Abstract

Background

Intellectual disability (ID) manifests in functional difficulties in three main domains: conceptual, practical, and social. The definition currently accepted by experts and opinion leaders in this field, in Israel and around the world, describes ID as a dynamic phenomenon that can change during an individual’s lifespan depending on personal and environmental factors. This dynamism and the complex medical conditions that usually characterize adults with ID require repeated evaluations and the provision of therapeutic support accordingly.

However, multiple factors can impede collecting reliable information regarding these changes: complex morbidity, multiple disabilities, communication impairments, challenging behaviors, premature aging, and multiple medications that may mask the underlying condition. Additionally, the lack of appropriate assessment tools, professional therapists, and sufficient funding sources make it difficult and sometimes impossible to provide an adequate therapeutic response to the needs of this population.

A possible solution to streamlining the therapeutic process lies in the development of a functional screening tool adapted for use by the caregivers who are in direct, daily contact with service recipients.

Aim:

Building an efficient, valid and reliable screening tool for detecting changes in the functional status of adults with ID by their direct caregivers, and testing its clinical applicability in mapping functional and environmental changes over time.

Research Tools

The ABAS-II questionnaire for adults is the "gold standard" in this field. The Hebrew version was found to be valid and reliable and was adopted by the diagnostic committee of the Israel Ministry of Social Affairs, combined with other accepted tools in the field. It served as an basis for building a new survey tool, the FST-ID (Functional Screening Tool for Adults with Intellectual Disabilities). This tool contains 17 items representing the three domains of conceptual, practical, and social functioning, plus two additional items: use of assistive devices and environmental changes. There is also an option to add comments. Responses are given on a five-point Likert scale ranging from 0 to 4. The overall functional score, the General Adaptive Composite (GAC), ranges between 0 = complete functional limitation and 68 = no functional limitation.

The new tool underwent a strict content validation procedure and reliability tests from the beginning to the end of the research. It was developed in an online format, so that it can be filled out conveniently via an internet link to the direct caregivers’ mobile phone or personal computer.

Sample

The sample included 37 direct caregivers and eight members of a multi-professional healthcare team who treat 88 service recipients aged 21 and over, with mild, moderate, and severe/profound levels of ID. The service recipients receive treatment at three day-care centers operated by the Amichai Association in Hod Hasharon, Israel. In addition, seven experienced content evaluators participated in the validation process for this study.

The Study

The research was carried out in two main phases: construction and validation (September 2019 - September 2020) and clinical use (September 2020 - June 2022).

In the construction and validation phase, the ABAS-II questionnaire was completed by the direct caregivers for each of the 88 service recipients. Concurrently, weekly focus groups were held with the participation of the direct caregivers and the members of the multi-professional healthcare team, for the purpose of constructing the new tool.

The draft version was submitted to the seven content experts for review. It was corrected according to their comments and adapted for use on the mobile phones of the direct caregivers and service providers, who retested and approved it. Following validity and reliability tests for this version, a new screening tool with high psychometric values ​​was obtained. It allows direct caregivers and service providers to identify the current level of functional disability of service recipients, with an accuracy of over 90%.

Based on this tool, an attempt was made to develop another tool for the purpose of quarterly evaluation of changes. However, unsatisfactory psychometric values ​​were obtained for this tool because the short-term participation of the direct caregivers (ranging from a few weeks to several months) did not allow for evaluation of changes over time. Therefore, only the first tool, the report on current functional state, was used in the second phase of the study

In the second, clinical, phase of the study, the new tool was used for the purpose of mapping functional and environmental changes during and after the Covid-19 pandemic at four points in time: Beginning (September 2020), Middle (August 2021), End (February 2022), and After (June 2022). During this time, caregivers for 76 of the 88 service recipients in the original sample took part. Additionally, in-depth interviews were conducted with the multi-professional team and direct caregivers for a sample of 20 of the service recipients, to explore the source of the changes in the functional scores and the environmental changes found during those four points of time.

The Articles

A first article was written as an introduction to the current research. It presents the various difficulties faced by the professional entities in providing quality care and making healthcare services accessible to this population, especially those with severe/profound levels of ID. The conclusion was that there is a need to build a new functional screening tool for that population.

The second article describes the procedure for developing the tool and the rigorous validation and reliability tests that were carried out to obtain a reliable tool, accessible online for use by the direct service providers and therapists.

The third article describes the clinical use of the new tool during 18 months of the Covid-19 pandemic (September 2020 - February 2022). It presents findings similar to those described in studies conducted around the world: a functional decline in the condition of the service recipients with mild and moderate levels of ID. It also describes surprising findings regarding the functional improvement in the group with severe/profound ID. This contributes research-based evidence to the claim that functionality can be improved at any age and at any level of disability, given the appropriate supports.

The fourth article summarizes the entire research period (September 2019 – June 2022), and describes the "watershed" in February 2022, when there was a gradual return to normalcy and reversal of the trends in functionality among the three groups. This article also presents the economic advantages of the new tool in improving efficiency in the future allocation of resources.

Contribution and Innovation of the Research

The present study developed an inexpensive, valid, reliable, and accessible survey tool for use by direct caregivers for adults with ID. This tool enables the detection of changes in the functional status of the service recipients, and thus improves the accessibility of healthcare services to this population. Additionally, this study offers evidence regarding the dynamics of ID, the influence of environmental factors, and degree of support for individuals with ID. It shows how these factors, taken together, affect the person’s functioning and degree of participation in daily life. This is in accordance with the multidimensional model currently accepted by opinion leaders in Israel: the Director of Disabilities in the Ministry of Welfare and Social Security, and internationally: the World Health Organization, the American Association for Developmental Mental Disabilities and Developmental Disabilities, and the American Psychiatric Association.

To the best of our knowledge, such a tool has not been previously developed in Israel or anywhere else in the world. The clinical effectiveness of the tool was proven during the Covid-19 pandemic. During the study, changes were mapped and functional differences were identified between people with various levels of ID as well as between those in the different settings. Moreover, the new tool will be able to help provide more effective future monitoring of all the personal and environmental factors that affect the functioning of adults with intellectual disabilities.