of participation go beyond the classroom and the educational activities are not only linked to learning, the extraordinary support needs of students with ID can be related to different areas beyond curriculum, such as social activities, activities in the community and neighborhood, or activities related to self-determination, all of these relevant for a global development of the person (Verdugo, Amor et al., 2018).

Within the supports paradigm, students with ID are understood from the perspective of their global support needs. Thus, the student with ID is no longer defined by his/her significant limitations in intellectual functioning and in adaptive behavior, but by presenting a pattern and intensity of support needs that extend beyond what most of their typically functioning peers need to access, participate in, and learn in the same activities and contexts (Amor, 2019). The key, therefore, is to understand the pattern and intensity of the extraordinary supports that students with ID require to overcome the contextual barriers to learning and participation for all the contexts and activities relevant for their integral education, always putting the emphasis on how to modify and adapt the environment to meet the needs of the learners and not *vice versa* (Amor, Hagiwara et al., 2019).

Together with the social-ecological approach, the supports paradigm adopts a strengths-based perspective which assumes that, together with the support needs, students with ID have strengths to build upon and which should be known in the same way as their extraordinary support needs (Amor, 2019). Additionally, it is argued that the student should be the causal agent on the supports he/she receives, taking an active role in the definition of relevant goals for his/her life – including those pertaining learning – and in the vision of a desired future on which to determine his/her strengths and support needs (Thompson et al., 2018).

Implementation of the Supports Paradigm

The active role of students with ID and the respect for their self-determination in the definition of vital goals, and the knowledge of their strengths and support needs relevant to participation in education contexts and activities, are the bases for the implementation of systems of supports. Systems of supports focus on: (a) meeting their needs; (b) boosting their strengths; (c) improving their functioning; and (d) achieving their personal-desired outcomes aligned with the goals of access, participation, learning, and fullest development within general education contexts (Amor, 2019). In the field of education, supports aim at reducing the mismatches experienced by the students with ID, regardless of the type of support that is provided. That is, although some supports are aimed at improving the student's competencies (e.g., an augmentative and/or alternative communication system), others are aimed at modifying environmental demands to make them more accessible (e.g., Universal Design for Learning), and others address both, the ultimate purpose of systems of supports is to reduce the misfit *student x environment*, and not to eliminate the disability (Booth, Ainscow, 2011).

The Assessment of Support Needs

Although the goal of the supports paradigm is to provide personalized supports to cover the unique needs of each student, the emphasis in developing standardized tools can help in the efficiency and effectiveness of supports planning through the identification of areas where the need for supports and resources is extraordinary, something critical regarding the cuttings in education (Amor, 2019). At the time, the first and only standardized instrument designed to the measurement of extraordinary support needs in children with ID is the *Supports Intensity Scale-Children's Version* (*SIS-C*; Thompson et al., 2016). The tool has been developed to assess, under a social-ecological approach, the type, frequency, and the daily timeof the extraordinary support that students with ID (aged between 5 and 16 years) require to participate in 61 activities in seven contexts of daily living: Home life, community and neighborhood, school participation, school learning, health and safety, social activities, and advocacy. Further, the tool also provides a comprehensive assessment of the exceptional medical and behavioral support needs that the students with ID may require. The tool offers a "Support Needs Index", which provides information on the students' global support needs; and a "Support Needs Profile" that depicts the intensity of the support needs in each of the seven areas aforementioned. This tool is critical to provide accurate information for the development of personalized educational plans (PEP) that allow to reduce the mismatch experienced by students with ID in these areas, thus improving their options to participate in a wide variety of contexts, consistently with a view of education that focuses on the globality of the students and that goes beyond literacy and numeracy (Amor, 2019).

Examples of Using Supports to Maximize the Person-Environmental Fit

Until now, we have highlighted the conceptual importance of the supports paradigm and the availability of tools aimed at measuring extraordinary support needs to develop PEP's. However, it is necessary to present examples of the implementation of the supports paradigm to reduce the *student x environment* mismatches in different contexts and activities relevant for IE. Regarding the improvement of access and participation, Virginia L. Walker, Stephanie N. DeSpain, James R. Thompson, and Carolyn Hughes (2014) implemented the supports paradigm with two students with ID in general education contexts. Specifically, these authors presented the "support needs assessment and problem solving" (SNAP) process. Through this methodology, the authors implemented the *SIS-C* (then under development) and trained teachers to improve the PEP's that were being implemented with their students with ID. Specifically, the update of these PEP's was based on the emphasis on a holistic understanding of supports and students' support needs, thus going beyond the definition of behavioral and instructional goals. The SNAP process is characterized by: (a) the observation of students with ID in school environments to become familiar with the classrooms routines and generate a good working climate among the student, the teachers, the peers, and other professionals; (b) the *SIS-C* administration to obtain information on the global support needs of the students; (c) the involvement of the classroom teams to review the students' support needs and readjust the supports that are currently being implemented; (d) the training and guidance of teachers and classroom teams on how to implement new strategies and support plans from this perspective; and (e) the interview to the classroom teams to analyze the social validity of the SNAP process. In their study, the authors found that, through the provision of personalized supports in the areas detected (e.g., use of public transport in the community), the discrepancies experienced by the students were reduced, thus contributing to improve their access and participation in community contexts and activities (Walker et al., 2014).

Notwithstanding the above, procedures like the SNAP are framed in the so-called second generation of inclusive practices, characterized by generating access and participation outcomes, but not learning (Hagiwara et al., 2019). In addition to access and participation, the IE of students with ID also requires quality learning experiences, which means to provide the required supports to access and learning from age-appropriated curriculum within general education contexts (Wehmeyer, 2014). With this aim, starting from the supports paradigm, Thompson et al. (2018) have proposed the "general education supports planning model", which addresses this challenge through three questions to answer: What to teach?, How to teach?, and Where to teach?

Regarding the first question, the evidence suggests that students with ID can benefit from the learning of age-appropriate general education curricular content (e.g., Lee et al., 2010). Therefore, the supports paradigm advocates for the teaching of general education curricular content to answer the "what to teach" question. However, answering this question requires that the educator understands the general education curricular content to identify: (a) the learning objectives for the student with ID based on his/her current level of achievement and future curricular demands (i.e., learning support needs, marked by the mismatch between the student's learning competences and the expectations of learning from the curriculum); and (b) the learning objectives that are relevant to the student (according to his/her preferences and future learning environments) and that are not addressed in the curricular content. Curricular adaptations (understood as a proactive differentiation of the curriculum) are examples of supports that, aligned with these critical questions, work best with respect to "what to teach", since they make the general education curriculum accessible and identify additional important content for the student (Thompson et al., 2018).

After the access to the curriculum is facilitated, "how to teach" becomes the key question to answer. The "how to teach" question refers to the field of pedagogy and teaching and learning practices. Generally, deciding the best pedagogical strategy for the student with ID will depend on his/her learning support needs. Thus, there is no good or bad pedagogy, nor can a traditional pedagogy be considered as more inclusive than a pedagogy coming from the field of special education, since the most suitable will be the one that, implemented within general education settings, is aimed at reducing the learning discrepancies that the student with ID experiences. In this sense, employing strategies that make the instruction that is normally delivered in general classrooms accessible, and incorporating evidence-based practices (mostly coming from special education) are two strategies to answer the "how to teach" (Thompson et al., 2018).

Once the "what to teach" and the "how to teach" questions have been answered, it is time to address "where to teach". *A priori*, the answer to this question is simple: in general education contexts. However, this answer is partially correct from the point of view of the supports paradigm. As environmental demand, instruction must take place in the reference settings where students with ID and their typically functioning peers participate. This means that if, for example, supplementary instruction strategies that require leaving the classroom are adopted (e.g., to travel to community settings to facilitate learning generalization), the ID should not be a reason for these strategies to be used with higher or lower incidence in students with ID (Thompson et al., 2018).

Going Beyond the Supports Paradigm in Inclusive Education

Despite the contributions of the paradigm presented in this section, more efforts are needed to guide education systems towards the inclusion of students with ID, especially regarding the adoption of approaches that focus on the maximum development of all students. In fact, although it is embodied in the UNCRPD (United Nations, 2006), ensuring the development of students with ID to their fullest potential is a goal of IE that is not often highlighted explicitly in the literature regarding IE, which tends to focus mainly on access, learning, and participation (e.g., Booth, Ainscow, 2011; Hernández-Sánchez, Ainscow, 2018). Therefore, beyond the supports paradigm, developing education systems that provide better inclusion opportunities to students with ID, makes it necessary to rethink education as a process that pays attention to all the four goals stated in the UNCRPD's Article 24. Thus, it is necessary to adopt approaches to education that are student-centered, and which consider education as a process which is aimed at providing growth opportunities to the students (with and without disabilities) and ensuring their outcomes in all relevant areas of their life and not only regarding their learning (i.e., "whole child approach to education") (Amor, Verdugo et al., 2018). To this end, in the following section, we present the QoL model by Robert L. Schalock and Miguel Á. Verdugo (2002) as a framework which can provide education systems with the conceptual and applied underpinnings that a "whole child approach to education" require to enhance inclusion opportunities in students with ID.

2. Quality of Life and Inclusive Education

Different authors have highlighted the need to adopt a QoL framework to support the transformation processes that education systems require to include students with ID into regular educational programs (e.g., Amor, Fernández et al., 2017; Amor, Verdugo et al., 2018; Muntaner, 2013; Muntaner et al., 2010; Pazey et al., 2016; Verdugo, 2009; Verdugo, Amor et al., 2018). These proposals strive to highlight the several keys that an approach based on the student's QoL can contribute to IE. Understanding these keys requires understanding what we mean by individual QoL as a starting point. To this end, prior to presenting how the adoption of a QoL framework can support the development of inclusive education and enhance the opportunities of inclusion for students with ID, we present the conceptual and applied implications (as a measurement framework and change agent) that a QoL framework focused on the person brings into action.

The concept of Quality of Life

QoL is composed of a number of core domains (Schalock et al., 2002). Of all the existing approaches to individual QoL (Cummins, 2000, 2005; Felce, Perry, 1995, 1996; Petry, Maes, Vlaskamp, 2005, 2007; Schalock, Verdugo, 2002), an internationally validated and frequently referenced conceptual model is the multidimensional model of Schalock and Verdugo (2002). As a conceptual framework, the model is based on a solid basis aimed at understanding what QoL is, and integrating current work in the field. The model also provides a basis for application (Schalock et al., 2016) by going beyond the conceptual domain and is oriented to action. This action allows the evaluation of QoLoutcomes through observable and measurable indicators and basing decision-making on evidence of the results (Amor, Verdugo, 2018).

Regarding the evidences that support the QoL model by Schalock and Verdugo (2002), these are based in more than two decades of rigorous research that make it the most relevant QoL model in the field of disability (Alcedo et al., 2008; Arias et al., 2010; Fernández, 2019; Gómez et al., 2014; Gómez et al., 2015; Gómez, Verdugo, Arias, 2010; Schalock, Verdugo, 2013; Schalock, Verdugo, Gómez, 2011), and the most accepted and recognized one internationally (Balboni et al., 2013; Carbo-Carreté, Guàrdia-Olmos, Giné, 2015; Gómez et al., 2011; Schalock et al., 2005; van Hecke et al., 2018; Wang et al., 2010). Although the development and application of the model has been mainly in the field of ID (Schalock et al., 2016), it has been studied and validated in different populations, including: (a) persons without disabilities (e.g., Gómez-Vela, Verdugo, 2009); (b) drug users (e.g., Arias et al., 2010); (c) persons with visual impairments (e.g., Caballo et al., 2005); (d) persons with physical disabilities (e.g., Aguado, Alcedo, 2005); (e) social services recipients (e.g., Gómez et al., 2012); (f) elderly people (e.g., Alcedo et al., 2008; Vanleerberghe et al., 2017); and, most recently, (g) persons with acquired brain injury (e.g., Verdugo, Gómez et al., 2018) and (h) persons with autism spectrum disorders (e.g., Arias et al., 2018; Gómez et al., 2018).

Beyond the development and validation of indicators to measure personal outcomes in different target groups, the research on the implementation of the QoL model has allowed the identification of personal and environmental characteristics associated with personal outcomes (e.g., Verdugo, Fernández et al., 2019). Regarding the studies which have addressed the QoL construct structure, most of the works support a factorial structure of eight first-order correlated factors matching the eight central QoL domains (e.g., Verdugo, Fernández et al., 2019; Gómez et al., 2011). The development and application of the Schalock and Verdugo's model (2002) are allowing the development of a theory of individual QoL as an integrative construct based on facts and experiences that allows generating hypotheses that can be tested and used as a basis for providing explanations of QoL (Schalock et al., 2016).

Quality of Life as a Measurement Framework and Change Agent

Through the lens of this model, QoL is understood as a state of personal well-being that: (a) is multidimensional; it is composed by eight domains related with key areas in the life of the person (i.e., personal development, emotional well-being, interpersonal relations, physical well-being, material well-being, self-determination, social inclusion, and rights); (b) has universal and cultural properties; (c) has objective and subjective components (related to how an external person considers another's well-being, and self-perception of one's QoL, respectively); and (d) is influenced by personal and environmental factors, as well as by the interaction between them (Schalock, Verdugo, 2002).

QoL domains are operationalized through their core indicators (Fernández, 2019; Gómez, 2010; Schalock, Gardner, Bradley, 2007; Schalock, Verdugo, 2002), which are defined as perceptions, behaviors, or specific conditions of the QoL domains that reflect the person's well-being, and which facilitate the measurement of personal outcomes (Schalock, Verdugo, 2002). While there is a consensus about the universal (i.e., cross-cultural) nature of the QoL domains (Jenaro et al., 2005; Schalock et al., 2005; Wang et al., 2010), indicators are culturally sensitive. Hence, QoL indicators must be validated for the specific populations to which they are directed (Fernández, 2019; Gómez, 2010). The operationalization of QoL domains through their core indicators is essential for implementing the model in practice as a measurement framework and as a change agent. As a measurement framework, the indicators are specified through items that allow for the measurement of personal outcomes, which reflect the person's aspiration and situation in the indicators that operationalize the QoL domains (Schalock et al., 2007) and which makes it possible to gather evidences on the person's well-being. The following table describes the eight-domain structure of QoL along with the indicators that operationalize them.

The operationalization of the QoL domains through indicators and the importance of the assessment of personal outcomes, has resulted in multiple standardized tools as shown in Table 2, which also organizes these tools regarding their target group, developmental stage, and QoL assessment approach (i.e., self-report vs. report of others).

The information obtained through the assessment of personal outcomes can be analyzed as disaggregated (i.e., individual) or aggregated data, bringing different types of information to use depending on the goal of assessment. This analysis of QoL scores can be used to support evidence-based decision-making processes regarding different levels (Verdugo, 2018). The uses of evidences on personal outcomes to support decision-making, makes QoL a change agent (Schalock, Verdugo, 2002). Understanding the role of QoL as a change agent makes it necessary to highlight another important characteristic of the model: QoL is based on a systems perspective (Bronfenbrenner, 1979). This perspective assumes that persons live in a complex social system made up of different levels (i.e., microsystem, mesosystem, and macrosystem) that encompass the necessary areas for the persons to live, develop, and have the opportunity to improve, and which influence the development of the persons' values, beliefs, behaviors, and

Table 1. Conceptual and measurement framework of Schalock and Verdugo's (2002) model (Amor, 2019, pp. 59–60)

QoL domain	Description	Indicators
Emotional well-being	Feeling safe, without worries, relaxed	Satisfaction, self-concept, and lack of distress or negative feelings
Interpersonal relations	Having relations with different people, having friends and getting on well with others	Social interactions, having identified friends, familiar interactions and relations, positive social contacts, relationships, and sexuality
Material well-being	Having enough money to buy whatever one needs and/or wants, having a proper household or workplace	Housing, workplace, salary (pension, income), belongings, and savings
Personal development	Having the possibility of learning different things, accessing knowledge, and having the possibility of self-realization	Limitations/capacities, access to information and communication technologies, learning opportunities, work-related skills (or other activities), and functional abilities
Physical well-being	Being healthy, feeling fit, having good eating habits	Health care, sleep, health and its alterations, activities of daily living, access to technical aids, and food
Self-determination	Being able to self-decide and having the opportunities to choose the things that one considers relevant, choosing one's life, employment, leisure time, living, and the people to be with	Goals and personal preferences, decisions, autonomy, and choices
Social inclusion	Going to different places in the city or neighborhood where other people go and participating in different activities with other people	Inclusion, participation, accessibility, and supports
Rights	Being considered and treated equally with other people and being respected (i.e., personality, opinions, wishes, privacy)	Intimacy, respect, knowledge, and exercise of rights

attitudes, thereby affecting their QoL (Fernández, 2019). The microsystem refers to the immediate context in which the person lives and that affects the person directly (e.g., household, family, friends, co-workers/classmates). The mesosystem, for its part, includes everything that directly affects the functioning of the microsystem (e.g., neighborhood, community, organizations, schools and high schools). Finally, the macrosystem refers to the broader cultural patterns, socio-political trends, and economic factors that directly affects values and beliefs. Examples of the use of the personal outcomes assessed regarding different sys-

Table 2. Summary of quality of life assessment tools based in Schalock and Verdugo's model (2002)

Scale	Target group	Developmental stage	Approach
CVI-CVIP: Quality of life assessment questionnaire in childhood (Sabeh et al., 2009)	Children with and without special educational needs	Children aged between 8 and 11 years	Self-report and report of others
CCVA: Questionnaire for assessing quality of life in adolescent students (Gómez--Vela, Verdugo, 2009)	Adolescents with and without special educational needs	Adolescents aged between 12 and 18 years	Report of others
KidsLife (Gómez et al., 2016)	Children, adolescents, and youth with ID	Children, adolescents, and youth aged 4 to 21 years	Report of others
KidsLife-Down (Gómez et al., 2017)	Children, adolescents, and youth with Down's Syndrome	Children, adolescents, and youth aged 4 to 21 years	Report of others
KidsLife-TEA (Gómez et al., 2018)	Children, adolescents, and youth with ID and ASD	Children, adolescents, and youth aged 4 to 21 years	Report of others
FUMAT Scale (Verdugo, Gómez, Arias, 2009)	Elderly persons recipient of social services	Adults	Report of others
GENCAT Scale (Verdugo, Arias et al., 2009)	Social services recipients	Adults	Report of others
Integral Scale (Verdugo, Gómez, Arias et al., 2009)	ID	Adults	Self-report and report of others
INICO-FEAPS (Verdugo et al., 2013)	ID	Adults	Self-report and report of others
San Martín Scale (Verdugo et al., 2014)	ID and extensive support needs	Adults	Report of others
CAVIDACE Scale (Verdugo, Gómez et al., 2018)	Acquired brain injury	Adults	Report of others (self-report under development)

tem levels can be found in the social services (González, 2019; Schalock, 2018; Schalock, Verdugo, 2013). For example, at microsystem level, personal outcomes provide information regarding the domains that make up the person's QoL and, in turn, serve as a basis for the development of personalized support plans and for assessing their impact in the person's QoL, which is useful to identify the practices that work best for providing best personal outcomes. At mesosystem

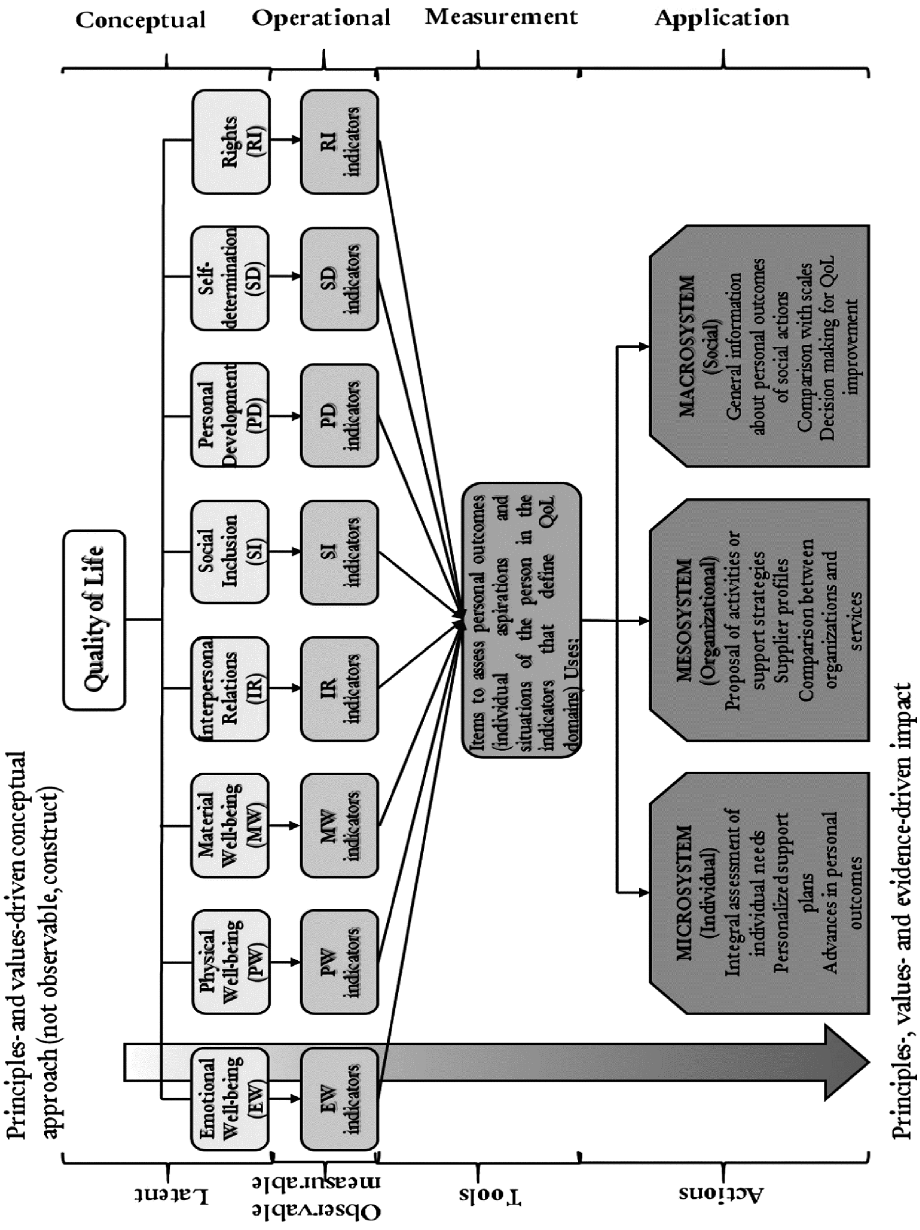

Figure 1. Quality of life as a conceptual and applied framework

level, the use of aggregated data (i.e., aggregated information of the personal outcomes of the users of an organization or school) enables the ongoing improvement of organizational quality and the organizational redefinition, allowing also organizations to establish suppliers profiles and decision-making regarding the enhancement of plans implemented to improve their outputs. The comparative analysis of the aggregated data provides information about the functioning of a given organization (i.e., analyzing how these aggregated outcomes vary over time) and facilitates the comparison between different organizations. Last, concerning macrosystem, the implementation of QoL concept makes it possible to guide new ways of developing, implementing, monitoring, and assessing public policy (Amor, Verdugo, 2018). Figure 1 depicts Schalock and Verdugo's QoL model (2002) as a conceptual and applied framework (i.e., measurement framework and change agent) from a systems perspective.

Using the QoL Conceptual Model in Inclusive Education: The Whole Child Approach

The conceptual and applied nature of the Schalock and Verdugo's model (2002) are the bases which support the proposals for its use within general education contexts. From a conceptual point of view, the emphasis is placed on the importance of focusing on the whole person, thus attending to all the relevant vital domains of the student with ID (i.e., "whole child approach to education"). The concept of QoL is consistent with the values espoused in the UNCRPD (Amor, Verdugo, 2018; Buntinx, 2013; Navas et al., 2012; Verdugo et al., 2012). This congruity highlights the need to assume an educational perspective based on the global view of students with ID to contribute their fullest development, thus favoring their inclusion in society beyond schooling age (Amor, Verdugo et al., 2018; Hagiwara et al., 2019; Verdugo, Amor et al., 2018). Regarding the UNCRPD, QoL shares the same set of positive values about persons with ID (Buntinx, 2013). Not in vain, QoL already included "rights" as a central domain before the UNCRPD was passed (Schalock, Verdugo, 2002). Further, QoL indicators are sensitive to the goals embodied in the UNCRPD's articles, making QoL a framework aligned with these goals and, therefore, useful to guide the necessary actions for the persons with disabilities to enjoy their rights (Navas et al., 2012; Verdugo et al., 2012). Concerning this, already-existing examples on alignment between IE legislation goals and QoL domains can help to shed light on the relationship between the goals embodied in the UNCRPD's Article 24 and Schalock and Verdugo's QoL domains. Barbara L. Pazey et al. (2016) summarized the alignment provided by H. Rutherford Turnbull, III, Ann P. Turnbull, Michael L. Wehmeyer, and Jiyeon Park (2003) between the core goals of the "Individuals with Disabilities Education Act" (2004) and QoL domains: (a) equality of opportunities would be related to "rights"; (b) full participation to "social inclusion" and "interpersonal relations"; (c) independent living to "self-determination”; and (d) economic self-sufficiency to “material well-being”. On the other hand, “physical and emotional well-being”, and “personal development” were conceived as “foundational skills” necessary to reach the outcomes inherent to all the four goals. Following this work, a proposal of alignment between the key outcomes to achieve in students with ID (following Article 24 of the UNCRPD) and the QoL domains could be the following: (a) access: “rights”; (b) participation: “social inclusion” and “interpersonal relations”; (c) learning: “self-determination” and “personal development”; and (d) full development: “emotional well-being”, “physical well-being”, “material well-being”, “self-determination”, and “personal development”. Like in the proposal by Turnbull et al. (2003), “emotional and physical well-being”, and “personal development” could be considered as foundational skills relevant for achieving all the goals.

The “whole child approach to education” means to go beyond the traditional view of education as a process focused mainly on the instruction on basic competencies such as literacy, sciences or numeracy (Amor, Verdugo et al., 2018; Verdugo, Amor et al., 2018). Besides that, it means to provide opportunities and supports to students to achieve their fullest potential (United Nations, 2006). In this sense, education of quality means integral education (Muntaner, 2013) and, beyond instruction, it is necessary to support all students to acquire the foundational skills that are relevant for all the areas important in their lives, which means to provide learning opportunities concerning curricular and extracurricular content, and the acquisition of competences in the school and in the community (Amor, Hagiwara et al., 2019; Hagiwara et al., 2019). This is a requisite for achievement and for students to be “college and career ready” (Morningstar et al., 2017). Although an integral education is important since early stages of development, it becomes critical in secondary education and transition to adulthood, being a key to the inclusion of persons with ID after schooling (Morningstar et al., 2017; Verdugo, 2009).

The Concept of Quality of Life and the Development of Inclusive Education Systems

Beyond its conceptual implications, QoL also offers an applied framework to support the development of education systems that could offer better opportunities to include students with ID. As an applied framework, QoL: (a) shares values with IE and makes it possible to bring them into action, thus updating practices with students with ID (Pazey et al., 2016; Schalock, Garner, Bradley, 2007; Verdugo, 2009); and (b) is focused on the assessment of personal outcomes (Amor, Verdugo et al., 2018; Verdugo, Amor et al., 2018), turning QoL into a framework that makes it possible to assess the quality of education through the monitoring of students’ outcomes and which supports decision-making in education for an ongoing improvement of these outcomes (Muntaner, 2013; Muntaner et al., 2010; Verdugo, 2009). Precisely, this emphasis on measuring and improving students’ outcomes in all the relevant areas of their lives, makes QoL an applied framework consistent with the aforementioned "whole child approach to education" (Amor, 2019).

First, QoL shares with IE the values of equity, equality, empowerment, and supports (Pazey et al., 2016; Verdugo, 2009). These values are central to the vision of "education for all" (*The World Declaration on Education for All*, 1990) and are supposed to defend the need to educate in equity following the principle of social justice. Equity is supposed to provide the personalized educational and social supports that each person requires to reduce the inequity that he/she experiences (Hernández-Sánchez, Ainscow, 2018). The QoL model can bring these values into practice and its dynamizing role of the supports paradigm acquires special relevance in this regard (Amor, Verdugo et al., 2018; Verdugo, Amor et al., 2018). In this sense, although the supports paradigm offers the tools for an equitable education, the QoL model is critical to mobilize the supports paradigm and to assess its impact on students' outcomes. Basically, the QoL model incorporates the core domains for a life of quality that are relevant to make operative the vital goals of the person, making it possible to specify through desired-life experiences the inclusion contexts defined by the UNCRPD (United Nations, 2006). The goals (learning goals and other relevant goals for the person) defined with the active role of the person within educational settings are linked to specific contexts and activities for their achievement. Thus, the QoL model contributes to define the support needs on which to base the provision of personalized supports (through the supports paradigm) that guarantee the equity in education regarding learning and other relevant outcomes. In addition, QoL allows for the assessment of the impact that the systems of supports have in all the relevant areas in the students' lives, and not only concerning their learning, something consistent with a global view of education which goes beyond instruction (Amor, 2019). Related to these principles, the QoL model, as a multidimensional and holistic approach, offers four guidelines to update professional practices toward students with ID: (a) the need to adopt a holistic and multidimensional approach to understand students and students' lives; (b) a community-based approach, which is the context for a life of quality; (c) the use of best practices to reduce the mismatches *person x environment* through the training in foundational skills, the use of technological supports, the access to natural supports, and environmental accommodations; and (d) the use of personalized supports and their relation with QoL core indicators (Schalock, Gardner, Bradley, 2007; Verdugo, 2009).

As an applied framework, orientating the focus on measuring personal outcomes has resulted in the use of the QoL concept and the supports paradigm to improve quality of education through transforming the education systems toward IE always bearing in mind the improvement of students' outcomes (Muntaner, 2013; Muntaner et al., 2010; Verdugo, 2009). Amor (2019) summarizes the contributions made by Miguel Á. Verdugo (2009), Joan Jordi Muntaner (2013), and Joan Jordi Muntaner et al. (2010) on the use of QoL as a framework for evaluating the quality of education and organizes their proposals within a systems perspective. This author gives importance to the twofold use of personal outcomes: (a) to monitor the extent to which advances are being made in areas operationalized through sensitive indicators to the goals of the UNCRPD; and (b) to support decision-making processes related to educational practices (i.e., microsystem), and schools organization and the redefinition of their relations with the community (i.e., mesosystem), without forgetting the importance of the development and evaluation of educational policy (i.e., macrosystem). Regarding the microsystem, personal outcomes could be used with different purposes. They could be used to monitor the impact of the implemented supports on indicators sensitive to the goals of access, participation, learning, and maximum development. The evidence on personal outcomes could also be used to support decision-making regarding practices. For example, after assessing personal outcomes in a PEP in two different times (i.e., prior to the definition of personal-desired goals and after the implementation of the supports necessary to achieve the goals), the evidence of change in personal outcomes would allow for identifying those supports that are most effective and efficient in producing changes in the outcomes (Amor, 2019). This information could be used, in turn, to make practices evolve from best practices to evidence-based practices (Schalock et al., 2011), or to make an external or internal evaluation of education practices, something critical for improving quality in education (Verdugo, 2009). The use of aggregated data on students outcomes (i.e., mesosystem) allows to know on which QoL domains the school organization is focusing (as a set of school practices, cultures, and policies), and this information can be used for an ongoing improvement in the ways of organizing school toward new leaderships, cultures, and school policies that are focused on a global understanding of their students (Muntaner, 2013; Muntaner et al., 2010), for a comparison between different schools in a community regarding the personal outcomes achieved in their students, or for a comparison of the same school in two different moments. Finally, Amor (2019) connects the previous proposals with other approaches with more weight within educational contexts, such as the one included in the *Index for Inclusion* (Booth, Ainscow, 2011). The *Index for Inclusion* supports the reflection by the school team on the current practices, cultures, and policies implemented to provide inclusion opportunities to diverse learners. In a complementary way, Antonio M. Amor (2019) proposes to support these reflections with evidence on personal outcomes, thus moving beyond reflecting on processes (i.e., what schools are doing) toward reflecting on outcomes (i.e., what schools are achieving through their actions). Through the provision of evidences on personal outcomes, these reflections can be sharpened, and this can help decision-making and focus it on key areas to improve in the students for enhancing their access, participation, learning, and maximum development.

Adopting a framework for assessing personal outcomes requires providing education systems with tools to use as resources that facilitate its implementation. In this sense, although there are tools aimed at assessing personal outcomes in children and adolescents with ID that allow for the use of these personal outcomes as disaggregated and aggregated data (e.g., Gómez et al., 2016; Gómez et al., 2018; Gómez et al., 2017), these tools have been validated in special schools, so their use within general education contexts would not be correct, because indicators must be validated regarding the specific groups to which they are directed. Regarding tools aimed at assessing personal outcomes in general education contexts, the *CVI-CVIP* (Sabeh et al., 2009) and the *CCVA* (Gómez-Vela, Verdugo, 2009) would be valid alternatives because they are directed to assess personal outcomes in students with and without disabilities, including those with ID. However, these tools do not include all QoL domains. Then, there is a need for specific tools aimed at assessing personal outcomes within IE contexts, being necessary to develop a new measure that puts the focus on the assessment of personal outcomes of students with and without disabilities under a holistic approach to the student. To address this need, framed in a European Project (IE+, reference 2017-338/001-001), Miguel Á. Verdugo, Antonio M. Amor, and Inés Heras (2019) are developing a "Quality of Life Index for Inclusive Education" to support educational decision-making with the evidence of the personal outcomes that schools are achieving in their students. The first version of the tool is being developed for students in primary education (aged from 6 to 12 years). The development of a specific measure focused on secondary and postsecondary education (for students aged from 12 to 18 years old) will be addressed later.

Notwithstanding the aforementioned, it is one thing to have a QoL conceptual and measurement framework which is consistent with a "whole child approach to education", and another is to focus education efforts toward the promotion of personal QoL-related outcomes: Implementing the first, will greatly depend on adopting the second. While, as we have discussed, the measurement of personal outcomes is useful for monitoring and supporting educational decision-making processes, focusing efforts on improving personal outcomes of students with ID involves questioning and restructuring the way schools offer growth opportunities to these students in relation to their access, participation, learning, and maximum development. In the final section of this article, we present a systematic approach that aligns the perspectives of rights, supports, and QoL for the continuous improvement of personal outcomes of students with ID. This effort is necessary to frame adequately the use of personal outcomes to support decision-making and improve inclusion opportunities in students with ID.

3. A Systematic Approach Toward Enhancing Personal Outcomes in General Education Contexts

In the above sections, we have presented the rights approach (United Nations, 2006), the supports paradigm (Schalock et al., 2010), and QoL conceptual model (Schalock, Verdugo, 2002). The question to answer now is how to focus the efforts of education toward the improvement of personal, QoL-related outcomes. Specifically, it is necessary to justify why and how to do it. Regarding the first question, the answer is that the core indicators of the QoL domains are sensitive to the goals embodied in the different articles of the UNCRPD (Navas et al., 2012; Verdugo et al., 2012). In this sense, evidence on the improvement of personal outcomes can mirror a better enjoyment of students with ID regarding their access, participation, learning and full development (Amor, 2019). But how? Robert R. Schalock, Jos van Loon, and Remco Mostert (2018) offer a systematic framework that is based on the alignment between rights, supports, and QoL. Their proposal follows a logic model of horizontal alignment between *input*, *throughput*, *output*, and *outcomes*.

Inputs: Resources, Foundation Principles, and Student's Support Needs

Inputs refer to all the factors and elements provided to the education systems, like: (a) resources (fiscal and social capital, time, expertise, and technology); (b) foundational principles; (c) alignment of policy goals and desired outcomes; and (d) pattern and intensity of students' support needs. Regarding foundational principles, the articles 7 (human rights and fundamental freedoms for children), 24 (inclusive and equal education), 30 (participation), and 21 (freedom of expression) of the UNCRPD offer a basis for those principles that drive valued outcomes in students with ID because they are aligned with the core QoL principles of inclusion, equity, empowerment, and self-determination. The alignment between policy goals and desired outcomes can serve as a framework that enables policy makers, education providers, and support teams to begin to focus on what needs to be in place for the desired (and measurable) outcomes to occur. A way to make this operative is to align QoL indicators with QoL domains. Last, it is also necessary to gather information on the intensity and pattern of the extraordinary support needs of students with ID (Schalock, van Loon, Mostert, 2018).

Throughputs: Strategies and Support Practices

Throughputs allude to the strategies and educational and support practices that bring the *inputs* component into action. These authors specify three main *throughputs*: (a) the education reform foundational priorities; (b) the provision of personalized supports; and (c) the establishment of IE environments. Education reform foundational priorities allude to the communities of equality, respect, and social supports; strengths-based models of disability; analysis of barriers and facilitators to change; and the need to develop 21st century skills. These priorities influence the provision of personalized supports, which involves the planned and integrated use of support strategies and resources composing system of supports (made up by natural supports, technology, prosthetics, reasonable accommodations, etc.). Last, inclusive education environments are built upon the education reform foundational priorities aforementioned and provide personalized systems of supports. These environments are focused on enhancing participation and the fullest development of the students with ID by mediating access to education and community resources. The culture of these environments is focused on the students, respects them, and there is a commitment with the improvement of students' well-being. This culture should be based on a strong leadership, shared responsibility, teamwork, and openness to new ideas and permeability to change (Schalock, van Loon, Mostert, 2018).

Output: Products of an Inclusive Education Environment

Under this systematic approach, *output* focuses on the product of an IE environment in which interventions, services, and supports are provided to enhance the students' participation and development (and thus improving their well-being). The assessment of the outputs requires analyzing indicators related to the structure, functioning, and culture of these IE environments. Regarding the structure, it is necessary to analyze the degree to which the classroom provides opportunities and supports students (e.g., assistive technology or modified curricula). Analyzing the function makes it necessary to pay attention to the extent to which the classroom enhances participation and development through mediating access to education and community resources, facilitating everyday participation in regular education activities and relationships, supporting opportunities for self-determination, and allowing students to build social capital. Last, the analysis of culture implies the study of the degree to which the classroom reflects values such as the respect for the students, student centeredness, and the commitment to enhancing the students' well-being (Schalock, van Loon, Mostert, 2018).

Outcomes: Measures of Personal Well-being

Outcomes component refers to the assessment of personal outcomes that reflect personal well-being of students with ID (Schalock, van Loon, Mostert, 2018) and which makes operative this "whole child approach to education". The uses related to the evidences of personal outcomes have been discussed previously, but it is worthy to highlight these uses again: (a) to monitor the extent to which advances are being made in core indicators of QoL domains that are sensitive to the articles of the UNCRPD; and (b) to support decision-making strategies within education contexts from a systems perspective to support the transformation of educational practices, cultures, and policy (Amor, 2019). The following table summarizes the implementation guidelines for the four components explained.

The following figure exposes the systematic approach to enhancing personal well-being of students with ID highlighting the relationships between the different components described.

Table 3. Implementation guidelines for the components of the systematic approach (Schalock, van Loon, Moster, 2018)

Implementation guidelines			
Input	**Throughput**	**Output**	**Outcomes**
– Develop school-related policies based on foundational principles embedded in the UNCRPD and the QoL concept – Align policies and practices to measurable outcomes – Assess the pattern and intensity of support needs	– Base educational practices on education reform foundational priorities – Recognize that supports can be administered by everyone who interacts with the student. This includes family members, teachers, paraeducators, friends, and professionals – Use a “user-friendly” plan such as one-page PEP that lists the specific support strategies provided and who is responsible for their implementation (including the person and his/her family, and the teachers and support staff) – Develop the supports or education plan using a QoL framework in which specific support strategies are provided to enhance each QoL domain – Use the characteristics of the IE environment for strategic planning, organization transformation, and output evaluation	– Conduct a contextual analysis of the current environment and determine the factors that facilitate and hinder change (e.g., Amor, 2019) – Analyze the current environment in terms of its structure, function, and culture. The analysis should be based on operational definitions of these three characteristics of IE environment: (a) “S*tructure*”: To provide opportunities and support people; (b) “*Function*”: To enhance participation and development; and (c) “*Culture*”: To create environments that enhance personal well-being – Use the results of this analysis to determine significant discrepancies between the listed characteristics and current practices – Use strategic planning and organization transformation strategies to reduce the discrepancies	– Align policies and practices with measurable outcomes – Use a whole-life approach to assess those outcomes – Use an assessment instrument that is based on a well-formulated and validated conceptual model, which uses culturally sensitive indicators, employs a standardized scoring metric, has good psychometric properties, and has standardized administrative procedures – Use outcome measures for multiple purposes (as has been described in detail in the section “Quality of Life as a Measurement Framework and Change Agent”)

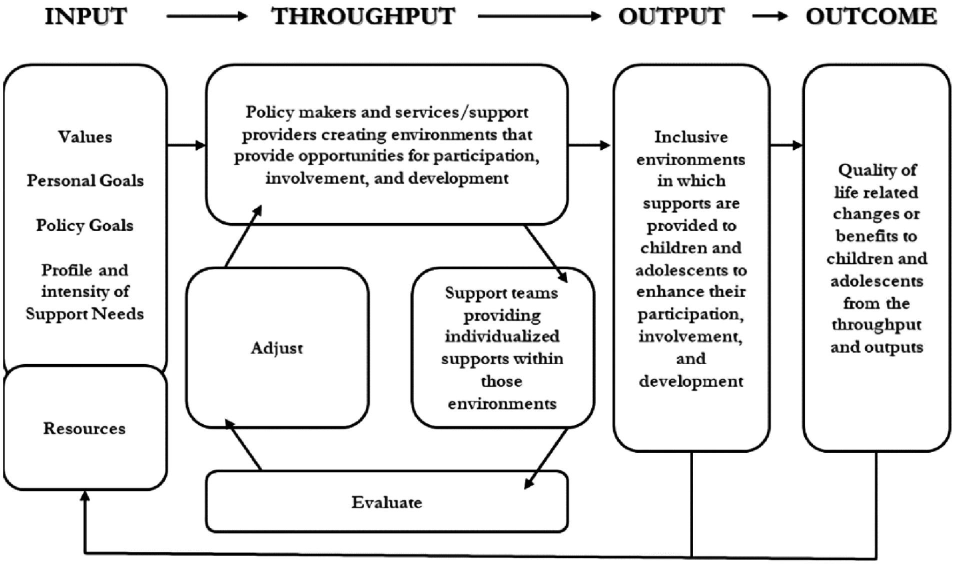

Figure 2. A systematic approach to enhancing personal outcomes of students with intellectual disability (Schalock, van Loon, Mostert, 2018, p. 198)

Conclusion

Education systems face the duty of offering all students an enhanced QoL and an inclusive educational experience. In this sense, decades of research and practice in the field of ID has enabled the development of approaches that allow addressing this challenge. The supports paradigm offers a new conceptual vision, tools, and a methodology that allows us to bring equity to education. QoL, on the other hand, shares values with UNCRPD and with IE, offers a “whole child approach to education”, brings the supports paradigm into action, and makes it possible to gather evidence of personal outcomes in areas sensitive to the goals of access, participation, learning, and full development from which to support educational decision-making regarding practices, cultures, and policies. The challenge for providing better IE opportunities for students with ID is twofold: (a) to offer resources to education systems to work in the desired direction; and, at the same time, (b) motivate them to change so that they can adopt systematic approaches that align the perspectives of rights, supports, and QoL.

We are aware that this task is complex, and that the development of IE systems takes time and changes are slow. Thus, it is normal and expected that there are different realities and that they overlap: Currently, some schools offer inclusive opportunities, some are ready to provide those opportunities in a short- or mid-term, for other schools this possibility is still far away. Similarly, we understand that changes do not have to continue in a linear fashion, and that there will be different threats to change. Lack of commitment, fears, changes in leadership, or public spending reductions are just some of them. However, the "Right to Inclusive Education" is not an option that can be negotiated, and the goal is more important than the sacrifices to be made: The development of a more inclusive and fair society for all.

References

Aguado, A.L., Alcedo, M.A. (2005). Una visión psicosocial del envejecimiento de las personas con lesión medular [A psychosocial view of aging in persons with spinal cord injury]. *Intervención Psicosocial*, *14*(1), 51–63.

Alcedo, M.A., Aguado, A.L., Arias, B., González, M., Rozada, C. (2008). Escala de Calidad de Vida (ECV) para personas con discapacidad que envejecen: studio preliminar [Quality of Life Scale for persons who are ageing: Preliminary study]. *Intervención Psicosocial*, *17*(2), 153–167.

Amor, A.M. (2019). *Bringing the supports paradigm to the Spanish educational system for support needs assessment and planning with students with intellectual disability* (Doctoral Dissertation, University of Salamanca). https://gredos.usal.es/handle/10366/140357.

Amor, A.M., Fernández, M., Aguayo, V., Verdugo, M.Á. (2017). Hacia la inserciónsocio-laboraldesde la planificación de apoyos en los servicios sociales y educativos [Toward social and labour inclusion through supports planning in the social and educational services]. *Deficiência Intelectual*, *7*(12), 36–43.

Amor, A.M., Hagiwara, M., Shogren, K.A., Thompson, J.R., Verdugo, M.Á., Burke, K.M., Aguayo, V. (2019). International perspectives and trends in research on inclusive education: A systematic review. *International Journal of Inclusive Education*, *23*(12), 1277–1295. doi: 10.1080/13603116.2018.1445304.

Amor, A.M., Verdugo, M.Á. (2017). *Evaluación y análisis diferencial de necesidades de apoyo en alumnos con y sin discapacidad intelectual* [Assessment and differential analysis on the support needs of students with and without intellectual disability]. Pozoblanco: PRODE.

Amor, A.M., Verdugo, M.Á. (2018). Quality of life and its role for guiding practices in the social and educational services from a systems perspective. *Człowiek – Niepełnosprawność – Społeczeństwo*, *41*(3), 15–27. doi: 10.5604/01.3001.0012.7817.

Amor, A.M., Verdugo, M.Á., Calvo, M.I., Navas, P., Aguayo, V. (2018). Psychoeducational assessment of students with intellectual disability: Professional-action framework analysis. *Psicothema*, *30*(1), 39–45. doi: 10.7334/psicothema2017.175.

Arias, B., Gómez, L.E., Verdugo, M.Á., Navas, P. (2010). Evaluación de la calidad de vida en personas drogodependientes mediante el modelo de Rasch [Quality of life assessment of drug users through Rasch model]. *Revista Española de Drogodependencias*, *35*(2), 206–219.

Arias, V.B., Gómez, L.E., Morán, L., Alcedo, M.A., Monsalve, A., Fontanil, Y. (2018). Does quality of life differ for children with autism spectrum disorder and intellectual disability compared to children without autism? *Journal of Autism and Developmental Disorders*, *48*(1), 123–136. doi: 10.1007/s10803-017-3289-8.

Balboni, G., Coscarelli, A., Giunti, G., Schalock, R.L. (2013). The assessment of the quality of life of adults with intellectual disability: The use of self-report and report of others assessment strategies. *Research in Developmental Disabilities*, *34*(11), 4248–4254. doi: 10.1016/j.ridd.2013.09.009.

Booth, T., Ainscow, M. (2011). *Index for Inclusion. Developing learning and participation in schools* (3rd edition). Bristol: CSIE.

Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

Buntinx, W.H.E. (2013). Understanding disability: A strengths-based approach. In M.L. Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability* (pp. 7–18). Nueva York, NY: Oxford University Press.

Caballo, C., Crespo, M., Jenaro, C., Verdugo, M.A., Martinez, J.L. (2005). Factorstructure of the Schalock and Keith Quality of Life Questionnaire (QOL-Q): Validation on Mexican and Spanish samples. *Journal of Intellectual Disability Research*, *49*, 773–776. doi: 10.1111/j.1365-2788.2005.00750.x.

Carbó-Carreté, M., Guàrdia-Olmos, J., Giné, C. (2015). Psychometric properties of the Spanish version of the Personal Outcomes Scale. *International Journal of Clinical and Health Psychology*, *15*(3), 236–252. doi: 10.1016/j.ijchp.2015.04.002.

Cummins, R.A. (2000). Objective and subjective quality of life: An interactive model. *Social Indicators Research*, *52*, 55–72. doi: 10.1023/A:1007027822521.

Cummins, R.A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, *49*(10), 699–706. doi: 10.1111/j.1365-2788.2005.00738.x.

Felce, D., Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, *16*(1), 51–75. doi: 10.1016/0891-4222(94)00028-8.

Felce, D., Perry, J. (1996). Assessment of quality of life. In R.L. Schalock (Ed.), *Quality of life*, vol. I: Conceptualization and measurement (pp. 63–73). Washington, DC: American Association on Mental Retardation.

Fernández, M. (2019). *Assessment of quality of life in persons with acquired brain injury: The CAVIDACE Scale* (Doctoral Dissertation, University of Salamanca). https://www.researchgate.net/publication/337772057_Tesis_MariaFernandez_2019.

Gómez, L.E. (2010). *Evaluación de la calidad de vida en servicios sociales: validación y calibración de la Escala Gencat* [Quality of Life assessment in the social services: Validation and calibration of the Gencat Scale] (Doctoral Dissertation, University of Salamanca). https://gredos.usal.es/handle/10366/76489.

Gómez, L.E., Alcedo, M.A., Verdugo, M.Á., Arias, B., Fontanil, Y., Arias, V.B., Monsalve, A., Morán, L. (2016). *Escala KidsLife: Evaluación de la calidad de vida de niños y adolescentes con discapacidad intelectual* [KidsLife Scale: Quality of life assessment for children and adolescents with intellectual disability]. Salamanca: Publicaciones INICO.

Gómez, L.E., Arias, B., Verdugo, M.Á., Navas, P. (2012). An outcomes-based assessment of quality of life in social services. *Social Indicators Research*, *106*(1), 81–93. doi: 10.1007/s11205-011-9794-9.

Gómez, L.E., Arias, B., Verdugo, M.Á., Tassé, M.J., Brown, I. (2015). Operationalisation of quality of life for adults with severe disabilities. *Journal of Intellectual Disability Research*, *59*(10), 925–941. doi: 10.1111/jir.12204.

Gómez, L.E., Morán, L., Alcedo, M.A., Verdugo, M.Á., Arias, V.B., Fontanil, Y., Monsalve, A. (2018). *Escala KidsLife-TEA: Evaluación de la calidad de vida de niños y adolescentes con trastorno del espectro del autismo y discapacidad intelectual* [KidsLife-TEA Scale: Quality of life assessment in children and adolescentes with autism spectrum disorders and intellectual disability]. Salamanca: Publicaciones INICO.

Gómez, L.E., Peña, E., Alcedo, M.A., Monsalve, A., Fontanil, Y., Verdugo, M.Á., Arias, V.B., Arias, B. (2014). El constructo de calidad de vidaenniños y adolescentes con discapacidades múltiples y profundas: propuesta para suevaluación [Quality of life construct in children and adolescents with multiple and profound disabilities: A proposal for its assessment]. *Siglo Cero*, *45*(1), 56–69.

Gómez, L.E., Verdugo, M.Á., Arias, B. (2010). Calidad de vida individual: advances en su conceptualización y retos emergentes en el ámbito de la discapacidad [Individual quality of life: Advances on its conceptualisation and emerging challenges in the disability field]. *Psicología Conductual*, *18*(3), 453–472.

Gómez, L.E., Verdugo, M.Á., Arias, B., Arias, V.B. (2011). A comparison of alternative models of individual quality of life for social service recipients. *Social Indicators Research*, *101*(1), 109–126. doi: 10.1007/s11205-010-9639-y.

Gómez, L.E., Verdugo, M.Á., Rodríguez, M.M., Arias, V.B., Morán, L., Alcedo, M.A., Monsalve, A., Fontanil, Y. (2017). *Escala KidsLife-Down: Evaluación de la calidad de vida de niños y adolescentes con síndrome de Down* [KidsLife-Down Scale: Quality of life assessment in children and adolescents with Down syndrome]. Salamanca: Publicaciones INICO.

Gómez-Vela, M., Verdugo, M.Á. (2009). *Cuestionario de evaluación de la calidad de vidaenalumnosadolescentes (CCVA)* [Questionnaire for assessing quality of life in adolescent students (CCVA)]. Madrid: CEPE.

González, J.A. (2019). Intensidad de apoyos, salud mental, empleo y surelación con resultados de calidad de vida [Intensity of supports, mental health, employment, and their relationship with quality of life outcomes]. *Siglo Cero*, *50*(2), 73–88. doi: 10.14201/scero20195027388.

Hagiwara, M., Amor, A.M., Shogren, K.A., Thompson, J.R., Verdugo, M.Á., Burke, K.M., Uyanik, H., Aguayo, V. (2019). International trends in inclusive education intervention research: A literature review. *Education and Training in Autism and Developmental Disabilities*, *54*(1), 3–17.

Hernández-Sánchez, A.M., Ainscow, M. (2018). Equidad e inclusión: retos y progresos de la escuela del siglo XXI [Equity and inclusion: Challenges and progress of school in 21st century]. *Retos XXI*, *2*, 15–22.

Individuals with Disabilities Education Act (IDEA) of 2004, PL 108-446, 20 U.S.C. §§ 1400 et seq. (2004). https://sites.ed.gov/idea/.

Jenaro, C., Verdugo, M.Á., Caballo, C., Balboni, G., Lachapelle, Y., Otrebski, W. (2005). Cross-cultural study of person-centered quality of life domains and indicators. *Journal of Intellectual Disability Research*, *49*, 734–749. doi: 10.1111/j.1365-2788.2005.00742.x.

Lee, S.H., Wehmeyer, M.L., Soukup, J., Palmer, S.B. (2010). Impact of curriculum modifications on access to the general education curriculum for students with disabilities. *Exceptional Children*, *76*(2), 213–233. doi: 10.1177/001440291007600205.

Morningstar, M.E., Lombardi, A., Fowler, C.H., Test, D.W. (2017). A college and career readiness framework for secondary students with disabilities. *Career Development and Transition for Exceptional Individuals*, *40*(2), 79–91. doi: 10.1177/2165143415589926.

Muntaner, J.J. (2013). Calidad de vidaen la escuelainclusiva [Quality of life in inclusive school]. *Revista Ibero-Americana de Educação*, *63*, 35–49.

Muntaner, J.J., Forteza, D., Rosselló, M.R., Verger, S., de la Iglesia, B. (2010). *Estándares e indicadores para analizar la calidad de vida del alumnado con discapacidad en su proceso educativo* [Standards and indicators for analyzing the quality of life of students with disability in their educational process]. https://pape.uib.es/digitalAssets/530/530951_EstaIndares_calidad-de-vida_alumnado-con-discapacidad.pdf.

Navas, P., Gómez, L.E., Verdugo, M.Á., Schalock, R.L. (2012). Derechos de las personas con discapacidad intelectual: implicaciones de la Convención de Naciones Unidas [Rights of persons with intellectual disability: Implications of the United Nation’s Convention]. *Siglo Cero*, *43*(3), 7–28.

Pazey, B., Schalock, R.L., Schaller, J., Burkett, J. (2016). Incorporating quality of life concepts into educational reform: Creating real opportunities for students with disabilities in the 21st century. *Journal of Disability Policy Studies*, *27*, 96–105.

Petry, K., Maes, B., Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, *18*(1), 35–46. doi: 10.1111/j.1468-3148.2004.00209.x.

Petry, K., Maes, B., Vlaskamp, C. (2007). Support characteristics associated with the quality of life of people with profound intellectual and multiple disabilities. The perspective of parents and direct support staff. *Journal of Policy and Practice in Intellectual Disabilities*, *4*, 104–110. doi: 10.1111/j.1741-1130.2007.00107.x.

Sabeh, E.N., Verdugo, M.Á., Prieto, G., Contini, E.N. (2009). *CVI-CVIP*: *Cuestionario de la evaluación de la Calidad de Vida en la infancia* [CVI-CVIP: Quality of life assessment questionnaire in childhood]. Madrid: CEPE.

Schalock, R.L. (2018). Six ideas that are changing the IDD field internationally. *Siglo Cero*, *49*(1), 7–19. doi: 10.14201/scero2018491719.

Schalock, R.L., Brown, I., Brown, R., Cummins, R.A., Felce, D., Matikka, L., Keith, K.D., Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, *40*(6), 457–470. doi: 10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2.

Schalock, R.L., Borthwick-Duffy, S.A., Bradley, V.J., Buntinx, W.H.E., Coulter, D.L., Craig, E.P.M., Gomez, S.C., Lachapelle, Y., Luckasson, R., Reeve, A., Shogren, K.A., Snell, M.E., Spreat, S., Tassé, M.J., Thompson, J.R., Verdugo, M.Á., Wehmeyer, M.L., Yeager, M.H. (2010). *Intellectual disability: Definition, classification, and systems of support* (11th edition). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schalock, R.L., Gardner, J.F., Bradley, V.J. (2007). *Quality of Life for persons with intellectual and other developmental disabilities: Applications across individuals, organizations, communities, and systems*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schalock, R.L., van Loon, J., Mostert, R. (2018). A systematic approach to enhancing the personal well-being of children and adolescents. *International Journal of Child, Youth and Family Studies*, *9*(4), 188–205. doi: 10.18357/ijcyfs94201818647.

Schalock, R.L., Verdugo, M.Á. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.

Schalock, R.L., Verdugo, M.Á. (2013). The impact of the quality of life concept on the field of intellectual disability. In M.L. Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability* (pp. 37–47). Nueva York, NY: Oxford University Press.

Schalock, R.L., Verdugo, M.Á., Gómez, L.E. (2011). Evidence-based practices in the field of intellectual and developmental disabilities: An international consensus approach. *Evaluation and Program Planning*, *34*(3), 273–282. doi: 10.1016/j.evalprogplan.2010.10.0.

Schalock, R.L., Verdugo, M.Á., Gómez, L.E., Reinders, H.S. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities*, *121*(1), 1–12. doi: 10.1352/1944-7558-121.1.1.

Schalock, R.L., Verdugo, M.Á., Jenaro, C., Wang, M., Wehmeyer, M., Jiancheng, X., Lachapelle, Y. (2005). Cross-cultural study of quality of life indicators. *American Journal of Mental Retardation*, *110*(4), 298–311. doi: 10.1352/0895-8017(2005)110[298:CSOQOL]2.0.CO;2.

The Dakar framework for action. (2000). Paris: UNESCO.

The Salamanca Statement and Framework for Action on Special Needs Education. (1994). Paris: UNESCO. *The World Declaration on Education for All*. New York, NY: UNESCO.

Thompson, J.R., Bradley, V., Buntinx, W.H.E., Schalock, R.L., Shogren, K.A., Snell, M.E., Wehmeyer, M.L., Borthwick-Duffy, S., Coulter, D.L., Craig, E.P.M., Gomez, S.C., Lachapelle, Y., Luckasson, R.A., Reeve, A., Spreat, S., Tassé, M.J., Verdugo, M.Á., Yeager, M.H. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, *47*(2), 135–146. doi: 10.1352/1934-9556-47.2.135.

Thompson, J.R., Walker, V.L., Shogren, K.A., Wehmeyer, M.L. (2018). Expanding inclusive educational opportunities for students with the most significant cognitive disabilities through personalized supports. *Intellectual and Developmental Disabilities*, *56*(6), 396–411. doi: 10.1352/1934-9556-56.6.396.

Thompson, J.R., Wehmeyer, M.L., Hughes, C., Shogren, K.A., Seo, H., Little, T.D., Tassé, M.J. (2016). *Supports Intensity Scale-Children's version. User's manual*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Turnbull, H.R., Turnbull, A., Wehmeyer, M.L., Park, J. (2003). A quality of life framework for special education. *Remedial and Special Education*, *24*, 67–74.

UNESCO. (2008). *Inclusive education: The way of the future*. Paris: UNESCO.

UNESCO. (2015). *Education 2030. Incheon Declaration and framework for action for the implementation of Sustainable Development Goal 4: Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all*. Paris: UNESCO.

United Nations. (2006). *United Nation's Convention on the rights of persons with disabilities*. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

Vanleerberghe, P., De Witte, N., Claes, C., Schalock, R.L., Verté, D. (2017). The quality of life of older people aging in place: a literature review. *Quality of Life Research*, *26*(11), 2899–2907. doi: 10.1007/s11136-017-1651-0.

Van Hecke, N., Claes, C., Vanderplasschen, W., De Maeyer, J., Se Witte, N., Vandevelde, S. (2018). Conceptualisation and measurement of quality of life based on Schalock and Verdugo's model: A cross-disciplinary review of the literature. *Social Indicators Research*, *137*(1), 335–351. doi: 10.1007/s11205-017-1596-2.

Verdugo, M.Á. (2009). El cambio educativo desde una perspectiva de calidad de vida [Educational change from a quality of life perspective]. *Revista de Educación*, *349*, 23–43.

Verdugo, M.Á. (2018). Conceptos clave que explican los cambios en la provisión de apoyos a las discapacidades intelectuales y del desarrollo en España [Key concepts and principles that explain changes in the provision of supports for intellectual and developmental disabilities in Spain]. *Siglo Cero*, *49*(1), 35–52. doi: 10.14201/scero20184913552.

Verdugo, M.Á., Amor, A.M., Arias, V.B., Guillén, V.M., Fernández, M., Arias, B. (2019). Examining measurement invariance and difference across groups in the support needs of children with and without intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *32*(6), 1535–1548. doi: 10.1111/jar.12649.

Verdugo, M.Á., Amor, A.M., Fernández, M., Navas, P., Calvo, M.I. (2018). La regulación de la inclusión educativa del alumnado con discapacidad intelectual: una reforma pendiente [The regulation of inclusive education of students with intellectual disability: A pending reform]. *Siglo Cero*, *49*(2), 27–58. doi: 10.14201/scero20184922758.

Verdugo, M.Á., Amor, A.M., Heras, I. (2019). *Desarrollo y validación de un índice de calidad de vida para la educación inclusiva* [Development and validation of quality of life index for inclusive education]. Salamanca: University of Salamanca.

