Research in Developmental Disabilities 74 (2018) 1–13

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

Review article

Access to dental services for children with intellectual and developmental disabilities – A scoping review

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ARTICLE INFO

Number of reviews completed is 2

Keywords:
Children
IDD
Intellectual and developmental disabilities
Dental services
Access

ABSTRACT

Background: Children with Intellectual and Developmental Disabilities (IDD) face considerable challenges in participating in dental services. These challenges include resource constraints and inadequate skills of health service providers to work with this population.
Aim: The aim was to scope published studies that addressed access to dental services for children with IDD in order to determine the extent to which various barriers have been researched, using an access framework derived from the literature. Access was defined to include the six dimensions of accessibility, availability, affordability, accommodation, acceptability, and appropriateness.
Method: Arksey and O'Malley's scoping review framework was used. Relevant databases (e.g., Medline) were searched for all empirical studies conducted from January 2000 to February 2017 that met inclusion criteria. Data were extracted along the six dimensions of the access framework.
Results: Sixteen international studies were identified which indicated common key barriers to dental service use: the difficulties of physical inaccessibility, lack of access to information among carers, lack of knowledge of disability issues, and low experience and skills in caring for children with IDD among dental practitioners.
Conclusions: Key recommendations made were exploring dental practitioners' understanding of disability legislation and developing training for practitioners to expand on issues specific to IDD.

What this paper adds?

This paper, to our knowledge, is a first review of published empirical research data on access to dental services for children with IDD in the last 17 years. Authors of international studies from 11 countries (US, Australia, The Netherlands, Canada, France, Poland, Jordan, Kuwait, Saudi Arabia, Brazil, India) identified physical inaccessibility, lack of access to information, insufficient insurance cover among carers, and dental practitioner lack of knowledge of disability issues, and little experience and skills in providing services to children with IDD as key obstacles. These issues aligned with the conceptual access framework and were themed according to the dimensions of Accessibility, Availability, Affordability, Accommodation, Acceptability, and Appropriate. The review highlighted the practice, policy, and research gaps in the dental service system and support structure, calling attention to the contextual social and environmental influences that must be addressed to ensure full participation of children with IDD in dental health service

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https://doi.org/10.1016/j.ridd.2017.12.022
Received 20 October 2017; Received in revised form 29 November 2017; Accepted 30 December 2017
Available online 30 January 2018
0891-4222/

utilisation and reducing oral health disparity.

1. Introduction

Children with Intellectual and Developmental Disabilities (IDD) face considerable challenges in participating in dental services despite high burden of oral disease. In comparison to children without disability, children with IDD have been found to be at a higher risk of dental caries (tooth decay) and periodontal (gum) diseases (Davis, 2009; Desai, Messer, & Calache, 2001; Fisher, 2012; Purohit, Acharya, & Bhat, 2010). A number of factors contribute to this risk, and these are further exacerbated by challenges in participating in dental health services (Ahmad, Razak, & Borromeo, 2015; Davis, 2009; Fisher, 2012; Lehl, 2013; Raposa, 2009; Waldman & Perlman, 2002; World Health Organization and World Bank, 2011). The focus of this paper was access barriers that contribute to the oral health inequalities experienced by children with IDD.

There are a number of factors that increase risk of common oral diseases. Poor oral hygiene has been associated with neuromuscular problems (Davis, 2009; Desai et al., 2001; Fisher, 2012), which increases risk of dental disease for children with some forms of IDD. In addition, there is evidence that children with IDD are often prescribed medications that can be high in sugar or reduce saliva flow, which in turn increases their susceptibility to dental caries and periodontal conditions (De Camargo & Antunes, 2008; Desai et al., 2001; Fisher, 2012). Reduced clearance of food from the mouth, and frequent consumption of sugar further contributes to their poor oral health (De Camargo & Antunes, 2008; Desai et al., 2001; Purohit et al., 2010).

