Self-compassion and psychological distress in parents of young people and adults with intellectual and developmental disabilities

Suzanne Robinson1,2 | Richard P. Hastings3 | Jonathan A. Weiss1 | Jaffni Pagavathsing2 | Yona Lunsky2

1York University, Toronto, ON, Canada
2Centre for Addiction and Mental Health, Toronto, ON, Canada
3University of Warwick, Coventry, UK

Correspondence
Yona Lunsky, Centre for Addiction and Mental Health, Toronto, ON, Canada.
Email: Yona.lunsky@camh.ca

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Background: Parenting an individual with intellectual and developmental disabilities (IDD) can be challenging, particularly during adulthood. It is important to better understand ways of supporting families as individuals with IDD age. Self-compassion is a potential internal coping resource for parents, and is strongly linked to positive mental health outcomes, though research has yet to examine it in parents of adults with IDD.

Method: The current study examines the association between self-compassion and measures of well-being for 56 parents of adults with IDD.

Results: Greater self-compassion was related to lower levels of stress and depression, even after accounting for other known stressors, such as economic disadvantage, having a child with an Autism Spectrum Disorder diagnosis, and high parent burden.

Conclusions: Self-compassion may offer resiliency against these parenting challenges.

Keywords: developmental disabilities, intellectual disabilities, mental health, mindfulness, parents, self-compassion

1 | INTRODUCTION

Parenting an individual with Intellectual and Developmental Disabilities (IDD) can be challenging (Davis & Carter, 2008) while at the same time, have positive effects for parents and other family members (Hastings, 2016). The stressors likely increase as individuals with IDD enter adulthood, when parents are faced with unique difficulties (Dillenburger & McKerr, 2011). Pearl’s “wear and tear” hypothesis suggests that long term exposure to stress can deplete coping capacity of caregivers and can result in decreased resiliency to stressors (Pearl, Menaghan, Lieberman, & Mullan, 1981). At this time, parents face new challenges in terms of their own aging or health concerns, and future planning for their child, as they leave the school system and enter the adult services sector. Waiting for services can be particularly stressful for families because waitlists are long and services can be scant (Lakin, 1998). It is important to better understand ways of supporting parents of individuals with IDD as they age, particularly when parents are faced with multiple stressors.

Emerging research suggests that self-compassion is a potential internal coping resource for parents, which is linked to positive mental health outcomes. Defined as “being touched by and open to one’s own suffering, not avoiding or disconnecting from it, generating the desire to alleviate one’s suffering and to heal oneself with kindness,” self-compassion also involves “offering nonjudgmental understanding to one’s pain, inadequacies and failures, so that one’s experience is seen as part of the larger human experience” (Neff, 2003, p. 87). The concept of self-compassion is closely linked to mindfulness; being present and aware in the current moment without judgement (Kabat-Zinn, 2003). One integral component of self-compassion involves mindful awareness of one’s suffering and shortcomings rather than ruminating or avoidance. Self-compassion also entails loving kindness and forgiveness towards oneself rather than self-criticism, and an understanding...
that our failures and pain connect us to a common human experience rather than isolate (Neff, 2003). Research shows that these self-compassion components are interrelated and contribute to well-being including improved mental health (MacBeth & Gumley, 2012), less rumination and worry (Raes, 2010), and increased use of adaptive emotion-focused coping strategies (Neff, Hsieh, & Dejitterat, 2005).

It is helpful to study self-compassion in families who are faced with chronic stress, and can find themselves in difficult situations without obvious solutions. Promoting self-compassion may help such families cope better with challenges. Few studies have explored the link between self-compassion and psychological outcomes for parents of individuals with IDD. Neff and Faso (2015) reported that self-compassion was a significant predictor of parental well-being above and beyond child symptom severity, in a sample of 51 parents of children with ASD between the ages of 4–12 years. Building upon this, Wong, Mak, and Liao (2016) found that among 180 parents of children with ASD, self-compassion acted as a protective buffer between perceived stigma and psychological distress. Whether similar associations exist for parents of adults with ASD and other developmental disabilities is not known.

