

# Families under pressure: stress and quality of life in parents of children with an intellectual disability

Emma Staunton<sup>1\*</sup>, Claire Kehoe<sup>2</sup> and Louise Sharkey<sup>3</sup>

<sup>1</sup> Linn Dara CAMHS ID, Cherry Orchard Hospital Campus, Dublin 10, Ireland

<sup>2</sup> Linn Dara CAMHS North Kildare, Celbridge, Co. Kildare, Ireland

<sup>3</sup> Linn Dara CAMHS ID, Tallaght Hospital, Dublin 24, Ireland

**Objective.** To evaluate stress and quality of life in parents of children with an intellectual disability (moderate–severe–profound), who attend a Child and Adolescent Mental Health Intellectual Disability Service (CAMHS ID), and to estimate the perceived levels of challenging behaviour and satisfaction with supports.

**Methods.** Data from children attending the service from 2014 to 2017, along with clinician and parent rating scales were collected.

**Results.** Most children had medical comorbidities, autism spectrum disorder (ASD), and challenging behaviours. Half had a diagnosis of a mental health disorder. Less than half received respite care. Challenging behaviours and ASD were found to be correlated with increased parental stress while perception of support was inversely correlated with stress. Intellectual disability, ASD, and parental stress were correlated with a decrease in perceived family quality of life.

**Conclusions.** This study concurs with previous studies, outlining that parents of children with intellectual disability, in particular, where there is a diagnosis of comorbid ASD and challenging behaviour, experience increased psychological distress and lower quality of life.

Received 07 September 2018; Revised 16 January 2020; Accepted 20 January 2020; First published online 28 February 2020

**Key words:** Autism spectrum disorder, family quality of life, intellectual disability, stress, support.

## Introduction

Intellectual disability is a neurodevelopmental disorder with an onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains (DSM 5 2013). The prevalence of intellectual disability worldwide has been estimated to be about 1% (Maulik *et al.* 2011). In Ireland, approximately 0.7% of the child population have been diagnosed with an intellectual disability, up to 65% of these children are male, and the majority (63.5%) are registered as having a mild/moderate disability (Department of Children and Youth Affairs 2016).

One-fifth (23%) of children in Ireland with an intellectual disability have been found to meet the diagnostic criteria for a mental health disorder (Department of Children and Youth Affairs 2016). Similarly in the United Kingdom, prevalence rates of mental health disorders in children with intellectual disability are estimated to be 36% (Emerson & Hatton 2007). In one study, children with an intellectual disability were found to have higher rates of anxiety than children of typical cognitive development (Green *et al.* 2015).

Children with an intellectual disability are not only at an increased risk of developing a mental health disorder but also are more likely to develop severe and impairing behavioural difficulties (Blacher & McIntyre 2006; Einfield *et al.* 2011; Einsenhower *et al.* 2005; Kliegman *et al.* 2016).

Children with an intellectual disability, in particular those with an additional comorbid mental health disorder, require more intensive and ongoing care than children of typical development. This care which is both physical and emotional is provided by parents/families within the family home. These parents can encounter many challenges relating to their children's disability and this may have a detrimental impact on their own emotional and physical well-being. There is emerging evidence to support a correlation between parenting a child with an intellectual disability and parental stress (Baker *et al.* 2002; Emerson *et al.* 2010; Mansell & Wilson 2010; Miodrag & Hodapp 2010; Patton *et al.* 2018; Plant & Sanders 2007; Singer 2006).

Parental stress can negatively impact on the parent-child relationship and in turn can impact on the child's behaviour (Baker *et al.* 2002, 2003; Emerson *et al.* 2010; Families Special Interest Research Group of IASSIDD 2014; Neece *et al.* 2012). The levels of parental stress are influenced by both intrinsic factors (severity of disability, verbal abilities, and challenging behaviours)

\*Address for correspondence: Dr E. Staunton, Buttercup Suite, Linn Dara CAMHS, Cherry Orchard Hospital, Ballyfermot, Dublin 10, Ireland. (Email: emma.staunton1@hse.ie)

and extrinsic factors (family circumstances, social, and systemic support) (Hassall *et al.* 2005; Nurullah 2013).

