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Psychometric validation of the Family Outcomes Survey-Revised in Japan

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ABSTRACT

According to a revision of Japan's Basic Law for Persons with Disabilities in 2011, Article 17 stipulated the government's obligation to provide early intervention to children with disabilities. However, the concept of family outcomes in early intervention has not really been considered in Japan yet. This article describes the development and validation of the Japanese version of the Family Outcomes Survey Revised (FOS-R). Our goal was to determine whether this survey for assessing how families of children with disabilities are affected by early intervention would be appropriate for use in early intervention in Japan. Both the Japanese version of the FOS-R and an anonymous, self-administered questionnaire about background factors were given to 394 mothers of children who were either currently using or had in the past year used early intervention at an early intervention facility or medical institution. Survey responses were obtained from 335 mothers (response rate of 85.0%). The total number of subjects in the analysis was 301 mothers who answered the Japanese version of the FOS-R completely. To assess content validity, another survey was given to 115 experts involved in supporting children with disabilities and their families. The family outcomes indicator items as well as the helpfulness indicators items showed good psychometric properties. Although the components of the FOS-R worked better as individual subscales than as a single scale, we confirmed that a total score was also psychometrically valid. We also confirmed both content validity and external validity. The Japanese version of the FOS-R appears to be a valid tool for assessing the benefits experienced by families as a result of services received, but further research is needed to determine the nature of practices most likely to lead to positive family outcomes.

1. Introduction

To maintain and improve the quality of life for children with disabilities, it is important to provide appropriate services for their families (Samuel, Rillotta, & Brown, 2012; Sloper, Greco, Beecham, & Webb, 2006). A Japanese version of the Family Needs Survey (FNS-J), which aims to better understand the needs of families of children with disabilities, has been previously evaluated and shown to be reliable and valid for use in Japan (Ueda et al., 2013). The purpose of this article is to determine

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how to assess whether families understand what support includes, whether families actually benefit from the support, and what further actions should be taken given individual family needs.

In the United States, the Individuals with Disabilities Education Act calls for the implementation of efforts to assess and continue monitoring outcomes of families of children with disabilities. Family outcomes are defined as benefits experienced by families as a result of receiving a service. Family outcomes are different from satisfaction. Satisfaction is important for assessing the quality of a service, but it is not suitable for investigating whether a service brings about an outcome that is beneficial for families. Family outcomes are the result of receiving a service or support (Bailey et al., 2006; Epley, Summers, & Turnbull, 2011).

The U.S. Office of Special Education Programs (OSEP) established the Early Childhood Outcomes (ECO) Center to help guide the development and implementation of assessment tools for child and family outcomes for infants, toddlers, and preschool children with disabilities. A major ECO Center activity involved identifying five broad outcomes that could serve as a framework to assess the efficacy of family support (Bailey et al., 2006):

(a) Families understand their child's strengths, abilities, and special needs.
(b) Families know their rights and advocate effectively for their children.
(c) Families help their child develop and learn.
(d) Families have support systems.
(e) Families access desired services, programs, and activities in their community.

These outcomes form the basis for state and federal governments to determine whether families clearly benefit from early intervention or preschool programs. To assess these outcomes, ECO Center investigators developed the Family Outcomes Survey (FOS) for use in the United States, drawing on literature reviews, several stakeholders' review and feedback, and psychometric analysis (Bailey et al., 2006). After practice-based revisions, the Family Outcomes Survey-Revised (FOS-R) became available (Bailey et al., 2011). A recent paper demonstrated that the FOS-R was valid for use in Singapore (Poon, Ooi, Bull, & Bailey, 2014). The present article extends this work by testing its psychometric properties in Japan.

Japan has established "early intervention (the law expresses Medical Treatment and Education)" in its laws, partially revising the Basic Act for Persons with Disabilities in August 2011 to accommodate early intervention. The provision of early intervention is expected to be increasingly widespread; however, measuring the effects of early intervention has received less attention. In fact, there is some debate as to whether the effects of early intervention should really be measured and whether a uniform approach to assessment is possible, given the fact that early intervention is provided in accordance with individual needs and the extent of disability. The projected spread of early intervention and the resulting increase in the number of institutions and organizations that provide early intervention will warrant the use of certain assessment functions not currently in place.

This article describes the development and validation of the Japanese version of the FOS-R (the FOS-J). Our goal was to determine whether this survey for assessing how families of children with disabilities are affected by early intervention would be appropriate for use in early intervention and preschool programs in Japan.

2. Methods

2.1. Instruments: Creating the FOS-J

With authorization from the senior author of the FOS-R (Bailey), a person skilled in both English and Japanese translated the scale into Japanese, and another person skilled in both English and Japanese back-translated the survey into English. Dr. Bailey was asked for his opinion on the back-translation. He then returned a back-translation that better reflected the correct meaning, which provided a basis for minor edits to the translation, resulting in a draft of the FOS-J. Early intervention experts in Japan evaluated the FOS-J to determine whether it was appropriate for the social and cultural background of families of children with disabilities. The FOS-J was also evaluated for plain language to determine whether study participants would find the survey easy to read. The edited FOS-J draft was tested with 10 families who had children with disabilities, after which the survey was finalized. The FOS-J consists of two sections. Section 1 contains the family outcomes items that ask families about what they learned from the intervention and what actions they have taken after receiving early intervention. Section 2, the helpfulness indicators items, asks families how helpful they felt early intervention was. The score on the FOS-J is calculated using rating scales similar to those used in the FOS-R. Section1 uses the scale: 1 = not at all, 2 = a little, 3 = somewhat, 4 = almost, and 5 = completely. Section 2 uses the scale: 1 = not at all helpful, 2 = a little helpful, 3 = somewhat helpful, 4 = very helpful, and 5 = extremely helpful.

2.2. Subjects and procedures

Both the FOS-J and an anonymous, self-administered questionnaire about background factors were given to 394 mothers of children who were either currently using or had in the past year used early intervention at an early intervention facility or medical institution. Informed consent was obtained prior to distributing questionnaires. Survey responses were obtained