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Review article

A systematic review of social support for siblings of children with neurodevelopmental disorders

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ABSTRACT

Background: Social support is a protective factor for siblings of children with neurodevelopmental disorders.
Aims: We reviewed studies on social support received by siblings of children with neurodevelopmental disorders.
Methods and procedures: We conducted a pre-registered systematic review (CRD42020207686), searching PsycINFO, MEDLINE, Web of Science, and Scopus.
Outcomes and results: Fifteen articles were eligible for the review, 13 of which used cross-sectional designs. Two studies investigated sibling social support after an intervention. Multiple variables were negatively related to social support (e.g., sibling depression, loneliness, stress). Variables that were positively related to social support included prosocial behavior, competence (academic, social, and activity-related), problem-focused coping, and family quality of life. Potential moderators of the relationship between social support and psychosocial adjustment included the type of disorder of the affected sibling and the type of social support provider. We conclude with an overview of the reliability and validity of the seven social support measurements used across the studies.
Conclusions and implications: Lower levels of social support are associated with more negative psychosocial adjustment among siblings of children with neurodevelopmental disorders. We encourage future researchers to further investigate ways to increase social support for siblings to improve outcomes.

1. Introduction

The sibling relationship encompasses multiple developmental opportunities. Through care, play, and conflicts, siblings learn about themselves, each other's feelings, and physical and emotional boundaries. Positive sibling relationships can foster the development of resilience (Buist, Deković, & Prinzie, 2013; Dirks, Persram, Recchia, & Howe, 2015; Kramer, 2014). However, for siblings of children

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with neurodevelopmental disorders (NDs), sibling-related developmental possibilities may unfold differently. NDs represent an umbrella term covering a broad range of congenital and enduring disorders with biological etiology associated with the central nervous system (Thapar, Cooper, & Rutter, 2017). Examples include autism spectrum disorder, Down syndrome, and rare genetic disorders. NDs can affect cognitive, behavioral, and psychosocial functions, are chronic and can be difficult to treat. Herein, we defined NDs as disorders involving disruption to the development of the central nervous system, affecting cognitive, social and/or motor functioning. This definition is similar to that found in the Diagnostic and Statistical Manual of Mental Disorders–Fifth edition (DSM-5; (APA, 2000) and ICD-11 (World Health Organization, 2018). Cerebral palsy and rare genetic disorders can be included under this definitions as well (Thapar et al., 2017). Down syndrome is strongly associated with intellectual or cognitive disabilities as well as autistic features (Nærland, Bakke, Storvik, Warner, & Howlin, 2017) and is therefore also considered an ND. The prevalence of NDs varies globally (Bitta, Kariuki, Abubakar, & Newton, 2018). For individual disorders such as attention deficit/hyper activity disorder (ADHD) the mean prevalence per 1000 individuals is 60.8 and for learning disabilities the prevalence is 80.0/1000 (Bitta et al., 2018). Estimates for the prevalence of ASD range from one in 100 people (Richards, Jones, Groves, Moss, & Oliver, 2015), to one in 44 for children aged 8 years (Maenner et al., 2021).

Many, if not most, of the children with NDs have siblings.

1.1. Risk and protective factors

Siblings of children with NDs are at risk of various negative emotional and behavioral outcomes (Rossiter & Sharpe, 2001; Shivers et al., 2019; Vermaes, van Susante, & van Bakel, 2012) including internalizing problems such as anxiety and depression symptoms (Hastings, 2003; Petalas et al., 2012; Verté, Roeyers, & Buysse, 2003). A recent review examining psychosocial adjustment in siblings of children with ADHD found more mental health problems (small to large effect sizes) compared to siblings of typically developing siblings (Orm, Fjermestad et al., 2021). Moreover, siblings experienced more family conflicts and less support compared with controls (medium effect sizes) and poorer quality of life and less resilience (large effect).

Differences in sibling outcomes have been identified across disorders, with siblings of children with autism spectrum disorders found to be at higher risk for negative psychosocial functioning compared to siblings of children with Down syndrome and other developmental and intellectual disabilities (Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2012; Shivers et al., 2019; Tomeny, Barry, & Bader, 2012). Although these results indicate group differences in sibling outcomes there is support for taking a cross-disorder approach in sibling research because there is not a unique effect of the type of disorder on sibling adjustment (Vermaes et al., 2012). A cross-disorder approach involves considering sibling outcomes across various disorder and not by diagnosis, name, or type. Rather, a more probable factor in sibling adjustment is the impact of the disorder on everyday family life (Vermaes et al., 2012). A cross-disorder approach is useful because differences in sibling outcomes appear to vary according to the presence or absence of various individual, parental, familial, and contextual risk factors, rather than varying according to the specific features of individual disorders (Orm, Fjermestad et al., 2021). From an empirical perspective, siblings of children with chronic disorders who experience less open family communication (D. S. Cohen, Friedrich, Copeland, & Pendergrass, 1989; Incledon et al., 2015; Petalas, Hastings, Nash, Dowey, & Reilly, 2009), more parental stress (Giallo & Gavidia-Payne, 2006; O'Brien, Duffy, & Nicholl, 2009), and poorer coping strategies (Cate, (Ineke), & Loots, 2000) have been found to be more at risk than siblings with open family communication, well-adjusted parents and better coping strategies. Unpredictability of the family situation, with associated factors such as sense of control and access to information, has also been found to affect sibling risk (Incledon et al., 2015). Having a sibling with a chronic disorder is also associated with positive outcomes such as effective coping skills, development of compassion and empathy, and positive attitudes towards providing aid to others (Bontinck, Warreyn, Paelt, der, Demurie, & Roeyers, 2018; Ferraioli, Hansford, & Harris, 2012; Orm & Vatne, 2021; Shivers, 2019). Conceptually, there are therefore strong implications for understanding sibling adjustment through a family system framework which presupposes that siblings are influenced by the bidirectional and dynamic family context, and also the wider cultural and societal systems in which they grow up (Kovshoff, Cebula, Tsai, & Hastings, 2017; Rossiter & Sharpe, 2001).

