An Investigation into the Stress Levels of Irish Caregivers of Children with Intellectual Disabilities; Social Support and Child Behaviours

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Abstract

Aims: The present study investigated the stress levels of caregivers of children with intellectual disabilities. The study contributes to previous research by examining the relationship between parental stress and a child's difficult behaviour, and by examining which individual behaviours uniquely predict parenting stress. The study also examined the relationship between social support and a child's difficult behaviours and the relationship between parental stress and social support. **Methods:** 164 caregivers of children with intellectual disabilities took part in the study. The behaviours analysed in this study consisted of hyperactivity, peer problems, conduct problems, emotional symptoms, and prosocial behaviour, as categorized from the Strengths and Difficulties Questionnaire. The parents reported their stress levels using the Parental Stress Scale and the Family Support Scale, which was administered online through a questionnaire. **Findings**: Conduct problems and peer problems significantly predicted parenting stress. Parents who reported more social support reported less difficult child behaviours and had less parental stress. Parents of children with higher levels of difficult behaviour, also reported more parental stress. **Conclusions**: Caregivers should focus on utilizing many social supports to reduce stress and their child's difficult behaviour. Children must be encouraged to socialize with their peers and early signs of conduct problems must be targeted.

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Literature Review

Parental stress

Stress can be defined as a response to a stressor within our environment (Hassall, Rose & McDonald, 2005). Research on the effects of stress has concluded that higher levels of stress are associated with increased cardiovascular diseases, compromised immune systems and poorer physical health (Schneiderman et al., 2005). Perceived stress relates to the feelings pertained to uncontrollable, unpredictable or new situations in our lives and the consequences of one's ability to deal effectively with these situations (Hassall, Rose & McDonald, 2005). Perceived stress focuses on the amount of stress an individual believes they have, rather than the number of stressful experiences the person may have. The term parental stress has since emerged, which can be defined as the difficulties that arise from the demands of parenting, which subsequently impacts the parent's behaviour and well-being, as well as their child's ability to adjust (Anthony et al., 2005). Parental stress is higher in parents who are separated, unemployed, from lower socioeconomic backgrounds, have lower incomes and those with more children (Aldubayee et al., 2020; Hustedt et al., 2017; Teng, Kuo, & Zhou, 2018). Research also shows that parental stress can lead to a lower quality of life (Hsiao, 2018), marital strain, sleep problems (McQuillan et al., 2019) and can negatively impact parent-child relationships (Choi et al., 2019).

The term intellectual disability (ID) refers to a diverse range of conditions, which are characterised by below-average intellectual functioning and reduced adaptive skills (WHO, 2018). Parental stress experienced by parents of children with IDs has been widely researched and finds that these parents report higher levels of psychological distress compared to parents of typically developing children (Dunn et al., 2001; Eisenhower et al., 2005). While raising a child with an ID can have a positive effect, such as higher self-compassion and improved family closeness (Beighton & Wills, 2017; Hastings et al., 2002), there is also a lot of extra

pressures on families of children with IDs (Horton & Wallander, 2001). Research has shown that these increased pressures, such as marital strain and financial difficulties, can lead to higher stress levels (Sampson, 2012; Sansom & Farnill, 1997). If parents are experiencing high levels of stress and perceive their child as "difficult", they may lack warm responses and engage in inconsistent parenting styles (Herring et al., 2006). The impact that elevated parental stress can have on a caregiver's functioning, such as poor well-being, has been shown to impede a child's development and the success of early interventions (Osbourne et al., 2008). It is therefore vital that research is carried out to investigate parenting stress and its correlates that can be targeted through intervention and prevention strategies. Previous research has examined the role of stress in caregivers of children with IDs, these results have found that parents of children with a severe ID report higher levels of stress than those with a mild ID (Huh et al., 2006). Research into the stress levels of mothers of children with IDs has shown that this stress can be linked to their child's behavioural and communicative skills (Aunos, Feldman & Goupil, 2008; Azad, Blacher & Marcoulides, 2013). Comparative studies have shown that mothers experience more parental stress than fathers and that this stress is associated with an inability to cope with the everyday demands that arise from their child's behaviour (Kleefman, Reijneveld & Jansen, 2015). Research has shown that parental stress is more likely influenced by their child's behaviour than the severity of their disability, with studies showing that a child's behavioural problems can account for more variance in parental stress levels than the reported severity of their child's disability (Herring er al., 2006). This finding would suggest that stress levels do not correspond with their child's diagnosis and are more influenced by their child's behaviour, regardless of the severity of their child's ID. Based on these findings, further research is needed to assess the role of individual child behaviours on the stress levels of caregivers, irrespective of the severity of the child's diagnosis.

Parental stress and child behaviours

Difficult behaviours can occur in children with IDs, these behaviours include oppositionality, destructiveness and explosiveness (Gadow et al. 2004). A child engaging in difficult behaviours may be reflective of their attempt to reduce anxiety or distress by escaping aversive activities or by reacting in frustration (Brewer et al. 2014; Larson 2006). Difficult behaviours can result in a child experiencing or engaging in peer problems, conduct problems, emotional symptoms or hyperactivity (Larson 2006). Children with IDs are three to five times more likely to experience emotional or behavioural problems than typically developing children and are more prone to problem behaviours such as hyperactivity and conduct problems (Hastings, 2002). A study in 2005 suggested that children with IDs are three times more likely to have clinically significant behavioural problems than typically developing children (Baker et al., 2005). Children with IDs have been found to show lower levels of prosocial behaviour, which have been found to negatively affect peer and family relationships (Emerson, 2003). A child's difficult behaviour can also have a negative impact on parent-child interactions (Garriga, Martínez-Lucena & Moreno, 2019). According to research, these behaviours may make it more difficult for a parent to respond positively, thus influencing a negative parent-child relationship, which consequently leads to higher levels of parental stress (Huh et al., 2006). As well as influencing the parent-child relationship, difficult child behaviours can also impact a parent's mental health. Studies have shown that a child's behaviour, such as hyperactivity or impulsivity, can coincide with increased parental anxiety and stress (Achenbach & Rescorla, 2000). Hence, it is important to examine the relationship between child behaviours and parenting stress, particularly of those caring for children with IDs.

A study conducted in 2007 showed that mothers who were experiencing more stress, caused by their child's difficult behaviours, were less likely to interact with their child

(Wheeler et al., 2007). Many studies have shown that difficult child behaviours influence parental behaviours, such as inconsistent parenting styles and avoidance (Baker et al., 2003; Burke, Pardini & Loeber, 2008). The more challenging and frequent the behavioural difficulties are, the more stress is produced which may subsequently lead to an inability to respond to a child positively and effectively, thus potentially resulting in more difficult behaviours (Huh et al., 2006). A 2004 longitudinal study found that behavioural problems increased maternal stress while simultaneously, the increase in maternal stress levels led to an increase in behavioural problems (Beck et al., 2004). This suggests a bidirectional relationship between parental stress and a child's difficult behaviour. This finding supports previously mentioned research as high levels of stress can negatively impact a parent-child relationship, thus resulting in more difficult behaviours. Simultaneously, difficult behaviours can increase parenting stress over time.

While previous research has shown a strong link between a child's behaviour and parental stress, little is known about the individual contribution of specific behaviours and how these contribute to the parenting stress of those caring for children with IDs. Through the identification of such behaviours and their impact, more effective interventions can be developed to target specific behaviours. A study conducted in 2014 examined the relationship between individual child behaviours and parenting stress, however, this study focused solely on the caregivers of children with autism (Huang et al., 2014). This study found that conduct problems and emotional symptoms significantly predicted parental stress, however, peer problems were not found to be associated with parenting stress (Huang et al., 2014). Research into the effects of stress and child problem behaviours have been studied alongside the role of social support (Halstead et al. 2018). These findings have predominantly identified social support as a protective factor against parental stress, thus influencing a parent's ability to effectively cope with their child's difficult behaviours (Dunlap et al., 2001). Parents of

children with IDs are more prone to parental stress and exposure to experiences of difficult child behaviours. It is therefore important for researchers to identify the role that social support plays in reducing both stress and difficult behaviours, particularly for caregivers of children with IDs.