Verdugo, M.Á., Arias, B., Gómez, L.E., Schalock, R.L. (2009). *Formulario de la Escala Gencat de Calidad de Vida. Manual de aplicación de la Escala Gencat de calidad de vida* [Gencat quality of life assessment scale form. Handbook of application of the Gencat quality of life scale]. Barcelona: Departamentd'Acció Social i Ciutadania, Generalitat de Catalunya, 2009.

Verdugo, M.Á., Fernández, M., Gómez, L.E., Amor, A.M., Aza, A. (2019). Predictive factors of quality of life in acquired brain injury. *International Journal of Clinical and Health Psychology*, *19*(3), 189–197. doi: 10.1016/j.ijchp.2019.06.004.

Verdugo, M.Á., Gómez, L.E., Arias, B. (2009). Evaluación de la calidad de vidaen personas mayores: la Escala FUMAT [Quality of life assessment in elder people: FUMAT Scale]. Salamanca: Publicaciones INICO.

Verdugo, M.Á., Gómez, L.E., Arias, B., Santamaría, M., Clavero, D., Tamarit, J. (2013). *Escala INICO-FEAPS: Evaluación integral de la calidad de vida de personas con discapacidad intelectual o del desarrollo* [INICO-FEAPS Scale: Integral assessment of quality of life in persons with intellectual and developmental disabilities]. Salamanca: Publicaciones INICO.

Verdugo, M.Á., Gómez, L.E., Arias, B., Santamaría, M., Navallas, E., Fernández, S., Hierro, I. (2014). *San Martín Scale: Quality of life assessment for persons with significant disabilities*. Santander: Fundación Obra San Martín.

Verdugo, M.Á., Gómez, L.E., Arias, B., Schalock, R.L. (2009). *Escala Integral. Evaluación objetiva y subjetiva de la calidad de vida de personas con discapacidad intelectual* [Integral scale: Objective and subjective quality of life assessment for persons with intellectual disability]. Madrid: CEPE.

Verdugo, M.Á., Gómez, L.E., Fernández, M., Aguayo, V., Arias, B. (2018). *Escala CAVIDACE de evaluación de Calidad de Vida. Manual de aplicación y corrección* [CAVIDACE Quality of Life assessment scale. Application and correction manual]. Salamanca: Publicaciones INICO.

Verdugo, M.Á., Navas, P., Gómez, L.E., Schalock, R.L. (2012). The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, *56*(11), 1036–1045. doi: 10.1111/j.1365-2788.2012.01585.x.

Walker, V.L., DeSpain, S.N., Thompson, J.R., Hughes, C. (2014). Assessment and planning in k-12 schools: A social-ecological approach. *Inclusion*, *2*(2), 125–139. doi: 10.1352/2326-6988-2.2.125.

Wang, M., Schalock, R.L., Verdugo, M.Á., Jenaro, C. (2010). Examining the factor structure and hierarchical nature of the quality of life construct. *American Journal on Intellectual and Developmental Disabilities*, *115*, 218–233. doi: 10.1352/1944-7558-115.3.218.

Warnock, M. (1978). *Meeting special educational needs. A brief guide by Mrs. Mary Warnock to the Report of the Committee of Equity into [the]education of handicapped children [and] Scottish Education Department [and] Welsh Office*. London: HMSO.

Wehmeyer, M.L. (2014). Disability in the 21st century: Seeking a future of equity and full participation. In M. Agran, F. Brown, C. Hughes, C. Quirk, D.L. Ryndak (Eds.), *Equity and full participation for individuals with severe disabilities: A vision for the future* (pp. 3–25). Baltimore, MA: Paul Brookes Publishing Co.

SHAPING THE FACES OF THE PRISM: RIGHTS, SUPPORTS, AND QUALITY OF LIFE FOR ENHANCING INCLUSIVE EDUCATION OPPORTUNITIES IN STUDENTS WITH INTELLECTUAL DISABILITY

Abstract

Although inclusive education has evolved from a general principle to a recognized right, a quality inclusive education is still not a reality for students with intellectual disability. In this article, we discuss three approaches that can bridge the gap between “what is” current education of these students and “what should be”. First, we address the underpinnings of Article 24 of the United Nation’s *Convention on the Rights of Persons with Disabilities* and its implication for educational systems concerning placement and goals to achieve in these students. Second, we provide a general overview of the supports paradigm and its conceptual and practical implications regarding inclusive education. Third, we present a quality of life model as a value-based and evidence-driven framework to enhance inclusive opportunities in students with intellectual disability and to support decision-making in education from a “whole child approach”. Finally, we provide a comprehensive, systematic framework that brings these three approaches together to improve students’ outcomes linked to the goals of access, participation, learning, and development.

Keywords: inclusive education, students with intellectual disability, rights, supports paradigm, quality of life

NOWY PRYZMAT: PRAWA, WSPARCIE ORAZ JAKOŚĆ ŻYCIA W TWORZENIU EDUKACJI WŁĄCZAJĄCEJ DLA UCZNIÓW Z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ

Abstrakt

Pomimo tego, że edukacja inkluzyjna przeszła ewolucję stanowienia ogólnej zasady do uznanego prawa, wciąż dużo brakuje do tego, żeby stała się rzeczywistością dla uczniów z niepełnosprawnością intelektualną. Artykuł ten opisuje trzy podejścia, które mogą połączyć to, jak wygląda obecnie edukacja tych uczniów, z tym, jak wyglądać powinna. Na początku zaprezentowane zostały podstawy Artykułu 24. *Konwencji o prawach osób niepełnosprawnych* ONZ oraz implikacje dla systemów edukacyjnych dotyczące celów do osiągnięcia przez osoby niepełnosprawne, jakie z nich wynikają. Następnie, artykuł przedstawia ogólny obraz systemów wspierania, jak i konceptualnych oraz praktycznych implikacji dotyczących edukacji inkluzyjnej. Kolejno zaprezentowano model jakości życia jako ramę opartą na wartościach oraz dowodach naukowych służącą do wzmocnienia możliwości inkluzyjnych dla studentów z niepełnosprawnościami oraz do wsparcia procesów decyzyjnych bazujących na podejściu holistycznym do dziecka. Na koniec, opisano wszechstronne, systematyczne ramy, które łączą te trzy podejścia w celu poprawy sytuacji uczniów w takich obszarach, jak dostępność, uczestnictwo, uczenie się oraz rozwój.

Słowa kluczowe: edukacja inkluzyjna, uczniowie z niepełnosprawnością intelektualną, prawa, system wsparcia, jakość życia

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO”
CNS nr 3(49) 2020, 35–52

ISSN 1734-5537
DOI: 10.5604/01.3001.0014.3574

DIANE L. RYNDAK, DEBORAH J. TAUB,
CHRISTIE CAVANAUGH, KARI ALBERQUE*

THE IMPACT OF OPPORTUNITIES TO LEARN WITH GRADE-LEVEL CLASSMATES WITHOUT DISABILITIES ON SELF-ACTUALIZATION AND AUTONOMY FOR STUDENTS WITH EXTENSIVE AND PERVASIVE SUPPORT NEEDS

Introduction

Becoming self-actualized and being able to demonstrate autonomy in life does not happen quickly or easily for any individual, but it is even more difficult for individuals with extensive and pervasive support needs. Students with extensive and pervasive support needs sometimes are referred to as students with severe or significant disabilities. The very nature of disabilities that result in extensive and pervasive support needs frequently decreases an individual's opportunities to learn and use behaviors that demonstrate self-actualization and autonomy, as other people in their lives might provide too much assistance and limited situations in which self-actualization and autonomy could be demonstrated to make either immediate or life-changing decisions.

Opportunities to learn and use skills, including those for self-actualization and autonomy, are necessary throughout educational experiences for all students, but

---

* Diane L. Ryndak (https://orcid.org/0000-0002-4957-8343); University of North Carolina Greensboro, 300 Spring Garden Street Greensboro, NC 27412, USA; e-mail: dlryndak@uncg.edu

Deborah J. Taub (https://orcid.org/0000-0002-4575-1540); University of North Carolina Greensboro, 1300 Spring Garden Street Greensboro, NC 27412, USA; tel. + 1 336 3344668; e-mail: djtaub@uncg.edu

Christie Cavanaugh; University of North Carolina Greensboro, 1300 Spring Garden Street Greensboro, NC 27412, USA; e-mail: clcavana@uncg.edu

Kari Alberque (https://orcid.org/0000-0001-5965-543X); University of North Carolina Greensboro, 1300 Spring Garden Street Greensboro, NC 27412, USA especially for students with extensive and pervasive support needs. This paper describes: (a) equitable schools and opportunities to learn; (b) theoretical constructs that underlie equitable education that provides opportunities to learn for every student, including students with extensive and pervasive support needs, in general education classes with grade-level classmates; (c) variables and practices that lead to opportunities to learn; and (d) the impact of opportunities to learn on one student's self-actualization and autonomy.

Equitable Schools and Opportunities to Learn

Schools are a microcosm of society. If the goal is to create an equitable society where adults have the ability to be active and engaged members of that society, then it is imperative that we build equitable school communities where all students have and share opportunities to learn (Taub, McCord, Ryndak, 2017). It follows that equitable school communities must present equitable opportunities to learn for each student. It must be noted that equitable opportunities to learn are different from equal opportunities to learn. Both equitable and equal opportunities to learn involve all students making progress toward the same post-school outcomes (Taub, McCord, Ryndak, 2017), such as having agency over where to live, with whom to socialize, and in what work and in which hobbies to be engaged. If the opportunities to learn were equal those opportunities would look exactly the same for every student, regardless of each student's learning need. If the opportunities to learn were equitable those opportunities would look different, with each student provided planned and organized instruction to meet their own learning needs, allowing each student to effectively access those opportunities. Thus, as needed, some students would receive supports, accommodations, and/or modifications to have the same opportunities as their general education classmates to learn the instructional content (Taub, McCord, Ryndak, 2017).

In an equitable school community, all students work, play, and learn together across the entire school day and other school-sponsored activities. Students with and without disabilities take turns teaching and learning from each other, sharing their strengths and supporting each other. The adults in the school do not identify students as being either "general" or "special" education students; they all are just students, with whom every adult is engaged. Instruction and classwork is adapted to match how each student engages with it, accesses it, and/or responds to it. While instruction, activities, and content are modified to include less complex expectations for some students, ultimately all the students have opportunities to learn the same overarching concepts and skills. Thus, when all students have opportunities to learn together there would be alignment between the general education content all students are expected to learn, the content that is taught to all students, and the content on which each student's progress is assessed (Taub, McCord, Ryndak, 2017).

By definition a student with a disability experiences barriers to learning that might not exist for their general education classmates who do not have disabilities. For instance, if a student uses an augmentative or alternative communication (AAC) system to interact with others during instruction or other school-sponsored activities, then that student's instruction must incorporate the use of that AAC system, otherwise the student would not have either opportunities to learn the content or demonstrate their acquisition of the content. This would be the case for students with all types of disabilities (e.g., deafness, blindness, autism, intellectual disability, physical disability, multiple disabilities). As Deborah A. Taub, Jessica A. McCord, Diane L. Ryndak (2017) noted, research consistently has determined that students with extensive and pervasive support needs who receive special education services in segregated, self-contained special education classes and schools have limited chances to engage in opportunities to learn grade-level academic content, or acquire and generalize the use of embedded essential skills, such as social interaction skills, self-care, mobility, communication, self-advocacy, self-determination (Carter, 2018; Soukup et al., 2007). Thus, it follows that the acquisition and use of both grade-level academic content and embedded essential skills would be greater when they receive instruction on both sets of skills, and that instruction is embedded within inclusive general education contexts (Ruppar et al., 2018).

Theoretical Constructs that Underlie Equitable Education and Opportunities to Learn

There are several theoretical constructs that underlie the practice of equitable education for all students and, therefore, facilitate the provision of opportunities to learn for all students. Two of these constructs, least dangerous assumption and presumed competence, are particularly critical to the practice of equitable education, and ensuring that each student has opportunities to learn. Let's explore why.

Many students with extensive and pervasive support needs have difficulty demonstrating and expressing their knowledge, feelings, concerns, and thoughts due to physical, cognitive processing, or communication/language issues (Kearns et al., 2011). Because of this, it is easy for others to assume that they do not have knowledge, feelings, concerns, or thoughts to share on any given topic, with any given person, or during any given activity. This assumption frequently leads to a lack of expectation for a student with extensive and pervasive support needs to engage in activities; this lack of expectation results in a lack of ensuring a student has consistent opportunities to learn.

As early as 1984, Anne Donnellan discussed this phenomenon within the framework of long-term goals of education and the possibility of limiting opportunities to learn for students with physical, cognitive processing, or communication/language issues by suggesting the adoption of the criterion of the least dangerous assumption:

> *Given that the long-term goal of education is to ensure that students acquire the skills necessary to be able to live, work, and recreate as independently as possible as adults; and given that there are a variety of educational means or strategies currently available for instruction; and given that, through lack of conclusive data, we are currently forced to make assumptions about the relative impact of various strategies on the long-term goals, which assumptions will have the least dangerous effect on the likelihood that the goal will be attained?* [author-added emphasis] (p. 148).

Her answer to this pivotal question was that we *must* assume every student is competent and, therefore, provide students the supports required to ensure that each student has opportunities to learn that are consistent with high expectations. In contrast, the other alternative of assuming incompetence and/or low expectations could result in doing more harm to a student, if that assumed incompetence about any student eventually is proven to be incorrect.

As an example, consider a 15-year-old student with extensive and pervasive support needs who for 10 years received special education services in segregated classes that served only students with similar needs. Imagine this student does not demonstrate progress in academic (e.g., reading, math) nor embedded essential skills (e.g., self-care, social interactions, compliance). Within this segregating setting there are often only special educators. The students in this class have a wide range of ages. Now imagine this student leaving that segregated special education class and joining general education classes of students her own age. Her general and special education teachers, as well as any instructional assistants and therapists, have the option of either: (a) presuming this student is incompetent and provide instruction on content only at the student's testing level of performance, which is at least 12 years behind the general education classmate and from which there has been no progress documented for multiple years; or (b) presuming this student is competent and provide instruction on some or all of the same general education curriculum content provided for the general education classmates, with accommodations and/or modifications to the content, instruction, and/or materials as needed to ensure opportunities to learn. If at some time in the future the student's education team has documentation that demonstrates this student cognitively understands content but has difficulty expressing knowledge and understanding of content, which assumption would have done the student less harm ---- assuming incompetence, or assuming competence? (Note: this example will be referred to again later in this paper).

This issue of "competence" was further discussed over a decade later when Douglas Biklen (1999, p. 50) argued that "as a matter of basic sensitivity and good educational practice, educators must presume that the person is intelligent". Because students with extensive and pervasive support needs increasingly were gaining access to general education curriculum content and settings, these concepts were further operationalized by Cheryl M. Jorgensen (2006; as cited in Jorgensen, McSheehan, Sonnenmeier, 2007) who proposed that "the least dangerous assumption is to presume a student is competent to learn general education curriculum and to design educational programs and supports based on that assumption.” Thus, the acceptance and use of the theoretical constructs of *least dangerous assumption* and *presumed competence* are essential to the provision of opportunities to learn for students with extensive and pervasive support needs.

Variables and Practices that Lead to Opportunities to Learn

For students with extensive and pervasive support needs to have increased opportunities to learn, access is a key variable. The question of how best to access the curriculum involves consideration of instructional setting, content, and instructional practices or strategies. An emphasis on the general education classroom as the instructional setting is embedded in other sections of this paper as it serves as a fundamental goal of inclusive education; therefore, the following section focuses on content, as in the general education curriculum, essential skills, and modifications; instructional practices; and self-determination.

General Education Curriculum: Access, Content, and Practices

The general education curriculum is the content taught to students at a particular age or grade level, such as reading, writing, math, science, and social studies. Curriculum is comprised of intended, enacted and assessed components. The intended curriculum is based on the standards or grade level expectations that become the adopted standards, or what all students are expected to learn or know and be able to do, also referred to as knowledge and skills. The enacted curriculum is the content and skills actually presented to students, which may be guided by specific curricular programs or other approaches teachers use to teach the intended curriculum. The assessed curriculum is what is assessed to determine both individual progress and student outcomes at the grade level, school level, or even state level. In the United States, two laws state clearly that all students, including students with extensive and pervasive support needs, are expected to access and make progress in the general education curriculum (IDEA, ESSA); and thus, have access to the intended curriculum, practices and approaches implemented to teach, or enact, the curriculum, and appropriate assessments to determine progress on the assessed curriculum. Although there are often issues of alignment between these curriculum components (Anderson, Brown, Lopez-Ferrao, 2003; Martone, Sireci, 2009), the same considerations should be in place for students with extensive and pervasive support needs as they are for all students.

General education curriculum content. It is clear: Students with extensive and pervasive support needs will have the greatest access to the general education curriculum in the general education classroom (Jackson, Ryndak, Wehmeyer, 2009; Soukup et al., 2007). However, placement alone does not guarantee that instruction in the general curriculum will occur appropriately. Access to the general education curriculum and standards requires careful consideration of the content and how to modify content and instruction in ways that preserve the intent of the standards, or the intended curriculum. Implementation of UDL and MTSS is an important step in preserving the standards and teaching all students, but it is also necessary to maintain focus on fundamental well-validated teaching strategies such as task analysis, least to most prompts, mnemonics, graphic organizers, and time delay, for example to focus on *how* we teach the curriculum rather than changing the curriculum goals.

Embedded essential skills. Although some researchers have debated that students with extensive and pervasive support needs require instruction that focuses on functional skills (Hunt, McDonnell, Crockett, 2012), more recently, researchers have suggested that the general education, standards-based curriculum, and functional curriculum are not mutually exclusive (Ryndak et al., 2014). Students with extensive and pervasive support needs often require instruction on essential skills such as choice making, how to engage appropriately with peers and adults, and how to communicate, in addition to fundamental academic skills that most other students have mastered. In the past, these types of skills have been conceptualized as “functional” skills; however, the curricula built upon a functional framework are often dated and focus on skills that may no longer be useful for many students or lacking in some skills that are essential for living in the twentieth century.

These essential skills are more purposeful and generalizable when embedded into natural routines and contexts rather than taught in isolation or through massed trial teaching out of context (Hunt, McDonell, Crockett, 2012). There are fundamental differences between tasks such as completing a worksheet by filling in missing alphabet letters and using the alphabet to access a communication device to express a need or communicate with peers. The latter activity represents an essential skill that is embedded easily into multiple natural routines with natural consequences (e.g., the student’s needs are met; student interacts with peers). Further, generalization to other opportunities for interaction is built into the instruction and practice of the skill. With small changes to the context such as embedding instruction into natural routines, there may be a significant change in a student’s demonstration of knowledge and ability to use that knowledge appropriately. Pam Hunt, John McDonell, Margret A. Crockett (2012) noted an increase in students’ abilities to generalize essential skills when they were embedded as a part of natural routines in inclusive contexts. Addressing generalization purposefully is an inherent guideline of Universal Design for Learning, UDL (described in the following section) that impacts students' opportunities for action and expression and engagement and expands teachers' implementation of options for representation.

Curriculum modifications. Suk-Hyang Lee, Michael L. Wehmeyer, Jane H. Soukup, and Susan B. Palmer (2010) investigated the impact of curriculum modifications on student behavior and found that high school students with disabilities demonstrated increased academic responding when curriculum modifications were present. Curriculum modifications in the form of adaptations or augmentations (Thompson et al., 2018; e.g., see Wehmeyer, Lattin, Agran, 2001; Wehmayer, Lance, Bashinksaki, 2002) promote access to the general curriculum for students with extensive and pervasive support needs (Lee et al., 2010). The adaptations do not alter the content; rather, they provide additional ways for students to access content and respond which is consistent with the UDL framework. For example, using technology to present content in multiple formats and with visual supports or allowing students to use technology to communicate what they have learned are considered curriculum adaptations – same content, different way to see or hear it or to demonstrate understanding.

Curriculum augmentations include additional strategies or skills that students may need to succeed or benefit from the general education curriculum such as learning supports, memory strategies, or goal setting. Evidence-based practices and the use of technology to increase access to the general education curriculum *if* they are implemented in the general education classroom when students with extensive and pervasive support needs are learning alongside grade-level peers. The use of curriculum modifications and UDL are closely aligned and serve as critical approaches to ensuring all students have appropriate access to the general curriculum that leads to improved student outcomes.

Instructional Practices and Supports

A clear vision and philosophy about how students with extensive and pervasive support needs should be afforded opportunities to learn in the same context as their peers in a general education setting are essential for adopting an inclusive approach that moves behind physical placement alone. For inclusion with positive outcomes to become a reality for students with extensive and pervasive support needs, key instructional practices and instructional content warrant consideration.When evidence-based practices are implemented, student outcomes improve (Kuntz, Carter, 2019). This is true for all students; and, it is no different for students with extensive and pervasive support needs. The term, evidence-based practices (EBPs), refers to strategies or practices that have been validated empirically to have a positive impact on student outcomes. Because research on how to teach students with extensive and pervasive support needs has accelerated over the past 40 years (Browder, Wood, Thompson, Ribuffo, 2014), there is little confusion about the selection of EBPs, yet implementation of EBPs varies. Implementation variables, such as context in which students receive services, the focus of the intended curriculum, and match between what students need at various points in time and access to curriculum and services, determine outcomes for students beyond the mere selection of EBPs. The following practices will be described as fundamental EBPs to support students with significant disabilities in the context of an inclusive setting during the school-age years: Universal Design for Learning, Multi-Tiered Systems of Support, and Peer Supports. In addition, a framework for personalized supports planning (Thompson et al., 2018) will be introduced to provide further guidance on how to increase access to the general education classroom and curriculum in meaningful ways.

Universal Design for Learning. Universal Design for Learning (UDL), is a teaching framework that reduces barriers to learning and increases opportunities for all students to learn and benefit from instruction in general education classrooms (Meyer, Rose, Gordon, 2014). A primary assumption that guides the implementation of UDL is that the barriers to learning exist in the environment and therefore, can be modified rather than learners adjusting to the environment. Three guidelines and the related checkpoints within the UDL framework, provide teachers flexibility to meet the needs of all learners through means of Engagement, Representation, and Action and Expression. The implementation of each guideline is possible when teachers follow the checkpoints for providing options; and, while there are multiple ways to address each one, there is no set number that determines whether UDL is implemented effectively or not. The most important key to effective implementation is that teachers consider the barriers in the environment, content, and context to address the needs of all students prior to planning lessons rather than developing a lesson and modifying it later to fit a specific student's needs. James R. Thompson and colleagues (2018) discussed how implementation of the UDL framework is part of personalized support planning for students with extensive and pervasive support needs.

Representation refers to the "what" of learning: the content or knowledge and skills taught to students. When teachers address means of representation, they are presenting content in various ways while appealing to the recognition network of learners' brains to develop an understanding of information, details, facts, and other discrete knowledge for students to acquire, retain, and apply learned knowledge. For example, when teachers provide options for how content is presented such as an audio-recording of text read or images paired with key vocabulary, they are following guidelines for means of representation. For a student whose reading ability is below grade level or for one who has difficulty comprehending complex language structures, the use of audio recordings and visual aids serves to decrease barriers to learning and increase access to the curriculum.

Action and Expression refers to the "how" of learning: the ways that students demonstrate learning and understanding. Teachers who address means of action and expression are providing options for students to respond and are addressing the brain's strategic network. When teachers implement UDL and are planning lessons with all students in mind, they generate opportunities for students to demonstrate learning in multiple ways. For example, if the goal is for students to demonstrate they comprehend text (whether they read it independently or with support or listen to an audio recording – all options under means of representation), students may have the option to write a response, select answers to multiple-choice questions using technology, listen to a recorded summary of a section and use a gesture or response mechanism to indicate the accuracy of the summary. Additionally, students may have the option to illustrate or select pictures that convey the meaning of the reading.

Engagement refers to the "why" of learning, or motivation and engagement. As teachers consider means of engagement for UDL implementation, they acknowledge the affective network and incorporate guidelines for increasing motivation and engagement for all students. Teaching students to set goals, self-monitor progress, collaborate, and reflect all relate to means of engagement. In addition, teachers who consider students' interest and select materials and experiences that are relevant and authentic and who challenge students strategically, are implementing a UDL framework.

Multi-Tiered Systems of Support. Multi-Tiered Systems of Support (MTSS) is a framework that schools implement to provide systematic support for all students to succeed academically through levels or tiers that increase in intensity and individualization. Two specific MTSS frameworks are Response to Intervention, RTI, and Positive Behavior Interventions and Supports, PBIS. While RTI focuses more specifically on academic content, usually reading and math, and PBIS focuses on behavior, implementation of MTSS through either RTI or PBIS or a combination, academic and behavioral outcomes improve for all students (Fuchs, Fuchs, Stecker, 2010; Mumbardó, Shogren, Guàrdia-Olmos, Giné, 2017; Walker et al., 2018). This description and examples will address MTSS more generally, but the fundamental components are similar for both RTI and PBIS.

Within an MTSS framework, there are multiple layers or tiers of support with most implementations including three tiers. All students, including students with disabilities, benefit from instruction at the core level, or Tier 1. Tier 1 instruction is that which is implemented in the classroom for all students and when a program or approach is used that is built on evidence-based practices and it is implemented effectively, most students succeed. A fundamental component of any MTSS implementation is the use of assessment data (Jimerson, Burns, VanDerHeyden, 2016). Assessments are administered and data analyzed at key time points in a given school year for multiple purposes: to confirm if students are on track for meeting standards or benchmarks, to identify students who are not on track and may benefit from additional support provided through Tier 2 or Tier 3 intervention, and to determine if Tier 1 instruction is effective for most students, or at least 80% of the class or grade. Tier 1 instruction for reading or math is based on the grade level standards and the programs implemented to teach those standards. Supports already in place for students with disabilities would also be considered as part of Tier 1 instruction.

For any students who are not meeting grade level expectations or standards, schools provide support through intervention at Tier 2 or Tier 3. Generally, the intervention is provided in small groups or individually and is designed to target the specific areas that students may need to accelerate progress and meet the expectations or standards. Tier 2 intervention for reading or math focuses on fundamental skills such as phonics or fluency for reading and computation or problem-solving for math. Tier 2 intervention for behavior may focus on coping skills, making friends, anger management, or impulse control. The classroom teacher may be the person to implement Tier 2 interventions or a specialist is likely if available. While students receive Tier 2 support, they continue to benefit from instruction in Tier 1 so the Tier 2 support is additive and not a replacement for Tier 1.

When an instructional team determines through data analysis that Tier 2 support in addition to Tier 1 is insufficient for accelerating student progress, the student then receives Tier 3 intervention. A primary difference between Tier 2 and Tier 3 intervention is intensity, which is adjusted through group size (often one on one or one teacher working with 2 students) and duration (amount of time per intervention session increases). The focus of the intervention is similar to Tier 2 for academic foundational skills or challenging behavior and brief assessments and review of student data occur at least as frequently as every other week to determine the effectiveness of the intervention. When Tier 2 intervention support transitions to Tier 3, the student still continues to receive Tier 1 so core instruction to teach grade level standards remains intact. For students with extensive and pervasive support needs, Tier 2 and Tier 3 interventions would focus on the fundamental skills necessary to make progress toward individual goals and standards. Again, Tier 1 instruction would continue with supports already in place, but students would benefit from intervention to make further progress and any specific instructional or support needs for students with disabilities may occur at all three tiers.

Peer supports. When students with extensive and pervasive support needs have access to peers without disabilities in general education classrooms, the use of peer supports is possible and more importantly, effective. The effectiveness of peer supports has been validated across contexts and with students of varying disabilities and severity (Jameson et al., 2008; Stenhoff, Lignugaris, 2007), but are unlikely to be implemented unless students with extensive and pervasive support needs are learning alongside their peers who can serve as supports. Thus, the use of peer supports in inclusive settings helps to ensure that all students are benefitting from instruction. Peers with and without disabilities can play a vital role as tutors and as models for social interaction, communication, behavior, and other skills that support social and academic achievement (Hudson, Browder, 2014; Malone, Fodor, Hollingshead, 2019). Students with extensive and pervasive support needs have experienced increased numbers of social interactions (Carter et al., 2010) and peers without disabilities have shown improvements in academic outcomes when peer supports were implemented (Carter et al., 2011). While regular and daily interaction between peers with and without disabilities is a fundamental feature, deliberate action is equally fundamental. The effectiveness of peer supports improves when teachers use them systematically and intentionally and teach peers how to fulfill the role (Biggs, Carter, Gilson, 2019; Carter et al., 2010). For example, peers without disabilities need to be taught how to engage students with extensive and pervasive support needs, model behavior or steps of a task, use technology such as AAC, or prompt responses.

Personalized supports planning. Thompson and colleagues (2018) suggest that consideration of students' support needs is necessary to focus on changes or enhancements to the general education classroom environment for the purpose of teaching students with significant [cognitive] disabilities and to facilitate "personalized learning." This concept aligns very closely with the tenets of UDL and is grounded in accumulating research evidence supporting the positive outcomes associated with inclusive education for students with extensive and pervasive support needs. With the assumption that we understand "what" to teach students, as described in a previous section on curriculum content and that we maintain "appropriately ambitious" goals (see Yell, Bateman, 2017) for students with extensive and pervasive support needs, attention to personalized supports addresses further "how" to teach students in the general education classroom. With the goal to provide support for students to make progress toward appropriate goals, Thompson and colleagues provide a framework for planning personalized supports that includes categories and subcategories of supports: (a) curricular adaptations (i.e., supplementary, modified, and alternative goal adaptations); (b) instructional supports (i.e., instructional and alternative adaptations); and (c) participation supports (i.e., accommodations, modifications, and personalized supports). As goals are developed and opportunities to address the goals are embedded into the students' classroom schedule and routines, specific supports are identified to support student attainment of the goals.

Self-Determination

Self-determination is the ability to control the direction of one's own life (Shogren et al., 2015a). Skills associated with self-determination include setting goals, evaluating options, making choices and achieving goals (Morningstar, Clavenna-Deane, 2018). Since all students benefit from developing and using these skills both immediately and throughout their lives, they can be used to by students to make decisions about their own involvement in general education classes and other activities, as well as the general education curriculum (Palmer et al., 2004). Research has demonstrated that when students with disabilities who have acquired self-determination skills exit their school program, they are more likely to be employed and live independently as adults in the community of their choice (Morningstar et al., 2010; Shogren et al., 2015b). As with acquiring other academic and embedded essential skills, the educational services provided for students with extensive and pervasive support needs must be systematic and reflect evidence-based practices if they are to acquire and use self-determination skills (Kurth, Marks, Bantz, 2017; Taub, McCord, Ryndak, 2017).

Several research-based self-determination models have been developed, including:*The Self-Directed IEP* (Martin et al., 1996), *Steps to Self-Determination* (Field, Hoffman, 1994), *Self-Advocacy Strategy* (Van Ruesen et al., 1994), and *Self-Determination Learning Model of Instruction* (SDLMI) (Agran et al., 2006). The use of these models has been linked to positive outcomes of students with extensive and pervasive support needs, such as increased (a) student participation in the development of their educational program (Martin et al., 1996), (b) student self-identification of strengths and opportunities for growth (Test, Neal, 2004), and (c) overall development of behaviors that reflect self-determination (Wehmeyer et al., 2011). Mary E. Morningstar and Elizabeth Clavenna-Deane (2018) describe several components that reflect evidence-based practices, including self-assessment, goal development, identification of support resources, and self-advocacy. When used consistently over a student's educational career, these components have led to improved acquisition and use of the skills that reflect the degree to which a student's life is self-determined.

Equitable schools have used models such as the *Self-Determination Learning Model of Instruction* (SDLMI) for students with extensive and pervasive support needs, resulting in increased access to general education curriculum (Agran et al., 2006) and improvement in students' use of self-determination skills. These skills are fundamental to ensuring equitable access to opportunities and resources for individuals with extensive and pervasive support needs both during students' school experiences and in adults' engagement in their community of choice. When schools increase opportunities to learn through the development of student-directed instructional plans, students gain foundational skills for self-actualization in adulthood.

Impact of Opportunities to Learn on Self-Actualization and Autonomy

In a seven-year case study of a student's services and progress on both grade-level academic content and embedded essential skills, Diane L. Ryndak, Andrea P. Morrison and Lynne Sommerstein (1999) provide an excellent comparison of this student's opportunities to learn first in segregated, self-contained special education classes, and then in inclusive general education classes, for a student with significant intellectual, language, and speech disabilities. In this study, the student had received special education services in self-contained classrooms for 10 years (i.e., 5–15 years of age). Over multiple years the student's test scores consistently demonstrated 1st and 2nd grade performance levels in reading and mathematics; her behavior and social interactions demonstrated a need for her to have constant adult supervision; and her anticipated limited growth was interpreted to predict an adulthood that required her living in a fully supervised group living facility, as well as a fully supervised day activity program for only adults with disabilities, instead of work in an equitable community. Although this student had been working on the same basic reading and math skills for 5 consecutive years, she had demonstrated little to no progress on those skills and her social behaviors and interactions with both adults and students in school settings increasingly were problematic and aggressive.

This student's family saw her perform differently in the community and at home and, therefore, had a different long-term vision for her. They believed that when she exited high school at age 18, she would attend a university and later work at a regular competitive job, live in her family's community where she already had friends, live in her own apartment, and advocate for herself as independently as she could with supports provided as needed.

Through the family's advocacy for her school to follow the education laws in the United States, they were able to change this student's educational placement and services. She was moved from the segregated, self-contained special education classes to grade-level general education classes where she was a fully engaged member of all class instruction, routines, and other school-sponsored activities with same-aged classmates who did not have disabilities. This student's opportunities to learn quickly changed dramatically, as did the content she learned, the amount of that content she learned, her use of that content across contexts, and her overall behaviors. She became self-driven; her behaviors and social interactions became consistent with those of her same-aged general education classmates; she began reading openly for classes, for pleasure, and everyday activities; and she developed many more friendships.

To accomplish this her general and special education teachers, as well as other educational personnel (e.g., speech/language pathologist, occupational therapist), provided instruction on math, reading, and embedded essential skills within and during the general education class instructional activities, as well as during other school-sponsored activities. Her work became age- and grade level-appropriate, which provided her opportunities to learn and practice foundational academic skills within meaningful activities and contexts with her general education classmates; she also, however, had access to higher level math and language arts concepts and skills, to which she previously had no access. While this student's formal assessment scores did not change, the differences in her acquisition and use of academic and embedded essential skills was dramatic, both immediately upon having opportunities to learn that content and over the remaining 7 years of her educational experiences.

The difference in this student's outcomes were related directly to her increased opportunities to learn grade-level and embedded essential skills through the identification and use of accommodations and/or modifications to instruction, activities, materials, and curriculum content that were determined with the student and her family through person-centered planning approaches. These four variables (i.e., instruction, activities, materials, curriculum content) can be considered as barriers to providing services for students with extensive and pervasive support needs in inclusive general education classes, they also can be considered facilitators of the provision of opportunities to learn.

Conclusion

The importance of every student having opportunities to learn and use the general education curriculum content, as well as embedded essential skills, is critical for each student's long-term success. Research clearly demonstrates that students with extensive and pervasive support needs acquire and use more skills when they receive instruction embedded within general education settings with general education classmates. To develop and sustain effective services in general education settings, however, requires a change in how teachers, administrators, parents, therapists, and other personnel think about students with extensive and pervasive support needs, as well as how they envision the purpose of educational services for all students.

In this paper we provided information about some of the educational practices that have been found to be effective at building equitable schools that serve all students in the same grade-level appropriate general education classes. This is not an exhaustive review of such strategies, but is meant to lay the foundation for an understanding of inclusive education for students with extensive and pervasive support needs. Such changes in how individuals think about these issues and how they develop and sustain this type of education system requires a great deal of collaborative teaming. While collaboration frequently is discussed in relation to general and special education teachers co-planning, co-teaching, and co-evaluating instruction with other service providers, the same need for collaboration exists among school system administrators, policy makers, and advocates. This type of change requires coordinated efforts at all levels; that is, classroom, school, school system, and national levels.

To accomplish this type of systemic change and ensure it is sustained over time, a field of science is newly being applied to the field of education – implementation science. While this field began to look at getting a specific practice used consistently by everyone in a system (e.g., a specific hand washing regimen in hospitals), what those researchers found now is being reviewed for potential effectiveness in relation to developing and sustaining equitable schools that facilitate inclusive education for students with extensive and pervasive support needs (Lazarus et al., 2019).

References

Agran, M., Cavin, M., Wehmeyer, M., Palmer, S. (2006). Participation of students with moderate to severe disabilities in the general curriculum: The effects of the self-determined learning model of instruction. *Research & Practice for Persons with Severe Disabilities*, *31*(3), 230–241. doi: 10.1177/154079690603100303.

Anderson, B.T., Brown, C.L., Lopez-Ferrao, J. (2003). Systemic reform: Good educational practice with positive impacts and unresolved problems and issues. *Review of Policy Research*, *20*(4), 617–627. doi: 10.1046/j.1541-1338.2003.00042.

Biggs, E.E., Carter, E.W., Gilson, C.B. (2019). A scoping review of the involvement of children's communication partners in aided augmentative and alternative communication modeling interventions. *American Journal of Speech-Language Pathology*, *28*(2), 743–758. doi: 10.1044/2018_AJSLP-18-0024.

Biklen, D. (1999). The metaphor of mental retardation: Rethinking ability and disability. In H. Bersani, Jr. (Ed.), *Responding to the challenge: Current trends and international issues in developmental disabilities. Essays in honor of Gunnar Dybwad* (pp. 35–52). Cambridge, MA: Brookline.

Browder, D.M., Wood, L., Thompson, J., Ribuffo, C. (2014). Evidence-based practices for students with severe disabilities (Document No. IC-3). University of Florida, Collaboration for Effective Educator, Development, Accountability, and Reform Center website. http://ceedar.education.ufl.edu/tools/innovation-configurations/.

Carter, E.W. (2018). Supporting the social lives of secondary students with Severe disabilities: Considerations for effective intervention. *Journal of Emotional and Behavioral Disorders*, *26*(1), 52–61. doi: 10.1177/1063426617739253.

Carter, E.W., Moss, C.K., Hoffman, A., Chung, Y.-C., Sisco, L. (2011). Efficacy and social validity of peer support arrangements for adolescents with disabilities. *Exceptional Children*, *78*, 107–125.

Carter, E.W., Sisco, L.G., Chung, Y.-C., Stanton-Chapman, T.L. (2010). Peer interactions of students with intellectual disabilities and/or autism: A map of the intervention literature. *Research & Practice for Persons with Severe Disabilities*, *35*(3/4), 63–79. doi: 10.2511/rpsd.35.3-4.63.

Donnellan, A. (1984). The criterion of the least dangerous assumption. *Behavioral Disorders*, *9*, 141–150.

Field, S., Hoffman, A. (1994). Development of a model for self-determination. *Career Development for Exceptional Individuals*, *17*(2), 159–169. doi: 10.1177/088572889401700205.

Fuchs, D., Fuchs, L.S., Stecker, P.M. (2010). The "Blurring" of special education in a new continuum of general education placements and services. *Exceptional Children*, *76*(3), 301–323. doi: 10.1177/001440291007600304.

Hudson, M., Browder, D.M. (2014). Improving listening comprehension responses for students with moderate intellectual disability during literacy class. *Research & Practice for Persons with Severe Disabilities*, *39*(1), 11–29. doi: 10.1177/1540796914534634.

Hunt, P., McDonnell, J., Crockett, M.A. (2012). Reconciling an ecological curricular framework focusing on quality of life outcomes with the development and instruction of standards-based academic goals. *Research & Practice for Persons with Severe Disabilities*, *37*(3), 139–152. doi: 10.2511/027494812804153471.

Jackson, L., Ryndak, D.L., Wehmeyer, M.L. (2009). The dynamic relationship between context, curriculum, and student learning: A case for inclusive education as a research-based practice. *Research and Practice for Persons with Severe Disabilities*, *33*(4)/*34*(1), 175–195.

Jameson, M., McDonnell, J., Polychronis, S., Riesen, T. (2008). Embedded, constant time delay instruction by peers without disabilities in general education classrooms. *Intellectual & Developmental Disabilities*, *46*(5), 346–363. doi: 10.1352/2008.46:346-363.

Jimerson, S., Burns, M., VanDerHeyden, A. (Eds.). (2016). *Handbook of response to intervention: The science and practice of Multi-Tiered Systems of Support* [2nd edition]. New York New York: Springer. doi: 10.1007/978-1-4899-7568-3.

Jorgensen, C.M. (2006, August). *The least dangerous assumption: A challenge to create a new paradigm*. Keynote presentation at the 8th Annual Autism Summer Institute, University of New Hampshire, Durham, New Hampshire.

Jorgensen, C.M., McSheehan, M., Sonnenmeier, R.M. (2007). Presumed competence reflected in the educational programs of students with IDD before and after the Beyond Access professional development intervention. *Journal of Intellectual & Developmental Disability*, *32*(4), 248–262. doi: 10.1080/1366825070170423.

Kearns, J.F., Towles-Reeves, E.L., Kleinert, H.L., Kleinert, J.O., Thomas, M.K. (2011). Characteristics of and implications for students participating in alternate assessments based on alternate academic achievement standards. *The Journal of Special Education*, *45*, 3–14. doi: 10.1177/0022466909344223.

Kuntz, E.M., Carter, E.W. (2019). Review of interventions supporting secondary students with intellectual disability in general education classes. *Research & Practice for Persons with Severe Disabilities*, *44*(2), 103–121. doi: 10.1177/1540796919847483.

Kurth, J., Marks, S., Bartz, J. (2017). Educating Students in Inclusive Classrooms. In M. Wehmeyer, K. Shogren (Eds.), *Handbook of research-based practices for educating students with intellectual disability* (pp. 274–295). New York: Routledge, Taylor & Francis Group.

Lazarus, S.S., Ryndak, D.L., Howley, C.B., McDaid, P., Liu, K.K., Taub, D., Howley, A., Cosier, M., Clifton, J., Telfer, D., Holden. K., Thurlow, M.L., Vandercook, T. (2019). *Using systems change efforts to implement and sustain inclusive education practices in general education settings for students with the most significant cognitive disabilities: A review of the literature* (TIES Center Report 102). Minneapolis, MN: University of Minnesota, The TIES Center.

Lee, S., Wehmeyer, M.L., Soukup, J.H., Palmer, S.B. (2010). Impact of curriculum modifications on access to the general education curriculum for students with disabilities. *Exceptional Children*, *76*(2), 213–233.

Malone, K.W., Fodor, J.A., Hollingshead, A. (2019). Peer tutoring to support inclusion of students with the most significant cognitive disabilities at the secondary level. *Inclusion*, *7*(1), 1–11. doi: 10.1352/2326-6988-7.1.1.

Martin, J.E., Marshall, L.H., Maxson, L.M., Jerman, P.L. (1996). The Self-Directed IEP. Longmont, CO: Sopris West.

Martone, A., Sireci, S.G. (2009). Evaluating alignment between curriculum, assessment, and instruction. *Review of Educational Research*, *79*(4), 1332–1361. doi: 10.3102/0034654309341375.

Meyer, A., Rose, D.H., Gordon, D. (2014). Universal Design for Learning: Theory and Practice. Wakefield, MA: CAST.

Morningstar, M., Clavenna-Deane, B. (2018). *Your Complete Guide to Transition Planning and Services*. Baltimore, MD: Paul H. Brookes Publishing Company.

Morningstar, M., Frey, B., Noonan, P., Ng, J., Clavenna-Deane, B., Graves, P., Kellems, R., McCall, Z., Pearson, M., Bjorkman Wade, D., Williams-Diehm, K. (2010). A preliminary investigation of the relationship of transition preparation and self-determination for students with disabilities in postsecondary educational settings. *Career Development for Exceptional Individuals*, *33*(2), 80–94.

Mumbardó, A.C., Shogren, K.A., Guàrdia-Olmos, J., Giné, C. (2017). Contextual predictors of self-determined actions in students with and without intellectual disability. *Psychology in the Schools*, *54*(2), 183–195. doi: 10.1002/pits.21987.

Palmer, S.B., Wehmeyer, M.L., Gipson, K., Agran, M. (2004). Promoting access to the general curriculum by teaching self-determination skills. *Exceptional Children*, *70*(4), 427–439. doi: 10.1177/001440290407000403.

Ruppar, A.L., Knight, V.F., McQueston, J.A., Jeglum, S.R. (2018). Involvement and progress in the general curriculum: A grounded theory of the process. *Remedial and Special Education*, *3*(41), 152–164. doi: 10.1107/0741932518806045.

Ryndak, D.L., Morrison, A.P., Sommerstein, L. (1999). Literacy prior to and after inclusion in general education settings. *Journal of the Association for Persons with Severe Handicaps*, *24*(1), 5–22.

Ryndak, D.L., Taub, D. Jorgensen, C.M., Gonsier-Gerdin, J., Arndt, K., Sauer, J., Ruppar, A.L., Morningstar, M.E., Allcock, H. (2014). Policy and the impact on placement, involvement, and progress in general education. *Research and Practice for Persons with Severe Disabilities*, *39*(1), 65–74. doi: 10.1177/1540796914533942.

Shogren, K., Wehmeyer, M.L., Palmer, S., Forber-Pratt, A., Little, T., Lopez, S. (2015a). Causal agency theory: Reconceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities*, *50*(3), 251–263.

Shogren, K.A., Wehmeyer, M.L., Palmer, S.B., Rifenbark, G.G., Little, T.D. (2015b). Relationships between self-determination and postschool outcomes for youth with disabilities. *Journal of Special Education*, *48*(4), 256–267. doi: 10.1177/0022466913489733.

Soukup, J.H., Wehmeyer, M.L., Bashinski, S.M., Bovaird, J.A. (2007). Classroom variables and access to the general curriculum for students with disabilities. *Exceptional Children*, *74*(1), 101–120. https://doi.org/10.1177/001440290707400106.

Stenhoff, D.M., Lignugaris, B. (2007). A review of the effects of peer tutoring on students with mild disabilities in secondary settings. *Exceptional Children*, *74*(1), 8–30. doi: 10.1177/001440290707400101.

Taub, D.A., McCord, J.A., Ryndak, D.L. (2017). Opportunities to learn for students with extensive support needs: A context of research-supported practices for all in general education classes. *The Journal of Special Education*, *51*(3), 127–137. doi: 10.1177/0022466917696263.

Test, D., Neale, M. (2004). Using the self-advocacy strategy to increase middle graders' IEP participation. *Journal of Behavioral Education*, *13*(2), 135–145. doi: 10.1023/B:JOBE.0000023660.21195.c2.

Thompson, J.R., Walker, V.L., Shogren, K.A., Wehmeyer, M.L. (2018). Expanding inclusive educational opportunities for students with the most significant cognitive disabilities through personalized supports. *Intellectual & Developmental Disabilities*, *56*(6), 396–411. doi: 10.1352/1934-9556-56.6.396.

Van Reusen, A.K., Bos, C.S., Schumaker, J.B., Deshler, D.D. (1994). *The self-advocacy strategy for education and transition planning*. Lawrence, KS: Edge Enterprises.

Walker, V., Loman, S., Hara, M., Park, K., Strickland-Cohen, M. (2018). Examining the inclusion of students with severe disabilities in school-wide positive behavioral interventions and supports. *Research and Practice for Persons with Severe Disabilities*, *43*(4), 223–238.

Wehmeyer, M.L., Lance, G.D., Bashinkski, S. (2002). Promoting access to the general curriculum for students with mental retardation: A multi-level model. *Education and Training in Mental Retardation and Developmental Disabilities*, *37*, 223–234.

Wehmeyer, M.L., Lattin, D., Agran, M. (2001). Achieving access to the general curriculum for students with mental retardation: A curriculum decision-making model. *Education and Training in Mental Retardation and Developmental Disabilities*, *36*, 327–342.

Wehmeyer, M.L., Palmer, S.B., Lee, Y., Williams-Diehm, K., Shogren, K. (2011). A randomized-trial evaluation of the effect of whose future is it anyway? On self-determination. *Career Development for Exceptional Individuals*, *34*(1), 45–56. doi: 10.1177/0885728810383559.

Yell, M.L., Bateman, D.F. (2017). Endrew F. v. Douglas County School District (2017): FAPE and the U.S. Supreme Court. *Teaching Exceptional Children*, *50*, 7–15. doi: 10.1177/0040059917721116.

THE IMPACT OF OPPORTUNITIES TO LEARN WITH GRADE-LEVEL CLASSMATES WITHOUT DISABILITIES ON SELF-ACTUALIZATION AND AUTONOMY FOR STUDENTS WITH EXTENSIVE AND PERVASIVE SUPPORT NEEDS

Abstract

Inclusive education encompasses both theoretical constructs (e.g., least dangerous assumption, presumed competence) and implementation variables (e.g., curriculum, settings, instructional practices). When these variables are addressed collectively, the complex and multilayered process of developing equitable schools and implementing evidence-based practices that facilitate inclusive education results in students with extensive and pervasive support needs demonstrating unpredicted progress in the acquisition and use of both academic and embedded essential skills across situations that are meaningful in their lives, as well as progress related to self-actualization and autonomy. These variables are discussed, and examples of how opportunities to learn with grade-level peers without disabilities impacted self-actualization and autonomy for one individual with extensive and pervasive support needs, following 15 years of educational segregation followed by 7 years of inclusion at school and in the community.

Keywords: self-actualization, autonomy, self-determination, equitable education, opportunities to learn, access, content, practices, essential skills, Universal Design for Learning (UDL), Multi-Tiered Systems of Support (MTSS), peer supports, personalized learning

WPŁYW MOŻLIWOŚCI NAUKI Z UCZNIAMI BEZ NIEPEŁNOSPRAWNOŚCI NA PROCES SAMOREALIZACJI I AUTONOMIĘ UCZNIÓW ZE ZNACZNĄ I TRWAŁĄ POTRZEBĄ WSPARCIA

Abstrakt

Edukacja inkluzyjna zawiera w sobie zarówno konstrukty teoretyczne (np. najmniej ryzykowne założenie, założenie kompetencji), jak i zmienne wdrożeniowe (np. program nauczania, otoczenie, praktyki instruktażowe). Jeśli zmienne te są rozpatrywane razem, wyłania się złożony i wielowarstwowy proces rozwoju szkół włączających. Dodatkowo, istnieje proces wdrażania praktyk opartych na badaniach naukowych, które pomagają uczniom z potrzebą wsparcia. Pomoc ta owocuje niespodziewanym postępem w nabywaniu oraz wprowadzaniu w życie nowych umiejętności, a także rozwojem procesów samorealizacji i autonomii. Wspomniane zmienne są opisane na przykładzie historii osoby z niepełnosprawnościami, która przez 15 lat uczyła się w odosobnieniu, a przez kolejne 7 – z rówieśnikami, uczestnicząc w życiu społeczności. Różnica ta miała znaczące przełożenie na proces samorozwoju oraz nabywania autonomii przez opisaną uczennicę.

Słowa kluczowe: samorealizacja, autonomia, determinacja, edukacja inkluzyjna, możliwości uczenia się, treść, praktyki, niezbędne umiejętności, Universal Design for Learning – UDL (Powszechne Ramy Edukacyjne), Multi-Tiered Systems of Support – MTSS (Wielopoziomowe Systemy Wsparcia), wsparcie rówieśnicze, personalizowane uczenie się

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO”
CNS nr 3(49) 2020, 53–62

ISSN 1734-5537
DOI: 10.5604/01.3001.0014.3575

PATRICIA O’BRIEN*

CROSSING THE HIGHER EDUCATIONAL DIVIDE FOR PEOPLE WITH INTELLECTUAL DISABILITY

Introduction

This article arose as a result of invitation from the Maria Grzegorzewska University to look into the unity in diversity as an important aspect of inclusive education. Phenomenon of disability in the wider areas is a multi-layered concept involving personality, self-actualization, responsibility, safety, and autonomy. In this article different models of inclusion of students with intellectual disability experiencing university life are outlined. A rationale is given for selecting full inclusion such as within *uni 2 beyond* – an initiative at the University of Sydney. Challenges regarding making such initiatives fully inclusive are covered leading to a call for an international network to be set up for all stakeholders of inclusion within university settings.

Background to inclusion within university settings

The title for my article was *Crossing the higher educational divide for people with intellectual disability,* the content of which is now expanded within this article. The article is set within the context of Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) which reinforces that all persons with disabilities have the right to an inclusive educational system. The CRPD did not arise in isolation but reflected earlier international influences, such as, the Civil Rights movement of the 1960’s (Janken, 2010), where Rosa Parks sat in the front of the bus as part of the Montgomery Bus Boycott for the rights of African Americans to be recognised;

---

* Patricia O’Brien (https://orcid.org/0000-0001-6890-2447); University of Sydney, Camperdown NSW 2006, Australia; tel. +61 02 90363600; e-mail: patricia.obrien@sydney.edu.au

another influence was that of Legal Class Suits to close institutions that can be traced back to theorists who focused on the lack of humanity where people with disabilities were congregated together in large residential settings (Blatt, Kaplan, 1974; Wolfensberger, 1972, 1983); another major influence was the parent movement arising from the advocacy of family members wanting their sons and daughters with disability to gain equal opportunity, with education being one of the major areas of their focus (Temby, O’Brien, 2019). With respect to education the 1970’s saw the start of legislation being introduced across the western world enabling all children with disabilities to have a right to education, ameliorating prevalent attitudes that children with moderate, severe and profound disabilities were considered to be in educable (Keogh, 2007). Two decades on into the 1990’s inclusive educational pioneers saw the opportunity for further advancement in the provision of equal educational opportunity where students sat beside their same aged peers within mainstream settings (Ainscow, 1997, 1999, 2005). As a result, the right to *inclusive education* was born with children with disabilities across early childhood, primary and secondary school settings, starting to be educated in the same settings as their peers without disabilities. The right of choice for family members to choose between special and inclusive education for their sons and daughters was no longer a concept but had become a reality, aided by such statements as Salamanca (UNESCO, 1994) that called for inclusion to be the norm and more recently the CRPD in 2006 with its foundational emphasis on inclusion. However, crossing the divide between secondary to university education has needed a depth of understanding to counteract how students with intellectual disability have been shut out of university life for lack of linguistic, logical and mathematical skills. Howard Gardner (1983, 1993) through his theory of multiple intelligences has suggested that we have been asking the wrong question, not *how smart are you* but *how are you smart*? He argues that there are many forms of intelligence, such as, being music smart, people smart, word smart, logic smart, nature smart, body smart and picture smart. The theory of multiple intelligences has shifted our thinking away from the normal curve and replaced it with an abundance of intelligences making it easier to bridge this chasm between the finish of secondary schooling and opportunities within university settings for students with intellectual disability.

Models of inclusion within university setting

My first experience of inclusive education for students with intellectual disability within a university setting arose from the birth of my granddaughter in England who was diagnosed with Rett Syndrome, a neurological condition. Evie is now 18. In the early 2000’s after her diagnosis I looked for work in Europe to move from New Zealand so that my husband and I could be closer in providing support for Evie and the family. As the luck of the Gods would have it I was appointed in 2004 to Trinity College Dublin to set up the National Institute of Intellectual Disability (NIID) where we developed the first accredited qualification for students with intellectual disability within a university setting across Europe, the *Certificate in Contemporary Living* (CCL) (O'Brien et al., 2008; O'Brien et al., 2009). The CCL comprised both core and elective units, with the core units including: Written and Oral Communication, Mathematics and Financial Management, Information and Communication Technology, and Inclusive Studies and Research. This latter unit gave students a choice of undertaking a course from the undergraduate offerings of the University. The CCL was a great success with students graduating in the same hall as famous others that had gone before them: Oscar Wilde, Jonathan Swift and Mary Robinson. All Ireland celebrated with the students. They had succeeded in showing the world that the last frontier of inclusion for students with intellectual disability of gaining a university qualification had been broken through.

Reaction from the students and staff to the outcomes of being and becoming university students at Trinity College Dublin was positive as outlined below:

> *Our mentors are not treating us like we have disability. They are treating us more like ordinary people… they have not got a disability and we have got disabilities so like, they don't treat you like a kid* (Student voice, O'Brien et al., 2009, p. 290).

> *What I like about the course is where we learn different things, like we get to sit in on mainstream lectures… I like everything… talking about different issues… also I like International Awareness and now the course is running I like the lot and learning new things* (Student voice, O'Brien et al., 2009, p. 290).

> *I am more independent. I am not reliant on my parents, I have great support. I am really getting more independence and it is great … and I meet people and at 31 I am ready to move on and get a life of my own* (Student voice, O'Brien et al., 2009, p. 290).

Then from a lecturer perspective, Barrie O'Connor, John Kubiak, Deborah Espiner and Patricia O'Brien (2012, p. 250) spent time in conversation with lecturing staff from across the university who commented on the CCL program as "an inherently morally worthwhile thing to do to be inclusive and to give opportunities to students who might otherwise not get them". Another lecturer remarked, "I think it's an excellent thing to be more inclusive generally with the students" (O'Conor et al., p. 250).

In 2009 I returned to Australia to take up a position as Director, Centre for Disability Studies, affiliated with the University of Sydney, where I started to consider how to introduce students with intellectual disability into the life of the campus. Apart from setting up a steering committee I reflected on what would be the best model? Three types of models had been identified by Debra Neubert, M. Sheril Moon, Meg Grigal and Vanessa Redd (2001): Segregated, Hybrid and Full Inclusion. Segregated one was where students were on the university campus but learned as a student group without any interaction with other undergraduate students; hybrid was where students learned both within classes set up for people with learning disabilities as well as attended mainstream university classes; full inclusion meant that the students were sitting in mainstream lectures with peers who did not have a disability participating in the same university course.

To date the efficacy of these approaches has only been studied independent of one another, with the need for a major comparative international research study. My own world view at the time of choosing a model to introduce students with intellectual disability into Sydney University was influenced by a visit to the University of Sydney by Bruce Uditsky, Inclusion Alberta and Professor Anne Hughson, University of Calgary, who had been instrumental in developing a fully inclusive post-secondary model that had been adopted and funded by the state of Alberta and introduced across all its universities (Uditsky, Hughson, 2012). Their writing in this area had indicated that students with intellectual disability who experience university life through a fully inclusive model benefit both economically and socially (Hughson, Uditsky, 2019). Their work coupled with my own observations, later confirmed by Niamh Lally, Patricia O'Brien and Robert Gilligan (2019), that a hybrid approach did not easily facilitate transition into employment, higher education settings, or sustain university friendship. This led to the Canadian model of full inclusion being introduced as a pilot program on the University of Sydney campus. The choice of this model was premised on the assumption that it would not only promote lifelong learning but sustain social connections.

My own experience of working with people with intellectual disability is that the need for social connection if not met can lead to loneliness which can be manifested in behavioural issues (Gilmore, Cuskelly, 2014). The pilot programme that became known as *uni 2 beyond* supported students with intellectual disability to attend lectures and socialise within the university. This was facilitated by the co-ordinating staff of the Centre for Disability Studies but was also dependent upon each student being introduced to both an academic and social peer mentor. Academic mentors attended the same course giving content support both prior to the lectures and afterwards, while the social mentor arranged to share lunches, coffee, university club activities as well as activities beyond the university. Research on *uni 2 beyond* found that the students with intellectual disability were perceived to have increased both in confidence and independence (Rivas et al., 2012; Gadow, MacDonald, 2019), with their peer mentor relationships being of prime importance. A recent study captured the stories of students involved in the initiative being told to and interpreted by two members of the Centre for Disability Studies (CDS) inclusive research network (Kelly, Wagstaff, 2018). These stories reflected how increased confidence and independence gained by *uni* 2 *beyond* students was linked to feeling more accepted as evidenced by their mentor relationships.

The CDS inclusive research network began in 2012 where co-researchers with intellectual disability partnered with university co-researchers in undertaking research projects that people with intellectual disability saw as having meaning for their lives (Walmsley, Johnson, 2003). This approach to research is relevant when considering *concept* versus *reality*, as hearing the voice of students with intellectual disability through being interviewed by their disabled peers is likely to capture more closely the reality of the concept of inclusion (O'Brien, McConkey, García-Iriarte, 2014).

The model that has been implemented at the University of Sydney where students are fully included can bereferred to an auditing model where students participate in lectures and tutorials,as non-credit students. They are encouraged to complete academic work to the level that suits their strengths, abilities and interests and receive a Certificate of Completion issued by CDS at the end of the 2-year program (Gadow, MacDonald, 2019).

Apart from mentor support, family support is also critical with families being invited to attend a family support group twice a year, as well as six monthly formal presentations by the students on a specific topic that has captured their interest in the lecture series they have attended. Family feedback as reported in a follow up study at the end of the two-year program in 2018 identified several areas that families believed had impacted positively their sons and daughters through being fully included at the university. These covered increased independence; higher expectations by the family on what their son or daughter, brother or sister could achieve; acknowledgement that families could and needed to step back from being involved in all decision making; and acceptance by university peers. This last point connects with my premise that being fully included would lead to social connection and not only to academic knowledge. Family members raised that the life at university for their sons and daughters brought with it"a more open type of acceptance from their university peers in comparison with their experience of the secondary schooling system" (O'Brien, Murray, 2019, p. 201). The following quote sums up that university life focused less on the person's disability.

> *One of the great things about the programme was total inclusion, and that disability was not in the language, which I think makes it such a big success for the students because they've lived a world of disability and it's forever in their mind to come into this environment and not to be labelled, be part of the university* (A family member perspective, O'Brien, Murray, 2019, p. 199).

