Disability and Rehabilitation

ISSN: 0963-8288 (Print) 1464-5165 (Online) Journal homepage: www.tandfonline.com/journals/idre20

Well-being and support preferences of siblings of individuals with a neurodevelopmental condition in regional and remote Australia: a mixed methods investigation

Samuel Antonio , Kate Jamieson , Kate P. Dorozenko , Emma J. Glasson & Chloe Maxwell-Smith

To cite this article: Samuel Antonio , Kate Jamieson , Kate P. Dorozenko , Emma J. Glasson & Chloe Maxwell-Smith (08 May 2026): Well-being and support preferences of siblings of individuals with a neurodevelopmental condition in regional and remote Australia: a mixed methods investigation, Disability and Rehabilitation, DOI: 10.1080/09638288.2026.2663921

To link to this article: https://doi.org/10.1080/09638288.2026.2663921

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2026.2663921

Taylor & Francis
by informa

RESEARCH ARTICLE

Well-being and support preferences of siblings of individuals with a neurodevelopmental condition in regional and remote Australia: a mixed methods investigation

Samuel Antonio[a,b], Kate Jamieson[a], Kate P. Dorozenko[c], Emma J. Glasson[c] and
Chloe Maxwell-Smith[a,b,d]

[a]School of Population Health, Faculty of Health Sciences, Curtin University, Perth, Australia; [b]Behavioural Science and Health Lab Group, Faculty of Health Sciences, Curtin University, Perth, Australia; [c]The Kids Research Institute Australia, Centre for Child Health Research, The University of Western Australia, Perth, Australia; [d]Curtin Medical Research Institute, Cancer Domain, Faculty of Health Sciences, Curtin University, Perth, Australia

ABSTRACT
Siblings of individuals with neurodevelopmental conditions are vulnerable to poor mental health and well-being, with additional challenges for those in rural areas.
Purpose: This convergent parallel mixed methods study examined the role of protective factors (resilience, family functioning, and social support) in explaining sibling well-being, alongside this population's support preferences and experiences.
Materials and Methods: We surveyed 93 siblings of individuals with a neurodevelopmental condition aged between 16–30 years, currently or previously living in regional and remote areas of Australia. The majority of the sample identified as women (79.6%), with an average age of 23 years (SD = 4.6).
Results: A hierarchical multiple regression showed resilience and social support combined, but not family functioning, accounted for a significant 58% of variance in well-being. A reflexive thematic analysis of qualitative data identified that siblings were often self-reliant through necessity, and desired services and supports that acknowledged them first as individuals, not just siblings. Siblings commonly accessed social support through their local communities, and preferred support from people who understood neurodevelopmental conditions and the sibling role.
Conclusion: Providing accessible, resilience-based interventions for siblings, and empowering local communities to provide greater support will benefit the well-being of rural siblings and their families.

ARTICLE HISTORY
Received 16 September 2025
Revised 16 April 2026
Accepted 18 April 2026

KEYWORDS
Neurodevelopmental conditions; regional and remote residence; sibling wellbeing; support; young people

IMPLICATIONS FOR REHABILITATION

- Emerging adult siblings of individuals with neurodevelopmental conditions living in regional and remote areas express a need for more support, both informal and formal, for themselves and their families.
- Resilience and social support, particularly local community support, are important to the wellbeing of siblings.
- Online delivery of supports and services, and activity-based opportunities, are methods that are highly regarded by siblings and can have positive benefits for their perceived wellbeing.

Introduction

The siblings of individuals with neurodevelopmental conditions[1] (NDCs) can be vulnerable to experiencing poor mental health and wellbeing [1,2]. Throughout childhood, siblings experience challenges, such as difficulties spending time alone with parents, bringing friends into their homes, or advocating for their sibling with a NDC [3,4]. Additionally, siblings report guilt and shame in voicing their needs, particularly when coping with challenging behaviours from their siblings with NDCs [5]. Some siblings consider

CONTACT Chloe Maxwell-Smith Chloe.maxwell-smith@curtin.edu.au Building 400, Curtin University, Kent Street, Bentley, Western Australia, Australia, 6102.

---

[1] Neurodevelopmental disorders (NDDs), also known as neurodevelopmental conditions (NDCs), originate during early development and are associated with varying degrees of impairment in intellectual, social, motor, and/or emotional domains [72,73]. We refer to individuals who have an NDC as 'siblings with NDCs', and siblings without NDCs as 'siblings'.

themselves “glass children”, feeling overlooked, invisible, or “seen-through” due to the care needs of their siblings with a NDC [6]. Siblings report high rates (70.9%) of mental health concerns, such as depression, anxiety, and sleep disorders, compared to a lower rate (33.6%) among individuals without siblings with NDCs [7]. Siblings can also develop strengths by maintaining normative levels of empathy [8] or displaying improved empathic abilities [9] and developing stronger prosocial skills [8,10]. These investigations suggest that siblings’ experiences are complex and may shape their wellbeing, the subjective level of satisfaction with one’s life [11]. The methods siblings employ to improve well-being require further investigation, particularly within their unique geographical contexts.

Australia has a vast geographical spread of communities, with a low population density of 3.5 people per square kilometre (Australian Bureau of Statistics, [12]). Consequently, regional and remote Australians experience greater difficulty accessing appropriate resources [13, Kavanagh et al. [14]) and are at greater risk of social isolation [15,16] compared to those in urban areas. Whilst the inaccessibility of resources and supports can reduce opportunities to maintain well-being [13], people living in rural areas may have alternative channels to support their well-being, such as frequent and meaningful engagement with friends and community members [15,17]. However, young people may be less able to utilise and develop social connections in regional and remote areas, due to being dependent on others to facilitate social opportunities, putting them at higher risk of poorer well-being [18]. Additionally, young siblings may face unique challenges in navigating and balancing social connections and relationships, and conflict may occur between spending time with friends and family care responsibilities [4]. During adolescence and early adulthood, siblings experience roles such as being a teacher and assisting with caregiving [19], which can develop into becoming full-time primary caregivers of individuals with NDCs in adulthood [20]. Social and familial conflicts are pertinent for emerging adults aged 18–30 years [21], as this period typically involves significant life changes, including making decisions to move away from regional and remote areas for employment, study, or relationships [22]. These changes for emerging adults can be difficult, acting as barriers to high wellbeing, and are sometimes associated with distress [23] and social isolation (Simone et al. [24]).

Resilience is an individual’s ability to withstand challenges by adapting to them. Siblings have consistently reported resilience as a necessary trait to cope with their individual challenges [25], and high resilience is positively associated with sibling well-being [2,7]. In Australia, sibling support and advocacy groups have called for the consideration of additional positive correlates to wellbeing to be scaffolded into interventions and resources for siblings [25]. Whilst resilience can be a protective factor for well-being, it is an individual trait, and the influence of siblings’ family and friends upon wellbeing is important to explore and understand [26].

Social support is the comfort or assistance one receives from other sources when coping with challenges in life [27]. Social support from friends, family, and significant others is critical for siblings, as it is positively related to improved family quality of life and self-concept and negatively related to barriers to wellbeing, such as stress and loneliness (Kirchhofer et al. 2022). The combination of social support and resilience was investigated in a Korean study of siblings of individuals with NDCs, wherein social support, especially being emotionally supported by parents and friends, positively moderated the relationship between resilience and wellbeing [28]. However, social support alone may not capture the role of family members as informal supports for siblings.