Three intervention studies have also included self-compassion as an outcome measure after incorporating content on compassion into mindfulness-based stress reduction (MBSR) programs for parents of individuals with IDD (Bazzano et al., 2013; Benn, Akiva, Arel, & Roesser, 2012; Jones et al., 2017). All three studies reported that self-compassion increased following intervention and posited that self-compassion may help explain improvements in parent mental health. If in fact self-compassion is associated with positive mental health and is a modifiable variable, then it may be a worthwhile target for interventions designed to improve outcomes for parents. Although these intervention studies demonstrated self-compassion changes following mindfulness training, the association between self-compassion and mental health was not directly studied.

To date, no studies have explored the construct of self-compassion in parents of adults with IDD. In contrast to younger parents, these parents have long term exposure to stressors, or “wear and tear” of child rearing over the years, and are often confronted with an absence of resources for their child in adulthood. To address this gap in the literature, we examined the association between self-compassion and measures of well-being for parents of adults with IDD. It was hypothesized that self-compassion would be significantly associated with parental stress and depressive symptoms when controlling for stressors that have been identified as important in previous research, namely: child diagnosis, income, and parental burden.

2 | METHOD

2.1 | Participants

Demographic and clinical information were available for fifty-six parents seeking developmental disability services for their adult son or daughter in an urban setting, as shown in Table 1. Parents were eligible to take part in the study if their child with IDD was 16 years old or older, they were currently waiting for adult services, and had sufficient working knowledge of English to complete questionnaires. Families begin the adult service application process when their children are as young as 16 years old, so parents of older adolescents were eligible to take part in this study.

2.2 | Recruitment and procedure

The current study uses baseline data from a trial evaluating an MBSR intervention for parents of adults with IDD (Lunsky et al., 2017). Parents were recruited through the local adult services intake centre, where families have assistance in finding and accessing services for their adult son or daughter with IDD. Interested parents were screened for eligibility and invited to an initial orientation session where they completed consent forms and baseline questionnaires. An honorarium was offered to participants for completing questionnaires. The study received ethics approval from the relevant hospital ethics board (REB # 095_23).

2.3 | Measures

2.3.1 | Demographic information

Demographic information about the son or daughter with IDD included age, sex, diagnosis. Parent demographics included: age, sex, second language spoken at home, and neighborhood income. The neighbourhood median household income was obtained from Statistics Canada’s 2006 Canadian Consensus (Statistics Canada, 2006), based on the first three digits of participants’ postal codes.

### TABLE 1 Participant demographics

<table>
<thead>
<tr>
<th>Measures</th>
<th>Participants (N = 56)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent demographics</td>
<td></td>
</tr>
<tr>
<td>Age, mean (SD)</td>
<td>56.5 (8.8)</td>
</tr>
<tr>
<td>Age min-max</td>
<td>37–81</td>
</tr>
<tr>
<td>Gender (% female)</td>
<td>39 (70.0)</td>
</tr>
<tr>
<td>Second language (%)</td>
<td>23 (41.1)</td>
</tr>
<tr>
<td>Child demographics</td>
<td></td>
</tr>
<tr>
<td>Age, mean (SD)</td>
<td>23.0 (5.9)</td>
</tr>
<tr>
<td>Age min-max</td>
<td>16–40</td>
</tr>
<tr>
<td>Gender (% female)</td>
<td>24 (42.8)</td>
</tr>
<tr>
<td>Child disability</td>
<td></td>
</tr>
<tr>
<td>ASD (%)</td>
<td>23 (41.1)</td>
</tr>
<tr>
<td>Genetic syndrome (%)</td>
<td>8 (14.2)</td>
</tr>
<tr>
<td>Psychiatric disorder (%)</td>
<td>6 (10.7)</td>
</tr>
<tr>
<td>Child day activity</td>
<td></td>
</tr>
<tr>
<td>School (%)</td>
<td>28 (50.0)</td>
</tr>
<tr>
<td>Home (%)</td>
<td>15 (26.8)</td>
</tr>
<tr>
<td>Work/day program (%)</td>
<td>10 (17.9)</td>
</tr>
</tbody>
</table>
2.3.2 | Perceived parent burden

Burden was assessed using the 9-item burden subscale from the Revised Caregiver Appraisal Scale (Lawton, Kleban, Moss, Rovine & Glicksman, 2000). Items assess the perceived negative impact caregiving has on parent health, well-being, social life and personal relationships. Responses are scored on a 5-point Likert scale, ranging from “No impact” (1) to “Severe Impact” (5), with total scores range from 9 to 45. The internal consistency for the current sample was .88, and the scale has shown solid internal consistency in other studies involving parents of individuals with IDD (e.g., Pruchno & McMullen, 2004).