Despite these oral health issues, access to dental services among children with IDD has been reportedly poor in international literature. Davis (2009), based on a 2004 United States (US) survey of children with special care needs (which included IDD), reported that approximately 75% did not access dental services in any given year. Desai et al. (2001), who investigated dental treatments of children with IDD (as well as other disabilities) in Australia found that despite 41% requiring a simple treatment, their dental needs were unmet. In Brazil, De Camargo and Antunes (2008) found that children with cerebral palsy had a higher burden of untreated dental caries compared to other children. Low participation in dental services appears to arise because of various factors, including physical (e.g., poor transportation), economic (e.g., limited coverage of services under the public dental care resulting in out of pocket expenses by carers), and behavioural (e.g., difficulty in children cooperating during dental appointments), as well as a shortage of general dental practitioners willing to provide service to people with IDD (Ahmad et al., 2015; Davis, 2009; Fisher, 2012; Lehl, 2013; Newacheck et al., 2009; Raposa, 2009; Waldman & Perlman, 2002; World Health Organization and World Bank, 2011).

These access issues exist despite international policies relating to service inclusion of people with disabilities. More than 40 nations adopted disability discrimination legislation during the 1990s (Quinn et al., 2002 in World Health Organization and World Bank, 2011), such as 1990 Americans with Disabilities Act in the United States (US), the Disability Discrimination Act of 1995 in the United Kingdom (UK), and the Persons with Disabilities Act 1995 (India) (World Health Organization and World Bank, 2011). Further, the United Nations Convention on the Rights of People with Disabilities, which has been widely ratified, provides a human rights driver for equal access to health services, including oral health World Health Organization and World Bank (2011). Guidelines reflecting inclusive policies have also been developed internationally to guide dental practitioners to facilitate equitable access to people with disability. Examples can be found in the UK (British Society for Disability and Oral Health, 2000; Childhood Disability Research, 2013; The Faculty of Dental Surgery The Royal College of Surgeons of England, 2012) and US (Council on Clinical Affairs, 2012, 2015; The National Institute of Dental and Craniofacial Research, 2014a, 2014b).

Specific to Australia, the Commonwealth Disability Discrimination Act 1992 (DDA 1992) states that people with disabilities have the same right to access mainstream services as others in the community. The mainstream health sector has an ongoing obligation to address structures and systems that create access barriers. This obligation includes providing reasonable accommodations to meet the needs of people with disabilities (Australian Government Federal Register of Legislation, 2016). As the DDA 1992 specifies *any* services that are provided by any profession or those by the government, it legally obligates Australian dental services (Australian Government Federal Register of Legislation, 2016). In line with the inclusive legislation, the Australian Dental Association has also developed a dental policy to inform good practice for patients with IDD: (a) *Policy Statement 2.3.6–Delivery of Oral Health: Special groups: Individuals with Disabilities* (Australian Dental Association, 2016).

1.1. Operationalising access to dental services

As shown in Table 1, access to dental services has been largely conceptualised using six dimensions over the last few decades (Alborz, McNally, & Glendinning, 2005; Dougall & Fiske, 2008; Gulliford et al., 2002; Owens, Dyer, & Mistry, 2010; Owens, Mistry, & Dyer, 2011; Penchansky & Thomas, 1981). Dougall and Fiske (2008) described access as a dimension of *physical accessibility* that includes accessibility to the dental clinic and chair by the patient, and to the mouth of the person with disability by the dental practitioner. Gulliford et al. (2002), Owens et al. (2010), and Penchansky and Thomas (1981), on the other hand, considered access to be more complex, requiring consideration beyond the dimension of physical accessibility. The dimensions recommended also were to include *Availability, Accommodations, Affordability, and Acceptability* (Table 1). Gulliford et al. (2002) suggested that access comprises (a) having access to services (i.e., whether services are available and in adequate supply), and (b) gaining access to services (i.e., service user's entry into the healthcare system), which is influenced by financial, organizational, and social factors. In considering specific factors of access to quality services for people with intellectual disability,[1] Owens et al. (2011) modified the framework to

[1] The term used by the authors was *learning disability*, reflecting common usage in the UK.