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Risk and protective factors for the health of primary care-givers of children with autism spectrum disorders or intellectual disability: a narrative review

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Abstract

Background: Primary care-givers of children with autism spectrum disorder (ASD) or intellectual disability (ID) have poorer health and quality of life than primary care-givers of typically developing children. We aimed to review original research which described factors impacting the health of primary care-givers of children with ASD or ID and to discuss how these factors might influence care-giver health.

Methods: We searched electronic databases and retrieved 33 relevant research articles.

Results: Factors impacting primary care-giver health included child behaviour, support and diagnostic issues. We explain how these factors might impact care-giver health and how they might act differentially in care-givers of children with different types of ASD or ID. Interventions to moderate one or more risk factors could pave the way for improved primary care-giver health.

Keywords: Autism, intellectual disability, mothers; care-givers, health, review

Introduction

A person with autism spectrum disorder (ASD) has a life-long neuro-developmental disability which is diagnosed by severe deficits in social communication and interaction, along with restricted or repetitive behaviour and interests [1]. Intellectual disability (ID) is diagnosed in persons with an IQ below 70 along with impairments in adaptive functioning both of which must be present before 18 years [1]. The prevalence of ASD varies between countries with a median of about 60 per 10,000 [2] while the prevalence of ID is higher at 104 per 10,000 [3].

There is a general consensus among researchers that Quality of Life (QoL) incorporates measures of physical functioning, mental health and engagement in social interaction [4]. A plethora of research has identified poorer health and QoL in the primary care-givers (here after referred to as care-givers) of children with ASD or ID than in other care-givers [5-11]. For example, using linked data, we demonstrated that in the years after their child's birth, mothers of children with ASD or ID had higher rates of psychiatric disorders than other mothers [9,10]. Furthermore, we also identified health differentials in mothers of children with different sub-types of ASD or ID [12]. Using the 12 Item Short Form Health Survey (SF-12), parents of children with ASD without ID were also reported as experiencing lower QoL and more stress than parents of children with ASD with ID [7]. Moreover, mothers of children with ASD had more self-reported anxiety and depression than mothers of children with Down syndrome [13]. Care-giver health issues challenge a family's QoL and may impact the care and healthy development of all children within the family [14,15]. Identifying risk factors for care-givers of children with a particular developmental disorder would enable the identification of groups whose health is especially vulnerable. In addition, identifying both risk and protective factors would enable a better understanding of the health trajectories of care-givers of children with ASD or ID. In such ways, informed interventions and services might be developed to assist in optimising care-giver health. Therefore, we aimed to review the research literature in the area of care-giver health, ASD and ID to locate original research which described risk and/or protective factors for health in care-givers of children with ASD or ID. Our second aim was to discuss how
these factors might influence care-giver health.

**Methods of the review**

We searched the electronic databases, *Web of Knowledge*, *Medline*, *Scopus* and *Google Scholar*, using combinations of the following groups of search terms associated with ASD and ID along with care-giver health. These included terms which are related to:

- ASD, ID or sub-groups such as *autism, autistic, pervasive development disorder, intellectual disability, mental retardation, disability, disabled, Down, Asperger*;
- Health such as *health, depression, physical, mental, psychiatric, psychological, phenotype, quality of life, well-being*;
- Care-givers such as *mothers, parents, care-givers*.

We included an original paper in our review if it:

- Was published between 1st January 1990 and 31st December, 2016
- Described original research in a peer-reviewed article which was written in English
- Used a study population of 15 persons or more
- Described a risk or protective factor for poorer health in mothers, parents or care-givers of a child with ASD or ID or a sub-type (such as ASD with ID or Down syndrome).

Using research [16,17], we developed a simple and objective five-level tool to assess the strength of evidence provided by the papers in this review (*Table 1*).

**Results**

We retained 33 articles. *Table 2* summarizes each paper, provides an assessment of the quality of evidence, methods of data collection and recruitment, country of origin, study population, comparison group and the strength of the assessed relationship or a key result.