Research on sibling risk factors is important and increasing. However, there is a parallel stated need to uncover potential protective factors to inform sibling caregivers and interventionists who aim to prevent potential negative psychological and behavioral outcomes for siblings (K. Cebula & Kovshoff, 2020; Vermaes et al., 2012). Examples of modifiable protective factors include open parent-sibling communication (Haukeland et al., 2020) and social support (Cate et al., 2000; Incledon et al., 2015; Vermaes et al., 2012). Incledon and colleagues (2015) reviewed 17 studies on modifiable factors associated with mental health in siblings. The authors concluded that parental and sibling psychoeducation and social support may enhance children's mental health. The review focused on siblings of children with a variety of chronic health conditions. The majority focused on siblings of children with cancer, similar to other major reviews (Vermaes et al., 2012). The focus of the current paper is on social support for siblings of children with ND in an effort to identify protective factors to this population.

1.2. Definition of social support

Social support has been defined in various ways. Cobb (1976) classical definition of social support entails three components; feeling loved, feeling valued, and belonging to a group or network. A common understanding is that social support entails emotional, practical, or informational elements such as receiving expressions of empathy, love, and care, help that alleviates stress, and trustworthy information (e.g., about the diagnosis and the child's prognosis) (APA Dictionary of Psychology, n.d.). Social support has been understood to benefit recipients through two possible mechanisms; as a moderator or buffer against stress (S. Cohen & Wills, 1985;

Vangelisti, 2009), or through meeting a fundamental need for attachment (Harel, Shechtman, & Cutrona, 2011; Sandler & Barrera, 1984; Sarason & Sarason, 2009).

It is also important to consider the different providers of support, such as informal providers (family and friends) versus more formal support systems, such as clinical support services or schools (Sandler & Barrera, 1984; Sarason & Sarason, 2009). Another important aspect is the potential recipient's *perception* of the support. Sarason and Sarason (2009) suggested that social support may be linked to the relational self in the way that people are inherently "wired" to perceive others as supportive or not (e.g., depending on their attachment style and cognitive schemas). The perception of the availability of support and the amount of support received are the two most common psychological perspectives on social support (Sarason & Sarason, 2009; Vangelisti, 2009). Uchino (2009) mapped the beneficial influence of social support on physical and mental health and highlighted the distinction between the perception of support and the amount of support received. Perceived support was reported to be more strongly linked to better health outcomes than objectively measured levels of support received (Uchino, 2009).

Social support is considered bidirectional (i.e., person→environment and vice versa). Furthermore, social support is considered to be moderated by gender, culture, personal development, and the relationship between the recipient and the provider (Sarason & Sarason, 2009). The sibling relationship operates in the broader context of the family and community (Rossiter & Sharpe, 2001). Hence, some siblings may benefit more from formal forms of support than others, and benefits may vary throughout childhood and according to the severity of the disorder of the affected child. Social support has been found to be a strong predictor of resilience, both in the general and in the chronic illness populations (Incledon et al., 2015; Uchino, 2009). For siblings of children with chronic disorders, both emotional and informational support has been found to be associated with fewer behavior problems and can play a protective role for mental health (Hastings, 2003; Incledon et al., 2015).

The current study is a systematic review of the level of social support received by siblings of children with NDs. We also investigate variables associated with social support and potential moderators. Moreover, we identify and present an overview of social support measurement instruments used in this field and provide recommendations for the use of the social support construct in future sibling research.

We investigated the following research questions: 1) What is the level of social support received by siblings of children with NDs? 2) Is there a difference in social support levels between groups of siblings who have a brother or sister with different NDs, or between different types of support providers? 3) Which variables are social support related to, and are there potential moderators between social support and other variables? 4) How is social support for siblings of children with ND measured across studies, and what is the reliability and validity of these instruments?

2. Method

This systematic review was pre-registered in PROSPERO (CRD42020207686) to avoid duplication of reviews, and to ensure transparency of the research plan, adherence, and reproducibility (Stewart, Moher, & Shekelle, 2012).

2.1. Search strategy

On the 6th of October 2021 we searched four databases: PsycINFO, MEDLINE, Web of Science, and Scopus. We used a search string comprising search words related to social support, NDs, and siblings. See Table 1 for the search string. We also hand-searched the reference lists of all included articles for additional studies.

2.2. Study selection and procedure

The software program Rayyan (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016) was used for study screening and selection by the first and second author independently. Studies were first selected by relevant title or abstract (see Fig. 1). The two reviewers had substantial agreement (Cohen's kappa =0.64, percentage agreement = 87.4%). Disagreements were resolved by discussion. Three additional authors (author three, four and six) participated in selecting articles by reading the full text of the initially selected studies. Each study was checked for eligibility by at least two authors. The first and second author screened in different pairs with the third, fourth and sixth author. We used the PRISMA checklist and flow chart in reporting of the results (Moher, Liberati, Tetzlaff, Altman, & Group, 2009).

Table 1
Search terms for PsycINFO, MEDLINE, Web of Science, and Scopus.

Search string	
Concept	Search words
Social support	"social support"
Neuro-developmental disorders	"autis* " OR "ASD" OR "developmental disabil* " OR "intellectual disabil* " OR "communication disorder* " OR "attention deficit* " OR "learning disorder* " OR "motor disorder* *" OR "learning disabil* " OR "tourette syndrome" OR "tic disorder* " OR "rare disorder* " OR "down syndrome" OR "williams syndrome" OR "cerebral palsy" OR "fragile x syndrome" OR "rett syndrome" OR "obsessive compulsive disorder* " OR "OCD" OR "specific language impairment"
Sibling	"sibling* "

