



Development and validation of a questionnaire to measure the service needs of families with children with developmental disabilities

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ABSTRACT

The aim of this project was to develop and validate a Service Needs Questionnaire (SNQ) on the service needs of families with children with developmental disabilities. The SNQ and a measure of parenting stress were administered to 105 parents of children diagnosed with learning/behaviour problems and 233 parents of children attending primary schools. Initial Rasch analysis results indicated inadequate distinction of the categories and the fit statistics of three items were outside the acceptable range. The categories were collapsed and the removal of two misfitting items resulted in a scale which conformed to the Rasch expectations. For validity, the scale correlated positively with parenting stress, and it could differentiate between parents of children diagnosed with learning/behaviour problems and those attending primary schools. The internal consistency estimate (the Cronbach α) was above .70. The SNQ could be used to help identify the needs of families with children with developmental disabilities.

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1. Introduction

The Salamanca Statement (UNESCO, 1994) asserts that every child “must be given the opportunity to achieve and maintain an acceptable level of learning” (p. viii). In Hong Kong, the Education Bureau (2007) encourages “students with diverse learning needs to receive appropriate education alongside their peers so as to help them develop their potentials”. Mainstream schools are encouraged to make flexible use of existing resources, and to adopt a whole-school approach to cater for students’ diverse learning needs effectively. To adequately meet the needs of children with developmental disabilities in mainstream schools and their families, it is important to understand the service needs from their perspectives.

Some studies employed qualitative methods and interviewed parents on their experiences and perceptions. For example, Swicks and Hooks (2005) interviewed five parents whose children were placed in inclusive early childhood education settings in the United States. The parents were keen to be involved in their children’s education and to provide opportunities for their children to achieve their potential. Kenny and McGilloway (2007) interviewed 32 parents of children with learning disability in Dublin to examine parents’ coping. They found that availability of support services was important for parents’ coping. In a qualitative study on parents of children with developmental disability in mainland China, five categories of needs were identified (Wong et al., 2004). Wong, Pearson, Ip, and Lo (1999) conducted focus groups and individual interviews with Hong Kong parents with children with developmental disabilities and found that though the parents endorsed inclusive

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education, they experienced various obstacles in reality. However, few of these authors made use of the qualitative data to develop questionnaires suitable for large scale surveys or quantitative studies.

In studies using questionnaires to survey the parents' opinions about the services they needed for their children with developmental disabilities, results were often presented in terms of percentages of services indicated or mean number of services needed. For example, in an American study on children with emotional disturbance (Marcenko, Keller, & Delaney, 2001), caregivers were presented a list with 41 services and resources and they were asked to indicate the services and resources they needed. Mean number of services indicated and percentages were calculated. The most needed services were services focused on children, especially recreational activities, counselling/support services for children and parent training. Another American study on children with special health care needs asked the respondents to indicate whether their children needed a given service and whether they actually received the service. Access problems such as problems in getting a referral, problems in finding a suitable provider, problems in getting enough visits to the provider and financial problems involved were surveyed. Results were mainly reported in terms of percentages. It was found that the most needed services were specialty doctors, speech therapy, occupational therapy and physical therapy (Warfield & Gulley, 2006). In another study on children with intellectual disability in Netherlands, use of service was assessed by 62 yes–no items covering 10 domains such as medical and paramedical help, help with development and education and family support and the like. It was found that families with younger children used more formal services than those with older children (Haveman, van Berkum, Reijnders, & Heller, 1997). In a study on participants in early intervention programmes in the United States, parents were requested to rate the responsiveness of services to their needs on a 6-point scale (Mahoney & Filer, 1996). It was found that parents were more concerned about the developmental well-being of their children than other family concerns. The average age of the children was 20.7 months. In all four cases, there was no information on the psychometric properties of the service needs rating scales/questionnaires used.

Other studies requested case workers to rate the service needs of children with special education needs. In a study on children with emotional problems in rural communities in the United States (Jensen, Turner, Amero, Johnson, & Werrbach, 2002), clinical and executive directors of a case management agency were asked to rate the service needs of children retrospectively on a 4-point scale (extreme, high, medium and low). It was found that the ratings were related to number of psychiatric bed days, medical reimbursement and monthly case management hours. Another American study on children with severe emotional disturbance requested the primary case workers to indicate the most needed services for these children. The most needed service for school age children were school and home-based service, as well as respite care (Trupin, Forsyth-Stephens, & Low, 1991). In both cases, there was little information on the psychometric properties of the rating scales used.

Hendricks, De Moor, Oud, and Franken (2000) in Netherlands focused on types of services and they employed more rigorous psychometric techniques in the development of their questionnaire. In their study, parents of children with toddlers attending treatment classes were presented a questionnaire with 33 items on service needs. Factor analysis revealed five subscales (information, support, help in explaining child's condition to others, respite care and family functioning), with the reliabilities of all subscales above .70 for mothers. Though the psychometric properties of this scale were satisfactory, it was developed for toddlers and might not be suitable for children with developmental disabilities in mainstream primary or secondary schools.

In Hong Kong, there is no valid local instrument for measuring the needs of children with developmental disabilities and their parents. Existing surveys dealt with their service satisfaction (Chan, Lau, Fong, Poon, & Lam, 2005; Yam, Chow, Lau, & Yu, 2005) but not their service needs. Wong (2002) used a structured questionnaire to examine the needs of parents with children with developmental disabilities in mainstream schools in Hong Kong but no information on the psychometric properties of the scale was reported. It was found that academic work was a great burden to children and parents.

The above review of literature points out some gaps in the attempt to map out the service needs of children with developmental disabilities in mainstream schools. First, some studies only adopted a qualitative approach and few of the authors made use of the qualitative information to develop questionnaires suitable for large scale survey or quantitative study. Second, in the existing service needs survey questionnaires, the researchers provided a list of services or needs for the respondents to address. The list is more likely to represent the perspective of the researchers. However, these might not capture or represent the actual needs and perspectives of the respondents. Third, information on the psychometric properties of questionnaires on service needs is lacking. Fourth, the questionnaires may not deal with children with developmental disabilities in mainstream schools. With the inclusive education approach, it is important to understand the needs of this particular group of children and their families so they can reap the most benefit from their education.

The aim of the present study was to develop and validate a questionnaire to survey the service needs of parents with children with developmental disabilities studying in mainstream schools. Two types of developmental disabilities, learning problems and behaviour problems, were targeted, because they were not "visible disabilities", and their difficulties might be overlooked or misunderstood.

There were two stages in the development. Stage one employed a qualitative design involving the use of focus groups. Qualitative methods such as focus groups or individual interviews are useful in understanding the parents' experiences and perceptions from their own perspectives (Pope & Mays, 1995; Kitlinger, 1995). Four focus groups were conducted with 33 Chinese parents of children with learning and/or behaviour problems. These parents were receiving services at Child Assessment Service (CAS), Department of Health, which provides comprehensive assessment, rehabilitation prescriptions and management services to children and families (Department of Health Child Assessment Service, 2007). Based on the

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