Social support and parental stress

Social support can be described as the emotional, physical, informational and instrumental assistance that individuals receive from their social networks (Leu et al, 2015). Both perceived and received social support have since emerged as two prominent factors in the reduction of stress (Szkody & McKinney, 2019). Perceived social support is described as the belief that support is available and given adequately if needed, such as knowing that a friend is available to provide babysitting services (Thoits, 1982). Whereas received social support is the physical act of receiving support, such as the time spent attending day services for a child (Szkody & McKinney, 2019). Perceived social support has been found to be more beneficial than received social support in reducing stress (Szkody & McKinney, 2019).

Social support has emerged as a protective factor against parental stress (Sharda et al., 2019). Having a good network of social support has been shown to improve the mental well-being of parents (Sharda et al., 2019), marital relationships (Brunstein, Dangelmayer & Schultheiss, 1996), health-seeking behaviours (Berglund, Lytsy & Westerling, 2019) and life satisfaction (Newsom & Schulz, 1996). Parenting stress can be reduced by supportive grandparents (Trute, 2003) and a supportive spouse (Brunstein, Dangelmayer & Schultheiss, 1996). Sources of support from parents who are in similar situations are important for families who have children with IDs as it creates a sense that the stress caused by their child's behaviour is a normal part of life, which strengthens their resilience and coping skills (Thoits, 2011). In addition, social support has also been shown to be an important factor in preventing stress that arises specifically from caring for a child with additional needs, such as IDs (;

Halstead et al. 2018; Handley & Chassin 2008). Studies have shown that informal support from friends and family can be more beneficial than formal professional services (White & Hastings, 2004). A study conducted on caregivers of teenagers with severe IDs found that informal support (such as support from friends and family) was effective in improving well-being, but the use of formal, professional support services was not (White & Hastings, 2004). This research has shown that informal support, may be more important than formal support in reducing parental stress of parents of children with IDs. Luther, Canham, and Cureton (2005) found that parents of children with a developmental disability have a higher need for social support than those caring for typically developing children. Research has also found that caregivers of children who display high levels of difficult behaviours, are less likely to pursue social supports (Siklos & Kerns, 2006). These findings have huge implications for caregivers of children with IDs. Such parents report needing more social support than those with typically developing children; however, they are less likely to utilize such supports, based on these findings. It is therefore important to examine the role of social support of Irish caregivers, and how they utilize and perceive their available social supports.

Social Support and Difficult Child Behaviours

In recent years, there has been a huge shift in the way that difficult behaviours are understood and addressed (Dishion & Stormshak, 2007). Many support services are now more family-centred, meaning that interventions are most effective when they are implemented by individuals who are in regular contact with, and who have a unique knowledge regarding their child. Previously mentioned research has shown that the formation of a child's behaviour can often be influenced by their caregivers (Baker et al., 2003; Burke, Pardini & Loeber, 2008). This research has outlined the importance of parent-child interactions as being a major part of the need to involve parents in the efforts to address a child's difficult behaviour. In addition to the effects that parents can have on both

exacerbating and alleviating the occurrence of difficult behaviours, they also possess vital information regarding their child's history, preferences, and behavioural patterns in a multitude of differing contexts (Dunlap et al., 2001). The use of this knowledge is crucial to the success of forming highly functional interventions (Dunlap et al., 2001). Hence, research has begun to focus on parent-led interventions for targeting early child problem behaviours (Dishion & Stormshak, 2007; Gardner, Burton & Klimes, 2006; Hutchings et al., 2007). The use of such interventions, focusing greatly on parent management training, have shown to be low-cost, effective and can be adapted to engage the most marginalized families (Turner & Sanders, 2006; Dishion, Nelson, & Kavanagh, 2003). As an increased focus is put on parents to intervene and prevent difficult child behaviours, it is simultaneously important to acknowledge the stress and demand that such behaviours can have on the mental health of such carers. To successfully manage the difficult behaviours that can arise from parenting a child with a disability, families need to draw upon a variety of social supports (Weis, 2002). Research conducted in 1999 found that the more resources a family had available, the more effectively the family could manage the challenges presented by a child's difficult behaviour (Dunlap & Fox, 1999). Regarding this study, resources refer here to both tangible resources such as money, and intangible supports such as emotional support and friendships. Research into the effectiveness of family social support has found that the development of social support can predict parental competence in dealing with problematic behaviours and reducing the parents stress levels (Haldy & Hanzlik 1990; Weis, 2002). Hence, the current study aims to focus on the role of social support and parental stress and the influence these have on how parents report their child's difficult behaviours.

The current study

Previous literature has outlined the susceptibility of parents of children with IDs to the experience of high stress levels (Dunn et al., 2001). The current study aims to contribute to the research by investigating the stress levels experienced by Irish caregivers of children with IDs. Previously mentioned research has suggested that children with IDs are more prone to difficult behaviours, thus, the current study will expand on previous research by investigating the relationship between a child's difficult behaviour and parental stress levels. Previous research has identified a relationship between parenting stress and a child's difficult behaviour; however, further research is needed to examine which specific behaviours contribute to parental stress levels. The current study will use the subscales of the Strengths and Difficulties Questionnaire (Goodman, 1997), which will include hyperactivity, conduct problems, emotional symptoms, peer problems and prosocial behaviour as predictors of parental stress. This scale was chosen as it incorporates behaviours that are often seen in children with IDs, encompassing both externalizing and internalizing behaviours (Hastings, 2002). The current research further aims to identify a relationship between parental stress and social support within caregivers of children with IDs. The study will address the role of parental social support and the reporting of their child's difficult behaviours. Previous literature has suggested that parents play a vital role in preventing their child from engaging in difficult behaviours, and an increase in social support has been found to increase a parent's ability to cope with their child's difficult behaviours (Haldy & Hanzlik 1990; Weis, 2002). Based on the literature, the current study will address the four research questions identified below.

Research question 1: What is the relationship between Irish parents of children with intellectual disabilities' stress levels and their child's difficult behaviour? Hypothesis for

research question 1(H1): There will be a positive relationship between parental stress and a child's difficult behaviour.

Research question 2 aims to examine which child behaviour will be most predictive of parental stress when looking at hyperactivity, conduct problems, emotional symptoms, peer problems and prosocial behaviours.

Research question 3: What is the relationship between Irish parents of children with intellectual disabilities' stress levels and perceived social support? Hypothesis for research question 3(H3): Parents who report high levels of parenting stress will report low levels of social support.

Research question 4: What is the relationship between a parent's perceived social support and their reporting of their child's difficult behaviour? Hypothesis for research question 4(H4): Parents who report low levels of social support will report more difficult child behaviours.

Methodology

Participants

The study recruited a sample of 164 caregivers, with 152 females (92.7%) and 12 males (7.3%), with a mean age of 42.45. The sample size was calculated using Tabachnick and Fidell's (2013) formula for calculating the sample size for multiple regression analysis which is as follows: (N > 50 + 8m), where n = number of participants and m = number of PVs, therefore the minimum sample size for the current study had to be n = 90. Participants were all residing in Ireland. Of the participants recruited; 102 were married (62.2%), 25 were in a relationship (15.2%), 19 were single (11.6%), 12 were divorced (7.3%) and 1 participant was widowed (.6%). Majority of participants, 122, were living with their spouse or partner (74.4%) and 38 participants were living alone (23.2%). Of the participants, 6 had a family income of less than 10,000(3.7%), 48 were between 10,000 and 29,000 (29.3%), 39 were between 30,000 and 49,000 (23.8), 28 were between 50,000 and 69,000 (17.1) and 34 were over 70,000 (20.7%). According to participants, 49 of their children had a mild ID (29.9%), 75 had a moderate ID (45.7%) and 32 had a severe ID (19.5%). Of the participants, 8 were unsure of their child's diagnosis (4.9%). The children's age ranged from 4 to 17, with a mean age of 9.8. Of the children, 72.6% had at least one other sibling. Some participants did not fall into a category for the questionnaire, as 9 participants chose other for their income (5.5%), 4 chose other for their living situation (2.4%) and 5 chose other for their marital status (3%). A total of six participants were excluded from the study as their child's age range did not fall between four and seventeen, as per the requirements of the SDQ questionnaire. The study implemented a nonprobability, convenience sampling strategy to recruit participants as recruitment relied heavily on participants willingness to partake. Participants were recruited from social media, from two special primary schools in Waterford and from TUSLA.

Materials

Google forms was used to create the survey for this study. The survey consisted of a demographic's questionnaire containing questions regarding the participants gender, age, marital status, current living situation, family income, and the number of children in their care. Demographics collected relating to their child consisted of their age and severity of their intellectual disability (mild, moderate, or severe). The survey also contained the three scales reported in more detail below.

