

## **Individuals and Families with IDD**

### **Literature Review and Synthesis**

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### **Introduction:**

This literature review and synthesis provides an overview of sources of stress and conflict in the lives of people with intellectual and developmental disabilities and of the methods and resources used to minimize or resolve stress and conflict. It focuses on four specific domains: 1) family roles and responsibilities, 2) living arrangements (including access to services and relationships), 3) education and vocation, and 4) autonomy and risk. This literature review and synthesis begins with a brief background on key demographics and other statistics related to people with intellectual and developmental disabilities.

### **Background:**

The demographic data related to intellectual and developmental disabilities in the United States is not easily parsed, because both intellectual and developmental disabilities are broad categories that encompass many people across the lifespan.

According to the American Community Survey of 2019, there are approximately 15.8 million Americans living with the broadly defined “cognitive difficulty.”<sup>1</sup> The number of Americans living with the more narrowly defined “intellectual and developmental disability” is approximately 7 to 8 million. People with IDD comprise 3% of the US population. Data gathered from the 2010 census indicate that approximately 2/3 or 66% of people with IDD live at home with their family. About 22% of people with IDD live in a supported residential setting with supervision. Approximately 14% of people with IDD live alone or with a roommate. These data correspond roughly with the finding that 75% of people with IDD rely on family support and approximately 25% of people with IDD receive services through Medicare or Medicaid. Nearly half, or 40%, of people with IDD live with a caregiver under age 41; 35% of people with IDD live with a caregiver between the ages 41 to 59; 25% of people with IDD live with a caregiver over age 60 (Empower-WNY).

An article in the *American Journal on Intellectual and Developmental Disabilities* used Medicaid data from 2008-2013 to identify people with intellectual or developmental disabilities (IDD) in five states (Delaware, Iowa, Massachusetts, New York, and South Carolina). Many people with disabilities are insured through Medicaid, so this study’s results can help states plan

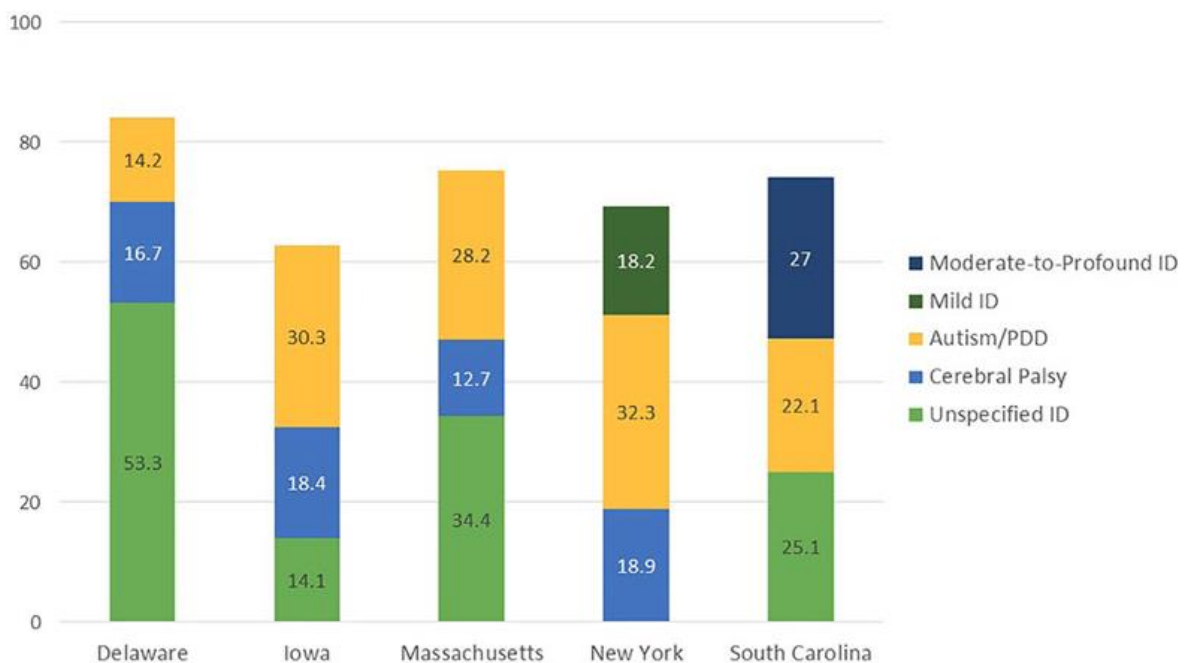
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<sup>1</sup> “Cognitive difficulty” includes learning disabilities, Alzheimer’s, senility, or dementia, intellectual disabilities, developmental disabilities, and “other mental/emotional conditions.” (Americans with Disabilities Household Economic Studies 2014).

for services for this important population. The researchers found that about 11.4 million people were insured through Medicaid in these states, and about 1 in 35 were found to have IDD, ranging from 1 in 42 in New York to 1 in 24 in South Carolina (CDC).

The following chart from the CDC shows the diversity of IDD in five states (CDC).

### Percentages of Top 3 IDD Diagnoses for Medicaid Users with IDD by State (2008–2013)\*



In 2015, nearly six-million students with disabilities age 6-21 received services under the Individuals with Disabilities Education Act (IDEA). This number includes people living with “learning disabilities” who may not meet the definition of intellectually or developmentally disabled (IDD). The separation of “learning disabilities” from IDD has a well-documented history, which has roots in the racialized development of special education in the United States. Students with learning disabilities represent 38.8% of those served under the IDEA (U.S. Department of Education 2018a 2018b).

Congress funds over 70 Parent Training and Information Centers (PTIs) across the country, which are designed to educate and empower parents of children with IDD with respect to their special education rights. PTIs are the most common place parents turn to for advocacy, support, resources, and information (Burke et. al. 2017).

While social advocacy and changes in policy in the United States, such as the Americans with Disabilities Act (ADA, 1990), the Supreme Court's decision in *Olmstead v. L.C.* (1999) and the ADA Amendments Act (2008), have led to more adults with IDD living in the community, most of the research on adults living with IDD in the community has been conducted outside of the United States. Community living has not necessarily resulted in integration and in some cases may contribute to exclusion experienced by adults with IDD. The largest study of adults with IDD living in the community in England found that 32% of adults with mild or moderate IDD experienced material and social hardship; 74% were unemployed; 6% were married; and 31% reported having no friends. The lives of adults with IDD, even when living in community, in general are associated with hardship, deprivation, and abuse (Hastings and Beck 2004).

Programs have been designed and developed to reduce and resolve stress and conflict in the lives of people with IDD and their families. For example, in 2019, the US based Disability Rights Education and Defense Fund (DREDF) published, "[Behavior is Communication: A Guide for Advocates and Families on Positive Behavior Interventions and Supports \(PBIS\) in School.](#)" The purpose of the guide is to "give advocates, family members, and school personnel an introduction to the use of positive behavior interventions and supports in response to behavior and to shape good behavior." Through PBIS, DREDF aims to "help create equitable and safe classrooms for all students" (DREDF, 2019).

As a response to legal rights and responsibilities related to individuals with disabilities, the United States Department of Justice established the ADA Mediation Program in 1994. Since then, it has used ADA-trained mediators located throughout the United States to resolve over 5,000 complaints in both small and large communities. According to its own publications, 75% of the resolutions negotiated by the ADA mediation program have been "successful." Through this program, ADA mediators support parties in addressing issues related to emotional, social, mental and physical needs, discrimination, communication, modification of policies, practices, and procedures, and diverse limitations to "program accessibility." The DOJ defines "program accessibility" as allowing inclusion and welcoming participation in community activities and civic engagement at all levels (DOJ).