Healthy general family functioning is positively associated with sibling well-being [29,30]. General family functioning is an individual’s perceptions of familial conflicts and communication [31,32]. Conflicts can be more common in families with individuals with NDCs than in families without NDCs [30], and siblings perceive barriers to communication within their families [5,33]. Resiliency theory posits that combining resilience, the ability of an individual to withstand the challenges they face by adapting to them, with other assets, including general family functioning and social relationships, is important for general healthy development. Similarly, models of thriving through relationships suggest resilience and social connections, such as family relationships, are essential for coping with challenges and promoting greater well-being [34]. General family functioning may also be foundational to enabling the combination of resilience and social support. Systematic reviews have highlighted the importance of these predictors for the well-being of siblings [1,35]. Examining resilience, social support, and general family functioning can help identify their value in interventions, supports, or services. Furthermore, as young regional and remote Australians express desire for peer-based mental health support and systems of empowerment [18], understanding the perceptions and preferences for support services for siblings of individuals with an NDC living rurally is important.

This mixed methods study aimed to understand the factors associated with the well-being of siblings of individuals with NDCs in regional and remote Australia. Quantitative data were used to examine the question: What are the unique and combined roles of resilience, social support, and general family functioning in explaining variance in wellbeing? The qualitative component explored the question: What are the experiences with and preferences for formal and informal supports, among siblings of individuals with an NDC?

Method

Research design

A convergent parallel mixed methods design was used, as quantitative data alone would be insufficient to understand the utility of the three key constructs and siblings' experiences, employed by similar previous studies (Balachandran & Bhuvaneswari, [36, 37]). Qualitative data may highlight potential supportive factors that siblings felt were important for their wellbeing. The parallel design ensures methodologically established analyses will be conducted, allowing for data convergence to address the study objectives [38]. An online questionnaire focused on resilience, social support, general family functioning, well-being, and the lived experiences of siblings of individuals with an NDC. We used a cross-sectional, correlational quantitative strand and an exploratory qualitative strand, with the study underpinned by a constructivist epistemology. This epistemology enabled us to develop insightful findings based on siblings' lived experiences, founded in the concept that participants' truths are based on their own experience, informing an inductive analytical approach, thus complementing the thematic analysis [39]. Reflexive thematic analysis allowed constant reflection of the positionality and its influence on the authors, which assisted in elucidating experiences without the use of an external framework or a deductive approach [40,41].

Participants

Emerging adult siblings (aged 16–30 years) of individuals with NDCs who previously or currently live in regional and remote Australia were eligible for this study. We included mature minor participants, aged 16 and 17, as it was determined that they could understand the content of the questionnaire, give informed consent, and provide insightful data. The questionnaire was piloted with a consumer panel of four emerging adult siblings (including a mature minor) and facilitated by The Kids Research Institute. Three members of the consumer panel provided lived experience expertise on regional or remote Australia. This piloting resulted in a minor adjustment to the phrasing of one item and presentation of one scale measure to enhance clarity. The questionnaire was hosted on Qualtrics between June and December 2024. Participant demographics are detailed in Table 1, with information about the diagnoses of siblings with NDCs in Table 2.

Participants were recruited through advertisements posted to Australian regional and remote community Facebook groups, and in newsletters and social media pages of organisations that support the families of children with NDCs. A paid national social media campaign was also utilised. Drawing from population estimates for siblings of individuals with NDCs in rural Australia, the target sample size of the quantitative component was 163 participants, at 80% power, $\alpha = .05$. A sensitivity analyses *via* G*Power [42] with three predictors indicated a minimum detectable effect size of $f^2 = .069$, which is small to medium based on convention [43]. Previous pairwise associations between resilience, social support, and wellbeing for siblings have been within this range [Kirchofer et al. 2022, 2]. The target sample size for the qualitative strand was 50–70 participants, determined from information power of qualitative survey studies with niche populations (Vederhus et al. [44]; Whale et al., [45]).

Data and measures

Demographic items included age, gender identity, postcode of residence, number of siblings with NDCs, whether they lived with their siblings with NDCs, and sibling with NDCs' diagnoses. Participant postcodes

Table 1. Demographic characteristics of participants (siblings).

Characteristic	*n*	%
Gender		
Women	74	79.6
Men	14	15.1
Non-Binary/Other	5	5.3
Remoteness		
Urban	10	10.8
Inner regional	36	38.7
Outer regional	27	29.0
Remote/Very remote	6	6.5
Missing	14	15.0
Number of siblings with NDCs		
One	67	72.0
Two	18	19.4
Three	7	7.5
Four	0	0
Five	1	1.1
Currently living with sibling with NDCs		
Yes	55	59.1
No	38	40.9

Note. The total sample was 93 siblings. Participants' mean age was 22.9 years, SD = 4.6. Ten participants were included as Urban as they provided their current metropolitan postcode, despite previously living in a regional/remote location.

Table 2. Diagnoses of the individuals with neurodevelopmental conditions.

NDC Diagnosis	*n*	%
ASD	80	62.0
ADD/ADHD	57	44.2
Other	17	13.2
Intellectual disability	13	10.1
Specific learning disability	13	10.1
Down syndrome	9	7.0
Epilepsy	6	4.7
Cerebral Palsy	5	3.9
FAS/FASD	1	0.8
Fragile X	1	0.8

Note. $N=129$. Participants could select multiple NDC diagnoses for their sibling, given that the conditions can co-occur. ASD = autism spectrum disorder. ADD/ADHD = Attention-deficit/hyperactivity disorder. FAS/FASD = Fetal alcohol syndrome/spectrum disorder. Examples of 'Other' NDCs include Agenesis of the corpus callosum and Kabuki syndrome.

were coded by remoteness, ranging from inner regional, outer regional, remote, to very remote, according to the Accessibility/Remoteness Index of Australia (ARIA+; The Australian Centre for Housing Research & The University of Adelaide, 2023).

The Rugged Resilience Measure (RRM-10) measures subjective resilience [46]. The measure has 10 items, for example, "I believe in myself," where responses are ranked between 1 (not at all) and 5 (a lot), with higher overall scores indicating higher resilience. The RRM-10 had good internal consistency for this study, α=.86.

The Multidimensional Scale of Perceived Social Support (MSPSS) measures perceived social support [47]. The measure had good internal consistency in this study (α=.90), comprising 12 items, with responses ranging between 1 (very strongly disagree) and 7 (very strongly agree). An example item for this measure is "My friends really try to help me." Summated scores range from one to seven, with higher scores indicating higher perceived social support.

The general functioning subscale short version of the Family Assessment Device measures general family functioning (GF6+; [31,48]). The measure has six items, with responses ranging from 1 (strongly agree) to 4 (strongly disagree). One example item is "We can express feelings to each other". The final scores of the measure range between one and four, with higher scores indicating poorer general family functioning. The GF6+ had good internal consistency for this study, α=.90.

The Personal Wellbeing Index (PWI-A) measures subjective well-being [11], with good internal consistency for this study, α=.90. An example of the seven items is "How satisfied are you with your standard of living?". Item responses range from 1 (no satisfaction at all) to 10 (completely satisfied). Final scores are summed and calculated as a percentage, with higher scores indicating higher well-being.