The Parental Stress Scale developed by Berry & Jones, 1995 was used to measure parent's feelings about the positive and negative aspects of parenting (see appendix B). It contains 18 items representing a range of factors such as emotional benefits, self-enrichment, and demands on resources and restrictions. Respondents were asked to agree or disagree with items relating to their child or children. Each item has a five-point scale: strongly disagree (1), disagree (2), undecided (3), agree (4), and strongly agree (5). Eight of the positive items were reverse scored so possible scores can range from 18-90. Higher scores on the scale indicate greater stress levels. The scale has been used in many studies for both mothers and fathers of children with and without clinical problems (Nielsen, Pontoppidan & Rayce, 2020). This scale has demonstrated satisfactory levels of internal reliability (.83) and test-retest reliability (.81), while also showing satisfactory in validity when compared to various other measures of stress (Berry & Jones, 1995). The Cronbach's alpha for the current study was (α =.88), which suggests high levels of internal reliability for this scale.

The Strength and Difficulties Questionnaire developed by Goodman (1997) was used to screen for behaviours of the child (see appendix C). The measure has five subscales which assesses prosocial behaviour (e.g. "kinder to younger children"), the other four subscales assess difficult behaviours, which are subcategorized as emotional symptoms, conduct problems, hyperactivity and peer problems. The parents were asked to rate whether

the behaviour of their child with an ID is not true (0), somewhat true (1), or certainly true (2). To assess the child's difficult behaviours, scores from the 4 categories (excluding prosocial behaviour) were added. The higher the score, the more difficult the child's behaviour is. The scale has been shown to be reliable (Cronbach's $\alpha = .76$). This scale has been extensively used in research with children with IDs (Hastings, 2007). The Cronbach's alpha for the current study was ($\alpha = .72$), which suggests satisfactory levels of internal reliability for this scale.

The Family Support Scale developed by Dunst, Jenkins, and Trivette, 1984 is a 16-item scale used to measure the amount of perceived support given to parents (see appendix D). Participants were asked to choose the number that best represents the level of support, which ranged from 1(not at all helpful) to 5 (very helpful). The scale looks at different supports available, such as family, friends, social groups, and professional services. If a support is not available to a participant, the participant was asked to leave that section blank and was coded as 'missing' in SPSS. Higher scores on the scale indicate higher levels of perceived social support. The reliability and validity of the scale were established in a study of 121 parents of children with ID. Coefficient α computed from the average correlation among the scale items was .87 (Dunst et al., 1988). The items are summed and represent four subscales: familial support, spousal support, social support, and professional support. The total score is calculated by summing the results from all four subscales. This scale has been used previously in ID research (White & Hastings, 2004) and has been shown to be satisfactory when compared to other valid measures of social support (Taylor, 1999). Coefficient alpha for the scale was found to be .79, with split-half reliability of .77 corrected for length (Dunst, Jenkins & Trivette, 1984). The Cronbach's alpha for the current study was ($\alpha = .71$), which suggests satisfactory levels of internal reliability for this scale.

Study Design

The research employed a cross-sectional, within-groups design which was conducted from November 2020 to March 2021. A quantitative approach was employed for research question 2, with 5 predictor variables (PVs); emotional symptoms, peer problems, conduct problems, hyperactivity, and prosocial behaviour. The criterion variable (CV) was parental stress levels. Correlations were used for the remaining three hypotheses. As correlations cannot indicate causality, no dependant and independent variables were assumed.

Procedure

Special schools around Ireland were contacted to ask for their participation. Two schools based in Waterford agreed to participate and the questionnaire was sent to the parents of children attending these schools. Tusla – The Child and Family Agency were contacted and agreed to distribute the link to foster carers of children IDs residing in Waterford. The total numbers of participants contacted is unknown, so a response rate cannot be calculated. Social media was also used to recruit participants. Facebook was used to attach the link to posts in parenting groups around Ireland. Consent was obtained from the consent form/information sheet that was attached directly before the questionnaire (see appendix E). The consent form gave a brief description of the study, what was required of them for participation and what the estimated time frame was for completion (an estimated 10 minutes). They were also told that they could withdraw from participation at any time without penalty. Participants had to accept that they were over the age of 18 and that they consented to participation before having access to the questionnaire. Participants were then required to fill out their demographic's details, followed by the Parental Stress Scale, followed by the Strengths and Difficulties Questionnaire and finally the Family Support Scale questionnaire. After completion, the participants were directed to a 'debrief' page in which participants were thanked for participation and given the contact details of myself, the

research supervisor, and Inclusion Ireland, should they have any further questions and concerns (see appendix F).

Ethical Considerations

All data was collected in accordance with the NCI ethical guidelines. The risks and benefits were clearly outlined and there were no incentives for participation. All participants provided consent for participation, and confirmed they were over the age of 18. The right to withdraw from the study without penalty was clearly stated before participation and participants were told that once their data was submitted, they would not be able to withdraw their data due to how it was stored. The participants were told that the data would be submitted for a final year psychology project at NCI. Should participants have felt any distress from taking part, the contact details of Inclusion Ireland were given should they need further support or information.

Results

Descriptive Statistics

Table 1 shows the demographic characteristics of the caregivers and their children with IDs. A total of 164 caregivers took part in the study (*n* =164), with 92.7% females (*n* =152) and 7.3% males (*n* =12), with a mean age of 42.45 (*SD*= .625). Participants were all residing in Ireland. Of the participants recruited, 62.2% were married (*n*=102) and 74.4% were living with their spouse or partner (*n* =122). The family income of participants ranged from less than €10,000 to over €70,000, see table 1 for full details. According to participants, 29.9% of the children had a mild ID (*n*=49), 45.7% had a moderate ID (*n* =75) and 4.9% had a severe ID (*n* =32), 8 participants were unsure of their child's diagnosis (4.9%). The children's age ranged from 4 to 17, with a mean age of 9.8 (*SD*= .333), see table 2 for full details. Of the children, 72.6% had at least one other sibling (*n* = 119), see Table 1 for full details.

Table 1

Descriptive statistics for the characteristics of the caregivers and their children.

Variable	Frequency	Valid %
Gender		
Male	12	7.3
Female	152	92.7
Marital status		
Married	102	62.2
In a relationship	25	15.2
Single	19	11.6
Divorced	12	7.3
Widowed	1	.6
Other	5	3.0
Living situation		
Living with spouse/partner	122	74.4
Lone parent	38	23.2
Other	4	2.4
Family Income		
Less than 10,000	6	3.7

10,000-29,000	48	29.3
30,000-49,000	39	23.8
50,000-69,000	28	17.1
More than 70,000	34	20.7
Unknown	9	5.5
Severity of child's intellectual disability		
Mild	49	29.9
Moderate	75	45.7
Severe	32	19.5
Unknown	8	4.9
Children in care		
One	45	27.4
Two	69	42.1
Three	42	25.6
Four	8	4.9

Descriptive statistics were performed for all continuous variables. Means (*M*), Standard Deviations (*SD*), and Range were obtained and are presented below in Table 2. Preliminary analysis was performed on the data set to ensure no violations of the assumption of normality. The parental stress score and child's total difficulties showed a non-significant result ($p > .05$) of the Kolmogorov-Smirnov statistic with acceptable histograms, indicating that the data is normally distributed. However, preliminary analysis found that social support was non-normally distributed, as a significant result ($p < .05$) of the Kolmogorov-Smirnov statistic was found, indicating that the data is non-normally distributed. Inspection of the histograms show that the data is positively skewed. The non-normally distributed data is taken into consideration and appropriate nonparametric statistics are run accordingly.

Table 2

Descriptive statistics for all continuous variables (n=164)

Variable	*M* [95% CI]	*SD*	Range
Age of participant	42.45[41.28,43.62]	.625	25-57
Age of participant's child	9.80[9.15,10.46]	.333	4-17
Parental stress	50.73[48.97, 52.48]	11.41	22-85
Social Support	28.74[27.51,29.98]	7.99	12-51
Child's total difficulties	17.90 [16.95,18.85]	5.95	2-32
SDQ Subscales			
Emotional symptoms	4.51[4.07,4.95]	2.84	0-10
Conduct problems	3.50[3.15,3.85]	2.22	0-10
Hyperactivity	4.93[4.67,5.18]	2.69	1-10
Peer problems	5.09[4.75,5.44]	2.44	0-10
Prosocial behaviours	4.54[4.10,4.97]	2.77	0-10

Inferential statistics

The relationship between parental stress and a child's difficult behaviour was investigated using a Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. The child's difficult behaviour total score was calculated by adding scores on the emotional symptoms, conduct problems, hyperactivity, and peer problems. There was a moderate, positive correlation between the two variables (r = .36 [95% CI = .24, .47], n = 153, $p < .001$). Results indicate that higher levels of stress are associated with more difficult child behaviours.

