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Perceptions of Social Isolation During Institutional Rehabilitation among Adults with Intellectual Disabilities: Recommendations for Integration

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ABSTRACT

It is quite commendable that over the past 50 years, there has been a massive move towards deinstitutionalisation globally. However, this paper concurs with the view that despite the move towards deinstitutionalisation, people with intellectual disabilities sometimes feel the effects of institutionalisation in special schools which offer boarding arrangements and in day centres and workshops catering for large groups of adult persons. This qualitative study involved 12 participants with moderate intellectual disabilities and three key informants at an adult centre that caters for adults with intellectual disability in Zimbabwe. The study revealed that individuals with intellectual disabilities in institutional rehabilitation face a range of challenges, many of which are closely linked to the duration of their stay in these facilities. Participants expressed feelings of being left behind by societal changes while spending significant portions of their lives within the institution. Other challenges associated with institutional rehabilitation included the loss of social connections, distress stemming from uncertainty about familial care and love and a pervasive sense of abandonment by relatives. In addition, the study highlighted that orphans with intellectual disabilities face heightened vulnerabilities due to early abandonment, inconsistent care environments and systemic barriers. The study recommends the development of individualised transition plans, the eradication of systemic barriers, and the implementation of awareness campaigns to educate and shift societal perceptions. The study also recommends strengthening family and caregiver support systems, alongside advocacy for accessible healthcare, housing, education and employment services as critical for enhancing the well-being of individuals with intellectual disabilities.

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INTRODUCTION

Various definitions of the term intellectual disability have been applied by different disciplines based on their perception of the condition. The American Association on Intellectual and Developmental Disabilities (AAIDD) provided a widely recognised definition that intellectual disability is characterised by significant limitations in intellectual functioning and the conceptual, social, and practical skills that make up adaptive behaviour during developmental age.[1] Additional explanations have been provided in

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[1] American Association on Intellectual and Developmental Disabilities., "Intellectual Disability: Defining Criteria for Intellectual Disability," AAIDD, 2024, https://www.aaidd.org/intellectual-disability/definition.

the Diagnostic and Statistical Manual of Mental Disorders (5th ed, DSM-5) of the American Psychological Association (APA) and the International Statistical Classification of Diseases and Related Health Problems (ICD-10) of the World Health Organization. According to the diagnostic criteria for IDs in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), intellectual disability is a deficit in intellectual and adaptive functioning, which is evident during childhood or adolescence.[2]

Malapela defines rehabilitation as a targeted process focused on enhancing the best possible mental, social and physical functioning to attain a good quality of life.[3] Institutional rehabilitation typically involves structured programs in specialised facilities, where individuals receive intensive care and supervision. However, institutional rehabilitation has been criticised for failing to provide a stimulating and supportive environment conducive to personal growth and development.[4] In affirmation, Steele et al. attest that institutionalisation contradicts the human rights of people with disabilities, including the right to independent living and community inclusion in Article 19 of the UN Convention on the Rights of Persons with Disabilities.[5] Accordingly, there has been a massive move towards de-institutionalisation in developed countries. However, this move has created a situation whereby traditional institutions are being replaced by contemporary institutions.

Traditional institutions for people with intellectual disabilities were often large, isolated facilities where individuals were placed away from society.[6] These institutions operated under a medical model that viewed intellectual disabilities primarily as deficits to be managed rather than as aspects of human diversity to be embraced. Burghardt notes that individuals were often "hidden" in these facilities, which were located on the outskirts of communities, leading to their alienation and abandonment.[7] Some scholars argue that despite the move towards deinstitutionalisation; segregation, congregation and coercion continue in contemporary institutions often obscured by arbitrary binaries of institution/community.[8] Critical disability scholars propose the term “institutional archipelago” to refer to the network of “diverse services and spaces” – including closed and community settings – through which the rights of people with intellectual disability are undermined.[9]

The notion of “institutional archipelago” is supported by evidence that sometimes people with intellectual disability feel the effects of institutionalisation even in places that consider themselves neither traditional institutions nor contemporary institutions. McConkey et al. observe that institutional practices can also live on in special schools – especially those which offer boarding arrangements - and in day centres and workshops catering for large groups of adult persons.[10] In affirmation, Burghardt discusses the contemporary manifestations of institutionalisation, which are often reflected in segregated work arrangements and nominal "community living" situations.[11] This suggests that even when individuals are not physically housed in traditional institutions, they may still experience the effects of institutionalisation through limited access to rights and community integration.

This paper, therefore, explores the experiences of people who have moderate intellectual disability in rehabilitation institutions. In so doing, this study is an attempt to understand and prioritise the voices of people who have intellectual disabilities. This paper argues that the involvement of people with intellectual disabilities in sharing lived experiences is important to deepen public understanding of, reckoning with and repair of ongoing negative impacts of institutionalisation, segregation and exclusion of people with intellectual disability and to advance positive experiences of transformative equality and

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[2] American Psychiatric Association (APA), “Diagnostic Criteria for Intellectual Disabilities: DSM-5 Criteria,” 2022, https://www.mentalhelp.net/intellectualdisabilities/dsm-5-criteria.

[3] Rakgadi G. Malapela, “Challenges and Opportunities in Adolescent Intellectual Disability Care and Rehabilitation,” *South African Family Practice* 66, no. 1 (February 29, 2024), https://doi.org/10.4102/safp.v66i1.5798.

