ACCEPTANCE
PARTICIPATION
SOLIDARITY

THE IMPORTANCE OF THE INTERDISCIPLINARY APPROACH

Edited by Ewa Dąbrowa

The Maria Grzegorzewska University Press

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UNESCO / Janusz Korczak Chair’s Book Series

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Table of Content

Part 1
INCLUSIVENESS AS A “HIDDEN TREASURE” OF DISABILITY STUDIES

Part 2
FROM SOLIDARITY TO INTEGRATION: CHALLENGES IN INTERDISCIPLINARY STUDIES

Foreword

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The new volume in the UNESCO Chair book series, titled: *Acceptance, Participation, Solidarity. The importance of the interdisciplinary approach,* is an unique contribution to the series. Its publication coincides with the special anniversary. It has been 20 years since the establishment of the UNESCO Janusz Korczak Chair at The Maria Grzegorzewska University.

This significant jubilee not only calls for reflection but also invites us to explore new, abandoned, and long-forgotten realms of discourses on social inclusion and the protection of human rights. The initiatives spearheaded by the UNESCO Chair are not just timely; they align with the Sustainable Development Goals, rooted in the principles of diversity, acceptance, and social solidarity. Embracing an interdisciplinary perspective and engaging a diverse array of scientists, experts, and practitioners from across the globe imbues these matters with a multidimensional and universal character. This illumination reveals once invisible threads, concealed within local reflections.

The issues presented in this publication were inspired by the spirited international conference titled "Acceptance, Participation, Social Solidarity – Interdisciplinary Challenges in Creating a Society for All." This conference unfolded in December 2022, marking the culmination of the celebration of the 100 Year of The Maria Grzegorzewska University and the grand centennial festivities of the University, adding an extra layer of commemoration to this edited volume.

The title of the volume establishes a connection between the latter and the upcoming international conference dedicated to issues of social inclusion – an universal value that both the University and the Chair ardently promote and express in their mission. The title, "Supporting the Social Inclusion of Children and Youth with Intellectual and Developmental Disabilities," aligns with the unique focus of the selection of texts. This conference is organized as part of the international EU project titled "Removal of Barriers to Social Inclusion and Social Participation for Children and Young Adults with Intellectual and Developmental Disabilities."

These events closely correspond to each other and seamlessly integrate into Maria Grzegorzewska's enduring motto: "There is no «cripple[1]»; there is a human being." This timeless and intercontextual message inspires engagement in discourses of exclusion, particularly in conditions of need or even necessity, to foster social cohesion in a world marked by divisions, conflicts, instability, and uncertainty.

This volume was created thanks to researchers and practitioners from different parts of the world (Ukraine, Nigeria, South Africa, China, India and Poland). It continues the rich epistemic justice traditions of the UNESCO Janusz Korczak Chair. A publishing series is devoted to the promotion of social inclusion from an activistic perspective, assuming the participation and involvement of people at risk or experiencing marginalization. This perspective is important because of multidimensionality and interdisciplinarity. It allows for a comprehensive view of the presented issues, but also to discover new issues or research ways, which can make them more relevant to reality.

The key category is the rights of people with disabilities and the rights of other social groups, as well as activities aimed at making them visible in scientific discourses and in social life. Despite the protection of individual and group rights, the phenomenon of exclusion and marginalization regarding various characteristics is common. They push a person to the margin of social life, making them useless, unnecessary and devoid of value measured by social and economic status quo.

Anna Odrowąż-Coates opens the discussion by highlighting the multidimensionality of social integration within a holistic vision of the world and human beings, derived from humanistic theories. She emphasizes the need for an understanding of various social factors and the effects of exclusion phenomena. The imperative of solidarity resounds in the background and can serve as the focal point for creating and implementing policies. Furthermore, she points to the use of intersectionality to understand the disadvantages in the experience of social integration, aiming to build cohesive and self-sufficient communities.

The rest of the book is divided into two themes: *Inclusiveness as a "Hidden Treasure" of Disability Studies* and *From Solidarity to Integration: Challenges in Interdisciplinary Studies*.

The first one – *Inclusiveness as a "Hidden Treasure" of Disability Studies* – addresses problems related to the situation of people with disabilities in various social dimensions. The social inclusion of children and youth with intellectual and developmental disabilities is a challenge for social work and education. Nowadays, various methods of action are indicated, including art therapy, which combines various theoretical and methodological perspectives. It lets to recognise and unlock the potential of young people with disabilities and, above all, to search for more innovative, integrated and inclusive practices based on individual-based dispositions. This perspective is presented by *Yuyan Li*. *Onam Singh* and *Mehak Rawal,* who emphasise the difficulties in building inclusiveness in the world of systemic inequalities that expose people with disabilities to violations

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[1] The derogatory, stigmatizing term used in the early twentieth century, highlighting the negative connotations of perception of persons with disabilities. It's essential to use respectful and inclusive language, especially when discussing topics related to disabilities. The original passage has a historic value and indicates positive changes that have taken place since then.

of their rights and increase the risk of violence. Multiple discrimination (due to several reasons, including disability and non-heteronormativity) reinforced the occurrence of aggression and violence and also made the problem socially invisible. *Błażej Kmieciak* continues the theme of barriers experienced by people with disabilities in his article. His analyses indicate legal barriers to the implementation of the right to love, which is most visible in regulations regarding entering into marriage. This opens – as the author notes – a discussion on the issue of rights and their violation, as well as the justification for such conduct. Inclusiveness and social integration require the active involvement of various social groups, which makes society more diverse. Further in the volume, passive forms of spending free time by people with disabilities are presented on the basis of research results by *Agnieszka Franczyk* and *Weronika Kurcz*. There is a small chance of moving away from replicating unequal and exclusionary social relationships. In addition to the negative phenomena regarding people with intellectual disabilities *Karolina Grad* emphasizes the positive ones – extended life expectancy and increased professional and social activity. This is possible due to changing the ways of thinking about disability, its "humanization", and especially through health and social rehabilitation providing participation and acquisition of competencies for this participation. The view of exclusion and enslavement of people with disabilities is completed by Onyekachi Peter Onuoha in personal narratives. The using of personal narratives creates space to combat barriers, taking into account an intersectional perspective: theory of art, of trauma, of gaze and of closeness.

The second part of the book – *From Solidarity to Integration: Challenges in Interdisciplinary Studies* – presents the perspective of exclusion due to other reasons. *Natalia Tsumarieva* focused on the deprivation of orphaned children. Negative emotions lead to the development of numerous undesirable symptoms, which require early detection and correction, as well as psychiatric care. The perspective was explained based on behavioural and emotional characteristics of school-age children affected by emotional deprivation as a result of the loss of parents or other significant persons.

Protecting the child's rights is important in the situation of the absence of parents, as well as health care. Xi Chen emphasizes, that the actions of nation-states may lead to the elimination of positive policies and solutions. A critical perspective and in-depth analysis concerning diversity, self-agency and engagement create the space for rights to be respected or restored. The protection of human rights is the particular gauntlet in times of military conflicts. *Natalia Tsybuliak*, *Olha Hurenko* and *Olena Starynska* highlight the inclusive role of academic education during a full-scale war in Ukraine. It seems to be a key for sustainable and cohesive societies independent from the geopolitical situation. It's a call for proactive behaviour and support from other members of the community at once. Institutional inclusiveness is also underlined by *Olena Arsentieva*, *Halyna Tatarenko*, *Olena Karchevska*, *Liudmyla Pavlova*. The perspective proposed by the authors allows us to look at this problem globally, as well as through the needs of specific social groups (including people with disabilities). Using a holistic approach, *Zuzanna Chałubińska* focuses on the exclusion of people in a suicide crisis, and *Olga Lasocka-Bełc* – writes about the situation of prisoners and former prisoners. The present circumstances demand preventive educational and intervention activities aimed at overcoming stereotypes and prejudices and developing appropriate aid programs. In the article concluding the chapter, *Jean Paul Muambangu Milambo*, *Peter Nyasulu*, *David Niyukuri*, *John Akudugu* and *James Ndirangu* emphasize the need to integrate preventive and therapeutic measures for the early detection and prevention of cancer (regarding women in Africa), which will enable the creation of optimal solutions at various levels in healthcare systems.

Acceptance – participation – solidarity determine social cohesion and cooperation in solving global problems. They involve overcoming individual barriers created in the socialization process. Acceptance is the first stage of change, but not sufficient – it requires responsible commitment and action for the benefit of others. Solidarity – although it doesn't serve everyone equally – provides support for marginalised people and builds an integrated and responsible community. It's a kind of emancipation and a call to recognize the diversity and community of experiences. The analysis of the categories allows us to see – despite their unquestionable values – the reasons for excluding people with disabilities, people affected by war, mental crises or somatic diseases. The tension within the category and its discursiveness opens a space for reflection on key issues of inequality and exclusion in the perspective of inclusiveness, as well as for the reconstruction policies and searching for new impulses for social change.

A Multifaceted Reflection on Fostering Social Inclusion

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Motivation

This chapter aims to provide humanist perspectives supported by the rationale for social inclusion, under the umbrella of social cohesion and societal benefits. A multifaceted point of view considers various aspects, dimensions, or threads, offering a comprehensive understanding that reflects multiple factors or elements. The chapter starts with the social justice perspective, followed by the economic disillusion, a social policy perspective and the role of the welfare state, followed by identifying the intersectionality of barriers to social inclusion and existing tools to foster inclusion. Finally, due to the nature of the EU-funded research project focusing on the barriers to social inclusion[2], which inspired this chapter, we delve into reflection on specific issues hindering inclusion faced by people with deep intellectual disability.

Social justice vs. economic rationale

Social inclusion, when viewed through the lens of **social justice**, involves examining and dismantling barriers that prevent equal participation and opportunities for all members of society. While it is not solely a socialist concept, various social justice perspectives, including those from early philosophers to contemporary thinkers, emphasize the importance of addressing inequality and promoting inclusivity. In his works on ethics, Aristotle highlighted the concept of justice as fairness. He argued that a just society is one where individuals receive what they deserve based on merit, rather than arbitrary factors. This idea resonates with contemporary notions of social justice, emphasizing fairness and equal opportunities. John Locke's writings on property rights and the social contract laid the groundwork for discussions on justice and equality (1690/1980). While

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[2] *Removal of barriers to social inclusion and social participation for children and young adults with intellectual and developmental disabilities*. SIIDD. Erasmus+ 2019-1-SE01-KA203-060425, https://siidd.eu/

Locke's ideas were often linked to individual property rights, they also paved the way for later social justice theories by framing the importance of fair distribution and access to resources. John Rawls: In the 20th century, Rawls contributed significantly to social justice theory with his work *A Theory of Justice*. Rawls (1999) argued for a just society based on the principles of justice and fairness. His original position and veil of ignorance concepts suggest that a just society would prioritize the well-being of the least advantaged. This implies a role for redistributive policies to address systemic inequalities. His point of view is not new. Pioneer in anthropology Margret Mead claimed that for her the first sign of civilization is the skeleton with a broken bone (femur) that healed over time, which would not have been possible without the support of other humans. Something distinctive from the animal kingdom, where an individual with a broken bone would be weakened, unable to hunt or to protect themself and in consequence left to die before the bone has a chance to heal (cf. Brand, & Yancey, 1993). In other words, the ability of humans to protect the vulnerable members of their species is the first sign of civilization. Amartya Sen's (1985) capabilities approach emphasizes the importance of expanding people's capabilities to lead the lives they value. This perspective goes beyond economic indicators and advocates for a broader understanding of well-being. Sen's work aligns with social justice principles, acknowledging the multifaceted nature of barriers to inclusion. Feminist scholars, including Carol Gilligan, have contributed to social justice discussions by highlighting the gendered aspects of justice. Gilligan's work (1982) on the ethics of care emphasizes the importance of relationships and interconnectedness, challenging traditional justice theories that may overlook caregiving roles. This perspective broadens the understanding of social justice to include diverse experiences. The civil rights movement in the mid-20th century in the United States, led by figures like Martin Luther King Jr. (1967/2010), sought justice and inclusion for marginalized groups, particularly African Americans. This movement expanded the discourse on social justice beyond economic redistribution to encompass racial equality and civil rights. The development of international human rights principles, such as those articulated in the Universal Declaration of Human Rights, reflects a global commitment to social justice. These rights encompass not only political and civil rights but also economic, social, and cultural rights, acknowledging the interconnectedness of various dimensions of justice. Contemporary social justice theories continue to evolve. Scholars like Martha Nussbaum (1988, 1992) advocate for a capabilities-based approach, while others (e.g. Connell, 1993, 2005) explore intersectionality, recognizing the intersecting identities and systems of oppression that contribute to social exclusion.

In conclusion, the social justice perspective on social inclusion draws on a rich history of philosophical thought, encompassing notions of fairness, equality, and rights. While socialism may advocate for certain redistributive measures, the broader social justice framework incorporates diverse perspectives and historical contributions that transcend any single ideological stance. It emphasizes the importance of addressing systemic barriers and fostering an inclusive society that respects the dignity and rights of all individuals.

From an economic perspective, barriers to social inclusion are often rooted in the distribution and redistribution of capital. Tomas Piketty's book, *Capital in the Twenty-First*

Century (English edition 2014), offers insights into the dynamics of wealth accumulation and the implications for social inequality. Piketty's central argument revolves around the tendency of capital to accumulate faster than economic growth, leading to increasing wealth inequality. The accumulation of wealth among a small segment of the population can create barriers to social inclusion for others, as it consolidates economic power and limits access to resources. The concept of inherited wealth is crucial in understanding barriers to social inclusion. When wealth is passed down through generations, it can create a perpetuating cycle of advantage for certain families while creating barriers for others to enter the economic mainstream. This intergenerational transmission of wealth can limit social mobility and contribute to long-term inequality. Unequal distribution of income is a significant factor contributing to social exclusion. High-income individuals and families have more resources, better access to education, and greater opportunities, creating barriers for those with lower incomes to advance socioeconomically.

Education is a key component of social inclusion, and economic disparities often translate into unequal access to quality education. Wealthier individuals can afford better educational resources, private tutoring, and prestigious institutions, creating a divide that reinforces social and economic exclusion. Social capital, defined as networks, relationships, and social connections, plays a crucial role in economic success. Barriers to social inclusion can arise when certain groups have limited access to influential social networks, which can be instrumental in accessing job opportunities, business partnerships, and other avenues of economic advancement. Economic systems can perpetuate social exclusion when discrimination and bias exist. Certain groups may face systemic barriers due to race, gender, ethnicity, or other factors, limiting their access to economic opportunities and capital.

Global economic trends and technological advancements can create winners and losers. Those who are well-positioned to benefit from globalization and technological progress may experience economic growth, while others face displacement and job insecurity, contributing to social exclusion. Tax policies, as discussed by Piketty, can either exacerbate or mitigate wealth inequality. Progressive taxation can help redistribute wealth and contribute to social inclusion by funding public services and social programs. Conversely, regressive tax policies may reinforce economic disparities. Addressing these barriers to social inclusion requires comprehensive policies that promote economic fairness, equitable access to opportunities, and social mobility. Piketty's work emphasizes the importance of understanding and addressing the structural factors that contribute to long-term inequalities in the distribution of capital.

A social policy perspective

From a social policy perspective, barriers to social inclusion can be analysed through the lenses of existing theorists, politicians, and ethical considerations. Scholars like Pierre Bourdieu have emphasized the role of social structures in perpetuating inequality (1989, 1990, 1991, 1998, 2005). Structural inequalities in education, employment, and access to resources can create barriers to social inclusion. Some policymakers, such as Franklin D. Roosevelt (1937) in the United States, advocated for policies like the New Deal to address economic inequalities during times of crisis. A number of social policy theorists like Richard Titmuss (1958) and Esping-Andersen (1990) have explored the impact of welfare policies on social inclusion. Welfare systems can either contribute to or alleviate barriers based on their design and implementation. The development of comprehensive welfare states in Scandinavian countries, often associated with figures like Olof Palme in Sweden, has aimed at reducing social inequalities and promoting inclusion (Östberg, 2019). Some scholars like Amartya Sen (1985) highlight the importance of healthcare as a dimension of social inclusion. Limited access to healthcare services can be a barrier to well-being. Whilst, politicians like Tommy Douglas in Canada played a crucial role in the establishment of universal healthcare systems, addressing barriers related to healthcare access. Housing policies are addressed by theorists such as Manuel Castells (1993), who examines urbanization and its impact on social structures. Access to affordable housing is essential for social inclusion. Figures like Angela Merkel (cf. fightinequality.org, 2019; Mokski, 2022) in Germany have tackled housing affordability through policy initiatives aimed at addressing housing shortages. These policies included migrants and refugees. Yet, the shortage remains vast. Educational theorists like John Dewey emphasize the role of education in social inclusion (Danforth, 2019). Policies that ensure equal access to quality education can mitigate barriers. Nelson Mandela in South Africa advocated for education policies to dismantle apartheid and promote inclusivity (Abrehet, Devin, 2016). Ethical perspectives, including those from philosophers like John Rawls, argue for principles of justice that prioritize the well-being of the least advantaged. Ethical considerations provide a normative framework for social policies. Leaders like Mahatma Gandhi incorporated ethical principles in their advocacy for social justice and inclusive policies. Labour market policies, discussed by theorists like Karl Polanyi (cf. Cangiani, 2011), are crucial in understanding economic structures and their impact on social inclusion. Policies promoting fair wages and workers' rights contribute to inclusion. Leaders like Franklin D. Roosevelt implemented labour market policies, including the establishment of minimum wage standards (1937), to address economic inequalities (Due to economic depression a Fair Labor Standards Act of 1938 was introduced).

In conclusion, social policy perspectives on barriers to social inclusion draw on the work of theorists and the actions of politicians who have shaped policies to combat societal evils and social anomie. Ethical considerations underscore the need for policies that prioritize justice and well-being for all members of society. Effective social policies, informed by both theory and political action, play a crucial role in fostering a more inclusive and equitable society.

So should we focus on the path to achieving the welfare state?

The question of whether the welfare state is the best solution for social inclusion is complex and often debated. Different social theories offer various perspectives on how to address social inclusion and alternatives to the welfare state have been proposed. Here are some viewpoints from social theories and alternative approaches.

Social theorists like Esping-Andersen (1990, 1999), in his typology of welfare states (liberal, conservative, and social-democratic), argue that social policies can contribute to social inclusion by addressing economic inequalities, providing social services, and ensuring a safety net for vulnerable populations. Critics argue that welfare states may sometimes create dependency or disincentives for work, and the effectiveness of welfare policies depends on their design and implementation.

The idea of a Universal Basic Income (UBI) has gained attention as an alternative (Baranowski, Jabkowski, 2001). Proponents like Philippe Van Parijs (1992) or van der Veen and Groot (2000) argue that providing every citizen with a regular, unconditional sum of money could ensure economic security, reduce poverty, and promote social inclusion. Critics express concerns about the feasibility and financial sustainability of UBI, potential inflationary effects, and the need for additional policy measures to address specific needs.

Social Theory Support: Amartya Sen's capabilities approach (1985) focuses on expanding individuals' capabilities to lead lives they value. Policies that enhance education, healthcare, and economic opportunities align with this approach, fostering social inclusion by empowering individuals. The voices of criticism may argue that the capabilities approach may not offer concrete policy prescriptions and that there can be challenges in defining and measuring capabilities.

Social investment theorists argue for investing in human capital, such as education and training, to enhance individuals' employability and social inclusion. This perspective, advocated by scholars like Anton Hemerijck (2013, 2015), emphasizes proactive policies that prevent social exclusion. Critics suggest that the social investment approach might not address structural inequalities adequately and could lead to a narrow focus on individual responsibility.

Community-based approaches, drawing on theories of community development, emphasize local empowerment, participation, and social cohesion as ways to foster social inclusion. Scholars like Robert Putnam (Putnam et al., 1993, 1995) argue for the importance of social capital in building inclusive communities. Critics highlight potential challenges in ensuring equal access to resources and opportunities across diverse communities.

The idea of promoting social enterprises and cooperatives draws on theories of social economy. Scholars like Elinor Ostrom (1990) argue that these models can create economic opportunities, empower communities, and contribute to social inclusion. Critics note that the scalability and sustainability of social enterprises may vary, and they may not replace the need for comprehensive social policies.

In conclusion, the effectiveness of solutions for social inclusion depends on contextual factors, societal values, and the specific challenges faced by communities. A combination of policies informed by different social theories, along with ongoing evaluation and adaptation, may be necessary to address the multifaceted nature of social inclusion.

Intersectionality of barriers to social inclusion

Barriers to social inclusion can vary across different vulnerable minority groups, and individuals may face intersectional challenges due to multiple factors. Gender-based discrimination, unequal access to education and employment, gender pay gap, and societal expectations can hinder social inclusion for women. Harassment and violence may further marginalize individuals. Ageism can limit opportunities for both younger and older individuals. Young people may face challenges in accessing education and employment, while older individuals may encounter discrimination in the workforce and in social contexts. Stigma, lack of accessibility, and discrimination can create significant barriers for individuals with health conditions or disabilities. Limited access to healthcare services, education, and employment opportunities can contribute to social exclusion. Homophobia, discrimination, and prejudice can lead to exclusion for individuals with diverse sexual orientations. Limited legal protections, workplace discrimination, and societal bias can impact social inclusion. Racism, xenophobia, and cultural stereotypes can marginalize individuals from ethnic minority backgrounds. Unequal access to education, employment, and housing may contribute to social exclusion. Language barriers, cultural differences, discrimination, and limited access to social services can pose challenges for migrants and refugees. Legal restrictions and difficulties in obtaining employment may further contribute to exclusion. Long-term unemployment can lead to social isolation, financial instability, and a lack of access to resources. Stigmatization and loss of social connections can further exacerbate exclusion for unemployed individuals. Single parents, often women, may face challenges in balancing work and family responsibilities. Limited support systems, financial strain, and societal expectations can contribute to social exclusion. The stigma surrounding mental health issues can lead to social isolation and discrimination. Limited access to mental health services, employment challenges, and misunderstandings about mental health conditions can hinder social inclusion.

It's important to note that these barriers are interconnected, and individuals may face overlapping challenges due to multiple aspects of their identity. Additionally, the social and cultural context plays a significant role in shaping the extent and nature of these barriers. Efforts to address social inclusion should involve comprehensive and intersectional strategies that consider the unique experiences of each vulnerable minority group. This includes promoting policies, awareness campaigns, and social initiatives that foster inclusivity and challenge systemic inequalities.

Existing tools and solutions to foster inclusion

Addressing barriers to social inclusion and fostering access and equity of opportunity requires a multifaceted approach involving various tools and strategies. Enactment and enforcement of anti-discrimination laws and policies are the obvious ones. It is focused on providing legal frameworks that prohibit discrimination based on characteristics such as gender, race, age, disability, and sexual orientation to help create a foundation for promoting equity and inclusion.

Educational programs and awareness campaigns promote understanding, empathy, and awareness about diverse identities and experiences helping challenge stereotypes and biases and fostering a more inclusive society. Affirmative action policies and diversity initiatives introduce measures that actively promote the inclusion of underrepresented groups in education, employment, and other sectors that can help address historical and systemic inequalities. Universal design principles and accessible infrastructure, by creating physical spaces, technologies, and services that are accessible to people of all abilities ensures inclusivity in various aspects of daily life, from education to employment. Accessible mental health services and destigmatization efforts, by providing mental health support services and reducing the stigma around mental health issues help individuals seek help without fear of discrimination, contributing to their overall well-being.

Language interpretation and translation services are to ensure that individuals with limited English proficiency have access to information and services in their native languages help overcome language barriers and promote inclusion. Community-based initiatives and empowerment programs engage communities directly in decision-making processes, providing resources, and fostering leadership can empower marginalized groups to address their unique needs and challenges. Training programs on diversity, equity, and inclusion provide education and training to individuals and organizations to help raise awareness about unconscious biases, promote cultural competence, and create more inclusive environments.

Economic empowerment programs and support for entrepreneurship are aimed at creating opportunities for economic independence, and skill development, and entrepreneurship helps address barriers related to unemployment and financial stability. Flexible work policies are meant to implement flexible work hours, remote work options, and accommodating diverse family structures to support individuals facing challenges related to age, gender, and single parenthood.

Intersectional policies and analyses are focussed on the recognition of the intersecting nature of identities and experiences to help tailor interventions to address the unique challenges faced by individuals with multiple marginalized identities. Building social support networks and communities is aimed at creating spaces for social connection and support can combat social isolation and contribute to the overall well-being of individuals facing various barriers. Advocacy for policy changes and systemic reforms work towards influencing policy at local, national, and international levels to help address root causes of inequality and exclusion, leading to systemic change.

These tools work synergistically, and a comprehensive approach involves the integration of multiple strategies. Social inclusion requires ongoing efforts, collaboration among various stakeholders, and a commitment to dismantling systemic barriers that perpetuate inequality.

Inclusion focussed on intellectual disabilities

Social inclusion of people with deep intellectual disabilities is often considered challenging for several reasons, starting with the fact, that individuals with deep intellectual disabilities may face significant challenges in communication. This can make it difficult for them to express themselves and for others to understand their needs and preferences, leading to social isolation. There can be widespread societal stigmas and stereotypes associated with intellectual disabilities. These negative attitudes can create barriers to social inclusion, as individuals with disabilities may be perceived as different or incapable. Many people may lack awareness and understanding of the needs and capabilities of individuals with deep intellectual disabilities. This lack of understanding can lead to exclusion and discrimination. Individuals with deep intellectual disabilities may have fewer opportunities for social interaction and participation in community activities. A lack of accessible and inclusive programs and services further contributes to their exclusion. People with deep intellectual disabilities often require support services for their daily activities. The dependence on such services can sometimes result in segregation rather than integration into the wider community.

Conclusions

Despite these challenges, social inclusion is crucial for several reasons: every individual has the right to be treated with dignity and respect. Social inclusion is fundamental for upholding the human rights of people with deep intellectual disabilities, allowing them to live fulfilling lives. Inclusive communities contribute to a better quality of life for everyone, including individuals with deep intellectual disabilities. Being part of a supportive and accepting community enhances well-being and happiness (EDUCATORE, 2024). Promoting social inclusion can have economic advantages. When individuals with disabilities are included in the community, they can contribute to the workforce, fostering diversity and bringing unique perspectives. This, in turn, can lead to economic growth and productivity. Social inclusion can reduce the reliance on specialized support systems. When individuals with deep intellectual disabilities are integrated into mainstream society, the demand for exclusive support services may decrease (cf. Boyle, 2021; Grung et al., 2020). Inclusive communities foster diversity, leading to increased understanding and empathy among people (Dolan, 2022). This can create a more compassionate and tolerant society. Efforts to enhance social inclusion for individuals with deep intellectual disabilities require collaboration between communities, government agencies, advocacy groups, and educational institutions. Emphasizing the importance of inclusion from both a human rights and economic standpoint can help break down barriers and promote a more inclusive society. Understanding the diversity of factors and short-term and long-term social effects is crucial to implement more inclusive policies and provide resources for adequate support. Perhaps, the intersectionality of disadvantages for experiencing social inclusion is the key to building more cohesive, self-sufficient communities.

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ABSTRACT

This chapter delves into multifaceted perspectives on fostering social inclusion, anchored in humanist values and rationalized within the realms of social cohesion and broader societal benefits. The exploration unfolds through various lenses, beginning with a social justice perspective, highlighting the ethical imperative of inclusion. Subsequently, it navigates through economic disillusionment, offering insights into the reciprocal relationship between social and economic factors. A social policy lens is employed to dissect the role of the welfare state in shaping inclusive practices.

The chapter not only scrutinizes theoretical constructs but also investigates practical barriers to social inclusion, emphasizing intersectionality as a key dimension. By examining the intersection of various factors, it sheds light on the complex nature of exclusion and paves the way for a nuanced understanding. Practical tools and solutions for fostering inclusion are explored, providing a comprehensive toolkit for policymakers and practitioners.

The chapter concludes with a focused reflection on the specific challenges faced by individuals with deep intellectual disabilities. This in-depth analysis contributes valuable insights to the ongoing discourse on social inclusion, encouraging a holistic approach that considers diverse perspectives and real-world applications.

KEYWORDS

inclusion, tools, social policy, social justice, economy, education, intellectual disability

Part 1

INCLUSIVENESS AS A “HIDDEN TREASURE” OF DISABILITY STUDIES

Supporting the Social Inclusion of Children and Young People with Intellectual and Developmental Disabilities Using Art Therapy as a Means of Intervention

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Introduction

In the organisational structure of modern society, where different narratives converge and intertwine into a vast and rich human civilisation, the light of the marginalised has always had a unique and wonderful resonance, which is invariably ignored and suppressed in different contexts as society's rapid development progresses towards homogenisation and norms. These young souls are full of potential and unique perspectives, but they face a world of visible and invisible barriers that perpetuate the marginalisation of these young people, placing them in the shadow of participation and belonging. The need for social inclusion, a concept deeply rooted in the values of equity and respect to ensure that everyone, regardless of their specific situation, has the opportunity to participate fully and meaningfully in public life, is an action that society needs to take and practice thoughtfully. Social inclusion should go far beyond the simple notion of inclusion in school and community spaces, and encompasses a deep recognition of the right of every person to express, connect and grow in the social embrace. For supporting children and adolescents with intellectual and developmental disabilities, achieving this level of inclusion requires creative, empathetic strategies that go beyond traditional barriers to communication and interaction to develop more effective strategies. Art therapy emerged not only as a therapeutic practice, but also as an act of re-imagining inclusive society, utilising the infinite power of creative expression to map new realms of existence for young people. This paper dares to explore the promising paths that art therapy has opened up in the field of social inclusion, especially for young people and children coping with the challenges of intellectual and developmental disabilities. By integrating art therapy into a rich interdisciplinary framework, including the use of critical insights from sociology, empathetic approaches from social work, and customised strategies from special education, we begin to seek to unravel the intricate web of barriers to inclusion. Our quest is not satisfied with identifying these barriers, but rather attempts to dismantle them and build bridges of communication. In delving into the symbiotic relationship between art therapy and social inclusion, this study argues that creative expression transcends its role as a mere therapeutic tool and becomes a powerful force for social change. By combining theoretical rigour with empirical testing and practical wisdom, we shed light on the multifaceted role that art therapy plays in fostering ecosystems where diversity flourishes. The urgency of this quest cannot be overemphasised, and in a context where such differences are often met with indifference or outright hostility, the creation of an environment of acceptance and understanding is not only a noble quest, but also an imperative one. The significance of this study goes far beyond academia; it is a call to educators, therapists, policy makers and community members. It is a call to unite and advocate for us to go into practice for every child and adolescent to take their place in society, regardless of the developmental path they choose for themselves. In a world yearning for unity and understanding, advocating for social inclusion through the medium of art therapy not only heralds the possibility of a more empathetic, creative, and inclusive society, but also represents the possibility of hope. This narrative is a manifestation of hope for the future, a declaration of the untapped treasures that lie within every human being and are invaluable to human civilisation. We firmly believe that through the creative expression of art, we can realise a more inclusive society. Together, we can build a world where every voice is heard, every story is valued, and every child is seen not only for who they are, but for who they can become.

Existing research

In the second half of the 20th and 21st centuries, art therapy has taken on a more prominent role in educational settings and the beginnings of social work, with a significant shift in the understanding of its role in supporting diverse populations following the recognition that its unique ability to facilitate communication, enhance self-understanding and improve social skills in children and adolescents has a wide range of cognitive capacities and emotional needs, with theories emphasising the universality of creative expression as a means of exploration and communication. Pioneers such as Edith Kramer, regarded as the mother of art therapy, were instrumental in fostering this emerging discipline. Edith Kramer emphasised the therapeutic role of creativity itself, suggesting that the process of creating art can be inherently healing, facilitating self-expression and psychological resilience, supplying a means of expressing the repressed traumas and desires of reality beyond the traditional linguistic beyond the traditional mastery of language. This sheds light on repairing social structures fragmented by conflict, and it argues that art therapy can be used not only as a tool for personal healing, but also for social cohesion and inclusiveness. By challenging existing therapeutic and educational paradigms, art therapy allows us to confront and challenge the illusions that sustain social reality, including the stigmatisation of marginalised groups and the marginalisation of those who deviate from the norm. It prompts a radical re-imagining of the way society treats difference, championing a world where everyone can carve their own unique mark on the collective community. It rejects the capitalist discourse that reduces the individual to utilitarianism and instead celebrates the intrinsic value of creative expression as a means of communication, connection and understanding. From this perspective, art therapy emerges as a form of resistance, a declaration of the right to exist beyond predefined categories and to participate fully in the social sphere. The evolution of art therapy can be understood as a dynamic interplay of desire, trauma and symbolic identity in which the act of creation becomes a revolutionary gesture. It challenges the dominant ideologies that dominate the social inclusion of children and adolescents.

In the field of sociology, the literature is replete with analyses of the structures of exclusion and marginalisation that permeate modern society (Bourdieu, 1984; Foucault, 1977). They reveal the mechanisms by which the symbolic order perpetuates the marginalisation of people with intellectual and developmental disabilities. However, there is a distinct lack of dialogue about how art, and art therapy in particular, serves as a form of ideological resistance, a tool for deconstructing and reconceptualising the social narratives that govern inclusion and exclusion. This gap provides fertile ground for research exploring the potential of art therapy for social change. The field of social work offers rich insights into the practicalities of supporting disabled people (Payne, 2014). The focus here is usually on individual and community interventions aimed at promoting well-being and social inclusion. However, the literature often overlooks art therapy as a transformative force beyond traditional therapeutic interventions, offering space for collective healing and empowerment. This oversight marks a critical gap, suggesting that research is needed to bridge the divide between social work practice and art therapy, testing their potential synergies in fostering more inclusive societies. In the field of special education, there has been a significant amount of research directed towards methods and practices that meet the diverse needs of learners with disabilities (Tomlinson, 1999). These studies often advocate for difference-adapted pedagogical innovations, but rarely question how art therapy can be integrated into educational settings as a means of enhancing learning, promoting emotional and social development, and challenging educational paradigms that often marginalise those who deviate from the norm. This literature, while broad in scope, has yet to explore the potential of art therapy to redefine educational practice, marking another important avenue of inquiry.

Art therapy emerges not only as a therapeutic intervention, but as a radical practice, a site of resistance to popular narratives that seek to define, limit and isolate. This exploration goes beyond tradition and ventures into areas where art therapy becomes a powerful tool for subverting the symbolic order of expression and potential. Key to the effectiveness of art therapy is its ability to provide a language that transcends speech, a medium through which the ineffable can be expressed, the ability to make the invisible visible. Research in the field continues to demonstrate how art therapy facilitates a unique form of communication for people with intellectual and developmental disabilities, enabling them to express complex emotions and thoughts that might otherwise be trapped within the confines of their internal world (Betts, 2006; Chilton, 2013). This type of expression is more than just the delivery of information. It is about creating a space where the subject can emerge in their most authentic form, challenging the symbolic identity imposed on them by the social matrix. Furthermore, the emotional expression facilitated by art therapy is not only cathartic but also transformative. Research has highlighted how art therapy supports emotional regulation, enhances self-esteem and fosters a deeper sense of self in this population (Hartz, & Thick, 2005; Malchiodi, 2007). Key to the effectiveness of art therapy is its ability to provide a language that transcends speech, a medium in which the ineffable can be expressed and the invisible made visible. Research in the field continues to demonstrate how art therapy facilitates a unique form of communication for people with intellectual and developmental disabilities, allowing them to express complex emotions and thoughts that might otherwise be trapped within the confines of their internal world. This form of expression is more than just the transmission of information. It is about creating a space where subjects can emerge in their most authentic form, challenging the symbolic identities imposed on them by the social matrix. These findings are significant not only for their therapeutic implications, but also for their ideological impact. In order to enable people with intellectual and developmental disabilities to navigate and express their emotional landscapes, art therapy acts as a form of ideological critique, challenging social norms that often equate certain characteristics with deficiency, silence, and invisibility. Cognitively, art therapy has been shown to stimulate cognitive development and facilitate learning in ways that traditional educational methods may not provide for these individuals with disabilities (Silver, 2001; Gussak, 2004). The process of creating art involves a variety of cognitive functions, including planning, problem solving and abstract thinking, thus providing a unique avenue for cognitive enrichment and development. This aspect of art therapy not only emphasises its therapeutic value, but also has the potential to disrupt educational paradigms that often fail to meet the diverse learning needs of children. By promoting cognitive development through creative expression, art therapy challenges the simplified understanding of intelligence and ability that underpins the educational discourse surrounding children. It is an act of resistance to the symbolic order that seeks to define and limit the lives of people with intellectual and developmental disabilities. While affirming the efficacy of art therapy in facilitating communication, emotional expression, and cognitive development, research in this area also hints at its broader potential to subvert narratives and make visible the subjectivity of those who are often marginalised. Society. In this sense, art therapy is not just about addressing disability; it is about problem solving. It is about affirming the integrity of human experience, challenging the social structures that limit it, and opening up new spaces for expression, understanding and radical inclusion.

Reflections on the theoretical framework

Barriers to an inclusive society are not just physical barriers or policy gaps; they are manifestations of deeper ideological issues. These barriers are encoded in the language we use to talk about disability, in the institutional structures that govern education and social services, and in the cultural narratives that shape our perceptions of normalcy and difference. They reflect a fundamental refusal to face reality – an irreducible and disturbing difference that challenges the illusory wholeness of the social organism. In its relentless pursuit of homogeneity and order, society denies its own inherent lack, the emptiness at its core. The inclusion of people with disabilities exposes this lack, revealing the contingency and fragility of the symbolic order. This exposure is not to be feared or avoided, but rather seen as a site of real social change. In order to address barriers to inclusion, we must take radical action to reconceptualise. We must question not only the structures of exclusion, but also the underlying assumptions that underpin our understanding of capacity, normality, and community. This requires a dialectical reversal that recognises that the problem of inclusion is not the integration of the Other into the existing social order, but the transformation of that order in response to the Other. It requires a society that is not only tolerant of difference, but constituted through difference, in which the diversity of human experience and ways of being is not only tolerated, but seen as essential to collective richness.

Critiquing interdisciplinary approaches to social inclusion through the prismatic lens of art therapy, we find ourselves on the cusp of a profound ideological scrutiny. This exploration is not just academic, it is scholarly. It is a radical incursion into the nature of social structures, guided by sociological insights, the empathetic scope of social work, and the bespoke interventions of special education, all of which converge within the realm of art therapy.

In the labyrinth of social inclusion, art therapy becomes a beacon of hope, a tangible expression of resistance to the dictates of social norms. Many examples emerge from the literature where art therapy grounded in sociological theory provides a critical lens through which we can see the systemic barriers faced by people with disabilities. For example, Bourdieu's concept of habitus allows us to see how social structures perpetuate inequality, even in spaces designed for therapeutic intervention. In this interdisciplinary dialogue, art therapy acts as a countervailing force, challenging the preconceived notions of competence and values that are often internalised by children with intellectual disabilities. From a social work perspective, art therapy is re-imagined as a practice of empathy and empowerment. Social workers with a tradition of advocating for social justice have made an interdisciplinary commitment to removing barriers to inclusion. They emphasise the importance of creating therapeutic spaces that not only acknowledge an individual's experience of marginalisation, but actively work to subvert it. This is not a passive process; it is a reactive process. It is an active engagement with personal narratives, utilising art as a medium to reclaim agency and voice. Special education's focus on individualised and adaptive learning strategies provides a key pedagogical framework for integrating art therapy into wider educational and social inclusion work. Here, the literature reveals a nuanced understanding of how art therapy can be tailored to meet the diverse learning needs of children and young people, promoting not only cognitive and emotional development but also social connection. This approach emphasises the potential for art therapy to transcend traditional educational boundaries to provide a more holistic and inclusive model of learning and interaction. The synthesis of these different disciplinary perspectives in the context of art therapy and social inclusion is now evident in the research and practice that supports an integrated approach. For example, interdisciplinary teams of sociologists, social workers, special educators, and art therapists have been shown to develop more holistic and nuanced interventions to meet the multifaceted needs of children with intellectual disabilities. These initiatives often appear at the margins of mainstream therapeutic and educational practice, highlighting the transformative potential of collaborative interdisciplinary endeavours to promote social inclusion.

Individual-based practice

Embarking on a journey to explore the role of art therapy in social inclusion, particularly for children with intellectual and developmental disabilities, required an approach that was both innovative and deeply reflective of the unique context in which this therapeutic practice is applied. My experience as an art teacher at a charity organisation in Xi'an, China, provided me with invaluable insights into the transformative potential of the arts that became the cornerstone of this research. This exploratory approach is rooted in a combination of experience and empirical data collection methods. Quantitative data collected through structured assessments were designed to measure the impact of art therapy sessions on specific outcomes, such as improved communication skills, emotional expression, and cognitive development in the children I treated. These data provide a foundation for understanding the broader efficacy of art therapy in a structured, measurable way. At the same time, qualitative data collection methods were used to capture the nuances of these children's experiences. Through interviews, participant observation, and analyses of artwork created during the therapy sessions, we delved into the subjective experiences of the participants. In particular, the children's artworks were not only creative outcomes, but were seen as communicative artefacts, expressing their inner worlds, their struggles, and their triumphs in social inclusion. My personal experience as an art teacher in Xi'an was crucial in synthesising the interdisciplinary approach in this study. Practical insights gained from working directly with children with disabilities informed the application of theoretical frameworks from sociology, social work and special education, ensuring that the research was grounded in real-world experience. The transformative changes observed in the children – increased self-expression, improved social skills, and greater emotional regulation – attest to the power of art therapy. These changes are not just anecdotal; they are factual. They are integrated into the fabric of the study and illustrate the efficacy of art therapy in promoting social inclusion. Based on direct experience and a rigorous interdisciplinary approach, this research methodology aims to make a significant contribution to understanding the role of art therapy in social inclusion. By combining quantitative and qualitative data analysis with personal insights from my teaching experience in Xi'an, this study highlights not only the efficacy of art therapy, but also the importance of creative expression as a means of empowerment and inclusion for children with disabilities. Through this work, we not only investigate the impact of art therapy, but also celebrate the profound changes it can catalyse in children's lives, paving the way for a more inclusive and compassionate society.

