


# Factors Affecting the Health of Caregivers of Children Who Have an Intellectual/Developmental Disability

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## Abstract

There are a growing number of children with an ID/developmental disability. As well, there is evidence of poor health in the caregivers of these children. This article describes a narrative review of the literature regarding the mental and physical health of caregivers of children with ID/developmental disability. The review examined 162 papers. Twenty-three different factors were identified that may have an effect on the health of these caregivers. Social determinants, individual caregiver variables, characteristics of the child with the disability, family characteristics, and support factors can all affect caregiver health. These variables are inter-related and illustrate the need to account for complexity when studying the health of caregivers of children with ID/developmental disability.

**Keywords:** caregivers, children, health, ID, mental health

## Introduction

There is evidence that the number of children diagnosed with a disability and particularly with an I/DD is increasing in developed countries (de Graaf et al., 2011; Halfon, Houtrow, Larson, & Newacheck, 2012; Houtrow, Larson, Olson, Newacheck, & Halfon, 2014; Reichman, Corman, & Noonan, 2008; Shin et al., 2009). Houtrow et al. (2014) analyzed the U.S. National Health Interview Survey datasets from 2001 to 2011. They found that the prevalence of childhood disability increased by 15.6% between 2001 and 2011. However, in the same 10-year period, they also found that the percentage of disability cases as a result of a physical health condition declined by 11.8%, while the percentage of cases as a result of neuro-developmental or mental health conditions increased by 20.9%. Marquis et al. (2018) examined the prevalence of children with a developmental disability in British Columbia, Canada, and found that the prevalence increased from 0.4% of the total number of children in 1986 to 2.42% in 2013.

There is considerable evidence of stress (Davis & Carter, 2008; Estes et al., 2009; Firth & Dryer, 2013; Gallagher, Phillips, Drayson, & Carroll, 2009; Goudie, Narcisse, Hall, & Kuo, 2014; Gupta, 2007; IASSIDD, 2014; Lee, 2013; Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008; Murphy, Christian, Caplin, & Young, 2007; Seltzer et al., 2009; Webster, Majnemer, Platt, & Shevell, 2008) and poor

mental health in caregivers of children with an IDD (Bourke-Taylor, Pallant, Law, & Howie, 2012; Bourke-Taylor, Howie, Law, & Pallant, 2012; Cantwell, Muldoon, & Gallagher, 2015; Carr, 1988; Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010; Feldman et al., 2007; Gallagher et al., 2009; Gallagher & Hannigan, 2014; Gallagher, Phillips, Oliver, & Carroll, 2008; Gray et al., 2011; Ha, Hong, Seltzer, & Greenberg, 2008; Hartley, Seltzer, Head, & Abbeduto, 2012; Hedov, Annerén, & Wikblad, 2000; Resch, Elliott, & Benz, 2012).

In addition, there are a growing number of studies linking having a child with an I/DD to poor self-reported caregiver physical health (Allik, Larsson, & Smedje, 2006; Burke & Fujiura, 2013; Cantwell, Muldoon, & Gallagher, 2014; Gallagher & Whiteley, 2013; Ha et al., 2008; Miodrag, Burke, Tanner-Smith, & Hodapp, 2015; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Murphy et al., 2007; Olsson & Hwang, 2008; Seltzer et al., 2009).

Families are complex systems affected by individual characteristics, family level factors, and social determinants of health. This narrative literature review was conducted to establish factors that affect the health of caregivers of children with an I/DD and the weight of evidence for each factor. This information is critical for on-going research into the health of caregivers of children with an I/DD, for policy development, and for planning programs and services.

## Methods

Medline, Academic Search Complete, CINAHL, and ScienceDirect web bases were examined for the years 2000–17 for

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articles relating to the health of caregivers of children with an I/DD. Search terms used included caregiver, parents, children, developmental disability, ID, and disability. The references in each article and the citations for each article included in the review were also examined to identify additional papers. Criteria included: English language, children aged 0–19 years old, articles examining caregiver physical or mental health, articles examining the interactions between other factors and health, and articles including children who had an I/DD. Studies included involved a mixture of different types of I/DD and/or included a mixture of disabilities (including I/DD). Exclusion criteria included: articles solely about children with physical health problems or physical disabilities, reports of intervention studies, and reports from developing countries. Studies primarily came from the United States of America, United Kingdom, Australia, and Canada (Table 2). Additional studies were found from the Republic of Ireland, Sweden, Israel, the Netherlands, and Italy. A total of 162 studies were examined.

**Results**

A wide variety of variables which affect caregiver health were found in the literature. These factors can be grouped into five broad domains: social determinants of health, individual

TABLE 1  
Proposed range of variables which may affect the health of caregivers of a child with an I/DD

Domain	Variables
Social determinants of health	Income Neighborhood characteristics Employment Education Race/ethnicity
Individual characteristics of the parent	Sex Marital status Age of parent at birth of the child with the I/DD Age of parent at the time of the study Lack of sleep Self-esteem Coping strategies
Characteristics of the child with the I/DD	Severity of the I/DD Comorbidities Type of I/DD Behavior problems Age of the child Sex of the child
Family variables	Size of the family Families with more than one child with an I/DD
Support factors	Social isolation/stigma Formal services Informal support

caregiver characteristics, characteristics of the child with the I/DD, family variables, and support factors.

Based upon this review, five domains of variables were developed. See Table 1.

