19 Social and Psychological Stressors

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Children with IDD are at greater risk for psychopathology than their typically developing peers (de Ruiter, Dekker, Verhulst, & Koot, 2007). Developmental factors and their interaction with an individual's social environment offer a framework for intervention (Kiddle & Dagnan, 2011). In this chapter, stressors are discussed as risk factors for development and exacerbation of emotional and behavioral problems in individuals with IDD. The literature has shown the negative impact of environmental stress factors on individuals with IDD. However, the broader literature, not specific to individuals with IDD, shows although children experience adversity and stress, their mental health and well-being can still be positive (e.g., Alvord & Grados, 2005).

Why some individuals respond better than others to stress has been debated, but one theory is that this variability can be conceptualized as resilience. Resilience is generally seen as a positive construct that can be built upon and improved and encompasses many personal attributes and environmental factors. Rutter has defined resilience as "an interactive concept that is with the combination of serious risk experiences and a relatively positive psychological outcome despite those experiences" (Rutter, 2006, p. 2). Garmezy, Masten, and Tellegen (1984) presented a three-model approach to stress, compensatory, challenge, and protective factor models. Protective factors are defined as having a positive influence on behavior and moderate the relationship between risk and problem behaviors (Jessor, Van Den Bos, Vanderryn, Costa, & Turbin, 1995). Garmezy (1985) organized the protective factors into personality factors, family cohesion, and external support systems.

Resilience is being explored in individuals with IDD and their families, and attributes and skills related to resilience have begun to be identified. A study by Miller (2002) used open-ended questions to determine resilience in students with IDD. Resilience was described as a person experiencing achievement despite others having a low expectation of them. The students identified several attributes which they believed made them resilient, such as identifiable success experiences (having a job), areas of strength (e.g., being good at art/sport), having self-determination, having special friendships and encouraging teachers, and acknowledging the learning disability.

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Similarly, Raskind, Goldberg, Higgins, and Herman (1999) found six attributes in individuals with IDD who had been successful: self-awareness, proactivity, perseverance, emotional stability, appropriate goal setting, and the presence and use of effective support systems. Conversely, a lack of self-awareness, reactivity, lack of perseverance, emotional instability, lack of appropriate goal setting and self-directedness, and lack of presence or use of effective support systems led to more negative outcomes. Gilmore, Campbell, Shochet, and Roberts (2013) compared resilience in children with IDD to their typically developing peers (TD), and found children with IDD reported lower levels of tolerance, fewer future goals and higher levels of emotional sensitivity compared to TD peers, though other factors like optimism and self-esteem were reported at a similar level to TD peers.

In addition to building resilience, reviewing potential environmental risk factors and how they could be modified may lead to better outcomes in individuals with IDD (Fletcher, Loschen, Stavrakaki, & First, 2007; Hawkins, Catalano, & Miller, 1992). Dykens (2000) emphasized the need for researchers to go beyond measurement and prevalence studies of psychopathology in children with IDD, and identify the reasons why these children are prone to psychopathology to begin with. More recent research has turned to intervention on this basis of identified risk factors (Fisher, Moskowitz, & Hodapp, 2013; Jacola, Hickey, Howe, Esbensen, & Shear, 2014). Therefore, each section of this chapter considers not only how to reduce risk factors that impact on mental health and well-being, but also how to increase protective factors.

Rutter (1987) proposed resistance to stress is relative; a risk factor in one situation can be a protective factor in another (e.g., social support). Of particular importance is the family environment, reflecting elements such as parental stress, bidirectional relationships between emotional expressions of distress and child behavior problems, and the role of interventions targeting protective factors such as family cohesion and social support. Implications for intervention will be discussed.

Stress and Coping

Perceptions of stress predict current and future symptoms of psychopathology among adults with IDD (Hartley & MacLean Jr, 2005; Hastings, Hatton, Taylor, & Maddison, 2004). Lazarus (1991) describes "stress as harms, threats, and challenges," the reaction to which depends on "what a person has at stake with an encounter with the environment or in life in general" (Lazarus, 1991, p.1 35) Individuals feel more stress when they perceive a threat to self-esteem or are not confident in their coping abilities (Roe & Gray, 1991).

The literature suggests perceptions of stress may be higher in individuals with IDD. Bramston, Fogarty, and Cummins (1999) found when administering the Lifestress Inventory to individuals with IDD that they reported stressors less than their nondisabled peers. It was found that the IDD group tended to assign higher impact values to the stressors they did report experiencing. In addition, Hatton and Emerson found that individuals with IDD experience stress at a similar, if not greater level to the general population (Hatton & Emerson, 2004). Perceptions of stress may vary based on subtypes of IDD; adults with ASD experience higher levels of perceived stress than their peers with other forms of IDD (Gillott & Standen, 2007).

Coping is related to depression in adults with mild IDD (Hartley & MacLean Jr, 2005). Lunsky (2003) found depressed females with mild IDD used fewer coping strategies than their nondepressed peers. Hartley and MacLean Jr (2005) found that symptoms of depression were related to infrequent use of active coping and later found that a group of IDD participants with depression reported a higher frequency of stressful social interactions than the nondepressed group. Given our knowledge of high prevalence rates of depression in the IDD population, as discussed in Chap. 48, coping mechanisms are likely to be impaired in a considerable proportion of this population. Coping mechanisms are discussed further in Chap. 38.