Seven open-ended questions were included in the questionnaire to capture the lived experience of siblings living in regional/remote Australia, four of which explicitly focused on sibling experiences and engagement with formal and informal supports, and their support preferences as emerging adults living outside of metropolitan areas. These four questions were answered in separate text boxes and were analysed for this study.

1. What are some of the advantages of living in a regional or remote area as a sibling to someone with a neurodevelopmental condition?
2. What has been important in helping you overcome these challenges? (Referring to one of the seven questions that explored challenges siblings had experienced in regional and remote Australia). Please describe the supports and/or services that you use or have used.
3. Being the sibling of someone with a neurodevelopmental condition, in what ways have you felt supported by your regional or remote community?
4. What would you like to see implemented to better support siblings of people with neurodevelopmental conditions, who live outside of metropolitan areas?

Procedure

Ethical approval was granted by the Curtin Human Research Ethics Committee (HRE2024-0296). Participants accessed the online questionnaire link from the recruitment advertisement and provided informed consent prior to accessing the survey. Participants who did not consent, were not aged between 16 and 30 years, or did not have a sibling with an NDC, could not progress. Participants with current metropolitan postcodes were included if they previously lived in regional and remote Australia and reflected on this experience in the questionnaire. The questionnaire had a median completion time of 14 min. At the end of the questionnaire, participants were presented with support resources to access if required, thanked for their time, and provided with an opportunity to enter a random prize draw.

Data analysis

Quantitative data were imported into IBM SPSS version 29.02.0 for analysis [49]. The principal quantitative analysis was a hierarchical linear multiple regression, with social support, resilience, and general family functioning as predictor variables, explaining variance in wellbeing, beyond any confounding variables. Descriptive and correlational analyses were conducted on demographic items, resilience, social support, general family functioning, and well-being.

Qualitative data were pooled from all four questions and imported into NVivo 14 for reflexive thematic analysis, where the software assisted with the initial code generation, organisation, and subsequent mapping to support theme development. Codes were saved within NVivo to refer to the qualitative data throughout the analysis. The analysis was conducted iteratively, moving across the six steps of familiarisation, inductive coding, generating initial themes from pooled latent codes, reviewing the potential themes, naming and defining themes, and reporting on the constructed themes [40,50,51]. Analysis was conducted by the first author (SA), as part of their Master of Research (Psychology), under the guidance and supervision of the authorship team. SA has rural research experience from their psychology Honours project. SA identifies as a male emerging adult and grew up in regional Western Australia as a sibling to an individual with an NDC. The experiences of SA enabled an insider interpretation and analysis of the data, being familiar with and personally understanding the experiences of regional communities, which assisted in drawing links within the data and in constructing the reflexive narrative. Quality assurance measures included reflexive journaling to encourage active engagement with the data [51], collaborative discussions about data, coding, and themes, and periodical reviewing and debriefing amongst the research team. These measures were employed to ensure clarity between codes and constructed themes, and to refine the thematic narrative, avoiding descriptive topic summaries [40].

Results

Quantitative analysis

One hundred and fifty-six completed responses were recorded. After inspection, 63 responses were determined to be bot responses and excluded, detected by security measures such as hidden reCAPTCHA scores and attention check questions, resulting in 93 usable responses. The overall missingness of data were 10%, with the extent of missingness up to 20%, but Little's MCAR test was non-significant ($p = 0.58$), indicating data were missing completely at random. Little's MCAR testing was conducted under these conditions, as 20% missingness is common in psychological research, and determining patterns of missingness informed appropriate methods to address missing data [52,53]. The expectation maximisation algorithm in SPSS addressed the missing data for scale variables by imputing replacement values.

Table 3 presents the descriptive statistics the scale variables of resilience, social support, general family functioning, and wellbeing at each level of geographical remoteness. Twenty-nine percent of the sample reported low (0–49), 38.7% moderate (50–70), and 32.3% high (71–100) well-being, based on established norms (International Well-being Group, 2024).

Table 4 presents Pearson's correlations between wellbeing, whether participants lived with their siblings with NDCs (as this was found to be the only measured confounding variable), and predictors: resilience, social support, and general family functioning. Correlations between resilience and social support with wellbeing were strong and positive. General family functioning was negatively associated with wellbeing, at medium strength.

Due to a small, positive, significant association between wellbeing and whether participants lived with their sibling with NDCs, and the absence of other demographic variables correlated with wellbeing, a hierarchical multiple regression was conducted. The hierarchical regression examined the variance in wellbeing explained by resilience, social support, and general family functioning, controlling for the variance of whether participants lived with their sibling with NDCs. The first block of the regression examined whether participants living with their sibling with an NDC accounted for variance in wellbeing. This association was found to be significant, as living with their sibling with an NDC accounted for 6.3% of variance in sibling wellbeing, $R^2 = .06$, adjusted $R^2 = .05$, $F(1, 89) = 6.11$, $p < 0.05$. The second block indicated that resilience and social support, but not general family

Table 3. Descriptive statistics for each scale variable by geographical remoteness for the 93 participants.

	Resilience		Social support		General family functioning		Wellbeing	
	M, SD	95%CI	M, SD	95%CI	M, SD	95%CI	M, SD	95%CI
Overall ($N = 93$)	34.91, 7.00	[33.47, 36.36]	4.88, 1.15	[4.65, 5.12]	2.10, 0.68	[1.95, 2.29]	59.37, 20.00	[55.25, 63.49]
Currently Urban ($n = 10$)	34.70, 7.45	[29.37, 40.03]	5.00, 1.09	[4.22, 5.78]	2.30, 0.87	[1.67, 2.93]	64.14, 24.82	[46.39, 81.90]
Inner regional ($n = 36$)	34.14, 7.46	[31.61, 36.66]	5.03, 1.28	[4.59, 5.46]	2.12, 0.73	[1.87, 2.36]	59.29, 20.22	[52.44, 66.13]
Outer regional ($n = 27$)	37.56, 6.61	[34.94, 40.17]	5.07, 1.00	[4.63, 5.50]	1.86, 0.65	[1.60, 2.11]	64.02, 18.49	[56.71, 71.34]
Remote/Very remote ($n = 6$)	38.50, 2.59	[34.78, 41.22]	4.29, 1.02	[3.22, 5.36]	2.33, 0.53	[1.78, 2.89]	51.43, 26.70	[23.41, 79.44]

Note. Resilience was measured by the RRM-10, social support by the MSPSS, general family functioning by the GF6+, and wellbeing by the PWI-A. Urban participants were included as they provided current metropolitan postcodes, instead of postcodes when they lived in regional/remote areas. The very remote category was combined with remote, as it only included one participant. $n_{missing} = 14$.

Table 4. Bivariate correlations for demographic and predictor variables.

	1	2	3	4	5
1. Currently living with sibling with NDCs[a]	–				
2. Resilience	.34**	–			
3. Social support	.24*	.57**	–		
4. General family functioning	−0.19	−0.56**	−0.72**	–	
5. Wellbeing	.25*	.68**	.74**	−0.55**	–

Note. Correlations are based on Pearson's r, $N = 93$.

[a] 1 = Yes, 2 = No.