**Social Determinants of Health**

**Income.** Low income was one of the most often documented social determinants of health associated with having a child with an I/DD (Burke & Fujiura, 2013; Curran, Sharples, White, & Knapp, 2001; Eisenhower, Baker, & Blacher, 2009; Emerson, 2003a; Emerson, 2004; Emerson & Hatton, 2007c; Emerson & Spencer, 2015; Fujiura & Yamaki, 2000; Goudie et al., 2014; Halfon et al., 2012; Hogan, Msall, & Drew, 2006; Lopez et al., 2008; McManus et al., 2011; Mitchell & Hauser-Cram, 2008; Newacheck & Halfon, 1998; Olsson & Hwang, 2008; Ouyang, Grosse, Raspa, & Bailey, 2010; Parish & Cloud, 2006; Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008; Parish, Rose, & Swaine, 2010; Parish, Rose, Swaine, Dababnah, & Mayra, 2012; Parish, Seltzer, Greenberg, & Floyd, 2004; Park, Turnbull, & Turnbull, 2002; Rogers & Hogan, 2003; Warfield, 2005; Werner & Shulman, 2013).

Many studies found a negative relationship between income level and parental stress in families with a child with an I/DD (Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006; Emerson & Lewellyn, 2008; Goudie et al., 2014; Olsson & Hwang, 2008; Povee, Roberts, Bourke, & Leonard, 2012; Smith, Oliver, & Innocenti, 2001). As well, Emerson, McCulloch, et al. (2010) found that income level played a role in the effects of the presence of a child with an I/DD on mental health of caregivers. Using data from the Millennium Cohort Study in the United Kingdom, Emerson, McCulloch, et al. (2010) found that both mothers and fathers of children with cognitive delay were at higher risk of psychiatric disorders than were mothers and fathers of children without cognitive delay. However, controlling for between-group differences in socioeconomic conditions (income, job status, education, neighborhood deprivation, etc.) reduced the difference in probable psychiatric disorder to nonsignificance for fathers and significantly attenuated the relationship for mothers.

Only one study had a conflicting result. Bourke-Taylor, Howie, et al. (2012) found no correlation between maternal depression and family income in an Australian study of mothers of school-aged children with an I/DD.

**Neighborhood characteristics.** Msall, Avery, Msall, and Hogan (2007) used U.S. Census Tracts and administrative data from Rhode Island to assess rate of childhood disability in children living in severely distressed neighborhoods. They found that rates of childhood disability increased for each increasing level of neighborhood distress. Park et al. (2002) found that poverty among families with a child with a disability contributed to overcrowded housing and an increased risk of living in unsafe neighborhoods.

**Employment.** The effects of employment are mixed. Compared to parents of nondisabled children, parents of children with an I/DD who often reduce or change employment are less likely to work and less likely to work full-time (Burton & Phipps, 2009; Carr, 1988; Crettenden, Wright, & Skinner, 2014; Curran et al., 2001; Emerson & Hatton, 2007c; Gallagher et al., 2009;

TABLE 2  
References for caregiver paper

Author(s)	Year of publication	Country
Allik, Larsson, and Smedje	2006	Sweden
Baker, Blacher, Crnic, and Edelbrook	2002	United States
Baker, Blacher, and Olsson	2005	United States
Baker, McIntyre, Blacher, Crnic, Edelbrook, and Low	2003	United States
Bourke-Taylor, Howie, Law, and Pallant	2012	Australia
Bourke-Taylor, Pallant, Law, and Howie	2012	Australia
Bourke-Taylor, Pallant, Law, and Howie	2013	Australia
Burke, Urbano, and Hodapp	2011	United States
Cantwell, Muldoon, and Gallagher	2014	Ireland
Cantwell, Muldoon, and Gallagher	2015	Ireland
Carr	1988	United Kingdom
Churchill, Villareale, Monaghan, Sharp, and Kieckhefer	2010	United States
Cramm and Nieboer	2011	The Netherlands
Crettenden, Wright, and Skinner	2014	Australia
Curran, Sharples, White, and Knapp	2001	United Kingdom
Davis and Carter	2008	United States
Dodd, Zabriskie, Widmer, and Eggert	2009	United States
Dowling and Dolan	2001	United Kingdom
Eisenhower, Baker, and Blacher	2009	United States
Emerson	2003a	United Kingdom
Emerson	2003b	United Kingdom
Emerson and Hatton	2007a	United Kingdom
Emerson and Hatton	2007b	United Kingdom
Emerson and Hatton	2007c	United Kingdom
Emerson, Hatton, Llewellyn, and Graham	2006	United Kingdom
Emerson and Llewellyn	2008	Australia
	2010	

(Continues)

TABLE 2  
Continued

Author(s)	Year of publication	Country
Emerson, McCulloch, Graham, Blacher, Llewellyn, and Hatton		United Kingdom
Estes, Munson, Dawson, Koehler, Zhou, and Abbott	2013	United States
Fairthorne, deKlerk, and Leonard	2016	Australia
Falk, Norris, and Quinn	2014	Australia
Feldman, McDonald, Serbin, Stack, Secco, and Yu	2007	Canada
Firth and Dryer	2013	Australia
Foody, James, and Leader	2015	Ireland
Freedman, Kalb, Zablotzky, and Stuart	2012	United States
Gallagher and Hannigan	2014	Ireland
Gallagher, Phillips, and Carroll	2010	United Kingdom
Gallagher, Phillips, Drayson, and Carroll	2009	United Kingdom
Gallagher, Phillips, Oliver, and Carroll	2008	United Kingdom
Gallagher and Whiteley	2012	United Kingdom
Gallagher and Whiteley	2013	United Kingdom
Giallo, Seymour, Matthews, Gravidia-Payne, Hudson, and Cameron	2015	Australia
Glidden, Billings, and Jobe	2006	United States
Goudie, Narcisse, Hall, and Kuo	2014	United States
Gray	2002	Australia
Gray	2003	Australia
Gray, Piccinin, Hofer, MacKinnon, Bontempo, Einfeld, Parmenter, and Tonge	2011	Australia
Green, Davis, Karshmer, Marsh, and Straight	2005	United States
Green	2003	United States
Green	2007	United States
Grein and Glidden	2015	United States
Gupta	2007	United States
Ha, Hong, Seltzer, and Greenberg	2008	United States
Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, and Bolt	2010	United States
	2012	United States