In order to investigate the extent of the impact of having a child with an intellectual disability, a broad range of variables need to be examined including not only parental stress but also family well-being/quality of life and the supports available to families. Family Quality of Life (FQOL) has been defined as 'a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact' (Zuna *et al.* 2010: 262). Despite the significant challenges faced by families of children with an intellectual disability, satisfaction with quality of life has been reported in studies to be average to high (Hoffman *et al.* 2006; Summers *et al.* 2007; Turnbull *et al.* 2007).

Families of children with disabilities are more likely to experience social isolation, than families of typically developing children (Emerson & Brigham 2015; Griffith *et al.* 2012). This is significant as social support is recognised as a buffer to stress and loneliness (Hassall *et al.* 2005; Patton *et al.* 2018; Peer & Hillman 2014; Segrin *et al.* 2012). Some evidence-based group parenting training programs have been shown to improve parental well-being and reduce parental stress such as Parents Plus (Carr *et al.* 2016) and Triple P-Positive Parenting Program (Sanders *et al.* 2014). Families in Ireland can avail of limited support services through their General Practitioner (GP), Network Disability Teams, Hospitals, and community-based organisations.

Most research relating to children with an intellectual disability has been conducted internationally. To the authors knowledge, this is the first study of this kind in Ireland and so needs to be considered in the context of the demographics of the population of this study who reside in an urban catchment area in the Republic of Ireland, in addition to the limited amount of services currently available in this country for children with an intellectual disability.

The purpose of this study is twofold. (1) To investigate the impact on parental stress of parenting a child with an intellectual disability in a population of children referred to a Child and Adolescent Mental Health Intellectual Disability Service (CAMHS ID) serving an urban catchment area in the Republic of Ireland and (2) To examine the impact of the child's neurodevelopmental and mental health/behavioural difficulties on parents' quality of life and the impact of their perceived level of support on their stress levels.

## Methods

### *Participants and procedures*

All parents of children referred to the CAMHS ID Service between 2014 and 2017 were invited to

participate in this study either through a phone call from the psychologist on the team or in person by the psychologist or consultant psychiatrist at routine outpatient appointments, where verbal and written information was provided.

Thirty-three parents consented to participate in the study. Participants completed a number of self-report questionnaires: Aberrant Behaviour Checklist (ABC), Parenting Stress Index (PSI), Family Quality of Life Scale (FQOL), and modified Family Support Scale (M-FSS). One participant did not complete the ABC and one participant did not complete the Family Support Scale. In addition, the psychologist and the senior registrar completed the Children's Global Assessment Scale (CGAS).

Ethical approval was granted by the Linn Dara Ethics Committee. Of the parents who participated, 73% were married ( $n = 24$ ), with on average 2.6 children at home ( $SD 0.7$ ). One-third (30%,  $n = 10$ ) reported a history of mental health difficulties, of whom 50% ( $n = 5$ ) had a diagnosis of anxiety/ depression and one-third ( $n = 3$ ) had a history of addiction.

## Measures

### *Parental stress*

The PSI 4 (Abidin 2012) is a 120 item measure which evaluates the parenting system and identifies issues that may lead to problems in the child's or parent's behaviour. It examines three main domains of stress: child characteristics, parent characteristics, and situational/demographic life stress. Child subscales consist of Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability. Parent subscales consist of Competence, Isolation, Attachment, Health, Role Restriction, and Spouse/Parenting Partner Relationship. The PSI demonstrates good reliability and validity and has been previously used to evaluate parental stress in families of children with disabilities (Davis & Carter 2008; Hassall *et al.* 2005).

