

East African Medical Journal Vol. 98 No. 8 August 2021

BEYOND STEREOTYPES: WORKING TO IMPROVE LIVES AND LIVELIHOODS OF YOUNG PERSONS WITH INTELLECTUAL DISABILITIES: A QUALITATIVE STUDY

Ikenna Desmond Ebuenyi, Assisting Living & Learning (ALL) Institute, Department of Psychology, Maynooth University, Maynooth, Ireland, Ikuze Africa, Nairobi, Kenya, Isaiah Gitonga, Assisting Living & Learning (ALL) Institute, Department of Psychology, Maynooth University, Maynooth, Ireland, Ikuze Africa, Nairobi, Kenya, Lucy Wambui Kamau, Ikuze Africa, Nairobi, Kenya, Elena Vladimirovna Syurina, Faculty of Science, Athena Institute, Vrije Universiteit, Amsterdam, Netherlands.

Corresponding author: Isaiah Gitonga, Ikuze Africa, P.O Box 55287-00200, Nairobi, Kenya. Email: gitongaisaiah0@gmail.com

**BEYOND STEREOTYPES: WORKING TO IMPROVE LIVES AND LIVELIHOODS OF YOUNG PERSONS WITH INTELLECTUAL DISABILITIES: A QUALITATIVE STUDY**

I.D. Ebuenyi, I. Gitonga, L. W. Kamau and E. V. Syurina

**ABSTRACT**

***Background:*** Social inclusion of persons with disabilities thrives in societies with reduced cultural beliefs and practices that promote exclusion based on disabilities. Persons with disabilities face several barriers such as inadequate access to basic needs, inaccessible and non-accommodating environments, and attitudinal barriers. In some cultures, disability is perceived as a form of curse or cultural punishment and those living with disabilities seen as outcasts and a burden to the society. These perceptions and attitudes may limit their full participation in the society and have implications for their livelihood and survival. The aim of this case study is to describe the model of care of a community-based organization in Kenya to improve lives and livelihoods of young persons with intellectual disability.

***Methods:*** Using a qualitative case study approach, we explored the experience of education and livelihoods for young persons who are beneficiaries of Tuleane Afrika Initiative, a community-based organisation in Nairobi, Kenya.

***Results:*** We found that in a supportive and inclusive environment young people with intellectual disability can live and thrive successfully in the community. Socio-economic factors, poor perception of intellectual disability by the society and poor cognitive functioning are the key barriers to success for young persons with intellectual disability.

***Conclusion:*** Social inclusion of young people with intellectual disabilities requires active participation of all stakeholders. It is vital that government, policy makers and society show greater commitment and support for programs that promote wellbeing and livelihoods for young persons with intellectual disability.

## INTRODUCTION

Intellectual disability (ID) is a form of a developmental disorder characterized by less than average intelligence and significant limitations in adaptive behaviour and is associated with multiple aetiologies, including genetic defects and perinatal insults.<sup>1</sup> There are different levels of ID which can be determined by limitations in cognitive functioning or adaptive behaviour, either socially (self-esteem, naivety, victimization), conceptually (language, self-direction, writing and reading) or in practical skills (using transportation, dressing, preparing meals and other chores).<sup>2</sup> The level of functioning can be determined by the available social support and the inherent capabilities of persons with IDs.<sup>2,3</sup>

Depending on setting, ID is associated with lower standard of living and poverty thereby impacting negatively on the education and opportunity for competitive employment.<sup>1</sup> Moreover, poverty impacts negatively on ID through reduced access to health and education services which are useful for care and integration. According to Singer et al, ID requires de-stigmatizing which implies describing it as neurodiversity as opposed to a disease.<sup>4</sup> This has the potential to reduce the level of shame and guilt experienced by persons with ID and enhances the support from parents, carers and peers,<sup>5</sup> and conforms with the UN Convention on the Rights of Persons.<sup>6</sup> In addition, the inability of individuals with ID having the capability to make their own decisions is a stereotype that has been associated with intellectual impairment.<sup>7</sup> However, persons with IDs need to be given support to be empowered in making their own decisions. This ultimately contributes to social diversity through the different world views of persons with ID, their background and lived experiences. Important to note is that autonomy does not mean the absence of risks. It however gives

people with ID a voice, power, and influence over their own lives.

