

ABSTRAK

Golongan kurang upaya boleh dan pernah menyumbang dalam perkembangan individu dan pembangunan komuniti. Oleh itu, penting untuk mendokumentasi serta menilai kualiti hidup mereka. Kajian ini bertujuan meninjau kualiti hidup kanak-kanak autistik dan berdasarkan tujuh domain, iaitu kebendaan, kesihatan, produktiviti, intimasi, keselamatan, tempat dalam komuniti dan emosi. 3 orang peserta kajian dipilih daripada sebuah pertubuhan bukan kerajaan dan pendekatan kualitatif digunakan. Didapati domain tempat dalam komuniti paling kritikal bagi mereka kerana kurang upaya dari segi kemahiran sosial dan persepsi masyarakat terhadap keadaan kurang upaya mereka. Bagi domain intimasi, dua orang kanak-kanak bergantung kepada kawan rapat daripada pusat tersebut berbanding ahli keluarga. Pertubuhan tersebut membantu dari segi domain produktiviti, walaupun menunjukkan keperluan untuk penambahbaikan dari segi penggunaan teknologi. Kebebasan terhad bagi kanak-kanak ini memberi kesan negatif terhadap domain emosi. Domain kesihatan pula tidak kritikal. Walaupun terdapat masalah kesihatan ringan dan kurang upaya lain, keprihatinan ahli keluarga menjamin kesihatan mereka. Keselamatan mereka juga tidak kritikal kecuali situasi-situasi tertentu (seperti tempat-tempat sesak) menyebabkan perasaan cemas. Pengetahuan ahli keluarga akan situasi-situasi sedemikian membantu menangani anak-anak autistik mereka dengan baik. Domain kebendaan pula bergantung kepada status sosio ekonomi keluarga. Kepuasan yang dinyatakan oleh mereka berbeza-beza serta berdasarkan barangan yang sedia dan ingin dimiliki. Kajian ini telah berusaha mendokumentasi kualiti hidup ketiga-tiga kanak-kanak autistik tersebut, walaupun sukar untuk membuat satu kesimpulan umum mengenai kualiti hidup mereka berdasarkan dapatan kajian kualitatif ini.

ABSTRACT

Quality of Life of Disabled Children with Autism

People with disabilities can and have contributed towards personal growth and community development. Therefore, the need to document and evaluate their quality of life is equally important. The objective of this study is to explore the quality of life of children with autism. The study is based on seven domains, which are material well being, health, productivity, intimacy, safety, place in community and emotional well being. Three participants from a non-governmental organization were chosen and the study was undertaken with a qualitative approach. Findings show that the place in community domain is most critical (fail to achieve) for them due to the inability to acquire social skills and the perception of the community of these children's disabilities. Two of them are dependant on a close friend from the same centre for intimacy, compared to family members. Although there is a need for upgrading in the use of technology, this non-governmental organization helps the children in the productivity domain. Limited freedom for them affects the emotional well being domain. The health domain is not critical for these children. Even though they have mild health problems and other disabilities, with their family's care they are able to maintain their health. Their safety is also not critical except for certain situations (such as crowded places) cause anxiety. Knowledge of the above helps family members to manage these children better. The material well being domain is dependant on the socio-economic status of the family and the satisfaction of this domain differs in each child based on what they own and they want. Based on the qualitative findings, it is difficult to make a general conclusion of their quality of life. However, the study has made an attempt to document the quality of life of these children.