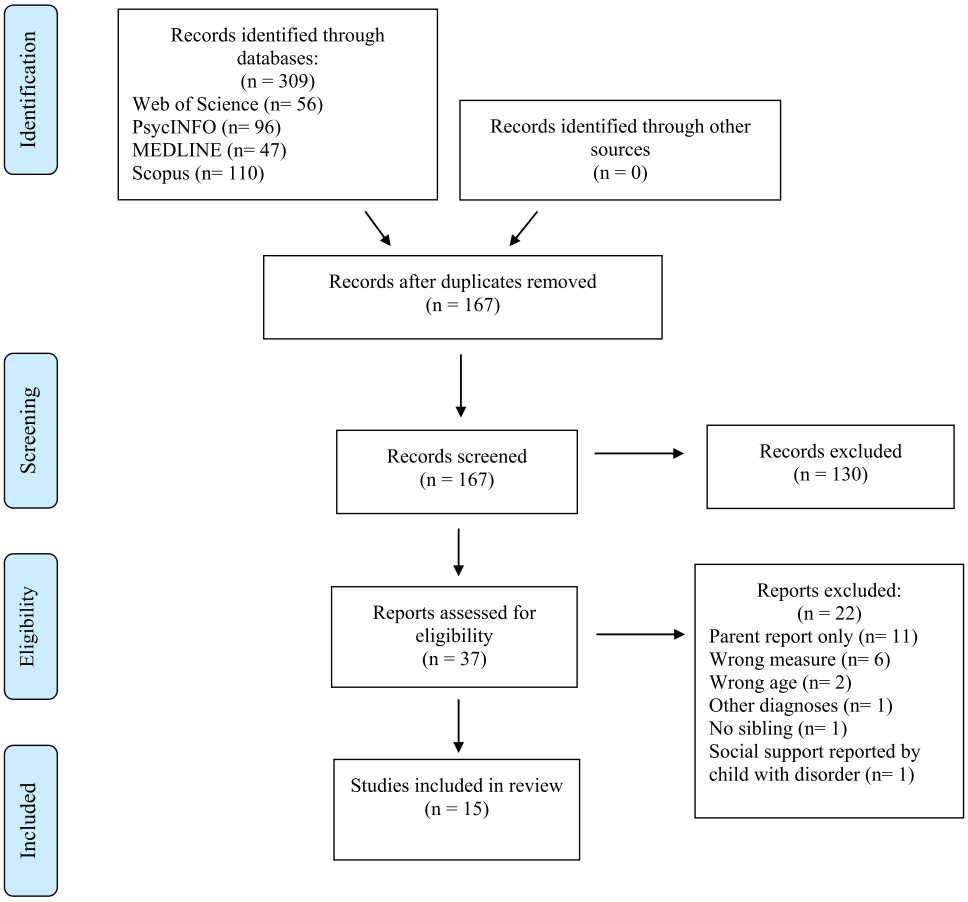

Fig. 1. PRISMA 2009 Flow Chart.

2.3. Eligibility criteria

We included studies if they (a) used measures of social support for siblings of children with NDs; (b) involved siblings aged 18 or under who have a brother or sister with a ND; and (c) were peer-reviewed quantitative studies published in English, ranging from descriptive cross-sectional studies to randomized controlled intervention studies. We had no restrictions on publication period up until the time of the search in October 2021.

2.4. Quality appraisal

We used the Mixed Methods Appraisal Tool (MMAT) for quality assessment (Hong et al., 2018). The MMAT allows for the appraisal of the methodological quality of a variety of empirical study methods. Interrater agreement percentage for the MMAT screening was generated as follows: Included studies were divided between the first, second, third, fourth and sixth author and screened individually using the MMAT and then divided and discussed in pairs. Following MMAT instructions, we scored each paper on seven screening questions with the categories “yes”, “no” or “cant tell” (no information). We followed the coding guidelines presented in the MMAT manual and for the one item regarding missing data we used the recommended cut-off value of 20%. The agreement was registered based on whether raters agreed or disagreed on category scores on the seven screening questions. At least two reviewers assessed each paper. Agreement percentage for the quality assessment was calculated based on the total number of agreements divided by the total number of questions (7) and multiplied by 100. The initial agreement between reviewers was 87.6%. All disagreements were resolved by discussion.

2.5. Data synthesis

Extraction of information from the included studies was distributed between the first, second, third, fourth and sixth author and completed individually. We calculated the levels of social support across studies based on the maximum possible level of support according to each scale. Effect sizes for the relationships between social support and other variables were extracted by the second,

Table 2
Included study characteristics.

Author/ year	Country	NDs and N (siblings)	Range or mean age in years (SD)	Gender ratio %	Study design and setting	Control group	Main social support-related research question
Cebula (2012)	UK	ASD 142	9.1–9.9 (2.3–3.3)	52% girls 48% boys	Quantitative non-randomized home-based ABA intervention	Comparison group (no ABA intervention)	Is social support comparable between ABA and control group and/ or related to sibling adjustment?
Cebula, Gillooly, Coulthard, Riby, and Hastings (2019)	UK	WS 41	10.6 (3.8)	78% girls 22% boys	Quantitative non-randomized	–	Investigate psychosocial adjustment in siblings of individuals with WS
Fisman et al. (1996)***b**	Canada	PDD 46 DS 45 TD 46	8–16	61% girls 39% boys 62% girls 38% boys 61% girls 39% boys	Quantitative non-randomized	Sibling of TD children	Factor analyzed with other variables
Fisman et al. (2000)***b**	Canada	PDD 42 DS 42 TD 43	4–18	n/a	Quantitative non-randomized Case control sample from longitudinal study	Sibling of TD children	Factor analyzed with other variables
Garrido, Carballo, and Garcia-Retamero (2020)	Spain/ Germany	ASD 41 TD 37	8.3 (2.1)	46% girls 54% boys	Quantitative non-randomized Case-control study	Siblings of TD children	Does social support predict family quality of life?
Kaminsky and Dewey (2002)	Canada	ASD 30 DS 30 TD 30	11.7 (3.0)	n/a	Quantitative non-randomized Case-control study	Sibling of TD children	Are feelings of social support and loneliness related to psychosocial adjustment in siblings of children with ASD?
Lovell and Wetherell (2016)	UK	ASD 20 TD 20	12.6 (3.1)	44% girls 56% boys	Quantitative non-randomized Case-control study	Sibling of TD children	Can individual variations in social support explain variation in siblings of children with ASD psychological and physiological adjustment?
Orsmond et al. (2009)	USA	ASD 56 (Excluding adult sample)	15.98 (SD 1.71)	64% girls 36% boys	Quantitative non-randomized, sample from longitudinal study	Compared diagnostic groups	Does social support predict engagement in shared activities and/ or affect sibling relationships?
Phillips (1999)	USA	DD 180	9–12	69% girls 31% boys	Quantitative non-randomized Intervention (After school program)	Active control group	Are social support levels affected by intervention?
Pollard, Barry, Freedman, and Kotchick (2013)	USA	ASD 81 DS 83	13.32 (1.90)	74% girls 26% boys	Quantitative non-randomized Case -control study	Compared diagnostic groups	Does social support, as part of sibling relationship quality, differ between groups of siblings? Is social support related to anxiety?
Rankin et al. (2017)***a**	USA	ASD 113	13.3 (1.8)	50% girls 50% boys	Quantitative non-randomized cross-sectional	–	Level of social support is compared between parent and child differences in risk report.
Shivers and McGregor (2019)	USA	ASD 116 DS 99	14.9 (1.8)	53% girls 47% boys	Quantitative non-randomized Case -control study	Compared diagnostic groups	Do siblings of children with ASD differ from DS siblings on social support?
Tomeny et al. (2019) ***a**	USA	ASD 112	13.3 (1.8)	49% girls 51% boys	Quantitative non-randomized cross sectional	–	Investigated the impact of discrepancy between the frequency and importance of social support on siblings emotional and behavioral problems.
Tsai, Cebula, and Fletcher-Watson (2016)	Taiwan & UK	ASD 155	12.7 (2.8)	Taiwan sample: 59% girls 41% boys UK sample: 63% girls 37% boys	Quantitative non-randomized cross-sectional	Compared diagnostic groups	Does social support influence sibling adjustment? Social support investigated as part of "family adaptive resources"
Wolf et al. (1998)***b**	Canada	PDD 46 DS 45 TD 46	8–16	61% girls 59% boys	Quantitative non-randomized Case control. Sample from longitudinal study.	Sibling of TD children	Correlations between provider of social support and mental health.