(Continues)

TABLE 2  
Continued

Author(s)	Year of publication	Country
Hartley, Seltzer, Head, and Abbeduto		
Hastings	2003	United Kingdom
Hastings, Kovshoff, Ward, degli Espinosa, Brown, and Remington	2005	United Kingdom
Hauser-Cram, Warfield, Shonkoff, Krauss, Sayer, Upshur, and Hodapp	2001	United States
Hedov, Anneren, and Wikblad	2000	Sweden
Kinnear, Link, Ballan, and Fischbach	2016	United States
Lach, Kohen, Garner, Brehaut, Miller, Klassen, and Rosenbaum	2009	Canada
Larson and Miller-Bishoff	2014	United States
Laxman, McBride, Jeans, Dyer, Santos, Kern, and Weglarz-Ward	2015	United States
Lecavalier, Leone, and Wiltz	2006	United States
Leiter, Krauss, Anderson, and Wells	2004	United States
Lewis, Abbeduto, Murphy, Richmond, Giles, Bruno, Schroeder, Anderson, and Orsmond	2006	United States
Lewis, Kagan, Heaton, and Cranshaw	1999	United Kingdom
Lopez, Clifford, Minnes, and Ouellette-Kuntz	2008	Canada
Lovell, Moss, and Wetherell	2015	United Kingdom
MacInnes	2008	United States
McCoyd, Akincigil, and Paek	2010	United States
McGill, Papachristoforou, and Cooper	2006	United Kingdom
McManus, Carle, Acevedo-Garcia, Ganz, Hauser-Cram, and McCormick	2011	United States
McStay, Trembath, and Dissanayake	2014	Australia
Minnes, Perry, and Weiss	2015	Canada
Mitchell and Hauser-Cram	2008	United States
Mitchell, Hauser-Cram, and Crossman	2015	United States
Morris	2012	United States

(Continues)

TABLE 2  
Continued

Author(s)	Year of publication	Country
Morris	2014	United States
Most, Fidler, Laforce-Booth, and Kelly	2006	United States
Msall, Avery, Msall, and Hogan	2007	United States
Mugno, Ruta, D'Arrigo, Mazzone	2007	Italy
Murphy, Christian, Caplin, and Young	2007	United States
Neely-Barnes, Graff, Roberts, Hall, and Hankins	2010	United States
Neely-Barnes and Marcenko	2004	United States
Nurullah	2013	Canada
Olsson and Hwang	2008	Sweden
Ouyang, Grosse, Raspa, and Bailey	2010	United States
Parish, Rose, Grinstein-Weiss, Richman, and Andrews	2008	United States
Parish, Rose, and Swaine	2010	United States
Parish, Rose, Swaine, Dababnah, and Mayra	2011	United States
Parish, Seltzer, Greenberg, Floyd	2004	United States
Plant and Saunders	2007	Australia
Povee, Roberts, Bourke, and Leonard	2012	Australia
Resch, Elliott, and Benz	2012	United States
Rivard, Terroux, Parent-Boursier, and Mercier	2014	Canada
Roehrer Institute	2000a	Canada
Roehrer Institute	2000b	Canada
Robert, Leblanc, and Boyer	2015	Canada
Rogers and Hogan	2003	United States
Roper, Allred, Mandleco, Freeborn, and Dyches	2014	United States
Runswick-Cole	2010	United Kingdom
Saunders, Tilford, Fussell, Schulz, Casey, and Kuo	2015	United States
Scott	2010	United States
Seltzer, Almeida, Greenberg, Savla, Stawski, Hong, and Taylor	2009	United States
Seltzer, Greenberg, Floyd, Pettee, and Hong	2001	United States
Seymour, Wood, Giallo, and Jellett	2013	Australia

(Continues)

TABLE 2  
Continued

Author(s)	Year of publication	Country
Sikora, Moran, Orlich, Hall, Kovacs, Delahaye, Clemons, and Kulthau	2013	United States
Smith, Romski, Sevcik, Adamson, and Barker	2014	United States
Smith, Oliver, and Innocenti	2001	United States
Song, Seltzer, Ryff, Coe, Greenberg, and Hong	2013	United States
Spratt, Saylor, and Macias	2007	United States
Urbano and Hodapp	2007	United States
Vogan, Lake, Weiss, Robinson, Tint, and Lunskey	2014	Canada
Walsh, Mulder, and Tudor	2013	United States
Warfield	2005	United States
Watson, Coons, and Hayes	2013	Canada
Webster, Majnemer, Platt, and Shevell	2008	Canada
Werner and Shulman	2013	Israel
Werner and Shulman	2014	Israel
Woodman	2014	United States
Woodman and Hauser-Cram	2013	United States
Wright, Tancredi, Yundt, and Larin	2006	Canada
Zablotsky, Bradshaw, and Stuart	2013	United States
Zaidman-Zait et al.	2014	Canada
Zaidman-Zait et al.	2017	Canada

Gray, 2003; Leiter, Krauss, Anderson, & Wells, 2004; Ouyang et al., 2010; Parish et al., 2004; Parish & Cloud, 2006; Roehrer Institute, 2000a, 2000b; Rogers & Hogan, 2003; Scott, 2010; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Stabile & Allin, 2012). In a study of two-earner families, Warfield (2005) found that greater work overload was related to greater parenting stress. At the same time, several studies found that lack of employment is a predictor of stress in parents of children with an I/DD (Churchill et al., 2010; Emerson et al., 2006; Ha et al., 2008), and there is evidence in the literature that paid employment can have a beneficial effect on the mental health and well-being of mothers who have a child with a disability (Ha et al., 2008; Larson & Miller-Bishoff, 2014; Lewis, Kagan, Heaton, & Cranshaw, 1999; Morris, 2012, 2014).

