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Supporting the social inclusion of children and young adults with IDD and psychiatric comorbidities: Autobiographical narratives of practitioners and academics from Europe

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ABSTRACT: The article provides a reflection on the social inclusion of children and young people with IDD and associated psychiatric comorbidity through the eyes of practitioners and academics from Norway, Scotland, Sweden, and Romania. Using an autoethnographic approach to share the first-hand experiences of supporting children and young adults with IDD from the perspective of experienced practitioners, telling their stories (individual case studies) and mapping the challenges and successes (best practice) through these professional narratives. The article also acknowledges psychiatric comorbidity in young people with IDD and how psychiatric disorders can impact social inclusion. The results of the self-reflection of active practitioners involved with complex disabilities may serve as a guide for others in sharing best practices and facing difficulties. It also shows the policy developments on a timeline of their practice. Practice-informed issues clinicians and support staff face may aid the training and share the knowledge with other experts. The value added is the interprofessional exchange created by the international contributors.

KEYWORDS: disability, social policy, nurse, social pedagogue, psycho-pedagogue, social worker, situated knowledge, autoethnography, psychiatric comorbidity, mental disorder, Intellectual and Developmental Disability (IDD)

INTRODUCTION

The nomenclature concerning children and young people with cognitive impairment can vary between countries (Cluley, 2018). For this paper, Intellectual and Developmental Disability (IDD) will be used to define individuals with a formal intellectual or learning disability diagnosis. Youth services worldwide are challenged by a number of issues related to the safeguarding and well-being of children and youths (Perumall, 2017), but it is the dynamics of the tension between the systemic and the individual that can make a real difference (cf. Streeck, 2023). Professionals are the active agents in the middle of this tension, representing both the interests of institutions and the individuals they support; therefore, their stories of first-hand experiences are valuable for preserving the current state of knowledge to register changes and reflect on society. As Baranowski and Odrowaz-Coates (2018, p. 7) confirm when commenting on the importance of educating society and registering change, "education is an extremely important element of not only 'the personal troubles', but also 'the public issues of social structure'" (cf. Baranowski, 2020).

Around 2% of children worldwide are diagnosed with IDD, with the exact prevalence likely to be greater due to epidemiological factors, variance in healthcare resources, and cultural or system variations in diagnosis and reporting (Glasson et al., 2020). It is well-evidenced that people with IDD have a higher risk of social exclusion, greater barriers to social inclusion, and are more likely to experience psychiatric comorbidities (Mutluer et al., 2022). Psychiatric comorbidity is commonly underdiagnosed in those without IDD (Pena-Salazar, 2020). Furthermore, the additional marginalising factors that are more prevalent in people with IDD may potentiate a magnified risk of misdiagnosis or underdiagnosis for children and young people with IDD, with diagnostic overshadowing a significant risk (Munir, 2016).

There is a significant body of research concerning people with IDD and the propensity for psychiatric co-morbidity, with a prevalence of more than one-third in people with IDD (Mazza et al., 2020). However, residual barriers remain when we attempt to objectively assess for symptoms of comorbidity to ensure an appropriate, timely, and accurate therapeutic response. This risk of treatment delay risk was exacerbated during the Covid-19 pandemic (Tromans et al., 2020). Therefore, delayed diagnosis, underdeveloped assessment capabilities, and cognitive impairment may all contribute to an increased risk of social inclusion.

This article explores how practices must be adapted to meet the challenges of supporting children and young adults with IDD and co-morbid mental health needs across professional boundaries. We will examine autobiographical accounts from practitioners and academics with vested experience in the field. After that, we will discuss emergent themes through the lens of interpersonal learning and collaboration to identify areas of development across the professional groups and how this may inform approaches to supporting better inclusion of children and young adults with IDD and comorbid needs.