2.3.3 | Self-compassion

The Self-Compassion Scale Short-form (SCS-SF; Raes, Pommier, Neff, & Van Gucht, 2011) is a self-report scale used to assess compassion towards oneself. The 12 items are rated on a 5-point Likert scale ranging from 1 “never” to 5 “very often”, with higher scores indicating greater levels of self-compassion. The scale total score has shown very strong correlations with long-form SCS total scores, and demonstrates solid internal consistency (Cronbach’s alpha ≥ 0.86 in English and two Dutch samples; Raes et al., 2010). In the current study, Cronbach’s alpha was .83.

2.3.4 | Parent depression and stress

To assess perceived feelings of parent stress and depression, the 7 item Depression and Stress subscales of the Depression Anxiety Stress Scale (DASS-21; Henry & Crawford, 2005) were used. Items measure feelings experienced over the previous week and are scored on a 4-point Likert scale from 0 (“did not apply to me at all”) to 3 (“applied to me very much, or most of the time”), providing total scores between 0 and 21 for stress and depression. The stress and depression subscales have both shown good internal consistency, with Cronbach alpha levels of .91 and .94 respectively in a study with a similar sample (Firth & Dryer, 2013). Both subscales had Cronbach alpha levels of .93 in the current study.

3 | RESULTS

Self-compassion scores ranged from 16–55 (M = 37.78, SD = 8.5), from a possible range of 12 to 60. Independent samples t-tests showed that self-compassion scores did not significantly differ for any dichotomous demographic or diagnostic variables (parent and child sex, second language spoken at home, child daytime routines/activities, child has additional ASD diagnosis, child has an additional psychiatric diagnosis), nor was self-compassion correlated with continuous measures of parental burden, estimated neighborhood income, parent age, or child age. Self-compassion was negatively correlated with depression (r(56) = −.33, p < .05) and stress (r(56) = −.38, p < .01).

Two step-wise regression models (one for depression, one for stress) were run to assess self-compassion’s association with parental stress and depressive symptoms while controlling for variables known to be associated with depression and stress (child additional ASD diagnosis, neighbourhood income, and perceived burden). For the two regression models, known stressors were entered as the first step, and self-compassion was added as a second step. As shown in Tables 1 and 2, greater self-compassion was significantly associated with both lower stress and depression. Parent stress was significantly associated with self-compassion, accounting for 14% unique variance, the child having an additional ASD diagnosis (6% unique variance), and parental burden (8% unique variance). For parent depression, self-compassion and child ASD diagnosis were significantly associated, accounting for 13% and 9% of unique variance respectively.

4 | DISCUSSION

To our knowledge, this is the first paper to examine self-compassion among parents of adults with IDD. Parents in this study reported a wide range of self-compassion levels, and self-compassion did not appear to be related to any demographic variables. Our results showed a significant association between self-compassion and parent mental health. Specifically, greater self-compassion was related to lower levels of stress and depression, even after accounting for other known stressors for parents of adults with IDD.

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>Self-compassion and depression (N = 53)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1</td>
<td>B</td>
</tr>
<tr>
<td>Constant</td>
<td>2.54</td>
</tr>
<tr>
<td>Neighborhood income</td>
<td>1.30</td>
</tr>
<tr>
<td>ASD</td>
<td>−3.35</td>
</tr>
<tr>
<td>Perceived burden</td>
<td>.16</td>
</tr>
<tr>
<td>Self-compassion</td>
<td>−.22</td>
</tr>
</tbody>
</table>

Model 1: R^2 = .12, F(3, 49) = 2.16, p = .10.
Model 2: R^2 = .24, ΔR^2 = .13, F(4, 48) = 3.88, p < .01.
*p < .05. **p < .01.
The experience of parenting a child with IDD can be fraught with self-criticism, isolation, and rare opportunities for self-care or mindfulness (Vasilopouou & Nisbet, 2016). Self-compassion may offer resiliency against these parenting challenges and it has emerged as an important potential resource for parents of adults with IDD. The current study adds to the growing literature demonstrating a link between self-compassion and well-being among the general population (see MacBeth & Gumley, 2012 for review), and parents of children with IDD specifically (Bazzano et al., 2013; Benn et al., 2012; Neff & Faso, 2015; Wong et al., 2016).

