

## Special Issue

## Individual, parent and social–environmental correlates of caregiving experiences among parents of adults with autism spectrum disorder

M. Burke<sup>1</sup> & T. Heller<sup>2</sup>

<sup>1</sup> Special Education, University of Illinois at Urbana-Champaign, Champaign, IL, USA

<sup>2</sup> Disability and Human Development, University of Illinois at Chicago, Chicago, IL, USA

### Abstract

**Introduction** Compared to parents of adults with other types of disabilities, parents of adults with autism spectrum disorder (ASD) experience worse well-being. Thus, it is crucial to identify the individual, parent and social–environmental correlates of caregiving experiences among parents of adults with ASD.

**Method** For this study, 130 parents of adults with ASD responded to a survey about caregiving satisfaction, self-efficacy and burden.

**Results** Greater future planning and community involvement related to more caregiving satisfaction and increased caregiving self-efficacy, respectively. Less choicemaking of the adult with ASD related to greater caregiving satisfaction and self-efficacy. Maladaptive behaviours and poor health of the adult with ASD related to greater caregiving burden.

**Conclusions** Implications for policymakers, practitioners and future research are discussed.

**Keywords** adult children, autism, burden, caregiving, satisfaction, self-efficacy

As individuals with intellectual and developmental disabilities (IDD) have longer lives, we are confronting greater challenges in family caregiving. Compared to agencies and other family members, parents provide the most long-term care for their offspring with IDD (Wolff & Kasper 2006). With an increasing population of ageing caregivers and their offspring with IDD, it is necessary to identify caregivers who require targeted support. Given that autism spectrum disorders (ASD) is a public priority (Steuernagel 2005) yet caregiving research about individuals with ASD is minimal (Perkins & Moran 2010), it is especially important to understand caregiving experiences of parents of adults with ASD.

Parents experience positive and negative aspects of caregiving. Lawton's two factor theory notes that caregiving experiences include caregiving satisfaction, efficacy and burden with different determinants for each (Lawton *et al.* 1982). Most caregiving studies focus on the negative (vs. positive) facets of caregiving (Williamson & Perkins 2014). However, many parents report positive caregiving experiences (Hastings & Taunt 2002). Indeed, research about individuals with IDD and their families has shifted from a stress and coping model to a positive psychology framework because of the positive benefits

Correspondence: Prof Meghan Burke, University of Illinois at Urbana-Champaign Special Education, Champaign, IL, USA (e-mail: meghanbm@illinois.edu)

of having a family member with IDD (Dykens 2006). Caregiving satisfaction refers to whether the caregiver enjoys or feels rewarded by the caregiving role (Caldwell & Heller 2003). Caregiving self-efficacy relates to whether caregivers feel competent in their caregiving skills (Heller *et al.* 1999). Identification of the correlates of positive caregiving can provide information for improving caregiving experiences.

In addition to understanding positive caregiving experiences, it is also important to understand negative experiences. For example, caregivers (vs non-caregivers) have worse psychological health (Bourke-Taylor *et al.* 2012) and increased stress (Song & Singer 2006). Caregiving burden refers to the impact of caregiving upon opportunities, finances and leisure (Caldwell & Heller 2007). Caregivers with high burden report needing more services (Pruchno & McMullen 2004; McConkey 2005). Increased burden can also lead to poor caregiving abilities (Navaie-Waliser *et al.* 2002) and eventual institutionalisation of the individual with a disability (McCann *et al.* 2004). By identifying the correlates of caregiving burden and low caregiving satisfaction, targeted support can be provided, thereby, potentially reducing institutional placements (McCann *et al.* 2004) and crisis situations (Heller & Caldwell 2006).

Although a need exists for research about caregiving experiences for individuals with IDD in general, research is especially needed regarding caregiving for adults with ASD. From 1980 to 2000 in the United States, the incidence rate of ASD has dramatically risen with its current prevalence of 1 per 68 children (Centers for Disease Control and Prevention 2014). The lack of attention to caregiving for adults with ASD is problematic given that, parents of offspring with ASD (vs. other types of disabilities) report greater stress (Hayes & Watson 2012) and worse health (Smith *et al.* 2012). Specifically, it is important to examine adults with ASD. Compared to children with ASD, adults with ASD face additional challenges including an eligibility (vs. entitlement) system which is unprepared to accommodate the growing disability population.