Notes. *a = siblings from the same sample, *b = siblings from the same sample. Because the social support related research questions and analyses differed across the various studies using the same samples, we present the study characteristics according to each paper. However, the overlapping samples were only counted as one in calculations and summaries of total results. ND= neurodevelopmental disorder, ASD= autism spectrum disorder, PDD= pervasive developmental disorder, DD= developmental disorder, DS= Down syndrome, WS= William syndrome, TD= typically developing siblings, USA= United States of America, UK= United Kingdom, ABA = Applied Behavior Analysis, SD= standardized deviation.

third, and sixth author individually and double checked by the first author. Disagreements were resolved through discussion. We calculated differences between groups using Cohen's *d* (mean group 1 – mean group 2 / SD pooled). For intervention studies, we calculated the difference in social support between the control and intervention groups. Furthermore, we extracted effect measures for correlations between social support and other variables including Pearson's *r* correlations, r-square, and standardized beta coefficients (β). Finally, we collected psychometric properties including validity and reliability (internal consistency) of the social support measurement instruments directly from the included studies.

3. Results

The initial search gave 309 hits. After screening for duplicates, 167 studies remained. These studies were screened for inclusion, resulting in 37 studies. Based on the screening of full texts, we excluded 22 studies. Fifteen studies remained and were included in this review. Screening of reference lists of the included studies did not result in the inclusion of more studies. See Fig. 1 (PRISMA flow chart) for an overview of the study selection process and reasons for exclusion of screened full-text articles.

3.1. Overview

The 15 included studies involved 1312 siblings aged between 4 and 18 years. Siblings had a brother or sister with a range of different NDs, labelled as autism spectrum disorder (n = 754 siblings), Down syndrome (n = 158), developmental disorder (n = 180), Williams syndrome (n = 41), and pervasive developmental disorder (n = 46). Of the 15 included studies seven specified by which diagnostic manual or screening methods the affected siblings met criteria for a ND diagnosis (DSM-TR-IV, DSM-5, ADI-R interview and ADOS-G: Garrido, 2020; DSM-IV: Kaminsky and Dewey (2002); genetic testing: Cebula, 2019; DSM-IZZ-R: Fisman et al. (1996); Fisman, Wolf, Ellison, and Freeman (2000) and Wolf, Fisman, Ellison, and Freeman (1998); ADI-R interview: Orsmond, Kuo, and Seltzer (2009). The remaining studies did either not specify this information or diagnosis were confirmed by parents or the families were recruited through clinical services or relevant support groups. A total of 133 siblings of typically developing children were used as controls across the studies. The included studies originated from North America (10) USA (n = 6), Canada (n = 4), Europe (n = 4), and Asia (n = 1). The 15 studies represented 13 unique samples of which two papers reported from the same sample (Rankin, Tomeny, & Barry, 2017; Tomeny, Rankin, Baker, Eldred, & Barry, 2019), and three papers (Fisman et al., 1996, 2000; Wolf et al., 1998) reported from the same longitudinal study. Two studies reported social support before and/or after an intervention or program (Cebula, 2012; Phillips, 1999). See Table 2 for an overview of the characteristics of the included studies.

3.2. Quality rating

All studies qualified for "yes" under the two initial screening questions regarding clarity of the research question and whether the collected data can answer the research question. Thirteen studies were categorized as *Quantitative non-randomized*. Four of these studies did not qualify for "yes" for representativeness of the sample to the target population (Cebula et al., 2019; Cebula, 2012; Garrido et al., 2020; Kaminsky & Dewey, 2002). One study did not qualify for "yes" regarding whether confounders were accounted for in the design and analysis (Cebula, 2012). One study fell under the study category *Quantitative randomized controlled trials* (Phillips, 1999). This study did not qualify for "yes" regarding whether outcome assessors were masked to the intervention, whether participants adhered to the assigned intervention or if randomization was performed appropriately as this information was not provided in the article. One study fell under the study category *Quantitative descriptive* (Pollard et al., 2013) and qualified for "yes" under four of five screening questions except for whether the risk of nonresponse bias was low. In sum, the quality of the included studies was satisfying, with main issue concerning representativeness of the samples to the target population, risk of nonresponse bias and lack of information on specific study-methods. See Table S1 for an overview of the MMAT ratings in supplementary material.

3.3. Level of social support

For the studies that presented social support scores and information on scale range (n = 6), we calculated the percentages of the maximum scores as an indication of the level of social support. Overlapping samples were only counted as one in calculations. In sum, these studies reported social support scores across siblings of children with a range of NDs and according to the providers, ranging from 51.0% (Pollard et al., 2013) to 92.5% (Kaminsky & Dewey, 2002) of the maximum score, with a mean of 75.6% social support score across all diagnostic groups. The percentages indicate the reported level of support when 100 is the maximum score. There was little variation in the mean level of social support percentage across diagnostic groups; siblings of children with Down syndrome = 72.0%, autism spectrum disorder = 70.0%, Williams syndrome = 80.5%. In comparison, the mean level of social support for siblings of typically developing children (controls) = 86.0%. There was considerable variation across different studies and little variation across diagnostic groups.

