

# Perceived Support Needs of Young People on the Autism Spectrum and their Caregivers

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## Project aim

Explore the perceived support needs of Australian young people on the spectrum and their caregiver(s).

## Background

With an increasing number of young people on the autism spectrum requiring health, disability and education services, wait-times and expenditure have become problematic.

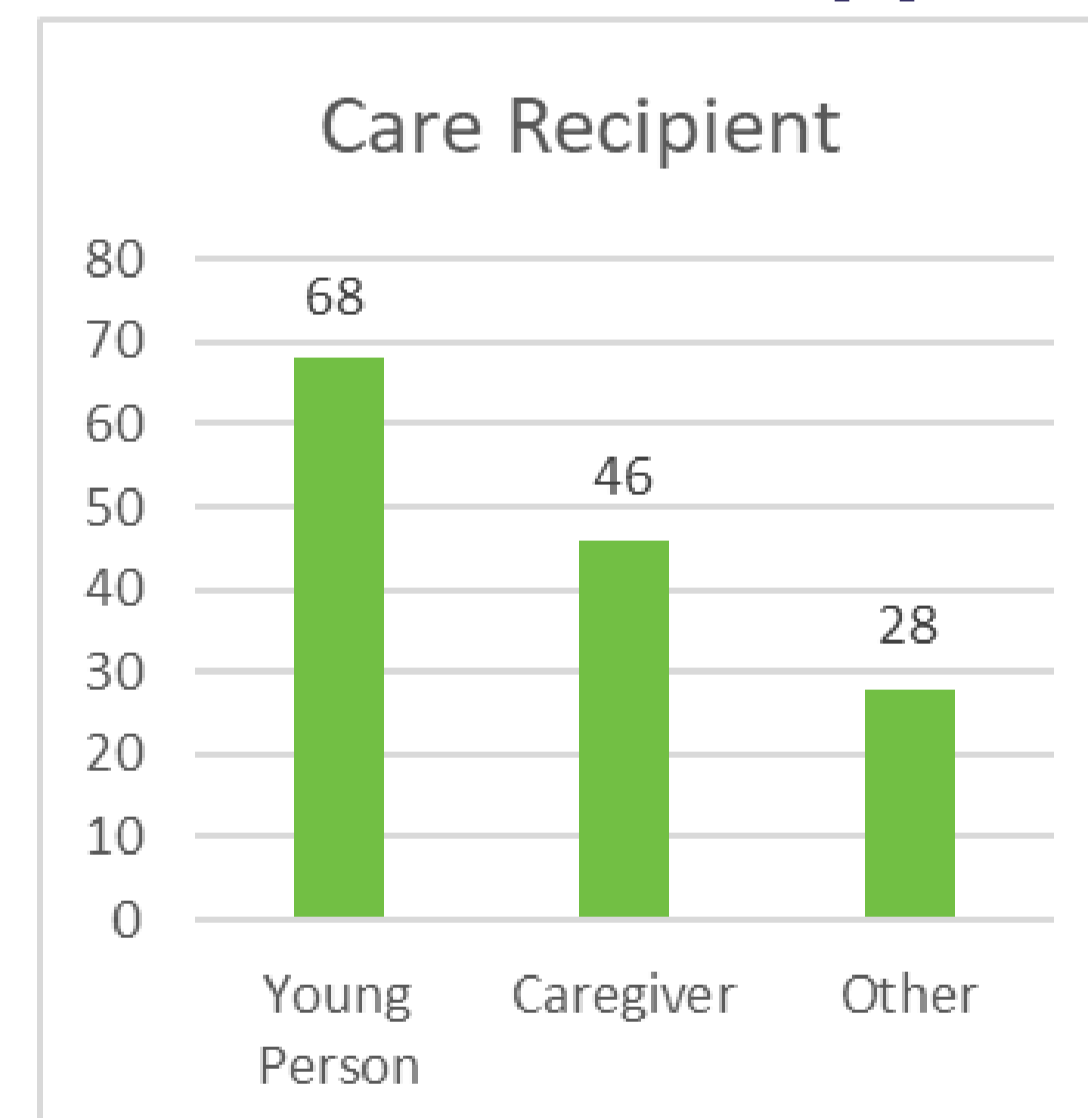
Innovative approaches are needed to determine and provide necessary supports in a timely and cost-effective manner, enabling individuals to achieve their prioritized goals and maximize their quality of life.