Using the ABCX model (McCubbin & Patterson 1983; Lazarus & Folkman 1984) and its disability-related adaptation, the Double ABCX model (Minnes 1988), parent stress is related to child characteristics, internal and external resources of the family, and perceptions of the child by the family.

Most research has focused on child characteristics, namely maladaptive behaviours. Parents of individuals with ASD with more maladaptive behaviours reported greater caregiving burden (Lounds *et al.* 2007; Barker *et al.* 2011). Indeed, mothers of children with more maladaptive behaviours and in worse health reported significantly greater caregiving burden (Miltiades & Pruchno 2001; Kring *et al.* 2008). When their children experience health problems (another child characteristic), parents may have worse caregiving burden as they worry about their children's health. Other child characteristics include the abilities of the individual with ASD. Orsmond *et al.* (2006) found that parents of children with co-occurring ASD and ID (vs. ASD only) experienced greater caregiving strains and more maternal pessimism. However, Orsmond and colleagues primarily examined families of adolescents with ASD.

Also, finances and age (i.e. external and internal resources) of the parent may be important to caregiving experiences. Greater fiscal resources can improve parent well-being (Coleman & Karraker 2000). Parents with higher household incomes may be more able to access needed supports thereby enabling parents to feel more efficacious and satisfied with their caregiving roles. Age may also relate to caregiving. Older parents may experience their own ageing issues thereby affecting their caregiving abilities (Navaie-Waliser *et al.* 2002; Esbensen & Seltzer 2011). In a study of parents of adults with IDD, older parents reported less caregiving satisfaction but more caregiving self-efficacy (Caldwell & Heller 2003). Given their longer duration of caregiving, older parents may feel more competent but less satisfied with their caregiving roles.

Finally, it is important to consider social-environmental factors, which usually include perceptions of the child by the family. For example, the degree of future planning may impact caregiving. Heller & Caldwell (2006) conducted a randomised control trial to examine the impact of a future planning intervention upon caregiving burden of parents of adults with IDD. Parents in the intervention (vs. control) group reported significantly less caregiving burden. Additionally, unmet service needs may also relate to caregiving burden. Lacking needed services, parents of offspring with greater unmet service needs may feel less efficacious about

their roles (Haveman *et al.* 1997). In a study of adolescents and adults with ASD, Weiss *et al.* (in press) found that barriers to services, child age, parent immigration status and caregiving burden significantly related to parenting self-efficacy. Our study builds on the Weiss and colleagues study, which included adolescents and young adults with ASD, by identifying other social–environmental correlates of caregiving experiences.

Other social–environmental factors include choicemaking abilities and community involvement. Choicemaking is included as a social–environmental factor as the setting and people close to the individual with IDD may impact opportunities to make choices. A principle of self-determination, greater choicemaking leads to positive outcomes for adults with IDD (Heller *et al.* 2011). However, it is unclear how choicemaking impacts caregiver experiences. Perhaps, because the individual has more choicemaking skills, caregivers may feel less needed and, thus, caregiving satisfaction and self-efficacy may decrease. Community involvement of the individual may also impact caregiving. In a study of caregivers of individuals with IDD, there was a positive relation between community involvement of the individual with IDD and caregiving self-efficacy (Caldwell & Heller 2003). When adults with ASD are more involved in the community, parents may feel more competent about their caregiving roles. By identifying whether social–environmental factors relate to positive and negative facets of caregiving, practitioners can target these factors to improve caregiving experiences.

Given the impending caregiving challenges for families, it is critical to identify the correlates of caregiving satisfaction, self-efficacy and burden. For this study, our research question was: among parents of adults with ASD, to what extent do individual (i.e. the adult offspring with ASD), parent and social–environmental factors significantly relate to caregiving experiences including caregiving satisfaction, self-efficacy and burden? We hypothesised that better health, fewer behaviours, the absence of ID, greater community involvement and future planning, fewer unmet service needs, greater household incomes and younger caregiver age would relate to increased caregiving satisfaction. Caregivers of individuals with more choicemaking would report less caregiving satisfaction. Also, we hypothesised that fewer health

needs and behaviours, the absence of ID, greater income, older age of caregivers, more future planning, fewer unmet needs and greater community involvement would relate to greater caregiving self-efficacy; however, greater choicemaking of the adult with ASD would relate to worse self-efficacy. Finally, we hypothesised that increased maladaptive behaviours, the presence of ID, less community involvement, little choicemaking, greater unmet service needs and poor health of the adult with ASD as well as lower household income, older age and lack of future planning would relate to greater caregiving burden.