In essence, art therapy is a revolutionary act – a method through which the real, in all its traumatic, ineffable splendour, pierces the veil of symbolism and provides a voice for those marginalised by society. For the children, especially those I have encountered in my work with the Xi'an charity, this form of therapy goes beyond mere art-making; it becomes a language through which their unspoken traumas, desires, and dreams can be embodied, unencumbered by the constraints of conventional discourse. In the embodiment of social inclusion, where marginalised voices seek a stage in the great theatre of society, art therapy emerges not only as a means of intervention, but as a form of communication and expression. The role of art therapy in facilitating communication and expression cannot be underestimated. Children, especially those struggling to cope with intellectual and developmental challenges, often find themselves caught in a web of social expectations and restrictions that stifle their voices. However, art therapy is a form of hedonism – a form of enjoyment that breaks through symbolic constraints and allows children to express themselves in ways that words cannot capture. Against this backdrop, practical examples from my work in Xi'an illuminate the transformative potential of art therapy. Children who had been shrouded in silence found in art a medium to express their inner world. One particular case that stands out is that of a child who, through the process of creating abstract paintings, began to express his experience of isolation and his desire for connection and friendship. These colourful and emotive works of art not only serve as a form of personal catharsis, but also as a bridge to others, promoting deeper understanding and empathy among the community and peers. An interdisciplinary approach to enhancing social inclusion efforts through art therapy becomes essential. By integrating sociological perspectives that examine the structures of exclusion; social work that advocates for individual and community empowerment; and special education that aims to tailor learning to diverse needs, art therapy can be reconfigured as a powerful tool for social change. This interdisciplinary approach has not only theoretical but also profound practical implications. In Xi'an, collaborations between art therapists, social workers, educators, and sociologists have fostered the development of community-based art projects that not only provide therapeutic benefits for children, but also engage the broader community in dialogue about inclusion and diversity. These projects, ranging from public art exhibitions to collaborative murals, transcend individual therapeutic environments and transform public spaces into sites of inclusivity and collective expression.

The true measure of this interdisciplinary, art therapy-based approach to social inclusion is evident in its results. One poignant case study involved a group of children with developmental disabilities who participated in a collaborative art project. Over the course of several months, these children worked with peers, educators, and artists to create a large mural depicting their vision of a more inclusive world. The challenging process, which culminated in a public unveiling, drew the attention of the wider community and sparked a dialogue about the rights, abilities and artistic contributions of people with disabilities. Another example comes from a series of workshops designed to foster peer connections through art-making. Based on the principles of social work and special education, these workshops provided a structured yet flexible environment in which children could explore their identities, share their stories and build friendships. The artwork created during these sessions – from individual portraits to group narratives – is a testament to the children's resilience, creativity and inclusivity.

Supported by an interdisciplinary approach, art therapy is not only a therapeutic endeavour but also a profound act of ideological subversion. It challenges social norms that silence certain voices and render certain identities invisible. Practical examples from Xi'an, China, emphasise the potential of art therapy not only to facilitate communication and expression for children with disabilities, but also to reconfigure patterns of social inclusion. This radical approach in vision and implementation sees art therapy as a catalyst for a society that truly embraces diversity, not as a symbol of tolerance, but as a basis for collective existence.

Conclusion

Our research shows that art therapy is not only a channel for therapeutic expression, but also a battleground for society's structural reflection on itself. It becomes a powerful means through which children with intellectual and developmental disabilities can express their aspirations, fears, and dreams, opening up visible spaces in the social fabric that often keep them invisible. An interdisciplinary approach emphasises the need to dismantle traditional silos and promotes the integration of perspectives to address the complexities of social inclusion more holistically. Practitioners in the fields of art therapy, social work, and special education are encouraged to cultivate collaborative, interdisciplinary projects that draw on the unique contributions of each discipline. These initiatives should prioritise participatory approaches that place the voices and experiences of children with disabilities at the forefront and advocate for art therapy as a means of empowerment and advocacy. Policymakers must respond to the call to re-evaluate the educational and social service frameworks for children with disabilities. We advocate for policies that support the inclusion of art therapy in mainstream education curricula and social inclusion initiatives, ensuring that these practices are not simply marginalised as adjuncts, but are seen as central to the project of building an inclusive society. This research is more than an academic exercise; it is an urgent call to recognise and act on the transformative power of art therapy in promoting social inclusion. We have revealed the deep-rooted cognitive underpinnings that dominate societal perceptions of children with intellectual disabilities, challenging us to envision a more inclusive society where difference is seen as an essential aspect of human diversity, not a deficiency. Let us not shy away from the confrontations and contradictions that our exploration reveals. Instead, let us embrace such tensions as a source of creativity and potential for change. The path to more inclusive societies is fraught with ideological barriers and structural obstacles, but it is a path worth travelling with courage and conviction, because change is not only possible, it is imperative. We stand at a crossroads, and the choice before us is stark: whether to maintain the existing order of marginalisation and silence, or to embark on a radical programme of transformation that will re-imagine inclusivity in its broadest sense. This is our call to action – a call for educators, therapists, policy makers and all members of society to work together to build a world where every child, regardless of ability, is seen, heard and valued. A world where art therapy is not the exception, but the norm, a beacon to guide us into a future where inclusion is no longer a lofty ideal, but a practical reality.

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ABSTRACT

This research explores the positive role of art therapy and sociology in ensuring the social inclusion of children and young people with intellectual and developmental disabilities. It carefully integrates social work and special education perspectives, highlighting how creative expression as a key therapeutic tool, combined with art therapy based on sociological understanding, can enhance the emotional and cognitive development of children with intellectual and developmental disabilities. The study promotes interdisciplinary collaboration to develop interventions that meet the unique needs of this population. The approach explored in this research not only supports the immediate challenges, but also highlights the importance of recognising and nurturing the diverse abilities and potential of children and young people with intellectual and developmental disabilities, and the need for innovative, effective and sustainable social inclusion practices.

KEYWORDS

art therapy, social inclusion, artistic expression, communication styles, social work, education

Building Bridges, Not Walls: Addressing Intersectional Inequalities for Individuals with Intellectual Disabilities

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Think of a world where all children grow up in an inclusive environment regardless of origin or ability. Unfortunately, for many kids and young adults with intellectual or developmental disabilities, the dream is yet to be realized. As much as there have been some changes towards creating more integrated societies, we still have several stumbling blocks that some people face due to overlapping inequalities.

The concept of intersectionality, which was introduced by Kimberlé Crenshaw (1989), emphasizes how social categories such as race, gender, class, disability, and sexuality are interrelated and accumulated to affect an individual's experiences. When it comes to intellectual and developmental disabilities (IDD), intersectionality intensifies their problems, thereby magnifying their feelings of being left out as well as marginalized. IDD intersects with different factors like race, gender, socioeconomic status and geographical location, thus further marginalizing them from accessing rights, opportunities and resources. However, other identity markers such as race, gender, socioeconomic status, and geographical location intersecting with a disability will give rise to unique barriers which inhibit access to participation and social inclusion.

Equality and inclusiveness are two words in today's world that have regard for aspects like race, gender, socioeconomic status, and disability. This quest is based on human rights and social justice principles to acknowledge every person's inner worthiness. Nevertheless, there has been significant progress in this area over the years; however, ensuring equity remains an uphill task occasioned by continual intersectional inequalities. Moreover, recognizing diversity has brought power relations from multiple factors, including privilege and oppression, into light. Consequently, despite some improvements in several spheres of society, disparities still exist, thus impeding fairness and all-inclusive societies. Therefore, children and young people with intellectual and developmental disabilities (IDD) encounter real challenges to social inclusion in areas such as education, health services provision, employment opportunities, and relationships within societies, among others. Meeting such inequalities requires understanding these complex intersections that shape their encounters, which fosters a sense of belongingness and strengthens social harmony.

However, addressing intersectional inequalities is a complex task. It involves a thorough and wholehearted understanding of the intricate and changing interplay among various aspects of personality and how they shape lives lived by intellectually challenged persons. In addition, it necessitates collective action from different quarters like health, education, social work, law, policy advocacy, community development and more. These sectors must, therefore, work together in developing and implementing effective interventions to address the diverse range of needs faced by IDD individuals from different backgrounds. Building inclusive societies in which all people can participate and contribute would be unattainable if discrimination were seen as separate from other forms of disadvantageous practices that operate on intersecting axes such as race, gender or class. Policymakers should identify these intersections so that practitioners, together with communities, are able to come up with specific policies as well as interventions meant for IDD individuals who come from diverse backgrounds.

Intersectionality reveals the cumulative discrimination and disadvantage experienced by those who have IDD and belong to marginalized groups. For instance, women with IDD are at higher risk for violence and abuse due to disability and gender intersections. Also, it means that LGBTQ+ people with IDD experience discrimination both in the disability community as well as the LGBTQ+ community, thus requiring support systems that cater for their unique challenges.

In this paper, we explore intersectional inequalities experienced by individuals with IDD by examining the impact of factors such as race, gender, socioeconomic status, and geographical location. An emphasis is placed on interdisciplinary collaboration as a strategy for addressing these inequalities, whereby underlying principles and practices are discussed alongside case studies that show how they can be helpful. The paper aims to contribute towards more inclusive societies where people with IDD can participate entirely rather than being excluded from mainstream society by understanding intersectionality and taking an interdisciplinary approach. The discussion begins by placing this issue within the broader context of striving for equality and inclusivity in modern societies; it then looks at intersectionality and its increased vulnerability when multiple identities exist together. The paper argues that interdisciplinary collaboration is essential for effective disease management, integrating and sharing knowledge, methods and perspectives from different disciplines. It provides examples and recommendations for implementing this approach, provides a theoretical framework, reviews empirical evidence, discusses best practices, and draws implications and directions for future research.

Understanding Intersectionality and its Implications for Individuals with IDD

Intersectionality, first brought up by Kimberlé Crenshaw, illustrates how different social and political identities mingle to construct a person's experiences of advantage or disadvantage. Kimberly Crenshaw's concept explains that intersectional identities create unique types of discrimination and marginalization. Intersectionality suggests that IDD intersects with other social indicators to increase the complexities faced by this group (Shakespeare, & Watson, 2001).

Intersectionality and Disability: Examining the Unique Challenges Faced by Individuals with IDD

Ableism, together with sexism, may increase women with IDD's vulnerability to violence, while queer individuals with IDD are often subjected to double marginalization within both disability and LGBTQ+ communities (Kuvalanka et al., 2014).

Intersecting Factors: Race, Gender, Socioeconomic Status, and Geographical Location

For people living with intellectual disabilities, there is a mixture of things like racism and gender inequality, amongst others, which make their challenges more complex.

This can be explained by the fact that minority racial or ethnic backgrounds may suffer various disparities in healthcare access, education and job opportunities because of intertwined discrimination (Krahn et al., 2015). Likewise, those from low-income families or rural settings could experience more challenges when trying to get assistance or community services (Thomas, & Woods, 2003).

Impact of Intersectionality on Different Groups:

The nature of intersectional inequalities is multifaceted and, therefore, calls for an interdisciplinary approach beyond traditional disciplinary boundaries to meet the diverse needs of people with intellectual disabilities (IDs) (Thomas, & Watson, 2002). The complexity of these inequalities suggests that one perspective alone cannot be relied upon but instead a need for interdisciplinary collaboration towards comprehensive support and advocacy programs (Oliver, 1990).

It is through working together from different fields that a holistic understanding of individuals' needs can be achieved, including understanding how several factors contribute to inequality and exclusion. Nonetheless, this work often involves bringing ideas from different disciplines to improve interventions that acknowledge the intersectionality characterizing IDD discrimination and disadvantage faced by these individuals (Thomas, & Woods, 2003).

Besides, the promotion of a strengths-based perspective is a significant result of interdisciplinary teams that use each member's unique perspectives and expertise to enhance self-determination and choice for people with intellectual disabilities (Biklen, & Bogdan, 2007).

Manifestations of Intersectionality in Specific Groups with IDD

Analysis of intersectional identities from different groups within the IDD community uncovers peculiar problems generated by disability interacting with other social identities. There are three particular categories: girls having IDD, LGBTQ+ youth having IDD, as well as children belonging to IDD minority groups who undergo distinct experiences on account of multiple factors interconnecting their lives.

Girls with IDD:

Girls with IDD face compounded challenges stemming from the intersection of gender and disability. The research showed that they suffer more frequently from such problems as sexual abuse, exploitation or reproductive health inequalities (Valenti-Hein, & Schwartz, 1995). For instance, a study found that girls with IDD are significantly more likely to experience sexual abuse than their counterparts without disabilities.

Personal stories also elaborate on these experiences. Sarah is a 16-year-old girl who has Down syndrome, and she shared her experiences of being bullied and harassed because of her disability and gender identity. Despite efforts to seek assistance from the school authorities, Sarah felt like an outsider, emphasizing the urgent need for broad intervention measures.

LGBTQ+ Youth with IDD:

LGBTQ+ youth with IDD face complex forms of discrimination based on their sexual orientation, gender identity, and disability status. They are reportedly at a higher risk of bullying, rejection and mental health disparities compared to other heterosexuals or cis-gendered individuals with IDD (Perrin et al., 2018). For instance, there was a survey that revealed LGBTQ+ youth with IDD were more likely to be lonely, anxious or depressed. On top of that fact, these young people may still face discrimination as well as exclusion from both the disability community and the larger LGBTQ+ community itself. Alex is an autistic young person who identifies himself as transgender; he expressed his feelings regarding being misunderstood within LGBTQ+ spaces due to his autism. He, likewise, met challenges in finding LGBTQ+ – affirming support services for people with IDD.

Children with IDD from Minority Backgrounds:

The intersection of race and ethnicity with disability gives rise to particular challenges faced by children with IDD from minority backgrounds. According to research, they face disparities in access to healthcare, education opportunities and community support as compared to white individuals with IDD (Durón et al., 2020). For instance, there is research that showed that Latinx kids who have IDD are not likely to receive early intervention services or specialized health care.

Moreover, minority background children may also suffer cultural stigma and language obstacles that hinder their access to culturally competent supports and services. Personal narratives have revealed families' experiences navigating these difficulties. Maria narrated the problems she went through when trying to find culturally appropriate resources for her son's medical treatment. The specific vulnerabilities of girls with IDD, LGBTQ+ youth with IDD, and those from minority backgrounds show how intersectional identities bring about discrimination experiences among them.

Critical Principles of Interdisciplinary Practice

Holistic Assessment: Understanding the Full Spectrum of Needs and Experiences

An interdisciplinary approach can be used to address intersectionality problems faced by people living with IDD. For example, incorporating principles of collaboration into a project and working as a team brings together expertise from various fields, leading to an innovative solution for social inclusion and equity among individuals with IDD. The interdisciplinary practice also calls for an emphasis on a holistic assessment of patients' needs because such an approach is vital in appreciating the complexity behind IDD experiences.

Smith & Zigmond (2018) pointed out that a holistic assessment provides a holistic and panoramic lens into their strengths, difficulties, choices, and dreams by eliciting insights from many sources, such as individuals, their families, caregivers and professionals from diverse fields. In this method of approach, individuals with IDD are seen to have multidimensional characteristics that are believed to be affected by several things, including physicality, cognition, emotions and socialization, among others (Guralnick, 2015).

Holistic assessments offer interdisciplinary teams an opportunity to understand how various intersecting factors result in inequality and exclusion for some individuals. Such profound understanding enables service providers to customize intervention plans that meet the unique requirements of each person's condition, thus promoting high levels of inclusiveness towards empowerment (Turnbull, & Turnbull, 2018). Besides that, Guralnick (2015) indicated that holistic assessment encourages teamwork between members who can share information about their clients, fostering a shared support system.

Collaborative Goal-Setting: Empowering Individuals with IDD in Decision-Making

Another fundamental tenet of interdisciplinary practice is collaborative goal-setting, which emphasizes the importance of the involvement of people with IDD in decisions concerning their lives. This strategy recognizes individuals with intellectual and developmental disabilities as experts in their experiences and preferences, respecting their right to self-determination and autonomy (Wehmeyer, & Kelchner, 2016). Collaborative goal-setting entails facilitating the involvement of persons with IDD, their family members, and social support systems in identifying things they want to achieve in life (Abery et al., 2020). Interdisciplinary teams ensure that interventions and supports are aligned with values, preferences, and aspirations by involving individuals with IDD in goal-setting procedures (Stark, & Bruscia, 2013). This promotes a sense of ownership and agency, which enhances motivation, engagement, and satisfaction with the services received by an individual (Rosenberg et al., 2015). Moreover, collaborative goal-setting facilitates trust between people living with IDD and those providing support, including fostering good communication between team members during the intervention (Lorenz et al., 2014).

Cross-Disciplinary Training: Building Competencies and Fostering Collaboration

Promoting interdisciplinary collaboration in supporting individuals with IDD requires cross-disciplinary training to build the relevant competencies for adequate service provision. To achieve this, Gilmore and Campbell (2015) recommend bringing together professionals from various fields to interact with one another and gain insights into their perspectives, practices, and methods. Interdisciplinary training will promote respect among team members and foster a culture of collaboration and teamwork (Dewey et al., 2018). By enabling experts to gain competencies from different disciplines, interdisciplinary teams can meet the diverse needs of people experiencing IDD (McDougall et al., 2020). This includes developing skills such as effective communication, conflict resolution, shared decision-making, and learning about the social determinants of health that shape people's experiences of inequality and exclusion (Chadwick, & Broussard, 2018). Furthermore, a cross-disciplinary training approach encourages innovation among professionals in promoting creativity, thus leading to more comprehensive and effective interventions (Hancock et al., 2017).

Implementing an Interdisciplinary Approach: Case Studies

In this part, we will look at real-life examples showing how an interdisciplinary approach can address intersectional inequalities for individuals with intellectual and developmental disabilities (IDD). Broadly, we explore through case studies the support children with IDD receive from different backgrounds in education systems, collaborative interventions within school environments and community-based drives that enhance inclusiveness.

CASE STUDY 1: Holistic Support for a Child with IDD from a Diverse Background

In a recent study by Smith et al. (2023), they not only provided holistic care to one child but also used some other multidisciplinary teams such as teachers, social workers, therapists and community supporters to ensure holistic care is received by the child suffering from IDD whose cultural background is diverse. By recognizing that its intersectionality involves various forms of marginalization like race, ethnicity, and disability, the team embraced culturally responsive assessment and intervention. The analysis was meant to consider all aspects of this child's culture. This means that family dynamics, linguistic background based on ethnicity, and assessment of available community resources were part of this assessment. These plans were developed through partnerships with families where collaboration between family members and the child was critical in formulating goals for these programs. In addition to incorporating life experiences within their cultural context, the interdisciplinary team harnessed local solutions, including indigenous knowledge systems, to realize tailored interventions, leading to improved wellness and academic outcomes for affected children.

CASE STUDY 2: Collaborative Intervention to Address Intersectional Inequalities in Educational Settings:

Another case study reported by Johnson and Garcia (2022) had an interdisciplinary team of educators, psychologists and disability advocates engaging in a collaborative effort to address intersectional inequalities experienced by students with IDD in an educational setting. The team used inclusive education and social justice as foundations for developing intervention approaches to promote support and inclusivity within the learning environment. The interventions involved formulating individualized education plans (IEPs) that recognized the various identities intersecting amongst students with IDD, including those coming from marginalized racial, ethnic or socioeconomic backgrounds. This included developing individualized education plans (IEPs) based on multiple intersectional identities and diverse needs of children with IDD from racially minoritized communities, ethnic backgrounds or lower socioeconomic classes. Through ongoing collaboration and professional development, the team implemented evidence-based practices such as differentiated instruction, universal design for learning (UDL), and positive behavioural supports for all students' academic achievement and social-emotional development. However, by removing systemic barriers and promoting inclusionary activities, this interdisciplinary group achieved the desired goal of widening access to quality education for these pupils' disabilities.

Challenges and Considerations in Interdisciplinary Collaboration

Interdisciplinary collaboration is a potential for addressing intersectional inequalities and promoting social inclusion for individuals with intellectual and developmental disabilities (IDD). However, there are several challenges and considerations to ensure the effectiveness and sustainability of such collaborative efforts.

Barriers to Effective Collaboration: Addressing Communication and Coordination Challenges

Clear communication and seamless coordination among team members from diverse professions lay the foundation of effective interdisciplinary collaboration (Holland, & Reardon, 2017). Nevertheless, there could be some barriers to communication, including differences in jargon, terminology or communication styles that can hamper good collaboration (Cummings, & Worley, 2020). Besides, the geographical dispersion of team members may pose challenges to coordination and information sharing, making it more complex (Lewin et al., 2017).

To address these communication and coordination challenges, interdisciplinary teams need to focus on setting up clear lines of communication, encouraging open discussions, and fostering a culture of teamwork where everyone respects each other's opinions (Bridges et al., 2011). Effective sharing of information and decision-making processes can be facilitated through regular meetings conducted by the team and structured communications protocol supported by the use of technology like collaborative technology platforms (Baxter et al., 2015). Team members should also be trained in communication skills and conflict-resolution approaches to strengthen interpersonal relationships and support productive collaboration (Baldwin, & Ford, 1988).

Overcoming Bias and Stereotypes: Promoting Cultural Competence and Sensitivity

The racial biases and stereotypes built on their skin colour, origin, sex, or disability can shape the attitudes and actions within interdisciplinary teams (Sue et al., 2019). Moreover, such biases manifest themselves in differential treatment, assumptions about the abilities of individuals or their needs, and microaggressions that erode trustworthiness and cooperation among teammates (Cohen et al., 2020). Lastly, a lack of cultural competence and appreciation for different viewpoints may contribute to disparities in the provision of services, perpetuating existing inequalities (Sue, 2010).

Training and education are necessary to enhance interdisciplinary teams' cultural competency (Bhugra, & Becker, 2005). Awareness programs should expose unconscious bias and challenge stereotypes while developing cross-cultural communication skills and empathy (Hawkins et al., 2016). Also, allowing various outlooks to be heard and respected within a team creates an inclusive culture that recognizes diversity (Salas et al., 2012).

Resource Allocation: Addressing Resource Disparities to Ensure Equitable Access to Support Services

Interdisciplinary collaboration is challenging due to resource disparities that arise mainly from financial limitations, low staffing and infrastructure (Atun et al., 2015). It is common for these inequalities to cause inequitable delivery of support services where disadvantaged communities have problems accessing primary resources and interventions (Barnett, & Whiteside, 2002). Consequently, differences in priorities and limited resources may create conflicts amongst interdisciplinary teams, undermining their ability to effectively address intersectional inequalities (Bower et al., 2018).

Thus, reducing gaps between resource availability across different regions will encompass initiatives such as advocacy, policy reform and strategic allocation of available resources (Hudson et al., 2005). Multidisciplinary groups can help push for more funding, among others, towards IDD services supporting individuals from marginalized areas with low earning capacity or impoverishment due to institutional reasons like racism and inadequate policies that hinder their social inclusion into various societies (Atun et al., 2013). Furthermore, existing resources may be better utilized by working collaboratively through community organizations and governmental agencies to bring about social change, promoting equality and enhancing social inclusion (Burgess et al., 2016).

Future Directions and Recommendations

For the social inclusion of children and young persons with intellectual and developmental disabilities (IDD), it is essential that future directions be charted, and interdisciplinary approaches should be built upon. Research gaps will be addressed, practice recommendations will be made, and policy changes will be advocated for by different players working collaboratively to create environments that promote equity, justice, and inclusion for people with IDD.

Research Agenda: Addressing Intersectional Inequalities

Moving forward, research must prioritize addressing intersectional inequalities experienced by individuals with IDD, including as they relate to disability, race, ethnicity, gender or socioeconomic status (Jones, 2020; Krahn et al., 2022). Longitudinal studies that track the impact of interventions and programs focused on the social inclusion of developmentally disabled youth need to include long-term outcomes (Lindsay et al., 2023). Furthermore, it is necessary to investigate and evaluate culturally responsive approaches in different communities for enhancing social inclusion (Hernandez et al., 2021). Furthermore, there should be an investigation into how technology can promote social inclusion while ensuring accessibility issues are dealt with efficiently across a wide range of population groups (Petty et al., 2022).

Practice Recommendations: Enhancing Interdisciplinary Collaboration

Practitioners act as central figures in implementing inclusive practices and support for interdisciplinary collaboration. To improve provision for young people and children with IDD, the practitioners should:

1. **Promote Cultural Competence:** Practitioners need cultural competence training to understand better the diverse needs and experiences of individuals with IDD from different cultures (Gammeltoft, 2017).
2. **Enable Person-Centered Planning:** Embracing approaches that place the person at the centre of planning allows persons with IDD to participate actively in decision-making concerning their care or support (Bogart, & Dunn, 2019).
3. **Build Collaborative Partnerships:** Developing strong collaborative partnerships between families, educators, healthcare providers, and community organizations enhances the continuity and effectiveness of support for individuals with IDD (Turnbull et al., 2020).
4. **Use Technology Wisely:** Technology–based interventions like telehealth and mobile applications help overcome geographical barriers, expanding access to support services for individuals with IDD (Ragusa et al., 2021).

Policy Implications: Advocating for Systemic Changes

Policy changes are essential for creating systemic conditions that support the social inclusion of individuals with IDD. Advocacy efforts should focus on:

1. **To ensure equal access to education**, policies must foster inclusion practices and provide enough resources and support services needed by students with learning disabilities in mainstream schools (United Nations, 2019).
2. **Inclusive Funding Models:** Foster funding models that enhance inclusive education and personalized community-based services for individuals (European Commission, 2021).
3. **Public Awareness Campaigns:** Allocate volumes of capital for public awareness campaigns to dispel opposing views on people with IDD while encouraging positive attitudes towards them (Special Olympics, 2023).
4. **International Collaboration:** Promote cooperation and exchange of experiences to address global challenges and best practices in promoting social inclusion of children and young people living with IDD (World Health Organization, WHO, 2023).

Conclusion

Recapitulation: The Significance of Interdisciplinary Approaches in Addressing Intersectional Inequalities

In this paper, we examined the intricate intersectional inequalities experienced by individuals with intellectual and developmental disabilities. We have emphasized how interdisciplinary collaboration is crucial to addressing these problems.

The concept of intersectionality, as defined by Kimberlé Crenshaw (1989), stresses the relatedness between different social identities and how these connections affect a person's social standing or lack thereof. The interlocking systems of oppression that are race, gender, class, ability and more all affect people differently. This means that for persons with IDD who may be confronted by both exclusion and discrimination, the comprehensive approaches that support their social inclusion should necessarily be multidimensional (Thomas, & Watson, 2002).

The paper suggests interdisciplinary collaboration as an effective way to address the complex needs of individuals with IDD. It brings together professionals from divergent fields, such as psychology, social work, education, healthcare and advocacy, among others, into one care team, ensuring collective support that takes note of a range of combined factors resulting in inequality and disadvantage for the individuals (Biklen, & Burke, 2006). Thus, practitioners can form purposeful interventions meant for individuals with IDD with diverse cultural backgrounds to promote their autonomy and well-being (Biklen, & Bogdan, 2007).

Call to Action: Fostering Collaboration and Advocacy to Create Inclusive Societies for All Individuals with IDD

As we end this paper, we must recognize that our work will not stop here. Although interdisciplinary approaches are seen as having the potential to address intersectional inequalities for people with intellectual and developmental disabilities, collaborations and advocacies are indispensable at every level of society. While working with individuals with IDD, professionals should still strive to embrace interdisciplinarity so that various perspectives can be incorporated in efforts towards inclusivity (Thomas, 1999). Additionally, social change is possible only when systemic changes are advocated through policy formulation supported by policies such as those addressing societal hindrances like unfriendly environments, exclusions, and inadequate support (Shakespeare, & Watson, 2001). It is also essential that intersectional inequalities faced by individuals with IDD be made known to all people and they be allowed to make their own decisions about their rights in order to reduce the problem (Oliver, 1990).

Looking Ahead: Commitment to Continued Efforts in Promoting Equality, Inclusivity, and Social Justice

Looking forward, let us commit ourselves to continuous campaigns for equality, inclusion, and social justice for persons with IDD. To attend to the complex and intersecting problems they experience, perpetual teamwork, lobbying and creativity are needed. This will enable us to work together across disciplines, sectors and communities to build an inclusive society, allowing individuals, irrespective of intersections, to live with dignity, respect and fulfilment.

Expanding Employment Opportunities: Policy initiatives should encourage employers to create workplaces that are fully integrative by making reasonable adjustments for individuals who have IDD in order for them to participate in the labour market (Rosenberg, & Rosenberg, 2020).

Protecting Rights and Dignity: Policies should respect the rights of persons with IDD while protecting their dignity by ensuring autonomy, self-determination, access to justice, and legal representation (United Nations, 2006).

At times, policy-level advocacy for systemic changes can make specific environments facilitate social inclusion into a society that enhances the full participation of IDD individuals. In conclusion, advancing the social inclusion of children and young people with intellectual disabilities requires a concerted effort from researchers, practitioners, policymakers and advocates. The vision of an all-inclusive society can only be achieved if research priorities are addressed, inclusive practices are implemented, and policy changes are advocated among the stakeholders. For a start, addressing intersectional inequalities for individuals with intellectual and developmental disabilities (IDD) cannot be separated from concerted efforts across research, practice, and policy domains. This range includes the identification of gaps, prioritization of strategies, and advocacy for systemic changes to ensure equality and justice among IDD individuals from diverse backgrounds (Aldridge et al., 2018).

Research Agenda: Identifying Gaps and Priorities in Addressing Intersectional Inequalities for Individuals with IDD

Research plays a vital role in informing evidence-based practices and policies aimed at addressing intersectional inequalities for individuals with IDD. To guide future research endeavours, it is essential to identify critical gaps and priorities in the field:

1. **Longitudinal Studies:** Carry out longitudinal studies that would explore lives bearing people suffering from IDD have different ethnic affiliations (Mavragani et al., 2020).
2. **Intersectional Perspectives:** Designing research based on intersectionality ideas enables researchers to capture life experiences in people with IDD on various dimensions like race, gender, sexuality, and socioeconomic socioeconomic class (Burgess-Proctor, 2006).
3. **Participatory Research:** Involving people living with IDD in active participation and co-researcher roles where their perspectives will guide the whole investigation, and their voices will be heard through the process (Goodley, & Runswick-Cole, 2016).
4. **Comparative Analyses:** Within several cultural contexts, comparisons should be made to appreciate the manifestations and counter-interventions in intersectional inequalities across different communities and systems (Hall, & Greene, 2016).

Practice Recommendations: Strategies for Enhancing Interdisciplinary Collaboration and Inclusive Support

Effective practice is contingent upon collaborative efforts that leverage interdisciplinary expertise to provide inclusive support for individuals with IDD. To enhance interdisciplinary collaboration and promote inclusive practices, the following strategies are recommended:

1. **Professional Development:** The training programs provided by other fields should be adopted and schedules for offering such courses drawn out to enhance the competence of practitioners in addressing intersectional inequalities and promoting inclusive practices (National Center on Disability and Journalism, 2015).
2. **Interagency Collaboration:** Partnership among agencies that serve people with IDD is essential as a means of sharing information, pooling resources and coordinating services (Matson et al., 2017).
3. **Culturally Responsive Practices:** It is essential that within interdisciplinary teams, cultural competence training be embedded so that they can have culturally responsive practices that respects the diverse backgrounds and identities of individuals with IDD (Ballan, & Freyer, 2012).
4. **Client-Centered Approaches:** These approaches are characterized by individual's preferences, strengths, and aspirations enable them to participate actively in decision-making. Such moves empower them as autonomous actors who can choose paths or set objectives (Nisbet, & Houghton, 2019).

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ABSTRACT

In contemporary societies, pursuing equality and inclusivity is a paramount objective. However, intersectional inequalities often impede achieving these ideals, which impact various facets of identity. Among those most affected are individuals with intellectual and developmental disabilities (IDD), whose experiences of exclusion are compounded by intersecting factors such as race, gender, socioeconomic status, and geographical location.

Addressing intersectional inequalities is not merely a matter of justice; it is essential for building inclusive societies where everyone can participate and contribute. By recognizing the intersecting nature of discrimination and disadvantage, policymakers, practitioners, and communities can develop targeted interventions that address the specific needs and challenges faced by individuals with IDD from diverse backgrounds.

The paper underscores the heightened vulnerability faced by individuals with IDD harbouring intersecting identities, highlighting examples like increased risk of violence and abuse for women with IDD and discrimination within both disability and LGBTQ+ communities for LGBTQ+ individuals with IDD.

KEYWORDS

intersectional inequalities, intellectual disabilities, inclusive societies, exclusion, race, gender, socioeconomic status

The Right to "Legalize" Love? Reflections on the Possibility of Getting Married for People with Intellectual Disabilities

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Introductory remarks

At the end of 2022 the media in Poland reported the death of Tommy Pilingow. This character is probably not widely known. It turns out, however, that the story of this man could become material worth attention for many people. This man was a person diagnosed with Down Syndrome. It is worth noting that his wife Maryanne (they married in 1995) was also born with the genetic disorder mentioned here. The couple was the first British marriage between people with Down Syndrome. These people met in the early 1990s: they lived together in one of the British nursing homes. (Onet material, online) You can easily find wedding photos of these people on the Internet. Their marriage lasted almost thirty years.

It is also worth referring to another example here. At the end of September 2021 the premiere of the film "Sonata" took place in Polish cinemas. This film describes the story of Grzegorz Płonka. It is a production based on facts presenting the life of a boy who was suspected of having intellectual disabilities and developmental disorders on the autism spectrum. As it turned out, the boy was primarily experiencing severe hearing impairment. This condition negatively affected the young man's daily developmental functioning. Providing Grzegorz with a hearing aid tailored to his needs completely changed his life. Thanks to this change, he began to enter interpersonal relationships more and more confidently. In the film, we can see this young man's mother talking to him about the structure of the male body. The woman was aware that her son might enter into emotional (and over time also sexual) relationships with other people. In one of the most important threads of this film, we see that Grzegorz began to get emotionally close to a young girl. It turns out that the woman was undergoing psychiatric treatment: she was diagnosed with paranoid schizophrenia (See Pilacińska, 2022, online).

By following similar stories, one may ask several important questions: Were people diagnosed with Down syndrome in childhood aware of the importance and importance of their marital decision? Wasn't intellectual disability, in the court's opinion, a significant obstacle to marriage? In the context of the second example, it is worth noting that the emerging feelings between a young man and a young woman could be difficult to formally finalize. In other words, if these people wanted to get married, it would turn out that they did not have such a right. The Polish Family and Guardianship Code introduces a ban in this respect, in relation to people diagnosed with intellectual disability or mental illness. Only a separate consent of the court may allow such action. Does this mean that Polish law openly discriminates against a certain group of people? Perhaps Polish regulations are "precautionary" to some extent? Perhaps it is necessary to recognize that the law responsibly protects society against specific threats? But are we able to locate and define these dangers?

The text below aims to attempt to answer these questions. This action will be taken based on document analysis, known especially in the sociology of law. This is about examining the content of one of the judgments of the Polish Constitutional Tribunal. The court cited here commented on the compliance with the Polish Constitution of the so-called a "relative ban on marriage" applicable to both people suffering from mental illnesses and intellectual disabilities. The last of the key issues mentioned here will be the focus of attention in the discussion part. This discussion will be based on an attempt to indicate the unique meaning of marriage. Moreover, the author will try to locate important social concerns that are expressed when discussing marriage concluded by people with intellectual disabilities. This activity – similarly to the introduction – will be carried out by pointing out two examples.

Dispute over the possibility of marrying

According to Article 12. § 1 of the Polish Family and Guardianship Code (KRiO), "A person suffering from a mental illness or mental retardation cannot enter into marriage. However, if the state of health or mind of such a person does not threaten the marriage or the health of future offspring and if the person has not been completely incapacitated, the court may allow him to enter into marriage" (Act, 1964). Further in this provision it is added that "Annulment of marriage with either spouse may demand due to mental illness or mental retardation of one of the spouses. As we read in § 3: A marriage cannot be annulled due to the mental illness of one of the spouses after the illness has ceased" (Act, 1964). This provision has been criticized for a long time, in particular by the circles of people with disabilities and their relatives. It was emphasized that taking away the competence to enter into marriage is an example of discrimination. It was also pointed out that this state of affairs was inconsistent with the content of the Convention on the Rights of Persons with Disabilities, which in Art. 23(1), states that "States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, in such a way as to ensure: (a) recognition of the right of all disabled persons who are of marriageable age, to marry and to found a family, on the basis of the freely expressed and full consent of the future spouses" (Convention, 2012).

The Polish Ombudsman (RPO), Adam Bodnar (2015–2021), fully shared the arguments presented by the cited Convention. The official cited here decided to challenge the content of Art. 12 KRiO to the Polish Constitutional Tribunal (TK).

As stated in the announcement of the Office of the Commissioner for Human Rights, "The Ombudsman claims that the marriage ban covering persons suffering from mental illness or mental retardation violates the principle of dignity" (Document 2016, online). It was added that this position "results from the fact that undoubtedly society, a person who, by definition, cannot, in the light of applicable law, establish a model family based on marriage is treated as an inferior person" (Document 2016, online, see also Świtaj, 2005, pp. 137–144). The application in question was supplemented with observations resulting from the practice of working with adults with intellectual disabilities. The communication and the application to the Constitutional Tribunal emphasized that: "...in the opinion of the Commissioner for Human Rights, the challenged regulation does not meet the proportionality criterion, because the marriage ban is not able to prevent people suffering from the above-mentioned mental dysfunctions from having children. These people enjoy sexual freedom, and therefore, their children will be born in a de facto union, and not in a legally protected marriage" (Document 2016, online, see also Kurowski, 2014, p. 176). At the end of November 2016 indicated in the official announcement: "The Constitutional Tribunal ruled that Art. 12 § 1 and 2 of the Act of February 25, 1964 – Family and Guardianship Code is consistent with the principle of specificity of legal provisions resulting from Art. 2 of the constitution, from art. 30 and Art. 47 in connection with Art. 31 section 3 of the constitution. The ruling was unanimous. The Constitutional Tribunal determined that the archaic terms «mental retardation» and «mental illness» referred to in Art. 12 of the Family and Guardianship Code (...), are identified in the doctrine and case law with the current concepts of «mental retardation» and «psychotic disorders», appearing in the Mental Health Protection Act, which in turn do not raise any doubts in principle." It was further added that: "Art. 12 § 1 and 2 of the Family and Guardianship Code therefore, it does not raise any interpretation problems. Any court findings regarding the meaning of the above concepts must be based on and preceded by seeking the opinion of experts in the field of specialist knowledge, namely psychiatry. These concepts are therefore given a meaning that reflects contemporary knowledge in the field of medicine" (Judgment of the Constitutional Tribunal, 2016).

The Polish Tribunal pointed out that the concepts of "mental illness" and "mental retardation" "are identified in the doctrine and case law with the current concepts of «mental retardation» and «psychotic disorders», appearing in the Act on mental health protection" (Judgment of the Constitutional Tribunal, 2016). It is difficult to agree with this position at this point. The first of the concepts indicated here is widely and loudly criticized by Polish psychiatrists. Experts point out that this phrase contributes to the stigmatization of people with mental disorders. It is further recalled that this term is not used by international standards for diseases and disorders (Pużyński, 2015, pp. 136–138). Referring to the concept of "mental retardation" that interests us, it is surprising to note that the Constitutional Tribunal did not present any critical voice on this issue. This is a clear indication that similar vocabulary harms and offends people declaring intellectual disability. Monika Zima-Parjaszewska rightly points out in this context that "mental retardation is neither a disease, nor a syndrome, nor a symptom, it is a state of disability, revealed in the individual's behaviour, and there are many causes of this state." This condition also represents mild, rather than profound, disturbances in a person's intellectual functioning. We are talking here about disorders that arose during the developmental period, not when a given person functioned independently as an adult. Terms such as "mental impairment" and "mental retardation" are not synonyms. The former is much broader (Zima-Parjaszewska, on-line, 5).

However, it should be noted here that when analysing the content of Art. 12 pairs 1 and 2 KRiO, we can experience important observations.

First, this provision has existed unchanged for over fifty years (Romaniuk, 2012, pp. 244–245). Secondly, it is necessary to note (which is pointed out both in the literature on the subject and in court practice) that the purpose of its existence and maintenance are the principles of family law indicating the need to protect the family, as well as potentially appearing in her offspring. There are opinions that point out that the basis for such actions is not the fear of the hereditary nature of intellectual disability, but the assumption that a person who has the type of disorder indicated here will not be able to responsibly assume marital and parental responsibilities (Ignatowicz, & Mazur, 2005, p. 102; Supreme Court Judgment, 1978; Andrzejewski, 1999, pp. 30–31).

Remaining in this area of considerations, it should be emphasized that Polish law does not contain any mention of the marriage ban applicable to other groups, e.g. patients experiencing mental disorders. Yes, the ban on marrying applies to incapacitated people. This situation may concern, for example, people struggling with addiction to psychoactive substances and alcohol. In the context discussed here, Anna Romaniuk points out that in this situation, the addicted person does not have to ask for the consent of the family court before getting married. She experiences mental disorders, which are not, however, a mental illness or intellectual disability (Romaniuk, 2012, p. 144). A patient who was diagnosed with autism spectrum developmental disorders in childhood (a person functioning within the intellectual norm) may also be in a similar situation. Also in his situation there is no need to ask the court for consent. Summarizing the above part of the considerations, we can come to the conclusion that a situation is likely in which, for example, people addicted to alcohol or people experiencing severe anxiety or neurotic disorders will retain the possibility of getting married. As emphasized in the case of intellectually disabled people who want to get married, there is a concern about the possibility of assuming certain responsibilities. It is surprising that the Polish Family Code is silent about the persons mentioned here who also experience mental disorders. The state of non-psychotic disorders they experience may have a very negative impact on the developing marital and family relationship (Ignatowicz, & Mazur, 2005, p. 104).

Analysing the content of the judgment upholding the "relative ban on marriage" regarding, for example, people with intellectual disabilities, it is difficult to fully understand this sentence of the Polish constitutional court: "The Constitutional Tribunal assumed that maintaining the relative ban on marriage for persons suffering from psychotic disorders or mental retardation, provided for in Art. 12 § 1 of the Family and Guardianship Code may be considered necessary from the point of view of protecting marriage and the family based on it, as well as the best interests of the child." (Judgment of the Constitutional Tribunal). A similar position in this respect was presented years ago by the Polish Supreme Court. As noted in the judgment of December 29, 1978 "Contained in Art. 12 pairs 1 K.R.O. the concept of «threat to the health of future offspring» should be understood in the sense that it concerns not only the issue of the possibility of transmitting a mental illness to possible offspring, but also the issue of whether the mental condition of a specific person does not exclude the proper upbringing of children in accordance with the accepted principles and the exercise of parental authority in general. Raising children in accordance with generally accepted views should take place in an atmosphere of mental health, without disruptions caused by other serious deviations from the norm" (see Judgment of the Supreme Court of December 29, 1978, 475/78, OSPiKA 1980, issues 7–8, item 14).

