Social support for people with an intellectual disability: an universal-design adaptation of a self-report measure.

Cindy Diacquenod

PhD project outline (10.2013)

1. Purpose

The present project proposes to adapt the Arizona Social Support Interview Schedule (ASSIS, Barrera, 1981) in a form which will be more accessible for people with an intellectual disability (ID). This adaptation will be based on the principles of the « universal-design »¹ (United Nations, 2006). Moreover, this project aims at assessing the psychometrics properties of the ASSIS’s adapted version in order to estimate its pertinence and validity for people with an ID.

The ASSIS instrument seems very interesting because it captures multiple dimensions of the social support (types, source, quality, and quantity of support; needs for support; support satisfaction). In addition, it enables to identify supportive relationships that could be considered as sources of conflict by the person. Moreover, it is a self-report instrument of social support and an ASSIS’s valid french is available.

This study promotes principles of accessibility, integration and social participation. Furthermore, it is compatible with the recent emphasis on the importance to dispose self-measures expressed by persons with an ID (Guerdan, Petitpierre, Moulin, & Haelewyck, 2009). It is also in line with the empowerment and self-determination perspectives, which aim at placing persons with an ID in the most active position to participate in decisions and projects that concern them (Beart, Hardy, & Buchan, 2004 ; Wehmeyer, 2012).

2. Research question

The present project proposes to create an universal-design version of the Arizona Social Support Interview Schedule (ASSIS, Barrera, 1981) and check benefits of this adapted version for people with an ID.

Accessibility of each version (standard vs. universal-design) and their advantages for people with an ID, specially according to their verbal and visual memory capacities, will be assessed² (cf. setting p. 5). Finally, psychometrics properties of the ASSIS’s adaptation will be measured. This procedure will allow estimating the validity and pertinence of an universal-design version of ASSIS for people with an ID.

¹ Universal design is a strategy which aims at offering an accessibility (physic, sensory, cognitive) in spaces, products, technolgies and services of information and communication (Ginnerup, 2009).

² This assessment will allow to judge the pertinence of the suggested adaptations in light of people with an ID’s verbal and visual memory capacities.
3. Links to the thematic focus of PROWEL

This project aims at studying different dimensions of people with an ID’s social support. To date, no consensus exists to define this concept (López & Cooper, 2011). However, researchers agree to say that it is a multidimensional concept which generally refers to 3 subdimensions: 1) social network; 2) received social support; and 3) perceived social support (= social support’s availability and satisfaction) (Beauregard & Dumont, 1996; López & Cooper, 2011). These dimensions of social support are important to consider because they influence the personal wellbeing (Chen & Hugh Feeley, 2013) and quality of life (García, Banegas, Pérez-Regadera, Cabrera, & Rodríguez- Artalejo, 2005).

4. Theoretical frame

Throughout recent years, along with the evolution of the philosophy of normalization, the community-based movement, social movements to promote social participation of people with ID and the contemporary emphasis on quality of life, the « support paradigm » has been gaining prominence in the field of intellectual disability (Thompson et al., 2002). It is currently established that an adequate support contributes to improve the functioning of persons with ID (Luckasson et al., 1992, 2002; Schalock et al., 2010). Moreover, the evaluation of the person with an ID is based not only on his/her strengths and weaknesses, but also on the quantity of support that he/she needs to function in his/her daily environment (Thompson et al., 2004).

There are different forms of social support (eg: social, physical, environmental). Social support is usually defined through the different resources of support and aid (eg: tangible aid, emotional support, cognitive support, etc.) accessible to the person by his/her environment. This type of support is an important variable to consider in the ID’s field because it contributes to improve the functioning (Thompson et al., 2002), and to increase the social participation (Fougeyrollas, Cloutier, Bergeron, Côté, & St-Michel, 1998), as well as to enhance the wellbeing and the quality of life of people with an ID (Lippold & Burns, 2009; Lunsky & Benson, 2001a).

An assessment is necessary, for instance, to identify needs of support (quantity and type) and the social network’s size, as well as to assess the adequacy of the social support. It seems important to include perspectives of individuals with an ID themselves in this procedure, as they are the best placed to describe their expectations, their conditions of life and their received support (Schalock et al., 2002). Moreover, differences may exist between persons with an ID’s opinion and that of their family’s members or supportive personnel (Claes et al., 2012). Finally, people with a mild ID can be reliable to report about their own social support (Lunsky & Benson, 1997).

Investigated literature shows only few researches based on self-reported social support’s measures by persons with an ID. This lack of self-report measures can be explained by methodological difficulties met by persons with an ID in this type of assessment. Indeed, studies show for instance that persons with an ID have by definition language and cognitive impairments, particularly in comprehension, memory and expression (Edgin, Pennington, & Mervis, 2010; Finlay & Lyons, 2001). Moreover, few existing instruments to assess social
support could be administrated directly to person with an ID. Finally, the risk of bias (acquiescence, social desirability) during the interviews raises the question of validity of the collected information (Finlay & Lyons, 2002). These difficulties can be circumvented with an adapted methodology (Guillemette & Boisvert, 2003; Marshall & Willoughby-Booth, 2007).

Heterogeneity of cognitive, language and adaptative skills of persons with ID have to be emphasized (Julien-Gauthier, Jourdan-Ionescu, & Héroux, 2009). Performances of people involved need to be understood in a three-dimensional perspective that combines the subject (eg: cognitive abilities, functioning, expertise), the task (inherent complexity, internal informational sources and support) and the environment (external informational sources and support) (Newell, 1986). During a task or an action, some environmental factors can as much be barriers as they can be facilitators by supporting the subject’s activities of elaboration. Any context and any task offer affordances, defined as properties which can facilitate the ability to apprehend the perceptual and cognitive data, as well as the subject’s levels of comprehension (Gibson, 1977).

