

Strategies for Transition of Adolescents with Intellectual Disabilities into Adulthood

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Abstract

Introduction: Transition of adolescents with intellectual disabilities into adulthood is a concern to caregivers and the society at large. Transition is still a challenge to health care and non-health care system. Studies on legal and ethical issues have been done regarding the care, treatment and treatment of adolescents with intellectual disabilities. Strategies for transitioning of these adolescents have not been given a priority.

Purpose: To develop strategies for transition of adolescents with intellectual disabilities into adulthood.

Method: A sequential exploratory mixed method was undertaken with 149 caregivers as participants informed the development of the strategies for transitioning from adolescence to adulthood. Multiple data collection method including individuals interviews, focus group and survey questionnaires were used to arrive at the findings.

Results: Five main themes emerged from the analysis as transition possibility, the role of different stakeholders, the provision and development of working skills, caregivers' knowledge and understanding of guidelines and alterations to adapt to changes.

Conclusion: The findings of this study indicated that the majority of caregivers working with adolescents with intellectual disabilities do not have the skill to effectively care for them. Hence, the developed strategies would provide caregivers with knowledge and skill to improve the care of adolescents with intellectual disabilities.

Keywords: *Adolescents; adulthood; development, intellectual disabilities; strategy, transition.*

Introduction

Previous studies indicate that adolescents with IDs rely on caregivers due to their limitations in cognitive, social, physical and emotional functioning¹. On the contrary, according to the study conducted in Western Australia (WA)² due to improved health and technologies, the life expectancy of adolescents with IDs has improved and 17 in 1000 live birth accounts to the prevalence of intellectual disability. This implies

that there is high population of individuals with IDS and therefore they need to be given much attention than any other population. In the African and South African context, individuals with IDS constitute 2-4 % of the general population, mostly have mild retardation, approximately 20% have moderate and 5% have severe and profound intellectual disability³. High percentage of mild to moderate intellectual disability is of significant value as this indicates that transition care is quite a possibility among these adolescents.

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According to the study conducted in the United States there is a need for research that focuses on the transition care, self-perceived quality of life (QoL) and health outcomes of adolescents with IDs transitioning into adulthood⁴. ⁵concludes that transition is a concept of significance in the context of health care context, it implies a shift, change, movement from one direction

to the other levels such as the individual, group, organization, family or societal level. In this study, transition would mean moving and shifting from the current condition, stage, level, functioning, performance and capacity to the next positive level/stage. This requires healthy transition care as this study suggests.

Method

A mixed sequential exploratory mixed method was used to develop strategy for the transition of adolescents with IDS into adulthood. The first phase used qualitative phase followed by quantitative phase. A purposive and snowballing non-probability sampling method was used to recruit participants and recruitment period was from 2016 November -2017 June. Participants who were directly involved in the care, treatment and rehabilitation of adolescents were eligible to participate in this study. Caregivers such as teachers, district subject specialists, parents of adolescents with IDs, health care workers and managers were from special schools, Non-Governmental Organizations and governmental organizations. Caregivers were from the age of 21 years irrespective of age, race, culture and ethnicity. Focus group interviews were conducted with health care workers and managers working in Non-Governmental Organizations.

Quantitative data was used to collect data from nurses, school nurses, psychiatrists, occupational therapists, physiotherapists and social workers directly involved in the care, treatment and rehabilitation of adolescents with IDs. Respondents were from special schools, non-governmental and governmental organizations. Most of the respondents were between the ages of 30-39 years, mostly black females.

Content analysis was used for qualitative data and SPSS25.0 was used with the quantitative data.

Findings: The Five main themes emerged from the analysis as transition possibility, the role of different stakeholders, the provision and development of working skills, caregivers' knowledge and understanding of guidelines and alterations to adapt to changes formed the strategies developed.

The proposed strategies developed provide information to be cascaded to different role players in order to equip them with knowledge, skills and attitudes that enables the transition of adolescents with intellectual disability into adulthood. Policy development leg will include a range of policies and procedures to be

followed. In accordance with the policy guidelines for the child and adolescent mental health and Mental Health Care Act (MHCA No.17:2002), a number of policies has been instituted to protect and develop adolescents with intellectual disabilities. According to the MHCA, N0.17, 2002:Chapter II(3ai), the Act regulates that the mental health care should provide the best possible mental health care, treatment and rehabilitation services available to the population equitably and efficiently in the best interest of the mental health care users within the limits of the available resources. The need for prioritizing the provision and development of working skills was neglected. Transition possibility should be inclusive to all individuals with intellectual disabilities. The need for policy development that caters for the transition possibility to all should be prioritised and taken into considerations.

For the alteration strategy, a shift in focus from academic performance to development of skill is a necessity. Provision of institutions working with the IDS should emphasize the need for skill development interests of adolescents with ID. According to⁶, staff should be in a position to offer skills that will assist individuals with IDs attain their highest potential and to be independent. In this study, most participants reported that they encourage individuals with IDs to be independent through empowering them with skills in order to make a living and to create wealth. This in turn will reduce the burden and dependence over social grants.

Participants emphasised on the need for active participation and independence. ⁷supports that individuals with IDs need training to gain increased independence in everyday life.

Socialisation into the community will enable the community to accept and support these adolescents to achieve their potentials. People with disabilities are seen to be unproductive without any returns in investment⁷. Centres that are dealing with intellectually disabled children need to be productive through the development of projects that will benefit the community and public at large. Integration with business sectors is pivotal to ensure that the projects are more recognised and of great value. In accordance with ICF, there is a need for integrated approach that promotes needs assessment, treatment planning, education, training and social activities⁷. Individuals with IDs struggle with getting employment and community participation in adulthood⁸⁻⁹.

Conclusion

The findings of this study indicated that the majority of caregivers working with adolescents with intellectual disabilities do not have the skill to effectively care for them. Hence, the developed strategies would provide caregivers with knowledge and skill to improve the care of adolescents with intellectual disabilities.

Previous studies recommended the need for research that considers transition process of individuals with IDs into adulthood as it is limited and needs further attention¹⁰. Therefore, the study proposes and suggests the provision and development of working skills as a means and ways to bring about positive change amongst individuals with IDs and their families. In conclusion, this study fills the significant gap on knowledge by identifying the strategy for transition of adolescents with IDs into adulthood.

Conflict of Interest: The authors declare no conflict of interest.

Source of Funding: The study was supported by the University of South Africa.

Ethical Clearance: Ethical approval was granted by the University of South Africa, Department of health, higher degrees committee (Ref) and the Department of health IRB in Pretoria South Africa (Ref:)

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