Like parents of younger children, parents in this sample reported varying degrees of self-compassion, and self-compassion was not associated with any parent demographics. In contrast to parents of younger children, these parents have had more years to adjust to their situation, but also experience continued exposure to stressors. At the time of this study, each of the parents were needing services for their son or daughter, but not receiving them. The study sample was unique in that all parents were applying for adult services for their son or daughter, and had elected to participate in their own parent support program. Parents waiting for services often have to rely on themselves to manage stressors, and are faced with a situation that is difficult to change, so self-compassion may be especially important in such contexts.

While these findings begin to help us understand self-compassion among parents of adults with IDD, there are a number of limitations and areas for future research. Although diverse, the sample size was small. It would be important to study this in a larger group and results should be interpreted with this in mind. Additionally, the associations reported here may not be replicated with parents of adults who are not interested or able to take part in parent based interventions. Further, we were unable to consider additional variables known to be stressors like child behaviour problems. In the Neff study, self-compassion was found to be important irrespective of behaviour but we were unable to confirm this with an adult population. The short form measure of self-compassion was also used, and it is important to study the construct of self-compassion in greater depth. While the short form shows solid internal consistency and near perfect correlations with the full measure, the full measure is ideal for examining specific self-compassion subscales. Some aspects of self-compassion might be more amenable to change than others which is best studied with the full form measure. Added measures on participant's background would have also been informative. In our study, self-compassion was significantly associated with mental health, irrespective of speaking a second language. Research has shown this association between mental health and self-compassion is consistent across various cultures, although levels of self-compassion vary (Neff, Pisitsungkagarn, & Hsieh, 2008). The concept of self-compassion derives from a Buddhist psychology, and may be more intuitive or valued in certain cultures. A more detailed measure of participant's background, or comparing samples across multiple countries may be necessary to capture these differences. Finally, qualitative studies on self-compassion would be informative and would enhance our understanding of the construct. Future studies would benefit from qualitative components, longitudinal data with broader measures and larger, more representative samples.

Self-compassion may be an effective coping process for parents of adults with IDD. For the parents in this study, self-compassion was important to well-being regardless of parent stressors such as child diagnosis or parental burden. Understanding more about what internal and external influences lead some parents to become more self-compassionate than others would be an important area to explore. There is a need to further explore how best to enhance self-compassion through parent interventions, group programs, or independent work like self-care. One approach may be offering a manualized self-compassion group to these parents, and another would be to further integrate aspects of self-compassion teaching into existing interventions which have been studied with these caregivers. Targeting self-compassion in parents of young people and adults with IDD may be an effective way to help alleviate their stress and depression.

**CONFLICT OF INTEREST**

No conflict of interest is declared by the authors.

**ACKNOWLEDGMENTS**

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### TABLE 3  Self-compassion associated with stress (N = 53)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
<th>Model 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE B</td>
</tr>
<tr>
<td>Constant</td>
<td>2.85</td>
<td>2.73</td>
</tr>
<tr>
<td>Neighborhood income</td>
<td>2.85</td>
<td>.00</td>
</tr>
<tr>
<td>ASD</td>
<td>−2.59</td>
<td>1.42</td>
</tr>
<tr>
<td>Perceived burden</td>
<td>.20</td>
<td>.08</td>
</tr>
<tr>
<td>Self-compassion</td>
<td>−.22</td>
<td>.07</td>
</tr>
</tbody>
</table>

Model 1: \( R^2 = .15, F(3, 49) = 2.96, p < .05 \).
Model 2: \( R^2 = .30, \Delta R^2 = .15, F(4, 48) = 5.04, p < .01 \).
*p < .05.  **p < .01.
expressed in this report are the views of the research team and do not necessarily reflect those of the funders. We wish to thank Carly McMorris, Johanna Lake, Arielle Dryer, Lisa Chan for their help in carrying out the project, and all of the parents for their participation.

**ORCID**

Jaffni Pagavathising [http://orcid.org/0000-0001-9686-4919](http://orcid.org/0000-0001-9686-4919)

Yona Lunsky [http://orcid.org/0000-0002-1866-9728](http://orcid.org/0000-0002-1866-9728)

**REFERENCES**