**Discussion**

In the first section, we discuss the papers retrieved for the review according to the reported risk or protective factors for poorer care-giver health or QoL. In the second section, we examine care-giver health disparities according to the child’s diagnosis and the likely impact of particular risk or protective factors. The final section examines how risk and protective factors might impact the health of care-givers of children with ASD or ID.

**Challenging child behavior**

Challenging child behaviour, the most commonly identified risk factor for poorer care-giver health and QoL outcomes, was reported in ten of the 33 studies. Researchers provided substantial evidence that the social impact of the child's disability [18] and challenging behaviours [19-25] in children with ASD or ID was associated with poorer care-giver mental health. At the same level of evidence, challenging child behaviours in children with ID were related to poorer care-giver physical health in subsequent years [26]. The total score for the Jenkins Behaviour Questionnaire was higher in children with care-givers having two or more symptoms of depression (p=0.004) [27]. Symptoms of anxiety (p=0.06) and stress (p=0.08) were related also to challenging child behaviour though the associations did not reach statistical significance. These associations were predominantly due to issues of discipline (control, tantrums, demanding attention) and disturbances in sleep [27].

Challenging child behaviours had a negative effect on care-giver and family QoL. One research group administered the Parental-Developmental Disorders-Quality of Life Scale (Par–DD-QoL) to the parents of children with ASD and provided weak evidence that challenging child behaviour was an independent risk factor for poorer QoL [28]. Results from a qualitative study were similar [24].

**Level of support**

Support networks were associated with improved care-giver health and QoL in families of a child with ASD or ID. For example, substantial evidence indicated that family support reduced care-giver burden in families with a child with ASD [20,29] and that family and neighbourhood support was associated with improved parental mental health [20,30,31] and reduced parental aggravation or irritability [32]. Further substantial evidence [33] [as classified by our descriptors on *Table 1*] was provided using the *Multidimensional Scale of Perceived Social Support* (MSPSS) which indicated that greater social support was associated with lower levels of individual distress (apart from anxiety and depression) in the families of children with ASD [25]. Alternatively, substantial evidence demonstrated that mothers of children with ASD had poorer mental health than other mothers but no less social support for parenting [34].

Higher levels of support had a similar favourable effect

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**Table 1. Assessment of level of evidence**

<table>
<thead>
<tr>
<th>Level of evidence</th>
<th>Narrow descriptor</th>
<th>Broader descriptor</th>
<th>Description of study</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Strong</td>
<td>Substantial</td>
<td>Validated scores &amp; magnitude of effect assessed</td>
</tr>
<tr>
<td>4</td>
<td>Moderate</td>
<td>Substantial</td>
<td>Validated scores but no magnitude of effect assessed</td>
</tr>
<tr>
<td>3</td>
<td>Mild</td>
<td>Substantial</td>
<td>Magnitude of effect assessed but no validated scores</td>
</tr>
<tr>
<td>2</td>
<td>Weak</td>
<td>Less substantial</td>
<td>No validated scores or assessment of magnitude of effect</td>
</tr>
<tr>
<td>1</td>
<td>Indication only</td>
<td>Less substantial</td>
<td>Descriptive study</td>
</tr>
</tbody>
</table>
Table 2. Details of papers included in the review.