[4] Roy McConkey et al., “A Longitudinal Study of Post-school Provision for Irish School-leavers with Intellectual Disability,” *British Journal of Learning Disabilities* 45, no. 3 (September 24, 2017): 166–71, https://doi.org/10.1111/bld.12190.

[5] Linda Steele et al., “Listening to People with Intellectual Disability about Institutions,” *International Journal of Disability and Social Justice* 3, no. 3 (2023), https://doi.org/10.13169/intljofdissocjus.3.3.0049.

[6] Steele et al., “Listening to People with Intellectual Disability about Institutions.”

[7] Madeline Burghardt, “Institutional Survivorship: Abandonment and the ‘Machinery of the Establishment,’” *Canadian Journal of Disability Studies* 6, no. 3 (August 21, 2017): 118, https://doi.org/10.15353/cjds.v6i3.368.

[8] Steele et al., “Listening to People with Intellectual Disability about Institutions.”

[9] Chris Chapman, Allison C Carey, and Liat Ben-Moshe, “Reconsidering Confinement: Interlocking Locations and Logics of Incarceration,” in *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (Springer, 2014), 3–24.

[10] McConkey et al., “A Longitudinal Study of Post-school Provision for Irish School-leavers with Intellectual Disability.”

[11] Burghardt, “Institutional Survivorship: Abandonment and the ‘Machinery of the Establishment.’”

inclusion. Steele et al. add that the narratives and perspectives of people with intellectual disabilities are often overlooked in discussions about institutional care.[12] Kiernan notes that it was not until the 1980s that people with intellectual disabilities were involved, even as interviewees in research that was about them.[13] Therefore, this study aims to shed light on the experiences of individuals with intellectual disabilities in institutions, as expressed in their own words.

LITERATURE REVIEW

The Historical Context of Institutionalisation

Before the 19th century, people with intellectual disabilities were often cared for within their families or communities. However, they were frequently marginalised and stigmatised, viewed as "unfortunates" or even as embodiments of moral or spiritual failings.[14] The 19th century saw the establishment of specialised institutions for people with intellectual disabilities, driven by several factors including industrialisation and the medicalisation of disability whereby Intellectual disabilities began to be viewed through a medical lens, with the belief that specialised institutions could provide "treatment" and "training".[15] In the late 19th and early 20th centuries, the eugenics movement argued that intellectual disabilities were hereditary and posed a threat to societal progress leading to forced sterilisation and increased institutionalisation. This culminated in the heyday of institutionalisation (mid-20th century) where large-scale institutions had become the primary model of care for people with intellectual disabilities. Conditions in many institutions were deplorable, with reports of abuse, neglect and overcrowding.

Unlike Western contexts, where institutionalisation emerged primarily in the 19th century, Africa's experience with institutional care is more recent and deeply intertwined with colonialism as well as post-independence challenges. The colonial period (late 19th to mid-20th century) marked the introduction of Western-style institutions in Africa. Colonial powers established asylums, orphanages, and hospitals, often as part of broader efforts to "civilise" and control local populations.[16] Similar to trends in the global north, the late 20th century saw the emergence of disability rights movements in Africa, influenced by global advocacy and the United Nations Convention on the Rights of Persons with Disabilities.[17] However, the legacy of institutionalisation continues to shape the lives of people with intellectual disabilities today.

Legacy of Institutionalisation

While deinstitutionalisation has led to significant improvements, the legacy of institutionalisation persists. Many former residents continue to face challenges related to trauma, social isolation, and limited opportunities for community integration.[18] Additionally, some forms of institutional care, such as group homes, have been criticised for replicating the restrictive practices of larger institutions.[19] Mertc and Köşgeroğlu note that despite being designed to provide more tailored support, rehabilitation centers often maintain control-oriented environments that mirror the restrictions faced in traditional institutions.[20] Research indicates that care in such settings primarily focuses on the direct assessment and management of physical health needs rather than emphasising autonomy and person-centered care.[21] Rehabilitation centers often employ standardised, one-size-fits-all approaches to care that fails to account for the unique

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[12] Steele et al., “Listening to People with Intellectual Disability about Institutions.”

[13] McConkey et al., “A Longitudinal Study of Post-school Provision for Irish School-leavers with Intellectual Disability.”

[14] James W. Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley: University of California Press, 1994).

[15] Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States*.

[16] Tsakani Chauke et al., “Experiences of Parents of an Adolescent with Intellectual Disability in Giyani, Limpopo Province, South Africa,” *Health SA Gesondheid* 26 (April 15, 2021), https://doi.org/10.4102/hsag.v26i0.1538.

[17] Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States*.

[18] Steele et al., “Listening to People with Intellectual Disability about Institutions.”

[19] Burghardt, “Institutional Survivorship: Abandonment and the ‘Machinery of the Establishment.’”

[20] Selda Mert and Nedime Köşgeroğlu, “Meeting the Care Needs of People with Intellectual and Developmental Disabilities and Their Families through the Model of Nursing Based on Activities of Living,” *Journal of Intellectual Disabilities* 26, no. 3 (September 27, 2022): 687–703, https://doi.org/10.1177/17446295211010023.