A multiple regression analysis was conducted to examine how well parental stress levels of caregivers could be explained by individual child behaviours as characterised by the SDQ. Scores on the Parental Stress Scale were used as the criterion variable and the five

subscales of the SDQ which included emotional problems, conduct problems, hyperactivity, peer problems and prosocial behaviour, were used as the predictor variables. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. The correlations between the predictor variables and the criterion variable included in the study were examined (see Table 4 for full details). Four of the five predictor variables were significantly correlated with the criterion variable, and these significant effects ranged from r = .10 (hyperactivity) to r = .34 (peer problems). The correlations between the predictor variables were also assessed with r values ranging from .05 to .37. Tests for multicollinearity also indicated that all Tolerance and VIF values were in an acceptable range. These results indicate that there was no violation of the assumption of multicollinearity and that the data was suitable for examination through multiple linear regression analysis.

Table 4

Variable	1.	2.	3.	4.	5.	6.
1. Parental stress	-					
2. Emotional Symptoms	.25**	-				
3. Conduct Problems	.29***	.36***	-			
4. Hyperactivity	.10	.16*	.36***	-		
5. Peer problems	.34***	.25**	.22**	.13	-	
6. Prosocial behaviour	-.20**	.18*	-.09	.05	-.37***	-

Note: *p < .05; **p < .01; ***p < .001

Since no a priori hypotheses had been made to determine the order of entry of the predictor variables, a direct method was used for the analysis. The five predictor variables explained 19% of variance in parental stress levels ($F(5, 150) = 6.88$, $p < .001$). Two of the

five variables were found to uniquely predict parental stress to a statistically significantly level: Conduct problems (β = .18, p = .04) and peer problems (β = .22, p = .01) (see Table 5 for full details).

Table 5

Standard multiple regression model predicting parental stress total score.

Variable	R^2	*B*	*SE*	B	*t*	*p*
Model	**.19*** **					
Emotional symptoms		.62	.34	.15	2.81	.073
Conduct Problems		.91*	.44	.18	2.07	.039
Hyperactivity		-.10	.55	-.01	-.17	.864
Peer problems		1.11*	.44	.22	2.55	.012
Prosocial behaviour		-.54	.35	-.13	-1.56	.121

Note. R^2= R-squared; β = standardized beta value; *B* = unstandardized beta value; *SE* = Standard errors of B; N = 155; Statistical significance: *p < .05

Preliminary analyses were performed to ensure no violation of the assumptions of normality which found that social support was non-normally distributed. Therefore, a Spearman's Rank Order correlation coefficient was run to assess the relationship between parental stress and social support. There was a small, negative correlation between the two variables (*r* = -.27 [95% CI = -.42, - .11], *n* = 164, *p* = .001). Results indicate that higher levels of parental stress are associated with lower levels of social support.

Preliminary analyses were performed to ensure no violation of the assumptions of normality which found that social support was non-normally distributed. Therefore, a Spearman's Rank Order correlation coefficient was run to assess the relationship between social support and a child's difficult behaviour. There was a small, negative correlation between the two variables (*r* = -.18 [95% CI = -.34, -.01], *n* = 164, *p* = .026). Results indicate

that parents who report higher levels of social support, also report fewer difficult behaviours exhibited by their child.

To summarize, results indicate that there is a moderate, positive correlation between parental stress and a child's difficult behaviour. These results indicate that the more difficult a child's behaviour is, the more stress a caregiver experiences. Results also indicate that of those behaviours, conduct problems and peer problems were statistically significant in predicting higher stress levels. A significant negative correlation was found between parental stress and perceived social support, meaning that lower levels of social support predict higher levels of parental stress. Finally, results indicated that caregivers who scored higher on perceived social support, also reported less difficult child behaviours.

Discussion

The current research aimed to examine the relationship between parental stress, social support and a child's behaviour among Irish caregivers of children with IDs. The current study sought to expand on previous research and provide further insight into the causes of stress among Irish caregivers, while examining the role of both social support and a child's behaviour. The current study tested three hypotheses, in which all were accepted and are evaluated in detail below. The study also examined an explorative research question, which found that peer problems and conduct problems were significant predictors of parental stress, when also examining the role of emotional symptoms, hyperactivity and prosocial behaviour.

The current study hypothesized that there would be a positive relationship between parental stress and a child's difficult behaviour (H1). Results from this study found that there was a significant positive relationship between both variables. This finding shows that parents who report higher levels of stress also report more difficult child behaviours. The current research adds to previous literature through supporting the results that a child's behaviour, when seen as difficult, can negatively impact a caregiver's stress levels (Baker et al., 2003; Burke, Pardini & Loeber, 2008). Studies on children without IDs indicate that high stress levels in parents can predict heightened levels of difficult behaviours in their children (Owens & Shaw 2003; McCarty et al. 2005; Deater-Deckard et al. 2006). Previous literature has also found that early child difficult behaviours can predict parenting stress (Wheeler et al., 2007). The current finding concurs with this in that caregivers of children with more difficult behaviours were found to have higher levels of stress. This finding highlights the importance of support systems in targeting both parental stress and difficult child behaviours in caregivers of children with IDs.

A multiple regression analysis was used to examine the effects of child behaviours on parental stress. Results found that peer problems and conduct problems were significant

predictors of parental stress, when also examining the effects of emotional symptoms, hyperactivity, and prosocial behaviour. These findings are both consistent and inconsistent with previous research. A study conducted in 2014 found that conduct problems were a significant predictor of parental stress in caregivers of children with autism (Huang et al., 2014), similar to the findings of the current study. Conduct problems are disruptive, rule-breaking behaviours, which can contradict a caregiver's expectations and go against societal norms. For example, stealing and cheating are often viewed as serious problems within society, especially when compared to hyperactivity or emotional symptoms (Haung et al., 2014). The desire to conform to society's expectations may explain why parents experience high levels of stress when their children exhibit conduct problems. A study in 2013 found that children with conduct problems impacted a parent's ability to carry out day to day tasks, form a close relationship with their child, or to cope with negative feelings they have about their child (Vaughan et al., 2013). These findings may explain why caregivers report high levels of stress due to conduct problems. Peer problems were also a significant predictor for parenting stress. Interestingly, a study in 2014 found that peer problems did not significantly predict parental stress in caregivers of children with autism (Haung et al., 2014). The differing results may be due to the studies focus on children with autism rather than children with IDs. The school life of a child with an ID plays an important role on a child's development. Hence, a child experiencing peer problems may impact a caregiver's stress levels, as some carers may place a large emphasise on their child's school life. Research has also found that a child's social skills significantly predicted parental stress more than a child's intellectual status or child behavioural problems (Neece & Baker, 2008). This study found that the development of social skills led to a decrease in parenting stress. A study in 2001 found that social skills were a stronger predictor of parenting stress than their adaptive behaviour or cognitive skills (Smith, Oliver & Innocenti, 2001). This may explain why peer problems significantly

predicted parental stress within the current study. Children may experience peer problems due to a lack of social skills, thus leading to an increase in parenting stress. This may be explained by the role that social skills also play in positive parent-child interactions (Lewallen & Neece, 2015). Thus, meaning that children with peer problems, may lack social skills, which in turn negatively impacts the parent-child relationship. These findings, as well as the current study, highlights the needs for interventions to focus on effectively targeting social skills to prevent peer problems in children with IDs.

