![United States Consumer Product Safety Commission]

**CPSC Staff Statement on Fors Marsh Group Report,
"Consumers with Intellectual and Developmental Disabilities: Review
Investigating Safety Behaviors, Perspectives, and Attitudes"[1]
September 2021**

The report titled, "Consumers with Intellectual and Developmental Disabilities: Review Investigating Safety Behaviors, Perspectives, and Attitudes," presents the results of a literature review and environmental scan conducted by Fors Marsh Group (FMG) to determine whether individuals with intellectual and developmental disabilities (IDDs) are exposed to unique safety hazards from consumer products.

Somewhere between 7 and 8 million people in the United States have an IDD diagnosis, which can encompass a range of intellectual, developmental, physical, and behavioral experiences (Reynolds et al., n.d.). The most common IDDs documented in the United States are cerebral palsy, autism spectrum disorder (ASD), and Down syndrome (Mai et al., 2019; Zablotsky et al., 2017).

Findings from the literature review reveal that the IDD population experiences life expectancies that are about 20 years lower than the general population and mortality rates that are approximately 10 percent to 50 percent greater than the general population.

Those with IDDs are at greater risk of injury and death from the everyday hazards posed by consumer products, notably those found in the home, compared to those without IDDs (Finlayson et al., 2010). According to one study, about 75 percent of injuries to young individuals with IDDs occur within the home (Sherrard et al., 2002). Product hazards are prevalent within the home. Uneven or slippery surfaces, as well as miscellaneous small parts (*e.g.*, stray pen caps, loose change, refrigerator magnets), pose a risk for falls, ingestion, and choking, even in the most vigilant homes. For individuals with IDDs who have greater personal independence, burns from water or kitchen appliances are a regular risk as well.

Outside the home, drowning and wandering away from supervision remain worrisome risks for individuals with IDDs, who have significant mobility or greater independence. An unsupervised individual with an IDD may be unable to communicate his or her distress to others if drowning or experiencing a consumer product-related injury (*e.g.*, a fall, laceration, ingestion, choking, or burn). Such communication disconnects make it difficult to mitigate these types of incidents.

Findings from the environmental scan highlight the importance of caregivers as primary safety providers for individuals with IDDs. Caregivers are often the ones who produce and share important safety-related information (*e.g.*, through online blogs) for individuals with IDDs. The majority of government and nonprofit organizations that support safety for individuals with IDDs orient their information toward caregivers.

Additionally, FMG conducted in-depth interviews with stakeholders from the IDD community (in the areas of education, health care, caregiving, play, and product manufacturing). Overall, many of those interviewed articulated some of the same product safety concerns revealed in the literature

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[1] This statement was prepared by the CPSC staff, and the attached report was produced by Fors Marsh Group for CPSC staff. The statement and report have not been reviewed or approved by, and do not necessarily represent the views of, the Commission.