International perspective on inclusion

In 2019 a group of international colleagues who had been instrumental in opening up universities to students with intellectual disability collaborated on a book entitled, *People with intellectual disability experiencing university life:*

Theoretical underpinnings evidence and lived experience (O'Brien, Bonati, Gadow, Slee, 2019). The reader is introduced to inclusive educational programs across several universities, specifically Trinity College Dublin, University of Iceland, University of Calgary, Canada, University of South Carolina, United States, University of Sydney and Flinders University, Australia. Within the respective universities there were variations around how inclusion was interpreted ranging from a hybrid approach to that of full inclusion. The alternative to full inclusion found students attending only a percentage of mainstream courses while other courses were an extension of what students had experienced within their secondary schooling. Specialised courses and activities related to preparation for employment as well as skills for independent living "placed the student back in the world of disability" (O'Brien, Murray, 2019, p. 199). In turn, full immersion brought with it what John O'Brien (2019, p. 272) described as "typical and valued expectations and experiences of student life as the primary medium for their growth and development". Regardless of the model adopted, these universities have broken down the barriers that have existed for centuries associated with shutting out students with intellectual disability. Their innovation has begun to build pathways for students with intellectual disability to cross into higher education post-secondary schooling. What needs to be safeguarded against ,however, is that a divide does not become entrenched philosophically between universities about what constitutes inclusion at this level. Patricia O'Brien, Michelle Bonati, Friederike Gadow and Roger Slee (2019) have called for a worldwide network to support one another in setting up postsecondary initiatives for people with intellectual disability. Their call is best summed up by them in the following way,

> *To ensure that such initiatives follow values underpinned by human rights and inclusion, we believe that an international network, consisting of peers and stakeholders who champion inclusive education at the tertiary level should be formed... It would support one another to navigate common obstacles, such as rigid university structures and polices, barriers to funding and overcoming resistance from key decision makers* (O'Brien, Bonati, Gadow, Slee, 2019, p. 285).

O'Brien and Bonati (2019) have expanded on what they see as being needed for inclusive rhetoric to become reality and also have called for collective action to ensure that the following elements are in place, starting with choice of model. They see something as fully inclusive if it reflects the CRPD' s principle of full participation (United Nations, 2006). Funding also needs to be secured through government and recurrent subsidies otherwise such initiatives run the risk of being "one off". Also, of challenge to universities is admission to non-accredited courses requiring alternative entry standards and accessible assessment requirements. Here advocacy is needed to resist students being directed to vocational courses outside of university offerings. Similarly, without government subsidies university support services may not be officially available to students who do not meet entry requirements. Apart from lack of support services inclusive of learning and teaching aid, graduation policies are likely not to approve students who have completed an inclusive initiative to walk across the same graduation stage and at the same time as all other students.

Such barriers will need the support of an international network, if inclusive practice within university settings is to be grounded sustainably. Universal human rights legislation spoke about the *unity in diversity* regarding discrimination and lack of distribution of resources (Birkenbach, 2009). However, often general limitation clauses in such can argue that in certain circumstances the implementation of such rights can be interpreted as both unreasonable and demonstrably unjustifiable (e.g., Queensland Government, 2018). Importantly, Nancy Roseneau's work (2004) on relational social justice provides another lens through which to promote acceptance of students with intellectual disability within university settings. She focuses on the connection between mind and heart and sees the development of relationships as a human right, levelling the relational playing field between those in hierarchical positions with those who are stigmatised as different. Narratives of the outcomes for students with intellectual disability experiencing university life are rich in documenting relational social justice between mentors and students as well as lecturers and students (Messenger, Lindsay, Rillota, 2019; Montissol, Cook, 2019; Turley, 2019; Walker, MacDonald, 2019).

Conclusion

In closing the article, I would like to return to my opening comments that came from recognising inclusion as a multi-layered concept involving personality, self-actualisation, responsibility, safety and autonomy. Research on the outcomes for students with intellectual disabilities attending university is in its early stages. However, published research associated with descriptions of programmes and stories of students who have attended university, and also ongoing research (O'Brien, Bonati, Gadow, Slee, 2019) suggest that students grow in responsibility, confidence and demonstrate self-determination and autonomy reflecting the subthemes of the conference. Further investigation of the drivers and facilitators to inclusion within university settings for students with intellectual disability, particularly international, would shed light on what can cross the divide and sustain the encouraging outcomes. The positive effects for those with disability can be observed specifically in the following areas: personality, self-actualisation, responsibility, safety and autonomy.

References

Ainscow, M. (1997). Towards inclusive schooling. *British Journal of Special Education*, *24*(1), 3–6. doi: 10.1111/1467-8527.00002.

Ainscow, M. (1999). *Understanding the development of inclusive schools*. London: Falmer.

Ainscow, M. (2005). Developing inclusive education systems: What are the levers for change? *Journal of Educational Change*, *6*(2), 109–124. doi: 10.1007/s10833-005-1298-4.

Bickenbach, J. (2009). Disability, culture and the Unconvention. *Disability and Rehabilitation*, *31*(14), 1111–1124. doi: 10.1080/09638280902773729.

Blatt, B., Kaplan, F. (1974). *Christmas in purgatory*. Syracuse, NY: Human Policy Press.

Gadow, F., Macdonald, J. (2019). Scope, Challenges and Outcomes of an Inclusive Tertiary University Initiative in Australia. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: Theoretical underpinnings, evidence and lived experience* (pp. 129–140). Boston: Brill Sense Publication.

Gardner, H. (1983). *Frames of mind: The theory of multiple intelligences*. New York: Basic Books.

Gardner, H. (1993). *Multiple intelligences: The theory in practice*. New York: Basic Books.

Gilmore L., Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: an explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, *11*, 192–199. doi: 10.1111/jppi.12089.

Hughson, E.A., Uditsky, B. (2019). 30 years of inclusive post-secondary education: Scope, challenges and otucomes. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 51–68). Boston: Brill Sense Publication.

Janken, K.R. (2010). *The civil rights movement: 1919–1960's*. http://nationalhumanitiescenter.org/tserve/freedom/1917beyond/essays/crm.htm.

Kelly, J., Wagstaff, S. (2018). *Photo Tales*. Conference presentation at the ASID Conference, 14–16 November, Gold Coast Convention Centre, Queensland.

Keogh, B.K. (2007). Celebrating PL 94-142: The Education of All Handicapped Children Act of 1975. *Issues in Teacher Education*, *16*(2), 65–69.

Lally, N., O'Brien, P., Gilligan, R. (2019). What comes next? Sustaining outcomes post-university. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 219–228). Boston: Brill Sense Publication.

Messenger, K.A., Lindsay, L., Rillota, F. (2019). Journey "up the hill" to my hopes and dreams. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 173–178). Boston: Brill Sense Publication.

Montissol, L., Cook, A.L. (2019). Expanding pathways to university: Student experience of inclusive programming. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 185–188). Boston: Brill Sense Publication.

Neubert, D.A., Moon, M.S., Grigal, M., Redd, V. (2001). Post-secondary education practices for individuals with mental retardation and other significant disabilities. A review of the literature. *Journal of Vocational Rehabilitation*, *16*, 155–168.

O'Brien, J. (2019). Exploring the growing edges of inclusion. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 267–275). Boston: Brill Sense Publication.

O'Brien, P., Bonati, M. (2019). From institutionalisation to inclusion. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 3–20). Boston: Brill Sense Publication.

O'Brien, P., Bonati, M., Gadow, F. Slee, R. (2019). *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience.* Boston: Brill Sense Publication.

O'Brien, P., McConkey, R., García-Iriarte, E. (2014). Co-researching with people who have intellectual disabilities: Insights from a national survey. *Journal of Applied Research in Intellectual Disability*, *27*(1), 65–75. doi: 10.1111/jar.12074.

O'Brien, P., Murray, R. (2019). A conversation with families of young people with intellectual disability for whom the dream of attending university came true. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 195–204). Boston: Brill Sense Publication.

O'Brien, P., Shevlin, M., O'Keeffe, M., Fitzgerald, S., Curtis, S., Kenny, M. (2009). Opening up a whole new world for students with intellectual disabilities within third level setting. *British Journal of Learning Disabilities*, *37*(4), 285–292. doi: 10.1111/j.1468-3156.2009.00584.x.

O'Brien, P., Shevlin, M., O'Keeffe, M., Kenny, M., Fitzgerald, S., Edwards, S., O'Shea, A. (2008). *Inclusive education: a tertiary experience and transferable model? Lessons learned from the Certificate in Contemporary Living.* Programme. Report prepared for the National Disability Authority by the National Institute for Intellectual Disability (pp. 1–97). National Institute for Intellectual Disability, Trinity College Dublin.

O'Connor, B., Kubiak, J., Espiner, D., O'Brien, P. (2012). Lecturer responses to the inclusion of students with intellectual disabilities auditing undergraduate classes *Journal of Policy and Practice in Intellectual Disabilities*, *9*(4), 247–256. doi: 10.1111/jppi.12009.

Queensland Government. (2018). Human Rights Bill 2018. https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2018/5618T1768.pdf.

Rivas, M., Doukakis, E., O'Brien, P., Lally, N., Gadow, F., Knox, M., Mills, A. (2012). *Inclusive education at the University of Sydney. Tertiary education for people with intellectual disability (Final report).* Sydney: Centre for Disability Studies.

Roseneau, N. (2004). The feeling of power and the power of feelings: theorising in everyday life. *Mental Retardation*, *42*(4), 263–271. doi: 10.1352/0047-6765(2004)42<263:TFOPAT>2.0.CO;2.

Temby, E., O'Brien, P. (2019). *Ethel's story: Seeing red, From anger to inclusion*. Melbourne: STAR, Inc.

Turley, M. (2019). My name is Margaret and this is my story. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 189–194). Boston: Brill Sense Publication.

Uditsky, B., Hughson. E. (2012). Inclusive postsecondary education– An evidence-based moral imperative. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(4), 298–302. doi: 10.1111/jppi.12005.

UNESCO. (1994). *World conference on special needs education: Access and quality (Final report).* Salamanca: UNESCO and the Ministry of Education and Science, Spain.

United Nations. (2006). *Convention on the rights of person with disabilities*. New York: UN General Assembly.

Walker, S., MacDonald, J. (2019). My life as a university student. In P. O'Brien, M. Bonati, F. Gadow, R. Slee (Eds.), *People with intellectual disability experiencing university life: theoretical underpinnings, evidence and lived experience* (pp. 179–184). Boston: Brill Sense Publication.

Walmsley, J., Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present and Futures.* London: Jessica Kingsley Publishers.

Wolfersberger, W. (1972). *Normalization: The Principle of Normalization in Human Services*. Toronto, Canada: National Institute on Mental Retardation.

Wolfensberger, W. (1983). Social role valorisation, A proposed new term for the principle of normalisation. *Mental Retardation*, *21*(6), 234–239.

CROSSING THE HIGHER EDUCATIONAL DIVIDE FOR PEOPLE WITH INTELLECTUAL DISABILITY

Abstract

In this paper university life for people with intellectual disability will be described across international boundaries, with a particular emphasis on the model of inclusion at the University of Sydney. How the latter model was developed, researched and implemented will be included in the presentation followed by a critique of positive and challenging outcomes reported by universities that have opened their doors to students with intellectual disability. The student voice and that of lecturing staff will be digitally heard within the presentation exemplifying how unity in diversity has enabled students to self-actualize, through increasing their responsibilities and autonomy as adult learners. In keeping with the philosophy of the Maria Grzegorzewska University it will be argued that inclusion at the higher education level means a "good university for all". Within the presentation the work of the Inclusive Research Network (IRN) at the Centre for Disability Studies will illustrate how in real life both co-design and co-researching between people with intellectual disabilities and people without can add to the concept of both building unity across diversity and crossing the divide.

Keywords: people with intellectual disability, the model of inclusion at the University of Sydney, self-actualize, responsibilities, autonomy, adult learners, the Inclusive Research Network (IRN), the Centre for Disability Studies, co-design and co-researching between people with intellectual disabilities and people without

POKONYWANIE PODZIAŁÓW NA POZIOMIE SZKOLNICTWA WYŻSZEGO DLA LUDZI Z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ

Abstrakt

Artykuł opisuje życie uniwersyteckie ludzi z niepełnosprawnością intelektualną na świecie, a w szczególności skupia się na modelu inkluzyjnym na Uniwersytecie w Sydney. Artykuł przedstawia, jak ów model był stworzony, zbadany i wprowadzony w życie. Następnie opisane zostają pozytywne rezultaty, ale także i wyzwania, z jakimi mierzą się uniwersytety, które otworzyły swoje drzwi dla osób z niepełnosprawnością intelektualną. Wybrzmi głos zarówno studentów, jak i wykładowców, którzy podkreślą, w jaki sposób jedność w różnorodności umożliwiła studentom samorealizację poprzez zwiększanie ich własnej odpowiedzialności i autonomii. W zgodzie z filozofią Akademii Pedagogiki Specjalnej im. Marii Grzegorzewskiej, artykuł sugeruje, że integracja na poziomie szkolnictwa wyższego oznacza „dobry uniwersytet dla wszystkich". Prace Sieci Badań Integracyjnych (Inclusive Research Network, IRN) w Centrum Studiów nad Niepełnosprawnością (Centre for Disability Studies) obrazują, w jaki sposób w życiu codziennym zarówno wspólne planowanie, jak i prowadzenie badań przez ludzi z niepełnosprawnościami z ludźmi bez niepełnosprawności może przyczynić się do idei budowy jedności w różnorodności oraz pokonywania podziałów.

Słowa kluczowe: ludzie z niepełnosprawnością intelektualną, model inkluzyjny na Uniwersytecie w Sydney, samoaktualizacja, odpowiedzialność, autonomia, dorośli studenci, Sieć Badań Inkluzyjnych (Inclusive Research Network, IRN), Centrum Badań nad Niepełnosprawnością (Centre for Disability Studies), wspólne badania naukowe prowadzone przez ludzi z niepełnosprawnością intelektualną i bez niepełnosprawności

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO”
CNS nr 3(49) 2020, 63–78

ISSN 1734-5537
DOI: 10.5604/01.3001.0014.3576

BEATA SZABAŁA*

FUNKCJONOWANIE ZAWODOWE OSÓB Z NIEPEŁNOSPRAWNOŚCIĄ WZROKOWĄ – UWARUNKOWANIA I MOŻLIWOŚCI WSPIERANIA

Wprowadzenie

Praca jest definiowana jako „celowe i zorganizowane działanie, w wyniku którego przekształca się rzeczywistość (przedmioty, materiały, wiadomości, informacje), celem uzyskania nowych dóbr (wartości), służących zaspokojeniu różnych potrzeb społeczeństwa. Polega ona na wykonywaniu określonych zadań, w wyniku których uzyskuje się te dobra” (Majewski, 2004, s. 23). Anthony Giddens (2006) podkreśla, że praca obejmuje zajęcia o charakterze umysłowym i fizycznym, zmierzające do tworzenia dóbr i świadczenia usług ukierunkowanych na realizację ludzkich potrzeb. Wprawdzie praca zajmuje istotne miejsce w życiu każdego człowieka, lecz stosunek do niej poszczególnych ludzi jest zróżnicowany. Podczas, gdy jedni traktują ją autotelicznie – jako wartość samą w sobie, inni postrzegają instrumentalnie, tzn. jako szansę na dostarczenie środków materialnych do realizacji potrzeb życiowych. Są też ludzie, których stosunek do wykonywanej pracy ma charakter punitywny, co oznacza, że utożsamiają ją z przykrą koniecznością życiową, a nawet złem, które należy w miarę możliwości eliminować (Kozek, 1994, za: Rutkowska, Filipek, 2008).

Nie jesteśmy w stanie przecenić znaczenia pracy jako naturalnej formy aktywności i podstawowego czynnika rozwoju dorosłego człowieka, także doświadczającego niepełnosprawności. Trzeba jednak zdawać sobie sprawę z tego, że rolę pracy zawodowej w życiu osób z niepełnosprawnością należy rozpatrywać wieloaspektowo. Właściwie dobrana praca ma znaczenie terapeutyczne, które ujawnia się w następujących zakresach:

---

* Beata Szabała (https://orcid.org/0000-0002-1154-4690); Uniwersytet Marii Curie-Skłodowskiej, pl. Marii Curie-Skłodowskiej 5, 20-400 Lublin; tel. +48 81 5376336;
e-mail: szabalabeata@poczta.umcs.lublin.pl

- zapewnienie warunków bytowych – stwarzanie okazji do uzyskania pełnej lub znacząco zwiększonej niezależności ekonomicznej, czego efektem jest odciążenie systemów ubezpieczeń społecznych i opieki socjalnej (Kobus-Ostrowska, 2018);
- stymulowanie aktywności życiowej – transfer aktywności z obszaru zawodowego na życiowy przeciwdziała bierności w kontaktach społecznych, powoduje poszerzenie grupy znajomych, przyjaciół (Majewski, 2008) oraz wdraża do podejmowania decyzji i kierowania własnym życiem (Stańko, 2009);
- rozwijanie strategii radzenia sobie – mobilizowanie wysiłków zmierzających do pokonywania trudności, poszukiwania innego sposobu wykonywania zadania, przełamywania barier emocjonalnych związanych z otrzymywaniem porad u innych (Majewski, 2008);
- poprawa stanu zdrowia – umożliwianie powrotu do częściowej lub pełnej sprawności, kompensowanie ograniczeń wynikających z niepełnosprawności, czego następstwem jest wyższa jakość życia (Kwitok, 2017);
- nadawanie życiu sensu – praca staje się główną wartością, dla której warto żyć, pozwalającą na ustalanie celów i regulującą aktywność osoby z niepełnosprawnością, szczególnie samotnej (Rutkowska, Filipek, 2008);
- kształtowanie określonych aspektów osobowości – zwiększanie poczucia własnej wartości, stabilizacja samooceny, rozwijanie kreatywności i obniżanie lęku przed nowymi zadaniami (Kirenko, Sarzyńska, 2010);
- stwarzanie warunków do samorealizacji – rozwijanie aspiracji życiowych i zawodowych, zapewniających osiągnięcie pewnego statusu zawodowego oraz społecznego (Stańko, 2009);
- zmiana wizerunku społecznego – postrzeganie osób z niepełnosprawnością nie przez pryzmat istniejącej niepełnosprawności, lecz jako ludzi posiadających określone kompetencje zawodowe, prawa i obowiązki (tamże);
- wzmacnianie integracji społecznej – kształtowanie poczucia integracji z otaczającym środowiskiem społecznym, zwłaszcza środowiskiem pracowniczym, poczucia przynależności, bycia jednym z wielu innych pracowników (Majewski, 2008).

Terapeutyczna rola pracy w życiu osób z niepełnosprawnością jest szeroko analizowana w literaturze przedmiotu, co starano się syntetycznie ująć we wprowadzeniu. Biorąc pod uwagę zatrudnienie wspomnianej grupy, niezwykle istotne jest to, że kwestie dotyczące funkcjonowania zawodowego mają swoje odzwierciedlenie w wielu dokumentach prawnych. Ideę włączenia osób z niepełnosprawnością do aktywnego uczestnictwa w różnych obszarach życia, a więc także zawodowego, podkreślają liczne dokumenty o charakterze międzynarodowym, np. Dyrektywa Rady Unii Europejskiej 2000/78/EC, Deklaracja Madrycka (2002), Wspólnotowy Program Przeciwdziałania Społecznemu Wykluczeniu na lata 2002–2006, oraz krajowym, np. Konstytucja RP, Karta Praw Osób Niepełnosprawnych (Kobus-Ostrowska, 2018). Zważywszy jednak na to, że w Polsce praca jest wartością trudno dostępną dla wielu ludzi, również możliwości zatrudnienia osób z niepełnosprawnością są w pewnym zakresie ograniczone. Istnieje jednak w tym obszarze duże zróżnicowanie. Dotychczasowe analizy dotyczące funkcjonowania zawodowego osób z niepełnosprawnością prezentują szeroki zakres uwarunkowań. Wśród omawianych znajdują się czynniki odnoszące się do wszystkich rodzajów niepełnosprawności, np. socjodemograficzne, społeczne, oraz wynikające z istoty danej niepełnosprawności. Z taką sytuacją mamy do czynienia m.in. w przypadku niepełnosprawności wzrokowej, której poświęcono prezentowane opracowanie. Skupiono się w nim na analizie czynników socjodemograficznych, medycznych, posiadanych umiejętnościach, zasobach podmiotowych i społecznych, by w ten sposób przedstawić możliwie szeroki zakres uwarunkowań funkcjonowania zawodowego osób niewidomych i słabowidzących. (W artykule zastosowano pisownię łączną, zgodną z sugestiami językoznawców. Natomiast w tytułach prac źródłowych zachowano pisownię oryginalną). Ich syntetyczne ujęcie ma nie tylko znaczenie dla teorii pedagogiki specjalnej, gdyż wzbogaca stan wiedzy, lecz także dla praktyki, ponieważ wskazuje na obszary wymagające oddziaływań terapeutycznych. W tym kontekście zwrócono uwagę na możliwości wspierania funkcjonowania zawodowego osób z niepełnosprawnością wzrokową.

Uwarunkowania funkcjonowania zawodowego osób z niepełnosprawnością wzrokową

W dostępnych opracowaniach zwraca się uwagę na czynniki socjodemograficzne, które mogą wyznaczać funkcjonowanie osób z niepełnosprawnością wzrokową w analizowanym obszarze (m.in. La Grow, 2004; Lee, Park, 2008; Darensbourg, 2013). Jednym z nich jest wiek. Yuh Jang ze współpracownikami (2013), poddając eksploracji osoby niewidome i słabowidzące (N = 313; średnia wieku: 37,86 lat), zauważyli, że młodszy wiek badanych istotnie wiąże się z aktywnością zawodową. Niestety autorzy nie wyjaśnili, jak rozumieją młodszy wiek. Bardziej precyzyjna jest eksploracja zrealizowana przez Stevena J. La Growa (2004), który ujawnił, diagnozując czynniki związane z funkcjonowaniem zawodowym osób niewidomych i słabowidzących (N = 150; wiek: 18–63 lata), że wskaźniki pracujących ustalone wśród młodszych respondentów, których wiek mieści się w przedziałach 18–32 lata oraz 33–47 lat (odpowiednio: 42,5% i 45,7%), są wyższe od wskaźnika ustalonego wśród respondentów reprezentujących starsze grupy wiekowe, tj. powyżej 47. roku życia (34,2%). Z kolei Brandi L. Darensbourg (2013), realizując badania w bardzo licznej grupie osób niewidomych i słabowidzących (N = 3610; wiek: 18–65 lat), zauważył, że wiek 36 lat lub poniżej jest najsilniejszym predyktorem ich zatrudnienia. Poza tym w literaturze przedmiotu można także odnaleźć eksploracje wskazujące na nieistotną rolę wieku w kontekście aktywności osób niewidomych i słabowidzących w obszarze zawodowym (Capella-McDonnall, 2005; Lee, Park, 2008; Bell, Mino, 2015). Równie niejednoznaczna sytuacja dotyczy udziału zmiennej płci. Ik S. Lee i Soo K. Park (2008), poddając badaniom 874 osób niewidomych i słabowidzących (wiek: 18–65 lat), stwierdzili, że płeć jest ważną zmienną wiążącą się z ich zatrudnieniem, przy czym mężczyźni istotnie częściej niż kobiety są aktywni zawodowo. Verena R. Cimarolli i Shu-wen Wang (2006), realizując eksplorację w grupie 97 osób niewidomych i słabowidzących (wiek: 25–64 lata), zauważyły, że wśród pracujących jest znacznie więcej mężczyzn, natomiast wśród niepracujących – kobiet. Podobne prawidłowości ustalili także La Grow (2004) oraz Darensbourg (2013), podczas gdy inni autorzy wskazali na brak powiązań pomiędzy płcią a zatrudnieniem badanych niewidomych i słabowidzących (m.in. Capella-McDonnall, 2005; Shaw, Gold, Wolffe, 2007; Bell, Mino, 2015; Jang i in., 2013).

Bardziej spójny obraz funkcjonowania zawodowego osób z niepełnosprawnością wzrokową zarysowuje się w pracach analizujących udział takich zmiennych socjodemograficznych, jak wykształcenie (m.in. La Grow, 2004; Bell, Mino, 2015) i wcześniejsze doświadczenia zawodowe (m.in. Capella-McDonall, Crudden, 2009; Joseph, Robinson, 2012). La Grow (2004), wykazał, że respondenci niewidomi i słabowidzący legitymujący się wykształceniem średnim częściej podejmują pracę niż respondenci bez wykształcenia (odpowiednio: 70,4% i 45,8%). Z kolei Lee i Park (2008) ujawnili, że posiadanie co najmniej wykształcenia średniego zawodowego jest predyktorem zatrudnienia badanych osób niewidomych i słabowidzących. Interesujące są ustalenia będące efektem pracy Edwarda C. Bella i Natalii Mino (2015), którzy zrealizowali eksplorację w licznej grupie osób niewidomych i słabowidzących (N = 1056; wiek: 18–70 lat). Autorzy zauważyli, że największe szanse na znalezienie pracy mają ci badani z niepełnosprawnością wzrokową, którzy legitymują się wykształceniem prawniczym lub tytułem doktora (80%). W następnej kolejności znalazły się osoby z tytułem magistra (65%) bądź licencjata (59%). Natomiast najmniejsze szanse na aktywne funkcjonowanie w analizowanym w obszarze mają badani, którzy ukończyli wyłącznie szkołę średnią czy też zawodową (36%). Poza tym również inni autorzy wykazali, że możliwość zatrudnienia wzrasta wraz z poziomem wykształcenia osób niewidomych i słabowidzących (Cimarolli, Wang, 2006; Shaw, Gold, Wolffe, 2007; Giesen, Cavenaugh, 2012).

Uwzględniając rolę wcześniejszych doświadczeń zawodowych, stwierdza się, że są one pozytywnie powiązane z aktywnością zawodową osób z niepełnosprawnością wzrokową, o czym świadczy eksploracja Michele E. Capella-McDonall i Adele Crudden (2009), przeprowadzona wśród 41 młodych osób niewidomych i słabowidzących (wiek: 15–21 lat). Autorki ustaliły, że badani z doświadczeniem zawodowym częściej podejmowali pracę niż badani pozbawieni go (odpowiednio: 58,3% i 23,5%). Wniosek ten koresponduje z doniesieniami, z których wynika, że doświadczenie zawodowe zdobyte w okresie dorastania motywuje młodych niewidomych i słabowidzących do poszukiwania bardziej wymagających i odpowiedzialnych prac. Umożliwia bowiem przyswajanie konkretnej wiedzy na temat środowiska pracy oraz rozwijanie kompetencji niezbędnych do efektywnego funkcjonowania w miejscu pracy, np. podejmowanie decyzji, tempo wykonywania zadań (Joseph, Robinson, 2012). Poza tym autorzy ujawnili, że istotnym predyktorem aktywności zawodowej osób z niepełnosprawnością wzrokową jest posiadanie zatrudnienia w momencie jej zdiagnozowania (Capella-McDonall, Crudden, 2009).

Czynniki medyczne tworzą kolejną grupę zmiennych, którą wielu badaczy uwzględniło w prowadzonych eksploracjach. Analiza ich znaczenia dla funkcjonowania zawodowego osób niewidomych i słabowidzących, w porównaniu z kontekstem wyznaczonym przez czynniki socjodemograficzne, prowadzi do bardziej jednoznacznych wniosków, zwłaszcza odnośnie do czasu istnienia niepełnosprawności wzrokowej (Leonard, D'Allura, Horowitz, 1999; La Grow, 2004) oraz występowania dodatkowej niepełnosprawności (La Grow, 2004; Lee, Park, 2008). Robin Leonard, Tana D'Allura i Amy Horowitz (1999), diagnozując czynniki kształtujące zatrudnienie 167 osób niewidomych i słabowidzących (wiek: 18–79 lat), ustalili, że posiadanie wrodzonej niepełnosprawności wzrokowej jest istotnie z nim powiązane, gdyż wyznacza podejmowanie pracy zgodnie z posiadanymi umiejętnościami. Autorzy sugerują, że ważną funkcję pełni system rehabilitacji. Osoby z wrodzoną niepełnosprawnością z racji swojej sytuacji są wcześnie poddawane odpowiednim oddziaływaniom, pozwalającym na zdobycie umiejętności i kompetencji niezbędnych w środowisku pracy, co jednocześnie sprawia, że ich atrakcyjność jako pracowników przewyższa analogiczną będącą udziałem osób, u których niepełnosprawność wzrokowa pojawiła się później. W tym kontekście interesujące wyniki uzyskał La Grow (2004), który badając osoby niewidome i słabowidzące, zauważył, że zdiagnozowani we wczesnym dzieciństwie (do 5. r.ż.) mają większe szanse na zatrudnienie niż zdiagnozowani w wieku 6–39 lat bądź po ukończeniu 40. roku życia. Wskaźniki osób pracujących ustalone dla poszczególnych kategorii wiekowych wynosiły odpowiednio: 44,4%; 27,4%; 25%. Biorąc pod uwagę występowanie dodatkowej niepełnosprawności, autor ujawnił, że respondenci ze złożoną niepełnosprawnością (28,1%) rzadziej są aktywni zawodowo niż respondenci, u których występuje wyłącznie niepełnosprawność wzrokowa (47,7%). Podobne prawidłowości stwierdzono także w innych badaniach (Lee, Park, 2008).

Pewne zróżnicowanie wyników zauważa się, analizując rolę kolejnej zmiennej medycznej, a więc stopnia niepełnosprawności wzrokowej. Wspomniani już Leonard, D'Allura i Horowitz (1999) ustalili, że badani niewidomi częściej niż słabowidzący podejmują pracę. Do podobnych ustaleń doszedł Jang ze współpracownikami (2013), którzy także poddali eksploracji respondentów niewidomych i słabowidzących. Autorzy zauważyli, że wśród zatrudnionych masażystów przeważają osoby niewidome (80%). Z innych prac wynika natomiast, że osoby słabowidzące, w porównaniu z niewidomymi, w większym zakresie są aktywne w obszarze zawodowym. Na przykład Alexander Shaw, Deborah Gold i Karen Wolffe (2007), diagnozując doświadczenia młodych osób niewidomych i słabowidzących związane z zatrudnieniem (N = 328; wiek: 15–30 lat), ujawnili, że słabowidzący niemal dwukrotnie częściej niż niewidomi podejmują pracę (odpowiednio: 36%; 19%). La Grow (2004) wykazał, że wskaźniki zatrudnienia wśród badanych niewidomych i słabowidzących są znacząco zróżnicowane i uzależnione od zachowanej zdolności widzenia. Wynoszą one odpowiednio: 36% dla osób niewidomych i 64% dla osób słabowidzących. Poza tym dostępne są inne doniesienia empiryczne, które wskazują, że respondenci słabowidzący znacząco przewyższają niewidomych pod względem aktywności w obszarze zawodowym (Lee, Park, 2008; Giesen, Cavenaugh, 2012; Darensbourg, 2013).

W literaturze poruszającej problematykę funkcjonowania zawodowego osób z niepełnosprawnością wzrokową akcentuje się znaczenie posiadanych umiejętności, np. w zakresie posługiwania się pismem (m.in. Leonard, D'Allura, Horowitz, 1999; Bell, Mino, 2015). Leonard, D'Allura i Horowitz (1999), ustalili, że wykorzystywanie materiałów drukowanych przez respondentów niewidomych i słabowidzących jako głównego nośnika informacji sprzyja podejmowaniu pracy. Natomiast Ron Ryles (1996), badając osoby niewidome (N = 74; wiek: 18–55 lat), zauważył, że posługiwanie się pismem punktowym jest ważnym predyktorem zatrudnienia. Okazało się, że respondenci wykorzystujący pismo Braille'a jako główny środek przekazu i dostępu do informacji istotnie częściej są zatrudniani niż respondenci będący użytkownikami druku jako pierwotnego medium. Poza tym większe szanse na podjęcie pracy mają osoby znające pismo punktowe od dzieciństwa i posługujące się nim intensywnie jako początkowym nośnikiem informacji. Do podobnych wniosków doszli także Bell i Mino (2015). Autorzy ujawnili, że umiejętność posługiwania pismem Braille'a różnicuje aktywność badanych niewidomych w obszarze zawodowym. Użytkownicy pisma punktowego, w przeciwieństwie do osób nie posługujących się pismem Braille'a, są istotnie częściej zatrudniani. Rolę znajomości pisma punktowego w kontekście analizowanej problematyki akcentują w swoich pracach także inni autorzy (Golub, 2006; Lee, Park, 2008).

Wielu badaczy zawraca uwagę na umiejętności osób z niepełnosprawnością wzrokową w zakresie posługiwania się współczesnymi technologiami komunikacyjnymi i informacyjnymi (m.in. Capella-McDonall, Crudden, 2009) oraz orientację przestrzenną (m.in. Leonard, D'Allura, Horowitz, 1999) jako czynniki zwiększające ich szanse na zatrudnienie. Capella-McDonall i Crudden (2009), ustaliły, że aż 91% aktywnych zawodowo respondentów niewidomych i słabowidzących potrafi efektywnie korzystać ze współczesnych technologii. Szczególnie przydatna jest dobra znajomość obsługi komputera (Lee, Abdullah, Mey, 2011). Li Zhou i współpracownicy (2013), realizując eksplorację wśród 390 osób niewidomych i słabowidzących (wiek: 15–30 lat), stwierdzili, że badani wyżej oceniający swoje kompetencje w tym zakresie, w porównaniu z badanymi niżej oceniającymi swoje umiejętności, istotnie częściej podejmują pracę. Zważywszy na to, że wiele stanowisk pracy wymaga posługiwania się komputerem, technologie komunikacyjne i informacyjne pomagają pokonywać trudności związane z pracą zawodową, np. konieczność zorganizowania transportu, przeczytania materiału drukowanego, uzyskania informacji na temat możliwości zatrudnienia. Analizując natomiast mobilność osób niewidomych i słabowidzących, Leonard, D'Allura i Horowitz (1999) ujawnili, że większe umiejętności w zakresie orientacji przestrzennej sprzyjają aktywności zawodowej. Do podobnych wniosków doszli także inni autorzy (m.in. Golub, 2006; Lee, Abdullah, Mey, 2011). W tym obszarze problemowym interesujące są również ustalenia Bella i Mino (2015). Autorzy zauważyli, że badani niewidomi poruszający się za pomocą białej laski istotnie częściej podejmują pracę niż ci, którzy jej nie używają. Ponadto, w znacznie większym zakresie są zatrudniani respondenci wykorzystujący laskę sztywną, w przeciwieństwie do posługujących się laską składaną czy też krótką.

Równie spójny obraz funkcjonowania zawodowego osób z niepełnosprawnością wzrokową zarysowuje się w pracach analizujących udział posiadanych zasobów podmiotowych (m.in. Cimarolli, Wang, 2006; Lee, Abdullah, Mey, 2011). Capella-McDonall i Crudden (2009), badając młode osoby niewidome i słabowidzące, ustaliły, że poczucie umiejscowienia kontroli jest zmienną wiążącą się z ich zatrudnieniem. Badani cechujący się kontrolą wewnętrzną istotnie częściej podejmowali pracę po ukończeniu szkolenia zawodowego niż badani cechujący się kontrolą zewnętrzną. Cimarolli i Wang (2006), zwróciły uwagę na rolę lęku i satysfakcji z życia jako ważnych czynników wyznaczających aktywność zawodową osób niewidomych i słabowidzących. Przeprowadzone badania wykazały, że respondenci pracujący, w porównaniu z niepracującymi, ujawniali istotnie niższy poziom lęku i znacznie wyższą satysfakcję z życia. W tym kontekście interesujące wyniki uzyskali Melissa N. Lee, Yen Abdullah i See Ch. Mey (2011), którzy objęli eksploracją niewidomych i słabowidzących nauczycieli (N = 24; wiek: 25–30 lat). W ich opinii, zasobami odgrywającymi znaczącą rolę podczas poszukiwania pracy przez osoby niewidome i słabowidzące są optymizm, pewność siebie, prężność osobowa, rzetelność, otwartość (także w odniesieniu do niepełnosprawności). Tak szeroko pojmowana otwartość wiąże się z akceptacją niepełnosprawności. Osoby akceptujące ograniczenia wynikające z uszkodzenia wzroku traktują niepełnosprawność jako źródło siły, dzięki której potrafią wykorzystać własne umiejętności i efektywnie funkcjonować na rynku pracy (Jo, Chen, Koscieluk, 2010), gdzie pojawia się konieczność przeprowadzenia rzeczowej rozmowy z pracodawcą na temat niepełnosprawności wzrokowej, posiadanych kompetencji, potrzeby dokonania niezbędnych adaptacji w miejscu pracy itp. (Joseph, Robinson, 2012). Z ujawnionymi we wspomnianych badaniach tendencjami nie korespondują doniesienia dotyczące samooceny i depresji, z których wynika, że zarówno poziom samooceny (Capella-McDonall, Crudden, 2009), jak i depresji (Cimarolli, Wang, 2006) nie różnicuje aktywnych i nieaktywnych zawodowo osób niewidomych i słabowidzących.

Interesującym dyskusjom podlega problematyka funkcjonowania zawodowego osób z niepełnosprawnością wzrokową w kontekście oddziaływania czynników społecznych. Zalicza się do nich wsparcie społeczne (m.in. Leonard, D'Allura, Horowitz, 1999; Lee, Park, 2008) oraz postawy pracodawców i współpracowników (m.in. La Grow, Daye, 2005; Lee, Abdullah, Mey, 2011). Leonard, D'Allura i Horowitz (1999), badając osoby niewidome i słabowidzące, ustalili, że wsparcie otrzymywane przez nich od członków rodziny, przyjaciół, podczas poszukiwania zatrudnienia wiąże się z pomyślnymi efektami w tym zakresie. Poza tym okazało się znaczącym predyktorem podjęcia pracy, w której zakres obowiązków jest zgodny z posiadanymi umiejętnościami. Określone powiązania wskazują zatem na konieczność uwzględniania sieci wsparcia społecznego w procesie rehabilitacji, zwłaszcza wsparcia uzyskiwanego od najbliższych, którzy motywują osoby niewidome i słabowidzące do aktywności w obszarze zawodowym. Warto w tym miejscu odwołać się do eksploracji Cimarolli i Wang (2006). Autorki zauważyły, że wsparcie społeczne jest zmienną, która różnicuje respondentów niewidomych i słabowidzących pracujących i niepracujących. Osoby pracujące, w porównaniu z niepracującymi, cechowały się istotnie wyższym poziomem spostrzeganego wsparcia społecznego od przyjaciół oraz rzadszym doświadczaniem nadopiekuńczości ze strony najbliższych. Rolę wsparcia społecznego w kontekście analizowanej problematyki akcentują w swojej pracy także Lee i Park (2008), którzy badając liczną grupę osób niewidomych i słabowidzących, ustalili, że wsparcie praktyczne od członków rodziny, w przeciwieństwie do wsparcia emocjonalnego i informacyjnego, jest predyktorem ich zatrudnienia. Stwierdzona zależność ma jednak charakter ujemny, co oznacza, że wyższe natężenie percypowanego wsparcia praktycznego zmniejsza szanse badanych na znalezienie pracy. Wyjaśniając ustalone powiązanie, autorzy zasugerowali, że prawdopodobnie wsparcie materialne, dzięki eliminacji trudności ekonomicznych, obniża motywację ukierunkowaną na podejmowanie zatrudnienia.

Wyraźną spójność stanowisk przyjmowanych przez poszczególnych autorów zauważa się, analizując rolę innego czynnika społecznego kształtującego aktywność w obszarze zawodowym osób z niepełnosprawnością wzrokową, a mianowicie postaw pracodawców i współpracowników. Z dostępnych opracowań wynika, że dyskryminowanie osób niewidomych i słabowidzących przez pracodawców i współpracowników, ignorowanie ich umiejętności, niezapewnianie warunków bezpieczeństwa utrudniają odnalezienie się na rynku pracy (La Grow, Daye, 2005; Lee, Abdullah, Mey, 2011; Joseph, Robinson, 2012). W tym kontekście interesujące wyniki otrzymał Dawn B. Golub (2006), którego eksploracja dotyczyła modelu efektywnego zatrudniania osób niewidomych i słabowidzących. Autor objął badaniami 22 pracodawców, spośród których 36,5% pracowało w instytucjach działających na rzecz osób z niepełnosprawnością wzrokową. W proponowanym modelu pracodawcy wskazali przede wszystkim na znaczenie wzajemnego przystosowania oraz czynników społecznych i kulturowych, kształtujących harmonijną integrację pracowników niewidomych i słabowidzących. Oprócz konieczności poznania umiejętności takich pracowników, ich możliwości, potrzeby dokonania stosownych adaptacji na stanowisku pracy, pracodawcy wyakcentowali także inne kwestie. Znalazły się wśród nich następujące działania: stawianie jednakowych wymagań wszystkim pracownikom, stwarzanie warunków ułatwiających akceptację pracowników niewidomych i słabowidzących, edukowanie członków zespołu, zwłaszcza w kontekście mitów i stereotypów odnoszących się do osób z niepełnosprawnością wzrokową.

Możliwości wspierania funkcjonowania zawodowego osób z niepełnosprawnością wzrokową

Oczekiwaniom osób niewidomych i słabowidzących w zakresie funkcjonowania zawodowego, uwarunkowanego licznymi czynnikami, wychodzi naprzeciw aktywizacja zawodowa, która jest procesem polegającym na uruchomieniu zespołu specjalnych działań przez różnego rodzaju pomioty. Działania te wiążą się głównie z przygotowaniem do pracy, udzieleniem pomocy w wejściu na rynek pracy, zatrudnieniem określonych osób lub grup społecznych. Na uwagę zasługują tutaj działania, niejednokrotnie wieloletnie, ukierunkowane na przygotowanie do pracy, np. po wcześniejszym okresie rehabilitacji zawodowej. Aktywizacja zawodowa wymaga uwzględnienia wielu czynników, które doprowadzają do podjęcia pracy i jej wykonywania (Garbat, 2013). Kluczowym aktem prawnym w kontekście aktywizacji zawodowej jest Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych, wraz z późniejszymi zmianami (Dz.U. 2019, poz. 1172), gdzie znajdują się regulacje dotyczące specjalnych potrzeb zawodowych osób z niepełnosprawnością.

W Polsce działa wiele instytucji rządowych, które aktywizują i wspomagają zatrudnienie osób z niepełnosprawnością wzrokową. Wśród nich znajdują się: Państwowy Fundusz Rehabilitacji Osób Niepełnosprawnych, Powiatowe Centra Pomocy Rodzinie, Powiatowe Urzędy Pracy, Miejskie Ośrodki Pomocy Społecznej. Instytucje te proponują różne formy aktywizacji zawodowej. Są wśród nich m.in.: refundacja kosztów poniesionych przez pracodawcę związanych z zatrudnianiem osób z niepełnosprawnością oraz wyposażaniem dla nich stanowisk pracy, współfinansowanie projektów realizowanych ze środków pomocowych UE (Państwowy Fundusz Rehabilitacji Osób Niepełnosprawnych); przyznanie osobom z niepełnosprawnością środków na podjęcie działalności gospodarczej, refundacja wynagrodzenia oraz składek na ubezpieczenie społeczne pracodawcy zatrudniającego osoby z niepełnosprawnością (Powiatowe Centra Pomocy Rodzinie); staże, przygotowanie zawodowe dorosłych, szkolenia (Powiatowe Urzędy Pracy); integracja zawodowa osób z niepełnosprawnością, udzielanie pomocy na zakup sprzętu rehabilitacyjnego (Miejskie Ośrodki Pomocy Społecznej) (Kobus-Ostrowska, 2018). W aktywizacji zawodowej osób z niepełnosprawnością wzrokową istotne znaczenie mają także organizacje pozarządowe, które podobnie jak organizacje rządowe, organizują różne formy rehabilitacji zawodowej, prowadzą szkolenia zawodowe, a także szkolenia w zakresie zatrudniania. Najbardziej wartościowe są te działania, których efektem są programy zmierzające do podniesienia kwalifikacji zawodowych i zwiększenia możliwości zatrudnienia (Becker-Pestka, 2012). W literaturze przedmiotu opisywane są różne przedsięwzięcia, w tym programy i projekty, realizowane w celu aktywizacji zawodowej osób niewidomych i słabowidzących (m.in. Czerwińska, Żejmis, 2007; Konieczna, 2009; Majewski, 2011; Obłączek, 2013; Wittich i in., 2013; O'Mally, Antonelli, 2016; Kobus-Ostrowska, 2018).

Inicjatywy proponowane w ramach aktywizacji zawodowej osób z niepełnosprawnością wzrokową powinny być dopasowane do ich aktualnej sytuacji. Dopasowanie to wiąże się nie tylko z koniecznością uwzględnienia stopnia niepełnosprawności, lecz także indywidualnych potrzeb odbiorcy uzależnionych np. od fazy radzenia sobie z utratą sprawności. Pracownicy zajmujący się wspieraniem funkcjonowania zawodowego osób z niepełnosprawnością powinni świadczyć m.in. następujące usługi: indywidualne doradztwo zawodowe, indywidualne porady prawne, indywidualne porady psychologiczne, udział w grupach wsparcia, udział w warsztatach psychologicznych, korzystanie z pomocy trenera pracy, pośrednictwo pracy, udział w stażach, korzystanie z informacji o systemie wsparcia zatrudnienia (Wolski, 2010). Szeroki zakres proponowanych usług wskazuje, że w proces aktywizacji zawodowej osób z niepełnosprawnością wzrokową zaangażowanych jest wielu specjalistów, wśród których nie może zabraknąć tyflopedagogów. Ich rolę i zadania doskonale ujęła Marzenna Zaorska (2015).

W polityce zatrudnienia realizowanej w odniesieniu do osób niewidomych i słabowidzących można wyróżnić trzy kierunki/formy aktywizacji zawodowej: zatrudnienie na otwartym rynku pracy, samozatrudnienie, zatrudnienie na chronionym rynku pracy.

Pierwsza forma oznacza zatrudnienie m.in. w zakładach produkcyjnych lub usługowych i jest wyrazem rzeczywistej integracji społecznej osób z niepełnosprawnością wzrokową. Szczególnie cennym rozwiązaniem w tym obszarze jest zatrudnienie wspomagane, czyli „specjalna forma zatrudnienia osób z umiarkowanym i znacznym stopniem niepełnosprawności w zwykłych zakładach pracy przy zapewnieniu potrzebnego wsparcia przez tzw. trenera pracy lub asystenta pracy (jobcoach)" (Majewski, 2011, s. 42). Przez samozatrudnienie należy rozumieć prowadzenie własnej działalności gospodarczej, natomiast zatrudnienie na chronionym rynku pracy wiąże się z podjęciem pracy w specjalnych warunkach, czyli w zakładach pracy chronionej (tamże). Analizując tę formę zatrudnienia, trzeba pamiętać o tym, że chroniony rynek pracy stanowi zagrożenie dla procesu integracji społecznej, nie sprzyja przedsiębiorczości osób z niepełnosprawnością wzrokową i utrudnia rozwijanie kompetencji niezbędnych do funkcjonowania w środowisku osób pełnosprawnych (Rimmerman, Morgenstern, 2003).

Niezależnie od warunków, w jakich pracują osoby niewidome i słabowidzące, każdy rynek pracy może być przykładem dobrych praktyk, które można określić jako sposób pracy z osobami z niepełnosprawnością ukierunkowany na zwiększenie ich kompetencji zawodowych oraz uzyskanie trwałego zatrudnienia, będącego ostatecznym celem całego procesu aktywizacji zawodowej (Majewski, 2011; Kobus-Ostrowska, 2018). W literaturze przedmiotu podawane są przykłady dobrych praktyk wskazujących na efektywne zatrudnianie osób z niepełnosprawnością wzrokową na otwartym (Majewski, 2011; Obłączek, 2013; Kobus-Ostrowska, 2018) i chronionym rynku pracy (Kobus-Ostrowska, 2018). Ważną inicjatywą jest zatem promowanie pracodawców, którzy zatrudniają osoby niewidome i słabowidzące. Przedsiębiorcy ci są najbardziej wiarygodną rekomendacją, która może skutecznie motywować innych pracodawców do podejmowania podobnych działań (Wolffe, Candela, 2002), co jest skutecznym narzędziem w walce z istniejącymi w tym obszarze stereotypami.

Planując działania zmierzające do wspierania funkcjonowania zawodowego osób niewidomych i słabowidzących trzeba pamiętać o tym, że z ich zatrudnienia wynikają korzyści nie tylko dla nich samych. Zyskują pracodawcy osób z niepełnosprawnością wzrokową, ich współpracownicy, a w szerszej perspektywie również całe społeczeństwo. Jest to jednak bardzo duże wyzwanie dla państwa i organów ponoszących odpowiedzialność za aktywizację zawodową osób z niepełnosprawnością (Becker-Pestka, 2012).

Zamiast zakończenia

Praca ma istotne znaczenie w życiu każdego człowieka. Przyjmuje się, że osoby z niepełnosprawnością wzrokową przypisują jej większą rolę niż osoby pełnosprawne, umieszczając na wysokiej pozycji w systemie wartości (Kuczyńska-Kwapisz, 2009), co niewątpliwie powiązane jest z terapeutycznym znaczeniem pracy. Niewidomi i słabowidzący mają szerokie możliwości zawodowe. Są w stanie wykonywać wiele zawodów i zajmować różnorodne stanowiska, a ich funkcjonowanie w analizowanym obszarze wyznaczane jest przez liczne czynniki, np. socjodemograficzne, medyczne, zasoby podmiotowe, posiadane umiejętności. Zważywszy na możliwości zawodowe osób z niepełnosprawnością wzrokową, w literaturze przedmiotu nie wskazuje się już na zawody dostępne dla tej grupy osób, lecz wymienia profesje, których z oczywistych względów nie mogą wykonywać, co oznacza, że inne są dostępne, chociaż pod pewnymi warunkami (Majewski, 2009). Bardzo trafnym wyrazem tego stanowiska są słowa wieloletniego prezesa Amerykańskiej Federacji Niewidomych (za: Duda, Kukla, Zając, 2014, s. 110), który stwierdził, że „przeciętna osoba niewidoma może wykonać przeciętną pracę w przeciętnym zakładzie pracy, tak samo jak jej widzący kolega, pod warunkiem, że otrzyma odpowiednie przeszkolenie i stworzy się jej odpowiednie warunki pracy". Znamienne jest także to, że osoby z niepełnosprawnością, wykonujące zadania dostosowane do ich umiejętności, kompetencji i możliwości, są postrzegane jako wartościowi pracownicy. Obowiązki zawodowe wykonują sumienne, z ogromnym zaangażowaniem, poświęceniem i oddaniem, szanują pracę i są odpowiedzialne, krótko mówiąc – posiadają wiele zalet i umiejętności. Badania prowadzone w tym obszarze problemowym pozwoliły na określenie atutów pracowników z niepełnosprawnością, zarówno niespecyficznych, jak i specyficznych. Znalazły się wśród nich m.in. następujące cechy: kwalifikacje merytoryczne, kompetencje osobiste i społeczne, pracowitość, życzliwość (Smoczyńska, 2008, za: Becker-Pestka, 2012). Skutkuje to tym, że osoby z niepełnosprawnością, także niepełnosprawnością wzrokową, są coraz częściej doceniane jako pracownicy (Duda, Kukla, Zając, 2014).

W Polsce wiele osób z niepełnosprawnością, ale także pełnosprawnych, ma status bezrobotnego. Wprawdzie pełnienie roli zawodowej przez osoby z niepełnosprawnością jest znacząco utrudnione, jednak są wśród osób niewidomych i słabowidzących takie, które wykazują dużą aktywność ukierunkowaną na zmianę swojej sytuacji zawodowej, włączając się w różne inicjatywy mieszczące się w ramach szeroko pojmowanej aktywizacji zawodowej. Aktywizacja zawodowa osób z niepełnosprawnością jest procesem dwufazowym, który obejmuje działania o charakterze wewnętrznym i działania o charakterze zewnętrznym. Pierwszy typ działań wiąże się z niwelowaniem barier motywacyjnych, rozpoznawaniem potrzeb, możliwości, zainteresowań zawodowych, określaniem gotowości do zmiany sytuacji zawodowej. Drugi typ działań dotyczy natomiast likwidowania barier informacyjnych, co urzeczywistnia się poprzez dostarczanie wiedzy i kształtowanie umiejętności praktycznych w zakresie aktywnego poszukiwania pracy i funkcjonowania w miejscu pracy. Można zatem przyjąć, że aktywizacja zawodowa odnosi się nie tylko do konkretnych działań, lecz także obejmuje naukę umiejętności i kształtowanie postaw aktywności w odniesieniu do własnej sytuacji zawodowej (Mrzygłocka-Chojnacka, 2013, za: Kleszcz-Ciupka, Drozd, Kornasiewicz, 2014).

W procesie aktywizacji zawodowej istotny jest sposób rekrutowania pracowników z niepełnosprawnością wzrokową. Sytuacja na rynku pracy nie jest żadnym uzasadnieniem dla praktyk polegających na proponowaniu stanowisk o niskim wynagrodzeniu, niespełniających oczekiwań i zagrażających zdrowiu.

Zatrudnienie niezgodnie z preferencjami i predyspozycjami zawodowymi jest zjawiskiem bardzo niekorzystnym, gdyż hamuje rozwój zawodowy i społeczny. Poza tym należy przywiązywać większą uwagę do możliwości wspierania osób niewidomych i słabowidzących w procesie samozatrudnienia, które, podobnie jak zatrudnienie na otwartym rynku pracy, jest źródłem satysfakcji i twórczej stymulacji rozwoju. Dzięki dobrze przeprowadzonemu treningowi zawodowemu i konsultacji prawnej, ta forma aktywności zawodowej, może stać się narzędziem pozwalającym odnaleźć się na rynku pracy (Kobus-Ostrowska, 2018). W ostatnich latach coraz bardziej wzrasta rola jeszcze jednej formy zatrudnienia pracowników z niepełnosprawnością wzrokową – telepracy. Jest to praca wykonywana przy pomocy nowoczesnych technik informatycznych i telekomunikacyjnych, w dowolnej odległości od miejsca, gdzie jest tradycyjnie rozliczana, np. wprowadzanie danych do komputera, tłumaczenie tekstów (Majewski, 2011).

Analizując funkcjonowanie zawodowe osób niewidomych i słabowidzących, należy zauważyć, że problem ich aktywizacji zawodowej w różnym stopniu i zakresie znajduje się w centrum zainteresowania instytucji działających w obszarze zatrudnienia. Taka sytuacja wiąże się z koniecznością włączenia wielu struktur w proces realizacji zadań składających się na aktywizację zawodową. Wzajemna współpraca oraz spójne programy i plany działań są gwarantem stworzenia innowacyjnych i właściwych rozwiązań. Specyfika funkcjonowania osób z niepełnosprawnością wzrokową w społeczeństwie wymaga właściwego podejścia do zagadnień dotyczących ich miejsca w przestrzeni życia publicznego. Wsparcie ekonomiczne jest ważnym rozwiązaniem, lecz niestety niewystarczającym. Istotne są warunki do rozwoju. W polityce społecznej zarówno rehabilitacja, jak i zatrudnienie osób z niepełnosprawnością mają istotne znaczenie, gdyż są czynnikami sprzyjającymi integracji (por. Becker-Pestka, 2012).

Bibliografia

Becker-Pestka, D. (2012). Aktywizacja społeczna i zawodowa osób niepełnosprawnych – problemy i wyzwania. *Colloquium Wydziału Nauk Humanistycznych i Społecznych AMW, 4*, 29–50.

Bell, E.C., Mino, N.M. (2015). Employment outcomes for blind and visually impaired adults. *Journal of Blindness Innovation and Research*, *5*(2), https://nfb.org/images/nfb/publications/jbir/jbir15/jbir050202.html. doi: 10.5241/5-85.

Capella-McDonnall, M.E. (2005). Predictors of competitive employment for blind and visually impaired consumers of vocational rehabilitation services. *Journal of Visual Impairment & Blindness*, *99*(5), 303–315. doi: 10.1177/0145482X0509900505.

Capella-McDonnall, M.E., Crudden, A. (2009). Factors affecting the successful employment of transition-age youths with visual impairments. *Journal of Visual Impairment & Blindness*, *103*(6), 329–341. doi: 10.1177/0145482X0910300603.

Cimarolli, V.R., Wang, S. (2006). Differences in social support among employed and unemployed adults who are visually impaired. *Journal of Visual Impairment & Blindness*, *100*(9), 545–556. doi: 10.1177/0145482X0610000906.

Czerwińska, K., Żejmis, M. (2007). Doradztwo zawodowe dla osób niewidomych i słabo widzących w projekcie „Per linguas mundi ad laborem”. *Niepełnosprawność i Rehabilitacja*, *3*, 76–86.

Darensbourg, B.L. (2013). Predictors of competitive employment of VR consumers with blindness or visual impairments. *Journal of Vocational Rehabilitations*, *38*, 29–34. doi: 10.3233/JVR-120618.

Duda, W., Kukla, D., Zając, M. (2014). *Elementy zarządzania karierą zawodową osób z niepełnosprawnością. Poradnik dla doradców zawodowych*. Częstochowa: Akademia im. Jana Długosza.

Garbat, M. (2013). *Aktywizacja zawodowa osób z niepełnosprawnością – bariery i koszty*. Zielona Góra: Oficyna Wydawnicza UZ.

Giddens, A. (2006). *Socjologia*. Warszawa: WN PWN.

Giesen, J.M., Cavenaugh, B.S. (2012). Transition-age youths with visual impairments in vocational rehabilitation: a new look at competitive outcomes and services. *Journal of Visual Impairment & Blindness*, *106*(8), 475–487. doi: 10.1177/0145482X1210600804.

Golub, D.B. (2006). A model of successful work experiences for employers who are visually impaired: the results of a study. *Journal of Visual Impairment & Blindness*, *100*(12), 715–725. doi: 10.1177/0145482X0610001203.

Jang, Y., Wang, Y.-T., Lin, M.-H., Shih, K.J. (2013). Predictors of employment outcomes for people with visual impairment in Taiwan: the contribution of disability employment services. *Journal of Visual Impairment & Blindness*, *107*(6), 469–480. doi: 10.1177/0145482X1310700608.

Jo, S.J., Chen, R.K., Koscieluk, J.F. (2010). Employment outcomes among individuals with visual impairments: the role of client satisfaction and acceptance of vision loss. *Journal of Applied Rehabilitation and Counseling*, *41*(3), 3–8. doi: 10.1891/0047-2220.41.3.3.

Joseph, M.A., Robinson, M. (2012). Vocational experiences of college educated individuals who are visually impaired. *Journal of Applied Rehabilitation*, *43*(4), 21–28. doi: 10.1891/0047-2220.43.4.21.

Kirenko, J., Sarzyńska, E. (2010). *Bezrobocie – niepełnosprawność – potrzeby*. Lublin: Wydawnictwo UMCS.

Kleszcz-Ciupka, E., Drozd, S., Kornasiewicz, A. (2014). Elastyczne formy zatrudnienia szansą na aktywność zawodową osób niepełnosprawnych. W: E. Rutkowska, W. Otrębski (red.), *Aktywizacja osób z niepełnosprawnością. Wybrane problemy psychospołeczne* (s. 103–117). Biała Podlaska: AWF.

Kobus-Ostrowska, D. (2018). *Aktywizacja zawodowa osób z niepełnosprawnością. Aspekty ekonomiczne i społeczne*. Łódź: Wydawnictwo UŁ.

Konieczna, K. (2009). Projekt „Wsparcie osób niewidomych na rynku pracy”, *Laski*, *1–2*, 130–133.

Kuczyńska-Kwapisz, J. (2009). Pedagogika osób słabo widzących i niewidomych. W: D.M. Piekut-Brodzka, J. Kuczyńska-Kwapisz (red.), *Pedagogika specjalna dla pracowników socjalnych* (s. 88–102). Warszawa: Wydawnictwo APS.

Kwitok, A. (2017). Znaczenie pracy zawodowej dla jakości życia osób niepełnosprawnych. W: D. Wolska (red.), *Osoby niepełnosprawne w drodze do aktywności zawodowej* (s. 21–34). Kraków: WN UP.

La Grow, S.J. (2004). Factors that affect the employment status of working-age adults with visual impairments in New Zealand. *Journal of Visual Impairment & Blindness*, *98*(9), 546–560. doi: 10.1177/0145482X0409800906.

La Grow, S.J., Daye, P. (2005). Barriers to employment identified by blind and vision-impaired persons in New Zealand. *Social Policy Journal of New Zealand*, *26*, 173–185.

Lee, M.N., Abdullah, Y., Mey, S.Ch. (2011). Employment of people with disabilities in Malaysia: drivers and inhibitors. *International Journal of Special Education*, *26*(1), 112–124.

Lee, I.S., Park, S.K. (2008). Employment status and predictors among people with visual impairments in South Korea: results of a National Survey. *Journal of Visual Impairment & Blindness*, *102*(3), 147–159. doi: 10.1177/0145482X0810200303.

Leonard, R., D’Allura, T., Horowitz, A. (1999). Factors associated with employment among persons who have a vision impairment: a follow-up of vocational placement referrals. *Journal of Vocational Rehabilitation*, *12*, 33–43.

Majewski, T. (2004). *Rehabilitacja i zatrudnienie osób niewidomych i słabo widzących*. Warszawa: KIG-R.

Majewski, T. (2008). Psychologiczne znaczenie pracy zawodowej dla osoby niepełnosprawnej. W: A. Barczyński, M. Strzałkowski (red.), *Społeczne korzyści zatrudniania osób niepełnosprawnych* (s. 42–45). Warszawa: KIG-R.

Majewski, T. (2009). Aktualne poglądy na możliwości zawodowe osób niewidomych. *Szkoła Specjalna*, *4*, 245–251.

Majewski, T. (2011). *Wsparcie osób niewidomych na rynku pracy II – podręcznik dobrych praktyk*. Warszawa: PFRON.

Obłączek, A. (2013). Aktywizacja zawodowa w praktyce. *Niepełnosprawność i Rehabilitacja*, *2*, 91–109.

O'Mally, J., Antonelli, K. (2016). The effect of career mentoring on employment outcomes for college students who are legally blind. *Journal of Visual Impairment & Blindness*, *110*(5), 295–307. doi: 10.1177/0145482X1611000502.

Rimmerman, A., Morgenstern, H. (2003). Quality of life of visually impaired adults who are employed in extended-employment programs in Israel. *Journal of Visual Impairment & Blindness*, *97*(9), 551–561. doi: 10.1177/0145482X0309700906.