**Caregiver education.** On a population basis, evidence exists for a correlation between poverty, caregivers having less than a high school (Goudie et al., 2014; Hogan et al., 2006) or college education (Halfon et al., 2012), single parenthood, and presence of a child with a disability (Emerson, 2004; Fujiura & Yamaki, 2000).

Smith et al. (2001) found a correlation between parent's educational level and measures of parent stress. Eisenhower

et al. (2009) reported that higher maternal education was associated with better self-reported health in mothers of children with an I/DD. In a study using state-wide administrative data, Urbano and Hodapp (2007) found in both families with and without a child with Down syndrome, parents' education was inversely associated with divorce.

### Race/Ethnicity

In a study of population trends in the United States, Hogan et al. (2006) found much higher rates of disability among black children. However, using National Health Interview Survey data, Fujiura and Yamaki (2000) found that income and family status (single vs. two parent families) accounted for differences between racial/ethnic groups in the prevalence of childhood disability in the United States.

Studies have varied in their findings of the effects of having a child with a disability on different ethnic/racial groups. Neely-Barnes and Marcenko (2004) examined the families of 505 children with an I/DD in the 1995 U.S. National Health Interview Study Disability Supplement. The impact on families was measured through six questions regarding parents' ability to work, changed sleep schedules, and family finances. White and Hispanic families reported slightly greater impact of a child with a disability on the family than did African American families. Blacher, Begum, Marcoulides, and Baker (2013) found that Latino mothers of children with an ID reported more positive impact than did Anglo mothers of a child with an ID.

However, Ha et al. (2008) found significantly higher levels of psychological well-being among non-Hispanic White parents of children with developmental problems when compared to parents of other races and ethnicities. Gupta (2007) found that ethnicity did not contribute to group differences in parental stress; however, having English as a second language was associated with greater stress of parents with a child with an I/DD compared to parents of typically developing children.

### Individual Caregiver Characteristics

**Gender of the parent.** Many studies have reported that mothers are the primary caregivers of children with disability (Gray, 2003; Roehrer Institute, 2000a) and that mothers report more caregiving burden compared to fathers (Gray, 2003; Hedov et al., 2000; Roper, Allred, Mandelco, Freeborn, & Dyches, 2014). In addition to other workforce and domestic responsibilities, Leiter et al. (2004) estimated that mothers spent at least 20 h/week providing support to their child with a disability.

In a study of gender role differences between men and women who were parents of children with high functioning autism, Gray (2003) reported that despite considerable variation in backgrounds, political affiliations, and religious beliefs, the existence of a child with autism had the effect of "reducing all of the families to a largely traditional pattern of gender relations." Gray attributed this to greater economic opportunities available to men and the need for one parent to be available to care for the child.

Few studies have compared stress or health between mothers and fathers of children with an I/DD. Some studies have found differences between genders with mothers having significantly lower levels of well-being than fathers (Olsson & Hwang, 2008), reporting more health problems than fathers (Resch et al., 2012), and having poorer mental health than fathers (Emerson & Lewellyn, 2008; Foody, James, & Leader, 2015). In families with a child with Autism Spectrum Disorder (ASD), Foody et al. (2015) found higher levels of distress, depression, and anxiety in mothers compared to fathers, but also higher blood pressure and heart rate variability in fathers compared to mothers. Rivard, Terroux, Parent-Boursier, and Mercier (2014) reported that compared with mothers, fathers of young children with ASD reported higher levels of stress.

Other studies of parents of children with disabilities have found no differences between genders in overall stress, depressive symptoms, or psychological well-being (Churchill et al., 2010; Davis & Carter, 2008; Ha et al., 2008; Hastings, 2003; Warfield, 2005). Mugno et al. (2007) found poorer self-reported health in mothers compared to fathers of children with cerebral palsy and Pervasive Development Disorder, but no differences in mothers compared to fathers of children with Down syndrome.

In parents of children with autism, Davis and Carter (2008) found that different aspects of children's behaviors were predictive of parenting stress for mothers compared to fathers. Mothers' stress was particularly affected by their children's difficulty with self-regulation (defined as issues of eating, sleeping, and emotion regulation). For fathers, externalizing behaviors (aggression, defiance, and impulsivity) were the primary child behaviors associated with stress.

Hauser-Cram et al. (2001) also found differences in stress patterns between mothers and fathers. They found that, for mothers, child behavior problems, the type of disability, social support available, negative life events, and mother-child interactions were all predictors of stress. For fathers, child behavior problems, gender of the child with a disability, mother-child interactions, and negative life events were predictors of stress.

As well, several authors have reported a positive correlation between maternal and paternal stress (Hastings et al., 2005; Hauser-Cram et al., 2001; Warfield, 2005) and depression (Hartley et al., 2012).

**Marital status.** In a review of studies on the relationship between having a child with a disability and the prevalence of divorce and separation, Risdal and Singer (2004) found an average increase in the rate of divorce of 5.97% (range 2.9%–6.7%) in families with a child with a disability compared to families with a child without a disability.

Using a large national database in the United States, McCoyd, Akincigil, and Paek (2010) found that overall the birth of a child with a disability did not lead to relationship dissolution. However, the instability of the child's condition and extremely high levels of caregiving burden were positively associated with separation. Mitchell, Szczerka, and Hauser-Cram (2016) found that greater partner stress was negatively correlated with family cohesion for both mothers and fathers.

Several studies indicate that the type and severity of the child's disability affects divorce rate. Some studies (Carr, 1988;

Urbano & Hodapp, 2007) have reported lower rates of divorce in families of children with Down syndrome compared to controls. Freedman, Kalb, Zablotzky, and Stuart (2012) reported that in a sample of families with a child who had ASD, there was no increase in parental separation or divorce. McCoyd et al. (2010) found that overall the birth of a child with a disability did not lead to relationship dissolution. However, the instability of the child's condition and extremely high levels of caregiver burden were positively associated with separation.

