



Evaluating Support Worker Ratings of Support Needs for Individuals with Intellectual Disabilities

Joseph Miller, Julia Harries, & Neil Kirby
Disabilities Research Unit
School of Psychology
University of Adelaide
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Disability Models

- The move to the use of support needs measures has, in part, been driven by a change in the way disability is conceptualised.
- Previously, disability was viewed as a characteristic of the person, with assessment focusing on the identification of skill deficits (e.g. Adaptive Behaviour scales).
- Current conceptualisations view the experience of disability not as a fixed state of the individual but as a dynamic interaction between the individual and the context in which the person lives.

Disability Models & Assessment

- This conceptualisation of disability underlies the WHO's International Classification of Functioning, Disability, and Health (ICF) and the American Association on Intellectual and Developmental Disabilities (AAIDD) intellectual disability classification system.
- These systems challenge traditional assessment approaches by considering not only an individual's functional limitations, but also factors external to the individual that may contribute to the disadvantage being experienced (i.e. factors acting as barriers to independence).
- These systems also encourage consideration of the supports and / or services needed to address both these internal and external factors to facilitate independent functioning.

Uses of Support Needs

Assessments

- In recent years a number of support needs measures have been developed, both within Australia and overseas, to address this assessment challenge.
- These measures are increasingly being used to:
 - Guide the development of individual support plans
 - Inform decisions at the service provider and funding body levels (e.g. allocation of funding resources, management of waiting lists, service planning, monitoring outcomes).
- The use of support needs measures to guide such important decisions underscores the need to understand the support needs construct and ensure its accurate assessment.

What are Supports and Support Needs?

- Supports are the resources and strategies that provide the bridge between “*what is*” (i.e. a mismatch between personal competency and environmental demands) and “*what can be*” (a life with meaningful activities and personal positive outcomes).
- Support needs refer to the “*pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning*”

(Thompson et al., 2009, p. 136)



Support Needs Assessment

- The Disabilities Research Unit (DRU) at the University of Adelaide, in collaboration with the SA Department for Families and Communities (DFC), has recently developed an assessment instrument to measure the pattern and intensity of supports required by an individual with a disability.
- The overall aim has been to develop a support needs assessment system to provide a basis for a transparent and equitable distribution of support services to people having different types, levels and combinations of disabilities.
- The instrument is called the Disability - Support, Training and Resource Tool (D-START).

D-START Features

- Designed to assess the support needs of people with different types, levels and combinations of disabilities.
- The underlying structure is compatible with the ICF framework to ensure comprehensive coverage of life domains.
- Features an hierarchical model using short and long assessments for different purposes (e.g. short forms to assess levels of funding, long forms for Individual Support Plans).
- Incorporates qualitative as well as quantitative assessments of support needs to enable unique needs to be identified.
- Includes contextual assessment (i.e. assessment of environmental and personal risk factors).

D-START Features

- Identifies changing or fluctuating needs (for funding or planning implications associated with changing needs).
- Incorporates a functional abilities scale to refine support need estimates and control for “gaming”.
- Assessor Training Program to maximise accuracy and effective use of D-START.
- Computerised format for:
 - Assessment efficiency (i.e. assessor only sees relevant areas for assessment);
 - Enhanced data management for agencies and funding bodies (e.g. management of waiting lists, or identification of unmet needs);
 - Report generation (for individuals or groups);

D-START Structure

- D-START is a multidimensional instrument assessing:
 - *Medical/Health Supports* (e.g. for medication administration, treatments, seizures).
 - *Supports for Activities of Daily Living* (e.g. for daily tasks such as dressing, eating, bathing; Community and Household tasks such as shopping, housework, community travel; Recreation and leisure activities; Day/Night supervision).
 - *Behavioural Supports* (i.e. the nature and intensity of supports required for problem behaviours).
 - *Functional Skills* (communication skills, motor skills, interpersonal interactions, social/emotional skills, and general tasks and demands).
 - *Personal Risk Factors* (i.e. Personal characteristics that could place the person or others at risk such as Personal vulnerability; Household safety; Community safety; Cultural background; Legal issues or orders; Life stage transitions etc).
 - *Environmental Factors* (i.e. External factors impacting on the person's independence, participation &/or well-being such as Products & technology; Attitudes; Supports & relationships; Services, systems & policies etc).



Evaluating D-START: Reliability

- D-START reliability has been established:
 - Test-retest reliabilities for subscales and total score range from .80 to .98
 - Inter-rater reliabilities for subscales and total score range from .56 to .98
- These test – retest and inter-rater reliabilities are comparable with, and in some cases exceed, other widely used support needs assessments and adaptive behaviour scales.



Evaluating D-START: Validity

- Validity for D-START is supported by high correlations with other instruments used to determine support needs, including the Inventory for Agency and Client Planning (ICAP: Bruininks et al., 1986) and the Estimate of Requirement for Staff Support Instrument (ERSSI).
- Validity is also supported by the capacity of D-START to discriminate between sub-groups in expected ways (e.g. across severity of impairment, single vs. multiple disabilities).