## Method

### Participants

The sample included 130 parents (109 females, 21 males) of individuals with ASD. On average, caregivers were 54.64 years of age ( $SD = 9.77$ , range from 37 to 87). Most caregivers were married (66.2% or  $n = 86$ ); none of the participants were married to each another. Most caregivers were employed (67.7% or  $n = 88$ ). The individuals with ASD were, on average, 25.02 years of age ( $SD = 6.59$ , range from 18 to 61). The majority (93.1% or  $n = 121$ ) of participants lived with their offspring with ASD. Participants reported that 34.62% ( $n = 45$ ) of their adult offspring with ASD were non-verbal. Also, of the 75.4% ( $n = 98$ ) who reported that their child had an ID, 48.97% ( $n = 48$ ) reported moderate to profound ID. Additionally, 24.31% ( $n = 29$ ) of the participants reported that their offspring had co-morbid psychiatric disorders (e.g. anxiety). See Table 1 for a description of the participants.

### Recruitment procedures

The study was conducted in Illinois in the United States, wherein 10,894 individuals with IDD were on the waiting list for a Home and Community Based Services (HCBS) Medicaid waiver. The purpose of the survey was to understand the caregiving experiences of families of adults with IDD. In the fall of 2013, the Department of Human Services disseminated the Caregiver Survey (described below) to a random sample of 3000 of the 10,894 caregivers of individuals with IDD across the state. The surveys were distributed via the mail service in hard copy form. Of the 3000 caregivers, 554 caregivers

**Table 1** Participant demographics

Characteristics	% (n)
<i>Caregiver characteristics</i>	
Educational background	
High school degree	20.8% (27)
Some college	17.7% (23)
College degree	34.6% (45)
Graduate degree	26.9% (35)
Gender	
Female	83.8% (109)
Geographic location	
Urban	80.8% (105)
Rural	19.2% (25)
Income	
Less than \$15,000	13.1% (17)
Between \$15–25,000	13.8% (18)
Between \$25–50,000	13.8% (18)
Between \$50–75,000	18.5% (24)
Over \$75,000	40.8% (53)
<i>Individual with ASD characteristics</i>	
Gender	
Female	27.7% (36)
Race	
Caucasian	73.8% (96)
African American	16.2% (21)
Asian	1.6% (2)
Hispanic or Latino	3.8% (5)
Other	4.6% (6)
Health	
Poor	1.5% (2)
Fair	12.3% (16)
Good	33.1% (43)
Very good	32.3% (42)
Excellent	20.8% (27)

completed the survey (response rate = 18.47%). We compared respondents to all of the individuals who were waiting for HCBS Medicaid waiver services. We found no significant demographic differences in relation to gender, age or residence. Latino individuals with IDD were under-represented in our sample.

We excluded caregivers whose family members did not have ASD ( $n = 370$ ). We also excluded respondents who were state guardians ( $n = 41$ ). We imputed data according to the guidelines of Harrell (2001). Thirteen respondents were excluded because they were missing data on entire scales. Inclusionary criteria required the respondent to be over 18 years of age; the offspring of the caregiver also had to be over 18 years of age as well as have ASD.

The authors received the completed surveys by winter of 2014. A graduate student input all survey data into SPSS (IBM Corp 2013). The first author checked 20% of the data to verify accuracy.

### Caregiver Survey

The Caregiver Survey was comprised of demographic questions and established scales. After reviewing the literature about caregiving, the two authors chose which established scales to include in the survey. The Caregiver Survey included 74 questions and took 25–30 min to complete. After completing the survey, participants mailed the survey to the first author using the self-addressed stamped envelope. This study was approved by the Institutional Review Board.

### Dependent variables

#### *Caregiving satisfaction (Lawton et al. 1982)*

We included five statements about caregiving satisfaction. Statements included ‘My relative shows a real appreciation for what I do for him/her’. Each statement was rated on a five point Likert scale from 1 (strongly disagree) to 5 (strongly agree); we used a summed variable ranging from 5 to 20. Previous studies demonstrated that this scale had high reliability ( $\alpha = .78$ , Miltiades & Pruchno 2002). For this study,  $\alpha = .78$ .