In comparison to these findings, Hartley et al. (2010) reported on a longitudinal study of children with ASD. They found that when families were matched for child characteristics (age, sex, and birth order) and maternal characteristics (age, education, and ethnicity) there was a significantly higher divorce rate in families who had a child with ASD (23.53%) compared to families who did not have a child with ASD (13.81%). In addition, the risk of divorce decreased in the child's late childhood (after age 8) and was extremely low by the time the child was a young adult in families who did not have a child with ASD. In families with a child with ASD, the risk of divorce remained high throughout the child's adolescence and early adulthood and did not decrease until the child had reached age 30.

Many studies have found that the prevalence of childhood disability is higher in single-parent families compared to two-parent families (Emerson, 2004; Emerson et al., 2006; Emerson & Hatton, 2007b; Fujiura & Yamaki, 2000; Goudie et al., 2014; Halfon et al., 2012; Newacheck & Halfon, 1998). In contrast, Ha et al. (2008) reported no significant differences in marital status between parents of children with an I/DD and parents of children without an I/DD.

Studies have also found a link among poverty, single-parent families, and the presence of a child with a disability (Emerson, 2004; Emerson & Hatton, 2007a; Fujiura & Yamaki, 2000; Parish et al., 2012). In Britain, Emerson and Hatton (2007b) found that in all areas of risk that were measured (income, housing, family savings, etc.), single-parent families supporting a child with an I/DD were significantly more disadvantaged than two-parent families. Similarly, Parish et al. (2012) found that compared with both married mothers and single mothers of children with and without an I/DD, single mothers of children with an I/DD had markedly worse financial well-being across a range of income and asset-based measures.

In families that have a child with a disability, many studies have found a relationship between marital status and stress or depression, with single caregivers experiencing more stress than caregivers in a married or common-law relationship (Churchill et al., 2010; Emerson et al., 2006; Ha et al., 2008; Mitchell & Hauser-Cram, 2008; Parish et al., 2008). Ha et al. (2008) found that being currently employed and being married predicted significantly better psychological well-being for parents of children with an I/DD.

**Age of the parent.** Maternal age at birth of the child with the disability may be a risk factor for poorer outcomes of caregivers of children with a disability. In a review article, Hodapp, Robert, Burke, and Urbano (2012) reported that older mothers of children with a disability were associated with higher maternal education, more social support, higher family income, greater stability of marriages, and maternal maturity. Younger

age of caregivers has been associated with a higher risk of divorce (Urbano & Hodapp, 2007). Several studies have found no correlation between parent's age at the time of the study and the incidence of depressive symptoms (Bourke-Taylor, Howie, et al., 2012; Churchill et al., 2010; Resch et al., 2012) or stress (Lecavalier, Leone, & Wiltz, 2006). In contrast, Ha et al. (2008) reported results from the Study of Midlife in the United States. They found that parents of children with an I/DD had poorer well-being than a comparison group, but that these effects attenuated with parental age.

There are very few longitudinal studies that have examined the effects of aging on parent stress. Most, Fidler, LaForce-Booth, and Kelly (2006) found no changes in stress over time in mothers of children with a variety of developmental disabilities but did find an increase in stress levels for mothers of children with Down syndrome over time. In a longitudinal study of children with various disabilities over a 7-year period, Hauser-Cram et al. (2001) found that the stress levels of both mothers and fathers increased significantly over time.

**Lack of sleep.** Caregivers of children with a disability experience lack of sleep, poor sleep quality, and changed sleep patterns (Bourke-Taylor, Pallant, et al., 2012; Bourke-Taylor, Pallant, Law, & Howie, 2013; Gallagher et al., 2009; Gallagher, Phillips, & Carroll, 2010; Lee, 2013; Neely-Barnes & Marcenko, 2004; Rogers & Hogan, 2003; Wright, Tancredi, Yundt, & Larin, 2006). Studies have found a relationship between fatigue and stress in parents of children with a developmental disability (Seymour, Wood, Giallo, & Jellett, 2013), poor sleep quality and mental health (Bourke-Taylor et al., 2013; Lee, 2013), and poor physical health (Bourke-Taylor et al., 2013).

**Caregiver self-esteem/perception of mastery of caregiving situation.** Several studies have found a relationship between caregiver self-esteem and sense of competence and stress (Hassall & Rose, 2005; Song et al., 2013) or sense of well-being (Werner & Shulman, 2013).

**Coping strategies.** An increasing number of studies are finding a relationship between parental coping strategies and parent mental health, stress, or well-being (Biswas, Moghadam, & Tickle, 2015; Glidden, Billings, & Jobe, 2006; Zaidman-Zait et al., 2017). Zablotsky, Bradshaw, and Stuart (2013) reported that strong maternal coping strategies reduced the risk of stress and poor mental health in families with a child with ASD. Feldman et al. (2007) also found that coping strategies predicted parent mental health in families with a child with a developmental delay. Woodman and Hauser-Cram (2013) found that specific coping strategies moderated the impact of adolescent behavior problems on maternal depression in mothers of children with a developmental disability. Minnes, Perry, and Weiss (2015) found that coping strategy predicted parental distress of mothers with children with a developmental disability. After conducting a systematic review, Peer and Hillman (2014) reported that coping strategy and optimism were both related to resilience in parents who had a child with an ID or developmental disability.

However, in a small study of parents of preschoolers, Lopez et al. (2008) found that parents of children with developmental delays experienced greater stress than parents of children without delays, but they found no differences between the two groups in coping scores or coping strategies.

## Characteristics of the Child with the I/DD

**Severity of the disability.** Some studies have indicated that the severity of the child's disability is associated with parental stress (Churchill et al., 2010; Falk, Norris, & Quinn, 2014; Neely-Barnes & Marcenko, 2004; Plant & Sanders, 2007; Rivard et al., 2014; Rogers & Hogan, 2003) and depression (Churchill et al., 2010). Vogan et al. (2014) found that ASD severity was a predictor of parental burden in families with a child with ASD and an ID.