Local and national governments have created departments and programs, such as the Los Angeles Department of Disability [Mediation Program](#), the Centre for Resolution [Disability Mediation Worcester](#) (UK), and the National Institutes of Health (US) to provide services that recognize the benefits of mediation in resolving conflicts and disputes. These have proven effective and efficient in addressing issues related to transportation, employment, housing, and other reasonable accommodations as outlined by the ADA. Many of these and other organizations and departments also offer training programs in mediation and disability awareness training sessions. These training programs are ensuring dignity and human rights while promoting self-determination and supported decision making of people with disabilities while implementing accessible and federally compliant policies in the workplace. The Centre for Resolution (UK) and the National Institutes of Health (US), in particular among these groups, emphasize the need for employers to offer anti-harassment and anti-discrimination seminars in

the workplace. On the whole, these programs assert that mediation is often the most effective way of solving ADA disputes, as well as IDD related family and community matters. Both advocates and individuals find mediation and other forms of alternative dispute resolution empower people with disabilities and also reduce stress and the use of resources associated with costly and time consuming adversarial legal proceedings.

The remainder of this literature review and summary will focus on peer-reviewed research findings in the four areas noted in the introduction: 1) family roles and responsibilities, 2) living arrangements (including access to services and relationships), 3) education and vocation, and 4) autonomy and risk.

### **Family Roles and Responsibilities:**

Most of the research on family roles and responsibilities impact on individuals with IDD and their families focuses on parent-child relationships. However, recent research has also studied issues related to impact on parent-parent relationships, on sibling relationships and on aging parents and their adult children living with IDD. As noted, about 66% of people living with IDD in the United States live with their families where family members make up the primary support system. In the United States and Canada, most studies involving people living with IDD focus on children and young adults defined as living on the autism spectrum or having “autism spectrum disorder” (ASD). This focus may be a reflection of access and qualifications for the population. The Center for Disease Control and Prevention (2018) found that the overall prevalence of Autism Spectrum Disorders (ASD) in the United States is one in 59 children age eight years and that males are four times more likely than females to be identified with ASD.

Hickey and colleagues (2019) studied the ways in which the “emotional quality” of family “subsystems” (parent-child and parent-parent relationships, including mothers and fathers) impacts and shapes family responses to children living with “autism spectrum disorder” (ASD). The study, focused on 148 U.S. families of children with ASD (86% male) aged 6 to 13 years, reported that about 1/3 of the parents did not have a college degree and more than 2/3 were of non-Hispanic white origin. Hickey et. al. found that the quality of support and communication was critical in determining the quality relationships among parents and their children and between parents.

Hickey et. al. found that family subsystems for children living with ASD could be described in terms emotional climate in parent-child and parent-couple relationships for both mothers and fathers. They found that the most commonly formed class of family emotional climate (43%) was “*Family Resilient*,” defined as “high warmth and low criticism across all family relationships.” Only 12% of the sample was characterized by low warmth and high criticism, identified as “*Family Distressed*.” The high-warmth and low-criticism family emotional climate, or the resilient family, encouraged and facilitated adaptive behavior and coping skills in children with ASD.

It is important to note that Hickey et. al. revealed significant gender differences in emotional quality in the development of family relationships. Mothers of children with ASD were more likely than fathers to express “high criticism” in the parent child-relationship. Additionally, mothers were also more likely to express “high criticism” in the parent-parent relationship. In their study, emotional and behavioral issues of the child with ASD were found to affect the family emotional climate, with an inverse relationship between “emotional and behavioral problems” and family climate. They concluded that family dynamics and climate would be favorably affected by reducing “emotional and behavioral problems” of children. The interdependence of family members was noted as particularly impactful. Interventions focused on supporting relationships of mothers with their children and wives with their partners, tended to reduce or eliminate emotional and behavioral “problems” for their children, what Hickey et. al. call “spill over” stress or emotionality.

White and colleagues (2012) note that the prolonged and significant stress of providing care for individuals with ASD can lead to moments of familial crisis. Their study, conducted in the greater Toronto area and Ontario, examines experiences of crisis in families of children with ASD (early childhood through adulthood). White et. al. found that challenging behaviors, emotional problems, school conflict, family adjustment, and expectations of advocacy can precipitate crisis in families. While family ability to cope and recalibrate to crisis changed as individuals with ASD aged, White et. al. found, in particular, that stress and crisis could be mitigated through support interventions. Those interventions include specialized education and health care programs, early intervention services, and specialized training/vocational programs for adults with ASD.

Boström and Broberg (2014), who conducted a longitudinal study of fathers in Sweden, note that fathers of children with IDD have typically been cast as being less affected by a disability diagnosis than mothers of children with IDD (based on the notion that a father’s tendency is to be avoidant and withdrawn). However, they found that changes in family gender roles and increased involvement of fathers in the lives of their children with IDD induced new ways of managing and living with children with disabilities. Boström and Broberg contend that being open and vulnerable, and finding ways to adapt and cope to stressful situations factored into how fathers appraised their relationships with their children with IDD. On the whole, Boström and Broberg find that the most effective support for fathers, rather than being problem-focused, should be designed to improve tools for building and supporting better relationships, “with the aim of promoting child development through the contribution that fathers can make as parents.”

Minnes, Woodford, and Passey (2007) explore the relationship between aging family caregivers and adults with intellectual disabilities. This study focuses on the role of carer resources (services and support networks) and the carer’s own appraisal of their quality of life in order to discuss the effect of aging and stress. Noting that the number of parents providing support and home care for adults with IDD continues to grow, this article also discusses how the role of adults with IDD changes as their parents age (adults with ID provide care for their parents



in some cases). Minnes, Woodford, and Passey found that the ability of carers to assess and appraise their experience in caring for an adult with ID helped to mitigate stress in their lives as they faced questions about long-term accommodations for their adult children, including social and emotional support, and financial considerations.

Begum and Blacher (2011) were among the early researchers to move beyond the focus on parent-child relationships that dominates family studies literature, to study the relationship between siblings with and without intellectual disabilities (ID). Their study described four factors in the sibling relationship (1) warmth, (2) rivalry, (3) conflict and (4) relative status/power. They found that sibling conflict related to behavior problems for both typically developing (TD) adolescents and adolescents with ID, typically arises from caretaking responsibilities, chores, and desire for “tangible goods” (e.g., toys). While conflicts between siblings led to increased depressive symptoms and further external behavioral issues for adolescents with ID, Begum and Blacher found that TD adolescents were able to learn from those experiences to work out peer conflict in other settings outside the home, such as a school setting. These findings seem to support the work of Floyd and colleagues (2009), who found that conflict and warmth between siblings with and without ID facilitated an increase in social skills and the social competence of adolescents with ID.