#### *Caregiver self-efficacy (Heller et al. 1999)*

We used a six item scale; responses were summed for a total score. Sample items included ‘I honestly believe I have the skills necessary to be a good caregiver to my relative’. Each statement included a five point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The measure has been used in previous studies about caregivers of individuals with IDD with high reliability ( $\alpha = .82$ , Heller & Caldwell 2006). For this study,  $\alpha = .71$ .

#### *Caregiving burden (Heller et al. 1994)*

We included nine statements about the effects of caregiving on job opportunities, finances, worry, personal time and social opportunities. Items included, for example, ‘Caring for my family member hurts my job opportunities’. Each statement included

a five point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). In previous studies, this scale had high reliability ( $\alpha = .72$ , Haveman *et al.* 1997). For this study, we used the sum of the nine items and  $\alpha = .87$ .

#### Independent variables: adult with ASD

##### *Maladaptive behaviour (Bruininks et al. 1986)*

We used the 8-item Scales of Independent Behaviour—Revised (SIB-R), which provides a General Maladaptive Index (GMI, summed variable) with higher scores implying more serious behaviours. Maladaptive behaviours included asocial, internalising, and externalising behaviours. Previous studies indicated high reliability ( $\alpha = .75$ , Burke & Hodapp 2014). For this sample, Cronbach's  $\alpha = .81$ .

##### *Presence of an ID*

We asked one question about whether the family member had an ID. The response was dichotomous: (0) no or (1) yes.

##### *Health (Idler & Benyamini 1997)*

Based upon previous studies, one question about health can be predictive of mortality. Thus, for this study, we asked: 'In general, how would you consider your family member's health?' Individuals had five Likert response options.

#### Independent variables: parent

##### *Household income*

We asked one question about household income (i.e. 'What is your annual household income?') with five response options.

##### *Caregiver age*

We asked one question: 'What age are you?'. Responses were treated as a continuous variable.

#### Independent variables: social–environmental characteristics

##### *Community involvement (Heller et al. 1999)*

We measured community involvement by the frequency of participating in fourteen activities

including visiting family or friends outside of the home. Each statement included a four point Likert scale ranging from 1 (none) to 4 (two or more times per week). Previous studies indicate that this scale has high reliability ( $\alpha = .85$ , Heller *et al.* 1999). Summing the fourteen items, the  $\alpha = .85$ .

##### *Choicemaking (Heller et al. 2000)*

The Daily Choice Inventory was used to measure the degree of daily choicemaking by the individuals with ASD. The scale is the sum of 12 items with a three point Likert scale ranging from 1 (never chooses) to 3 (chooses whenever he/she wants to). Choicemaking items included: what to eat and what to do in leisure time. Previous studies indicate that this scale has high reliability ( $\alpha = .71$ , Dos Santos *et al.* 2009). For this sample,  $\alpha = .71$ .

##### *Future planning (Heller & Caldwell 2006)*

The Future Planning Scale included sixteen items to gauge the degree of long-term planning for the individual with a disability. Participants were asked whether they completed each future planning activity including developing a special needs trust. Each item had two potential responses: (0) no or (1) yes. Using the sum of the sixteen items, the Kuder–Richardson coefficient was .91.

##### *Unmet service needs inventory (Heller & Factor 1993; Caldwell 2008)*

We used the Unmet Service Needs Inventory, which included seventeen domains to measure the number of unmet service needs. Each participant was asked whether the person with ASD received the service. If the person did not receive the service, the participant was asked whether the individual needed the service. Participants who indicated that their family member needed a service but did not currently receive the service were coded as having an unmet service need. Services included recreation and respite. Summing the number of unmet needs, the Kuder–Richardson coefficient = .83.

#### Analyses

First, we conducted preliminary analyses. We examined the distribution of each variable and found that the variables were normally distributed. We



conducted descriptive analyses of each independent variable. After conducting the descriptive analyses, we created a correlation matrix of the independent variables to identify any multicollinearity.

Then, we performed three hierarchical regressions with all of the independent variables to determine the correlates of caregiving satisfaction, self-efficacy and burden. In each of the regression models, independent variables were entered into three blocks to control for child and parent characteristics. In all three models, Block 1 included characteristics of the child with ASD (i.e. health, maladaptive behaviour and presence of an ID), Block 2 included parent characteristics (i.e. income and age) and Block 3 included social–environmental factors (i.e. community involvement, future planning, choicemaking and unmet service needs). We entered child characteristics in the first block as maladaptive behaviour is a strong predictor of caregiver well-being. For the first two blocks, we included parent and child characteristics as, for this study, we were most interested in how social–environmental characteristics relate to caregiving experiences.