[21] Mert and Köşgeroğlu, “Meeting the Care Needs of People with Intellectual and Developmental Disabilities and Their Families through the Model of Nursing Based on Activities of Living.”

needs and preferences of individuals.[22] This rigidity contrasts with the principles of person-centered planning, which emphasise individualised support and choice

Moreover, previous studies show that many institutions still rely on a medical rather than a rehabilitative model of care, which emphasises the need for more holistic approaches that are often lacking.[23] This persistence of control-driven practices raises concerns about the quality of life and personal agency for residents in rehabilitation facilities. Decisions about schedules, activities, and even personal care are frequently made by staff, mirroring the paternalistic practices of older institutions.[24] This lack of autonomy undermines the goal of empowering individuals to live independently. In addition, some rehabilitation centers are physically isolated from the broader community, perpetuating the segregation historically associated with institutional care. This isolation limits opportunities for social interaction, community integration and the development of independent living skills.

THEORETICAL FRAMEWORK

This study deems the systems theory a highly applicable framework for understanding the complex dynamics of social isolation and rehabilitation for adults with intellectual disabilities. Payne defines the systems theory as those concepts that view individuals as part of interconnected systems, emphasising the interactions between individuals, their environments and broader societal structures.[25] Accordingly, it provides a robust and comprehensive framework for understanding the complex dynamics of social isolation and rehabilitation for adults with intellectual disabilities. At the core of systems theory is the idea that individuals are embedded within multiple systems, each influencing their experiences and outcomes.[26] For adults with intellectual disabilities in rehabilitation centers, social isolation can be understood as a breakdown in these systems.

The microsystem, which includes the immediate environment such as interactions with staff, peers and family, plays a critical role in shaping perceptions of isolation.[27] For example, limited opportunities for meaningful social interaction within the rehabilitation center can exacerbate feelings of loneliness. The mesosystem, which refers to the connections between different microsystems (e.g., between the rehabilitation center and the family), can either mitigate or exacerbate these feelings.[28] Stronger connections between these systems, such as family involvement in the rehabilitation process, can help reduce isolation.[29] Beyond these immediate systems, the exosystem, which includes external factors like policies and funding for rehabilitation services, indirectly influences the quality of care and opportunities for social interaction.[30] Finally, the macrosystem, which encompasses broader societal attitudes toward disability and inclusion, shapes the experiences of individuals in rehabilitation centers.[31] Negative societal attitudes can reinforce stigma and exclusion, while positive attitudes can promote acceptance and integration.

METHODOLOGY

This research made use of a qualitative research design. The unit of analysis was people with moderate intellectual disability at a rehabilitation institution in Zimbabwe. Data was gathered from a rehabilitation Centre that caters for adults with ages ranging from 18 to over 54 who have intellectual disability. The research made use of quota sampling with three people with moderate intellectual disability filling each age cohort of the categories, namely 18-29, 30-41, 42-53, and 54 and above, to make a total of 12 participants. Three key informants were purposively selected based on the strategic positions they occupied, which were deemed critical to addressing the objectives of the research. To collect data, the

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[22] Burghardt, “Institutional Survivorship: Abandonment and the ‘Machinery of the Establishment.’”

[23] Burghardt, “Institutional Survivorship: Abandonment and the ‘Machinery of the Establishment.’”

[24] McConkey et al., “A Longitudinal Study of Post-school Provision for Irish School-leavers with Intellectual Disability.”

[25] Malcolm Payne, *Modern Social Work Theory*, 4th ed. (London: Palgrave Macmillan, 2014).

[26] Urie Bronfenbrenner, *The Ecology of Human Development: Experiments by Nature and Design* (Cambridge, MA: Harvard University Press, 1979).

[27] Bronfenbrenner, *The Ecology of Human Development: Experiments by Nature and Design*.

[28] Payne, *Modern Social Work Theory*.

[29] Ted Lippold and Jan Burns, “Social Support and Intellectual Disabilities: A Comparison between Social Networks of Adults with Intellectual Disability and Those with Physical Disability,” *Journal of Intellectual Disability Research* 53, no. 5 (2009): 463–73.

[30] Bronfenbrenner, *The Ecology of Human Development: Experiments by Nature and Design*.

[31] Bronfenbrenner, *The Ecology of Human Development: Experiments by Nature and Design*.

study employed interview guides tailored to the specific expertise of the informants, along with a focus group discussion guide to facilitate broader engagement and obtain diverse perspectives. The data gathered was analysed using thematic content analysis, a method that allowed for the identification and interpretation of recurring themes and patterns relevant to the research focus. This approach ensured that the data analysis was systematic and aligned with the study's objectives. The study adhered to a comprehensive set of ethical guidelines, such as the attainment of ethical clearance to ensure the integrity and ethical conduct of the research process.