Hypothesis 3 (H3) stated that parents who report high levels of parenting stress will report low levels of social support. H3 was investigated using a Spearman's correlation and found a significant negative relationship between parental stress and social support, thus accepting the studies hypothesis. This finding suggests that parents who report higher levels of social support also report less parental stress. More specifically, the current study found this relationship among caregivers of children with ID's. This finding highlights the important role that social supports, both formal and informal, can have on the mental health of these caregivers. Previous literature has found that caregivers of children with IDs are often excluded from social contacts (Fisman, Wolf & Freeman, 2000). The current study would support this as caregivers within this study had overall low levels of social support. Previous research has identified that caregivers of children with IDs require more social support (Luther, Canham & Cureton, 2005). Despite the need for high levels of social support, this was not found within the current study. Having a good network of social support has been found to increase family adjustment, physical and emotional well-being, and positive coping strategies in families of children with IDs (Trivette & Dunst, 1992; Weiss, 2002). These findings may be suggestive of how the role of social support subsequently reduces parental stress in those caring for children with IDs. Research has also found that parents who experience high levels of stress are less likely to utilize available social supports

(Luther, Canham & Cureton, 2005). This finding therefore may suggest that caregivers experiencing high levels of parental stress also report low levels of social support, due to their reluctance to utilize social supports. The current finding highlights the importance of services in effectively encouraging and promoting high levels of social support to reduce parentals stress.

Finally, hypothesis 4 (H4) stated that parents who report low levels of social support will report more difficult child behaviours. The results identified a significant positive correlation between the two findings, thus accepting the studies hypothesis. This relationship may be explainable by several other research findings. Firstly, previous research has found that parents of children with clinically significant behavioural problems tend to withdraw from social situations as they find their child's behaviour difficult to manage. These parents also reported being less content with the social support they receive and were more vulnerable to high levels of stress (Solem, Christophersen & Martinussen, 2011). Therefore, parents of children who exhibit higher levels of difficult behaviour may also report low levels of social support due to the stigma that is attached to parenting a child who exhibits such behaviour. A study which focused on the role of foster carers found that social support acted as a buffer between a child's behavioural issues and challenges with foster caring and found that those who reported less social support also had more perceived difficulties with child behavioural problems (Cooley, Thompson & Newell, 2019). This finding might suggest that parents with lower levels of social support report more difficult behaviours due to a lack of support, thus resulting in an inability to deal effectively with their child's behaviour. The role of social support has been widely studied in terms of resilience and parental stress, and predominantly these findings have suggested that social support allows a caregiver to develop resilience and reduce parental stress (Palacio et al, 2020; Plumb, 2011). The current study, and previous research, has found that less parental stress is associated with more difficult

child behaviours. It may therefore be assumed that having higher levels of social support increases resilience and decreases stress, thus allowing caregivers to effectively deal and cope with their child's difficult behaviours. This ability to cope and manage behaviours may lead to caregivers reporting less difficult behaviours, which may explain the current study's finding. The current study highlights the need for caregivers to utilize the social supports available to them, in order to alter the perceptions they hold of their child's difficult behaviours.

Practical implications and future research

The current results indicate that social support plays an important role in reducing the stress levels of caregivers. Caregivers of children with IDs experience multiple care demands that go beyond those associated with parenting in general, and therefore many may need more support. Caregivers caring for children with IDs should be made aware of the importance of social support for their own well-being. The results of the study have implications for intervention services, as the study highlights the importance of focusing on the caregivers needs as well as the child's. Support services should place huge importance on providing satisfactory levels of support, as well as highlighting the importance of informal social support to those caring for children with IDs. Based on the current findings, by offering high levels of social support to caregivers, it may be assumed that this will in turn reduce caregivers stress levels and alter their perceptions of their child's difficult behaviours. Support services should aim to provide caregivers with information regarding social support, such as available support groups within their area or online. Caregivers should aim to increase their time spent with family and friends to reduce their stress levels, thus allowing them to better cope with the demands that arise from caring for a child with an ID. The study found that low levels of social support are linked with high levels of difficult child

behaviours. This further highlights the need for these caregivers to be encouraged and educated in the importance of utilizing available social supports.

Fundamental to the system of care philosophy, particularly within Ireland, is addressing the individual needs of children and their families (Tolan & Dodge, 2005). This research on the impacts of children's difficult behaviours on their caregiver's well-being is crucial in meeting this aim. The current study has identified that conduct problems and peer problems significantly predicted parental stress levels, in those caring for children with IDs. This finding highlights the need for both clinicians and caregivers to focus on improving social skills and encouraging positive interactions between children and their peers. The study also highlights the need for clinicians and caregivers to be aware of early signs of conduct problems. These behaviours should be targeted as early as possible to minimize the negative effect such problems can have on the caregiver's well-being, which in turn will improve the positive outcomes for the child's future development.

Future research should consider which social supports are most beneficial in reducing a caregiver's perception of their child's difficult behaviours. This research would identify whether it is formal, professional services that offer guidance and skills to cope with their child's behaviour, or if it is informal social support from family and friends that reduces a parent's perception of their child's difficult behaviour. Future research should also consider utilizing a third party, such as a teacher, to report on their child's behaviour. This would reduce the influence that stress or other variables may have on how a parent perceives and reports their child's behaviour, thus removing such influences. It would be beneficial for future research to distinguish between types of IDs and investigate the role of difficult behaviours in respect to their diagnosis and parental stress levels. This would provide insight for clinicians and caregivers in understanding which behaviours are most prominent based on their diagnosed ID and how this influences parental stress levels. Future research would also

benefit from distinguishing between children's age groups, as parents may experience more stress caused by specific child behaviours, depending on their age.

Strengths and limitations

The current study utilized a cross-sectional, correlational design and therefore cannot indicate causality. All critical variables were gathered using self-report measures, which may have led to bias responses. It must also be considered that parents experiencing high levels of stress may have over-reported their child's behaviours or social support, thus resulting in biased results. Similarly, parents may engage in self-serving bias thus leading to their inability to correctly report their child's difficult behaviours. A convenience sampling method was utilized, with large focus on parenting groups. Parents who are members of such parenting groups may report more social support than other members of the population. While efforts were made to recruit male participants, the study consisted mainly of female participants. Thus, differing results may have been found had the study recruited equal parts male to female. Majority of participants were also living with their spouse or partner which may have increased their reporting of social support. These factors may influence the studies generalisation to a wider population.

The current study did not distinguish between types or severity of IDs. Different diagnoses may have differing outcomes for children with intellectual disabilities and some child behaviours may be more prominent depending on the child's diagnosis. As the current study did not distinguish between intellectual disabilities, this may be seen as a limitation. However, the current focus of this study was on children with ID's, regardless of the severity of their diagnosis. This can be seen as a strength as previous studies have found that the severity of a child's ID is less predictive of parental stress than their child's behaviour (Baker et al. 2005; Neece et al. 2012). Therefore, this study highlights the importance of focusing on the child's behaviour rather than the disability. It must also be noted, however, that parents of

children with a severe ID may have been unable to answer some questions relating to their child's behaviour. A child with a severe ID who may be non-verbal or absent from school, may not show obvious signs of prosocial behaviours or peer problems as characterized by the SDQ. Therefore, these parents may have reported less difficult child behaviours, but which may not have been representative of other difficulties faced by these parents.

The FSS, which measures only perceived social support, was used to measure social support in this study. Previous research has suggested that this does not encompass the role of social support and its many multidimensional concepts, such as actual social support, access to and availability of social support, the quality of the relationships one has, and the size and the interconnectedness of one's network (Sarason, Sarason & Pierce, 1990). Therefore, the study may have benefited from utilizing measures that gather information about these other facets of social support and examining their relationship with the variables examined in this study. However, a measure of perceived social support was chosen as it has been found to be more beneficial in reducing stress levels compared to actual received social support (Szkody & McKinney, 2019).

A notable strength of the study is its large sample size of 164 participants which improves its generalizability. The study also recruited participants who showed equal variation in their income level, which ranged between below 10,000 to above 75,000. This variation would have limited the influence that income may have had on participants stress and social support levels, as previous research has identified a relationship between the two (Cramm & Nieboer, 2011). The study also recruited a variety of participants who reported their child's diagnosis as either mild, moderate, or severe. This would have limited the influence of the severity of diagnosis on the caregiver's stress levels and their child's difficult behaviours, as previous research has identified a relationship between the two (Holden & Gitlesen, 2004).