*$p < 0.05$.

**$p < 0.001$.

functioning, accounted for an additional and significant 58.4% of the variance in wellbeing, beyond what could be accounted for by whether participants lived with their sibling with an NDC, $\Delta R^2 = .58$, adjusted $\Delta R^2 = .58$, $\Delta F(4, 89) = 48.61$, $p < 0.001$. Table 5 details the unique effect sizes of the predictor variables.

Qualitative analysis

Three themes and two sub-themes were identified within the open-ended responses ($N = 71$) to understand the supports that siblings engaged with, and their support preferences. The three themes: (1) *No significant support, except for myself,* (2) *Focus on me, the sibling,* and (3) *Being embraced by the community*, captured the supports and services siblings had accessed, and their experience of these supports. The two subthemes: *Having my own supports* and *Normalisation of NDCs and inclusion* specifically captured participants desires for accessing formal and informal services, and a preference for supportive local communities that understand and accept NDCs. Whilst 71 participants informed this analysis, the individual characteristics of the 16 participants quoted in these findings are presented in Table 6.

Theme 1: No significant support, except for myself

Many siblings explained that they did not access mental health supports or felt that this was not an option for them. Reflecting on their support experiences living in a regional community, P1 stated: "I have not had any significant support except for myself". P2, a 16-year-old inner regional man added: "There are no support groups for siblings of people with neurodevelopmental disabilities." Some siblings reflected that they had other personal issues unrelated to their 'sibling identity', and in the absence of formal mental health supports and services, they had to navigate these on their own. P3 explained: "I didn't seek help, it never seemed like a problem … I had my own issues to deal with".

Table 5. Unstandardised (B) and standardised (β) regression coefficients and squared part correlations (sr^2) for predictor variables explaining variance in well-being.

Variables	B [95% CI]	β	sr^2
Block One			
Currently living with sibling with NDCs[a]	10.16 [2.00, 18.31]**	.25	.06
Block Two			
Currently living with sibling with NDCs[a]	−0.28 [−5.71, 5.15]	−0.01	.00
Resilience	1.11 [0.65, 1.58]**	.39	.09
Social support	9.99 [6.70, 13.29]**	.58	.15
General family functioning	2.22 [−3.28, 7.73]	.08	.00

Note. $N = 93$.
[a] 1 = yes, 2 = no.
*$p < 0.05$.
**$p < 0.001$.

Table 6. Characteristics of participants presented in the qualitative analysis (n = 16).

Participant	Remoteness	Age	Gender	Resilience	Social Support	General Family Functioning	Wellbeing
P1	Urban	27	Woman	29 (Moderate)	2.92 (Low)	2.33 (Poor)	21.43 (Low)
P2	Inner regional	16	Man	19 (Low)	2.33 (Low)	2.67 (Poor)	18.57 (Low)
P3	Outer regional	26	Woman	35 (Moderate)	5.42 (High)	2.67 (Poor)	58.57 (Moderate)
P4	Outer regional	27	Woman	50 (High)	6.83 (High)	1.00 (Good)	97.14 (High)
P5	Inner regional	21	Man	37 (Moderate)	5.00 (Moderate)	1.67 (Good)	55.71 (Moderate)
P6	Outer regional	29	Woman	41 (Moderate)	6.25 (High)	1.33 (Good)	82.86 (High)
P7	Inner regional	29	Woman	33 (Moderate)	3.17 (Moderate)	3.33 (Poor)	67.14 (Moderate)
P8	Inner regional	21	Man	25 (Low)	6.50 (High)	1.00 (Good)	45.71 (Low)
P9	Remote	29	Woman	39 (Moderate)	5.00 (Moderate)	2.17 (Poor)	40.00 (Low)
P10	Urban	16	Woman	35 (Moderate)	4.41 (Moderate)	2.17 (Poor)	80 (High)
P11	Inner regional	26	Woman	38 (Moderate)	6.33 (High)	1.67 (Good)	74.29 (High)
P12	Remote	20	Man	41 (Moderate)	5.83 (High)	1.67 (Good)	95.71 (High)
P13	Remote	29	Woman	38 (Moderate)	3.58 (Moderate)	2.33 (Poor)	51.43 (Moderate)
P14	Inner regional	26	Woman	41 (Moderate)	5.58 (High)	1.00 (Good)	71.43 (High)
P15	Outer regional	29	Woman	39 (Moderate)	5.67 (High)	1.33 (Good)	60.00 (Moderate)
P16	Outer regional	24	Woman	45 (High)	6 (High)	1.00 (Good)	67.14 (Moderate)

Note. Urban postcodes were provided by participants who no longer live in their regional or remote community.

Throughout these statements is a thread of self-reliance, regardless of the availability of informal or formal supports: "I never really spoke or got support from the community school regarding my sibling. In fact [it was] the opposite. I coped by trying to be my own person…" (P4, 27-year-old outer regional woman). Some felt they had no other option to address their challenges alone, with P5's statement: "just gotta get past it, I guess". The self-reliance described by some may have resulted from a lack of support available, or a perception of low support, suggesting that supports may be utilised if provided or recognised, rather than supports not being necessary.

Theme 2: Focus on me, the sibling

This theme captures participants' engagement with, and preference for, activities and services that acknowledge them as an individual person with their own experiences and needs first and foremost. Almost 60% of participants no longer lived with their sibling with NDCs. For some, this separation from their sibling was instrumental to the development of their sense of self, and in some cases, improved the quality of their relationship with their sibling with NDCs and family: "I saw a lot of improvements in my relationship with my parents and brother once I moved out" (P6). P6, a 29-year-old outer regional woman, also indicated that greater accessibility of services and supports for the family would have been beneficial; if their sibling with an NDC was better supported, the positive impacts would flow onto them: "… to see services be more accessible, even if that's telehealth. Services for my brother could have freed up my parent's time and attention so it could have been more equally given to me as well." Furthermore, P7 reflected similarly: "…parents with both kinds of children should pay attention to both equally and try not to focus everything on the child with the condition, disregarding the other child because they're seen as 'fine'." Siblings emphasised the importance of parents being well supported, having their own needs acknowledged, and explained that this recognition may contribute positively to family relationships.

Subtheme: Having my own supports

Participants described formal supports and services they had accessed, preferring services that recognised them as unique individuals. Siblings directly mentioned "psychologists" and "therapy" as helpful supports, with one sibling elaborating that their therapist was "a big help in so many different things with my sister and my own issues I was dealing with. It felt much more 1-1" (P8). Siblings also described engaging in different after school and social activities that acted as informal supports, for example, "having an extra-curricular activity that I went to and was my space for respite was good to have growing up. I did dancing, and so when I was performing, it meant I had my parents' attention for a moment." (P9). Group activities specifically designed for children and young people who have a sibling with an NDC were also accessed by some siblings, with P10, a 16-year-old presently urban woman describing:

> There used to be an in-person program quite a few years ago. They would go on camps and run relevant workshops on each disability and hang out. I think programs like Siblings Australia where you can (use) Zoom or Discord is helpful, as we are still included.