## Methods

- Phenomenographic Support Needs Interviews<sup>1</sup> were conducted by occupational therapists during home-visits.
- Caregivers of 68 young people on the spectrum (5–17 years) lived in four states of Australia.
- Asked to identify and describe up to ten new (unmet) or existing (partially or fully met) support needs → ranked from most to least important.
- Summaries de-identified and analysed in NVivo using seven-step phenomenographic process<sup>2</sup>.

## Results

### Overview of Support Needs

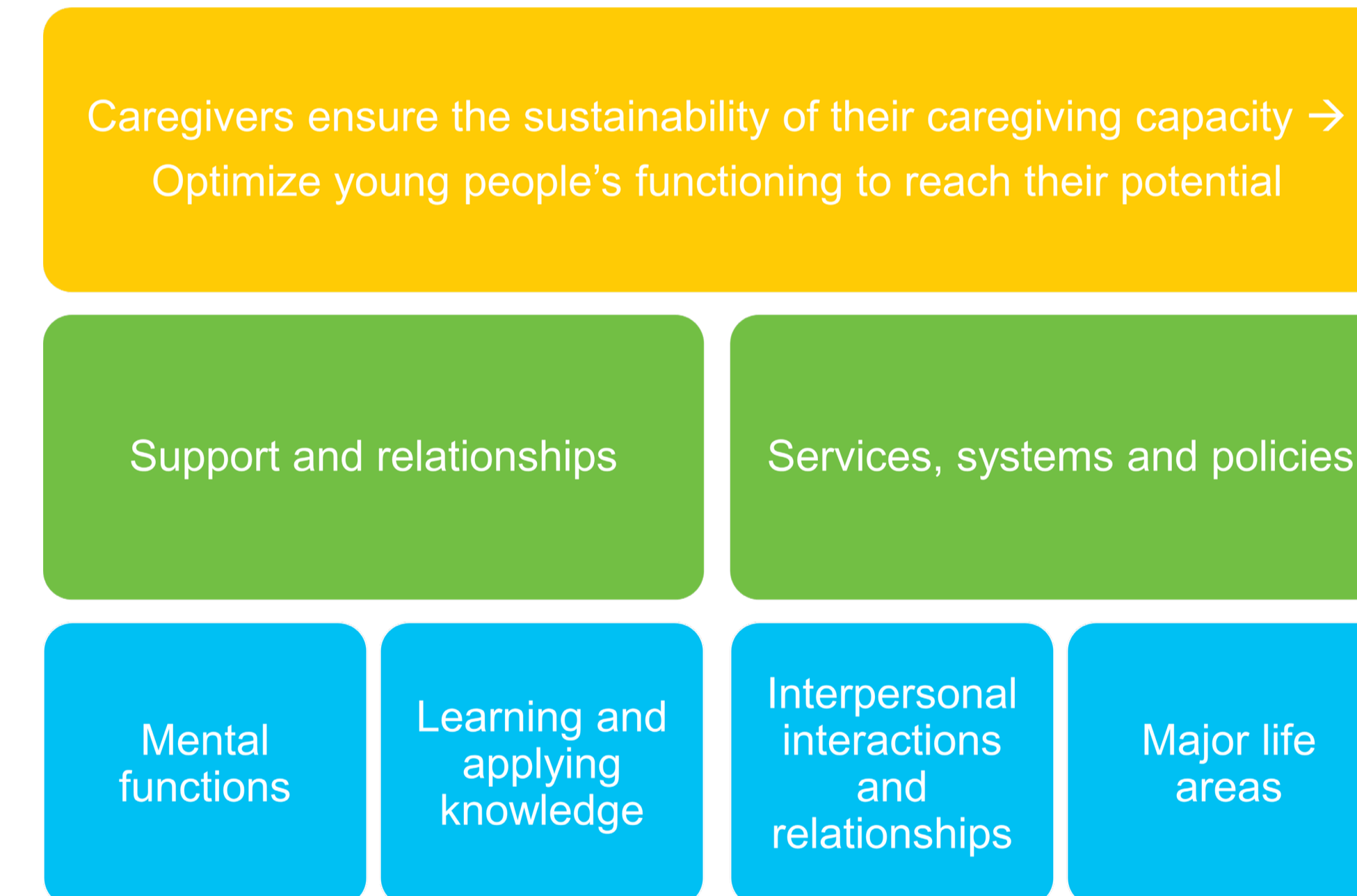


Caregivers report an average of 6 support needs (range=3–10), spanning multiple aspects of functioning (often concurrently). Included most (6/8) Body Function, all Activity / Participation and all Environmental Factors chapters<sup>3</sup>.

Caregivers had support needs that were currently met (n=34), partially met (n=65) and/or unmet (n=28). Supplementary support included: increasing frequency, duration and/or scope; introducing a new support; changing provider or location; prescribing a product or environmental change; and/or facilitating informal supports.

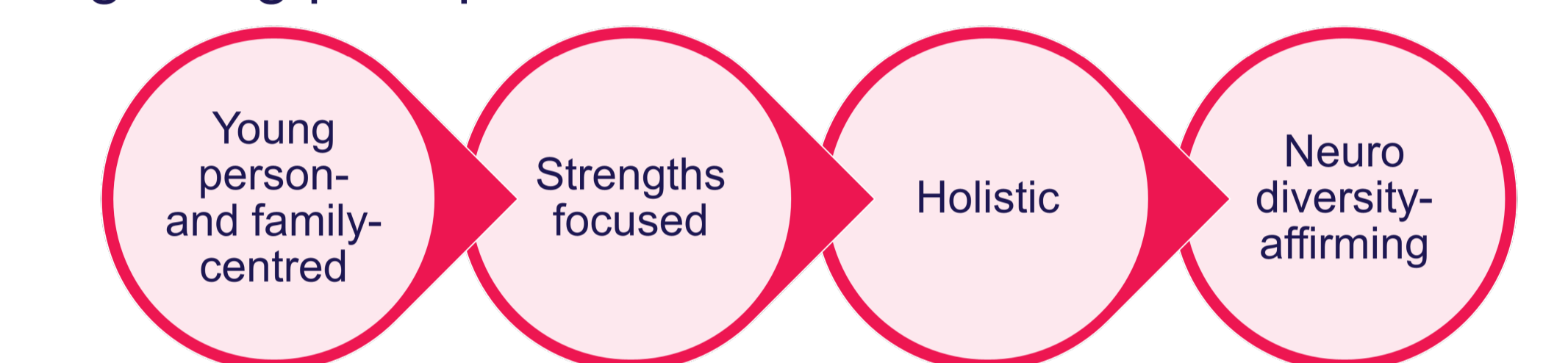
### Phenomenographic Outcome Spaces

The support needs of young people and their caregivers were described using two hierarchical outcome spaces that showed the relationship between the aim of supports (yellow), suggested supports (key supports in green) and two - three levels of support needs (key needs in blue).



## Conclusions

Caregivers described a vast array of complex and interacting support needs and suggested supports related to 68 Australian young people on the spectrum and their support people. The ICF Core Sets for Autism<sup>4</sup> provided a sound framework to explore support needs whilst meeting the following guiding principles<sup>5</sup>:



### Recommendations

**Service providers** - Support needs should be central during the assessment, support and evaluation phases of the clinical cycle.

**Funders** – Provide funding aligned to individualized needs, that maintains existing supports and prioritizes one to two new important support needs (including a top-down approach when relevant).

**Researchers** - Develop and validate support needs measures that are aligned evidence-based guidelines for support needs assessment and based on the ICF Core Sets for Autism.

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**References:** <sup>1</sup> <https://www.tandfonline.com/doi/full/10.1080/07294360.2020.1833844> | <sup>2</sup> <https://onlinelibrary.wiley.com/doi/full/10.1046/j.1365-2648.2002.02375.x> | <sup>3</sup> <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health> | <sup>4</sup> <https://journals.sagepub.com/doi/10.1177/1362361318755522> | <sup>5</sup> <https://www.autismcrc.com.au/access/national-guideline> | Photo by Unknown Author is licensed under CC BY-NC

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