However, in the context of protective factors buffering risk, coping could be a protective factor in the IDD population as it is a skill that can be developed and positive coping mechanisms have been demonstrated to protect against negative outcomes in the general literature and with parents of children with IDD (Hastings & Brown, 2002; Heiman, 2002; Rutter, 1987; Werner, 2000). Rutter suggested the concept of resilience “focuses attention on coping mechanisms, mental sets, and the operation of personal agency. In other words, it requires a move from a focus on external risks to a focus on how these external risks are dealt with by the individual” (Rutter, 2006, p. 8). Few studies have focused on coping strategies used by individuals with IDD; however, Hartley and McLean Jr (2009) found that use of active coping vs. avoidant coping accounted for a significant portion of the variance in psychological distress experienced by individuals with IDD in stressful social situations. Janssen, Schuengel, and Stolk (2002) found in addition to developing low self-esteem and a general feeling of incompetence, individuals with IDD are at risk of developing learned helplessness, a process they compare to development of learned helplessness in people affected by the demoralizing conditions of chronic poverty (Olson & Schober, 1993). These factors could lead to ineffective coping mechanisms.

A final consideration is that stress measured subjectively can be difficult to assess. Subjective stress is often measured by self-report questionnaires, and as much as reliability can be a matter of concern for the general population (Turner & Wheaton, 1995), this concern may be even greater among the IDD population (Heal & Sigelman, 1995). Bramston, Bostock, and Tehan (1993) acknowledged many stressors individuals with mild ID experience may not be covered in scales like the Lifestress Inventory (Fogarty, Bramston, & Cummins, 1997). However, the Lifestress Inventory has been shown to be internally reliable, and the informant version a suitable parallel instrument (Lunsky & Bramston, 2006). Typically, past researchers have used a combination of qualitative and quantitative methodologies to measure stress, more recently, the Bangor Life Events Schedule for Intellectual Disabilities (BLESID-SR: Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011), has been designed as a measure of significant life events occurring in the life of someone with IDD. In the BLESID-SR an interviewer uses a semi-structured interview to guide the conversation and reflect in the scoring what the individual has said about their life events. The BLESID-SR is available in both a self-report and proxy version. Research exploring caregiver reports of stress and self-reports of stress has suggested that it is important to assess stress from two perspectives when possible (Cummins, 2005).

Life Events

The Impact of Life Events

The connection between life events and mental health problems has been found in the general population (Tennant, 2002). Similar patterns are found in adults with IDD, as life events experienced by this population are associated with emotional disorders, depression, and behavior problems (Esbensen & Benson, 2006; Hastings et al., 2004). Cooper, Smiley, Morrison, Williamson, and Allan (2007) assessed mental health in 1023 adults with intellectual disabilities and found as a significant factor the number of life events experienced in the prior 12-month period. Hulbert-Williams and Hastings (2008) conducted a narrative review of research on exposure to adverse life events as a risk factor for psychological problems and found association of life events with clinically significant depression. Research links experience of life events to behavior difficulties in adults with IDD (Esbensen & Benson, 2006; Hulbert-Williams et al., 2011; Owen et al., 2004). Stress is often associated with negative outcomes in individuals with IDD, including symptoms of mental illness in adults with mild IDD and depression in adults with moderate IDD (Hastings et al., 2004; Lunsky, 2003).

Unfortunately, a gap in the literature concerns the relationship between pre-existing psychological problems in adults with IDD and the susceptibility of this population to trauma and other psychological problems (Hulbert-Williams & Hastings, 2008). Research is needed to investigate further temporal associations between psychological problems and life events (Hulbert-Williams & Hastings, 2008; Kraemer et al., 1997). One study provided tentative evidence that life events may be a risk factor for psychological problems in adults with IDD using a longitudinal approach (Esbensen & Benson, 2006). Additional research is needed into the mechanisms by which experience of adverse events becomes a risk factor for psychological problems, and whether this is mediated by protective factors such as social support.

Major Life Events

The link between major life events (e.g., loss of a spouse, loss of a job, major illness or injury, moving) and the experience of stress and related physical and mental conditions is established in the general population (Harkness & Monroe, 2016). Research has suggested individuals with IDD are more susceptible to psychological distress, and the development of comorbid psychiatric conditions or behavioral problems, after experiencing major life events (Magiati, Tay, & Howlin, 2014). The pattern of increased susceptibility of individuals with IDD to life events begins in childhood. Children with IDD experience a wider range of life events and are reported to experience such events more frequently than children without IDD (Hatton & Emerson, 2004). The discrepancy in risk exposure to adverse life events between individuals with IDD and TD peers continues into adulthood, and may be explained by aspects such as increased dependency on paid and family caregivers, increased negative social interactions, and a relatively restricted social circle compared to nondisabled peers in the same age range (Bramston et al., 1999; Fogarty et al., 1997; Levitas & Gilson, 2001). The greater dependency of adults with IDD on family and paid caregivers is a source of additional risk for major life events, as the loss of a friend or family member may also equate to the loss of a home or a carer (Hollins & Esterhuyzen, 1997; Levitas & Gilson, 2001). Gilrane-McGarry and Taggart (2007) suggest lack of support during bereavement is a major factor in individuals with IDD susceptibility to a complicated grief process, where the failure of grief to resolve over a long time period results in the development of psychopathology including chronic depression.

In retrospective studies, significant major life events and their relationship to mental health crises in those with IDD has been well documented (Ghaziuddin, 1988; Hastings et al., 2004; Hatton & Emerson, 2004). Although the literature shows associations between life event frequency and mental health in individuals with IDD, there is still variability in the psychopathology of individuals with IDD when experiencing life events. One explanation for this may be variation among subgroups. Maag and Reid (2006) found moderators such as gender, age, and ethnicity seem to cause significant variability in depression as an outcome. Taylor, Hatton, Dixon, and Douglas (2004) found significant differences in the rates for particular disorders across gender, age, and residence type. Studies suggest the prevalence of mental disorders may peak at the moderate level of IDD, at least for depression, anxiety, and psychosis (Holden & Gitlesen, 2009; Myrbakk & von Tetzchner, 2008). Psychopathology models in IDD should consider the level of IDD and demographics in the variability of results. There is a need for more differentiation in research regarding gender and severity of disability (Wong, 2003).