### *Family quality of life*

The Beach Center Family Quality of Life Scale (FQOL Scale; Hoffman *et al.* 2006) is a 25-item questionnaire which assesses families' perceptions of their satisfaction with different aspects of family quality of life on a 5-point scale, from 'very dissatisfied' to 'very satisfied'. It defines FQOL as consisting of five domains (1) family interaction – relationships among family members, (2) parenting – activities that adult family members do to help children grow and develop, (3) emotional well-being – the aspects of family life that address the emotional needs of family members, (4) physical/material well-being – the aspects of family life that address the physical needs of family members, and

**Table 1.** Characteristics of the children

Age (range, in years)	13 (7–17)
Male	73%, <i>n</i> = 24
Moderate intellectual disability	94%, <i>n</i> = 31
Mobile	100%, <i>n</i> = 33
Non-verbal	54%, <i>n</i> = 18
Visual/hearing impairments	9%, <i>n</i> = 3
Medical comorbidities	64%, <i>n</i> = 21
Sleep issues	48%, <i>n</i> = 16
ASD	76%, <i>n</i> = 25
Challenging behaviour	88%, <i>n</i> = 29
Mental health diagnosis	45%, <i>n</i> = 15
Prescribed medication	70%, <i>n</i> = 23
Living at home	91%, <i>n</i> = 30
Special school	94%, <i>n</i> = 31
Respite	53%, <i>n</i> = 16
CGAS score	42 (30–52)

(5) supports for family member with a disability – informal and formal supports to benefit the family member with a disability. This measure has been described as the ‘most well established measure of FQOL available to date’ (Perry & Isaacs 2015; Poston *et al.* 2003) and demonstrates good reliability and validity (Hoffman *et al.* 2006).

#### Satisfaction with support

A support scale was developed for the purpose of this study to measure the perceptions of satisfaction with support available for families of children with disabilities. This scale was based on the Family Support Scale (Dunst & Leet 1985) and was adapted to reflect the supports available to the parents attending a CAMHS ID Service. The support scale consisted of 14 items measuring perceived support from family, social, and professional sources. Family supports consisted of partner, parents/partner’s parents, extended family, and other children. Social support consisted of social groups, friends/neighbours, and work colleagues. Professional sources of support consisted of GP, Disability Team, child’s school, home support services, respite services, residential care, and professional services (e.g. hospital paediatrics, psychiatry). Responses are measured on a 5 point Likert scale from ‘not at all helpful’ to ‘extremely helpful’, a ‘Non Applicable’ category is also available.

#### Child behaviour

The Aberrant Behavior Checklist (ABC; Aman *et al.* 1985a) is a 58 item rating scale that measures the severity of a range of problem behaviours commonly

observed in individuals with intellectual and developmental disabilities. These include (1) Irritability, (2) Lethargy, (3) Stereotypy, (4) Hyperactivity, Non-compliance, and (5) Inappropriate Speech. Previous research has demonstrated that the ABC has sufficient psychometric properties (Aman *et al.* 1985b; Brown *et al.* 2002; Rojahn *et al.* 2003).

#### Child functioning

The CGAS (Shaffer *et al.* 1983) is a numerical scale utilised in mental health settings to estimate the general functioning of children. The clinician rates the child based on the most severe level of emotional and behavioural functioning within the past 3 months. Scores range from 1 to 100, with high scores indicating better functioning.

#### Data/statistical analysis

Data were anonymised, stored on a private hospital-based network, and analyzed using the Statistical Package for Social Sciences (SPSS 20.0). Pearson’s coefficients were calculated between scale totals, to measure the relationship strength between the continuous variables.

## Results

#### Characteristics of the children

Table 1 displays the demographic characteristics of the thirty-three children and their families included in the study. The average age of children was 13 years (SD 2.77). Most were male (73%, *n* = 24), with a moderate level of intellectual disability (94%, *n* = 31). Forty-six per cent (*n* = 15) had identified intellectual disability aetiologies (nine with genetic syndromes including three with Down’s syndrome, three with perinatal illnesses, and three with neurodevelopmental conditions).

About two-thirds had additional medical co-morbidities (64%, *n* = 21), three with epilepsy. Sleep issues were present in half of the children (48%, *n* = 16).