METHODOLOGY

Undertaking the mapping of individual experiences of practitioners involved in supporting children and young people with an intellectual and developmental disability (IDD) relies on qualitative approaches. Within this exploration, the Stake (2005) approach to qualitative case studies is followed, remaining aware that closeness and participation in the field of study can offer an advantage for seeing deeply into the research field but also poses a threat to objectivity (cf. Yin, 1994). However, since Haraway's (1988) contribution to the concept of situated knowledge, this closeness can be seen as highly advantageous, especially in the context of transnational contributions comparability of the circumstances within shared or similar experiences. The paper contains a collection of autoethnographic, autobiographical individual case studies (cf. Tellis, 1997; Stevenson, 2013) based on self-reflective narratives of professionals from Norway, the United Kingdom, Sweden, and Romania, summarising their professional experiences. This is done to identify potential best practices and institutional barriers to the social inclusion of children and youths with IDD. Stake (2005) identified that case studies are connected to identity studies and aim to capture and understand certain social phenomena. The lived experiences and professional observations of the contributors to add an ethnographic dimension to the case studies. As part of the observed environment, they have gained an insight into health, social care, and education systems and the practices within these and demonstrate how they shape the support available and the challenges for inclusion of children and young people with IDD. Cohen and Court (2003) conceptualized this ethnographic researchers' positioning 'perfect spies' within, while Rosen (1991) claims that the mundane of organizational life is the key to understanding ethnographic research.

This study's composition of contributors, experts in their field, and experienced practitioners across several European countries makes this research unique. They were tasked to reflect and summarise the key elements of their lived experiences of supporting children and youths with IDD on their path to being socially included. This form of self-reflection is often used in auto-ethnographic studies (c.f. Odrowaz-Coates, 2015) that describe or explore the situation from the personal perspective of the researcher, who is aware of their central position in the process of narration and the corresponding biases. Zaviršek (2006) provides a comprehensive overview of the use of ethnographic research in social work and other professions of care and public trust to gain insight and critical knowledge.

The chosen study method has been used and recognized in previous social work and nursing or care studies for decades. Amongst studies related to lived experiences or situated knowledge of practitioners, one may find Hughes (1984), Moreno (1995), Strauss et al. (1985), White (1997), Hirsch (1998), Westerman (1998), Hinshelwood and Skogstad (2000), Green (2002), Riemann (2005), White and Riemann (2010), and Leigh

(2021).

REFLECTIONS ON SOCIAL INCLUSION FROM A SOCIAL EDUCATOR

I graduated as a Social Educator in 2001 in Norway. My first job in this role was within the municipal healthcare services for persons with IDD and autism, referred to as users. A user is defined in Norwegian legislation as a person who applies for or receives services from municipal healthcare services that are not health services. Examples of users are persons receiving assisted living services (i.e. support in activities of daily living) and respite services.

I ask the reader to think about the meaning of concepts and how these can seem alienating and thus stand in the way of fundamental professional values and aims, such as social inclusion. It is easier to establish or facilitate relationships between «John» and «Alex» than between «John» and the «user». The term ‘user’ is alienating, and, in addition, there is no social status, personal independence or individuality attached to the user’s identity.

Back to my first jobs as a social educator—did I work towards establishing meaningful social relations between the people I provided health and social services to and people within the wider society (i.e. social inclusion)? The answer is no. I did not do anything related to social inclusion during my first years in the social educator profession.

Social inclusion was not a priority during my training as a Social Educator. We learned about valued social roles, integration, and stigma, but the focus was behaviour analysis and its application within services for persons with IDD. Social inclusion was neither emphasized during placement periods nor during academic training. As a student, if you had a good overview of behavioural analysis and its concepts and were good at communicating this to other students and some of the teachers, practical and academic achievement was more or less given. However, after more than 20 years, I wish I could say that I have at least tried to deliver professional work toward social inclusion.

It takes time to «grow up» as a professional, and I assert that professionals do not understand their role until they understand that it is all about showing virtue, and good character, not success. Even professionals with extensive experience do not consistently achieve success with their professional measures. They probably experience more failures than successes; challenging behaviours still occur, self-injurious behaviours are never eliminated, and we struggle to «achieve» social inclusion. But failures do not reduce competency or quality of the work. It is about trying to deliver the values we are obliged to deliver—the ethical guidelines, professional ethics, and codes of conduct. The central pegs for our professional work are adjusted information, self-determination, consent, and individuality. If these values are present in our professional work, it is difficult to talk about failures. From that point, when the professional understands that it is about trying and not about success per se, then the professional has understood its role, in my eyes.