Cumulative Life Events

The extent to which a person with IDD is exposed to negative life events is an important factor in development of related mental health problems. Cumulative exposure to life events on the mental health of people with IDD has been studied, with multiple exposure found to correlate with development of affective disorders such as depression (Tsakanikos et al., 2006). Accumulated exposure to life events, and risk factors that are related to cumulative exposure such as poverty and greater presence of physical disability, is linked to poor physical and mental health in this population (Brooks, 2006; Masten, 2001).

What makes a person vulnerable to poor mental health outcomes after a life event will differ based on persons and circumstances (Spini, Hanappi, Bernardi, Oris, & Bickel, 2013). Abravanel and Sinha (2015) conducted a population-based study of 745 adults exposed to cumulative life events, distinguishing between those "at risk" based on pre-morbid mood disorder, and those "never depressed." They found that emotion regulation, assessed using the Difficulties with Emotional Regulation Scale (Gratz & Roemer, 2004), accounted for 50% of the variance in depressive symptomology independent of risk status. Emotion regulation is a complex process drawing on use of cognitive, experiential, and emotion-based strategies to affect the way adverse life events are interpreted across the life course (Garnefski, Kraaij, & Spinhoven, 2001). Relative impoverishment of effective emotion regulation strategies in individuals with IDD compared to their TD peers may begin in childhood and continue throughout the life course (McClure, Hapern, Wolper, & Donahue, 2009) indicating this is a prominent risk factor and suitable for targeting through early intervention. Janssen et al. (2002) argue ineffective attachment models developed by children with IDD are a major risk factor for experience of chronic stress, depression, and problem behaviors during social interactions, persistent through adulthood. This provides one example of how a specific failure in emotion regulation strategies can serve as a risk factor for developing psychopathology during the experience of life adverse events.

Trauma

The development of post-traumatic stress disorder from exposure to life events has been studied in individuals with IDD (Murphy, O'Callaghan, & Clare, 2007) though research is constrained by a lack of ways to measure trauma in this cohort (Wigham, Taylor, & Hatton, 2014). Other than a handful of studies that are largely record reviews concerning sexual and physical assault (see Bowman, Scotti, & Morris, 2010), a dearth of research exists on the types of trauma occurring in the lives of individuals with IDD. Martorell and Tsakanikos (2008) emphasize separating between "non-traumatic" life events and "traumatic" life events may be difficult for this population, as difficulty understanding a stressful situation can lead the person with IDD to experience greater levels of distress than nondisabled peers.

Research suggests a disproportionate number of children with IDD are victims of abuse, with more severely disabled children at greatest risk (Fisher, Hodapp, & Dykens, 2008). There is a tendency for individuals with IDD who have been abused to receive psychiatric diagnosis, such as schizophrenia and depression (e.g., Ryan, 1994). Therefore, it is unclear whether the apparently strong association between trauma and psychiatric disabilities is due to increased risk of abuse in individuals with psychiatric disorders, thus the possibility of a shared etiology between the two.

As in the general population, one of the most prominent consequences of violent victimization in persons with IDD is PTSD. The limited data suggests that, as expected, individuals with disabilities are at increased risk for developing PTSD. For example, Ryan (1994) performed evaluations on 310 consecutive admissions to a team consultation service for persons with IDD and found that 16.5% met criteria for current PTSD. This rate is approximately double the rate of lifetime PTSD in the general population (e.g., Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995).

For example, post-traumatic stress reactions, up to and including the onset of post-traumatic stress disorder, are highly prevalent in adults with IDD when exposed to environmental stressors as well as to abuse, neglect, and violence (Wigham & Emerson, 2015). Adults with IDD experience more traumatic life events compared to the TD population, and have fewer psychological and social resources for dealing with these stressors (Magiati et al., 2014). Adults with IDD frequently "suffer in silence" the higher rate of traumatic life events that they are prone to experience, and have less control over their environment so as to allow them to avoid (whether through internal or external means) reminders of past trauma (Wigham & Emerson, 2015). Staff training on the affective experience of adults with IDD, promoting the idea that they are aware of, and suffer from, life stressors, are needed to address this problem. However, a finding posited by Wigham et al. (2014) is the lack of moderation between social support and significant behavioral disturbances after traumatic life events, which may contribute to the onset of PTSD after experience of trauma. The difficulty people with IDD have in keeping social support may make a difference (Gilrane-McGarry & Taggart, 2007).

Protective factors that mitigate exposure to traumatic life events and adverse psychological outcomes include intelligence, perceived self-efficacy, and optimism, as studied in both disabled and nondisabled children exposed to trauma (Masten, Narayan, Silverman, & Osofsky, 2015) and intellectually disabled children in this situation (Finzi-Dottan & Karu, 2006). Social support is shown in many studies to be protective against adverse effects of trauma (Ozbay et al., 2007) though a distinction has been made between types of support which are more protective, with higher-quality relationships (i.e., allowing for more emotional expression and shared problem-solving) having greater protective qualities (Platt, Keyes, & Koenen, 2014).