Conclusions

The current study expands on previous literature by examining the relationship between individual child behaviours and parental stress. Findings suggest that there was a positive relationship between parental stress and a child's difficult behaviour. Parents who reported more stress also reported more difficult child behaviours. Further analysis found that of these behaviours, conduct problems and peer problems were significant predictors of parental stress, while hyperactivity, prosocial behaviour, and emotional symptoms were not. This research highlights the importance of support services focusing their attention on both the child and the caregiver. The current research also found a significant negative relationship between social support and parental stress, in that parents who report more social support also report less parental stress. Social support was also found to have a positive relationship with a parent's reporting of their child's difficult behaviour, parents who report greater social support reported less child difficult behaviours. These findings highlight the important role that social support plays in reducing a caregivers stress and perceptions of their child's difficult behaviours. Caregivers should be encouraged to utilize and seek out many supports, from professional services to family and friends. Caregivers should also put emphasise on improving their own mental health while caring for their children, as this can have positive outcomes both for themselves and their child. Intervention services must focus on targeting individual child behaviours and should encouraging positive socialization among children. Emphasis should be placed on early identification of conduct and peer problems. Effective early interventions must be identified and put in place to prevent the impact these behaviours have on a parent's stress levels and to ensure each child is given the opportunity to reach their individualised, holistic and optimal potential.

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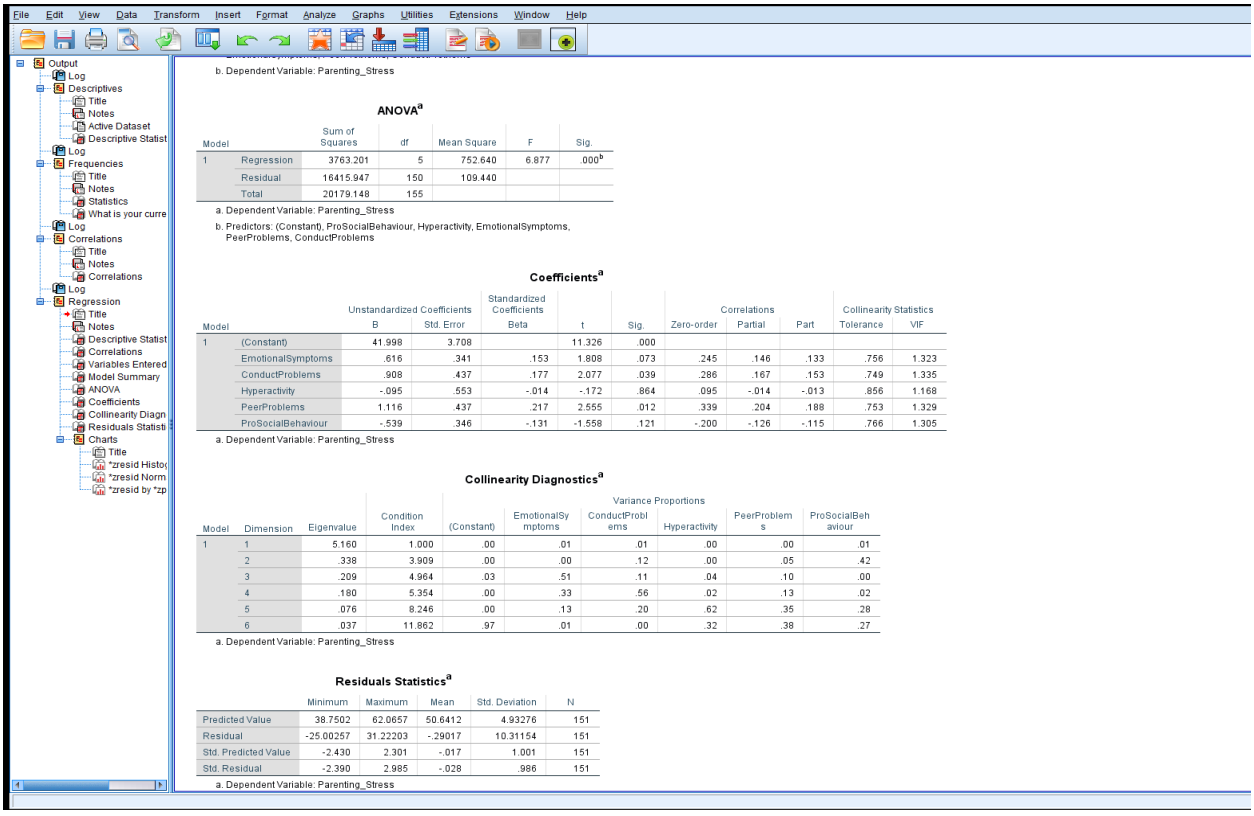
Appendices

Appendix A

Evidence of data



b. Dependent Variable: Parenting_Stress

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3763.201	5	752.640	6.877	.000[b]
	Residual	16415.947	150	109.440		
	Total	20179.148	155			

a. Dependent Variable: Parenting_Stress

b. Predictors: (Constant), ProSocialBehaviour, Hyperactivity, EmotionalSymptoms, PeerProblems, ConductProblems

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	41.998	3.708		11.326	.000					
	EmotionalSymptoms	.616	.341	.153	1.808	.073	.245	.146	.133	.756	1.323
	ConductProblems	.908	.437	.177	2.077	.039	.286	.167	.153	.749	1.335
	Hyperactivity	-.095	.553	-.014	-.172	.864	.095	-.014	-.013	.856	1.168
	PeerProblems	1.116	.437	.217	2.555	.012	.339	.204	.188	.753	1.329
	ProSocialBehaviour	-.539	.346	-.131	-1.558	.121	-.200	-.126	-.115	.766	1.305

a. Dependent Variable: Parenting_Stress

Collinearity Diagnostics[a]

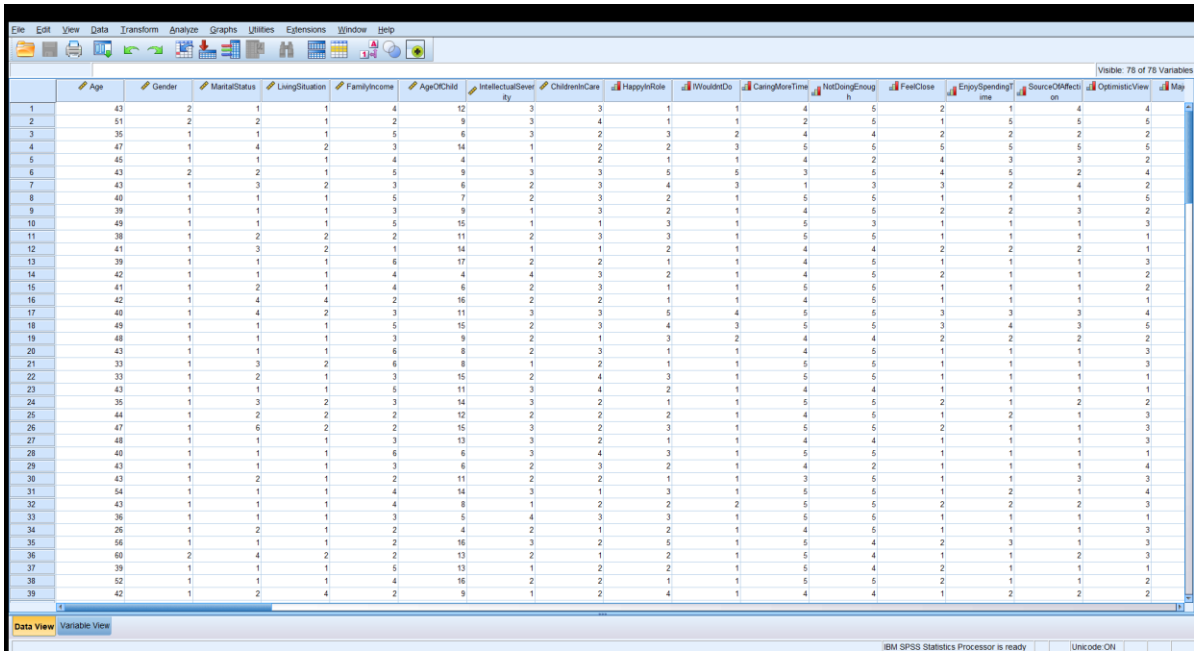
Model	Dimension	Eigenvalue	Condition Index	Variance Proportions					
				(Constant)	EmotionalSymptoms	ConductProblems	Hyperactivity	PeerProblems	ProSocialBehaviour
1	1	5.160	1.000	.00	.01	.01	.00	.00	.01
	2	.338	3.909	.00	.00	.12	.00	.05	.42
	3	.209	4.964	.03	.51	.11	.04	.10	.00
	4	.180	5.354	.00	.33	.56	.02	.13	.02
	5	.076	8.246	.00	.13	.20	.62	.35	.28
	6	.037	11.862	.97	.01	.00	.32	.38	.27