In other words, it should be assumed that the Polish justice system has introduced a ban on marriage for some people due to concerns about their real competences both in terms of entering into a lasting emotional relationship and having the ability to raise and care for children. Unfortunately, when analysing subsequent statements presented in the official statement of the Constitutional Tribunal, it is difficult to avoid the impression that the analysed problem is treated too superficially. The Constitutional Tribunal's ruling emphasized that "The marriage ban provided for in Art. 12 § 1 of the Family and Guardianship Code does not apply to all persons suffering from mental and intellectual disabilities, but only to those who exhibit psychotic disorders or are mentally disabled. The above disorders or the degree of impairment must also pose a threat to the marriage or the health of future offspring, and determining the existence of these threats is up to the court, which should seek the opinion of an expert psychiatrist in this regard" (Judgment of the Constitutional Tribunal, 2016). It is therefore interesting that the Court, on the one hand, emphasizes that the relative marriage ban does not apply to all mentally ill and mentally disabled people, but at the same time we are talking about those who have mental disorders and intellectual problems. On the other hand, it was indicated that these symptoms must occur in such an intensity that they may threaten the well-being of the marriage and family. A similar situation reveals to us the serious inconsistency of the Polish Constitutional Tribunal's judgment discussed here and its sometimes internally contradictory nature. We must come to the conclusion that from a clinical perspective, we may encounter a surprising situation when:

- in mental illness, we will not notice psychotic disorders,
- in mental retardation we will not locate disturbed intellectual processes.

The Constitutional Tribunal added in its position that "The prohibition is also of a relative nature, i.e. it is subject to repeal by the court that allows marriage if psychotic disorders or mental disabilities do not threaten the marriage or the health of future children. The institution of a relative marriage ban (...) seems adequate to limit the possibility of entering into marriage by mentally or intellectually disabled people whose serious psychotic disorders or a significant degree of mental retardation deprive them of the opportunity to create a proper marriage and a family based on it in accordance with the social interest. Above all, ensuring the safety and well-being of children" (Judgment of the Constitutional Tribunal, 2016). It is worth asking key questions here:

- Which psychotic disorders and what level of these disorders do not pose a threat to marriage and children?
- What level of intellectual functioning of a given person is, in the opinion of the Constitutional Tribunal, sufficient to determine that there will be no threat to his/her spouse or descendants?

Unfortunately, the opinion of the Constitutional Tribunal expressed above is clearly exclusionary. First of all, it should be noted – as experts in criminal law know perfectly well – that we are often unable to indicate objective measures that would clearly determine the health status of a given person in a given case (Lisowska, 2016, pp. 85–98). Secondly, subsequent judgments and positions emphasize the existence of a potential threat to marriage and offspring. It's hard not to have negative historical associations here. We are talking here about the situation when, for the "good of society", regulations were formally introduced that made it difficult for disabled people to marry (Magowska, 2008, pp. 206–218).

Discussion and conclusions

As Anna Kotlarska-Michalska emphasizes: "The communal nature of marriage may mean the unity of two previously separate individuals, i.e. husband and wife, as well as the unity of the goals for which the marriage was concluded. The community approach means unity of actions, community of existence, common accumulation of goods, cooperation, joint planning and implementation of tasks, developing a strategy for common life. This approach to marriage dominates in psychological concepts of marriage, which emphasize the essence of intimacy of experiences, emotional, emotional, sexual and intentional community. Community in this approach is unity of expectations, unity of values, unity of actions and unity of responsibility for the durability of the relationship" (Kotlarska-Michalska, 1998, p. 55). This approach points to a special form of a similar marital relationship. On the one hand, it is certainly a formal contract concluded by two adults. From the other perspective, it is clear that the modern psychosocial approach defines marriage as a community in which two people give each other not only feelings, but also responsibility for each other. In the opinion of Jan Winiarz and Janusz Gajda, marriage is: "a lasting legal relationship, usually for life, between a man and a woman who, while maintaining the constitutive conditions provided for in the provisions of the Family and Guardianship Code. have performed the legal act of concluding a marriage and, as a result of its completion, they have become equal subjects of the complex of marital rights and obligations in order to optimally implement the social functions of the family established by their union" (Kozyra, 2014, p. 20). From a psychological perspective, it is worth paying attention to the approach presented by Maria Ryś. The author draws attention to the key psychological elements that guarantee the durability of a marital relationship. In the opinion of this researcher: "Communication between spouses, including the ability to resolve conflicts, plays a special role in high-quality marriage. In determining the mutual relationship between the quality of marriage and communication and the ability to resolve conflicts, one should resort to the circular understanding of causality. Good communication and proper conflict resolution contribute to the high quality of the marital relationship. High quality of the relationship in its other dimensions (e.g. love, trust, honesty) also facilitates conflict resolution" (Cited by Ryś, 2005, p. 58; see also Grulkowski, 2001, pp. 238–276).

In turn, Stanisława Steuden points out that: "Marriage is a dynamic covenant in which people, having achieved a basic level of understanding its essence and the ability to implement the rights and obligations arising from the marriage contract, are capable of further mutual improvement and transmission of life. Maturation, which is continuous, dynamic and takes place throughout life, also applies to marriage. It is in marriage that a person realizes himself for a long period of life, here he realizes his calling, matures into motherhood and fatherhood and faces the real difficulties of life. The ability to create a community by two different people from different backgrounds is the result of the long and positive development of the individual, and is also its adaptive capacity" (Steuden, 2000, pp. 55–56). In other words, marriage is a relationship that is based on: mutual satisfaction of psychological needs and mutual assistance in achieving goals, joint pursuit of plans, as well as the desire to have children who will then be raised according to mutually acceptable norms (Bryk et al., 2011, pp. 28–46).

When we refer these elements to the issue presented above, the so-called relative ban on marriage – in particular for people experiencing intellectual disabilities – we will reach a place in the discussion where it will be necessary to answer the key question: What exactly is the State afraid of when it introduces similar regulations limiting the subjective rights of people with intellectual disabilities discussed here?

When trying to answer the question indicated here, it is futile to look for a solution in the cited judgment of the Constitutional Tribunal. This court, as indicated above, only confirmed the previously accepted view pointing to concerns about both the durability of the marriage and the safety of the family. But what exactly do these concerns mean? We are probably talking about concerns about, on the one hand, the objective ability to enter into marriage and, on the other hand, the ability to maintain a lasting relationship with another person. There may be specific concerns about future offspring. This issue was presented in an interesting way in the film "I, am. «Sam»" starring Sean Penn. This production tells the story of an intellectually disabled father whose several-year-old daughter is put up for adoption. According to local social welfare workers, the girl's father had increasing difficulties in caring for the child on a daily basis (the man was raising the child alone). On the one hand, viewers can see how an almost ten-year-old girl begins to function better socially than her father. From the other perspective, however, we see how this man creates an atmosphere of love and emotional security at home in an extraordinary way (Varma, 2011, pp. 297–305). Therefore, probably paying attention to the concerns regarding the free access of people with intellectual disabilities to the possibility of entering into marriage, we see an element of a pedagogical nature. We are afraid that parents in a similar situation will not be able to take care of their children. However, it is important to realize that people with intellectual disabilities can and do enter into intimate relationships. They may result in pregnancy. However, this does not mean that each such situation will end in tragedy. This is perfectly demonstrated by the example of Sada, a young Syrian whose father is a person with Down Syndrome. This man is a dentistry student and in numerous media statements he indicates that it was the emotional care he received from his father that always gave him the strength to act. In one of the interviews, he stated that "A child raised by a parent with Down syndrome can count on enormous love and tenderness. Such a young person grows into an emotionally and socially balanced person, capable of achieving anything he wants... Contact with someone whom we tend to perceive as a person who has it worse in life, who is dependent on the people around him, and who nevertheless undertakes extraordinary effort and provides everything the child needs, it naturally encourages me in my efforts to be a good person" (Aleteia, 2023, online).

To complement the example given here, it should be emphasized that this man's mother is a person who does not experience intellectual disability. Interestingly, in his numerous reflections, Sada emphasizes that it was his father's unique approach to people that made him want to be someone who would support other people in the future. That's why he decided to study medicine.

Conclusions

Certainly, a situation in which two young people with intellectual disabilities want to get married requires special care. It is also necessary to check whether they have a broadly understood awareness of the actions they take. (Do they consciously consent to entering into marriage?) However, such action should be based on concern and not on the arbitrary exclusion of a given group of people. Unfortunately, in Poland we have a situation that, by definition, excludes the possibility of marriage for people experiencing a lower level of intellectual functioning. The provision stating that: "A person cannot enter into marriage..." very clearly indicates the existence of a prohibition, block and barrier. We are therefore talking here about an arbitrary restriction affecting a specific group of people. Concerns regarding – as mentioned in the Constitutional Tribunal's judgment – the situation of, for example, intellectually disabled parents seem to have no significance in the matter of sexual activity of the group of people discussed here. However, this ban is a clear and negative signal showing that a certain group of people is prohibited from taking specific formal actions. From the perspective of respecting the rights of people with disabilities and taking into account the dignity of every human being, a conclusion must be reached that a similar provision should be deleted or significantly modified. Taking into account the numerous challenges and dilemmas related to the support and social rehabilitation of people with intellectual disabilities, it is reasonable to consider introducing a provision that would be activated in a specific situation. This means, for example, the moment when a civil registrar would notice that a given person intends to take an action whose consequences he or she is not aware of. A similar approach may be based on focusing on the individual and caring, rather than exclusion and discrimination.

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ABSTRACT

“Love” is a word, term and phrase that writers, poets and scientists have been trying to define for centuries. There is no single, satisfactory explanation of the concept of love. However, it is certain that one of the most important human features is the ability to love. It is important that the experience of love is close not only to people, e.g. highly educated people, but also to people who experience intellectual disabilities on a daily basis. Our experience of love for another person very often ends in a formal confirmation of this state. We are talking here about entering into a marriage. Analysing Polish law, it can be seen that the Polish Family and Guardianship Code introduces an arbitrary ban on marrying people diagnosed with intellectual disabilities. Is a similar action by the legislator justified? Is it an example of discrimination? Maybe it is a shameful symbol of the presence of eugenic mentality in Polish law? Perhaps However, is this a justified preventive action that protects individuals from difficult consequences?

An attempt will be made to answer these questions.

KEYWORDS

human rights, marriage, discrimination, dignity, intellectual disability

Leisure Time of Adults with Moderate and Severe Intellectual Disabilities

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Introduction

Leisure time is commonly perceived as the opposite of busy time, dedicated to fulfilling obligations arising from various social roles, as well as daily activities related to satisfying the biological needs of the body (Berbeka, Makówka, & Niemczyk, 2008, p. 42). Developing valuable leisure time skills in childhood and adolescence pays off in adult life and often becomes a source of life energy. It is worth noting that not only intellectual abilities influence the choice of one's activities in leisure time, but also environmental factors (Plichta, 2017). It can be assumed that the leisure of individuals who reside in a family environment on a daily basis will differ from those living in an institutional environment. This text will present a fragment of original research on leisure activities among adults with intellectual disabilities who live with their parents or in social welfare homes such as L'Arche homes, known for their family-like atmosphere. The model of their functioning has been developed by the international L'Arche Foundation.

Leisure time of individuals with intellectual disabilities

Engaging in leisure activities holds great significance for the personal development of individuals with intellectual disabilities. Well-organized and actively spent leisure time constitutes a significant source of satisfaction, joy, and a realm of extensive rehabilitative possibilities. It contributes to the regeneration of mental and physical strength, satisfies the needs for expression, creativity, self-realization, belonging, and multidirectional action. If the leisure time of individuals with disabilities is characterized by loneliness, passivity, and boredom, it becomes a barrier to their development and attainment of satisfactory quality of life (Anasz et al., 2012, p. 213). Passive forms of leisure activities (such as solitary reading, watching television, or using a computer) correlate negatively with well-being, whereas active forms like physical exercise foster psychological well-being (Holder et al., 2009).

Often, individuals with moderate to severe intellectual disabilities struggle to fill their leisure time actively. This stems from a lack of organizational and social skills, as well as due to the absence of appropriate resources. Such individuals fill it with schematic, stereotypical activities, i.e. they watch television, or engage in repetitive, mundane tasks (such as moving objects from one box to another for hours). Residents of nursing homes also mention spending time together in common areas among their leisure activities. This prevents acquiring new skills or gaining new experiences, leads to personality impoverishment, and fosters motor stereotypes, which serve serving as a form of self-stimulation. The majority of adults with intellectual disabilities lack any particular passion or hobby (Kościelska, 2001, pp. 81–87).

A somewhat more optimistic view of the functioning of residents of 24-hop. 66. To gather information on the leisure activities preferences of residents of the St. Brother Albert Adult Nursing Home in Poraj, she conducted a survey among 40 women with intellectual and physical disabilities. As far as their preferred leisure activities are concerned, the dominant choices were walks (22%), tourism (18%), dancing (11%), listening to music (13%), and watching television (8%). Based on data analysis, the researcher concluded that over half of the respondents preferred active forms of leisure.

Participation in activities organized by occupational therapy workshops provides an opportunity to discover one's preferences and find a form of activity that can be pursued in leisure time. Engaging in employment also contributes to more effective use of leisure time. Firstly, due to the clear division of the day into working hours and leisure time, and secondly, thanks to organizational and social skills acquired at the workplace (Tylewska-Nowak, 2011, p. 39).

From the report based on the research conducted under the direction of Natalia Marciniak-Madejska (2014) among adults with intellectual disabilities residing with their parents in the Wielkopolskie Voivodeship (*N* = 204), it emerges that the most common leisure activities they engage in include chatting with friends and neighbours (130 indications), visiting friends and family (117 indications), participating in religious meetings (71 indications), engaging in sports activities (59 indications), or meeting with others in clubs or associations (43 indications). It was found that the vast majority of the respondents spent their time watching television from 3 to even 10 hours per day (respectively: 44.1% from 3 to 5 hours, 11.3% from 6 to 9 hours, 4.4% at least 10 hours daily). Only 4.4% of the individuals declared that they did not watch TV at all (Marciniak-Madejska et al., 2014, pp. 111–116).

The research conducted among 75 individuals with moderate and severe intellectual disabilities, employees of a Vocational Activity Centre, and participants of occupational therapy workshops, indicates that the most popular leisure activities among them were listening to music/radio (25.3%), watching television (22.7%), reading (18.2%), visiting acquaintances (14.7%), walking (14.7%) and sitting or lying down (10.7%) (Anasz et al., 2012, pp. 155, 214–216).

Beata Cytowska (2011) conducted interviews with adult individuals with intellectual disabilities (*N* = 27). The majority of the interviewes were employed at various companies or at a vocational activity centre, while the others participated in occupational therapy workshops. During the interviews, the researcher paid attention to the quality of rest, independence and autonomy of the respondents in terms of their leisure activities. Based on the analysis of the collected data, she identified five categories, naming them based on the most characteristic phrases used in the respondents' statements: "I like to relax", "I love computers", "Just looking for something to do outside of work", "Traveling is my great passion", "We have various events" (Cytowska, 2011, pp. 367–382). The researcher noted that, one the one hand, "The individuals who engage in physically demanding work usually adhere to the feudal principle of dividing time between work and leisure, believing that since they work, they also deserve the rest, as it is their privilege. Therefore, they were not embarrassed to admit that they enjoyed spending time at home, as they were tired after work, so they relaxed by engaging in typical entertainment: watching TV or listening to music. On the other hand, they attached great importance to being busy during leisure time." She also concludes that this may be a consequence of a specific rehabilitation policy followed by the parents of children with disabilities implementing, who fear wasting time or failing to fulfill their rehabilitation recommendations. Probably, the tendency to engage in important and valuable activities during leisure time by adult children is a result of disciplining practices of their parents (Cytowska, 2011, p. 382).

It is worth adding that "serious leisure" among individuals with intellectual disabilities contributes to combating disability stigma and negative attitudes, provides an opportunity to be noticed, and also allows for gaining respect from others. Furthermore, participation in serious recreational activities and a high level of engagement enable them to develop self-confidence and strengthen self-esteem (Patterson, & Pegg, 2009).

In L'Arche homes operated by the L'Arche Foundation, there are typically four to eight individuals with intellectual disabilities living alongside assistants without disabilities. Their primary mission is to create a family-like environment together with the residents (McDonald, & Keys, 2005; Kornas-Biela, 2014). In Poland, there are seven such homes located in Gdynia, Poznań, Śledziejowice, Warsaw, Wieliczka, and two in Wrocław. Residents of L'Arche homes take turns performing various duties such as cleaning and meal preparation. Those who are not on duty on the given day, can enjoy their leisure time. In the afternoons, assistants accompany residents and encourage them to engage in various activities or pursue their interests. They also work together with them in the garden, take them for walks, shopping, to visit friends, cafes or to a swimming pool to make sure they stay fit and spend time outdoors. Occasionally, they participate in cultural activities together, attending concerts, exhibitions, or movies. When they have to stay in their home, they engage in group activities such as playing board games, reading aloud, watching TV together or using the Internet. Activities are tailored to individual preferences and needs. L'Arche strives to ensure that individuals have the opportunity to spend time individually with assistants, so group meetings are not too frequent (Sokołowska, 2019, p. 142).

Methods

Research problems and hypotheses

In the presented research project, the following problems were formulated:

1. What are the forms of leisure activities among adult individuals with moderate and severe intellectual disabilities?
2. Do forms of leisure activities among adult individuals with moderate and severe intellectual disabilities differ depending on where they live (family home, nursing home, L'Arche home) and if so, to what extent?

Based on the analysis of the literature (Duvdevany, & Arar, 2004; Buttimer, & Tierney, 2005; Tylewska-Nowak, 2011; Cytowska, 2011; Marciniak-Madejska et al., 2014; Plichta, 2017), it was assumed that passive forms of leisure activities would predominate over active ones among individuals with moderate and severe intellectual disabilities. Additionally, it was hypothesized that individuals living with parents or in L'Arche homes would engage in active leisure more frequently than residents of nursing homes.

Participants

The study covered a group of 133 adults with moderate to severe intellectual disabilities, ranging in age from 18 to 68 years ($M = 38.82$; $SD = 12.71$), including 74 females (55.6%) and 59 males (44.4%). The sample was non-probabilistic. It included individuals who were highly functional, capable of independently responding to questions during a Paper Assisted Personal Interview (PAPI).

The study group comprised of 62 adult individuals with intellectual disabilities living with their parents in Opole and the Opole County, 40 residents of several nursing homes located in the Opole Voivodeship, and 31 residents of L'Arche homes operated by the L'Arche Foundation.

Tools

To gather the necessary data, a self-authored Interview Questionnaire for an adult with intellectual disabilities was used. The tool included an introduction and brief instructions for interviewers, 33 questions covering areas of life such as daily routine, safety, relationships, autonomy, and development. Most questions were closed-ended and featured a four-point scale with responses: Yes, Rather yes, Rather no, No, or a dichotomous scale – Yes/No. Additionally, each question included open-ended follow-up questions with space for responses. This study focused on the issue of leisure time among adults with moderate and severe intellectual disabilities.

The research procedure

The research was conducted between June and October 2022. The diagnostic survey method was utilized for data collection. The survey team comprised of individuals with experience in working with people with intellectual disabilities who were adequately trained for the task. The presented results represent an unpublished excerpt from the research conducted as part of the project of the L'Arche Foundation titled "Change Architects: Actions for the Social Inclusion of People with Intellectual Disabilities" (Change Architects, n.d.).

Results

During the questionnaire interview, the respondents were asked the following question: "How do you spend your leisure time?" The obtained responses were categorized (Table 1).

Table 1. Forms of spending leisure time by adult individuals with intellectual disabilities

Category	Forms of spending leisure time	Adults with ID ($N = 133$)	
Using mass media	Watching TV, movies	36	27.1
	Listening to music	29	21.8
	Using phone or laptop	4	3.0
	Reading or listening to someone reading a book	6	4.5
Sports	Walking	12	9.0
	Cycling	5	3.8
	Playing football	1	0.8
	Exercising	6	4.5
Social activities	Talking with friends, visiting friends	4	3.0
	Visiting family	1	0.8
Relaxation	Being outdoors	9	6.8
	Sitting in the room, lying on the bed	9	6.8
	Drinking coffee, eating ice cream	4	3.0
	Doing puzzles	1	0.8
	Shopping	2	1.5
Artistic activities	Painting	3	2.3
	Crocheting	1	0.8
	Dancing and singing	1	0.8
	Writing stories	1	0.8
	Playing the keyboard	1	0.8

* The percentages do not sum up to 100 because the respondent could list more than one form of leisure activity or could list none. Source: own research.

The analysis of the research material allowed for the identification of five categories of leisure activities: using mass media, sports, social activities, relaxation, and artistic activities. The most frequently mentioned activities by the respondents belong to the first category. These are watching TV (27.1%) and listening to music (21.8%). Almost one in ten respondents (9%) declared that they go for walks in their leisure time. Some respondents indicated that they spend time outdoors (6.8%), while others mentioned that they sit in their rooms, resting while lying on the bed (6.8%). Idications of sports, artistic and social activities were rare.

As part of the research, an attempt was made to determine whether the forms of spending leisure time by adults with intellectual disabilities differ depending on the environment in which they live (family home, nursing home, L'Arche home). A detailed breakdown of the obtained responses has been presented in Table 2.

Table 2. Forms of spending leisure time by adult individuals with intellectual disabilities depending on where they live

Individuals living in a family home (*n* = 62)	Residents of nursing homes (*n* = 40)	Residents of L'Arche homes (*n* = 31)
Watching TV (18)	Watching TV (14)	Listening to music (11)
Listening to music (13)	Sitting in the room (6)	Watching movies (4)
Walking (7)	Spending time in the yard/ garden (6)	Walking (3)
Exercising (5)	Listening to music (5)	Riding a bicycle (3)
Time spent in the plot or garden (3)	Walking (2)	Reading (2)
Playing games on the phone or laptop (2)	Drinking coffee (3)	Listening to someone reading a book (2)
Reading books (2)	Browsing the Internet (1)	Painting pictures (2)
Talking with friends (2)	Tablet browsing (1)	Lying in bed (2)
Riding a bicycle (2)	Visiting friends in the city (1)	Grocery shopping (2)
Playing soccer (1)	Talking with friends (1)	Writing stories (1)
Crocheting (1)	Painting (1)	Visiting family (1)
Doing puzzles (1)	Lying on the bed (1)	
Dancing and singing (1)	Exercising (1)	
Playing the keyboard (1)		
Eating ice cream (1)		

* The number of responses is provided in parentheses. Source: own research.

The analysis of the data presented in Table 2 indicates certain differences in leisure activities undertaken by adults with intellectual disabilities depending on the type of their living arrangement. Individuals living with parents most commonly reported watching TV or listening to music. Among residents of nursing homes, watching TV was the most popular activity, while among residents of L'Arche homes, listening to music was the most common, being nearly three times more frequently mentioned than watching movies.

In order to determine the proportions between active and passive leisure activities in the three types of homes, the percentage share of activities mentioned by respondents was calculated (Table 3). Active leisure forms included sports and creative activities (painting, writing stories, crocheting), while passive activities included media consumption, lying down, sitting in the room or outside the house.

Table 3. The ratio of passive to active forms of spending free time by adults with i ntellectual disabilities, taking into account the type of residential facility

Form of leisure	Family home (*n* = 62)		Nursing home (*n* = 40)		L'Arche home (*n* = 31)		Overall (*N* = 133)	
	N	%	*N*	%	*N*	%	*N*	%
Passive	41	66.1	38	95.0	21	67.7	100	75.2
Active	19	30.6	5	12.5	12	38.7	36	27.1

* The percentages do not sum up to 100 because the respondent could list more than one form of leisure activity or could list none. Source: own research.

Based on the analysis of the data (Table 3), it was found that the ratio of active to passive forms of leisure was similar among individuals living in family homes and in L'Arche homes, while it was least favourable in the case of nursing homes, where passive forms of leisure clearly prevailed.

Discussion

In the course of the research, an attempt was made to establish: what are the forms of leisure time activities for adults with moderate and severe intellectual disabilities? Based on the analysis of the data, five categories were identified: using mass media, sports, social activities, relaxation, and artistic activities. The most frequently chosen activities were watching television, listening to music, occasionally walking, spending time outdoors, or resting in own's room. Several individuals also indicated engaging in sports, artistic, and social activities. The obtained results correspond to previous research on the leisure time of individuals with intellectual disabilities (Buttimer, & Tierney, 2005; Cytowska, 2011; Marciniak-Madejska et al., 2014; Plichta, 2017).

In our own study, we also sought answers to the following question: Do forms of leisure activities among adults with moderate and severe intellectual disabilities differ depending on where they live and if so, to what extent? It was found that among individuals living in family homes and in L'Arche homes, over half of the individuals engaged in passive forms of leisure. However, in nursing homes, passive forms of leisure significantly outweighed active ones. This may be due to the fact that in round-the-clock care institutions, the staff members focus excessively on meeting the biological needs of the residents while overlooking their psychosocial needs. The forms and methods of support in nursing homes do not promote development; on the contrary, they limit the autonomy and independence of the residents (Żółkowska, 2002). Furthermore, residents of L'Arche homes and individuals living with their parents, as compared to residents of nursing homes, can exercise a significantly greater degree of freedom in terms of being able to decide how they want to spend their leisure time/vacations (Franczyk, & Kurcz, 2022).

Also, substitute family environments are more beneficial than institutional ones. Individuals with intellectual disabilities living in foster families ($N = 40$) were more engaged and independent in their recreational activities than those living in nursing institutions ($N = 45$) in Israel (Duvdevany, & Arar, 2004).

In L'Arche homes, the advantage is that relationships are reciprocal. This means that the assistant not only accompanies the resident in various activities but also invites the person with intellectual disabilities to participate in activities beyond community life. For example, they may take them to meetings with their own family and friends or to various cultural events (Sokołowska, 2019), which may contribute to high quality leisure.

Recommendations arising from the research

- It is worth investing in supported living arrangements with a family-like character because the conditions in such environments, especially the relationship with the assistant, promote active and diverse leisure activities.
- It is important to carefully select staff for nursing homes so that they have appropriate education and aptitude for working with individuals requiring support and thus encourage them to engage in active forms of leisure and allow them to pursue their own preferences (Wyczawski, 2009, p. 82).
- Regardless of the living environment of adults with intellectual disabilities, whether familial or institutional, they should be able to engage in social, sports and artistic activities as well as participate in cultural events or public gatherings, which will undoubtedly promote social inclusion.
- Another recommended approach is to provide opportunities for individuals with intellectual disabilities to utilize the creative potential of information and communication technologiy (ICT), to reduce passive consumption of content prepared by others, which is not much different from watching television, and instead, support creative activities, even if in a limited extent (Plichta, 2017, p. 150).

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ABSTRACT

The main aim of the research was to determine how adults with moderate and severe intellectual disabilities ($N = 133$) spend their leisure time. The perspective of adult individuals living with their parents ($n = 62$), residents of nursing homes ($n = 40$), and residents of L'Arche homes ($n = 31$) was taken into account. The age of the respondents ranged from 18 to 68 years ($M = 38.82$; $SD = 12.71$). The diagnostic survey method was used. An author-designed Interview Questionnaire for an adult with intellectual disabilities was used to collect the necessary data. Analysis of the research material allowed for the identification of five categories of leisure: using mass media, sports, social activities, relaxation, and artistic activities. It was found that the most common forms of leisure among the respondents was watching television and listening to music. Passive forms of recreation were dominated in all three groups. The ratio of active to passive forms of leisure was least favourable in the case of nursing homes.

KEYWORDS

leisure time, intellectual disability, L'Arche homes, nursing homes, family homes

The Occupational Therapy Workshop as a Place of Activation for Young Adults with Intellectual Disabilities – Analysis of Research

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Intellectual disability – a definitional approach

“Intellectual disability is a disorder characterized by both intellectual deficits and deficits in cognitive functioning with onset development” (DSM-5, 2013). Differences in the way they perform activities of daily living, in social functioning and in physical fitness depend on the degree of their intellectual disability. In this article, the considerations are focused on a group of young adults with moderate and severe intellectual disability, hereinafter also referred to as more severe intellectual disability. These people are most often dependent on the support of their immediate environment and have difficulties with independent functioning and self-determination. This fosters loneliness and poverty in contacts with the environment.

Adulthood is the longest phase of life, it begins at the age of 18–20 and lasts until the age of 60–65 (Brzezińska, 2015). The concept of “adulthood” has a legal, social and psychological dimension. Legally, it means achieving full civil rights, m.in. the right to vote, enter into contracts, marry, hold a driver’s license, and even travel without the consent of legal guardians. Socially, this term is associated with increased responsibility for oneself and the environment, with earning money and independent functioning. For minors, adulthood is a long-awaited and long-awaited state, associated mainly with breaking restrictions and liberation from responsibilities (Kijak, 2012). The question remains, however, whether adults with intellectual disabilities associate adulthood in the same way.

Organization of Occupational Therapy Workshops

Adults with profound intellectual disabilities make up a growing part of society. In Poland, they are a huge and strong, but untapped potential. Each form of activity has a positive effect on increasing their participation in social life and can be treated as a motivation to achieve independence (Kobus-Ostrowska, 2018). In Poland, one of the institutions whose main objective is to prepare a person with a disability for an integral life in society, rehabilitation and professional activation is the Occupational Therapy Workshops (WTZ). The number of Occupational Therapy Workshops is increasing every year, and the State Fund for the Rehabilitation of the Disabled indicates that there are currently over 700 of them. The main objective of these institutions is to develop the participants' ability to work, develop self-reliance and social functioning skills.

Occupational Therapy Workshops are institutions providing comprehensive rehabilitation of people with disabilities. The Act of 27 August 1997 on Vocational and Social Rehabilitation and Employment of Persons with Disabilities and the Regulation of the Minister of Economy, Labour and Social Policy of 25 March 2004 on occupational therapy workshops are the legislative foundations for the functioning of these institutions. The aim of the workshops, which have the character of a day-care facility, is to carry out tasks in the field of social and vocational rehabilitation aimed at the most independent, self-reliant and active life of each participant, with the use of occupational therapy.

The participants of the WTZ are adults over 18 years of age who have been declared incapable of work and indicated for rehabilitation through occupational therapy in these institutions.

The workshops are a stage in the vocational rehabilitation of a person with a disability, i.e. a transition from education to employment in a protected or open labour market. This is very important in the current situation in Poland, as people with disabilities still have difficult access to employment. In Poland, only about 20% of people with disabilities are professionally active and the labour force participation rate has been declining for a number of years. Currently, only 2 out of 10 people with disabilities of working age are employed. Unfortunately, there are no available studies on the professional activity of people with intellectual disabilities, we can only guess that the rate of their professional activity is lower.

The skills acquired during therapeutic classes are to be helpful in fulfilling oneself in everyday life. Although the facility is not a medical facility, it bases its activity on occupational therapy, which in its assumptions is to be focused on maintaining or restoring the individual's ability to be active in various areas, in accordance with his or her individual preferences. This activity is the most important in terms of therapy. Occupation, i.e. active, purposeful and meaningful action for the individual. Adults with intellectual disabilities, regardless of their level of functioning, need an occupation that allows them to participate in social life, just like any other person.

Due to the wide variety of disorders, various forms of occupational therapy are implemented in the institutions, which are particularly focused on social and professional development. Participation in classes is not only an opportunity for artistic activity, which is conducive to the development of their interests, but above all it is about showing the participant the possibilities of their social functioning, learning basic behaviours accepted by their local environment and competences necessary to take up or maintain employment.

Despite significant ideological changes, there are still a lot of stereotypes in society. Interestingly, very often those associated with adults with intellectual disabilities are copied by their caregivers, who forget that intellectual deficits in many cases are not synonymous with the inability to function independently and actively act in society.

Work on strengthening an adult with an intellectual disability at WTZ also involves intensive work with the family and the closest environment. The institutions are not alone, they operate in various fields – support circles, training/assisted housing, assistantship, which strengthen the independence of the participants. Social tendencies vary. Despite the actions taken, caregivers continue to infantilize adults with more severe intellectual disabilities. It is not uncommon to find these people dressed in age-inappropriate attire, and the actions they face and the way they relate to them are appropriate for preschool children.

Those around them, who have been obliged to take care of them for years, are often unable to break their habits, and with the passage of time, a growing sense of responsibility grows in them. When these people reach adulthood, there is a fear and fear of wanting them to function independently, or even to temporarily move away from a familiar place (Kijak, 2012).

Thanks to the therapeutic activities implemented for people with intellectual disabilities and their caregivers, it is possible to fold a "caring umbrella" and create conditions for these people to fulfil their basic social roles, be socially active and act for the benefit of their own self (Godawa, 2017).

Activities carried out as part of occupational therapy are aimed at restoring social independence to a person with a disability. These activities also aim to show society that an adult with an intellectual disability has the right to participate in social life to the same extent as others. The most effective activities are those that involve both the person with a disability and his/her immediate environment.

Active participation in social life, carried out as part of occupational therapy through trips to public places, gives society a chance to actively interact with people with profound intellectual disabilities. Importantly, due to the specificity of the group, these exits are always grounded in reality, there is no room for artificial staging. In this way, participants can observe behaviours and norms desired by the local community and employers. As part of the therapy, workshops organize fairs, exhibitions, and conferences where people with intellectual disabilities can show their hidden potential, which is also conducive to counteracting social isolation. And the popularization of the art of people with disabilities is one of the inseparable elements of their social reintegration.

Occupational therapy gives adults with intellectual disabilities the opportunity to be actively present in social life by strengthening their self-confidence. Mainly through acceptance of one's own limitations, inclusion in one's own environment and support in removing social barriers.

Occupational Therapy Workshops provide occupational therapy, strengthening the life resourcefulness of an adult with a deeper intellectual disability, engaging them in a variety of activities aimed at strengthening their self-determination. This is how the Self-Advocates program works, which is dynamically developing in the workshop environment of the Polish Association for People with Disabilities. It creates space for adults with intellectual disabilities to make informed decisions and express their opinion on matters that are directly related to them, but also to learn assertiveness and negotiation.

There are many ways to use the activity in therapeutic work, it is important to recognize the potential of people with profound intellectual disabilities and look for new ways to integrate them into society.

Research area and study group

As a rule, all activities carried out in the Occupational Therapy Workshops directly or indirectly serve vocational rehabilitation. The aim of the study was to assess how the assumptions of rehabilitation of people with intellectual disability to a deeper degree are implemented in the Occupational Therapy Workshops. The evaluation concerned the functioning of the facility from the point of view of the people organizing and conducting this rehabilitation.

The research was carried out in 24 Workshops in the Silesian Voivodeship, a total of 70 respondents were surveyed.

Two groups of people were asked questions in the form of a questionnaire:

- the persons in charge of the establishment (or providing information at their request);
- instructors in laboratories conducting classes with persons with intellectual disabilities.

The data was collected differently in the two groups, in the first group the respondents were asked directly and the answers were entered into the questionnaire; In the second group, the respondents received written questions and answered them, describing the activities carried out towards the selected participant.

Conclusions from the conducted research

In the conducted research, it is possible to indicate a clear tendency in the implementation of tasks in the field of activation and vocational rehabilitation carried out by the Occupational Therapy Workshops.

1. To a small extent, WTZ fulfils the role of an institution of vocational training. They mainly carry out general development tasks, focusing on social rehabilitation. They often play a caring role, as they are the only form of support for an adult with an intellectual disability in the area or the participants have been in the facility for many years.
2. An important problem in the functioning of WTZ is their weak legal basis, for this reason the type of activities undertaken is accidental. It is tailored to the artistic activity and interests of the participant, and does not respond to tasks in the field of vocational rehabilitation.
3. An inseparable element of activities aimed at making people with intellectual disabilities independent and professionally active is creating their image. In Poland, Occupational Therapy Workshops are mainly presented as places conducive to fun, trips, various types of events, which are in no way related to the professional activation of the participants. With regard to the perception of the facilities, the way of addressing the participants as a “ward” is also extremely important, which is not justified in view

of the fact that WTZ is not a care facility. Presenting the facility in this way raises doubts among potential employers as to the legitimacy of employing a person from the Occupational Therapy Workshop. Vocational rehabilitation is an integral part of the activities, which is why the facilities should be focused on showing the work and commitment that the participant puts in.

4. Instructors draw attention to the need to introduce holistic, comprehensive, internally consistent solutions to support people with disabilities. One in which each institution has a clearly defined role and works closely together. An additional result of such activity is the building of communities open to diversity. Institutions that have built a network of partnerships have greater effectiveness and durability of professional activation of participants. The cooperation is related to the entire local society, not only to entities related to disability on a daily basis. Circles created in this way result in the inclusion of the participant in society as an integral part of it. As a result, they aim to introduce the most effective form of activation, i.e. apprenticeships. Conducting trainings related to working outside the workshop area, thus enabling participants to experience working in natural conditions. Instructors emphasize the importance of working in real workplace spaces. Classes in Occupational Therapy Workshops are not able to create the same conditions as participants will experience at the employer's. Internships show the participant what work entails, and it is also an ideal space for social integration.
5. The analysed data indicate that people with the lowest level of professional activity and the largest group among participants are people with intellectual disabilities. Difficulties also arise for people who, after graduating from school, even in the form of an apprenticeship, cannot find employment or cannot support themselves in work, despite the fact that many people want to take up a job in order to be at least partially independent of their environment. People with a profound intellectual disability value the opportunity to earn at least a little money in the workshop and this fact contributes to their systematic attendance at classes and diligent performance of recommended activities, which is conducive to their rehabilitation. Although they are generally not able to manage these funds completely on their own, it gives them a sense of greater self-worth and independence. Such people particularly value contact with others and this factor is the main motive for their participation in classes.
6. In the majority of people with a profound intellectual disability participating in WTZ classes, the positive impact of this way of organizing life is visible, compared to long-term, often inactive stay at home for a long time. Many of these people have no other alternative, it is the only possibility of an interesting and useful way of fulfilling their needs. Instructors notice that they are getting better and better to work with, that they are becoming more independent, independent and responsible, which can have a positive impact on their later on, taking up a job adapted to them. The facility is a very important element of support for families of people with intellectual disabilities. Facilities are a way to organize the lives of these families, reducing the need for round-the-clock care and allowing more people with disabilities to stay with their families in their own environment.

Summary

To sum up, rehabilitation and professional activation of young adults with intellectual disabilities is a kind of challenge that is an inseparable element of activities for people with intellectual disabilities. The activation process is difficult and long-lasting, so it is important that the activity is a response to the current needs of the individual and society. In addition to artistic activities, the Occupational Therapy Workshops undertake activities specifically aimed at preparing participants to take up work. It is primarily the development of transferable skills needed at work (e.g. responsibility, punctuality, compliance with rules) and visits to workplaces. In addition, in accordance with the needs of the society, facilities are increasingly including not only products but also services in their therapeutic daily routine. Which is proof of their development and the use of the resources and competences of the participants.

However, it is important to introduce legislative changes that will systematize and standardize the way Occupational Therapy Workshops are organized in Poland. Institutions that have been run for several decades are not conducive to the professional activity of people with intellectual disabilities, they usually focus on social rehabilitation and artistic experiences of the participants. And fulfilling the assumptions related to the independence and vocational rehabilitation of people with intellectual disabilities is extremely important for these people to be able to find themselves and fully function in an increasingly diverse society.

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ABSTRACT

Until a few years ago, the adulthood of people with intellectual disabilities was an area of little research interest. The research only showed that the situation of the cared for community was balanced in specially created facilities, and the exclusion and the system did not cause discomfort to the society.

Over the years, there have been significant changes for the society of adults with intellectual disabilities, due to the increasing number of this group and the increase in its life expectancy, the population was no longer completely excluded. These people ceased to be anonymous and began to assert their rights.

Nowadays, no one denies a person with an intellectual disability the right to be an adult, and the term “eternal children” is becoming a thing of the past. Despite this, there is still a lot of debate about how to prepare these people for independent adult life. The article is an attempt to present selected issues in the field of professional activity, preparation for work, implementation of vocational and social rehabilitation of young people with intellectual disabilities – participants of the Occupational Therapy Workshops.

KEYWORDS

occupational workshop, intellectual disability, professional activation, young adults, inclusion

Patterns of Disability Narratives of Exclusion in Adeleke's Facebook *Blind Chronicles*

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Introduction

The use of various models in disability studies are products of personal proximity and gaze, which are strongly disciplinary concepts, and learning, which attempts to provide certain entablements for people living with disabilities. Writers and critics of African literature in the Global South are, to some extent, late when it comes to the models of disability studies. However, the concept of inequality, exclusion, and exploitation as a form of disability was imposed by the "able-bodied" colonial administration. The earliest attempt at questioning the social structure of disability as organised by colonialism was the nationalist questioning of exploitation and exclusion of Africans from the stead of humanity by virtue of colonialist policies and actions. Disruptions of systemic exploitation, inequalities, and exclusions are products of the narrative gaze and the refocusing of narratives of these barriers in society. The earliest West African writers, when they acquired the western tools of their oppressors, fought against colonialism and its exploitations, inequalities, and exclusion, and this was done through nationalists' narratives and fearless gazing at colonialism through the eyes of the oppressed. Some years later, African women used narratives and personal gaze to account for their oppression in traditional African societies, and this they did by telling "herstories." Stories that centred on women and their existences in patriarchal societies. These narratives of oppression, exploitation, and exclusion provide forms of proximity and mirroring in gendered society. However, these two oppressed groups, as they emerged and achieved relative liberations, continued different forms of oppression with their gendered groups. For instance, African men oppress the masses, including men, women, and children, because of political power. The new nationalists embezzled public funds while the women oppressed their fellow women who did not have agency of education or economic power, as is clearly illustrated in female-gazed feminists' African narratives. "The liberates" both from colonialism still exhibit the neurosis of their subjugation, including the liberated African women. The focusing of gaze because of proximity of the 'other' politically and in gendered relations did not allow the African male and female to note that the majorities are disadvantaged in terms of the effect of corruption. While some women have agency, because of their proximity, they do not see that some women are also oppressed by them. The African written literature provides a framework that illustrates the exclusion and exploitation of people living with disabilities. People living with disabilities are abused. They are used as comic relief or as a narrative foil, as it is indicative of Isidore Okpe's *Last Duty*, Cyprian Ekwensi's *The Drummer Boy*, Elechi Amadi's *The Concubine*, and Aminata Sow *Fall's The Beggars Strikes*. The scanty creative literature on the non-inclusivity of people living with disabilities is indicative of the exclusion of people living with disabilities in the cultural framework of knowledge production and distribution. The postcolonial narratives and gendered studies in the Global South have consistently focused on the effect of colonialism on the postcolonial, while the battle of feminism and patriarchy is still ranging as it is indicative in gendered studies in Departments of English across Africa. However, disability studies are rarely considered in curriculum reviews and the introduction of new courses in universities across Africa. This is the result of the focusing of the lens and the proximity of people living with disabilities. Many years after the establishment of African literature, which did much of the gazing and mirroring of the effects of colonialism and patriarchy, there is still a lack of close gazing on impairments, which focused completely on people living with disabilities. The cognitive gazing because of the proximity narratively excludes those living with impairments because of their relegation to the peripheries within peripheral discourses of oppression and exclusion. Some who have achieved some levels of liberation, as it is indicative of nationalists' movements and feminism, turn their attention to different issues without any attempt to build an inclusive society. The constant exclusion of the narrative of people living with disabilities and their representation makes them tell their own stories. Jay Dolmage affirms that "the ways we tell particular stories condition our understanding of disability (and this of all identity and all bodies" (30). Adeleke stories allow us to have an inside view of what disability exclusion entails, as it is analysed in this study.