Most children were living in the family home (91%, *n* = 30), half (53%, *n* = 16) benefited from respite and most attended special schools (94%, *n* = 31), two were in a special class in mainstream school.

The majority had a diagnosis of comorbid autism spectrum disorder (ASD, 76%, *n* = 25), representing a significant sub group of the population. Most displayed challenging behaviours (88%, *n* = 29) with physical aggression and self-injurious behaviour the main concerns. Almost half had comorbid mental health diagnoses (45%, *n* = 15, DSM 5), the most common was mood/anxiety (93%, *n* = 14), followed by hyperkinetic disorders (20%, *n* = 3), and psychosis (6%, *n* = 1).

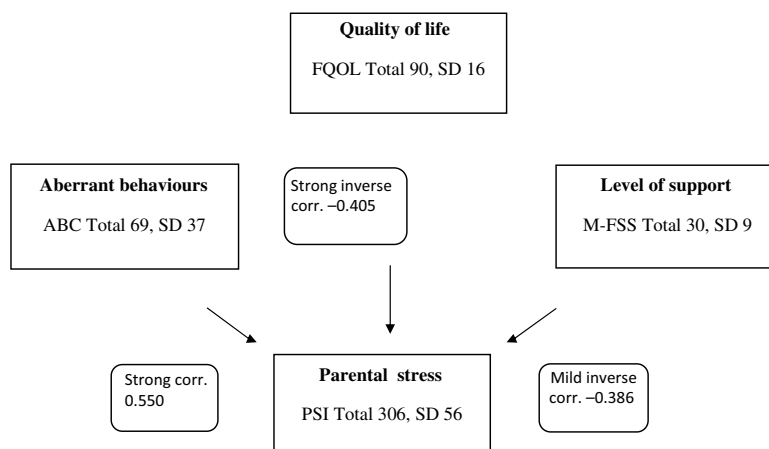


Fig 1. Relationships between PSI, ABC, FQOL Scale and M-FSS and Correlation coefficients.

About two-thirds were taking at least one prescribed medication (70%,  $n = 23$ ), on average 1.33 medication per child (sd 1.24), mainly antipsychotics (61%,  $n = 15$ ), Melatonin (48%,  $n = 11$ ), anti-depressants (39%,  $n = 9$ ), and stimulant/non-stimulant medication (9%,  $n = 9$ ).

All children benefitting from respite care displayed challenging behaviours (100%,  $n = 16$ ) which was statistically significant (Pearson’s  $\chi^2(1) = 5.275, p = 0.022$ ). Out of the children not benefitting from respite care, 71% ( $n = 10$ ) had challenging behaviours. Comorbid mental health difficulties (45%,  $n = 15$ ) were present in both sexes, ages, moderate or severe intellectual disability, home or residential setting, with or without respite care, having medical conditions, ASD, sleep issues or displaying challenging behaviours. The average clinician-rated CGAS was 42 (30–52), in the ‘Obvious Problems’ range.

**Parents’ questionnaires**

The PSI average was 306 (PSI, sd 56,  $n = 33$ ); Child domain average was 158, Parent domain average was 147. Scores can range from 101 to 505. The ABC average was 69 (ABC, sd 37,  $n = 32$ ). Scores can range from 0 to 174. The main concerns related to Hyperactivity/Non-compliance (mean 1.4), then Irritability (mean 1.3), Stereotypy (mean 1.3), Inappropriate Speech (mean 0.9), and Lethargy (mean 0.8).

The Family Quality of Life average was 90 (FQOL, sd 16,  $n = 33$ ). Scores can range from 25 to 125. Satisfaction on the FQOL scale was reported highest for physical well-being (mean 4), family interaction (mean 3.9), parenting (mean 3.5), disability-related supports (mean 3.4), and lowest for emotional well-being (mean 2.9).

