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Family Resilience – An Important Indicator When Planning Services for Adults with Intellectual and Developmental Disabilities

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Abstract

Background: Parents of individuals with intellectual and developmental disabilities (IDD) are increasingly called upon to provide supports well into their child's adult years. Research points to the complex relationship among service need, service use and stress experienced by families caring for individuals with IDD. Caregivers' view of how well they think they can provide for their child in the future is a strong predictor of service need. This paper examines the relationship between resilience in families at the time they made a new service request for their adult child with IDD and their perception of crisis six months later. Methods: Self-reported data from 154 parents were collected upon request for services and six months later. Results: Family resilience was associated with not approaching or being in crisis. Parents 54 years or younger and those who had a child over the age of 21 were less likely to approach or be in crisis. Conclusions: Resilience is an important construct to assess among parents requesting adult developmental services for their sons or daughters, and it can be quickly measured at the time of service request. Resilience is a good indicator for system improvement as it can help identify families who should receive services faster.

Parents of individuals with intellectual and developmental disabilities (IDD) are increasingly called upon to provide supports well into their sons' and daughters' adult years. Research points to the complex relationship between service need, use and stress experienced by families caring for individuals with IDD (Lunsky, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014). Some parents feel very competent to support their son or daughter, and their needs are very different from parents who do not feel this way (Chou, Yee, Lin, Kroger, & Chang, 2009; Engelhardt, Brubaker, & Lutzerl, 1988; Smith, 1997). Caregivers' own subjective view of how well they think they can provide for their child in the future is one of the foremost predictors of service need (Caserta, Connelly, Lund, & Poulton, 1987; Chiu & Hung, 2006). As well, higher levels of maternal burden and stress have been found to predict greater use of services (Freedman, Griffiths, Krauss, & Seltzer, 1999; McConkey, 2005; Pruchno & McMullen, 2004; Smith, 1997).

While diverse services and supports may be funded by governments to support families caring for adults with IDD, caregivers often report that the right services and supports are not available in the right place at the right time. There are ample examples in the media of families reaching crisis levels when not adequately supported [for example see CBC News (2014, May 20) Re: *Mother threatens to leave disabled daughter at minister's office* (online broadcast).

Crisis, defined as "the subjective reaction to a stressful life experience that compromises the individual's stability and ability to cope or function," (Roberts & Ottens, 2005, p. 331) may be averted through the effective use of coping mechanisms. In efforts to prevent crisis among families supporting adults with IDD, attention should be given to understanding the factors that enable certain families to react well to adversity (Kirmayer, Dandeneau, Marshall, Kahentonni Phillips, & Williamson, 2011).

Resilience is an attribute that is thought to stem from the effects of brief repeated exposure to negative circumstances that allow individuals to successfully cope with a stressful experience (Rutter, 2013). Factors such as planning and having a sense of self-reflection as well as a sense of agency and confidence to deal with challenges have also been associated with resilience (Hauser, Allen, & Golden, 2006; Rutter, 2013). Social relationships are known to play a key role in promoting long-term resilience following a mental disorder (Rutter, 2013). Further, Walsh (2003) identifies relationships as a central influence of resilience and that resilience requires ongoing growth and development within the context of emerging challenges. Applied to families, resilience "highlights families' positive adjustment in the context of challenging life conditions" (Gardner, Huber, Steiner, Vazquez, & Savage, 2008, p. 107).

The question of what makes some parents go into crisis is a critical question from both a research and policy perspective. In monitoring service demands, and service outcomes, particularly when there is a shortage of services and many families have to wait, indicators are required that quickly capture how well families are functioning and who is at risk of not being able to continue supporting their son or daughter. In this paper, we examine whether families who are more resilient at the time of requesting a service are more likely to avert crisis six months later.

Methods

Ethics approval for this study was received from Research Ethics Boards at Queen's University and the Centre for Addiction and Mental Health.

Design

Data were collected prospectively starting at the time of request for services, and every three months thereafter as part of an ongoing study following parents up to 24 months. Only data collected at the time of request for services and six months later are reported in this paper. Responses to the study questions were self-reported.