Inclusion of people with ID in all aspects of life, school, work, and community is key to their wellbeing. Available literature suggests that children with ID have a much higher chance of excelling in schools (especially in grammar and vocabulary) when they are included in general education as opposed to being taken to schools for special education.<sup>8</sup> Additionally, they can develop adaptive skills which are a key milestone in the optimization of their independence thus promoting their participation and inclusion in the community. It also reduces the costs incurred in caring for them upon reaching adulthood.<sup>9</sup> Inclusion also entails involving them in making decisions that affect their lives, taking into their strengths, weaknesses, and interests. This eases the transition process and ensures that the personal needs of people with ID are met for independent living.<sup>5,8</sup>

There are, however, difficulties for people with ID to access post basic and vocational training thereby limiting their opportunity to achieve a level of training that would allow them to be included in society upon their reaching adulthood.<sup>10</sup> These experiences of exclusion are worse in low- and middle-income countries where policies and systems for inclusion are sometimes not implemented. In Kenya, ID constitutes about 8% of people with disabilities according to the world report on disability.<sup>11</sup> Due to many years of systemic and societal marginalization, persons with ID do not have proper access to education, employment, rehabilitation, health, and basically socio-economic services that are available to the public.<sup>12</sup> Despite these challenges being identified and highlighted, there is still very little information on the progress made so far in terms of support programs for persons with ID as well as their transition into the community.

Although the government as duty bearer has an important role in improving the lives and livelihood of persons with disabilities, other players such as non-governmental organizations and community-based organizations (CBO) also contribute to this important role. The methods adopted by these organizations may serve as models for innovation and large-scale replication. The aim of this case study is to describe a model adopted by a CBO in Nairobi to improve the experience of young persons with ID from across the country.

## METHODS

*Setting:* This study is based on the experiences of Tuleane Africa Initiative (TAI) (which literally means “let’s grow each other”) Afrika program, a not for -profit community-based organization (CBO) in Nairobi, Kenya.

*Design and data collection:* We adopted a qualitative case study approach. This involved the use of in-depth interviews and observation of activities at the CBO. Interviews were conducted with the founder and director of the program and staffs present (three) during the field visit in May 2018. The interviews focused on the process of recruitment of children with ID into the program, their training and curriculum, and challenges faced by the CBO and some of the mitigation measures. The interview with the founder was undertaken twice. The first time was at a neutral location and the second time was at the TAI facility. The visit to the TAI facility enabled the researcher to inspect and observe the centre, their mode of operations and some of the children with ID. The staff present were interviewed, and field notes were taken from the discussions during the visit. Informed consent was obtained prior to the interviews. Interviews were recorded, transcribed, and translated into English.

*Analysis:* Thematic analysis was done through coding of key themes that were

noted during the interviews. The initial coding was conducted by LWK and reviewed with IDE and IG. The codes identified by the research team were shared with the program director through follow up emails and telephone calls to ensure that the information gathered during the analysis was accurate and a correct representation of the operations of the initiative.

## RESULTS

The findings from this study describe the program operation, the challenges and success factors for the program.

*Mode of operation of TAI:* TAI operates as a not-for-profit CBO for young people with ID. It is registered under the National Council for Persons with Disability as a community organization working with persons with disabilities. There are three different levels in the program in which the young people must complete before they are fully integrated into the community. The first level is labelled “bronze”. This is for the new children who join the program. It involves teaching the children basic skills such as bathing, changing their clothes and life skills. For some of the children, this level takes about four months. In some instances where the impairments are severe, some children never get to progress to the next level. In this case, the parents and learning support assistants agree to teach the child activities for daily living and thereafter link them with activities or jobs that are not tasking such as in factories. The second level is “Silver”, and the final level is “Gold”. In “silver”, the children are taught numeracy, the language that the child understands, social studies which emphasizes more on Mind in the Making activities. “Gold” level focuses on capacity building, training on career guidance, adaptation, and shared practices of social and life skills. Progress from one level to another is dependent on the ability of the child and successful completion of the previous level.