In a more recent study, Laghi and colleagues (2018) extend the analysis of typically developing (TD) siblings of persons living with IDD. Their study focused specifically on: 1. family functioning (defined as the ability of family members to manage stressful events, intimate and social relationships), 2. family happiness and satisfaction, and 3. sibling impact on families with a child with ASD. This study enrolled TD adolescents and young adults who have a sibling with ASD in order to consider attachment and caregiving roles and possible interventions for conflict. While TD early adolescents in the study had more negative interactions with their sibling(s) with ASD than young adults, there was no meaningful differentiation between age groups when it came to perceived attachment and actual caregiving. Importantly, Laghi et. al. suggest that for TD siblings “the key element that characterizes their past memories and their present life is a sense of duty due to the recognition of vulnerability of their disabled sisters or brothers and to alleviate parents’ fatigue and stress.” Additionally, this study found that a high value for and level of family satisfaction and family functioning, significantly decreased conflict between TD siblings and their siblings with ASD.

Bigby and colleagues (2015), conducted research in Australia, that studied relationships between older group home residents, their sibling caretakers, and 17 supervisory staff over a three-year period. Their study found that siblings valued the relationship they had with their brother or sister with intellectual disabilities, and that siblings played a significant role in influencing the quality of care and safeguarding the well-being of older group home residents. They also found that the quality and character of sibling-staff relationships fluctuated over time depending on perceptions of attention and care for the residents. With few protocols guiding these particular relationships, Bigby et. al. findings suggest the need for greater attention by service organizations to sibling-family relationships, and recognition of the unique contribution

and long-term commitment of some siblings to the well-being of their brother or sister who lives in a group home.

Findings of these studies promote the value of supportive, positive relationships with open communications and point to evaluating the appropriateness and efficacy of specific forms of intervention designed to address, mediate or eliminate stress and conflicts within families living with IDD.

Recognizing that parents of children with IDD face their own psychological challenges related to parenting, including anxiety, depression, and burnout, Blackledge and Hayes (2006) review the use of Acceptance and Commitment Therapy (ACT) to help parents cope and adjust to raising their children. ACT workshops introduce and raise awareness, teach skills, and share knowledge, that help parents outline goals (individual and familial) and build competence to diffuse and address difficult emotions. Blackledge and Hayes found that participation in ACT workshops over a three-month period helped parents of children living with autism reduce stress and cope more effectively when faced with challenging behaviors and difficult parenting decisions.

In their research on family dynamics, Bluth and colleagues (2013) discuss a therapeutic response model that addresses the impact of stress on family dynamics between parents and children living with ASD. This model considers the potential benefits of mindfulness intervention and additional resources for parenting couples to help strengthen familial relationships and promote positive outcomes. Their study builds on both recognized and potential impacts of stress on couple relationships in families of a child with IDD, including higher rates of divorce and lower rates of reported relationship satisfaction, as compared to other parent couples. Bluth et. al. propose a framework of mindfulness-based approaches that promote and cultivate empathy between parent couples of children with ASD, and facilitate better parent-child relationships. They propose this model as an effective formal intervention (Mindfulness Based Stress Reduction Program and/or Acceptance and Commitment Therapy (ACT)), as a valuable resource for both individuals and couples. The approach outlined in their study allows for the practice of forgiveness, emotional and personal growth, and self-compassion among individuals. It also promotes tolerance, nonjudgement and increased marital quality for couples. The approach is found to improve parental ability to more effectively cope with and manage stress related to having a child with ASD. The study also suggests that parent practices of mindfulness could lead to a decrease in challenging behavior and an increase in regulatory behavior among children with ASD. Although Bluth et. al. focus exclusively on issues of couples parenting children with ASD and those associated with IDD, the model builds on accepted and proven interventions meeting the dialogue and conflict needs for individuals and families in both formal and informal settings.

Finally, Jones et. al. (2014) discuss how acceptance and mindfulness may help mitigate psychological distress in parents of children with ASD. In their study of mothers and fathers of children with ASD, participants reported that receiving guidance and training in mindful parenting, situational awareness, and acceptance strategies contributed to reduced anxiety,

depression, and stress among mothers of children with ASD and lowered rates of depression among fathers of children with ASD. Jones et. al. note that parental stress is often related to children's "problem behaviors," and that the process of mindfulness ("less judgmental of experiences, less reactive, and more aware of internal processes") was key for mediating such problem behaviors, as well as contributing to improved well-being of parents of children living with ASD.

### **Living Arrangements, Access to Services, and Relationships:**

Research that engages in assessment of the experiences of people with IDD or ASD who live in supported environments in the community as adults, is primarily found in Canada, Europe, and Australia. Fewer studies conducted within the United States focus on situations and relationships more relevant to adults with IDD.

While it is a literature review, Amado and colleagues (2013) note that individuals with IDD are increasingly living in the general community and discuss the current state of research concerning the function and level of social inclusion and community participation for individuals with IDD. Their review includes social inclusion in schools, jobs, residential services, recreational activities, and the degree to which individuals with IDD were integrated and included in the community. Such inclusion significantly mattered to overall well-being, contributing to increased friendship and decreased loneliness. This study considers a variety of issues, and challenges researchers to think about belonging and social inclusion as more than just physically living in community. The issues include effective support for individuals with IDD in intimate relationships, conceptual frameworks for social inclusion (social networking, self-determination), and evaluating the impact of social media on inclusion. Based on this literature review, increased inclusion would provide opportunities for shifts toward fuller social inclusion, (civic participation, social capital, trust, reciprocity), and improved services and support implemented by the community for individuals with IDD.

Bigby, Bould, and Beadle-Brown (2017) explore innovative living arrangements for individuals with ID that consider housing and support as two distinct experiences. Individuals with IDD interviewed shared their thoughts about traditional group home models. Many found they were too rigid and inflexible or otherwise too expensive. Those individuals who participated in the study of supported living arrangements reported better quality of life, increased sense of freedom and security, more control over their daily life choices, and less restriction than when they relied on low-income housing, although they still reported lacking a sense of community and experiencing loneliness. On the whole, this study found that supported living was largely beneficial for people with IDD when it provided access to external support, proper technology, and medical services in the community.

There are a number of conditions limiting housing options for people with IDD (financial considerations, eligibility, etc), while living at home with family members can be restrictive. Attack and colleagues (2019) evaluate the living arrangement plan, "Friendly



Housemates,” in which people with IDD share housing with students (or with students and their families) in an effort to enable people with IDD to live independently in a supportive environment. This study analyzes interviews of people with IDD, their housemates, family members, and support staff to look at the benefits of “Friendly Housemates” as a transitional living arrangement for people with IDD. Numerous benefits to this living arrangement for people with IDD include opportunities to learn new skills, practice mutual respect, increase independence (particularly in urban areas), develop new friendships and relationships, and try new activities. This new model allowed for an expanded and innovative understanding of what constitutes a supportive environment and semi-independent living arrangements and the benefits of creating inclusive housing models for people with IDD. Concurrently, Atack et. al. found that for families and support staff, defining roles, role adjustment, and the idea of long-term commitment were inherent complications in this social model of inclusive housing.

Friedman and Rizzolo (2018) researched dynamics of friendship and quality of life for people living with IDD. They interviewed 1,300 people with IDD to study how friendship affected conflict resolution, community participation, and quality of life (defined as housing security, community, relationships, and personal goals). They found that people with IDD tend to have less opportunities to build and cultivate friendships, and that people with IDD considered paid support staff their friends, which has problematic implications for the development of future friendships (reciprocity). Friendship, is critical to successful outcomes in the community, and Friedman and Rizzoli found that when people with IDD have friends, and are satisfied with the quality of those friendships, they are five times more likely to participate in the community. They are also approximately four times more likely to perform different social roles and have intimate relationships. (i.e., friendship improved quality of life, decreased loneliness, and increased inclusion). However, the study notes existing barriers that prevent people with IDD from forming friendships, particularly for those with high support needs. Those who need constant care have a more difficult time forming friendships due to the level of involvement of support staff, lack of employment, and lack of transportation access. Friedman and Rizzolo call for disability services that can help facilitate friendships for people with IDD in a mutually respectful environment.