However, Bourke-Taylor, Howie, et al. (2012) reported that in a sample of mothers with school-aged children with an I/DD, the severity of the child's condition was not predictive of self-reported maternal mental health. Povee et al. (2012) reported that functional ability of children with Down syndrome was not a predictor of family functioning or marital adjustment.

Crettenden et al. (2014) found that severity of disability was strongly related to participation in employment for mothers of children with a developmental disability. Burton and Phipps (2009) found that severity of the child's condition had the largest association with parents reducing their employment. They also reported that disability-related conditions with an early onset were associated with a higher probability of families experiencing labor market difficulties. Income may also affect the impact of the severity of the disability. Using data from the Millennium Cohort Study in the United Kingdom, Emerson, McCulloch, et al. (2010) found that both mothers and fathers of children with severe and less severe cognitive delay were at higher risk of psychiatric disorders than were mothers and fathers of children without cognitive delay. Controlling for between-group differences in socioeconomic conditions reduced the difference in probable psychiatric disorder to nonsignificance for fathers of children with either severe or less severe cognitive delay. Controlling for between-group differences in socioeconomic conditions attenuated the relationship for both mothers of children with severe cognitive delay and mothers of children with less severe cognitive delay but had the greatest effect on mothers of children with less severe cognitive delay.

**Comorbidities.** The prevalence of poor mental health is higher in children with an I/DD compared to children without an I/DD (de Ruiter, Dekker, Verhulst, & Koot, 2007; Einfeld, Piccinin, et al., 2006; Einfeld, Ellis, & Emerson, 2011; Einfeld, Tonge, Gray, & Taffe, 2006; Eisenhower et al., 2009; Emerson, 2003b; Emerson, Einfeld, & Stancliffe, 2010; Emerson & Hatton, 2007a). The mental health of children with an I/DD has also been found to be associated with caregiver stress (Cramm & Nieboer, 2011; Webster et al., 2008).

Mitchell and Hauser-Cram (2008) found that child health problems combined with an I/DD were a predictor of maternal stress but not of maternal depression. Saunders et al. (2015) reported that ASD combined with an ID resulted in greater financial burden for parents compared to parents of children with either an ID or autism.

**Type of disability.** Many researchers have examined the effect of type of child disability on parental stress, particularly comparing families with a child with autism to families of children with other types of developmental disabilities. Some of these studies reported greater effects on stress levels and depression in families which have a child with autism (Estes et al.,

2009; Hayes & Watson, 2013). In comparison, Estes et al. (2013) found no difference in psychological distress between parents of children with ASD and parents of children with other types of I/DD. Watson, Coons, and Hayes (2013) reported greater parental stress in parents of children with FAS compared to parents of children with ASD.

Hauser-Cram et al. (2001) found that type of disability was predictive of maternal stress patterns but not of paternal stress patterns. Werner and Shulman (2014) reported that type of disability affected the level of affiliate stigma experienced by parents.

Some studies have reported a “Down syndrome advantage” with parents of children with Down syndrome experiencing less stress (Povee et al., 2012; Smith, Ronski, Sevcik, Adamson, & Barker, 2014), fewer psychiatric problems (Fairthorne, de Klerk, & Leonard, 2016), or greater well-being (Grein & Glidden, 2015) than parents of children with other I/DD. However, Mitchell, Hauser-Cram, and Crossman (2015) reported no differences in parental stress in parents who had a child with Down syndrome compared to parents of children with other developmental disabilities, once mothers’ age, education and social support, and child behavior problems were considered.

However, other studies have found that type of I/DD is not predictive of parental stress or depression (Lewis et al., 2006; Mitchell et al., 2015; Mitchell & Hauser-Cram, 2008).

**Behavior problems.** The prevalence of behavior problems is significantly greater in children with an I/DD compared to non-disabled children (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker et al., 2003; Freedman et al., 2012; Lach et al., 2009; Lopez et al., 2008; McGill, Papachristoforou, & Cooper, 2006).

Many studies have found that in families with a child who has an I/DD, child problem behavior is a significant predictor of parental stress (Davis & Carter, 2008; Estes et al., 2009; Falk et al., 2014; Firth & Dryer, 2013; Gallagher et al., 2009; Hastings et al., 2005; Hauser-Cram et al., 2001; Lecavalier et al., 2006; Lee, 2013; Lovell, Moss, & Wetherell, 2015; McStay, Trembath, & Dissanayake, 2014; Mitchell & Hauser-Cram, 2008; Most et al., 2006; Plant & Sanders, 2007; Spratt, Saylor, & Macias, 2007; Walsh, Mulder, & Tudor, 2013; Warfield, 2005; Woodman, 2014; Zaidman-Zait et al., 2017), caregiver depression (Baker, Blacher, & Olsson, 2005; Churchill et al., 2010; Falk et al., 2014; Feldman et al., 2007; Firth & Dryer, 2013; Gallagher & Hannigan, 2014; Gallagher et al., 2008; Giallo et al., 2015; Gray et al., 2011; Lach et al., 2009; Lee, 2013; Mitchell & Hauser-Cram, 2008; Woodman & Hauser-Cram, 2013), poorer family functioning (Povee et al., 2012; Sikora et al., 2013), caregiver self-reported physical health problems (Allik et al., 2006; Eisenhower et al., 2009; Gallagher & Whiteley, 2013; Lach et al., 2009), caregiver self-reported stigma (Gray, 2002), caregiving burden (Vogan et al., 2014), and poor immune responses in caregivers (Gallagher et al., 2009).

There is evidence, however, that mothers and fathers find different child behaviors stressful (Baker et al., 2005; Davis & Carter, 2008). In a longitudinal study, Baker et al. (2005) found that behavior problems in children with developmental delays were predictive of maternal depression over time, but not of paternal depression overtime.

