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Chapter

Transition Possibilities for Adolescents with Intellectual Disabilities into Adulthood

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Abstract

Transition possibilities for adolescents with intellectual disabilities into adulthood remain a complex issue and often neglected by the healthcare system and non-healthcare system. Given the responsibilities and roles that the healthcare system, non-healthcare system and families have to fulfil to address the transition possibility issue, the lack of knowledge, skills and resources negatively impacts on the transition possibility. In favour of situating adolescents with intellectual disabilities into adulthood, the provision and development of working skills need to be prioritised. Transition possibilities are to be considered to all adolescents with intellectual disabilities.

Keywords: adolescents, adulthood, intellectual disabilities, transition and possibility

1. Introduction

Adolescence is a time of transition, involving multidimensional changes, namely biological, psychological and social [1]. These changes occur simultaneously and at different paces for each adolescent. Extant literature reports that the world is home to 1.2 billion adolescents aged between 10 and 19 years. Transition for adolescents is not only biological, but it also includes emotional transition [2]. The United Nations statistics has reported that there are more than 600 million people with disability and that 80 million live in Africa. There is also an estimation that more than 300,000 adolescents have intellectual disabilities. Majority of adolescents with intellectual disabilities (IDs) adolescents would be excluded from acquiring some education and employment opportunities, as well as to suffer discrimination Nyangweso [3]. In addition, Meleis, Sawyer, Im, Messias, Schumacher [4] transition is perceived to be complicated. Adolescents with IDs will grow into adulthood as a result of improved healthcare and related technologies. Pandey and Agarwal [5] wrote that even though transitions are almost normal as they happen often, it is, however, very challenging for adolescents moving into adulthood especially for those with intellectual disabilities who may remain wholly dependent on their parents for emotional wellbeing.

This chapter provides a clear and detailed definition of the concept of transition, transition of adolescents with intellectual disabilities (IDs), followed by governmental intervention. Transition possibilities for adolescents with ID are discussed under various roles of the government, healthcare workers and communities.

2. Transition as a concept

The concept of 'transition' has been in existence for more than three decades. It is among the concepts that are debated on its meaning and uses in literature. Transitions occur throughout life and are the processes faced by all humans, from birth, to adolescence and to adulthood, from being immature to mature and from being dependent to independent [6]. Transition is often associated with movement from a more shielded environment to a more self-directed environment. It is characterised by the ability to make decisions and to take care of oneself [7]. Transition also includes many adjustments that have to occur in life. Such events include leaving parents to boarding school, leaving home after parental death to an orphanage and all other life events that may render one to transit from one area to another [8]. Chick and Meleis [9] summarises transition by defining it as 'a passage or movement from one state, condition or place to another' (p239). Ally et al. [10] are of the opinion that transitions are aimed at improving one's quality of life. It is a movement from one area of dependency to one area of independence, where one can do activities of daily living with minimal assistance. The authors further noted that it is about the cognitive and adaptive functioning of the individual. The process of transitioning is very difficult for most adolescents and could be particularly difficult for those adolescents with intellectual disabilities [11]. Shaw and DeLaet [12] define transition as a process, a point in time and a perception. As a process, transition needs people with ID their families, caregivers and the healthcare system to work together towards a common goal. The authors argue that transition entails the period starting from the anticipation of transition until the new status and change have been achieved. Lastly, the authors are of the view that transition depends on the individuals' interpretations of what transition mean to them rather than being an event. Furthermore, this depends upon the setting in which the transition process takes place. Eighteen years is globally believed to be an age of maturity, and hence adolescents when they turn 18 are expected to have reached a certain level of independence and are able to make life decisions such as employment and career. In accordance with Patterson and Pegg [13] past history reflects that adolescents with IDs were devalued and not allowed to live independently. These assumptions and beliefs pose challenges for those who are intellectually disabled.