Rutkowska, E., Filipek, D. (2008). Praca zawodowa osób niepełnosprawnych jako element rehabilitacji kompleksowej. W: M. Piasecki, J. Śliwiak (red.), *Wybrane zagadnienia z aktywizacji zawodowej osób niepełnosprawnych* (s. 69–77). Lublin: Norbertinum.

Ryles, R. (1996). The impact of braille reading skills on employment, income, education and reading habits. *Journal of Visual Impairment & Blindness*, *90*(3), 219–226. doi: 10.1177/0145482X9609000311.

Shaw, A., Gold, D., Wolffe, K. (2007). Employment-related experiences of youths who are visually impaired: how are those youths faring? *Journal of Visual Impairment & Blindness*, *101*(1), 7–21. doi: 10.1177/0145482X0710100103.

Stańko, I. (2009). Rola pracy w integracji osób niepełnosprawnych w społeczeństwie równych szans. *Socius*, *2*, 2–4.

Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych (Dz.U. 2019, poz. 1172).

Wittich, W., Watanbe, D.H., Scully, L., Bergevin, M. (2013). Development and adaptation of an employment – integration program for people who are visually impaired in Quebec, Canada. *Journal of Visual Impairment & Blindness*, *107*(6), 481–495. doi: 10.1177/0145482X1310700609.

Wolffe, K., Candela, A. (2002). A qualitative analysis of employers experiences with visually impaired workers. *Journal of Visual Impairment & Blindness*, *96*(9), 622–635. doi: 10.1177/0145482X0209600903.

Wolski, P. (2010). *Utrata sprawności. Radzenie sobie z niepełnosprawnością nabytą a aktywizacja zawodowa*. Warszawa: Scholar.

Zaorska, M. (2015). *Tyflopedagog wobec problem aktywności życiowej – zawodowej i prozawodowej osób dorosłych z niepełnosprawnością wzrokową*. Toruń: Wydawnictwo Edukacyjne Akapit.

Zhou, L., Smith, D.W., Parker, A.T., Griffin-Shirley, N. (2013). The relationship between perceived computer competence and the employment outcomes of transition-aged youths with visual impairments. *Journal of Visual Impairment & Blindness*, *107*(1), 4–53. doi: 10.1177/0145482X1310700104.

FUNKCJONOWANIE ZAWODOWE OSÓB Z NIEPEŁNOSPRAWNOŚCIĄ WZROKOWĄ – UWARUNKOWANIA I MOŻLIWOŚCI WSPIERANIA

Abstrakt

Praca ma istotne znaczenie w życiu każdego człowieka. W literaturze przedmiotu podkreśla się, że osoby z niepełnosprawnością wzrokową przypisują jej większą rolę niż osoby pełnosprawne, co niewątpliwie powiązane jest z terapeutyczną funkcją pracy. Wprawdzie osoby niewidome i słabowidzące są w stanie wykonywać wiele zawodów i zajmować różnorodne stanowiska, lecz ich aktywność zawodowa kształtuje się bardzo różnie. Wobec tego warto bliżej przyjrzeć się czynnikom wyznaczającym efektywne funkcjonowanie osób z niepełnosprawnością wzrokową w analizowanym obszarze. Dokonując przeglądu dostępnej literatury, w artykule omówiono m.in. czynniki socjodemograficzne, medyczne, zasoby podmiotowe, posiadane umiejętności. Poza tym zwrócono uwagę na możliwości wspierania funkcjonowania zawodowego osób niewidomych i słabowidzących.

Słowa kluczowe: znaczenie pracy, niepełnosprawność wzrokowa, uwarunkowania funkcjonowania zawodowego, aktywizacja zawodowa

PROFESSIONAL FUNCTIONING OF PEOPLE WITH VISUAL IMPAIRMENT – DETERMINANTS AND POSSIBILITIES OF SUPPORT

Abstract

Work plays a significant role in every person's life. In the literature of the subject it is highlighted that persons with visual impairment ascribe a greater role to it than persons without disabilities, which is undoubtedly related to a therapeutic function of work. Even though visually impaired persons or partly sighted ones are capable of performing many jobs and holding various positions, their professional activity may take different forms. Therefore, it is worth taking a closer look at the factors determining effective functioning of people with visual impairment in the researched area. Based on the bibliographic review, the article focuses on the analysis of factors such as socio-demographic and medical ones, personal resources and skills possessed, to name but a few. In addition, the emphasis is placed on the opportunities for the support of professional activities undertaken by visually impaired and partially sighted people.

Keywords: significance of work, visual impairment, determinants of professional functioning, employment support policy

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO”
CNS nr 3(49) 2020, 79–93
ISSN 1734-5537
DOI: 10.5604/01.3001.0014.3577

MAŁGORZATA ZABORNIAK-SOBCZAK*

WSPARCIE SPOŁECZNE W ROZWIJANIU KOMUNIKACJI JĘZYKOWEJ SŁYSZĄCYCH DZIECI W NARRACJACH NIESŁYSZĄCYCH RODZICÓW

Wprowadzenie

Występowanie głuchoty w rodzinie ma wpływ na wiele aspektów życia rodzinnego, m.in. na interakcje i zasoby w rodzinie, rodzicielstwo, potrzebę wsparcia społecznego (Hintermair, 2000; Jackson, Turnbull, 2004). Na łamach prezentowanego artykułu zajęto się problematyką wsparcia społecznego w rozwijaniu komunikacji językowej słyszących dzieci w narracjach niesłyszących rodziców. Słyszące dzieci niesłyszących rodziców bywają czasem określane akronimem CODA od Children of Deaf Adults. Termin ten jednak, jak wyjaśnia Urszula Bartnikowska (2010, s. 91), „wydaje się być zarezerwowany dla osób identyfikujących się ze społecznością CODA, którzy uznają, że bycie słyszącym dzieckiem niesłyszących rodziców w znaczący sposób wpłynęło na kształtowanie się ich tożsamości”. Stąd używanie go nie zawsze bywa adekwatne, zwłaszcza w odniesieniu do małych słyszących dzieci wychowywanych przez głuchych rodziców, które nie są świadome swojej sytuacji, nie identyfikują się jeszcze z odmienną kulturą, wynikającą z użycia odmiennego sposobu porozumiewania się. Skrót CODA został wybrany przez Millie Brother, założycielkę (w 1983 r.) organizacji CODA International, której głównym celem jest wsparcie i propagowanie wiedzy na temat doświadczeń słyszących dzieci głuchych rodziców (szerzej: https://www.coda-international.org). W Polsce, w roku 2010, powstało Stowarzyszenie CODA Polska Słyszące Dzieci – Niesłyszący Rodzice, zrzeszające osoby zainteresowane działalnością na rzecz słyszących dzieci niesłyszących

---

* Małgorzata Zaborniak-Sobczak (https://orcid.org/0000-0002-0262-4787); Uniwersytet Rzeszowski, ul. ks. J. Jałowego 24, 35-010 Rzeszów; tel. +48 17 8721816;
e-mail: gosiazs@ur.edu.pl

rodziców (szerzej: http://www.codapolska.org). W tym artykule bardziej adekwatnym określeniem jest Kid/Kids of Deaf Adults, a więc KODA – ponieważ odnosi się do dzieci w wieku do 17. r.ż. (Czajkowska-Kisil, Klimczewska, 2016, s. 6) i dlatego skrót KODA będzie stosowany zamiennie z określeniem „słyszące dzieci niesłyszących rodziców".

Szacuje się, że ponad 90% dzieci urodzonych przez niesłyszących rodziców słyszy (Mitchell, Karchmer, 2004). Dzieci te są z reguły dwujęzyczne (por. dwujęzyczność równoległa, Kurcz, 2007) – posługują się językiem migowym lub/i językiem fonicznym. Jednocześnie są bimodalne (por. Emmorey, Borinstei, Thompson, 2005) – w procesie odbioru i nadawania komunikatów językowych wykorzystują modalność słuchowo-głosową lub/i modalność wzrokowo-gestową, co w konsekwencji może wymuszać również dwukulturowość – identyfikację ze społecznością osób słyszących i kształtowanie tożsamości osoby słyszącej lub/i identyfikację ze społecznością osób głuchych/Głuchych i kształtowanie tożsamości osoby głuchej/Głuchej (por. Bartnikowska, 2010; Toohey, 2010; Zaborniak-Sobczak, Perenc, 2017).

Problematykę specyfiki środowiska językowego i jego znaczenia w procesie rozwoju mowy i języka słyszących dzieci niesłyszących rodziców omawiali m.in.: Naomi B. Schiff, Ira M. Ventry, 1976; Michael L. Jones, Stephen P. Quigley, 1979; Jacqueline Sachs, Barbara Bard, Marie L. Johnson, 1981; Judith Murphy, Neil Slorach, 1983; Naomi B. Schiff-Myers, Harriet B. Klein, 1985; Jeanne M. Johnson, Ruth V. Watkins, Mabel L. Rice, 1992; Marzenna Zaorska, 1996; Lorn Allsop, Jim Kyle, 1997; Jenny L. Singleton, Matthew D. Tittle, 2000; Tim Brackenbury, Tiffany Ryan, Trinka Messenheimer, 2006; Ginger Bianca Pizer, 2008; Urszula Bartnikowska, 2010; Erin N. Toohey, 2010; Laura Kanto, Kerttu Huttunen, Marja-Leena Laakso, 2013; Malwina Kocoń, 2019. W systemie rodzinnym proces wymiany werbalnych i niewerbalnych sygnałów, celem osiągnięcia lepszego poziomu współdziałania, umiejscowiony jest w szerszym kontekście relacji między wszystkimi członkami rodziny (Braun-Gałkowska, 1987; Radochoński, 1998; Harwas-Napierała, 2008; Krok, 2010; Gurba 2013; Wach, 2016).

Życie rodzinne jest uniwersalnym doświadczeniem niemalże każdego człowieka. Jednak żadna z dwóch osób nie dzieli się dokładnie tym samym doświadczeniem, częściowo z powodu unikalnego wzorca komunikacji w każdym systemie rodzinnym. Wzorce komunikacji w rodzinie służą do konstruowania, a także odzwierciedlania, rodzinnych doświadczeń. Jako członkowie rodziny posiadamy pewne przekonania, które wpływają na to, jak postrzegamy własną rodzinę i panujące w niej wzorce komunikacji (Galvin, Braithwaite, Bylund, 2015). Autorzy książki *Family Communication. Cohesion and Change* (2015) przyjmują podstawowe założenia dotyczące współczesnej rodziny:

1. Istnieje wiele sposobów na bycie rodziną. Życie rodzinne jest tak różnorodne, jak osoby, które tworzą rodzinę.

2. Rodzina „doskonała” nie istnieje. Każda rodzina musi walczyć o stworzenie własnej rodziny, jako że przez wiele lat przeżywa dobre czasy i stresujące ją czasy. Wszystkie rodziny są pod wpływem większego kontekstu, w jakim istnieją.
3. Komunikacja służy budowaniu i odzwierciedlaniu relacji rodzinnych. Odbywa się to przez porozumiewanie się, w czasie którego osoby definiują swoją tożsamość, negocjują swoje relacje z innymi członkami rodziny, z resztą świata.
4. Komunikacja jest procesem, za pomocą którego członkowie rodziny tworzą i dzielą się znaczeniami. Członkowie rozwijają kulturę relacyjną, wspólny światopogląd, który przyczynia się do tworzenia dość wyjątkowego systemu komunikacji.
5. Rodziny socjalizują członków do swoich podstawowych wartości i przekonań na temat istotnych aspektów życia społecznego, kwestii życiowych, takich jak: płeć, zdrowie, miłość i religia.
6. Rodziny obejmują wielopokoleniowe wzorce komunikacji. Członkowie są pod wpływem wzorców poprzednich pokoleń, nawet jeśli tworzą one własne wzory, które z kolei wpływają na przyszłe pokolenia.
7. Rodziny odzwierciedlają także wzorce komunikacji kulturowej. Pochodzenie rasowe i etniczne wpływają na styl życia i zachowanie, jak również na normy komunikacji, które z kolei wpływają na przyszłe pokolenia, chyba że zostaną one świadomie zmienione.
8. W dobrze funkcjonujących rodzinach członkowie pracują nad wzajemnym zrozumieniem, uznają, że rozwój i utrzymanie związku wymaga wysiłku. Członkowie rozwijają zdolność adaptacji, tworzenia relacji, radzenia sobie z konfliktami, większość z nich stara się osiągnąć cel efektywnej komunikacji (tamże, s. 16).

Wymienieni autorzy podkreślają, że współcześnie próba zdefiniowania, czym jest rodzina, jest zadaniem niezwykle trudnym oraz że nie istnieje szeroko uzgodniona definicja terminu „rodzina”. W ostatnich trzech dziesięcioleciach rodziny zostały opisane zgodnie z powiązaniami biologicznymi i prawnymi jako sieci osób, które mieszkają ze sobą przez pewien czas, wspierając się nawzajem, oraz jako grupy ludzi, którzy mają ze sobą związki małżeńskie i/lub pokrewieństwa. Autorzy publikacji, analizując literaturę naukową dotyczącą rodziny, zauważają, że rodziny zmieniają swój rozmiar i kształt w całej swojej historii, przez cały czas, lecz mimo zmian, rodzina nadal pozostaje rodziną (Stewart i in., 1997, s. 245–246). Obecnie rodzinę można postrzegać szerzej jako grupę ludzi z przeszłością, historią, rzeczywistością w teraźniejszości i oczekiwaniami w przyszłości, dotyczącymi wzajemnego oddziaływania na siebie. Członkowie często, ale niekoniecznie, są związani przez dziedziczenie, prawne związki małżeńskie, adopcję lub dobrowolne więzi. Frederick S. Wamboldt i David. Reiss (1989, s. 728) definiują rodzinę jako „grupę intymną”, która generuje poczucie tożsamości domowej i grupowej, co wiąże się z silnymi więzami lojalności i emocji oraz doświadczeniem historii i przyszłości. W systemie rodzinnym autorzy podkreślają centralną rolę komunikacji we wszystkich aspektach życia rodzinnego. Obecnie rodzina staje się coraz mniej „tradycyjna”, biorąc pod uwagę wzrost liczby rodziców samotnie wychowujących dzieci, rodziny przybrane, adopcyjne i rodziny prowadzone przez lesbijki albo gejowskich partnerów. Wydłuża się wiek życia człowieka, stąd także wiek podejmowania pierwszego rodzicielstwa, poprawia się stan zdrowia osób starszych, zmienia się hierarchia wartości, prestiż społeczny w związku z rosnącym wykształceniem ludzi. Zmieniają się również role społeczne poszczególnych członków rodzin, w tym role dziadków, które są ostatnimi spośród najważniejszych ról tak zwanych przypisanych, to znaczy nie wybieranych, ale narzuconych jednostce przez przynależność do środowiska rodzinnego: po roli dziecka, partnera seksualnego i rolach rodzicielskich (Chodkowska, 2010).

Wsparcie społeczne odgrywa istotną rolę w procesie normalizacji życia każdej rodziny, żadna bowiem nie funkcjonuje w izolacji społecznej. Środowisko społeczne stanowi szczególne źródło wsparcia dla rodzin obciążonych niepełnosprawnością któregoś z jej członków. Brak racjonalnego i adekwatnego do potrzeb wsparcia może prowadzić do patologizacji życia rodzinnego (Krause, 2004). W badaniach własnych, przyjmując systemowe ujęcie rodziny, zainteresowano się sieciami wsparcia społecznego na rzecz rodzin osób z niepełnosprawnością słuchową. W szczególności starano się zrozumieć, jakie znaczenie w rozwijaniu komunikacji językowej KODA ma wsparcie społeczne, od kogo jest ono otrzymywane i najbardziej oczekiwane przez niesłyszących rodziców.

Metoda

Badania realizowano w latach 2015/2016, 2016/2017 w ramach projektu badawczego *„Głuche” rodzicielstwo. Wybrane aspekty psychopedagogiczne funkcjonowania osób z wadą słuchu w roli rodziców*; badania statutowe – rozwój potencjału badawczego (507) Wydziału Pedagogicznego Uniwersytetu Rzeszowskiego. Zebrany materiał badawczy został wykorzystany do opracowania dwóch innych artykułów (Zaborniak-Sobczak, Perenc, 2017; Zaborniak-Sobczak, 2020). Badania przeprowadzono zgodnie z założeniami badań jakościowych, w paradygmacie konstruktywistyczno-interpretatywnym, który przyjmuje relatywistyczną ontologię – zakłada wielość rzeczywistości, subiektywną epistemologię – poznający i badany współtworzą rozumienia, oraz naturalistyczny zespół procedur badawczych, metodologicznych – badanie odbywa się w naturalnym środowisku badanego (Denzin, Lincoln, 2009, s. 52). Celem całego projektu badawczego było:

- poznanie, opis i zrozumienie przebiegu procesu wychowania językowego dziecka słyszącego, wychowywanego przez niesłyszących (migających) rodziców (szerzej w: Zaborniak-Sobczak, Perenc, 2017);

– wyłonienie, w subiektywnej perspektywie niesłyszących rodziców, problemów związanych z:
    - codzienną komunikacją językową w relacji niesłyszący rodzic – słyszące dziecko (szerzej w: Zaborniak-Sobczak, 2020);
    - wsparciem społecznym otrzymywanym przez niesłyszących rodziców w zakresie rozwijania komunikacji językowej, adekwatnej do potrzeb słyszącego dziecka (ocena realnego wsparcia, wskazanie oczekiwań w tym zakresie), co uczyniono przedmiotem opisu na łamach tego artykułu.

Wiodącą metodą badawczą był wywiad narracyjny, który pozwolił odpowiedzieć na pytania o to, jak badani doświadczają rzeczywistości społecznej. Wywiad narracyjny koncentruje się na historiach opowiadanych przez badanych, jest subiektywnym sprawozdaniem z przebiegu całego życia danej osoby – narracja kompletna lub jego fragmentów – narracja tematyczna. „Jest poznawczą reprezentacją rzeczywistości, w której jednostka retrospektywnie porządkuje doświadczenia, przedstawia siebie, swój świat, zaistniałe wydarzenia jako historie” (Kos, 2013, s. 96, por. Kvale, 2012).

Badania prowadzono wśród pięciu rodzin Głuchych z województwa małopolskiego. Uprzednio spotkano się z kilkoma rodzinami (7) z województwa podkarpackiego. Rozmowy prowadzone podczas tych spotkań (w obecności tłumacza języka migowego) nie były jednak odnotowywane, a jedynie sporządzono luźne notatki, stąd materiał nie został wykorzystany do dalszych analiz.

Założono, że uczestnikami badań będą dorosłe osoby niesłyszące, posiadające orzeczenie o niepełnosprawności z uwagi na głuchotę (03-L), wychowujące słyszące dzieci, w wieku od 2 do 18 lat – KODA. Po wstępnej rozmowie z rodziną, przedstawieniu celu badania, uzyskano słowne zgody na spotkanie i przeprowadzenie wywiadu. Wywiady prowadzono od stycznia do marca 2017 roku. Każdy wywiad trwał średnio do trzech godzin. Trzy wywiady przeprowadzono z niesłyszącymi rodzicami w ich mieszkaniach. Pozostałe dwa spotkania odbyły się poza domem rodzinnym niesłyszących matek, ponieważ ojcowie nie uczestniczą w wychowaniu dzieci. Wszystkie badane osoby zostały poproszone o wyrażenie zgody na nagranie (audio-video) prowadzonego wywiadu. Niestety, w większości przypadków badani nie wyrazili zgody na nagrania, najczęściej tłumacząc się skrępowaniem, chęcią zachowania większej anonimowości. W każdym wywiadzie, prowadzonym i notowanym osobiście przez autorkę artykułu, uczestniczył wykwalifikowany i doświadczony tłumacz języka migowego, zatrudniony na podstawie stosownej umowy. Prowadząca badania, posługuje się językiem migowym (SJM), z czego także korzystała w czasie wywiadów.

Tabela 1. Charakterystyka badanych osób

Lp.	Badani (płeć, wiek w latach)	Stopień ubytku słychu	Wykształcenie	Liczba dzieci (płeć, wiek w latach)
1.	A. (K 40) B. (M 45)	głęboki głęboki	średnie zawodowe	1 (Ch 13)
2.	C. (K > 51)	głęboki	średnie	1 (D 17)
3.	D. (K 36)	znaczny	zawodowe	1 (D 12)
4.	E. (K 42) F. (M 47)	umiarkowany głęboki	średnie średnie	2 (D 8, Ch 5)
5.	G. (K 35) H. (M 40)	znaczny głęboki	zawodowe średnie	2 (D 10, D 5)

Legenda: K – kobieta, M – mężczyzna, Ch – chłopiec, D – dziewczynka. Imiona badanych zostały zmienione w ten sposób, że inicjałom imion nadano kolejne litery alfabetu, celem ochrony danych osobowych respondentów.

Źródło: opracowanie własne.

Wyniki badań

Tę część artykułu podzielono na cztery fragmenty, nadając im osobne śródtytuły. Prezentowany podział jest odzwierciedleniem treści, które wyłoniły się w narracjach badanych, związanych z szeroko rozumianą problematyką wsparcia społecznego otrzymywanego przez niesłyszących rodziców w zakresie rozwijania komunikacji językowej KODA. Zabieg ten posłużył przede wszystkim zachowaniu porządku i przejrzystości całości analiz (por. Bartnikowska, 2010; Kijak, 2019; szerzej o procesie analizy, porządkowania i prezentowania jakościowego materiału badawczego pisze również Dorota Podgórska-Jachnik, 2013, s. 231 i dalej).

Pomoc w opiece nad małym słyszącym dzieckiem, z uwzględnieniem wsparcia rozwoju jego mowy i języka, w narracjach niesłyszących rodziców

Naturalnymi dawcami wsparcia (w pierwotnym systemie wsparcia) są często członkowie rodziny – bliżsi i dalsi, jak dziadkowie, krewni (por. Kawczyńska-Butrym, 1998).

> „Babcia, dziadek [rodzice C. – przyp. M.Z.-S. tu i w pozostałych wypowiedziach respondentów], jak W. [córka C.] płakała w nocy, **to mnie budzili**.” (wypowiedź C.)

> „Teściowa [badanej D.] pomagała w wychowaniu, **gdy trzeba było iść do lekarza**, coś załatwić, ale w domu to sama wychowywałam córkę. Jeszcze bratowa, jest pielęgniarką i ona też **pomagała na zewnątrz**.” (wypowiedź D.)

> „Jak **dziecko w nocy płakało, to teściowa** [matka H.] **mnie budziła**. Osiem lat mieszkaliśmy razem. Początkowo babcia [matka H.] **chodziła też z dziećmi do lekarza**. Teraz lepiej jak mieszkają osobno. To była ważna pomoc, babcia [matka H.] **rozmawiała, opowiadała, czytała dzieciom, dużo mówiła do wnuczek**, mówiła co robi, uczyła je i opiekowała się dziećmi, gdy my byliśmy w pracy.” (wypowiedź E.)

Przypadki badanych C., D. i E. pokazują, jak ważną rolę odegrali słyszący rodzicie obecnie dorosłych niesłyszących osób, znajdujących się w nowej dla nich roli – rodziców. Przytoczone wypowiedzi wskazują, że zwłaszcza słyszące babcie (co pokazują także inne badania, por. Bartnikowska, 2010, s. 343 i dalej) częściowo przejęły funkcje opiekuńcze nad niemowlęciem, jednocześnie nie odbierając matce obszaru jej własnego działania w tym zakresie, a tym samym przestrzeni do kształtowania nowych umiejętności związanych z macierzyństwem. Reprezentowały niesłyszącą matkę tam, gdzie mogły, jednocześnie jej nie wyręczając.

Kolejny wątek, na który zwrócono uwagę, związany był z nauką mowy werbalnej. Krewni, najczęściej dziadkowie, mając świadomość niepełnych kompetencji w zakresie porozumiewania się fonicznego osób niesłyszących, wspierali także ten aspekt rozwoju małego słyszącego dziecka.

> „Około 1 r.ż. W. [córka C.], a może jak W. miała 2 lata, W. **mówiła z babcią** [matka C.], a do mnie zwracała się przez gesty. Pierwsze migi to było około 3 r.ż.” (wypowiedź C.)

> „Pierwsze jednak były słowa, gdy P. [córka D.] na przykład oglądała książeczki, **teściowa** [matka męża D.] **zaczęła do niej mówić i to ona wspierała ten język**. Jak P. była niemowlęciem, to ja do niej mówiłam proste słowa, jak płakała. […] **Teściowa pomagała nauczyć mówić** P. – **wyjaśniała** słowa, zawsze była w wychowaniu.” (wypowiedź D.)

> „Dziadkowie, babcia i dziadek – jedni i drudzy na zmianę mieszkają na wsi i **bardzo pomagali**, to była ważna pomoc.” (wypowiedź E.)

> „Jak D. [syn A. i B.] był mały spędzał wakacje u dziadków [rodziców B.]. Babcie **słyszące to rozmawiał z nimi**. **One tłumaczyły**, co jest niebezpieczne. Ja mówiłam «uważaj to jest niebezpieczne», ale nie umiałam tłumaczyć, wakacje spędzał u babci i może **ona tłumaczyła**.” (wypowiedź A.)

Babcie słyszących wnucząt, wychowywanych na co dzień przez niesłyszących rodziców, mając już doświadczenia w zakresie wspierania rozwoju mowy i języka własnych niesłyszących dzieci, odgrywały istotną rolę w nauce mówienia. Wiedziały bowiem, co robić, jak wspierać ten rozwój, np. czytając wnukom, tłumacząc niezrozumiałe dla nich słowa. Jak pisze Urszula Bartnikowska (2010, s. 344), „rodzice głusi, szczególnie posługujący się językiem migowym, często nie są w stanie sprostać temu zadaniu rozwojowemu [nauka mowy – przyp. M.Z.-S.]. Również ci rodzice, którzy posługują się mową mogą mieć problemy w tym zakresie, ponieważ sposób wypowiadania się może być specyficzny [z tej odmienności zdają sobie sprawę objęte badaniami własnymi osoby niesłyszące: „Córka (P.), jak była mała pytała mnie dlaczego tak słabo mówię, ja tłumaczyłam, że nie słyszę.” (wypowiedź D.) – przyp. M.Z.-S.]. Konieczne wydaje się zatem pojawienie innych osób, które będą stanowiły dla dziecka wzór posługiwania się tym typowym dla ludzi słyszących środkiem komunikacji”.

Znaczenie opieki logopedycznej nad małym słyszącym dzieckiem w narracjach niesłyszących rodziców

W procesie opanowania przez dziecko podstaw języka może pojawić się wiele trudności i wątpliwości, które niejednokrotnie budzą zainteresowanie wśród ogółu rodziców. Część z identyfikowanych przez rodziców problemów w rozwoju mowy i języka ich dzieci zaliczana jest przez specjalistów (logopedów, pedagogów, psychologów) do zachowań normatywnych (np. nieprawidłowości artykulacyjne w wielu poniemowlęcym, będące jednak zjawiskiem rozwojowym, jak substytucje głosek czy ich elizje, później neologizmy dziecięce). Część zachowań językowych ma jednak charakter pozanormatywny (np. zniekształcenia wymawianych głosek – realizacje zdeformowane, międzyzębowe), co wymaga wsparcia logopedy. Niesłyszący rodzice mają znaczne trudności w identyfikowaniu tych zjawisk, a następnie wspieraniu prawidłowego rozwoju mowy i języka swoich słyszących dzieci, stąd niezbędna staje się interwencja specjalistyczna.

> „Dawno W. **zgłoszona była do logopedy**, ale ona powiedziała, że nie trzeba, pomagała babcia [w rozwijaniu mowy]. Potem, jak W. była mała, to chodziła do **poradni logopedycznej**, tam była pani nauczycielka, która pomagała dzieciom uczyć się to była poradnia dla głuchych przy PZG.” (wypowiedź C.)

> „D. [syn A. i B.] **był w żłobku** od 1. r.ż. i tam mówił, **do domu przychodzili studenci**, co robili kurs języka migowego przy PZG – przychodzili i **pomagali** też w nauce D. Ta pomoc była ważna, wszyscy byli zadowoleni z tego. D. jest słyszący i potrzebował pomocy, my – niesłyszący popełniamy błędy w języku, a inni ludzie to zauważają i poprawiali D. – to było dla nas ważne. Jak D. był mały miał ok. 2, 3 lata, **chodził do logopedy** i ona poprawiała błędy, bo ja nie wiem czy dobrze mówił. Chciałam, żeby dobrze mówił, żeby mu dzieci nie dokuczały, bo były takie sytuacje i on się wtedy wstydził.” (wypowiedź A.)

> „Najpierw **logopedka powiedziała**, że P. może nie mówić, bo ok. 1. r.ż. zaczęła miganie, szybko łapała. Potem P. **chodziła do logopedy** jak miała 6 albo 7 lat, w zerówce – wtedy ktoś wysłuchał, że źle mówi i zaczęła chodzić, ale krótko, może 3, 4 miesiące, potem pani z zerówki kontynuowała te ćwiczenia, już jak się poprawiło to był koniec. Byłam zadowolona z tej logopedy.” (wypowiedź D.)

> „Przedtem jak K. [córka E. i F.] miała około 3,5 roku to przez 2 lata **chodziła do logopedy**, prywatnie, ja chciałam, żeby K. uczyła się mówić. Teraz K. [syn E. i F.] też

> chodzi, bo przestał mówić. Chodzi do centrum pomocy osobom niepełnosprawnym. Tam jest praca w zespole **psycholog, logopeda, pedagog**.” (wypowiedź E.)

> „Nie mamy pomocy w nauce dzieci i to jest dla nas trudne, czasami kiedyś przychodzili studenci, teraz czasem babcia [matka H.]. O. [córka E. i H.] **chodzi do logopedy** w przedszkolu 1 raz w miesiącu, ale logopeda mówi, że O. słabo mówi. D. [córka E. i H.] też chodziła do logopedy co 2 tygodnie od 2,5. r.ż. do 5. r.ż.” (wypowiedź E.)

Warto nadmienić, że obserwacja córek D. i O. państwa E. i H. wskazuje na opóźniony rozwój mowy jednej z nich. Młodsza córka O. (lat: 5,9) ma wymowę z licznymi substytucjami: [r] na [l], dentalizowane zębowe i dziąsłowe na środkowojęzykowe, miękkie, miejscami ubezdźwięcznia, zauważa się agramatyzmy, głos dźwięczny, dość wysoki, typu dziecięcego. Starsza córka D. (lat: 10,6) ma obecnie prawidłową wymowę, sporadycznie formułuje zdania agramatyczne, ma trudności na starcie mowy, z widoczną tendencją do tłumaczenia, wyjaśniania. Do rodziców chętniej od siostry miga O. – mniejszy udział w jej wychowaniu mieli dziadkowie. D. miga niechętnie, wstydzi się, mimo że rodzice namawiają ją do takiego sposobu komunikowania się.

Niesłyszący rodzice, czy to z własnej inicjatywy, czy też za sugestią krewnych, w procesie rozwijania mowy i języka swoich małych słyszących dzieci korzystają z zasobów instytucji wspierających – najczęściej poradni logopedycznych. Stąd ważne wydaje się, by poradnie te, często znajdujące się przy klubach Polskiego Związku Głuchych, obejmowały swą opieką również dzieci słyszące. Niezwykle istotne są również profilaktyczne badania lekarskie związane z bilansem dziecka i czujność lekarza pediatry, także w zakresie obserwacji małego pacjenta w aspekcie rozwoju jego mowy i języka. Małe słyszące dziecko niesłyszących rodziców, nieobjęte jeszcze z reguły żadną opieką instytucjonalną, narażone bywa na niewystarczający monitoring i wsparcie, stymulację w zakresie rozwoju mowy i języka.

Nauczyciele i ich rola we wsparciu słyszących dzieci niesłyszących rodziców w narracjach respondentów

Państwo E. i H. zwracają szczególną uwagę na rolę szkoły w wychowaniu ich słyszących córek, wskazując jednocześnie, że pomoc ta jest zdecydowanie za mała i nieadekwatna do potrzeb. Na pytanie o to, co nauczyciele w szkole mogliby zrobić odpowiadają:

> „Więcej, dłużej uczyć, żeby w domu nie było nauki, żeby nauczyciele indywidualnie wyjaśniali wątpliwości, bo ja nie umiem, nie wiem. Jak D. [córka E. i H.] była w szkole, to potem ja się pytam, jakie ma oceny, a ona mówi, że dobre, sprawdzam w komputerze i widzę że słabe. Do świetlicy nie chce chodzić, pani ma dużo dzieci i nie ma czasu żeby pomóc indywidualnie D. Pedagog szkolny nie chce pomagać.” (wypowiedź H.)

> „Pytam pani wychowawczyni, żeby ktoś pomógł dziecku w odrabianiu zadań, a pani wychowawczyni odesłała mnie do świetlicy, a córka nie chce tam chodzić. Na przykład zeszyt lektur – D. [córka E. i H.] musi sama nad tym pracować, bo my nie wiemy, nie potrafimy jej pomóc.” (wypowiedź E.)

Rodzice niesłyszący wskazują także na bierność nauczycieli, na trudność zadań, która niekiedy przekracza możliwości dzieci.

> „W nauce pomagała trochę babcia dawniej, a teraz W. (córka C.) **ma korepetycje**.” (wypowiedź C.)

> „P. [córka D.] ma teraz słabe oceny, to teść załatwił **panią korepetytorkę**, która pomaga w nauce, tłumaczy jej. P. nie traktuje poważnie tego, co ja jej mówię, tłumaczę. Ta pani przychodzi odpłatnie 2 lub 3 razy w tygodniu po 1 godzinie. Przedtem przychodzili wolontariusze, ale nieregularnie.” (wypowiedź D.)

> „Teraz dziadek [ojciec F.] przychodzi codziennie i odbiera dzieci, **pomaga też w nauce**, czasami przez telefon.” (wypowiedź E.)

Z narracji niesłyszących rodziców wyłania się obraz niewystarczającej pomocy płynącej ze środowiska edukacyjnego placówek oświatowych. Wydaje się, że słyszące dzieci niesłyszących rodziców nie są objęte w szkołach odpowiednią do ich potrzeb pomocą psychologiczno-pedagogiczną. Pomoc psychologiczno-pedagogiczna polega na rozpoznawaniu i zaspokajaniu indywidualnych potrzeb rozwojowych i edukacyjnych ucznia oraz jego możliwości psychofizycznych i czynników środowiskowych wpływających na jego funkcjonowanie w placówce, w celu wspierania potencjału rozwojowego i stwarzania warunków do aktywnego i pełnego uczestnictwa ucznia w życiu przedszkola, szkoły i placówki oraz w środowisku społecznym (Rozporządzenie MEN z dnia 9 sierpnia 2017, Dz.U. 2017, poz. 1591, § 2). KODA mogą wymagać pomocy psychologiczno-pedagogicznej w procesie edukacji z powodu niedostatecznie opanowanego języka, podobnie jak uczniowie dwukulturowi czy dwujęzyczni, stając się tym samym uczniami o specjalnych potrzebach edukacyjnych (por. Czajkowska-Kisil, Klimczewska, 2016). Wsparcie zatem nie tylko dziadków, logopedów, lecz także nauczycieli wydaje się niezbędne, celem prawidłowego przebiegu procesu rozwoju mowy i języka słyszących dzieci niesłyszących rodziców.

Język migowy w komunikacji ze słyszącym dzieckiem w narracjach niesłyszących rodziców

W narracjach badanych rodziców wyłonił się jeszcze jeden wątek dotyczący kwestii języka. Tym razem dotyczył on języka migowego, czyli języka preferowanego przez rozmówców.

> „**Babcia** [matka C.] **nie miga**, ale miga W. [córka C.] i to jest dla mnie ważne, że zna ten język, że możemy porozmawiać.” (wypowiedź C.)

> „Chciałabym, żeby córka nauczyła się migać, żeby też rodzina widziała, że słyszące dziecko umie migać, bo **ani teściowie, ani moja mama nie potrafią migać**. Prosiłam moją mamę, żeby nauczyła się migać, ale ona mi tłumaczyła, że mnie kocha, ale nie ma czasu na naukę, bo ma czworo dzieci. Oddała mnie do internatu, tam nauczyłam się migać. W domu byłam na uboczu i teraz też jestem, nie rozumiem, co mówią. Teraz tak samo jest, oni razem, ja mam swoje życie – inne. **Oni nie chcieli się nauczyć migać**. Głusi są dyskryminowani, spychani na bok, czasem jestem ciekawa, o czym rozmawiają, ale nie chcą mi tłumaczyć, więc już nie pytam. Jak już mieszkałam w internacie to rodzice nie pozwolili mi na życie towarzyskie, bali się o mnie. Jak wracałam z internatu, to nie mogłam nigdzie chodzić. Nic nie wiedziałam, oni nie próbowali mi niczego tłumaczyć.” (wypowiedź D.)

> „**Nasi rodzice nie uczyli się migać**, tylko mówili. Nauczyciele w szkole nie pozwalali migać i rodzicom też zabraniali. Nasi rodzice, widząc jednak, że migamy, nie denerwowali się. Tylko moi rodzice [F.] nie chcieli, żebym migał w miejscach publicznych. Teraz K. [córka E. i F.] wstydzi się migać na ulicy, a K. [syn E. i F.] jeszcze mały, to nie rozumie i się nie wstydzi.” (wypowiedź E. i F.)

Stosunek do języka migowego słyszących dzieci uzależniony jest nie tylko od postaw niesłyszących rodziców wobec komunikacji migowej, lecz przede wszystkim od osób z najbliższego otoczenia rodziny – wspierających tę rodzinę, np. dziadków, krewnych. Jeżeli osoby z najbliższego otoczenia nie akceptują migowych sposobów komunikacji, wówczas słyszące dzieci (wnuki, krewni) mogą mieć słabsze umiejętności w zakresie języka migowego. Dzieci w kontaktach ze słyszącymi członkami rodziny naturalnie dostosowują formy komunikacji. Wybierają formy foniczne, język migowy może być traktowany marginalnie, także z powodu braku akceptacji takiego sposobu komunikacji przez słyszących członków rodziny, którzy nie nauczyli się migać (por. Mallory, Zingle, Schein, 1993).

Zakończenie

Komunikacja w rodzinie pełni zasadniczą funkcję scalającą i regulującą działania członków rodziny. Prawidłowy proces porozumiewania się powoduje, że ludzie wymieniają między sobą informacje, dzielą się swoimi emocjami, przeżyciami, obawami. Komunikacja pełni funkcję regulującą życie w rodzinie. Za jej pomocą można rozwiązać konflikty, doskonalić funkcjonowanie życia rodzinnego. Nietypowa komunikacja w rodzinie będzie miała miejsce wówczas, gdy jej członkowie, z powodu chociażby różnych możliwości percepcyjnych i realizacyjnych (Grabias, 1997) będą musieli posługiwać się mniej typowymi kodami językowymi, różne będą ich potrzeby i preferencje w tym zakresie. Proces nabywania kompetencji językowych i komunikacyjnych, następnie umiejętności językowych (tamże), ich doskonalenie, są procesem wymagającym stałego uczestnictwa w komunikacji z użyciem określonego języka. Odmienna jest zatem sytuacja rozwoju i doskonalenia mowy i języka słyszących dzieci niesłyszących rodziców. KODA obserwują sposób porozumiewania się Głuchych rodziców – za pomocą języka migowego, a jednocześnie mają pełne zdolności percepcyjne i realizacyjne, by nabyć umiejętności komunikowania się w języku fonicznym. Niezbędny staje się zatem udział osób trzecich we wspieraniu rozwoju mowy i języka dziecka – najczęściej dziadków i krewnych, ale także logopedów i nauczycieli. Od tych ostatnich wymaga się zrozumienia specyficznej sytuacji językowej, w jakiej znajdują się słyszące dzieci niesłyszących rodziców i uruchomienia niezbędnej pomocy psychologiczno-pedagogicznej w celu dalszego stymulowania mowy i języka tak, by dziecko bez przeszkód mogło nabywać wiedzę i umiejętności na podstawie języka fonicznego.

W procesie szeroko rozumianego wsparcia społecznego należy uświadamiać niesłyszących rodziców, że ich słyszące dzieci mogą opanować biegle język migowy (mniejszości) oraz język foniczny (większości), jednak dzieci nie mogą być pozostawione „same sobie" w procesie nabywania języka fonicznego. Ważne jest, aby w procesie wychowania językowego korzystać z doświadczenia osób słyszących, krewnych, profesjonalistów (nauczycieli, logopedów), od możliwie wczesnych lat życia dziecka (w tym celu można przykładowo zorganizować w warunkach domowych pomoc słyszącej opiekunki (por. strategie nauczania dzieci drugiego języka, strategia: osoby, miejsca, czasu, przemienna – Kurcz, 2007), możliwie szybko zapisać dziecko do żłobka, następnie przedszkola, umożliwić dziecku korzystanie z zajęć logopedycznych (np. w poradni psychologiczno-pedagogicznej, poradniach logopedycznych często działających przy ośrodkach Polskiego Związku Głuchych). Podkreślić należy, że nie można podważać kompetencji rodzicielskich, w tym językowych i społecznych, niesłyszących rodziców, jedynie z powodu ich głuchoty. Należy ich jednak, w miarę możliwości, wspierać w procesie wychowania językowego słyszących dzieci. Istotne jest, aby słyszące osoby z otoczenia dzieci (np. dziadkowie, krewni, nauczyciele, logopedzi) wspierały także komunikację w języku migowym i rozumiały, że jest to sposób porozumiewania się dziecka z niesłyszącymi rodzicami (por. znaczenie prestiżu języka w rozwoju dwujęzyczności, tamże). Brak możliwości komunikacji z rodzicami może mieć poważne konsekwencje psychologiczne (Bene, 1977; Halbreich, 1979). Dlatego należy organizować dzieciom kontakty z różnymi osobami niesłyszącymi, w tym z dziećmi głuchymi (migającymi), doskonalić komunikację w języku migowym, np. przez udział w imprezach kulturalnych dla osób głuchych/Głuchych. Osoby z otoczenia społecznego dziecka (niesłyszące i słyszące) powinny szanować wzajemnie swoją odrębność językową/kulturową, a także dawać dziecku poczucie bezpieczeństwa i możliwość budowania dwujęzycznej tożsamości.

Bibliografia

Allsop, L., Kyle, J. (1997). *Deaf Parents and their Hearing Children. A Research Report*. Bristol: Deaf Studies Trust.

Bartnikowska, U. (2010). *Sytuacja społeczna i rodzinna słyszących dzieci niesłyszących rodziców*. Toruń: Wydawnictwo Edukacyjne Akapit.

Bene, A. (1977). The Influence of Deaf and Dumb Parents on a Child's Development. *The Psychoanalytic Study of the Child*, *32*(1), 175–194.

Brackenbury, T., Ryan, T., Messenheimer, T. (2006). Incidental Word Learning in a Hearing Child of Deaf Adults. *Journal of Deaf Studies and Deaf Education*, *11*(1), 76–93, http://jdsde.oxfordjournals.org, dostęp: 21.01.2016.

Braun-Gałkowska, M. (1987). *Psychologia domowa*. Olsztyn: Warmińskie Wydawnictwo Diecezjalne.

Chodkowska, M. (2010). Realizacja ról dziadków w rodzinach polskich tradycyjnych i współczesnych. W: B. Balogova (red.), *Elan vital v priestore medzigeneratčných vzt`abov: zbornik prispevkov z konferenci medzinárodnau účast`ou 15.01.2010* (s. 241–248). Prešov: Prešovská univerzita v Prešove.

Czajkowska-Kisil, M., Klimczewska, A. (2016), *CODA – Inność nie rozpoznana. Słyszące dzieci – niesłyszący rodzice. Pakiet informacyjny dla szkół i poradni*. Warszawa: Biuro Rzecznika Praw Obywatelskich.

Denzin, N.K., Lincoln, Y.S. (2009). Wprowadzenie. Dziedzina I praktyka badań jakościowych. W: N.K. Denzin, Y.S. Lincoln (red.), *Metody badań jakościowych*, tom I (s. 19–76). Warszawa: WN PWN.

Emmorey, K., Borinstein, H.B., Thompson, R. (2005). Bimodal Bilingualism: Codeblending between Spoken English and American Sign Language. W: J. Cohen, K.T. McAlister, K. Rolstad, J. MacSwan (red.), *Proceedings of the 4th International Symposium on Bilingualism* (s. 663–673). Somerville: Cascadilla Press.

Galvin, K.M, Braithwaite, D.O., Bylund, C.L. (2015). *Family Communication. Cohesion and Change*. London: Taylor & Francis Group.

Grabias, S. (1997). Mowa i jej zaburzenia. *Audiofonologia*, *10*, 9–36.

Gurba, E. (2013). *Nieporozumienia z dorastającymi dziećmi w rodzinie. Uwarunkowania i wspomaganie*. Kraków: Wydawnictwo Uniwersytetu Jagiellońskiego.

Halbreich, U. (1979). Influence of deaf-mute parents on the character of their offspring. *Acta Psychiatrica Scandinavica*, *59*(2), 129–138.

Harwas-Napierała, B. (2008). *Komunikacja interpersonalna w rodzinie*. Poznań: WN UAM.

Hintermair, M. (2000). Hearing Impairment, Social Networks, and Coping: The Need for Families with Hearing-Impaired Children to Relate to Other Parents and to Hearing-Impaired Adults. *American Annals of the Deaf*, *145*, 1, 41–53. https://doi.org/10.1177/02711214040240010201.

Jackson, C.W., Turnbull, A. (2004). Impact of Deafness on Family Life: A Review of the Literature. *Topics in Early Childhood Special Education*, *1*, 15–29. https://doi.org/10.1177%2F02711214040240010201.

Johnson, J.M., Watkins, R.V., Rice, M.L. (1992). Bimodal bilingual language development in a hearing child of deaf parents. *Applied Psycholinguistics*, *13*(1), 31–52. https://doi.org/10.1017/S0142716400005415.

Jones, M.L., Quigley, S.P. (1979). The Acquisition of Question Formation in Spoken English and American Sign Language by Two Hearing Children of Deaf Parents. *Journal of Speech, Language, and Hearing Research*, *44*(2), 196–208.

Kanto, L., Huttunen, K., Laakso, M.L. (2013). Relationship Between the Linguistic Environments and Early Bilingual Language Development of Hearing Children in Deaf-parented Families. *Journal of Deaf Studies and Deaf Education*, *18*(2), 242–260. https://doi.org/10.1093/deafed/ens071.

Kawczyńska-Butrym, Z. (1998). *Niepełnosprawność – specyfika pomocy społecznej*. Katowice: Wydawnictwo Śląsk.

Kijak, R. (2019). *Rodzice z niepełnoprawnością intelektualną*. Warszawa: WN PWN.

Kocoń, M. (2019), Wyzwania rodzicielskie i komunikacyjne Głuchych matek słyszących dzieci (KODA). *Zeszyty Pracy Socjalnej*, *24*, z. 2, 135–144. https://doi:10.4467/24496138ZPS.19.011.11088.

Kos, E. (2013). Wywiad narracyjny jako metoda badań empirycznych. W: D. Urbaniak-Zając, E. Kos (red.), *Badania jakościowe w pedagogice* (s. 91–116). Warszawa: WN PWN.

Krause, A. (2004). Ryzyko osłabienia wsparcia społecznego jako podstawowy dylemat współczesnej rehabilitacji. W: Z. Palak, Z. Bartkowicz (red.), *Wsparcie społeczne w rehabilitacji i resocjalizacji* (s. 47–54). Lublin: Wydawnictwo UMCS.

Krok, D. (2010). Systemowe ujęcie rodziny w badaniach dobrostanu psychicznego jej członków. W: D. Krok, P. Landwójtowicz (red.), *Rodzina w nurcie współczesnych przemian* (s. 359–368). Opole: Redakcja Wydawnictw Wydziału Teologicznego Uniwersytetu Opolskiego.

Kurcz, I. (2007). Jakie problemy psychologiczne może rodzić dwujęzyczność? W: I. Kurcz (red.), *Psychologiczne aspekty dwujęzyczności* (s. 9–39). Gdańsk: GWP.

Kvale, S. (2012). *Prowadzenie wywiadów*. Warszawa: WN PWN.

Mallory, B.L., Zingle, H.W., Schein, J.D. (1993). Intergenerational Communication Modes in Deaf-Parented Families. *Sign Language Studies*, *78*, 73–92. doi: 10.1353/sls.1993.0005.

Mitchell, R.E., Karchmer, M.A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, *4*(2), 138–163.

Murphy, J., Slorach, N. (1983). The Language Development of Pre-Preschool Hearing Children of Deaf Parents. *British Journal of Disorders of Communication*, *18*(2), 118–127.

Pizer, G.B. (2008). *Sign and Speech in Family Interaction: Language Choices of Deaf Parents and their Hearing Children*. https://repositories.lib.utexas.edu/handle/2152/17720, dostęp: 10.11.2019.

Podgórska-Jachnik, D. (2013). *Głusi. Emancypacje*. Łódź: Wydawnictwo Naukowe Wyższej Szkoły Pedagogicznej w Łodzi.

Radochoński, M. (1998). Wybrane zagadnienia psychopatologii w ujęciu systemowej koncepcji rodziny. *Roczniki Socjologii Rodziny*, *10*, 91–109.

Rozporządzenie MEN z dnia 9 sierpnia 2017 r. w sprawie zasad organizacji i udzielania pomocy psychologiczno-pedagogicznej w przedszkolach, szkołach i placówkach (Dz.U. 2017, poz. 1591).

Sachs, J., Bard, B., Johnson, M.L. (1981). Language learning with restricted input: Case studies of two hearing children of deaf parents. *Applied Psycholinguistics*, *2*(1), 33–54. https://doi.org/10.1017/S0142716400000643.

Schiff, N.B., Ventry, I.M. (1976). Communication problems in hearing children of deaf parents. *Journal of Speech and Hearing Disorders*, *4*(3), 348–358.

Schiff-Myers, N.B., Klein, H. (1985). Some phonological characteristics of the speech of normal hearing children of Deaf parents. *Journal of Speech and Hearing Research*, *28*(4), 466–474.

Singleton, J.L., Tittle, M.D. (2000). Deaf Parents and Their Hearing Children, *Journal of Deaf Studies and Deaf Education*, *5*(3), 221–236.

Stewart, A.J., Copeland, A.P., Chester, N.L., Malley, J.E., Barenbaum, N.B. (1997). *Separating together: How divorce transforms families*. New York: Guilford Press.

Toohey, E.N. (2010). Phonological Development in Hearing Children of Deaf Parents, Honors Scholar Theses. Paper 153. http://digitalcommons.uconn.edu/srhonors_theses/153, dostęp: 10.11.2019.

Wach, T. (2016). Pedagogiczna racjonalizacja transgeneracyjnych kodów socjokulturowych w rodzinach zagrożonych demoralizacją. W*:* E. Domagała-Zyśk, A. Borowicz, R. Kołodziejczyk (red.), *Język i wychowanie. Księga Jubileuszowa z okazji 45-lecia pracy naukowej Profesor Kazimiery Krakowiak* (s. 639–652). Lublin: Wydawnictwo KUL.

Wamboldt, F.S., Reiss, D. (1989). Defining a family heritage and a new relationship identity: Two central tasks in the making of a marriage. *Family Process*, *28*, 317–335.

Zaborniak-Sobczak, M. (2020). Komunikacja niesłyszących rodziców ze słyszącymi dziećmi (problemy w relacjach codziennych). *Konteksty Pedagogiczne* (w druku).

Zaborniak-Sobczak, M., Perenc, L. (2017). Wiedza językowa słyszących dzieci niesłyszących rodziców. Studium przypadku. *Logopedia*, *46*, 337–353.

Zaorska, M. (1996). Sprawność językowa słyszących dzieci niesłyszących rodziców. *Roczniki Pedagogiki Specjalnej*, *7*, 444–455.

WSPARCIE SPOŁECZNE W ROZWIJANIU KOMUNIKACJI JĘZYKOWEJ SŁYSZĄCYCH DZIECI W NARRACJACH NIESŁYSZĄCYCH RODZICÓW

Abstrakt

W artykule omówiono znaczenie komunikacji dla życia rodzinnego, a następnie ukazano wagę wsparcia społecznego w rozwijaniu komunikacji w środowisku językowym tworzonym przez niesłyszących rodziców wychowujących słyszące dzieci. Niezbędny wydaje się tu udział osób trzecich, przede wszystkim najbliższych słyszących krewnych – dziadków, także specjalistów – logopedów i nauczycieli.

Słowa kluczowe: komunikacja językowa, słyszące dzieci niesłyszących rodziców (KODA), wsparcie społeczne

SOCIAL SUPPORT IN DEVELOPING VERBAL COMMUNICATION FOR HEARING CHILDREN IN THE NARRATIVES OF DEAF PARENTS

Abstract

The article discusses the meaning of communication for family life, and then shows the importance of the social support process in developing this communication in the lingual environment created by deaf parents bringing up hearing children. The participation of third parties seems to be necessary here, above all the closest hearing relatives – such as grandparents, and also specialists – speech therapists and teachers.

Keywords: verbal communication, hearing children of deaf parents – Kid/Kids of Deaf Adults (KODA), social support

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO”
CNS nr 3(49) 2020, 95–114
ISSN 1734-5537
DOI: 10.5604/01.3001.0014.3578

SEBASTIAN MRÓZEK*

OSOBA Z NIEPEŁNOSPRAWNOŚCIĄ W STRATEGIACH ROZWIĄZYWANIA PROBLEMÓW SPOŁECZNYCH – ANALIZA ZAPISÓW W PERSPEKTYWIE TEORII URIE BRONFENBRENNERA

Wprowadzenie

Gminy, powiaty i województwa jako jednostki samorządu terytorialnego są zobligowane do oferowania i praktycznego realizowania działań wpierających oraz pomocowych wobec przedstawicieli grup i środowisk defaworyzowanych – w tym także osób z niepełnosprawnościami. Jest to wyraz polityki opartej o decentralizację struktur państwa. Niepełnosprawność w perspektywie społecznej, a co za tym idzie także administracyjnej czy samorządowej, jest wciąż rozpatrywana w ramach problemu społecznego. Potwierdza to procedura opracowywania przez gminy *Strategii rozwiązywania problemów społecznych* i lokowanie w nich zagadnień dotyczących niepełnosprawności.

W polityce społecznej realizowanej wobec osób z niepełnosprawnościami należy rozróżnić terminy: *niepełnosprawni* i *niepełnosprawność*. „Niepełnosprawni rozumiani są jako określona grupa funkcjonująca w danej społeczności i wymiarze czasowo-przestrzennym. Niepełnosprawność interpretowana jest z kolei jako zjawisko, któremu należy zapobiegać, ale też antycypować jego powstawanie, rozwój i skutki” (Kołaczek, 2010, s. 29). Przyjmuję więc, za Tadeuszem Majewskim (1994, s. 35), że osoba z niepełnosprawnością (osoba niepełnosprawna) to jednostka, „w przypadku której istotne uszkodzenie albo obniżenie sprawności funkcjonowania organizmu powoduje utrudnienie, ograniczenie lub wręcz uniemożliwia wykonywanie zadań życiowych oraz wypełnianie ról społecznych wynikających z jej wieku, płci oraz czynników społecznych, środowiskowych

---

* Sebastian Mrózek (https://orcid.org/0000-0002-9490-2640); Uniwersytet Śląski w Katowicach, ul. Bankowa 12, 40-007 Katowice; tel. +48 32 3592222; e-mail: sebastian.mrozek@us.edu.pl

oraz kulturowych". Definicja ta jest szczególnie trafna, gdyż wieloaspektowo oraz z uwzględnieniem kontekstu społecznego i kulturowego (bardzo ważnego dla każdego człowieka) przedstawia sytuację i główne problemy osób z niepełnosprawnością.

Podejście do osób z niepełnosprawnościami na przestrzeni dziejów przeszło znaczącą ewolucję (por. Kulbaka, 2012). Była (i wciąż jest) to droga zmierzająca w kierunku respektowania praw do godności i poszanowania oraz włączania w nurt życia społecznego. Współcześnie propagowane i wdrażane są przedsięwzięcia i działania oparte na partnerstwie i wzajemnym szacunku. Oczywistym jest, że część z nich przyjmuje postać pozorną, mającą niekiedy za główny cel inne interesy, niż dobro osób z niepełnosprawnościami. Jednakże w wielości różnych działań zawsze znajdą się te autentyczne, które sprzyjają rozwojowi obecnie propagowanego nurtu inkluzji społecznej.

Dość trudna pozostaje zmiana względnie trwałych postaw społecznych i wyobrażeń, nacechowanych fałszywymi stereotypami. Człowiek często nie jest nawet świadomy tego, że posiada określone oczekiwania w stosunku do innych ludzi. Jego prawdziwe nastawienie staje się widoczne wtedy, gdy jakaś osoba nagle nie odpowiada danym normom, nie wypełnia oczekiwań, czy nie posiada wszystkich cech, które były jej dedykowane (Lejzerowicz, Książkiewicz, 2012). Spory toczą się nie tylko w aspekcie realnych postaw i stosunku pełnosprawnych wobec osób z niepełnosprawnościami, lecz także w aspekcie etyki języka i określeń stosowanych wobec tej grupy, np. pojęcie osoba niepełnosprawna *versus* osoba z niepełnosprawnością (por. Przyłuska-Fiszer, 2013).

Niewystarczającym jest już oferowanie przez jednostki samorządów terytorialnych działań pomocowych czy wspierających, bezpośrednio adresowanych do osób z niepełnosprawnościami. Ważna jest edukacja i aktywizacja zróżnicowanych środowisk i grup wchodzących w skład gminy, powiatu czy województwa. Chodzi o edukację społeczności lokalnej na temat niepełnosprawności. Do realizacji takich zamierzeń i celów jednostki samorządu terytorialnego wykorzystują współcześnie podejście o charakterze strategicznym.

Przedłożone opracowanie składa się z czterech części. W pierwszej z nich dokonano charakterystyki gminnych *Strategii rozwiązywania problemów społecznych*, a w drugiej bioekologicznej teorii systemów Urie Bronfenbrennera. Sedno opracowania stanowi część trzecia, w swoim zakresie obejmująca prezentację wyników badań własnych. To badania dotyczące zapisów i wynikających z nich przedsięwzięć o znamionach inkluzji, adresowanych do osób z niepełnosprawnościami i ulokowanych w *Strategiach rozwiązywania problemów społecznych*. Całość podsumowują konkluzje zestawione w czwartej części.

Celem tego artykułu jest rozpoznanie zapisów i wynikających z nich działań inkluzyjnych, przeznaczonych dla osób z niepełnosprawnościami, zapisanych w *Strategiach rozwiązywania problemów społecznych* powiatów żywieckiego (14 gmin) oraz cieszyńskiego (12 gmin). Celem jest ponadto rozpatrzenie wspomnianych zapisów na podstawie bioekologicznej teorii systemów Urie Bronfenbrennera.

Strategie rozwiązywania problemów społecznych jako narzędzia pomocne w kreowaniu lokalnej polityki inkluzyjnej

Termin „strategia" używany był głównie na potrzeby działań o charakterze militarnym, wojskowym lub politycznym. Dopiero w XX w. znalazł zastosowanie w teorii oraz praktyce szeroko rozumianego zarządzania organizacją. Przemiany ustrojowe zapoczątkowane w 1989 r. sprawiły, że gminy, a po 1999 r. także powiaty, stały się pewnego rodzaju samodzielnymi organizacjami, które działają w zróżnicowanych i zmiennych warunkach (m.in. demograficznych, gospodarczych, politycznych). Potrzebują długookresowych planów działania, by zagwarantować stałość w realizacji wyznaczonych celów. Planowaniem strategicznym dla potrzeb gminy określa się podejmowanie systematycznych i ciągłych działań, podczas których samorząd przewiduje i planuje przyszłość, a także dokonuje analizy zmian zachodzących w otoczeniu, obiera priorytetowe cele rozwoju, określając odpowiednie etapy i procedury ich realizacji oraz realne zasoby służące do ich osiągnięcia (Krzyszkowski, Przywojska, 2011).

Etymologicznie termin „strategia" pochodzi od greckiego słowa „strategós", które jest zbitką: „stratós" i „agein". „Stratós" oznaczało armię rozłożoną obozem, a „agein" przywództwo. Słowo „strategós" opisywało więc kogoś, kto przewodził armii i tworzył plan walki (Obłój, 2001). Obecnie strategia uchodzi za jeden z podstawowych instrumentów zarządzania. W najbardziej ogólnym świetle bywa utożsamiana z celowym i zamierzonym działaniem (Obłój, Trybuchowski, 2006). Definicji wyjaśniających podstawowy zakres tego pojęcia jest wiele. Przykładowo George A. Steiner, John B. Miner i Edmund R. Gray (1986, s. 5, cyt. za: Obłój, Trybuchowski, 2006, s. 127) uważają, że: „Podjęcie strategii odnosi się do formułowania głównych misji, zamierzeń i celów organizacyjnych; polityki i programów osiągania ich; metod niezbędnych, aby strategie zostały wdrożone dla osiągnięcia celów organizacyjnych". Herbert Simon (1976, s. 163, cyt. za: Obłój, Trybuchowski, 2006, s. 127) charakteryzuje ją jako „ciąg decyzji określających zachowanie w pewnych przedziałach czasu". Strategia jest skrupulatnym i wnikliwym planem działania o jasno wyznaczonych celach oraz określonych zasobach, które może wykorzystać organizacja lub jednostka do podjęcia działań w wyznaczonym do tego obszarze. Dobre strategie powinny respektować ponadto wymiar czasowo-przestrzenny, gdyż konstruowane są na daną kadencję, podczas której panują określone warunki.

