



What we learned:

The relationship between cognitive decline in a person with ID and mental distress in their carer is moderated by social support satisfaction. Carers' physical health, their subjective appraisal of burden, and a second caring role also play an important role in predicting carer mental distress.

Background

People with intellectual disability (ID) are living longer than previously. The impact of age-related problems like cognitive decline on their family carers' mental health is not well understood.

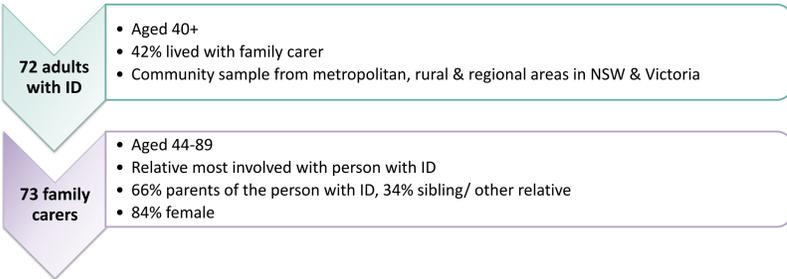
In other groups of carers, better mental health is associated with factors relating to:

- The care recipient: e.g. cognitive function, behaviour [1-2]
- The carer: e.g. appraisal of the caring role [3], physical health [4]
- Their situation: e.g. social support [5-6], relationship to each other [7].

The aim of this study was to explore the carer and care-recipient factors associated with mental health in family carers of people with ID aged 40+.

Method

Participants:



Measures & methods:

Table 1 lists the measures used, domains captured, and descriptive statistics.

Cognitive status for the person with ID:

- Determined by clinician case consensus using DSM-5 criteria
- Based on all available data, including:
 - Dementia screening Questionnaire for individuals with Intellectual Disability [8]
 - Adaptive Behaviour Dementia Questionnaire [9]
 - Cambridge Examination for Mental Disorders of Older People with Down [10]
 - 17 participants completed a face-to-face assessment covering memory, executive function, language, praxis, vision, hearing, and motor slowing.

Participants were rated as:

- **Normal:** No evidence of declines
- **Non-normal:** Major or mild neurocognitive disorder, OR Ambiguous (meets some but not all criteria for neurocognitive disorder)

Participants with insufficient data were not rated.

Domain	Measure and description	n	Descriptive Statistics
Carer self-report measures			
Psychological distress	General Health Questionnaire-28 (GHQ-28) [11] • 28-item survey measuring psychiatric distress • Scores > 4 suggest probable distress.	68	M = 3.78 SD = 5.47
Age	Single item	73	M = 68.44 SD = 9.65
Rurality	Regional/rural vs metropolitan • From postcode	71	63% metropolitan
Subjective burden	The Zarit Burden Interview [12] • 22 items • Questionnaire format	66	M = 29.40 SD = 16.92
Satisfaction with Social Supports	Social Support Questionnaire 6 [13] Mean-per-item satisfaction with supports (SSQ6-S) score: • 6 items on different forms of support • Each a Likert scale: 1 (very satisfied) - 6 (very unsatisfied).	72	M = 1.54 SD = 0.74
Physical Health	Short Form 12 Physical health component score (PCS) [14]	72	M = 45.68 SD = 9.72
Additional caring role	Single binary question	72	42% yes
Care recipient (person with ID) measures completed by the person's main carer			
Cognitive decline	Clinician case consensus based on available data for each person.	53	77% normal 23% non-normal

M = Mean, SD = Standard deviation.

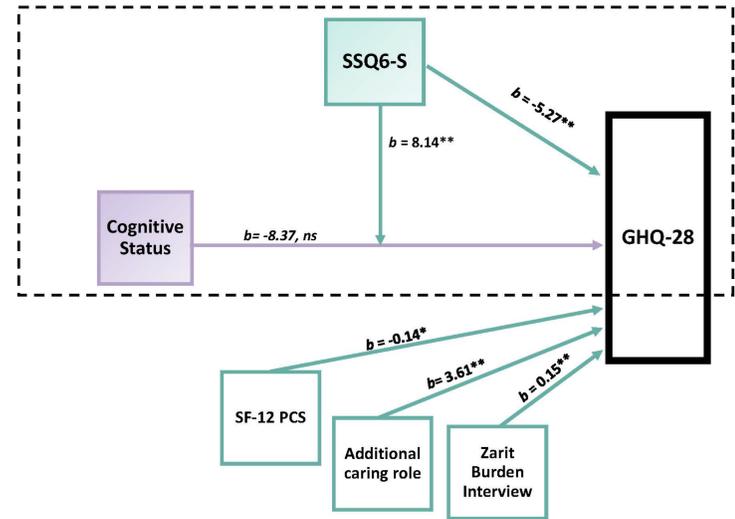
Table 1: Measures retained in the final model, the domains measured, and descriptive statistics.

Statistical Analysis: We used IBM SPSS 24.0 to conduct a linear regression with GHQ-28 as the outcome.