There was no apparent preferences for in-person or online support, with siblings describing both delivery methods as helpful. However, siblings consistently expressed the importance of being valued as individual people. For some, their relationship with their parents or with others outside their immediate family bolstered their sense of being valued:

> Informal supports for me specifically were the parents of friends taking time to check in with me and also include me in special events (in hindsight, this was informal respite for me), the support and care offered by my friends and extended family, and the efforts my parents went to making sure that I didn't feel forgotten or left out. (P11, inner regional 26-year-old woman)

Siblings' access to formal services and informal supports that recognised their individuality allowed siblings the space to develop their own sense of self, beyond their relationship with their sibling with an NDC.

Theme 3: Being embraced by the community

This theme captured the importance of understanding and accepting individuals and their siblings with NDCs within their local communities. Siblings valued connections with people who were aware of their unique home circumstances and embraced their sibling with an NDC, including P12 a 20 year-old remote man: “people are way more accepting and don’t make fun of him [sibling with NDCs]. It’s just him.” Siblings also appreciated those relationships with community members who were open, accepting, aware of NDCs, and understanding how various conditions could impact an individual. P11 described “the adults and other kids were more patient with the needs of my siblings and made accommodations for them, even pre-diagnosis, (or) if they did not have an understanding of the disorders”. Furthermore, P13 described how living in a remote area as a 29-year-old woman, outside of a busy metropolitan area created closer community bonds, and contributed to a sense of wellbeing: “more time in nature and a different sense of belonging and community to that of living in a city helps me to stay healthy and happy, and I believe (it) helps my sibling too.” Siblings spoke of close community relationships that were characterised by acceptance, openness, and support as fostering their mental health and wellbeing.

Subtheme: Normalisation of NDCs and inclusion

Normalising the need for support without labels around ability and disability was seen as important to some participants. P14 described how her inner regional community helped normalise their sibling with NDCs’ life: “He attended a lot of mainstream services, so he wasn’t treated as disabled but just needed a little extra support. This meant he wanted to fit in and wasn’t treated as ‘special’ or had different rules”. Similarly, siblings described feeling valued by their communities, where “all the families and my friends made having a sibling with special needs something exciting” (P15). P15, a 29-year-old woman, also suggested “there should be normalisation of disability in these areas full stop and that would make it easier to exist here [outer regional community] as a sibling”. The normalisation of disability and valuing the difference and diversity that exists within the community bolstered comfort and wellbeing.

Sibling resilience and perceptions of community support

Qualitative data were considered according to scores on the quantitative scale measures (i.e., resilience, social support, and general family functioning), which were grouped based on the cut-off categories each of the scale measures. Observations of social support and general family functioning offered no discernible pattern in the qualitative responses. However, an interesting pattern emerged whereby the advantages of local community support identified by siblings in the qualitative responses varied across the categories of low, medium, and high resilience, as measured by the Rugged Resilience Measure (RRM-10).

Sibling perception of local community support per level of resilience score is presented in Table 7, with example quotations showing increasing perceived community support with increasing resilience scores. Some siblings with lower resilience reported that community support did not exist for them, or they did not seek it. In comparison, some siblings with higher resilience praised the support experienced in their local regional or remote communities. However, we cannot ascertain whether participants with higher resilience more commonly sought community support, or if higher community support may have helped bolster siblings’ resilience.

Table 7. Example quotes identifying informal community support in regional and remote Australia grouped by siblings’ resilience scores.

Sibling Resilience	n	Level of perceived support from local communities
Low (10–27)	15	“There are no advantages with or without a sibling with a neurodevelopmental condition.” (P2)
Moderate (28–41)	63	“The area has less access to services / supports that would typically be provided for those with neurodevelopmental disorders, so a lot of the support was provided by the community” (P11)
High (42–50)	15	“We lived in a small community outside of town which was very supportive. We had people we could go to if we needed, and people would keep checks on each other.” (P16)

Note. Sibling Resilience is measured by the Rugged Resilience Measure (RRM-10).

Discussion

This study explored the role of resilience, social support, and general family functioning in wellbeing and the experiences and support preferences of siblings of individuals with NDCs in regional and remote Australia. Resilience and social support, but not general family functioning, accounted for significant variance in wellbeing, in addition to the smaller variance contributed from participants no longer living with their sibling with NDCs. Local community qualities such as understanding, acceptance, and social inclusion were important sources of support for siblings. A critical element of support services was receiving validation as individuals, separate from their siblings with NDCs and family. Mixed methods findings identified that maintaining resilience and social support, particularly from within local communities, would likely benefit wellbeing and be highly preferred by siblings.

Siblings consistently reported insufficient access to formal mental health services, either citing self-reliance or turning to their local communities to assist with coping with emotional challenges associated with being a sibling to someone with an NDC. When accessing services such as one-on-one therapy, personalised extracurricular activities, and online peer support groups that bolstered individuals' sense of self, siblings felt valued and equipped to care for themselves and their families. As such, interventions that harness resilience and educational or support initiatives may be valuable [25,35], as siblings can develop adaptive coping skills, such as journaling emotions and breathing exercises [54,55]. Layering in discussions around identity [19], and the validation and strengthening of individual identities beyond a 'sibling identity' may be preferred by siblings. Group-based interventions with a focus on peer-support elements may be particularly effective, where members can model resilience coping skills for others [55], capitalising on the utility of social support and resilience in improving wellbeing. Furthermore, group interventions can establish peer communities, which have been endorsed by siblings [19] and in rural Australian youth [18], which helps address the concern of low resource availability raised by siblings in this sample.

Social support and resilience, in combination, accounted for more variance in well-being than either factor alone. Given the small unique variance of social support and resilience in explaining wellbeing, their combined variance indicates that both should be incorporated into interventions to support well-being. The large shared variance of resilience and social support aligns with empirically supported pathways to greater well-being [33] and models of thriving through relationships [34]. Additionally, siblings in the current study had average well-being scores that were lower than the general Australian population [e.g., 56], but had moderate resilience scores, consistent with other samples of emerging adults across cultures [e.g., 46]. Siblings reported experiencing moderate social support scores across all remoteness categories, wherein 5.10 or above was considered high perceived support [57]. Siblings valued the emotional support of their friends and family, especially those understanding of NDCs. Interestingly, siblings' descriptions of social support in this study went beyond the scope of the quantitative measure of social support, wherein the MSPSS only includes narrow perceptions of support received only from friends, family, and significant others, and does not capture the social support offered by the local community more broadly.

Siblings described that support from their communities allowed them to feel a stronger sense of normalcy and belongingness, which may counter commonly raised concerns of stigma and discrimination associated with the sibling role [35,58]. Interventions that upskill community members to be knowledgeable and confident in supporting families and individuals with NDCs, potentially through activity-based interventions (e.g., sports, dancing, arts and crafts, and utilising nature). Such programmes may improve inclusion and promote friendships between individuals with NDCs and neurotypical individuals [59]. However, whilst some siblings in our study preferred in-person activities and formal support, others stated preferences for online delivery. There is strong evidence of improved well-being through online delivery of services and interventions for emerging adults in America [60], where online services can be more accessible and delivered at a lower cost than in-person options [61]. New resources for wellbeing in regional and remote Australia offer online participation (e.g., 62] to minimise travel burdens associated with face-to-face services and connect people from low-population areas (Kavanagh et al. 2023; 16]. This availability can increase capacity and capability to reach and support more siblings. In their 2018 report, Siblings Australia, a national organisation supporting siblings of individuals with NDCs, highlighted significant gaps for support services for siblings living in regional and remote Australia [25]. This study echoes their call to fund, adapt, and develop supportive services that can be delivered creatively online to support sibling wellbeing.