Hartley and MacLean (2008) discuss coping strategies of adults with mild intellectual disability living in the Rocky Mountain region of the United States. Their study finds that adults with IDD who experience high stress during social interactions often turn to maladaptive coping strategies. Hartley and MacLean found that people with mild ID tend to utilize avoidant coping strategies (i.e. *Behavioral-Avoidance* coping and *Cognitive-Avoidance* coping), like suppression, denial, and avoidance, more often than active coping strategies (i.e., *Problem-Focused* coping and *Emotion-Focused* coping, and *Support-Seeking* coping). As psychologists, and because their research focuses on individuals with mild intellectual disabilities, Hartley and MacLean emphasize interventions at the level of the individual. They propose that family and support staff work with adults with mild ID to develop active communication and coping strategies that are problem focused.

Access to transportation is critically important in determining levels of independence, overall quality of life, and general well-being for people living with IDD in the community. In addition to structural/environmental issues such as lack of efficient, reliable, safe, and wheelchair accessible public transit, access to transportation can be limited by inadequate training programs for people with IDD in using public transit.

Friedman and Rizzolo (2016) analyze how transportation for people living with IDD can impact community integration and the formation of relationships. Their study cites a lack of available public transportation or otherwise inaccessible transportation systems. They found that people living with IDD often do not have the skills required to access public transportation. A lack of accessible transportation has negative impacts on the ability of people with IDD to live independently. Part of the lack of access of public transportation to people living with IDD is rooted in their lack of access to financial resources (personal savings, a living wage, etc.). Friedman and Rizzolo found that transportation services (public transit, taxi services) enabled people with IDD to participate more fully in the community (errands, recreation, social activities). They recommend expanding transportation services for people with IDD in ways that facilitate community access and living options, reduce their dependency on family and friends for transportation, and instituting a program that provides people with disabilities greater accommodations for commuting and traveling.

Ali et. al. (2013) discuss access to health care among people with intellectual disabilities. They study barriers and discrimination that people with ID and their caregivers experience when attempting to access healthcare services. Participants were interviewed and common experiences of stress were related to discrimination involving negative staff attitudes and behavior, lack of reasonable accommodation and knowledge about service eligibility, inadequate support from caregivers, and language barriers among minority groups with intellectual disabilities. At the same time, some participants also reported that when staff are flexible with appointment times, show friendliness, respect, and good communication, and provide health checks, people with IDD had an easier time accessing healthcare services.

### **Education and Vocation:**

Buchanan and Clark (2017) discuss the barriers that inhibit effective, productive communication between parents of children with Emotional and Behavioral Disorders (EBD) and their teachers. They conducted interviews with parents and teachers of children with EBD, who were participants in the Students With Involved Families and Teachers (SWIFT) study. They describe SWIFT as a “program to support students with EBD transitioning from treatment to less restrictive school settings,” located in Eugene, Oregon. Students attended “day-treatment, neighborhood, military charter, and private treatment” schools. Buchanan and Clark found that parents’ experiences depended on the type of school their child attended and identified technology issues, institutional structures, school transportation, time constraints, and ineffective

or inadequate parent-school communication as key factors that contributed to stressful adversarial interactions between parents and schools.

Buchanan and Clark found three effective ways to mitigate such issues and thereby reduce conflict between parents of children with EBD and schools: (1) regular, scheduled communication between teachers and parents about student's school progress, (2) regular, communication between teachers and parents about stress and trauma in the family home, and (3) increased parent involvement in school culture with teachers citing the need for school administration and staff to welcome parents of more diverse socio-economic and education backgrounds into the conversation. Parents "reported greater overall satisfaction with the method and tone of communication at schools where they felt informed about their child's progress and included in planning and decision making." Teachers also highlighted their desire to have effective communications with their students' parents. Teachers reported feeling confused or frustrated when parents did not engage with or utilize communication strategies provided by the school, including daily point cards, weekly emails to parents, and up-to-date online gradebooks. Both parents and teachers suggested strategies to build better rapport, including casual dress for parent meetings, emphasizing a team approach that includes parent input, and an increased focus on what students are doing well.

Lake and Billingsley (2000), who conducted their research 17 years before Buchanan and Clark, took a broader approach to thinking about the parent school relationship in the lives of children living with IDD. Lake and Billingsley conducted telephone interviews with parents of students with disabilities, school administrators, and mediators. They identified eight factors that commonly contribute to parent-school conflict involving children with disabilities: discrepant views of a child or child's needs, knowledge, service delivery, reciprocal power (a shifting imbalance of power), constraints, valuation, communication, and trust. Lake and Billingsley discuss these factors and offer ways to de-escalate parent-school conflicts. They suggest listening to and incorporating parent's goals into educational planning, considering family routines and levels of support when making student goals, a focus on relationships between schools and parents that are mutually productive and respectful (as a way to decrease power struggles), and a re-centering and valuing of trust between parents and educators.

At the core of Lake and Billingsley's study is a call to reassess the negative connotations of conflict and to view conflict as an opportunity to build constructive, positive behavior. They report that a "number of important and positive effects have been attributed to conflict, including preventing stagnation, stimulating creative problem-solving, contributing to self-assessment and skill testing, and engendering personal, organizational, and societal change." They conclude that a goal of parent-school relationships should be to view conflict as an opportunity for growth and change, rather than as something that impedes or prohibits constructive relationships. Conflicts can "serve a purpose and can result in improved services to students."

In their research, Staples and Diliberto (2010) outline some procedures and actions that can alleviate problems in parent-school relationships concerning students with disabilities. As outlined in the 2004 Individuals with Disabilities Education Act (IDEA), schools must provide

an Individualized Education Program (IEP) that includes the parents of children with disabilities in decision making about educational progress. Staples and Diliberto found that while IEP meetings can induce frustration and tension, steps can be taken to mediate such conflict and promote equal participation. They outline steps such as report cards, journals, progress reports, in-person communication, newsletters, appreciation events, parent-attended field trips, and parent-organized schoolwide activities as ways of improving communication among parents, teachers, and school administrators. Staples and Diliberto stress that time and collaboration are crucial for the success of IEPs and child-centered approaches to education. They conclude that building positive parent and teacher relationships is time consuming, but it is essential for the optimal success of the child.

Burke, Chan, and Neece (2017) found that parents of children with IDD experience significant stress which can be fueled by tense relationships between parents and the special education services available for their children, especially IEP (Individual Education Program) meetings. The study finds mindfulness-based interventions, including focusing on the present moment, practicing nonjudgmental responses, and practicing purposeful attention may help reduce parental stress. As part of the study, parents of children with IDD attended the Mindful Awareness for Parenting Stress (MAPS) program, where they learned to use purposeful breathing, meditation, and taking breaks as a way to relieve stress. Parents then applied those techniques before and during IEP meetings. Burke and colleagues found that by implementing mindfulness techniques, parents of children with IDD were able to better advocate for their children, which in turn decreased parent-school conflict and increased parents' positive outcomes for their children's education.