review and environmental scan, including falling, choking, and safety risks associated with communication difficulty.
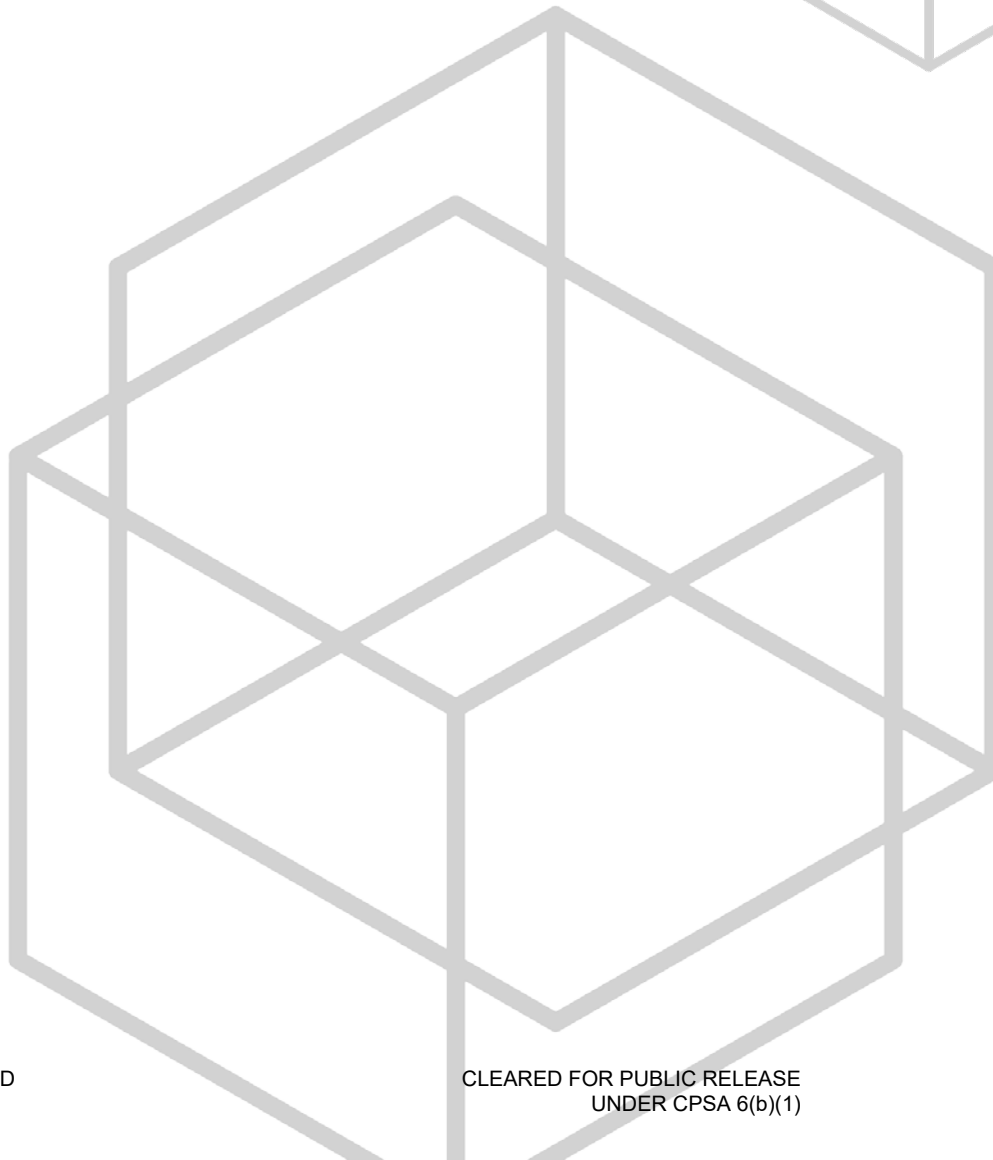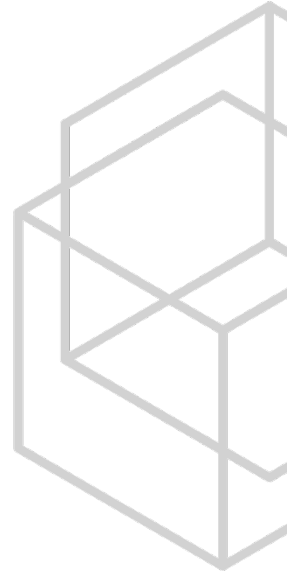
Staff intends to build upon this initial report, conducting further research into the hazards to consumers with disabilities, and to use the results to inform standards development and information and education campaigns.

Attachment

FMG Report: "Consumers with Intellectual and Developmental Disabilities: Review Investigating Safety Behaviors, Perspectives, and Attitudes"

Consumers with Intellectual and Developmental Disabilities: Review Investigating Safety Behaviors, Perspectives, and Attitudes

September 13, 2021

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Introduction

Study Background

Somewhere between 7 and 8 million people in the United States have an intellectual or developmental disability (IDD), a diagnosis that encompasses a range of intellectual, developmental, physical, and behavioral experiences (Reynolds et al., n.d.). The most common IDDs documented in the United States are cerebral palsy, autism spectrum disorder (ASD), and Down syndrome (Mai et al., 2019; Zablotsky et al., 2017). Due in part to omissions in public health efforts, individuals with IDD experience numerous health disparities (Anderson et al., 2013). Such disparities include decreased life expectancy and greater rates of oral health and obesity-related conditions. Individuals with IDD are also at a greater risk of falls, drowning, burns, choking, ingestion, and furniture tip-over as compared to those without IDD (Hsieh et al., 2012; Lauer & McCallion, 2015; Pearn & Franklin, 2013; Yung et al., 2014).