3. Transition of adolescents with intellectual disabilities

Intellectual disability is characterised by several limitations in mental, emotional, cognitive and physical functioning. People with intellectual disabilities display very problematic behaviours that require attention at all times [14]. The definition of intellectual disability is also wrought with many controversies. To date there is no single definition that is acceptable for all. For instance, it is believed that people with intellectual disability's social and practical skills differ significantly from what is accepted as normal by his or her society (American Association of Intellectual and Developmental Disabilities (2011 cited in Aldersey [15])). On the contrary, Werner [16] and Lancaster et al. [17] define ID as characterised by significant limitations in intellectual functioning with an IQ below 75 which originates before the age of 18 years. To this end, intellectual disability has been defined by limitations in intellectual functioning and adaptive behaviours. They need more attention and assistance to cope with activities of daily living Shogren and Plotner [18].

The transition of adolescents with ID into adulthood is challenging in that they are expected to go through psychological and social maturation just like their able counterparts. There is a range of issues associated with transition of adolescents with ID into adulthood. They include rehabilitation and special education issues.

However, in most countries, especially developing countries, they do not have structures in place to assist them achieve this milestone [8]. Most often, there are no programmes and policies suited for addressing their needs.

Disability is a developing concept in Africa as it is entrenched within the culture [19]. In the African context, disability is associated with supernatural causes that affect the way family members would treat the individual with ID [20]. Aldersey [15] posits that disability in Africa is a formation of one's culture. Etiyiebo and Omiegbe [20] also support this view that culture defines an individual with intellectual disability as less than human. The two studies quoted above gave examples of other studies in Africa, such as Botswana, Zimbabwe and Cameroon, that define intellectual disability according to norms of the society they live in. These negative stereotypes in most of the African countries have led to the exclusion of individuals with ID from the mainstream society [21]. This has even led to some families to hide their adolescents allowing them to grow in isolation with no proper transition. It is therefore not surprising that in most of Africa, there is lack of relevant policies for individuals with ID, and this poses many challenges for them and their families. Most of these challenges relate to social, occupational and parental issues.

3.1 Social challenges with transition of adolescents with intellectual disability

Lack of support and labelling of individuals with ID by communities are some of the challenges that affect adolescents with ID. These lead to isolation and loneliness. Other studies [2, 22, 23] also reported that individuals with ID are ridiculed, not supported and unaccepted by the society they live in. Stigma and discrimination, especially in African countries where disability is associated with witchcraft and other supernatural causes, influence the way the individuals with ID are treated. Incidences of individuals with ID being locked in the houses and hidden from the larger society are still rife in some parts of Africa [24].

Adolescents with ID may not even have the opportunity to volunteer for some activities in their communities. Friendships and peer interactions are limited mostly because other peers with no ID may react negatively towards those with ID, and it is because they have differing conceptions of friendships [25].

3.2 Occupational challenges with transition of adolescents with intellectual disabilities

Adolescents with ID face many challenges, especially in developing countries. There are very few schools open to adolescents with ID. The majority of them end at the seventh grade. This is especially true if they come from poor families who may not afford few private schools. In a study by Malapela [26], she found that out of the 25 adolescents admitted in two special schools in South Africa, only one of them was given a vocational job after completion. In other countries, there are social grants with which these individuals and their families depend on, whereas in other countries where there are no disability grants, their livelihood is dependent on their parents and families. Pandey and Agarwal [5] reported that adolescents with ID are most likely not to be employed and less likely to complete secondary education.

3.3 Leisure challenges with transition of adolescents with intellectual disabilities

It is generally believed that leisure promotes emotional and psychological wellbeing for individuals with ID [27]. Leisure activities develop general skills and adaptive behaviours. However, in most countries leisure activities for individuals with ID are limited or non-existent Majoko [28]. Lack of leisure or recreational

activities leave the individual with ID to have television as an only option. For some who do not have television, they spend most of the time in the house watching movements of their people depending on the degree of their disability. For some, parents may not allow their adolescents with ID to play with others for fear that they would be hurt, mocked or ridiculed. Jerome, Frantino and Sturmey [29] see this as being overprotective, which does not benefit the individual with ID as taking risks of being hurt is part of growing up. All these are daily challenges faced by these individuals.