Transition

Resilience has been posed as being not a fixed attribute, but as changing with circumstances (Rutter, 1987; Werner, 1989). There are certain points in an individual's life when they may be more vulnerable to stress and this may contribute to changeability in coping and perceptions of stress in individuals with IDD. The transition to adulthood, during which young adults with IDD leave behind the relative structure of the school environment to pursue uncertain employment and residential outcomes, is a period in which many individuals with IDD report being vulnerable to feelings of stress and anxiety (Williams & Heslop, 2005). This is in keeping with Raskind et al. (1999) who theorized the change over time from childhood to adolescence may be due to participants having more power in decision-making concerning their own education at the time.

The transition period is often perceived as a stressful time for young adults with IDD and their families. Many individuals with IDD face poorer outcomes than their TD peers across measures of transition success, such as social relationships, supported and competitive employment, and the ability to live independently (Foley, Dyke, Girdler, Bourke, & Leonard, 2012). Increased rates of psychological distress experienced during transition increases the risk for problem behaviors (Williams & Heslop, 2006). A qualitative interview study of young people with IDD found many young adults with IDD reported subjective feelings of being pressured by parents and teachers to make particular decisions related to their schooling and post-secondary community participation choices, as opposed to feeling free to make their own decisions (Williams & Heslop, 2005). The feeling that one has lost control over decision-making is exacerbated by loss of social networks that occurs when young adults with IDD transition from school environments (Raghavan & Pawson, 2008).

A second stressor faced by young adults with IDD and their families during transition is the unclear pathway of post-secondary supports. Transition-related changes in social roles and lack of supports for families can negatively impact family well-being (Neece, Kraemer, & Blacher, 2009). This combined with loss of social networks can increase problem behaviors during transition (Williams & Heslop, 2006). Williams and Heslop (2006) recommend approaching problem behaviors during transition from the stance of strengthening the individual's social networks. Forte, Jahoda and Dagnan (2011) used a mixed methodology approach to explore resilience in young people with IDD to examine the worries experienced by young people aged 17–20 with IDD during transition into adulthood. Their worries differed significantly in type as well as intensity. Young people with IDD were most worried about making friends, being bullied, and losing people they were dependent upon like parents, vs. TD peers who were most worried about getting a job, not having enough money, and having to make decisions about future choices. The IDD group also reported significantly greater levels of rumination over these worries. Forte, Jahoda, and Dagnan (2011) suggest obtaining insight into these patterns can strength a resilience-based intervention. For example, psychological interventions that target rumination could mitigate development of depression during this period.

Social Environment

Social Competence

The ability to navigate social interactions and benefit from positive aspects of social communication varies in the IDD population. Social competence has been defined as an individual's ability to successfully adapt to his/her social environment (Vaughn & Haager, 1994). Schafer and Semrud-Clikeman (2008) review difficulties that children with IDD experience with social competence.

Individuals with certain IDD diagnoses, such as Down syndrome (DS) and Williams syndrome (WS), are often characterized by having proficient social skills, including empathy and social communication, and in turn enables positive responses to others in distress (Di Nuovo & Buono, 2011). Conversely, individuals with IDD with an autism spectrum disorder (ASD) diagnosis demonstrate more social difficulties than individuals without comorbid ASD. Kau et al. (2004) found greater impact of social communication difficulties on problem behavior, in the case of individuals with Fragile X syndrome (FXS) with comorbid ASD as opposed to individuals with FXS without comorbid ASD. Individuals with Down syndrome (DS) who meet the screening criteria for comorbid ASD report milder social difficulties than children with ASD without any diagnosis of DS (Howlin, Wing & Gould, 1995). Diagnosis type and associated differences in social competence may create differential outcomes when attempting to integrate children with IDD into mainstream classroom settings. For example, integrated with TD peers in mainstream classrooms, children with ASD may be at high risk for social isolation (Locke, Ishijima, Kasari, & London, 2010).

Social difficulties encountered by this population extend beyond difficulties from the increased behavior disorders; also implicated are deficiencies in peer-related social competence. Guralnick (2006) estimates 60–65% of children with IDD fail to use appropriate social strategies during social tasks. Social isolation may be found in children besides the 25% of those with IDD who have behavior problems.

Larkin, Jahoda, MacMahon, and Pert (2012) found correlations between hostile attributional style, and increased experience of social conflict, in young adults with IDD. Increased likeliness of perceiving threat in ambiguous interactions, and a lack of coping strategies for use when faced with social threats, may be responsible for the higher rates of aggressive and affective disorders often observed in adults with IDD (Emerson & Jahoda, 2013).

As social interactions have long been identified as a potential stress factor for individuals with IDD, there is evidence of several interventions aimed at improving social skills for children and adults with IDD as is discussed further in Chap. 38. Szumski, Smogorzewska, Grygiel, and Orlando (2017) identified a significant improvement in the social skills of pre-school children with ASD using a “Play Time / Social Time” intervention designed to develop social skills compared to a problem-solving intervention. A meta-analysis of 55 social intervention skills studies with individuals with ASD (Bellini, Peters, Benner, & Hopf, 2007) found only minimal effect of these interventions; however, they did highlight that the setting of the interventions, such as resource rooms, were frequently inappropriate. In contrast, greater efficacy was observed when interventions took place in classroom / playtime settings. A meta-analysis of 19 studies (Gates, Kang, & Lerner, 2017) found that group social skills interventions led to moderate overall improvements in social competence. The authors also identified a large self-report effect, which they attributed to increased social knowledge, but not perceived changes in the individuals' own social behavior. These effects were found in studies including data from parents, children, observers, and tasks. The same trend was not observed in studies based on teachers' observations. Gates et al. (2017) emphasized that differences in efficacy rates are likely to reflect the variations by reporting sources.

Peer Interactions

Adults with mild IDD report more frequent and severe stress from negative social interactions than from other categories of stress events, and have more difficulty adaptively coping with everyday stressful social situations than other stressful events (e.g., Bramston et al., 1999; Hartley & MacLean Jr, 2005).