Rossen (2018) examines the possibility of integrating trauma-informed approaches with special education services as outlined in the 2004 Individuals with Disabilities Education Act. This study connects family engagement (communication, meetings, encouragement, participation) in the school setting with trauma-informed assessments (discussion of triggers, family histories, trust building processes, more inclusive IEP meetings). Findings support understanding that trauma-informed IEP planning can help build skill sets for individuals with disabilities such as self-regulation, predictable behavior, and promote peer assistance. Rossen calls for an acknowledgement of the role of trauma in the lives of students with disabilities and a recognition of how such trauma can impact learning and social environments throughout their lives.

Sometimes, advocating for students living with ASD requires parents to seek outside assistance. Burke and Goldman (2015) explore how and why families of students with ASD choose to pursue "procedural safeguards," such mediation and due process more often than families of students with other types of disabilities. Citing that these procedural safeguards are directly linked to provisions stipulated by IDEA, including the notion that all children should have access to a free and appropriate public education (FAPE), Burke and Goldman find that mediation and due process are crucial not only for advocacy, but can help parents, schools, and students with ASD resolve or mitigate conflict in mutually beneficial and creative ways. At the

same time, Burke and Goldman also point out that mediation and due process can add to parental frustration due to the technical language, paperwork, and bureaucratic hurdles associated with these interventions.

In a national, web-based survey of parents of children with IDD, Burke and Goldman (2015) found that parents who filed for due process or mediation in education matters were more likely to advocate for their child, have poor family-school partnerships, and have a greater household income. Parents were also more likely to utilize the safeguards of due process if their children were older, experiencing more internalizing behaviors, and were being educated in segregated placements (i.e., their children were not “mainstreamed” with other students). In some cases, due process and mediation can be expensive and unaffordable, discouraging families from advocacy services. In a national study, Ahearn (2001) found that 15 out of the 50 states lacked free, minimal/reduced-cost due process or pro bono attorneys for these cases. In a later national survey of state special education directors (Seven and Zirkel, 2002), only half of the directors indicated that parents had made arrangements for or had access to legal representation and this number decreased dramatically when parents were unable to afford representation. Considering how access to due process or mediation can contribute to conflict resolution, it is especially important for all parents, regardless of socioeconomic status, to have equal access to early and effective interventions.

On the whole, Burke and Goldman (2015) contend that utilizing procedural safeguards help to prevent additional familial stress in the future. Through their study, they found: (1) families that had negative or weak family-school relationships were more likely to utilize mediation and due process, (2) families use of procedural safeguards often corresponded to child classroom placement (parents wanted a more inclusive school setting for their child), (3) families of students with ASD who have more internalizing behavior were more likely to pursue mediation and due process because they worried schools would only work to address external behaviors, and (4) families with a more privileged socio-economic background and greater income pursued procedural safeguards more often.

Often, the stress and conflict associated with advocating for services and accommodations does not end when children with disabilities graduate from, or age out of, high school. Taylor and Seltzer (2011) discuss how the relationship between mothers and children with ASD is affected by an exit from high school. This longitudinal study collected data four times over seven years and found that relationships between mothers and youth with ASD after secondary school was generally a time of increased risk. Taylor and Seltzer found that unmet service needs after secondary school, including appropriate day activities and lack of occupational and/or educational activities created stress and conflict. Gender is important in influencing the quality of post-secondary relationships. Mothers and daughters with ASD tended to have better relationships after high school than mothers and sons with ASD. ID status (comorbidities) and family income (income-based disparities when it comes to accessing disability services), also contributed to increased family frustrations and stress.



Some people living with ID attend inclusive post-secondary educational programs. Harrison, Bisson, and Laws (2019) discuss how students with intellectual disabilities responded to inclusive postsecondary education programs (IPSE). IPSE programs are intended to provide additional support, academically and socially, to college-aged students living with ID by offering assistance in college courses and extracurricular activities. Harrison and colleagues found that college students also experienced a desired shift in attitude toward students with ID. IPSE increased awareness and knowledge about education and intellectual disability, but also contributed to a more positive assessment toward students with intellectual disabilities.

Beyer, Meek, and Davies (2016) studied the experience of students living with IDD who have transitioned from school to employment. Their research, focused specifically on the relationship between the Regional Special Education Needs Transition to Employment project and the employment of people with IDD and/or ASD, found that active parent/family support, job support coaches, and increased education and vocational training improved outcomes of individuals with IDD achieving successful employment. In particular, Beyer and colleagues emphasize that job coaches are crucial for providing effective support in the labor market, especially when family support is ambiguous or otherwise lacking.

Roux and colleagues (2013) discuss experiences of postsecondary employment of young adults with ASD, as compared to young adults with other disabilities. Using data from a longitudinal study of young adults who had received special education services and held paid jobs between the ages of 21-25, they analyze employment rates, wages, and job types. They found that young adults with ASD had the lowest rate of employment among disability groups, low wages compared to hours worked, and limited job availability. Roux and colleagues point to the need for occupational training and employment for students with ASD during high school and that without intervention, these employment patterns lead to increased stress related to financial hardship and inability to support themselves to live independently.

In another review of qualitative and quantitative research studies, Nevala and colleagues (2019) found that employment of people with intellectual disabilities contributes to important psychosocial and economic benefits, new friendships, increased self-determination and meaningful societal participation. Program services providing family support, specialized job-coaching, an accessible work environment, active employer intervention and accommodation, and postsecondary education can facilitate opportunities for individuals living with IDD to participate in the labor market.

An accounting of barriers to employment found that sheltered work, discrimination during vocational training, a lack of work experience and poor instruction led to frustration among individuals with ASD and impeded their own interests and goals.

Ham and colleagues (2014) discuss two case studies of young adults with ASD, Kristen and Darnell, who were able to find and keep employment. Their discussion of the career trajectory for both points to common factors in Kristen's and Darnell's successful employment. Those factors include services of a Positive Behavior Support Facilitator, collaborative, professional goal setting between employees with ASD and their employers, technology and



scheduling accommodations, and self-monitoring. The authors suggest that these interventions dramatically increase effective communication and successful employment in young adults with ASD.

### **Autonomy and Risk:**

Bigby, Whiteside, and Douglas (2019) conducted individual and focus group interviews with adults living with ID, their families, and support workers. to study the benefits of supported decision making among adults with ID. Their research found that interventions such as day-to-day support, shared, communicative relationships, the purposeful creation of opportunities for decision making, and taking a neutral and respectful position when listening to decisions of adults with ID allowed for all groups to feel supported while also acknowledging the risks that accompany such processes.

Dowling and colleagues (2019) studied the relationship between people with intellectual disabilities (ID) and personal assistants (PA) and/or support workers in order to analyze “relational autonomy,” or how people with ID and their support workers facilitate a specific kind of joint-decision making. Their research examined the “detail of nine hours of naturally occurring video-recorded interactions among nine individuals with ID and seven support staff members.” Selecting six extracts to illustrate different types of joint decision making, they focused on the ways in which: (a) future plans are discussed; (b) choices are offered during an activity; and (c) people reflect on their decisions. PAs or support workers identified options and the individuals with ID made choices based on those available options. Then together, PAs, or support workers, and individuals with ID discussed considerations and reflected upon how the person with ID was impacted by their decision process. Daily activities were found to give natural opportunities for teachable moments. Foregrounding any restriction or constraint on a decision was often appropriate and may help the person with ID make a good decision. Additionally, the study noted that supporting autonomy does not always equate with encouraging people living with ID to perform a task and contends that the relationship between individuals with ID and their support workers must be built on trust and mutual respect for the personal choices of individuals with ID.