Tworzenie przez gminy lokalnych strategii rozwiązywania problemów społecznych jest jednym z instrumentów tworzenia spójności społecznej (Hryniewiecka, Lipke, 2011). *Strategię rozwiązywania problemów społecznych* przedstawia się jako „uogólnione, stosunkowo trwałe i często – choć nie zawsze realizowane w toku działalności prowadzonej przez wyspecjalizowane organizacje, wzory interwencji społecznych” (Frieske, Popławski, 1999). Niczym odkrywczym jest to, że zasadniczym powodem ich tworzenia przez gminy jest przymus prawny wnikający z art. 17 Ustawy z dnia 12 marca 2004 o pomocy społecznej (za: Krzyszkowski, Przywojska, 2011), który na te najmniejsze jednostki samorządu terytorialnego nakłada obowiązek opracowywania wspomnianego dokumentu. To niekiedy przyczynia się do niepożądanego zjawiska pozorowania zawartych w strategiach działań.

Lokalna polityka społeczna oznacza taką działalność jednostek samorządu terytorialnego, która zaspokaja potrzeby wszystkich członków społeczności lokalnej. Należy więc dokładnie rozpoznać potrzeby mieszkańców z niepełnosprawnością (którzy także reprezentują zróżnicowane warstwy społeczne) i określić priorytety związane z podejmowanymi aktywnościami (Głąbicka, 2013). Taki stan rzeczy dobrze wpisuje się w rozwój inkluzji społecznej, która przeciwdziała społecznemu wykluczeniu. Inkluzja jest rozumiana jako włączanie poszczególnych jednostek lub grup (głównie tych zagrożonych społecznym wykluczeniem i defaworyzowanych) do możliwie pełnego uczestnictwa w życiu społecznym. O efektywnie przebiegającym procesie inkluzji można mówić wtedy, gdy osoby funkcjonujące w określonej przestrzeni czują się zintegrowane z daną społecznością i w pełni uczestniczą w jej życiu (Fidelus, 2016) oraz niwelowane są skutki negatywnej stereotypizacji i postaw. W tym przypadku cele społecznej inkluzji, jak i realizacji polityki spójności, której narzędziami mogą być *Strategie rozwiązywania problemów społecznych*, są ze sobą zbieżne i dobrze się dopełniające. Wedle strategicznych założeń podejmowane są na różnych poziomach próby aktywizacji społecznej i zawodowej takich grup osób oraz udzielanie im fachowej pomocy doradczej, terapeutycznej czy psychologicznej (Głąbicka, 2013).

Przygotowanie dobrej *Strategii rozwiązywania problemów społecznych* wymaga od przedstawicieli jednostek samorządów terytorialnych znacznego nakładu czasu poświęconego na wnikliwą diagnozę potrzeb środowiska lokalnego oraz zaangażowanie w procedurę jej opracowywania instytucji i podmiotów zewnętrznych, które zajmują się fachowym poradnictwem czy udzielaniem wsparcia konkretnego typu. Zdaniem Michała Porowskiego (1998, s. 43) tworzy to „sieć powiązanych ze sobą służbowo lub funkcjonalnie albo pozostających w układach komplementarnych urzędów, organizacji pozarządowych, niesformalizowanych grup zadaniowych bądź pojedynczych osób, które z profesjonalnego obowiązku, na zasadzie wolontariatu czy z własnej woli i własnym sumptem realizują w granicach swojej kompetencji, pod kontrolą prawa lub tylko sumienia działania polegające na pomaganiu człowiekowi w odzyskaniu poczucia własnej wartości, unikaniu skutków bezradności, usprawnieniu lub odzyskaniu zdolności społecznego funkcjonowania przez odpowiednio dobrane czynności wspierające, wyręczające, ochraniające, rehabilitacyjne czy korekcyjne, a także tworzeniu makrostrukturalnych i środowiskowych warunków potrzebnych do osiągnięcia tych celów”.

Prawidłowo skonstruowana *Strategia rozwiązywania problemów społecznych* może być narzędziem szczególnie przydatnym oraz porządkującym wspomniane kwestie. Powinna być czytelna przede wszystkim dla odbiorców proponowanych w niej rozwiązań, a lokowane w niej aktywności być właściwie realizowane oraz odpowiednio umotywowane. Tylko w taki sposób działania proponowane przez jednostki samorządu terytorialnego mogą się faktycznie przyczynić do wspomagania nurtu inkluzji, co za tym idzie podnieść jakość życia osób dotkniętych niepełnosprawnością.

Bioekologiczna teoria systemów Urie Bronfenbrennera – podstawowe założenia

Choć bioekologiczna teoria systemów Urie Bronfenbrennera jest powszechnie znana z różnych opracowań, to jednak w aspekcie podjętej problematyki warto przypomnieć jej podstawowe założenia. Będą one przydatne do klasyfikacji i uporządkowania materiału badawczego zgromadzonego na potrzeby tego opracowania.

Środowisko społeczne jawi się jako twór, w którym w sposób kontekstowy przebiega rozwój jednostki. Niewątpliwie istnieje stały, dynamiczny obustronny i wzajemny związek między rozwijającą się osobą a otoczeniem, w którym przyszło jej funkcjonować (Brzezińska, 2005). Urie Bronfenbrenner i Ann C. Crouter (1983, za: Brzezińska, 2005) środowisko rozwoju ujmują jako: związki między ludźmi, szczególnie w rodzinie (jak u Zygmunta Freuda); pole psychologiczne, przestrzeń życiowa (jak u Kurta Lewina); wewnętrzna konstrukcja umysłowa (jak u Jeana Piageta); socjalizacja w kontekście kulturowym (jak u Granville Stanley’a Halla); zbiór symbolicznych interakcji (jak w szkole chicagowskiej symbolicznego interakcjonizmu, z ujęciem socjalizacji podkreślającym rolę „znaczących innych” w rozwoju jednostki zarówno w rodzinie, jak i poza nią); czy kontekst kulturowy, ze szczególną rolą bardziej zaawansowanych uczestników kultury (np. dorosłych), pełnioną względem mniej zaawansowanych (np. dzieci) i podkreślaniem roli mowy w rozwoju człowieka (jak u Lwa S. Wygotskiego).

Bronfenbrenner (1979, za: Brzezińska, 2005) traktuje środowisko społeczne, w którym funkcjonuje człowiek jako układ wzajemnie oddziałujących na siebie podsystemów, umiejscowionych jedne w drugich (jak rosyjskie lalki – matrioszki). Analizując wpływ otoczenia na jednostkę, podkreśla, że:

- każdy człowiek w indywidualny dla siebie sposób spostrzega i interpretuje otoczenie, w którym funkcjonuje i to jest „jego rzeczywistość”, w której podejmuje różne działania, samodzielnie lub przy partycypacji innych osób, każdy człowiek rozwija się więc w innym środowisku i w innym kontekście;

- wpływ otoczenia może być bezpośredni – związany z tym, z kim i w jakie interakcje wchodzi jednostka w danym siedlisku oraz pośredni – zdarzenia i sytuacje w innym siedlisku, w którym sama jednostka bezpośrednio nie uczestniczy, a nawet nie funkcjonuje na zasadzie obserwatora mają na nią jednak wpływ albo przez innych uczestniczących w nich ludzi (powiązanych z tą jednostką), albo poprzez stwarzanie w ten sposób warunków do działania zarówno samej jednostce, jak i powiązanych z nią ludzi; to co się dzieje w jednych siedliskach oddziałuje na to, co dzieje się w innych;
- jednostka w czasie swojego życia zmienia środowiska (siedliska), w których funkcjonuje, zajmuje wtedy inną pozycję społeczną, uczy się pełnienia nowych ról, wchodzi w odmienne interakcje, podejmuje nowe działania, określane to bywa „przesunięciem ekologicznym”;
- wyróżnia się pięć rodzajów systemów, w których rozwija się jednostka: mikrosystem, mezosystem, egzosystem, makrosystem, chronosystem (tamże).

Mikrosystem to ta część środowiska społecznego osoby, z którą ma ona bezpośredni kontakt. Charakterystyczne jest dla niego to, że zachodzą w nim wzajemne bezpośrednie relacje między członkami. Mniejsze środowiska mikrosystemu określane są jako siedliska (*setting*). Najczęściej ich egzemplifikacją są: dom rodzinny, żłobek, przedszkole, grupa rówieśnicza. Mezosystem odnosi się zaś nie tylko do określonego środowiska czy siedliska, lecz także do powiązań oraz wzajemnych zależności między poszczególnymi siedliskami mikrosystemu. Ujmuje on ścisłą zależność między tym, co się dzieje w jednym siedlisku a tym, jak osoba funkcjonuje w każdym z nich. Egzosystem to z kolei środowisko, w którym osoba nie uczestniczy bezpośrednio, lecz uczestniczą w nim inni członkowie jego mikrosystemu. Egzosystem ma wpływ zarówno na mikrosystem, jak i poszczególne jego siedliska. Makrosystem rozumiany jest jako polityka państwa, która przekłada się na kwestie gospodarcze, ekonomiczne, kulturowe czy oświatowe – czyli wszystkie obszary życia człowieka wchodzące w skład sfery społecznej. Chronosystem pojawił się w koncepcji Bronfenbrennera jako ostatni. Związany jest on z czasowym wymiarem doświadczeń osoby. Łączy się z kontekstem historycznym, który kreuje teraźniejszość życia, warunki gospodarcze, kulturowe, społeczne. Mogą nimi być np. kryzys gospodarczy, zmiana ustrojowa, postęp techniczny (Chrzanowska, 2015).

Osoby z niepełnosprawnościami, funkcjonując w społeczeństwie w interakcjach z innymi ludźmi czy organizacjami, znajdują się często w trudnych sytuacjach deprywacji, przeciążenia i zagrożenia. Współczesny świat szczególny nacisk kładzie na wartości o charakterze utylitarnym. Konkurencja i trudna sytuacja, chociażby na rynku pracy, przyczyniają się do powstawania licznych barier odnoszących się do osób z niepełnosprawnościami, które często słabiej bronią swoich praw lub z góry skazują się na niepowodzenia (Stochmiałek, 2004). Bioekologiczna teoria systemów Urie Bronfenbrennera będzie przydatna do przeprowadzenia swoistej diagnozy sytuacji osób z niepełnosprawnościami na terenach gminnych. Rozpatrzenie na jej podstawie omawianego obszaru najmniejszych jednostek samorządu terytorialnego umożliwi rozpoznanie uwarunkowań i zależności, które determinują społeczno-gminne funkcjonowanie osób z niepełnosprawnościami na poziomie wyróżnionych przez Bronfenbrennera systemów. Interesująco wydaje się przedstawiać ponadto zagadnienie dotyczące zapisów i działań związanych z szeroko pojętą inkluzją osób z niepełnosprawnościami, które lokowane są przez włodarzy gminnych w *Strategiach rozwiązywania problemów społecznych*. Zweryfikowanie zapisów przez pryzmat bioekologicznej teorii systemów pozwoli na ich uporządkowanie oraz ukazanie wzajemnych powiązań międzysystemowych, które przyczynić się mogą do poprawy sytuacji społecznej (na poziomie społeczności lokalnych) osób dotkniętych niepełnosprawnością, a także upowszechnienie dobrych praktyk.

Koncepcja badań własnych

Stanisław Kowalik (2007) wskazuje, że w rozwiązywaniu problemów i barier o charakterze psychospołecznym tak samo ważne są oddziaływania skierowane na osobę usprawnianą, jak i na ludzi, którzy tworzą jej społeczne środowisko. Kieruje uwagę na założeniowo bliską teorii Bronfenbrennera koncepcję ekosystemów społecznych opracowaną przez Juliana Rappaporta (por. Rappaport, 1977). Osoba z niepełnosprawnością zwykle jest mniej lub bardziej uwikłana we własny ekosystem społeczny. Jeśli te więzi są silne, wówczas ekosystem ma duże możliwości regulowania aktywności swych członków. Z kolei, gdy uwikłanie w ekosystem jest niewielkie, wówczas w zasadzie znikają jakiekolwiek możliwości wywierania wpływu. Stanisław Kowalik (2007) proponuje uwzględnić w procesie rehabilitacji następujące postulaty, które mogą się także przyczynić do zlikwidowania bądź niwelowania barier społecznych:

1. Należy zainteresować możliwościami rehabilitacyjnymi członków rodziny osoby dotkniętej niepełnosprawnością. Mogą oni stać się najważniejszymi sprzymierzeńcami w aktywizowaniu członka swej rodziny. Niestety, często w tym mikrośrodowisku można napotkać na najsilniejszy opór wobec działań usprawniających (nadopiekuńczość). Niezbędne jest więc prowadzenie w rodzinie działań edukacyjnych na rzecz rehabilitacji.
2. Proces mobilizowania do aktywności osób z niepełnosprawnością powinien obejmować całą społeczność lokalną. Im więcej ludzi będzie zaangażowanych w usprawnienie, tym bardziej ta działalność będzie traktowana jako naturalna i pozbawiona znamion wstydu.
3. Należy umożliwić osobom z niepełnosprawnością uczestniczenie w programach rehabilitacyjnych w dogodnych miejscach i w dogodnym czasie. Chodzi o to, aby w ekosystemie społecznym działali odpowiedni specjaliści w zakresie rehabilitacji, aby był zapewniony transport do miejsca zajęć, aby oso-

by z poważnymi dysfunkcjami miały zapewnioną pomoc w dojściu do tego miejsca i przygotowania się do zajęć.
4. Należy dążyć do tego, aby wszelkie zajęcia rehabilitacyjne były prowadzone w małych grupach (8–15 osób). Taka grupa może w większym stopniu mobilizować swoich członków do podjęcia większej aktywności. Grupy bardziej liczne uniemożliwiają tworzenie się bardziej intymnych relacji między osobami rehabilitowanymi oraz mogą zwiększać poczucie wstydu.
5. Należy starać się stopniowo integrować zorganizowane grupy osób z niepełnosprawnością z szerszą społecznością lokalną (m.in. poprzez występy artystyczne, zawody sportowe przy współudziale rodzin, prezentacje w mass mediach osiągnięć zawodowych). To najlepszy sposób na usuwanie negatywnych stereotypów społecznych, które ciągle dominują w świadomości społecznej.

W ramach podjętego zagadnienia analizie poddano kwestie związane z zapisami w *Strategiach rozwiązywania problemów społecznych* oraz wynikające z nich działania o znamionach inkluzji wobec osób z niepełnosprawnościami. Problematyka badawcza została zawarta w następujących pytaniach badawczych:

- Na poziomach jakich systemów wyróżnionych w teorii Bronfenbrennera realizowane są propozycje działań włączających wobec osób z niepełnosprawnościami zapisane w *Strategiach rozwiązywania problemów społecznych*?
- Jakie formy zapisy te przyjmują w obszarze zidentyfikowanych systemów?

Szukając odpowiedzi na postawione problemy badawcze, jakościowej analizie dokumentów zostały poddane *Strategie rozwiązywania problemów społecznych* gmin wchodzących w skład powiatu żywieckiego (14 gmin) oraz cieszyńskiego (12 gmin). Dokładny spis analizowanych strategii został umieszczony po bibliografii. Strategie zostały pozyskane z domen BIP (Biuletyn Informacji Publicznej) gmin, witryn internetowych urzędów gmin lub poprzez bezpośredni kontakt z przedstawicielami gmin. Uzyskano dostęp do wszystkich strategii z gmin powiatu cieszyńskiego (12 gmin). W przypadku powiatu żywieckiego dostęp uzyskano do 14 z 15 strategii wchodzących w skład powiatu gmin. W przypadku jednej gminy dostęp do strategii okazał się niemożliwy, ze względu na obecną jej aktualizację). Jest to kolejny etap badań pilotażowych związanych z lokowaniem problematyki niepełnosprawności w strategiach gminnych. Wybór gmin wchodzących w skład tych dwóch powiatów jest celowy. Są one porównywalne ze sobą pod względem wielkości i demografii oraz ze względu na bliskie sąsiedztwo. Taki dobór obszaru badań wynika też z planowanych szerzej zakrojonych badań eksploracyjno-diagnostycznych, które będą dotyczyły częstotliwości występowania w strategiach gminnych określonych zapisów. Ich celem będzie: rozpoznanie i opisanie zapisów dotyczących osób z niepełnosprawnościami w *Strategiach rozwoju gmin* i w *Strategiach rozwiązywania problemów społecznych*, szczegółowe rozpoznanie procedury opracowywania gminnych strategii i lokowania w nich problematyki niepełnosprawności, określenie wskaźników realizacji proponowanych w strategiach badań. Będą one jednak przedmiotem innego opracowywania. W badaniach prezentowanych na łamach tego artykułu skupiono się na wybranym wycinku wspomnianej problematyki.

W ramach przybliżanych badań jako metoda została zastosowana analiza dokumentów o charakterze jakościowym, porządkującym. Poddano jej *Strategie rozwiązywania problemów społecznych* gmin wchodzących w skład powiatu żywieckiego oraz cieszyńskiego.

Analiza dokumentów jest metodą, która pomaga w doprecyzowaniu odpowiedzi na pytania, takie jak: co chciał przedstawić autor danego dokumentu, jakie wyraził w nim treści, o czym te treści mogą świadczyć bądź w jaki sposób są oryginalne i wyróżniające się (Łobocki, 2011). Przyjmuje się, że w analizie jakościowej klucz kategoryzacyjny to określony wynik badania lub lista zagadnień ujmowanych w materiale badawczym, która podkreśla ich zróżnicowanie oraz różnorodność (Szczepaniak, 2012). Analiza kategoryzowania przynależności pozwala badaczowi jakościowemu na odkrywanie reguł dokonywania opisu jako takiego oraz dotyczy normatywnych i kognitywnych form zakładanych społecznych relacji, które są zawarte w procesie tworzenia i rozumienia tekstów (Peräkylä, 2010).

W przypadku przedłożonego opracowania ważne jest, po pierwsze zidentyfikowanie (z pomocą założeń teorii Bronfenbrennera) systemów, na poziomie których realizowane są działania i przedsięwzięcia włączające osoby z niepełnosprawnościami w nurt życia społecznego. Ponadto założono, że w wyniku prowadzonej analizy do zidentyfikowanych systemów przypisane zostaną sprecyzowane zapisy w ich obrębie ulokowane w strategiach. Przyjęto, że ukaże to ich zróżnicowanie oraz różnorodność, a także stanowiło będzie kolejny przyczynek do dalszej diagnozy sytuacji osób z niepełnosprawnościami na terenie środowiska lokalnego. Oczywiście na podstawie badań pilotażowych trudno jednoznacznie potwierdzić, które działania o charakterze włączającym osoby z niepełnosprawnościami realizowane są faktycznie, a które tylko pozornie. Tych zagadnień będzie jednak dotyczył kolejny etap badań. Pewnym jest natomiast, że powinny być to oddziaływania zawierające kompleksową ofertę pomocy, a to pomogą już ustalić badania zrealizowane na potrzeby tego opracowania.

Prezentacja i omówienie wyników badań

Prezentowane wyniki badań pilotażowych są dopełnieniem wcześniejszych, rozpatrywanych w różnych kontekstach rozważań, dotyczących sytuacji osób z niepełnosprawnościami w strategiach gminnych (por. Gajdzica, Mrózek, 2017; Mrózek, 2019a, 2019b). Wraz z nimi stanowią podstawę szerzej zakrojonych badań w obrębie wspomnianej tematyki, które uwzględniać będą częstotliwość występowania sprecyzowanych zapisów dotyczących osób z niepełnosprawnościami w wybranych gminach polskich (uwzględniając podział na gminy miejskie, miejsko-wiejskie, wiejskie). Weryfikacji poddane zostaną także procedury lokowania problematyki niepełnosprawności w dwóch typach strategii gminnych: *Strategii rozwoju gmin* i *Strategii rozwiązywania problemów społecznych*.

Umieszczone w tym artykule wyniki stanowią porządkującą analizę w aspekcie bioekologicznej teorii systemów Urie Bronfenbrennera. W *Strategiach rozwiązywania problemów społecznych* wspomniane zapisy ulokowane są w różnych miejscach – głównie we fragmentach poświęconych na analizę SWOT gminy oraz w rozdziałach dotyczących celów strategicznych gmin na najbliższe lata. W dokumentach zapisy te nie tworzą uporządkowanej całości, tylko rozmieszczone są w różnych częściach składowych strategii. Tym bardziej trudno rozpatrywać je jako konkretne, realizowane postulaty. Wprawdzie przy wybranych z nich znajdują się wskaźniki dotyczące ich realizacji, jednak nie są to skonkretyzowane dane liczbowe, a jedynie orientacyjne hasła (np. liczba rodzin korzystających z pomocy PCPR, liczba osób z niepełnosprawnościami korzystających z WTZ). Prezentowana analiza powinna być traktowana w umownych ramach, gdyż nie rozpatruje danych każdej z gmin z powiatu żywieckiego i cieszyńskiego w sposób oddzielny, a zwraca uwagę na zapisy dotyczące głównych obszarów i rozwiązań na poziomie różnych systemów społecznych (często się o siebie zazębiających).

Za zapisy wobec osób z niepełnosprawnościami w obrębie mikrosystemu przyjęto te, które w sposób bezpośredni odnoszą się do osób z niepełnosprawnościami i ich najbliższego otoczenia (rodzina, opiekunowie). Do mezosystemu przyporządkowano zapisy związane ze zmianami i przeobrażeniami środowiska na poziomie lokalnym (pod względem problematyki funkcjonowania osób z niepełnosprawnościami). W obrębie egzosystemu wyodrębniono zapisy dotyczące szeroko pojętej diagnozy sytuacji osób z niepełnosprawnościami w środowisku lokalnym. W przypadku makrosystemu wyróżniono zaś zapisy związane z regulacjami prawnymi oraz systemowymi dotyczące osób z niepełnosprawnościami na poziomie ogólnokrajowym. W chronosystemie odnaleźć można zapisy świadczące o zmianie postrzegania samej niepełnosprawności na przestrzeni lat. Ich szczegółowe uporządkowanie znajduje się w dalszej części artykułu.

Analizując uporządkowany w tabelach materiał, można zauważyć, że najwięcej zapisów w *Strategiach rozwiązywania problemów społecznych* przyporządkowanych zostało do mikrosystemu. Na potrzeby badań własnych przyjęto za nie zapisy i wynikające z nich przedsięwzięcia, które odnoszą się do osób z niepełnosprawnościami i ich najbliższego otoczenia, w przypadku których zachodzić mogą bezpośrednie relacje między stronami tych oddziaływań. Katalog zapisów, które zostały przyporządkowane do mikrosystemu jest dość bogaty, zawierając w sobie treści związane z rehabilitacją, pomocą socjalną, wsparciem

Tabela 1. Zapisy dotyczące osób z niepełnosprawnościami w obrębie mikrosystemu

Zapisy bezpośrednio odnoszące się do osób z niepełnosprawnościami i ich najbliższego otoczenia (np. rodzina, opiekunowie)
– Działalność Miejskich Ośrodków Pomocy Społecznej: udzielanie świadczeń pracy socjalnej, udzielnie pomocy finansowej (zasiłki stałe i okresowe), organizowanie form opiekuńczych, udzielenie konsultacji oraz porad dotyczących praw, przywilejów, możliwości rozwoju dla osób z niepełnosprawnościami (nauka, praca, rehabilitacja społeczna i zawodowa); – Wypłacanie przez Zakład Ubezpieczeń Społecznych świadczeń typu rentowego; – Realizowanie programów Państwowego Funduszu Rehabilitacji Osób Niepełnosprawnych (programy aktywizujące zawodowo, społecznie), adresowane bezpośrednio do osób z niepełnosprawnościami i ich najbliższych; – Działalność na terenach gmin lokalnych oddziałów Państwowego Urzędu Pracy i Ochotniczych Hufców Pracy informujących o dostępności wolnych miejsc pracy dla osób z niepełnosprawnościami, prowadzących ich regularną rejestrację oraz realizujących staże i szkolenia do nich adresowane; – Działalność na terenach wybranych gmin Warsztatów Terapii Zajęciowej i Klubów Integracji Społecznej; – Funkcjonowanie na terenach wybranych gminy zakładów pracy chronionej, zakładów aktywności zawodowej i innych form pracy alternatywnej adresowanych do osób z niepełnosprawnościami; – Funkcjonowanie na terenach wybranych gmin placówek krótkoterminowego pobytu dla osób z niepełnosprawnościami; – Funkcjonowanie/tworzenie na terenach gmin domów pomocy społecznej przeznaczonych i oferujących specjalistyczną opiekę dla osób z niepełnosprawnościami; – Funkcjonowanie na terenach gmin szkół specjalnych, integracyjnych lub z oddziałami integracyjnymi oraz OREW-ów oferujących zajęcia rewalidacyjne, korekcyjno-kompensacyjne, wyrównawcze, nauczanie wielopoziomowe, stymulowanie rozwoju, treningi społeczne; – Możliwość dowozu dzieci do szkół i placówek specjalistycznych funkcjonujących na terenach gmin; – Możliwość skorzystania w wybranych gminach z wypożyczalni sprzętu rehabilitującego; – Udzielanie pomocy rodzicom w wychowaniu, edukacji oraz terapii dziecka o specjalnych potrzebach edukacyjnych (np. organizowanie zajęć z zakresu wczesnego wspomagania rozwoju dziecka, konsultacje w poradniach PPP); – Funkcjonowanie na terenach gmin placówek służby zdrowia oferujących osobom z niepełnosprawnościami pomoc medyczną czy rehabilitacyjną oraz działania profilaktyczne; – Dowozy posiłków do miejsca zamieszkania osób z niepełnosprawnościami, dowóz opału w okresie zimowym i inne formy świadczeń rzeczowych; – Funkcjonowanie na terenach gmin Asystentów Osoby Niepełnosprawnej; – Funkcjonowanie grup wsparcia dla osób z niepełnosprawnościami i ich opiekunów (opieka psychologa); – Organizowanie warsztatów informacyjnych i treningów dla opiekunów osób z niepełnosprawnościami, z udziałem specjalistów z PFRON, ZUS, PCPR, GOPS.

Źródło: opracowanie własne.

Tabela 2. Zapisy dotyczące osób z niepełnosprawnościami w obrębie mezosystemu

Zapisy dotyczące zmian i przeobrażeń środowiska na poziomie lokalnym, w którym funkcjonują osoby z niepełnosprawnościami
– Realizowanie zadań inwestycyjnych i remontowych pod kątem dostosowania gmin do potrzeb mieszkańców z niepełnosprawnościami; – Realizowanie zadań opartych na PFRON: dofinansowanie na likwidowanie barier funkcjonalnych, organizowanie turnusów rehabilitacyjnych, zaopatrzenie w przedmioty ortopedyczne i inne środki niezbędne dla osób z niepełnosprawnościami; – Włączanie i angażowanie osób z niepełnosprawnościami w zadania z zakresu rozwoju kultury, sportu, rekreacji; – Propagowanie nurtu społecznej integracji czy inkluzji poprzez tworzenie szkół i klas integracyjnych, inkluzyjnych oraz podejmowanie działań uwrażliwiających społeczeństwo na potrzeby osób z niepełnosprawnościami; – Organizowanie przez samorządy lokalne imprez integracyjnych (sportowych, kulturalnych itp.), wycieczek, w które zaangażowane są zarówno osoby pełnosprawne, jak i z niepełnosprawnościami; – Działalność fundacji, stowarzyszeń oraz innych podmiotów (organizacji pozarządowych) przeznaczających pozyskane środki na poprawę sytuacji życiowej, mieszkaniowej, zdrowotnej osób z niepełnosprawnościami oraz podejmujących się działań aktywizacyjnych poprzez pracę, edukację osób zagrożonych społecznym wykluczeniem oraz zwalczanie fałszywych stereotypów; – Propagowanie wśród mieszkańców uprawiania zdrowego i aktywnego trybu życia; – Zwiększanie udziału i roli sektora niepublicznego oraz aktywności mieszkańców w realizacji zadań społecznych; – Rozwój i propagowanie wśród społeczności lokalnej wolontariatu działającego na rzecz osób starszych oraz osób z niepełnosprawnościami; – Realizowanie projektów propagujących pozytywny wizerunek osób z niepełnosprawnościami w społeczeństwie (źródła finansowania z funduszy unijnych); – Kreowanie przyjaznego osobom z niepełnosprawnościami lokalnego rynku pracy (zakłady pracy chronionej, Asystent Pracy, telepraca, praca w środowisku domowym); – Systematyczny rozwój kapitału społecznego wspierającego osoby z niepełnosprawnościami na terenach lokalnych.

Źródło: opracowanie własne.

społecznym i zawodowym osób, czasem wolnym. Choć z treści zapisów wynika, że są to przeważnie działania oferowane przez zróżnicowane podmioty (zarówno wsparcie formalne, jak i nieformalne), to jednak przeznaczone są one dla konkretnego odbiorcy, którym w tym przypadku jest osoba z niepełnosprawnością lub jej opiekunowie.

Na poziomie mezosystemu wyróżniono zapisy, które pod względem znaczeniowym odnoszą się do przeobrażeń środowiska lokalnego w aspekcie niepełnosprawności. Są one niekiedy analogiczne i bezpośrednio związane z zapisami ulokowanymi w mikrosystemie, ponieważ mezosystem sam w sobie ukazuje zależności zachodzące pomiędzy poszczególnymi siedliskami mikrosystemu. W tym przypadku chodzi o zależność między najbliższym środowiskiem funkcjonowania osób z niepełnosprawnością a kreowaniem bardziej rozległego śro-

Tabela 3. Zapisy dotyczące osób z niepełnosprawnościami w obrębie egzosystemu

Zapisy związane z diagnozą sytuacji osób z niepełnosprawnością w gminnym środowisku lokalnym
– Działalność w wybranych gminach oddziałów Powiatowych Centrów Pomocy Rodzinie diagnozujących sytuację podmiotów oferujących wsparcie, współpracujących z PFRON; – Działalność powiatowych i wojewódzkich zespołów do spraw orzekania o niepełnosprawności; – Diagnozowanie, opiniowanie, prowadzenie mediacji przez Poradnie Psychologiczno-Pedagogiczne, wydawanie orzeczeń do celów edukacyjnych oraz współpraca z przedszkolami, szkołami przy opracowywaniu indywidualnych programów edukacyjno-terapeutycznych; – Przeprowadzanie w jednostkach samorządu terytorialnego Narodowych Spisów Powszechnych Ludności i Mieszkań – uwzględniających sytuację społeczną i liczbową osób z niepełnosprawnościami na terenach konkretnych gmin; – Wzajemna współpraca i przepływ informacji pomiędzy placówkami socjalnymi, edukacyjnymi, wychowawczymi czy opiekuńczymi oferującymi zróżnicowane rodzaje wsparcia; – Systematyczny monitoring sytuacji osób z niepełnosprawnościami poprzez powołane do tego w gminach specjalistyczne komisje o charakterze socjalnym; – Dostępność szerokiego zaplecza eksperckiego (ekspertów ogólnokrajowych, zagranicznych), konsultacji ze specjalistami z różnych dziedzin, których propozycje mogą przyczynić się do poprawy sytuacji społecznej osób z niepełnosprawnościami; – Rozwój darmowego poradnictwa specjalistycznego; – Funkcjonowanie na terenach gmin i powiatów interdyscyplinarnych zespołów pomocowych (wspomagających pracę asystentów, koordynujących współpracę i działania miejskich ośrodków pomocy społecznej, szkół i innych instytucji wspierających); – Organizowanie kursów i szkoleń dla specjalistów/nauczycieli/opiekunów pracujących z osobami z niepełnosprawnościami; – Wczesna diagnostyka i opieka – funkcjonowania na terenach gmin oddziałów wczesnego wspomagania i wczesnej interwencji dziecka z niepełnosprawnością.

Źródło: opracowanie własne.

dowiska lokalnego i przeobrażeń w nim zachodzących, np. pod względem postrzegania osób z niepełnosprawnościami.

W egzosystemie wyróżniono zapisy związane z diagnozowaniem sytuacji osób z niepełnosprawnościami na poziomie lokalnym. Osoby z niepełnosprawnościami nie uczestniczą w tych działaniach bezpośrednio, a raczej przyjmują rolę warstwy społecznej, której potrzeby są rozpoznawane, a dopiero w następnej kolejności dobierane są do nich poszczególne rozwiązania w tym zakresie. W przytoczonych zapisach przeważają więc te opisujące działalność takich placówek czy instytucji o charakterze diagnostycznym, rozpoznającym sytuację, jak PCPR czy Poradnie Psychologiczno-Pedagogiczne.

Zapisy na poziomie makrosystemu dotyczą przede wszystkim kwestii związanych ze środowiskiem społecznym ogólnokrajowym oraz prawem państwowym. Zostały przyporządkowane do zestawienia, aby wyrażać spójność działań podejmowanych wobec osób z niepełnosprawnościami i realizowanych na po-

Tabela 4. Zapisy dotyczące osób z niepełnosprawnościami w obrębie makrosystemu

Zapisy związane z regulacjami prawnymi oraz systemowymi dotyczącymi osób z niepełnosprawnościami na poziomie ogólnokrajowym
– Działalność ZUS-u, orzekającego o niezdolności do pracy osoby z niepełnosprawnością; – Realizowanie postulatów w oparciu o Ustawę o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych z dnia 27 sierpnia 1997 roku; – Realizowanie postulatów na podstawie Ustawy o pomocy społeczne z dnia 12 marca 2004 roku; – Partnerstwo z sektorem obywatelskim; – Funkcjonowanie na terenach gmin lokalnych oddziałów Państwowego Funduszu Rehabilitacyjnego Osób z Niepełnosprawnościami; – Prowadzenie systematycznej diagnozy sytuacji lokalnej (porównując z sytuacją ogólnokrajową) ludzi starszych i z niepełnosprawnościami; – Dofinansowania pochodzące z budżetu państwa na działalność specjalistycznych placówek opiekuńczych i medycznych; – Uwzględnienie w lokalnej strategii zapisów znajdujących się w dokumentach na poziomie wojewódzkim: Strategia Rozwoju Województwa Śląskiego „Śląskie 2020+”, Strategia Polityki Społecznej Województwa Śląskiego na lata 2006–2020 i ogólnokrajowym: Strategii Długookresowej Kraju Polska, Strategii Średniookresowej Kraju Polska, Krajowej Strategii Rozwoju Regionalnego, Narodowego Programu Zdrowia, Strategii Rozwoju Kapitału Ludzkiego, Strategii Rozwoju Kapitału Społecznego, Krajowego Programu Działań na Rzecz Integracji Społecznej, Krajowy Program Przeciwdziałania Ubóstwu i Wykluczeniu Społecznemu 2020.

Źródło: opracowanie własne.

Tabela 5. Zapisy dotyczące osób z niepełnosprawnościami w obrębie chronosystemu

Zapisy związane z przemianami środowiska życia osób z niepełnosprawnościami
– Niepełnosprawność nie jest już rozumiana jako rezultat uszkodzenia ciała czy choroby, lecz jako rezultat barier społecznych, ekonomicznych, fizycznych występujących w środowisku; – Niepełnosprawność jest jednym z ważniejszych problemów współczesnego świata; – Funkcjonowanie terminu „osoba z niepełnosprawnością” zamiast „osoba niepełnosprawna”; – Osobom z niepełnosprawnościami powinny przysługiwać pewne szczególne prawa, tak aby w takim samym stopniu mogły korzystać z praw przysługujących wszystkim ludziom; – Wzrost społecznej akceptacji osób z niepełnosprawnościami, starszych i chorych; – Upowszechnianie w mediach problematyki niepełnosprawności w celu kształtowania pozytywnych postaw wobec tej grupy osób; – Respektowanie praw osób z niepełnosprawnościami na podstawie dokumentów i aktów krajowych oraz ogólnonarodowych: Uchwały z dnia 1 sierpnia 1997 r. Karta Praw Osób Niepełnosprawnych, Konstytucji RP, Powszechnej Deklaracji Praw Człowieka, Konwencji Praw Dziecka, Standardowych Zasad Wyrównywania Szans Osób Niepełnosprawnych, Konwencji ONZ o Prawach Osób Niepełnosprawnych oraz Międzynarodowej Klasyfikacji Funkcjonowania Niepełnosprawności i Zdrowia (ICF).

Źródło: opracowanie własne.

ziomie lokalnym z tymi, które obowiązują na wyższych pod względem administracyjnym poziomach. Stąd w tym systemie odnaleźć można różne programy, akty prawne czy dokumenty krajowe, z którymi lokalne strategie są spójne.

Przynajmniej teoretycznie powinno to przyczyniać się do stałości wprowadzanych rozwiązań i braku wyraźnych różnic między poszczególnymi jednostkami administracyjnymi. Tylko poprzez działania konsekwentne i precyzyjnie dobrane można rozszerzyć nurt inkluzji, również na poziomie lokalnych środowisk. Są to jednak także kwestie wynikające z legislacji prawnych (ustawy i rozporządzenia), którym muszą się podporządkować wszystkie jednostki samorządu terytorialnego.

W chronosystemie wyróżnione zostały ogólne zapisy dotyczące osób z niepełnosprawnościami. Są one związane z przemianami środowiska życia osób z niepełnosprawnościami, a także zmianami historycznymi i mentalnymi w postrzeganiu samej niepełnosprawności. Zapisy ulokowane w *Strategiach rozwiązywania problemów społecznych* pod tym względem ukierunkowane są na zmianę paradygmatu niepełnosprawności i odejścia od modelu medycznego na rzecz społecznego i biopsychospołecznego. W opisach lokalnej sytuacji osób z niepełnosprawnościami akcentowany jest nacisk na to, że niepełnosprawność jest rezultatem nie tylko uszkodzeń fizycznych, organicznych, lecz w dużej mierze także barier o charakterze społecznym. Strategie w swoich treściach przytaczają również ważne dokumenty, które z pewnością przyczyniły się do szerokiej zmiany w postrzeganiu osób z niepełnosprawnościami na poziomie ogólnonarodowym: Europejska Konwencja Praw Człowieka (1953), Standardowe Zasady Wyrównywania Szans Osób Niepełnosprawnych (1993), Konwencja ONZ o Prawach Osób Niepełnosprawnych (2006) oraz Międzynarodowa Klasyfikacja Funkcjonowania, Niepełnosprawności i Zdrowia (*ICF*, 2001). W analizowanych treściach zauważalna jest ponadto tendencja do odchodzenia (w kwestiach terminologicznych) od określeń „upośledzenie", „osoba niepełnosprawna", „separacja" na rzecz „niepełnosprawność intelektualna", „osoba z niepełnosprawnością" czy „włączanie społeczne". I choć inkluzja jest równoznacznym terminem co do tego ostatniego, to ciekawym jest, że pojawia się ona bardzo rzadko – wciąż jakby była tylko kolejnym etapem integracji.

Zakończenie

Analiza zapisów dotyczących osób z niepełnosprawnościami ulokowanych w *Strategiach rozwiązywania problemów społecznych* gmin powiatów żywieckiego i cieszyńskiego umożliwiła przyporządkowanie ich do poszczególnych ekosystemów. Zapisy zostały przypisane do wszystkich pięciu wyróżnionych w teorii Bronfenbrennera systemów, począwszy od mikrosystemu, poprzez mezo-, egzo-, makro- po chronosystem. Świadczy to o tym, że gminy, opracowując strategie, w sposób kompleksowy podchodzą do kwestii niepełnosprawności, a same osoby z niepełnosprawnościami (przynajmniej teoretycznie) mają zagwarantowane wieloaspektowe wsparcie udzielane przez zróżnicowane podmioty i na różnych poziomach. Rozpoczyna się ono od najbliższego, codziennego środowiska funkcjonowania osób z niepełnosprawnościami, po zmiany mentalne i wyobrażeniowe na poziomach społeczności lokalnych, aż po respektowanie i wdrażanie przez samorządy gminne rozwiązań obowiązujących na skalę ogólnokrajową czy nawet ogólnoświatową, zgodnie z polityką spójności. Choć o inkluzji społecznej nie mówi się w strategiach incydentalnie, to jednak z analizowanych zapisów wynikają przedsięwzięcia, które można określić jej znamionami.

Wielość i zróżnicowanie zapisów w strategiach nie może jednak świadczyć o jakości realnych działań pomocowych podejmowanych w środowisku lokalnym. Należy mieć świadomość tego, że część z nich przyjmuje tylko postać pozorną, na potrzeby umieszczenia ich w strategiach. To, że jest ich dużo oraz zazębiają się ze sobą zarówno pod względem treściowym, jak i na poziomie poszczególnych systemów, ma też słabsze strony. Brak ich uporządkowania (zajmują różne miejsca w strategiach), bardzo ogólne sformułowania treściowe oraz niedobór konkretnych danych liczbowych w obrębie ich wskaźnikowania w poważny sposób utrudniają, a wręcz niekiedy całkowicie uniemożliwiają rozliczenie gminy z realizacji proponowanych zamierzeń. Potrzebne są do tego dokładniejsze dane liczbowe i statystyki prowadzone przez włodarzy gminnych, które nie zawsze są publicznie dostępne. Stąd zaplanowany kolejny etap badań, weryfikujący częstotliwość występowania zapisów w strategiach gminnych.

Dla osób z niepełnosprawnościami i ich najbliższych strategia powinna uchodzić za dokument klarowny i zrozumiały w obcowaniu z nim – niestety tak nie zawsze jest. Oczywistym jest, że w przypadku *Strategii rozwiązywania problemów społecznych* osoby z niepełnosprawnościami są tylko jedną z wielu grup, do której dokument jest adresowany. Trudno jednak uporządkować wszystkie zapisy, które zwykle znajdują się w różnych miejscach: przy definiowaniu samej niepełnosprawności, w miejscu poświęconym na analizę SWOT, czy w wyznaczonych to tego celach strategicznych i formach ich ewaluacji, przyjmując zwykle dość ogólne formuły. To wydłuża czas poświęcony na znalezienie przez osoby z niepełnosprawnościami i ich opiekunów, konkretnej formy pomocy, o którą muszą się jeszcze później (zazwyczaj w toku procedur administracyjnych) ubiegać. Analiza danych przygotowana na potrzeby tego opracowania ma charakter umowny i nie odnosi się w sposób indywidualny do każdej z gmin. Pozwala jednak zakreślić ogólne ramy wsparcia osób z niepełnosprawnościami, z wykorzystaniem do tego zróżnicowanych środowisk i siedlisk społecznych.

Uporządkowanie wspomnianych zapisów pozwoliło na ukazanie ich wieloaspektowości oraz wynikających z nich oddziaływań na różnych poziomach funkcjonowania człowieka. Odnoszą się one zarówno do sfery społecznej, edukacyjnej, zawodowej, jak i związanej z rehabilitacją lub specjalistyczną opieką, proponując w tych zakresach zróżnicowane rozwiązania. Ponadto bardzo ważnym jest, że przedsięwzięcia z nich wynikające nie odnoszą się tylko do osób z niepełnosprawnościami, lecz podejmują także rolę uświadamiającą i edukującą społeczeństwo na poziomie lokalnym. Taki stan rzeczy przyczynia się do rozpowszechniania kultury inkluzji oraz stałego podnoszenia jakości życia osób z niepełnosprawnościami.

Bibliografia

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge Mass: Harvard University Press.

Bronfenbrenner, U., Crouter, A.C. (1983). The evolution of environmental models in developmental research. W: P.H. Mussen (red.), *Handbook of Child Psychology*, tom I: *History, Theory and Methods* (s. 357–414). New York: John Wiley and Sons.

Brzezińska, A. (2005). *Społeczna psychologia rozwoju*. Warszawa: Wydawnictwo Naukowe Scholar.

Chrzanowska, I. (2015). *Pedagogika specjalna. Od tradycji do współczesności*. Kraków: Oficyna Wydawnicza Impuls.

Fidelus, A. (2016). Rola zasobów wewnętrznych i zewnętrznych w modelu relacyjnej inkluzji społecznej. *Forum Pedagogiczne*, *1*, 57–70. https://doi.org/10.21697/fp.2016.1.04.

Frieske, K.W., Popławski, P. (1999). *Opieka i kontrola. Instytucje wobec problemów społecznych*. Katowice: Wydawnictwo Śląsk.

Gajdzica, Z., Mrózek, S. (2017). Cele i zadania działań edukacyjnych w obszarze kształcenia uczniów z niepełnosprawnością oraz edukacji o niepełnosprawności zawarte w strategiach rozwoju gmin a problem rozwoju edukacji inkluzyjnej. *Studia Pedagogiczne. Wokół wyzwań pedagogicznych*, LXX, 277–290.

Głąbicka, K. (2013). Strategie rozwiązywania problemów społecznych jako przykład realizacji lokalnej polityki społecznej. *Wrocławskie Studia Politologiczne*, *15*, 182–193.

Hryniewiecka, A., Lipke, A. (2011). Strategie rozwiązywania problemów społecznych – synteza z badań. W: M. Grewiński, A. Karwacki (red.), *Strategie w polityce społecznej* (s. 270–296). Warszawa: Mazowieckie Centrum Polityki Społecznej.

Kołaczek, B. (2010). *Polityka społeczna wobec osób niepełnosprawnych*. Warszawa: Instytut Pracy i Spraw Socjalnych.

Konwencja o Ochronie Praw Człowieka i Podstawowych Wolności. (1953). W skrócie: Europejska Konwencja Praw Człowieka, sporządzona w Rzymie dnia 4 listopada 1950 r., zmieniona następnie Protokołami nr 3, 5 i 8 oraz uzupełniona Protokołem nr 2, ratyfikowana przez Polskę 19 stycznia 1993 roku. http://isap.sejm.gov.pl/isap.nsf/download.xsp/WDU19930610284/T/D19930284L.pdf (Dz.U. 1993, nr 61, poz. 284), dostęp: kwiecień 2020.

Konwencja ONZ o Prawach Osób Niepełnosprawnych. (2006). Sporządzona w Nowym Jorku dnia 13 grudnia 2006, ratyfikowana przez Polskę w dniu 6 września 2012 roku, http://isap.sejm.gov.pl/isap.nsf/download.xsp/WDU20120001169/O/D20121169.pdf (Dz.U. 2012, poz. 1169), dostęp: kwiecień 2020.

Kowalik, S. (2007). Bariery utrudniające włączanie osób niepełnosprawnych w życie społeczne. Próba sformułowania nowego podejścia teoretycznego. *Nauka*, *3*, 49–69.

Kulbaka, J. (2012). *Niepełnosprawni. Z dziejów kształcenia specjalnego*. Warszawa: Wydawnictwo APS.

Krzyszkowski, J., Przywojska, J. (2011). Lokalne strategie rozwiązywania problemów społecznych jako instrument decentralizacji polityki społecznej. W: M. Grewiński, A. Karwacki (red.), *Strategie w polityce społecznej* (s. 221–238). Warszawa: Mazowieckie Centrum Polityki Społecznej.

Lejzerowicz, M., Książkiewicz, I. (2012). *Osoba z niepełnosprawnością a instytucje pomocowe*. Wrocław: Wydawnictwo GASKOR.

Łobocki, M. (2011). *Metody i techniki badań pedagogicznych*. Kraków: Oficyna Wydawnicza Impuls.

Majewski, T. (1994). W sprawie definicji osoby niepełnosprawnej. *Problemy Rehabilitacji Społecznej i Zawodowej*, *1*, 33–37.

Międzynarodowa Klasyfikacja Funkcjonowania, Niepełnosprawności i Zdrowia (*ICF*, 2001), Światowa Organizacja Zdrowia, https://www.pfon.org/images/dodatki/20140723_icf.pdf, Polskie Forum Osób z Niepełnosprawnościami, dostęp: kwiecień 2020.

Mrózek, S. (2019a). Categories and activities in the area of inclusion of people with disabilities found within commune strategies – selected examples based on the communes of the counties of Żywiec and Cieszyn districts. *Interdisciplinary Contexts of Special Pedagogy*, *27*, 29–52. doi: 10.14746/ikps.2019.27.02.

Mrózek, S. (2019b). Typy wsparcia społecznego osób z niepełnosprawnością zapisane w strategiach rozwoju gmin i w strategiach rozwiązywania problemów społecznych – analiza problematyki w dobie inkluzji. *Niepełnosprawność. Dyskursy Pedagogiki Specjalnej. Współczesne oblicza*, *34*, 52–69.

Obłój, K. (2001). *Strategia organizacji w poszukiwaniu trwałej przewagi konkurencyjnej*. Warszawa: Polskie Wydawnictwo Ekonomiczne.

Obłój, K., Trybuchowski, M. (2006).Zarządzanie strategiczne. W: A.K. Koźmiński, W. Piotrowski (red.), *Zarządzanie. Teoria i praktyka* (s. 123–167). Wydanie piąte, zmienione. Warszawa: WN PWN.

Peräkylä, A. (2010). Analiza rozmów i tekstów. W: N.K. Denzin, Y.S. Lincoln (red.), *Metody badań jakościowych*, tom 2 (s. 325–349). Warszawa: WN PWN.

Porowski, M. (1998). Służba społeczna – zakres pojęcia. W: W. Kaczyńska (red.), *O etyce służb społecznych* (s. 38–43). Warszawa: Instytut Profilaktyki Społecznej i Resocjalizacji Wydziału Stosowanych Nauk Społecznych i Resocjalizacji Uniwersytetu Warszawskiego.

Przyłuska-Fiszer, A. (2013). *Niepełnosprawność jako przedmiot refleksji bioetycznej*. Kraków: Wydawnictwo Fall.

Rappaport, J. (1977). *Community psychology. Values research and action*. New York: Holt, Rinehard and Wineston.

Simon, H.A. (1976). *Działanie administracji*. Warszawa: PWN.

Steiner, G.A., Miner J.B., Gray E. (1986). *Management Policy and Strategy*. New York: Macmillan Pub.

Stochmiałek, J. (2004). Społeczna integracja dorosłych osób niepełnosprawnych. W: G. Dryżałowska, H. Żuraw (red.), *Integracja Społeczna Osób Niepełnosprawnych* (s. 76–97). Warszawa: Wydawnictwo Akademickie Żak.

Standardowe Zasady Wyrównywania Szans Osób Niepełnosprawnych (1993), uchwalone 20 grudnia podczas 48 sesji Zgromadzenia Ogólnego Narodów Zjednoczonych, http://www.tus.org.pl/uploads/dokumenty/standardowe_zasady_wyrownywania_szans_osob_niepelnosprawnych.pdf, dostęp: kwiecień 2020.

Szczepaniak, K. (2012). Zastosowanie analizy treści w badaniach artykułów prasowych – refleksje metodologiczne. *Acta Universitatis Lodziensis Folia Sociologica*, *42*, 83–112.

Spis analizowanych strategii

Powiat cieszyński:

Strategia Rozwiązywania Problemów Społecznych w Gminie Brenna na lata 2014–2020;
Gminna Strategia Rozwiązywania Problemów Społecznych na lata 2014–2020, Gmina Chybie;
Strategia Rozwiązywania Problemów Społecznych w Gminie Dębowiec na lata 2012–2020;
Strategia Rozwiązywania Problemów Społecznych Gminy Goleszów na lata 2016–2020;
Gminna Strategia Rozwiązywania Problemów Społecznych Miasta Cieszyna na lata 2014–2020;
Strategia Rozwiązywania Problemów Społecznych Gminy Hażlach na lata 2018–2020;
Gminna Strategia Rozwiązywania Problemów Społecznych w Gminie Istebna na lata 2016–2022;
Gminna Strategia Rozwiązywania Problemów Społecznych Gminy Skoczów na lata 2014–2020;

Strategia Rozwiązywania Problemów Społecznych Gminy Ustroń na lata 2016–2020;
Strategia Rozwiązywania Problemów Społecznych Gminy Strumień na lata 2019–2026;
Gminna Strategia Rozwiązywania Problemów Społecznych w Mieście Wisła na lata 2016–2024;
Strategia Rozwiązywania Problemów Społecznych Gminy Zebrzydowice na lata 2018–2024.

Powiat żywiecki:

Strategia Rozwiązywania Problemów Społecznych w Gminie Czernichów na lata 2019–2029;
Strategia Rozwiązywania Problemów Społecznych Gminy Gilowice na lata 2008–2020;
Strategia Rozwiązywania Problemów Społecznych dla Gminy Jeleśnia na lata 2018–2022;
Gminna Strategia Rozwiązywania Problemów Społecznych w Gminie Koszarawa na lata 2016–2021;
Strategia Rozwiązywania Problemów Społecznych Gminy Lipowa na lata 2018–2023;
Strategia Rozwiązywania Problemów Społecznych dla Gminy Łękawica na lata 2016–2025;
Strategia Rozwiązywania Problemów Społecznych Gminy Łodygowice na lata 2014–2024;
Gminna Strategia Integracji i Rozwiązywania Problemów Społecznych w Gminie Milówka na lata 2014–2020;
Gminna Strategia Rozwiązywania Problemów Społecznych Gminy Radziechowy-Wieprz na lata 2014–2020;
Strategia Rozwiązywania Problemów Społecznych Gminy Ślemień na lata 2016–2025;
Strategia i Rozwiązywania Problemów Społecznych Gminy Świnna na lata 2015–2020;
Strategia Rozwiązywania Problemów Społecznych Gminy Ujsoły na lata 2014–2020;
Strategia Integracji i Rozwiązywania Problemów Społecznych Gminy Węgierska Górka na lata 2014–2020;
Strategia Rozwiązywania Problemów Społecznych dla Miasta Żywca na lata 2014–2020.

OSOBA Z NIEPEŁNOSPRAWNOŚCIĄ W STRATEGIACH ROZWIĄZYWANIA PROBLEMÓW SPOŁECZNYCH – ANALIZA ZAPISÓW W PERSPEKTYWIE TEORII URIE BRONFENBRENNERA

Abstrakt

Artykuł składa się z czterech części. W pierwszej została zawarta charakterystyka gminnych *Strategii rozwiązywania problemów społecznych*. Obejmuje ona omówienie fundamentalnych założeń i funkcji tego rodzaju strategii, które pełnią w polityce społecznej – ze szczególnym uwzględnieniem potrzeb i sytuacji osób z niepełnosprawnościami. Druga część tego opracowania przybliża najważniejsze założenia bioekologicznej teorii systemów Urie Bronfenbrennera. Przez pryzmat tej teorii został zebrany i uporządkowany materiał badawczy. Meritum opracowania stanowi trzecia część. W swoim zakresie obejmuje uporządkowane, zgodnie z założeniami bioekologicznej teorii systemów, zestawienia tabelaryczne, zawierające zapisy i wynikające z nich działania realizowane przez gminy na rzecz społecznej inkluzji osób z niepełnosprawnościami. Całość opracowania zamykają konkluzje zestawione w czwartej części.

Celem opracowania jest jakościowa analiza *Strategii rozwiązywania problemów społecznych* gmin wchodzących w skład powiatu żywieckiego i cieszyńskiego. Umożliwi ona rozpoznanie zapisów i wynikających z nich działań inkluzyjnych, przeznaczonych dla osób z niepełnosprawnościami. Celem jest ponadto rozpatrzenie wspomnianych zapisów na podstawie bioekologicznej teorii systemów Urie Bronfenbrennera, w tym rozpoznanie, na jakich poziomach wyróżnionych we wspomnianej teorii zapisy te obecne są w strategiach oraz jakie działania z nich wynikają. Pozwoli to też na częściowe zweryfikowanie roli, jaką przyjmują gminy, najmniejsze jednostki samorządu terytorialnego w kreowaniu kultury inkluzji i przestrzeni przyjaznej osobom z niepełnosprawnościami.

Słowa kluczowe: osoba z niepełnosprawnością, strategie rozwiązywania problemów społecznych, inkluzja społeczna, środowisko społeczne

A PERSON WITH DISABILITY IN STRATEGIES FOR SOLVING SOCIAL PROBLEMS – ANALYSIS OF RECORDS IN PERSPECTIVE OF URIE BRONFENBRENNER'S THEORY

Abstract

The article consists of four parts. The first contains the characteristics of communal Strategies for solving social problems. It includes a discussion of the fundamental assumptions and functions of the types of strategies which play a part in social policy – with particular emphasis on the needs and situation of people with disabilities. The second part of study introduces the most important assumptions of the bioecological theory of Urie Bronfenbrenner's systems. Through the prism of this theory, research material has been collected and ordered. The merits of the study are captured in the part three. In its scope, it includes tabular systems ordered in accordance with the assumptions of the bio-ecological system theory, containing records and the resulting activities implemented by communes for the social inclusion of people with disabilities. The whole text ends with the conclusions presented in the fourth part.

The purpose of the study is a qualitative analysis of the Strategy for solving social problems of communes that are part of the Żywiec and Cieszyn counties. It will make it possible to recognize records and the resulting inclusion activities for people with disabilities. The purpose is also to consider these entries based on the bioecological theory of Urie Bronfenbrenner's systems and recognition what levels distinguished in the theory mentioned above are present in strategies and what actions result from them. This will also allow for partial verification of the role taken by municipalities – the smallest local government units in creating a culture of inclusion and a friendly space for people with disabilities.

Keywords: person with disability, strategies for solving social problems, social inclusion, social environment

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO” ISSN 1734-5537
CNS nr 3(49) 2020, 115–137

STUDIA NAD NIEPEŁNOSPRAWNOŚCIĄ – NAUKA

ANTONIO M. AMOR GONZÁLEZ, MIGUEL Á. VERDUGO ALONSO,
MARÍA FERNÁNDEZ SÁNCHEZ*

GATHERING EVIDENCES IN ALL SYSTEM-LEVELS FOR THE APPLIED IMPACT OF DISABILITY STUDIES ON PEOPLE WITH DISABILITIES' LIVES[1][2]

Keywords: medical sciences, special education, rehabilitation, post-socialism, critical social theory, interdisciplinarity

Introduction

Basic information about the country. Spain (officially Kingdom of Spain) is a parliamentary monarchy and a transcontinental country in the south of Europe with more than 500 years of history. The country's surface is over 500 thousand km^2 being the 52th biggest country in the world and the 3rd in Europe after Russia and France. According to the *National Institute on Statistics* (INE in Spanish), Spain's population in 2016 was over 46 million[3] (29th in the world and 7th in Europe) and its population density is 92 habitants/km^2 (as of 1 January 2016). The demography in Spain is characterized by elderly population and one of the highest life expectancy in the world with a mean of 82.8 years[4] (2nd

---

* Institute on Community Integration (INICO). Faculty of Psychology. University of Salamanca. Salamanca (Spain)

[1] Tekst pochodzi z książki *Studies on disability. International theoretical, empirical and didactics experiences* (2017) pod redakcją Joanny Głodkowskiej, Justyny Marii Gasik, Marty Pągowskiej (s. 115–139). Warszawa: Wydawnictwo APS.

[2] This work has been co-funded by the Ministry of Education, Culture, and Sports of Spain (FPU Program, reference FPU13/03897), the Autonomous Community of Castile and Leon (R & D Programs, SA120U13), and the Ministry of Economy and Competitiveness (Grant PSI2015-65193-P; MINECO/FEDER).

[3] http://www.ine.es/dyngs/INEbase/es/operacion.htm?c=Estadistica_C&cid=1254736176951&menu=ultiDatos&idp=1254735572981.

[4] http://apps.who.int/gho/data/node.main.688?lang=en.

in the world after Japan). Spain has one of the oldest universities in the world, the *University of Salamanca*, which has almost 800 years of history (funded in 1218). Since then, the number of universities has been growing in the country with a total of 82[5] (as of 31st of December 2016), of which 32 are private and 50 public.

Strategy for the development of education. Higher education in Spain has its own regulation with the *Organic Law on Universities* (LOU 6/2007). According to the *Ministry of Education, Culture and Sport* (MECD[6]) there are 8 domains regarding higher education: education; humanities and arts; social sciences and law; science and computational sciences; engineering, industry and building; agriculture and veterinary; health and social services; and services. Related to the studies on disabilities, the main focus is on the areas of humanities and arts, education, social sciences and law, health and social services, and services.

In Spain, research and development strategy and work is conducted primarily by Universities, Institutes of Research, Enterprises, and *The Spanish National Research Council* (CSIC in Spanish). Research in Spain is funded by both public and private budgets. Public funding composes approximately 50% of the total research funding[7] and is provided via "research and development projects" obtained across competitive calls where stakeholders submit their research and development projects to be assessed. The agency that funds and manages the public budget for research is the *State Agency of Investigation* (AEI[8] in Spanish). According to the *United Nations Institute on Statistics for the Education, Culture and Science,* summarized in a *World Bank* Report, in 2013 the expenses in Spain for research and development activities was a total of 1.26%[9] of the GDP, being in the 28th position in the world, but still far away from the 3% of the GDP that *European Union* (EU) encourages its members to reach by 2020[10]. However, due to political instability and the economic cuts in public expenses in research – among other areas-, the trend is negative, and data by the *INE* show that this amount, in the year 2015, has decreased until the 1.22%[11] of the total DGP.

---

[5] http://www.universia.es/universidades.

[6] https://www.educacion.gob.es/notasdecorte/rendimientos.action.

[7] http://marcaespana.es/talento-e-innovaci%C3%B3n/investigacion-desarrollo.

[8] https://europa.eu/european-union/topics/research-innovation_es, http://www.idi.mineco.gob.es/portal/site/MICINN/menuitem.8d78849a34f1cd28d0c9d910026041a0/?vgnextoid=664cfb7e04195510VgnVCM1000001d04140aRCRD.

[9] http://datos.bancomundial.org/indicador/GB.XPD.RSDV.GD.ZS.

[10] https://europa.eu/european-union/topics/research-innovation_es.

[11] http://www.ine.es/prensa/imasd_prensa.htm.

Taking into consideration the data provided by *Eurostat*[12)] (updated in February 2017), the number of researchers full-time in *EU* was of 1.82 million in 2015. Regarding these data, Spain is in the 4th position in *EU* after Germany, United Kingdom, and France (data still consider UK). Spanish researchers compose the 6.73% of the total number of researchers within the *EU*. According to *Scimago Journal & Country Rank*[13)], Spain's research activity regarding the number of publications is excellent, occupying the 10th position in the world and the 5th in Europe. About the strategies for developing the research and innovation activities, Spain has always been a collaborative country. In the eighties, the *Ibero-American Program of Science and Technology for Development* (CYTED) established a network of scientists in Latin America and Spain and, thanks to this program, nowadays more than 28,000 researchers are connected. Other relationships regarding science diplomacy take place between (Elorza et al., 2017): USA and Spain (i.e., increasing the visibility of Spanish researchers in different areas in USA), UK and Spain (i.e., establishing a Society of Spanish Researchers in the UK), and Germany and Spain (i.e., career development for Spanish researchers).