Furthermore, those with IDD are at a greater risk of injury and death from the everyday hazards posed by consumer products, notably those found in the home, compared to those without IDD (Finlayson et al., 2010). According to one study, about 75% of injuries to young individuals with IDD occur within the home (Sherrard et al., 2002). Between 2009 and 2017, there was a reported increase (16.2% to 17.8%) in the diagnosis of IDD among 3- to 17-year-olds. While partly explained by improved screening of IDD, this uptick indicates a growing need for consumer product safety information for those with IDD, their caregivers, and key supporters of this community (Zablotsky et al., 2019; Zablotsky & Black, 2020). Additional research is needed to determine the categories of risk that are the most common within and outside of the home (Finlayson et al., 2010).

The U.S. Consumer Product Safety Commission (CPSC) 2018–2022 Strategic Plan asserts the importance of improving the identification of hazards for consumers and the communication of consumer product safety information. Goals 2–4 of CPSC's Strategic Plan underscore the importance of providing effective safety information and resources to individuals with IDD and their caregivers. Developing meaningful safety interventions and product guidelines for those with IDD and their caregivers is a critical next step in improving the well-being of this population.

Topic History

Comprehensive product safety messaging is of the utmost importance, as an increasing number of individuals with IDD live on their own (S. A. Larson et al., 2014). Legislation, including the Community Mental Health Act (CMHA) of 1963, kickstarted the movement of allowing individuals with IDD to leave hospitals and institutions and move back into their communities (*An Act to Provide Assistance in Combating Mental Retardation through Grants for Construction of Research Centers and Grants for Facilities for the Mentally Retarded and Assistance in Improving Mental Health through Grants for Construction and Initial Staffing 1963—S. 1576*, n.d.). As a result, in 2011, as many as 460,597 individuals with IDD received residential services, compared to 267,682 individuals in 1988 (Lakin et al., 2003; S. Larson et al., 2013). In the future, one can anticipate that adults with IDD will continue to move away from parental homes and into residential facilities. However, there are significant gaps in the academic research on product-related safety risks in and outside their homes. In the absence of academic research, advocacy organizations have been at the forefront of providing guidance for individuals with IDD and their families on how to reduce exposure to and injury from product-related hazards.

Individuals with IDD have historically lacked inclusion within society at large and continue to face significant challenges on these fronts today (Karten, 2008). Only more recently have those with IDD begun to share their own experiences and language preferences. Beginning in the 1970s, IDD activists advocated for the use of terms such as "developmentally disabled" and "intellectually

