

Parenting children with additional needs

Key insights

- Parents of children with additional needs interact with their children in a very similar way to other parents.
- Parents of children with additional needs were more likely to be single, female and not in full-time paid employment than parents who did not have children with additional needs.
- Poor parent physical and mental health were associated with having a child with additional needs.
- Compared to other parents, parents whose child had psychological or behavioural difficulties were less likely to have confidence in their parenting.
- Family-centred support should take the needs of carers into consideration, particularly single parents, fathers and parents with low parenting confidence.

What is it like to parent a child with additional needs, and how do these parents seek help and information?

This Research Brief derives from the 2016 Parenting Today in Victoria Study conducted and analysed by the Parenting Research Centre, and funded by the Victorian Department of Education and Training.

Context

Parents and caregivers of children with additional needs such as disabilities and chronic health conditions are often required to adopt 'informal caregiving careers' that can span the child's lifetime, a responsibility exceeding that of typical parental care¹.

These parents are more likely to have poorer health and wellbeing than other parents², particularly if their children have behavioural challenges^{3,4}. Some aspects of socio-economic disadvantage, such as low employment and single parenthood, are also associated with having a child with additional needs^{5,6,7}.

If community-based and family-centred care for children with additional needs is to succeed, there needs to be attention given to how parents are supported and sustained in their caregiving role⁸.

The Parenting Today in Victoria Study aims to inform the decisions the Victorian Government makes in its support of Victorian parents. This Research Brief presents information on parents of children with additional needs. It looks at how they are faring, and explores their parenting behaviours and practices, including support and information-seeking.

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- 2 Dillon-Wallace, J.A., McDonagh, S.H., & Fordham, L.A. (2014). How stable is the well-being of Australian mothers who care for young children with special health care needs? *Journal of Child and Family Studies*, 23(7), 1215-1226.
- 3 Miodrag, N., Burke, M., Tanner-Smith, E., & Hodapp, R.M. (2015). Adverse health in parents of children with disabilities and chronic health conditions: a meta-analysis using the Parenting Stress Index's Health Sub-domain. *Journal of Intellectual Disability Research*, 59(3), 257-271.
- 4 Cousino, M.K., & Hazen, R.A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of Pediatric Psychology*, 38(8), 809-828.
- 5 Emerson, E., Hatton, C., Llewellyn, G., Blacker, J., & Graham, H. (2006). Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 50(12), 862-873.
- 6 Spencer, N. (2014). Impacts of caring for a child with chronic health problems on parental work status and security: a longitudinal cohort study. *Family Matters*, (95), 24.
- 7 Spencer, N., & Strazdins, L. (2015). Socioeconomic disadvantage and onset of childhood chronic disabling conditions: a cohort study. *Archives of Disease in Childhood*, 100(4), 317-322.
- 8 Orima Research (2013). Evaluation of the MyTime Peer Support Groups for Parents and Carers of Children with a Disability or Chronic Medical Condition. Report for Department of Families, Housing, Community, Services and Indigenous Affairs.

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Findings

What were the additional needs of children in our study?

All parents participating in the Parenting Today in Victoria survey were asked to provide information about parenting one child in their family – the focus child for the survey. Six hundred and fifty parents, that is about a quarter, said this child had a medical condition or learning difficulty lasting 6 months or more, and about a quarter of these children had more than one condition. Just over 70% of surveyed parents had more than one child, so it is possible some parents whose focus child did not have additional needs may have had other children with additional needs.

The greatest proportion of the 650 children with additional needs (61.8% of survey sample) were reported to have primarily physical conditions, 30.5% had developmental difficulties, 14.2% had a major disorder (e.g. autism spectrum disorder, Down syndrome, cerebral palsy), and 10.8% had primarily psychological or behavioural problems (Figure 1).

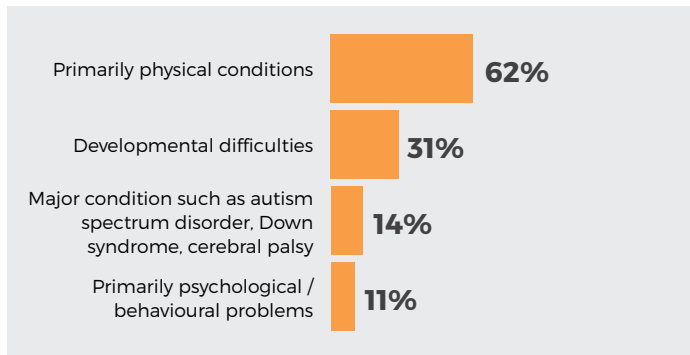


Figure 1. Categories of additional needs of the children in the Parenting Today in Victoria Study.