3.3.1. Comparison of social support levels for siblings of children with different diagnoses

Eight studies investigated social support in more than one group of siblings. Comparison groups were either siblings of children with different NDs (Pollard et al., 2013; Shivers & McGregor, 2019) or siblings of typically developing children as controls (Garrido et al., 2020; Lovell & Wetherell, 2016). Four studies compared with both different NDs and typically developing control siblings (Fisman et al., 1996, 2000; Kaminsky & Dewey, 2002; Wolf et al., 1998). However, three of these four studies reported from the same

longitudinal study sample and did not report the level of social support (Fisman et al., 1996, 2000; Wolf et al., 1998).

Among the two studies comparing social support between siblings of children with different disorders, one study found no significant difference between groups (Shivers & McGregor, 2019) and one study found higher levels of social support for siblings of children with Down Syndrome compared to siblings of children with autism spectrum disorder (effect size $d = 1.39$; Pollard et al., 2013). For the two studies that compared social support between siblings of children with a disorder to siblings of typically developing children, one study found no difference (Lovell & Wetherell, 2016). The other found significantly lower social support for siblings of children with autism spectrum disorder compared to typically developing controls (effect size $d = 1.98$; Garrido et al., 2020).

3.3.2. *Differences in levels of social support received based on provider of support*

In six studies, siblings reported receiving support from different providers, giving separate social support scores for each provider (e.g., subscales). We found no consistent pattern in levels of support according to the provider of support across siblings of children with or across sibling controls who had a typically developing brother or sister.

3.3.3. *Social support compared between intervention groups*

Two studies compared social support among siblings attending different programs or interventions. One study found no difference in social support levels between siblings of children with autism in families who had participated in an Applied Behavior Analysis program and those who did not attend this program ($d = 0.04$; Cebula, 2012). The aim was to investigate whether interventions aimed at the behaviors of the child with a disorder would benefit the sibling following family systems theory, emphasizing the reciprocal influences of family members on each other. Another study found that siblings of children with a ND reported significantly higher social support after attending an after-school intervention program compared with controls ($d = 3.88$–0.74; Phillips, 1999). This intervention was provided to siblings of children with NDs from low-income families from African American communities and involved a 15-week after-school program at a community center that included sibling group discussions about the disorder, recreational activities, and homework assistance. According to the study, the goal was to alleviate stress caused by having a sibling with a disorder by providing information about the disorder and by creating a context that provided social support from peers and adults (Phillips, 1999).

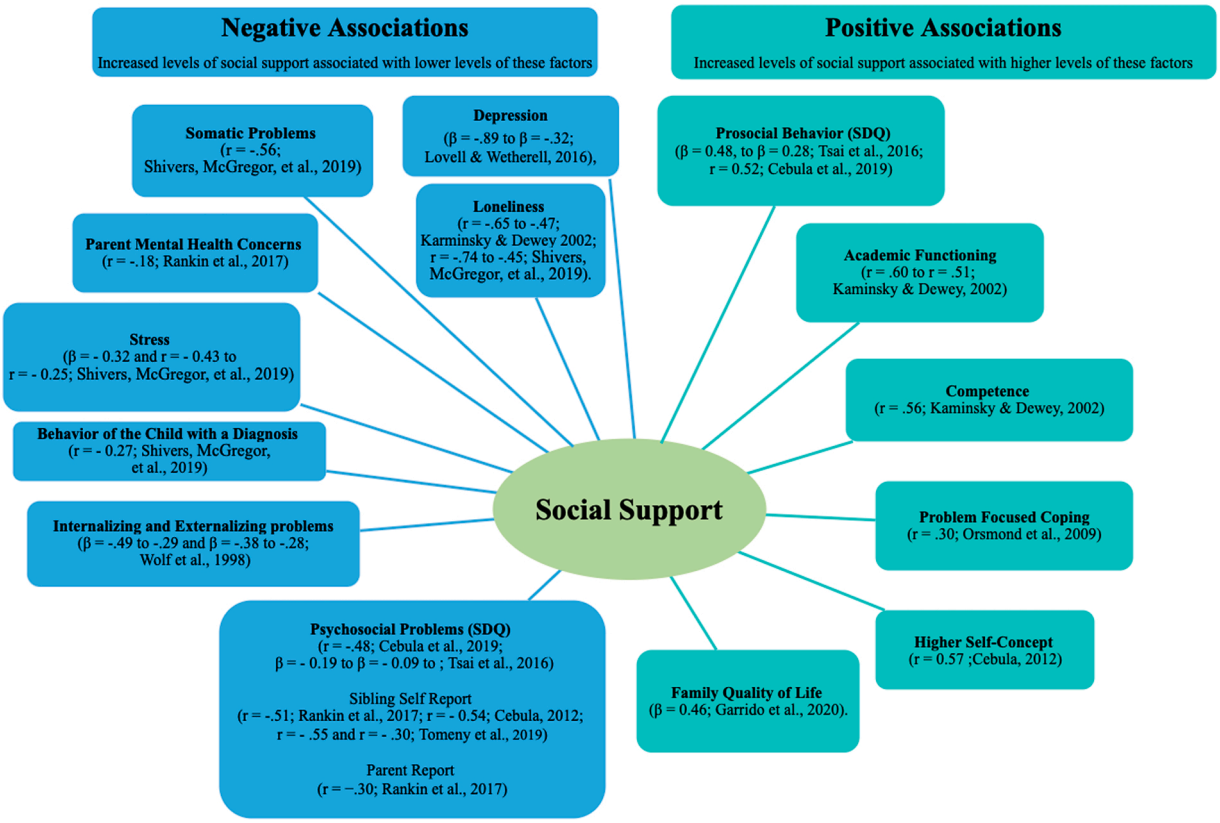

Fig. 2. Variables Associated with Social Support in the Included Studies. Notes. *SDQ = Strengths and Difficulties Questionnaire.