REFLECTIONS ON SOCIAL INCLUSION FROM A LEARNING DISABILITY NURSE

I began working with people with IDD in a non-nursing capacity in 2005. I then progressed to become a registered Mental Health Nurse before then augmenting this with further study to become a Registered Learning Disability Nurse.

My first role as a 'Learning Disability Nurse' was within an assessment and treatment unit for adults over the age of 16, normally with co-existing psychiatric and/or challenging behaviour needs. This was a locked unit, and almost all of the people receiving care within were detained under the Mental Health (Care and Treatment) Scotland Act (2015). They often had limited capacity to acknowledge their need for hospital care, or were indeed unable to voluntarily accept treatment. Detention under the Mental Health (Care & Treatment) Scotland Act 2015 was common, as the individuals in inpatient care often had associated behaviours that challenge. People with IDD in inpatient settings are commonly referred to as "patients" as they were felt to be in receipt of treatment. Immediately, this seems the antithesis of social inclusion whereby people who are unwell are locked away from society. I feel that consolidating my nursing practice in an environment where people were often held involuntarily, with a wide variety of unmet need, helps immensely to develop individuals into well-rounded and empathic practitioners. Furthermore, it acutely magnifies the need to consider psychiatric comorbidity, diagnostic overshadowing and behaviour that may vary from societal norms and how these can limit the successful social inclusion of people with IDD. It was apparent at an early stage of my career that the identification and correct diagnosis of psychiatric comorbidities in people with IDD was of the utmost importance.

Reflecting on my formative years as a nurse working with people with IDD, I do not think I was fully cognisant of social inclusion and its links to poorer health outcomes. However, there are also elements of customary nursing practice that are conducive to social inclusion. Social activities and accessing the wider community out with the hospital setting was a key feature of the nursing model, staff dressed in normal clothing, not uniforms. Serving the function of social camouflage when escorting patients outside of the hospital grounds—walking around with a person wearing a healthcare/nurses uniform will attract more attention and singles out individuals who are resident in hospitals unnecessarily.

I progressed to work as a Learning Disability Epilepsy Nurse Specialist in 2014. At this juncture, the transition of people between children's and adult services was of more relevance to my work with people with IDD. We know that transition in this context can be difficult for young people and their families, and that done poorly, and increased risk of isolation, exclusion, exacerbation of need and personal and carer stress can be a negative outcome (Brown, Higgins, & MacArthur, 2019).

Despite the plethora of professionals having a robust understanding of an individuals' needs, there are examples where young people with IDD are left with their families for several months after leaving school, without structure, routine, peer support, meaningful engagement. This can be particularly problematic in people with ASD, and increases the risk of psychiatric sequelae emerging, detention in an inpatient unit, and therefore very evident impacts on human rights and social inclusion. Is it a striking coincidence that these young people often only require admission after they leave school and are at the behest of "adult services"?

The key to social inclusion for people with IDD rests with truly integrating interprofessional collaboration. Thinking about the fundamental aspects of working with people with IDD—continuity, consistency, relationship building –there must be adequate development of partnerships, increased focus on interprofessional learning and collaboration and the ongoing development of overarching policy to reduce health inequalities and enhanced social inclusion for people with IDD.

REFLECTIONS ON SOCIAL INCLUSION FROM A CLINICAL PSYCHOLOGIST

I have a long history, nearly forty years, of working in the field of child development and learning. My theoretical foundation is in modern developmental psychology where human development is seen in relation to, and in interaction with other significant people and with environmental and social actors. A common theme of my research has been the study of interpersonal interaction and the development of communication and language as well as the emotional and cognitive development of children and young people with disabilities such as IDD. The aim was to find qualitative and descriptive patterns of interaction of a child's communication, interactions, and participation in different pedagogical settings. This is of vital importance when we organise educational settings for children with IDD; to participate in communicative-linguistic interaction in play and in learning are of great importance for their continuous development and social inclusion.

It is in the two sociocultural arenas—the vertical relations, with adults such as caregivers and teachers who are more experienced and therefore unequal in relation to the child, and the horizontal relations, with other 'equal' participating children—that development and learning takes place. Professionals must consider both individual conditions of the child as well as the interplay between the individual and the society. Diversity and complexity are concepts that characterize human development, therefore, need to be openminded and reflective when we meet a child with IDD. All children can be hindered in their development due to their partners or contexts inability to interact and support them properly. To be a reliable and supportive partner and to create a context in favour of the child, we need to have a multi oriented perspective and we cannot do that alone, it demands having colleagues from different professions to collaborate with.