disabled" to replace terms that were commonly used at the time (e.g., "mentally retarded" and "mentally handicapped") (Government of Ontario, n.d.). Certain terms that were proposed are more common in some settings than others (e.g., "special needs" in educational environments; Karten, 2008). Certain instances of "mentally retarded" can be found in literature written as recently as the early 2000s (Sherrard et al., 2001). Therefore, some of the literature in this review may include language that is no longer considered appropriate by the IDD community. Although we will not refer to the IDD community in this manner in our summation of the literature, we feel it is important to acknowledge that articles that do will be present in our references. Findings from these articles may require some additional caveats regarding the implicit or explicit biases of the researchers.
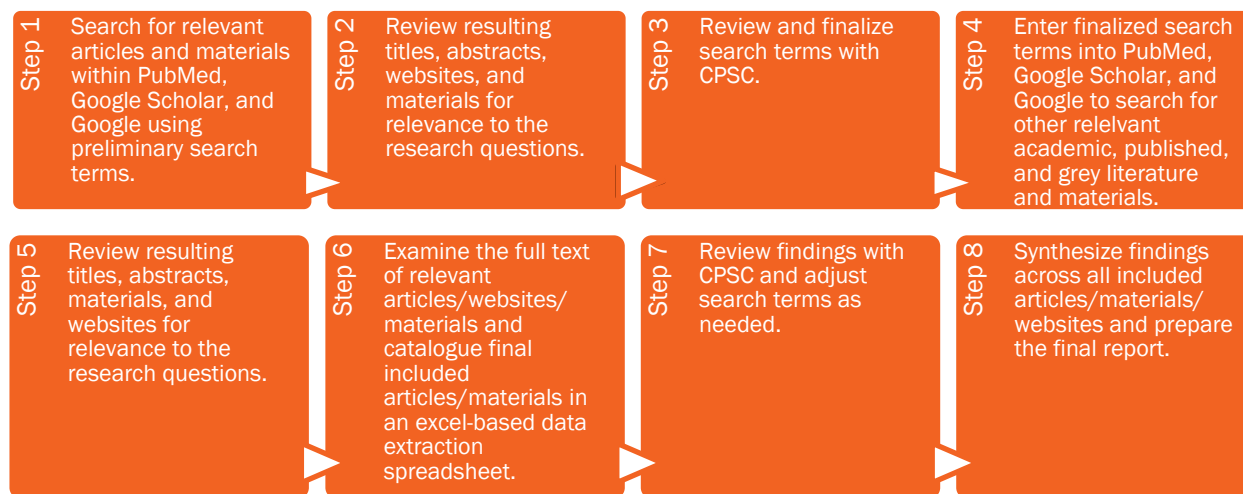
Additionally, it is important to remember that "IDD" itself is also used as an "umbrella" term. That is, IDD is a category that encompasses a diverse set of physical, intellectual, and/or developmental experiences and diagnoses. Ultimately, certain categories of IDD experience have received greater attention than others in the literature. For instance, ASD, attention-deficit/hyperactivity disorder (ADHD), and Down syndrome are comparatively well-represented in safety research, whereas Tourette syndrome (TS) or Fragile X syndrome (FXS) are less represented. As a result, even the most cross-cutting findings in this report will disproportionately draw on knowledge of ASD, ADHD, and Down syndrome.

Methodology

FMG conducted a literature review and environmental scan to determine whether individuals with IDD are exposed to unique safety hazards from consumer products. Additionally, the environmental scan sought to (a) identify organizations offering insight into characteristics that may put individuals with IDD at higher risk for injuries from consumer products (b) understand how these organizations address risks, and (c) highlight gaps in current outreach to individuals with IDD and their families. Findings from the literature review and the environmental scan reveal a clear need for effective messaging on safety information. FMG has also compiled recommendations for strategies on how to best communicate risks to the IDD community in a separate recommendations document.

FMG employed a systematic approach to ensure that the most relevant articles, websites, and materials were included in the literature review and environmental scan (see Figure 1).

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Figure 1: Literature Review and Environmental Scan Process

Step 1	Search for relevant articles and materials within PubMed, Google Scholar, and Google using preliminary search terms.	Step 2	Review resulting titles, abstracts, websites, and materials for relevance to the research questions.	Step 3	Review and finalize search terms with CPSC.	Step 4	Enter finalized search terms into PubMed, Google Scholar, and Google to search for other relelvant academic, published, and grey literature and materials.
Step 5	Review resulting titles, abstracts, materials, and websites for relevance to the research questions.	Step 6	Examine the full text of relevant articles/websites/materials and catalogue final included articles/materials in an excel-based data extraction spreadsheet.	Step 7	Review findings with CPSC and adjust search terms as needed.	Step 8	Synthesize findings across all included articles/materials/websites and prepare the final report.

FMG developed search terms that yielded relevant literature, websites, and materials. FMG first tested broad search terms (e.g., Intellectual disability safety hazards/constraints) and then gradually tested more specific terms (e.g., Intellectual disability safety continuum of care/health care provision). Through this process of refinement, FMG identified terms that produced the results most relevant to the research questions. FMG presented to CPSC a list of articles gleaned from this search process for their review. CPSC and FMG came to an agreement on the final search terms for the literature review and environmental scan (Appendix A: Literature Review and Environmental Scan Search Terms).