Children with IDD experience greater social isolation than TD peers and find it harder to develop positive peer relationships (Guralnick, 2006). Behavior problems are a prominent reason why children with IDD face social isolation (Crnic, Hoffman, Gaze, & Edelbrock, 2004; Guralnick, 2006). Children with IDD whose disabilities heighten the risk of aggression (such as autism spectrum disorder) are more likely to experience social isolation than children with IDD with lower levels of aggression, like Williams syndrome (Odom et al., 2006). Children with IDD with behavior problems and poor social skills are at greater risk of being bullied (Reiter & Lapidot-Lefler, 2007) and engage in bullying themselves (Christensen, Fraynt, Neece, & Baker, 2012).

The social isolation experienced by individuals with IDD often persists into adulthood (Lippold & Burns, 2009). Scott and Havercamp (2014) found a significant number of adults with IDD reported receiving less emotional support from others than nondisabled peers. Adults with IDD are more likely to receive social support from paid caregivers (Amado, 1993). These relationships are not reciprocal and are less likely to buffer against loneliness than other sources of support.

Social stressors such as negative social interactions are linked to physical and mental health problems in adults with IDD, including depression. Nezu, Nezu, Rothenberg, DelliCarpini, and Groag (1995) found associations between symptoms of depression and reported negative social interactions in a study of 107 adults with mild IDD. Hartley and MacLean Jr (2005) found that stress from negative social interactions predicted symptoms of depression in adults with IDD. Lunsky and colleagues also found a correlation between stress from negative social interactions and depressive symptoms; furthermore, continuing stress predicted the persistence of depressive symptoms 6 months later (Lunsky & Benson, 2001; Lunsky & Havercamp, 1999). Bender, Rosenkrans, and Crane (1999) found nonverbal individuals with IDD face a greater risk of suicide and posited that one reason for this may be social isolation.

There is a high prevalence of loneliness reported by adults with IDD. Stancliffe, Wilson, Bigby, Balandin, and Craig (2014) estimate up to 50% of adults with IDD are chronically lonely. Research by Cacioppo and colleagues (Cacioppo & Cacioppo, 2014) suggests loneliness contributes to poorer health through myriad pathways. Other risks for loneliness throughout the lifespan are family ecological variables like childhood attachment styles (Janssen et al., 2002). Adults with IDD, who lack coping resources or social supports to promote resilience during traumatic life events, are at greater risk for suicide (Gilmore & Cuskelly, 2014).

Social Support

It has been established that adults with mild to moderate ID are more vulnerable to stressful social interactions than nondisabled peers, and they report social stressors to have greater negative impact than other life events (Bramston et al., 1999; Fogarty et al., 1997; Hartley & MacLean Jr, 2005). Social support and positive peer interactions can be a protective factor for individuals with IDD as they promote resilience in the face of adverse life events (Bonanno, 2004) and moderate against development of PTSD (Brewin, Andrews, & Valentine, 2000).

A model linking social support to stress-buffering is provided by Cohen and Wills (1985). The buffering effects of social support persist across the lifespan. Rose and Espelage (2012) identify the ways that supportive peer relationships protect children with IDD from experiencing victimization during childhood. However, social support may not always moderate the relationship of trauma and behavioral changes (Wigham et al., 2014). It is likely that the stress-buffering effects of social support is affected by social-cognitive aspects such as whether one perceives such support as positive or negative (Lunsky, 2008).

Interventions to improve social interactions within persons with intellectual disabilities may be most effective in childhood, when social competencies are still developing (Guralnick, 2006). Carter and Hughes (2005) reviewed 26 interventions aimed at improving social interactions between students with IDD and nondisabled peers, and concluded additional research is needed to probe how interventions may have an impact on some but not all aspects of social interaction, such as improving social competence, reducing aggression, or facilitating environmental supports. In a similar light, Amado (1993) considers how to create a conceptual framework for studying interventions for adults with IDD, including bolstering social competencies.

Social Support and the Family

One stress-buffering resource is the availability and/or quality of social support in parents of children with IDD (Ekas, Lickenbrock, & Whitman, 2010; White & Hastings, 2004). Targeting social support can improve aspects of parental well-being including reduced mental health problems (Lovell, Moss, & Wetherell, 2012), reduced spousal problems (White & Hastings, 2004) and greater self-efficacy and coping (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006).

The role of informal support in the reduction of stress in parents of individuals with IDD is widely documented (Robinson, Weiss, Lunsky, & Ouellette-Kuntz, 2016; White & Hastings, 2004). Mothers' ratings of grandparent support in the care of their child are negatively correlated with stress (Hastings, Allen, McDermott, & Still, 2002). Parents' perceptions of the helpfulness of informal sources of support, rather than the number of supports, has the most consistent associations with parental well-being (Zaidman-Zait et al., 2017). There are also changes in the type of support most beneficial with age. Practical support is more associated than emotional support with greater parental well-being in parents of adolescents with ASD (White & Hastings, 2004). By the time a child reaches adolescence, parents might have come to terms with being a parent of a child with an IDD, and need less emotional support.

The role of formal support sources in parental well-being seems to be less clear. Support services for families of children with disabilities more commonly focus on the child's needs (White & Hastings, 2004); therefore parental support needs are often unmet (Freedman & Boyer, 2000). Furthermore, several studies revealed unhelpful relationships and disagreements with professional services, for example, an inability to provide an individualized service adding to stress (Sloper & Turner, 1992).

