



ORIGINAL ARTICLE

Early Intervention in Children (0–6 Years) with a Rare Developmental Disability: The Occupational Therapy Role



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Received 19 May 2014; received in revised form 28 November 2014; accepted 5 December 2014

Available online 3 March 2015

KEYWORDS

early intervention;
occupational therapy;
rare developmental
disabilities

Summary *Objective/Background:* This study aims to explore the occupational therapists' role in early intervention for children diagnosed with a rare developmental disability.

Methods: A survey was distributed by mail or online, to eligible occupational therapists currently used by the Disability and Community Care Services throughout Queensland, Australia. Eligible occupational therapists were those working with children aged 0–6 years. Two in-depth phone interviews were also undertaken.

Results: Eleven participants who had previously worked with at least one child with a rare developmental disability returned the survey. One participant nominated for a follow-up interview and a second interview with a speech and language pathologist was conducted to gain a multidisciplinary perspective. The most common areas requiring intervention were play support (85.3%), activities of daily living, communication, gross motor, and fine motor skills (79.4%).

Conclusion: Family-centred practice, play therapy, and individually tailored programmes are identified as key practice areas for this population. The important role occupational therapists play in early intervention teams is highlighted; however, further research is needed to develop the evidence base for best practice with particular rare developmental conditions.

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Conflicts of interest: One of the authors (SL) involved in developing and distributing the survey is employed by the Disability and Community Care Services, Queensland, Australia.

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<http://dx.doi.org/10.1016/j.hkjot.2014.12.001>

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Introduction

Although the general health status of Australian children has improved over the past 20–30 years, measures of developmental health and well-being indicate that some children are developmentally vulnerable (Australian Medical Association, 2010). The vulnerability of at risk groups, such as children born into poverty, indigenous children, and those with disabilities, highlights the need to ensure research continues to investigate ways, such as early intervention, to ameliorate risks to positive developmental outcomes. This study investigates the role of occupational therapy in early intervention of children with rare developmental disabilities.

A developmental disability is defined by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 as, “A severe, chronic disability originated at birth or during childhood”, which “...is expected to continue indefinitely, and substantially restricts the individuals functioning in several major life activities” (p. 7; Section 102). Developmental disability is attributable to a mental and/or physical impairment stemming from a number of physical or congenital causes and can affect language and speech development, social–emotional development physical, and cognitive development.

The term developmental disability is used to refer to numerous conditions; some of the more prevalent ones include autism, cerebral palsy, behavioural disorders, and Down syndrome (The Developmental Disabilities Assistance and Bill of Rights Act of 2000). The less prevalent, or “rare”, developmental disabilities include Angelman and Rett syndromes.

There is limited consensus regarding the prevalence of developmental disabilities in children generally; however, various studies have estimated the prevalence to range to between 3.34% and 5% (Blanchard, Gurka, & Blackman, 2006; Kirby, Brewster, Canino, & Pavin, 1995). In the United States, when behavioural and learning disabilities are included in statistics, developmental disability becomes more common than other chronic childhood conditions (excluding asthma or allergic rhinitis; Barbouth & Brosco, 2002).

Within Australia, information available from the 2003 census data indicates that 4% of children from birth to 4 years have a disability, with the majority of these children having severe limitation in activities of daily living (ADLs) including self-care, mobility, communication, and schooling (Australian Bureau of Statistics, 2003). Previous research has tended to focus on the conditions that are more prevalent, such as autism, and there is limited evidence around the prevalence and effect of the more rare developmental disabilities (Kirby et al., 1995).

Early intervention through occupational therapy has been found to be beneficial in supporting children with developmental disabilities (Johnson & Ethridge, 1989). The premise of early intervention is that services or intervention targeted early in life can support skill development and minimise the impact of disability on development (Case-Smith, 2013). Occupational therapists have been acknowledged as leaders in promoting and providing early intervention services to infants and young children with a disability across a range of settings (Case-Smith, 2013).

Although there is evidence to guide the treatment of common developmental disabilities, there is little available evidence to inform the practice of occupational therapists working with children with rare developmental disabilities. This study proposed to address this lack of information by exploring the occupational therapists’ role in early intervention for children who have a rare developmental disability in Australia. Findings of this study will contribute to the evidence base for service provision to this client group and support the leadership role that many occupational therapists take in provide early intervention services.

Methods

The study used a cross-sectional, mixed method approach, utilising both survey research and interviews for data collection. As an exploratory study looking to collect information from therapists working with a particular population, a cross-sectional survey research design was chosen as the primary methodology as it is an efficient way of collecting a snapshot of data over a large geographic area from respondents who are thought to be the best source of accurate information about the topic under investigation (Schofield & Knauss, 2010). This type of design provides a structured collection of data which can be analysed to provide description and comparison. Follow-up interviews were used to confirm and explore, in more depth, issues identified in the survey data (Hammel & Carpenter, 2004).

Participant selection

Australian paediatric occupational therapists working with children between the ages of birth and 6 years with a rare developmental disability were the target population for this study. A convenience sample was selected from all paediatric occupational therapists working in the state of Queensland, Australia, for the Department of Communities Disability Services (DACCS). The Family and Early Childhood Service (FECS) team within DACCS work with children from birth to 6 years and are the primary service for children with disabilities, including children with rare developmental disabilities, in Queensland. FECS teams are multi-disciplinary and family centred. They are also the main employer of occupational therapists providing early intervention services to children with developmental disabilities in Queensland. DACCS has service centres based in metropolitan and rural areas throughout Queensland, providing service coverage to most of the state. Twenty-eight occupational therapists who worked for the FECS teams across Queensland were invited to participate. Ethics approval was obtained from the James Cook University Human Ethics Research Committee, Townsville, Queensland, Australia (H3363) and approval to conduct research in the DACCS was received (COM 08729-2009).

Survey development and administration

Owing to the broad geographic spread of potential participants, a survey was deemed the most efficient and economical way of collecting exploratory data. The combination of

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