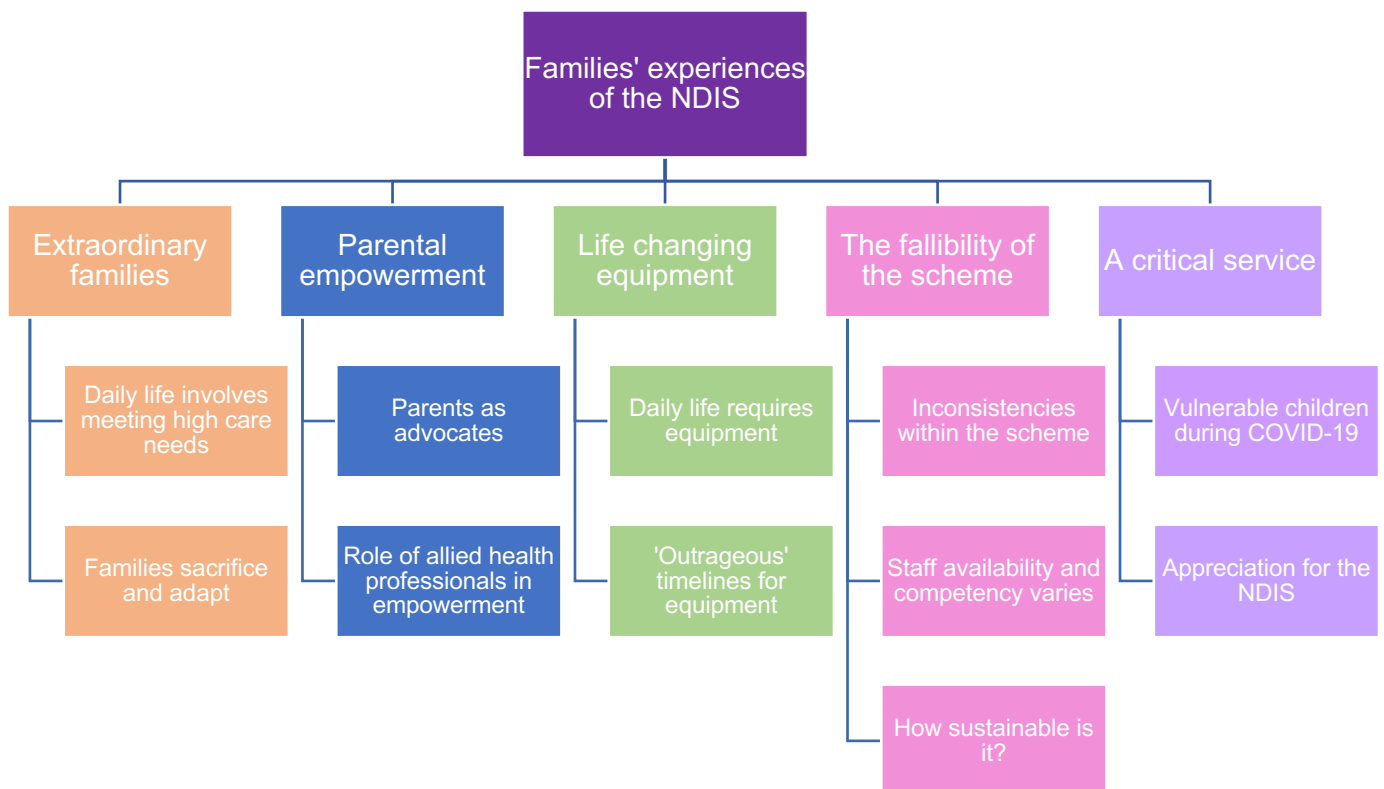


Findings from the study with Monash University

Families' experiences of the NDIS after 3 or more years

We interviewed **eight** parents at CPEC to gather their **opinions** and **experiences** of the NDIS, after **three or more years** of their child being a participant.

Parents in this study openly shared their experiences and provided insights into their personal lives. The following 'themes' or major ideas emerged throughout the interviews:



Extraordinary Families

- Parents and families in this study were deemed to be '**extraordinary**', due to the high level of care and support they provide. The love that parents had for their children was evident. Parents in this study enabled their child to participate in daily life.
- Parents had **structured daily routines**, including administering medications, completing their child's self-care tasks, and attending after school activities.
- The **importance of having support workers** funded through the NDIS was raised, to allow for parents to have respite, maintain employment, meet the needs of other

children/family members and look after themselves.

- Despite support from the NDIS, all parents in this study described to make **sacrifices** and **adapt** their lives, to best care for their child.

Parental Empowerment

- Some parents described to have developed a **greater understanding of the NDIS** and how to navigate it over the years, whereas other parents did not. Parents had **varying success** with attaining their child's required supports through the NDIS.
- Parents learned that they needed to '**fight**' for their child's needs within the NDIS, with parents becoming **strong advocates** for their child.

- Allied health professionals were described as **crucial** to accessing and navigating the NDIS.
- Many parents described to have a **strong reliance on their allied health professionals** to receive funding for supports and services, including assistive technology. This was particularly due to the specific language required within the NDIS reports and submissions.
- Parents in this study raised concerns about the **sustainability** of the NDIS and the capacity of the scheme to provide lifelong support.
- The **reporting** of the NDIS reported in the mainstream media caused concerns for parents, who rely on the supports accessed through the NDIS for their child.
- The **high costs** per hour for allied health professionals and expensive equipment through the NDIS, was raised. Parents suggested that the NDIS **review their policies and procedures** for purchasing new equipment, as many parents reported that they would happily purchase second-hand equipment.

Life Changing Equipment

- Children in this study **required equipment** to complete all daily activities. This also made equipment **essential** for families to function.
- Equipment was also critical to allow children to not feel like “**everything is a hassle,**” a quote from one parent.
- Equipment timelines were described as ‘**outrageous**’ through the NDIS. Following-up on the progress of equipment was also depicted as exhausting.

The Fallibility of the Scheme

- Multiple parents described the flaws, inconsistencies, and complexities within the NDIS.
- The NDIS was portrayed as a very **inconsistent** scheme, with varying plan values and accessible supports noted between participants. Some parents reported that their allocated budget changed with each NDIS plan, despite their child requiring a consistently high level of support.
- Some parents described their child to be receiving funding for a wide variety of supports. Whereas other parents described their child to be severely **lacking** essential funds.
- NDIA staff were overwhelmingly described to **lack an understanding** and **knowledge** about raising a child with a disability.

A Critical Service

- During the peak of the COVID-19 pandemic during the lockdowns, parents mostly described this a **terrible** time within their lives. Most parents reported that the NDIS **increased** their support worker hours during this time, which was highly beneficial for families to continue to function.
- Overall, parents acknowledged the **necessity of the NDIS** to enable their child and family to participate in daily life. Many parents described that their children would receive significantly less supports without the NDIS.

The Take Home Messages from Parents

- The NDIS was **appreciated**, however, it was also described as a **complex** and **inconsistent scheme**.
- Access to **equipment, support workers** and **allied health professionals**, is relied upon to enable daily participation for their child and family.
- NDIS/NDIA staff need to be more **educated** and **understanding**.
- Parents felt that their **child’s future** within the NDIS was not necessarily secured, particularly due to **fears of unsustainability** and **funding cuts**.