Methodology

This study adopts the qualitative methodological framework, which has to do with the analysis of data from a discourse perspective. In this study, data were elicited from Demola Adeleke's *Blind Chronicles* and subjected to textual analysis. This approach enabled the researcher to critically examine the data by subjecting them to literary concepts of gaze and proximity while interfacing other theoretical models in disability studies, which aids in the interpretation of the texts (without sticking to such models as the theoretical framework) for the conceptualization of this study. Using this approach enables the researcher to be able to account for the shifting and fluid nature of impairment in relation to society and how such structures exclude and include people living with disabilities through the reflective narratives of Adeleke's *Blind Chronicles*.

The Shifting Gaze and Proximity in Adeleke's Facebook *Blind Chronicles*

Every form of social impairment is unique and does not provide wholistic representation and exclusion of people living with disabilities, but it provides a glean of such social exclusions and enables policymakers to make informed decisions about issues of exclusion in society. Harriet Cooper submits that; "What do disabled children want tell us about their live?" (1). Demola Adeleke's *Blind Chronicles* enable us to see the dimension of exclusion in society and how social gaze enables social disabilities against people with impairments, using blindness as an illustrative autobiographical tool to question social practices. Social media autobiography is enabled by assistive technology for people living with blindness. The social media space and assistive technology are providing agency for personal gaze and personal narratives by persons living with disabilities to challenge the dominant narratives and their exclusion from society. Felicity Boardman affirms that "…experiential knowledge can be both empowering and transformative…" (54). The impaired are aware of their lives because of their proximity to their existence and in relation to others. People living with impairments and disabilities have relationships with society, and technology and social media enable them to share their stories of exclusion in society. Tanya Tilchkosky sees disability experience as a complex social phenomenon and went further to provide a certain form of gaze which enable interpretation which is geared within the frame of interrelated area which disability appears which include in interaction, in the production of knowledge/cultural images and in the physicality of both our bodies and social space (40). This shifting occurs as a product of gaze and proximity, and social media autobiographies enable a vivid portrayal of social exclusions. Hanjo Berressen affirms the foregoing; thus, "It is not only that all o individual life is «constrained life,» it in fact depends on specific constraints, be this temporal, spatial or operational from such a position, the field of disability can be defined in very general terms, as a multiplicitous field of site and time-specific constraints that play themselves out on an infinite number of levels simultaneously" (30). It is these levels of multiple dimensions of exclusion and an attempt to gleam a format of inclusion for those who are excluded because of social disability that this study attempts to critically analyse Demola Adeleke's *Blind Chronicles* published on Facebook. This study is focused on Adeleke's *Blind Chronicles* as a model of personal narrative of the collective narratives of people living with disabilities. Rosemari Garland-Thomson is of the opinion that disability narrative can generate knowledge (57). Adeleke's narrative enables us to generate knowledge on the dimensions of social exclusion for people living with disabilities. The autobiographical narratives of people living with disabilities are most often not concerned with theoretical models but attempt to create a safe space for their continuous existence by mirroring their lives in their interactions with society. Adeleke, in his *Blind Chronicles*, affirms the foregoing, thus:

> Sharing my past with you doesn't mean I'm yet to get over it. I just feel I've written enough fictitious stories, so presenting you a factual account of my experiences wouldn't be bad either. Yesterday, I was chatting with a female friend on Whatsapp. She had read my last post "blind chronicles" so she asked me "Demola,

> did you really go through all that? I was like "of course, that was even small". Then her next reply was what fetched me a good laugh or rather, a reminder of how old she is to have talked that way. Her response was that if it were to be her, she would have found the quickest way of leaving this world just to end the whole insults that could emanate from being blind. Did you say the girl must be crazy for saying that to me? no o, she wasn't at all, Amaka is always like that, so open minded and straightforward. Honestly, I on several occasions also thought of taking my life then. Or have you ever imagined looking at all directions without seeing even a flash of light? Yes, that's exactly what blindness offers. When I was like Amaka's age, rotten dry cells were all I was hunting for in the house so I could poison myself. I'd tried stabbing myself with a knife before of course but no o, that death isn't easy at all. Only an insane being will do that and for me, I only lost my sight and not sanity. All thanks to my parents' counselling and exhibition of the sorrow they will house in their heart if I'm gone, maybe I would have been 6 feet under by now. Then it got to a point, a point when I was even running away from that death which I was earlier craving. Well, it's not like life got better for me or something, just that I found some cogent reasons to stay alive and keep fighting. First is to pay my mum back for exhausting all her nights and days on mountains and churches, praying fervently for the restoration of my sight. *BLIND CHRONICLES* 2

Insults provide an alternate gaze for Adeleke and his attempts to take his life, and these insults are products of the proximity and ablism of society. Cooper note that; "…what it means for an experience of oneself to be transmitted via the gaze, and what kind of knowledge about disability is created via gaze" (25). The social gaze is an insult and pity, a gaze that bestows limitations on people living with disabilities in Nigeria to the extent that they want to take their lives, as is indicative of Adeleke's narratives. Adeleke parents were the ones who provided an alternate gaze different from the finality of society, and they did this by providing comfort and psychological support. This is also an indictment on society that excludes people living with impairments. Anne Waldschmidt is of the opinion that; "…disability is a social construction" (20). This social construction is transmitted through narratives and actions against people living with impairments. The Nigerian society is not structured in such a way to provide support for those with living impairments, which is different from the ablism practised in the society. Waldschmidt corroborates the foregoing; thus, "…disability is a form of inequality and disabled persons are a minority group that is discriminated against and excluded from mainstream society" (21). It is this inequality that made Adeleke attempt to live several years because of his impairment and the disability that society projected against him. Adeleke, aside from pushing back from his experience stifling him, acknowledges that the narratives of those who are blind perform functions, and he highlights these functions, thus:

> Well, don't get ahead of yourself and jump oafishly into conclusions, only the real blind can tell the tales of our living. Your assumptions can lie a lot. All these movies you see only animate their blind characters in accordance with the imaginations of the film director, not a thorough research was done to create a more plausible activity of the blind in them. Wait, have you ever imagined the blind

> playing football? Oh yes, a ball with a rattle in it does it all. Once the ball rolls, the rattle jingles along with it, we trace the ball's location with our sensitive ears and both teams with strictly blind players struggle to kick the ball to score some goals. Just like Chelsea and Arsenal do on the pitch. Many do think losing our sight makes our ears capture even a whisper from a distance. They believe that once you lose one of your sense organs, the closest sense organ to the lost one gets all its strength multiplied by two. And that's why my friend will always expect me to clearly hear the lecturer's talk even if I'm seated at the extreme back of the class. Get this right buddies, our ears only get more sensitive to voices and sounds, it's not like we hear clearer than those who have their sight. The eyes help the ears in getting a voice better, just like when someone whispers 'I love you' from a distance, reading the lips of the talker plus the faint voice you heard will converge in your brains for more effective apprehension. Where our ears seem more active is in cases of quickly notifying the brains about a sound heard. Our ears detect things travelling through the sound waves quicker and plainer. You probably do not know we see movies too. A keen attention on the characters' voices and the sound effects put us through. The advantage of our ears not having to depend on the eyes do the magic. Once we have recognised each character's voice within 2 to 3 scenes of their appearance, then forming our own image of the movie makes it a reality for us. *BLIND CHRONICLES* 26

Adeleke is of the view that those who lived with blindness are in the best position to tell their stories. That assumption cannot function within the framework of experiential living with those who experienced impairment and the effect of such impairment on their lives and the constructed disabilities by the ablism society. Waldschmidt is of the opinion that; "…it is not impairments perse which disable, but societal practices of «disablement» which result in disability" (21). And Adeleke's *Blind Chronicles* gives us various dimensions to this disability constructed by the ablism society in all aspects of their existence that restrict those living with blindness. Adeleke is of the opinion that cultural production is at the centre of the construction of people with impairments, which most of the time are in the director's imagination and are not backed by research or the actual existence of people who live in these spaces. Lennard J. Davis affirms that; "…what characterizes disability is that it is shifting, changing, morphing notion of identity that distinguish itself from other identity categories that seem to have developed overtime…" (43). Adeleke, through his writing, attempts to highlight this changing disability and educate people on the nature of blindness. Through his narrative, Adeleke dissuades the misconception that the blind hears far more than those who have sight, and he differentiates them to illustrate what the blind hears and not what has been imposed on them by the assumption of society. Adeleke, through his presentation, questions the narrative of personal gaze and people who, by proximity of sight, are not associated with blindness, and he attempts to present a world through his personal gaze and proximity to the blind and to use it to indicate that the world of those living with disabilities understands their world better than any attempt to imagine it through one closing of the eyes. People living with blindness are insulted because of their impairment and excluded from society. Adeleke affirms the foregoing when he submits that:

> When you insult me with my blindness, it pulls not a strand of hair from my body. After all, no-one is above the reach of disability. If you think I'm lying, ask Elizabeth, she will give you a perfect instance by citing herself. Ok, lemme tell you her story. She used to render humanitarian services to the disabled students in her school, but sadly, she had a terrible accident on her way home few weeks ago. Oyi readers, as I write now, Elizabeth is chilling on a wheelchair. Mind you, that's for someone who would go out of her way to help the challenged, how much more of those who feel they have the immunity to resist disabilities, thus, mocking the disabled and enjoying the act. Truth be told, I don't wish for even my enemies to be blind. I was at a lecturer's office one afternoon when I overheard a girl tell the lecturer about a dangerous eye disease she was diagnosed with, and even though I barely knew the girl, she always has a section in my prayers ever since that day. *BLIND CHRONICLES* 41

Adeleke has allowed the insults of the abled society to get at him because of the society's personal gaze on people living with disabilities. He observes that disability can happen to anyone, and as a result, people should treat others with love. He uses Elizabeth to affirm his point about how one suddenly becomes disabled because of life. He also knows a girl who suddenly has an eye problem, and it has become a concern for her. She has constantly prayed for it to go away, which is not going to happen any time soon. Adeleke observes that people have preconceived notions of those living with blindness, but this preconceived notion is not a fixed one, as we will see in the later part of this study. Adeleke observes that:

> I've got to realise some people's perception about me, or maybe the blind students generally. To many, I'm just a blind son from an educated family, so it's in my parents' orientation to support my decision to study in the university regardless of my disability, not necessarily because I'm up to the requirements which qualify a person to be an undergraduate. A blind student in the university? He definitely is passing time there, they will conclude. In fact, I could remember a friend, after a silent rehearsal on how to articulate her question, asked me if I will also work after graduating from college. *BLIND CHRONICLES* 43

Social perception and gaze exclude those living with impairments (blindness) and undermine their abilities on the premise of their blindness. Adeleke chronicles this social gaze; thus, "In my country, once you are blind, even if you've studied at Oxford university all your life, some persons with the lowest minimum brains will still perceive you as being dumb, a dunce or simply cursed. To them, knowledge goes into the human memory through the eyes: therefore, one who is short of sight has nothing in stock for humanity to benefit from. Just imagine this barbarism: you keep your distance with me because I'm blind, but it doesn't end there, you even discourage people against coming close to me, why?, simply because I'm blind." *Blind Chronicles* 56. They fail to acknowledge that those with impairments have the intellectual capacity to be in the university. Disability is a torment for those who come with impairments because of the personal gaze of the able society. The concepts of gaze and proximity are shifting political tools in the questioning of patterns of exploitation and exclusion in society. Those who experienced the foregoing because of the privileged gaze and proximity questions such exclusions and exploitations by "re-gazing" at themselves at proximity thereby develop resistances to such subjugations. Ewa Glapka is of the opinion that gaze is a discursive accomplishment of a social relation and identification by individuals (2). The gaze is also assigned by power and privileges and Glapka further sees gaze as a multiple and ambiguous ways in which participants engage with the gendered relation of power (2). Re-gazing questions inequality which comes in multiple and ambiguous ways as it is indicative of interactions between people with impairment and the society. Martin Fuller and Julie Ren accounting for the functionality of proximity observe that: "…the physical proximity of social actors is rendered significant when proximity enables contingent potentialities to proliferate including but not limited to those potentialities that are actualized" (3). The proximity of abled bodies in African society does not allow them to see the disabilities of the environment, which negatively excludes people with impairments. As a result of abled bodies' gaze and what R. Boschma refers to as social proximity and cognitive proximity, social proximity and cognitive proximity enable Ablism in such a way that people living with disabilities are excluded from society. Xinyan Yu in accounting for the political intent of gaze observe that; "Gaze is a kind of focused viewing, which reflects social rights and identity" (428). Ablism viewing of those living with disabilities is linked to colonialist looking during colonialism in Africa as well as patriarchal viewing of the female gender. Yu further notes that "The gaze is more than just looking, and it implies a psychological relationship of power in which the gazer is superior to the object being gazed at" (428). The exclusion of those living with disabilities is a product of gazing and proximity by agents of the state and society. Since their gazes are far from those who are experiencing these challenges, they tend to judge them based on their abilities, not considering the limitations the environment poses to their existence. All models of disability studies are products of disciplinary framing and contribute a building block to theorising and highlighting the realities of impairments and disabilities and how societal reactions to the concept of inclusion The World Health Organization defines disability as:

> Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers (WHO, 2011).

The foregoing indicates that disability is a complex, fluctuating reality that is constructed by power and privilege in society. Africans have continuously experienced different forms of disability in society. The end of one inaugurates another, as will be briefly analysed in this study. Adeleke suffers from the social gaze of society because of his impairment, and his friends are also subjected to this form of social gaze, and this gaze, because of its perception of inventiveness, is a source of concern. As a result of social gaze, Adeleke advises those who volunteer to walk in through the street and informs them that the weight of people's eyes will be on them, and if they cannot carry such weight, they should not attempt to assist him. Adeleke's proximity and inward gaze would account for the experiences of those who volunteered to assist him, thus:

> Hi dear. You've got to think it twice before choosing to hold my hand and walk me down the street. You see, I'm very much aware of the attention I command from passers-by, the long, contemptuous gaze they cast on you for walking a blind person isn't hidden. I know everything even though you don't say it out; so you'd better hold my wrist only when you're sure you won't be ashamed to walk with me. It is true that some parts of the society think I'm better off as an outcast. It's also true there are times when I walk unsteadily like I'm in a march-past. But that's because the ground is rocky and I need to calculate my steps. Cause it's better to have millions of eyes on me than to fall on my chest. I know how stressful it is for you for having to direct my movement every time. What sucks most is the lingering stare you receive from people for leading the blind. But you shouldn't really care about that if truly you are my friend. I could have done the same for you assuming you're the one in my mess. It's better I'm left stranded than to be the reason for your shame. I wouldn't mind crawling in the mud till I'm able to reach my aim. Don't befriend me only to make me feel like you're doing me a benefit. In the darkest of night, I'm the only one who can locate the matches to light your cannabis. So stop relegating me to a mere receiver of favours while you're the giver. If I stand all day under the sun without seeing whom to lead me, I won't die of fever. Shout-out to my friends who will stand by me even if the society perceives them as being strange. That's because it's in their beliefs that one who befriends the disabled will have his orientation stained. But my friends are my friends, they will hold my hands even when I've been diagnosed with Ebola. And I'm hoping a day will come when I'll be opulent enough to present them a Corolla. If you wouldn't defend me against societal scorn, then you are as good as a zipper on a wrapper. So it's better you remain a stranger than a friend who wouldn't Michelle my Obama. Let the whole world reject me with my disability, I really don't care. In as much as you will be there for me, then let's walk round without worrying on fare. If at all my face isn't tear-stained, then all thanks to you. For you're the one fuelling this scorching smile on my face, trust me; trust me. I'm a man of relevance, you can ask my buddies about me. I harbour no bitterness in my soul, just have a taste of my blind chronicles. *BLIND CHRONICLES* 52

The social gaze is a form of exclusion, and it carries forms of difference. Adeleke attests to the fact that some members of society perceive him as an outcast that those with sight should not associate with and, as such, is not worthy of their assistance. Adeleke mentioned the disdainful gaze society casts at those who aid him, and he advises those who have the courage to walk with him to hold his hands because many are not courageous enough to do so because of his impairment. Those living with disabilities because of the social gaze seem to be a source of entertainment for the abled society, and Adeleke is saying that only the one who can withstand this gaze should be able to walk him amidst many who have excluded him from the society. Adeleke wants to be treated as a human being, not just one whose favour and charity are directed at. He wants to be included in society and by those who associate with him. Lennard J. Davis corroborates the foregoing; thus, "Social discrimination is subtler but just as powerful. Staring at people with visible disabilities creates barriers. Asking probing questions about how a person got their disability creates barriers" (7). Adeleke wants to be treated with human dignity like every other person in society, and that is why he says that even if he stood under the sun without seeing anyone to lead him, he would die of fever. So Adeleke prefers to be under the sun than to be treated without dignity, and this would also be the mindset of some people living with impairments. The human gaze is meaning-related, and it affects how others are treated in society. Even Adeleke's ex-girlfriend is ashamed of him because of his impairment and because of the social gaze, which is a form of exclusion of people living with disabilities, and his ex did not want to be excluded from the ablism society. Adeleke observes that:

> One incident that transpired between my ex and I also made it to this discussion. That day, I was down with sore throat, and I couldn't talk at all. I was supposed to attend a meeting but because I was voiceless, I skipped the going and lay perturbingly in my room. The truth is, I was already getting scared of the condition; it started as a mere sore throat, of which I'd experienced times without number, but the one I'm talking about now was severe, even if I screamed on top of my voice, I would end up giving a faint whisper, so I was beginning to consider it the first face of dumbness. If I lost my sight, then lost my voice, so what's remaining? I thought quietly. Few minutes later, my girl knocked on the door; I welcomed her in, offered her a seat and nudged her into a suspended discussion. Of course, she'd already learnt about my ailment on the phone, but she never knew how serious it was until she had to put her ears close to my mouth before getting what I was saying. After like 20 minutes of her arrival, I asked her to help me go to the chemist at the neighbouring hostel to get some drugs, but I was startled at her response; she was complaining of the sun to be scorching, hence, she wasn't going anywhere. I honestly thought she was joking at first, but later confirmed the seriousness in her response when she got up after some time and bade me goodbye. When in fact, I had tried getting the drugs before her unexpected arrival but none of my friends was around, so I thought her coming was a blessing from God, never knew it was a mockery from devil. The instant she left, I just started wishing I could have my sight restored for only a few minutes so I could go get the drugs myself and come back before it turns blank again. Another time I get reminded of the importance of sight is during the long school holiday. Just like a reasonable Nigerian youth would do, I also wish I could learn a craft and perhaps, make some money. To be honest though, assuming I ain't blind, the only craft I'll be willing to learn is barbering; yea yea, you should know I don't have muscles to break rocks or carry cements. #smiles. Maybe I could have initiated hairstyles like Kukere, Azonto and Shakushaku by now; God punish devil. But because I can't learn all this things with my eyes shut, I spend the 3 months holiday sleeping, eating, writing and

> thinking about the future, whereas, my sighted friends are somewhere making some money and acquiring new skills. Who knows, maybe I would have gathered the money to also procure a Range Rover for my baby, just maybe. Listen, let me tell you how I get to know when there's power in the house. It's either I know through the air from the blowing fan or through the drone of the refrigerator. So any time I'm home alone, I always make sure the fans are on and also the fridge. Well, I learnt a new thing from a blind colleague few days ago. He neither has fan nor fridge in his room in the hostel, so whenever he wants to confirm if there's power or not, he'll just plug the electric cooker to the socket and put his palm an inch away from its face; if it generates heat, there's power, and if otherwise, then you know what it is. No no no, don't feel bad for the blind over nothing, It's what life poses to us, so we have to live it the possible way we can. I'm always having a smile on my face doesn't mean I don't have my gloomy and reflective moments, just that I'm more concentrated on securing a colourful future than regretting the shortcomings of living without eye-sight. *BLIND CHRONICLES* 54

Adeleke was down with an illness of a sore throat, but his girlfriend refused to assist him because her social gaze could not allow her follow him to get a drug for his illness. As a result of the nature of the environment, where persons with blindness cannot exist alone because the environment restricts them, Adeleke becomes worried whenever the school is on holiday because he cannot function alone in the environment. This brings sadness and accounts for the limitations imposed on him because of the design of the Nigerian university environment. People living with impairments like blindness are excluded from the work force as Adeleke's blindness is a source for his exclusion and the reason why he could not find a job during the holiday even when he is able to do certain tasks that would generate income for him, but the social and cognitive gaze of the abled society excludes him. Rebecka Mallett and Katherine Runswick-Cole foreground Adeleke's plight when they submitted that; "Impairment is produced by functional limitations of the body, but disability is the result of physical barriers" (17). Adeleke is restricted all around by the limitations of his sight. Adeleke, through the interfacing personal narratives of his and that of his friends, went further to indict the architecture of the Nigerian universities, specifically the hostels, and inform us how he knows when there is light in the hostel. He plugs a hot plate and brings it close to his face; if it generates heat, that means there is light. Those with impairments are excluded from social amenities that are tailored to their specific needs.

Adeleke's *Blind Chronicles* is a personal narrative of the effects of blindness and the social disability he faced because of his impairment, and his narrative provides some aspects of inclusivity that can help build an inclusive society. Garland-Thomson chronicles Adeleke's impairment; thus, "…almost all of us will experience disability sometimes in our lives…" (16). Adeleke started his narrative in his *Blind Chronicles* by accounting for his blindness and the pressure and challenges he faced in attempt to live with his new status (because he was not born blind). He observes that:

> I've had more than enough reasons to give up on my pursuit for a twinkling future but some drives just keep propelling me. Or what is it that I'm yet to experience?

> So many discouraging happenings and comments have crawled my way. In 2012, I found sense in my parents' advice to enroll for a rehabilitation training so I could go back to school cause I had to drop out from my secondary school owing to my bad sight. My blindness was not something that was very easy for my mum to bear, a quarter or two of her daily thinking always had my condition featured in it. She wouldn't stop crying, she was never a happy woman. Although, hearing only voices around without sight to supplement them was what constantly kept my eyes teary at that time too, but knowing my mum was so bothered and depressed all cause of me lent me that courage to approach her and assured her that she would never see my tears again as a result of deep thoughts over my blindness. All this I did just to stop her from crying all the time. Maybe you don't know, I'm the only son of my parents. Finally, I got to Ogbomoso [a town in Oyo state] where the rehabilitation centre was situated and was exposed to a new life entirely. There, I was trained on how to type using the typewriter, how to write braille etc. How to walk around with a guide stick was not a lesson I admired, so my interest in learning it was lifeless. Before I left home for Ogbomoso, I had this secret promise to myself never to shed tears again, "I will remain strong" was that statement I made. Even though I was wary of the potential provocative experiences and talks I may come across as a result of my blindness, I still held this promise so firm in my heart never to cry again. *BLIND CHRONICLES* 1

Demola Adeleke became blind at age 17, as his *Blind Chronicles* 1 indicate, and this became a source of sorrow for him because of the social disability people living with impairments face. Adeleke had to drop out of school because of the nature of schools in Nigeria, and he had to be sent to a special school where he had to be trained to live as a blind person away from his family, which provided him with support. Schools in Nigeria are not inclusive, and people living with disabilities are excluded from normal schools, which is indicative of the plight of Adeleke. He has a lot to worry about, which includes his blindness and social narratives that ridicule those living with disabilities. Garland-Thomson while the action of Adeleke's attempt be able through rehab note that; "Becoming disabled demands learning to effectively as a person with disability not just living as a disabled person trying to become nondisabled. It also demands the awareness and cooperation of others who don't experience these challenges. Becoming disabled means moving from isolation to community, from ignorance to knowledge abo who we are, from exclusion to access and from shame to pride" (19). Adeleke indicates that love can function as an inclusive model that can be adopted by the state and family for people living with disabilities, and that the state can adopt a mechanism to treat those with impairments and identify their needs to make them live a fulfilled life in society, just as it is indicative of the love and care Adeleke's family showed him. "Ablism" society should not stigmatise those living with impairment, as it is indicative of Adeleke's experience with his blindness. Adeleke demonstrated awareness of his impairment, which led to his disability in society.

The schools in the Global South should constantly be renovated to be inclusive and to accommodate people with special needs. Adeleke had to be excluded and sent to a separate school because his school did not anticipate his disability or be inclusive enough to accommodate his impairment. WHO Report 2011 observes that “there are different approaches around the world to providing education for people with disabilities.” The models adopted include special schools and institutions, integrated schools, and inclusive schools. “Across European countries, 2.3% of pupils within compulsory schooling are educated in a segregated setting – either a special school or a separate class in a mainstream school.” Irrespective of the model that has been adopted in Nigeria, they are not effective, as it is illustrated through the eye of the narrative of Adeleke. Davis writes that; “…inclusive world building seeks to integrate people with disabilities into the public world by creating an accessible, barrier free material environment” (52). The school that Adeleke was sent to was also a source of torment because of his new status, which further excluded him from the inclusive world they attempted to build through his training on how to live as a blind person. He notes that:

> Ogbomoso isn’t a very developed town... Temitope would greet me, and I would cheerfully reply, “how are you” “I’m fine” was usually what our conversation would base upon. At that time, I was 19 years old and as a grown up… (…) I sat down in class with my fellow blind colleagues, we were going through the previous lessons I guess. So, a windy air blew through the windows of the classroom and flung my braille paper away from my desk. Knowing Temitope was around saved me that stress of dragging my legs on the floor in search for the braille paper, so I called her name. “Tope, could you please help pick that paper up?” I said and expected either a response or the paper in my hand. On the contrary, I heard a hiss lingering in my ears then followed by a footstep towards the exit of the classroom. I was more than surprised. My offence was unknown to me. After like 5 minutes, I heard multiple footsteps coming into the classroom with Tope’s voice saying “see him here, this is him.” “Ahah, wetin I do?.” I asked without making a speech and to be honest, I was a bit panicky “and you, why are you calling a student teacher by her name?” a voice asked, my good oral perception was kind enough to reveal who the speaker was at once. It was mr Taiwo, the primary 6 teacher. Then he started this noise, “these people here are your teachers and there is nothing you can do about it. You have to respect them and call them aunty.” He floored me so badly, reminding me of how terrible it is to lose one’s sight. Even our braille teacher was taken aback at what was happening, I’m certain he wasn’t really happy with what was befalling me. Can’t really remember those hurtful words mr Taiwo said to me, but I knew it was such an awful moment for me. (…) For mr Taiwo, he was this hungry primary school teacher who was so insensitive to people’s trauma. I was just coming out of that horrifying ordeal of losing my sight and yet, a fully grown adult was tearing my heart away with those heavy scoldings? In the hostel later that evening, I couldn’t just keep to that promise of not crying again, I regurgitated on what my experience for the day was and burst babyishly into tears. (...). Mtcheew! To all those who belittled me and made me think of giving up, I’m coming back for you! *BLIND CHRONICLES* 1

Those who are employed to teach the impaired, as indicated in the case of Adeleke, are not trained, and even when they are trained, they allow their emotions to take the better side of them. Adeleke teacher was also his classmate, and he did not know that she was his teacher, so he called her by her name, which attracted different kinds of inventiveness from Taiwo, whom Tope reported him to. The school is a source of trauma for Adeleke and a social construction for his exclusion because his former school was not designed to accommodate persons living with disabilities, and he had to attend a special school that is designed for the blind where his teacher insulted him because of his blindness. After Adeleke left the rehabilitation centre, where he was taught how to live as a blind person, he was admitted to the University of Nigeria, and the university was structured in such a way that it did not make provision for those living with impairments. Adeleke narrated his ordeals about the environment that excludes him, thus:

> My first shout-out goes out to those deep gutters that love to see me fall. As if UNN gutters ain't enough, I went to see a friend in UI only to fall into their gutter again. I no know wetin I do them o. (…). Shout-out to my blind buddy "Charlse", he got to the shuttle park this morning and couldn't find any shuttle on turn. Even though his department isn't really far from the hostel, my guy kukuma turned back since there was none to walk him to his department, he missed today's lectures of course... Sorry bro. *BLIND CHRONICLES* 3

The University of Nigeria and the University of Ibadan are structured in such a way that the environment poses traits and limitations to those living with impairments. Sailaja Chennat note that; "For each domain, the level of functioning a person experience depends on both the body and the attributes of his or her environment that can either lower or raise the person's ability to participate in any activity" (3). The environment at the University of Nigeria, Nsukka, lowers the ability of blind people to participate in academic activities. Adeleke humourizes his falls on various university campuses because of a lack of inclusive architectural designs, and his falls also cause various physical wounds on his body, as the narrative indicates. Adeleke's narrative is self-referential to the plight of others living with blindness in society and writes about other of his blind friends, Chinedu, Nonso, and Nwanchor, but concentrates his narrative on Joseph, thus:

> Joseph stayed longer than usual in the bathroom on that day, trying to look fresher I suppose. There were four blind students in his class. Chinedu, Nonso, Nwanchor and the supposed dreamer but blind Joe himself. His lateness in the room, dressing carefully like a woman could have exhausted his fellow blind classmates' patience. They all left him at the hostel and set off for the matric venue. Minutes elapsed before our dear Joseph finally got ready. In a perfectly ironed dress plus well-polished pair of shoes, the blind boy slowly trailed along the hallway in the hostel with the shuttle park destination in mind. Oh, I forgot to tell you that most blind students don't relish the act of finding their way with a guide stick, we consider it too attention calling. So flagging pedestrians down has been the habit. The hostel was already scanty, students had gone up school and besides, poor Joseph didn't seem ready to seek help. Just as he came out of the Eni-Njoku hostel, His mobility angel forsook him. His instinct deserted him. His sense of smell abandoned him. He headed directly towards the deep, wide and dirty gutter collecting

> the running water from all the small channels inside the hostel and before his brains could interpret the distant shouts telling him to wait, his legs had already gone off the ground. He had a short struggle gripping the air in order to escape the fall but heck no! The gutter was particularly flooded with shit on that day specially for blind Joe. He dropped humbly inside the gutter and laid inside like a baby in his cot. All his clothes, head and body were covered in potopoto. The passers-by and shuttle drivers who had tried stopping him earlier rushed to the gutter and helped him up. His new clothes were later thrown away because not even a hungry dry-cleaner will agree to wash them. Poor Joe sadly went back to the bathroom and had another shower. Still with the pains of the cut on his leg, he bitterly dusted off the sand particles on his mattress and forced himself to sleep. I almost cried for him when he narrated the story. Fate should have chosen another time for that ordeal, not on his happy day. *BLIND CHRONICLES* 8

Adeleke's narrative indicates how the environment poses a disability for people living with impairments. Jospeh could not join others in celebration of his matriculation because he fell into a gutter that was right in front of his hotel. So, the Eni-Njoku hostel was not designed to accommodate those who are impaired, and even when they have some students living with disabilities, they do not modify the environment to ensure the safety of these students, and they allow them to be endangered by their environment. Adeleke's case and that of his friends are a critical representation of the exclusionary structures of the Nigerian university environment across the country. Tilckolay calls it access barrier (11). The Nigerian universities are not built to accommodate the various needs of people living with disabilities because of the personal gaze of those funding, approving, and designing these structures. Adeleke acknowledges environmental disabilities and how the environment restricts him because of his constant falls that pose a threat to his life. He submits thus:

> My lucky moment is when the gutter has no filth in it, I will humbly come out with a deep or superficial bruise on my leg and hope that will be all for the day. But if eventually my village people catch up with me in their chase, falling inside the pit wouldn't just be once for that day, it may be twice or thrice, depending on how powerful my village people are. And in most cases, I won't just sustain wounds, I will as well receive enough mockery from those who felt the passing lady was what stole my focus on where I was going. There wouldn't be a need to announce my blindness to them after all, so I will rather let it slide and slyly bounce out of the gutter. At times, my hard-earned brogues and moccasin lost their worth to the swallows of the disgusting filth flowing in the gutter. *BLIND CHRONICLES* 14

Adeleke falls into gutters and considers himself lucky when the gutter has no filth in it, and most times, he bruises his leg. The environment acts as a source of restriction for him to the extent that he falls more than once a day. Sometimes he is insulted by passersby until he announces his blindness. Aside from environment disability, there are no provisions for people living with disabilities in terms of the university providing audio books to make learning easier for people who are blind, and they had to go through stress to translate their own books and lecture notes to audios to enable them to listen to them. Their lectures are not pre-recorded, and with the failure of infrastructure in the global south, those living with impairment are doubly affected by these situations, as illustrated in the narratives of Adeleke as a personal gaze to his exclusion in society. Adeleke observes that:

> But wait, have you asked yourself on how I could perhaps read when there is power outage? Evidently, all my reading depends solely on gargets which wouldn't work without being powered. And during last semester's exam, it dawned on me big time. My hostel had a little issue with electrical connection, and I had to squat all day in a photocopy centre so as to power my devices. Oh, how I wish a ten-naira candle could as well illuminate my book pages. SMH No, this is ingratitude. If my only complaint is that my gargets are electrical, what about some of my blind buddies who spend extra sums on getting their notes recorded? Just yesterday, a friend was lamenting on the hollows in his pocket. His exams start next week and he has been photocopying materials upon materials. Now the problem is the money to pay someone that will record the materials for him. You may be asking why he can't scan them into his PC like I do but sadly, the contents of the materials are handwritten and the scanner wouldn't capture characters that ain't print. *BLIND CHRONICLES* 12

When there is a power outage in school, as is often the case, and exams are approaching, students who are blind face hardships in getting their materials into an audio form because the university did not make provision for their inclusion in the kind of education that was given to people with impairments. Blind students had to outsource their lecture notes and textbooks, which was an additional cost to their little resources, which they survived on. Giving the students pre-recorded notes would have solved their problem to some extent, but society, by its very design, excludes those living with blindness from the university learning environment. The environment constitutes a form of disability for those living with blindness, and they face various challenges to being educated. Adeleke highlighted one of these challenges in *Blind Chronicles* 13 when he states that:

> Had to run under the heavy rain with my buddy to get my exam answers printed at a cyber stand. The flood, however, was not helping matters at all. Na so I dey enter potholes filled with water one after the other. My guy will be like "jump for water fool!" But the anxiety of the invigilators' patience running out if I fail to get my exam answers to them on time wouldn't let me think straight. I would jump as instructed but kept landing inside the potholes. And for my buddy, he again paid the price of befriending a blind person as every splash made by my fall inside the water sprinkled his dresses with mud. Shout-out to the one who will sacrifice his time, energy and clothes to keep the blind dude fulfilled. *BLIND CHRONICLES* 13

The structure of the Nigerian university system constitutes one of the environments that excludes people living with blindness. Adeleke had to get his own exam print for him to be able to write the exam, and he had to contend with the temperament of the invigilator and try not to anger the person so as not to carry over the course. To meet up, he had to fall into potholes on his way back to the exam hall to print his answers for his invigilator. Adeleke is excluded from learning, and he is disabled by the environment of learning. Adeleke observes that:

> At the other end, Mr. Lecturer had already called the 1st question and was waiting for us to answer before calling the 2nd question. I was destabilised, perhaps because I don't joke with my marks. "Sir, please I'm having an issue here", I called on the lecturer for some help, at least to inform him of what sudden fault my typewriter had developed, but his response sounded saucy. Or what would you have thought if you got a response like, "yes Adeleke, what's your problem?!", with a very harsh voice. Well, I could instantly smell insult, but tell me what makes a man if he can't stand by his words. So I replied him thus, "sir, my typewriter just had a fault, but I'll be glad if I can get someone whom will help pen down my answers while I dictate them". Mind you, I made that suggestion because students who ain't members of my class were passing, and as a lecturer that he is, it was never an issue to beckon at a student to come write for the blind student in his class. Besides, that wasn't gonna be the 1st time of employing that method in cases of impromptu tests, so it was never a big deal. Oh lord of mercy! I heard the insults of my life that day. He started by mumbling some words, then graduated to yelling, "what's you guys problem? Who gave you admission to this school self? Why didn't you go to a blind university where you can cope? Why are you always giving me problem in this class?!". He ranted, raved and raged at me for some seconds before getting off my neck. Maybe I felt a little bad, probably because it was in the presence of a considerable number of students; but how to get the test done was my main worry. *BLIND CHRONICLES* 41

Adeleke is insulted and excluded because of his impairment; the lecturer insults him for expressing his challenge because of his faulty typewriter. Most lecturers at the university are not well-sanitized on how to build an inclusive learning environment. They verbally abused those living with disabilities and asked them various rhetorical questions that demoralised those with impairments from learning. For us to build an inclusive learning environment, the needs of those with impairments must be taken into consideration. Dan Goodley submission that: "…the non-disable are a curious lot, constituting a community that reacts in the most contradictory ways to the presence of disability" (xii), explains the attitude of Adeleke's lecturer. The Nigerian universities must retrain their staff on how to handle students with disabilities and make the learning environment an inclusive one. The unnamed lecturer even went as far as questioning the rationale of those who gave Adeleke admission to study at the university with others, suggesting that he should have attended a specialised school. This process of questioning is a method used to dehumanise those living with one form of impairment or another in Nigerian society. Aside from educational exclusion, Adeleke experiences social exclusion and frustration that are occasioned by society. Adeleke explains how society is a form of disability in an environment that is not structured to accommodate those living with disabilities. Adeleke in account for the restriction imposed on him, thus:

> One is the stress, dishonour and neglect I experience whenever I need to go somewhere urgently and my friends ain't all nearby. In most cases, I'll just step out of the hostel exit and stand quietly, hoping for a passer-by who's going my way. Sometimes, I'll flag people down but they will pass by me, pretending not to see the helplessness clouding over my appearance. Meanwhile, I don't give up despite the snub, instead, I'll continue flagging them down until the good Samaritan will come around. But sadly, due to the time wasted in looking for whom to walk me, I might have already missed my appointment by the time and my presence at the rendezvous may not be all necessary again. There also are similar instances related to lectures attending. We, the blind students, are sometimes devoid of whom to walk us to class; and that's because our friends cannot be our shadows who stick to us all day, they also have their personal matters to attend to, hence, we resort to the alternative way of attending lectures; I mean, going out of the hostel to flag down passers-by. But during our unlucky days, we may stand for roughly an hour still without anyone to help us. By the time a Godsent eventually lends a helping hand, it's already half-time into the targeted lecture and since the lecturer didn't know what we went through before getting ourselves down to class, he will blandly shut the door and say to us; "you are blind doesn't warrant your late coming to class, so get out of here!" Well, for someone like me who prefers reading to attending lectures, I'll happily find my way to a petty shop where I can buy some snacks and chill drink, provided there won't be any quiz or attendance-taking in the class I was banished. *BLIND CHRONICLES* 54

In the Global South, some of the lecturers and the environment constitute limitations for people living with disabilities. As a result of the limitations of the environment, Adeleke gets to his lecture venue, and his profile is based on his impairment, which the lecturer is supposed to know better. This is a mindset of disablism, and Goodley affirms that: "Disablism relates to the oppressive practices of the contemporary society that threaten to exclude, eradicate and neutralize these individuals' bodies, minds and community practices that fail to fit the capitalist imperative" (xi). Even when he crosses the hurdles of the environmental restriction, he is still prevented from participating because he came late to class, and the lecturer shut the door against him. Like other blind students, without acknowledging the effort they put into navigating the limitations of the environment in getting to class, Adeleke sees disability, in the words of Goodley, as : "…an identity position, often a negative, marked and stigmatized social position" (xi), and this is illustrated in his action. Those living with blindness because of their impairment are considered beggars with no alternatives to their personalities. Adeleke highlights this thus:

> "Take him outside, he can beg after my class". Those were the exact words of a lecturer to a student who came into the lecture hall with a blind guy. Little did the lecturer know that the blind guy in question was also a student; he also was part of the class. In Nigeria and some other countries of the world, the blind are often perceived as those with only one means of livelihood; begging. People don't care if the clothes in your wardrobe are better than their "bend-down-selects" or your cologne smells nicer than the 200 naira 'aboki perfume' they wear; in as much as

> your eyes have no life in them, you are, by default, in need of monetary assistance. Hence, even when you don't beg, people will approach you and offer you money. The above statement made by the lecturer shouldn't be second to the fact that she expected the blind guy on the street, begging for alms, and not in the classroom, receiving lectures with the non-disabled students. Listen people, it is true that roadsides in Nigeria are usually flooded with beggars, of which a considerable number of them are blind, but not all blind persons pick up this act of begging as a means of livelihood, there are many of us who have been certified in various fields of study, got employed, employed people and live a comfortable life afterwards. (…). This misconception held by many that the blind should be recipients of alms need to be cleared as soon as possible. Although, I'm not kicking against rendering help to the challenged, of course even the able-bodied need help, but it's somewhat embarrassing when you walk up to a blind person only to offer him a monetary assistance. It makes us feel like we're the societal piggy bank or something. Whereas, the person whom you perceive as being needy simply because he's blind might even have in his pocket what you can't earn in a month. Besides, we necessarily need not to be relegated to receivers, we can equally be givers, just like what I do for the street beggars. If at all you've got some change to spare for me; for the blind girl you admire her doggedness; for the disabled boy whose perseverance inspires you; please show some tact in order not to make your beneficiary feel like a beggar, especially if he didn't ask for your help. Not all the blind are beggars, believe me. *BLIND CHRONICLES* 66

In the social gaze, people with blindness are beggars, and that is why a lecturer assumed that his student was a beggar. Susan Baglieri an Arthur Shapino affirms the foregoing; thus, "We begin to form attitudes about disability early in life, from strong cultural influences, including school, media and literature" (3). The lecturer did not consider the possibility of a blind student being part of his class; this ablism view is enabled by social realities that exclude people living with impairments. Adeleke notes that those with blindness are profiled as beggars in Nigeria and other parts of the world. Due to this social gaze, even when people with blindness do not beg, people approach them and offer them alms. Adeleke's acknowledgment that the streets are flooded with beggars is an indictment on the Nigerian government's failure to provide an enabling environment for them to achieve their potential. Adeleke is of the opinion that not all blind people in Nigeria need alms from the people and that sometimes offering alms to the blind is a source of embarrassment.