PRESENTATION OF FINDINGS

The focus group discussions and in-depth interviews revealed that some of the challenges people with intellectual disabilities faced at the institution can be traced to the length of stay at the institution. Some participants stated feeling that they would never be able to catch up with the changes that are happening whilst spending a portion of their life at the institution. Some of the challenges linked to the length of stay at the institution that were revealed included the loss of social contacts and distress emanating from doubt about whether their families still had care and love for them. Participant One revealed;

> *“Ndava nenguva yakarebesa ndirimuno, zvekuti handifungi kuti ndichirikukwanisa kugara kunze”* (I have been at this institution for too long that I doubt I still have the ability to exist in the outside world). P.1

Four participants revealed that they felt abandoned by their relatives and families. They explained that despite the institution`s calendar clearly stipulating that they are supposed to go for holidays three months of the year, their relatives and families were not showing up to get them. One participant noted;

> “*Ndava nemakore 20 ndichigara pano, makore maviri ekutanga ndaiuya kuzotorwa nehama dzangu ndichimboenda kuholiday, asi ikozvino havachauye, uyezve pavanouya kuzonditora pacho, vanongogara neni kwemazuva matatu votondidzosa kuno, holiday ichangobva kutanga.”(*I have been here for 20 years, the first two years, my relatives would come to pick me up on holidays, but now they rarely come, and the few times they pick me up for holidays, I only stay home on the first three days of the holiday). P.2

Three respondents who used to stay in orphanages revealed that they had been at the institution for more than 10 years and had never left the institution to see anyone. One of them revealed;

> “*Patakasvika makore 18 takanzi hazvichaiti tigare kuhome nekuti takura, saka takabva taunzwa pano, ndipo patavakugara zvamuchose”* (Upon turning 18, the orphanage couldn’t keep us anymore because were adults, so we were sent to this rehabilitation institution which has turned to be a place of permanent residence for us).

Another participant, who was 68 years old, revealed that she last saw her relatives when she was in her thirties, about 30 years ago. One of the key informants confirmed this and revealed that one of her grandchildren was paying her fees from Canada but never came to see her.

DISCUSSION

Adjusting to Community Life after Long-term Institutionalisation

The fear by some participants that they could never be able to exist outside the institution is well-founded. As an illustration, Shum et al. indicate that individuals who have experienced prolonged institutionalisation often face developmental deficits that hinder their ability to adapt to community living even when they are brought back to the community.[32] In affirmation, Lippold and Burns highlight that while physical presence in the community is essential, it does not guarantee social integration since individuals with intellectual disabilities often find themselves marginalised, struggling to form

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[32] Michelle Hei Yan Shum et al., “Living in a Segregated Community? Interaction between Families and Service Organizations Supporting People with Intellectual Disabilities during the COVID-19 Pandemic,” *Journal of Social Work* 23, no. 5 (September 23, 2023): 876–97, https://doi.org/10.1177/14680173231164335.

meaningful relationships and social connections, which are crucial for a fulfilling life.[33] This social isolation can lead to feelings of exclusion and loneliness, further complicating their reintegration into society.[34]

In the African continent, one of the primary barriers to successful transition is the pervasive stigma associated with intellectual disabilities.[35] This stigma often results in social isolation and discrimination, which can hinder the acceptance of individuals with intellectual disabilities in community settings. In affirmation, Egan indicates that individuals with intellectual disabilities experience higher levels of loneliness and social isolation compared to their non-disabled peers, particularly in non-specialist long-term care facilities where there is a lack of understanding and acceptance from other residents.[36] This social exclusion is further exacerbated by the misconception that individuals with intellectual disabilities are mentally ill, which can lead to their marginalisation within both institutional and community contexts.[37]

Some scholars attribute the inability to transition from long-term institutional stay to the lack of adequate transition planning.[38] Research indicates that transition planning is often insufficient, particularly for older individuals with intellectual disabilities who may be aging out of family care or institutional settings.[39] In the Zimbabwean setting, the absence of transition planning is salient in the case of orphans who get stuck in rehabilitation institutions, as indicated in this study. Tilley et al. highlight that proactive planning is crucial for these transitions, yet many families and caregivers do not engage in this process, leading to uncertain futures for these individuals.[40] The transition process can lead to feelings of isolation and disconnection from social networks, particularly when individuals are moved into settings that do not promote community engagement.

Abandonment by Relatives

Another serious challenge pertains to feelings of abandonment by relatives and families. It is a noteworthy revelation by some participants that they felt abandoned by their families at the institution. The abandonment of individuals with intellectual disabilities in institutional settings can be attributed to various socio-cultural, economic and systemic factors that influence family dynamics and caregiving responsibilities. As an illustration, Chauke et al. trace the abandonment of people with intellectual disabilities to patriarchal dynamics inherent in some families, noting that in South Africa, the burden of care for children with intellectual disabilities predominantly falls on mothers, with fathers frequently exhibiting a lack of support.[41] This inadvertently places an overwhelming caregiving responsibility on mothers, leaving the mothers sometimes feeling a viable opportunity could be leaving their disabled relatives in institutions.

Another factor that has led to the abandonment of people with disabilities in institutions is stigma. Capri et al. provide an example of how Nigerian families often face significant stigma and discrimination, leading to the institutionalisation of individuals with disabilities as a means of coping with societal

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[33] Lippold and Burns, "Social Support and Intellectual Disabilities: A Comparison between Social Networks of Adults with Intellectual Disability and Those with Physical Disability."

[34] Shum et al., "Living in a Segregated Community? Interaction between Families and Service Organizations Supporting People with Intellectual Disabilities during the COVID-19 Pandemic."