<table>
<thead>
<tr>
<th>Study</th>
<th>Level</th>
<th>Outcome measurement*</th>
<th>Recruitment</th>
<th>Country of origin</th>
<th>Study population</th>
<th>Comparison groups</th>
<th>Variables investigated</th>
<th>Strength of relationship [1 vs 2] or key results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. BagdAdl, 2014 (28)</td>
<td>2</td>
<td>Parental-DD-Qol Scale</td>
<td>ASD evaluation clinics</td>
<td>France</td>
<td>152 mothers of children with ASD, 152 others</td>
<td>Child behaviour (ABC)</td>
<td>Parental Qol</td>
<td>Child behaviour was an independent risk factor for parental Qol.</td>
</tr>
<tr>
<td>2. Bourke, 2008 (39)</td>
<td>5</td>
<td>SF-12</td>
<td>Service providers</td>
<td>Australia</td>
<td>250 cases</td>
<td>DS, pop norm</td>
<td>Independence of learning skills (Wechsler)</td>
<td>Maternal PH</td>
</tr>
<tr>
<td>3. Bremsby, 2004 (20)</td>
<td>5</td>
<td>GHQ-12</td>
<td>Support services</td>
<td>UK</td>
<td>120 mothers</td>
<td>ASD</td>
<td>Parental distress</td>
<td>Maternal distress was associated with poor child behaviour and lower family support.</td>
</tr>
<tr>
<td>4. CathNB, 2008 (57)</td>
<td>5</td>
<td>SF-36</td>
<td>Service providers</td>
<td>UK</td>
<td>1,000 cases</td>
<td>DS, pop norm</td>
<td>Access to services (ISL modified)</td>
<td>Maternal PH</td>
</tr>
<tr>
<td>5. Cantwell, 2014 (38)</td>
<td>5</td>
<td>Physical Health Questionnaire</td>
<td>University/other</td>
<td>Ireland</td>
<td>120 cases</td>
<td>DD, TD</td>
<td>Support (ISP)</td>
<td>Maternal PH</td>
</tr>
<tr>
<td>6. Correre, 2009 (49)</td>
<td>4</td>
<td>Subjective Well-being, Child-Related Scale</td>
<td>Service providers &amp; community</td>
<td>UK</td>
<td>120 mothers</td>
<td>DS, DS, and DS</td>
<td>Personal rewards (TDI/WQ)</td>
<td>Maternal wellbeing</td>
</tr>
<tr>
<td>7. Dardas, 2014 (41)</td>
<td>3</td>
<td>WHOQOL-BREF</td>
<td>Community</td>
<td>Jordan</td>
<td>158 parents</td>
<td>AD</td>
<td>Income</td>
<td>Parental Qol</td>
</tr>
<tr>
<td>8. Del Gracex, 2014 (46)</td>
<td>1</td>
<td>Interview</td>
<td>Community</td>
<td>US</td>
<td>7 families</td>
<td>ASD</td>
<td>Family experiences</td>
<td>Not applicable.</td>
</tr>
<tr>
<td>9. EisenSovar, 2013 (26)</td>
<td>5</td>
<td>Single-item maternal PH</td>
<td>Service providers</td>
<td>US</td>
<td>110 cases</td>
<td>TD, DD</td>
<td>Children behaviour (ECRS)</td>
<td>Maternal PH</td>
</tr>
<tr>
<td>10. Emsong, 2003 (18)</td>
<td>5</td>
<td>GHQ-12</td>
<td>Survey participants</td>
<td>UK</td>
<td>243 cases, 0.491 control</td>
<td>TD, ND, ID</td>
<td>Social impact of children's difficulties (ODG)</td>
<td>Maternal MH</td>
</tr>
<tr>
<td>11. Emsong, 2010 (39)</td>
<td>3</td>
<td>Kessler-6</td>
<td>Previous study</td>
<td>UK</td>
<td>More than 5,000 parents</td>
<td>Cognitive delay, Less severe delay, TD (WICS &amp; NBS)</td>
<td>Maternal psychiatric disorder (MPD)</td>
<td>Maternal psychiatric disorder</td>
</tr>
<tr>
<td>13. Fith, 2012 (24)</td>
<td>5</td>
<td>PSS</td>
<td>Service providers &amp; community</td>
<td>Australia</td>
<td>100 parents</td>
<td>SDS, ID</td>
<td>Children behaviour (NCBRI)</td>
<td>Parental distress</td>
</tr>
<tr>
<td>14. Harvey, 1997 (27)</td>
<td>4</td>
<td>Items from OBI &amp; BRD-28</td>
<td>Service providers</td>
<td>Australia</td>
<td>65 cases</td>
<td>DD, TD</td>
<td>Children's behaviour checklist: Children's checklist</td>
<td>Children's behaviour checklist</td>
</tr>
<tr>
<td>15. Henning, 2006 (35)</td>
<td>4</td>
<td>GHQ-18</td>
<td>Child clinic</td>
<td>Australia</td>
<td>128 parents</td>
<td>PDD, DD, and ADHD</td>
<td>Parental PH</td>
<td>Parental PH</td>
</tr>
<tr>
<td>16. Hopkins, 1990 (44)</td>
<td>3</td>
<td>Affective questionnaire</td>
<td>Service providers</td>
<td>US</td>
<td>35 mothers</td>
<td>AOD, DS</td>
<td>Child's disability group</td>
<td>Maternal depression, Maternal anxiety</td>
</tr>
<tr>
<td>17. Ingersoll, 2011 (52)</td>
<td>3</td>
<td>CDI-D</td>
<td>ASD website</td>
<td>US</td>
<td>90 case mothers</td>
<td>ASD</td>
<td>BAI, ASQ, Autism severity (Seminar Behaviors Checklist)</td>
<td>Maternal depression, Maternal anxiety</td>
</tr>
<tr>
<td>18. Ingersoll, 2011 (36)</td>
<td>4</td>
<td>CDI-D</td>
<td>ASD website</td>
<td>US</td>
<td>108 parents</td>
<td>ASD</td>
<td>Social support (MOS-SSS)</td>
<td>Parental depression</td>
</tr>
<tr>
<td>21. Lach, 2009 (61)</td>
<td>5</td>
<td>Shortversion of CSSQ</td>
<td>Previous study</td>
<td>Canada</td>
<td>9,467 cases</td>
<td>Carers of child with neurodisability, behaviour problems, Carers of child with intellectual disability</td>
<td>Disability group (Health Utilities Index)</td>
<td>Carer depression</td>
</tr>
<tr>
<td>22. Lennard, 2005 (47)</td>
<td>3</td>
<td>* Ad hoc questionnaire</td>
<td>Service providers</td>
<td>Germany</td>
<td>112 DSM, DD, ID of unknown cause &amp; 6088 mothers</td>
<td>Mothers of children with unknown cause &amp; DD, ID of unknown cause, TD</td>
<td>Disability group</td>
<td>Maternal anxiety</td>
</tr>
<tr>
<td>23. Lingan, 2013 (40)</td>
<td>5</td>
<td>Uniform Quality of Life Inventory for Parents</td>
<td>Parents of patients with DD/DD at University Hospital</td>
<td>Denmark</td>
<td>95 mothers</td>
<td>Mothers of children with diagnoses, mothers of children without</td>
<td>Biological vs. nonbiological diagnosis (DD, ID, death, genetic testing)</td>
<td>Maternal QoL</td>
</tr>
</tbody>
</table>
Continuation of Table 2.