What has motivated me throughout my professional career as a Clinical Psychologist, a researcher and senior lecturer is finding best practises to support children with IDD to develop socially and educationally. I have seen good examples of teamwork around a child, unfortunately also inadequate ones. Interprofessional collaboration is of utmost importance to build a robust biopsychosocial and educational scaffolding around the child with IDD and their family. The support of scaffolding is not invasive, it supports growth, and is not taken down if there is a risk of a collapse. The support we as professionals offer must be flexible to change over time, considering for example the child's age, needs and the family situation.

REFLECTIONS ON SOCIAL INCLUSION FROM A SPECIAL EDUCATION PSYCHOLOGIST

Being formally prepared for the profession of psychologist, during my studies I did not think about the fact that I would work in the field of special education. But 17 years ago, in Romania, after graduation, professional opportunities were limited in the field of psychology and significantly more common in the field of special psycho-pedagogy—so I started my career at a large centre for inclusive education in Oradea, Romania. It was a period in which Romania was moving from institutionalization to inclusion and there was also great international pressure before joining the European Union. Distrust of my own skills applied in special education was high, as was anxiety about how I would be able to handle situations for which I was prepared only theoretically. But there was a great openness on the part of the institution's management towards innovation, exchange of experience and reorganization of activities, which led to an easier adaptation. And the contact with children with disabilities was a decisive one for me, both personally and professionally. I had the opportunity to work with children institutionalized in the first part of their childhood and who lived in conditions difficult to imagine, without emotional or social support of any kind. All of those children were primarily eager for basic emotional care, things that most of us consider implicit. It was also a blessing for many of them that they could learn in a clamorous environment, where their wishes were taken into account, where someone listened to them in the first place and took into account their needs.

Burn-out was increased at the beginning, because gradually I realized that beyond the professional goals, there were many more responsibilities in giving children a warm emotional climate in the first place and to help them acquire the feeling that they can achieve certain basic goals. Slow progress often or disruptive behaviours have led to increased levels of stress, but after the first two years of activity, the approach to work has begun to change. The problems related to burnout were no longer so significant, the relationship with children began to be much better and more natural and there were obvious signs of work results. The first four years of my professional activity, in which I worked in special education, were also defining for my subsequent practice as a Clinical Psychologist but also for understanding the spiritual dimension of disability and institutionalization.

DISCUSSION

One of the many accompanying social complications to IDD is stigma. This stigma may have a cumulative effect when added to the pre-existing stigma known to occur simply by having a diagnosis of IDD. If we further consider stigmatising conditions which are more prevalent in IDD; psychiatric comorbidity, behaviours that challenge, epilepsy—it becomes clear that there is an irrefutable link between risk of social exclusion, more complex and prevalent barriers to social inclusion, and as a result is one of many areas that can be addressed by interprofessional learning and collaboration.

MULTI-PROFESSIONALISM

Multi-professionalism is a mainstay of modern-day health and social care. It has many guises, and for the purposes of this paper, interprofessional collaboration/education/learning (IPL) will be utilised to discuss this concept. The concept itself is linked to learning with, from and about one another; and this concept is equally relevant to consider in relationships between professionals, as well as relationships between professionals, people with IDD and their families and carers (Saaranen et al., 2020).

Considering social inclusion and psychiatric comorbidity amongst people with IDD, the value of working collaboratively and creatively to conceptualise and operationalise both novel and revised practices and support for people with IDD is strongly evident (Abdulla et al., 2018). The need to expedite access to relevant professionals with appropriate skill sets is particularly important in people with IDD (O'Toole et al., 2017). IPL potentiates more positive outcome measures in various elements, such as polypharmacy review, student nurse education and inclusion of people with ASD and IDD in school (Gardner et al., 2022; Granas et al., 2019; Jones et al., 2015). Therefore, the early identification and collaboration to meet the developing needs of children and young people may proactively addresses formative trauma that may lead to more entrenched difficulties as older adults.