The most common concern was asthma (25.8%), followed by learning difficulties (22.5%), autism spectrum disorder (11.1%), anaphylaxis/allergies (9.1%) and behavioural problems (7.7%) (Figure 2). The children were more likely to be boys (58% compared to 42%) and they were older on average than children without additional needs.

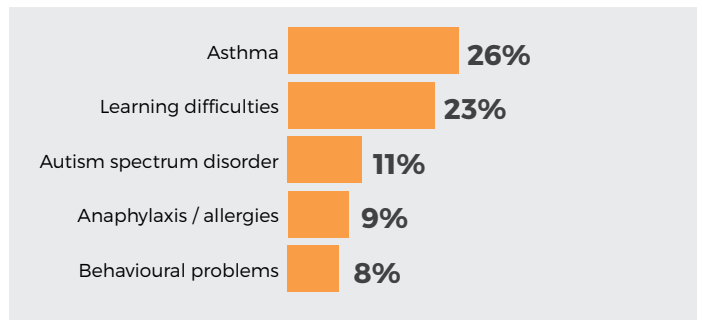


Figure 2. Top five additional needs of the children in the Parenting Today in Victoria Study.

How do parents of children with additional needs differ from other parents?

More survey respondents with children with additional needs were female (71% female compared to 57% of other surveyed parents).

They were also less likely than parents who did not have a child with special needs to:

- speak a language other than English at home (5% compared to 11%)
- be living with a partner (70% compared to 81%)
- be in full-time employment (34.3% compared to 46.6%)

How are parents of children with additional needs faring?

PHYSICAL HEALTH

More parents of children with additional needs reported their physical health as 'fair' or 'poor' (20%) compared with other parents (10%). Parents whose child had two or more conditions, who lived in a more disadvantaged neighbourhood^{9,10} and who were single were more likely to have poorer physical health.

MENTAL HEALTH

More parents of children with additional needs reported symptoms of depression or anxiety since becoming a parent (Figure 3).

9 Australian Bureau of Statistics [ABS]. (2006). Analysis of the Regional Distribution of Relative Disadvantaged Areas using 2001 SEIFA. Retrieved from [http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/3F98BA340A2BDF76CA25718D0017ACB5/\\$File/1351055013_jun%202006.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/3F98BA340A2BDF76CA25718D0017ACB5/$File/1351055013_jun%202006.pdf).
 10 ABS. (2016). 4125.0 Gender Indicators Australia. Retrieved from: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4125.0>.

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Parents of children with additional needs also had higher current psychological distress levels than other parents¹¹.

More of the parents of children with additional needs who reported past depression or anxiety were mothers, and single, and more of those reporting current psychological distress were single. In the study population as a whole, single parents reported having had symptoms of depression more so than parents with partners, and also had higher current psychological distress than partnered parents.

Parents of children with a major disorder or psychological difficulties, or both, had higher indications of psychological ill health. Around half of these parents had experienced depression and anxiety since becoming a parent, and they had higher levels of current psychological distress than other parents.

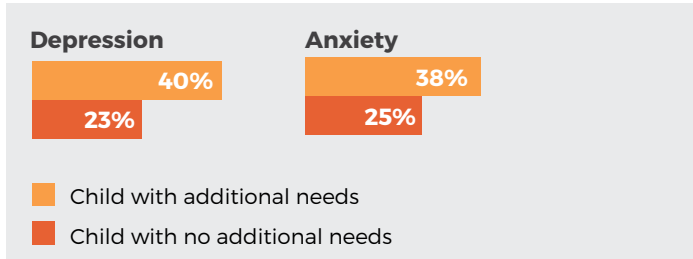


Figure 3. Proportions of parents with and without children with additional needs who have experienced symptoms of depression and anxiety since becoming a parent.