a. Dependent Variable: Parenting_Stress

Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	38.7502	62.0657	50.6412	4.93276	151
Residual	-25.00257	31.22203	-.29017	10.31154	151
Std. Predicted Value	-2.430	2.301	-.017	1.001	151
Std. Residual	-2.390	2.985	-.028	.986	151

a. Dependent Variable: Parenting_Stress



Visible: 78 of 78 Variables

	Age	Gender	MaritalStatus	LivingSituation	FamilyIncome	AgeOfChild	IntellectualSeverity	ChildrenInCare	HappyInRole	IWouldntDo	CaringMoreTime	NotDoingEnough	FeelClose	EnjoySpendingTime	SourceOfAffection	OptimisticView	Maj
1	43	2	1	1	4	12	3	3	1	1	4	5	2	1	4	4	
2	51	2	2	1	2	9	3	4	1	1	2	5	1	5	5	5	
3	35	1	1	1	5	6	3	2	3	2	4	4	2	2	2	2	
4	47	1	4	2	3	14	1	2	2	3	5	5	5	5	5	5	
5	45	1	1	1	4	4	1	2	1	1	4	2	4	3	3	2	
6	43	2	2	1	5	9	3	3	5	5	3	5	4	5	2	4	
7	43	1	3	2	3	6	2	3	4	3	1	3	3	2	4	2	
8	40	1	1	1	5	7	2	3	2	1	5	5	1	1	1	5	
9	39	1	1	1	3	9	1	3	2	1	4	5	2	2	3	2	
10	49	1	1	1	5	15	1	1	3	1	5	3	1	1	1	3	
11	38	1	2	2	2	11	2	3	3	1	5	5	1	1	1	1	
12	41	1	3	2	1	14	1	1	2	1	4	4	2	2	2	1	
13	39	1	1	1	6	17	2	2	1	1	4	5	1	1	1	3	
14	42	1	1	1	4	4	4	3	2	1	4	5	2	1	1	2	
15	41	1	2	1	4	6	2	3	1	1	5	5	1	1	1	2	
16	42	1	4	4	2	16	2	2	1	1	4	5	1	1	1	1	
17	40	1	4	2	3	11	3	3	5	4	5	5	3	3	3	4	
18	49	1	1	1	5	15	2	3	4	3	5	5	3	4	3	5	
19	48	1	1	1	3	9	2	1	3	2	4	4	2	2	2	2	
20	43	1	1	1	6	8	2	3	1	1	4	5	1	1	1	3	
21	33	1	3	2	6	8	1	2	1	1	5	5	1	1	1	3	
22	33	1	2	1	3	15	2	4	3	1	5	5	1	1	1	1	
23	43	1	1	1	5	11	3	4	2	1	4	4	1	1	1	1	
24	35	1	3	2	3	14	3	2	1	1	5	5	2	1	2	2	
25	44	1	2	2	2	12	2	2	2	1	4	5	1	2	1	3	
26	47	1	6	2	2	15	3	2	3	1	5	5	2	1	1	3	
27	48	1	1	1	3	13	3	2	1	1	4	4	1	1	1	3	
28	40	1	1	1	6	6	3	4	3	1	5	5	1	1	1	1	
29	43	1	1	1	3	6	2	3	2	1	4	2	1	1	1	4	
30	43	1	2	1	2	11	2	2	1	1	3	5	1	1	3	3	
31	54	1	1	1	4	14	3	1	3	1	5	5	1	2	1	4	
32	43	1	1	1	4	8	1	2	2	2	5	5	2	2	2	3	
33	36	1	1	1	3	5	4	3	3	1	5	5	1	1	1	1	
34	26	1	2	1	2	4	2	1	2	1	4	5	1	1	1	3	
35	56	1	1	1	2	16	3	2	5	1	5	4	2	3	1	3	
36	60	2	4	2	2	13	2	1	2	1	5	4	1	1	2	3	
37	39	1	1	1	5	13	1	2	2	1	5	4	2	1	1	1	
38	52	1	1	1	4	16	2	2	1	1	5	5	2	1	1	2	
39	42	1	2	4	2	9	1	2	4	1	4	4	1	2	2	2	

Data View | Variable View

IBM SPSS Statistics Processor is ready | Unicode:ON

Appendix B

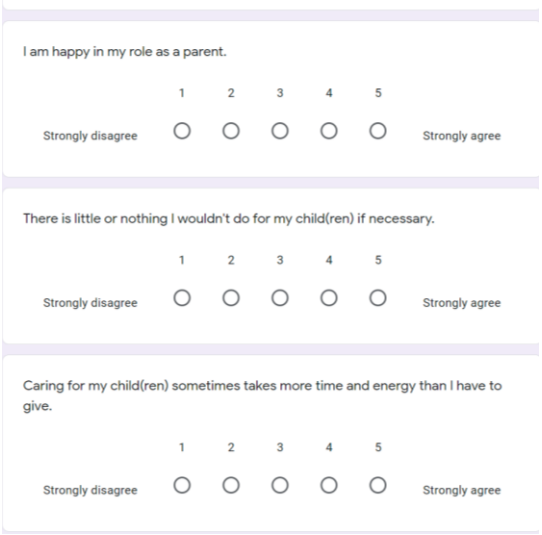
Parental Stress Scale (PSS), (BERRY AND JONES, 1995)

Participant instructions

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. This section is in regards to your stress levels as a parent in general, and can be answered in relation to how you feel about all your children. Please indicate the degree to which you disagree or agree with the following items by placing the appropriate number in the space provided. The higher the number, the more you agree.

Responses

Strongly disagree 1 2 3 4 5 Strongly agree.



Items

1. I am happy in my role as a parent
2. There is little or nothing I wouldn't do for my child(ren) if it was necessary
3. Caring for my child(ren) sometimes takes more time and energy than I must give
4. I sometimes worry whether I am doing enough for my child(ren)
5. I feel close to my child(ren)

6. I enjoy spending time with my child(ren)
7. My child(ren) is an important source of affection for me
8. Having child(ren) gives me a more certain and optimistic view for the future
9. The major source of stress in my life is my child(ren)
10. Having child(ren) leaves little time and flexibility in my life
11. Having child(ren) has been a financial burden
12. It is difficult to balance different responsibilities because of my child(ren)
13. The behaviour of my child(ren) is often embarrassing or stressful to me
14. If I had it to do over again, I might decide not to have child(ren)
15. I feel overwhelmed by the responsibility of being a parent
16. Having child(ren) has meant having too few choices and too little control over my life
17. I am satisfied as a parent
18. I find my child(ren) enjoyable

Scoring

To compute the parental stress score, items 1, 2, 5, 6, 7, 8, 17, and 18 should be reverse scored as follows: (1=5) (2=4) (3=3) (4=2) (5=1). The item scores are then summed.

Appendix C

Strengths and Difficulties Questionnaire (SDQ), (Goodman, 1997)

Participant's instructions

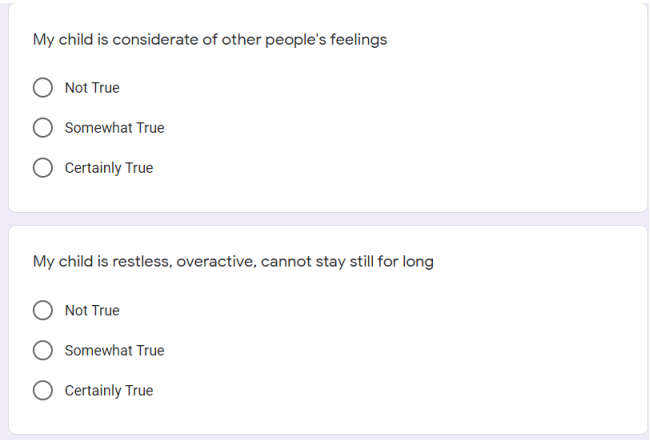
Please answer the following questions in relation to your child with an intellectual disability. If you have more than one child with an intellectual disability, please answer the questions in relation to the child you gave the age of in the above section. For each question, please mark the box either Not True, Somewhat True or Certainly True. It may be the case that a question is not applicable to your child, if this is the case you can skip that question. Please give your answer on the basis of your child's behaviour over the last six months.

Responses

Not true

Somewhat True

Certainly True



Items

1. My child is considerate of other people's feelings
2. My child is restless, overreactive, cannot stay still for long
3. My child often complains of headaches, stomach-aches or sickness
4. My child shares readily with other children (toys, treats, pencils etc.)