Each of the levels, Bronze, Silver and Gold have a teacher and a learning support assistant. Additionally, there is a trainer who ensures that the children are taught skills that they need in their everyday life. There is also a cook, a matron, and a trainer on good grooming. TAI takes up a total of 15 young persons at any given time with each child spending about two years in the program before they are integrated into the community. The charge per term for each child is between \$200- \$300 since the program gets very little funding that is not able to fully support the children being admitted into the program.

*Initiatives that have enhanced success of the program:* The TAI initiative and mode of operation is considered successful by the directors and most of her staff who suggest that that program has positively impacted on the children. There was also validation of success based on the feedback from the parents as reported by the director, *'I have had many parents now calling me back to say my son is doing much better, my son is comfortable to leave the house and go to class and come back, my daughter is doing envelops'*.

In the next section, we discuss the factors that they suggested have helped their initiates.

*Communication:* The theme on communication entailed practices that ensured inclusion and encouraging of the children to develop confidence and social skills. This encompasses involving children in decision making where they feel that their opinion matters and increases their confidence in their abilities.

*"Communication is not speech, communication could be anything, for as long as I understand that the child wants to help themselves, which child is hungry, that child is whatever it is, then we are moving forward"*.

The theme on communication also entailed promoting self-esteem to foster confidence:

*"What we need to do with children with intellectual or learning disabilities, autism is to start teaching them self-awareness, who am I,*

*where can I go, what can I do for myself, what can I accomplish, telling the child you can be as good as your brother"*.

These forms of positive motivation were perceived as pivotal in their acceptance of teaching, developing of social and life skills.

*Social participation:* We noted that the organizational structures for integration of children with ID into the community determines the level of independence of the child as a person as well as economically. There are three factors that were found to be essential in the successful social participation and integration into the community.

*Treating each child as an individual and involving them in decision making:* Treating the child as an individual and letting them know that nothing was ever built in a day. Everything takes time and commitment, but above everything, that they might not always get it right the first time. *"One milestone at a time, it doesn't really matter how long it takes with one child, but we get somewhere"*.

*Teaching by example:* Children with ID pick a lot from the people they are around. Their first point of learning is through observation of what is being done; this is not only in chores like cleaning and cooking but in all spheres of life. This means therefore that the people hired to stay with the children are not just selected because of their qualification but because of their interest and motivation in special needs care.

*"I don't really hire on papers; I hire on matters of the heart. It is about what else you can do; if this was your child, what could you do with them? Would you leave them here abandoned or would you just ignore them?"*

The importance of teacher motivation and understanding of their wards was further highlighted in these declarations.

*"I do not ...employ a teacher who is not self-motivated, who does not have a passion with children in learning disabilities or intellectual disabilities, and I want to see a teacher who has the vocation aspect, the transition aspect of that child in mind...."*

*"Internships/ apprenticeship and mentorship programs in their area of interest."*

In the interview the program director notes the factors that have led to success in the organization which starts from the level of the child to the teaching staff and mentorship programmes. Firstly, she noted that it is important to create self-awareness for children with ID.

*"Who am I, where can I go, what I can do for myself, what I can accomplish, telling the child, "You can be good as your brother".*

Despite these successes, there exist some challenges or problems such as:

*Social economic factors:* Poverty was perceived as a key barrier to access to basic needs as well as education for children with ID. Majority of the young people admitted at the centre come from very poor backgrounds and with parents and carers who cannot afford to pay for their daily maintenance costs at the center. This is particularly because the economic background of a person determines whether they can access the services they need, and in good time to avoid deterioration of their condition. According to one of the members of staff, only a complete understanding of the socioeconomic history of the children with disabilities will provide information about the impact of disability and whether such disability is very visible:

*"Unless you follow them up from their past, how they have grown up, any child with intellectual disability who has grown in a higher social economic space, you won't notice them, you won't notice... socioeconomic status is important".*

*Financial challenges*

The TAI program is partially funded which means that parents must pay part of the amount per term for their children who have children have enrolled into the program. For parents who cannot afford the fees required to provide the services needed by their children, TAI makes exceptions to provide support for the children based on what is available. Reflecting on the financial

commitment required for children placed in TAI, the founder and program director stated:

*".... our student pays us about 30000, but some parent cannot even afford to pay that 30000... I feel sorry for them..."*

According to her, most parents are unable to afford these, and the centre sometimes must take up the care of the children on credit or through donations.