## Results

### Descriptive analyses and correlation matrix

For means, standard deviations and ranges of each continuous variable, see Table 2. None of the

**Table 2** Descriptive statistics of independent and dependent variables

	Mean (SD)	Range
Independent variables: parent		
Age	54.64 (9.77)	37–87
Independent variables: individual		
Maladaptive behaviour	19.71 (6.66)	6–34
Independent variables:		
Social–environmental		
Community involvement	26.52 (6.17)	14–54
Choicemaking	20.88 (4.90)	12–32
Future planning	26.78 (5.78)	0–32
Unmet service needs	4.45 (3.33)	0–14
Dependent variables		
Caregiving burden	25.29 (5.57)	10–36
Caregiving satisfaction	15.68 (2.64)	5–20
Caregiving self-efficacy	18.56 (2.67)	12–24

independent variables had strong ( $r > .70$ ) inter-relations. The Variable Inflation Factor for all independent variables was below 2.5 indicating that multicollinearity was not a concern. See Table 3 for the correlation matrix.

### Hierarchical regression analyses

#### Caregiving satisfaction

With Block 3, the hierarchical regression model was significant explaining 7.8% of the variance ( $F = 3.77$ ,  $P = .007$ ). Future planning related to greater caregiving satisfaction ( $\beta = .25$ ,  $P = .012$ ). Choicemaking negatively related to caregiving satisfaction ( $\beta = -.34$ ,  $P = .003$ ). See Table 4.

#### Caregiving self-efficacy

The hierarchical regression model was not significant until Block 3 was included. With Block 3, the model was significant explaining 10.9% of the variance ( $F = 3.59$ ,  $P = .009$ ). Greater community involvement related to greater caregiving self-efficacy ( $\beta = .28$ ,  $P = .006$ ). Less choicemaking related to greater caregiving self-efficacy ( $\beta = -.32$ ,  $P = .004$ ).

#### Caregiving burden

Only with Block 1 was the hierarchical regression model significant explaining 20.9% of the variance ( $F = 10.75$ ,  $P < .001$ ). In Block 3, the regression model did explain more of the variance (22.6%); however, this was not a significant increase ( $F = 1.81$ ,  $P = .133$ ). In Block 1, better health of the child with ASD related to less caregiving burden ( $\beta = -.22$ ,  $P = .015$ ). Also in Block 1, maladaptive behaviours of the child with ASD related to greater caregiving burden ( $\beta = .34$ ,  $P < .001$ ). In Block 3, greater choicemaking related to less caregiving burden ( $\beta = -.21$ ,  $P = .034$ ).

## Discussion

Given the growing number of adults with ASD and the inability of the service delivery system to meet their needs, it is crucial to identify correlates of caregiving experiences including caregiving satisfaction, self-efficacy, and burden among parents of adults with ASD. In alignment with Lawton's two factor theory (1982), we found that caregiving satisfaction and burden are not opposite sides of the

**Table 3** Correlation matrix of independent variables

	1	2	3	4	5	6	7	8	9
1. Maladaptive behaviour	—								
2. Income	.11	—							
3. Health	-.15	.29**	—						
4. Unmet service needs	.06	-.21*	-.17**	—					
5. Choicemaking	-.23**	.17	.15	-.11	—				
6. Intellectual disability	.03	.07	-.23	-.09	.12	—			
7. Community involvement	-.06	.16	.17	-.21**	.39**	.05	—		
8. Age	-.09	.27**	-.09	.17	.08	.15	.07	—	
9. Future planning	.15	.02	-.15	.13	.04	.09	-.12	-.11	—

\*\*Indicates  $P < .01$ .\*Indicates  $P < .05$ .

same concept. Indeed, different variables were significantly related to each caregiving construct. We had four main findings.

First, we found that future planning related to increased caregiving satisfaction. As demonstrated in previous studies (Heller & Caldwell 2006), future planning impacts caregiving. However, although future planning is among the highest unmet needs for ageing parents (Heller & Factor, 1991), fewer than half of families report having engaged in future planning (Freedman *et al.* 1997). When thinking about the future, parents may worry about having ‘unfinished business’ (Smith *et al.* 1995). By engaging in future planning, parents of individuals with ASD may feel satisfied that they have provided for their offspring in both current and future contexts. Child and family characteristics did not significantly relate to caregiving satisfaction. It may be that, by addressing future planning, caregiving satisfaction can be increased among families with different individual and parent characteristics.