3.4. Relationships between social support and other variables

See Fig. 2 for an overview of the relationships between social support and other variables. Across the included studies, social support was significantly and negatively associated with a variety of sibling individual variables such as depression (Lovell & Wetherell, 2016), loneliness (Kaminsky & Dewey, 2002; Shivers & McGregor, 2019), stress (Shivers & McGregor, 2019), internalizing and externalizing problems (Wolf et al., 1998), general mental health measures (Cebula et al., 2019; Cebula, 2012; Rankin et al., 2017; Tomeny et al., 2019; Tsai et al., 2019), somatic problems (Shivers & McGregor, 2019), and with contextual and family-related variables such as parental mental health concerns (Rankin et al., 2017) and problem behavior of the child with ND (Shivers & McGregor,

Table 3
Overview of Social Support Measures.

SS Scale	Subscales	Items and scoring	Reliability and Validity Cronbach's alpha	Studies
The Social Support Scale for Children (Harter, 1985)	Parents Teachers Close friend Classmate	24 items, 6 per subscale with scores ranging from 1 to 4 and total range of 6–24 scores per subscale and total score from 24 to 96	Internal subscale reliabilities: α = 0.72–0.88. Validity data have shown a significant correlation between perceived support by classmates and parents and the child's self-concept.	Cebula (2012) Fisman et al. (2000) Fisman et al. (1996) Kaminsky and Dewey (2002) Lovell and Wetherell (2016) Wolf et al. (1998)
Child and Adolescent Social Support Scale (CASSS;Malecki & Demaray, 2002)	Parents Teachers Classmates People in school Friends	40–60 * -item self-report frequency of support rated from 1 (Never) to 6 (Always) yielding five subscale scores, corresponding to providors of support, and a total score.	Good internal consistency, test-retest reliability, and convergent and discriminant validity. Subscale perceived support from parents: α = 92. Importance and frequency subscale: α = 0.97 (found in both Taiwanese and UK samples for frequency subscale).	Rankin et al. (2017) Tomeny et al. (2019) Tsai et al. (2016)
Perceived Social Support Scale (Procidano & Heller, 1983)	Mother Father Friend	20 items, scores ranging from 0 to 20 with true or false for each statement/item.	Test–retest reliability, internal consistency, and construct validity of the measure = high. α = for adolescent were 0.86 for support from mother; 0.87, for support from father; and 0.87 for support from friends.	Orsmond et al. (2009)
Modified version of the Perceived Social Support Scale-Revised (PSSS-R;Dubois, Felner, Brand, Phillips, & Lease, 1996; Procidano & Heller, 1983)	Family Peers School personnel Centre staff (added)	30 items in total + 10 items for additional subscale. No further information available on scoring.	For the subscales α = above.85 and test-retest correlations ranging from.70 to.87. For this sample, α = 0.82 − 0.89. "Community center staff" subscale: α = 0.85	Phillips (1999)
Survey of Children's Social Support: short version (SCSS-SV:Dubow, Edwards, & Ippolito, 1997)	Peers Family Teacher	Scores ranging from 3 to 15 in each subscale.	Good internal consistency for subscales family: α = 0.80, teachers: α = 0.92, peers: α = 0.85	Cebula et al. (2019)
Structural Social Support (Berkman & Syme, 1979)	n/a, however measures amount, frequency of support and interaction.	Scores ranging from 3 to 30 in total. No further information available	Good internal consistency: Cronbach's = 0.94.	Garrido et al. (2020)
The sibling domain of the Network of Relationships Inventory (NRI;Furman & Buhrmester, 1986)	(a) reliable alliance (b) enhancement of worth (c) affection (d) companionship (e) instrumental help (f) intimacy (g) nurturance	Scores ranging from 1 to 5 on each item in subscales (3 items in each scale). Total maximum subscale score = 15 and minimum = 3. Total minimum score = 21 and total maximum = 105	Relationship quality α = 0.81, social support α = 0.93. Reliability of the responses to the NRI is acceptable with measures of α overall mean for each category equaling.80. Support (including satisfaction and the social provisions): α = greater than.90. Test–retest reliability was measured over a 1-month period with Pearson's r values for each of the qualities ranging from.66 − 0.70	Pollard et al. (2013)
Multidimensional Scale of Perceived Social Support (Dahlem, Zimet, & Walker, 1991)	Friend Family Significant other	12 items ranked on a 7-point Likert scale (1 = very strongly disagree to 7 = very strongly agree) for a total score ranging from 12 to 84.	Chronbach's α for total scale = 0.92. validated in children as young as 11years: α = 0.88	(Shivers & McGregor, 2019)

Notes. *Differences in items were reported across studies using the same scale

2019). Social support was significantly and positively associated with sibling individual factors such as problem-focused coping (Orsmond et al., 2009), prosocial behavior (Cebula et al., 2019; Tsai et al., 2016), higher self-concept (Cebula, 2012), family-related quality of life (Garrido et al., 2020), academic functioning (Kaminsky & Dewey, 2002), and competence (academic, social, and in activities) (Kaminsky & Dewey, 2002).

3.4.1. Potential moderators

Several studies reported that the association between social support and related variables depended on other specific variables. Such potential moderators included the type of disorder (e.g., autism spectrum disorders versus Down syndrome), the providers of social support (e.g., family, friends, teachers), informant discrepancies on child mental health scores (e.g., child versus parent); intervention status (e.g., receiving intervention or not), and perceived importance and amount of social support. The most commonly assessed potential moderator was sibling disorder type (autism spectrum disorder). This factor appeared to be a potential moderator for (1) the relationship between social support and anxiety when sibling relationship quality was low (Pollard et al., 2013). (2) ND type (autism spectrum disorder) was a potential moderator for the relationship between loneliness and social support from friends (Kaminsky & Dewey, 2002). (3) ND type (autism spectrum disorder) was a potential moderator for the negative effect of lower social support on family quality of life (Garrido et al., 2020). (4) ND type was found to be a potential moderator for the relationship between teacher and friend support and parent and teacher reports of externalizing problems (Wolf et al., 1998). Another study only found lower social support for siblings where there was a discrepancy between parent and sibling reports on sibling mental health (Rankin et al., 2017). These siblings also had parents with more mental health concerns about themselves and siblings with more severe symptoms of autism spectrum disorder (Rankin et al., 2017).