Spain is also following strategies and guidelines embodied in the *Strategic Framework for Education and Training 2020* for the development of education in the *EU*. Universities themselves in Spain are really concerned with the strategy for the development of education and are keeping track really closely to the developments made by the Government regarding this issue. For example, in 2013, a Commission composed by a team of experts provided guidelines in different areas on how to improve the educational system[14)]: the selection of research and teaching personnel, the assessment of universities' quality, the head of universities, the funding, and the undergraduate and post graduate programs.

The national reports documenting the phenomenon of disability. There is a lack of updating regarding the data about the phenomenon of disability (Verdugo, Gómez, Navas, 2013). Latest data come from the *Survey on Disabilities, Personal Autonomy and Dependency Situations* (EDAD in Spanish, 2008).

Taking into consideration the *EDAD* Survey[15)], data show that there were 3.8 million of persons with disability in Spain in 2008 (it was 8.5% of the total population). This Survey also provided information on the distribution of disabilities per age groups; the prevalence of disability per gender and region; the total number and percentage of people with disability that had

---

[12)] http://ec.europa.eu/eurostat/statistics-explained/index.php/R_%26_D_personnel#Source_data_for_tables_and_figures_.28MS_Excel.29.

[13)] http://www.scimagojr.com/countryrank.php.

[14)] http://www.usc.es/export9/sites/webinstitucional/gl/web/descargas/propuestas-reforma.pdf.

[15)] http://www.ine.es/dyngs/INEbase/es/operacion.htm?c=Estadistica_C&cid=1254736176782&menu=resultados&secc=1254736194716&idp=1254735573175#.

a job; the percentage of students with disability (and the percentage of those students who had academic success); the percentage of individuals with disability that suffer discrimination; and the kind of environment where people with disability live – and who lived with them – (Esparza, 2011). In Spain, the incidence of disability increases with biological age, especially after the 54 years of age (Verdugo, Gómez, Navas, 2013). Under a legal point of view, people with the "recognition" of disability are a total of 2.8 million habitants in Spain, according to official data provided by the *Institute of Elderly and Social Services* in 2014[16]. The *EDAD* Survey was supposed to be updated in 2016[17] according to the *National Statistical Plan* 2013–2016, but political instability has delayed it.

Apart from the statistical reports conducted, there has been a raise of the rights perspective towards people with disability in Spain. Although the *United Nations' Convention on the Rights of Persons with Disabilities* (*CRPD*, United Nations, 2006) claims that "every human being has the inherent right to life" (p. 10), the existing jurisdiction has been applied with fewer rigors to persons with disabilities (Verdugo, Gómez, Navas, 2013). The *CRPD* was signed in 2008 and since 2011 it's developed in Spain. Aligned with the *European Disability Strategy 2010–2020: A renewed commitment to a barrier-free Europe*, and the cited *CRPD*, Spain established its own *National Strategy on Disability 2012–2020* (Ministry of Health, Social Policies and Equality, 2011) which includes some guidelines on how to ensure the rights embodied on the *CRPD*, by addressing different areas, like: accessibility, employment, education and training, poverty and social exclusion, real and effective participation, equality, health, external actions, economy, and information.

The legal instrument for assuring the rights of individuals with disabilities, and both their social and educational inclusion in Spain, is the *General Law on the Rights of Persons with Disabilities and their Social Inclusion* (Ministry of Health, Social Services, and Equality, 2013). This law supposes the framework for all the actions regarding the obligations and rights of individuals with disabilities in different areas aligned with the *Spanish* and *European strategies*, and the *CRPD*.

Historical and contemporary approach towards disability

Facts – leading representatives. The first attempt for educating students with disability in Spain was back in the XVI century. Fray Pedro Ponce de León (1508?–1584), monk and pedagogue, was pioneer in the world by developing a new pedagogical approach to teach deaf students to speak, and he created a school where other representatives in the study and scientific approach towards

---

[16] http://imserso.es/InterPresent2/groups/imserso/documents/binario/bdepcd_2014.pdf.

[17] https://www.boe.es/boe/dias/2012/12/08/pdfs/BOE-A-2012-14907.pdf.

disability developed their work. One of those representatives was Juan Pablo Bonet (1573–1633), pedagogue and speech therapist, who wrote the first book about the education of deaf students in Spain. Regarding sensory disabilities, the XIX century was important due to Claudio Moyano y Samaniego (1809–1890), lawyer, philologist, philosopher and politician concerned about the educational system. In 1857, he initiated an important reform within educational system by developing *Moyano's Act* (1857). In this Act, the regulation of key aspects related to the education of blind and deaf students were addressed. However, this law didn't put the accent on individuals with intellectual disability (ID).

In comparison with other European countries, Spain was in the back of both research and professional practice towards students with disability. Regarding students with ID, Francisco Pereira Bote created a journal strictly dedicated to the study of *Abnormal Children* in 1907. He also created The *Psychiatric-Pedagogic Institute-Sanatorium* for children with mental retardation in 1908, and the *Psychiatric and Pedagogic Institute* in 1930 (Fernández-Santamaría, 2011).

However, they were not the first institutions in Spain regarding the education of students with ID. The *Central School for the Abnormal* was created in 1922 (Fernández-Santamaría, 2011), as a public school for addressing the education of children and adolescents with ID until 14 years old, and its importance is transcendental for the scientific studies on disability and special education in Spain (Molina, 2009). María Soriano Llorente (1900–1996), who was an elementary and middle-school teacher and the director of the *Central School for the Abnormal* since 1923, was one of the forerunners in the scientific study of disability and special education in Spain. She travelled to foreign countries where she received instruction on the newest scientific approaches, and she also participated in different scientific associations and international forums (Fernández-Santamaría, 2011), applying that knowledge and leading the changes in the special education field in Spain. The first legal document that addresses the education of students with ID was the *Law on Elementary Education* in 1945 (Scheerenberger, 1984). Finally, the *Central School for the Abnormal* changed his denomination in 1960, acquiring the name of *National Institute on Therapeutic Pedagogy*. Carmen Gayarre (1900–1996) was another pioneer of special education in Spain. She created different Schools and she was also interested in the transition processes, leading the creating of different workshops towards transition to adulthood in Spain (Fernández-Santamaría, 2011).

In 1975 the *National Institute on Special Education* was created as an autonomous organism dependent of the *Ministry of Education and Science*. Three years later, in 1978, the *National Plan on Special Education* was published based on Warnock's Report, and established the principles of special education in Spain: normalization of services, integration of students with special needs, sectorisation of services, and individualization of teaching (Fernández-Santamaría, 2011). These achievements aforementioned have lead the change from and exclusion perspective to the current paradigms in the study of disability.

General current trends – formulating paradigms. Looking throughout history of disability in Spain, there have been many changes regarding both the way of thinking as society about people with disability and the kind of services and supports provided by professionals (Verdugo, Gómez, Navas, 2013). When addressing the issue of the construction of disability paradigms in Spain, the Puig de la Bella Casa's perspective (1990) and the Demetrio Casado's one (1991), are the most commonly referred.

According to Puig de la Bella Casa (1990), there are three main paradigms in the building of phenomenon disability in Spain: the traditional paradigm, the rehabilitation paradigm and the personal autonomy paradigm. In the first one, people with disability were marginalized because they were dependent, with low performance, and had to be in segregated settings. Under the rehabilitation paradigm, disability was considered a deficit inside the person that determined the performance. The key aspect was the rehabilitation lead only by professionals, and was focused on the level of functionality restored and whether the person with disability had a remunerated employment or not. Finally, the personal autonomy paradigm, which is based in the independent living movement, is against the marginalization of people with disability. This paradigm is closely linked to people with sensory and physical disability and is near to the self-determination movement of people with ID who claimed control of their own lives and the suppression of social and physical barriers within society.

A similar review of paradigms in Spain is provided by Demetrio Casado (1991). This author identifies four paradigms: utilitarian integration, annihilation exclusion, specialized and technic intervention, and accessibility. In the utilitarian integration, the disability was considered as a God punishment (or proof), and the best option for individuals with disability was to work within the family, and they had marginal roles in society (e.g., crier or shoemaker). The annihilation exclusion paradigm coexisted with the previous one, and consisted in occulting persons with disability (overall with intellectual and/or developmental disability) by enclosing them at home. The specialized and technic intervention paradigm, put the focus on the improvement of the quality of attention towards people with disabilities but, professionals had the active role and people with disability were passive (they received supports normally in segregated settings).The accessibility paradigm is the current paradigm in Spain, closely linked to the interdisciplinary scientific work that nowadays takes place in the country. The normalization and inclusion are the key aspects for people with disability to enjoy the same rights than their equals without disability and to participate within their community of reference alongside their peers.

In the field of special education, three moments can be described in Spain (Echeita, 2013): the exclusion paradigm, the integration paradigm, and the inclusion paradigm. In the exclusion paradigm, students with disabilities of any kind were considered as non-teachable within general education settings and the main response towards them was special education centers. In Spain, the integration movement started in the eighties, with the *Social Integration of Disabled People Act* (1982), and was characterized by the presence (but not participation and learning) of students with disability within general education settings. Although this movement put the accent on environmental factors, it still was under a medical perspective and didn't analyze the difficulties that ordinary schools had in the education of students with disability. The inclusion paradigm started in Spain with the *Salamanca Statement and Framework for Action on Special Needs Education,* adopted by the *World Conference on Special Needs Education* and organized in Salamanca (Spain) in 1994. This paradigm is based on a socioecological understanding of the needs of students with disability and puts the accent on identifying and removing barriers for learning and participation of those students, guaranteeing their access, promotion, learning, and participation within general education settings alongside their peers without disability.

Disability studies – scientific discipline, field of study. In Spain, *Disability Studies* is understood as an interdisciplinary field and has the recognition of scientific study. The first *Cathedra* specifically dedicated to the scientific study on disability was created in the year 2002 at the *University of Salamanca*. The interdisciplinary and scientific study of disability in Spain, assumes the most advanced paradigms and models in the international framework: the biopsychosocial approach, based on the *World Health Organization's* International Classification of Functioning, Disability and Health (ICF); a strengths-based approach regarding the capability of the person; a personalistic approach that considers the active role of the person, its needs and its wanting; the supports paradigm for bridging the gap between personal capabilities and environmental demands; and the rights perspective assumed by the *CRPD*. Quality of Life (QoL) is considered the framework for the provision of supports that improves the functioning of individuals with disability and leads the achievement of their personal desired outcomes and enjoy their rights. Spain has not only assumed this perspectives, the country has also done important contributions in the development of those approaches, especially in the field of QoL (Schalock, Verdugo, 2002, 2007, 2012a, 2012b).

The first and only university institute on the scientific study about disability in Spain is the *Institute on Community Integration* (INICO). This institute was created in 1996 and is composed by interdisciplinary professionals that lead activities linked to training, research, and counseling in the field of disability with the aim of easing and enhancing the QoL and self-determination of people living at social disadvantages in different contexts and throughout their life cycle. Its scientific activity has been summarized recently due to its 20th anniversary. Table 1 shows *Institute's* scientific achievements. Data concerning all *INICO's* achievements are available[18].

---

[18] http://inico.usal.es/432/el-inico/20-aniversario-del-inico-1996-2016.aspx.

Table 1. Scientific activity of the *Institute* in terms of outputs

Kind of scientific activity	Number of activities	% of total activity
Scientific publications (articles, books, handbooks, chapters)	1295	31.98%
Contributions to scientific conferences and congresses (presentations, roundtables, communications, etc.).	1825	45.06%
Research Projects	542	13.38%
End-of-Master thesis	333	8.22%
PhD Thesis	55	1.36%

Source: self-elaboration.

Perhaps the most ambitious project developed by the *INICO* has been the creation of the *Service on Information about Disability* (SID in Spanish) in 1999. The *SID*, which was jointly created by the *Ministry of Health, Social Services and Equality* and the *INICO*, is a public internet portal that is aimed at professionals, politicians, and developers and managers of public policies. This service has three main functions: acquire, systematize, and spread information on disability.

The growth of the scientific study of disability in Spain has given place to the development of several post-graduate programs where professionals coming from different undergraduates (e.g., psychology, pedagogy, teaching, social work, medicine, law, or physiotherapy) receive an updated and scientific-based training regarding different issues pertaining disability studies. According to the *SID*, in Spain there are more than 100 post-graduate programs related to disability[19].

Two of the most important post-graduate programs in Spain are: *Master on Integration of People with Disability-Quality of Life*, co-developed by *INICO* and *Plena Inclusión* (a confederation of organizations that act in benefit of people with disability and their families in different areas like education, health, citizenship, employment, or rights) and the *University Master on Research in Disability*, developed by *INICO*. The first master is aimed to direct-practice professionals and its main goal is to train them under evidence-based approaches and strategies. This master was created in the year 1991. It lasts two academic courses and is currently on its 25th promotion. Due to the importance and impact of *INICO* in Ibero-American context, this master's degree has also an online version called *Master on Integration of People with Disability-Ibero-American Program* which is on its 9th edition. The *University Master on Research in Disability* was created in the year 2011 by *INICO*, and its aim is to provide a specialized training and improve the research abilities of future professionals in the field

---

[19] http://sid.usal.es/formacion.aspx.

of disabilities allowing them to access to the latest paradigms and current trends in scientific research in the field of disability.

Apart from the postgraduate programs, *INICO* organizes every three years the *International Congress on the Scientific Research on Disability* since 1995. The last *Congress* took place in 2015 and it was composed by 242 scientific activities, including: 3 plenary conferences, 1 scientific session, 1 colloquium about humor and disability, 7 roundtables, 30 symposium, 30 communication tables (120 presentations), and 72 posters. It gathered more than 500 people, from interdisciplinary fields and from different countries in Europe and America[20). The *INICO* has also established its own interdisciplinary and collaborative network of research between Spain and Ibero-America regarding the field of disability. Thus, the *Ibero-American Network on Research on Quality of Life* (REDICABI in Spanish) was created in 2012 with the aims of: spreading the QoL model developed by Schalock and Verdugo (2002, 2007, 2012a, 2012b), promoting organizational change, and spreading and adapting different tools for QoL assessment in different countries[21).

Different scientific journals are dedicated to the study of disability in Spain. These journals are: *Revista Española sobre Discapacidad* (Spanish Journal on Disability); *Siglo Cero. Revista Española sobre Discapacidad Intelectual* (Zero Century: Spanish Journal on Intellectual Disability); and *Autonomía Personal* (Personal Autonomy). All of them are based on an interdisciplinary understanding of disability.

As a conclusion of the picture of *Disability Studies* field in Spain, this is a well-defined field, and it is mainly accomplished by universities in general and by institutes of research. Apart from the aforementioned *INICO*, there are different universities that undertake *Disability Studies*, like the *University of Murcia* with the *Center on Disability Studies and Personal Autonomy promotion*, which promotes research and advocates for personal autonomy in individuals with disabilities[22).

Interdisciplinary empirical analysis of the phenomenon of disability

Research analysis in the positivist orientation. This orientation has three main goals: to explain, to control, and to predict. The positivist orientation has been mainly developed by the natural sciences, but nowadays it has been also adopted by the social sciences. The methodology of this orientation is quantitative and typically involves three methods: experimental, cuasi experimental and ex-post-facto (Sarrado, Cléries, Ferrer, Kronfly, 2004). This orientation has given

---

20) http://inico.usal.es/c52/jornadasdiscapacidad.aspx.

21) http://inico.usal.es/c152/rivicabi.aspx.

22) http://www.um.es/web/dipap/.

place to different scientific publications in Spain regarding the interdisciplinary fields that study disability (e.g., psychology, education, medicine, physiotherapy, or social work).

One of the most prolific fields of research under positivist orientation within disability field is psychology, because it is incardinated in health, social, and educational services. In the field of psychology, one of the main efforts under the positivist orientation is the study of different constructs pertaining disability, such as support needs, self-determination, and QoL – among others. The scientific study of those constructs has been addressed from different ways, like studying the relationship between them, or trying to act in those constructs somehow under socioecological perspectives. However, for each aim, a high level of accurateness is required, thus, it is necessary to assess those constructs for establishing statistical relationship between them, and it is also necessary a good assessment when providing interventions. That's why in Spain, an important branch of research has focused in the development of new assessment tools that will lead the development of evidence-based practices. Psychometric studies put the accent on the building of high-quality assessment tools (i.e., tests or questionnaires). Psychometry is commonly based in the hypothesis that the tool (and the items) will have a good functioning, being reliable and valid for measuring the proposed construct. Hypotheses are directly transformed into statistic tests (e.g., normality or colinearity). Thereby, there are many tools recently developed regarding support needs construct (Guillén, Verdugo, Arias, Vicente; 2015; Verdugo, Arias, Ibáñez, Schalock, 2010), QoL (Verdugo, Gómez et al., 2014; Verdugo, Aguilella, Sainz, 2012; Verdugo, Gómez, Martínez, Santamaría, Clavero, Tamarit, 2013; Gómez, Alcedo, Verdugo et al., 2016), and self-determination (Verdugo, Vicente et al., 2014).

Regarding support needs, one of the most important tools developed in Spain is the Supports Intensity Scale for Adults, which shows excellent psychometric properties regarding reliability and validity (SIS, Verdugo et al., 2010). The data obtained went in the same direction than those obtained in the different versions of the scale (i.e., English, French, Italian, Catalan, and Dutch). The SIS is commonly used in different organizations as a basis for providing supports to adults with ID in Spain. Similar results were found in the development of the Supports Intensity Scale for Children (SIS-C) aimed for children and adolescents with ID (Guillén et al., 2015; Verdugo, Arias, Guillén, Vicente, 2014; Verdugo, Guillén, Arias, Vicente, Badía, 2016). In those cases, the SIS-C also provided evidence of its reliability and validity in its different versions. Based on the use of these tools, different studies have been conducted within a positivist approach (Verdugo, Arias et al., 2016; Verdugo, Guillén, Amor, Aguayo, Arias, 2016). For example, Verdugo, Guillén et al. (2016), based on the use of the SIS-C, found that there were statistical differences on the support needs depending on the level of intellectual functioning in a sample composed by 400 students (100 with common development, 100 with mild ID, 100 with moderate, and 100 with severe, all of them aged 5–16 years old). The hypothesis they established was that if individuals had a high intellectual functioning, then they would have lower support needs. By using an ANOVA they found statistical differences on the statistic means of support needs between four different levels of intellectual functioning: higher level of intellectual functioning entails lower support needs and vice versa. Verdugo, Arias et al. (2016) found that there were statistical differences in the support needs depending on the age of students and that those differences tended to be concentrated in the means of the younger and older children (5–10 vs. 11–16 years old).

Other construct addressed under this orientation is the self-determination. Concerning the assessment of self-determination, Verdugo, Vicente et al. (2014) developed the ARC-INICO Scale, for assessing self-determination of students with ID aged 11–19 years old. This scale also showed good psychometric properties regarding reliability and validity (Vicente, Verdugo, Gómez-Vela, Fernández-Pulido, Guillén, 2015). There are some studies that have explored self-determination's relationship with other important constructs like support needs. These studies are useful in the design of interventions letting professionals to establish predictions and hypotheses. For example, Vicente, Guillén, Verdugo, Gómez-Vela, Arias, and Navas (2012), established the hypothesis that individuals with less self-determination would have higher support needs and vice versa. In the study, authors assessed a sample composed by 35 children and adolescent with ID and found a significant linear and inverse relationship between the support needs of children and adolescents with ID and the level of self-determination. The self-determination has also been important in the direct practice with individuals with disability (Arellano, Peralta, 2013; Arranz, 2007; Ortiz, Tárraga, 2015; Peralta, Arellano, 2014). For example, Ortiz and Tárraga (2015) developed and tested a program for improving self-determination in a child with mild ID. It was a pre-experimental pre-test and post-test design without control group. The findings showed an improvement on the self-determination assessed by using a questionnaire after program's implementation.

The most important construct of research in Spain within the disability field is QoL, because of its importance in the health, educational, and social services (Schalock, Verdugo, 2002). Regarding this issue two scales have been recently developed in Spain. San Martín Scale (Verdugo, Gómez et al., 2014) is aimed to individuals with significant disabilities. Its psychometric properties are excellent. Gómez, Alcedo, Verdugo et al. (2016) have developed the KidsLife Scale focused in children and adolescents with ID (aged 4–21 years old) and this scale also shows evidences of good psychometric properties (Gómez, Alcedo, Arias, et al., 2016). While the San Martín Scale provides both objective (based on the professional assessment) and subjective (self-report) information, KidsLife is objective. There are different works aimed to improve individuals' QoL. For example, Pascual-García, Garrido-Fernández, and Antequera-Jurado (2014) wanted to assess the impact of a program focused to improve self-determination, on the QoL of individuals with ID. Authors were based on an experimental design with experimental and control groups, and the hypotheses were: (1) at the beginning both groups would have similar QoL and (2), after the intervention, experimental group would have a better QoL. Results showed that there were not statistical differences on QoL between the two groups prior to the intervention but, after it, there was a QoL improvement within experimental group.

In the field of educational sciences, there are also many evidences under a positivist orientation in Spain. The efforts of researchers have been directed mainly to two areas: capacity building (i.e., academic performance), and improvement of inclusion outcomes. As an example of the first kind of research, Ripoll, Bravo-Iriso, Iruzun, Pérez-Pérez, and Zuazu (2016), developed a pre-experimental pre-test and post-test design with one group where they tested an intervention for improving reading skills in students with different conditions, including autism spectrum disorders. Results showed that there was statistical difference between the pre-test and the post-test in terms of number of read words per minute. Regarding the second kind of studies, Lozano-Martínez, Alcaraz-García, and Colás (2010) conducted a pre-experimental pre-test and post-test intervention with one group, where authors designed and assessed a program for improving the emotional and cognitive recognition in students with autism spectrum disorders. They found that the program also improved the social interactions between students with and without disability.

Research analysis in the humanistic orientation. This tradition includes those studies that provide original empirical data produced by researches within an epistemological logic framework under a subjectivist tradition, whether phenomenological, interpretative or critic perspective (Sarrado et al., 2004). This approach addresses the mental representation that different people (i.e., families, professionals, community members and people with disabilities themselves) have towards disability and different issues concerning about it (e.g., inclusion, QoL, barriers towards inclusion or attitudes).

Under families' perspective, different researches have been developed in Spain (Arellano, Peralta, 2015; Giné et al., 2011; González-del-Yerro, Simón, Cagigal, Blas, 2013; Lizasoáin, Onieva, 2010). For example, González-del-Yerro et al. (2013); were interested in how families of individuals with ID understood the term "family QoL", which variables concerning this issue families considered as important ones, the satisfaction with their own QoL, and their opinion on how familiar QoL could be improved. Based on interviews authors provided guidelines on how improve the QoL of individuals with disabilities and their families. Arellano and Peralta (2015) were concerned in identifying the key aspects of the relationships between families and professionals regarding their children with ID. Based on interviews, authors detected the needs in this issue and provided strategies on how to address those needs and improving the supports towards families' children with disability based on the collaboration families-professionals.

Another field commonly studied is the attitudes towards disability by different individuals of the community where people with disability live (Alemany, Villuendas, 2004; Fernández-Cid, 2010; Sepúlveda, Medrano, Martín, 2010; Suriá, 2012). The aim of these studies is to identify barriers that underlay attitudes towards disability and to provide guidelines on how to improve those attitudes as a way to promote the inclusion and participation of individuals with disability within mainstream settings. For example, Alemany and Villuendas (2004) described the attitudes towards students with disability of different kind among different teachers in a school in Spain. Using the interpretative approach and based in interviews, authors found that pedagogy teachers, special education teachers, music teachers, and hearing and language teachers, had positive attitudes toward students with disability. However, preschool teachers and foreign language teachers had negative attitudes, and elementary teachers and physical education teachers had ambivalent attitudes. Finally, authors summarized the aspects underlying the attitudes found. Surià (2012) interviewed teachers with the aim of detecting the difficulties that teachers had towards the inclusion of students with disability, and also the attitudes that teachers perceived from "typical-development students" towards their classmates with disability. Based on the interviews, author concluded that teachers didn't feel ready enough for providing support to students with disability and that students without disability had positive attitudes towards their peers with disability.

Different researches have focused on the perception and feelings of individuals with disability (Moriña, 2010, 2015; Moriña, Molina, 2011; Rojas, Haya, Lázaro-Visa, 2016). Rojas, Haya, and Lázaro-Visa (2016) studied a controversial issue: sexuality and relationships in people with ID. Based in the interview methodology, authors found out that people with ID claimed to have control over their (social and sexual) relationships but they also assured that there were still too many stereotypes surrounding this topic in Spain. Moriña and Molina (2011) were interested in analyzing both barriers and supports that students with disability found in the university. Thus, authors interviewed 44 students from the *University of Sevilla* with different kind of disability. Based on those interviews, authors managed to identify the barriers and the supports that students with disabilities themselves found in their daily life and, based on those findings, authors designed an online program for training *University's* teachers on how to address properly the real needs of their students with disability.

Another important focus is aimed to contrast different stakeholders' views and interpretations about different issues pertaining disability (Castro-Belmonte, Vilà, 2014; Pallisera, Fullana, Puyalto, Vilà, 2016; Pallisera et al., 2014; Verdugo, Rodríguez, 2012). Pallisera et al. (2016) conducted a qualitative case study in order to analyze barriers, difficulties, and supports in the transition process from the point of view of young people with ID and their families. Based on different qualitative strategies (interviews, focus groups, and visual methods), students with disability claimed to have experienced difficulties throughout their educational process especially in the transition process. Families complained about the guidance received from professionals upon finishing secondary school and about the lack of training options available to young people with disability. This was directly translated into fears towards the possibilities of inclusion and labor market integration. Based on the families' and people with disabilities' point of view, the authors of this study provided guidelines on how to improve opportunities for the social inclusion of young people with ID in their transition to adulthood. Verdugo and Rodríguez (2012) wanted to explore how the inclusion of students with ID was in Spain taking into consideration the point of view of students, families and professionals. This study found that the speech of participants changed depending of the educational level, being the secondary education (in Spain, from 12 to 16 years old) the point where all participants referred problems towards inclusion of students with ID. Based on this research, authors also highlighted the need of providing supports beyond curricular aspects going to other supports needs commonly forgotten inside schools.

Methodological pluralism. Such a complex field of study like disability needs both quantitative and qualitative procedures of research to address its multifaceted nature. Thus, there are many works under a mixed-methods perspective in Spain (Becerra, Montaner, Lucero, 2012; Cerrillo, Izuzquiza, Egido, 2013; González, Cortés, 2016; Moro, Jenaro, Solano, 2015; Pérez-Castañeda, Verdugo, 2008).

Moro, Jenaro, and Solano (2015) were interested in the study of fears, hopes, and claims of parents of children with autism spectrum disorders. Authors based their work on participant observation and interviews with 13 families that had children with autism spectrum disorders. In this study families claimed that professionals must provide the appropriate support and not only a diagnose. Families also claimed the need to receive resources, as well as guidance on how to raise up their children.

Pérez-Castañeda and Verdugo (2008) valuated the experience of having siblings with autism in the family because of the special characteristics this disability presents. Authors studied siblings' perceptions in two aspects: the influence of this experience on the fmily QoL, and the special characteristics that the relationship between siblings could have in this case. This study had two approaches: a quantitative approach, characterized by the assessment of family QoL by using a scale; and the second stage was characterized by using focus groups strategy. Findings showed that: the experiences of autistic siblings had not a negative impact on the family QoL; the most valued family QoL dimensions were health and security and supports for the person with disability; and that some autism characteristics, such as behavior disorders had an especial influence on siblings' relationship.

Luque and Luque (2015), using a mixed methods approach, assessed the relationship existing between the kind of disability and the friendship and acceptation of students with disability. They used a brief survey which had closed questions (quantitative approach) and an opened one (qualitative approach). Authors didn't find differences in friendship and acceptance by gender, sociocultural level, or sociocultural setting with regard to classmates with disabilities. Significant influence was found, however, as a function of age, educational level, and type of disability, associated with the individual characteristics of students with disabilities. Authors highlighted the importance of developing values of acceptance, respect, tolerance, positive consideration of diversity, as well as supports and selfless help between classmates, because students with disability commonly require individualized supports and thus have a greater probability of distancing themselves from their peers without disability.

Selected constructs of recognition of the phenomenon of disability

Personalistic perspective. Personalism puts the accent on the human being himself, as an actor and causal agent of its life. This consideration, normally assumed by and for people without disability, has been denied to individuals with disability, being marginalized in the society throughout history. Nowadays, the consideration of disability claims an active role of people with disability and defends a positive approach towards this condition, based on the capability of the person and not on their limitations. Thus, it is necessary that people with disability become the main characters of their lives. To add more, the personalistic perspective must be a key aspect towards the normalization and inclusion of individuals with disability, like the personal autonomy, accessibility, and inclusion paradigms defend. And this is especially important in individuals with intellectual and/or developmental disabilities, because those individuals have had more compromised their self-determination. All the constructs aforementioned, are considered not only under a socioecological perspective, they also consider the person with disability with an active role and assume a personalistic perspective by letting them to express their wanting and needs. Perhaps, the construct that better defines personalism is self-determination. Self-determination is understood as the independence to decide and act as the causal agent in one's life. These are unchanging demands by empowerment movements focused on people with disabilities and by people with disabilities themselves (Verdugo et al., 2015).

However, in Spain, personalism does not only define constructs, it also defines the understanding of disability, recognizing the identity, rights, and abilities of individuals with disability under a strengths-based perspective. The voices of individuals with disability under the personalistic perspective is a capital issue, and so it must be when providing supports for improving their functioning and personal desired outcomes, like self-determination, emotional wellbeing, inclusion, or rights. Thus, the understanding and professional practices towards people with disability takes two approaches: an objective approach, defined by families and professionals; and a subjective (personalistic) approach, based on the needs, wanting, beliefs and achievements desired by the own person with disability.

In an applied framework, the detection of needs also takes into consideration individual's view. For example, the assessment of self-determination with the ARC-INICO Scale has two approaches: the professionals scale, and the subjective scale, where the person provides information about its autonomy, self-regulation, empowerment, and self-knowledge. The same comment can be done with the INICO-FEAPS Scale (Verdugo, Gómez, et al., 2013) for assessing QoL of individuals with disability. Once the needs have been detected by professionals, families, and individuals with disabilities themselves, the provision of individualized supports starts. And, again, the person with disability has an active role. Firstly, because the provision of supports is based on individual's capability and strengths; secondly, because the provision of those supports is done mainly by natural supports, including those whom the person has freely elected. A common strategy of providing supports to individuals with intellectual and/or developmental disabilities is the development of individualized support plans (ISP). The development of an ISP starts by identifying desired goals and experiences in life of the person with disabitliy. The goal of this procedure, under the person-centered planning process (PCP), is to detect what is really important for the person with disability and what kind of barriers the person perceives. This PCP involves the person with disability itself (main character), and those individuals selected by the person from its reference group (i.e., natural supports). Once the goals to achieve are detected, it is also necessary to assess the needs of individuals with disability and, based on that assessment, to provide the supports that will improve their functioning and that will also lead the person to obtain the desired outcomes.

Self-determination is also transcendental regarding the normalization and inclusion of people with disability. What is more, in Spain, as research and evidence have determined, self-determination is considered a domain of QoL (Schalock, Verdugo, 2002, 2007, 2012a, 2012b). Thus, it is difficult to choose which constructs are mainly under a personalistic approach and which ones are mainly important for the normalization of individuals with disability. That's why, in general, all the constructs aforementioned, assume both an objective and personalistic approach, and are aimed towards the normalization and inclusion of individuals with disabilities.

Perspective of normalization of life of people with disabilities. QoL is the main framework for achieving normalization and inclusion of persons with disability. According to Schalock and Verdugo (2002, 2007, 2012a, 2012b), QoL refers to a desirable condition of personal well-being and life satisfaction, which is multidimensional in nature, has universal properties linked to culture, is influenced by personal characteristics and environmental factors, and is made up of objective and subjective aspects (i.e., authors recommend methodological pluralism to address its assessment). However, like any social construct, QoL cannot be directly measured; it has to be implemented through domains, indicators and personal results. The concept of a domain refers to the factors that comprise well-being (Schalock, Verdugo, Gómez, Reinders, 2016). Eight domains are proposed in this model: material well-being, physical well-being, emotional well-being, social inclusion, personal relationships, self-determination, personal development, and rights. The relative importance given to each of these domains may vary from one person to another, and even at different moments in the life of the same individual (Schalock, Gardner, Bradley, 2007). These domains are implemented through core indicators, which refer to specific QoL perceptions, behaviors and conditions that reflect personal or family well-being (Schalock et al., 2016). This model has been supported worldwide and, although it was first developed for individuals with ID, it is being adapted to other conditions in Spain, like: visual impairment, elderly, drugs dependency, multiple disabilities, and social services users in general (Verdugo, Gómez et al., 2013).

The QoL model acts as a framework for assessing the needs of individuals with disabilities of any kind and for the provision of supports (Schalock, Verdugo, 2007). It is also a framework for the organizational change (Schalock, Verdugo, 2012a), and it is commonly used as a framework for the assessment, development and enhancing of public policy regarding the field of disability (Schalock, Verdugo, 2012b). This understanding of QoL acting at the microsystem, mesosystem and macrosystem of individuals with disability, makes of it a key construct regarding the normalization and the inclusion of individuals with disability in the community. The QoL model aligns with the current paradigms regarding disability and the *CRPD*, and that's why beyond research, is a framework for practitioners. Since the mid-90's, *Plena Inclusión*, which includes almost 1,000 organizations in Spain, has adopted the QoL model as the main compromise with its users and families (Tamarit, Espejo, 2013).

There are evidences on how this model con promote the normalization and inclusion of individuals with disability (Badía et al., 2011; Badía, Orgaz, Verdugo, Ullán, Martínez, 2013; Longo, Badía, Orgaz, 2013). For example, Badía et al. (2013) explored the relationships between objective and subjective QoL and leisure participation of adults with developmental disability. Authors found that there weren't relationships between objective QoL and leisure participation, but correlations between some leisure participation dimensions and specific subjective QoL domains were observed. Complementary results were obtained by Longo, Badia, and Orgaz (2013). In this case, based on the assumption of the importance that leisure participation has in individuals' QoL, authors analyzed the patterns and predictors of participation in leisure activities outside school of Spanish children and adolescents with cerebral palsy. They found that, although the participants had low diversity and intensity of participation, they had high levels of enjoyment. The provision of leisure participation opportunities to individuals with disability and providing the supports for being in their community alongside their peers, is a good way for promoting their QoL and, what is more, their presence and participation in the community will lead to the normalization of disability and their inclusion.

Beyond research, *Plena Inclusión* keeps on developing "good practices handbooks" on how to promote QoL of their users. Thus, research and practice are acting jointly with a higher aim: to make the normalization and inclusion of individuals with disability come true. To reach this aim, research and organizations adopt a socioecological approach that considers the strengths, rights, and view of individuals with disability, and the goal of improving their functioning and their QoL by providing proper supports.

Cultural construct. As a cultural construct, disability is no longer something inside the person, so the response towards disability must be social. This understanding of disability emphasizes that the physical and social barriers within environment, as well as the practices, organizational structures, and social attitudes, define the disability. In Spain, the disability as a cultural construct started closely linked to individuals with physical and sensory disabilities. This way of understanding disability puts the accent on the participation of individuals as services consumers that must take an active role in the planning and development of those services. Under this perspective, the aim is to suppress physical and social barriers within environment and stress a political accent on the persons with disability movement (Verdugo, Gómez, Navas, 2013).

The implementation of social-constructivist approach towards disability has been weak in Spain (ibid.). Ferreira (2008) assumes that the key of it is that the social construction and identity of individuals with disability lies on a heteronomous mechanism triggered when people with disability face that they are different. Moreover, differences regarding different kind of disabilities add difficulty to the social identity of disability as a group. The group with the stronger social and cultural identity is the group of people with hearing impairment, because they claim to belong to a "Deaf Culture" with an own idiosyncrasy (e.g., different communication).

The lack of implementation of a social model in Spain, led to the development of the diversity model of disability (Verdugo, Gómez, Navas, 2013). The constructivist or social model aspired to a normalization which was incompatible with the diversity that individuals with disability present. The diversity model, however, changes the term "person with disability" by "person with functional diversity" without making any distinction on the kind of disability related to the person. The diversity model advocates for dignity, by detaching it from capacity and considering that diversity brings in wealth to the society.

However, although the models aforementioned brought a new perspective that was not considered before, and played a fundamental role in the rights movement, both of them suffer from certain limitations, because those models don't mention the individual perspective and they are mainly focused on a sociopolitical understanding of disability and not on the supports that the person may need (ibid.). The individual perspective, however, puts the focus on the strengths of the person, and is aimed at improving their functioning and desired outcomes. However, the study of the social-constructivist model does not put the focus on what abilities the person has, and how to enhance them. On the one hand, it claims the dignity and the rights of individuals; but, on the other hand, it doesn't create a framework for achieving what it demands.

Conclusion

In this article authors have put the focus on the evolution of the disability field in Spain, regarding both the social understanding and evolution of paradigms about disability, and the main constructs of research and the ways for addressing them. This paper is aimed to provide researchers in other countries an overview on how is this field currently in Spain, and how has been the path walked.

The current paradigms in Spain regarding the personal autonomy, the accessibility and the inclusion of individuals with disability are aligned with the rights perspective embodied in the *CRPD*. The main topics of research concerning disability in Spain are QoL, supports, self-determination and inclusion (educational and social), and are addressed using quantitative, qualitative and mixed-methods, taking into consideration the voices of people with disability and their normalization and inclusion. The final aim of the disability field in Spain, is not only to understand what disability is and what are the main constructs concerning disability and their relationships, is to generate an inclusive framework for the provision of supports based on the strengths of individuals with disabilities of any kind, to help them live a life of quality and enjoy their rights. QoL is the framework for the provision of supports for improving functioning of individuals with disability and for leading the achievement of their personal desired outcomes; for the organizational change; and for the policies' development and assessment.

The main challenge that disability field still has to face in Spain, is the development of inclusive public policies regarding disability. Although the research is directly related to the needs of individuals with disability and the organizations providing multidisciplinary supports to them, the administrations still keep on ignoring research and the voices of individuals with disability. Thus, the public policies regarding disability developed in Spain are really far away from reality, they are just a compendium of good wishes and general outlines, but don't generate an specific framework for achieving the rights of the *CRPD*. Although research provides the framework for the development and assessment of public policy regarding disability, political organisms still have to take it into consideration. Spain has always been a country with a majority in the Government, but the situation has changed. Current situation makes necessary a dialogue between political parties and creates a new opportunity for the development of new inclusive policies pertaining disability, policies that must be based on the rights of individuals with disabilities, on their voices, and on the evidences provided by research for making those rights come true.

References

Alemany, I., Villuendas, M.D. (2004). Las actitudes del profesorado hacia el alumnado con necesidades educativas especiales. *Convergencia. Revista de Ciencias Sociales*, *11*(*34*), 183–215.

Arellano, A., Peralta, F. (2013). Autodeterminación de las personas con discapacidad intelectual como objetivo educativo y derecho básico: estado de la cuestión. *Revista Española de Discapacidad*, *1*(*1*), 97–117.

Arellano, A., Peralta, F. (2015). El enfoque Centrado en la Familia, en el campo de la discapacidad intelectual. ¿Cómo perciben los padres su relación con los profesionales? *Revista de Investigación Educativa*, *33*(*1*), 119–132.

Arranz, P. (2007). La resiliencia en educación como elemento favorecedor del proceso de autodeterminación en las personas con discapacidad. In M. Liesa, P. Allueva, M. Puyuelo (Coords.), *Educación y acceso a la vida adulta de personas con discapacidad* (pp. 119–132). Madrid: La Muralla.

Badia, M., Longo, E., Orgaz, M.B., Verdugo, M.A., Arias, B., Gómez-Vela, M., González-Gil, F. (2011). Participación de niños y adolescentes con parálisis cerebral en actividades de ocio. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*, *42*(*3*), 23–34.

Badía, M., Orgaz, M.B., Verdugo, M.A., Ullá, A.M., Martínez, M. (2013). Relationships between Leisure Participation and Quality of Life of People with Developmental Disabilities. *Journal of Applied Research in Intellectual Disability*, *26*(*6*), 533–545.

Becerra, M.T., Montanero, M., Lucero, M. (2012). Programas de orientación y empleo con apoyo de personas con discapacidad intelectual. Modelos y estrategias de intervención. *REOP. Revista Española de Orientación y Psicopedagogía*, *23*(*3*), 9–15.

Casado, D. (1991). *Panorámica de la Discapacidad*. Barcelona: INTRESS.

Castro-Belmonte, M., Vilà, M. (2012). Los planes de transición al trabajo: una opción formativa inclusiva para personas con discapacidad. *REOP. Revista Española de Orientación y Psicopedagogía*, *25*(*2*), 24–39.

Cerrillo, R., Izuzquiza, D., Egido, I. (2011). Inclusión de jóvenes con discapacidad intelectual en la Universidad. *Revista de Investigación en Educación*, *11*(*1*), 41–57.

De la Rosa, L. (2016). La voz de las personas con discapacidad en la formación inicial de docentes. *International Journal of Educational Research and Innovation*, *5*, 160–169.

Echeita, G. (2013). Inclusión y exclusión educativa. De nuevo "voz y quebranto". *REICE. Revista Iberoamericana sobre Calidad, Eficacia y Cambio en Educación*, *11*(*2*), 99–118.

Elorza, A., Melchor, L., Orts-Gil, G., Gracia, C., Lacunza, I., Izquierdo, B., Fernández-Vera, J.I. (2017). Spanish science diplomacy: a global and collaborative bottom-up approach. *Science and diplomacy*, *6*(*1*), 1–12.

Esparza, C. (2011). Discapacidad y depender en España. Con base en la Encuesta sobre Discapacidad, Autonomía Personal y situaciones de Dependencia (EDAD), 2008. *Informes Portal de Mayores*, *108*, 1–20.

Fernández-Cid, M. (2010). Medios de comunicación, conformación de imagen y construcción de sentido en relación a la discapacidad. *Política y Sociedad*, *47*(*1*).

Fernández-Santamaría, R. (2011). El camino hacia la integración. *Revista de Participación Educativa*, *18*, 79–90.

Ferreira, M.A.V. (2008). La construcción social de la discapacidad: *habitus*, estereotipos y exclusión social. *Nómadas. Revista Crítica de Ciencias Sociales y Jurídicas*, *17*(*1*), 1–12.

Giné, C., Balcells, A., Simó, D., Font, J., Pro, M.T., Mas, J.M., Carbó, M.S. (2011). Necesidades de apoyo de las familias de personas con discapacidad intelectual de Catalunya. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*, *42*(*4*), 31–49.

Gómez, L.E., Alcedo, M.A., Arias, B., Fontanil, Y., Arias, V.B., Monsalve, A., Verdugo (2016). A new scale for the measurement of quality of life in children with intelectual disability. *Research in Developmental Disabilities*, *53*, 399–410.

Gómez, L.E., Alcedo, M.A., Verdugo, M.A., Arias, B., Fontanil, Y., Arias, V., Morán, L. (2016). *Escala KidsLife: Evaluación de la calidad de vida de niños y adoelscentes con discapacidad intelectual*. Salamanca: INICO.

González, J., Cortés, R. (2016). Actitudes y creencias hacia la discapacidad en clases de educación física. Una cuestión educativa. *Psychology, Society, & Education*, *8*(*2*), 105–120.

González-del-Yerro, A., Simón, C., Cagigal, V., Blas, E. (2013). La calidad de vida de las familias de personas con discapacidad intelectual. Un estudio cualitativo realizado en la Comunidad de Madrid. *REOP. Revista Española de Orientación y Psicopedagogía*, *24*(*1*), 93–109.

Guillén, V., Verdugo, M.A., Arias B., Vicente, E. (2015). Desarrollo de una escala de evaluación de necesidades de apoyo de niños y adolescentes con discapacidad intelectual. *Anales de Psicología*, *31*(*1*), 137–144. doi: 10.6018/analesps.31.1.166491.

Lizasoáin, O., Onieva, C.E. (2010). Un estudio sobre la fratría ante la discapacidad intelectual. *Intervención Psicosocial*, *19*(*1*), 89–99.

Longo, E., Badía, M., Orgaz, M.B. (2013). Patterns and predictors of participation in leisure activities outside of school in children and adolescents with Cerebral Palsy. *Research in Developmental Disabilities*, *34*, 266–275.

Lozano-Martínez, J., Alcaraz-García, S., Colás, P. (2010). La enseñanza de emociones y creencias a los alumnos con trastornos del espectro autista: una investigación colaborativa. *Profesorado. Revista de Currículum y Formación del Profesorado*, *14*(*1*), 367–382.

Luque, D.J., Luque, M.J. (2015). Relaciones de amistad y solidaridad en el aula. Un acercamiento psicoeducativo a la discapacidad en un marco inclusivo. *RMIE. Revista Mexicana de Investigación Educativa*, *20*(*65*), 369–392.

Molina, R.M. (2009). La escuela central de anormales de Madrid. In M.R. Berruezo, S. Conejero (Coords.), *Actas del XV Coloquio de Historia de la Educación. El largo camino hacia una educación inclusiva: la educación especial y social del siglo XIX a nuestros días. Volumen I.* Pamplona, 2009. ISBN: ISBN 978-84-9769-244-1. *Retrived on March 2017 from: https://dialnet.unirioja.es/servlet/articulo?codigo=2962591.*

Moriña, A. (2010). Vulnerables al silencio. Historias escolares de jóvenes con discapacidad. *Revista de Educación*, *353*, 667–690.

Moriña, A. (2015). ¿Contextos universitarios inclusivos? Un análisis desde la voz del alumnado con discapacidad. *Cultura y Educación*, *27*(*3*), 681–694.

Moriña, A., Molina, V. (2011). La universidad a análisis: las voces del alumnado con discapacidad. *Revista de Enseñanza Universitaria*, *37*, 23–35.

Moro, L., Jenaro, C., Solano, M. (2015). Miedos, esperanzas y reivindicaciones de padres de niños con TEA. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*, *46*(*4*), 7–24.

Ortiz, L., Tárraga, R. (2015). Mejora de la autodeterminación a través de las matemáticas en adolescentes con discapacidad intelectual. Un estudio de caso. *ReiDoCrea*, *4*, 292–307.

Pallisera, M., Fullana, J., Puyalto, C., Vilá, M. (2016). Changes and challenges in the transition to adulthood: views and experiences of Young people with learning disabilities and their families. *European Jorunal of Special Needs Education*, *31*(*3*), 391–406.

Pallisera, M., Fullana, J., Vilá, M., Jiménez, P., Castro, M., Puyalto, C., Montero, M., Martín, R. (2014). Análisis de los apoyos que reciben los jóvenes con discapacidad intelectual en su transición a la vida adulta en España: una investigación a partir de experiencias de profesionales y personas con discapacidad. *Revista Española de Discapacidad*, *2*(*2*), 17–43.

Pascual-García, D.M., Garrido-Fernández, M., Antequera-Jurado, R. (2014). Autodeterminación y calidad de vida: un programa para la mejora de personas adultas con discapacidad intelectual. *Psicología Educativa*, *20*(*1*), 33–38.

Peralta, F., Arellano, A. (2014). La autodeterminación de las personas con discapacidad intelectual: situación actual en España. *Revista CES Psicología*, *7*(*2*), 59–77.

Pérez-Castañeda, C.G., Verdugo, M.A. (2008). La influencia de un hermano con autismo sobre la calidad de vida familiar. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*, *39*(*3*), 75–90.

Puig de la Bellacasa, R. (1990). Concepciones, paradigmas, y evolución de las mentalidades sobre la discapacidad. En Real Patronato de Prevención y de Atención a Personas con Minusvalía (ed.), *Discapacidad e información* (pp. 63–96). Madrid: Autor.

Ripoll, C., Bravo-Iriso, J., Iruzun, M., Pérez-Pérez, E., Zuazu, A.B. (2016). Mejora de la lectura en 2 de Primaria mediante un programa de tutoría entre iguales. *Investigaciones Sobre Lectura*, *5*, 70–77.

Rojas, S., Haya, I., Lázaro-Visa, S. (2016). "My great hope in life is to have a house, family and a daughter": relationships and sexuality in intellectually disabled people. *British Journal of Learning Disabilities*, *44*(*1*), 56–62.

Sarrado, J.J., Cléries, X., Ferrer, M., Kronfly, E. (2004). Evidencia científica en medicina: ¿única alternativa? *Gaceta Sanitaria*, *18*(*3*), 235–244.

Sepúlveda, L., Medrano, C., Martín, P. (2010). Integración en el aula regular de alumnos con Síndrome Asperger o Autismo de Alto Funcionamiento: una mirada desde la actitud docente. *Bordón*, *62*(*4*), 131–140.

Schalock, R.L., Verdugo, M.A. (2002). *Calidad de vida. Manual para profesionales de la educación, salud y servicios sociales*. Madrid: Alianza editorial.

Schalock, R.L., Verdugo, M.A. (2007). El concepto de calidad de vida en los servicios y apoyos para personas con discapacidad intelectual. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*, *38*(*4*), 21–36.

Schalock, R.L., Verdugo, M.A. (2012a). *A leadership guide to redefining intellectual and developmental disabilities organizations: eight successful change strategies*. Baltimore, MD: Brookes.

Schalock, R.L., Verdugo, M.A. (2012b). A conceptual and measurement framework to guide policy development and system change. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(*1*), 63–72.

Schalock, R.L., Verdugo, M.A., Gómez, L.E., Reinders, H.S. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabiliities*, *121*(*1*), 1–12.

Scheerenberger, R.C. (1984). *Historia del Retraso Mental*. Usúrbil: Servicio Internacional de Información sobre Subnormales.

Surià, R. (2012). Discapacidad e integración educativa: ¿Qué opina el profesorado sobre la inclusión de estudiantes con discapacidad en sus clases? *REOP. Revista Española de Orientación y psicopedagogía*, *23*(*3*), 96–109.

Tamarit, J., Espejo, L. (2013). Experiencias de empoderamiento de personas con discapacidad intelectual o del desarrollo. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*, *44*(*2*), 22–35.

United Nations (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved from http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

Verdugo, M.A., Arias, B., Ibáñez, A., Schalock, R.L. (2010). Adaptation and psychometric properties of the Spanish version of the Supports Intensity Scale (SIS). *American Journal on Intellectual and Developmental Disabilities*, *115*(*6*), 496–503.

Verdugo, M.A, Arias, B., Guillén, V., Seo, H., Shogren, K.A., Shaw, L.A., Thompson, J.R. (2016). Examining age-related differences in support needs on the Supports Intensity Scale-Children's Version-Spanish translation. *International Journal of Clinical and Health Psychology*, *16*(*3*), 306–314. doi: http://dx.doi.org/10.1016/j.ijchp.2016.06.002.

Verdugo, M.A., Arias B., Guillén, V., Vicente, E. (2014). Escala de Intensidad de Apoyos para Niños y Adolescentes (SIS-C) en el contexto español. *Siglo Cero*, *45*(*1*), 24–40.

Verdugo, M.A., Gómez, L.E., Arias, B., Santamaría, M., Clavero, D., Tamarit, J. (2013). *Escala INICO-FEAPS: Evaluación Integral de la Calidad de Vida en personas con Discapacidad Intelectual o del Desarrollo*. Salamanca: INICO.

Verdugo, M.A., Gómez, L.E., Arias, B., Santamaría, M., Navalas, E., Fernández, S., Hierro, I. (2014). *Escala San Martín: Evaluación de la Calidad de Vida de Personas con Discapacidades Significativas*. Santander: Fundación Obra San Martín.

Verdugo, M.A., Gómez, L.E., Navas, P. (2013). Discapacidad e inclusión: derechos, apoyos y calidad de vida. In M.A. Verdugo, R.L. Schalock (Eds.), *Discapacidad e Inclusión: Manual para la Docencia* (pp. 17–41). Salamanca: Amarú.

Verdugo, M.A., Guillén, V., Amor, A.M., Aguayo, V., Arias, B. (2016, Jun). *Children and adolescents with and without Intellectual Diasbilities: comparative research of their support needs*. Poster sesión presente at the 140th AAIDD annual meeting, Atlanta, GA.

Verdugo, M.A., Guillén, V., Arias, M., Vicente, E., Badia, M. (2016). Confirmatory factor Analysis of the Supports Intensity Scale for Children. *Research in Developmental Disabilities*, 49–50, 140–152. doi: 10.1016/j.ridd.2015.11.022.

Verdugo, M.A., Rodríguez, A. (2012). La inclusión educativa en España desde la perspectiva de alumnos con discapacidad intelectual, de familias y de profesionales. *Revista de Educación*, *358*, 450–470.

Verdugo, M.A., Rodríguez, A., Sainz, F. (2012). *Escala de calidad de vida familiar: Manual de aplicación*. Salamanca: INICO.

Verdugo, M.A., Vicente, E., Fernández-Pulido, R., Gómez-Vela, M., Wehmeyer, M.L., Guillén, V.M. (2015). A psychometric evaluation of the ARC-INICO Self-Determination Scale for Adolescents with intellectual disabilities. *International Journal of Clinical and Health Psychology*, *15*, 149–159.

Verdugo, M.A., Vicente, E., Gómez-Vela, M., Fernández-Pulido, R., Wehmeyer, M.L., Badía, M., Calvo, M.I. (2014). *Escala ARC-INICO de Evaluación de la Autodeterminación: Manual de aplicación y corrección*. Salamanca: INICO.

Vicente, E., Guillén, V.M., Verdugo, M.A., Gómez-Vela, M., Arias, B., Navas, P. (2012). Relaciones entre las necesidades de apoyo y la conducta autodeterminada en niños y adolescentes con discapacidad intelectual. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*, *43*(*1*), 194–195.

Vicente, E., Verdugo, M.A., Gómez, M., Pulido, F., Guillén, V. (2015). Propiedades psicométricas de la escala ARC-INICO para evaluar la autodeterminación. *REOP. Revista Española de Orientación y Psicopedagogía*, *26*(*1*), 8–24

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO” ISSN 1734-5537
CNS nr 3(49) 2020, 139–158

SU-JAN LIN, CHEN-CHEN CHENG*

TAIWAN: FROM THE INCLUSIVE EDUCATION OF SCHOOLS TOWARD THE SOCIAL INTEGRATION[1)]

Keywords: people with disabilities, special education, pedagogy, sociology, equity

Introduction

Basic information about the country

Taiwan is an island state in the Southeast Asia with a population of 23,464,787 habitants (as of July 2016). Geographically it is strategically located off the southeastern coast of China with the Taiwan Strait in between (Central Intelligence Agency, 2016). Due to China's insistence that Taiwan belongs to China, most countries in the world do not recognize this tiny island state of 36,000 km2, slightly bigger than Belgium, as an independent country. The majority of international organizations including the *United Nations* and the *World Bank* have rejected Taiwan's membership applications. However, to its 23 million residents, Taiwan is a de-facto nation. It has a functional and democratic government that exercises sovereignty over a well-defined territory and population and conducts its own foreign relations. Han Chinese people make up around 98% of the population. The remaining 2% percent are comprised of native Taiwanese of Austronesian ancestry and recent immigrant spouses and workers from Southeastern Asian countries (Rubinstein, 2007; The Executive Yuan, 2016). The main language people speak on Taiwan is Mandarin Chinese, along with regional Chinese languages of Min, Hakka and aboriginal languages, and languages brought by immigrants from their home countries of Vietnam, Indonesia, Thailand, and others.

---

* National Kaohsiung Normal University

[1)] Tekst pochodzi z książki *Studies on disability. International theoretical, empirical and didactics experiences* (2017) pod redakcją Joanny Głodkowskiej, Justyny Marii Gasik, Marty Pągowskiej (s. 140–160). Warszawa: Wydawnictwo APS.

Strategy for the development of education

In 2014, Taiwan's compulsory education was extended to 12 years and students are required to finish elementary (6 years), junior high school (3 years), and high school (3 years). Special education is an integral part of the education system and students receiving special education services follow the same education pathways along with their typically developing peers.

Although each student will eventually find a school to attend up to high school, the idea about what schools are for, which has been formed and strengthened until the very recent past, continues to influence many parents', teachers', and teacher trainers' beliefs and practices in schools and teacher training institutions. Education in Taiwan, a Chinese-dominant society, has been viewed as a competition among students for high examination scores which are tickets to top-ranking schools and universities. Education qualifications are highly regarded and beneficial to securing a good job and therefore one's position in the society. The recent results of TIMSS 2015 revealed that students in Taiwan scored high on both Mathematics and Physics tests; however, the same students were at the bottom on a related context survey investigating their interest and self-confidence in Mathematics and Physics (Huang, 2016). Making high school a part of compulsory education in 2014 will not change people's ideas about education overnight but it is a good start. In addition to this new change, the *Ministry of Education*, agency responsible for national academic and education administration, is actually aware of the education situation described above and adopted the following education reform policies hoping to add alternatives or to change the current views about education in Taiwan.

- 'Exam free' pathways to upper secondary school
- Decentralized an overly restrictive curriculum
- High-quality early childhood education to all students
- Subsidized students from disadvantaged homes, and strengthened supports for disadvantaged students
- Improvement of vocational training and education programs
- Arts education available to all students
- Promotion of e-learning

The national reports documenting the phenomenon of disability

The special education has the dominating role within the field of disability in Taiwan. The parents' organizations and scholars promoted the equal rights with education and adult life for the people with disabilities. The approaches started from the legislation and then the supervision of government implementation.

The *Special Education Act* in Taiwan was first enacted in 1984 and had 25 sections. It was recently amended in 2009 and now has a total of 51 Articles (Ministry of Education, 2009).

The *Enforcement Rules of the Special Education Act* were amended to implement the *Special Education Act* in 2012. The least restrictive environment and the provision of appropriate education are the main principles for schooling of students with disabilities.

The main mission of special education in Taiwan is stated in the Article 1: *The Act is enacted for the purpose for individuals with disabilities and/or giftedness to receive appropriate education, fully develop their potential, develop a sound personality, and be empowered to provide social services to others* (Ministry of Education, 2009). Article 18 states that the provision and programming of special education and related services should be based on the principles of appropriateness, individualization, localization, accessibility, and inclusion. This stipulation clearly advocates inclusive education for students with special educational needs. In addition, Article 22 announces the zero-rejection policy in general education schools, including the public and private schools, and tests catered for students with special educational needs. Based on Taiwan's special education legislation, all school-age students with special educational needs are to attend an age-appropriate general education school in their neighborhoods alongside their peers without disabilities. As the special education legislation evolves, inclusive education has become the guiding principle and practice for special education policy in Taiwan.

Sufficient budget is needed for the special education sector to provide the appropriate education. Article 9 of the Special Education Act stipulates the amount of budget guaranteed for the special education. All governmental entities should configure the special education budget to the extent that is no less than 4.5% of the yearly educational budget in the central government and no less than 5% in the local government. When the local government plans for its budgets, special needs education is the top priority. In order to keep the quality of local special education development, the central government should reimburse the local government for budgets in special education personnel costs such as the teachers' salary. The *Ministry of Education* in Taiwan has been publishing national statistics pertaining to special education annually since 1999. Those data come from the national *Special Education Transmit Net* that collects special education-related information across the whole country. Based on the 2016 *Special Education Statistics*, the central government spent on the education of students with disabilities was around 290,195,204.73 EUR and it was 4.38% of the 2016 national education budget (if we include gifted education, the figure rose up to 4.54%). The central movement did follow the legislation requirement. All local governments spent about 698,255,317.31 EUR in the special education sector which was a total of the 5.80% of yearly educational budget. In the local government budget, it was about 642,297,359.67 EUR (91.99%) for students with disabilities and 8.01% for gifted students (Ministry of Education, 2016a).

Based on the legislation, special education services begin at early intervention, from age 2, and ends in the higher education phase. The *Special Education Act* also defines the continuum of the service system of special education schools and special education classes, or programs in the general education schools. When an authority considers the placement of students with disabilities, the principle of proximity is followed. The practice of special education is embedded in four different phases, which are stated in Article 10: (A) Preschool: in hospitals, families, kindergartens, nursery, social welfare facilities, preschools of special education, or other adequate places. (B) Compulsory education: in general, elementary schools, junior high schools, special education schools, or other adequate places. (C) Senior high school: in general, senior high schools, special education schools, or other adequate places. (D) Higher/adult education: in colleges, universities, or other adult education facilities.

Based on the 2016 *Special Education Statistics*, the vast majority of students with disabilities in grades K-12 studied in general education schools (94.32%) while the remainder of the students was placed in special education schools (5.68%). In general education schools, only 12.74% were in full-time self-contained classes. The most students with special education needs were served in the general education classes and received special education services with resource rooms programs (55.94%), itinerant programs (15.61%) and special education support in the general classes (15.72%). This data indicated that around 87.26% of students were in the inclusive education settings. This data also confirmed that special education services were implemented by general education teachers with some special educator cooperation and support.

Since 1997, the *Special Education Act* defines thirteen categories of disabilities, including *intellectual disabilities, learning disabilities, autism, developmental delays, severe/multiple impairments, cerebral palsy, severe emotional disorders, physical impairments, health impairments, hearing impairments, communication disorders, visual impairments and other disabilities.* When a student presents more than one category of disability, then he or she will be identified as having multiple disabilities.

Article 6 also stipulates that central and local authorities should set up a *Special Education Students' Diagnosis and Placement Counseling Committee* (DPCC) to identify the students with special educational needs. The central and every local *DPCC* need to invite scholars, medical experts, education and school administrators, and delegates of parents to participate in the processes of identification and schooling decisions. Article 16 of *Special Education Act* also stipulates that local authorities should provide diagnoses standard including diagnostic criteria, procedure, duration, educational needs assessment, reassessment procedure, and other details that are determined by central authorities within the *Disabled and Gifted Students Identification Regulation* (Ministry of Education, 2009)

Based on the 2016 *Special Education Statistics*, the percentages of the 13 legislative disabilities from ages 2–18 (total: 108,635 students) are as follows: learning disabilities (28.9%), intellectual disabilities (24.5%), autism (11.7%), developmental delays (10.6%), severe/multiple impairments (5.1%), severe emotional disorders (5.1%), hearing impairments (2.8%), health impairments (2.6%), physical impairments (2.5%), communication disorders (1.7%), cerebral palsy (1.7%), other disabilities (1.7%), and visual impairments (1.0%).