Second, greater community involvement of the adult with ASD was significantly related to greater caregiving self-efficacy. Previous research has suggested that parents of individuals with IDD may be less likely to encourage community involvement. Siblings of adults with IDD reported that their parents were reluctant to encourage their adults with IDD to engage in the community (Burke *et al.* 2015). Given the positive relation between caregiving self-efficacy and community involvement, it seems that parents should facilitate greater community

involvement not only for the benefit of their offspring but also for themselves. Alternatively, it could be that parents experience greater self-efficacy and, then, encourage more community involvement.

Third, parents of adults with ASD with less choicemaking reported greater caregiving self-efficacy and more caregiving satisfaction. Albeit not a significant model of caregiving burden, less choicemaking of the individual with ASD also related to increased caregiving burden. Decreased choicemaking may relate to greater caregiving self-efficacy and satisfaction because the caregiver has more decisions to make and, consequently, may feel more efficacious and satisfied with their roles. Yet, caregivers may simultaneously feel less worrisome about the future when their offspring can make more choices.

It is important to carefully consider the relation between choicemaking and caregiving. Choicemaking is also a principle of self-determination (Heller *et al.* 2011). When adults have increased choicemaking, they are more likely to have greater access to community and employment opportunities (Shogren *et al.* 2013). However, when adults with ASD have more choice, there may be conflict between parents and their offspring with ASD. Parents may struggle to retain their previous role of ‘decision-makers’ (Hewitt *et al.* 2013). There may be a tendency, from parents, to protect their offspring leading to reduced choicemaking and self-determination (Powers *et al.* 2002). To ensure that parents do not restrict choicemaking, practitioners may need to prepare

**Table 4** Hierarchical regression analyses

	<i>B</i> ( <i>SE</i> )	<i>Beta</i>	<i>P</i>	<i>R</i> <sup>2</sup> <i>change</i>
<b>Caregiving satisfaction</b>				
Block 1 (individual characteristics)				.02
Health	.09 (.25)	.04	.72	
Maladaptive behaviour	.02 (.04)	.05	.64	
Intellectual disability	.01 (.05)	.03	.80	
Block 2 (family characteristics)				.02
Income	-.10 (.19)	-.06	.59	
Age	-.03 (.03)	-.13	.22	
Block 3 (social–environmental factors)				.13*
Community involvement	.02 (.05)	.05	.47	
Future planning	.11 (.04)	.25	.01**	
Choicemaking	-.18 (.06)	-.34	.01**	
Unmet service needs	.06 (.08)	.07	.45	
<b>Caregiving self-efficacy</b>				
Block 1 (individual characteristics)				.05
Health	.29 (.25)	.11	.26	
Maladaptive behaviour	-.03 (.04)	-.01	.45	
Intellectual disability	.00 (.05)	-.01	.99	
Block 2 (family characteristics)				.02
Income	-.26 (.19)	-.14	.19	
Age	.01 (.03)	.01	.95	
Block 3 (social–environmental factors)				.12*
Community involvement	.14 (.05)	.28	.01**	
Future planning	.05 (.05)	.10	.27	
Choicemaking	-.18 (.06)	-.32	.01*	
Unmet service needs	-.08 (.08)	-.09	.31	
<b>Caregiving burden</b>				
Block 1 (individual characteristics)				.21**
Health	-1.13 (.46)	-.22	.01**	
Maladaptive behaviour	.28 (.07)	.34	.01**	
Intellectual disability	.09 (.09)	.09	.31	
Block 2 (family characteristics)				.01
Income	.34 (.36)	.09	.34	
Age	.01 (.06)	.01	.15	
Block 3 (social–environmental factors)				.05
Community involvement	-.01 (.09)	-.01	.99	
Future planning	.09 (.08)	.10	.25	
Choicemaking	-.24 (.11)	-.21	.03*	
Unmet service needs	.14 (.15)	.09	.33	

\*Refers to  $P < .05$ .\*\*Refers to  $P < .01$ .

parents to ‘let go’ of their adult offspring—to encourage adults with ASD to make their own decisions.