Pelletier and Joussemet (2017) explore the benefits of autonomy support (AS) among individuals with mild ID in their personal lives. They found that encouraging problem-solving and learning new tasks decreased the amount of anxiety experienced during the task and improved both the emotional response and motivations of people living with ID during new tasks. Pelletier and Joussemet define AS in operational terms by four elements: (1) offering rationales with requests (i.e., explain the reason/value); (2) offering choices in a manner to accomplish a task; (3) being empathic towards the other person’s perspective (i.e., recognize and accept the thoughts and feelings of the person living with ID); and (4) avoiding controlling language and strategies (e.g., “you should,” threats, rewards, or guilt induction. (Koestner et

al.1984). Autonomy support (AS) among individuals with mild ID is accomplished through structure and through the internalization of these guiding principles by support workers.

Frielink and colleagues (2018) applied the “tenets” of self-determination theory (SDT) in the support of persons with ID who had a “mild to borderline level of functioning.” Two imperative constructs of SDT were identified as crucial in optimal human functioning: autonomy and relatedness. Autonomy support involves an environment that minimizes control and pressure while supporting self-initiatives, offering pertinent information, providing choices, and taking the other’s perspective (empathy). The need for relatedness involves feeling connected to and taking care of (and/or for by) other people. The need for relatedness (and competence) is vital for people to flourish, to experience subjective well-being, and to prevent maladaptive functioning, regardless of their level of intellectual functioning. SDT can support individuals living with ID and help others to further understand the need for satisfaction and motivation among individuals with ID. Frielink et. al. found that even the perception of autonomy was correlated with increased satisfaction, competence, and psychological well-being in persons living with ID. On the other hand, when individuals with ID felt that they did not possess autonomy, their motivation declined and they were less satisfied physically and psychologically. Frielink and colleagues conclude that SDT should be integrated into interventions for people living with ID, and that SDT will contribute to furthering their well-being and quality of life.

Realizing barriers that exist in relation to their independence, Sandjojo et. al. (2019) discuss how people with ID, support workers, and legal representatives can work together to provide more independence to adults with ID. The study found that while people with ID do require additional support and intervention in their lives, they also desire more autonomy than they currently possess. Sandjojo and colleagues found barriers to independence for people with ID include inadequate staff support, insufficient time to make decisions, overinvolvement of family members in decision making, and general cognitive and emotional difficulties experienced by people with ID. Their study determined that clear requirements and communication, ample time among the three groups to discuss goals and decisions, and individualized staff qualified to provide specific coaching and verbal feedback could increase the independence of people with ID.

Sandjojo and colleagues (2019) give examples of helpful questions for people with ID, legal representatives and support staff. For people with ID: “What do you think independence means?”; “Is there something that causes you not to be as independent as you would want?”; “What would be the advantages of more independence?”; and “Are there also downsides if you can do more yourself?” For support workers and legal representatives: “Would the people you are representing/supporting want to become more independent?”; “If so, what would they want to learn?”; “What are current barriers that hinder people with ID from becoming more independent?”; and “What is required in order to increase the level of independence of people with ID?” Sandjojo and colleagues also areas of competencies, responsibilities and skills in which people with ID have expressed their desire more independence: Grocery shopping,

handling finances, using public or own transportation, regular employment, having a family, living independently, and listening to others.

Benson and Fuchs (1999) interviewed adults with ID who displayed aggressive behavior at work and reported feeling anger when faced with co-worker conflict, negative interactions with supervisors, and at home with siblings/parents. When experiencing these interactions, those interviewed reported that they used coping responses such as aggression, avoidance, ignoring, or talking to someone about the problem. The study found that understanding the context of these coping responses can help to create intervention programs for adults with ID who demonstrate aggressive behavior, particularly at work. Some of these interventions to de-escalate conflict could be performed by staff, and include: separating workers in conflict, interrupting problem behavior like teasing, and implementing policies against bullying. Other interventions may be more appropriate for supervisors, such as providing feedback on tasks, giving individual verbal instructions, and providing opportunities for employees with ID to participate in role playing as a supervisor. Adults living with ID who display aggressive behavior at home or at work may benefit from behavioral interventions, like anger management or assertiveness training, in learning how to cope with frustrations and stress.

## CONCLUSION/SUMMARY

The number of people living with “intellectual and developmental disability” (IDD) in the United States is approximately 7 to 8 million. People living with IDD comprise 3% of the US population. About 2/3 or 66% of people with IDD live at home with their family. About 22% of people with IDD live in a supported residential setting with supervision. Approximately 14% of people with IDD live alone or with a roommate. These data correspond roughly with the finding that 75% of people with IDD rely on family support and approximately 25% of people with IDD receive services through Medicare or Medicaid.

In the United States and Canada, most studies involving people living with IDD focus on children and young adults defined as living on the autism spectrum or having “autism spectrum disorder” (ASD). Prolonged and significant stress of providing care for individuals with ASD can lead to moments of familial crisis. Challenging behaviors, emotional problems, school conflict, family adjustment, and expectations of advocacy can also precipitate crisis in families. Conflicts between siblings can lead to increased depressive symptoms and further external behavioral issues for adolescents with ID, but they also can have more positive outcomes. TD adolescents were able to learn from their experiences how to work out peer conflict in other settings outside the home, such as a school setting. Conflict and warmth between siblings with and without ID can facilitate an increase in social skills and the social competence of adolescents with ID as well. While family ability to cope and recalibrate to crisis changed as individuals with ASD aged, stress and crisis could be mitigated through support interventions.

Those interventions include specialized education and health care programs, early intervention services, and specialized training/vocational programs for adults with ASD. Interventions focused on supporting relationships of mothers with their children and wives with their partners, tended to reduce or eliminate emotional and behavioral “problems” for children with ASD. Studies find that the quality of support and communication is critical in determining

the quality of relationships in families. High-warmth and low-criticism families, or the “resilient family,” encourage and facilitate adaptive behavior and coping skills in children with ASD.

Supportive, positive relationships with open communications and appropriate and effective interventions designed to address, mediate or eliminate stress and conflicts within families living with IDD such as Acceptance and Commitment Therapy (ACT) help parents cope and adjust to raising their children. ACT workshops introduce and raise awareness, teach skills, and share knowledge, that help parents outline goals (individual and familial) and build competence to diffuse and address difficult emotions. Mindfulness-based approaches that promote and cultivate empathy between parent couples of children with ASD, and facilitate better parent-child relationships (Mindfulness Based Stress Reduction Program and/or Acceptance and Commitment Therapy (ACT)) are a valuable resource for both individuals and couples. The approach outlined in these programs should allow for the practice of forgiveness, emotional and personal growth, and self-compassion among individuals. It should also promote tolerance, nonjudgement and increased marital quality for couples. This approach is found to improve parental ability to more effectively cope with and manage stress related to having a child with ASD. Participants in such programs reported that receiving guidance and training in mindful parenting, situational awareness, and acceptance strategies contributed to reduced anxiety, depression, and stress among mothers of children with ASD and lowered rates of depression among fathers of children with ASD.