<table>
<thead>
<tr>
<th>Study</th>
<th>Level</th>
<th>Outcome measurement</th>
<th>Recruitment</th>
<th>Country of origin</th>
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<th>Comparison groups</th>
<th>Variables investigated</th>
<th>Strengths of relationship (1 vs 2) or key results</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. Lees et al., 2010</td>
<td>5</td>
<td>SF-12</td>
<td>Service providers</td>
<td>Australia</td>
<td>64 older parent cases (640 years)</td>
<td>Parents of children with ASD vs PID norm</td>
<td>Age group, Care-giver MH</td>
<td>Amongst 25-44 years, mental health improved with age.</td>
</tr>
<tr>
<td>26. Montag, 2007</td>
<td>6</td>
<td>Previous study</td>
<td>US</td>
<td>61,772 mothers</td>
<td>Mothers of children with ASD or TD</td>
<td>Disability group, Maternal M</td>
<td>Having a child with ASD was associated with poorer MH.</td>
<td></td>
</tr>
<tr>
<td>27. Mazer, 2007</td>
<td>3</td>
<td>WHOQOL-BREF</td>
<td>Service providers</td>
<td>Italy</td>
<td>135 cases, 43 controls</td>
<td>Mothers of children with ASD or TD</td>
<td>Disability group, Maternal depression</td>
<td>Mothers from ASD group had less gratification than DS mothers</td>
</tr>
<tr>
<td>28. Olsson, 2001</td>
<td>3</td>
<td>BDI</td>
<td>Service providers</td>
<td>Sweden</td>
<td>216 case, 214 control mothers</td>
<td>Mothers of children with ID vs ID &amp; controls</td>
<td>Disability group</td>
<td>Mothers from ASD group had less gratification than DS mothers</td>
</tr>
<tr>
<td>29. Paynter, 2013</td>
<td>5</td>
<td>PSI, SF</td>
<td>Community</td>
<td>Australia</td>
<td>45 parents</td>
<td>ASD</td>
<td>Child behaviour, (BAS)</td>
<td>Positive association of stress &amp; poorer child behaviour (coef. 1.05)</td>
</tr>
<tr>
<td>30. Schulte, 2011</td>
<td>3</td>
<td>Aggravation in Parenting Scale</td>
<td>Previous study</td>
<td>US</td>
<td>872 cases</td>
<td>ASD, TD</td>
<td>Parental stress</td>
<td>Positive association of stress &amp; poorer child behaviour (coef. 1.05)</td>
</tr>
<tr>
<td>31. Singh, 1999</td>
<td>4</td>
<td>SBS</td>
<td>Service providers</td>
<td>India</td>
<td>50 case parents</td>
<td>ID, TD</td>
<td>ID, TD (Used 1 or 2 of items below to assess ID) GDT, GFS, MFS, VMS</td>
<td>Social burden</td>
</tr>
<tr>
<td>32. Werner, 2015</td>
<td>4</td>
<td>APS</td>
<td>Convention example</td>
<td>Israel</td>
<td>171 case-givers</td>
<td>DD</td>
<td>ID, ASD, PP</td>
<td>Affiliative stigma</td>
</tr>
<tr>
<td>33. Zabolotsky, 2013</td>
<td>3</td>
<td>1-stm health index &amp; 1-stm stress index</td>
<td>Previous study</td>
<td>UK</td>
<td>1,031 cases &amp; 55,593 controls</td>
<td>ASD, no ASD</td>
<td>Stress (1-stm index)</td>
<td>MH</td>
</tr>
</tbody>
</table>