Meanwhile, the higher education had 12,678 students with special education needs cross the 13 categories. The top three categories are: learning disabilities (22.5%), physical impairments (16.0%) and autism (12.7%) (Ministry of Education, 2016a).

Historical and contemporary approach towards disability

Facts – leading representatives

In 1891, the first special education institution was established in Taiwan. The founder was Dr. William Campbell who was the pastor of the British Presbyterian Church. This institution was founded for the persons with visual impairment to teach them Braille to read the Bible and other prints. They also were taught the skills of handicrafts for their independent living. In 1915, this institution was transformed to become a private school and enrolled students with hearing impairment (Ministry of Education, 2008a; National Taichung Special Education School for the visually impaired, 2016; Sheu, 1982). In those beginning years, the special education was developed by the Catholic and Christian church and private institutions in Taiwan. In 1922, during the Japanese colonial period, the government took over this school and it became the first public special education school in Taiwan. From that time on, the government has been responsible for special education for students with disabilities. Generally speaking, the church was the main institution for Taiwan's special education development. These special education pioneers were pastors, priests, and other church-related personnel who dedicated their whole life to the disability education in this land of Taiwan. They came from the oversea such as Scotland, Hungary, Holland, Italy, and the United States (Ministry of Education, 2008b; Ministry of Education, 2016b; Sheu, 1982).

Gradually, the government was responsible for the special education system established in the Japanese colonial period. The *Self-contained Class* was first founded in the public primary school for the students with intellectual disability in 1962. The self-contained class for the students with physical impairment was established in 1963. Afterwards, many primary schools and junior high schools started to receive the students with different categories of disability. To develop a better understanding of these children's educational needs, the government held the first *National Census for Children with Special Educational Needs* aged 6 to 12 years old in 1974. This survey reported that there were 31,053 students needing special education and they were grouped under six different categories: mental retardation, visual impairment, hearing impairment, physical impairment, health impairment, and multiple impairments. This educational population survey also facilitated the Taiwan first version of the *Special Education Act* in the 1984. The second national census for children with special educational needs was held in the 1990. This time children's age was extended up to 15 years old. This survey found there were 75,562 students with special educational needs. Five categories were also added in this national census: communication disorders, severe emotional disorders, learning disabilities, facial disability, and autism. The number of students classified as special education students, doubled during 16 years. This phenomenon caught government's attention and people started to realize the importance of special education and how special education is related to the equal education and civil rights (Ministry of Education, 2008a). This concern became an important social issue in the following days. It also influenced the second amendment of Special education Act in 1997 (Ministry of Education, 2008b).

General current trends – formulating paradigms

Currently, according to the *Special Education Law* of 2009, the implementation authority in the central government is the *Department of Student Affairs and Special Education within the Ministry of Education*. The local authorities are the *Special Education Division* in each city's or county's Education Bureau. Our special education service of the school system presents as shown in Table 1.

Table 1. Taiwan's Special Education System

Level	Age	Special Ed. Schools		Regular Schools
Higher Education	19–22	Universities and Colleges		Five-year colleges
Senior High Education	16–18	Senior High	Senior High/ Vocational [resource room program, Regular Classes]	
Civil Education	13–15	Junior High	Junior High Schools [resource room program, Regular Classes]	
	6–12	Elementary	Elementary Schools [resource room program, Regular Classes]	
Early Childhood	2–5	Kindergarten	Kindergarten [resource room program Regular Classes]	

Following an identification protocol, students with disabilities qualified for special education will be given an appropriate placement and related service. The schools will provide the proper education based on Individual Education Plans (IEP) for each student. The educational placement and arrangement of each student can be reassessed annually by competent authority (Ministry of Education, 2016b).

At the higher education level, the government has improved the university admission system for students with disabilities in the past decades. Through multiple admissions and separate entrance exams for students with disabilities, around 12,376 students with disabilities entered the higher education system in 2016. So far, 10.16% of higher education students were students with disabilities. There are a total of 157 universities and colleges in Taiwan. Almost every school has a Resource Room program to support their students with disabilities. When the university/college has at least 8 students with disabilities, the special education budget assumes the cost of hiring counselors working with students on campus. In addition, 13 universities with special education departments and centers have been providing professional consultancy, learning support and related service for students from all universities.

At the preschool level, the government encourages both public and private kindergartens to increase the number of special education teachers. It also provides additional special educational training and workshops for all preschool teachers in order to provide quality special educational service for students of preschool age with disabilities. The significant achievement is that the number of children with disabilities accepted in early intervention service rose from 9,612 in 2006 to 15,559 in 2016 (Ministry of Education, 2016a; Ministry of Education, 2016b).

Since 1997, the *Ministry of Education* biennially monitors the implementation of local governments with a focus on the special education process and products for each two years. In 2009, it extended to a three-year interval between required re-evaluations based on the law amendment.

From 1983 onward, the national curricula for students with disabilities (such as intellectual disabilities, visual impairments, hearing impairments and physical impairments) were developed as separate from the general education curriculum. Students with other categories of disabilities have been taught the general education curriculum with some adaptation for their special educational needs. This dual-track of the national curriculum, from elementary to high school level, existed in Taiwan until recently. Following the movement toward inclusive education, the dual-track curriculum became a problem, since most students with disabilities were receiving services in general education classrooms. The *Ministry of Education* was engaged in curriculum reform efforts through the amendments of the *Special Education Act* of 2009. The new national curriculum for special education is infused in the national twelve-year basic education curriculum and focuses cross-categories and access to the general curriculum. In addition to the general curriculum, a range of specific subjects are also offered as an alternative to formal curriculum for students with disabilities. These alternative curricula include life skills, social skills, communication training, learning strategies, orientation mobility training, and assistive technology among other areas. Instruction using alternative curriculum become the duty of special education teachers. Meanwhile, the abilities to perform core academic curriculum adaptation and differentiated instruction are required competencies for both special and general teachers.

Special education teacher training is under the same regulations as for general education in the *Teacher Education Act* in Taiwan. Basically, pre-service special education teacher training is treated as a specific academic program in our teacher education system. Currently, 13 universities have special education departments running special education teachers training programs to meet the needs of various school levels. To assure special education teacher quality, the Ministry of Education sets a minimum of 40 credits and credits references for courses designed in different universities. These 40 credits include four types of courses: educational foundations, common courses, specific requirement courses, and optional courses in disability topics. All 13 special education departments also offer 40 course credits that are similar and in accord with the requirements of the *Ministry of Education*. Actually, there are about totally 70–80 credits of special education related courses required for the special education major in the different universities. In addition to majors in special education, special education departments also offer minors in special education for students pursuing a general education major. Based on the 2016 special education statistics, of all teachers teaching students with special educational needs at various grade levels, 89% are qualified special education teachers, 4% are qualified general education teachers, and 7 % are without the teacher certification (Ministry of Education, 2016a).

The related services and interdisciplinary collaboration are identified in Article 24 of the *Special Education Act.* It requires combining services in the fields of health and medical treatment, education, social work, independent living, and vocational rehabilitation. As such, speech therapists, physical therapists, occupational therapists, and psychologists all could be involved in the program of a student with special educational needs in the school settings. This support services regulation was enacted in 1999 and re-enacted in 2012 with more comprehensive contents.

Disability studies – scientific discipline, field of study

As mentioned before, the education is the main force in the field of *Disability Studies* in Taiwan. Taiwan has been focusing on the scientific discipline in the special education for a long time. The research findings mostly came from the grant research and the graduate thesis and the dissertation. Most of the grant research applicants are university professors. Those professors could apply for research grant from the *Ministry of Science and Technology, Ministry of Education*, and the local governments to study any issues related to special education. The grant applicants are required to undergo a peer review process by reviewers from the *Ministry of Science and Technology* and the *Ministry of Education*. The *Ministry of Education* and the local government also commission research projects to support evidence-based policy making.

The most research grants of the special education are from the *Ministry of Science and Technology*. The predecessor to the *Ministry of Science and Technology*, the *National Science Council of the Executive Yuan*, traces its history back to the 1959. Currently, the *Ministry of Science and Technology* (MOST) has established 7 goals, 27 strategies and 58 important measures, all of which are jointly implemented by 22 government agencies, including the *MOST*, *Ministry of Economic Affairs*, *Ministry of Education, Ministry of Health and Welfare*, etc. (Ministry of Science and Technology2016). The study of the disability is benefited from its issues related to the *Ministry of Education* and the *Ministry of Health and Welfare.*

The special education studies focus on the empirical research for more than 30 years especially in teaching children with disabilities. The approved research mostly follows the social science methodology. The doctoral dissertations and master theses also produce much scientific research findings to improve the development of special education field. The field of special education in Taiwan also has more than 4 academic journals, 2 quarterlies, and others to publish these research results Three of them were recognized on the Taiwan Social Sciences Citation Index (TSSCI) list.

Meanwhile, we introduce alternative approaches to the above medical understanding of disability in Taiwan. To achieve this goal, we researched in articles and essays published in a major, possibly the largest, academic database in Taiwan, Airiti, and other online sources. The keywords we used for the search were, in Chinese, medical model of disability, social model of disability, or disability study. This search yielded 20 research studies and conceptual papers published between 2003 and 2015. We also found two books related to *Disability Studies*. The great majority of these publications were works of sociologists. These scholars have been problematizing the concepts of disability and questioning how historical, cultural, and societal contexts "produce" people with disabilities. Most of their works were introductory essays to bring disability study concepts into their professional fields which were mostly dominated by biomedical views of disability (Chang, 2007; Chiu, 2011; Wang, Lin, and Chang, 2012; Wang, 2011). They remained a minority in their own field of sociology and were almost unheard of to the special education professionals and researchers from the authors understanding.

Chiu (2011) traced the historical trajectory of how at different times, different people were categorized as having disabilities in Taiwan. He attempted to organize a localized historical frame to tackle questions such as what is disability, who are people with disabilities, what are the categories of disability, and how the identification process reflects what the society think of disability. Especially when the Taiwanese government decided to adopt the International Classification of Function, Disability, and Health (ICF) by the *World Health Organization* (WHO) for disability classification in 2012. Although ICF is a result of multinational discussions, this system remained a borrowed one for Taiwan. How the Taiwanese government utilized this system also reflected how disabilities were imagined in the local historical frame.

A textbook of *Disability Studies: Theories and Applications for Policies* edited by Wang, Lin, and Chang (2012) turned to a very different aspect of *Disability Studies* – universal design. The ideas of special education and *Disability Studies* came from the western societies. While promoting these ideas, Taiwanese scholars do not usually question the foundation and philosophical underpinnings of these theories and practices. Universal design is also one of these concepts.

From the policy aspects of *Disability Studies*, Wang, Lin, and Chang (2012) attributed the discrimination, prejudice, charity-based practices, and the violation of students' rights in special education schools to the lack of reflections and critical examinations of the meaning of disability. Even when there were articles about *Disability Studies* by Taiwanese scholars, they were meant for publications in overseas journals with a non-Taiwanese audience in mind. This tendency to produce works that matched the viewpoints of a western readership distracted Taiwanese scholars from local social phenomena and prevented them from forming a more systematic understanding of and reflections on disability based on our own local history and social contexts.

Wang (2011) concentrated on the application and contribution of ICF and ICF for Children and Youth (ICF-CY) to special education. Taiwan's adoption of ICF in its identification and classification of people with disabilities as mentioned previously demonstrated a paradigm shift in how disability was being understood. Wang stressed that the underpinning philosophy behind these ICF and ICF-CY tools was universal in nature and when these principles were making their way to Taiwan, they were not practices transplanted from the West. Wang also introduced how ICF-CY could be applied in special education.

Interdisciplinary empirical analysis of the phenomenon of disability

Research analysis in the positivist orientation

The purpose of educational research is looking for the new findings that help educators become better informed about teaching practices for learning, classroom management, and human development. At the same time educational research also could focus on the administration and the policy making to support the high quality of education service. In 1974, the Taiwan government held the first *National Census for Child with Special Education Needs*. The findings were used to define the categories of disabilities and appropriate educational placement. Following this research-based model, Taiwan's many important special education policies always had the research first to guide the practices.

The teaching and related issues in the special education have been encouraged with research orientated by the government. Most of researchers (professors) will apply their grant research from the *National Science Council* and now named *Ministry of Science and Technology*. Chiu (2005) analyzed 2000 to 2005 grant researches in the special education field. She pointed that the research topics included the different teaching approaches, positive behavior support, early intervention, curriculum adaptation, and transition. Ko (2005) also found out that reading and writing research were focus on the diagnosis, characteristics, intervention, and materials accommodation for the students with special educational needs during 2000–2005. Chang (2005) reported the different positive findings with different learning strategies for the students with disabilities at different levels. Those research reports guided the orientation for the pre-service teachers' training and related policy making. Pan et al. (2007) also analyzed the 2005 to 2006 popular grant researches in the special education field from the *National Science Council*. They found the research topics mostly focused on the curriculum and instruction for the students with autism, hearing impairments and intellectual disability. However, the appropriate process of identification and student's schooling with disabilities also got some attention from the researchers. The environment or the society issue also was explored by the researchers, such as general curriculum accommodation in the inclusive education, family support for students with disabilities, universal design of learning, supportive society in the early intervention, accessibility environment, and the support to the immigrant family with the disabilities child.

Chiu (2011) investigated how people with disabilities were categorized from 1905 when the first island-wide census was taken during the Japanese occupation. Five categories were noted and they were: blindness, deafness, muteness, craziness, and idiocy. The purpose of this census was related to the development of public health and medical policies. In 1931 and till 1953, to formulate criteria including and excluding candidates for positions in public services, people with contagious diseases, sensory and physical disabilities (loss of sight, language, hearing, or movement), and psychiatric illness were forbidden to serve in the government offices. Even in 1969, candidates who lost two feet were not eligible to run for legislator at the central level.

The earliest identification of disability for social welfare purpose was in 1957 when the government stipulated that people who *had corrected vision of 0.08 and below, were deaf in both ears, were mute, had lost two upper limbs or one* *lower limb, or had other obvious physical impairment with loss of functions* could use public transportation at a discount fare.

With the first *Taiwan Welfare Law for the Disabled* in 1980, the identification of people with disabilities was aimed for distributing social welfare resources and assistance. Finally in 1991, all restrictions on people with disabilities who ran for government offices were abolished. Also according to the law, employers in private sectors were not allowed to discriminate people with disabilities. In 2012, the government started to adapt ICF principles in identifying people with disabilities for their civil rights. However, the ICF-based classification process continued to be controlled by the medical professionals and people had to meet the medical requirement of the “loss or impaired body functions and structures” to be classified as people with disabilities. These different historical stages of disability identification reflected how the Taiwanese society viewed the civil rights of their citizens with disability.

Research analysis in the humanistic orientation

Chiu (2014) examined a wide range of church and government documents and records, reviewed government statistics, and interviewed persons with visual impairment to study how the education for the blind in Taiwan emerged and developed along with the political, social, and economic changes from 1870’s to 1970’s. Chiu first pointed out that different from how special education rose with industrialization and mass education in the West, Taiwan’s special education followed a distinct trajectory as a result of colonialism, proselytization of Christian church, and internationalization. The special education in the case of the persons with visual impairment is not necessarily a sign of progress or beneficial to their livelihood.

Methodological pluralism

In Taiwan, the disability research could be separated into two different fields: pedagogy and sociology. Therefore, the research methodology also showed the difference in the different professions and focuses. This article will use the quantitative, qualitative, and mixed research to present the diversity of the research methodology.

In pedagogy-focused *Disability Studies*, the above three paradigms were included but quantitative research was most popular (Pan et al., 2007). The main reason is the educational researchers are mostly from psychology and education background. When the research topics were related to the educational policy or the reality phenomena, then the survey, interview, focus group method and other types of qualitative research methods are used. When the topics were about the curriculum and instruction for the students with special educational needs, then the most popular methods were quasi-experimental designs, experimental designs and the single subject design. Some researchers also liked to conduct an experiment (quantitative) and followed by interview study with the participants (qualitative) to conclude the results (Chiu, 2005; Tjeng, 2005). The characteristics of people with disabilities also receive a great attention and, on those cases, the survey or the case study methods are used.

Scholars from rehabilitation medicine, public health, social work, teacher training, and special education also contributed to the area of disability study from their own professional perspectives. In sociology-focused *Disability Studies*, researchers applied ethnography, historical archival search, and many other qualitative research methods to develop deeper insight to the contexts of special education and disability issues.

Selected constructs of recognition of the phenomenon of disability

Personalistic perspective

The chapter of the *Great Harmony* was written by Confucius and has been spread for more than two thousand years in the Chinese societies. Confucius tried to build an ideal world and it should be pursued by the human beings. This peaceful world should take care of the *Helpless widows and widowers, orphans and the lonely, as well as the sick and the disable people*. Confucius was respected as the greatest teacher in the Chinese society and also the mentor of the virtue for everyone. Confucius wished that the society should take care of the people with disabilities and it became the duty of the government and educators (Zukeran, 2016).

The people with disabilities are the disadvantaged group in the society. It has been viewed as a virtue to care for people who need the support in our society. However, our attitude has been transformed from the negative pity to the positive "equality rights". The perspective of disabilities has been changing from a lack of the abilities to the lack of the opportunities for learning. Everyone has potential to learn even when they have significant disabilities. We believe that independent life skills could be taught successfully to people with severe disabilities. That is the reason why we need to invest in the national budget in the special education from early intervention when children are two years old. This basic value helps the parents' groups of children with disabilities and other advocates to push the society to gradually alter its perspectives. If we do not invest in the education today and tomorrow we will need to use more national resources in the welfare. Education is the best way to change the destiny of human beings, including people with disabilities.

Confucius was respected as the greatest teacher in the Chinese history. His birthday, September 28th, is a national holiday, the "Teacher's Day". The disciples of Confucius recorded his wise speech and talk in the Confucian Analects.

Confucius proposed a very powerful teaching principle that becomes the highest guideline for the education and special education. The principle, says that *in teaching should be no distinction of classes*. The "classed" also could be interpreted in terms of intellectual capacities and learning abilities. Based on this highest education guideline, there is no excuse for schools for not implementing the zero rejection and differentiated instruction for the students. The disabilities are caused by the physical and mental difference. These differences can be improved by the education, training and support. People could not change the existing differences or the disabilities but people could change their perspectives toward the disabilities. This is the focus and goal that the special education advocates have worked on.

Chiu (2014) also explained why the Taiwanese society was slow in applying universal design principles to enable people with disabilities to be more independent. Family has been traditionally supporting members of disabilities, relegating people with disabilities to recipients of assistance. The notion of an independent child hardly occurred to parents who believed they were responsible for their children's livelihood. This notion was extended to social welfare policies. Rather than encouraging people with disabilities to become independent, the support offered by the government often came in the form of a hired helper who oversaw the daily routines and activities of the person with a disability. With this type of manpower support, the society was relinquished of the responsibility to become more accessible to people with disabilities.

About the disability, rights, and the state, Chang (2007) introduced the social model of disability into the special education field. Reviewing studies and articles by mainly western scholars, Chang applied this social model of disability to the examination of the historical development of special education, criticized the inequality created by special education practices, and brought to fore the impact of labeling and stigma as the byproducts of special education.

Perspective of normalization of life of people with disabilities

The mission of the *Special Education Act* states that special education in Taiwan is to *fully develop their (students with disabilities) potential, develop a sound personality, and be empowered to provide social services to others*. The education is part of life for everyone. The *People with Disabilities Rights Protection Act* continues to support the people with disabilities after they have graduated from the schools. This act was amended from the title of *Physically and Mentally Disabled Citizens Protection Act* in the 2007 to its current title. The *Physically and Mentally Disabled Citizens Protection Act* was first enacted in 1980. This act aims to protect the legal rights and interests of people with disabilities, secure their equal opportunity to participate in social, political, economic, and cultural activities fairly, while contributing to their independence and development. In short, The *People with Disabilities Rights Protection Act* is the uppermost level of legislation to ensure that people with disabilities could have the equal opportunity to be independent regardless their disabilities. The central authority is the *Ministry of Health and Welfare*, and the county (city) governments are authorities at the local level. The *People with Disabilities Rights Protection Act* requires that any given government department (agency/organization) of individual levels, public school, or public business agency/organization/institution whose total number of employees is no less than 34 shall employ people with disabilities with capability to work and the number of employees with disabilities shall be no less than 3 percent of the total number of the employees.

Any given private school, association, or private business agency /organization/institution whose total number of employees is no less than 67 shall employ people with disabilities with capability to work and the number of employees with disabilities shall be no less than 1 percent of the total number of the employees, and no less than1 person (The Legislative Yuan, 2015).

In addition, employers can receive monthly reimbursements of NT$12,000 (US$380) for each person with disability employed and who was referred by a public job placement center. Persons with disabilities participating in state-run or government-commissioned vocational training programs can receive allowances equal to 60 percent of the nation's minimum monthly wage for up to one year (The Executive Yuan, 2016).

Based on the *Ministry of Labor* statistic report in 2016, The *Ministry of Health and Welfare* statistics showed that by 2014, there were 1.14 million people with disabilities (people who held disability certificates) in Taiwan. It was the 4.9% of the total population. The number of people with disabilities increased a 0.9% compared to 2004, and the 70% of the people with disabilities were in the mild and moderate ranges of disability. Among people with disabilities, 440,000 of them had a mild disability and 369,000 had a moderate disability (Ministry of Labor, 2016).

About the participation of people with disabilities in the labor forces, the *Ministry of Labor* conducted a survey on the participation of people with disabilities in the labor forces in June, 2014. They found that the percentage of people with disabilities who were in the labor forces was 19.7%, much lower than the national participation of labor forces (58.4%). Also in June, 2014, the unemployment rate of people with disabilities was 11%, much higher than the national unemployment rate of 3.9%, indicating that people with disabilities had great difficulty in finding jobs.

In 2014, the number of people with disabilities hired (74,000) was more than the quota set by the government for employers to hire people with disabilities and it was an increase of 23.8% since 2009. In 2009, the number of people with disabilities was 125.7% more than the government quota, and in 2014 it was 137.7%. The increase in the number of employed people with disabilities showed that the government's quota system was conducive to protecting the employment rights of people with disabilities (Ministry of Labor, 2016).

Chang (2015) published a more locally based study on the civil right movement initiated by people with disabilities in Taiwan. He followed two major disability groups in their campaigns and analyzed their strategies, rhetoric, and discourses using civil rights as the frame for their movements. He found that globalization and information from overseas via online social media served as mobilizing forces and motivated people with disabilities to push the government to act more carefully in its response to the demands of people with disabilities. For example, a local airlines company claimed that wheelchair users were not allowed to board the plane because the airport was not equipped with a jet bridge. The disability groups then demanded the government to provide jet bridges or any types of boarding ramps at domestic airports but were met with a bureaucratic reply that they could not find any appropriate jet bridges for that particular airport. A member from the disability group was studying in the US and found many kinds of boarding ramps and procurement information online. She posted the information and it was quickly re-posted by others online. Before long, the lawmakers were involved. Within one year, the *Ministry of Transportation* purchased suitable boarding ramps for all domestic airports and the year after, the law governing the welfare of people with disabilities stipulated that no airlines are allowed to refuse to serve people with disabilities.

Globalization and fast transmission of information on the internet helped Taiwanese disability groups more effectively spread their rights discourses while most people in Taiwan continued to regard the special treatment provided for people with disabilities were welfare benefits. Young people with disabilities especially rejected the welfare discourse and initiated campaigns to disrupt the conventional ideas about accessibility right to the public buildings. For example, a group of wheelchair users decided to "take a walk" in a park at the same time to protest against the barred entrance to that particular scenic park. The entrances to the park was barred and only allowed one able-bodied person to enter at a time. To enter the park in a wheelchair, the user had to nudge and adjust the angle of the wheelchair to get in. On the day of the protest, 10 wheelchairs lined up to enter the 10 barred entrances. Each person spent about 10 minutes to get through and entered the park ground. Many people who waited to get in took photos and wrote in their blogs to share their observations. Three weeks later, the park administration removed the bars and opened up the entrances.

Cultural construct

The most common view of disability in Taiwan continues to be medically-based. Disability is regarded as an individual's impairment that requires similar medical diagnosis and intervention. It is expected that with medical identification and treatment, people with disabilities probably could closer to the performance like the people without disabilities. In the past, some people believed that disability is a personal tragedy that although is unfortunate to this particular person, this person is responsible for the consequences his/her disability incurs. The purpose of special education corresponds to this medical view of disability. Special education teachers are entrusted with the tasks of identifying and providing services to students with disabilities in academic, social, emotional, and physical areas so the achievement gaps between students with disabilities and students without disabilities can be reduced as much as possible (Chang 2007; Cheng, 2010; Chang, Lin, 2009; Tseng, 2015).

Chiu (2014) summarized the meanings of disability in the Taiwanese society. First people with disabilities were regarded as a group of people whose social role was deemed as deviant and needed to be contained so the societal system would not be affected. Public health and medical professionals were entrusted with the responsibility for containing the negative impact that people of disabilities brought about and providing them with treatment so people with disabilities could return to the society as a productive member. Disability identification also was used as an administrative category for distribution of social welfare benefits. To manage limited social resources, the identification of people with disabilities could be manipulated according to the financial situations of the state. Identification of people with disabilities also meant needs assessment. In Taiwan, the government assumed that people with disabilities must have needs that were to be fulfilled. However, the government tended to lump all people with disabilities together and managed to conclude that people with disabilities shared the same *characteristics, living situations, medical needs, and social service needs* (Chiu, 2014, p. 201). This needs identification process inadvertently proclaimed that the needs of people with disabilities were different from needs of people without disabilities, further widening the divide between people with and without disabilities. At present, although ICF regarded disability as a dynamic and universal experience and in adopting ICF as the guiding principle of disability identification, the government recognized that the needs of people with and without disabilities were not that different. However, Chiu concluded that the line between people with and without disabilities should be maintained due to people with disabilities did face some unique political and social issues.

In general, the traditional values and educational influence make sure a smooth and successful implementation of inclusive education in the past 20 years. We did overcome discrimination, rejection, and isolation. Fortunately, today's society has the common understanding with a positive attitude toward the people with disabilities. In the Taiwanese culture, we have a strong family relationship like the most of the Chinese cultures. The family is the main decision maker for their children or siblings with disabilities (Lin, 2016). In addition, it seems that everyone agrees with the government and the family should take good care of the people with disabilities. On the other hand, people with disabilities become dependent on their family members to make decisions for them. Therefore, the overprotection from the parents sometimes is the big challenge for the educators and the employers. The self-determination and the self-advocacy are not the main focuses in the education like other western countries. When the government takes the responsibilities for education, social welfare and the medical care for the people with disabilities, the motivation of employment becomes a challenge for the educators and advocates in the special education field.

Conclusion

This article stresses the inclusive development in Taiwan with the placement and pedagogy of people with disabilities in the society. The idea of inclusion is meant for pursuing equity and fairness for people with disabilities. People with disabilities always have barriers for participation in the learning and living environments. Therefore, the society should create access to the same opportunities for the people with disabilities.

Education is one of the social phenomena. Today's class or school is the tomorrow society. Special education is a social evolution with gradual changes and progress was made on the way. Taiwanese people with disabilities were excluded from the school for the past 125 years. We did have a dark and difficult time on the road toward the inclusive education. After 1984, no school could reject the enrollment of the students with disabilities. After 2010, the teachers, including the special and general education teachers, must adapt the general education curriculum for their students with special educational needs. This change presents the shift of the power of decision making from the school and teachers to the parents and students themselves. For the parents and students, they had no choice in the past but now they could have many choices among general education school, special education school, and other special education services.

The parents' organizations, scholars and advocators stimulate the movement of the governments and the schools on their policy and attitudes. The legislation did produce a powerful guidance to ensure the equity for the people with disabilities in Taiwan. The Taiwan governments play a responsible role to implement the requirements of the special education regulations. Generally speaking, with efforts accumulated over the hundreds years, our law and the administration have arrived at the intended location for the special education. We could see it from the quantity perspective that we have achieved adequate number of laws, regulations, and special education service. We still need to make effort on the quality aspects of the pedagogy and social attitude toward the disabilities issues. We still have many tasks to accomplish such as teacher training, education studies, teacher professionalism, and civic literacy. These are the most difficult challenge on our way to the top of the equity mountain.

In this article, we only introduced a few sociological studies of disability in Taiwan. Their works represented various aspects and possibilities of studying disability. Our only wish is to see a dialogue happening between scholars of *Disability Studies* and special education. As there is a productive tension between medical and social models of disability and despite the strategic need to polarize these two models or choose one over the other for different agendas and purposes (Huang, 2014), professionals and scholars can make good use the contradictions and drastically different worldviews to reflect on the theories we subscribed to and question the daily practices we usually take for granted. It was about time to conduct the local *Disability Studies* issues to raise the awareness of *Disability Studies* and offer alternative views about disability in Taiwan.

References

Central Intelligence Agency. (2016). Taiwan. In The world factbook. Retrieved from https://www.cia.gov/library/publications/the-world-factbook/geos/tw.html.

Chang, H.-H. (2007). Special Education and Sociology of Disability: A Theoretical Reflection. *Education and Societal Studies*, *13*, 71–93.

Chang, H.-H. (2015). Disabled Citizens' Movement: Glocalization of Rights Discourse and Social Model in Taiwan. *Thought and Words: Journal of the Humanities and Social Science*, *53*(*2*), 89–136.

Chang, J.-H., Lin, H.-T. (2009). Exploring the Medicalization Phenomenon in the Special Education. *Bulletin of Special Education and Rehabilitation*, *21*, 1–17.

Chang, S.J. (2005). The review of learning strategy in the education field of National Science Council. Published in: *NSC Conference of Research Project Results*. Tainan: National Tainan University.

Cheng, C.-C. (2010). Mothers' experiences and interactions with professionals when caring for children in early intervention in Taiwan. (Doctoral dissertation). Available from ProQuest Dissertations and Theses database (UMI No. 3437296).

Chiu, S.-C. (2005). The issues in innovative teaching and teaching. Published in: *NSC Conference of Research Project Results*. Tainan: National Tainan University.

Chiu, T. (2011). Who Are the Disabled: An Examination of the Application of ICF in Light of the History of Disability Evaluations in Taiwan. *Social Policy & Social Work*, *15*(*2*), 187–213.

Chiu, T. (2014). Braille, amma and integration: the hybrid evolution of education for the blind in Taiwan, 1870s–1970s. *Paedagogica Historica*, *50*(*1–2*), 182–194. doi: 10.1080/00309230.2013.874362.

Huang, J.-J. (2016). Winning the competition of math and science but losing interest in learning? *United Daily News*. Retrieved from http://opinion.udn.com/opinion/story/6077/2148623.

Ko, H.-W. (2005). The review of reading and writing project in the education field of National Science Council. Published in: *NSC Conference of Research Project Results*. Tainan: National Tainan University.

Lin, S.-J. (2016). The study of transition model for the high school leve in Taiwan. The report of grant research. Taipei: K-12 Education Administration, Ministry of Education.

Ministry of Education. (2008a). The special education white paper. Taipei: Author.

Ministry of Education. (2008b). The special education development report. Taipei: Author.

Ministry of Education. (2009). The special education act. Taipei: Author.

Ministry of Education. (2015). Education in Taiwan 2015/2016. Taipei: Author.

Ministry of Education. (2016a). Annual special education statistics of 2016. Taipei: Author.

Ministry of Education. (2016 b). Special education information network in Taiwan. Retrieved from http://www.spc.ntnu.edu.tw/ensite.

Ministry of Labor. (2016). Labor statistics for the people with disabilities. Retrieved from www.mol.gov.tw/statistics/2462/19476/19049/.

Ministry of Science and Technology. (2016). Retrieved from https://www.most.gov.tw/most/attachments/30b1923c-f27c-44c3-8c95-c5002918dfbc?.

National Taichung Special Education School for the visually Impaired. (2016). The history of the school. Retrieved from http://www.cmsb.tc.edu.tw.

Pan, H.-L. et. al. (2007). The investigation of popular and prospective studies in the education fields. The report of graduate institute of educational policy. Taipei: National Taiwan Normal University.

Rubinstein, M.A. (2007). Taiwan: A new history (Expand ed.). Armonk, N.Y.: M.E. Sharpe.

Sheu, T.-W. (1982). Special education teaching training for 30 years in Taiwan. *Bulletin of Educational Resources and Research*, *7*, 153–194.

The Executive Yuan. (2016). The Republic of China Yearbook 2016. Taipei: Author.

The Legislative Yuan. (2015). The People with Disabilities Rights Protection Act. Taipei: Author.

Tjeng, S.-J. (2005). The analysis and thought of teaching study from the 2001–2005 NSC research projects. Published in: *NSC Conference of Research Project Results*. Tainan: National Tainan University.

Tseng, F.-T. (2015). ADHD and its Changing Network of Expertise in Taiwan. *Taiwanese Journal for Studies of Science, Technology and Medicine*, *21*, 15–75.

Wang, K.-Y. (2011). From the Perspective of Changing Paradigm on Disability Study to Discuss the Implication of ICF and ICF-CY in Special Education. *Special Education Quality*, *118*, 1–12.

Wang, K.-Y., Lin, C.-L., Chang, H.-H. (2012). Disability studies: theories and policy implications. Kaohsiung: Juliu.

Zukeran, P. (2016). Confucius. Retrieved from http://www.leaderu.com/orgs/probe/docs/confucius.html.

„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO” ISSN 1734-5537

CNS nr 3(49) 2020, 159–194

STUDIA NAD NIEPEŁNOSPRAWNOŚCIĄ – DYDAKTYKA

ANTONIO M. AMOR GONZÁLEZ, MIGUEL Á. VERDUGO ALONSO,
PATRICIA NAVAS MACHO, LAURA E. GÓMEZ SÁNCHEZ*

INSTITUTE ON COMMUNITY INTEGRATION: 20 YEARS RESEARCHING, TRAINING, AND LEADING CHANGES TOWARDS INCLUSION1)2)

Keywords: Disability Studies, Spain, Students with Disabilities, Inclusion, Rights, Quality of Life, Didactics

Introduction

Basic information about the country. Spain (officially Kingdom of Spain) is a parliamentary monarchy and a transcontinental country in the south of Europe with more than 500 years of history. The country's surface is over 500 thousand km^2 being the 52th biggest country in the world and the 3rd in Europe after Russia and France. According to the *National Institute on Statistics* (INE in Spanish), Spain's population in 2016 was over 46 million3) (29th in the world and 7th in Europe) and its population density is 92 habitants/km^2 (as of 1 January 2016). The demography in Spain is characterized by elderly population

---

* University of Salamanca. Faculty of Psychology. Institute on Community Integration (INICO). Salamanca, Spain

University of Oviedo. Faculty of Education. Institute on Community Integration (INICO). Oviedo, Spain

1) Tekst pochodzi z książki *Studies on disability. International theoretical, empirical and didactics experiences* (2017) pod redakcją Joanny Głodkowskiej, Justyny Marii Gasik, Marty Pągowskiej (s. 158–195). Warszawa: Wydawnictwo APS.

2) This work has been co-funded by the Ministry of Education, Culture, and Sports of Spain (FPU Program, reference FPU13/03897), the Autonomous Community of Castile and Leon (R & D Programs, SA120U13), and the Ministry of Economy and Competitiveness (Grant PSI2015-65193-P; MINECO/FEDER).

3) http://www.ine.es/dyngs/INEbase/es/operacion.htm?c=Estadistica_C&cid=1254736176951&menu=ultiDatos&idp=1254735572981.

and one of the highest life expectancy in the world with a mean of 82.8 years[4] (2nd in the world after Japan). Spain has one of the oldest universities in the world, the *University of Salamanca*, which has almost 800 years of history (established in 1218). Since then, the number of universities has been growing in the country with a total of 82[5] (as of 31st of December 2016), of which 32 are private and 50 public. In the academic year 2015–2016, a total of 1,496,017 students were registered as university students (1,269,926 in public universities, and 226,091 in private ones[6]).

Current status of higher education. According to *Eurydice* and the *Spanish Network on Information on Education*, *Spanish Higher Education System* comprises three mainly kind of studies: university studies, professional training (FP in Spanish), and special teaching studies, such as arts, fine arts, and sports[7]. Higher education training in Spain is divided into three levels: first cycle level, which comprises the "Degree" and "Higher Professional Training" programs; "Master's Degree", which are the second cycle programs; and "PhD Programs", which compose the third cycle.

According to the *Organic Law on Education* of Spain (LOE 2/2006), the "Degree" and the "Higher Professional Training" programs, although both of them are part of the first cycle, they are not comparable, because each one offers a completely different academic and professional teaching approach. Thereby, "Degree" programs are taught at universities and their approach is mainly academic; and "Higher Professional Training" programs provide students the qualification for a given employment, and they are not taught at university (typically in High Schools). "Degree" programs provide a level 2 within the *Spanish Framework on Higher Education Qualification* (MECES in Spanish), while "Higher Professional Training" programs provide a *MECES*-level 1[8].

The second cycle level is composed by the "Master's Degree". These programs are intended for the acquisition of an advanced, specialized, and multidisciplinary training, orientated to the professional and/or academic specializing. They are also aimed at improving the research skills of students. They compose the *MECES*-level 3. Thus, taking into account the aim of the "Master's Degree", they can be: professional, academic, or research programs. The knowledge areas of these programs are: humanities and fine arts; sciences; health sciences; social

---

[4] http://apps.who.int/gho/data/node.main.688?lang=en.

[5] http://www.universia.es/universidades.

[6] https://es.statista.com/estadisticas/479407/alumnos-matriculados-en-universidades-en-espana-por-tipo/.

[7] https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/Espa%C3%B1a:Educaci%C3%B3n_Superior.

[8] https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/Espa%C3%B1a:Programas_de_primer_ciclo.

and juridical sciences; engineering and architecture[9]. "Master's Degree" can be either official (recognized by the Ministry and universities) or not official (recognized only by universities).

The third cycle level is where the "PhD Programs" are located, and supposes the *MECES*-level 4. In the "PhD Programs", qualifications are aimed at providing an advanced training of students in research activities[10].

About the current status of higher education, the annual report on the *National Student Fee and Support System in European Higher Education* gives updated information on the fees and the grants that concern students within higher education system. In the case of Spain, in the academic year 2016–2017, approximately 71% of full-time students paid fees, which range from 714€ to 2,011€ (average 1,110€) in the first cycle, and from 1,298€ to 3,211€ in the second cycle programs (average 1,991€). The fees are determined by the study field, the level, the number of ECTS taken, and also the number of times a student has taken each subjects. The amount of fee also differs between Autonomous Communities (regions in Spain) as each one has a different fee range. There is no difference in fees between full-time and part-time students. Exemptions of the fees are possible depending of the needs of students (e.g., large families and people with disability have very significant discounts, and may even be exempt). About the supports given to students, in the academic year 2016–2017, the need-based grants ranged from 200€ to 6,797€ (average 2,164€). The national grant system has several components. For example, each student may receive one or more components depending on family incomes. The components are: a fixed amount of 1,500€ based on student's family income; a fixed amount of 1,500€ for living costs for students living outside their family home; and a variable amount, based on the student's family income and grades[11].

If we analyze the weight that the spending in higher education system has had in the Spanish GDP, we can find that regarding the general education system, the spending trend in Spain has been decreasing in the last years (data by UNESCO). In 2013, the total GDP spending on education was of the 4.3%[12], a 0.1% less than in 2012, and 0.56% less than 2011. Specifically looking at the spending on higher education (as % of the total Government's spend on education), it comprises a total of the 22.44% of the GDP dedicated to education[13].

---

[9] https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/Espa%C3%B1a:Programas_de_segundo_ciclo:_Master.

[10] https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/index.php/Espa%C3%B1a:Programas_de_tercer_ciclo:_Doctorado.

[11] https://webgate.ec.europa.eu/fpfis/mwikis/eurydice/images/5/58/EN_Fees_and_support_2016_17.pdf.

[12] http://datos.bancomundial.org/indicador/SE.XPD.TOTL.GD.ZS?locations=ES.

[13] http://datos.bancomundial.org/indicator/SE.XPD.TERT.ZS?locations=ES.

Finally, looking throughout the evolution in the number of total registered students in Spain, table 1 summarizes the number of students, and the kind of university where they are registered.

Table 1. Students registered in public and private Universities.

Academic Year	Public Universities		Private Universities		Total
	N	%	N	%	
2008/2009	1,275,143	89.16	155,004	10.84	1,430,147
2009/2010	1,302,926	88.53	168,793	11.47	1,471,719
2010/2011	1,336,517	87.36	193,345	12.64	1,529,862
2011/2012	1,371,355	87.20	201,262	12.80	1,572,617
2012/2013	1,344,695	86.84	203,839	13.16	1,548,534
2013/2014	1,325,197	86.07	214,512	13.93	1,539,709
2014/2015	1,284,772	85.30	221,407	14.70	1,506,179
2015/2016	1,269,926	84.89	226,091	15.11	1,496,017

Source: self-elaboration based on statista-Spain[14)]

As can be seen, in general, the total number of students have been increasing since the last 10 years, although it seems that lately this number has slightly decreased (trend has a form of inverse U). The only significant trend is the increasing number of students registered in private universities through the years (from 10.84% in 2008/2009 to 15.11% in 2015/16).

Strategy for the development of education. Higher education in Spain has its own regulation with the *Organic Law on Universities* (LOU 6/2007), According to the *Ministry of Education, Culture and Sport* (MECD[15)]) there are 8 domains regarding higher education: education; humanities and arts; social sciences and law; science and computational sciences; engineering, industry and building; agriculture and veterinary; health and social services; and services. Related to the studies on disabilities, the main focus is on the areas of humanities and arts, education, social sciences and law, health and social services, and services.

In Spain, research and development strategy and work is conducted primarily by Universities, Institutes of Research, Enterprises, and *The Spanish National Research Council* (CSIC in Spanish). Research in Spain is funded by both public and private budgets. Public funding composes approximately 50% of the total research funding[16)] and is provided via "research and development

---

[14)] https://es.statista.com/estadisticas/479407/alumnos-matriculados-en-universidades-en-espana-por-tipo/.

[15)] https://www.educacion.gob.es/notasdecorte/rendimientos.action.

[16)] http://marcaespana.es/talento-e-innovaci%C3%B3n/investigacion-desarrollo.

projects” obtained across competitive calls where stakeholders submit their research and development projects to be assessed. The agency that funds and manages the public budget for research is the *State Agency of Investigation* (AEI[17] in Spanish). According to the *United Nations Institute on Statistics for the Education, Culture and Science,* summarized in a *World Bank* Report, in 2013 the expenses in Spain for research and development activities was a total of 1.26%[18] of the GDP, being in the 28th position in the world, but still far away from the 3% of the GDP that *European Union* (EU) encourages its members to reach by 2020[19]. However, due to political instability and the economic cuts in public expenses in research –among other areas-, the trend is negative, and data by the *INE* show that this amount, in the year 2015, has decreased until the 1.22%[20] of the total GDP.

Taking into consideration the data provided by *Eurostat*[21] (updated in February 2017), the number of researchers full-time in *EU* was of 1.82 million in 2015. Regarding these data, Spain is in the 4th position in *EU* after Germany, United Kingdom, and France (data still consider UK). Spanish researchers compose the 6.73% of the total number of researchers within the *EU.* According to *Scimago Journal & Country Rank*[22], Spain’s research activity regarding the number of publications is excellent, occupying the 10th position in the world and the 5th in Europe. About the strategies for developing the research and innovation activities, Spain has always been a collaborative country. In the eighties, the *Ibero-American Program of Science and Technology for Development* (CYTED) established a network of scientists in Latin America and Spain and, thanks to this program, nowadays more than 28,000 researchers are connected. Other relationships regarding science diplomacy take place between (Elorza et al., 2017): USA and Spain (i.e., increasing the visibility of Spanish researchers in different areas in USA), UK and Spain (i.e., establishing a Society of Spanish Researchers in the UK), and Germany and Spain (i.e., career development for Spanish researchers).

Spain is also following strategies and guidelines embodied in the *Strategic Framework for Education and Training 2020* for the development of education in the *EU.* Universities themselves in Spain are really concerned with the strategy for the development of education and are keeping track really closely to

---

[17] https://europa.eu/european-union/topics/research-innovation_es, http://www.idi.mineco.gob.es/portal/site/MICINN/menuitem.8d78849a34f1cd28d0c9d910026041a0/?vgnextoid=664cfb7e04195510VgnVCM1000001d04140aRCRD.

[18] http://datos.bancomundial.org/indicador/GB.XPD.RSDV.GD.ZS.

[19] https://europa.eu/european-union/topics/research-innovation_es.

[20] http://www.ine.es/prensa/imasd_prensa.htm.

[21] http://ec.europa.eu/eurostat/statistics-explained/index.php/R_%26_D_personnel#Source_data_for_tables_and_figures_.28MS_Excel.29.

[22] http://www.scimagojr.com/countryrank.php.

the developments made by the Government regarding this issue. For example, in 2013, a Commission composed by a team of experts provided guidelines in different areas on how to improve the educational system[23)]: the selection of research and teaching personnel, the assessment of universities' quality, the head of universities, the funding, and the undergraduate and post graduate programs.

Education and rehabilitation of people with disabilities

Historical Overview. The first attempt for educating students with disability in Spain was back in the XVI century. Fray Pedro Ponce de León (1508?–1584), monk and pedagogue, was pioneer in the world by developing a new pedagogical approach to teach deaf students to speak, and he created a school where other representatives in the study and scientific approach towards disability developed their work. One of those representatives was Juan Pablo Bonet (1573–1633), pedagogue and speech therapist, who wrote the first book about the education of deaf students in Spain. Regarding sensory disabilities, the XIX century was important due to Claudio Moyano y Samaniego (1809–1890), lawyer, philologist, philosopher and politician concerned about the educational system. In 1857, he initiated an important reform within educational system by developing *Moyano's Act* (1857). In this *Act*, the regulation of key aspects related to the education of blind and deaf students were addressed. However, this law didn't put the accent on individuals with intellectual disability (ID).

In comparison with other European countries, Spain was in the back of both research and professional practice towards students with disability. Regarding students with ID, Francisco Pereira Bote created a journal strictly dedicated to the study of *Abnormal Children* in 1907. He also created The *Psychiatric-Pedagogic Institute-Sanatorium* for children with mental retardation in 1908, and the *Psychiatric and Pedagogic Institute* in 1930 (Fernández-Santamaría, 2011). However, they were not the first institutions in Spain regarding the education of students with ID. The *Central School for the Abnormal* was created in 1922 (Fernández-Santamaría, 2011), as a public school for addressing the education of children and adolescents with ID until 14 years old, and its importance is transcendental for the scientific studies on disability and special education in Spain (Molina, 2009). Finally, the *Central School for the Abnormal* changed his denomination in 1960, acquiring the name of *National Institute on Therapeutic Pedagogy.*

The basis for today's education towards students with disability started back in 1975 when the *National Institute on Special Education* was created as an autonomous organism dependent of the Ministry of Education and Science. Three

---

[23)] http://www.usc.es/export9/sites/webinstitucional/gl/web/descargas/propuestas-reforma.pdf.

years later, in 1978, the *National Plan on Special Education* was published based on Warnock's Report, and established the principles of special education in Spain: normalization of services, integration of students with special needs, sectorisation of services, and individualization of teaching (Fernández-Santamaría, 2011). These achievements aforementioned have lead the change from and exclusion perspective to the current paradigms in the study of disability.

Formally talking, these advances can be summarized into three moments regarding the education of students with disability (Echeita, 2013): the exclusion paradigm, the integration paradigm, and the inclusion paradigm. In the exclusion paradigm, students with disabilities of any kind were considered as non-teachable within general education settings and the main response towards them was special education centers. In Spain, the integration movement started in the eighties, with the *Social Integration of Disabled People Act* (1982), and was characterized by the presence (but not participation and learning) of students with disability within general education settings. Although this movement put the accent on environmental factors, it still was under a medical perspective and didn't analyze the difficulties that ordinary schools had in the education of students with disability. The inclusion paradigm, where different authors claim that Spain is (Echeita, 2013; Muntaner, Rosselló, de la Iglesia, 2016), will be discussed in the next section.

Present day. Current situation of education towards students with disabilities in Spain can be defined as inclusion movement (Echeita, 2013; Muntaner, Rosselló, de la Iglesia, 2016). However, this is more a given name for making the distinction with the integration movement described than a reality. There are different barriers that actually difficult the inclusion of students with disabilities within general education framework, especially regarding students with intellectual and/or developmental disability. These barriers are: the outdated procedures for assessing the needs of students with disabilities (especially ID) (Echeita et al., 2017), the need of professionals with more competencies and abilities to meet the needs of students with disabilities within general education framework (Anaya, Pérez-González, Suárez, 2011); and the increasing number of students with ID within especial education centers (Ramos, Huete, 2016). Nevertheless, this movement started in Spain with the *Salamanca Statement and Framework for Action on Special Needs Education,* adopted by the *World Conference on Special Needs Education* and organized in Salamanca (Spain) in 1994. This paradigm is based on a socioecological understanding of the needs of students with disability and puts the accent on identifying and removing barriers for learning and participation of those students, guaranteeing their access, promotion, learning, and participation within general education settings alongside their peers without disability.

The education and rehabilitation of students with disabilities nowadays will be discussed through the legislation for the education of these children, the candidate students to receive special education services, and the procedures for determining their needs and provision of supports, and the general functioning of the educational system for providing the required supports to these students.

Before this, it is necessary to clarify how students with disability are understood in *Spanish Educational System*. First, in *Spanish Educational System*, all students who need different to ordinary supports are defined as students with "Specific Educational Support Needs". Those students are classified into many groups for providing a general overview and systematize their needs' detection and provision of supports. Figure 1 provides a general overview of the classification of students with specific educational support needs, where students with disability can be found:

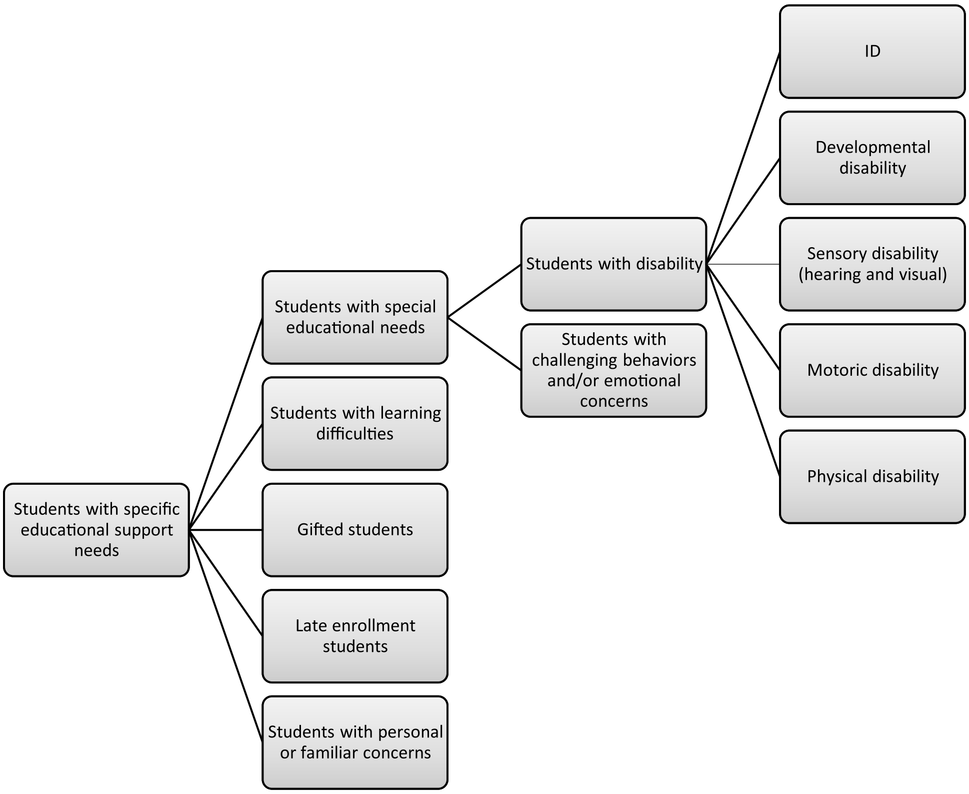

Figure 1. Students with disabilities within Spanish educational system

Source: self-elaboration based on Spanish educational law.

As can be seen, students with disabilities are a part of Students with "Special Educational Needs" (SEN). Those students are "those who require for all of their education or for a part, a different educational attention from the ordinary because of disability or challenging behaviors" (LOE, 2/2006, art. 71.2). Thus, in the rest of the chapter, students with disability will be named as students with "Special Educational Needs linked to Disability" (SWSEND).

About the current legislative mandates for the education SWSEND, Navas, Gómez and Verdugo (2017) have recently summarized the main characteristics of this issue in Spain. Although as has been aforementioned that the attention to SWSEND was established in the 70's of the XX century, the very first law ensuring access to education in either public or private schools for SWSEND was the *Royal Decree 334/1985*. The current educational law, *LOE* (LOE 2/2006), partially modified by the *Organic Law on the Improvement of the Quality of Education* (LOMCE 8/2013), states that education should be provided within ordinary settings and should be adapted to SWSEND so that they are able to access, permanence, and advance in ordinary environments, and only when the needs of students are extraordinary and the supports needed for addressing those needs are not generalizable within general education settings, then students should attend to a special education center. However, in Spain, each Autonomous Community has competences in Education, and so it has its own development and procedures regarding SWSEND. Thus, educational authority from each Autonomous Community must establish all the procedures and resources for the early identification of students' educational needs and provide the required supports and resources to meet the identified needs, so that SWSEND may achieve their maximum development as possible. Curriculum foresees many possibilities for adjusting to special education needs (general, ordinary, and extraordinary/specific attention to diversity measures) intended for students to overcome the difficulties they found within educational system. Measures are applied following steps, starting with the general attention to diversity measures and, if there's evidence on that measures don't cover students' needs, then ordinary measures will be adopted and, if again they are not successful, extraordinary ones are applied. At the end of each academic year, a specialized team evaluates the results achieved by each SWSEND, and all the procedures taken (including the kind of schooling of student) can be reversed and always looking to the least restrictive environments (Navas, Gómez, Verdugo, 2017). It is necessary to highlight that, although Spain has developed an adaptation of the *United Nations' Convention on the Right of Persons with Disabilities* for assuring students with disabilities' rights embodied there –specially within article 24-, the reasonable adjustments defined in the *Convention* are described in the aforementioned *LOE* (2/2006) (and its partial modification).

In regard of SWSEND eligible to receive special education, considering the total number of students (with and without disabilities) enrolled in public or private schools, students with SEN comprise around 2.1% of total students. According to Spanish *Ministry of Education, Culture, and Sports,* for the academic course 2013–2014, there was a total of 165,101 students with SEN: 131,349 (79.5%) were in regular classrooms with their peers without disabilities, while

33,752 students with SEN (20.5%) were receiving special education services, most of them with ID (43.6%) and severe developmental disorders and challenging behaviors (25.7%) (Navas, Gómez, Verdugo, 2017).

Students observed or suspected to be SWSEND are commonly referred by teachers, parents, or other members of community education, especially those working for special education services. In pre-elementary and elementary or primary education, counseling, guidance, and psychopedagogical services, which are dependent at Autonomous Community level, are responsible of the identification and assessment of special educational needs and, when necessary, the development of a report regarding the most suitable and appropriate kind of schooling for students. When parents of a child aged between 0–6 years old suspect that their son/daughter may present SEN, the child will be evaluated by the services even before enrolling school to determine the attention to diversity measures to be applied in the future. It is important to highlight that the needs assessment must be carried out by using different approaches and sources of information (Navas, Gómez, Verdugo, 2017).

In regard to the age range when addressing the education of SWSEND, in Spain, public compulsory education is provided for free to SWSEND from 3 to 16 years old (though they may remain in compulsory system until 18 years old depending on the extraordinary measures applied). In special education schools, the age of schooling may extend up to 21 years old. As different authors have appointed in Spain (Fullana, Pallisera, Martín, Ferrer, Puyaltó, 2015; Izuzquiza, Rodríguez, 2015) there is a lack of programs giving continuity to students with disability once they are out of the traditional transition programs: there is a lack of coordination when addressing higher education of students with ID. Based on this rationale and need, Fullana et al. (2015) developed the *Promentor Program* in 2004*,* a higher education program aimed at individuals with ID so that they can acquire both personal and employment competencies so that they will have more opportunities in the labor market. As data, in the year 2014, a total of 115 had graduated in the program, showing its strength and the possibility of higher education in students with ID (Izuzquiza, Rodríguez, 2015).

Taking a look into the places were supports are provided to SWSEND, as has been aforementioned, current educational law in Spain is based on the normalization and inclusion principles. However, the number of SWSEND in general education classrooms may depend on the severity of their disability. Thus, if SWSEND have extensive and pervasive support needs, students will receive the supports and aids within special education centers, when the resources are not generalizable within ordinary centers. If SWSEND present high support needs, the maximum number of students per class is two. In the year 2012–2013, of the 33,000 students with SEN receiving special education supports, almost the 80% (n = 26,390) were placed in special education schools, whereas 20% (n = 6,632) were receiving special education supports within ordinary settings (Navas, Gómez, Verdugo, 2017). The number of students with disabilities within inclusive settings sharing experiences and time with their peers, seems to have a decreasing trend as students grow. The *II Study on the inclusion level of Spanish Higher Education System regarding the disability reality,* showed that, in the academic year 2013/2014, of the total of university students in Spain, 17,702 (1.3%) have a disability. Of those students, 16,065 students (50.9% males, 49.1% females) studied undergraduate program (first cycle) composing a 1.3% of the total Spanish undergraduate students; 1,259 students (54.4% males, 45.6% females) studied a master's degree program (1.2% of total master's degree students); and just 378 students (49% males, 51% females) studied in a PhD program (0.6% of total PhD students). There is no differences between gender, but the main difference is in the kind of studies: when the university is a traditional one and students must attend to the classes, the number of students with disability in the academic year 2013/2014 comprised just a 0.9% of total students, but when the university had online undergraduate or master's degree programs, the percentage rose up to 3% of students[24). In the Spanish framework, only the 56% of the University Guidance Services claim to have a plan for providing psycho-educational guidance for students with disability.

The *LOE* (2/2006) defines that all the necessary resources for SWSEND should be guaranteed by each Autonomous Community, so that they can achieve their maximum personal development and, when possible, the academic objectives. Each education center must develop an educational project which has to embody the educational priorities for SWSEND aligned with the resources and attention to diversity measures to organize the resources in order to reach the priorities described. These priorities and procedures should guarantee significant learning and promote personal, academic, and professional/vocational development (Navas, Gómez, Verdugo, 2017).

Students receiving special education services are eligible for related services, which usually depend on the severity of student's support needs. For students with ongoing support needs, special education teachers commonly provide pedagogical aid and assistance within ordinary centers. Regarding both ordinary and special education centers, other related services are: physiotherapy (ratio 1 professional for every 15–20 students), speech therapy (ratio 1/15–20 for students with extensive and pervasive support needs and 1/20–25 for students with ID and less support needs). Regarding special education centers, if they have enrolled more than 20 students with severe developmental disorders, then they may have a permanent psychologist. This number rises to 1/90–100 regarding students with lesser support needs. If the ratio criterion is not met, special education centers are also eligible for a certain number of hours for psychological services per week (Navas, Gómez, Verdugo, 2017).

[24) http://sid.usal.es/idocs/F8/FDO26780/II_Estudio_universidad_discapacidad.pdf.

Finally, in relation to the prevalent practices used for providing supports to SWSEND, both in ordinary and special schools, the pedagogical principles underlying interventions take into account the SWSEND's developmental level (i.e., intellectual, communicative-linguistic, socio-affective, and motor). Interventions are focused on promoting significant learning in autonomous way (i.e., learning to learn), focusing not only on academic competencies but also on adaptive behavior skills (Navas, Gómez, Verdugo, 2017). Table 2 summarizes the kind of practices and supports typically provided to SWSEND depending on the disability:

Table 2. Practices commonly develop with SWSEND.

Disability	Supports Provided
Sensory disability	Strategies for promoting and strengthening alternative channels Organization of spaces (i.e., furniture, windows, floor, walls) Students' location (i.e., students with disability in preferential positions) Effective interaction teacher-student Braille materials usually free of charge Alternative communication systems (sign language, bimodal system) Audiological and oral rehabilitation
Students with physical disability	Develop their mobility in the classroom by manipulating objects, accessing educational resources, and receiving integrated information of verbal and visual type
Students with ID and developmental disability	Develop oral communication (e.g., speech therapist support) Alternative communication system (e.g., TEACCH, PECS) Behavioral techniques: imitation, modeling, elicitation techniques by providing visual and/or physical aids

Source: self-elaboration based on Navas, Gómez, Verdugo (2017).

Different initiatives are taken for SWSEND who are reaching adulthood. Transition services are intended for promoting personal autonomy and social inclusion. These services are available for students aged 16 years old with completed compulsory basic education in special school settings or those aged 16 without completed compulsory education but whose support needs can be appropriately addressed and met in these programs. Programs are organized in two years, which may extend depending of student's educational achievement and the availability of employment opportunities (Navas, Gómez, Verdugo, 2017).

Academic training preparing for working with people with disabilities

The origins and some representatives. All the historical facts aforementioned summarize the beginning of the studies on special education as approach for meeting the needs of SWSEND. Especially important is the creation of the

National Institute of Special Education in 1975 which established the basis and principles of special education in Spain. Apart from this, it is necessary to highlight the vital trajectories of the two main forerunners of special education field in Spain: María Soriano Llorente and Carmen Gayarre.