Fourth, parents of individuals with greater maladaptive behaviours and poor health reported significantly more caregiving burden. Consistent with past research, greater maladaptive behaviours of adults with ASD relates to worse caregiver well-being (Barker *et al.* 2011). Notably, researchers

have documented a reduction in maladaptive behaviours when individuals with ASD reach adulthood (Lounds *et al.* 2007). Although the incidence of maladaptive behaviours may decrease in adulthood, it seems that the negative relation between maladaptive behaviour and caregiver burden persists.

Poor health of the adult with ASD also related to caregiving burden. When their offspring experience



health problems, parents may worry about their children's health and have increased caregiving responsibilities. Given the relation between health and caregiving burden, it may be that parents of adults with ASD and co-occurring health issues require targeted support. Other individual, family and social–environmental characteristics did not significantly relate to caregiving burden. Indeed, past research has indicated that maladaptive behaviours (i.e. a characteristic of the child) is perhaps the greatest predictor of stress and burden (Barker *et al.* 2011). It may be that individual characteristics drive the degree of caregiving burden but not positive caregiving experiences.

#### Directions for future research

Future research should longitudinally examine individuals with ASD and their parents. By examining caregiving experiences over time, we can better discern when intervention is needed for individuals with ASD and their parents. Also, we can determine the directionality of effects among the identified correlates and positive and negative aspects of caregiving. For example, in examining the relation between behaviour and maternal well-being over a six year period, Orsmond *et al.* (2003) found that the relation was bidirectional. With respect to the findings of this study, it could also be true that maladaptive behaviours and caregiving burden have a bidirectional relation. Also, given the cross-sectional nature of this study, there could be cohort effects. Longitudinal research would be able to discern the effect of child and parent age in relation to caregiver experiences over time.

Additionally, future research should identify other correlates of caregiving satisfaction, self-efficacy and burden. Although this study identified some of the correlates of caregiving experiences, the parent, individual and social–environmental characteristics comprised a small percent of the variance of caregiving experiences. Notably, other studies about caregiving experiences have also explained little variance (e.g. Magaña *et al.* 2002; Caldwell & Heller 2003). Future research may also want to include other characteristics such as parent support (Singer *et al.* 1999). Other variables such as severity of ASD symptoms and number of hours engaged in caregiving could explain the additional variance. Future research should also examine whether similar correlates of

caregiving experiences are found for parents of adults with IDD (without ASD).

#### Implications for policymakers and practitioners

Practitioners should note that when adults with ASD were in better health, caregivers reported less burden. Thus, practitioners should consider educating adults with ASD and their parents about health promotion. Practitioners may consider using HealthMatters to teach adults with ASD and their families about physical activity, health and nutrition. HealthMatters has resulted in improved health outcomes for individuals with IDD (Heller *et al.* 2004). If practitioners offered an evidence-based curriculum (e.g. HealthMatters) to their clients with ASD, then adults with ASD may have improved health, and their parents may experience more caregiving satisfaction and less burden.

Policymakers should consider the implications of the relation between future planning and caregiving satisfaction. Although future planning is related to increased caregiving satisfaction, few policies offer supports for parents to access future planning services. In the United States, the Older Americans Act includes the National Family Caregiver Support program, which is intended to provide information, referral, counseling and respite to caregivers. Unfortunately, the National Family Caregiver Support Program is not directed toward parents of individuals with IDD. Policymakers should consider increasing access to future planning supports.

Although a jumping off point to identifying the correlates of caregiving burden, satisfaction and self-efficacy, this study has some limitations. This study has limitations related to sampling and the potential for response bias. Because this was a voluntary survey, the response rate may reflect a bias related to non-responders. Also, the sample size precluded sufficient power from conducting more analyses. The sample may not be generalisable especially given that the majority of the sample included adults with co-occurring ID and ASD. The high prevalence of individuals with ID and ASD may be related to the recruitment method. In the United States, the HCBS waiver provides for community-based supports (e.g. employment) for individuals with IDD. It may be that most individuals waiting for the HCBS waiver have ID. Other limitations relate to using parent-report for the ASD diagnosis and other measures. Also, although our measure for health accurately predicts

future mortality (Idler & Benyamini 1997), a longer measure of health may have been more comprehensive. Additionally, we did not ask about whether the family had any financial savings, which could also have influenced our findings.

Even in spite of these weaknesses, this study provides important information about the correlates of caregiving satisfaction, self-efficacy, and burden among parents of adults with ASD. To support the growing number of adults with ASD and their families, it is necessary to identify the determinants of caregiving.

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