Validation using Expert Opinion

- The Support Need construct is an emerging construct, consequently measures of support needs are relatively few for the purposes of establishing construct validity (unlike the numerous adaptive behaviour scales).
- Thus, “expert opinion” has also been used as a form of validation for support needs measures (Guscia et al., 2006; Thompson et al. 2002).
- The present study was concerned with the use of expert opinion as part of a validation of D-START. Expert opinion was provided by Support Workers for individuals with intellectual disabilities living at residential facilities in SA.

Study Aims

This study aimed to examine:

- The relationship between estimates provided by Support Workers and actual scores obtained on D-START (to further assess the criterion validity of D-START);
- The extent to which support worker estimates were altered by the experience of completing a D-START;
- The extent to which support worker ratings of overall need considered the individual holistically, including contextual factors, or were based on more limited salient characteristics (e.g. activities of daily living).

Study Participants

- Three residential facility support workers provided support need estimates and served as informants for the D-START, for 46 adults (23 females, 23 males) with intellectual disabilities.
- Thirty participants (65%) had co-existing disabilities, including autism (1), physical disability (12), neurological / epilepsy (6), vision (1), speech (3), and psychiatric (5).

| | Range | Mean |
|--|-------------------|------------|
| Age | 31 to 78 years | 51.6 years |
| Length of time participants known to Support Workers | 1 to 20 years | 8.8 years |
| Number of support hours received | 10-168 hours/week | 92.4 hours |

Study Method

1. *Pre D-START Estimates:* Support Workers initially provided estimates of the level of support needed by participants using a nine point Likert scale (1= total support &/or intense supervision to 9= infrequent or no assistance needed).

Estimates were obtained for the overall level of support required and for each D-START domain (i.e. medical, ADLs, behaviour, personal risks, and environmental barriers).

2. *D-START Completion:* Support Workers were then interviewed to complete the D-START for each participant.
3. *Post D-START Estimates:* Support Workers again provided an overall estimate of support needs and for each D-START domain using the same Likert scale.

Results: Relationship between support estimates and actual D-START scores.

- *Pre D-START estimates* correlated significantly with the respective D-START actual domain scores and overall support total score, except for the environmental barriers domain. These findings generally support the validity of D-START.
- *All post D-START estimates* correlated significantly with the respective D-START actual scores, including supports required to address environmental barriers.
- There was a tendency for greater accuracy following the completion of a D-START assessment, particularly for Medical/Health supports and Environmental Factors.

Results: Relationships between support estimates and actual D-START scores.

| D-START Support Domains | Pre D-START Estimates | Post D-START Estimates |
|-------------------------------------|-----------------------|------------------------|
| Medical/Health Supports | -.29* | -.42** |
| Activities of Daily Living Supports | -.69** | -.76** |
| Behaviour Supports | -.59** | -.63** |
| Personal Risk Factors | -.55** | -.50** |
| Environmental Factors | .09 | -.38** |
| Overall Support Level | -.68** | -.68** |

* $p < .05$, ** $p < .01$

Results: Correlations between Pre D-START estimates of overall level of need and D-START actual domain scores.

| D-START Support Domains | Pre D-START Overall Need Estimate |
|-------------------------------------|-----------------------------------|
| Medical/Health Supports | -.45** |
| Activities of Daily Living Supports | -.65** |
| Behaviour Supports | -.23* |
| Personal Risk Factors | -.46** |
| Environmental Factors | .08 |

* $p < .05$, ** $p < .01$

Pre D-START estimates of an overall level of support need correlated most highly with actual scores for D-START domains assessing salient aspects of the person (i.e. supports needed for activities of daily living) and less well with external factors (i.e. environmental barriers).

Other study findings

- Estimates of the levels of support provided by Support Workers did not increase or decrease significantly after completing the D-START.
- There was no association between accuracy of support estimates and participant age, gender or length of acquaintance with participants.
- Support Workers who were “*very confident*” about their support need estimates tended to be more accurate than when they were merely “*confident*” about their estimates.

Summary of major findings

- Using D-START as a measure of support needs, Support Workers made relatively accurate estimates of overall level of need, as well as support needed for activities of daily living, behavioural supports, and personal risks.
- Support Workers were less accurate at estimating the supports needed to address medical/health issues and environmental issues.
- Levels of support need estimates provided by Support Workers did not change significantly after completing the D-START.

Summary of major findings

Continued:

- Support Workers became more accurate at judging support needs relating to environmental issues and to some extent medical/health issues after they had completed a D-START.
- Support Worker estimates of need were most closely associated with salient characteristics of the person (i.e. support required for activities of daily living). This finding is consistent with Weiss et al. (2009) who found the strongest predictor of Clinician ranked level of need was the Home Living subscale of the Supports Intensity Scale (SIS).

Implications for the design and use of support needs assessments.

- Accurate assessment of support needs outside of familiar areas like activities of daily living, such as the effects of the environment and medical issues, requires specifically formulated items for these areas of support.
- The increased accuracy of estimates of overall environmental and, to some extent, medical support needs as a result of completing the D-START suggest that Support Supervisors may become more aware of these aspects of support as a result of completing D-START assessments.
- Expert opinion as a means of validating support needs assessments should include all domains and not just overall support as not all domains are predicted equally well.

References

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