In previous studies, healthy general family functioning has established positive correlations with well-being [29,32]. The current study supports this relationship, with poorer family functioning being negatively associated with improved well-being, but not as a significant predictor of variance in well-being compared to resilience and social support. One potential explanation for this finding is that resilience and social support, including support from family, contributes more to well-being than sibling-reported level of general family functioning. The majority of the current sample rated a poor level of general family functioning, reflecting findings from other research focusing on parents of siblings with NDCs [63,64] and also siblings to individuals with NDCs (Lamsal et al. [65]). Poorer family functioning has been observed across families of children with varying disabilities (Yildirim et al. [66]), but especially among families with autistic children, and where children with NDCs' behaviours are more severe [67]. Exploring general family functioning as a potential risk factor for adverse mental health outcomes may be valuable, given associations between mental health challenges, family relationships and general functioning [29,68]. Furthermore, interventions improving parent-child communication skills in parents and siblings of individuals with NDCs may improve relationship quality and sibling mental health (Fredriksen et al. [69]). Siblings in the current study showed preference for supports that consider their entire family's wellbeing, particularly those that address parental caring burdens.

Limitations and future directions

Our study contributes further insight into the well-being of emerging adult siblings, a difficult-to-reach population, living in non-urban areas. Our recruitment strategy utilised multiple support groups, which may have inflated perspectives from siblings already accessing support. However, the results still indicate lower average well-being scores for siblings than the general Australian population [56]. Recruitment *via* channels other than support groups may elucidate more diverse responses and reveal different sibling perspectives and support needs. The quantitative strand did not reach the target sample size, reducing statistical power and limiting confidence in applying the results to population inference. Further, the general family functioning scale may exhibit score-restricted variability in this sample, as scores were limited to 1–4. Restricted variability can attenuate correlations and regression coefficients, potentially underestimating the utility of general family functioning in the regression model [70,71].

Whilst age did not significantly correlate with wellbeing in this study, the sample included a range of ages (16–30) that may introduce heterogeneity in siblings' current family care roles and developmental contexts. Future investigations could include comparisons with same-aged siblings in metropolitan areas, or people without siblings with NDCs in rural Australia, as this may highlight support needs unique to the target population. This study did not collect data on ethnic, cultural, or immigrant background which, if employed in future studies, could reveal specific challenges to siblings living in more isolated areas. Differences in cultural backgrounds may shape how resilience, social support, and general family functioning are understood, and it is critical that we employ culturally appropriate measures. Moving forward, examination of nuances in siblings' experiences of family functioning and the role of community social support on well-being is warranted to direct intervention and support efforts.

Conclusion

Siblings living in regional and remote Australia have unique concerns for their wellbeing. They commonly feel overlooked or unimportant, and sometimes unsupported, making it critical to deliver meaningful support that is available when they need it. Maintaining high levels of resilience and social support, particularly local community support, were associated with better sibling wellbeing. Siblings preferred services, activities, and environments that bolstered their value as individuals. Enriching community resources and offering group-based intervention designs (in-person or delivered virtually) may assist in achieving this, along with ensuring visibility of siblings' experiences, and clear pathways to access mental health and wellbeing supports.

Acknowledgments

We would like to acknowledge Carers WA, Carers Victoria, Carers Australia, and Siblings Australia for their assistance in recruitment and support of this study.

Author contributions

CRediT: **Samuel Antonio**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Visualization, Writing – original draft, Writing – review & editing; **Kate Jamieson**: Conceptualization, Formal analysis, Methodology, Project administration, Writing – review & editing; **Kate P. Dorozenko**: Conceptualization, Formal analysis, Methodology, Project administration, Supervision, Writing – review & editing; **Emma J. Glasson**: Conceptualization, Funding acquisition, Methodology, Project administration, Supervision, Writing – review & editing; **Chloe Maxwell-Smith**: Conceptualization, Formal analysis, Funding acquisition, Methodology, Project administration, Resources, Supervision, Visualization, Writing – review & editing.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This research was supported by the Australian National Health and Medical Research Council (NHRMC, GNT1184770). The contents of the published material are solely the responsibility of the individual authors and do not reflect the views of NHMRC.

References

[1] Kirchhofer SM, Orm S, Haukeland YB, et al. A systematic review of social support for siblings of children with neurodevelopmental disorders. Res Dev Disabil. 2022;126:104234. doi: 10.1016/j.ridd.2022.104234.

[2] Wolff B, Magiati I, Roberts R, et al. Risk and resilience factors impacting the mental health and wellbeing of siblings of individuals with neurodevelopmental conditions: A mixed methods systematic review. Clin Psychol Rev. 2022;98:102217. doi: 10.1016/j.cpr.2022.102217.

[3] Gray C, Leonard H, Wong K, et al. Down syndrome or Rett syndrome in the family: parental reflections on sibling experience. J Intellect Dev Disabil. 2024;49(1):11–24. doi: 10.3109/13668250.2023.2225353.

[4] Leedham AT, Thompson AR, Freeth M. A thematic synthesis of siblings' lived experiences of autism: distress, responsibilities, compassion and connection. Res Dev Disabil. 2020;97:103547. doi: 10.1016/j.ridd.2019.103547.

[5] Bastiaansen JAJ, Veldhuizen EE, De Schepper K, et al. Experiences of siblings of children with neurodevelopmental disorders: comparing qualitative analysis and machine learning to study narratives. Front Psychiatry. 2022;13:719598. doi: 10.3389/fpsyt.2022.719598.

[6] Hanvey I, Malovic A, Ntontis E. Glass children: the lived experiences of siblings of people with a disability or chronic illness. Community & Applied Soc Psy. 2022;32(5):936–948. doi: 10.1002/casp.2602.

[7] Wolff B, Franco VR, Roberts R, et al. Stability and change in self-reported risk and resilience factors associated with mental health of siblings of individuals with and without neurodevelopmental conditions over 15 months. Adv Ment Health. 2024;22(3):653–681. doi: 10.1080/18387357.2024.2305726.

[8] Orm S, Haukeland Y, Vatne T, et al. Prosocial behavior is a relative strength in siblings of children with physical disabilities or autism spectrum disorder. J Dev Phys Disabil. 2022;34(4):591–608. doi: 10.1007/s10882-021-09816-7.

[9] Watson L, Hanna P, Jones CJ. A systematic review of the experience of being a sibling of a child with an autism spectrum disorder. Clin Child Psychol Psychiatry. 2021;26(3):734–749. doi: 10.1177/13591045211007921.

[10] Orm S, Vatne T, Tomeny TS, et al. Empathy and Prosocial Behavior in Siblings of Children with Autism Spectrum Disorder: a Systematic Review. Rev J Autism Dev Disord. 2022;9(2):235–248. 10.1007/s40489-021-00251-0

[11] International Well-being Group. ; 2024. Personal Well-being Index-Adult manual. (R. A. Cummins, Ed.; 6th ed., Vol. 1). Australian Centre on Quality of Live, School of Psychology, Deakin University - Melbourne campus.