In contrast to other studies, Zaidman-Zait et al. (2014) reported that in families with a child with ASD, parent distress (as measured by the Parenting Stress Index) predicted child problem behaviors but that child problem behaviors did not predict parent distress.

**Age of the child.** Studies differ in their findings regarding parental stress and age of the child with the disability. One study reported that parental stress decreased as the child with the disability aged (Lee, 2013). Other studies have found no changes in parental stress (Lecavalier et al., 2006; Most et al., 2006) or depression (Bourke-Taylor, Howie, et al., 2012) or family functioning (Povee et al., 2012) with child age. Still other studies have found that as children with an I/DD age there is an increase in parental stress (Hauser-Cram et al., 2001; Most et al., 2006) and worsening of self-reported maternal health (Eisenhower et al., 2009). Woodman (2014) reported that parental stress increased over time from early to middle childhood and then decreased through adolescence in families with a child with a developmental disability.

Changes in child behavior over time may be related to changes in the self-reported health and stress of parents. Several studies have found that behavior of children with an I/DD improved over time (Einfeld, Piccinin, et al., 2006; Einfeld, Tonge, et al., 2006). In a longitudinal study, Gray et al. (2011) reported that total behavior problems of children with an I/DD decreased over time but that specific problems of social relating increased with time and that these increases were associated with increased maternal anxiety and severe depression.

**Sex of the child.** The prevalence of childhood disability is higher in boys compared to girls (Emerson & Hatton, 2007b; Hogan et al., 2006; Houtrow et al., 2014; Newacheck & Halfon, 1998). However, only a few studies have looked at the association between gender of the child with a disability and caregiver stress and health. Churchill et al. (2010) and Mitchell and Hauser-Cram (2008) found no correlation between the child’s gender and parental depressive symptoms in families with children with special needs. Povee et al. (2012) found no effect of child gender on family functioning or marital adjustment in families with a child with Down syndrome.

## Family Characteristics

**Size of the family.** Several studies have noted that families which include a child with a disability have more children than comparison families (Burke, Urbano, & Hodapp, 2011; Seltzer et al., 2001). Burke et al. (2011) used administrative data in the state of Tennessee to look at population trends in family size. They compared families who had a child with Down syndrome or spina bifida to families in the population who did not have a child with Down syndrome or spina bifida. They found that families within the two disability groups had significantly larger families than the comparison group and that the families in the disability groups were more likely to have one or more children after the birth of the child with the disability. This finding held across the birth order of the child with the disability, maternal age, marital status, mother’s education, and maternal race. In addition, they found no differences in these parameters between



the families of children with Down syndrome and the families with a child with spina bifida. An additional finding was that there were no significant differences between the two disability groups and the comparison group in birth intervals, average birth interval for all three groups was 3 years. In contrast, MacInnes (2008) found evidence of longer birth intervals between children in families which had a child with a disability.

Very few studies have examined the effect of family size on parental stress in families who have a child with a disability. Warfield (2005) found that having more children predicted increased levels of stress for both mothers and fathers in these families. In this study, Warfield also found that increased family size was related to a lower income. Warfield postulated that the greater stress of these parents may be related to having fewer resources. Conversely, in a study using state-wide administrative data over a 12-year period, Urbano and Hodapp (2007) found that divorce rates were lower in both families with and without a child with Down syndrome when there were more than two children in the family.

**Families with more than one child with a disability.** Very few studies have looked at the effect of having more than one child with a disability. These studies report a negative effect, including higher levels of negative affect in parents of children with an I/DD (Ha et al., 2008) and greater maternal depression (Bourke-Taylor, Howie, et al., 2012). In a rare study of fathers of children with a disability, Hartley et al. (2012) found that having more than one child with a disability was a strong predictor of paternal depression.

## Support Factors

**Social isolation/stigma.** There is considerable evidence that families of children with a disability face stigma and social isolation (Ali, Hassiotis, Strydom, & King, 2012; Francis, 2012; Gray, 2002; Green, 2003, 2007; Green, Davis, Karshmer, Marsh, & Straight, 2005; Home, 2002; Kinnear, Link, Ballan, & Fischbach, 2016; Neely-Barnes, Graff, Roberts, Hall, & Hankins, 2010; Nur-ullah, 2013; Runswick-Cole, 2010; Ryan & Runswick-Cole, 2008; Werner & Shulman, 2013). In a systematic review, Ali et al. (2012) found that both individuals and family caregivers experienced stigma because of ID and that this stigma had a negative impact on the psychological well-being of family members. In families with a child with autism, Gray (2002) found that mothers were more likely than fathers to experience stigma. Green (2003) found an association between mothers' perceived level of stigma and maternal stress. Cantwell et al. (2015) found that parents who reported higher stigma had lower self-esteem and were more depressed.

**Formal services.** The literature indicated that the use of formal services for the child with the disability can have negative impacts on families (Dowling & Dolan, 2001; Neely-Barnes & Marcenko, 2004; Robert, Leblanc, & Boyer, 2015; Rogers & Hogan, 2003). Dowling and Dolan (2001) reported that sources of anxiety included long wait lists, having to reapply regularly for services, the cost and time of travel to and from services, long wait-times at appointments, missed recreational activities

for the whole family, and the lack of flexibility and responsiveness of service providers.

Rogers and Hogan (2003) found that families who used two or more rehabilitation, mental health or general health services for their disabled child in a year had a very high probability of financial loss, job change, and sleep disruption.

Mitchell and Hauser-Cram (2008) studied medical care utilization and mother's satisfaction with the healthcare available to their children. Mothers who were more satisfied with care reported experiencing less stress and fewer depressive symptoms than mothers who were less satisfied with care. In a similar study, McManus et al. (2011) found that difficulty navigating and accessing the healthcare system, and unmet healthcare needs of the child were associated with increased caregiver burden.