3.5. Measures of social support

See Table 3 for an overview of the measures of social support used in the reviewed studies including subscales, scale ranges, and reported validity and reliability data. The *Social Support Scale for Children* by Harter (1985) was used in four unique study samples (Cebula, 2012; Fisman et al., 1996, 2000; Kaminsky & Dewey, 2002; Lovell & Wetherell, 2016; Wolf et al., 1998) and the *Child and Adolescent Social Support Scale* (Malecki & Demaray, 2002) was used in two unique studies (Rankin et al., 2017; Tomeny et al., 2019; Tsai et al., 2016). The rest of the presented measurement instruments were only used once (single studies). There was considerable variation in what the scales measured regarding social support, ranging from measures of perceptions of support to amounts, importance, and frequency of support received. Moreover, different scales included different subscales for different providers of support. All measures of social support in the reviewed studies had some evidence of adequate psychometric properties, with alphas (i.e., internal consistency) in the range adequate (0.70 s) to excellent (0.90 s). The most widely used measure, *The Social Support Scale for Children* (Harter, 1985), also had evidence for convergent validity through significant correlation with the child's self-concept. However, the second most widely used measure, the *Child and Adolescent Social Support Scale* (CASSS; Malecki & Demaray, 2002) is more recent and has demonstrated more robust psychometric properties with excellent alphas (i.e.,.90 s), adequate test-retest reliability, and convergent and discriminant validity.

4. Discussion

We systematically reviewed studies of social support among siblings of children with NDs. To our knowledge, this is the first review to summarize the levels, related variables, and measurements of this potential protective factor for such siblings. Echoing the results of other sibling reviews (Meadan, Stoner, & Angell, 2010; Orm & Vatne, 2021; Orm, Fjermestad et al., 2021; Shivers et al., 2019; Tomeny et al., 2012) our review shows significant heterogeneity and mixed findings across studies. This is probably due to the fact that there is a large variation in how siblings adjust to their experience of being a brother or sister of a child with a ND. At the same time, our findings suggest that social support is important to consider in relation to siblings' adjustment and that social support may be an important protective factor for siblings at risk.

Our first research question concerned the level of social support for siblings of children with NDs. We found that overall siblings report receiving high levels of social support, with a tendency for somewhat lower support levels among siblings of children with autism spectrum disorders compared to siblings of children with the other ND types and typically developing children. These results may on one hand reflect that there may be disorder-specific differences in perceptions of social support, similar to the disorder-specificities reported in overall psychosocial functioning (Shivers, Jackson, & McGregor, 2019). On the other hand, our findings may parallel prior research pointing to the severity of the disorder and intrusiveness on everyday life as a more reliable predictive variable in sibling adjustment (Sharpe & Rossiter, 2002) as children with autism spectrum disorders have more symptoms affecting everyday life than children with other NDs such as Down syndrome (Shivers et al., 2019). Siblings of children with diagnoses such as autism spectrum disorders may experience more sibling-related stress and more unavailable parents because of the symptom severity of the affected child. An important question for future sibling research, apparent both from this review and previous reviews (Orm & Vatne, 2021; Shivers et al., 2019), relates to the cross-disorder approach versus a disorder-specific approach. To date, the scarcity of comparative data across different NDs prevents us from drawing clear-cut conclusions about whether the experience of siblings of children with NDs is characterized mostly by communalities across the different disorders (e.g., the level of intrusiveness), or whether there may be disorder-specificity with regards to sibling coping and psychosocial functioning. This review suggests mostly commonalities with regard to social support, but more research is needed.

The unique importance of family support and open parent-sibling communication has been established (Haukeland et al., 2020;

Incledon et al., 2015; Knecht, Hellmers, & Metzing, 2015). Such factors may be more challenged with autism spectrum disorders, and in part explain our findings. Our findings on social support levels for siblings of children with autism spectrum disorders may point towards family and parent characteristics (resources) as potential moderators of perceived social support and highlight the importance of facilitating parent support for this sibling group. This corresponds with individual studies that have found parental stress as one of the factors of importance within the family system level for sibling outcomes (Giallo & Gavidia-Payne, 2006) as well as with Incledon et al.s (2015) review with conclusion that open family communication may promote good sibling adjustment.

In the two studies included in this review that compared social support between siblings of children with a disorder to siblings of typically developing children, we note that the one study that found no difference (Lovell & Wetherell, 2016) had a relatively small sample size which influences the results. The other study found significantly lower social support for siblings of children with autism spectrum disorder compared to typically developing controls (Garrido et al., 2020).

We found no systematic difference in support levels based on the provider of support. However, the variation found across different studies and lack of variation across diagnostic groups may reflect that different measures were used across studies, measuring somewhat different aspects of social support such as the perception of support, actual amounts of support received, evaluation of the importance of support, and frequency of support received. The use of various measurement instruments of social support across the included studies reflects underlying conceptual issues that affect how social support is defined and operationalized. This is problematic, as differences in definitions and operationalization of the construct lead to difficulties comparing results across studies and hinder the important task of disentangling risk and protective factors in sibling research (Uchino, 2009; Vangelisti, 2009).

Our next research questions concerned variables related to social support, including potential moderators. To date, most studies have examined group differences rather than correlates and moderators among siblings of children with NDs (Orm, Fjermestad et al., 2021). This is somewhat problematic because group comparisons only provide information about whether siblings are at higher or lower risk of a particular outcome, whereas studies of correlates and moderators can provide important information regarding which factors should be targeted in clinical practice to enhance the psychosocial functioning of siblings of children with NDs. This review suggests that social support may buffer against the toll placed on siblings. We found a range of negative and positive variables associated with social support, with lower levels of support related to higher levels of psychosocial problems. We found higher levels of social support to be related to problem-focused coping, prosocial behavior, higher self-concept, family-related quality of life, competence, and academic functioning. This is in line with a range of research on social support that highlights the psychological and health benefits of social support (Cate et al., 2000; Incledon et al., 2015; Vermaes et al., 2012). The results may reflect the particular importance of social support in families with higher levels of parent mental health concerns, family stress, sibling anxiety, and behavior problems of the child with the ND and provide additional support for the use of a family systems perspective in sibling research (Mitchell, Morawska, Vickers-Jones, & Bruce, 2021; Rossiter & Sharpe, 2001). Moreover, social support from different providers may be important in mitigating various family-related problems.