COPING AND SUPPORT

In many respects, parents of children with additional needs are the same as the other parents surveyed. Most parents of children with additional needs agreed they had someone to turn to for advice on problems. However nearly 10% said they didn't have, or were unsure whether they had, this support. Fathers were less likely to say they had someone to turn to than mothers. Partnered parents rated partner support positively; however, mothers reported less satisfaction with how parental duties were shared than fathers did. In addition, lower levels of support were reported by parents in areas of greater socio-economic disadvantage.

PARENTING CONFIDENCE

We used the Me as a Parent Scale¹² to understand how parents were feeling about themselves as parents. We asked parents about how confident they felt as parents, including questions about their perceptions of how effective they felt in overcoming problems, how well they set goals and monitored their progress, the extent to which they believed that change was due to their own efforts, and how self-reliant they felt in their parenting role. A high score indicates that parents felt more confident in their parenting role.

Parents of children with additional needs were just as likely as other parents to have confidence in themselves as parents. However, the subgroup of parents with a child with psychological or behavioural difficulties were less likely to have confidence in their parenting. They also felt less self-sufficient and had a lower sense of personal agency, indicating, for example, a greater feeling of helplessness about their child's behaviour.

For all parents in the study, including those with children with additional needs, lower confidence as a parent was associated with higher levels of current psychological distress and feeling a lack of support. Fathers also had a lower confidence in specific areas of parenting. For example, they felt less able to participate in decisions that affected their children or more uncertain about how to help their children do well in education. Parents who felt supported by their partners, and supported in general, were the ones who also felt more confident in their parenting roles.

What are parents' activities with their children and their perceptions about their parenting?

We asked parents about the activities they did with their children, including playing indoors and outdoors, music, singing and dancing and someone reading regularly to the child. There were no major differences between parents who had children with additional needs and other parents in their reports of activities with their children.

Similarly there were no major differences in how these parents viewed their parenting approach – such as being impatient, consistent, praising, critical or punitive (yelling

¹¹ Kessler, R., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S.-L. T., . . . Zaslavsky, A. M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine*, 32, 959-976.
¹² Hamilton, V. E., Matthews, J. M., & Crawford, S. B. (2015). Development and Preliminary Validation of a Parenting Self-Regulation Scale: "Me as a Parent". *Journal of Child and Family Studies*, 24, 2853-2864.

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and smacking). This was also the case for how satisfied parents were with the amount of time they spent with their children.

The parenting differences of mothers and fathers of children with additional needs reflected those of the sample as a whole. Mothers talked slightly more with their children with additional needs. Fathers had less positive perceptions about their parenting (i.e. more impatient, inconsistent, and critical, and less time spent with child) than mothers.

What are parents' help-seeking experiences?

PARENTING SUPPORT

We asked parents of children with additional needs about their use of eight sources of information and advice, and these parents were more likely to say they used health professionals, education staff and parenting groups (Figure 4). Similarly, parents of children with additional needs reported seeking help from an educator, general practitioner and mental health or behavioural specialist more than other parents. A high percentage of parents with and without children with additional needs sourced information online.

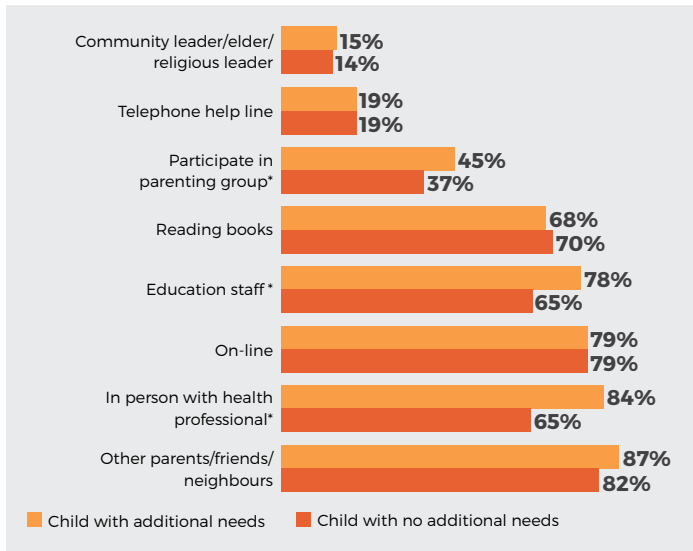


Figure 4. Differences in sources of information and advice used by parents with and without children with additional needs. * $p < .001$

Parents of children with additional needs felt generally positive about the help they were given. However, small though non-significant differences were found: parents of children with additional needs reported feeling less

satisfied with the interactions, and also feeling more judged and blamed, and less valued, by education professionals, compared to other parents.