*Cultural barriers:* Culture plays a huge role regarding the support a person with ID gets from the family and community in general. Most of the rural communities in Kenya still believe that a child with ID is an abomination and should be shunned by the society, which further exacerbates the situation and hinders integration.

*".... we have a girl with cerebral palsy we found in the street, who was abandoned in their community because in their tribe they kill children with disabilities...."*

These cultural practices and perceptions are also related to the poor awareness about ID. Interpersonal relationships where the lack of empowerment by the parents as well as their disbelief in the abilities of their children generally affect the self-perception/ esteem of the children. This is not just in the tasks that they are able to accomplish but in terms of their ability to participate in decisions that affect their lives. Hence disability or children with disabilities are perceived as commodities to hide or something kept hidden. According to the director, some parents hide their children.

*"They do not want them to mingle. you will never, never know that person has a disabled child and unless that child dies".*

## DISCUSSION

This study highlights the role of community-based organisations in the care and education of young people with ID. This study indicates that in a supportive and inclusive environment young people with ID can live

and participate fully in the community. Lack of a supportive environment coupled with poverty and poor awareness of ID hinder the children with ID from accessing services in the community. Further, inadequate financial support is one of the major challenges being faced by existing community initiatives such as the TAI program. However, despite the challenges, TAI have been able to offer successful services for children with ID. Experiences from this program show that there is a huge impact of the social environment in determining the participation and consequent successful integration of young people with ID into the community.

This program has further revealed that without a supportive environment, a child with ID feels neglected and this often leads to avoidance of the task and consequently cognitive exhaustion. This impacts negatively on their cognitive performance.<sup>13</sup> Therefore, affirmation of the abilities of the child is the prerequisite for their future success as individuals and adults who are capable and who can be a functional part of society. This calls for the need to focus on the “whole child” as well as their families. A child with ID is no different from other children except that they are a representation of diversity and spectrum of intellectual abilities leading to variability in functioning.<sup>14</sup>

Interpersonal relationship between the child and caregiver is a key contributor to the success of such programs. It calls for teaching by example, like other children, persons with ID learn more by what they see than what they are told.<sup>15</sup> This means that the values instilled in them are a direct representation of what they see and learn from around them. This also leads to their self-awareness not just in terms of what they can do but to the fact that they also matter. Moreover, the children are each treated as individuals which make them aware of their own uniqueness and the contribution they bring to their families and

the community. This is not forgetting the importance of organizational structures such as bridging of career choices to help the youths fulfil their job market niche. This is through community support systems with mentors where they can be interns or apprentices in acquiring new skills and competencies.<sup>16</sup> Employment and work are fundamental not only in social inclusion but also in achievement of other rights or persons with disabilities, including ID.<sup>17,18</sup> Additionally, supported engagement and the development of social connectedness and belonging helps to foster the wellbeing of persons with ID.<sup>19,20</sup>

As shown in this study, young people with ID face myriad of challenges emanating from negative perceptions and social exclusion that hinder their development as productive members of society. However, with a supportive environment that promotes social inclusion, young people with ID can grow and participate fully in the society. Initiatives such as TAI, improved awareness on disability and policy changes that enable availability and access to relevant assistive technologies need to be promoted and supported.

## CONCLUSION

The case of TAI program highlights how passion and interest in children with ID can lead to success despite existing challenges. There is a need for increased awareness of ID especially in low resourced settings like Kenya where stigma and cultural barriers hinder full participation of children with ID in the community. Further, the government needs to put in place supportive structures and legislations that support not only educational, but also supported employment for children with developmental impairments which includes supporting community initiatives such as the TAI program.