[35] Siyabulela Mkabile and Leslie Swartz, "Putting Cultural Difference in Its Place: Barriers to Access to Health Services for Parents of Children with Intellectual Disability in an Urban African Setting," *International Journal of Social Psychiatry* 68, no. 8 (December 31, 2022): 1614–22, https://doi.org/10.1177/00207640211043150.

[36] Caroline Egan, Helen Mulcahy, and Corina Naughton, "Transitioning to Long-Term Care for Older Adults with Intellectual Disabilities: A Concept Analysis," *Journal of Intellectual Disabilities* 26, no. 4 (December 10, 2022): 1015–32, https://doi.org/10.1177/17446295211041839.

[37] Mkabile and Swartz, "Putting Cultural Difference in Its Place: Barriers to Access to Health Services for Parents of Children with Intellectual Disability in an Urban African Setting."

[38] Elizabeth Tilley et al., "Transitions for Older People with Intellectual Disabilities and Behaviours That Challenge Others: A Rapid Scoping Review," *Journal of Applied Research in Intellectual Disabilities* 36, no. 2 (March 26, 2023): 207–29, https://doi.org/10.1111/jar.13054.

[39] Chauke et al., "Experiences of Parents of an Adolescent with Intellectual Disability in Giyani, Limpopo Province, South Africa."

[40] Tilley et al., "Transitions for Older People with Intellectual Disabilities and Behaviours That Challenge Others: A Rapid Scoping Review."

[41] Chauke et al., "Experiences of Parents of an Adolescent with Intellectual Disability in Giyani, Limpopo Province, South Africa."

pressures.[42] While social stigma is documented as a major challenge in Africa, Mkabile and Swartz caution against cultural misinterpretations, arguing that the focus on cultural differences in the literature tends to obscure the real, tangible barriers that families face.[43] While cultural beliefs and practices do play a role in shaping attitudes towards disability and health care, the authors contend that it is essential to consider the broader socio-political and economic factors that contribute to seeming like the only viable option.[44]

Amongst the broader socio-political and economic factors is the concept of embodied difficulties, as articulated by Mkabile and Swartz, encompassing everyday struggles, such as navigating crowded and unsafe transport systems that significantly hinder the ability to access health services.[45] These logistical challenges are compounded by the physical and emotional toll of caregiving, which often leaves parents feeling exhausted and overwhelmed. Caregivers often experience high levels of stress and emotional burnout, which can lead to conflictual family dynamics and a breakdown of supportive relationships.[46] Economic hardships often worsen this strain, resulting in families abandoning relatives with intellectual disabilities in rehabilitation institutions.

The abandonment of people with intellectual disabilities in institutional rehabilitation, as was noted by the participants, can be attributed to the inadequacy of resources and the quality of care in community settings. As an illustration, Capri et al. revealed that while families may recognise the potential benefits of community living, they also harbour concerns about the availability of resources in communities.[47] Similarly, a study by Doody confirmed that some families were worried that the shift from institutional care might lead to a decrease in the level of support their relatives would receive, raising questions about the sustainability of community-based services.[48] This concern is echoed in broader discussions about the challenges of implementing community integration policies, particularly in contexts where resources may be limited.[49] Therefore, support must be availed to make communities practical alternatives for people who have intellectual disabilities if institutionalisation is to be fully disbanded.

Orphans with Intellectual Disabilities

Orphans with intellectual disabilities (ID) face compounded vulnerabilities as they age, primarily due to early abandonment, inconsistent care environments, and systemic barriers to support.[50] The cycle of neglect for orphans with intellectual disabilities often begins in childhood, where inadequate interventions can lead to a cascade of adverse outcomes in adulthood, including mental health challenges and diminished life skills.[51] These factors create a complex interplay of challenges that can significantly impact their psychological well-being and overall quality of life. Their experiences can differ significantly from those of non-orphans with ID due to the absence of family structures that typically provide continuity and advocacy throughout life.[52] In addition, institutionalisation can lead to feelings of abandonment and alienation, which are particularly pronounced in orphans who may not have stable relationships to rely on.[53]

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[42] Charlotte Capri et al., “Intellectual Disability Rights and Inclusive Citizenship in South Africa: What Can a Scoping Review Tell Us?,” *African Journal of Disability* 7 (April 25, 2018), https://doi.org/10.4102/ajod.v7i0.396.

[43] Mkabile and Swartz, “Putting Cultural Difference in Its Place: Barriers to Access to Health Services for Parents of Children with Intellectual Disability in an Urban African Setting.”

[44] Mkabile and Swartz, “Putting Cultural Difference in Its Place: Barriers to Access to Health Services for Parents of Children with Intellectual Disability in an Urban African Setting.”

[45] Mkabile and Swartz, “Putting Cultural Difference in Its Place: Barriers to Access to Health Services for Parents of Children with Intellectual Disability in an Urban African Setting.”

[46] Julia W. K. Lo and Joyce L. C. Ma, “The Perceived Helpfulness of Structural Family Therapy in Caring for Hong Kong Chinese Families of an Adolescent with Intellectual Disabilities: A Qualitative Inquiry,” *British Journal of Learning Disabilities* 51, no. 3 (September 3, 2023): 440–49, https://doi.org/10.1111/bld.12510.

[47] Capri et al., “Intellectual Disability Rights and Inclusive Citizenship in South Africa: What Can a Scoping Review Tell Us?”

