

Name of the study: A New Functional Screening Tool for Adults with Intellectual Disabilities (FST-ID): Its Construction, Validation and Use

Year: 2023

Type of research: DoctorateCatalog Number: 890-277-2020

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Abstract

This research was conducted with the support of the Shalem Fund for the Development of Services for People with Intellectual Disabilities in the Israeli Regional Councils.

Background

Intellectual disability (ID) manifests in functional difficulties in three main domains: conceptual, practical, and social. The definition currently accepted by experts and leaders in this field in Israel – the Director of Disabilities in the Ministry of Welfare and Social Security and internationally, such as the American Association for Developmental Mental Disabilities and Developmental Disabilities, and the American Psychiatric Association, describes ID as a dynamic phenomenon that can change during an individual's life, depending on personal and environmental factors. This fluidity and the complex medical conditions that usually characterize adults with ID require repeated evaluations and appropriate changes in therapeutic support.

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

A possible solution to improving the therapeutic process lies in developing a functional screening tool adapted for use by the direct service providers who are in direct, daily contact with those 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 service providers and testing its clinical applicability in mapping functional and environmental changes over time.



Research Tools

The ABAS-II questionnaire for adults as the "gold standard" (Barhak, 2013). 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 a 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, in accordance with the multidimensional model: 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 from 0 = complete functional limitation to 68 = no functional limitation.

The new tool underwent a strict content validation procedure and reliability tests throughout the course 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 service providers' mobile phone.

Sample

The sample included 37 direct service providers and eight members of a multi-professional healthcare team who treated 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 non - profit Organization 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 service providers for each of the 88 service recipients. Concurrently, weekly focus groups were held with the participation of the direct service providers 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 service providers and the multi-professional healthcare team, who retested and approved it. Following validity and reliability tests for this version, a new screening tool with high psychometric values was constructed. It allows the direct service providers to identify the current level of functional disability of service recipients, with an accuracy of approximately 90% (Ben David et al., 2022b). 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, direct service providers for 76 of the 88 service recipients in the original sample participated. Additionally, in-depth interviews were conducted with the multi-professional team and direct service providers 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.

During this phase, (Ben David et al., 2022a) summarizes the entire research period (September 2019–June 2022), and describes the turning point in February 2022, when there was a gradual return to normalcy and reversal of the trends in functionality among the three groups. As the centers reopened and all the groups returned to receiving the full array of therapy, the service recipients with mild and moderate levels of ID returned nearly to their pre-pandemic levels of functioning, while those with severe or profound ID stopped improving and even declined once they were no longer the preponderance of the services. This article also presents the economic advantages of the new tool in reducing existing costs spent on expensive diagnostic procedures, allowing for better distribution of healthcare services for this population, and improving efficiency in the future allocation of resources (Ben David et al., 2022a; Ben David et al., in press).

Contribution and Innovation of the Research

The present study developed a valid, reliable, and accessible survey tool for use by direct service providers of adults with ID. This tool enables the detection of changes in the functional status of the service recipients and thereby 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 the degree of support for individuals with ID. It shows how these factors, taken together, affect the individual's functioning and degree of participation in daily life. The current findings are also consistent with the approach of the WHO multidimensional model, accepted by leaders in the field in Israel and abroad, suggesting that individuals with ID at all functional levels may improve or deteriorate in their functional abilities according to environmental changes.

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 three daycare centers. 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.



Keywords

Adults with intellectual disabilities, Functional and environmental changes, Screening tool, COVID-19

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