However, Peer and Hillman (2014) conducted a systematic review of literature regarding stress and resilience in parents of children with an ID. They found that formal support of parents was a predictor of resilience.

**Informal support.** There is very little research regarding participation in social activities by parents of children with an I/DD. Seltzer et al. (2001) reported that parents of children with an I/DD visited less frequently with their friends compared to parents of children without an I/DD. However, in a study of the contribution of leisure time to family functioning, Dodd, Zabriskie, Widmer, and Eggett (2009) found that families with a child with an I/DD reported nearly identical levels of family leisure involvement as a sample of families without a child with an I/DD.

Bourke-Taylor, Pallant, et al. (2012) studied mothers with school-aged children with high-care needs and an I/DD. They found that one of the strongest predictors of self-reported maternal mental health was mothers' participation in health promoting activities.

Several studies have found that for caregivers of children with an I/DD, poor social support is associated with increased parental stress (Cantwell et al., 2014; Falk et al., 2014; Gallagher et al., 2009; Plant & Sanders, 2007; Woodman, 2014; Zaidman-Zait et al., 2017), depression (Falk et al., 2014; Feldman et al., 2007; Gallagher et al., 2008; Resch et al., 2012), or poorer self-reported physical health (Cantwell et al., 2014). In a longitudinal study, Hauser-Cram et al. (2001) found that social support predicted changes in maternal stress but not in paternal stress. Mothers with low levels of support experienced a significant increase in stress over time; mothers with high levels of support experienced lower and stable levels of stress over time. Greater spousal support has been reported to be related to lower maternal depression (Laxman et al., 2015) and lower maternal and paternal stress (Warfield, 2005).

Peer and Hillman (2014) found evidence of a relationship between social support and parental stress management and resilience. Gallagher and Whiteley (2012) reported that levels of social support were predictive of parental blood pressure and that parents of children with a developmental disability had higher systolic blood pressure than did parents without a child with a developmental disability. However, in a related study, Gallagher and Whiteley (2013) found that social support was not predictive of self-reported health for parents of children with an ID.

## Discussion

In the current literature, 23 factors in 5 domains were found which are reported to affect the health of caregivers of children with an I/DD. Of these factors, there appears to be the most evidence regarding income. The literature shows that children with a disability are more likely to live in families with a low income and that families who have a child with a disability are likely to experience a decrease in income after the birth of their child with an I/DD. Type and severity of the I/DD and the presence of comorbidities may affect income and changes in income.

Any effect of having a child with an I/DD on marital stability may also be dependent upon the type and severity of the disability and age of the parents at birth of the child. It is clear however, that the prevalence of children with an I/DD is higher in single-parent families and that income is lower in these families compared to two parent families. Findings are also consistent that single-parent families with a child with an I/DD have higher stress levels and poorer self-reported health than dual parent families.

Studies consistently find that having a child with an I/DD results in changed work patterns, less full-time employment, and lower incomes, particularly for women.

Further research needs to examine the longitudinal effects of having a child with an I/DD on family income and the interactions between income, employment, marital status and ethnicity. Very few studies have examined the role of ethnicity or separated the effects of ethnicity from the effects of income.

Education is a social determinant of health closely linked to income, employment and divorce rate. Lower education of parents is associated with a higher prevalence of I/DD, although this pattern may be changing as more children are diagnosed with ASD (Houtrow et al., 2014).

There appears to be differing patterns of stress and health outcomes between fathers and mothers of children with an I/DD. However, there is very little research regarding the effects of gender, the majority of research has studied outcomes in mothers.

Findings on the effects of age of the parent on parental health and stress may depend upon the parent's age at the birth of the child and the type of I/DD studied. Future studies need to differentiate between age of the parent at birth of the child and longitudinal aging of the parent.

Studies that looked at sleep loss in caregivers of a child with an I/DD indicate that sleep loss occurs and is related to increased stress, increased rates of depression and poorer self-reported health.

A few studies have found that caregiver self-esteem is related to self-reported health.

The effects of type of I/DD, the severity of the disability, and problem behaviors have not been separated sufficiently in the literature to differentiate between their effects on parental health. Severity of the disability does appear to affect employment and therefore income. Increased severity also appears to result in increased caregiver stress, but it is unclear if this results in decreased caregiver physical health or increased caregiver mental health issues. Conversely, child behavior problems appear to be related to increased parental stress, an increase in the amount of stigma experienced, and poorer physical and mental health of

caregivers. These effects may be different for mothers and fathers, but current research is not definitive on this point.

As a result of the very low number of studies, it is not possible to conclude whether the age or gender of the child with the disability has an effect on caregiver health.

Several studies have found that family size is generally greater in families who have a child with an I/DD and that increased family size reduces family income. There is not enough information to determine if family size affects caregiver health.

There are very few studies of families with more than one child with an I/DD. However, those that exist indicate that caregivers in these families experience greater stress and an increase in depression.

Social isolation and stigma are experienced by caregivers of children with an I/DD and are related to increased caregiver stress and depression. Again these findings may differ between mothers and fathers, but existing research is not clear on this.

Formal services and therapies can both decrease and increase stress in these families. Services can interrupt caregivers' ability to work and result in job loss and lowered incomes. A few studies have found that lack of satisfaction with these services was related to stress in caregivers.

Lastly, informal support from family and friends is a factor that affects both stress levels and rates of depression. In particular, mothers who feel they have little support report increased stress and depression.

## Conclusion

This article provides a narrative review of research on the health of caregivers of children with an I/DD. Despite the large number of studies in this area, there is very little that can be concluded with confidence. Within each thematic area there are conflicting results. However, it is clear that caregiver health is influenced by complex interactions between social determinants of health, individual caregiver characteristics, characteristics of the child with the I/DD, and family factors. Further research, particularly longitudinal and life course research, is needed. To be effective, both future research and policy and practice should account for the effects of the complexity of these interactions in the lives of families with children with an I/DD.

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