## REFERENCES

1. Schalock RL, Borthwick-Duffy SA, Bradley VJ, Buntinx WHE, Coulter DL, Craig EM, et al. Intellectual disability: Definition, classification, and systems of supports. ERIC; 2010.
2. Pitetti K, Baynard T, Agiovlasitis S. Children and adolescents with Down syndrome , physical fitness and physical activity. *J Sport Heal Sci.* 2013;2(1):47–57.
3. Mitra S. The capability approach and disability. *Journal of Disability Policy Studies.* 2006.
4. Wang M, Singer GHS. Supporting families of children with developmental disabilities: Evidence-based and emerging practices. Oxford University Press; 2016.
5. Marshall N. Child and Youth Care and disability rights: Listening to young people, challenging our practice. *Relational Child Youth Care Pract.* 2017;30(2):55–69.
6. United Nations. Convention on the Rights of Persons with Disabilities (CRPD). UN Committee on the Rights of Persons with Disabilities (CRPD). 2021.
7. Hellzen O, Haugenes M, Østby M. ' It ' s my home and your work ': the views of a filmed vignette describing a challenging everyday situation from the perspective of people with intellectual disabilities. 2018;2631(May).
8. Bigby C. Social inclusion and people with intellectual disability and challenging behaviour: A systematic review. *J Intellect Dev Disabil.* 2012;37(4):360–74.
9. O'Connor M, Quach J, Goldfeld S, Gold L, Aston R, Beatson R, et al. Approaches to the provision of educational support for children and young people with additional health and developmental needs. *Park VIC Murdoch Child Res Inst.* 2015;
10. Ebuanyi ID, Rottenburg ES, Bunders-aelen JFG. Challenges of inclusion : a qualitative study exploring barriers and pathways to inclusion of persons with mental disabilities in technical and vocational education and training programmes in East Africa. *Disabil Rehabil.* 2020;42(4):536–44.
11. Bickenbach J. The World Report on Disability. *Disabil Soc [Internet].* 2011 Aug 1;26(5):655–8. Available from: <https://doi.org/10.1080/09687599.2011.589198>
12. Mitra S, Posarac A, Vick B. Disability and poverty in developing countries: a multidimensional study. *World Dev.* 2013;41:1–18.
13. Michal G, Smole T, Pilecka W. Consequences of Learned Helplessness and Recognition of the State of Cognitive Exhaustion in Persons with Mild Intellectual Disability. 2017;13(1):42–51.
14. Burack JA, Evans DW, Lai J, Russo N, Landry O, Kovshoff H. Edward Zigler ' s legacy in the study of persons with intellectual disability : the developmental approach and the advent of a more rigorous and compassionate science. 2020;d:1–6.
15. Knight VF, Wood L, McKissick BR, Kuntz EM. Teaching Science Content and Practices to Students With Intellectual Disability and Autism. *Remedial Spec Educ [Internet].* 2019 May 26;41(6):327–40. Available from: <https://doi.org/10.1177/0741932519843998>
16. Rapley M. The social construction of intellectual disability. Cambridge University Press; 2004.
17. Ndetei DM, Musyimi CW, Mutiso VN, Ruhara RW, Boycheva E, Gitonga I. Promotion of Recovery Through Socio-economic Inclusion for People Living with Severe Mental Illness. In: Okpaku SO, editor. *Innovations in Global Mental Health [Internet].* Cham: Springer International Publishing; 2020. p. 1–9. Available from: [https://doi.org/10.1007/978-3-319-70134-9\\_80-1](https://doi.org/10.1007/978-3-319-70134-9_80-1)
18. Ebuanyi ID, Guxens M, Ombati E, Bunders-Aelen JFG, Regeer BJ. Employability of persons with mental disability: understanding lived experiences in Kenya. *Front psychiatry.* 2019;10.
19. Ojok P. Participation of persons with intellectual disabilities in self-employment : experiences from a low-income country. *J Intellect Disabil Res.* 2019;63(7):632.
20. Wilson NJ, Jaques H, Johnson A, Brotherton ML. From Social Exclusion to Supported Inclusion : Adults with Intellectual Disability Discuss Their Lived Experiences of a Structured Social Group. 2017;847–58.