Amidst the disability for people with impairments, Adeleke also highlights Charle's plight, who missed the lecture because he could not find a shuttle going to his department. Adeleke's accounting for his plight highlights the plight of those who are impaired and foregrounds societal disabilities occasioned by the environment Adeleke, through his witnessing to social exclusion, erected a memorial for Ifeanyinwa teenagers living with disabilities. Adeleke observes that:

> Advise me on something peeps, am I really supposed to mourn over the death of Ifeanyinwa? Oh sorry, thought you'd known already. Well, after a long battle with

> a life-threatening disease or two, Ifeanyinwa; a blind 200-level student of Sociology and Anthropology department [UNN] yesterday, finally waved goodbye to the world. Hey, this isn't a news story or something, just get the point I'm trying to make here. This girl has suffered all her life. Reportedly, she died of breast cancer and wooping cough. Then I asked a friend who gave me the news, "isn't it just better that this girl died?" Learnt wails of grief took over the deceased's hostel yesterday and most of the statements filtered from the clamour were asking why the girl had chosen to leave her people behind. Hi mourners, it is true that no matter how bad, old-aged, terrible or uncomfortable someone's life may be, you will still never wish for them to die. But crying your eyes out isn't just worth it, I'm certain the girl is finally at peace now. Hmmm, the lord is indeed good. Just get this once and for all. At times, blindness can make you feel like a hammer with a plastic head. And yes, that's the only disease I have but almost felt like the end of the world to me initially. Then just imagine when the so called weaker vessel combines breast cancer and a dangerous cough to her blindness, isn't that too much for even a mortal sin? Oh, The lord is good all the time o. And whenever people reach the zenith of their compassion for the blind and feel they need to be consoled, they will be like, "maybe God only took your sight so you could achieve your dreams in life" And which I'm not disputing. But what of the case of Ifeanyinwa? An innocent girl who lived almost all the days of her life in a dreadful shadow. Did I hear you say it's also the plan of God? *BLIND CHRONICLES* 5

People with impairments are excluded from society, such as women who commit suicide and take their lives, and this is also indicative of Ifeanyinwa life. Davis observes that; "An impairments is something that limits you psychically or mentally" (7). Ifeanyinwa's impairment and social disability become a source of limitation for her. Many consider blindness an act of God that allow people living with impairments to achieve great heights. Adeleke questioned God and why Ifeanyinwa had to suffer from blindness and the stigmatisation and exclusion she experiences, and when she was diagnosed with other illnesses like breast cancer and a dangerous cough, she had to end her life. Peoples' attempts to console those living with impairments end up complicating their lives, as Adeleke's self-referential accounts for Ifeanyinwa's life and why she committed suicide. There is a need to train and include psychologists in universities and to assist those living with impairment, and there is a need for conscious and intentional education in the global south on how to relate to people living with impairment so that, in an attempt to encourage them, one does not drive them to commit suicide, like in the case of Ifeanyinwa, who did not have a family that had a psychological hold on her, like Adeleke's mother had on him and his continuous existence.

Healing plays a functional role in Pentecostalism in Nigeria. Healing in whatever form it takes gets the adherent to a particular faith stock with their religious leaders and increases the followership of such a religious leader, and as such, many of the religious leaders performed staged deliverance. Fiona Kumari; "Disablism is a set of assumptions/ conscious or unconscious/ and practices that promote the differential or inequal treatment of people because of actual or presumed disabilities" (4). This is the case of religious leaders in Nigeria, and through their feigned deliverance, ableist actions Kumari notes that; "…a chief feature of an ableist viewpoint is a belief that impairment or disability (irrespective of «type») is inherently negative and should the opportunity present itself, be ameliorate, cured, or indeed eliminated" (5). While they complicate the lives of people with one form of impairment or another by tagging them as not having faith, that is why they are not healed by the so-called religious leader. Adeleke used his own personal experiences to testify against the religious exploitation of people living with disabilities. David Bolt affirms; "…disabled people experience various degrees of subordinated and diminished lives through social, legal, religious and cultural discrimination" (16). Adeleke acknowledges that people living with impairment wants to be heal and that's why they visit religious houses that have demonstrated staged healings. Adeleke interfaces the experiences of his blind friends with his encourage with Pentecostal form of healing. He submits that:

> The Synagogue Church of all nations. Rings a bell? Yae, that gigantic church in Lagos owned by prophet T.B. Joshua. If the person get healed after some jumping and praying by Joshua, then I owe you my home address so I can be arrested for character assassination. I've got a few blind friends in my school and for we the blind folks, our friendship wouldn't become intimate without having asked questions on how we individually lost our sight and the measures that have been taken so far to restore it. And this is what two of my blind friends have got to say when asked whether they have tried visiting the Synagogue church in Lagos for their healing. Be aware that there are two different accounts here, but the two are similar, so I'm merging both into a single story. Mtcheeew! Which Synagogue church? Everything is a lie guy. I stay in Abuja but because I wanted to see by all means and the Synagogue church had so much been talked about as being a place of miracle and wonders, I urged my elder brother who also wanted for me to see again to assist me to Lagos which he meekly complied. I am a very good Christian, so it's not like I went without taking my faith along. When we finally got to the building of the church, we were ushered into a big room where we stayed throughout that Friday, Saturday, then before grabbing the chance to join the service on Sunday morning. The service was awesome, different people with distinct status crowded the hall to the exit, I knew my healing was near since I had earlier been told that I wouldn't return to Abuja with my blindness. We sang, prayed and worship for hours before the service was finally brought to a halt. Then an announcement was made; it was time for the healing session. On hearing this, people flocked to a certain direction as though they were acquainted with the environment already and in order not to carry last, my brother and I quickly followed the trend by going their way. We got to the entrance of a smaller hall and a man waiting at the door asked all the helpers of the challenged persons to leave. So, my brother had to leave and I was all by myself. We entered the hall and formed like three queues, then T.B. Joshua himself came and started attending to us. I was the third on the first queue, the two people in front of me had been taking to the healer and honestly, there were noise and screams, shouts and hullabaloos, praising Joshua and his god for healing the cripple who I was initially standing behind. Just as it was about to reach my turn, a man approached me and asked; are you in? The

> question was not really clear to me and judging from my sluggish reaction, the man could tell that I was finding his question strange. He gripped me by the hand and led me to another queue at the back, telling me that I was not meant to be on that former queue. I then noticed that a special set of people were healed on that day, none of us who had been in the same room since Friday got healed. Hmm. Isn't something fishy? *BLIND CHRONICLES* 23

Adeleke chronicles the experiences of his friends who spent their money seeking healing, as advertised by staged healing. The narrative indicated that various deliverances were staged and managed, causing those involved additional costs in getting to the deliverance centre. Through his friends' experiences with religious exploitation, Adeleke testifies to his personal exploitation by religious leaders in their pretence to provide healing for his blindness. He submits that:

> Now, it's the turn of the fake Alfas in islam. This one happened to me directly, so I can tell the story better. I was staying with a teacher when I was in SS1 and I got tired of staying with him. My freedom was miniaturized and I wanted to go back to my parents. Luckily, one weekend like that, my teacher gave me the chance to go home but return to his place on Monday. I didn't want to return so I spent the entire weekend marking out plans on how to gain my freedom again. On Monday morning, I was meant to go to school then from school, return to the teacher's house; but I did something. I stood from my bed and took a mouthful of water in my mouth, then lied recklessly on the floor and leaked the water slowly out from one corner of my mouth. My younger sister whom my mum had sent to wake me up so I could prepare for school on time saw me lying on the floor and got scared, she ran to my mum and gave her the news. There was pandemonium in the house that morning and everyone rushed to my room to revive me from dying. My acting was finger-licking perfect that morning. Making my mum cry upon a mere pretence deposited some guilt in my mind and so I came back to life after making sure I had convinced everyone that I had fainted. My plan later yielded my intention because my mum wanted me to be around her so she could keep her eyes on me. So I stopped staying with the teacher. The following weekend, my dad arrived from his journey and heard the story of my faint. Being a muslim, he drove me in his car to an Alfa [a man of God in islam] and narrated the whole story to him. I was damn scared, thinking he was going to see that all I did was just a pretence but no, all of those people are liars. The Alfa took my right palm and recited some arabic words, then did some nonsense which I didn't understand before finally breaking the silence. "Oh, he was shot an arrow in his sleep. Assuming you brought him immediately, I would have seen the face of the person that shot him". I smiled in my mind; this man is a creative fool I swear. Mind you, I'm not insinuating that there are no good men of God or that miracle doesn't exist, but they are really hard to come by these days. The last blind man that got healed and which I'm familiar with is the one Jesus healed at Bethsaida. Even though it's also a bible account, I wouldn't want to doubt it anyway. So, guys, if blindness is really remedial, then you wouldn't have seen quite a number of blind persons on

> the street and in school. There wouldn't have been anyone to be called 'a blind person'. Nollywood must have made you think blindness is some condition that can be treated through surgical operations; since you hardly see the protagonists go blind without seeing towards the end of the movie. *BLIND CHRONICLES* 23

Adeleke faked his fainting, and as a Muslim, he was taken to their Alfa a Muslim cleric , and as they got there, the man misinterpreted his action as a spiritual attack. Adeleke accounts for this action as a product of the misrepresentation of persons living with blindness in Nigerian home movies as premise for misinformation on persons living with blindness. This misinformation also strengthens the religious attempts to portray a staged cure for people with various kinds of impairments. Adeleke seems to suggest that Nigerian Nollywood needs more sensitization with regards to blindness and that not all forms of blindness are curable. Adeleke is saying that both Christian religious leaders as well as Muslim Alfas exploit people living with disabilities, as he has illustrated.

Adeleke, even as a student, is stigmatized, and exploited. Those living with blindness are vulnerable and are exploited by the ablism society. Some steal from those who are blind, and Adeleke illustrated his plight when he acknowledged his exploitation; thus:

> Then shortly, a faint noise penetrated through the tiny space between the rims of the earphones and the walls of my ears into my eardrum. So I hit the pause button and listened to what was generating the noise. A guy had sneak into the room, thinking all the occupants were blind. You know that surprising glance you cast when someone suddenly shows up at your side? Yes, that was exactly what my buddy did and got the suspected thief convinced that he ain't blind. Drenched in shivers, the guy asked my buddy with a trembling voice, "guy, you get garri? (…)." He turned promptly at the guy, fixed a gaze on him and asked mockingly, "guy, you smoke igbo?". That one struck my humour cords and got me wanting to beg for space so I could faint out of laughter. To start with, there was one of my roomies washing at the door post which the guy didn't ask of the garri. For me, I was inside the room but the guy passed me without saying a word to me. He asked my friend for garri when he noticed he ain't blind, judging from the way he turned around and looked at him. Maybe I would have recorded another loss of property by now. Like the way my recorder and phone were stolen last year when I most needed them. It was like this time last year [exam period], only to check where I kept my gargets and couldn't find them again. All my notes went with the incident, had to start recording them from the scratch. I can tell 7 of my blind buddies who had. *BLIND CHRONICLES* 15

Those who are blind are stolen from, including their laptops and phones; they are vulnerable, and they are easy targets for thieves. The blind are abused physically in society. Adeleke accounts for his experience thus:

> And when blindness comes with its price, we either pay by being punished for the things we did unknowingly, receive mockery from people or nurture shame, insult and other unpleasant feelings as a result of our reflexes or any act done

> blindly. Let me start by sharing a roommate's experience with you. He blindly trod on a lady while trying to alight from a bus and without a second thought, she threw the dude a thunderous slap, a slap which got his specs crashing into pieces and left his mouth gagged for seconds. The lady didn't even wait, she immediately walked away without knowing what sorrow she had just planted into a blind man's heart. Talking about my own personal experience now, I've got the good and the ugly ones. Just few days ago, some girls whose beauty was second to monkeys' showed me a reflection of their dark heart. I was going up school but because it was noon, there were no shuttles on turn, so I approached the ladylike footsteps pattering towards me and flagged down whoever it was. "Excuse me, are you going up school?" I asked just as they walked into my front but lo and behold, the girls who were later confirmed to be 3 instantaneously went mute and pretended to be deaf. *BLIND CHRONICLES* 35

Those who are blind have been punished for being blind and for the mistakes they committed because they were blind. Some in the able society have mocked those living with blindness, and some have inflicted pain on people with blindness. Adeleke used the experience of his friend to illustrate his subjugation, indicating that the abuse of people living with disabilities in Nigerian society should be a general concern for the abled persons in the society. Social gaze is intergenerational, and it is a project of the able society and their share of this religious perception of spiritual healing for people living with disabilities, as indicated in the case of Adeleke, and he foregrounds this intergenerational concept of gaze when he submits that:

> At the very dawn of the following day (Sunday), we both bathed, ate, exchanged a few love vows before finally setting out for her so-much-talked-about fellowship. We arrived there, the Redeem Christian Fellowship – UNN, within the flicker of an emotion and settled down afterwards. As a worker in church, Marvellous had to leave me amidst the congregation and headed for the podium where her service as a choir member was required. Oh yea, Jesus, yes, send down the holy spirit- my father my father my mother my my my my. The church service commenced at full blast. Then just like 15 minutes into the programme, I felt a hand on my shoulder, a tender palm round my wrist followed by a slight pull with an effort to raise my ass off the chair. I didn't resist what I felt, perhaps because I thought it was Mavis, so I calmly allowed to be led out of the seat track, then the aisle, then the church building. The loud sound from the generator and church instruments rendered my ears ineffective and thus, denied me a hint of what was happening around me. I was brought to a spot likely to be a yard away from the church's exit and because the noise had subsided, I could clearly hear the voices speaking to me already. I had been led outside by 2 young ladies (prayer warriors), they wanted to open my eyes. *BLIND CHRONICLES* 58

This act is a form of interested gaze by student prayer warriors, a new form of Pentecostalism, and they interrupt the peace of those living with impairments with a promise to heal them. This prayer warrior invaded Adeleke's space, offering healing without informed consent, and he played along, hoping that he would be healed. The drama started in earnest, thus:

> I felt embarrassed and disgruntled; I mean, how could some persons just walk up to my chair and lift me off my feet because they feel I need prayers? Is it that I can't attend a church without being offered some hands on my head? It's no problem. I vented my displeasure to the ladies, correcting them on the impropriety of their intrusion. After a few seconds of my polite ranting, the two of them apologised for their action but insisted on restoring my sight with their firry prayer. Well, it's not like I don't believe in God, but this nonsense of placing hands on my forehead for some cheap miracle is damn ridiculous. In fact, a pastor almost pushed in my eyeballs all in the name of praying for me. Back to the two ladies; their persistence to pray for me made me to succumb and so the prayer started. The chose one eye each. The first lady's hand on my right eye while my left eye was covered under the second lady's palm. "In Jesus name!" Shakarabata sco sco sco huuuuu. And the prayer went on for some lasting minutes. I was relieved to ear, "in Jesus" name we've prayed." And so they said to me, "now open your eyes and see the world". Lol, that's just what they made me do. Like, is this some joke or what? Ok. I did like they said, opened my eyes and looked around, then replied thus: "I see nothing". This sparked off a disappointment in them and hence resumed their prayer. After some while, I was told to open my eyes again and tell them what I see. And just like I did before, I told them how dark my surrounding was; very very dark like a sky without the moon. The one with a romantic voice then began to slap the pillar she was leaning on and asked, "Look here, what am I doing now?" Lol. And I was beginning to enjoy the irrationality. I replied her, "you're hitting a pillar". Omg! She was so elated. "you saw that, right?" She asked. But trust me na, I happily dashed her feeling by telling her "no!". And they continued praying on and on, on and on, their mouth merited my pity sha; as in, e no dey pepper them? I was asked to open my eyes again but still didn't see anything. They became uneasy, they were so ashamed of their inability to perform the intended miracle. Perceiving their disappointment, I almost admitted that my sight had been restored. Abi which kind wahala be this na? On the other hand, I was thinking of Marvellous; what if she steps out of the church and sees her boyfriend's face under the hands of some prayer warriors, trying to replace his blind eyes with the spare in their purse. Or was it Marvellous herself that sent them? No no, it wasn't her. Lo and behold, the two ladies held on to the belief that I should have received my sight after all the prayers and hence, asked me to follow them as they walked back into the church without holding my hand. That one vexed me somehow but I kept my cool. Wait, is it now a wrong thing to attend a church service? When will I ever attend a church without being seen as a mere miracle seeker? *BLIND CHRONICLES* 58

This attempt at healing Adeleke is an intergenerational gaze a hangover from watched television programmes. These young ones who feeds on gospel television programmes have been informed that those living with disabilities need spiritual healing and that those who serve God have the power to restore sight. This religious gaze has been constant molestation on the materiality of Adeleke's body and his psyche in the sense that he cannot freely attend church programmes without them offering healing and attempting to experiment with their powers on him. Some pastors inflict pain on him in feigned attempt to offer healing by almost pushing in his eyeballs. They experiment with Adeleke's impairment as needing healing, and they seem to imply that it was a punishment from God and their intercession would provide healing for him.

There is class privilege among those living with blindness, and Adeleke once affirmed this when speaking from his privileged position. There are ways in which privilege affects one's sense of the plight of people living with disabilities, and Adeleke affirms this when he observes that, thus:

> Few years ago, I was invited by a television presenter who grew fond of me to a TV programme. At the time, I was still an infant in blindness, probably just 3 or 4 months into the enrolment of my rehabilitation classes. I explained to the presenter on how I do give out alms to beggars even though I'm blind, how donating toiletries and other affordable materials to orphanages has formed a habit out of me, how I help my able-bodied friends financially whenever I'm boxed up and therefore, offering me alms by a pedestrian is like offering a fish in the ocean a droplet of water. Well, my response wasn't that bad though, but I forgot the fact that I was on air and judging from my answer, I might have created an impression that the disabled do not need any assistance. I felt like I should have answered more carefully so that the less privileged ones can get material help from the viewers at home, remember Demola is not less privileged. *BLIND CHRONICLES* 27

Adeleke performed self-criticism and indicated that there is no fixed decision for those living with disabilities. Although he does not need help, he understood that some people needed help in society, and the kind of help they needed was not the form of charity that the Nigerian society gave them but the creation of an enable society so that they could function and not rely on the charity of others to exist. Yinka, Adeleke's friend highlighted this approach to dealing with social gaze among his classmates when Adeleke asked him on a radio programme how he deals with social gaze because people think he is blind and so he needed charity to survive. His answer provided a glimpse into social exclusion and class structure for people living with disabilities. Adeleke asked thus:

> "Yinka, what would you do if someone approaches you and offers you alms?" (…). **Yinka answered**. When I was in my 2nd year, something of such happened to me. In spite of having spent a whole year with my classmates, some of them still mistook my condition for being less privileged. They believe that once you are handicapped, then you must be from a poor or pathetic background. One afternoon like that, a classmate came to me and asked if I needed some noodles or money. Being someone who was a close pal to me, I excitingly answered "yes", thinking he had got more than enough noodles or money and wanted to share some with his friends. Little did I know that some of my classmates had called a meeting on my matter, suggesting that some items like food and money be donated to me. know

> now, they wanted to help the blind student in their class. My friend who came to ask if I needed noodles and money was the one they contacted since they knew he was close to me. I felt a bit bad on discovering that I had been made a charity case by the same persons I was receiving lectures with, but I succeeded in brightening up my face with an appreciative smile and told them politely; 'thanks so much for wanting to help me, I know this obviously is a product of your kind hearts, but sharing the same disability as the beggars at the road side doesn't make me a needy too, your gesture would be better appreciated by the motherless babies starving in the orphanage. I made sure I didn't sound ungrateful or insulting. Infact, I made them realise that not all special students have the privilege of getting financial support from their parents or relatives. Therefore, they can always visit schools for the handicapped and provide the students' lacks. Wanting to help a blind student in your class who wears nice clothes, sweet cologne and expensive footwear can be likened to introducing corruption to Nigerian politicians. The only way you guys can really help me is to give me a scholarship to have my Masters degree abroad. *BLIND CHRONICLES* 27

Even among the educated, this social perception because of personal gaze still exists that the blind need charity to survive. Yinka indicates that there is class structure even among the people, while some, because of ablism, society needs alms to survive because of a lack of government support, and inclusive society does not need such assistance. The classmate of Yinka has taken the responsibility of the government to provide for the classmate out of pity because there is no law that protects the existence and economic survival of those living with impairments, even when the implementation is lacking in all seriousness. Adeleke corroborates the foregoing when he submits that:

> And for the professional beggars among us, it's actually not their fault. Maybe I also once condemned those who chose roadsides over classrooms, begging profusely under the scorching sun for money; but not anymore. A blind man approaches you for money and you reply thus; "why can't you go to school and be like Demola? Please get out of here!". It's possible you are forgetting that not everyone has the opportunity I have. I have both parents alive and they are so bent on assisting me with all my life endeavours. But Tony's story is a different one. Apart from losing his sight at a very tender age, his parents have also passed away and his extended family has shut him out of their ancestry. The government of his state is not helping matters either; he has written many letters to the state ministry but none was read. Poor Tony resorted to begging in order to feed his stomach and you want him to be like Demola? Ahba, we don't have the same story na. My people, don't you think it will be more productive and fulfilling if you can help Tony's kind? I mean the blind boy whose clothes look tattered and hair unkempt. Your hundred naira note will be better appreciated by our members on the street, not those of us who have followed a decent career path. If you indeed want to offer me, a proper looking blind person a monetary assistance, just pay my school fees, ask me what I'm lacking or impregnate my bank account. I'm tired of explaining to people that I'm not a beggar, I'm simply blind. The two words "blind"

> & "beggar" can stand separately, they mustn't go together. I'm "blind Demola", not a "blind beggar". Oh lord, let today, October 1st, set me free from all the misconceptions people harbour about me. I need my freedom! *BLIND CHRONICLES* 66

There is a classification of professional beggars: those who require arms to succeed and who are not in the same social class as Adeleke. He makes a case for them, which people should not use. He uses himself to illustrate privileges while his friend Tony's parents are late and there is no social security for him, and as such, he needs alms to continuously survive because of economic disabilities constructed by society that exclude people living with impairments. Even when the said Tony has written several letters to the government of his state, he receives no support from them to aid his education, which shows that those living with impairments are not taken care of in society, and there is no social welfare for their continuous existence in society. Adeleke makes a classification through his narrative of the social stratifications of people living with blindness and insists that these ones need assistance for their survival. As a result of social gaze and perception, Adeleke had to explain to others repeatedly that he is not a beggar, and this indicates the social exclusion of people with impairments and considering them as just one thing: "beggars." Adeleke did re-imaging himself against social gaze and perception when he called himself by his name and insisted on the fact that he is a human with a name and not a "blind beggar." Adeleke, based on class privilege among the blind, defines themselves thusly:

> Good day my compatriots, I bring to you the tidings of a new association in town, BBN. No, we ain't the x-rated reality show; BBN stands for Blind Boys of Nigeria. 'Vision sustained' is our motto, sunglasses is our logo. By our logo, you shall know us. We like it dark and opaque. While some wear it simply to protect their eye from harm, some put it on to prevent people from seeing their unattractive eye region. Adebisi Olajuwon likes to have his on because he thinks he looks more appealing in it; but for Larry Igho, he's a culprit who doesn't wear it at all. As a title holder in the association, I always have mine on; come rain, come night-time. Shush, no questioning, I need to live by example. It's also my responsibility to prescribe for our members what type of shades to get. Yahoo specs will bring us into disrepute, so I'd rather I prescribe shades sold on wheelbarrow. You know, we don't want anything yahoo yahoo rubbing off on our corporate image. We can't afford to be seen as those who hunt for women's lingerie. We have members in all the 36 states of the federation, from Abia to the FCT. The blind beggars? Mba, they ain't part of us. Literacy is a major requirement for membership in BBN; hence, barbarians are not welcomed. Besides, the association prohibits us from wearing tatters, so how our street brothers wan take do am?. All we can do, as stated in our constitution, is give them alms anytime we come across them. Who knows, maybe they just do not have our own kind of opportunity to be educated. In BBN, we don't make or receive video calls. It's a threat to our privacy. We had to ban it after a member's ridiculous experience. His admirer called him, asked him to show him the size of his penis by focusing the camera on it and invited her entire village to come watch the free show. So my people, that's how our dear member's mamba suffered in the

> eye of the beholders. Dindinrin boy. Meanwhile, it has come to our notice that some of our members are uncouth and flirtatious. We learnt they do the lazy man kind of greeting by raising their middle finger at every girl they encounter. Like, fuck you!. And there also was a report we received from an anonymous lady last week, complaining of how one of our members whom she assisted to his destination was sexually assaulting her afterwards. *BLIND CHRONICLES* 79

Through their privileges occasioned by education, they define their identity as BBN Blind Boys of Nigeria. Through their motto, they indicate that they are capable of sustained vision. Through his personal gaze, he attempts to describe the materiality of their physical existence as those wearing shades and the ones not wearing. This privilege class of BBN is occasioned by their education, and it is a source of exclusion for those living with blindness who are not educated.

Adeleke, through his narrative, provides a form of sensitization on sexual life and indicates that those with blindness are capable of romance and sexual life, although the able society has excluded them from it. Adeleke observe that; "My disability has nothing to do with my romance, so be sure to have a good married life" (*Blind Chronicles* 29). However, Adeleke acknowledges some limitations to his love life, which are associated with sight, and how he would not be able to admire his wife. Adeleke also wondered why abled society questioned their sexual feelings, which is a form of human's definition. Adeleke wondered why he was asked by a girl, thus:

> Then she brought forth this question; "sorry Demola, do you also get turned on when you touch a lady?" "Ahah, what a question? Is she forgetting that the human sense organs are five? I lost just one and not all of course." Even my friend was startled by the question, so the idiot started laughing and I followed suit. The naughtiness in me was what made me reply the girl with "I don't know", I told her that I'd never tried touching a lady but I will be willing to experiment her question if she can offer herself as a volunteer. (…). Lol. It was my friend's girl, my little prank had scared her away. It's funny though, but most of the disturbing questions I receive come from the opposite gender. I've delt with questions like: how do the blind have sex? Do you know where the female sex organ is located in the body? Have you touched some places on a woman's body before? Bla bla bla. Many a time, I do wish I could avoid these questions to spare myself from being vulgar during the course of answering; but if I do really want to enlighten the public on my world and what I do in it just like I've claimed, then maybe one only prize I'm going to pay is to break away from shyness and answer the most awkward questions with sheer confidence. *BLIND CHRONICLES* 30

Many associates impairment with sexual disabilities, given the kind of question they asked. Adeleke, through his narrative, helps us understand that the loss of sight is not the loss of sexual feelings and emotion. In fact, in *Blind Chronicles* 49, Adeleke experiences how he is emotionally excluded when he expresses his feelings to a girl and tells the girl that he loves her. The made jest of him among her friends wonders why, of all the people in the world, it was a person with blindness that would express his love for her. Through

Adeleke's narrative, we could see that those living with one form of impairment, or another are excluded from society because of the materiality of their bodies. Adeleke, in highlighting his humanity, notes that "I've got emotions as well; blindness didn't cast away my feelings. Once you are around me and you keep coming around, I'm bound to start liking you, then maybe love, and that's because we, often times, appreciate people, not by their looks, but their care and attention towards us. So, when I tell you I love you, don't make jest of me during your friends and make me feel like I came to the wrong world. You can always say 'no', probably because I'm blind, and you'll ashamed to have a blind partner…" (*Blind Chronicles* 49). Adeleke highlights the nature of people with blindness and that they become attracted to people who show them care and indict society, and that is why one who is abled is ashamed of dating or marrying someone with an impairment because of social narratives and perceptions.

Conclusion

The study has analysed the dimension of social gaze, which leads to disabilities in society. We have also seen that social gaze has affected the mobility of people with impairments because of the ableism of society. The social disablism of society has attempted to cure those living with blindness, thereby complicating their lives. We need strong laws backed by political will to build an all-inclusive society. People living with disabilities must be encouraged to tell their everyday stories because it is through these stories that people will be able to have different dimensions of insiders' views of the exclusions of people living with disabilities. The government must thrive in building inclusive societies through reforms in schools, job employment, and social amenities. The university environment as well as society at large should be redesigned to accommodate the challenges of people living with disabilities because they are part of the diversity index of a society. There is a need to set up counselling units in schools to take care of the psychological needs of those living with disabilities. There must be deliberate sensitization of the ableist society on how to relate to people with impairments. There is a need for the retraining of lecturers and teachers to be able to manage students with special needs. The government and school management should try to build an inclusive environment for learning. Provisions should be made to meet the needs of those living with disabilities. The society as well as parents have a role to play in providing support and encouragement for their children and friends when they are disabled. There should be laws that control religiously staged miracles with regards to those with disabilities, and informed consent must be obtained before any form of miracle is tried on people living with disabilities. The society as well as the government must try to create job opportunities for those living with disabilities by providing free and compulsory education as well as learning skills, and in this we can build all-inclusive society.

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ABSTRACT

People living with disabilities are excluded in various ways, like the infrastructure designs of Nigerian buildings, the school environment, job opportunities, and social services. Demola Adeleke's Facebook *Blind Chronicles* is a personal narrative of the collective narratives of people living with disabilities. This study adopts a discourse approach to textual analysis and observes that personal Facebook narratives allow survivors of social and institutional exclusions to bear witness to their subjugation in organic society. Through this mirroring, this study accounts for strategies for combating barriers to social inclusion for people living with disabilities. This study, through the application of an art-based research approach, trauma theory, and the concepts of "gaze" and "proximity," attempts to analyse dimensions of proximity and gazing as vectors of exclusion for people living with disabilities and the effects of such exclusions. This study concludes that sensitization, implementation of new laws, and enforcement would lead to social inclusion for people living with disabilities.

KEYWORDS

disabilities, Facebook, inclusion, gaze, proximity, trauma

Part 2

FROM SOLIDARITY TO INTEGRATION: CHALLENGES IN INTERDISCIPLINARY STUDIES

Behavioural and Emotional Characteristics of Emotionally Deprived Children of Primary School Age

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Introduction

An increasing number of studies in psychology and psychiatry (Allen, 2000; Baars, 2020; Beckett, & Sonuga-Barke, 2010; Harman, 2000; Hostinar, 2012; Kennedy, 2016; Kumsta, 2017; McMillen, 2005) have found the decisive influence of childhood on the rest of a person's life. This suggests that many factors such as the environment in which children live, the group's socio-psychological microclimate, opportunities for development, educational conditions and the psychological childhood trauma are of particular importance.

From this standpoint, the most vulnerable group include orphans, children deprived of parental care, children from dysfunctional families, children of migrant workers, "street children", and children from seemingly well-off families, where some psychotraumatic conditions of upbringing are traced. The lack of close emotional relations with a significant adult (parents, or persons acting in loco parentis) leads to early deprivation experiences of such children, their removal from dysfunctional families and their institutionalization by the state. This may explain why millions of children worldwide still live and grow up in institutional settings despite the increasing prevalence of family-based arrangements for orphans.

It is by now generally accepted that boarding schools cannot provide optimal conditions for the full mental development of children. In addition, emotional deprivation are the effect of an ill-treatment, emotional abuse, neglect, emotional neglect, indifference and the inability of biological parents to take proper care of their children. It often correlates with mental development and health problems that are diagnosed in these children when they move to boarding schools or foster families.

Emotional deprivation is, broadly speaking, a long-term situation in which a child is prevented from satisfying emotional needs and developing close emotional contacts. The range of physical, mental and social disorders described by researches illustrates the negative impact of emotional deprivation on children of different ages in residential institutions or in a dysfunctional family environment. Researches from different countries (USA, UK, Canada, Norway, Australia, Scotland, Romania, Poland, Ukraine, etc.) had investigated the mental health of orphans and adopted children in general, and also highlighted the prevalence of certain mental disorders and difficulties in this group of children.

The emotional sphere is the most vulnerable. The greatest number of abnormalities, disorders and problems resulting from emotional deprivation concentrates here. The negative range of emotions and feelings experienced by orphans and children from dysfunctional families, who were later adopted or placed in foster care, leads to a number of negative consequences that require early detection and correction, and in some cases psychiatric care.

The present paper aims to study the behavioural and personality characteristics that have developed in children of primary school age under the influence of emotional deprivation.

Background

In early childhood, adopted children often experience constant abuse and emotional neglect by biological parents or have to grow up in an emotionally depleted residential environment. In other words, the dysfunctional family and residential environment became a source of psychological trauma for children, and led to emotional deprivation (D'Andrea et al., 2012). Emotionally deprived children often experience mental retardation and difficulties, as well as various mental disorders (Harman et al., 2000; DosReis et al., 2001; Minnis et al., 2006). Possible patterns of emotional deprivation include quasi-autism, attachment problems, inattention, hyperactivity, and cognitive disorders (Rutter, 2010).

A group of orphanage researchers, following an extensive study, points out the disorders in the physical, mental and intellectual development of children. In particular, they demonstrate stereotypical self-stimulation, aggressive behaviour, are often distracted and unable to establish long-term emotional contact with their peers, have difficulties in controlling behaviour, are hyperactive and indiscriminately friendly (St. Petersburg-USA Orphanage Research Team, 2008).

Children who have long been affected by emotional deprivation also experience various forms of internal and external psychopathology at all ages. More recent evidence reveals that early emotional deprivation leads to cognitive impairment, difficulties in self-regulation, emotional lability, and depression (Milleret at al., 2020).

Emotionally deprived adopted children have serious emotional and behavioural problems in contrast to normal children. They have high rates of behavioural problems, low rates of social intelligence, aggressive and delinquent behaviour, and difficulties in relationships with their peers (Merz, & McCall, 2010). Moreover, the increase in behavioural problems correlates with the age of the children at the time of adoption. This confirms the fact that children who have been exposed to long-term institutional deprivation are less likely to be adopted or placed in foster care, than children who were in the emotionally impoverished environment of a boarding school or a dysfunctional biological family until 18 months of age. Again it must be pointed out that there are many reports of children returning from substitute families to boarding schools when adoptive parents are unable to cope with a range of psychological and behavioural problems of such children (Mojtabai, 2006; Pastor et al., 2012; Sawyer et al., 2007).

The development of the cognitive functions of the prefrontal cortex is also negatively affected by living in the boarding school and dysfunctional family environments. Emotionally deprived adopted children show problems in the functioning of cognitive processes and communication, in particular, they have lower levels of perception, memory, general difficulty in concentrating and maintaining attention, in contrast to the age norm (Pearset, 2008; Hostinar et al., 2012; Beckett et al., 2010; Loman et al., 2013).

Children leaving the adoptive care system need periodic assessment of their mental health and psychiatric care, as about 62% of this group have mental health problems. The most common are post-traumatic stress disorder, depression and mania (Dubner, & Motta, 1999; Allen et al., 2000; McMillen et al., 2005), a wide range of externalizing and internalizing symptoms, and comorbid mental disorders (Oswald et al., 2009), respiratory and nutritional disorders (Savenkova et al., 2019), suicide attempts (Tarren-Sweeney, 2006), emotional and mood disorders (Burge, 2007), bipolar disorder (Harman et al., 2000), reactive attachment and adaptation disorders (Millward et al., 2006; Steele, & Buchi, 2008).

It is important to note that the impact of deprivation experience in childhood can have delayed consequences. For example, the dysfunction of the hypothalamus-pituitary-adrenal gland axis and increased cortisol levels persist for a long time in children even after successful adoption and living in a healthy family environment (Kumsta, 2017). The negative effects of severe institutional deprivation in the form of attention deficit disorder and hyperactivity can be stored throughout childhood and manifest in adulthood, indicating deep changes in brain function and activity (Kennedy et al., 2016). So, we come to the conclusion that the impact of experience of emotional deprivation on health and illness continues throughout life (Pollak et al., 2010).

There are factors that can counteract or at least mitigate the effects of emotional deprivation. These include the following: age (the older the child is, the less susceptible to deprivation), experience of emotional deprivation and a safe atmosphere, strong nervous system type and willpower, formed coping-strategies, positive “I-concept”, intellectual ability, reflexivity, adaptability and flexibility of character (Nelson et al., 2014; Abdulla, & Kasese-Hara, 2020; Baars et al., 2020). In addition, emotional interaction with parents, peers and teachers, a positive microclimate in the adoptive family and school, extending social boundaries should be effective ways to enable children to be emotionally socialized and overcome the negative consequences of emotional deprivation (Nguyen, & Cutting, 2021). However, some researches points out a decline in children’s ability to develop protective mechanisms and coping-strategies in situations of deprivation, which in turn affects neurobehavioural development (Koss et al., 2014).

Methods

For the empirical study of the behaviour and emotional and personality characteristics of emotionally deprived children, we have used a set of psychodiagnostic methods such as observation, interviewing, conversation, expert assessment and testing, as well as quantitative and qualitative analysis of the results. A total of 180 participants (90 boys and 90 girls) were recruited for this study. They are junior pupils aged 6–10 years from the city of Kropyvnytskyi in Ukraine. The interviewes were divided into three groups of 60 persons each: (1) orphans and children deprived of parental care; (2) adopted children; (3) children raised in biological families. All participants are the pupils of the orphanage, the boarding school as well as ordinary secondary schools of the city.

The methodology of this study provides a holistic, systematic description of the impact of emotional deprivation on primary school children. Analysis and discussion of the results were carried out in a comparative way. We compared the groups of emotionally deprived children (orphans with a high degree of emotional deprivation) and partially emotionally deprived children (children from adoptive families with moderate and mild emotional deprivation) and control group children (children growing up in biological families and not affected by emotional deprivation).

A set of valid and complementary methods has become a psychodiagnostic tool for the study of emotional states: Colour Mood Chart (Lutoshkin, 1988), The Questionnaire Measure of Emotional Empathy (Mehrabian, 1996), Frustration Test (Rosenzweig, 1945), School Anxiety Test (Phillips, 1980), Observation Map (Stott, 1968), Range of child's emotional manifestations (Shvantsara, 1978), House-Tree-Person Test (Buck, 1948).

The Factor Analysis of the results of the study on the effects of emotional deprivation was carried out using the Principal Component Analysis with Varimax Rotation. The adequacy of the model was assessed by the Kaiser-Meyer-Olkin criterion. Factor weight 0.30 was chosen as a measure of the level of significance.

Before comparing the mean values in all three groups (control group, adopted children, orphans), we performed the Kolmohorov-Smirnov test using the statistical package SPSS Statistics22.

Results

The statistical data obtained from the research has provided us with a precious opportunity to identify the behavioural and emotional and personal characteristics that are the most typical for children affected by emotional deprivation, and to compare them with those of children from ordinary families.

This finding allowed to identify the impact of emotional deprivation on changes in the psyche and behaviour of such children, and to compare them with normative indicators that correspond to the primary school age.

We described the results of mood and emotional states of junior schoolchildren in a situation of emotional deprivation via the Lutoshkin method (Table 1).

In order to determine the most characteristic types of mood, we observed the children during the month. During this period the children marked in a special form at the end of each day the most typical mood, which they identified with a certain colour.

Table 1. Deviations from the norm in interviewers' emotional states and experiences (%)

Mood type	Orphans	Adopted children	Control group
Prolonged sadness, anxiety, dissatisfaction	8.1	5.6	4.5
Mismatch of emotional state with life situations	5.5	2.4	0
Increased emotional arousal	37.1	51.9	12.2
Sharp polarity in the tone of the emotional state	51.6	42.6	11.8
Long-lasting monotony of emotional state	7.8	3.7	3

The data in Table 1 confirms that all analysed groups are not characterized by high rates of prolonged sadness, anxiety and dissatisfaction. This score is 8.1% for orphans, 5.6% for adopted children and 4.5% for control children. This means that children of this age are not affected by these states and are not subjected to a prolonged negative emotional state.

The discrepancy between an emotional state and a life situation is not typical in the control group, that is, children express emotions according to the experienced life circumstances and situations. Orphans (5.5%) and adopted children (2.4%) showed low rates of deviation from the norm. So, these results suggest that children are responding adequately to life's circumstances and changes in them.

The increase in emotional arousal is typical for both orphans (37.1%) and adopted children (51.9%) and the control group (12.2%). This indicates that children who have experienced emotional deprivation are emotionally aroused in situations of uncertainty, fear of adaptation, and orphans are emotionally aroused and strained when their needs are not met.

The sharp polarity in the tonality of the emotional state demonstrate that orphan children had the highest rate (51.6%), foster children had 42.6% and control children had 11.8%. This confirms that mood swings are common among children of this age: they may quickly switch from feeling happy to feeling sad and vice versa. However, more than half of children who have experienced emotional deprivation are more likely to show changes in emotional state and mood than children from biological families.

Indicators of long-term monotony of emotional state in all analysed groups were low: 7.8% of orphans, 3.7% in adopted children and 3% in control group. This shows that children throughout the day, during the week, experience a variety of emotions, corresponding to the age norm.

We may summarize by saying that the most common characteristics of emotionally deprived children are increased emotional arousal and sharp polarity in emotional state, which can often be observed in behaviour: the excitement can quickly turn into crying, screaming, and a very good mood can quickly turn into gloom, aggression.

We must of course also speak about the results of the study on the scale of assessment of the emotional states by I. Schwanzar. Grouping of seventeen emotional states provided by the method of principal component analysis with rotation of varimax allowed distinguishing three factors describing 69.74% (Table 2). We have identified certain factors as describing various forms of child negativism.

Table 2. Factor structure of emotional states by I. Schwanzar methodology

Factors	Factor weights*	Contribution to sample variance	Total contribution to sample variance
Factor 1 «Active Form of Negativism»	5.67	34.09	34.09
Factor 2 «Passive Form of Negativism»	4.19	25.48	59.57
Factor 3 «Demonstration Form of Negativism»	1.42	9.90	69.47

* Factor weight was calculated as the sum of squared factor loadings after rotation variability

Factor 1 is the most weighted or most informative (34.09%). Its positive pole is defined by positive poles of 8 emotional states: bitterness, aggression, cruelty, impatience, envy, jealousy, anxiety, and capriciousness. The negative pole is defined by the negative poles of four states: kindness, compassion, cheerfulness, arrogance. So, at the positive pole of the factor is irritating indignation, at the negative pole is depression. This factor can be identified as a factor of "active form of negativism".

Factor 2 (informativeness 25.48%) is determined by 8 emotional states with positive factor loadings and 2 negative ones. The positive poles are determined by the positive poles of the variables (in descending order of factor loadings): tearfulness, fearfulness, resentment, hypersensitivity, jealousy, envy, excitability, excitement, impatience. The negative poles are determined by the negative poles of two variables: arrogance and fun. This factor can be defined as the "passive form of negativism".

Factor 3 (informativeness 9.9%) is determined by 5 variables with positive poles (in descending order of factor loadings): stubbornness, capriciousness, excitability, aggression, resentment. This factor is defined as the "demonstrative form of negativism".