[12] Australian Bureau of Statistics. 20245. Regional population. ABS, Canberra. https://www.abs.gov.au/statistics/people/population/regional-population/latest-release. https://www.abs.gov.au/statistics/people/population/regional-population/2023-24

[13] Flavel, Kedzior, Isaac, Cameron, (2024). Regional health inequalities in Australia and social determinants of health: analysis of trends and distribution by remoteness. RRH doi: 10.22605/RRH7726.

[14] Kavanagh BE, Corney KB, Beks H, et al. A scoping review of the barriers and facilitators to accessing and utilising mental health services across regional, rural, and remote Australia. BMC Health Serv Res. 2023;23(1):1060. doi: 10.1186/s12913-023-10034-4 37794469

[15] Allen J, Inder KJ, Lewin TJ, et al. Social support and age influence distress outcomes differentially across urban, regional and remote Australia: an exploratory study. BMC Public Health. 2012;12(1):928. doi: 10.1186/1471-2458-12-928.

[16] Osborne SR, Alston LV, Bolton KA, et al. Beyond the black stump: rapid reviews of health research issues affecting regional, rural and remote Australia. Med J Aust. 2020;213 Suppl 11(S11):S3–S32.e1. doi: 10.5694/mja2.50881.

[17] Butterworth P, Handley TE, Lewin TJ, et al. Psychological distress in rural Australia: regional variation and the role of family functioning and social support. J Public Health. 2014;22(6):481–488. doi: 10.1007/s10389-014-0640-9.

[18] Klinner C, Glozier N, Yeung M, et al. A qualitative exploration of young people's mental health needs in rural and regional Australia: engagement, empowerment and integration. BMC Psychiatry. 2023;23(1):745. doi: 10.1186/s12888-023-05209-6.

[19] Calio C, Higgins-D'Alessandro A. "It's really unexplainable, but everyone here got it:" Analysis of an ASD sibling support group for emerging adults. Res Autism Spectr Disord. 2021;88:101857. doi: 10.1016/j.rasd.2021.101857.

[20] Lee C. e, Burke M, Arnold CK, et al. Correlates of current caregiving among siblings of adults with intellectual and developmental disabilities. J Appl Res Intellect Disabil. 2019;32(6):1490–1500. doi: 10.1111/jar.12644.

[21] Arnett JJ. 2024. Emerging adulthood. Oxford University Press: New York. doi: 10.1093/oso/9780197695937.001.0001.

[22] Fray L, Gore J, Harris J, et al. Key influences on aspirations for higher education of Australian school students in regional and remote locations: a scoping review of empirical research, 1991–2016. Aust Educ Res. 2020;47(1):61–93. doi: 10.1007/s13384-019-00332-4.

[23] Segrin C, Pavlich CA, McNelis M. Transitional instability predicts polymorphous distress in emerging adults. J Psychol. 2017;151(5):496–506. doi: 10.1080/00223980.2017.1335687.

[24] Simone M, Loth K, Peterson CB, et al. Social Isolation in a Population-Based Sample of Emerging Adults: Who Is on Their Own?. Emerg Adulthood. 2022;10(5):1247–1255. doi: 10.1177/21676968211021677 36111319

[25] Siblings Australia. ; 2018. Mapping Project: supports for Siblings of Children and Adults with Disability.

[26] Meltzer A, Muir K. An ecological and systems thinking approach for support to siblings with and without disabilities. Soc Theory Health. 2022;20(4):346–362. doi: 10.1057/s41285-020-00158-6.

[27] American Psychological Association. 2018. Social support. https://dictionary.apa.org/social-support.

[28] Shin E, Park M. Moderation effect of social support in the relationship between family resilience and psychological well-being perceived by teenagers who have siblings with a disability. Korean J Special Educ. 2019;54(3):123–143 doi: 10.15861/kjse.2019.54.3.123.

[29] Fredriksen T, Marie Vatne T, Bjartveit Haukeland Y, et al. Siblings of children with chronic disorders: family and relational factors as predictors of mental health. J Child Health Care. 2023;27(1):145–159. doi: 10.1177/13674935211052157.

[30] Orm S, Fjermestad K. A scoping review of psychosocial adjustment in siblings of children with attention-deficit/hyperactivity disorder. Adv Neurodev Disord. 2021;5(4):381–395. doi: 10.1007/s41252-021-00222-w.

[31] Boterhoven de Haan KL, Hafekost J, Lawrence D, et al. Reliability and validity of a short version of the general functioning subscale of the mcmaster family assessment device. Fam Process. 2015;54(1):116–123. doi: 10.1111/famp.12113.

[32] Lewandowski AS, Palermo TM, Stinson J, et al. Systematic review of family functioning in families of children and adolescents with chronic pain. J Pain. 2010;11(11):1027–1038. doi: 10.1016/j.jpain.2010.04.005.

[33] Fergus S, Zimmerman MA. adolescent resilience: a framework for understanding healthy development in the face of risk. Annu Rev Public Health. 2005;26(1):399–419. doi: 10.1146/annurev.publhealth.26.021304.144357.

[34] Feeney BC, Collins NL. A new look at social support. Pers Soc Psychol Rev. 2015;19(2):113–147. doi: 10.1177/1088868314544222.

[35] Wolff B, Magiati I, Roberts R, et al. Psychosocial interventions and support groups for siblings of individuals with neurodevelopmental conditions: a mixed methods systematic review of sibling self-reported mental health and wellbeing outcomes. Clin Child Fam Psychol Rev. 2023;26(1):143–189. doi: 10.1007/s10567-022-00413-4.

[36] Balachandran KP, Bhuvaneswari M. Expressed Emotion in Families of Children with Neurodevelopmental Disorders: A Mixed-Method Approach. Ann Neurosci. 2024;31(2):105–114. doi: 10.1177/09727531231181014 38694716

[37] York AM, Miller KG, Cahill MJ, et al. An exploratory mixed-methods analysis of factors contributing to students' perceptions of inclusion in introductory STEM courses. LSE. 2024;23(3). doi: 10.1187/cbe.23-04-0055.

[38] Mauceri S. Integrating quality into quantity: survey research in the era of mixed methods. Qual Quant. 2016;50(3):1213–1231. doi: 10.1007/s11135-015-0199-8.

[39] Shannon-Baker P. ; 2023. Philosophical underpinnings of mixed methods research in education. In International Encyclopedia of Education(Fourth Edition). (pp. 380–389). Elsevier, Philadelphia. doi: 10.1016/B978-0-12-818630-5.11037-1.

[40] Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qual Res Psychol. 2021;18(3):328–352. doi: 10.1080/14780887.2020.1769238.

[41] Braun V, Clarke V. Toward good practice in thematic analysis: avoiding common problems and be(com)ing a *knowing* researcher. Int J Transgend Health. 2023;24(1):1–6. doi: 10.1080/26895269.2022.2129597.

[42] Erdfelder E, FAul F, Buchner A, et al. Statistical power analyses using G*Power 3.1: tests for correlation and regression analyses. Behav Res Methods. 2009;41(4):1149–1160. doi: 10.3758/BRM.41.4.1149.

[43] Cohen J. ; 1988. Statistical power analysis for the behavioral sciences. Routledge, Milton Park. doi: 10.4324/9780203771587.