[48] Owen Doody, “Families’ Views on Their Relatives with Intellectual Disability Moving from a Long-stay Psychiatric Institution to a Community-based Intellectual Disability Service: An Irish Context,” *British Journal of Learning Disabilities* 40, no. 1 (2012): 46–54.

[49] Doody, “Families’ Views on Their Relatives with Intellectual Disability Moving from a Long-stay Psychiatric Institution to a Community-based Intellectual Disability Service: An Irish Context.”

[50] Lonnie Embleton et al., “Models of Care for Orphaned and Separated Children and Upholding Children’s Rights: Cross-Sectional Evidence from Western Kenya,” *BMC International Health and Human Rights* 14 (2014): 1–18.

[51] Egan, Mulcahy, and Naughton, “Transitioning to Long-Term Care for Older Adults with Intellectual Disabilities: A Concept Analysis.”

[52] Burghardt, “Institutional Survivorship: Abandonment and the ‘Machinery of the Establishment.’”

[53] Burghardt, “Institutional Survivorship: Abandonment and the ‘Machinery of the Establishment.’”

Orphans with ID frequently lack transitional planning that prepares them for adulthood.[54] This includes the absence of guardians or advocates to facilitate access to adult services such as housing, employment, or healthcare. Tilley et al. highlight that transition planning should be proactive and involve comprehensive strategies that account for the unique needs of individuals with ID, especially when they are aging out of orphanages.[55] However, studies have shown that many individuals with ID experience limited involvement in their own transition planning, which can lead to feelings of disempowerment and uncertainty about their future.[56] This lack of engagement in the planning process is concerning, as it often results in poorly tailored support that fails to address the specific needs of these individuals. In addition, research indicates that orphans become older adults in long-stay institutions who often experience a form of "social death," where their needs are neglected due to institutional practices that prioritise efficiency over individualised care.[57] Some orphans who have intellectual disabilities grow up to be elderly and have no one outside rehabilitation institutions. Basheer confirms that the institutionalisation of the elderly can lead to a negative experience, where they are left to await death in a negligent manner, reflecting a broader societal abandonment of this demographic.[58]

RECOMMENDATIONS

Transition plans

This study recommends that there is a need to enable the transition of people with intellectual disabilities from long term stay in rehabilitation institutions. The transition of people who have disabilities from long term institutional rehabilitation may only be facilitated through the development of individualised transition plans. Angell et al. define individualised transition plans as plans that consider the unique needs, preferences, and goals of each person.[59] Research indicates that individualised transition planning significantly improves outcomes for individuals with disabilities. For instance, studies such as by Tilley et al. have shown that when transition plans are customised to reflect the strengths and preferences of individuals, they experience better participation and satisfaction in community life.[60] This is driven by the understanding that by adopting a person-centred approach, customised plans not only empower individuals but also enhance their ability to actively participate in community life, thus fulfilling the goals of integration.

Transition to community life can be aided by social relationships and community connections. As an illustration, participants in the study by Angell et al. emphasised that building friendships and social networks were vital for the sense of belonging and overall well-being of people who have disabilities.[61] The study also underscored the role of community organisations in fostering these connections by providing inclusive programs and activities that encourage participation.[62] This finding aligns with the plea by participants in this study, who emphasised the importance of social capital in the form of supportive family and relatives in enhancing the quality of life for individuals with disabilities.

This study also contends that social skills training is vital in facilitating transition. Social skills training for people with intellectual disabilities refers to structured interventions designed to enhance the ability of individuals with intellectual disabilities to interact effectively with others in a variety of social

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[54] Tilley et al., “Transitions for Older People with Intellectual Disabilities and Behaviours That Challenge Others: A Rapid Scoping Review.”

[55] Tilley et al., “Transitions for Older People with Intellectual Disabilities and Behaviours That Challenge Others: A Rapid Scoping Review.”

[56] Sofie Wass et al., “Transitions from School to Sheltered Employment in Norway – Experiences of People with Intellectual Disabilities,” *British Journal of Learning Disabilities* 49, no. 3 (September 26, 2021): 373–82, https://doi.org/10.1111/bld.12414.

[57] Capri et al., “Intellectual Disability Rights and Inclusive Citizenship in South Africa: What Can a Scoping Review Tell Us?”

[58] Najuah Sael Basheer et al., “Social Death of the Older Adult Population Reinforced in Pandemic Times,” *Revista Bioética* 31 (2023), https://doi.org/10.1590/1983-803420233407en.

[59] Amber M. Angell et al., “‘Starting to Live a Life’: Understanding Full Participation for People With Disabilities After Institutionalization,” *The American Journal of Occupational Therapy* 74, no. 4 (July 1, 2020): 7404205030p1–11, https://doi.org/10.5014/ajot.2020.038489.

[60] Tilley et al., “Transitions for Older People with Intellectual Disabilities and Behaviours That Challenge Others: A Rapid Scoping Review.”

[61] Angell et al., “‘Starting to Live a Life’: Understanding Full Participation for People With Disabilities After Institutionalization.”