Further analysis of the grouping of emotional states in the analysed groups revealed that there is not a 3-factor, but a 4-factor model in the group of orphans and the control group (Table 3):

An additional factor was called "hidden form of negativism". In the group "orphans" it has an informativeness of 11.12% and is determined by positive poles of variable envy and jealousy and the negative pole of the variable fun. In the control group, this factor is 19.8% of the variance and is described as 3 variables with positive poles (jealousy, envy, impatience) and 2 variables with negative poles (arrogance, empathy).

So, it is absolutely necessary to admit that emotionally deprived children have a high rate of negativity. It manifests itself in the form of a psychological protest against the demands of adults, through which children try to defend their individual rights. However, in emotionally deprived children, negativism does not act as a situational behavioural response, as in a control group of children, but as a personal trait caused by the need for self-assertion and protection of own "I", which is expressed in refusal to comply with the proposed requirements and actions, the opposite of the necessary and socially acceptable.

A general analysis of the results of the study on the manifestations of behaviour, empathy, frustration and anxiety, revealed their peculiarities in groups of children with

Table 3. Factor structure of negativism by group

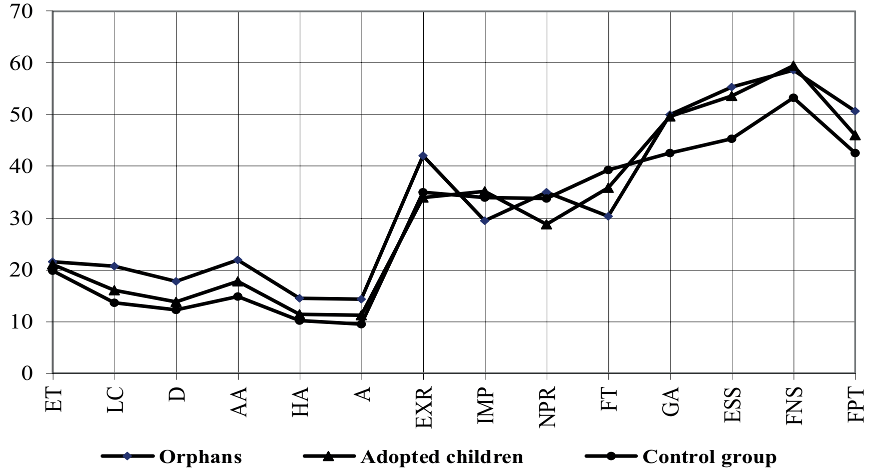
Groups	Factors	Contribution to sample variance	Total contribution to sample variance
Orphans	Factor 1 «Active Form of Negativism»	32.50	32.50
	Factor 2 «Passive Form of Negativism»	20.11	52.60
	Factor 3 «Hidden Form of Negativism»	11.12	63.72
	Factor 4 «Demonstration Form of Negativism»	8.90	72.62
Adopted children	Factor 1 «Active Form of Negativism»	34.00	34.00
	Factor 2 «Passive Form of Negativism»	26.59	60.59
	Factor 3 «Demonstration Form of Negativism»	10.26	70.86
Control group	Factor 1 «Active Form of Negativism»	20.07	20.07
	Factor 2 «Hidden Form of Negativism»	19.80	39.87
	Factor 3 «Passive Form of Negativism»	16.44	56.31
	Factor 4 «Demonstration Form of Negativism»	11.48	67.79

varying degrees (levels) of deprivation: orphans who have and have no experience of living in a family, adopted children living in adoptive families and non-deprived children living in regular families. Comparison of group averages by methodology Stott's Map, Empathic Tendency Methodology, the children's form of the Rosenzweig Frustration Test, the Phillips' School Anxiety Test, One Factor Analysis of Variance (ANOVA) was used to construct a psychological profile of emotional deprivation to check the uniformity of the variances of the obtained data. In order to determine the statistical significance and the level of reliability of the differences between the indicators of the analysed groups, the F-criterion was used when checking the uniformity of the variance according to the Livin criterion.

According to ANOVA, it was obtained a profile of average group indicators in the analysed groups, which differ statistically significantly ($p < 0.05$) for 14 variables out of 32 studied according to certain methods: empathic tendency ($p = 0.002 < 0.05$). A similar situation can be traced by the criterion of equality of group averages on indicators: lack of confidence in new things, people, situations (0.004), depression (0.013), anxiety towards adults (0.027), hostility towards adults (0.041), asociality (0.042), extrapunitive (0.009) and impunitive (0.047) responses, need-persistent type of reaction (0.003), frustration tolerance (0.0001), general anxiety (0.018), experience of social stress (0.01), frustration of the need for success (0.042), fear and problems with teachers (0.035).

The profile of emotional and personal characteristics of emotional deprivation is represented graphically (Figure 1) on average values that differ statistically ($p < 0,05$).

Figure 1. Profile of indicators of emotional and personal characteristics of emotional deprivation based on data of variance analysis (ANOVA)



ET – Empathic tendency; LC – Lack of confidence in new things, people, situations; D – Depression; AA – Anxiety towards adults; HA – Hostility towards adults; A – Asociality; EXR – Extrapunitive response; IMP – Impunitive response; NPR – Need-persistent type of reaction; FT – Frustration tolerance; GA – General anxiety; ESS – Experience of social stress; FNS – Frustration of the need for success; FPT – Fear and problems with teachers.

The profile shows that averages in the group of orphans are higher than for other groups. The empathic tendency by groups is: orphans have the highest score of 21.58. There is also a high rate of extrapunitive response in orphans (42.14), a low rate of imunitive response (29.47), and a low rate of frustration tolerance (30.40). Orphans (49.7) and adopted children (49.7) have a high anxiety rates.

For children in the control group are typical a lower rate of empathic tendency (19.75), a lower rate of extrapunitive response (35.04) and a high rate of impunitive response (33.98), with a high rate of need-persistent type of frustration reaction (53.31) simultaneously with orphans (58.56), a high rate of frustration tolerance (39.33), low anxiety rates (14.76).

In the group of adopted children high anxiety rates (17.8), low rate of need-persistent type of frustration reaction (35.91), low rate of asociality (11.26), moderate rate of frustration tolerance (35.91) are expressed simultaneously.

According to ANOVA, it was obtained a profile of test of homogeneity of variances, which differ statistically ($p < 0.05$) for 18 variables out of 32. So, testing the homogeneity of the variance of the obtained data according to the Livin's criterion showed that the ANOVA results can be considered correct only partially, as the variances of empathic tendency (0.013), general anxiety (0.014), fear of testing knowledge (0.012), fear of inconsistency with the expectations of others (0.021), lack of confidence in new things, people, situations (0.0001), depression (0.0001), self-care (0.028), anxiety towards adults (0.0001), hostility towards adults (0.0001), asociality (0.0001), hostility towards children (0.001), restlessness (0.032), neurotic symptoms (0.026), adverse environmental conditions (0.0001), sexual development (0.021), mental development (0.0001), physical development (0.012) differ statistically.

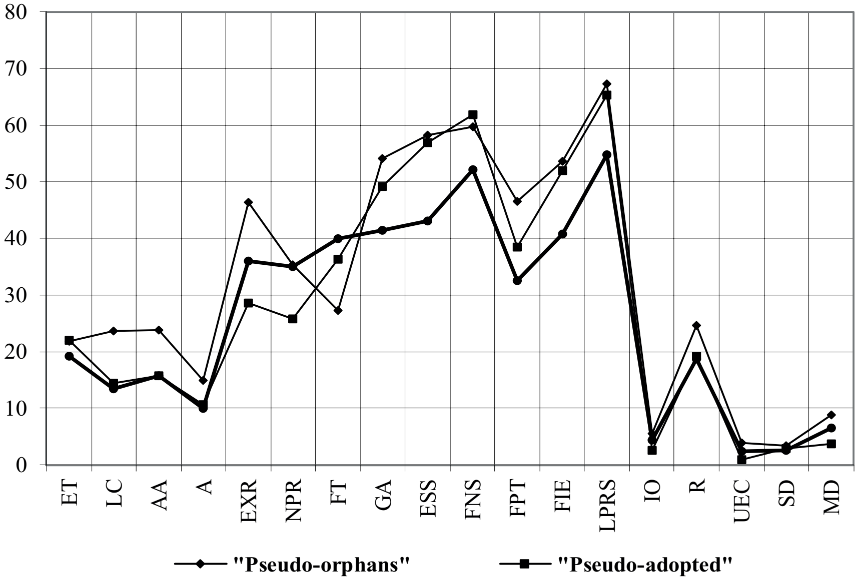
In order to obtain a statistically correct profile of indicators, which can be used to differentiate the rate of manifestation of emotional deprivation, we used discriminant analysis. Discriminant analysis allowed determining the variables on the basis of which the child can be related to the analysed group, i.e. a group with a certain level of emotional deprivation with an accuracy of 84.7%. According to discriminant analysis, the rate of canonical correlation is quite high (0.844), indicating that the results of the classification are adequate. This fact is confirmed by the Lambda Wilks coefficient, which is 0.495. The projected groups were called "pseudo-orphans", "pseudo-adopted", "pseudo-control".

The group of "pseudo-orphans" consisted of 54 children. Of these, 46 are orphans, 4 are from adoptive families and 4 are from the control group. The group "pseudo-adopted" consisted of 48 children: 47 children from adoptive families and 1 from the control group. The "pseudo-control" group consisted of 81 children: 62 children from the control group, 3 children from adoptive families and 16 orphans.

As a result of discriminant analysis, 18 variables out of 32 were identified, the rate of manifestation of which can determine the rate of emotional deprivation of the child.

The profile of group averages for certain variables is presented in Figure 2.

Figure 2. Profile of indicators of emotional-personal characteristics of emotional deprivation based on data of discriminant analysis



ET – Empathic tendency; LC – Lack of confidence in new things, people, situations; AA – Anxiety towards adults; A – Asociality; EXR – Extrapunitive response; NPR – Need-persistent type of reaction; FT – Frustration tolerance; GA – General anxiety; ESS – Experience of social stress; FNS – Frustration of the need for success; FPT – Fear and problems with teachers; FIE – Fear of inconsistency with the expectations of others; LPRS – Low physiological resistance to stress; IO – Immersion in oneself; R – Restlessness; UEC – Unfavourable environmental conditions; SD – Sexual development; MD – Mental development.

The re-profile included ten indicators from the previous profile and eight new indicators, namely: empathic tendency, lack of confidence in new things, people, situations, anxiety towards adults, asociality, extrapunitive response, need-persistent type of frustration reaction, frustration tolerance, general anxiety, social stress experience, frustration of the need for success, fear of testing knowledge, fear of inconsistency with the expectations of others, low physiological resistance to stress, immersion in oneself, restlessness, unfavourable environmental conditions, sexual development, mental development.

In the group of "pseudo-orphans" there is a high profile in terms of the indicators of the empathic tendency (22.04), lack of confidence in new things, people, situations (23.7), anxiety towards adults (23.81), asociality (15), extrapunitive response (46.37), general anxiety (54.09), experience of social stress (56.94), fear of testing knowledge (46.61), fear of inconsistency with the expectations of others (53.63), low physiological resistance to stress (67.3), restlessness (24.57), unfavourable environmental conditions (3.96), mental development (8.8), low level of frustration tolerance (27.34).

For the group "pseudo-adopted" is typical a high rate of frustration of the need for success (61.85). At the same time we note high indices for such variables: empathic tendency (22.04), experience of social stress (56.94), low physiological resistance to stress (65.33) low exponential response (28.65), need-persistent type of frustration reaction (25.74), and immersion in oneself (2.58). It is similar to the group "pseudo-orphans". Simultaneously with the "pseudo-control" group, there are low indicators of variables: lack of confidence in new people, things, situations (14.46), anxiety towards adults (15.7), asociality (10.73), sexual development (2.94).

The profile of the "pseudo-control" group is characterized by low empathic tendencies (19.21), lack of confidence in new things, people, situations (13.41), anxiety towards adults (15.7), asociality (9.93), general anxiety (41.49), experience of social stress (43.1), frustration of the need for success (52.2), fear of testing knowledge (32.52), fear of inconsistency with the expectations of others (40.81), higher physiological resistance to stress (54.69); moderate indicators of extrapunitive tendency (35.98), unfavourable environmental conditions (2.48), mental development (6.6).

In general, the profile of "pseudo-orphans" is characterized by signs of disadaptive behaviour, high anxiety rates, a low frustration tolerance with a high rate of extrapunitive responses, and a high rate of empathy.

The profile of "pseudo-adopted" children is characterized by high levels of empathy, adaptive behaviour with high anxiety rates, a moderate level of frustration tolerance with low rates of extrapunitive responses and the need-persistent type of frustration.

The profile of the "pseudo-control" group is characterized by a low level of empathy, adaptive behaviours with low anxiety rates, high levels of frustration tolerance with moderate extrapunitive response and the need-persistent type of frustration.

We can state that individual prerequisites (gender, age, constitutional qualities, and mental properties) are important for the characteristics of development and the degree of influence of emotional deprivation from the minimum to the greatest possible threat to the mental health of children but are not decisive.

Children living in the emotionally prosperous atmosphere of the adoptive family and the provision of psychological services for adoptive parents and their families contribute to a decrease in behavioural and emotional problems, as evidenced by comparing the results in three groups of primary school children.

Discussion

On the basis of the findings of our study, we confirm the scientific assumption that emotionally deprived children often experience delays and difficulties in their mental development, as well as various mental disorders (Harman et al., 2000; dosReis et al., 2001; Minnis et al., 2006). For example, in the group of orphans who are still under state care and have been the most affected by emotional deprivation, there are high anxiety rates and extrapunitiveness, low resistance to stress, low frustration tolerance, prone to depression.

It is interesting to note a high level of empathy, which is inconsistent with the classical understanding of the consequences of emotional deprivation. High empathy rates in orphans can be explained by the mechanism of "empathic distress". These findings are supported by a high level of distrust. It was diagnosed by the rate of an indicator "lack of trust in new things, people, and situations" by the Stott's map and our own observations and experience of working with orphans, since in a true empathy the level of trust is optimal. We speculate that the formation and manifestation of empathy in orphans is due to the child's position in which he accepts the conflict situation, which prevents the satisfaction of his needs, desires and aspirations. Indifference to the frustrater is accompanied by the assumption that everything will work itself out. The child shows sympathy and antipathy, interest in joint activities and games, and communication with children and adults, but indiscriminately friendly.

Our results on diagnosis are demonstrate that the analysis of structural and spatial relationships of the empathic tendency with indicators of emotional deprivation has confirmed the deformity of empathy in children with emotional deprivation and has showed that it is caused by other factors, than normal development. Thus, the formation of empathy in the case of a moderate rates of emotional deprivation is due to the child's emotionless attitude to situations in which his or her needs are not met, and the child behaves in a normative, sympathetic and antipathic manner, showing an interest in joint activities and games, communicating with adults, responds to the request for activity. At a low rate of deprivation, the formation of empathy is caused by conditions of a social environment. Due to the fact that the deprived child has low tolerance to stress, the experience of stress does not contribute to the development of empathy. Under unfavourable conditions of the social environment, isolation, negativism and a lack of interest in good relations with adults and children arise. In the case of a non-deprived child, the development of empathy is due to the child's expectations of assessments provided by significant individuals in situations of demonstrating their capabilities and abilities. While waiting for positive assessments and their confirmation, empathy rates increase. If positive expectations are not met or they are negative, empathy rates are decreased.

The results of the study on the consequences of emotional deprivation in primary school children are consistent with previous works (e.g., Merz, & McCall, 2010) which have found a link between emotional deprivation and behavioural problems. Thus, our research confirms high rates of disadaptive and aggressive behaviour, behavioural inhibition, and low rates of social intelligence, difficulties and fears in relationships with peers and adults in emotionally deprived junior school children.

Also, many authors (Pears et al., 2008; Hostinar et al., 2012; Beckett et al., 2010; Loman et al., 2013) made an assumption about the impact of emotional deprivation on cognitive functions, in particular, on reducing its productivity. Therefore, further research is needed to diagnose cognitive abilities in emotionally deprived children of primary school age.

In addition, the long-term effects of emotional deprivation, which can manifest as a psychopathological disorder in adulthood (Pollak et al., 2010; Kumsta, 2017; Kennedy et al., 2016), require further research. It will take at least 20 years from the time of our study to compare our performance in childhood and adulthood and prove the link between emotional deprivation and depression, substance abuse, psychopathy, eating disorders, etc. However, such a study may be complicated by the fact that there is secrecy of adoption in Ukraine and we may not be able to locate these children in adulthood.

In a situation of prolonged emotional deprivation, protective mechanisms of the psyche and coping strategies are formed to counter the development of mental disorders and disorders in children (Nelson et al., 2014; Abdulla, & Kasese-Hara, 2020; Baars et al., 2020). However, unlike previous studies, the results show that in the group of orphans who still remain in boarding schools and continue to experience emotional deprivation, the efficiency of self-regulation and management has been significantly reduced, acting as a protective factor in stressful situations and contributing to social adaptation. This conclusion is therefore consistent with the previous study, which notes that the protective mechanisms that could have helped to counteract the effects of emotional deprivation are weakened, their functions are disrupted (Koss et al., 2014).

We also believe that the simple relocation of orphans and children deprived of parental care to adoptive families and their adoption will not yield quick and lasting results in overcoming a number of behavioural and emotional disorders. For example, adopted children have high anxiety rates, low rate of the need-persistence type of frustration and a moderate rate of frustration tolerance. This shows that, apart from the emotional communication with parents, peers and teachers, the positive microclimate in the adoptive family and school (Nguyen, & Cutting, 2021) is not sufficient to compensate for all behavioural and psychological disorders, resulting from emotional deprivation. Long-term psychological, social and medical support for emotionally deprived children, as well as psychological services for adoptive families, should be effective ways.

Thus, we see that the long-term stay of children in a situation of emotional deprivation can have consequences both individual and multiple deficit and disorders and disorders requiring early detection and correction.

Conclusions

So, the emotional and personal characteristics of the groups of children that we have studied revealed that the profile of the children who are most affected by emotional deprivation is characterized by signs of disadaptive behaviour, high anxiety rates, Low frustration tolerance with high rates of extrapunitive responses and high empathy. Adopted children had high rates of empathy, adaptive behaviour with high anxiety rates, moderate rates of frustration with low rates of extrapunitive response and a need-persistent type of frustration reaction. Children in the control group were characterized by low empathy, adaptive behaviours with low anxiety rates, high rates of frustration tolerance with moderate extrapunitive responses and need-persistent type of frustration reaction.

Thus, children with high rates of emotional deprivation are characterized by low rates of arbitrariness, uncontrolled affect, a delayed response to aggression against real or perceived obstacles to achieving the desired, guilt and shame, moral dissatisfaction is not focused, nor is there a willingness to constructively resolve the situation on the basis of our own resources.

In children with moderate rates of emotional deprivation, the arbitrariness and control of affect are more developed, but a high level of responsibility, self-criticism, guilt prevent the realization of constructive overcoming of frustrating situations by relying on their own resources. For children with moderate rates of emotional deprivation, it is typical in situations of frustration to impose excessive demands on others by manifesting and demonstrating various forms of aggression, which is an indirect manifestation of inadequate self-esteem, Low level of arbitrariness, controlled emotions. They are reluctant to admit their guilt for what happened or admit it under pressure from adults. They are ready for action to eliminate frustration. The consequences of these actions are not predictable or unable to predict. They rely on their own resources to demonstrate aggression, autonomy, independence, but don't feel that way.

Children with a mild emotional deprivation tend to feel moral dissatisfaction with themselves, self-critical, insecure, reduce traumatic, unpleasant, aggressive reactions directed at others. There are no demands to meet the needs, because their efforts are aimed at controlling affect and developing arbitrariness, preserving and protecting "I". They are not ready to act constructively to overcome frustrating situations. They are not relying on their own resources. They're vulnerable with a low rate of independence.

Not deprived children tend to feel moral self-satisfaction, self-critical, reduce traumatic, unpleasant, outwardly directed at others aggressive reactions in making demands to meet their own needs. Have a developed level of control and arbitrariness of affect, adequate self-esteem. They have a developed level of control and arbitrariness of passion, adequate self-esteem. They are ready to act to overcome frustrating situations and can predict them. The level of autonomy is moderate and high.

So, we can generalize that the structure of the psyche in emotionally deprived children of primary school age is covered by changes that lead to disadaptive behaviour, low tolerance to stress, inability to overcome frustration, problems in the emotional and personal sphere.

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ABSTRACT

Emotional deprivation experienced by children results in a range of persistent behavioural and psychological disorders. Negative emotional states and long-term unmet emotional needs of children lead to a wide range of negative symptom complexes that require early detection and correction and, in some cases, psychiatric care.

In order to identify the behavioural and emotional characteristics of primary school-age children affected by emotional deprivation we used a set of interrelated methodologies: Color Mood Chart (Lutoshkin), The Questionnaire Measure of Emotional Empathy (Mehrabian), Frustration Test (Rosenzweig) School Anxiety Test (Phillips), Observation Map (Stott), Range of child's emotional manifestations (Shvantsara), House-Tree-Person Test (Buck).

The statistical package SPSS Statistics22 enabled us to perform statistical data analysis. We also carried out the Factor Analysis of the obtained results of the study on the effects of emotional deprivation using the Principal Component Analysis with Varimax Rotation. The adequacy of the model was assessed by the Kaiser-Meyer-Olkin criterion.

A factor weight 0.30 was chosen as a measure of the level of significance. Discriminatory analysis allowed us to differentiate the level of emotional deprivation.

The profile of orphans who are the most affected by emotional deprivation is characterised by disadaptive behaviour, high anxiety rates, low frustration tolerance at a high level of extrapunitive responses and empathy.

Adopted children showed high levels of empathy, adaptive behaviour and anxiety, moderate level of frustration tolerance at low rates of extrapunitive responses and a need-persistent type of frustrating reaction.

The findings of this study indicate that a prolonged stay of children in a situation of emotional deprivation can result in individual and multiple deficiency disorders as well as behavioural and emotional disorders, which require early detection and correction.

KEYWORDS

emotional deprivation, orphans, adopted children, consequences of emotional deprivation, behavioural and emotional and personal characteristics

Capability and Rural Children's Health in China

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Introduction

Economic marketization in China, boosting social prosperity and affluence, has alleviated the nation's devastating poverty since the end of the 1970s. It also has liberated the nation from struggles in and sufferings from severe public health lags such as come-and-go epidemiological crises, population malnutrition, and scarcity of health intervention programs. However, similar to developments of other states such as the U.S. and Japan, equality and justice do not always come with China's booming economy. Due to the household registration mechanism (*hukou* system) that legitimizes separate economic and social developments between the urban and the rural, a sharp gap engendered from the dual approaches creates inequalities and injustice in terms of economics, cultures, political rights, education, and health. The urban-rural divisions, delineated in multiple sources such as demographic statistics, governmental surveys and inquiries, evaluative data of social interventions, academic research, films and documentaries, and the mass media, are in an alarming station that necessitates national efforts to lessen inequalities and associated societal problems. With regards to public health, divergences existing among health conditions of people living respectively in urban regions and rural areas, indicate significant plights for the parts of the rural residents that their human development are not well-planned or are even placed in total neglects. For instance, urban citizens, in comparison with their rural counterparts, experience knife-edged privileges in terms of healthcare insurances, familial dietary customs, illness prevention, and access to quality healthcare services (Chen, & Zhao, 2021, pp. 80–81).

The long-term national plans exert great guidance and influences onto the state's social, economic, cultural, and political development. Health disparities, resulted from the urban-rural dual paths of developments, are one of the state's main targets of governmental and social interventions (Chen, & Zhao, 2021, p. 81). One of the national plans' focuses is purported to promote well-being of the state's younger generations with special attention paid to human development of children from rural families (Liu, Fang, & Zhao, 2013, pp. 294–295). As I mentioned in the preceding paragraph, rural children's well-beings concerning both physical health and psychological comfort appear to be much left behind in contrast with those of urban children. Rural children are more prone to suffer from lacks in nutritious diets, delays in physical growth and cognitive development, and problems regarding their school performances and psycho-behavioural well-beings. In consequence, intervention programs aiming at promoting rural children's health stay as one of the keen interests of the nation's development plans (Chen, & Zhao, 2021, p. 83).

Social policies are often debated on preferences and feasibility between the universal programs and targeted social supports, with universal programs aiming at promoting the holistic welfare, and targets plans providing supports to individuals and families afflicted with specific obstacles. From our perspectives, as I think many other policy makers would agree, it is more of a sound and efficient approach to integrate both universal and targeted programs rather than sole emphasis of either of them. An integration of both programs, if effectively planned and implemented, would facilitate social welfare as a whole and increase utility for problematic families and individuals. China is noted for its endeavours in learning from other nations that promote successful welfare interventions. An integrated plan, embedded within its double focuses on both universal and targeted policy interventions, turns out to be a good choice for China's national plannings. And health promotion for rural children is not an exception. Universal health plans, as one as the major poverty reduction strategies, are implemented in rural areas. Universal interventions include increase in financial assistance, health insurance coverage, and quality community healthcare services. Families of children with specific health issues are incorporated into the targeted intervention and are provided with specialized supports (Chen, & Zhao, 2021, p. 84). For instance, a family from a rural community supported by standard healthcare infrastructure and services would be assessed and assisted at individual basis. Specialized supports in terms of familial guidance and healthcare services are offered to families affected by their children's health problems such as malnutrition, developmental delays, disabilities, acute illnesses, and chronic diseases (Chen, & Zhao, 2021, p. 84).

I am in full support for the state's emphasis on health support for rural children. But I am in a doubtful position to match rationales behind this health promotion planning with a utilitarian discourse, which is often critiqued as to increase societal happiness at the costs of ignoring marginalized groups. Alleviating health issues of children in rural China would be an opposite of a utilitarian method, for the state's efforts is to guard and promote interests of a neglected and marginalized group – children from rural families. In addition, neither do I have any intentions to rationalize this planning as a functionalist approach. China used to be panned internationally for its application of functionalist doctrines to social and political interventions, for its restrictions of social groups that are taken as negatively impacting on social stability and wholesomeness due to their outlining abnormality and incompleteness. Nevertheless, the health promotion strategies do not abide with functionalism, given that rural children's social positionality does not endanger social stability or wholesomeness but are open to inclusiveness and social equality.

Although equality and justice are targeted, I think there would be ethical concerns when employing common standards such as efficiency and effectiveness as health programs' protocols and evaluations. Such standards as efficiency and effectiveness are often programmed and attained to certain degree through impinging on individual freedoms, social diversity, equity, and human rights. And I think health plannings for China's rural children would also produce disadvantages to individual freedom, rights, and equity of the rural children.

Herein, I propose this noteworthy economic theory – the capability approach, as a possible theoretical "assistance" to analyse or maybe mould ethical rationalization regarding health intervention for rural children in China. The later sections of this article comprise of two main parts. The first part is grounded on a review of capability decorum and its theoretical application to health. The second segment intends to draw insights of capability theories to examine rural children's health in association with social-cultural diversity epitomized by rural children, children's agency in health, and their rights to quality healthcare. I will respectively explicate in detail the rationales why health equity, agency, and rights to healthcare are essential components of capabilities concerning to promote rural children's health.

Capability and health

Capability approach, formulated in accordance with Aristotle's concept of human flourishing – human's progress into rational and happy beings and doings, denotes that economic resources should not be considered as appropriate measures for the social (Ruger, 2009, pp. 50–51). Capability is pointed to individuals' functioning – states of being and doings that individuals can attain, and capability is signified by freedom to achieve a combination of functioning, to lead a life as they would love to. A person also enjoys freedom to achieve alternative sets of functioning, or put it simple, to have multiple life choices.

"A person's «capability» refers to the alternative combinations of functioning that are feasible for her to achieve. Capability is thus a kind of freedom: the substantive freedom to achieve alternative functioning combinations (or, less formally put, the freedom to achieve various lifestyles)" (Sen, 1999, p. 75).

Capability deals with both actual and potential functions of ability, consisting of functioning that are not available now but will be accomplished in the future (Ruger, 2009, p. 50). For instance, a person who does not have the functioning of knowing a foreign language, will gain the ability of using a foreign language after participating in relevant language-learning activities.

Jennifer Prah Ruger categorizes five components that connect health and capability approach. First, to maintain well-being requires a combination of functioning, thus capability of functions is a prerequisite for well-being and freedom to well-being (Ruger, 2009, p. 51). Second, capability stresses human heterogeneity when evaluating equality of well-being (Ruger, 2009, p. 53). Third, preferences and desires, instead of a set of functioning, are not appropriate gauges for well-being (Ruger, 2009, p. 54). Fourth, capability aspect of freedom underscores two parts of freedom: opportunity (resources and environments that a person has to employ to achieve functions) and process (the path to well-being constitutes deliberation and autonomy of decision-makings) (Ruger, 2009, p. 54). Moreover, valuing and selecting capabilities involve distinguishing between basic capabilities that address basic needs and more advanced capabilities that are based on accomplishment of basic capabilities (Ruger, 2009, pp. 55–57). Ruger refers the association of well-being and capability to health capability, an idea capturing both functions of well-being, and individuals' autonomy and agency of well-being.

With respect to well-being, rural children used to be placed in a jeopardized position that their rights to health, basic health needs, and diversity concerning their well-being are often neglected in Chinese society. I hold that a capability approach would foster valuable discussions and analyses of rural children's health. At this point, a series of question are formed regarding how to engage capability tenets to investigate health of rural children in China. What points should be addressed to examine rural children's health, their social-political environments, their freedom of well-being, and equality and justice regarding their health? Will capability approach downplay rationales of attempts to improve health conditions of rural children? Or on the contrary, will it facilitate interventions to their health problems?

Neoliberalism and diversity

A capability analysis of rural children's health dismisses neoliberal doctrine that has been widely applied to rationalize and direct interventions to children's development. Neoliberal agenda, stressing cultivation of individual competence, economic productivity, and universalized managements of child development, exert negative impacts on rural children's health in general. First, the investment in human capital and social capital under the neoliberal umbrella, calling for enhancing children's potentials and readiness to participate in future economic activities, sabotages the objectives of active participation not just in health decision-makings but also in education and living habits. Neoliberal economists consider health as a part of a children's education agenda, in which education is prioritized. In terms of fostering economic productivity, Heckman and Masterov make a clear suggestion: "education and human skill are major factors determining productivity, both in the workplace and in society. The family is a major producer of the skills and motivation required for producing successful students and workers. The most effective policy for improving the performance of schools is supplementing the childrearing resources of the disadvantaged families sending children to the schools" (Heckman, & Masterov, 2007, p. 448). Though neoliberal theorists ask for intervention programs for disadvantaged children, systematic inequality that creates such disadvantages are not addressed enough (Sims, 2017, p. 4). The interventions for young children of lower class are still in shortage of family and community supports. Finally, early intervention programs originated in the discourse of universalized child development theory do not celebrate human diversity, and in some cases even place local cultures and customs under threats. Here is a typical example. The New Zealand early childhood education curriculum, Te Whariki, has gathered mixed worldwide reviews, being criticized for its lack of rigorous literacy and mathematics curriculum (Sims, 2017, p. 4). However, Stuart (2016, p. 138) argues that Te Whariki is designed for sociocultural inclusion and anti-racism, and hindrances of its enactment from neoliberal theorists is derived from economic imperialism.

In neoliberalism, rural children are regarded as potential *homo economicus*, or future entrepreneurs. However, prospects of fostering competitiveness and entrepreneurship undermine children's social agency for certain populations, or in broader sense, social equality. In the matter of developing *homo economicus*, young children are programmed to increase their cognitive and social capacities which are to be translated into economic productivity. In this social engine boosted by neoliberal, rural individuals with underprivileged backgrounds such as disabilities, ethnic minorities, illnesses, and lower social-economic-status are often shortfall, for their agencies to develop competence and productivity are often hampered by *a priori* societal inequality. Another drawback of integrating health promotion programs with neoliberalist rhetoric is related to ethics. With respect to the competitions extended into childhood including merits gained from community and academic works, cognitive tests scores, and creativity, social collectiveness and solidarity, which should be cultivated to some extent at early stages of life, would be endangered. Effects of *homo economicus* harm moral development of rural children, rendering it more difficult to foster virtues such as caring for others and the community, initiation to address the common good, and conscious reflection on social life.

In addition, epistemology of rural children in terms of neoliberalist theory and rural children's health is flawed, due to three paradoxes I identify between factual positionalities of children and discourse of capability theory. First, though experts in health and health education acknowledge differences among rural children regarding their social-economic status (SES), gender, nationality, culture, and disability, characteristics of their backgrounds (e.g. SES, gender, culture) though are coexisting and interactional and relational. For instance, rural children without proper care and education are more prone to develop lower literacy and higher criminality eventually. Interactions between the social-economic backgrounds of children, their expected literacy skills, and their delinquency rates are easily calculated and assessed. Such inferences are drawn, insinuating a pathological symptom of poverty – its causal links with illiteracy and criminality. The second part of this story is explicated in the tradition of neoliberal theory, that enhancing one's competitiveness and competency through intervening into their health and education would produce personal and social affluence. However, cultural capital analysis of children's health reveals the problematic correlation between prospects of education and environments where a child lives and interacts. One's disposition toward the world, including habits, knowledge, and codes of conducts, is determined by one's social environments, and more specifically, one's social class. The disposition based on social class "reproduces inequality because people in privileged positions act in ways to secure privilege for their children, while those who are poor see only a limited set of opportunities for their future" (Dumais, 2006, p. 84). In this way, the cultural capital approach challenges application of neoliberal theory to rural children's health issues, rendering the discourse on interaction between health and life success conflicted.

Children's agency

This part is to contest the idea of rural children as passive objects in social interaction by using capability approach as a theoretical foundation. Instead, I hope to treat rural children not as merely recipients of benevolence and orders regarding their health issues, but as active members of social participation in community's health activities. Rural children would be regarded as subjects of health activities, with their own views and decision-makings considered and valued.

A capability understanding of children's active participation comprises of three reasons:

> (1) the competencies, resources and capabilities of a subject, in particular of children, are tied to the possibility of being acted, understood and being recognized as significant. In other terms, capabilities are strictly dependent on the forms (social and individual) and by the possibilities (environment) of agency; (2) the different forms of participation and the environmental conditions that enable its expression need to be valorised and sustained to enable them to reproduce over time: there are no "natural" capabilities (understood as opportunities) but only those socially built; and (3) different cultures and many social contexts that denote, and in which capabilities are built, can be considered only if they become visible along with the practices and the orientations that inspire them (Comim, Ballet, Biggeri, & Iervese, 2011, p. 12).

First, children are presupposed as targets of paternalistic guidance, for they are considered shorthanded in terms of adequate rationality and autonomy. Endowed with insufficient reason and self-awareness, children are not trusted for their deliberation and decision-makings in terms of health matters. However, a capability sense of analysing children and health would draw a different picture. Aforementioned components of capability theory underline one major point – potential capabilities, which refer to a set of functioning a person will acquire in the future given sufficient and suitable resources and environments. Children in general are societal participants with potentials that will evolve and flourish. Thus, it is necessary displace children from the positions that confine them within authority and beneficence from adults. Children should be seen with evolving abilities of both rationality and autonomy. In terms of rural families and communities in China, rural children are of evolving capabilities, a combination of various functions they would be able to achieve. To view rural children as individuals with potential capabilities, is to abandon restrictions on their agency, and to extend assessment of rural children to their future beings and doings. The scope of well-being capability should also be broadened to consider rural children as future active participants of activities relevant to their health issues, for rural children are in the process of developing skills and knowledge regarding judgement, deliberations, and decision-makings. For instance, a rural child with disabilities should not be taken "statically" as a passive recipient of paternalistic charity. Instead, he or she should be included into the learning and discussion about promotion and intervention of his or her health. Appropriate resources are offered to this child as solid assistance to develop his or her potentials, to foster evolving capabilities, and to acquire functioning such as living skills, learning abilities, and values and norms of how to flourish one's life.

Another key attribute relating agency to rural children's health is pertained to resources and social environments in which capabilities are built. Herein, relevant to capabilities development, I need clarify the division between internal factors and external factors. Internal factors comprise of personal elements such as age, physical conditions, sex, skills, talents, and intelligence (Comim, Ballet, Biggeri, & Iervese, 2011, p. 29). Internal factors are to be converted into individual functioning. Environments and resources construct societal and environmental conversion factors, including public policies, institutions, legal rules, traditions, social norms, discriminating practices, gender roles, societal hierarchies, power relations, public goods, natural environment, public infrastructure (Comim, Ballet, Biggeri, & Iervese, 2011, p. 29). Societal and environmental conversion factors contribute to transforming individual's external characteristics as well as his or her individual functioning into salutary conditions for individual's flourishing in life. Apart from rural children's internal characters which are entitled to be cultivated into individual functioning, their external factors – resources and social environments attribute to their capabilities creation. Changes on external factors such as health policies, rules and customs, social roles, family structures, and healthcare infrastructure would bring about positive outcomes for rural children's health promotion. Moreover, incorporating external conversion factors in rural children's capabilities renders alternative vectors of functioning, thus eventually results in alternative choices of health. It is quite common that beneficial changes of surroundings and resources generate alternative opportunities and alternative processes of living, and even affect the whole paths of living. Let me explain this by presenting an example. A rural child with a chronic illness, from a family of severe poverty, may have few possibilities of getting to know about rights and freedom for people with such predicaments. Maybe, he also has no idea of how to better manage his well-being, how to further his education, and even has no plans to change his life. His family's poverty and his illness have prevented him from imagining a possible better life. He is offered an effective medical treatment for free according to the new health policy issued by the local government. His health conditions improve significantly, as he continues to be supported with free medications and better dietary plans. Furthermore, the child's family receive financial and professional supports for treating his illness and furthering his education. As his cognitive and physical development multiply, he would be equipped with more functions such as capability to walk fast and run, better living habits, and masterful social and learning skills. It is highly possible that a child whose chronic illness has been well managed like that would seek further opportunities and may have alternative choices of life.

Interaction between social-environmental factors and social actors who are developing their potentials contributes to another important aspect of children's agency in health. The social interaction highlights two points regarding agency: (1) social structure helps to shape individual life; and (2) individuals are devoted to creating social meanings (Comim, Ballet, Biggeri, & Iervese, 2011, p. 29). Agency is more attuned to meaning making. At very young ages, children are actively engaging in social interaction, reciprocal exchange of meanings and information, and creating meanings (Comim, Ballet, Biggeri, & Iervese, 2011, p. 28). Rural children project interaction with resources and social environments and enrich their life with social meanings. However, their interaction and meaning making are under four constraints. First, rural children's conversion from functioning to capabilities are subjected by parents, caretakers, and teachers whose services may not be good enough to invigorate children's capacities. Second, backgrounds and entitlements of parents and caretakers may hamper rural children's growth and progress and may render a path dependency of intergenerational injustice. Third, due to interconnection of capabilities, certain functioning hindered by underdevelopment of other capabilities cannot maintain reliable communications with resources and environments. Fourth, capabilities are bound by children's ages, that rural children are not likely to acquire equivalent skills and knowledge once they have passed to a different stage of life. To sustain quality interaction between rural children and health-related social aspects, these four drawbacks need to be evaluated and moderated.

Rights to health

Capability approach validates a right to health for rural children in China. The health capability tenets endow theoretical understanding of a right to health with a much positive face with regards to ethics and legality, integration of means and ends, and advancement of positive rights and negative rights. I am explicating this in following three respective points. First, a capability approach to rural children's health is a realization of a right to health in terms of both ethics and legislation. Ruger writes:

"The health capability paradigm proposes an ethical commitment to the right to health. This commitment sees the right to health as the basis and inspiration for new and specific legislation. It also sees it as an ethical claim, in this case on all individuals, especially the wealthier, to redistribute some of their resources to help meet the health needs of others, those who are unable to afford care. Under a health capability paradigm, this obligation involves an interest in significant capabilities and freedoms of others, operationalized in terms of health needs, health functioning, health agency and health capabilities, not preferences, desires, or utilities" (Ruger, 2009, p. 123).

Ethics of the society in general regarding promoting health for rural children has changed, as it is justified and praiseworthy, according to social norms and values, to redistribute wealth and resources to assist the rural regions, especially the rural children. Moreover, welfare rules of wealth redistribution and resource allocation have been legalized in China. For instance, written protocols provide guidance to activities like how to allocate health-related resources, how to organize fund-raising, and how to manage health practitioners' volunteering. In all, social regulations through both ethics and legislation are prepared for confirming the right to health for rural children.

Second, the crucial theme that capabilities engender is its conjunction of means and ends of health development, in this case, for rural children in China. This decorum of capability approach is noted, as capabilities are practicable to attain Kant's means-ends juxtaposition. According to Kant's conceptualization, one's rights are respected since one is treated not only as means to interests, but also as ends of interests. A successful combination of means and ends indicates fulfilment of rights. In the view of capabilities theory, a vector of functioning such as being able to attend school, to have personal savings prepared for accidents and mishaps, to maintain a good health, which are usually regarded as means or preparedness to human flourishing, are rationalized and operationalized as ends or a part of goals of individual freedom and autonomy. Capabilities consisted of sets of functioning are both means and ends of achieving goods of life. A set of basic functioning are incremental to build more functioning for rural children. Advanced capabilities are created by accumulation of preceding basic capabilities. Basic functioning such as to have sufficient food and nutrition, to have personal or external funding, to have spare time beside housework and labour on the farmlands will induce more advanced functioning like capability of attending schools and furthering education. Means of having sufficient food and nutrition, to have personal or external finances, and to have spare time for schools produce capabilities of maintaining good health conditions and of being educated. And a new set of functioning regarding good health and schooling would create new capabilities such as furthering education and to move to the city. The accumulation can go on as it generates alternative paths of living for rural children. Interventions to rural children's health would expedite this incremental process of building capabilities, for a good health, itself a concept juxtaposing both means and ends of a good life, plays an essential role in creation of new sets of functioning.

At last, it is deemed appropriate to employ interconnection of health and capabilities as essential elements of realizing both positive rights and negative rights. Positive rights refer to respects to one's capacity to act upon one's will, while negative rights mean not to externally restrain one's will to act. Health capability constitutes meanings related to attain and sustain a healthy condition, a vector of functions that vitalize one's life, and a quintessential kind of goods that prepare human flourishing. When addressing the concept of a positive right to health, it is necessary to interpret the positiveness of a right to health as a way of respecting one's free will's act on things associative with one's health conditions. A rural child with physical disabilities is exercising the freedom to act upon his will if he chooses not to move the city or further his education. Instead, he chooses to be stay in the rural areas and to work as a fisher. However, the positive rights of becoming a fisher are respected providing that both opportunity justice and process justice are guaranteed as he is offered appropriate social environments and resources to have his characters and talents cultivated. His life choice of becoming a fisher is not hampered for he has full access to his surroundings resources and alternative sets of functions for selection. Health capability also actualizes rural children's negative rights – no constraints on one's will to act. Rural children are of multiple restrictions to fulfil their wills. For example, it is quite typical in rural China that a child would not be able to have sufficient nutrition nor to secure food safety. Such hindrances are negatively associated with a child's physical and cognitive development, or his general health. A capability approach protecting a child's negative right to health, refers to that restrictions and constraints on realizing functioning of a good health condition have been removed. Thus, this rural child's negative right to health is respected and fulfilled.