Persons with an ID can take advantages of accessible tasks. The principle of «universal-design» (also known as « universal conception » or « universal accessibility ») may be applied to a self-report instrument of social support in order to make procedures more accessible for a population with an ID. Universal conception is a strategy that aims at providing a maximal accessibility (physical, sensorial, cognitive) in spaces, products, technologies and services of information and communication (Ginnerup, 2009). Recent studies show that "cognitive ramps" may be proposed in order to facilitate people with an ID to be successful in problem solving (Center for Applied Special Technology, 2011).

This present project proposes to adapt the Arizona Social Support Interview Schedule in a form based on universal conception’s principles. The ASSIS is an instrument developed by Barrera (1981) to assess social network, needs of social support, and social support perception (available support, received support, satisfaction towards social support) in different dimensions (material aid, physical assistance, intimate interaction, guidance, feedback and social participation).

A panel of accommodations will be offered to optimize persons with an ID's participation in the procedure of the ASSIS and help them to overcome existing barriers or obstacles of the standard version. Adaptations will concern ASSIS’s format and procedure. For example, adaptations to guide and maximize attention abilities, to enhance sensitivity to perceptual cues, to help to handle, memorize and recall information, and finally to formulate the answer will be considered. Moreover, some methodological precautions will be taken in order to optimize the validity of data.
5. Methodological approach

Participants

Participants with an ID (n=100-130)

Inclusion criteria:

- Reside in a supported living for adults with an ID;
- Age between 20 and 60 years;
- French main language;
- Resistance to suggestibility (Cummins, 1997, assessment acquiescence scale translated);
- Adequate communication skills:
  - Understand the consent form;
  - Reach a score above (to define) on the Indice of Verbal Comprehension (WAIS IV, Wechsler, 2008);
- Capacity to use a Likert scale (Cummins, 1997, adapted procedure).

Measures

- WAIS IV (Wechsler, 2008)
  - Indice of Verbal Comprehension (IVC): Subtests Similarities, Vocabulary and Information;
  - Indice of Working Memory (IWM): Subtests Memory of chiffers and Arithmetic;

Additional informant group’s inclusion criteria (n=10-15):

- Family’s member or staff educational’s member cited by the participant with an ID
- Know the person with an ID since at least 3 months.

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3 Some participants (n=20-30) will be consulted to guide us to adapt the ASSIS. Other participants (n=80-100) will form the experimental sample.
4 Supported living for adults with mental retardation refers to a house or apartment in the community with staff support for daily living tasks as required. Thus, staff do not live in the house, and their role is that of facilitator (Lunsky & Benson, 2001b, p.80).
4 Participants must be able to paraphrase the consent form’s content.
5 A family’s member or staff educational’s member could be present during the interview in order to help the person with an ID.
Experimental protocol

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<tr>
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<th>ASSIS's Standard condition(^a)</th>
<th>ASSIS's Universal-design condition(^b)</th>
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<tbody>
<tr>
<td>1(^{st}) time</td>
<td>$G_1$ ($=G_1'$ &amp; $G_1''$)</td>
<td>$G_2$ ($=G_2'$ &amp; $G_2''$)</td>
</tr>
<tr>
<td>2(^{nd}) time</td>
<td>$G_1''$ ($=\text{test-retest}$)</td>
<td>$G_2'$ ($=\text{test-retest}$)</td>
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\(^a\)Standard condition: Participants use the standard dispositive. Interviewer reads each question. He/she answers every participant's request of precision. Respondants rely only on interviewer's help (\(=\) external help).

\(^b\)Universal-design condition: Participants use the adapted dispositive. In this condition, respondents benefit from the interviewer's aid and adaptations of the ASSIS (visual supports, simplified language, training to use a Likert's scale, etc.).

The equivalence of groups ($G_1'$, $G_1''$, $G_2'$ and $G_2''$) will be researched, by systematic variation with matching criterion on the verbal memory span (IWM, WAIS IV).

Participants of $G_1''$ and $G_2''$ will be placed in the two conditions (standard et universal-design conditions), according to a counterbalanced order, with a two weeks gap between the two versions. Participants of $G_1'$ and $G_2'$ will be placed twice in the same condition (respectively standard and universal-design condition) in order to assess and compare the test-retest fidelity of the two versions. An accessibility's questionnary will be proposed to participants of $G_1''$ and $G_2''$ (two weeks after the 2\(^{nd}\) time) and to additional informant group's in order to complete informations about the accessibility of each version and their advantages for people with an ID.

Method of data's analysis

- Descriptive statistics of scores "needs external help "\(^{*}\) between standard and adapted conditions (\("\text{=Number of interviewer's interventions to help participant during the procedure [eg: repeat the question, answer to a vocabulary question, remember the proposed responses, etc.}]\));
  - Comparison $G_1$ et $G_2$ at the 1\(^{st}\) time ;
  - Comparison $G_1''$ et $G_2''$ between the two conditions;
  - Interindividual comparison between the two conditions.

- Descriptive analysis of qualitative observations raised during the two conditions (eg: duration of the passation; type(s) of aid(s); comprehension and contradictory responses etc.);
- Descriptive analysis of subjectives measures on accessibility of versions (responses to the accessibility's questionnary).
References