Family Environment

Parenting Stress

High parenting stress is an important environmental risk variable. It is associated with many undesirable outcomes, including parent depression (Hastings, Daley, Burns, & Beck, 2006), marital conflict (Kersh et al., 2006), poor physical health (Eisenhower, Baker, & Blacher, 2009), less effective parenting (Crnic, Gaze, & Hoffman, 2005), and increased child behavior problems (Baker et al., 2003). Parents of children with IDD typically report more stress than parents of TD children (Baker et al., 2003; Emerson, 2003).

Parenting a child with an IDD is frequently a lifelong responsibility. Robinson et al. (2016) found nearly 50% of family members of individuals with IDD reported more caregiving responsibilities than they could handle, notably if there are more children living at home. Increased burden on parents of individuals with IDD are linked to the severity of symptoms and level of disability (Irazábal et al., 2012). High levels of behavioral support needs are linked to increased parental burden (Al-Krenawi, Graham, & Al Gharaibeh, 2011). This is also evident when the individual with IDD has health complications (Valicenti-McDermott et al., 2015) or a mental health problem (Irazábal et al., 2012). These profiles are reported consistently cross-culturally irrespective of majority / minority ethnicity or the country's level of income (Blacher & McIntyre, 2006; but also see Valicenti-McDermott et al., 2015).

There is a wealth of literature reporting greater deficits in psychosocial functioning and a greater prevalence of psychological distress in parents of children with IDD (Blacher & Hatton, 2007; Hastings, 2016; Singer, 2006). These include psychological distress, anxiety, depression, demoralization, and loss of freedom due to caregiving duties (Robinson et al., 2016). However, a population-based sample found 40% of mothers of children with IDD reported clinically significant emotional problems, whereas 60% did not (Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). Though the prevalence of parental depression is greater than the general population, evidence suggests most parents of children with IDD do not suffer from clinically significant depression.

Although there is evidence that stress experienced by parents of children with IDD can be chronic, there is marked individual variation in its trajectory over the life course (Glidden & Schoolcraft, 2003). Parents' psychological health and children's developmental health is especially vulnerable during the early years of a child's schooling (Fontil & Petrakos, 2015). Parental concerns include acceptance of their child by new teachers and peers and whether schools can meet the child's learning needs (Hirst, Jervis, Visagie, Sojo, Cavanagh, 2011). There is also evidence of declines in parental psychological well-being with increasing age of the child (Orsmond, Seltzer, Greenberg, & Krauss, 2006), though some research reports decreases in parental stress in adolescence (Woodman, 2014). Young adulthood may be especially challenging due to impending transition from school to work, and cause concerns about the child's future (Lueckling & Fabian, 1997; but see Goff et al., 2016). Social support may reduce during this time (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011).

Another concern is the continued co-residence of the child in the family home, often well past the age when most TD children become independent. Seltzer, Floyd, Song, Greenberg, and Hong (2011) reported a higher rate of co-residence of adults with IDD when their parents were in midlife and in early old age than in a comparison group. An adult child living at home is generally associated with poorer well-being for parents in midlife and early old age, more so in mothers (Pudrovska, 2009). A longitudinal study of 117 families before and after residential relocation (Seltzer, Krauss, Hong, & Orsmond, 2001) found levels of direct caregiving decreased and parents had less frequent contact with residential staff during the first 3 years after the adult child moved from home, resulting positively on parental well-being.

Sociodemographic Variables

Higher education level (Al-Krenawi et al., 2011), higher income (Santiago, Wadsworth, & Stump, 2011), and more effective coping style (Mak & Ho, 2007; Stuart & McGrew, 2009) are factors associated with less parental burden. Families supporting a child with IDD are more likely to be exposed to adverse socioeconomic circumstances (Emerson, 2007; Emerson & Hatton, 2009). They have lower rates of employment, return to employment later after childbirth, and are less likely to work full-time (Parish, Seltzer, Greenberg, & Floyd, 2004), and thus have less financial security later in life.

The relationship of family circumstances to psychopathology in children with IDD appears to be bidirectional. It has been found children with IDD often reside in single-parent, lower-socioeconomic families (Emerson, 2007). Emerson and Hatton (2007) found significant associations between gender, age and eight social variables and the risk of having behavioral disorders as well as hyperkinesis. Emerson and Hatton (2009) found that socioeconomic position moderated associations between child behavior problems and maternal anxiety, depression and self-assessed health.

However, some research suggests that raising a child with IDD contributes to parental stress and depression regardless of the buffering effects of socioeconomic status. Hoare, Harris, Jackson, and Kerley (1998) did not find parental depression to be related to either marital or socioeconomic status (also see Olsson & Hwang, 2001). In contrast, low levels of socioeconomic support along with parents' negative perceptions of their ability to influence their children's behavior are associated with increased stress and depression (Falk, Norris, & Quinn, 2014). Zaidman-Zait, Most, Tarrasch, and Haddad (2018) found during transition, more disadvantaged parents experienced more stress and depression, and their children had lower adaptive behavior and more behavior problems than comparison groups. However, when controlling for between-group differences in family socioeconomic circumstances, poorer well-being among parents of children with disabilities may be attenuated or even eliminated (Emerson, Baines, Allerton, & Welch, 2010; Olsson & Hwang, 2008). As such, socioeconomic status may not serve as a buffer against depression in parents of children with IDD (but also see Stoneman, 2007).

Minority status (Luthar, 1991; Masten, 2011) and racial discrimination (Brooks, 2006) also predict poor outcomes for children and youth. Children of African and Hispanic descent are often disadvantaged due to living in severely distressed neighborhoods with reduced accessibility to social supports, community services, employment opportunities, and high-quality schools. Age of the individual with IDD is important when considering life course vulnerabilities. Raskind et al. (1999) found a reduction in the perceived intensity of stressors from childhood to adolescence, particularly perception of having an IDD. Older women with IDD remain the least studied members of the disability population, and yet they often live well into late adulthood. LeRoy, Walsh, Kulik, and Rooney (2004) found older women with IDD to have limited resources, and social networks; yet they reported that their health was good, though it often limited their activities. Despite their societal limitations, these women reported this is the happiest period of their lives.