Conclusion

Capability approach, deemed more than a toolkit for promoting health among rural children in China, is purported to instigate questionings and doubts cast upon neoliberal agenda of guiding and facilitating child health programs, and is to reorient the rationalization and empirical efforts to include, evaluate, and value rural children's health agency, and also fulfil the objectives of respect this underprivileged populations' rights and access to quality health. Capability theory has been “applied” to canvass several alarming social issues in China including health, rural education, poverty reduction, and population ageing. For example, Jiang, guided by an in-depth study of a most poverty-stricken region in China, appeals to inquire and intervene into health issues of people in poverty through installing theories of distributive justice and capability approach (Jiang, 2015, pp. 58–60). A study by Wu and Liu, per theoretical orientations of capability, contributes to optimizing community-based assistance and social interventions to a city’s seventeen families of individuals with disabilities (Wu, & Liu, 2020, pp. 43–50). However, there are none academic endeavour of this lieu specifically targeting on theoretical investigation on children’s health, especially concerning those from rural areas. Hence, this article hopes to offer its humble but critical scholarship to academic investigations to rural children’s health in China. This article also hopes, not only to enrich critical perspectives in terms of studies on rural children’s health interventions, but also to provide valuable insights to channelling policy-making and empirical practices in health promotion for children and their families living in rural regions.

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ABSTRACT

Children living in the rural regions of China are under the state's efforts for their health promotion. However, the discourse and pragmatics of these governmental approaches are jeopardized due to its neoliberal paradigms. Capability approach, a noteworthy theoretical guidance initially elicited by Sen will offer a critical perspective and will engage a comprehensive analysis, respectively in terms of diversity, agency, and rights to health, for rural children's health in China.

KEYWORDS

children, rural China, health, rights

Echoes of War: Inclusion of Students with War Trauma in Ukrainian Universities

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Introduction

The higher education globally is increasingly adapting to challenges, among which the impacts of conflict stand out with profound immediacy and complexity. In Ukraine, the ongoing war has not only reshaped the socio-political landscape but has also deeply penetrated the realms of higher education, necessitating a revaluation of inclusivity practices within universities. The significance of inclusivity within universities transcends mere compliance with global educational standards or norms. It embodies a commitment to embracing diversity and ensuring equitable access to educational opportunities for all students, irrespective of their backgrounds or experiences.

This imperative is further amplified in contexts affected by conflict, where the educational environment can play a pivotal role in the healing and recovery process for students impacted by war. The UNESCO-led "Education to Transform Lives" campaign, with its emphasis on the Sustainable Development Goals, particularly SDG 4, which advocates for inclusive and equitable quality education for all, underscores the global consensus on the importance of educational inclusivity.

The ramifications of war on the educational sector are profound and far-reaching, resulting in substantial human casualties, a significant exodus of students, widespread displacement, and a consequent increase in diversity within universities (Ivanchenko et al., 2023; Nenko et al., 2023; Vincent, 2008; Aydin, & Kaya, 2020; Selvaratnam et al., 2023; Lopatina et al., 2023). Given these challenges, fostering an inclusive learning environment emerges as a critical priority for universities. It ensures that every individual, especially those from vulnerable groups, is acknowledged and valued, thereby providing the essential foundation for accessing quality higher education.

A new challenge for the Ukrainian higher education system is a group of students with war trauma. The studies about the war-related trauma among university students, particularly in war-affected regions, highlight the high prevalence of trauma exposure and PTSD symptoms among students in these areas, emphasizing the enduring impact of war trauma on the mental health and well-being of students (Mohsen et al., 2021; Abu-Saba, 1999; Tsybuliak et al., 2023). Students who have experienced war trauma bring distinct needs and perspectives into the university setting, influencing their academic engagement, sense of belonging, and overall mental health and well-being. Understanding and addressing these needs is not only crucial for the personal development and recovery of these students but also for fostering a supportive and inclusive academic community that can contribute to the broader societal healing process post-war recovery.

This study aims to explore and elucidate the perceptions and attitudes of students who identify with experiences of war trauma regarding the efforts of Ukrainian universities to foster an inclusive educational landscape and discusses the potential changes of inclusive practices for post-war recovery. By focusing on these students' perception, the research seeks to contribute to the ongoing dialogue on how higher education can adapt its policies, practices, and cultures to better support all students.

Method

This cross-sectional analytical study employed an online survey methodology to collect data from November to December 2023. The target population consisted of students from various Ukrainian universities. To facilitate data collection, a questionnaire was disseminated via email using Google Forms. Participation in the study was both anonymous and voluntary. Prior to participation, individuals were informed about the research objectives and the nature of the study, and their consent was obtained. It is important to note that the inability to track the number of individuals who viewed the online invitation precluded the determination of the study's response rate.

The instrument used for data collection was a self-report questionnaire designed to evaluate students' perceptions of inclusivity within HEIs. This questionnaire aimed to assess the process of creating a comfortable, safe, barrier-free, and friendly inclusive environment that caters to the needs of a diverse student body, including those considered vulnerable. The framework for the questionnaire was based on the Inclusion Index by Booth and Ainscow (Booth, & Ainscow, 2011), which was originally developed for schools but has been adapted in recent literature for application within the higher education context (Pérez, & Meza, 2015; Ibáñez, & Salceda, 2015; Solís-Grant et al., 2022; Márquez et al., 2021). The Index of Inclusion focuses on three core dimensions of inclusion: culture, policies, and practices, providing a comprehensive approach to understanding and enhancing inclusivity in educational settings.

For the purposes of this study, the Index was modified to align with the specific characteristics of higher education and the Ukrainian context. The questionnaire covered expected inclusive culture, policies, and practices in HEIs, organized into six units. These included: "Building a community" (8 items) and "Promoting inclusive values" (7 items) for the 'Inclusive Culture' section; "Openness of the university to all" (6 items) and "Support for diversity" (9 items) for the 'Inclusive Policies' section; and "Adaptation of curricula and courses" (4 items) and "Orchestrating learning" (5 items) for the "Inclusive Practices" section.

Responses were collected using a six-point Likert scale, ranging from "Strongly Disagree" (1) to "Strongly Agree" (6), allowing for a nuanced analysis of students' perspectives on inclusivity within their learning environment.

Results

The study's participant pool, comprising 150 students who have self-identified with experiences of war trauma, spans various stages of higher education. Of these, eighty undergraduate students in their first and second years constitute the majority, reflecting a significant portion of respondents at the early phase of their university journey, primarily focused on foundational coursework and adapting to the academic environment. Thirty-four students in the advanced years (third and fourth) of their undergraduate programs concentrate on specialized topics and the completion of their culminating academic endeavours. Additionally, thirty-six master's students are engaged in postgraduate studies, undertaking in-depth investigation in their respective fields in preparation for professional advancement or research opportunities. This varied distribution allows for an in-depth examination of the higher education experience against the backdrop of ongoing conflict, showcasing the engagement of students from diverse educational backgrounds.

Notably, within the context of this all – Ukrainian study examining the inclusivity of higher educational environments, only 4.5% of respondents self-identify as experiencing war-related trauma. Given the extensive nature of military operations within Ukraine, this percentage might seem modest. However, it reflects the current understanding of war's impact, which remains under continuous evaluation due to the war's ongoing status and the delayed onset of trauma manifestations. This figure underscores the complexities of assessing war trauma within an academic setting, suggesting that perceptions and reported incidences of trauma may evolve with changing circumstances and over time.

The initial dimension explored in this study pertains to the inclusive culture within Ukrainian universities, as delineated in Table 1. The findings derived from student responses provide a comprehensive evaluation of the effectiveness of current inclusivity strategies implemented by these institutions.

Table 1. Participants' distribution based on their perceptions and attitudes towards inclusive culture (strongly disagree = 1 to strongly agree = 6)

Indicators of university's inclusive culture	**n (%)**					
	1	**2**	**3**	**4**	**5**	**6**
Unit "Building community"						
The university provides a comfortable learning environment for all students	8 (5.33%)	4 (2.67%)	16 (10.67%)	26 (17.33%)	40 (26.67%)	56 (37.33%)
The university ensures a safe learning environment for all students.	8 (5.33%)	4 (2.67%)	12 (8.00%)	28 (18.67%)	40 (26.67%)	58 (38.67%)
The university offers a barrier-free learning environment for all students.	12 (8.00%)	4 (2.67%)	12 (8.00%)	26 (17.33%)	40 (26.67%)	56 (37.33%)
The university community fosters a friendly environment for all students.	4 (2.67%)	2 (1.33%)	20 (13.33%)	28 (18.67%)	34 (22.67%)	62 (41.33%)
At university, everyone feels part of the community.	8 (5.33%)	0	16 (10.67%)	32 (21.33%)	38 (25.33%)	56 (37.33%)
University accepts diversity and takes into account the needs of all participants in the educational process.	6 (4.00%	4 (2.67%)	6 (6.67%)	36 (24.00%)	40 (26.67%)	54 (36.00%)
At university, there is mutual assistance and respect between students, teachers and management.	6 (4.00%	4 (2.67%)	8 (5.33%)	26 (17.33%)	54 (36.00%)	52 (34.67%)
University is an example of a democratic society.	8 (5.33%	2 (1.33%)	14 (9.33%)	34 (22.67%)	36 (24.00%)	56 (37.33%)

Indicators of university's inclusive culture	n (%)					
	1	2	3	4	5	6
Unit "Promoting inclusive values"						
The university actively promotes the values of diversity within its community.	12 (8.00%)	2 (1.33%)	14 (9.33%)	28 (18.67%)	36 (24.00%)	58 (38.67%)
The university fosters respect for human rights.	6 (4.00%)	2 (1.33%)	6 (4.00%)	24 (16.00%)	38 (25.33%)	74 (49.33%)
The university community demonstrates equal respect for everyone.	6 (4.00%)	6 (4.00%)	8 (5.33%)	28 (18.67%)	36 (24.00%)	66 (44.00%)
The university actively opposes any form of discrimination within its community.	6 (4.00%)	0	22 (14.67%)	28 (18.67%)	30 (20.00%)	64 (42.67%)
The university actively combats any form of bullying within its community.	12 (8.00%)	2 (1.33%)	16 (10.67%)	12 (8.00%)	42 (28.00%)	66 (44.00%)
Community education at the university promotes non-violent interactions and effective conflict resolution among its members.	8 (5.33%)	2 (1.33%)	12 (8.00%)	24 (16.00%)	34 (22.67%)	70 (46.67%)
The university is committed to caring for the mental health and well-being of its community.	12 (8.00%)	4 (2.67%)	20 (13.33%)	12 (8.00%)	38 (25.33%)	64 (42.67%)

The data shows positive perceptions towards the university's efforts in creating a comfortable and safe learning environment, with significant percentages of respondents strongly agreeing on these aspects. A significant majority of respondents felt that their institutions provided a comfortable (37.33% strongly agree) and safe learning environment (38.67% strongly agree). Additionally, the acceptance of diversity and consideration for the needs of all participants were positively viewed, with 36.00% strongly agreeing on this aspect. Students with war trauma are likely to be particularly sensitive to the nuances of safety and comfort within their learning environment. The positive feedback in these areas is crucial, as it indicates that the university's environment can potentially facilitate their healing process and improve their academic experience. A comfortable and safe environment not only supports their learning but also contributes to their overall well-being and integration into the university community.

However, certain areas showed room for improvement. The perception of a barrier-free learning environment, though positive, was comparatively lower (37.33% strongly agree). This finding suggests that while efforts to remove physical, social, and academic barriers are acknowledged, there remains a segment of the student population that perceives existing limitations. For students with war trauma, barriers might not solely be physical but also psychological, requiring tailored support systems to fully engage with the academic and social aspects of university life. Furthermore, the mutual assistance and respect between students, faculty, and management, while relatively strong, suggested potential for further enhancement (34.67% strongly agree). The slightly lower percentage of strong agreement suggests that there are perceived gaps in communication, understanding, or support among the various groups within the university.

The subsequent dimension examined in the study focuses on inclusive policies within the educational framework. Table 2 presents the students' perceptions and attitudes of these policies, offering a detailed view of their effectiveness from the student perspective.

Table 2. Participants' distribution based on their perceptions and attitudes towards inclusive policies (strongly disagree = 1 to strongly agree = 6)

Indicators of university's inclusive policies	**n (%)**					
	1	**2**	**3**	**4**	**5**	**6**
Unit "Openness of the university to all"						
Events focusing on issues of inclusiveness and equality are regularly held at the university.	14 (9.33%)	12 (8.00%)	32 (21.33%)	20 (13.33%)	24 (16.00%)	48 (32.00%)
The university implements programs and initiatives that take into account the diverse needs and capabilities of students.	8 (5.33%)	16 (10.67%)	12 (8.00%)	24 (16.00%	38 (25.33%)	52 (34.67%)
Mechanisms for ensuring the availability and diversity of education, and for facilitating the participation of all members of the academic community, have been established at the university.	4 (2.67%)	2 (1.33%)	14 (9.33%)	28 (18.67%	38 (25.33%)	64 (42.67%)
The university has specific standards and policies in place to prevent discrimination and promote an inclusive environment through its regulatory framework.	12 (8.00%)	8 (5.33%)	38 (25.33%)	46 (30.67%)	18 (12.00%)	28 (18.67%)
The university regularly provides resources and support for the individual development and academic achievement of its students.	6 (4.00%)	4 (2.67%)	18 (12.00%)	32 (21.33%)	32 (21.33%)	58 (38.67%)
The university actively cooperates with student self-governance bodies and representatives to ensure inclusiveness in management and decision-making processes.	4 (2.67%)	8 (5.33%)	14 (9.33%)	18 (12.00%)	32 (21.33%)	74 (49.33%)

Indicators of university's inclusive policies	n (%)					
	1	2	3	4	5	6
Unit "Support for diversity"						
The university provides social support for students from vulnerable groups.	10 (6.67%)	8 (5.33%)	24 (16.00%)	24 (16.00%)	30 (20.00%)	52 (34.67%)
The university offers psychological support for students who require additional support or counselling.	18 (12.00%)	6 (4.00%)	16 (10.67%)	16 (10.67%)	32 (21.33%)	62 (41.33%)
The university offers methodological support for students from vulnerable groups.	6 (4.00%	4 (2.67%)	28 (18.67%)	30 (20.00%)	28 (18.67%)	54 (36.00%)
The university has effective strategies, which are regularly evaluated, to ensure accessibility and support for students from vulnerable groups.	8 (5.33%	6 (4.00%)	28 (18.67%)	24 (16.00%)	34 (22.67%)	50 (33.33%)
The university actively promotes the development of individual curricula and programs for students from vulnerable groups.	6 (4.00%)	10 (6.67%)	20 (13.33%)	24 (16.00%)	26 (17.33%)	64 (42.67%)
All forms of social, psychological, and methodological support are coordinated.	12 (8.00%)	6 (4.00%)	22 (14.67%)	16 (10.67%)	36 (24.00%)	58 (38.67%)
The university takes measures to prevent any form of discrimination among students and ensures equal conditions for education for all.	10 (6.67%)	0	14 (9.33%	28 (18.67%)	36 (24.00%)	62 (41.33%)
The university has specialized services, departments, and centres, and support programs for students from vulnerable groups are implemented.	8 (5.33%)	4 (2.67%)	34 (22.67%	28 (18.67%	28 (18.67%)	54 (36.00%)
The university provides students with opportunities to participate in various cultural and educational activities, promoting mutual understanding and inclusion among different vulnerable groups.	8 (5.33%)	6 (4.00%)	4 (2.67%)	16 (10.67%)	50 (33.33%)	66 (44.00%)

The assessment of inclusive policies reveals several strengths within the educational framework. Firstly, the implementation of diverse programs and initiatives is highly regarded, with 34.67% of respondents strongly affirming their effectiveness. This positive perception underscores the importance of such measures in cultivating an inclusive academic environment where every student, including those affected by war trauma, feels acknowledged and supported. Such initiatives are particularly vital for facilitating the recovery and academic integration of students with traumatic experiences.

Secondly, the data indicates a robust institutional commitment to inclusiveness, as evidenced by the high level of agreement (49.33%) regarding active cooperation with student governance bodies. This collaboration signifies a constructive dialogue between the student body and university administration, promoting a culture of community and mutual responsibility towards achieving inclusivity. Furthermore, this collaboration highlights the university's dedication to incorporating student feedback, a critical component for effectively meeting the diverse needs of its student population.

On the other hand, the assessment of inclusive policies highlights certain areas for improvement. Notably, while there is recognition of the university's efforts to establish standards and policies aimed at preventing discrimination, only 18.67% of respondents strongly agree with their effectiveness. This relatively modest agreement underscores the necessity for enhanced clarity, communication, and enforcement of these policies to ensure they are comprehensively understood and implemented across the university community. Such measures are particularly pivotal for students who have encountered war trauma, for whom clear and actively enforced anti-discrimination policies are fundamental to fostering a secure and supportive educational environment.

Additionally, although there is a positive perception of the coordination between various support services, with 38.67% strongly agreeing on its effectiveness, this indicates room for improvement in the integration of these services. A more cohesive and streamlined approach to coordinating academic support, mental health services, and social inclusion initiatives could significantly improve the support infrastructure for students, especially those with specific needs such as survivors of war trauma. The current fragmentation within the support system contribute to some students feeling overlooked or inadequately supported, highlighting the critical need for more integrated support mechanisms.

The following dimension addressed in this research pertains to the implementation of inclusive practices within the educational infrastructure. Perception and assessment of inclusive policies by students is presented in Table 3.

Table 3. Participants' distribution based on their perceptions and attitudes towards inclusive practices (strongly disagree = 1 to strongly agree = 6)

Indicators of university's inclusive practices	**n (%)**					
	1	**2**	**3**	**4**	**5**	**6**
Unit "Adaptation of curriculum and courses"						
Academic staff provide teaching and learning experiences that accommodate diverse learning styles and meet the needs of students.	10 (6.67%)	12 (8.00%)	14 (9.33%)	24 (16.00%)	34 (22.67%)	56 (37.33%)
Academic staff adapt courses to accommodate the individual capabilities and needs of students.	14 (9.33%)	4 (2.67%)	20 (13.33%)	26 (17.33%)	32 (21.33%)	54 (36.00%)
Courses and learning materials at the university are easily accessible to all students.	10 (6.67%)	2 (1.33%)	4 (2.67%)	36 (24.00%)	36 (24.00%)	62 (41.33%)
The university provides individual study plans for students.	12 (8.00%)	6 (4.00%)	24 (16.00%)	20 (13.33%)	30 (20.00%)	58 (38.67%)

Indicators of university's inclusive practices	n (%)					
	1	2	3	4	5	6
Unit "Orchestrating learning"						
Academic staff involve all students in the learning process, taking into account their individual capabilities and needs.	10 (6.67%)	8 (5.33%)	8 (5.33%)	20 (13.33%)	32 (21.33%)	72 (48.00%)
Academic staff offer guidance to all students who require assistance with learning materials.	2 (1.33%)	4 (2.67%)	10 (6.67%)	26 (17.33%)	30 (20.00%)	78 (52.00%)
Academic staff meticulously assess the needs of students and provide tailored support to each individual.	14 (9.33%)	4 (2.67%)	16 (10.67%)	20 (13.33%)	36 (24.00%)	60 (40.00%)
Academic staff foster cooperation and interaction among students, thereby promoting diversity within the learning environment.	4 (2.67%)	8 (5.33%)	18 (12.00%)	20 (13.33%)	36 (24.00%)	64 (42.67%)
Academic staff employ adaptive teaching and assessment methods to accommodate students from vulnerable groups.	8 (5.33%)	10 (6.67%)	20 (13.33%)	26 (17.33%)	26 (17.33%)	60 (40.00%)

Table 3 delineates the strengths of inclusive practices as perceived by the student population, emphasizing two primary areas: engagement and support, and adaptive teaching methods. The data reveal that 48.00% of respondents strongly agree that academic staff actively engage all students, and 52.00% confirm the provision of targeted guidance for those in need. This evidence a robust culture of engagement and personalized support within the university, characterized by the academic staff's commitment to inclusivity through proactive inclusion and assistance of students. Such engagement is particularly advantageous for students experiencing war trauma, providing them with a sense of community and the tailored support necessary to navigate academic challenges effectively.

Furthermore, the appreciation for adaptive teaching and assessment methods is significant, with 40.00% of respondents strongly agreeing on their effectiveness for accommodating vulnerable groups. This adaptability, essential for an inclusive educational environment, facilitates a tailored approach to learning that accommodates the unique needs of students, including those impacted by war trauma. The university's adoption of flexible educational practices underscores a commitment to optimizing student well-being and academic performance, affirming its dedication to fostering an inclusive learning atmosphere that respects and addresses the diversity of student experiences and requirements.

Table 3 also highlights areas within inclusive practices where improvements are warranted, notably in the accessibility of learning materials and the customization of individual study plans. Despite a positive assessment overall, with 41.33% of respondents strongly agreeing on the accessibility of courses and learning materials, this percentage points to the existence of significant room for enhancement. Ensuring comprehensive accessibility is fundamental for the full participation of all students in their educational pursuits, particularly for those facing specific challenges such as war trauma. The reported data suggest that barriers to accessing learning resources persist for a subset of students, potentially detracting from their academic experience and success.

Additionally, the implementation of individual study plans receives a favourable view, with 38.67% of respondents strongly agreeing on their provision. However, this response also indicates the necessity for a greater degree of personalization in academic planning to meet the varied needs of the student body effectively. Tailored academic planning is essential for a genuinely inclusive educational environment, enabling students to pursue their studies in a manner that respects and accommodates their unique circumstances, including considerations for the impacts of war trauma. This calls for an ongoing assessment and refinement of academic planning processes to better support the diverse requirements of the student population.

Discussion

The findings from this investigation present a notably positive perception among students who self-identify with war trauma concerning the inclusivity of the university environment. A substantial majority of respondents perceive their educational settings as both comfortable and safe, underscoring the dedicated efforts by institutions to cultivate a sense of belonging and security amidst wartime conditions. This favourable perception is particularly salient for supporting students who have experienced war trauma – a vulnerable group for whom safety and comfort transcend mere desirability to become essential prerequisites for academic engagement and success.

The university environment emerges as a critical factor in these students' healing process and academic accomplishments (Sun et al., 2021). Comfort and safety within this context extend beyond the physical to include psychological safety, fostering a sense of normalcy and stability instrumental in their recovery and academic endeavours. Specifically, in the Ukrainian context, exacerbated by the ongoing conflict, there emerges an acute need for more adaptable and inclusive programs designed to address the diverse requirements of student populations (Tsybuliak et al., 2023). The exigencies of wartime have precipitated significant alterations, including the expansion of distance learning methodologies, the differentiation of individual study plans, and the employment of varied psychological interventions to mitigate panic attacks during air alarms or frequent power outages across numerous Ukrainian regions. Moreover, the escalating presence of vulnerable student groups necessitates curriculum adaptations to meet their needs amidst the backdrop of conflict, emphasizing a critical demand for inclusive education that is responsive to the varied needs of students (Ivanchenko et al., 2023). Consequently, adopting online learning modalities has become essential in ensuring the continuity of educational services during conflict periods, thereby preserving the university structure, safeguarding employment positions, and preventing the erosion of human potential (Marchenko, 2023).

The evidence from our study aligns with existing research, which robustly supports the notion that environments marked by inclusivity and support are instrumental in promoting student well-being and academic achievement (Lizzio et al., 2002; Moriña, 2017; O'Shea et al., 2016; Lopatina et al., 2023; Kenworthy, & Opatska, 2023). Such environments extend beyond satisfying academic requisites, encompassing the emotional and psychological wellness of the student population. This aspect is particularly critical for students belonging to vulnerable groups, such as those experiencing war trauma, who present special needs and face unique challenges. An inclusive and supportive educational setting serves as a pivotal factor in fostering these students' engagement, resilience, and overall success, laying a solid groundwork for their academic pursuits and personal development. This emphasizes the urgency for universities to place a heightened focus on inclusivity, ensuring that their environments are conducive to the growth and well-being of all students, especially those from demographics that are at a higher risk of marginalization and adversity.

Among the notable strengths identified in this study is the positive appreciation for adaptive teaching methods within Ukrainian universities, particularly during wartime. These methods, which customize learning experiences to address the diverse needs of students, are pivotal in creating an inclusive learning environment (Cavanagh et al., 2020). They guarantee equitable access to learning opportunities for all students, irrespective of their backgrounds or the challenges they face (Peng, & Spector, 2019). Adaptive teaching is especially advantageous for students affected by war trauma, offering the necessary flexibility in learning approaches to accommodate their distinct circumstances and the possible interruptions in learning due to trauma.

Furthermore, the study highlights the critical role of individualized support services as another significant strength. Ranging from academic accommodations to mental health support, these services are indispensable for catering to the unique needs of each student (Ezarik, 2022; Hyseni Duraku, Davis, & Hamiti, 2023). For students experiencing war trauma, this individualized support may encompass counselling services, extensions on assignments, and alternative examination arrangements (Abelson et al., 2022). Collectively, these measures contribute to the establishment of a supportive learning environment that recognizes and addresses the specific challenges faced by these students, thereby facilitating their academic and personal development within the university setting.

While the findings from this study reflect positively on the inclusivity within Ukrainian universities, they concurrently underscore areas that necessitate further enhancements. Among these, the perceptions related to the establishment of barrier-free environments and the extent of mutual respect within the academic community highlight a significant scope for improvement. Addressing these facets is crucial for fostering a learning environment that is fully supportive and responsive to the needs of the entire student body, including those impacted by war trauma. The implications of such improvements are far-reaching, potentially affecting both mental health outcomes and academic achievement.

The notion of a barrier-free environment encompasses more than just physical accessibility; it also involves eliminating social, psychological, and informational barriers that may limit a student's full engagement in both academic and campus life (Li et al., 2023). The current study reveals that, although efforts to enhance physical accessibility are recognized, other dimensions of inclusivity may not receive equivalent attention. Particularly for students experiencing war trauma, the existence of "invisible" barriers – including inadequate mental health support, a lack of acknowledgement for trauma-informed teaching practices, and restricted access to customized academic accommodations – can significantly impede their academic progression and overall well-being.

Establishing a genuinely barrier-free environment requires a comprehensive and holistic approach, one that adequately addresses the varied needs of the student demographic. This entails the development and implementation of extensive support systems that encompass mental health services, academic adjustments, and initiatives aimed at fostering social inclusion. Moreover, it necessitates cultivating a campus atmosphere where students feel empowered to seek assistance and access resources designed to meet their specific requirements.

Another area highlighted for improvement is the level of mutual respect among students, faculty, and staff. Mutual respect is foundational to creating an inclusive and supportive learning environment. It influences students' sense of belonging, impacts their engagement with their studies, and affects their overall university experience (Thabet, & Abusultan, 2016). For students dealing with the aftermath of war trauma, a university culture that promotes understanding, empathy, and respect can be particularly therapeutic. It can facilitate their reintegration into academic life and support their recovery process (Alotaibi, 2021). Improving mutual respect within the university setting involves promoting open dialogue, increasing awareness and understanding of diverse experiences and backgrounds, and implementing policies that actively discourage discrimination and bias. Educating the university community about the impacts of war trauma and the importance of a supportive environment can also contribute to fostering a more inclusive atmosphere (Davidson, 2020).

The study also uncovers areas where inclusive policies and practices could be improved. One significant area of concern is the consistency in the application of these policies across different departments and faculties. Students' experiences suggest that while some areas of the university excel in inclusivity, others lag, creating a patchwork of support that can lead to feelings of exclusion and inequality. This inconsistency can be particularly disorienting for students with war trauma, who may require a stable and predictable support system to thrive academically.

A notable concern is the variability in the application of inclusive policies across different universities. The data reveal that while certain areas of the university demonstrate a great level of inclusivity, others fall short, resulting in a fragmented support system that may engender feelings of exclusion and disparity among students. This inconsistency poses a particular challenge for students with war trauma, who necessitate a consistent and reliable support framework to facilitate their academic success. It highlights a deficiency in the awareness and training of faculty and staff regarding the distinct needs of students from diverse backgrounds, including those who have encountered war trauma. The absence of comprehensive training may lead to an inadvertent neglect of the specific challenges faced by these students.

The long-term impact of war trauma on students is a critical concern that demands proactive measures from Ukrainian universities. Research indicates that the effects of war trauma are enduring and can significantly affect the learning of students (Kataoka et al., 2012; Mougrabi-Large, & Zhou, 2020). The long-term impact of war trauma on students demands a strategic and empathetic response from universities. The 'echoes of war' are not merely historical footnotes but active factors influencing the academic and social dynamics within Ukrainian universities. As institutions confront the realities of a student population increasingly affected by war trauma, especially in the wake of the ongoing war in Ukraine, the imperative to foster an inclusive learning environment becomes paramount. This encompasses acknowledging the 'echoes' as the lingering effects of war trauma and implementing measures that go beyond traditional support mechanisms. Unclear responsibilities and lack of awareness can create a fragile basis for decision-making and the possibility of abandoning inclusive actions (Solis-Grant et al., 2023).

It's important for a forward-looking approach by universities to not only accommodate but also to anticipate the increasing presence of students affected by war trauma within their student body. The predictable rise in this vulnerable group underscores the urgency for universities to prepare for future demands to foster an inclusive environment that acknowledges and mitigates the impact of war trauma.

To align educational practices with the socio-political reality Ukrainian universities must undertake a series of targeted actions. These include developing a framework that recognizes the nuanced impact of war trauma. Such a framework would guide the enhancement of staff training, ensuring that academic and support personnel are equipped with the understanding and skills necessary to engage effectively with students carrying the weight of these 'echoes.' Moreover, improving support systems and fostering collaboration among higher educational institutions are essential steps towards realizing the vision of inclusivity.

Limitation

This study offers valuable insights into the inclusivity of Ukrainian universities for students with war trauma, yet it is not without its limitations. The participant pool of 150 students, while providing significant data, represents only a small fraction of the university population and limits the findings' generalizability. The reliance on self-reported data through an online survey might introduce response bias, and the cross-sectional design captures only a snapshot in time, not accounting for the evolving nature of war trauma's impact or institutional efforts towards inclusivity. Additionally, the study's response rate and potential selection bias remain unknown due to the method of data collection, which might skew the results towards those with stronger opinions on inclusivity. The adaptation of the Inclusion Index for this context, though innovative, may not fully capture all nuances of inclusivity relevant to the war-affected student population. Furthermore, the ongoing conflict in Ukraine could affect the study's relevance over time, necessitating continuous research to keep pace with changes. The absence of a control group also limits the ability to make comparative analyses between students with and without war trauma experiences. Despite these challenges, the research contributes to understanding educational inclusivity in wartime, highlighting the need for further, more nuanced studies to better support all students, especially those experiencing war trauma.

Conclusion

This study has illuminated the complexities and nuances of fostering an inclusive environment for students with war trauma within Ukrainian universities in wartime. Through a comprehensive analysis of students' perceptions regarding inclusivity, our research offers a unique lens into the current state and potential future directions for enhancing inclusivity in an educational context marked by ongoing war. The findings highlight a landscape where positive strides have been made towards creating a welcoming and supportive environment for all students yet underscore the necessity for targeted improvements to address existing gaps and inconsistencies.

The study's insights into the areas requiring improvement – such as enhancing barrier-free environments, fostering a culture of mutual respect, accessing learning resources, awareness and specialized training among faculty and staff – point towards actionable directions for universities. To truly support students with war trauma and other vulnerable groups, universities must strive for a consistent and holistic application of inclusivity principles. This includes expanding trauma-informed educational practices, increasing accessibility in all its forms, and nurturing an environment of empathy and understanding that permeates every facet of the university experience.

Moreover, the ongoing war in Ukraine and its impact on students accentuates the urgent need for universities to not only adapt to the current realities but also anticipate the evolving needs of their student populations. This foresight involves recognizing the prolonged effects of war trauma and preparing to support an increasing number of affected students in the years to come. The establishment of a robust framework for inclusivity, reinforced by continuous evaluation and adaptation of policies and practices, will be critical in this endeavour.

In conclusion, this study reaffirms the importance of inclusivity in higher education as a dynamic and evolving process, particularly in a war context. By acknowledging the strengths and addressing the areas for improvement identified through this research, Ukrainian universities can enhance their support for all students, thereby fulfilling their pivotal role in shaping an equitable, accessible, and resilient educational landscape. As Ukraine continues to navigate the challenges posed by the ongoing war, the commitment of its higher education to inclusivity will remain a beacon of hope and a crucial factor in collective healing and recovery.

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ABSTRACT

This study investigates the inclusivity of Ukrainian universities based on the perception of students with war trauma during the ongoing full-scale war. An online survey methodology collected data from 150 students across various stages of higher education, focusing on their perceptions of the university's inclusive culture, policies, and practices. The findings indicate a broadly positive perception of inclusivity, highlighting the universities' efforts to create a comfortable and safe learning environment. However, areas requiring improvement, such as enhancing barrier-free access and fostering mutual respect, were identified. The study emphasizes the significance of adaptive teaching methods and individualized support services, particularly for students with war trauma. The findings underscore the need for continuous improvement in inclusivity practices to effectively address all students' diverse needs. Given the ongoing war in Ukraine, the study calls for a proactive and anticipatory approach by universities to accommodate the evolving needs of students affected by war trauma, emphasizing the importance of inclusivity in higher education for societal healing and recovery.

KEYWORDS

inclusivity, war trauma, university, Ukraine

Inclusivity of Higher Education as a Basis for the Efficiency of the Educational Process and Social Adaptation in European Countries of Sustainable Development

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Providing all participants in the educational process with equal opportunities according to their potential and aspirations, supporting the equal involvement of individuals with diverse socio-economic, professional, cultural, and educational backgrounds, entails the construction of a socially inclusive higher education system with enhanced capabilities and tools. This system is capable of supporting a sustainable, united, and peaceful Europe – this is the main focus of the fundamental strategies and principles in the development of modern education.

Developed European communities are united in the need to find potential for integrating individuals with disabilities into society by creating an inclusive living environment. “Accessibility” does not only refer to the absence of architectural and transportation barriers; it primarily involves breaking down barriers to access education, cultural values, and creating a fully communicative space that does not confine the interaction of people with special needs to the virtual world. Concerns for people with disabilities, in "healthy" societies, cease to be the problems of individual persons or groups of people; they acquire general significance and become a real social problem, the solution of which requires not only significant financial expenditures but also certain moral-psychological efforts. The collective support of such individuals helps them move out of exclusion and begin to live a full, independent life (Hamretskyi, & Stoliarenko, 2012).

Scientific studies in the field of inclusive education abroad cover the context of those social and legal changes that have taken place in the educational policies of countries where the inclusion of people with disabilities has long been a successful and stable practice. Inclusive education, first and foremost, is considered in the context of forming new norms of social morality and respect for differences among people, combating discrimination, and liberal-democratic reforms. The transition from the differentiation of special education to inclusion in Western European countries occurred during economic prosperity, which not only politically but also financially enabled the change in the integration model of education. Inclusive education is part of the educational and social policies of any state and inevitably reflects its specificity, internal logic, and development direction (Sadova, 2020, p. 189).

The quality inclusiveness of university education becomes a powerful tool for integrating people with disabilities into society. It offers the opportunity to acquire prestigious professions, secure rational employment, develop leadership qualities, achieve self-realization, become economically independent, and provide for not only oneself but also one's family. Education eliminates barriers associated with special needs, promoting a full and meaningful life.

A wave of discussions and the activation of the legislative process in the field of inclusive education began after Ukraine ratified the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol on December 16, 2009, (Convention on the Rights of Persons with Disabilities, 2010), which entered into force in Ukraine on March 6, 2010. In 2020, the participating states of the Bologna Process adopted the Rome Ministerial Communiqué (2020), which considers the European Higher Education Area (EHEA) as a space where students, staff, and graduates can freely move to study, teach, conduct research, based on and respecting the fundamental values of higher education, democracy, and the rule of law, ensuring equal opportunities and tools for all participants in the educational process to search for and use in accordance with their potential and aspirations. The overall goal is to build an inclusive, innovative, and interconnected space by 2030 that can become the foundation for a sustainable and peaceful Europe. The same year, Principles and Guidelines to Strengthen the Social Dimension of Higher Education in the EHEA (2020) were defined, where the 9th principle states that higher education institutions must ensure that community participation in higher education promotes diversity, fairness, and inclusivity through processes of interaction and involvement of all interested parties in society.

The attention to the issue of equal opportunities intensified due to the war with the Russian Federation, which has been ongoing for the past 10 years, resulting in numerous casualties and a critical increase in the number of people with disabilities. The result is the emergence of a large number of individuals with specific educational needs: individuals who have sustained injuries, significant impairments; individuals experiencing symptoms of post-traumatic stress disorder, psychosomatic manifestations, apathy, chronic fatigue, mutism – loss of ability to speak following psychological trauma, and so on; internally displaced persons; war veterans, participants of the Anti-Terrorist Operation/Operation of Ukrainian Joint Forces, and others.

Therefore, the National Strategy for Creating an Accessible Space in Ukraine until 2030 identifies the creation of equal opportunities and free access to education, lifelong learning, as well as acquiring different professions, improving qualifications, and gaining additional competencies as strategic directions. It aims to meet the special educational needs of all participants in the educational process by creating an inclusive educational environment (Approval of the National Strategy for Creating an Accessible Space in Ukraine until 2030, April 14, 2021).

The Development Strategy for Higher Education in Ukraine for 2021–2031 emphasizes the priority of ensuring accessibility and inclusivity in higher education (Development Strategy of Higher Education in Ukraine for 2021–2031, October 2, 2021).

The implementation of inclusive elements into the national education system signifies the necessity of raising the level of social culture, tolerance, expanding opportunities for every individual and their inclusion in societal life, including vulnerable categories such as people with disabilities, children, the elderly, migrants, and military personnel. However, the main problem is that due to the war, a certain number of education seekers are forced to interrupt their studies due to the mismatch of conditions in higher education institutions to their specific educational needs, which have arisen due to the relocation of many universities and active combat actions on the territory of our state. This complicates the implementation of the main strategies and principles of European education development.

However, the implementation of inclusivity in the education sector faces challenges not only in Ukraine. For example, in Belgium, the implementation of inclusive education is slow and faced with global contradictions, much of which is caused by deeply rooted rigid approaches to segregating special and general education.

Greece also faces a set of difficulties hindering the expansion of access to education for people with special educational needs. This is due to factors such as the absence of a balanced educational policy for people with special educational needs in Greece; inadequate qualification levels of educators and the material-technical provision of higher education institutions; insufficient time for planning individual educational programs for such learners.

The experience of different countries confirms that the transition to inclusive education is becoming more multidimensional. Although in each country inclusivity of education is ensured by leadership, relying on its own traditions and based on urgent needs and opportunities, its practical support remains a crucial aspect.

Ukraine adapts the positive experience of inclusive development from European countries and implementing it, taking into account its own challenges related to Russian aggression. In documents such as the "National Action Plan for the Implementation of the Convention on the Rights of Persons with Disabilities for the period up to 2025" (Approval of the National Action Plan for the Implementation of the Convention on the Rights of Persons with Disabilities for the period up to 2025, April 7, 2021) and the "National Strategy for Creating an Inclusive Environment in Ukraine for the period up to 2030", inclusivity is defined as a core value for the development of our state.

Ukraine supports the initiative to create the European Higher Education Area, which is defined as an inclusive, innovative, and interconnected space to support a sustainable, cohesive, and peaceful Europe. Inclusivity is planned to be ensured through access to higher education for various socially vulnerable groups, refugees and migrants, orphans, people with disabilities, ethnic and religious minorities, and others.

To support the aforementioned initiative, the Ministry of Education and Science of Ukraine has made changes to the standards of higher education (Accessibility. Amended Higher Education Standards, February 8, 2024), which will come into effect from the new 2024 admission campaign. Now, educational programs for specialists in "Psychology" and "Medical Psychology" include the study of methods for providing psychological assistance to individuals who have experienced psychological trauma as a result of war. The changes will provide psychological individual and group rehabilitation and psychotherapy for patients with war-related injuries.

The educational programs for "Architecture and Urban Planning" and "Construction and Civil Engineering" have also been updated. The preparation of these specialists will involve special professional competencies, namely the creation of an accessible architectural and construction environment.

An important aspect of solving the problems of the involvement of students with disabilities in the educational process and public life of a higher education institution is the implementation of the principle of autonomy of higher education institutions, including financial autonomy, which will enable higher education institutions to allocate funds for the arrangement of educational space independently, taking into account the needs of people with disabilities and representatives of groups with reduced mobility. In order to adapt people with disabilities and representatives of low-mobility groups to the educational process and public life, Ukrainian institutions of higher education create groups in which all students study together. Universities provide educational services to students taking into account the individual characteristics of educational and cognitive activities, taking into account the recommendations of an individual rehabilitation program that takes into account the student's nosology; with the use of personally oriented teaching methods and individual study plans for such students. The principle of universal design of educational trajectories is taken into account; compliance with the requirements of state construction regulations, standards; special means of correction of psychophysical development and necessary methods of communication that take into account the peculiarities of students with impaired hearing and vision are introduced – Ukrainian sign language, relief-dotted font (Braille) with the involvement of relevant specialists and pedagogical workers; the availability of information in various formats is ensured – Braille, enlarged font, audio and electronic formats.

Similar practices are widespread regardless of the military situation in the country. Conducting sign language courses for students and teachers already has a good example. Thus, on the basis of the Vinnytsia Institute of the University "Ukraine" hosts the "Center for Foreign Language Learning", where not only students, but also police officers learn Ukrainian and English sign languages. It is noteworthy that students specializing in "Physical Rehabilitation" are required to study both English and Ukrainian sign languages (M. Tarasova. Hearing the deaf. Why did Vinnytsia policemen start learning sign language, 2024).

In developed EU countries, the educational landscape model includes an inclusive component based on Recommendation No. R(92)6 of the Council of Europe on consistent policy for people with disabilities, according to which, young people should attend special institutions only if they have a degree of disability that prevents them from being in an inclusive group and requires special medical or social care. The domestic inclusive educational landscape is in the early stages of formation. In recent years, there has been an increase in universities oriented towards inclusion as a paradigm of their activities. Among them are Lviv Polytechnic National University with the "Open Doors" Inclusive Education Centre, Taras Shevchenko National University of Kyiv with the "Accessible Education" program, V.N. Karazin Kharkiv National University and its project "Inclusive Education for All," the Student Support Centre for Students with Disabilities at Igor Sikorsky Kyiv Polytechnic Institute, and others.