Participants

Parents of adolescents and adults (age 16 and above) with IDD living at home and seeking services through a Developmental Services Ontario (DSO) organization between July 4, 2011 and March 31, 2012 were invited to participate. Parents unable to understand and respond to written or oral English or French were excluded.

Of the 209 parents who enrolled in the study, 55 were excluded because they had not completed both the Compensating Experiences Subscale of the Inventory of Family Protective Factors (measure of resilience; n = 3) and the Brief Family Distress Scale (measure of perceived crisis; n = 52) six months later.

A single imputation method using the median was used to impute missing values for parent's level of education (n = 2) and household income level (n = 5). Based on information given in other variables, a "No" response was imputed for the parent's medical and/or physical condition variable (n = 1), marital status variable (n = 1) and loss of support at six months variable (n = 6). Several variables were collapsed into two or three categories.

Table 1 compares the parents who were included in the analysis and their child (n = 154) to those who were excluded (n = 55). As shown, parents who were excluded tended to have lower household incomes and to be less likely to have obtained post-secondary education.

Table 1. Comparison of Those Included and Excluded From the Analysis Across Parent, Child and Household Characteristics

Characteristic	*Included* (n = *154)* *Percentage*	*Excluded* (n = *55)* *Percentage*	X^2 p-*value*
Parent's age			
≤ 54 years	66.2	58.8	0.33
> 54 years	33.8	41.2	
Missing (*n*)	0	4	
Parent's gender			
Female	87.7	78.2	0.08
Male	12.3	21.8	
Parent's relationship status to the child's other parent			
Married	66.2	56.4	0.19
Not Married	33.8	43.6	
Parent's employment status			
Employed	62.3	54.5	0.31
Not employed (includes homemakers)	37.7	45.5	
Parent's level of education			
Post-secondary education	75.3	53.0	0.002
No post-secondary education	24.7	47.0	
Missing (*n*)	0	4	
Parent has a mental health problem			
No	76.0	67.3	0.20
Yes	24.0	32.7	
Parent has a medical or physical condition			0.31
No	55.2	47.3	
Yes	44.8	52.7	
Child's age			
≤ 21 years	58.4	57.7	0.92
> 21 years	41.6	42.3	
Missing (n)	0	3	
Child's gender			
Female	34.4	38.2	0.61
Male	65.6	61.8	
Child has a mental health or behavioural problem (dual diagnosis)			
No	61.7	72.7	0.14
Yes	38.3	27.3	
Child has medical support needs			
No	50.7	38.2	0.11
Yes	49.3	61.8	
Child has a mobility impairment			
No	74.7	63.6	0.11
Yes	25.3	36.4	

Table 1. Comparison of Those Included and Excluded From the Analysis Across Parent, Child and Household Characteristics *(continued)*

Characteristic	*Included* (n = *154)* *Percentage*	*Excluded* (n = *55)* *Percentage*	X^2 p-*value*
Number of other household members with special needs			
0	74.0	74.5	0.83*
1	15.6	17.7	
2 or 3	10.4	7.8	
Missing (n)	0	4	
Household income level			
$45,000 or less	34.4	59.6	0.007*
$45,001–95,000	39.0	27.7	
$95,001 or more	26.6	12.8	
Missing (n)	0	8	
Requesting services for more than one child			
No	96.8	100	0.17
Yes	3.2	0	

** Fischer's Exact Test Used*

Measures

Our exposure of interest, family resilience, was measured using the four-item Compensating Experiences Subscale of the Inventory for Family Protective Factors (Gardner et al., 2008). Parents rated their experiences of mastery in overcoming adverse or stressful situations by rating four statements (e.g., "our family has coped well with one or more major stressors in our lives") on a five-point Likert scale, which ranged from "Not true at all" to "Very true." A mean score was calculated from the four items, with higher scores indicating greater resilience. Previous studies have reported high internal consistency (.68 to .87) and discrimination ability of the subscale with regards to clinical judgment of adaptation (Gardner et al., 2008). The subscale is correlated with longer measures of family hardiness such as the Family Hardiness Index by McCubbin and colleagues (1987).