ABC, Aberrant Behavior Checklist; AD, autistic disorder; AFS, Affilite Stigma Scale; Array-based comparative genomic hybridization, aCGH; Autistic disorder; ASD, Autism spectrum disorder; ASD/ID, ASD or ID; ASQ, Autism Spectrum Quotient; BAP, Broad Autism Phenotype; BASC-2, Behaviour Assessment System for Children, Second Edition;BBCS, Bracken Basic Concept Scale; BDI, Beck Depression Inventory; carer, care-giver; CBC, Child Behaviour Checklist;CES-D, Center for Epidemiological Studies-Depression Scales; DAS, Dyadic Adjustment Scale; DBC, Developmental Behaviour Checklist;DBC-P, DBC-Primary Carer Version; DD, developmental disability, disorder or delay; dis, disability; DS, Down syndrome; DSSI, Delusions Symptoms States Inventory; FAD, MacMaster Family Activity Device; FQOL, Family QOL; FSI, Family Support Index; GDT, Gessel's Drawing Test; GFS, General Functioning Scale; GHQ-12, General Health Questionnaire-12-item version; GHQ-28, General Health Questionnaire-28-item version; HFA, High-functioning ASD; ID, intellectual disability; Level, Level of evidence; MCS, Mental Component Summary of SF-36; MH, Mental health; MIB, Malinis Intelligence Scale; MSPSS, Multidimensional Scale of Perceived Social Support; MOS-SSS, Medical Outcome Study-Social Support Survey; NCBRF, Nisonger Child Behaviour Rating Form; neuro, neurological; NVS, Naming Vocabulary Subscale; PCS, Physical Component Summary of SF-36; PH, Physical health; pop, population; PSS, Parental Stress Scale; OR, odds ratio; PD, physical disabilities; PDD, Pervasive development disorder; PSI, Parenting Stress Index; PSI-SF, PSI: Short Form; QoL, Quality of Life; RR, risk ratio; SBS, Social Burden Scale; SQD, Strengths and Difficulties Questionnaire 4–10 years; version for Australia; SF-12, 12-Item Short Form Health Survey; SF-36, 36-Item Short Form Health Survey; SFR, Seguin Form Board; SFS, Social Functions Scale; S-T-A-I, State-Trait Anxiety Inventory; German form; TD, typically developing; TDRWQ, Transition Daily Rewards and Worries Questionnaire; VMS, Vineland Social Maturity Scale; WeeFIM-m, Functional Independence Measure for Children; modified; WHOQOL-BREF, World Health Organization Quality of Life-Brief.
on parents with a child with ID [31-34]. Using the SF-12, an Australian study [35] provided substantial evidence (as defined in Table 1) that better mental health in parents older than 60 years was associated with having a partner and a large and supportive network of family, friends and neighbours. Others [36] used the Beck Depression Inventory and reported that single mothers living with a child with ID were more depressed than similar mothers living with a partner. There is also substantial evidence that poorer physical health in female care-givers of adults with developmental disabilities was associated with a lack of services [37] and that the effect of stress on physical health was moderated by parental social support [38].