However, a significant drawback in the implementation of the inclusive component in the national education system is the lack of continuity and accessibility of inclusive opportunities at all levels of education: school – college – university (education at all levels from the first (bachelor's) to the third (educational-scientific) – informal education – adult education.

Ukraine, moving towards European integration, seeks to comply with the best practices of European legislation and adopt the best experience in implementing the principles of accessibility of education at all its levels. This includes studying and implementing models of inclusive education from European countries with sustainable development. The experience of Germany is illustrative, where there are institutions of inclusive education alongside special educational institutions for children with complex disabilities. In German higher education institutions, 19% of learners with health limitations and 4–8% of students with disabilities are educated. These students are provided with legislative social and medical support, special technical aids necessary for daily life, and services from state social agencies.

Higher education institutions in EU countries have not fully addressed the issue of access to higher education for students with special educational needs and the provision of their psychological rehabilitation and adaptation. The Council of Europe regularly monitors the accessibility of education, including higher education, and provides recommendations that are considered when adopting national laws. The focus is on legislative and financial support for special services and the creation of appropriate conditions. Romania, Slovenia, the Czech Republic, and Poland emphasize the human factor in providing access to education for students with disabilities, involving advisory services and personal assistantship.

France, Sweden, the Netherlands, and the UK allocate significant funds for technical and engineering retrofitting of educational institutions. Norway, Sweden, Finland, the Netherlands, and the UK are leaders in the accessibility of education. They have implemented the main directions of the inclusive education paradigm and addressed the issues of access to higher education for learners with special educational needs, introducing principles of psychological rehabilitation and adaptation, methodological support for inclusive education, and solving various organizational issues in implementing inclusive education in higher education institutions. These countries have ensured a high level of physical access to educational institutions, technological and methodological support, and a developed system of psychological support and mentoring. In these countries, social policy has reached the highest level, administrative reforms have been carried out in the organization of inclusion, and inter-university collegial bodies have been created.

Psychological adaptation of students with disabilities becomes one of the key directions in implementing inclusive policies in European countries. Psychological rehabilitation may focus more on consultative, supportive, adaptive, or problem-solving issues and involves the work of higher education institution specialists, government agencies, and independent centres.

Since European states have distinct socio-pedagogical traditions and varying levels of funding for educational reforms, inclusivity in higher education may be implemented fragmentarily. Issues remain regarding the adaptation of university infrastructure, the placement of service facilities on upper floors, and the inadequacy or absence of elevators in existing buildings.

The experience of educating youth with disabilities in European countries indicates that inclusive education is predominantly the primary form of education for such individuals. Children and youth with special educational needs have the opportunity to receive education both in special educational institutions and mainstream schools, including higher education institutions. Education systems vary greatly in structure and methods of achieving their goals. However, there are common trends, one of which is the implementation of inclusive education, which entails making education accessible to all and eliminating any discrimination in the educational process, as observed in educational systems of different countries.

In summary, it should be noted that: Modern higher education in Ukraine is based on domestic and international legislation, norms, principles, and a system of measures to ensure the inclusive component of education. An increasing number of higher education institutions are actively implementing educational landscape models that include an inclusive component.

Universities, as centres of education and culture, public opinion, and socially oriented institutions that consider the needs of the community and are based on a student-centred approach, should create conditions to improve access to higher education and provide full support during the learning process for people with disabilities. This includes the establishment of Inclusive Resource Centres, contributing to the enhancement of the social dimension of higher education.

We believe that this will contribute to the implementation of the social strategy of the university as a focal point, focused on the introduction of inclusive culture, informational and educational activities to shape inclusive culture, values, and goals, creating a friendly educational environment for inclusive learners and individuals in need of support. This involves establishing a partnership network with institutions and agencies responsible for social protection, civic associations, and organizations to conduct volunteer activities aimed at engaging and supporting learners with special educational needs and people with disabilities.

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ABSTRACT

Peculiarities of involving people with disabilities in the educational process and public life of a higher education institution. Research on the involvement of students with disabilities in the educational process and social life on the example of higher education institutions of Ukraine and European countries.

KEYWORDS

socially inclusive system of higher education, people with disabilities, equal opportunities, accessibility of higher education

Social Exclusion of People in Suicidal Crisis

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Introduction

Over the last few years, as a society we have faced the problem of social exclusion. Many authors have attempted to define this phenomenon, using such various terms as "social isolation" or "social marginalisation". Maria Jarosz in her article defines social exclusion in a simple way, writing about it as living outside the margins and privileges of society (Jarosz, 2015, p. 60). In other publications we can find a more complex definition that outlines the problem of exclusion in detail. In the collective work "The multi-dimensional analysis of social exclusion", social exclusion is defined as: "a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas" (Levitas et al., 2007, p. 9). Thus, we can refer to people affected by this phenomenon as people, who are "excluded from life".

"Exclusion from life" is a concept that can refer both to issues of functioning in society and to the situation of people in suicidal crisis, where the severance of ties with society culminates in death by suicide (Jarosz, 2015).

E.S. Shneidman proposes that we look at the phenomenon of suicide in a multidisciplinary way. In this case, a broader view of the problem is necessary, as no single specialty has complete knowledge of suicidology. The author emphasises that each case of suicide should be considered holistically, from the perspective of many specialties, and understanding it requires the knowledge of specialists from many fields. "Any sensible scientist should take warranted umbrage, if an associate in a specialty other than his own states that his piece of the action is the whole pie" (Shneidman, 1989, p. 14). To help a person in suicidal crisis, to begin with, we need to understand the phenomenon of suicide itself. In the process of helping, it is essential that different scientific disciplines work together to create a comprehensive intervention plan. Only then we will be able to effectively identify the main risk factors, develop personalised support strategies and tailor interventions to the specific needs of the individual. Collaboration between professionals will allow us to better understand the complexity of suicide and develop more precise, effective prevention methods to save lives and improve the mental health of individuals in suicidal crisis.

Sociological approach

The first issue to be noted is how many scientific disciplines treat the phenomenon of suicide as an object of research and analysis. The term "suicide" should even be defined in interdisciplinary terms. Thanks to this view, a separate science of "suicidology" has emerged, which focuses on suicidal behaviour (Formella, 2015, pp. 269–370).

The first revolutionary to address the issue of suicide from a sociological perspective was Emile Durkheim, who in his work "Le suicide", published in 1897 in France, pointed out that the cause of suicidal behaviour is not, as previously thought, to be found in genetic conditions. Durkheim found a link between social conditioning and the incidence of suicidal behaviour by analysing the suicide statistics of the time (Formella, 2015, p. 372). "Thus, E. Durkheim's thesis that social disorganisation and the dysfunctionality of social environments are the most important phenomena influencing the scale and rate of suicides is verified and still valid. [„Sprawdza się zatem i wciąż pozostaje aktualna teza E. Durkheima, że dezorganizacja społeczna i dysfunkcyjność środowisk społecznych są najważniejszym zjawiskiem wpływającym na skalę i współczynnik samobójstw"]" (Konieczny, 2023, p. 207).

Emile Durkheim distinguished the following types of suicide: anomic, egoistic, altruistic and fatalistic. The first of these, anomic, which is directly related to the phenomenon of anomie, concerns the loosening or breaking of ties between the individual and society. An individual makes the decision to take his own life after a sudden change or event in his life. Chaos and confusion in society can lead to disorientation due to the lack of clearly defined norms and rules. These include undesirable situations such as the loss of a job, where the person experiences financial instability, as well as not being able to find one's way in a new environment by sudden enrichment (Domańska, 2017, p. 190). The second type is egoistic suicide – resulting from not forming a sufficient bond with society (Domańska, 2017, p. 190). The individual is isolated or isolates him/herself, which leads to a lack of social support and, as a consequence, such person is unable to cope with his/her problems and find any solutions.

Altruistic suicide refers to sacrificing oneself for a higher purpose. One of examples of such are Islamic terrorist attacks, in which a fanatic sacrifices his life in the name of his god and death by suicide is honourable for such person (Domańska, 2017, p. 191). The last type is fatalistic suicide – people who are threatened by it are primarily those "trapped in an unwanted life situation" [„uwięzieni w niechcianej sytuacji życiowej"] (Jarosz, 1997, p. 47) – they see no prospect of correcting the situation, in which they are. It also concerns mass suicides among cults, as well as euthanasia.

In this paper, we will focus primarily on the egoistic type, which is directly related to the phenomenon of social isolation.

Social exclusion of suicidal people in historical perspective

Suicide had already been condemned and socially unacceptable since the Middle Ages. Earlier references to it can be found in antiquity, but at that time the principle of the "right to choose" was practised. Suicide in ancient Rome was only condemned, if it was "without good reason". On the other hand, if there was a good reason, Roman law did not prohibit people from taking their lives (Michalska-Suchanek, 2011, p. 23).

In its origins, Christianity did not consider suicide by choice. It was not until St. Augustine (354–430) in his creation "De Civitate Dei" (On the State of God) stated that suicide was a sin and an unholy act. He justified it by breaking the fifth commandment of the Decalogue, which states: Thou shalt not kill. The commandment concerned both the prohibition of killing another human being and oneself under the threat of divine punishment that awaits suicidal people after death (Zwoliński, 2013, pp. 98–100). The Christian Church in later years continued to condemn the suicidal act and recognised it as a grave sin (Michalska-Suchanek, 2011, p. 30). Several other publications also provide information on the desecration of the corpses of those, who performed a suicidal act. In Breslau in the seventeenth century, the bodies of suicidal people were handed over to special officials – executioners – and buried in "cursed cemeteries", usually on execution sites. Before burial on weekdays, bodies were transported around the city to show the citizens, how people, who decided to leave before their time, were treated (Wojtucki, 2010, pp. 253–254). Disposing of corpses in landfill sites also occurred, but these were not the worst methods of treating bodies. Until the 19th century in England, the bodies of suicidal people were pierced with a dowel, while in Europe, the carcasses were most often burned, put into barrels and drowned in order to prevent the souls of such people from returning to the world of the living. All these desecrations took place according to the law (Michalska-Suchanek, 2011, p. 31), not only for show but also with the public. The mentality of the time persisted for a long time, effectively encoding in people's minds the awareness that person in suicidal crisis deserves social condemnation.

Today, Christianity still regards suicide as a disrespect for the sanctity of life. The Church has had a huge influence on the perception of suicide over the centuries, although it now has no influence on the law and the suicidal people deserve a decent burial after death. This involves a greater understanding of the mental anguish that affects those in suicidal crisis. The body can even be buried in a church cemetery, but several factors are taken intoaccount, including the person's mental state before death, age or capacity (Szwagrzyk, 1960, pp. 236–237). "(...) in the light of contemporary Church teaching, the approach to the suicide itself has changed. A suicidal person can achieve salvation, but the act of suicide itself is treated as an act of the devil, as a result of severe stress, sacrifice, depression or other mental disorder" (Kielan et al., 2017, p. 161).

It is currently assumed that religious participation is associated with a lower risk of suicide. "Many studies have shown that suicide rates, especially for men, are lower in countries where religious or cultural systems traditionally view suicide negatively, and higher in countries where belief systems sanction it." ["Wiele badań wykazało, że współczynniki samobójstw, dotyczące zwłaszcza mężczyzn, są niższe w krajach, w których systemy religijne lub kulturowe tradycyjnie oceniają samobójstwo negatywnie, a wyższe w krajach, w których systemy wiary sankcjonują je"] (Hołyst, 2012, p. 114).

In religious environment, the phenomenon of suicide is often treated as a taboo subject, which can significantly affect and discourage people in crisis from seeking help. Despite this, some churches also provide support for people in suicidal crisis and help for families and relatives of people, who have taken their own lives. Hołyst puts the problem of this phenomenon in the hands of institutions that are involved in developing suicide prevention programmes. In his view, the complexity of human suffering includes internal conflicts, social problems and both religious and existential crises, which should not be exclusively associated with psychiatric problems (Hołyst, 2012, p. 115).

Thus, looking at this phenomenon holistically is certainly the basis for action, where both the social and cultural perceptions of suicide in different settings and the individual needs of a person in suicidal crisis are relevant.

Social exclusion as a cause of suicide attempts

Despite progress and development, modern society faces many challenges, including the effective prevention of social exclusion. It is impossible to determine unequivocally what was the immediate cause of each suicide attempt. It is known that a person makes an attempt to take his or her life, guided by individual motives and, in fact, it is difficult to find a common feature for each case (Jarosz, 1997, p. 44). Nevertheless, suicide is a global phenomenon and in many different social groups this suicide rate is higher and in others lower. It may be worthwhile, therefore, to focus on particular communities, not looking for a golden rule, but putting in place appropriate prevention programmes that will have an effective impact on a particular social group.

Durkheim wrote "(...) that for each social group there is a specific tendency to suicide, explained neither by the organic-psychic constitution of individuals, nor the nature of the physical environment. Consequently, by elimination, it must necessarily depend upon social causes and be in itself a collective phenomenon" (Durkheim, 1952, p. 97). Many of these groups share the common phenomenon of social exclusion to a greater or lesser extent. Among those, who commit suicide there are people, who are unemployed, divorced, addicted to alcohol or other drugs – usually men, who predominantly make up the statistics. Suicide also affects older people who, in a technologically evolving world, find themselves less and less understood (Witkowska, 2021, p. 30). These are not the only social groups, where the risk of suicidal crisis is high, while it is certain that they face exclusion on a daily basis.

Analysing suicide statistics in terms of motives, it is clear that the most numerous group, which takes its own life, are people who struggle with mental illnesses and disorders (Gawliński, 2018, p. 30). The specificity of the exclusion of people with mental health problems is most often related to a lack of knowledge about how these people function. This very often results in avoidance due to fear and the assertion that a mentally ill person is unpredictable (Rasmus et al., 2013, p. 6). This situation largely affects people with schizophrenia, who in particular function with a sense of shame, hiding their illness from the world (Dziwota, 2014, p. 19). Society assumes that such people are unfit for social roles. It is estimated that suicide is the most common cause of death among people with schizophrenia and 10% of suicides committed statistically involve people diagnosed with this disorder (Bohaterewicz et al., 2019, p. 23). Long-term social isolation, subjecting a person to a stigma and marginalisation is associated with the occurrence of resignation thoughts and, consequently, taking one's life.

There is also the phenomenon of self-stigma, which occurs when an individual accepts society's view of their illness or disorder, which results in a lowered sense of self-worth and affects the effectiveness of treatment (Dziwota et al., 2015, p. 234).

Man is a social being, who needs other people in order to function properly. The loss of social ties through social exclusion of the individual can have disastrous consequences. In order to prevent stigmatisation, especially of people who suffer from mental illnesses such as schizophrenia, society needs to be made aware and better educated on these issues. The mass media mainly focus on providing information about depressive disorders, addiction or suicide (Podgrodzka-Niell, & Tyszkowska, 2014, p. 1202). Undeniably, these activities are educational, but from year to year statistical data show an increasing trend of suicidal behaviours. The mass media have a strong influence on their audience, so using them to educate the public on the topic of mental illness and disorders could increase awareness and thus reduce stigma and social isolation.

Suicide as a modern problem – warning signs

Police General Headquarters statistics show, how the number of suicide attempts has increased dramatically over recent years, particularly among children and young people. Various scientific communities have found a link between the COVID-19 pandemic and the rising suicide rate. During the course of it, we, as a society, were particularly vulnerable to social isolation. Although some people treated this time as a respite from everyday life and responsibilities, many others faced tremendous stress due to limited contact with relatives or confinement in a violent environment. (Necessary, 2023, p. 316) Ultimately, as a society, we see disturbing statistics and a struggle within the scientific community for active suicide prevention policies.

“Of any ten persons who kill themselves, eight have given definite warnings of their suicidal intentions” (Shneidman, 2010, p. 13). When we speak of the symptoms of a suicidal crisis, we are referring to the warning signs, by which we are able to detect the intention to taking one’s own life early. One of the clearest descriptions of the presuicidal syndrome was created by Erwin Ringel. In 1949, he examined 745 people after an unsuccessful suicide attempt, making the observation that certain symptoms occurred with greater regularity. Through this, he singled out the following elements of the presuicidal syndrome: constriction, inhibited aggression turned against the victim’s self and suicide fantasies (Lönqqvist, 2002, p. 167).

The first of these, narrowing, concerns the lack of prospects for a normal life. Narrowing of consciousness manifests itself as a limited way of perceiving the world. It can take forms such as a sense of helplessness in the face of the environment, pressure to end one’s life, loss of close relationships or lack of life values. It is a state, in which the individual loses the prospect of a better life and considers death as the only alternative (Groszek et al., 2005, pp. 400–401). The second element relates to self-aggression. The individual is unable to cope with the problem by accumulating aggression within him/herself, which he/she first transfers to the outside world and, when he/she suppresses the anger, directs it towards himself/herself. Lastly, the moment of fantasising about suicide is particularly dangerous. When initially the thoughts seem less damaging, over time they begin to escalate to finally take the form of planning a suicidal act (Groszek et al., 2005, p. 401).

In suicide prevention guidebooks we can find a lot of important information on warning signs that should be taken seriously. The National Institute of Health provides a list with behaviours to look out for in particular. These include verbal signs both direct and indirect – talking about death, feeling guilt or shame, being a burden to others. Any behavioural signs – explicit feeling of anxiety or distress, risk-taking behaviour, social withdrawal, giving away valuables, especially if the person has not exhibited such behaviour before – are a signal that there is a high risk of suicide (National Institute of Health, 2022). Observation, direct conversation and enquiry about suicidal thoughts can save someone's life, even if the individual denies having suicidal thoughts. This also does not preclude facing other mental health problems and an appropriate response can provide comfort and emotional support. Acknowledging suffering, accepting and not judging the other person in their condition can be the first step to taking appropriate action in seeking help from a professional.

Conclusion

The lack of appropriate social approach towards those, who have given up hope of getting out of a problematic situation turns out to be an individual tragedy for such people. Stereotypes about mental disorders and illnesses are also a barrier to building adequate prevention measures against suicidal phenomena. Focusing only on support for people in suicidal crisis without considering factors, including social exclusion, will be rather of intervention than prevention. Historical analysis shows us, how society has approached the topic of suicide over the centuries. Despite the evolving view of the phenomenon, there is still prejudice and marginalisation of people in crisis in some communities.

Sound media education in the context of the functioning of people affected by mental disorders and the provision of information, on where people affected by such stigma can seek help may significantly influence the level of social exclusion and, consequently, prevent attempts of taking their own lives. In an era of widespread digitisation, every user of social media can contribute to suicide prevention, e.g. by sharing infographics or help many people in crisis. In suicide prevention it is worth educating the people, who may be on the front line of contact with a person in crisis – teachers, doctors, school educators, clergy – they are the ones that a person, who has thoughts of giving up will turn to first. Adequate intervention preparation can not only support the person in crisis, but also reduce queues of people waiting for a meeting with specialists.

Halszka Witkowska, a Polish suicidologist, proposes multi-dimensional solutions that work in other countries. These range from architectural solutions that would limit accessibility to the suicidal method, to conducting reliable scientific research, increasing one's knowledge in the context of suicide, and most importantly, facilitating access to psychological and psychiatric help. The last aspect also includes the prophylaxis of taking care of mental well-being, which is in a worse state for more and more people nowadays (Witkowska, 2022, p. 281).

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ABSTRACT

Social exclusion is a phenomenon that has been occurring for centuries. Many authors attempt to define it as life outside the social margins, while emphasizing its complexity and multidimensional nature. This paper focuses on the analysis of the phenomenon of suicide and its links to social exclusion as a potential cause in a multidisciplinary approach. A holistic approach is essential in order to understand the topic and take preventive measures. The article draws attention to the relevance of the problem by also analysing the exclusion of people in suicidal crisis from a historical perspective. The paper's conclusions emphasize the need for preventive measures including public education and intervention for people in suicidal crisis.

KEYWORDS

suicidal crisis, suicide, social exclusion, multi-dimensional, prevention

Prisoners' Perceived Issues for Inclusion and Reintegration with Society

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Introduction

This text will explore the challenges prisoners believe they face in terms of being included in and reintegrated into society.

Someone who spends months or years in prison receives many labels from society. For example, they are often perceived as unable to function properly in society, or there is a fear that they might commit the same or even worse crimes. Due to these labels, reintegration into free life becomes challenging, leading individuals to revert to their old behaviour patterns. When their environment remains unchanged, breaking free from bad habits and preventing a relapse into criminal behaviour becomes increasingly difficult.

Erving Goffman (1963) defined stigma as an "attribute that is deeply discrediting", such as skin colour, ethnicity, or religion. According to Thornicroft (2006), people rely on insufficient or inadequate knowledge, leading to the reinforcement of stereotypes. The consequences of such behaviour include prejudice, discrimination, and social withdrawal, ultimately resulting in the social exclusion of the stigmatized individual. Overcoming the stigma associated with prisoners is challenging, but prisons in Poland offer various programs, workshops, and support to facilitate better functioning both within and outside prison walls. This, in turn, fosters the belief that most released prisoners can reintegrate successfully into society. According to the Prison Service at the end of 2022 in Polish prisons were 71 228 prisoners and 37 550 were recidivists, compared to the end of the year 2021 where in prison were 71 874 and 37 246 were recidivists. In total, the number of prisoners is rising and also this one which were already in prison at least once.

Types of Support

Irena Heszen and Helena Sęk (1997) posit that insufficient or no social support can significantly diminish the quality of life and negatively impact mental health. The source of support is also crucial. Charles Terdy (1985) identifies six groups from which support can be derived: family, friends, neighbours, co-workers, the community, and professionals. He emphasizes that support is not confined to the material sphere, categorizing it into emotional support, appreciative support, instrumental support, and informational support.

Emotional support addresses needs for trust, love, empathy, and care. Regular contact with close and important individuals is essential for the well-being of the detainee. Appreciative support aims to provide constructive feedback, helping the individual understand correct behaviours. Instrumental support involves material assistance, time, or skills, with the goal of developing constructive habits. The last type of support is advice, which can be especially valuable when offered by professionals such as psychologists, therapists, or tutors.

Programs and Workshops for Prisoners

Another avenue of support for prisoners involves the development of skills or acquiring new ones. Article 132 of the Polish Criminal Code mandates certain prisoners to participate in workshops or practical vocational training. While not obligatory for all convicts, these activities allow prisoners to develop various skills, including artistic ones. Artistic workshops can serve as a means for prisoners to express themselves through mediums such as painting, drawing, playing instruments, journalism, or writing.

Linguistic courses can contribute to prisoners' future prospects, especially when seeking employment in Poland or abroad. Since 2016, the Ministry of Justice has initiated the "Work for Prisoners" program, aiding prisoners in their reintegration by providing real-life job opportunities. Additionally, prisons implement programs for violence prevention, aggression replacement training, and addressing addiction to drugs or alcohol.

What Happens to Prisoners When They Leave Prison

In 2021, I conducted a pilot study on support for prisoners in one of Warsaw's prisons, surveying 64 male prisoners.

My method of data collection was a short quantitative diagnostic survey, including questions about their worries for when they leave the prison. The method was simple, it included basic descriptive statistics that were not meant to be representative of the population of prisoners in Poland but were serving as a preliminary pilot study, that allowed me to touch the problem and bring it to the surface. The findings revealed various concerns about leaving prison, including worries about housing, employment, family relations, returning to old environments, societal acceptance, and financial stability.

Under paragraphs 1 and 2 of Article 164 of the Penal Enforcement Code, the period up to six months before release is crucial for assisting prisoners in preparing for their reintegration into society. Initiatives such as contacting probation officers or associations, foundations, organizations, and institutions focused on rehabilitation can significantly aid this transition. Assistance may also include facilitating a transfer to a prison closer to their future permanent residence and helping prisoners obtain necessary identity documents.

Table 1. Fears of Prisoners after Leaving the Prison

I worry about the place to live	I worry that I will not find a job	I worry that my family will not want to have contact with me	I worry I will come back to my old bad environment	I worry that society will not accept me	I worry about the finances for daily life	I don't have any worries
9 prisoners	32 prisoners	5 prisoners	7 prisoners	13 prisoners	24 prisoners	24 prisoners

Source: own elaboration.

Conclusions

The array and types of support available for prisoners or former prisoners are extensive, but many programs are provided by foundations and institutions that may face financial constraints. Government programs, mostly mandatory for prisoners, may not allow them to choose programs aligned with their interests. After release, former prisoners often have to rely on non-governmental organizations for support. If the government fails to provide adequate post-penitentiary assistance, individuals are more likely to revert to old behaviour patterns, leading to a return to prison.

Breaking the societal stigma associated with ex-convicts requires challenging stereotypes. Organizing meetings or workshops with former prisoners can be instrumental in dispelling stereotypes and demonstrating that resocialization works effectively.

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ABSTRACT

This article helps with understanding how the situation in prison or outside of that works for prisoners. Support toward prisoners is more developed every year. Government and nongovernmental organizations still searching for a new method of support for a prisoner during their sentence or after that. Helping them understand their behaviours and accept different types of support that are offered to them is one of the main goals to achieve. The hardest part of helping them is to adapt to the new society and be accepted by them. This process can take a long time and sometimes it is arduous process. It also shows the perspective of prisoners and what kind of support they are looking for.

KEYWORDS

prisoners, support, workshops, society, family, reintegration, resocialization

Prediction of Cardiovascular Markers Associated with Aromatase Inhibitors Side Effects Among Breast Cancer Women in Africa: Observational Cohort Study

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Introduction

The finding that the 10-year predicted risk for cardiovascular disease (CVD) equals or exceeds recurrence risk of breast cancer (BC) in postmenopausal patients, led to recommendations to offer chronic disease screening programs in cancer survivors (Bardia, Arieas, Zhang, Defilippis, Tarpinian, & Jeter, 2012; Mehta, Watson, Barac, Beckie, Bittner, & Cruz-Flores, 2018). Aromatase inhibitors (AIs) are main treatment strategy for hormone receptor-positive BC patients (Friesenhengst, Pribitzer-Winner, Miedl, Pröstling, & Schreiber, 2018; Foglietta, Inno, de Iuliis, Sini, Duranti, Turazza et al., 2017). Co-morbidities associated with anti-cancer treatment adds to this complexity (Friesenhengst, Pribitzer-Winner, Miedl, Pröstling, & Schreiber, 2018). A study conducted on genetic testing services available through the National Health Laboratory Service, revealed a shortage of geneticists, counsellors and medical scientists trained to deliver personalized genomic medicine to the African public (Kromberg, Sizer, & Christianson, 2013). Since pathology tests, such as those used to assess hormone receptor status or high-sensitivity C-reactive protein (hs-CRP) levels may reflect obesity, this multi-gene assay currently performed using real-time polymerase chain reaction (PCR) methodology, combines pathology and genetic test results with lifestyle risk factors for clinical interpretation of the test results. Turn-around time using the pathology supported genetics testing (PSGT) approach is typically 1–2 weeks before the laboratory results are available (van der Merwe, Peeters, Pienaar, Bezuidenhout, van Rensburg, & Kotze, 2017). Study conducted by Milambo et al. (2021) on the efficacy of medically supervised exercises (MSE) in preventing aromatase inhibitors induced adverse events revealed that MSE can be used to improve range of motion (ROM) and heath related quality of life (HRQOL) in postmenopausal BC patients and associated comorbidities (Milambo, Ndirangu, Nyasulu, & Akudugu, 2022). A number of shared risk factors between postmenopausal status and CVD should be considered, while treating postmenopausal BCS. The results of meta-regression revealed that there was moderate evidence that medically supervised exercises (MSE) decreased the mean difference (MD) of inflammatory markers in BCS with CVD risk factors. Ideally, genetic testing should be performed at the point of care (POC) to reduce the time from sample collection to obtaining a result. While risk reduction intervention guided by a patient's genotype may be associated with decreased medication side effects/comorbidities, the potential benefits of POC testing remains to the demonstrated in postmenopausal BC patients in resource-limited clinical settings of Africa where data of this kind are missing. This study was conducted to assess the impact of point of care technology (PCOT) as part of pathology supported genetic testing (PSGT) to prevent BC therapy-associated comorbidities in African settings.

Methods and materials

We summarized the research findings from published PhD thesis using existing statistical analysis to identify the gaps reported in different chapters by the authors including the scoping review of published studies for evidence-based communication for further studies to be conducted in African settings. The cross-sectional study was conducted in six African countries to assess the level of BC diagnosis, management pathways comparing to the current tools used in developed countries. Study conducted by the authors included 126 BC women from South African population using aromatase inhibitors (AIs) at their menopausal age.

Pathology-supported genetic testing (PSGT) algorithm aims at preventing/reversing disability for complex diseases (cancers, cardiovascular conditions, diabetes, cholesterol disorder and other metabolic syndromes, etc.). PSGT is starting with a questionnaire-based risk assessment, including family history and lifestyle factors. Measurement of clinical profiles, biomedical and genetic predictors. POCT or PSGT is a component of interventional strategy based on the concept of gene-environment-lifestyle factors. The point of care technology (POCT) is defined as pathology supported genetic testing which includes assessment of clinical markers (BMI), biomedical markers (hs-CRP) and genetic markers to identify Aromatase inhibitors associated side effects during the period of time for BC survivorship. The primary study conducted by the authors included 126 BC women from South African population using aromatase inhibitors (AIs) at their menopausal age. These women were from colored population from Western Cape Province of South Africa. demographics data were published in the main studies (Milambo, Ndirangu, Nyasulu, & Akudugu, 2022; Baatjes, Peeters, McCaul, Conradie, Apffelstaedt, Conradie, & Kotze, 2020; Mampunye, van der Merwe et al., 2021). The six African countries surveyed including DRC, Burundi, South Africa, Eswatini, Ghana and Mali.

All the patients provided signed informed consent prior participation. Principle Investigator, statisticians and researchers did not have physical contact with the patients. All statistical analyses are reported previously (Milambo, Ndirangu, Nyasulu, & Akudugu, 2022). The primary study was approved by Health Research Ethics Committee (HREC) of Stellenbosch University (HREC Reference # S18/07/150 (PhD) (Milambo, Ndirangu, Nyasulu, & Akudugu, 2022). Conceptual framework worked described in details in previous published study (Milambo, Ndirangu, Nyasulu, & Akudugu, 2022).

Results

The results of 126 female BC patients with stages ranging from 0-III initially subjected to AIs and subsequently followed up for 24 months. Follow up visits were carried out at the commencement of the study, month 4, month 12 and month 24. Mean age of 61 years (*SD* = 7, 11; 95% CI: 60–62). Linear regression revealed that hs-CRP was associated with waist circumference (OR: 7.5; $p = 0.0116$; 95% CI: 1.45 to 39.61), and BMI (OR: 2.15; $p = 0.034$, 95% CI: 1.02 to 4.56). Random effects model revealed that different BC treatment strategies did not have effects on hs-CRP, BMI after 24 follow up. In contrast, there was stronger statistically association between BMI and homocysteine ($p = 0.021$, 95% CI: 0.0083 to 0.1029), weight and total body fat were strongly associated after 24 months follow up using multiple imputation data. Hs-CRP was associated with BMI ($p = 0.000$), and hs-CRP was associated with other inflammatory markers such as calcium ($p = 0.021$, 95% CI: 0.0083 to 0.1029), phosphate ($p = 0.039$, 95% CI: 0.0083 to 0.1029), and ferritin ($p = 0.002$, 95% CI: 0.0199 to 0.084). There was statistically significant variation between BMI, TBF, weight, hs-CRP, homocysteine, ferritin and calcium between baseline and after 24 months follow up. HyBeacon® probe technology at POC for AI-associated adverse events was cost-effective in Africa while adjunct to standard practice. Table 1 summarizes the impact of AIs on markers of inflammation at baseline and study endpoint.

Table 1. The effects of ais on BMI and hs-CRP after 24 months of follow-up

Aromatase inhibitors at month 24	Coef	P-value	95% CI
TBF	0.119	0.0001	0.070 to 0.160
Weight	0.353	0.001	0.340 to 0.360
Hs-CRP	0.006	0.113	-0.001 to 0.014
Homocysteine	0.055	0.021	0.008 to 0.102
Phosphate	13.256	0.056	-0.364 to 26.878
Calcium	-35.945	0.017	-65.530 to -6.359
Phosphate	0.928	0.039	0.0470 to 1.809
Ferritin	0.052	0.002	0.019 to 0.084
BMI	0.835636	0.001	0.502 to 1.168

Legend: BMI = body mass index, coef = coefficient, pth = phosphate, hs CRP = high sensitivity C reactive protein

The appropriate pathways for implementation of POC testing in postmenopausal BC survivors need further investigation in different clinical settings with real data for external validity. The barriers for implementation of POCT application among six African countries for diagnosis of BC included governance issues, insufficient awareness and insufficient training, lack of lab equipment, insufficient funding and ethical guidance issues for conducting genetic testing in African context. Table 2 summarizes the cross-sectional data from six African countries focused on knowledge and barriers for implementation of POCT in Africa.

However, there is a lack of data on costs and effects of POCT in BC patients and associated comorbidities using real patient data in the rest Africa for external validation.

This study revealed that hs-CRP and BMI are predictors of CVD-related adverse events in obese postmenopausal patients. Calcium, phosphate, homocysteine, and ferritin should also be incorporated in POCT. There were statistically significant variations in TBF, weight, hs-CRP, BMI, homocysteine, ferritin, and calcium between baseline and after 24 months of follow-up. This is the first study assessing the feasibility of POCT in identifying unifying risk factors associated with BC therapy side effects in African settings, including barriers for implementation of personalized medicines were documented in six African countries (Milambo, Ndirangu, Nyasulu, & Akudugu, 2022).

Both mathematical modelling and clinical data identified that POC genotyping may be cost effective in clinical African settings. A POCT must ideally be cost-effective, rapid, functional without excessive prior-processing of samples, highly sensitive to enable

Table 2. Breast Cancer diagnosis and ParaDNA feasibility in African setting

Questionnaire	Number (*N*) = 50	Percentage (%)
Knowledge on diagnosis of BC		
Sanger sequencing	20/50	40
Microscopy/histology	37/50	74
Nanopore sequencing BRCA1/2	24/50	48
MammaPrint	5/50	10
Breast ultrasound	15/50	30
Mammogram/MRI	22/50	44
TaqMan genotyping	4/50	8
Knowledge on ParaDNA genotyping		
Benefit of ParaDNA/Sanger	21/50	42
Identification of BRCA1/2	20/50	40
Prediction of CVD/comorbidities	6/50	12
Turnaround within 75 minutes	16/50	32
Easy to perform	15/50	30
Can be cost effective/Sanger	5/50	10
Automated DNA extraction, PCR and sequencing	7/50	14
Can be used by non-specialized person	25/50	50
Barriers to ParaDNA implementation		
Limited accessibility	2/50	4
Knowledge gaps	33/50	66
Governance issues	23/50	46
Lack of molecular lab for cancers	11/50	22
Lack of trainings and awareness	20/50	40
Lack of policy on point of care genetic testing	20/50	40
Ethics and law regarding genetic testing	8/50	16
Application of POCT in diagnostic of COVID-19		
Yes	21/50	42
No	29/50	68
Recommendations		
Training and equipment	11/50	22
Providing molecular lab and devices	39/50	78

detection of BC and associated comorbidities for differential diagnosis, and specific to prevent therapy side effects, underdiagnoses, or over-diagnosis. POCT must facilitate "self-use" or use by a general practitioners or nurses in primary care settings from low limited settings of Africa. Results must be returned in a timely manner to initiate treatment as soon as possible, which ultimately leads to the enhancement of the patient's wellbeing. The knowledge assessment from HCW from African settings on the implementation of POCT testing revealed that low level knowledge on diagnosis in BC patients among six countries of Africa. The most predominated barriers for knowledge gaps identified including limited accessibility to molecular laboratories, knowledge gaps governance issues, lack of molecular laboratory or BC diagnosis, insufficient trainings and ParaDNA equipment, lack of policy on point of care genetic testing, ethical concerns regarding genetic testing and limited scientists in molecular diagnosis and public health awareness on BC risk factors, diagnosis and management. Comparison of POCT genotyping showed similarity with other studies.

Implementation of POC genetic testing based on the current level of evidence will facilitate differential diagnosis and reduce the waiting time and costs associated with payment of scientists, while waiting for negative results from Sanger sequencing (Milambo, Ndirangu, Nyasulu, & Akudugu, 2022). NCD screening may occur in clinical settings and remote communities to guide the therapeutics, especially considering the fact that there is a scarcity of cancer diagnosis in various African settings. The other aspect to consider is policy on the genetic testing in Africa. Policy guidelines, acceptability, and feasibility of HyBeacon® probe genotyping need further studies, since Sanger sequencing is not yet feasible for the unique characteristics of African clinical settings.

In conclusion, this study revealed that hs-CRP, BMI, calcium, phosphate, homocysteine, and ferritin should be incorporated in PSGT. POCT can be used with PSGT strategy to facilitate early diagnosis and prediction of side effects associated in African settings. The barriers for implementation of POCT application among six African countries for diagnosis of BC included governance issues, insufficient awareness on breast cancer risks, insufficient trainings, lack of lab equipment, insufficient funding and ethical guidance issues for conducting genetic testing in the African context.

Limitations

Mathematical equations involving decision trees maybe confusing, if at all possible, and require numerous simplifying assumptions than real life events. Genotyping test has not yet been used in postmenopausal BC patients on AIs to identify the high penetrant genes in many African settings. Although, its applicability to assess the cost-effectiveness of genotype-guided dosing in CVD patients may differ according to different settings and population diversity (Milambo, Ndirangu, Nyasulu, & Akudugu, 2022). The characteristics of South African BC survivors may not be similar to those studies used in the current computations. Other studies should be conducted at large public health scales to consider a disruptive commissioning model that includes reimbursement and other incentives to affect the large-scale adoption of suitable multi-array POC devices, including specified CYP19A1 alleles with the potential to reduce cost and maximize patient benefits (Napoli, Rastelli, Ma, Colleluori, Vattikuti, & Armamento-Villareal, 2015; Cai, Shu, Egan et al., 2018; Baatjes, Peeters, McCaul, Conradie, Apffelstaedt, Conradie, & Kotze, 2020; Mampunye, van der Merwe et al., 2021).

Abbreviations

AIs: Aromatase inhibitor
BC: Breast Cancer
BCS: Breast cancer survivors

CVD: Cardiovascular diseases
HCW: Healthcare workers
ICER: Incremental cost effectiveness ratio
NPV: Negative predictive value
PPV: Positive predictive value
POCT: Point of care technology
POC: Point of Care

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Declarations:

- Ethics approval and consent to participate: the research was approved by the Health Research Ethics Committee (HREC) of the Faculty of Medicine, University of Stellenbosch (Ethics Approval number S18/07/150). All the participants signed inform form prior study participation.
- Consent for publication: all the authors have approved and read the final manuscript of this work.
- Availability of data and materials: upon request on request.
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- **Contributions:** MJP – assisted with study design, search strategy, registering of review protocol, protocol writing, data extraction, risk of bias assessment, critical appraisal, data analysis, and interpretation of final report and writing of manuscript; MJP and JN Assisted with study design, conceptual framework, data analysis and modelling component of this study. JN assist with editorial input, critical appraisal, data extraction, risk of bias assessment, quality improvement.
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ABSTRACT

Purpose: Aromatase inhibitors (AIs) are indicated in the treatment of hormone-receptive breast cancer (BC) in postmenopausal women in various settings. Studies have shown cardiovascular events in some developed countries. To date, the data are sparce for evidence-based recommendations in African clinical settings due to lack of cancer registries, capacity building and surveillance systems. Therefore, this study was conducted to assess the feasibility of HyBeacon® probe genotyping adjunctive to standard care for timely prediction and diagnosis of Aromatase inhibitors (AIs) associated with adverse events in BC survivors in Africa.

Methods: Cross sectional study was conducted to assess the knowledge of POCT among six African countries using online survey and telephonically contacted. Incremental cost effectiveness ratio (ICER) was calculated, using diagnostic accuracy study. This was based on mathematical modelling.

Results: One hundred twenty-six participants were considered for analysis (mean age = 61 years; *SD* = 7.11 years; 95% CI: 60–62 years). Comparison of genotyping from HyBeacon® probe technology to Sanger sequencing showed that sensitivity was reported at 99% (95% CI: 94.55% to 99.97%), specificity at 89.44% (95% CI: 87.25 to 91.38%), PPV at 51% (95%: 43.77 to 58.26%), and NPV at 99.88% (95% CI: 99.31 to 100.00%). Based on the mathematical model, the assumptions revealed that ICER was R7 044.55.

Conclusion: POCT using HyBeacon® probe genotyping for AI-associated adverse events may be cost effective in many African clinical settings. Integration of preventive measures for early detection and prevention guided by different subtype of BC diagnosis with specific clinical, biomedical and genetic screenings may improve cancer survivorship. Feasibility of POCT was demonstrated but the implementation could be achieved by improving the integration of POCT within primary health cares, referral cancer hospitals with capacity building activities at different level of health systems. This finding is pertinent for a future envisioned implementation and global scale-up of POCT-based initiative as part of risk communication strategies with clear management pathways.

KEYWORDS

aromatase inhibitors, point of care testing, postmenopausal breast cancer, cardiovascular risk factors

Biographical notes

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Onam Singh currently enrolled in the Economics Department at Dr. B.R. Ambedkar University, Delhi, pursuing undergraduate degree with Economics as major and

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His overarching goal is to foster inclusive and equitable economic development across all sectors. He firmly believes in the significance of addressing welfare, inclusion, and equal development across all sectors. For far too long, these fundamental aspects have been overlooked. Now, with a fresh perspective and innovative ideas from the new generation, it is time to usher in a transformative era of inclusive growth and sustainable development. To this end, he is continuously refining programming codes and economic theories aimed at enhancing welfare and inclusivity.

Mehak Rawal is an early career scholar and student of Economics at Dr. B.R. Ambedkar University, Delhi. With Politics as my minor, I possess a profound understanding of both economic principles and the political landscape.

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In my view, this edited volume is an important contribution to the literature on how to foster social change and improve inclusion by offering diverse perspectives on disability, intersectionality, education, mental health, and reintegration into society. It promotes an interdisciplinary approach, encouraging collaboration across fields to address complex social issues.

Jude Tah
Stokholm University

The volume promotes interdisciplinarity and international perspectives. It provides practical and theoretical information that may be useful for exploring the issues of social change, disparities in the world and of course the issues of acceptance, participation and solidarity.

Anna Perkowska-Klejman
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