Residential placement can have a significant impact on stress and health in adults with IDD. Taggart (2014) found adults with IDD who live in supported residential placements, especially in institution-like settings, are at greater risk of psychopathology than adults who live with family members. Hastings et al. (2004) found people with IDD living in staffed accommodation have significantly more life events. Owen et al. (2004) found participants were exposed to at least three adverse life events the past year, and life event exposure was linked with increased aggressive behavior and greater incidence of emotional disorders.

Adults with IDD often become emotionally as well as practically dependent on the paid support staff assisting them with community access and daily living activities (Lunsky, 2008). When support staff leave due to job changes, or when adults with IDD leave behind support persons with whom they had positive experiences, feelings of bereavement can result (Hartley & MacLean Jr, 2005). Accumulation of multiple stressors combined with an impersonal staff attitude has been found to perpetuate challenging behaviors in people with IDD (Griffith, Hutchinson, & Hastings, 2013).

Family Environment

Along with the established relationship between socioeconomic position within a family, and the health of the child with IDD, there are a number of factors associated with nonoptimal child development (Guralnick, 2005). It is well established that parents of children with IDD show increased stress compared to parents of children without IDD (Emerson, 2003; Hastings & Beck, 2004). Experiencing child behavioral problems with a child with IDD has been shown to be a high risk for poorer health and well-being in cross-sectional research (Baker et al. 2002; Totsika et al., 2013).

However, there has been variability shown in parental well-being and other outcomes as seen similarly in the psychopathology of individuals with IDD. Totsika et al. (2011) found 60% of mothers of children with IDD did not report concerning clinical levels of their emotional problems. Positive outcomes are also established in the literature (e.g., Hastings & Taunt, 2002; Scorgie & Sobsey, 2000). Researchers have explored moderating or mediating factors in the relationship between child behavioral problems and maternal outcomes such as Plant and Sanders (2007) who explored behavioral problems and parental stress, with social support as a moderator. They found social support had a positive effect on this relationship. In addition, Halstead, Ekas, Hastings, and Griffith (2018) found perceived social support functioned as a protective factor, when perceived social support was higher, social support moderated the relationship between child behavioral and emotional problems and maternal outcomes, such as depression and life satisfaction. Social support has been found to be a protective factor between life events and parenting stress and outcomes such as depression, and social isolation (Dunn, Burbine, Bowers, & Tantledd-Dunn, 2001).

Family climate has an impact on child behavioral and emotional problems, including cohesiveness, expressiveness and conflict (Greenberg et al., 2012). Adverse characteristics associated with poorer child mental health include low parental intellectual level (Feldman, 1997), mental illness, particularly depression (Seifer & Dickstein, 2000), and parental neglect or abuse (Barnett, 1997). Guralnick (1998, 2005) suggests family climate risk factors are mediated by nonoptimal patterns of family interaction, such as high levels of expressed emotion and family conflict. Many family interaction patterns are affected by family risk factors, and contribute to poorer outcomes for the child with IDD (e.g., Phelps, Belsky, & Crnic, 1998). Individual risk factors might not exert an adverse impact on child outcomes in the absence of nonoptimal patterns of family interaction, suggesting optimal patterns can protect against the effect of other risk factors (Werner, 1995).

Family Cohesion

Family cohesion relates to positive outcomes for parents and children. Maintaining cohesion may be challenging for families of individuals with IDD (Mitchell, Szczerepa, & Hauser-Cram, 2016), and parents may be at greater risk of relationship breakdown. Research has found somewhat higher divorce rates in parents of individuals with IDD compared with parents of TD children (Hartley et al., 2010). Certain groups may be more susceptible to marital breakdown, such as parents of individuals with ASD (Hartley et al., 2010). Greater depressive symptoms have been found in single mothers of children with IDD (Olsson & Hwang, 2001).

Preventing domestic discord may promote parental mental health in families with children with IDD, as a positive marital relationship can predict lower parenting stress (Benson & Kersh, 2011). The well-being of one parent affects the stress experienced by the other parent (Hastings et al., 2005). This is important for parents of individuals with IDD as they may differ in their perceptions of family life. Studies have found mothers to be more stressed than fathers in having a child with an IDD (Dabrowska & Pisula, 2010; Oelofsen & Richardson, 2006), though this is not a consistent finding (Hastings, 2003; McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006). Alternatively, parents may differ in their predictors of stress (Hastings, 2003). While parents of children with ASD reported no differences in overall stress, children's problem behaviors and their partner's mental health were predictive of mothers' levels of stress

(Hastings, 2003). However, marital satisfaction positively predicted cohesion for both parents (Mitchell et al., 2016).

Expressed Emotion

Recently, researchers have focused on expressed emotion as an explanatory variable among families of children with disabilities. Expressed emotion is defined by high levels of criticism and/or emotional over-involvement from one family member directed toward another family member with a disability or illness. Expressed emotion is associated with relapse among adults with schizophrenia (Butzlaff & Hooley, 1998) and has been recently examined in families of children with intellectual disabilities (Hastings et al., 2006) as well as autism spectrum disorder (Greenberg, Seltzer, Hong, & Orsmond, 2006).