We measured perceived crisis, our outcome of interest, using the Brief Family Distress Scale (BFDS; Weiss & Lunsky, 2011) six months after the measure of family resilience was completed (approximately six months after the parent's request for services). The BFDS is a single item measure on a ten-point scale with statements corresponding to a point along a continuum of stress from 1, "Everything is fine, we are not in crisis at all," to 10 "We are currently in crisis, and it could not get any worse." Responses were categorized into two levels of perceived distress: those that are approaching or in crisis (6–10), and those that are not (1–5). Weiss and Lunsky (2011) have reported that the BFDS has good construct validity with the Caregiving Burden subscale of the Revised Caregiving Appraisal Scales (Lawton, Moss, Hoffman, & Perkinson, 2000) and parental mental health problems as measured by the Kessler six-item Psychological Distress Scale (Kessler et al., 2003).

Other variables of interest included factors related to the parent, child and the household (see Table 2). We also categorized parents with regard to whether they experienced a loss of support in the three months just before the crisis assessment. This includes a loss of paid support (complete discontinuation of a service or reduction in hours) or unpaid support (reduced support from friends, family, neighbours, or volunteers; or reduction in child's activities such as volunteering, or sports).

Table 2. Co-Variates of Interest Related to the Association Between Family Resilience and Crisis Six Months Later

Parent	*Child*	*Household*	*Loss of support in 3 months before the crisis assessment*
1. Age (< = 54/ > 54)	1. Age (< = 21/ > 21)	1. Number of other household members with special needs (0/1/2+)	1. Loss of paid or unpaid supports (N/Y)
2. Gender (F/M)	2. Gender (F/M)	2. Income level (< = 45,000/ 45,001–95,000/ 95,001+)	
3. Relationship status to the child's other parent (married/not married)	3. Mental health or behavior problem (N/Y)		
4. Employment status (employed/not employed)	4. Medical support needs (N/Y)		
5. Level of education (post-secondary/no post-secondary)	5. Mobility impairment (N/Y)		
6. Mental health problem (N/Y)			
7. Medical or physical condition (N/Y)			

Procedure

DSO organizations across the province assisted with recruitment by distributing Request for Information forms, instructing parents of adolescents and adults with IDD living at home and seeking services through the DSO between July 4, 2011 and March 31, 2012 to contact the research team if they were interested in learning more about the study. Upon return of the request forms, the parent was mailed a package that included a study information sheet, consent form and questionnaire expected to take 15 minutes to complete, along with self-addressed stamped envelopes to return consent and survey documents separately. Two weeks after the package was mailed, the parent was called to follow-up.

Once the signed consent form was received, a telephone interview was conducted which took approximately 30 minutes to complete. After three months, the parents were contacted for a brief telephone check-in, and after six months, they were asked to complete a second mailed survey and another 30-minute telephone interview. This data collection cycle was repeated for up to two years with each parent. Only the results of the first six months are presented in this paper.

Analysis

All analyses were undertaken using SAS software, Version 9.3. Descriptive statistics were used to characterize families' resilience at baseline and perceived crisis at six months. Chi-square tests for independence were used to compare the parent, child, and family characteristics between included and excluded participants. The association between co-variates of interest and resilience was examined by comparing mean scores for different levels of each co-variate using independent samples t-tests and one-way analysis of variance (ANOVA). Sensitivity analyses using non-parametric tests were performed. Unadjusted modified Poisson models were fit for each parent and child variable to estimate the crude relative risk of having a low crisis score. Sensitivity analyses were performed using log binomial regression models. The final multivariate analysis was performed using modified Poisson regression with robust error variance estimation to examine the relationship between resilience and crisis while controlling for other variables. All potential variables of interest were entered into the model and a manual deletion process was used to remove non-significant variables. All *p*-values were two-sided, with value less than .05 considered statistically significant.

Because some parents requested services for two of their children with IDD (n = 5), only the child for whom the parent was reporting a higher level of distress was included in the analysis. A sensitivity analysis was performed retaining the child for whom the parent reported the lowest crisis level to examine any differences in the results.