Research questions for the literature review and environmental scan are outlined below:

Literature Review Research Questions

1. What types of injuries are most prevalent for individuals with IDD?
2. What unique risk factors for harm/injury exist for individuals with IDD?
3. What are common knowledge, attitudes, and behaviors related to consumer safety for those with IDD and their caregivers?
4. What are known barriers and/or facilitators for safety for individuals with IDD?
5. What stakeholder (e.g., individuals with disabilities/self-advocates, physician, caregiver) strategies exist for assessing product safety for individuals with IDD?
6. What evaluations of safety interventions exist for products used by individuals with IDD?
7. What gaps in product safety research exist for individuals with IDD?

Environmental Scan Research Questions

1. What are the most trusted/used/valued organizations by the IDD community?
2. Where do these organizations have the greatest investment (by risk type/IDD type)?
3. What is the nature of the support being given (videos, trainings, toolkits, etc.)?

Literature Review

FMG thoroughly reviewed academic, published, and grey literature through PubMed, Google Scholar, and additional academic databases using the approved key search terms. Grey literature refers to unpublished information that has not been through peer review. Government reports,

conference proceedings, technical papers, and theses and dissertations are all examples of grey literature. To ensure that we captured the latest research, FMG set a date range of 10 years (2010–2020) as a criterion for the literature review. FMG made exceptions for any seminal articles in the field published prior to this date range. FMG assessed the article titles and abstracts of all search results for relevance to the research questions. FMG then examined the full text of relevant articles. We included a total of *N* = 133 articles in the final literature review.

After assessing an article's alignment to the research questions, the team made a final decision to include or exclude the article. FMG included articles that discussed product safety or hazards for the IDD community. To fill in gaps, we also included articles about product hazards for individuals with *any* type of disability. We then cataloged all articles selected for inclusion in a Microsoft Excel-based data extraction spreadsheet. The extraction spreadsheet captures the following information for each article: (1) author(s); (2) publication year; (3) publication title; (4) journal title; (5) journal volume, issue, and page numbers; (6) key topics/keywords; (7) study design/methodology; (8) sample characteristics; (9) a concise summary statement of main article findings; and (10) any limitations of the study.

Environmental Scan

Using the approved search terms, FMG researchers conducted Google searches with the goal of finding organizations with expertise in the consumer product safety experiences of individuals with IDD. A team of researchers scanned through the search results to (1) identify relevant organizations, (2) catalog how the identified organizations address consumer product risks to the IDD community, and (3) highlight gaps in current communications outreach from the organizations. FMG included websites and/or materials that provided pertinent information to the environmental research questions. We then catalogued the most relevant materials (*N* = 51) in a Microsoft Excel file and captured the following information for each source: (1) the justification for inclusion, (2) the URL, (3) the focus/mission, (4) the specific expertise relevant to IDD, (5) the language and origin, (6) the affiliation (e.g., research agency, author, etc.), (7) the primary media type (e.g., print, digital, television), (8) the content type (e.g., blog post, YouTube video, study, report, website, etc.), (9) the intended audience (e.g., individuals with IDD), (10) the intention/designated use, (11) push/pull (e.g., pulling the audience to do something or pushing the audience information/stating facts), (12) the call to action, and (13) the overall readability level.

In-Depth Interviews (IDIs)

FMG conducted eight 60-minute virtual in-depth interviews (IDIs) with stakeholders from the IDD community to further understand the risk and contextual factors that influence consumer product safety for the IDD population. FMG approached IDI recruitment with the goal of soliciting a wide range of diverse backgrounds and expertise. IDI participants fell under one of the categories listed in Table 1. Categories were prioritized to ensure that a wide range of perspectives and experiences within the IDD community were heard and incorporated into the conversation. To recruit the sample for this study, FMG's research team called the stakeholders to gauge their overall interest in participating. The interviews fielded from May 4, 2021, through August 12, 2021. Each participant received a $150 incentive as a token of appreciation for their time.