PARENTING GROUPS

Parents with children with additional needs were more likely than other parents to attend a playgroup or 'other' parenting group. In our overall sample, mothers were more likely than fathers to say they attended a Maternal and Child Health first-time parents group and 'other' parent groups, and this was the same for parents of children with additional needs.

We asked parents the reasons they did not attend playgroups or parenting groups. There were no differences between parents with and without children with additional needs in reasons for non-participation.

We also asked parents to rate the importance of ten characteristics of parenting programs. Parents of children with additional needs were more likely than other parents to view information about the benefits of the program as important. In the study population as a whole, both mothers and fathers valued program characteristics such as 'facilitator understands me', 'location convenient', 'convenient time', 'I understand what's involved' and 'facilitator same gender'.

Implications for policy

The Victorian Department of Education and Training invests in a range of supports for parents and children, some of which are specifically for children with a disability or developmental delay and their families. This includes the Strengthening Parent Support Program for parents of children from birth to 18 years with a disability or developmental delay, enhanced transition to school supports, Kindergarten Inclusion Support Packages, the Program for Students with Disabilities and various support services within Victorian government schools.

Our study identified few differences between parents whose focus children had additional needs and the study population as a whole. Most parents reported doing well in coping, support and confidence, and in their physical and psychological health. However, the differences that we identified between parents with and without children with additional needs are important and have direct relevance to these government initiatives. In addition, the findings are

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pertinent to the rollout of the National Disability Insurance Scheme that allows for tailored and flexible support plans and recognises the right of individuals to be central to decision-making about their life¹³.

IMPLICATIONS FOR FAMILY-CENTRED SUPPORT

Family-centred approaches to service delivery recognise the importance of acknowledging the needs of all family members, not just those of the person with additional needs¹⁴. Family-centred practice emphasises the need for interventions and supports to consider parent and contextual factors as well as child factors. The survey findings underscore the need for this, particularly for family members in a caring role, single parents, fathers, and parents with lower confidence in themselves as parents.

Being a parent (especially a mother) of a child with additional needs is associated with greater risks to parent health and wellbeing. This means services for children's medical conditions and learning and behavioural difficulties should consider a parent's health and wellbeing and incorporate this into a family-centred approach to intervention.

The differences between subgroups of parents – irrespective of whether or not their children had additional needs – also have implications for family-centred support.

Being without a partner was associated with poorer physical and psychological health, therefore targeted support for this group of parents is justified. Mothers were more likely than fathers to be single parents.

A focus on fathers is also warranted. Fathers' responses revealed less perceived parenting confidence and support. They were less likely to say they had someone to turn to for advice on problems, or to attend parenting groups. They talked a bit less to their children, and had less positive perceptions about their parenting than mothers. This points to the need to address fathers' support needs and to identify ways to improve fathers' engagement with parenting supports.

Of parents whose children had additional needs, only those who had children with psychological or behavioural difficulties reported lower confidence in their parenting

abilities. However, parenting confidence is related to a range of other factors including parents' current psychological distress, partner support, and parent activity with the child.

The general measure of parenting confidence also showed small but positive relationships with confidence in knowing where to get help, confidence and communication in educational settings, and attendance at Maternal and Child Health first-time parents' groups.

These findings point to the need to take parenting confidence into account when adopting a family-centred approach to services for children with additional needs. This would mean routinely monitoring parenting confidence as part of a service plan.

STUDY DETAILS

The 2016 Parenting Today in Victoria study used computer-assisted telephone interviewing, conducted in English, to randomly survey 2600 Victorian parents and carers of children aged 0-18 years. In each family, one parent was interviewed and asked questions about one child (the focus child). The sample was weighted to match Victorian parents in the 2011 Census for the key characteristics of age (sample age was adjusted upward), education level (sample education lowered) and residential location (sample adjusted towards more metro/city dwellers).

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¹³ Australian Productivity Commission (APC). (2011). Disability Care and Support. Canberra: Publisher.

¹⁴ Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centered services for children with a disability. Topics in Early Childhood Special Education, 28(1), 42-52.