

Support Needs in Intellectual Disability

Subjects: Psychology, Developmental | Public, Environmental & Occupational Health

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“Support needs” is a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning.

Keywords: support needs ; assessment ; disability ; quality of life

1. Introduction

The concept of “support needs” refers to the pattern and intensity of supports that are necessary for a person when it comes to participating in typical activities^[1]. Understanding individuals based on their need for supports is the main premise of the support paradigm. By assuming this paradigm, organizations become the coordinators of support that people with disabilities and their families need, and which are often related to access to inclusive education, supported employment, or independent living, among other rights^{[1][2][3][4][5][6][7]}. To the extent that the supports provided are aligned with the person's needs and their objectives and desires, the person's functioning in their environment will improve.

An individual's support needs are used as the bases of developing individualized support plans, and aggregate data on the support needs of many individuals aim to improve organizational efficiency and resource allocation^{[8][9][10][11][12]}. The support needs assessment serves to design individualized and generic support systems that enhance the quality of life for individuals with disabilities and their families, when maintained over time. Thus, the assessment of support needs is part of best practices in intellectual and developmental disabilities^{[13][14][15][16][17][18]}.

2. The Current Challenges

The challenge is to find a support needs assessment measure that captures all the influential variables in the planning of individual interventions, and which also contributes to resource allocation^{[19][20]}. In fact, in one of the first publications on support needs assessment, Thompson et al. (2002) recognized that this is a “slippery construct” that requires specific procedures to systematically identify support needs in different activities in different contexts^[21].

Over time, support needs have been assessed by using different methodologies, including clinical judgment, functional competency measures, estimation of educational and health needs, and standardized tools^{[14][19][21][22]}. First, clinical judgment relies on expert opinion about the level of an individual's support needs, usually considering different intensities (e.g., low, medium, and high). Second, scales of adaptive behavior and functional competency (e.g., daily living activities) have informed support needs by assuming that an individual's decreased skills relate to increased support needs. Third, support needs have been understood as health care needs, in terms of “complex health needs,” “complex support needs,” or as educational support needs^{[23][24][25]}. Their assessment considers the presence of different disabilities and focuses on specific areas (health, education). Finally, standardized scales have been developed to assess support needs. However, their validation has been hampered by the lack of criterion variables to contrast the measurements.

Although there is no agreement among researchers on the best support needs tool, it seems that a standardized and objective measure, as opposed to other forms of psychological assessment, could be a useful facilitator for planning teams within support provider systems^{[21][26][27][28]}. Such an assessment should be responsive to changes over time, capture the medical, behavioral, and day-to-day needs of the person's life in multiple settings, and serve the purposes of planning and resource allocation. The assessment should be integrated into a holistic support planification and implementation process that considers the person's goals and embraces the person's self-determination to decide on activities relevant to him or her^{[4][5][6]}.

In order to provide this measure, the American Association on Intellectual and Developmental Disabilities (AAIDD) elaborated the Supports Intensity Scale (SIS). The SIS^[28] aims to facilitate the implementation of the support model in service delivery organizations. It is intended to provide a standardized measure of the intensity of support that a person with an intellectual or developmental disability requires in order to perform daily activities.

The SIS has been translated and adapted to more than 16 countries, becoming a reference tool for measuring support needs. However, it has not been free of criticism^{[19][29]}. The debate mainly focused on the adequacy or otherwise of estimating support needs through a standardized set of activities that may not be part of a person's life. In addition, its application procedures have been discussed, as well as the validation of its measurement model and its generalization among groups of individuals. Recent research also identified a ceiling effect on the scale and warns about the difficulty of its use in people with greater support needs^{[31][32][33]}.

3. Future Research

The extensive literature suggests that some variables are closely related to support needs: age, type of disability, additional needs, and levels of intellectual disability and adaptive behavior. However, very few studies analyzed support needs profiles considering different support domains and specific characteristics. On the contrary, the studies aggregate data on the support needs. Further research is required to add to the description of the profiles of people with disabilities involved in assessing their support needs—especially, aspects related to the environment in which they live, and the accessibility of community service.

Although support needs profiles are individualized, more comprehensive profile descriptions could guide research on particular support strategies. In this regard, very few studies have been published on the effectiveness of different interventions or support strategies. These studies should relate support needs to desired personal outcomes (e.g., quality of life) or organizational effectiveness and efficiency.

In relation to scales of assessment, forthcoming research is needed on the measurement of support needs of people with greater levels of intellectual disability, as well as on the generalization of support needs to different conditions.

4. Conclusion

The assessment of support needs has focused mostly on the adult population with developmental disabilities, although its application extends to children and other conditions. Most research has focused on the development and validation of assessment scales, with few studies investigating the effectiveness of using support needs to achieve desired personal outcomes and improve organizational effectiveness and efficiency. There is a need for future research to examine support needs in people with higher levels of need and further analyze the methodological quality of the scales used in the support needs assessment.

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