Table 1. Participant Professions and Industries

Participant #	Professional Title	Industry/Area of Expertise
1	Special Education Specialist	Special Education
2	Behavior Specialist	Special Education
3	Caregiver	Home and Family Care
4	Caregiver	Home and Family Care
5	Health Care Provider	Internal Medicine

6	Health Care Provider	Internal Medicine
7	Adaptive Apparel Designer	Manufacturing
8	Play Specialist and Consultant	Special Education/Play Specialist

FMG developed the IDI discussion guide to assess: (1) what circumstances make someone with IDD more at risk of harm from product hazards; (2) how have/could individuals adjust their use of potentially hazardous products to decrease likelihood of incidents; (3) what strategies for communicating product safety are most or least effective for various stakeholder groups (those with IDD, their caregivers, health care providers [HCPs], manufacturers, etc.); and (4) what messages (or messaging strategies) might be effective for communicating product safety to key stakeholder groups (those with IDD, their caregivers, HCPs, manufacturers, etc.) Additionally, the guide was designed to cover four main topic areas throughout the conversation: general knowledge about product design and safety for the IDD community, barriers and facilitators to supporting the IDD community, communication and messaging with the IDD community, and the future priorities for supporting IDD communities.

A trained notetaker was present for and listening to each interview to ensure that the moderator could fully focus on the participant. Once all interviews were completed, trained qualitative analysts reviewed the notes from the IDI discussions and identified key themes.

Overview of Findings

Early on in this effort, it became clear that no studies have been conducted about how specific consumer products (e.g., toaster, vacuum, laundry detergent) commonly result in injury to individuals with IDD. Instead, most of the literature found in response to the research questions focuses on broad categories of injury (e.g., falls, burns, drowning) that this community experiences and how to best address or prevent them. As such, this literature review focuses first on overall trends in morbidity and mortality for those with IDD. It then outlines what is known about major categories of injury. To further supplement these findings, this review also includes findings from literature about those whose intellectual and developmental challenges are a result of a traumatic occurrence, such as a traumatic brain injury (TBI). Although those with TBI experience intellectual or developmental challenges for different reasons than those with IDD, the types of consumer product safety risks they face can be very similar (e.g., limited proprioception, difficulties with speech production). Given the relative paucity of literature related to specific consumer product safety risks for those with IDD, we have included consumer product safety literature for this population as an additional reference point for this discussion.

The environmental scan findings focus largely on organizations that support the IDD community by sharing information, resources, and educational tools with families and parents. Notably, the environmental scan revealed that caregivers and families, more so than individuals with IDD, are the intended audience for these organizations' communications. Further underscoring the importance of caregivers within the landscape of online IDD-related information, the environmental scan also reported on the caregiver-generated content in the form of "mommy blogs," or parenting blogs. In these blogs, parents and/or caregivers of individuals with IDD provide parenting tips and offer their perspectives on the daily struggles that individuals with IDD and their families encounter. The environmental scan also charted major developments in current events related to IDD, including policies that are being implemented to support the safety of individuals with IDD in their homes and the effects of COVID-19 on individuals with IDD.

IDI findings provide essential context around how those with IDD and their caregivers encounter everyday consumer products. FMG conducted interviews with those in education, health care, caregiving, and product manufacturing. These conversations revealed a range of specific product safety risks that were not uncovered through the literature review or environmental scan. At the same time, the interviews further serve to verify key findings from those two endeavors. Overwhelmingly, interviewees expressed a strong desire for practical information about how to better manage product safety risks for those with IDD.

Literature Review Findings

The health and safety of individuals with IDD is improving. Individuals with IDD are living longer, having more diverse experiences, and living independently more often. Although many individuals with IDD still rely heavily on others for basic caretaking and decision-making, the improved life outcomes for this population underscore the need to review the current body of research on the safety experiences of individuals with IDD.

Overall Trends

Over the last few decades, morbidity and mortality rates for those with IDD have improved. While health outcomes for those with IDD continue to lag behind those of the general population, communities and social institutions are paying greater attention to improving such outcomes for those with IDD.