3.4 Parental challenges

Literature has reported stress and depression for parents of adolescents with ID. Parents experience caregiver burden because in most cases they are left alone to care for their adolescents with no external assistance. In most instances, the parents are responsible for attending to all the activities of daily living for their adolescents with ID. A study conducted in United Kingdom by Rogers [30] reported that parenting an individual with intellectual disability incapacitates the whole family. It puts more pressure and burden on the family as more attention is needed from parents and mothers of these individuals to assist them to achieve activities of daily living including bathing, feeding, mobility, toilet training, socialising and others. The caregiver burden is aggravated by lack of professional support and unavailability of services. The American Psychological Association (2016) is of the view that where there is support and services the caregiver burden would be lessened. In other countries, where there is absence of such facilities or the lack of knowledge about their existence, then parental stress can be exacerbated [26].

4. Governmental interventions

Transition of adolescents with ID into adulthood has been a concern not just for researchers but for national governments as well. Most governments encourage the principle of inclusion in schools and employment [7]. In some instances, policies have been developed that encourage inclusion and provide more opportunities for adolescents with ID aiming at maximising their interaction with the wider community.

In South Africa, for instance, a number of legislative regulations and policy framework have been developed to protect individuals with intellectual disabilities from exploitation, vulnerability and discrimination. However, numerous concerns and challenges have been reported regarding their care, treatment and rehabilitation that are detrimental to their general wellbeing and their future prospects. According to the policy guidelines on child and adolescent mental health and reconstruction and development programme (RDP), adolescents with ID are still faced by many challenges in their transition to adulthood. It is for this reason that transition possibilities need to be prioritised.

The Mental Health Care Act No.17 of 2002 that directs care, treatment and rehabilitation of adolescents with intellectual disabilities states that individuals with ID have the right to a sheltered employment and fair treatment. However, the demands of this act have not been realised fully, and this impacts negatively on their transition.

Given all the limitations that affect the transition possibilities, proper understanding of transition possibilities in the context of intellectual disabilities needs urgent attention. There must be a change that would have positive impact in the

lives of individuals with ID. These changes must take cognisance of their level of mental, physical, social and emotional functioning.

5. Transition possibilities

There are numerous transition possibilities that could be done to assist adolescents with ID. Most of these possibilities centre on what governments and healthcare workers can do to mitigate the many challenges associated with their transitions. The possibilities for governments are on policy development and involvement of other stakeholders. For healthcare workers, the main theme is on educating different players such as parents, families and communities.

6. The role of governments

Poor outcomes for adolescents with ID on employment, education and social activities call for an active path for changing the post high school scenery**.** Governments can strive to make transition easier by ensuring structures that accommodate adolescents with ID are in place. Firstly, governments should ensure that all the schools from primary to secondary have facilities for special education. Such an arrangement will ensure that adolescents with ID and those without ID are taught in the same schools. Arrangements could be made that in such schools there will exist common courses that are taken together such as physical education. This will have multiple benefits for all. Adolescents with no ID will be able to accept those with ID and can understand their shortcomings and be able to assist them.

Firm friendships can be built at this stage, and this would ensure that adolescents with IDs leisure time are well taken care of [5]. The authors reported that adolescents with ID believe that they are just like others and consider themselves able to interact with peers with no ID. Research by Kurth and Mastergeorge [31] suggest that inclusive education has more enhanced academic results for students with disabilities.

The use of technology in such schools will also improve the academic outcomes for students with ID. Therefore, governments should strive to make all this available for adolescents with ID. Maxey and Beckett [7] posit that special education which is in the same environment with the mainstream education plays a vital role on how adolescents with ID are perceived by both the teachers and their peers. Currently in most countries, especially in developing countries, there are very few special schools, hence governments should be encouraged to build some and make them inclusive.

Governments can also expand employment opportunities for adolescents with ID. These they could do through collaborating with employment agencies. A study done by Plotner and Mashall [32] in the United States found that 28.4% of adults with ID were in formal employment compared to 71% of those adults without ID. However, in developing countries the statistics would even be lower. Adolescents with ID should be taught courses that would link them with particular employment opportunities.