Results

Parents included in the study were aged 38 to 84, and requesting services for their children 16 to 53 years of age. While the majority of respondents were mothers, 19 fathers were included. Two thirds were married to their child's other parent, 62.3% were employed and 75.3% had a post-secondary education. The annual household income of respondents included a wide range. Nearly a quarter of parents reported having a mental health problem and 44.8% had a medical or physical condition. Over a quarter of parents reported having at least one other household member with special needs. The children for whom the parents in this study were requesting services were more likely to be male (65.6%). Nearly 40% had a mental health or behaviour problem, almost half (49.3%) had medical support needs, and 25.3% had a mobility impairment.

Family resilience, as measured by the Compensating Experiences Subscale of the Inventory for Family Protective Factors at the time of entry into the study, ranged widely (from 4 to 20). The mean resilience score was 14.0 with a standard deviation of 3.44. As shown in Table 3, parent, child and household factors were associated with resilience. Parents who had a mental health problem or a physical or medical condition reported lower resilience scores. Lower resilience was also seen in families of children with mental health or behaviour problems. Finally, the presence of additional members with special needs in the household or an annual household income less than $45,000 were also associated with lower resilience.

Six months after entry to the study, 19.5% had received some or all of the services requested. At that time, 23.4% of parents provided ratings to the Brief Family Distress Scale suggestive that they were approaching or in crisis (see Figure 1). In the three months preceding the crisis assessment, 18.8% of parents reported a loss in supports.

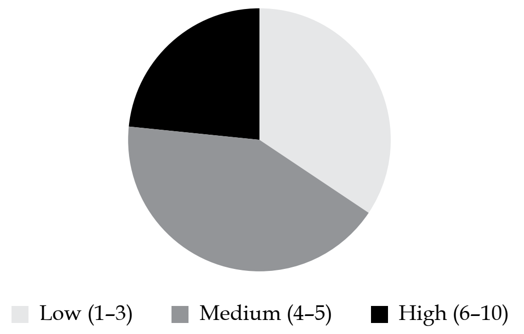

Figure 1. Distribution of parents' level of perceived crisis six months after requesting services (Note: a score > 5 indicates approaching or in crisis)

As shown in Table 4, family resilience was associated with not approaching or being in crisis. For every additional point on the resilience scale, the chance of not approaching or being in crisis six months later increased by 3% (so a five point difference – the equivalent of an additional condition being "very true" versus "not true at all" – would represent a 15% increase in the probability of not approaching or being in crisis). Not approaching or being in crisis was also associated with being 54 years or younger, and having a child who is over the age of 21.

None of the sensitivity analyses performed (e.g., using excluded child, using log binomial regression) changed the results obtained.

Discussion

The parents included in the study represent a broad cross-section of parents requesting services. The clinical profile of the adult children for whom they were requesting services is consistent with a recently published study of prevalence of co-morbid conditions in adults with IDD in Ontario (Lin et al., 2013).

After six months, very few families had received requested services and some parents reported having lost supports. As hypothesized, we found that greater resilience at the time of service request was associated with a greater chance of not being close to or in crisis six months later. This highlights the importance of considering resilience of families requesting

Table 3. Association Between Parent, Child and Household Characteristics and Family Resilience Score as Given by the Compensating Experiences Subscale of the Inventory of Family Protective Factors (N = 154)