Socio-economic status
Higher socio-economic status (SES) was a protective factor for parental health and particularly maternal health [39-41]. For example, correlational analyses showed that parents of children with ASD with higher incomes had less distress and an improved QoL compared with those of lower incomes [41]. Similarly, there was strong evidence that socio-economically disadvantaged mothers had a greater risk of a psychiatric disorder than socio-economically advantaged mothers with a child with a similar disability [39,40].

Rewards and stigma
In a comparison of mothers of children with Down syndrome (n=21) and mothers of children with ASD (n=17), researchers provided some evidence of greater attachment and gratification in the mothers of children with Down syndrome [42]. A case-control study, with a lower evidence-base [43], reported that mothers of children with Down syndrome felt more rewarded by parenting than mothers of children with other developmental disabilities.

Affiliate stigma (or self-stigmatization) was higher among care-givers of persons with ASD compared to care-givers of persons with ID or physical disabilities although the level of evidence was not strong [44]. There was also evidence that there was additional societal stigma towards the care-givers of children who appear normal but manifest abnormal behaviours [45].

Diagnostic issues
Diagnostic uncertainty and an unclear prognosis are factors which can cause the greatest concern to care-givers of children with ASD and those for whom a cause of their child’s ID has not been identified [45-47]. The first of these studies [45] used a combination of interviews or focus groups with care-givers and the second [46] provided qualitative evidence by interviewing care-givers. In the third [47], German researchers compared the mothers of children with Down syndrome, ID of unknown cause and typically developing children with respect to anxiety, guilt and emotional burden using the State-Trait-Anxiety-Inventory and the Balanced Inventory of Desirable Responding. They concluded that uncertainty was a major cause of stress in mothers of children with ID of unknown cause [47]. A fourth study used the Ulm Quality of Life Inventory for Parents to examine the QoL of parents of a child with a developmental disability before genetic testing and after receiving a genetic cause for their child’s disability. The results provided strong evidence that maternal QoL was improved once the underlying diagnosis was known [48].

Broad Autism Phenotype
The concept of mild autistic traits in the relatives of a person with ASD is termed the Broad Autism Phenotype [49]. Validated questionnaires such as the Autism Spectrum Quotient [50] and the Broad Autism Phenotype Questionnaire [51] are used to quantify the extent of this trait on a linear scale. Two research groups [30,52] provided mild and weak levels of evidence that persons exhibiting the Broad Autism Phenotype were at an increased risk of depression.