Living in the community can be difficult for people with IDD. Finding affordable, accessible, supportive housing and accessing transportation can be difficult. Access to transportation is critically important in determining levels of independence, overall quality of life, and general well-being for people living with IDD in the community. In addition to structural/environmental issues such as lack of efficient, reliable, safe, and wheelchair accessible public transit, access to transportation can be limited by inadequate training programs for people with IDD in using public transit. When people with IDD have friends, and are satisfied with the quality of those friendships, they are five times more likely to participate in the community. They are also approximately four times more likely to perform different social roles and have intimate relationships. (i.e., friendship improved quality of life, decreased loneliness, and increased inclusion). Making friends can be difficult, especially for people who require a higher level of care. People with IDD can consider paid support staff as friends. This can be confusing and damaging to relationships.

Going to school and finding employment when school is no longer an option can be difficult for students and families living with IDD. There are multiple ways parents and schools can reduce stress when planning a child’s education: listening to and incorporating parent’s goals into educational planning, considering family routines and levels of support when making student goals, focusing on relationships between schools and parents that are mutually productive and respectful (as a way to decrease power struggles), and re-centering and valuing trust between parents and educators can all help the planning process. It is helpful to view conflict as an opportunity to build constructive, positive behavior. Other approaches that can be used in preparation for or during IEP meetings include: report cards, journals, progress reports,

in-person communication, newsletters, appreciation events, parent-attended field trips, and parent-organized schoolwide activities. These are all good ways of improving communication among parents, teachers, and school administrators. Time and collaboration are crucial for the success of IEPs and child-centered approaches to education.

Mindfulness-based interventions, including focusing on the present moment, practicing nonjudgmental responses, and practicing purposeful attention may help reduce parental stress during IEP meetings. By implementing mindfulness techniques, parents of children with IDD may be better able to advocate for their children, which in turn can decrease parent-school conflict and increase parents' positive outcomes for their children's education. Although it is usually considered a last resort, especially for those people who cannot afford mediation or due process, access to due process or mediation can contribute to conflict resolution, it is especially important for all parents, regardless of socioeconomic status, to have equal access to early and effective interventions.

When children leave school, finding employment is often beneficial. Generally, active parent/family support, job support coaches, and increased education and vocational training improved outcomes of individuals with IDD achieving successful employment. Employment of people with intellectual disabilities can contribute to important psychosocial and economic benefits, new friendships, increased self-determination and meaningful societal participation. Program services providing family support, specialized job-coaching, an accessible work environment, active employer intervention and accommodation, and postsecondary education can facilitate opportunities for individuals living with IDD to participate in the labor market.

While people with ID do require additional support and intervention in their lives, they also desire more autonomy than they currently possess. Supporting the autonomy of people with intellectual disabilities and encouraging them to take risks is an important part of their development. Sometimes these situations can lead to conflict and stress. Supporting autonomy does not always equate with encouraging people living with ID to perform a certain task. Sometimes situations are more complicated. The relationship between individuals with ID and their support workers must be built on trust and mutual respect for the personal choices of individuals with ID. Even the perception of autonomy by people with ID is correlated with increased satisfaction, competence, and psychological well-being. On the other hand, when individuals with ID feel they do not possess autonomy, their motivation declines and they are less satisfied physically and psychologically. Barriers to independence for people with ID include inadequate staff support, insufficient time to make decisions, overinvolvement of family members in decision making, and general cognitive and emotional difficulties experienced by people with ID.



## Works Cited

- Ali, Afia, Katrina Scior, Victoria Ratti, Andre Strydom, Michael King and Angela Hassiotis. (2013). Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLOS One* 8, 8.
- Amado, Angela Novack, Roger J. Stancliffe, Mary McCarron and Philip McCallion. (2013). Social Inclusion and Community Participation of Individuals with Intellectual/Developmental Disabilities. *Intellectual and Developmental Disabilities* 51, 5, 360-375.
- American Community Survey. 2019. U.S. Census.  
<https://data.census.gov/cedsci/table?q=United%20States&t=Disability&tid=ACST1Y2019.S1810&hidePreview=false> (Accessed January 20, 2021).
- Americans with Disabilities Household Economic Studies. 2014. U.S. Census.  
<https://www.census.gov/content/dam/Census/library/publications/2018/demo/p70-152.pdf> (Accessed January 20, 2021).
- Atack, Lynda, Judy Versegny, Janet Maher, Marilyn Herie, Matthew Poirier, Frances MacNeil, and Michelle Grimley. (2019). An Emerging Model for Semi-Independent Living for Persons with Intellectual and Developmental Disabilities. *Inclusion* 7, 1, 57-70.
- Begum, Gazi and Jan Blacher. (2011). The Sibling Relationship of Adolescents with and without Intellectual Disabilities. *Research in Developmental Disabilities* 32, 5, 1580-1588.
- Benson, Betsey A. and Carola Fuchs. (1999). Anger-arousing situations and coping responses of aggressive adults with intellectual disability. *Journal of Intellectual and Developmental Disability* 24, 3, 207-214.
- =
- Beyer, Stephen, Andrea Meek, and Amy Davies. (2016). Supported work experience and its impact on young people with intellectual disabilities, their families and employers. *Advances in Mental Health and Intellectual Disabilities* 10, 3.
- Bigby, Christine, Emma Bould and Julie Beadle-Brown. (2017). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual & Developmental Disability* 42, 4, 309-319.
- Bigby, Christine, Mary Whiteside and Jacinta Douglas. (2019). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disability* 44, 4, 396-409.
- Bigby, Christine, Ruth Webber, and Barbara Bowers. (2015) Sibling roles in the lives of older group home residence with intellectual disability: Working with staff to safeguard well-being. *Australian Social Work* 68, 4, 453-468.



Blackledge, John T. and Steven C. Hayes. (2006). Using Acceptance and Commitment Training in the Support of Parents of Children Diagnosed with Autism. *Child & Family Behavior Therapy* 28, 1, 1-18.

Bluth, Karen, Patricia N. E. Roberson, Rhett M. Billen, and Juli M. Sams. (2013). A stress model for couples parenting children with autism spectrum disorders and the introduction of a mindfulness intervention. *Journal of Family Theory & Review* 5, (September): 194-213.

Boström, P. K. and M. Broberg. (2014). Openness and avoidance – a longitudinal study of fathers of children with intellectual disability. *Journal of Intellectual Disability Research* 58, 9, 810-821.

Buchanan, Rohanna and Miriam Clark. (2017). Understanding Parent-school Communication for Students with Emotional and Behavioral Disorders. *The Open Family Studies Journal* 9, 122-131.

Burke, Meghan M. and Samantha E. Goldman. (2015). Identifying the associated factors of mediation and due process in families of students with autism spectrum disorder. *Journal of Autism Development and Disorders* 45, 1345-1353.

Burke, Meghan M., Neilson Chan, and Cameron L. Neece. (2017). Parent Perspectives of Applying Mindfulness-Based Stress Reduction Strategies to Special Education. *Intellectual and Developmental Disabilities* 55, 3, 167-180.

CDC. Using Medicaid Data to Characterize Persons with Intellectual and Developmental Disabilities in Five U.S. States. <https://www.cdc.gov/ncbddd/disabilityandhealth/features/kf-medicaid-data-disabilities.html> (Accessed January 20, 2021).