- Simple linear regression identified covariates related to GHQ-28 with $p < .15$.
- Variables of interest were entered simultaneously in a linear regression model, refined using backwards elimination to remove those with $p > .10$. Missing data was deleted listwise.
- The interaction between SSQ6-S and Cognitive status was probed using *Process* [15]. 95% confidence intervals were calculated with bootstrapping to 5,000 repeats

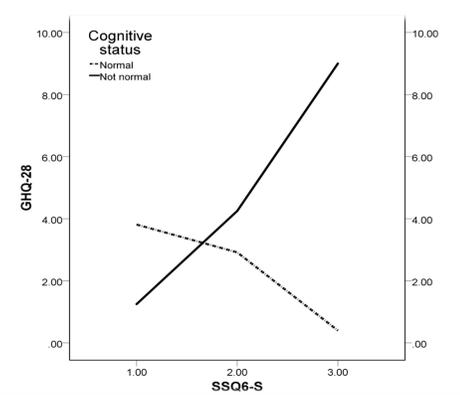
Results

Figure 1: Unstandardised regression coefficients showing the relationship between Cognitive status and GHQ-28, moderated by SSQ6-S, with covariates SF-12 PCS, Additional caring role, and Zarit Burden Interview.



Notes: Model adjusted for non-significant variables: Family carer age, & family carer rural. Adjusted R^2 was 0.578, b, unstandardized regression coefficient; p, probability; * $p < .05$; ** $p < .01$; ns non-significant

Figure 2: Line graph showing the interaction between SSQ6-S and Cognitive status



The interaction between Cognitive status and SSQ6-S on GHQ-28:

- resulted in R^2 change of .082 ($p = .007$).
- Cognitive status significantly predicted GHQ-28 scores only when SSQ6-S was above 1.35 (45% of the sample).

Variables tested but eliminated from the final analysis included:

Carer	
• gender	• marital status
• employment status	• financial situation
• social support number score	• caring activities last week
• co-residence with person with ID	• respite access in prior 12 months
• relationship to person with ID	
Person with ID	
• chronic illness	• adaptive behaviour
• additional disability	• behaviour problems

Discussion

The relationship between mental distress and cognitive status in the care recipient was moderated by carers' degree of satisfaction with their own social supports.

- Family carers experience poorer social relationships than others [16].
- Highlights the need to promote social supports for carers throughout their caring role.

Over 40% of carers had at least one other caring role.

- This was associated with poorer carer mental health.
- Providing effective support may require coordination across multiple service systems.

Study limitations:

- small sample size - low power may explain some null findings.

What might effective support for carers of people with both ID and cognitive decline look like?

- Identify the entire family unit as the 'client' & involve both the person with ID and the carer
- Tailored interventions that facilitate service access across sectors: Aged care, Disability, Health & mental health
- Seek to strengthen support networks for the carer:
 - Include existing supports in interventions
 - Expand supports through local networks [17] & referral to carer support groups (including online) [18]
 - Early in their caring role, and as new challenges occur.

Strategies to facilitate cross-sector collaboration could include:

- Policy changes to facilitate collaboration & communication between service sectors
- Joint training for staff from health, disability & aged-care sectors
- Sharing information and expertise across agencies supporting people with ID and carers
- A funded liaison officer position at the local level to broach sectors & assist carers with unique needs.

Conclusion

- Support for family carers of people with an ID and dementia would best be achieved with cross-sector cooperation between aged care, health and disability services.
- Future research could investigate the impact of an intervention spanning different sectors, supporting the entire family unit.

Contact: lizevans@unsw.edu.au

References:

- [1] G. Meshefedjian, J. McCusker, F. Bellavance, M. Baumgarten, 1998. *Gerontologist* [2] Schoenmakers, B., Buntinx, F. & Delepeleire, J. 2010. *Maturitas*, [3] Blacher, J. & McIntyre, L. L. 2006. *Journal of Intellectual Disability Research*. [4] Haley, W. E., & Perkins, E. A., 2004. *Journal of Policy and Practice in Intellectual Disabilities* [5] Mittelman, M. S., Haley, W. E., Clay, O. J. & Roth, D. L. 2006 *Neurology*, [6] Uewellyn, G., Mcconnell, D., Gething, L., Cant, R. & Kendig, H. 2010 *Research in Developmental Disabilities* [7] Dillenburger, K. & Mckerr, L. 2010. *British Journal of Learning Disabilities*, 39, 29-38. [8] Deb, S., Hare, M., Prior, L. & Bhaumik, S. 2007. *The British Journal of Psychiatry* [9] Adaptive Behaviour Dementia Questionnaire (ABDQ), developed by V.Prasher, A. Faraoo and R. Holder. *Neuropsychological Assessments of Dementia in Down syndrome and Intellectual Disabilities*, [10] Ball, S. L., Holland, A. J., Huppert, F. A., Treppner, P. & Dodd, K. 2006. *The Camdex-DS: The Cambridge Examination for Mental Disorders of Older People with Down's syndrome and others with Intellectual Disabilities*, Cambridge University Press [11] Goldberg, D. P. 1978. *Manual of the general health questionnaire* [12] Zarit, S. H., Orr, N. K. & Zarit, J. M. 1985. New York University Press. [13] Sarason, I. G., Sarason, B. R., Shearin, E. N. & Pierce, G. R. 1987. *Journal of Social and Personal Relationships* [14] Ware, J. E., Jr., Kosinski, M. & Keller, S. D. 1996. *Medical Care*. [15] Hayes, AF. 2018 Guilford Press. [16] Totsika, V., Hastings, R. P., & Vagenas, D. (2017). *Health & social care in the community*. [17] Brodaty, H., & Donkin, M. 2009. *Dialogues in clinical neuroscience* [18] Perkins, E. A. and LaMartin, K. M. 2012. *Journal of Policy and Practice in Intellectual Disabilities*.