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# **Support Needs of ASD Families in the Manawatu DHB Catchment Area**

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## **Abstract**

Autistic Spectrum Disorder (ASD) is becoming increasingly understood as being both widely heterogeneous and complex for the individual on the spectrum (Baranek, 2002; Dunlap & Fox, 1999; Fox, Dunlap, & Cushing, 2002; Fox, Dunlap, & Philbrick, 1997; Gardiner & Iarocci, 2012; Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014; Ministries of Health and Education, 2008; Oono, Honey, & McConachie, 2013). Similarly, families are also highly variable and complex; they are arguably the most important support unit a child with ASD has, with their own resources, constraints, values and beliefs (Dunlap & Fox, 1999; Fox et al., 2002; Gardiner & Iarocci, 2012; Moes & Frea, 2002). Service individualisation, which accounts for such variances within the individual, and the collective, is broadly seen as critical for service delivery success (Baranek, 2002; Billstedt, Gillberg, & Gillberg, 2011; Dunlap & Fox, 1999; Fava et al., 2012; Fox et al., 2002; Fox et al., 1997; Ministries of Health and Education, 2008; Odom, Hume, Boyd, & Stabel, 2012).

To date, little research has gauged the extent of ASD service individualisation abroad, and an understanding of how this is done in Aotearoa New Zealand is absent. The intent of this research was to investigate whether or not existing services and supports target the uniqueness of both the individual with ASD, and their families to enable them to participate in society. In particular, a key focus was if services are appropriate, accessible and sufficient.

To accomplish the intent of the research a concurrent triangulation mixed-methods design was utilised. Both quantitative and qualitative data was gathered from caregivers of autistic children – firstly, through an online survey featuring several lifespan themes, and subsequently, qualitative data was collected through caregiver interviews carried out with participants recruited from the MidCentral and Nelson Marlborough District Health Board (DHB) areas.

Analyses of the prioritised qualitative data indicated that a variety of service delivery factors prevented families with autistic children from optimal functioning, and participating in society. Furthermore, systemic issues were theorised to be the underlying causes of several of the difficulties faced by autistic children, and their families. The importance of individualised care packages that meet the needs of the families spoken to was emphasised, and the 'wicked problem' (Stace, 2011) of services that are appropriate, accessible and adequate remains ongoing. Recommendations for meeting the needs of individuals with ASD and their families are discussed.

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