Community centres that are open for adolescents with ID need to be in place. The government can achieve this by forming partnerships with community agencies. The benefit of this would be that it would allow for integration of adolescents with ID into the community. Pallisera et al. [33] argued that transition partnerships and collaboration are key factors in the facilitation and fostering of the transition

process. This means an inclusion of a wide range of professionals, agencies, centres or services throughout the transition process.

Healthcare services are fragmented in most countries. For adolescents with ID, this would compound the problem of caregivers; hence, the governments need to bring them together. In most countries there are no services tailored for adolescents. There are health services for children and for adults, and there are very few for adolescents such as youth centres. This gap in service provision should be attended to, and youth-friendly services and skill centres should be made available even for adolescents with ID.

7. The role of healthcare workers

In order to ensure successful healthy transitions in healthcare, partnership work with families, communities, societies, education and other relevant stakeholders is needed. Ramalhal et al. [34] assert that nurses have the responsibility to assist individuals and their families to deal with the transition process. On the contrary, Shaw and DeLaet [12] argue that the physicians should take the first critical step to improve the transition process to adult-oriented healthcare. According to Meleis' Transition Theory, nurses are the partners of individuals and their families as they will be able to follow changes and outcomes regarding the transition process.

Healthcare workers are also responsible for educating parents on the adolescent's condition and what parents should expect. This would lessen the stress and ensure that parents know what to do with their adolescents. Education should focus on the adolescent behaviour. This would help parents to develop healthy relationships with their adolescent. This education should involve not just primary caregivers but extended family such as siblings, grandparents, aunts and other significant parties.

Healthcare workers are also charged with explaining to families about the level and scope of healthcare services that are available for such individuals. In most cases, families get confused because they are not aware of services that are available to adolescents with ID. Healthcare workers can facilitate their formation so that families can support and encourage each other.

Families should also be educated on the importance of a friendly, safe and stimulating environment to enable adolescents with ID to maximise their potentials and to cushion emotional and behavioural challenges [26]. Internet should be used where possible, and computer skills should be developed. Seal [35] and Seal and Pockney [36] hold a strong view that the use of the Internet allows individuals with ID to express themselves.

Provision of counselling is another viable transition possibility [26]. Individuals with ID should be counselled if they get frustrated in their inability to solve problems and be encouraged if they are able to solve problems on their own. Healthcare in most countries is very fragmented; healthcare workers should support their integration so that counselling is offered with other services. This would ensure that individuals with ID receive total quality care when is needed.

In a study by Malapela [26], it was found that the majority of parents lacked the knowledge and skill to care for their adolescents with ID. The study recommended that educating caregivers on the care of their adolescents and knowledge about their limitations would promote positive transition outcomes.

8. The role of communities

Teaching communities and socialisation of the intellectually disabled children into the community are the key factors that form the basis for assisting adolescents with

IDs transition into adulthood. If communities understand the abilities and limitations of adolescents with ID, they would have a nondiscriminatory attitude that would assist in the transition outcomes for individuals with ID. A non-judgemental and nondiscriminatory attitude is key towards achieving healthy transition experience.

Community partnerships with parents and professionals would relieve parents from being alone in the care of their intellectually disabled. Therefore, working together as a team would ensure a healthy transition of individuals with ID. For transition to bring about change and difference, individuals, their families and health and non-healthcare professionals should make necessary efforts and changes that enable these individuals and their families to adapt to their new roles and expectations. A community approach is necessary to assist these individuals, their families and their caregivers adapt to new changes and routines. Therefore, community education is essential to ensure that transition process promote positive experiences.

More community resources should be available and accessible to support these individuals and their families during the transition experience and process.

9. Conclusion

Positive transition of adolescents with ID would ensure improvement of quality of life for individuals with ID. Governments and other stakeholders need to further develop the policy framework needed to assist individuals with ID and related interventions. Education, employment and leisure are key to a fruitful integration of individuals with ID in the mainstream society. Studies quoted in this chapter support those individuals with ID to have the same opportunities as for all individuals without ID. Prioritisation of provision and development of working skills are the determining factors for facilitating transition of adolescents with IDs into adulthood. The need for further research is necessary to ensure that adolescent with ID can live an independent life.

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