Mortality

The life expectancy of those with IDD is lower, and their mortality rate is greater, than that of the general population (Kirpke, 2018; Lauer & McCallion, 2015). The IDD population experiences life expectancies that are about 20 years lower than the general population and mortality rates that are approximately 10–50% greater than the general population. A recent systematic review of studies (N = 53) with the IDD population demonstrates that standardized mortality ratios for children and adults with IDD are three to four times higher than those of the general population (Bourke et al., 2017).

Despite these sobering differences, the mean age of death for individuals with IDD has risen significantly in the last several decades and continues to improve (Lauer & McCallion, 2015). In the 1930s, the mean age of death for this population was 19 years. Current estimates suggest that it is now 66 years. Furthermore, the increase in life expectancy for those with IDD parallels the trends found in the general population, with the exception of those with severe and/or multiple IDD (Coppus, 2013). Even a few decades ago, middle and old age were not recognized as distinct age groups for this population. Now, they are now considered to be important life stages for those with IDD. Currently, older individuals with IDD constitute a small, but significant proportion of older individuals in this community (Coppus, 2013). According to the CDC, approximately 5 million adults over 65 years of age live with some sort of cognitive or intellectual disability (Okoro et al., 2018). Researchers have attributed increases in life expectancy for those with IDD to changes at the social level, including work done by community organizers and to supportive policies (Coppus, 2013).

Morbidity

Due to higher incidence of co-occurring conditions and proneness to injury, individuals with IDD are at a much greater risk of increased morbidity than the general population. Furthermore, those with IDD can struggle to articulate their health experiences to caregivers and professionals, impeding accurate and timely diagnosis (May & Kennedy, 2010). Symptoms related to ADHD are the most frequently co-occurring disability for youth with learning disabilities (Stanford & Hynd, 1994). One study (N = 457) demonstrated that approximately 30% of children and adolescents with IDD meet the criteria for a comorbid ADHD diagnosis (e.g., Willcutt et al., 2010). Another study found that children with ASD, ADD/ADHD (N = 102,353) were 2–3 times more likely than unaffected controls to experience an injury that needs medical attention (Lee et al., 2008). Such potentially fatal hazards as falls, choking, burns, drowning, poisoning, and wandering all pose greater injury risk to those with IDD than those without IDD (Hsieh et al., 2012; Lauer & McCallion, 2015; Pearn & Franklin, 2013; Yung et al., 2014). One study among adults with IDD (N = 511) showed that incidence of one injury in a 12-month period was 20.5% (105), of which 12.1% (62) was due to falls (Finlayson et al., 2010). Adults with IDD experience a higher rate of injuries, falls, and hospitalizations compared to the general population (Finlayson et al., 2010).

Categories of Risk and Hazard

Individuals with IDD face risks that overlap with the hazards that the general population, particularly young children and aging adults, face. In the following section, we will explore categories of risk and hazard that affect individuals with IDD both inside and outside the home. While this section primarily draws from research about individuals with IDD, in some cases we present analogous insights from research conducted with young children and aging adults.

Falls

Fall-related injuries are by far the most common types of injuries experienced by individuals with IDD (Willgoss et al., 2010). According to one study, falls are the cause of 50–62% of all recorded injuries for individuals with IDD (Willgoss et al., 2010). The onset of falls happens at an earlier age for those with IDD than for the general population (Pal et al., 2014). Adults with IDD are more likely

to fall more frequently than the neurotypical population. Adults with IDD are more likely than the general population to fall during a hygiene-specific activity (e.g., showering, shaving) or while eating. This population is also more likely to injure their head or legs and to receive superficial injuries such as open wounds (Finlayson et al., 2010). Further, the National Survey of Children's Health (NSCH) survey found that 17% of children who reported having an intellectual disability have serious difficulty walking or climbing stairs, which puts them at a higher risk for injury (Child and Adolescent Health Measurement Initiative, 2019).