The M-FSS average was 30 (M-FSS, sd 9,  $n = 32$ ). Scores can range from 0 to 70. Parents reported the highest level of support being received from Family (mean 2.5) and Professional services (mean 2.5) and lastly Social (mean 1.4).

**Table 2.** Correlation coefficients between ABC, PSI, FQOL, M-FSS, and ASD

	ABC	PSI	FQOL	M-FSS	With ASD
ABC	-				
PSI	0.550**	-			
FQOL	-0.227	-0.405*	-		
M-FSS	-0.122	-0.386*	0.386	-	
With ASD	0.023	0.282	-0.347*	0.074	-

mild, moderate, strong correlations.  
\*5% level of significance, \*\*1% level of significance.

Figure 1 displays the relationships between scales and correlation coefficients. There was a strong correlation between the level of parental stress and challenging behaviours (ABC and PSI, Pearson’s  $r = 0.550$ , 1% level); inverse moderate correlations with quality of life (PSI and FQOL, Pearson’s  $r = -0.405$ ) and perceived level of support (PSI and M-FSS, Pearson’s  $r = -0.386$ , 5% level).

An inversely moderate correlation existed between family quality of life and intellectual disability (Pearson’s  $r = -0.457$ , 1% level).

The presence of ASD was weakly correlated with parental stress (presence of ASD and PSI, Pearson’s  $r = 0.282$ , 5% level), inversely with quality of life (presence of ASD and FQOL, Pearson’s  $r = -0.347$ , 5% level) but not with challenging behaviours or family support (See Table 2).

**Discussion**

**Summary of findings**

Most of the children who participated in this study were male, non-verbal with moderate intellectual

disability, and medical comorbidities. Almost three quarters had an additional diagnosis of ASD.

The rate of ASD recorded in our population is higher than that reported in other published studies (Centers for Disease Control and Prevention 2018; National Disability Authority 2017) and most likely reflects our study cohort, recruited from a CAMHS ID population, all functioning within the moderate–severe–profound intellectual disability range. Most of the children in our study population were referred for assessment of behaviours that challenge, approximately 50% met the criteria for a DSM 5 mental health diagnosis in addition to sleep disturbance. These findings are similar to those from a UK study of referrals to a specialist child neurodisability service (Gangadharan *et al.* 2001).

Our study found that parents caring for a child with an intellectual disability, in addition to comorbid complexities, experience high levels of psychological stress. Although a control group was not used in this study, our findings are in line with previous research showing that parents of children with an intellectual disability experience higher levels of stress than those of typically developing children (Patton *et al.* 2018). The authors acknowledge that additional stressors may also impact on parental mental health such as addiction, marital status, and parent's own mental health; however, for the purpose of this study, these were not evaluated and may also have impacted on our findings.

Our study demonstrated elevated parental stress levels when compared with studies looking at other parent populations, for example parents of children with developmental delays, ASD, and ADHD (Abidin 2012; Miranda *et al.* 2015). Child domain scores on the PSI in our study were found to be significantly higher than parent domain scores. High child scores tend to be associated with certain behaviour qualities that make it difficult for parents to fulfil their parenting roles, suggesting that child characteristics may be a major factor in the overall stress in the parent–child dyad. Of note, the child domain score is usually found to be greater than the parent domain for parents of children with disabilities.

Parents' perception of their own stress levels correlated strongly with their child's behaviour, rated as challenging. Our findings are consistent with previous studies demonstrating an association between child behavioural difficulties and higher levels of parental stress (Baker *et al.* 2002, 2003; Plant & Sanders 2007).

A diagnosis of intellectual disability in addition to ASD has been shown to be associated with an increased risk of challenging behaviour and increased parental stress in comparison to children with intellectual disability alone (Blacher & McIntyre 2006; Einsenhower *et al.* 2005; Totsika *et al.* 2011). In our study, parents

of children with comorbid ASD reported high levels of stress and lower quality of life.