[62] Angell et al., “‘Starting to Live a Life’: Understanding Full Participation for People With Disabilities After Institutionalization.”

contexts.[63] In affirmation, Daly and Kinsella emphasise that social skills are not merely a set of behaviours but are integral to an individual's ability to navigate social situations effectively.[64] These training programs typically focus on teaching essential skills such as communication, problem-solving, emotional regulation, recognising social cues and building relationships. Moreover, the role of social skills training extends beyond mere skill acquisition; it encompasses the development of self-management and decision-making abilities, which are vital for successful transitions into community life. Research has demonstrated that social skills training can lead to improved communication abilities and social competence, which are directly linked to better life outcomes.[65] This enables effective social interactions, which are essential for building relationships and securing employment.

Eradication Systemic Barriers

The responses of the participants in this study highlight the need for the eradication of systemic barriers. Systemic barriers for people with intellectual disabilities refer to structural, institutional, and societal obstacles that limit access to opportunities, resources and full participation in society.[66] Thus, in order to promote full participation for individuals with disabilities, it is essential to address the structural, institutional and societal obstacles that persist in community settings. This includes advocating for policies that enhance accessibility, provide adequate funding for support services, and promote awareness and acceptance of individuals with disabilities within the community.[67] This study recommends a collaborative approach that involves stakeholders at all levels, including policymakers, service providers and community members to create environments that facilitate meaningful participation.

Systemic barriers may also be eradicated through consistent social work support, the presence of skilled staff, and creative engagement with individuals and their families for proactive planning.[68] Additionally, this study advocates for access to quality healthcare services as essential to prevent unwanted or inappropriate transitions, particularly during crisis points. Therefore, this study accentuates the need for a more integrated approach to health service delivery that is more accessible and responsive to the needs of families, particularly in urban settings where logistical challenges are pronounced. This includes improving transportation options, ensuring safety in public spaces and providing culturally sensitive training for health care providers.[69] Hence, this study draws attention to the fact that systemic change is necessary to create environments that support the social development of individuals with Intellectual Disability, thereby promoting their inclusion in society.

Awareness Campaigns

The participants in the study highlighted that stigma is a major challenge during attempts to integrate back into society. Thus, this study agrees with Gieniec and Jurkiewicz, who assert that awareness campaigns as a form of education can play an instrumental role in shaping perceptions.[70] Bahador adds that awareness campaigns can play an instrumental role in reducing stigma because the lack of knowledge about intellectual disabilities contributes to stigma and discrimination.[71] Thus, educational initiatives aimed at increasing awareness and understanding can significantly alter public perceptions and foster a

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[63] Udeme Samuel Jacob, Isioma Sitamalife Edozie, and Jace Pillay, "Strategies for Enhancing Social Skills of Individuals with Intellectual Disability: A Systematic Review," *Frontiers in Rehabilitation Sciences* 3 (September 13, 2022), https://doi.org/10.3389/fresc.2022.968314.

[64] Maeve Daly and William Kinsella, "A Systemic Approach to Social Skills Training for Adults with Intellectual Disability: An Irish Perspective," *International Journal of Technology and Inclusive Education* Special Issue, no. 2 (March 1, 2014), https://doi.org/10.20533/ijtie.2047.0533.2014.0053.

[65] Daly and Kinsella, "A Systemic Approach to Social Skills Training for Adults with Intellectual Disability: An Irish Perspective."

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[68] Tilley et al., "Transitions for Older People with Intellectual Disabilities and Behaviours That Challenge Others: A Rapid Scoping Review."

[69] Mkabile and Swartz, "Putting Cultural Difference in Its Place: Barriers to Access to Health Services for Parents of Children with Intellectual Disability in an Urban African Setting."

[70] Weronika Gieniec and Beata Jurkiewicz, "Perception of People with Intellectual Disabilities by Residents of the Tarnów Region, Poland," *Health Promotion & Physical Activity* 24, no. 3 (December 20, 2023): 1–6, https://doi.org/10.55225/hppa.532.

[71] Raziyeh Sadat Bahador et al., "Experiences of Family Caregivers of People with Intellectual Disabilities from Rural Areas in Southeastern Iran: A Qualitative Study," *BMC Psychiatry* 23, no. 1 (August 22, 2023): 613, https://doi.org/10.1186/s12888-023-05077-0.

more inclusive environment. This aligns with the view by Mkabile and Swartz that community education is important in promoting acceptance and reducing the stigma associated with disabilities.[72]

Awareness campaigns can target addressing the misconceptions surrounding the capabilities of individuals with intellectual disabilities. These campaigns can educate the public about the diverse talents and contributions of people who have intellectual disabilities. In affirmation, Gieniec and Jurkiewicz assert that with appropriate education and support, individuals with intellectual disabilities can engage in safe and constructive social interactions, including healthy relationships.[73] In corroboration, Angell et al. attest that community members often express a willingness to accept individuals with disabilities but may hesitate to form closer relationships due to a lack of understanding or prior contact.[74] Thus, education can be critical in reducing stigma and enabling the acceptance of people who have intellectual disabilities. Social workers can facilitate educational programs that promote awareness and understanding of intellectual disabilities, thereby fostering a more inclusive environment.