Characteristic	*Mean Resilience Score (Standard Deviation)*	*p-value*
Parent's age		
< = 54 years	13.89 (3.25)	0.63
> 54 years	14.16 (3.81)	
Parent's gender		
Female	14.12 (3.25)	0.31
Male	13.00 (4.59)	
Parent's relationship status to the child's other parent		
Married	13.73 (3.49)	0.51
Not married	14.11 (3.43)	
Parent's employment status		
Employed	14.25 (3.36)	0.20
Not employed (includes homemakers)	13.53 (3.56)	
Parent's level of education		
Post-secondary education	14.02 (3.53)	0.80
No post-secondary education	13.86 (3.20)	
Parent has a mental health problem		
No	14.47 (3.40)	0.002
Yes	12.50 (3.16)	
Parent has a medical or physical condition		
No	14.61 (3.01)	0.01
Yes	13.20 (3.80)	
Child's age		
< = 21 years	13.86 (3.32)	0.61
> 21 years	14.15 (3.62)	
Child's gender		
Female	14.52 (3.36)	0.15
Male	13.70 (3.44)	
Child has a mental health or behavioural problem		
No	15.03 (2.94)	
Yes	12.33 (3.56)	< 0.0001
Child has medical support needs		
No	13.97 (3.78)	0.96
Yes	14.00 (3.09)	
Child has a mobility impairment		
No	13.87 (3.54)	0.50
Yes	14.30 (3.14)	
Number of other household members with special needs		
0	14.27 (3.45)	0.04*
1	13.91 (3.14)	
2 or 3	12.00 (3.36)	
Household income level		
$45,000 or less	12.88 (3.91)	0.01*
$45,001–95,000	14.36 (2.90)	
$95,001 or more	14.85 (3.25)	
Requesting services for more than one child		
No	14.05 (3.43)	0.19
Yes	12.00 (3.74)	

* *ANOVA* (F *test*)

Table 4. Association Between Parent, Child and Household Characteristics Including Family Resilience with Low to Medium Perceived Crisis (score 1–5) (N = 154)

Characteristic	*Unadjusted Relative Risk (95% Confidence Interval)*	*Multivariate Adjusted Relative Risk (95% Confidence Interval)**
Parent's age		
≤ 54 years	1.22 (0.99–1.50)	1.35 (1.09–1.68)
> 54 years	1.00	1.00
Parent's gender		
Male	0.99 (0.75–1.29)	–
Female	1.00	
Parent's relationship status to the child's other parent		
Married	0.98 (0.81–1.17)	–
Not married	1.00	
Parent's employment status		
Employed	1.08 (0.90–1.29)	–
Not employed	1.00	
Parent's level of education		
No post-secondary	1.09 (0.92–1.30)	–
Post-secondary	1.00	
Parent has a mental health problem		
No	1.15 (0.89–1.49)	–
Yes	1.00	
Parent has a medical or physical condition		
No	0.98 (0.82 –1.17)	–
Yes	1.00	
Family resilience (per 1 point increase)	1.03 (0.98–1.09)	1.03 (1.01–1.06)
Child's age		
> 21 years	1.05 (0.89–1.25)	1.21 (1.02–1.45)
16–21 years	1.00	1.00
Child's gender		
Male	1.01 (0.84–1.21)	–
Female	1.00	
Child has a mental health or behavior problem		
No dual diagnosis	1.06 (0.87–1.30)	–
Dual diagnosis	1.00	
Child has medical support needs		
No	1.11 (0.93–1.32)	–
Yes	1.00	
Child has a mobility impairment		
No	1.05 (0.85–1.30)	–
Yes	1.00	
Number of other household members with special needs	1.12 (0.76–1.50)	–
0	1.11 (0.69–1.53)	
1	1.00	
2		
Household income level		
$45,000 or less	1.00	–
$45,001–95,000	1.16 (0.95–1.38)	
$95,000 or more	1.09 (0.85–1.34)	
Loss in support in previous three months		
No	1.29 (0.96–1.73)	–
Yes	1.00	

* *Adjusted for parent's age, gender, relationship status to the child's other parent, employment, level of education, presence of mental health problems, presence of physical and/or medical conditions, and resilience; and child's age, gender, presence of dual diagnosis, presence of medical support needs, and presence of mobility impairments; number of household members with special needs, household income level, and loss in support in the previous three months.*

services for their adult sons or daughters with IDD to support family functioning. A family's resilience is reflected in their sense of control and adaptation to life events and stressors, and the confidence that they can endure challenges (McCubbin, McCubbin, & Thompson, 1987). The fact that it is related to crisis six months later speaks to the notion that parents are able to reliably gauge their ability to manage the stressors that they are faced with.

Self-reported crisis six months following a service request was also associated with a number of child and broader family factors. Parent and child age are additional factors that predict crisis after six months, independent of resilience. Interestingly, being younger (≤ 54 years) and having a child over the age of 21 are independently associated with low perceived crisis. This unexpected finding raises questions about the impact of parental age at birth of the child, birth order, and the stressors associated with parental aging (near or past retirement) while one's child with IDD is still of school age.