Research from Hastings et al. (2006) and Greenberg et al. (Greenberg et al., 2006; Greenberg et al., 2012) suggests a bidirectional relationship between child behavior problems and expressed emotion. Hastings et al. (2006) studied mothers of children with IDD at two time points, assessing maternal distress, mental health, expressed emotion, and child behavior problems. Criticism in particular was cross-sectionally, but not longitudinally, related to child externalizing behavior and maternal distress. Greenberg found links between high expressed emotion and maladaptive behavior in autism (Greenberg et al., 2006) and Fragile X syndrome (Greenberg et al., 2012). The latter study also found significant correlations between lack of criticism and fewer behavior problems. Smith et al. (2012) studied behavior problems and disability-related symptoms in adolescents and adults with FXS over a 3-year period, and found an association between maternal warmth, lower levels of symptoms, and higher levels of adaptive behavior. Maternal depression and criticism were associated with more psychological symptoms in individuals with FXS.

However, only examining the negative aspects of the family affective climate may be limiting for understanding the full range of family processes that influence development. Negative and positive well-being, for instance, are not necessarily on the same continuum of mental functioning. There remains a need to examine the positive aspects of emotional expression and other family processes among families with children with autism spectrum disorder.

Family Resilience

Family resilience can be conceptualized as a “renewable power” (Sobotková, 2004), a dynamic property of families’ strengths which allow families to adapt despite stressors. Sobotková (2004) identifies multiple factors that support family resilience: family functioning, stress appraisals, problem-solving skills, coping strategies, and sources of familial durability. Sources of familial durability can be external, such as socioeconomic status or social support networks, or internal, such as mutual value orientation and shared belief systems (Sobotková, 2004).

Several potential resilience factors have been explored, including hope (Lloyd & Hastings, 2009) and self-efficacy (Hastings & Brown, 2002). More recently, a systematic review by Peer and Hillman (2014) suggested that coping style, optimism, and social support may all be factors that influence resilience in parents of children with IDD. Ruiz-Robledillo, De Andrés-García, Pérez-Blasco, González-Bono, and Moya-Albiol (2014) found resilience showed associations with overall general physical and psychological health of caregivers of children with ASD. Research suggests that resilience is associated with mental health, such as anxiety, insomnia, and depression in caregivers (e.g., Tang et al., 2013). The Resilience Scale for Adults (RSA: Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003) has been used in a small population of parents of children with IDD, as part of a comparison between parents of children with IDDs and parents of children with Sanfilippo syndrome (Grant et al., 2013). Parents rated social resources as their highest protective factor, and planned future as their lowest protective factor, both of which are subscales of the RSA.

Resilience research in the IDD field typically uses cross-sectional research. However, Bayat (2007) suggested resilience is a process that can only be shown over time, thus the need for longitudinal studies. One longitudinal study with parents of children with IDD (Gerstein, Crnic, Blacher, & Baker, 2009) studied trajectories of daily parenting stress in parents of young children with IDD, and found factors such as psychological well-being, marital adjustment, and positive relationships affected parenting stress differently in mothers and fathers, and concluded that parents affect each other's resilience. In contrast, Halstead, Griffith, and Hastings (2018) found no longitudinal association between resilience and maternal well-being outcomes, and little evidence of the role of resilience as a protective factor between child behavior problems and maternal well-being. However, they did observe maternal resilience functioned as a compensatory factor, having a significant independent main effect relationship with well-being outcomes in mothers of children with IDD and ASD.

Family Interventions

The Double ABCX model (McCubbin & Patterson, 1983) supports analysis of factors (i.e., protective resources, or risk factors including family discord) related to family adaptation (Saloviita, Itälinna, & Leinonen, 2003). The Double ABCX Model examines stressors that "pile up" post-crisis along with the original stressor (aA), post-crisis resources and those first used to meet the crisis (bB), post-crisis perceptions and those first applied to the crisis (cC) and the overall likelihood of adaptation to future crises on the basis of these developments (Xx).

Multiple components of family intervention programs can contribute to external support of family adaptation. Guralnick (1997, 1998) categorizes these intervention components as resource supports, social supports, and information and services. These components can be adapted to specific family needs to create a successful intervention capable of improving family patterns of interaction. Guralnick (1997, 1998) emphasizes that such interventions are primarily successful when they are delivered consistently with a family's goals, values, priorities and routines.

Mindfulness is typically described as being in the present moment, and responding without judgment to the unfolding of physical, mental, and emotional experiences (Kabat-Zinn, 2003). MBIs may help parents develop non-judgmental ways to focus on their children's behaviors, improving acceptance (de Bruin, Blom, Smit, van Steensel, & Bögels, 2015). Recent research demonstrates the efficacy of MBIs to improve well-being in caregivers of children with IDD (Neece, 2014). For parents of children with IDD, mindfulness is associated with reduced stress and anxiety, and increased positive parent-child interactions (Beer, Ward, & Moar, 2013). Chapters 9 and 42 explore further interventions for parents of children with IDD.

Conclusion

This chapter has reviewed risk and protective factors in the IDD field to date. Our approach considers multiple dimensions over the life course, with particular attention paid to social support, family environment, and individual differences. Moreover, our resilience-based approach has led us to consider how specific factors, such as the family environment, can present as both risk factors and protective factors based on differences in persons and circumstances. We believe that development of problem behaviors and poor mental health outcomes is best understood as a transactional process between the individual and complicated social systems including the family environment, school, and post-secondary outcomes such as residential placement. Exploring the interplay of risk and protective factors during these transactional processes is how best to identify targets for intervention. Continuing research is required to find new ways to promote resilience for people with IDD, and this research should focus on precise identification of risk and protective factors, conceived dynamically as changing over time, and changing in its significance for the individual with IDD based on persons and circumstances.

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