

## Research Paper

# Development and psychometric properties of a scale assessing the needs of caregivers of children with disabilities

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**Abstract**

**Background:** Planning and evaluation of health care services for children with disabilities requires information on their caregivers' needs.

**Objective:** This paper aims to present the development and psychometric properties of the Caregiver Needs Scale (CNS), a scale assessing the needs of caregivers of children with disabilities aged 0–12 years in Malaysia.

**Methods:** Development of the scale went through a multistage process of literature review, modification of an existing instrument, input from experts and feedback from service users. Literature review identified content domains and response options. An exploratory factor analysis (EFA) was undertaken to identify subscales of caregiver needs. The internal consistency reliability, convergent validity and discriminant validity of the new scale were examined.

**Results:** 273 caregivers of children with disabilities completed the fielded questionnaire. EFA revealed 4 subscales of caregiver needs: need for 'Help getting information and services for the child,' 'Help coping with the child,' 'Help getting child care' and 'Help with finances.' Three items with factor loading <0.4 were dropped. Cronbach's alpha coefficients of the subscales ranged from 0.813 to 0.903. Total CNS score correlated with number of child's needs and unmet needs. The score was also higher in families with financial and employment problems.

**Conclusion:** A new instrument was developed to assess the needs of caregivers of children with disabilities for use in the Malaysian population. The CNS showed satisfactory psychometric properties but further examination is warranted to confirm its validity. © 2015 Elsevier Inc. All rights reserved.

**Keywords:** Children with disabilities; Caregivers; Needs assessment; Instrument development; Psychometric properties

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The World Disability Report 2011 recommends improving disability data collection as one of the efforts to overcome barriers that restrict participation for people with disabilities.<sup>1</sup> Knowledge of the demand, supply and existing efficiency of disability services is important to inform decisions on allocation of scarce resources in service systems. According to the Behavioural Model of Health Services Use, people's use of health services is a function of their predisposing characteristics, enabling resources and their need for care.<sup>2</sup> Hence, studying health care needs gives important information on the demand for health services which would impact on their utilization.

In Malaysia, the Persons with Disabilities (PWD) Act 2008 defines persons with disabilities as those who have

long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society.<sup>3</sup> This definition mirrors the one adopted by the Convention on the Rights of Persons with Disabilities.<sup>4</sup> The Ministry of Health, Ministry of Education and Department of Social Welfare under the Ministry of Women, Family and Community Development are the main stakeholders of service provision for children with disabilities in the country.

Disability in a child not only affects the child but also impacts on the child's family.<sup>5–9</sup> Prior to 1990, services for children with disabilities mainly targeted the medical and therapeutic needs of the child with the aim of improving child functioning, and it was only in later years that the focus of services expanded to include the needs of families living with a child with disability.<sup>10</sup> By understanding the circumstances of families caring for a child with disability, service providers can identify areas for improvement in the delivery of disability services.

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The Family Needs Survey (FNS) developed by Bailey and Simeonsson and modified versions of it have been widely used to measure family needs.<sup>11–15</sup> In Malaysia, to date, there is only one published study on the family needs of children with disabilities. Locally, Suriati et al used the original version of the Family Needs Survey to investigate the unmet needs among caregivers of children with disabilities recruited from community based rehabilitation centers in Selangor, a state in central Malaysia.<sup>16</sup> The FNS translated to the Malay language was found to have good internal consistency reliability with Cronbach's alpha coefficient of 0.91 overall, and ranging from 0.74 to 0.88 for the respective subscales.

However, reliability analysis for internal consistency is insufficient to test whether a scale has good psychometric properties. One of the reasons is because Cronbach's alpha coefficient is sensitive to the number of items in the scale, and inter-item correlation may be increased by simply adding the number of items within each subscale.<sup>17</sup> Even though the FNS has shown good internal consistency reliability in the Malaysian population, other psychometric properties of the FNS such as construct validity and factor analysis have not been examined.

One of the criticisms directed at survey instruments is that some yield assessment results that capture a lot of detail but do not provide practical implications for intervention.<sup>15</sup> Our objective was to study the service needs of caregivers of children with disabilities aged 0–12 years in Penang, a state in Northern Malaysia. In order to meet this objective, we wanted an instrument which could capture information on caregiver needs which were of direct interest to service providers. At the same time, the instrument had to be simple and brief.

This paper describes the development process and psychometric properties of a scale to assess the needs of caregivers of children with disabilities, hereafter referred to as the Caregiver Needs Scale (CNS).

## Methods

### *Instrument development*

Development of our Caregiver Needs Scale went through the multistage process of (i) literature review to identify content domains, (ii) modification of the original FNS, (iii) getting input from experts, and (iv) obtaining feedback from service users through a pre-test.

A literature review was conducted to find measurement operationalizations or instruments assessing the needs of families or caregivers of children with disabilities. The objective was to determine item content and response options for use in our scale. Because there was a paradigm shift in the way disability services were provided in the 90s from child focused to family focused, we decided to search only articles after 1990. Also, because the needs of families caring for a child with disability are fairly universal and are independent

of the child's diagnosis,<sup>18</sup> we did not search for studies which were disease or condition specific.

Articles were searched from Medline and Cinahl for articles from 1990 to 2012, using the following search terms: "Children with Disabilities," "Children with Special Needs," "Unmet Needs" and "Needs Assessment." We took into account study populations of children with disabilities (regardless of the type of disability), children with special health care needs, and children with chronic health conditions to include more instruments.

Articles were also searched by manually searching references from original articles. We also searched for methodological reports of country disability surveys that were available online. Only articles in the English language, studies which involved assessment of family or caregiver needs, and studies which described how they operationalized the measurement of these needs adequately were included for examination.

Examination of these articles and reports revealed that family needs could be summarized into support, information, finances, child care and professional services domains.

Because the Family Needs Survey and modified versions of it was most widely used to measure family needs, we chose to model our instrument based on the FNS. The original FNS has 35 items categorized into 5 domains and a revision of the FNS<sup>19</sup> resulted in the items being re-categorized into 7 domains.

Our Caregiver Needs Scale retained the domains of 'need for information,' 'need for social support,' 'need for community services' and 'need for financial support' from the original FNS. The 'need for help with family functioning' and 'need for help explaining to others' domains were not included in the new scale because we considered these subscales to be of less direct relevance to service providers in the context of Malaysian culture. In Asian societies, families tend to keep family problems within the family unit and there may be minimal expectation for formal support services to help out with these aspects.

The proportion of both mothers and fathers who needed 'help explaining to others' was comparatively lower than other constructs in the Japanese version of the FNS.<sup>14</sup> Besides that, 'need for help with family functioning' was found to be the least important service need in a Dutch study among parents of children with motor or multiple disabilities.<sup>12</sup>

Items in each subscale were generated by selecting and modifying items from the FNS and also from other instruments. In the end, a total of 20 items were generated for the CNS (Table 1).

Response options in other studies came in the form of dichotomous yes/no answers or in the form of Likert categorical scales. In the FNS, respondents were asked to select one of three responses for each item: 1 = definitely do not need help with this, 2 = not sure, 3 = definitely need help with this, and the total number of reported needs was obtained by summing the number of items rated 3. Table 2

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