Maternal health by the child's diagnosis or sub-type and the impact of risk factors
In a previous review [12], we found that mothers of children with Down syndrome generally had better health than mothers of children with other intellectual disabilities. In turn, mothers of children with intellectual disabilities other than Down syndrome, generally had better health than mothers of children with ASD [especially ASD without ID] (Figure 1).

The disparities in the health of care-givers of children with ASD or ID may be partially explained by child characteristics associated with the particular diagnostic category. For example, challenging behaviours occur more often and are usually more severe in children with ASD than children with Down syndrome [53]. Thus, a commonly cited risk factor for poorer care-giver health and QoL outcomes, challenging child behaviour, is more often associated with ASD than Down syndrome. The increased likelihood of parents of children with ASD manifesting a Broad Autism Phenotype and its association with depression [30,52] could explain why poorer
mental health is more common in parents of children with ASD than in parents of children with other developmental disabilities. Furthermore, personality type influences a person’s willingness to seek support [54]. Hence, the lower social support evidenced in families with a child with ASD could be mediated by parental personality traits which are associated with the Broad Autism Phenotype. The consequent overall reduction in social support could thereby further increase the risk of poorer mental health in these parents. Moreover, the lag-time to diagnosis in comparison to Down syndrome, where children are diagnosed at birth, could also impact negatively on the mental health of parents of children with ASD. Furthermore, mothers of children with Down syndrome mostly reported that parenting was more fulfilling than did mothers of children with other disorders [42]. In contrast, care-givers of children with ASD were the most negatively affected by stigma [44], a risk factor for care-giver health. Moreover, Down syndrome is the most common genetic form of ID and children are readily recognised and supported by members of the community due to their distinctive phenotype [55]. On the other hand, children with ASD have no distinguishing phenotype and mostly appear physically normal to community bystanders [56]. Thus, there is the expectation that their behaviour would be normal which may not be the case [45].

How risk and protective factors might impact care-giver health

We have identified a total of seven risk or protective factors for health and QoL in the care-givers of children with ASD or ID. The impact of challenging child behaviour seems likely to be mediated by the increased parental stress generated by antisocial, and the sometimes dangerous and self-limiting behaviours in the child [57]. Challenging antisocial child behaviours such as running away and self-injurious behaviour such as head-banging can also severely limit family activities and thereby increase family social isolation [58]. Additionally, antisocial behaviour, when unexpected by the outsider, could further exacerbate the stigmatisation of parents [59]. Increased levels of extended family support and other support given to parents and their family were positively associated with parental well-being [20,30,31]. Support provides relief for care-givers and in so doing provides opportunities for respite and thus engagement in social activities which might normally be reduced in care-givers of children with ASD or ID [54]. Socio-economic status may further impact on care-giver health since only well-resourced families may be able to gain networking with parents of children with a similar diagnosis. Furthermore, these parents may feel ongoing pressure to search for a cause for their child’s condition when either there is no clear aetiology or a lack of available technology to test a plausible diagnosis [47]. For example, the CDKL5 disorder is a genetic condition causing severe neuro-developmental impairment and refractory epilepsy from infancy [62]. Unfortunately, in Western Australia (along with many other cities in the Western world), genetic testing to confirm a diagnosis is not currently available. Such issues might negatively impact care-giver health.

Summary and implications

Care-givers of children with ASD are more likely to experience many of the risk factors and less likely to experience the protective factors we identified as contributing to poorer mental health. Interventions to reduce risk factors and increase protective factors could pave the way for improved care-giver health. For example, workshops to train parents to better manage challenging behaviours in their children and earlier diagnosis of ASD (and particularly ASD without ID) would seem likely to improve parental wellbeing. Similarly, helping to expand support networks might reduce care-giver burden and stress leading to improved health. High SES is a protective factor for care-giver health. Hence, increased subsidised supports for those of low SES, such as care-giver respite and home help, might also assist care-givers of children with ASD or ID to maintain their health.

Competing interests

The authors declare that they have no competing interests.

Authors’ contributions

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