At the time of service request, some families present with low resilience with a profile that is consistent with models of family coping, such as the Double ABCX Model (Lavee, McCubbin, & Patterson, 1985; McCubbin & Patterson, 1983). This model (depicted in Figure 2) suggests that family coping is related to a pile-up of demands both pre- and post-crisis (the aA), the adaptive personal resources of family members (e.g., self-efficacy, health), family system resources (resilience), and social support (the bB), and the family members' appraisal of the situation (the cC). Indeed, the current study found that families with low resilience or a reduced ability to deal with adversity are more likely to have children with mental health or behaviour problems, which constitutes a stressor that has consistently been found in the literature (Weiss et al., 2013). These families also tend to be living with other household members who also have special needs, speaking to the experience of a "pile-up" of stressors (aA). Parents of individuals with IDD are more likely to have a medical or physical condition and to have mental health problems themselves compared to parents of individuals without IDD, which represents a lack of personal resources (Ben-Zur, Duvdevany, & Lury, 2005), and are more likely to have annual household incomes less than $45,000, reflective of lower family systems resources (bB).

A = Stressor

B = Family's existing resources

C = Family's perception of the stressor

X = Produces the Crisis

Interaction Components:

Stressor (A) > interacts with resources (B) > family's perception of stressor/how stressor defined (C) > produces the crisis (X).

Figure 2. Double ABCX model components

Limitations

We have identified four limitations to our study related to generalizability of findings, the timing of measures, and the potential for residual confounding. Each is briefly discussed.

Those who completed the six-month follow-up were more likely to have a post-secondary education and a higher household income. As such, our findings may not be generalizable to the broader group of parents requesting services particularly those who have a lower socioeconomic status. We did, however, confirm that there were no significant differences between mean resilience scores in parents that were included ($M = 13.98$) versus excluded ($M = 13.73$) ($p = 0.64$).

Since we did not control for perceptions of crisis at the time of request for services, it is possible that the associations reported are in part due to a baseline level of crisis. Further longitudinal study of crisis is needed.

The cross-sectional nature of assessment of resilience and the presence of a mental health problem in parents means we cannot establish temporality. It is possible that low resilience leads to the development of mental health problems in parents or the converse that mental health problems in parents lead to low resilience.

The literature indicates that social relationships promote resilience. Social supports also mitigate crisis. Since we did not control for this factor in our analysis, it possibly in part explains the observed association between resilience and low perceived crisis.

Strengths

Our province-wide recruitment allows for greater representation than previous studies that have tended to report on local or regional groups of parents. The parents recruited represented diverse personal, family and service circumstances. The prospective assessment of crisis relative to other factors adds to previous studies which have tended to be cross-sectional. The inclusion of parent, child and household factors in the model strengthens our findings. Finally, our relatively large sample size increases the accuracy of our estimates providing narrow confidence intervals.

Conclusion

Resilience is an important factor in helping parents avoid crisis when waiting for services for their child with IDD. It is therefore a key construct to assess among parents requesting adult developmental services for their sons or daughters. It is possible to quickly measure resilience using a four-item scale such as the Compensating Experiences Subscale of the Inventory for Family Protective Factors (Gardner et al., 2008) at the time of service request. Knowing about resilience can help service providers know about the strengths that parents possess while they wait for services. Resilience can serve as a good indicator for system improvement as it can be used to target parents who should receive services faster. Further research is needed to determine the impact of earlier provision of supports to less resilient parents on later perceptions of crisis. Research should also be directed at identifying how to foster resilience in families of individuals with IDD so they are better able to cope when services are not readily available.

Key Messages From This Article

Persons with disabilities: We need to help parents when they feel like they can't handle taking care of their sons or daughters without services.

Professionals: It is important to assess how much parents can manage when making decisions about how to best provide supports to their children.

Policymakers: Consideration of the needs of parents is as important as the child's assessed support needs when developing policy on how to allocate resources across families seeking services.

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