[44] Vederhus J-K, Høie M, Birkeland B. One size doesn't fit all: a thematic analysis of interviews with people who have stopped participating in Narcotics Anonymous in Norway. Addict Sci Clin Pract. 2020;15(1):18. doi: 10.1186/s13722-020-00191-w 32448354

[45] Whale K, Ingram JC, George S, et al. Exploring the acceptability of using low-friction bedding for patients with burns: Qualitative results from the SILKIE study. Burns. 2018;44(5):1251–1258. 10.1016/j.burns.2018.03.017 29753452

[46] Jefferies P, Vanstone R, Ungar M. The rugged resilience measure: development and preliminary validation of a brief measure of personal resilience. Applied Research Quality Life. 2022;17(2):985–1000. doi: 10.1007/s11482-021-09953-3.

[47] Zimet GD, Dahlem NW, Zimet SG, et al. The multidimensional scale of perceived social support. J Pers Assess. 1988;52(1):30–41. doi: 10.1207/s15327752jpa5201_2.

[48] Epstein NB, Baldwin LM, Bishop DS. The McMaster family assessment device. J Marital Family Therapy. 1983;9(2):171–180. doi: 10.1111/j.1752-0606.1983.tb01497.x.

[49] IBM Corp. ; 2023. IBM SPSS Statistics for Windows (29.02). IBM Corp, New York.

[50] Braun V, Clarke V. ; 2012. Thematic analysis. In. APA handbook of research methods in psychology, Vol 2: research designs: quantitative, qualitative, neuropsychological, and biological. (pp. 57–71. American Psychological Association, Washington. doi: 10.1037/13620-004.

[51] Byrne D. A worked example of Braun and Clarke's approach to reflexive thematic analysis. Qual Quant. 2022;56(3):1391–1412. doi: 10.1007/s11135-021-01182-y.

[52] Dong Y, Peng C-YJ. Principled missing data methods for researchers. Springerplus. 2013;2(1):222. doi: 10.1186/2193-1801-2-222.

[53] Madley-Dowd P, Hughes R, Tilling K, et al. The proportion of missing data should not be used to guide decisions on multiple imputation. J Clin Epidemiol. 2019;110:63–73. doi: 10.1016/j.jclinepi.2019.02.016.

[54] Hayden NK, McCaffrey M, Fraser-Lim C, et al. Supporting siblings of children with a special educational need or disability: an evaluation of Sibs Talk, a one-to-one intervention delivered by staff in mainstream schools. Support for Learning. 2019;34(4):404–420. doi: 10.1111/1467-9604.12275.

[55] Jones EA, Fiani T, Stewart JL, et al. Randomized controlled trial of a sibling support group: mental health outcomes for siblings of children with autism. Autism. 2020;24(6):1468–1481. doi: 10.1177/1362361320908979.

[56] Khor S, Fuller-Tyszkiewicz M, Capic T, et al. ; 2024. Australian normative data for subjective wellbeing. In R. A. Cummins (Ed.), Personal wellbeing index manual. 6th Edition (1st ed., Vol. 290224, pp. 53–55. Australian Centre on Quality of Life, Melbourne.

[57] Zimet G. ; 2016. Multidimensional Scale of Perceived Social Support (MSPSS) - Scale Items and Scoring Information. https://www.researchgate.net/publication/311534896_Multidimensional_Scale_of_Perceived_Social_Support_MSPSS_-_Scale_Items_and_Scoring_Information.

[58] Trew S. Made to feel different: families perspectives on external responses to autism and the impacts on family well-being and relationships. Autism. 2024;28(8):2120–2139. doi: 10.1177/13623613231221684.

[59] Andrews J, Falkmer M, Girdler S. Community participation interventions for children and adolescents with a neurodevelopmental intellectual disability: a systematic review. Disabil Rehabil. 2015;37(10):825–833. doi: 10.3109/09638288.2014.944625.

[60] Yeo G, Loo G, Oon M, et al. A digital peer support platform to translate online peer support for emerging adult mental well-being: randomized controlled trial. JMIR Ment Health. 2023;10:e43956. doi: 10.2196/43956.

[61] Bernecker SL, Williams JJ, Caporale-Berkowitz NA, et al. Nonprofessional peer support to improve mental health: randomized trial of a scalable web-based peer counseling course. J Med Internet Res. 2020;22(9):e17164. doi: 10.2196/17164.

[62] Staples LG, Dear BF, Nielssen O, et al. Characteristics and treatment outcomes for patients of a digital psychology service in regional and remote parts of Australia. Aust J Rural Health. 2025;33(2):e70032. doi: 10.1111/ajr.70032.

[63] Kostiukow A, Strzelecki W, Poniewierski P, et al. The estimation of the functioning of families with ASD children. AIMS Public Health. 2019;6(4):587–599. doi: 10.3934/publichealth.2019.4.587.

[64] Schiltz HK, McVey AJ, Gonring K, et al. Examining differences in parenting stress, parenting efficacy, and household context among mothers of youth with autism and/or ADHD. J Child Fam Stud. 2022;31(3):774–789. doi: 10.1007/s10826-021-02083-2.

[65] Lamsal R, Ungar WJ. Impact of growing up with a sibling with a neurodevelopmental disorder on the quality of life of an unaffected sibling: a scoping review. Disabil Rehabil. 2021;43(4):586–594. doi: 10.1080/09638288.2019.1615563 31106599

[66] Yildirim MS, Firat MÖ, Atay ME, et al. Effects of demographic characteristics on burnout, psychological resilience, and family functioning in parents of children with disabilities. BMC Psychol. 2025;13(1):872. doi: 10.1186/s40359-025-03238-2 40770778

[67] Jackson SZ, Pinto-Martin JA, Deatrick JA, et al. High Depressive Symptoms, Low Family Functioning, and Low Self-Efficacy in Mothers of Children With Autism Spectrum Disorder Compared to Two Control Groups. J Am Psychiatr Nurses Assoc. 2024;30(2):300–312. doi: 10.1177/10783903221104147 35708452

[68] Ozturk Y, Onat M, Ozyurt G, et al. Relationships between family functioning, parenting and peer victimization inadolescent depression: A cross-sectional study. North Clin Istanb. 2021;8(3):212–221. https://doi.org/10.14744/nci.2020.36744

[69] Fredriksen T, Vatne TM, Haukeland YB, et al. Evaluation of Siblings' Perceived Relationship Outcomes with Their Parents in an Open Trial of the SIBS Intervention for Children with Chronic Disorders. J Child Fam Stud. 2024;33(7):2271–2285. 10.1007/s10826-024-02824-z

[70] Carretta TR, Ree MJ. Correction for range restriction: lessons from 20 research scenarios. Mil Psychol. 2022;34(5):551–569. doi: 10.1080/08995605.2021.2022067.

[71] Preston CC, Colman AM. Optimal number of response categories in rating scales: reliability, validity, discriminating power, and respondent preferences. Acta Psychol (Amst). 2000;104(1):1–15. doi: 10.1016/S0001-6918(99)00050-5.

[72] American Psychological Association. Publication Manual of the American Psychological Association. (7th ed.). American Psychological Association; 2020.

[73] World Health Organisation. International Statistical Classification of Diseases and Related Health Problems. Eleventh Revision. ICD-11). https://icd.who.int/en/. 2019;