Strengthening Family and Caregiver Support

This study recommends the strengthening of family and caregiver support based on two important premises. Firstly, families play a critical role in this transition, as they often have insights into the needs and preferences of their relatives.[75] Therefore, by involving families in the planning and implementation of community-based services, support systems can be tailored to better meet the unique needs of individuals with intellectual disabilities, ultimately leading to more successful integration into society. Secondly, family and caregiver support needs to be strengthened because research such as by Bahador indicates that the emotional burden on family caregivers is significant since caregivers often experience high levels of stress, anxiety, and depression due to the demands of caregiving.[76]

Stress experienced by caregivers can be exacerbated by societal stigma and a lack of understanding from the community regarding the challenges faced by families of individuals with intellectual disabilities. Therefore, Bahador emphasises the importance of social support networks for caregivers.[77] In affirmation, Gieniec noted that connections with other families facing similar challenges provided emotional support and practical advice, which helped alleviate feelings of isolation.[78] Thus, social workers can facilitate community-based support systems that can facilitate peer interactions and provide resources for caregivers. Bahador confirms that enhancing social support networks could lead to improved mental health outcomes for caregivers and better care for individuals with intellectual disabilities.[79]

Advocacy for accessible healthcare, housing, education and employment services for people with intellectual disabilities

This study recommends advocacy for accessible healthcare, housing, education and employment services for individuals with intellectual disabilities as vital to promoting their rights and ensuring equity in society. Angell et al. attest that accessible healthcare must prioritise removing physical, financial and systemic barriers to medical services.[80] This may include training healthcare professionals to communicate effectively with individuals who have intellectual disabilities and providing specialised services tailored to their needs. In addition, as recommended by Carnemolla et al., policies should also

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[72] Mkabile and Swartz, “Putting Cultural Difference in Its Place: Barriers to Access to Health Services for Parents of Children with Intellectual Disability in an Urban African Setting.”

[73] Gieniec and Jurkiewicz, “Perception of People with Intellectual Disabilities by Residents of the Tarnów Region, Poland.”

[74] Angell et al., “‘Starting to Live a Life’: Understanding Full Participation for People With Disabilities After Institutionalization.”

[75] Doody, “Families’ Views on Their Relatives with Intellectual Disability Moving from a Long-stay Psychiatric Institution to a Community-based Intellectual Disability Service: An Irish Context.”

[76] Bahador et al., “Experiences of Family Caregivers of People with Intellectual Disabilities from Rural Areas in Southeastern Iran: A Qualitative Study.”

[77] Bahador et al., “Experiences of Family Caregivers of People with Intellectual Disabilities from Rural Areas in Southeastern Iran: A Qualitative Study.”

[78] Gieniec and Jurkiewicz, “Perception of People with Intellectual Disabilities by Residents of the Tarnów Region, Poland.”

[79] Bahador et al., “Experiences of Family Caregivers of People with Intellectual Disabilities from Rural Areas in Southeastern Iran: A Qualitative Study.”

[80] Angell et al., “‘Starting to Live a Life’: Understanding Full Participation for People With Disabilities After Institutionalization.”

address the affordability of healthcare, ensuring that those with intellectual disabilities have access to insurance and government-assisted programs that cover essential treatments and therapies.[81]

The revelation by Capri et al., as well as participants in the study, that the abandonment of people with intellectual disabilities in institutional rehabilitation can be attributed to the inadequacy of resources and the quality of care in community settings, prompts a recommendation for housing.[82] Individuals with intellectual disabilities often face challenges in finding safe, affordable, and supportive living environments.[83] Therefore, housing is a critical area where advocacy is needed. The study recommends that advocacy efforts should promote inclusive housing policies that provide a range of options, from independent living arrangements with support services to group homes that foster community. These housing solutions should also ensure accessibility and prioritise the integration of individuals into their communities, combating isolation and promoting independence.

The study also contends that in order for institutionalisation to be abolished, there is a need for significant attention to inclusivity and resource allocation. Carnemolla proposes that advocacy should push for the implementation of policies that support inclusive classrooms where students with intellectual disabilities learn alongside their peers.[84] Whilst education is important, it must be accompanied by prospects of meaningful employment. In affirmation, Capri et al. attest that employment is essential for empowering individuals with intellectual disabilities and fostering their participation in society.[85] Thus, advocacy in this area should focus on creating pathways to meaningful and sustainable employment opportunities. This includes encouraging employers to adopt inclusive hiring practices and offering vocational training programs that enhance job readiness.

CONCLUSION

This paper has highlighted that despite the move towards deinstitutionalisation. People with an intellectual disability sometimes feel the effects of institutionalisation in special schools which offer boarding arrangements and in day centres and workshops catering for large groups of adult persons. The study has revealed that some of the challenges faced by individuals with intellectual disabilities in institutional settings can be linked to the length of their stay. Participants in the study expressed feelings of being left behind by societal changes while spending significant portions of their lives within the institution. Other challenges associated with extended institutionalisation included the loss of social connections, distress stemming from uncertainty about familial care and love, and a pervasive sense of abandonment by relatives. In addition, the study highlights that orphans with intellectual disabilities face heightened vulnerabilities due to early abandonment, inconsistent care environments and systemic barriers. To address these challenges, the study recommends the development of individualised transition plans, the eradication of systemic barriers, and the implementation of awareness campaigns to educate and shift societal perceptions. The study also recommends strengthening family and caregiver support systems, alongside advocacy for accessible healthcare, housing, education and employment services. These recommendations are critical for enhancing the well-being of individuals with intellectual disabilities.

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