María Soriano Llorente (1900–1996), who was an elementary and middle-school teacher and the director of the *Central School for the Abnormal* since 1923, was one of the forerunners in the scientific study of disability and special education in Spain. She travelled to foreign countries where she received instruction on the newest scientific approaches, and she also participated in different scientific associations and international forums (Fernández-Santamaría, 2011), applying that knowledge and leading the changes in the special education field in Spain. The first legal document that addresses the education of students with ID was the *Law on Elementary Education* in 1945 (Scheerenberger, 1984).

Carmen Gayarre (1900–1996) was another pioneer of special education in Spain. She created different Schools and she was also interested in the transition processes, leading the creation of different workshops towards transition to adulthood in Spain (Fernández-Santamaría, 2011).

Current professional training. There are specific undergraduate programs to become a pre-elementary or elementary teacher. Pre-elementary teachers don't necessary require to have an undergraduate degree, but they must complete a professional training education program. However, in the case of those professionals specifically working with SWSEND in specific services as early intervention programs, they are often required to have a master's degree or specific and specialized training (Navas, Gómez, Verdugo, 2017). According to the Spanish *Ministry of Education, Culture and Sport,* the aforementioned undergraduate programs are four years (*European Higher Education Area*). Education programs for pre-elementary and elementary teachers are organized in a way in which pedagogical and practical training are provided ar the same time as courses in specific subjects. The consecutive model (i.e., pedagogical and practical training follow the education training) is more common for secondary teachers (Navas, Gómez, Verdugo, 2017).

Due to the nature of Spanish educational system, there is not a specific undergraduate program for training teachers specialist in special education. Special education teacher or therapeutic pedagogy teacher is a specialization within the broader undergraduate on education. However, the education of SWSEND is not only a matter of teachers, it involves a wide variety of professionals. Thus, in addition to teachers licensed or certified to teach in special education settings, the related-personnel team involved in the education of SWSEND may vary depending of the nature of the school (ordinary or special) and student's intensity of support needs. However, this team usually includes: physiotherapist, speech and language therapist, psychologist, pedagogue, psychopedagogist, and social worker (Navas, Gómez, Verdugo, 2017).

In the case of teachers providing supports to SWSEND, all teachers, no matter if they are specialist in special education or not, are required to complete between 250 and 300 hours of activities every six years pertaining lifelong learning and professional development. This requisite is essential if they want any promotion or salary increase. The content of the professionals' development programs and activities is mandated and specified by regional education authorities (Navas, Gómez, Verdugo, 2017).

Faculties and specialties. Currently, special education doesn't exist as an own undergraduate program. There are only two undergraduate programs for future pre-elementary and elementary teachers who will provide educational supports and services to SWSEND: pre-elementary education undergraduate program and elementary education undergraduate program25).

Thereby, as a part of these two undergraduate programs, in-training teachers who are interested in working and providing supports to SWSEND must choose different optional courses and create an itinerary which will allow them to get the special education mention. Teacher candidates must pass a competitive examination to get a job within public educational system, either general setting or special one. Secondary teachers don't need to have a specialized training for meeting the needs of SWSEND. However, as part of their requirement, they must pass a master's degree called *University Master on Secondary Education* where they can take different ECTS addressing attention to diversity measures and procedures (Navas, Gómez, Verdugo, 2017).

There are different options of specialized training within master's degree programs in Spain regarding how to properly address the needs of SWSEND under an inclusive perspective. In this regard, the *Service on Information about Disability* (SID in Spanish) has developed a dossier where shows more than 100 master's degree programs pertaining disability26), with a total of 16 official master's degree programs in the academic year 2016–2017 pertaining education of SWSEND (see table 3).

Disability studies as a field of study or specialization. In Spain, *Disability Studies* are understood as an interdisciplinary field and have the recognition of scientific study. Next section gives an accurate overview of this field at *University of Salamanca*. The *Institute on Community Integration*, interdisciplinary institute for promoting research aimed at improving quality of life of individuals with disability, is the main value in the *Disability Studies* field in Spain, as well as the first and only research institute entirely dedicated to the interdisciplinary and scientific study of disability.

Apart from the aforementioned *INICO*, there are different universities that undertake *Disability Studies*, like the *University of Murcia* with the *Center on*

---

25) https://www.educacion.gob.es/notasdecorte/busquedaSimple.action.

26) http://sid.usal.es/formacion.aspx.

Table 3. Master's degree addressing education of SWSEND.

Master's Degree Program Title	**Province**	**Region**	**University**
Advances studies on learning difficulties	Salamanca	Castile and Leon	University of Salamanca
Inclusive education and society	Burgos	Castile and Leon	University of Burgos
Special Education Master	Almeria	Andalusia	University of Almeria
Special Education Master	Huelva	Andalusia	University of Huelva
Special Educational Needs and Attention to Diversity in Schools	Seville	Andalusia	University of Seville
Educational Psychology. Advances on Psychoeducational Intervention and Special Educational Needs	Seville	Andalusia	University of Seville
Attention to Diversity in Inclusive Education	Gerona	Catalonia	University of Gerona
Educational and Psychological Intervention	Navarra	Navarra	University of Navarra
Special Education	Valencia	Valencia	University of Valencia
Cognitive Neurosciencie and Specific Educational Support Needs	Valencia	Valencia	University of Valencia University of La Laguna
Educational Psychology: Development and Learning	La Coruña	Galicia	University of Santiago de Compostela
Specific Educational Support Needs	Pontevedra	Galicia	University of Vigo
Learning Difficulties and Cognitive Processes	Pontevedra	Galicia	University of Vigo
Educational Intervention and Innovation	La Rioja	La Rioja	University of La Rioja
Special Educational Needs	Vizcaya	Basque Country	University of Deusto
Socioeducational Intervention and Research	Principality of Asturias	Principality of Asturias	University of Oviedo
Educational and Social Inclusion and Exclusion Processes: Policies, Programs, and Practices	Murcia	Murcia	University of Murcia

Source: self-elaboration. Only official masters. On-line masters excluded.

Disability Studies and Personal Autonomy promotion, which promotes research and advocates for personal autonomy in individuals with disabilities[27]. However, due to its tradition and the vast number of research lines, R & D projects

---

[27] http://www.um.es/web/dipap/.

conducted, and the numerous activities developed for promoting the inclusion of individuals with disabilities, the present chapter gives an in-depth analysis on the *Disability Studies* at *University of Salamanca*, specifically at the *INICO.*

Disability studies at University of Salamanca. The Institute on Community Integration

The history of the University of Salamanca and the present day. The *University of Salamanca* was created in 1218 and along with *Paris, Oxford*, and *Bologna* universities is one of the oldest universities in the world, and is the only Spanish university which has maintained its activity through the centuries. The *University of Salamanca* met a great period of expansion throughout the XV and XVI centuries. Many of the American universities (within Spanish Empire) were created following the same statutes than *University of Salamanca*. More than the 70% of the universities created in the XV, XVI, and XVII centuries considered the *University of Salamanca* as their alma mater. In these years, the *University of Salamanca's* prestige was worldwide and started to gather students from different parts from Spain, Europe, and even America. According to the number of students, at the end of the XIV century, more than 500 students were enrolled. This number increased up to 2,500 students in the XV century, 6,500 students in the XVI century, and decreased in the XVIII to 2,000. Since the 90's of the XX century, the University has a stable number of 30,000 enrolled students more or less28).

In the *University of Salamanca* there have been many faculties and specialties addressing the needs of SWSEND. This issue and the current situation of the educational system providing support to SWSEND, as well as the training that must receive teachers, have already been addressed during the chapter. Thus, it is necessary to put the focus on the recent history of the university regarding the *Disability Studies* as a scientific field. The first *Cathedra* specifically dedicated to the scientific study on disability was created in the year 2002 at the *University of Salamanca*. The *Cathedra* was created mainly based on the studies and researches conducted by the *Institute on Community Integration*. Next section provides an in-depth analysis of the conceptual framework of the disability studies in Spain, as well as *the Institute on Community Integration's* scientific activities and contributions for both the research and applied work with individuals with disabilities and their families with the aim of promoting the quality of life of individuals with disability of any kind in different settings, including the social, health, and educational services, where SWSEND interact and develop.

Characteristics of the Disability Studies in University of Salamanca. The Institute on Community Integration. The interdisciplinary and scientific study of disability in Spain assumes the most advanced paradigms and models in the

---

28) http://www.usal.es/node/941.

international framework: the biopsychosocial approach, based on the *World Health Organization's* (WHO) International Classification of Functioning, Disability and Health (ICF); a strengths-based approach regarding the capability of the person; a personalistic approach that considers the active role of the person, its needs and its wanting; the supports paradigm for bridging the gap between personal capabilities and environmental demands; and the rights perspective assumed by the *United Nations' Convention*. Especially important is the Quality of Life (QoL) framework, which is considered the framework for the provision of supports that improve the functioning of individuals with disability and leads the achievement of their personal desired outcomes and enjoy their rights. The QoL is the framework for detecting the needs of individuals with disability (microsystem), the needs of organizations providing supports (mesosystem), and the needs of public policies (macrosystem). Spain has not only assumed this perspectives, the country has also done important contributions in the development of those approaches, especially in the field of QoL (Schalock, Verdugo, 2002, 2007, 2012a, 2012b).

The first and only University Institute on the scientific study about disability in Spain is the *Institute on Community Integration* (hereafter INICO). This institute was created in 1996 and is composed by interdisciplinary professionals that lead activities linked to training, research and counseling in the field of disability with the aim of easing and enhancing the QoL and self-determination of people living at social disadvantages in different contexts and throughout their life cycle. Its scientific activity has been compiled recently due to its 20th anniversary. Table 4 summarizes the main scientific achievements by *INICO* on its 20 years:

Table 4. Scientific activities of the *Institute* on in terms of outputs.

Kind of scientific activity	Number of activities	% of total activity
Scientific publications (articles, books, handbooks, chapters)	1295	31.98 %
Contributions to scientific conferences and congresses (presentations, roundtables, communications, etc.).	1825	45.06%
Research Projects	542	13.38%
End-of-Master thesis	333	8.22%
PhD Thesis	55	1.36%

Source: self-elaboration based on *INICO's* webpage[29].

Currently, the *Institute* has a total of 55 members working in different universities in Spain and in other countries. The main research lines held at *INICO* are:
- Environment, participation, and QoL.
- Autism and severe disabilities.

---

[29] http://inico.usal.es/432/el-inico/20-aniversario-del-inico-1996-2016.aspx.

- QoL, supports, and self-determination.
- Inclusive education.
- Employment inclusion, supported employment, and social policies.
- Health, mental health, and disability.
- Transition to adulthood, employment, and QoL.
- Demography and disability.
- Technology and disability.
- Others.

Of the total of the scientific production within *INICO*, research projects, scientific contributions to congresses, and publications can be organized according the research lines aforementioned. Figures 2 to 4 systematically organize and summarize this information according to the topics described:

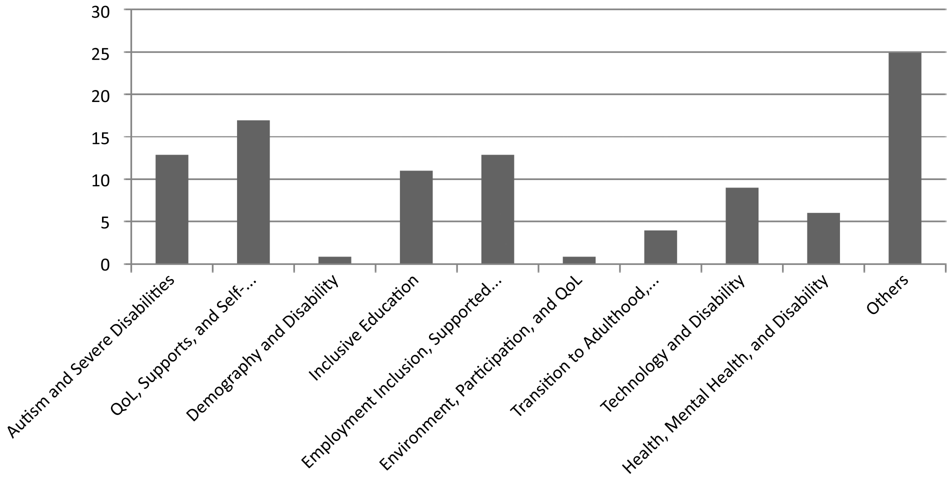

Figure 2. Research Projects in percentages (1996–2016)

Source: self-elaboration.

Perhaps the most ambitious project developed by the INICO has been the creation of the *Service on Information about Disability* (SID in Spanish) in 1999. The *SID*, which was jointly created by the *Ministry of Health, Social Services and Equality* and the *INICO*, is a public internet portal that is aimed at professionals, politicians, and developers and managers of public policies. This service has three main functions: acquire, systematize, and spread information on disability.

The *INICO* also carries out a total of three master's degree programs for training future professionals who are interested on providing supports to people with disabilities of any kind, at any age, including SWSEND. These programs, which will be deeply discussed later, are:

- *Master on Integration of People with Disability-Quality of Life*. This is a professional master's degree aimed at direct-practice professionals wor-

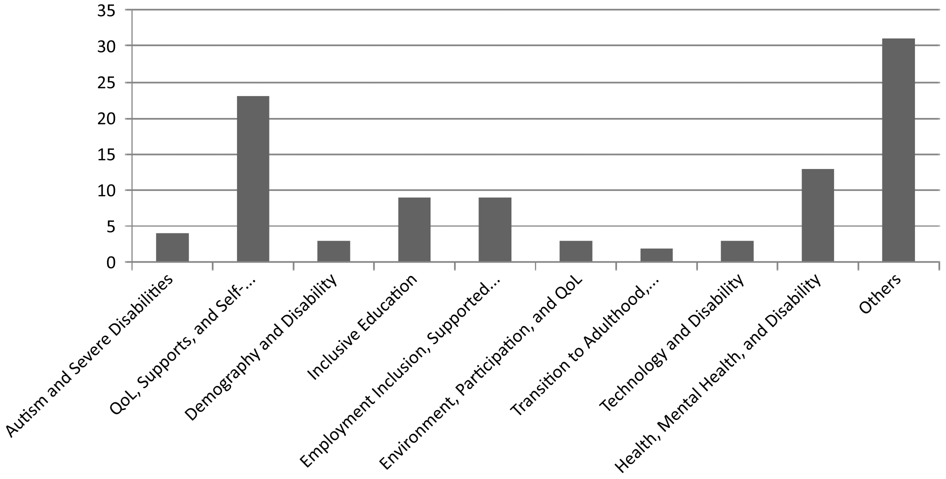

Figure 3. Scientific publications in percentages (1996–2016)

Source: self-elaboration.

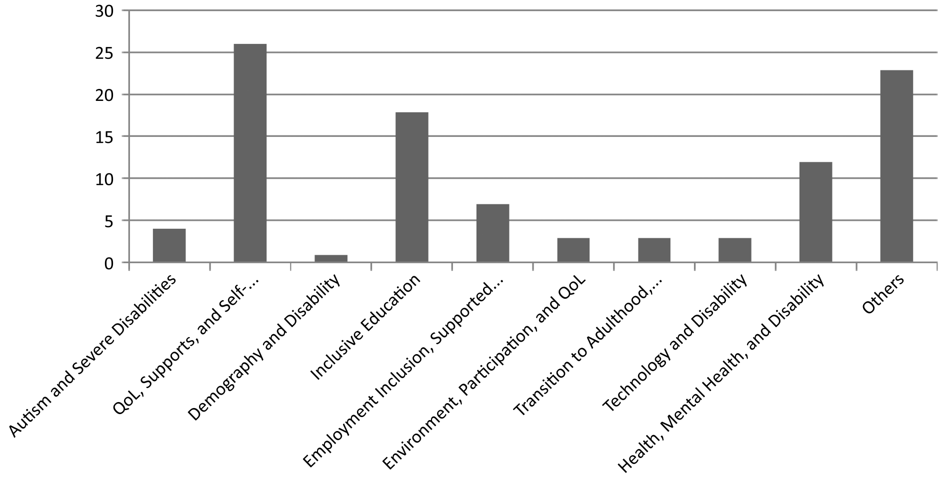

Figure 4. Contributions to Congresses in percentages (1996–2016)

Source: self-elaboration.

king at organizations providing supports in the educational, social, or health services.

- *University Master on Research in Disability*. The master's degree is mainly focus on the development of advanced research skills, and also prepares students for doing the PhD.
- *Master on Integration of People with Disability*-Iberoamerican Program. The master's degree is similar to the first one, but co-developed between INICO and other organizations from different countries in South America.

Two main aspects must been addressed when specifying the characteristics that *Disability Studies* has as a scientific discipline in Spain: ongoing and updating learning for professionals and the scientific journals. Apart from the master's degree programs, *INICO* organizes different activities for the ongoing training and lifelong learning of professionals working with people with disabilities, including those working with SWSEND. For example, INICO organizes every three years the *International Congress on the Scientific Research on Disability* since 2005, and specifically talking about the development of good practices in the field of education of SWSEND, *INICO* co-develops yearly alongside the *Cultural Exchange Association from Uruguay* (AICU in Spanish) the international congress on inclusive education since 1999, where different professionals actively join in this knowledge-sharing experience[30]. More programs and activities are developed, but they will be described later due to their impact and benefit in the life of individuals with disabilities. Finally, different scientific journals are dedicated to the scientific study of disability in Spain. These journals are: *Revista Española sobre Discapacidad* (Spanish Journal on Disability); *Siglo Cero. Revista Española sobre Discapacidad Intelectual* (Zero Century: Spanish Journal on Intellectual Disability); and *Autonomía Personal* (Personal Autonomy). All of them are based on an interdisciplinary understanding of disability.

General information about the program and the characteristics of the graduate profile. As has been described, three main master's degree programs are carried out by *INICO*. In this section, basic information about the programs and the plans for training future professionals are presented.

The very first master's degree that systematically started to train future professionals for working with individuals with disabilities of any kind was the *Master on Integration of People with Disability-Quality of Life*. This master's degree was co-created by INICO and Plena Inclusión, a confederation of organizations that act in benefit of people with disability and their families in different areas like education, health, citizenship, employment, or rights, which final aim is to improve the QoL of individuals with disabilities and their families. This master's degree program saw the light more than 25 years ago and is aimed at improving direct-practice professionals' abilities in their direct work with these individuals for improving their QoL.

The program targets interdisciplinary training and is aimed at people with a different training that habilitates them for working with individuals with disabilities of any kind. As general pre-requisites for accessing the master's degree program, it is necessary to have a degree title within the "Social and Juridical Sciences", like Pedagogy, Psychopedagogy, Sociology, Social Work, Teacher, Especial Education Teacher, or Social Education; or within the "Health Sciences", specially Psychology, Occupational Therapy, Nursery, and Physiotherapy.

---

[30] http://inico.usal.es/c122/formacion-continua-periodica-discapacidad.aspx.

This master's degree is a two-year program that started in 1991 and is currently on its 25th promotion and is mainly interested in the development of practical and professional skills, and also addresses a scientific vision of research understood as the natural and logic steps for the development and assessment of evaluation and intervention programs that are intended for improving the QoL of people with disabilities.

It is important to highlight the shared nature of this program. As has been aforementioned, this master's degree is co-developed by *INICO* and *Plena Inclusión*. Thus, about a 25–30% of the students joining this program are continuing their studies (after their degree), and the 75–70% of the students are in-service professionals working within *Plena Inclusión Confederation* that keep on with their training as an ongoing activity for learning the latest scientifically-based approaches for a better understanding of disability, support needs, inclusion, rights, and QoL of individuals with disability. The program admits a total of 40 students per promotion, and the fact that students and professionals share their work and space is already important for knowledge and experiences sharing.

As a general overview, based and starting from an interdisciplinary perspective, the theory-practical specialized training that this master's degree program offers, aims at (a) preparing different professionals in the knowledge, abilities, and attitudes that are necessary for working with individuals with disabilities of any kind, (b) training in the development of innovation and ongoing quality improvement of the services providing supports to people with disabilities, and (c) developing management tasks and coordination of interdisciplinary teams. The specific aims are especially directed to the competencies of future professionals working with individuals with disabilities:

a) Professionals have and apply the most important knowledge towards disability, in order to identify and differentiate the individualized needs of each person; (professionals) know the main action's guidelines in different kind of services and with different kind of deficiencies; as well as (professionals) are able to properly channel in each moment the rehabilitation process of a person in a given moment.
b) Professionals know how to conduct research within disability field and are able to plan, implement and assess the necessary rehabilitator processes for each person with disability, under an interdisciplinary approach and synergic collaboration with others.
c) Professionals may have management and direction abilities regarding centers, programs, and services aimed at population with disabilities of any kind.
d) Professionals manifest and know how to promote positive attitudes towards people with disabilities of any kind, so that they assume a personal and professional commitment to defend and improve the situation of these individuals, by assuming a leadership role as community agents.

Both the general and the specific aims are addressed using different methodologies of education, which combines the traditional lessons, with practices, seminaries, information and communication technologies, and visits to centers that actually provide supports to individuals with disabilities. Specifically, the training includes different modules:

1. **First Academic Year:**
    1. **Module A: Conceptual and Introductory Issues (6 ECTS).** Main topics to study and work within the first module:
        1. Rights, conceptual fundaments of disability, and functional assessment.
        2. Social policy and legal and welfare aspects.
        3. QoL.
        4. Ethics and disability.
    2. **Module B: People with ID I (9 ECTS).**
        1. Concept, classification, and system of supports.
        2. Social adaptation skills assessment.
        3. Interpersonal relationships and emotional wellbeing.
        4. QoL assessment.
        5. Personal development, individualized programs, and practical skills.
        6. Sexuality and disability.
        7. Good Practices: Plena Inclusión framework.
    3. **Module C: Support Services (9 ECTS).**
        1. Self-determination.
        2. Person-Centered Planning. Facilitators' roles.
        3. Early intervention and stimulation.
        4. Education for all.
        5. Living, residence, and day services.
        6. Families' attention.
        7. Good Practices: Plena Inclusión framework.
    4. **Module D: Professionals' Skills and Competencies (6 ECTS).**
        1. Work-team abilities.
        2. Attitudes towards individuals with disability.
        3. Organizational and professional competencies.
        4. Documentary sources within disability studies.
        5. Information and communication technologies.
    5. **Module E: External Practices I (10 ECTS).** Students must visit and have training in the direct practice with people with disability in different organizations providing supports to those individuals. Because of the master's degree program is co-developed, the practical training of students takes place mainly within *Plena Inclusión Confederation's* entities, although students are free to establish any agreement with any organization they consider relevant, as long as the mission and vision of the entity is aligned with the master's degree purposes and with the improvement of the QoL

of individuals with disability. Practices are supervised closely by master's degree staff and a tutor is assigned while student is in-training within the designed organization. Once the training is finished, student must develop a memory of their training period which will be evaluated both by the tutor and the master's degree program staff.

2. **Second Academic Year:**
    1. **Module F: People with ID II (5 ECTS).**
        1. Extensive and pervasive support needs.
        2. Autism and other development disorders.
        3. Rare syndromes related to ID and supports.
        4. Aging.
        5. Mental health issues and concerns.
        6. Positive behavior support.
        7. Leisure activities and disability.
    2. **Module G: Employment Integration (5 ECTS).**
        1. Employment integration and supported employment.
        2. Professional guidance and training.
        3. Good Practices: Plena Inclusión framework.
    3. **Module H: ID and other Disabilities (5 ECTS).**
        1. Rehabilitation Psychology.
        2. People with Cerebral Palsy.
        3. People with hearing disability and with ID; and people with visual disability and ID.
        4. Universal design (and universal design for learning) and cognitive accessibility.
    4. **Module I: Management, Organization, and Program Assessment (5 ECTS).**
        1. Programs' assessment based on the QoL Model.
        2. Organizational development and bases. The Plena Inclusión project. People policies. Key for changing.
        3. Quality on the third sector.
        4. Direction and direction efficiency.
    5. **Module J: External Practices II (10 ECTS).**
3. **Ongoing Activity since the beginning of the program: End-of-Master's degree Dissertation (30 ECTS).** All students attending the program must develop a research project based on the contents that are being worked during the whole program. Projects are related to different areas, taking into account the multifaceted nature of the program: inclusive education, social services, physiotherapy, organizational change and transformation towards QoL model, and so on.

Due to the importance and impact of *INICO* in Ibero-American context, this Master has also an online version called *Master on Integration of People with Disability-Ibero-American Program* which is on its 9th edition. It shares the general aim, the specific aims, as well as the contents, and is targeted at iberoamerican professionals developing their work with individuals with disability in different countries of South America and Caribe.

Finally, as was previously appointed, research training for future researchers is also really important for the development of models, as well as data-based and research-based practices. Thus, the *INICO* yearly develops the *University Master on Research in Disability* created in 2011, and aimed at providing a specialized training and improving the research abilities of future professionals in the field of disabilities allowing them to access to the latest paradigms and current trends in scientific research in the field of disability.

This master's degree is aimed at training professionals in the areas of research and practices within the disability field, by developing abilities, competencies, strategies and specialized attitudes that lead students to assess, guide, and provide supports in the educational, social, and cultural environments of individuals with disabilities of any kind at every community setting. This training allows students to: (a) do assessments, interventions, and support planning; and (b) develop innovative research practices pertaining disability studies, putting the accent in the QoL promotion, self-determination, supports, and participation in the community under a right-based approaches aligned with the *United Nations' Convention on the Rights of Individuals with disabilities*.

This program is also aimed at the same professionals than the previous ones. Regarding the training of professionals, as shown in table 5, the specialized training is more oriented to the development of research skills for addressing the aims described:

Finally, the other main training program within disability studies was the *PhD Program on Advances in research on Disability*, which was absorbed by the PhD on Psychology due to political decisions within University of Salamanca back to the academic year 2014/2015. This program offered a wide and diversified training aimed at the knowledge of disability nature, as well as promoting the research skills and improving treatment and intervention programs' efficacy.

The PhD Program arose as the answer to the need of training more specialized researchers that would assume the responsibility of developing researches focused on the characteristics and needs of individuals with disabilities of any kind. Graduated students are trained following a very specialized profile, which main domains are: (a) the knowledge of the current challenges of the research pertaining characteristics, biological grounds, and intervention ways in the different manifestations disability may have, (b) current problems related to the impact that disability has in the immediate context of the person, as well as the intervention ways, problems and challenges concerning educational attention and social and employment integration of people with disability, (c) the study and knowledge about the social exclusion phenomenon, and, finally, (d) in-depth training on the latest research methodology in the disability area.

Table 5. University Master on Research in Disability's training program

Module	**Content**	**Semester**		**ECTS**
		First	**Second**	
M1: Research methodology (10.5 ECTS)	Information resources for research	X		3
	Methodology for the design and development of scientific works	X		1.5
	Tests construction (Psychometry)	X		3
	Qualitative research methodology	X		3
M2: People with disability (10 ECTS)	ID and supports	X		2
	Assessment and treatment in autistic spectrum disorders	X		3
	Research and intervention in cerebral palsy	X		1.5
	People with visual disability	X		1.5
	People with hearing disability	X		1
	Person-Centered Planning	X		1
M3: Inclusive education (9 ECTS)	Inclusion within educational system	X		6
	Developing inclusive educational centers		X	3
M4: QoL and Self-determination (4 ECTS)	Research in QoL		X	2.5
	Research in Self-determination		X	1.5
M5: Environment and participation (6 ECTS)	Transition to adulthood		X	1.5
	Supported employment		X	1
	Employment QoL		X	2
	Environment and social participation		X	1.5
M6: Habilitation and health (5.5 ECTS)	Functional abilities' habilitation		X	3
	Assessment and psychological intervention in people with chronic pain: fibromyalgia		X	1.5
	Bio-psycho-social health of caregivers of people living in dependent situations		X	1
M7: Research in mental health	Research in mental health (optative*)		X	3
M8: Early intervention and stimulation	Early intervention and stimulation (optative*)		X	3
End-of-Master's degree Dissertation (12 ECTS)	End-of-Master's degree Dissertation	X	X	12
Total (ECTS)				60

* Students must choose one of the two optative offered. Source: self- elaboration based on University of Salamanca and INICO information about the master's degree in their websites[31].

---

[31] http://www.usal.es/node/57859/plan_estudios.

Within this PhD, all the training skills used to have a theory-practical character, aimed at strengthening a technical and applied knowledge for the developing of researches. The technic training was compensated with different practical activities, intended for PhD students so that they could apply their dissertations and researches in the practical and professional life[32].

Previous academic experience and prognosis. All the mentioned master's programs have strong tradition within *University of Salamanca*. For example, for the next academic year 2017/2018, the program *Master on Integration of People with Disability-Quality of Life* has been positively informed by the *University of Salamanca*, and next year will start its 26th promotion[33]. This program has always been qualified in good ranks among master's degree programs aimed at training future professionals providing supports to individuals with disabilities, winning the 2013 award as the best master's degree program within the category "Family and Integration"[34] in Spain.

More detailed data can be provided in relation to this master's degree. According to the memories about *INICO's* activity (i.e., both academic and scientific), in total, 455 professionals have been trained in this master's degree program ($M = 35$ students per promotion) who have applied the acquired knowledge for transforming organizations working and providing supports to individuals with disability. Thus, in the last years, more than the 50% of professionals who have been trained in the program have reached responsibility positions within their organizations as managers and directors, actively acting in services and organizations' transformation processes towards the QoL framework applied at organizational level[35].

About prognosis, the program is stable and the new promotion has been positively informed and next year is starting.

University activities undertaken for the benefit of people with disabilities. Many activities have been promoted and accomplished by *INICO* for the benefit of people with disabilities of any kind, especially ID. Most of the activities developed by *INICO* within the *University of Salamanca* overlap with each other, due to the multifaceted nature of the activities developed. However, as a didactic presentation, different activities can be described: (a) research outcomes that impact in the life of individuals with disability, (b) guides for practitioners and families of people with disability, (c) programs and experiences for promoting the inclusion of individuals with disabilities within society, (d) counseling to foreign countries' ministries for the development of inclusive education, (e) collaboration and scientific guidance to organizations that act in benefit of individu-

---

[32] http://inico.usal.es/c143/formaci%C3%B3n-doctorado.aspx.

[33] http://inico.usal.es/c147/master-propio.aspx.

[34] http://sid.usal.es/idocs/F1/ACT47272/250MASTER2013.pdf.

[35] http://inico.usal.es/c44/el-inico.aspx.

als with different kind of disabilities, especially ID (and others, like traumatic brain injury or cerebral palsy) (f) ongoing training programs for professionals, and (g) activities for promoting the normalization, inclusion, and recognition of people with disability in the mainstream community.

Researches outcomes that impact in the life of individuals with disability. As a result of different researches, *INICO* has developed different assessment tool based on the most important constructs pertaining disability nowadays, such as: support needs, QoL or self-determination. The aim of developing tools is to provide professionals a reliable and valid framework which they may use as a starting point when working with individuals with disabilities, organizations, and communities, for both detecting the needs in those system's levels, as well as for meeting those needs. Thus, by conducting research activities, the *Institute* can improve community's, organization's, and individual's outcomes, acting at different levels of the system. Table 6 summarizes some of the developed tools and their aim.

Table 6. Assessment tools based on scientific models for the development of evidence-based practices

Tool	Population	Aim
Kidslife Scale (Gómez et al., 2016)	Children, adolescents, and young adults with ID	QoL assessment
ARC-INICO Scale (Verdugo et al., 2014)	Children and adolescents with intellectual and/or developmental disability	Subjective self-determination assessment
Organizational's Efficiency and Eficacy Handbook (Schalock et al., 2015)	Organizations providing supports of individuals with ID	Help organizations providing supports to be more effective, efficient, and sustainable
INICO-FEAPS Scale (Verdugo, Gómez, Arias, Santamaría, Clavero, & Tamarit, 2013)	Adults with intellectual and/or developmental disabilities (above 18 or above 16 when working)	QoL assessment under an integral approach (i.e., both objective and subjective assessment)
San Martín Scale (Verdugo, Gómez, et al., 2014)	Adults with multiple and significative disabilities (above 18 years old or above 16 when out of educational system)	Objective QoL assessment
Family Quality of Life Scale (Verdugo, Rodríguez, & Sainz, 2012)	Families of individuals with disability	Family QoL assessment

Source: self-elaboration. All information at INICO webpage[36].

---

[36] http://inico.usal.es/c135/coleccion-herramientas.aspx.

More scales are being developed (and many others have already been published), but the table only summarizes the scales aimed at population with disability and organizations providing supports to individuals with disabilities that are free and accessible (other scales are developed under international treaties and are not for free). All the presented tools can impact within the social, health, and educational services, as well as in the different levels of the system.

Guides for practitioners and families of people with disability. The *Institute* has also developed guides for practitioners and families aimed at providing an updated framework for the understanding of the needs of individuals with disabilities as well as for the provision of the proper supports. Some of the remarkable guides developed by the institute have been: (a) the guide for teachers working with students with disabilities, called "*Apreciamos las diferencias: orientaciones didácticas y metodológicas para trabajar sobre la discapacidad en educación primaria* [We appreciate differences: didactic and methodological guidelines for working and addressing disability within primary education]" (Verdugo, González, Calvo, 2003); (b) the "*Guía de ayuda en la programación educativa para alumnos con discapacidades graves y mútiples* [Guide for helping in the lesson planning for students with severe and multiple disabilities]" (González, Canal, Centro Obregón, 2008); and (c) the family guide "*Un niño con autismo en la familia: guía básica para familias que han recibido un diagnostico de autismo para su hijo o hija* [A child with autism in the family: basic guide for families who have received an autism diagnose for their son or daughter]" (Bohórquez et al., 2008). The two first guides are aimed specifically at professionals, so that they can promote the inclusion of students with disability addressing the attitudes and other components closely linked to them (Verdugo, Gómez, Calvo, 2003), and develop individualized lesson planning related to the needs of students with pervasive and extended support needs (González, Canal, Centro Obregón, 2008). The last guide is aimed at families so that they can manage the initial impact which diagnose has, and the guide also provides resources and information on the needs in the different areas of their children's development and also in the different services providing supports to children with autism in the social, educational, and health services (Bohórquez et al., 2008).

Programs and experiences. Two of the newest programs developed by *INICO* and directly aimed at promoting the social inclusion and participation of people with intellectual and/or developmental disabilities are the programs: *PRACTICAPACES* and *YOTUEL*.

The *PRACTICAPACES* program started in 2016 and is defined as an employment practices program aimed at people with intellectual and/or developmental disabilities. It was developed jointly by *University of Salamanca* (Faculty of Psychology) and the *INICO*. The program is focused on the practical training of people with intellectual and/or developmental disability in employment issues based on the supported employment. Students from Occupational Therapy and the *University Master on Research in Disability* closely participate in this program's development. Table 7 summarizes the purpose, aims, and targeted population of the program:

Table 7. Purpose, aims, and target population of *PRACTICAPACES* program

Purposes	Aims	Targeted Population
Improving the access possibilities to ordinary employment settings in individuals with intellectual and/or developmental disability	To develop job experiences within ordinary settings for people with intellectual and/or developmental disability	People with intellectual and/or developmental disability
Increasing the employment access opportunities for Occupational Therapy and University Master on Research in Disability students through professional practices	To develop professional practices for students from Occupational Therapy and the University Master on Research in Disability	Occupational Therapy and University Master on Research in Disability students

Source: self-elaboration.

The program would not have been possible without the active collaboration and participation of direct-practice organizations that act in Salamanca, like *Ariadna Association, Asprodes Association, Down Salamanca Association*, and *Insolamis Association*. This gives an example on the links established between INICO and the different organizations providing supports to individuals with disability. The program and its results have been shared in the *INICO's* social media. Result of its impact are freely available on *INICO* webpage[37].

Based on the direct collaboration with the aforementioned organizations providing supports to individuals with intellectual and/or developmental disability, *INICO* and *University of Salamanca* also have developed the *YOTUEL* Program. This program is aimed at the development of participation, contact, and knowledge about people with intellectual and/or developmental disability, under inclusive approaches, by developing shared leisure activities. All students from university community are invited to actively join the program. More information about the program is available on *INICO* webpage[38].

---

[37] http://inico.usal.es/431/programas-servicios/-practicapaces-programa-de-practicas-laborales-para-personas-con-discapacidad-intelectual-o-del-desarrollo.aspx.

[38] http://inico.usal.es/458/programas-servicios/-yotuel-programa-de-actividades-compartidas.aspx.

Counseling activities. The *INICO* as also actively collaborated with foreign countries' governments, in the development of research for the promotion of inclusive education. This has been the case of Costa Rica[39)] and Ecuador[40)].

Collaboration and scientific guidance with organizations that act in benefit of individuals with disability. In Spain, different organizations have asked *INICO* to develop researches for the updating and data collection pertaining the needs and current status to certain group of people with disability. *Plena Inclusión* asked *INICO* to develop a research related to the rights and QoL of individuals with ID with extensive and pervasive support needs. This initiative was co-funded by *Plena Inclusión, Spanish Royal Board on Disability* (see annex), and the *Ministry of Health, Social Services, and Equality* of Spain. As a result, an executive report has been recently published addressing deeply this issue (Verdugo, Navas, 2016). Currently, the latest research that has been asked *INICO* to develop is a report on the characteristics, health state, and access to socio-sanitary services in aging individuals with ID. This research has been funded by the *Ministry of Economy and Competitiveness.*

Ongoing training programs for professionals. As has already been described, *INICO* develops different training programs. Apart from the postgraduate programs, *INICO* organizes every three years the *International Congress on the Scientific Research on Disability* since 1995. The last *Congress* took place in 2015 and it was composed by 242 scientific activities, including: 3 plenary conferences, 1 scientific session, 1 colloquium about humor and disability, 7 roundtables, 30 symposium, 30 communication tables (120 presentations), and 72 posters. It gathered more than 500 people, from interdisciplinary fields and from different countries in Europe and America[41)]. Next year 2018 coterminous with the 800th anniversary of the *University of Salamanca*, the city of Salamanca is holding the *X International Congress on the Scientific Research on Disability*[42)]. The *INICO* has also established its own interdisciplinary and collaborative network of research between Spain and Ibero-America regarding the field of disability. Thus, the *Ibero-American Network on Research on Quality of Life* (REDICABI in Spanish) was created in 2012 with the aims of: spreading the QoL model developed by Schalock and Verdugo (2002, 2007, 2012a, 2012b), promoting organizational change, and spreading and adapting different tools for QoL assessment in different countries[43)]. Other programs are the Transversal

---

[39)] http://inico.usal.es/integra-contenidos-inico.aspx?num=34#a5.

[40)] http://inico.usal.es/integra-contenidos-inico.aspx?num=34#a6.

[41)] http://inico.usal.es/c52/jornadasdiscapacidad.aspx.

[42)] http://jornadas-inico.usal.es/.

[43)] http://inico.usal.es/c152/rivicabi.aspx.

Competencies program[44] (for people with disabilities that are unemployed) and the Employment Trainer program[45].

Activities promoting the normalization and inclusion of people with disabilities. Last but not least, there are initiatives conducted for improving the normalization and inclusion of people with disabilities of any kind within their mainstream community. Thus, since 2003 *INICO* with the collaboration of *North Group Foundation* started a photography contest which aim is to show people with disability within ordinary and daily life. The contest seeks to sensitize society through photography, showing a normalized and integrated view of people with disability. Thereby it focuses on everyday life showing people with disability in their day to day. In addition, the contest also rewards especially the best image that relates disability and university, with the same normalizing and integrating nature[46]. Image 1 shows the winner of the 12th Contest in 2014:

Title: The New Sexy

Author: Elisa Pullara (2014).

Awarded with the first place in the 12th edition of *INICO-North Group Foundation's* "People with Disability in the daily life" photography contest.

Image 1. The new sexy. Winner of the 12th edition of INICO-North Group Foundation's "People with Disability in the daily life" photography contest.

Discussion. Present work has provided a general overview of the organization of *Disability Studies* as a scientific, recognized, and well-defined field of study within Spanish context. Although the starting point in the provision of supports towards individuals with disabilities was mainly conducted in the educational

---

[44] http://inico.usal.es/c158/Competencias%20Transversales.aspx.

[45] http://inico.usal.es/c167/Preparadores%20Laborales.aspx.

[46] http://inico.usal.es/c157/concurso-fotografia.aspx.

system (it was the main interest of special education), today is clear the necessity of addressing the needs and providing the supports not only within educational system but also in the social and health services. The key concepts regarding the *Disability Studies* field in Spain are the *WHO* framework, the positive psychology and the strengths-based approach regarding the capability of the person and not only their limitations, the personalistic approach that considers the active role of the person, its needs and wanting, the supports paradigm for bridging the gap between personal capabilities and environmental demands, the rights perspective assumed by the *United Nations' Convention*, and the QoL framework.

Current situation in Spain regarding this field makes necessary to change the focus from the quantity to the quality of the training that professionals working with individuals with disability have. Thus, as future lines of research within this field, it is necessary to systematically organize and compare the training received by professionals in the different training programs, to see if there is still a lack of updating with the newest key constructs. This is important because proper training is the first step for overcoming the repeating structures (and problems) that some programs and traditions have created (especially in the field of special education and education). However, having research-based constructs for the developing of training programs, will shed lights on the establishment of evidence-based practices in no matter which environments (i.e., social, educational, or health services), but with a clear goal: guaranteeing the rights of individuals with disabilities and improving their QoL within their community.

References

Anaya, D., Pérez-González, J.C., Suárez, J.M. (2011). Los contenidos de formación de los profesionales de la orientación educativa desde la perspectiva de los propios orientadores. *Revista de Educación*, *356*, 607–29.

Bohórquez, D.M., Alonso, J.R., Canal, R., Martín, V.M., García, P., Guisuraga, Z., Herráez, L. (2008). *Un niño con autismo en la familia. Guía básica para familias que han recibido un diagnóstico de autismo para su hijo o hija*. Salamanca: INICO.

Echeita, G. (2013). Inclusión y exclusión educativa. De nuevo "voz y quebranto". *REICE. Revista Iberoamericana sobre Calidad, Eficacia y Cambio en Educación, 11*(2), 99–118.

Echeita, G., Simón, C., Márquez, C., Fernández, M.L., Moreno, A., Pérez, E. (2017). Análisis y valoración del área de Educación del III Plan de Acción para Personas con Discapacidad en la Comunidad de Madrid (2012–2015). *Siglo Cero*, *48*(1). In press.

Elorza, A., Melchor, L., Orts-Gil, G., Gracia, C., Lacunza, I., Izquierdo, B., Fernández-Vera, J.I. (2017). Spanish science diplomacy: a global and collaborative bottom-up approach. *Science and diplomacy*, *6*(*1*), 1–12.

Fernández-Santamaría, R. (2011). El camino hacia la integración. *Revista de Participación Educativa*, 18, 79–90.

Fullana, J., Pallisera, M., Martín, R., Ferrer, C., Puyaltó, C. (2015). La transición a la vida adulta de jóvenes con discapacidad intelectual. Evaluación de un programa de formación para la mejora de las competencias personales. *Revista de Investigación en Educación*, *13*(*1*), 53–68.

Gómez, L.E., Alcedo, M.A., Verdugo, M.A., Arias, B., Fontanil, Y., Arias, V., Morán, L. (2016). *Escala KidsLife: Evaluación de la calidad de vida de niños y adoelscentes con discapacidad intelectual*. Salamanca: INICO.

González, R., Canal, R., Centro Obregón (2008). *Guía de ayuda en la programación educativa para alumnos con discapacidades graves y múltiples*. Salamanca: INICO.

Izuzquiza, D., Rodríguez, P. (2015). Programa Promentor (UAM-PRODIS). Un análisis de resultados de la primera experiencia de formación en España para personas con discapacidad intelectual en el ámbito universitario. *Síndrome de Down: Vida Adulta*, 19. Retrieved from: http://www.sindromedownvidaadulta.org/no19-febrero-2015/articulos-n19/programa-promentor-uam-prodis/.

Molina, R.M. (2009). La escuela central de anormales de Madrid. In M.R. Berruezo, S. Conejero (Coords.), *Actas del XV Coloquio de Historia de la Educación. El largo camino hacia una educación inclusiva: la educación especial y social del siglo XIX a nuestros días. Volumen I.* Pamplona, 2009. ISBN: ISBN 978-84-9769-244-1. *Retrieved on June 2017 from: https://dialnet.unirioja.es/servlet/articulo?codigo=2962591.*

Muntaner, J.J., Rosselló, M.R., de la Iglesia, B. (2016). Buenas prácticas en educación inclusiva. *Educatio Siglo XXI*, *34*(*1*), 31–50.

Navas, P., Gómez, L.E., Verdugo, M.A. (2017). Spain. In M.L. Wehmeyer, J.R. Patton (Eds.), *The Praeger International Handbook of Special Education: Volume 2 – Europe and Africa* (pp. 224–238). New York: Praeger.

Ramos, C., Huete, A. (2016). La Educación Inclusiva, ¿un bien necesario o una asignatura pendiente? *Prismasocial*, *16*, 251–277.

Schalock, R.L., Verdugo, M.A. (2002). *Calidad de vida. Manual para profesionales de la educación, salud y servicios sociales*. Madrid: Alianza editorial.

Schalock, R.L., Verdugo, M.A. (2007). El concepto de calidad de vida en los servicios y apoyos para personas con discapacidad intelectual. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*, *38*(4), 21–36.

Schalock, R.L., Verdugo, M.A. (2012a). *A leadership guide to redefining intellectual and developmental disabilities organizations: eight successful change strategies*. Baltimore, MD: Brookes.

Schalock, R.L., Verdugo, M.A. (2012b). A conceptual and measurement framework to guide policy development and system change. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(*1*), 63–72.

Schalock, R.L., Verdugo, M.A., Lee, Ch.S., Lee, T., Van Loon, J.H.M., Swart, K., Claes, C. (2015). *Manual de la Escala de Eficacia y Eficiencia Organizacional (OEES): Un enfoque sistemático para mejorar los resultados organizacionales*. Salamanca: INICO.

Scheerenberger, R.C. (1984). *Historia del Retraso Mental*. Usúrbil: Servicio Internacional de Información sobre Subnormales.

Verdugo, M.A., Gómez, L.E., Arias, B., Santamaría, M., Clavero, D., Tamarit, J. (2013). *Escala INICO-FEAPS: Evaluación Integral de la Calidad de Vida en personas con Discapacidad Intelectual o del Desarrollo.* Salamanca: INICO.

Verdugo, M.A., Gómez, L.E., Arias, B., Santamaría, M., Navalas, E., Fernández, S., Hierro, I. (2014). *Escala San Martín: Evaluación de la Calidad de Vida de Personas con Discapacidades Significativas*. Santander: Fundación Obra San Martín.

Verdugo, M.A., González, F., Calvo, I. (2003). *Apreciamos las diferencias: orientaciones didácticas y metodológicas para trabajar sobre la discapacidad en educación primaria.* Salamanca: INICO.

Verdugo, M.A., Rodríguez, A., Sainz, F. (2012). *Escala de calidad de vida familiar: manual de aplicación*. Salamanca: INICO.

Verdugo, M.A., Vicente, E., Gómez-Vela, M., Fernández-Pulido, R., Wehmeyer, M.L., Badía, M., Calvo, M.I. (2014). *Escala ARC-INICO de Evaluación de la Autodeterminación: Manual de aplicación y corrección*. Salamanca: INICO.

Annex

Selected acts of law

- **Real Decreto 334/1985, de 6 de marzo, de ordenación de la Educación Especial.** https://www.boe.es/boe/dias/1985/03/16/pdfs/A06917-06920.pdf.
- **Ley Orgánica 2/2006, de 3 de mayo, de Educación.** https://www.boe.es/boe/dias/2006/05/04/pdfs/A17158-17207.pdf.
- **Ley Orgánica 8/2013, de 9 de diciembre, para la mejora de la calidad educativa.** http://www.boe.es/boe/dias/2013/12/10/pdfs/BOE-A-2013-12886.pdf.
- **Real Decreto Legislativo 1/2013, de 29 de noviembre, por el que se aprueba el Texto Refundido de la Ley General de derechos de las personas con discapacidad y de su inclusión social.** http://www.boe.es/boe/dias/2013/12/03/pdfs/BOE-A-2013-12632.pdf.
- **Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia.** https://www.boe.es/buscar/pdf/2006/BOE-A-2006-21990-consolidado.pdf.

List of selected national institutions working for people with disabilities

- **Plena Inclusión.** Webpage of Plena Inclusión (established in 1964), a confederation of organizations that act in benefit of people with disability and their families in different areas like education, health, citizenship, employment, or rights, which final aim is to improve the quality of life of individuals with disabilities and their families. http://www.plenainclusion.org/.
- **ONCE** (**National Organization of Spanish blind people**, *Organización Nacional de Ciegos Españoles*, in Spanish). Spanish organization (established in 1938) which aim is to facilitate and support, through specialized social services, the personal autonomy and social and employment inclusion of people with visual disability and blindness. http://www.once.es/new. ONCE created its foundation in 1988 (Foundation ONCE http://www.fundaciononce.es/) for enhancing the inclusion of individuals with different disabilities different from visual one, through employment, training and different programs aimed at removing physical and sensory barriers; and the ONCE Foundation for Latin America (FOAL http://www.foal.es/), for helping people with visual disability in the region.
- **CNSE** (**State's Confederation of Deaf People**, *Confederación Estatal de Personas Sordas*, in Spanish). The CNSE (established in 1936) is a NGO which fights for ensuring equal opportunities for people with hearing disability, through the development of policies aimed at suppressing barriers. http://www.cnse.es/index.php.
- **FIAPAS** (**Spanish Confederation of Families of Deaf People**, *Confederación Española de Familias de Personas Sordas*, in Spanish). FIAPAS (established in 1978) is a national confederation composed by 46 organizations which aim is the representation and defense of the rights and global interests

of individuals with hearing disability and their families, both at national and international level, before the Society, Administrations, and other Institutions, integrating and promoting with this aim the action of the Autonomous Federations and the Associations of Parents of Deaf People. http://www.fiapas.es/FIAPAS/index.html.

- **Spaish Mental Health Confederation** (previously named FEAFES, *Federación de Asociaciones de Familiares y Personas con Enfermedad Mental,* in Spanih). This confederation (established in 1983) has the aim of improving the quality of life of people with mental illness and their families as well as defending their rights and representing the associative movement. https://consaludmental.org/.
- **COCEMFE** (**Spanish Confederation of People with Physical and Organic Disability**, *Confederación Española de Personas con Discapacidad Física y Orgánica*, in Spanish). COCEMFE (established in 1980) is a NGO aimed at grouping, strengthening, training, and coordinating all the efforts and activities of all the entities (+1600) which work in favor of people with organic and physical disabilities and are aimed at defending their rights and improving their quality of life. http://www.cocemfe.es/portal/.
- **RPD** (**Royal Board on Disability**, *Real Patronato sobre Discapacidad*, in Spanish). The RPD (established in 2000) is an autonomous organism attached to the Spanish Ministry of Health, Social Services, and Equality, which mission is (a) to promote the deficiencies prevention, the rehabilitation, and the social insertion of people with disability; (b) to facilitate the exchange and collaboration among different public administrations, as well as in between public administrations and the private sector, both at national and international level; (c) to give support to organisms, entities, specialists, and promoters in areas of studies, research and development, information, documentation, and training; and (d) to emit technical advices and recommendations in areas related to disability. http://www.rpd.es/.
- **CERMI** (**Spanish Committee on Legal Representatives of People with Disability**, *Comité Español de Representantes de Personas con Discapacidad*, in Spanish). The CERMI (funded in 1997) is the platform of representation, defense, and action in benefit of Spanish citizens with disability (more than 3.8 million). www.cermi.es/.
- **Other (research and information)**
    - **INICO** (**Institute on Community Integration**, *Instituto Universitario de Integración en la Comunidad*, in Spanish). The INICO (created in 1996) is composed by interdisciplinary professionals that lead activities linked to training, research, and counseling in the field of disability with the aim of easing and enhancing the QoL and self-determination of people living at social disadvantages in different contexts and throughout their life cycle. http://inico.usal.es/.

- **Spanish Network on Information and Documentation on Disability:**
    - **SID (Service on Information about Disability**, *Servicio de Información sobre Discapacidad*, in Spanish). The SID (1999) is a public internet portal that is aimed at professionals, politicians, and developers and managers of public policies. This service has three main functions: acquire, systematize, and spread information on disability. http://sid.usal.es/default.aspx.
    - **CEDD** (**Spanish Center on Documentation about Disability**, *Centro Español de Documentación sobre Discapacidad*, in Spanish). The CEDD is a Service that the RPD offers to public and private entities, professionals, and any other person interested in the disability field. It systematically collects and catalogues the relevant scientific literature as well as the documents edited by the international organisms, public administrations, and third sector entities in the disability field. http://www.cedd.net/.
    - **OEDD (State's Observatory on Disability**, *Observatorio Estatal de la Discapacidad*, in Spanish). OEDD is a technic instrument from the General Administration of the State (related to the Ministry of Health, Social Services and Equality, General Direction of Policies in Support of Disability and the RPD) which collects, systematizes, updates, generates, and disseminates information related to the disability field so that individuals with disability and other citizens, public administrations, universities, and the third sector can access to it. http://observatoriodeladiscapacidad.info/.

INFORMACJE DLA AUTORÓW

Redakcja kwartalnika *Człowiek – Niepełnosprawność – Społeczeństwo* przyjmuje do opublikowania oryginalne, recenzowane prace naukowe, artykuły polemiczne, recenzje, sprawozdania z wydarzeń naukowych, przeglądy czasopism.

Nadsyłane materiały powinny być zapisane za pomocą typowego edytora tekstu (preferowany edytor: MS WORD). Tekst należy przygotować zgodnie z następującymi zasadami:

- format A4 z marginesem 3,5 cm z lewej strony;
- tekst – 30 wierszy na stronie i ok. 60 miejsc znakowych w wierszu, nie powinien zawierać poprawek;
- objętość artykułów i rozpraw:
  – minimalna: 20 tys. znaków (0,5 arkusza wydawniczego),
  – maksymalna: 40 tys. znaków (1 arkusz wydawniczy);
- praca powinna zawierać streszczenia w języku polskim i angielskim (maksymalnie po 200 słów łącznie z tytułem w każdym języku) oraz słowa kluczowe (*keywords*);
- wykresy, ilustracje (ponumerowane i opatrzone informacją, do którego miejsca w tekście się odnoszą) należy umieszczać w oddzielnych plikach, podając nazwy programu, za pomocą którego zostały wykonane;
- literatura przedmiotu powinna być umieszczana na końcu pracy w układzie alfabetycznym;
- odwołania należy umieszczać w tekście głównym (bez przypisów); powinny mieć postać: (Zaorska, 2002).

Sporządzanie bibliografii

Pozycje bibliograficzne muszą być pełne, z DOI, w porządku alfabetycznym, pisane z dokładnym przestrzeganiem kolejności poszczególnych składników, z jednolitą interpunkcją. Kolejność zapisu bibliograficznego jest następująca:

(1) autor(zy) – wszyscy, niezależnie od liczby,
(2) rok wydania pozycji,
(3) tytuł książki, rozdziału, artykułu, dysertacji, pracy dyplomowej, referatu lub raportu,
    (a) książka: miejsce wydania i nazwa wydawnictwa,
    (b) rozdział: redaktor(zy), tytuł książki, strony, miejsce wydania, wydawca,
    (c) artykuł: tytuł czasopisma, tom (vol.) i strony,
    (d) praca dyplomowa (dysertacja): wydział (instytut), uczelnia (instytucja) i miejscowość,
    (e) referat: oryginalna nazwa konferencji (kongresu itp.) i miejscowość,
    (f) raport: rodzaj i numer grantu, miejscowość, uczelnia (instytucja) i wydział (instytut).

Kursywą piszemy: tytuł książki, również książki, w której znajduje się odpowiedni rozdział, tytuł czasopisma i jego tom, tytuł referatu, tytuł pracy dyplomowej (dysertacji), tytuł raportu. Poniżej podano przykłady zapisu poszczególnych pozycji bibliograficznych z uwzględnieniem wymaganej interpunkcji, rodzaju pisma (proste – kursywa) i liter (wielkie – małe).

Książki

(a) polska

Kościelska, M. (2004). *Niechciana seksualność. O ludzkich potrzebach osób niepełnosprawnych intelektualnie.* Warszawa: Jacek Santorski & Co.

(b) polska, redagowana

Strelau, J., Ciarkowska, W., Nęcka, E. (red.). (1992). *Różnice indywidualne. Możliwości i preferencje.* Wrocław: Zakład Narodowy im. Ossolińskich.

(c) obcojęzyczna, redagowana

Steiner, M., Yonkers, K., Eriksson, E. (red.). (2001). *Mood disorders in women.* London: Martin Dunitz.

(d) książka o kolejnym wydaniu

Osofsky, J.D. (red.). (1998). *Handbook in infant development.* New York: Wiley.

Rozdziały w książkach

(a) publikacja polska

Sidor, B. (2001). Ojciec w rodzinie z dzieckiem z niepełnosprawnością umysłową. W: D. Kornas-Biela (red.), *Oblicza ojcostwa* (s. 381–389). Lublin: Towarzystwo Naukowe KUL.

(b) publikacja obcojęzyczna

Greenberg, M.T. (1999). Attachment and psychopathology in childhood. W: J. Cassidy, P.R. Shaver (red.), *Handbook of attachment: Theory, research and clinical implication* (s. 469–496). New York: The Guilford Press.

Artykuły w czasopismach

Kościelska, M. (1993). Koncepcja osoby z upośledzeniem umysłowym jako uczestnika życia społecznego. *Przegląd Psychologiczny*, *3*, 341–353.

Nieopublikowane dysertacje i prace magisterskie

Jackowska, E. (1976). *Wpływ środowiska rodzinnego na przystosowanie społeczne dziecka* w *młodszym wieku szkolnym.* Nieopublikowana rozprawa doktorska, Wydział Filozoficzno-Historyczny, Uniwersytet Jagielloński, Kraków.

Domurad, M. (1996). *Efektywność rozwoju umiejętności czytania u dziecka upośledzonego umysłowo* w *stopniu lekkim za pomocą „metody baśniowych* *spotkań"*. Nieopublikowana praca magisterska, Wydział Rewalidacji i Resocjalizacji, Wyższa Szkoła Pedagogiki Specjalnej, Warszawa.

Referaty wygłoszone na konferencjach i innych spotkaniach

Jackowska, E. (1997). *Poczucie jakości życia u kobiet i mężczyzn po przebytym urazie mózgu.* Referat wygłoszony na II Sympozjum Opieki Paliatywnej – Hospicyjnej, Lublin.

Dosen, A. (1997). *Etiology, specific onset mechanisms of mood disorders among people with intellectual disablement and prelevance.* Referat wygłoszony na European Course on Mental Retardation, Nunspeet, The Netherlands.

Raporty z badań

Strelau, J., Oniszczenko, W., Zawadzki, B. (1994). *Genetyczne uwarunkowania i struktura temperamentu młodzieży i dorosłych.* (Raport KBN 1108.91.02). Warszawa: Uniwersytet Warszawski, Wydział Psychologii.

Wykaz literatury nie powinien zawierać informacji prywatnych, prac w przygotowaniu. Odwołanie się do takich źródeł może występować jedynie w tekście (bez przypisów dolnych i końcowych).

Do przesłanego wydruku tekstu i jego wersji elektronicznej należy dołączyć:

1) prośbę wraz z podpisem, w której autor zwraca się do redakcji o wydrukowanie pracy w czasopiśmie *Człowiek – Niepełnosprawność – Społeczeństwo*, zamieszcza informację o zatrudnieniu, podaje swój tytuł naukowy, ORCID, zajmowane stanowisko, adres, numer telefonu, adres e-mailowy;
2) pisemne oświadczenie, że praca nie była dotąd publikowana i nie została złożona w innej redakcji. Druk oświadczenia znajduje się na stronie www.cns.aps.edu.pl w zakładce *Informacje dla autorów.*

Zmiany i odstępstwa od podanych zasad należy uzgadniać z członkami Komitetu Redakcyjnego. Redakcja nie zwraca nadesłanych materiałów i zastrzega sobie prawo do dokonywania zmian w tekstach, bez ingerencji w treść merytoryczną.

Rzetelność naukowa

Autorzy są zobowiązani do ujawnienia wkładu poszczególnych autorów w powstanie publikacji (z podaniem ich afiliacji oraz kontrybucji, tj. informacji, kto jest autorem koncepcji, założeń, metod itp. wykorzystywanych przy publikacji) oraz źródła finansowania publikacji, wkładu instytucji naukowo-badawczych, stowarzyszeń i innych podmiotów (*financial disclosure*). Za nieujawnienie wyżej wymienionych danych odpowiedzialność ponoszą autorzy zgłaszający manuskrypt.

Wszelkie wykryte przejawy nierzetelności naukowej (*ghostwriting* – brak ujawnienia wkładu innych osób w powstawanie publikacji, *guest authorship* – sytuacje, gdy udział autora/współautora w powstanie publikacji jest znikomy lub nie miał miejsca) będą dokumentowane i nagłaśniane, włącznie z powiadomieniem odpowiednich podmiotów. Dotyczy to także łamania i naruszania zasad etyki, które obowiązują w nauce.

Recenzowanie

Artykuły recenzowane są poufnie i anonimowo („podwójna ślepa recenzja") przez dwóch zewnętrznych ekspertów niepozostających w konflikcie interesów z autorem/autorami manuskryptu zgodnie z „Dobrymi praktykami w procedurach recenzyjnych w nauce" (2011) opracowanymi przez MNiSW.

Procedura recenzowania oraz etapy obiegu pracy zgłoszonej do opublikowania znajdują się na stronie: www.cns.aps.edu.pl w zakładce *Zasady recenzowania*.

Lista recenzentów publikowana jest w czasopiśmie raz w roku w numerze czwartym.

Materiały należy nadsyłać na adres: redakcjacns@aps.edu.pl

Redakcja czasopisma *Człowiek – Niepełnosprawność – Społeczeństwo*
Akademia Pedagogiki Specjalnej im. Marii Grzegorzewskiej
ul. Szczęśliwicka 40
02-353 Warszawa