Dowling, Sandra, Val Williams, Joe Webb, Marina Gall, Deborah Worrall. (2019). Managing relational autonomy in interactions: People with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 32, 1058-1066.

DOJ. n.d. “The ADA Mediation Program: Questions and Answers,” Civil Rights Division, Disability Rights Section.

(DREDF) published, “Behavior is Communication: A Guide for Advocates and Families on Positive Behavior Interventions and Supports (PBIS) in School.” (June 8, 2019). <https://dredf.org/behavior-is-communication-a-guide-for-advocates-and-families-on-positive-behavior-interventions-supports-pbis-in-school/> (Accessed January 18, 2021).

Eastgate, Gillian, Mieke L. Van Driel, Nicholas G. Lennox and Elly Scheermeyer. (2011). Women with intellectual disabilities – a study of sexuality, sexual abuse, and protection skills. *Australian Family Physician* 40, 4, 226-230.

Empower-WNY. <https://empower-wny.org/wp-content/uploads/2016/08/Fact-Sheet-final3.pdf> (Accessed January 20, 2021).

Floyd, Frank J., Susan E. Purcell, Shana S. Richardson and Janis B. Kupersmidt. (2009). Sibling relationship quality and social functioning of children and adolescents with intellectual disability. *American Journal of Intellectual and Developmental Disabilities* 114, 2, 110-127.

Focht-New, Ginny, Paul T. Clements, Beth Barol, Martha J. Faulkner and Kathryn Pekala Service. (2008). Persons with Developmental Disabilities Exposed to Interpersonal Violence and Crime: Strategies and Guidance for Assessment. *Perspectives in Psychiatric Care* 44, 1, 3-13.

Friedman, Carli and Mary Rizzolo. (2018). Friendship, Quality of Life, and People with Intellectual and Developmental Disabilities. *Journal of Developmental and Physical Disabilities* 31, 1, 39-54.

Friedman, Carli and Mary Rizzolo. (2016). The State of Transportation for People with Intellectual and Developmental Disabilities in Medicaid Home and Community-Based Services 1915© Waivers. *Journal of Disability Policy Studies* 27, 3, 168-177.

Frielink, Noud, Carlo Schuengel, and Petri J. C. M. Embregts. (2018). Autonomy Support, Need Satisfaction, and Motivation for Support Among Adults with Intellectual Disability: Testing a Self-Determination Theory Model. *American Journal on Intellectual and Developmental Disabilities* 123, 1, 22-49.

Ham, Whitney, Jennifer McDonough, Alissa Molinelli, Carol Schall, Paul Wehman. (2014). Employment supports for young adults with autism spectrum disorder: Two case studies. *Journal of Vocational Rehabilitation* 40, 2, 117-124.

Harrison, Ashley J., Jennifer B. Bisson, and Carol B. Laws. (2019). Impact of Inclusive Postsecondary Education Program on Implicit and Explicit Attitudes Toward Intellectual Disability. *Intellectual and Developmental Disabilities* 57, 4, 323-336.

Hartley, Sigan L. and William E. MacLean, Jr. (2008). Coping Strategies of Adults with Mild Intellectual Disability for Stressful Social Interactions. *Journal of Mental Health Research in Intellectual Disabilities* 2, 109-127.

Hickey, Emily J., Robert Nix, and Sigan L. Harley. (2019). Family Emotional Climate and Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 49, 8, 3244-3256.

Jones, Leah, Richard Patrick Hastings, Vasiliki Totsika, Lisa Keane and Neisha Rhule. (2014). Child Behavior Problems and Parental Well-Being in Families of Children With Autism: The Mediating Role of Mindfulness and Acceptance. *American Journal of Intellectual and Developmental Disabilities* 119, 2, 171-185.

Laghi, Fiorenzo, Antonia Lonigro, Susanna Pallini, Ambra Bechini, Alexandra Gradilone, Graziana Marziano and Roberto Baiocco. (2018). Sibling Relationships and Family Functioning

in Sibling of Early Adolescents, Adolescents and Young Adults with Autism Spectrum Disorder. *Journal of Child and Family Studies* 27, 793-801.

Lake, Jeannie F. and Bonnie S. Billingsley. (2000). An Analysis of Factors That Contribute to Parent-School Conflict in Special Education. *Remedial and Special Education* 21, 4, 240-251.

Minnes, Patricia, Lynn Woodford and Jennifer Passey. (2007). Mediators of Well-being in Ageing Family Carers of Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 20, 539-552.

Nevala, Nina, Irmeli Pehkonen, Antti Teittinen, Hannu T. Vesala, Pia Pörtfors, and Heidi Anttila. (2019). The Effectiveness of Rehabilitation Interventions on the Employment and Functioning of People with Intellectual Disabilities: A Systematic Review. *Journal of Occupational Rehabilitation* 29, 773-802.

Pelletier, Julie Emond and Mireille Joussemet. (2017). The Benefits of Supporting the Autonomy of Individuals with Mild Intellectual Disabilities: An Experimental Study. *Journal of Applied Research in Intellectual Disabilities* 30, 5, 830-846.

Rossen, Eric. (2018). Creating trauma-informed individualized education programs: Integration of ACEs into the development of IEPs for students through grade 12. *American Psychological Association*. <https://www.apa.org/pi/families/resources/newsletter/2018/11/trauma-teaching>

Roux, Anne M., Paul T. Shattuck, Benjamin P. Cooper, Kristy A. Anderson, Mary Wagner, and Sarah C. Narendorf. (2013). Postsecondary Employment Experiences Among Young Adults With an Autism Spectrum Disorder RH: Employment in Young Adults with Autism. *Journal of the American Academy of Child & Adolescent Psychiatry* 52, 9, 931-939.

Sandjojo, Janice, Winifred A. Gebhardt, Aglaia M. E. E. Zedlitz, Joop Hoekman, Jeanet A. den Haan and Andrea W. M. Evers. (2019). Promoting Independence of People with Intellectual Disabilities: A Focus Group Study Perspectives from People with Intellectual Disabilities, Legal Representatives, and Support Staff. *Journal of Policy and Practice in Intellectual Disabilities* 16, 1, 37-52.

Schaafsma, D, G. Kok, J. M. T. Stoffelen, and L. M. G. Curfs. (2017). People with Intellectual Disabilities Talk About Sexuality: Implications for the Development of Sex Education. *Sexuality and Disability* 35, 21-38.

Staples, Kelli E. and Jennifer A. Diliberto. (2010). Guidelines for Successful Parent Involvement: Working with Parents of Students with Disabilities. *TEACHING Exception Children* 42, 6, 58-63.

Taylor, Julie Lounds and Marsha Mailick Seltzer. (2011). Changes in the Mother-Child Relationship During the Transition to Adulthood for Youth with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders* 41, 10, 1397-1410.

Wheeler, Jessica R., William R. Lindsay, and Isabel C.H Clare. (2018). Community services for offenders or alleged offenders with intellectual disabilities. William R. Lindsay and John L. Taylor, editors, *The Wiley Handbook on Offenders with Intellectual and Developmental Disabilities: Research, Training, and Practice*. 407-420.

White, Stacy E., Carly McMorris, Jonathan A. Weiss and Yona Lunskey. (2012). The Experience of Crisis in Families of Individuals with Autism Spectrum Disorder Across the Lifespan. *Journal of Child and Family Studies* 21, 457-465.