In our search for moderators, we found a relationship between the level of social support and variables such as anxiety, loneliness, and family quality of life measures for siblings of children with autism spectrum disorders. This did not appear to be the case for the other included disorders. This could be an artifact of autism spectrum disorder being the most studied disorder. However, these findings may as well reflect the effects of symptom severity and the impact on everyday life on sibling psychosocial adjustment or simply some disorder-specific factor related to autism spectrum disorder (e.g., genetics), and hence support needs, rather than reflecting disorder-specific features in sibling support needs. On the other hand, siblings of children with autism spectrum disorders often display the Broader Autism Phenotype (BAP) and have a genetic risk of psychosocial maladjustment that other sibling groups do not (Ingersoll & Wainer, 2014). Siblings of children with autism spectrum disorders may have greater psychosocial maladjustment than siblings of children with other NDs, not solely because the disorder is more intrusive but because they have more autism symptoms and higher genetic risk themselves (Charman et al., 2017). However, we did not conduct moderator analysis and encourage this to be investigated more rigorously in future research.

Our final research question concerned how social support is measured. We found that there was a range of different measurement instruments used across the included studies, with varying information on reliability and validity provided in the articles. This is worrying because the lack of availability of this information complicates comparison across measures and limits researchers' ability to assess their strengths and limitations in performing different assessment functions. The wide range of measures used also limits our ability to reproduce results and to compare results across studies. The two most utilized scales would be excellent choices in future studies with regard to securing comparability across studies, i.e., both are widely used and psychometrically sound. However, although the *Child and Adolescent Social Support Scale* (CASSS; Malecki & Demaray, 2002) is both a widely used measure and well-documented with good psychometric properties, it measures frequency and importance of support from various sources, whilst the *The Social Support Scale for Children* (Harter, 1985) measures perception of support from parents, teachers, close friend, and classmates.

Based on our review and the documented health benefits of the perception of social support compared to measures of amounts of support (Uchino, 2009), we propose that future studies on siblings' social support utilize the *Social Support Scale for Children* (Harter, 1985). Using the same or comparable measures will secure consistency and comparability across studies (and hopefully also across the different NDs).

The comparison of the level of support across instruments and sibling groups may not reflect uniquely positive outcomes. In fact, discussion about possible negative effects of social support is a neglected area in social support research. Vangelisti (2009) suggested that it is problematic to assume that the outcomes of social support are solely positive. This bias enhances the probability that research directs focus on only one side of the effects. Possible negative sides of social support for siblings include unwanted attention to the sibling situation that may call the child's self-esteem or coping strategy into question, heighten children's awareness of their negative circumstances, or create concerns of the visibility of their distress (Vangelisti, 2009).

The complexity of the social support construct, which encompasses potentially simultaneously negative and positive aspects as well as -person and situation-specific aspects, renders it a tricky concept to measure. We argue in line with Sandler and Barrera (1984) and Uchino (2009) that this complexity is not captured by scales that measure amounts of support, and that the subjective appraisal of the support is essential to assess. Overall, our findings regarding the included social support instruments point toward the need for a more unified understanding of the concept and more coordinated use of validated instruments in sibling psychosocial adjustment.

4.1. Limitations

Some limitations that affect the interpretability of our findings derive from the nature and quality of the reviewed studies. Several of the included studies did not meet criteria regarding the representativeness of the population in the MMAT quality screening process which limits the generalizability of our findings. The level of social support found in this review may be affected by selection bias through the recruitment procedures. Several studies recruited samples from resource centers, hospitals, or special schools which may represent a population of siblings who receive much support and perhaps the families of children with the most intrusive disorders. Moreover, the represented disorders through the included studies may not be representative of the NDs in general as there is an overrepresentation of siblings of children with autism spectrum disorder and Down syndrome which have been well documented to potentially represent "two ends of a scale" when it comes to sibling risk (Shivers et al., 2019). The definition of NDs vary across diagnostic classification systems, and a limit to this review might therefore concern the selection of disorders applied in the search process. Although this group involve disorders that are highly heterogeneous as to clinical characteristics, we based our selection of this specific sibling group on solid rationale for considering them together based on their commonly early onset of neurocognitive deficits, steady courses, are multifactorial in origin and that they involve high overlap of constituent symptom dimensions (Thapar et al., 2017). Another characteristic of the included studies is the overrepresentation of studies from high-income countries such as the USA. Moreover, our results must be interpreted with the heterogeneity of measurement in mind. The heterogeneity of measurement instruments also poses limitations on the calculated percentages because this will vary with the distribution of scores on each instrument and possible ceiling effects making comparisons across different measures difficult.

Some limitations also apply to how we conducted the review. First, we did not include a search for gray literature (dissertations, preprints, unpublished manuscripts, etc.) which could have contributed to a selection bias. Second, we only included studies published in English. The inclusion of studies published in other languages could have provided further insight. Third, we did not calculate interrater reliability for the variables related to social support that were extracted individually from the included studies. However, the first author double checked the extracted variables, and any disagreements or mistakes were discussed and resolved through discussion. Finally, the heterogeneity of the studies in terms of study design, research question(s), and included NDs prevented us from conducting a meta-analysis of findings.

4.2. Implications

Results from this review highlight the potential importance of providing social support for siblings of children with ND, due to several associations with other psychosocial variables. The associations seem to be strongest for NDs affecting families' everyday life. Parent social support for siblings of children with an autism spectrum disorder in families with a higher level of stress, parent health concerns, and sibling depression symptoms, and psychosocial adjustment problems may be particularly important. Because parents and health personnel were not the only providers of support across the studies, the results also support actions to ensure support for siblings from important individuals outside the family and provide options for social activities to strengthen support from peers, friends, and teachers.

Our findings yield an overall positive picture of social support levels for this sibling group. However, there is a need for the use of a more homogenous definition of the construct and better agreement regarding measurement methods. The results indicate the need for further investigation of variables related to self-reported social support and reveal that siblings are reliable sources of information about their own experiences. Moreover, we encourage researchers to focus on perceived social support as it has been found related to health benefits and may provide potential guidance for the need for preventive interventions for siblings of children with NDs.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ridd.2022.104234.

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