Perception of support was found in this study to be inversely correlated with stress, which highlights the important role support plays in influencing parental levels of stress. Previous studies have demonstrated the impact of perceived social support on reducing parental stress (Patton *et al.* 2018; Peer & Hillman 2014; Segrin *et al.* 2012). Satisfaction with support was shown to be higher for family and professional sources, with satisfaction with social support from social groups, friends, neighbours, or colleagues rated lower. Given parental reliance on family and professional support, it is important that families are well resourced and that professional supports are provided to meet their needs.

Family quality of life was found to be in the average range, which is consistent with previous research investigating families of children with intellectual disabilities (Hoffman *et al.* 2006; Summers *et al.* 2007; Turnbull *et al.* 2007); however, emotional well-being in our study was reported as being below average.

The level of intellectual disability, a diagnosis of ASD, and parent self-reported stress are inversely correlated with family quality of life, which indicates that the more complex a child's presentation is and the more stress a parent feels, the less likely the family are to experience a good quality of life.

### Limitations

The correlational nature of the research design prevents casual inferences being confirmed and statements about the direction of effects can only be made with caution. Not all factors which potentially contribute to parental stress and quality of life such as parents own mental health were examined in this study.

Given the small sample size, it is possible that differences in parental subgroups may be present but the number of participants did not allow for meaningful analysis of these subgroups. No control group was employed in this study.

The measures employed, with the exception of the CGAS, rely solely on parental self-report data. This is appropriate as parental perceptions were the principal subject of this study, but some parents may over or under report their own stress or their child's difficulties due to factors such as socially desirable responding (Paulhus & Vazire 2009).

### Future research

Future studies with this population could be conducted over a longer period of time to further investigate relationships between perceived parental stress, quality of



life, support, and child characteristics with the addition of a control group.

The possible differences in subgroups of parents of children with intellectual disability could also be explored.

A qualitative research study could yield rich and illustrative examples of parents lived experience of parenting a child with intellectual disability.

## Conclusion

These findings have important clinical implications. This study demonstrated that families of children with moderate–severe–profound intellectual disability experience significant stress. As parents are the primary providers of care to these children with complex needs, it is vital that more resources are made available to reduce parental stress and prevent carer burnout.

As parents value both family and professional support in enabling them to care for their child, professional services also need to adapt to meet the needs of these families. Parenting programs which are tailored to the needs of these parents may enable them to understand and cope with the stressors they face caring for a child with an intellectual disability and mental health difficulties, along with offering some peer support which parents may not currently have access to.

## Conflict of interest

Dr ES., Dr CK., and Dr LS have no conflicts of interest to disclose.

## Ethical standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. The study protocol was approved by the local Ethics Committee. Written informed consent was obtained from all study participants.

## Financial support

This research received no specific grant from any funding agency, commercial or not-for profit sectors.

## Supplementary material

To view supplementary material for this article, please visit <https://doi.org/10.1017/ipm.2020.4>