5. My child often has temper tantrums or hot tempers
6. My child is rather solitary, tends to play alone
7. My child is generally obedient, usually does what adults request
8. My child has many worries, often seems worried
9. My child is helpful if someone is hurt, upset or feeling ill
10. My child is constantly fidgeting or squirming
11. My child has at least one good friend
12. My child often fights with other children or bullies them
13. My child is often down-hearten, unhappy or tearful
14. My child is generally liked by other children
15. My child is easily distracted, concentration wanders
16. My child is nervous or clingy in new situations, easily looses confidence
17. My child is kind to younger children
18. My child often lies or cheats
19. My child is picked on or bullied by other children
20. My child often volunteers to help people (parents, teachers, other children)
21. My child thinks things out before acting
22. My child steals from home, school or elsewhere
23. My child gets on better with adults than with other children
24. My child has many fears, is easily scared
25. My child sees tasks through to the end, has good attention span

Scoring

Total difficulties score: This is generated by summing scores from all the scales except the prosocial scale. The resultant score ranges from 0 to 40

Table 1: Scoring symptom scores on the SDQ for 4-17 year olds

	Not True	Somewhat True	Certainly True
Emotional problems scale			
ITEM 3: Often complains of headaches… *(I get a lot of headaches…)*	0	1	2
ITEM 8: Many worries… *(I worry a lot)*	0	1	2
ITEM 13: Often unhappy, downhearted… *(I am often unhappy….)*	0	1	2
ITEM 16: Nervous or clingy in new situations… *(I am nervous in new situations…)*	0	1	2
ITEM 24: Many fears, easily scared *(I have many fears…)*	0	1	2
Conduct problems Scale			
ITEM 5: Often has temper tantrums or hot tempers *(I get very angry)*	0	1	2
ITEM 7: Generally obedient… *(I usually do as I am told)*	2	1	0
ITEM 12: Often fights with other children… *(I fight a lot)*	0	1	2
ITEM 18: Often lies or cheats *(I am often accused of lying or cheating)*	0	1	2
ITEM 22: Steals from home, school or elsewhere *(I take things that are not mine)*	0	1	2
Hyperactivity scale			
ITEM 2: Restless, overactive… *(I am restless…)*	0	1	2
ITEM 10: Constantly fidgeting or squirming *(I am constantly fidgeting….)*	0	1	2
ITEM 15: Easily distracted, concentration wanders *(I am easily distracted)*	0	1	2
ITEM 21: Thinks things out before acting *(I think before I do things)*	2	1	0
ITEM 25: Sees tasks through to the end… *(I finish the work I am doing)*	2	1	0
Peer problems scale			
ITEM 6: Rather solitary, tends to play alone *(I am usually on my own)*	0	1	2
ITEM 11: Has at least one good friend *(I have one goof friend or more)*	2	1	0
ITEM 14: Generally liked by other children *(Other people my age generally like me)*	2	1	0
ITEM 19: Picked on or bullied by other children… *(Other children or young people pick on me)*	0	1	2
ITEM 23: Gets on better with adults than with other children *(I get on better with adults than with people my age)*	0	1	2
Prosocial scale			
ITEM 1: Considerate of other people's feelings *(I try to be nice to other people)*	0	1	2
ITEM 4: Shares readily with other children… *(I usually share with others)*	0	1	2
ITEM 9: Helpful if someone is hurt… *(I am helpful is someone is hurt…)*	0	1	2
ITEM 17: Kind to younger children *(I am kind to younger children)*	0	1	2
ITEM 20: Often volunteers to help others… *(I often volunteer to help others)*	0	1	2

Appendix D

Family Support Scale (FSS), (Dunst, Jenkins & Trivette, 1984)

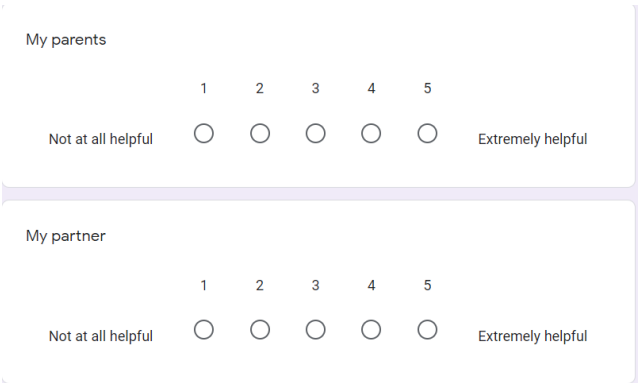
Participant instructions

Listed below are people and groups that are often helpful to caregivers and to families of a child with an Intellectual Disability. This questionnaire asks you to indicate how helpful each of the following people or groups of people have been to you and your family. If any of these people or groups of people are unknown to you and your family, then you can skip that question.

Please choose the number that best describes how helpful these people or groups of people have been to you and your family during the past 3 to 6 months. The higher the score, the more helpful the person has been. You may not find a number that exactly describes your feelings or opinions, so you need to circle the number that comes closest to describing how you feel. Your first reaction to each statement should be your answer.

Responses

Not at all helpful 1 2 3 4 5 Extremely helpful



Items

1. My parents
2. My partner
3. My partners parents

4. My relatives
5. My partners relatives
6. My friends
7. My partners friends
8. My other children
9. Other parents
10. Co-workers
11. Parent groups
12. Social groups
13. Early childhood intervention programmes
14. School/Day-care centre
15. Professionals (ie. Therapists, social workers)
16. Professional Agencies (ie. Hospital, clinic, social services)

Scoring

If a participant leaves a section blank it is scored as 0. Scoring is from 1 = not at all helpful to 5 = extremely helpful. Scores are summed to attain the participants overall level of social support. Answers can range from 0 to 80.

Appendix E

Consent Form

What is this study about?

As part of my degree I must carry out an independent research project. This research will be an investigation into the stress levels experienced by parents/guardians of children with intellectual disabilities. The study will ask questions relating to demographics, social support, parental stress and your child's behaviour. This research project will be supervised by Dr. Conor Nolan. Should you agree to take part in this study, you will be required to fill out 4 short questionnaires that will take no longer than 10 minutes.

Who can take part?

You can take part in this study if you are a parent or guardian of a child/children with an intellectual disability. If you have more than one child with an intellectual disability, you will be required to answer the questions based on just one of your children. Which child you decide to base your answers on is completely up to you. You can fill the survey out more than once if you have more than one child with an intellectual disability. Your child must be under the age of 18 and be living in your full time care. I strongly encourage both mothers and fathers of the same household to fill out the survey separately, in order to get a male and female representation.

What are the possible risks and benefits of taking part?

Taking part will contribute to research that helps us understand the varying stress levels of parents of children with intellectual disabilities, and the different factors that may contribute to this stress.

There is a minor risk that participants may feel uncomfortable discussing their stress levels or their child's behaviour. Should you feel in any way uncomfortable or distressed during the research you are free to leave the questionnaire by closing out of the browser.

Support information is also provided on the debrief page at the end of the questionnaire. There are no consequences to leaving the study. Once you have submitted your answers it will not be possible to withdraw from the study, as all data are anonymous

Will taking part be confidential and what will happen to my data?

The questionnaire is anonymous, it is not possible to identify a participant based on their responses to the questionnaire. All data collected for the study will be treated in the strictest confidence. The data will be stored under password protected files and will only be assessed by the researcher and the research supervisor. Data will be retained for 5 years in accordance with the NCI data retention policy and will only be used for the proposed study.

What will happen to the results of the study?

The results of this study will be presented in my final dissertation, which will be submitted to National College of Ireland.

Right of withdrawal

You have the right to withdraw your data at any time during the questionnaire should you wish to do so. However, due to the questionnaire being anonymous, you will not be able to withdraw your data following submission of your results as they will no longer be identifiable.

Do you give informed consent to participate?

Yes

No

Do you confirm you are over the age of 18?

Yes

No

Appendix F

Debriefing Form

Thank you for participation

Thank you for participating in this study. Your willingness to contribute to this research is greatly appreciated.

It is unlikely that you should experience any discomfort from this study, however, if you feel you need information or support in regards to your child you can contact Inclusion Ireland: 01 855 9891

Should you have any queries or questions about this research please do not hesitate to contact me by email: Elizabethfosterfyp@gmail.com or my research supervisor: Conor.nolan@ncirl.ie

Please click the submit button below.