While we recognise that the expressive and receptive communicative capabilities of people with learning disabilities are likely to be compromised (Smith et al., 2020). Here we are focussed instead on the deficits in communication as related to professional groups. Doyle (2008) clearly indicated that effective communication and the timely sharing of information was a key facilitator in addressing the needs of children and young people with complex health and social care needs.

EDUCATION AND PROFESSIONAL PREPARATION

The preparation of health, social care, and education professionals rarely focuses on supporting the development of the appropriate skills to address the needs of children and young people with IDD and their families. This must be addressed, especially as we see more children and young people with higher levels of support needs and changing models of care which promote more inclusive approaches to the health and social care needs, and education of this group of people. The health inequalities for adults and children and young people with IDD are well documented (Emerson & Baines, 2011; Truesdale & Brown, 2017) and the competence and capacity of services in making the required adaptions to address these gaps are also understood. For the teaching profession, it is recognised that developing inclusive teaching spaces, while being of political and social importance adds significant stress to the workforce, especially given the perceived lack of preparation (Engelbrecht et al., 2010) increasing the risk of burnout.

Furthermore, the importance of interprofessional learning at both pre and post-graduate level should not be underestimated as a facilitator to more integrated working. To reduce the fragmentation of a workforce, practitioners must be prepared to work effectively within teams to deliver person-centred outcomes (Schampire et al., 2018). When we consider the implementation of IPL within the context of the experiences of the practitioners within this article. This is an area of enhancement across professional preparations, how can we anticipate the workforce of today, or tomorrow, to work effectively together when we are not appropriately equipping them with the skills to do so effectively?

We might also ask professional education to consider curricula that extend beyond the theoretical frameworks and singular professional interventions and instead consider how and what their role is to wider political and societal advancement of people with IDD and other stigmatised and marginalised groups.

MULTIMORBIDITY AND COMPLEXITY

It is well evidenced that people with IDD are more likely to experience multiple co-morbidities, including but not limited to Autism Spectrum Disorder (ASD); Epilepsy; Thyroid dysfunction; a myriad of psychiatric disorders; thus people with IDD are also more likely to be exposed to polypharmacy (i.e. over medicated) (Sun et al., 2022; Olsen et al., 2021). This has a significant effect on health and quality of life indicators, as well as the degree to which social inclusion can be successfully achieved, directly impacting the health and well-being of people with IDD (Merrels et al., 2019).

Consideration must be given to the additional assessment needs inherent within people with IDD, and thus the risk of diagnostic overshadowing and misdiagnosis (Tyrer et al., 2018). Furthermore, in individuals exposed to polypharmacy there is a greater risk of iatrogenic effects being misinterpreted as physical, psychological or psychiatric sequelae and thus further medication being prescribed to an individual regime to try to counteract this (Espadas et al., 2020). Diagnostic uncertainty and hypothesis led care is more prevalent due to the inherent communication difficulties, contributing to ill-health, iatrogenic effects and barriers to inclusion and well-being (Kerns et al., 2021).

Children and young people with IDD and psychiatric comorbidities are at greater risk of avoidable developmental delay and evident harms if cognisance is not given to the additional complexity of assessment, as well as delivering non-pharmacological therapies to individuals who have atypical cognition and additional support needs (Gobrial, 2019).

CONCLUSIONS

Across Europe the clinicians within this paper have identified the significant risks presented by the addition of psychiatric disorder to an individual with IDD, and the importance of recognising the challenges to ensure we advocate for young people, potentiate growth and development, and strive to support them to access services and lead an inclusive and meaningful life (Olsen et al., 2021). One of the key concepts in facilitating positive change and appropriate support for children and young people with IDD is the integration of well-developed interprofessional collaboration/education/learning (IPL) (Grung et al., 2020).

This project has evidenced ideas, knowledge and good practice shared from across Europe. Despite decades of political and social drivers which advocate for more inclusive, holistic approaches to meeting the needs of children and young people with IDD, we remain subject to barriers which are established through professional education and the subsequent practice in that field. To truly meet person-centred outcomes, we need to ensure that the barriers constructed by miseducation, professional tribalism and institutional constraints are washed away by the momentum of those who are invested and motivated to make our society a better place for people with IDD.

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