## References

- Abidin RR** (2012). *Parenting Stress Index, Fourth Edition Professional Manual*. Psychological Assessment Resources, Lutz, FL.
- Aman MG, Singh NN, Stewart AW, Field CJ** (1985a). The Aberrant Behavior Checklist: A behavior rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency* **89**, 485–491.
- Aman MG, Singh NN, Stewart AW, Field CJ** (1985b). Psychometric characteristics of the Aberrant Behavior Checklist. *American Journal of Mental Deficiency* **89**, 492–502.
- American Psychiatric Association** (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM–5)*. American Psychiatric Association: Washington, DC.
- Baker BL, Blacher J, Crnic KA, Edelbrock C** (2002). Behaviour problems and parenting stress in families of three year old children with and without developmental delay. *American Journal of Mental Retardation* **107**, 433–444.
- Baker BL, McIntyre LL, Blacher J, Crnic K, Edelbrock C, Low C** (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research* **47**, 217–230.
- Blacher J, McIntyre LL** (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact. *Journal of Intellectual Disability Research* **50**, 184–198.
- Brown EC, Aman MG, Havercamp SM** (2002). Factor analysis and norms for parent ratings on the Aberrant Behavior Checklist-Community for young people in special education. *Research in Developmental Disabilities* **23**, 45–60.
- Carr A, Hartnett D, Brosnan E, Sharry J** (2016). Parents plus systemic, solution-focused parent training programs: description, review of the evidence base, and meta-analysis. *Family Process* **56**, 652–668.
- Center for Disease Control and Prevention – Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network**. (<https://physicians.utah.edu/echo/pdfs/addm-community-report-on-autism-2018.pdf>). Accessed 10 October 2019.
- Darling SM, Gallagher PA** (2004). Needs of and supports for African American and European American caregivers of young children with special needs in urban and rural settings. *Topics in Early Childhood Special Education* **24**, 98–109.
- Davis NO, Carter AS** (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. *Journal of Autism and Developmental Disorders* **38**, 1278–1291.
- Department of Children and Youth Affairs** (2016). *State of the Nation's Children: Ireland 2016*. Government Publications, Dublin.
- Dunst CJ, Jenkins V, Trivette CM** (1984). The family support scale: reliability and validity. *Journal of Individual, Family, and Community Wellness* **1**, 45–52.
- Dunst CJ, Leet HE** (1985). *Family Resource Scale: Reliability and Validity*. Winterberry Press, Asheville, NC.

- Einfield SL, Ellis LA, Emerson E** (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability* **36**, 137–143.
- Einsenhower AS, Baker BL, Blacher J** (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems and maternal well being. *Journal of Intellectual Disability Research* **49**, 657–671.
- Emerson E, Brigham P** (2015). Exposure of children with developmental delay to social determinants of poor health: cross-sectional case record review study. *Child: Care Health and Development* **41**, 249–257.
- Emerson E, Hatton C** (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry* **191**, 493–499.
- Emerson E, McCulloch A, Graham H, Blacher J, Llewellyn GM, Hatton C** (2010). Socioeconomic circumstances and risk of psychiatric disorders among parents of children with early cognitive delay. *American Journal on Intellectual and Developmental Disabilities* **115**, 30–42.
- Eskow K, Pineles L, Summers JA** (2011). Exploring the effect of Autism waiver services on family outcomes. *Journal of Policy and Practice in Intellectual Disabilities* **8**, 28–35.
- Families Special Interest Research Group of IASSIDD** (2014). Families supporting a child with intellectual or developmental disabilities: the current state of knowledge. *Journal of Applied Research in Intellectual Disabilities* **27**, 420–430.
- Galpin J, Barratt P, Ashcroft E, Greathead S, Kenny L, Pellicano E** (2017). ‘The dots just don’t join up’: understanding the support needs of families of children on the autism spectrum. *Autism* **22** (5), 571–584.
- Gangadharan S, Bretherton K, Johnson B** (2001). Pattern of referral to a child learning disability service. *British Journal of Developmental Disabilities* **47**, 99–104.
- Green SA, Berkovits LD, Baker BL** (2015). Symptoms and development of anxiety in children with or without intellectual disability. *Journal of Clinical Child and Adolescent Psychology* **44**, 137–144.
- Griffith GM, Totsika V, Nash S, Jones RS, Hastings RP** (2012). “We are all there silently coping”. The hidden experiences of parents of adults with Asperger syndrome. *Journal of Intellectual and Developmental Disability* **37**, 237–247.
- Hassall R, Rose J, McDonald J** (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research* **49**, 405–418.
- Hoffman L, Marquis J, Poston D, Summers JA, Turnbull A** (2006). Assessing family outcomes: psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and Family* **68**, 1069–1083.
- Kliegman RM, Stanton BMD, Geme JS, Schor NF** (2016). *Nelson Textbook of Paediatrics* 20th edition; Intellectual Disabilities (Chapter 36). Elsevier.
- Maulik PK, Mascarenhas MM, Mathers DC, Dua T, Saxena S** (2011). Prevalence of intellectual disability: a meta analysis of population based studies. *Research in Developmental Disabilities* **32**, 419–436.
- Mansell I, Wilson C** (2010). ‘It terrifies me, the thought of the future’: listening to the current concerns of informal carers of people with a learning disability. *Journal of Intellectual Disabilities* **14**, 21–31.
- Miodrag N, Hodapp RM** (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current Opinions in Psychiatry* **23**, 407–411.
- Miranda A, Tárraga R, Fernández MI, Colomer C, Pastor G** (2015). Parenting stress in families of children with autism spectrum disorder and ADHD. *Exceptional Children* **82**, 81–95.
- National Disability Authority** (2017). Models of good Practice in Effectively Supporting the Needs of Adults with Autism, without a Concurrent Intellectual Disability, Living in the Community. National Disability Authority Publications, Dublin.
- Neece CL, Green SA, Baker BL** (2012). Parenting stress and child behavior problems: a transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities* **117**, 48–66.
- Nurullah AS** (2013). “It’s Really a Roller Coaster”: experience of parenting children with developmental disabilities. *Marriage & Family Review* **49**, 412–445.
- Patton KA, Ware R, McPherson L, Emerson E, Lennox N** (2018). Parent-related stress of male and female carers of adolescents with intellectual disabilities and carers of children within the general population: a cross-sectional comparison. *Journal of Applied Research in Intellectual Disabilities* **31**, 51–61.
- Paulhus L, Vazire S** (2009). The self-report method. In *Handbook of research methods in personality psychology* (eds. R. W. Robins, R. C. Fraley and R. F. Krueger), pp. 224–239. Guilford Press: New York, NY, USA.
- Peer JW, Hillman B** (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: a review of key factors and recommendations for practitioners.. *Journal of Policy and Practice in Intellectual Disabilities* **2**, 92–98.
- Perry A, Isaacs B** (2015). Validity of the family quality of life survey-2006. *Journal of Applied Research in Intellectual Disabilities* **28**, 584–588.
- Plant KM, Sanders MR** (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research* **51**, 109–124.
- Poston D, Turnbull AP, Park J, Mannan H, Marquis J, Wang M** (2003). Family quality of life outcomes: A qualitative inquiry launching a longterm research program. *Mental Retardation* **41**, 313–328.
- Rojahn J, Aman MG, Matson JL, Mayville E** (2003). The aberrant behavior checklist and the behavior problems inventory: convergent and divergent validity. *Research in Developmental Disabilities* **24**, 391–404.
- Sanders MR, Kirby JN, Tellegen CI, Day JJ** (2014). The triple P-positive parenting program: a systematic review and meta-analysis of a multi-level system of parenting support. *Clinical Psychology Review* **34**, 337–357.

- Summers JA, Marquis J, Mannan H, Turnbull AP, Fleming K, Poston DJ, Wang M, Kupzck K** (2007). Relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programs. *International Journal of Development, Disability, and Education* **54**, 319–338.
- Segrin C, Burke TJ, Dunivan M** (2012). Loneliness and poor health within families. *Journal of Social and Personal Relationships* **29**, 597–611.
- Shaffer D, Gould MS, Brasic J, Ambrosini P, Fisher P, Bird H, Aluwahlia S** (1983). A children's global assessment scale (CGAS). *Archives of General Psychiatry* **40**, 228–231.
- Singer GHS** (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal of Mental Retardation* **111**, 155–169.
- Totsika V, Hastings RP, Emerson E, Lancaster GA, Berridge DM** (2011). A population based investigation of behavioural and emotional problems and maternal mental health: associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology and Psychiatry* **52**, 91–99.
- Turnbull AP, Summers J, Lee SH, Kyzar K** (2007). Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* **13**, 346–356.
- Zuna N, Summers JA, Turnbull AP, Hu X, Xu S** (2010). Theorizing about family quality of life. In: *Enhancing the Quality of Life of People with Intellectual Disability: From Theory to Practice* (ed. R. Kober), pp. 241–780. Springer: Dordrecht.