Research suggests that there are three types of risk factors for falls among individuals with IDD: individual (e.g., impaired mobility, urinary incontinence), behavioral (e.g., limited attention span), and environmental factors (e.g., slippery floors, uneven pathways; Cahill et al., 2014; Finlayson et al., 2010). One study demonstrates that a substantial portion of the IDD population have one or more individual risk factors that put them at risk for falls: difficulties with verbal communications (55%), epilepsy (32%), orthopedic-related conditions (21%), and problems with balance (24%) (Pal et al., 2014).[1] Individuals with IDD can improve balance and gait capacities, suggesting that exercise interventions may reduce falls in the IDD population (Enkelaar et al., 2012).

Choking

Because individuals with IDD tend to frequently put non-food items in their mouths, swallowing impairments predict increased morbidity and mortality in this population (Thacker et al., 2008). A survey of caregivers of adults with learning disabilities (N = 674) found greater occurrence of choking among individuals with severe learning disabilities, those with Down syndrome, those with incomplete dentition, or those taking a large number of psychotropic drugs (Thacker et al., 2008). Regardless of the severity of disability, adults with IDD have a higher risk of death from choking, defined as "aspiration, ingestion, or inhalation of gastric contents, food, or other objects" (Landes et al., 2021).

Of note, a significant portion of choking cases for all children, not just those with IDD, involve foods and latex balloons (Cyr et al., 2012). Virtually all deaths and serious injuries from choking are preventable, and particularly incidents of choking in the first four years of life (Cyr et al., 2012).

Swallowing Magnets

Magnets can be extremely harmful if ingested and are deemed a hazard for young children. Young children often put non-food objects in their mouth and sometimes even digest those objects (Nonfatal Choking-Related Episodes Among Children---United States, 2001, n.d.). Objects typically pass through the digestive system safely, but this is not the case with high-powered magnets. When multiple magnets are swallowed along with a metal object, the objects attract each other and can cause significant internal damage. Damage from swallowing magnets can include bowel perforation, bowel obstruction, and necrosis (De Roo et al., 2013).

Some children's toys contain small, high-powered magnets. These include "Magnetix" building sets and "Polly Pocket" magnetic playsets. After numerous incidents related to magnets and a death involving Magnetix, the manufacturers entered into joint recalls with CPSC to recall the products in 2006 (Child's Death Prompts Replacement Program of Magnetic Building Sets, 2006; Serious Injuries Prompt Recall of Mattel's Polly Pocket Magnetic Play Sets, 2006). A 2013 study found that only half of the rare-earth magnet-related incidents with children came from toys designed for use by children (49.3%). The other half were from products intended for adults (50.7%) (De Roo et al.,

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[1] In this study, difficulties with verbal communications were a common risk factor for individuals who experienced falls and not identified as a cause of the falls per se.

2013). CPSC issued a Notice of Proposed Rulemaking after identifying that the injuries were from items, such as magnet sets, specifically marketed to adults. The notice banned all magnetic toy and entertainment sets that contain more than one magnet small enough to fit within a small parts test device, unless the magnets have a flux index of 50 kG2 mm2 or less (Final Rule, 2014). Recently, CPSC took another major step in preventing further high-powered magnet injuries among children: In August 2021, CPSC issued a mandatory recall on high-powered magnetic balls sold under the brand Zen Magnets and Neoballs magnets, which are manufactured by Zen Magnets, LLC. CPSC issued the mandatory recall due to ingestion hazards. Ingestion of Zen Magnets has resulted in significant injury among children and teenagers, and one child died after ingesting similar high-powered magnets. However, there are likely numerous items, whether marketed to children or adults, that contain dangerous, small high-powered magnets in homes across the world.

Research indicates that children with a disability may be at greater risk for swallowing magnets. A study that reviewed 20 cases of magnet ingestion found that five of the children had some type of IDD, including ASD, ADHD, developmental delays, and neurologic disorders (Centers for Disease Control and Prevention (CDC), 2006). Another study posited ASD as a predisposing condition to swallowing magnets (Oestreich, 2006; CDC, 2006). A survey conducted among radiologists found that 12 out of 128 cases of patients swallowing magnets were children known to have ASD (Oestreich, 2009). Oestreich (2009) further reported that the hand-to-mouth behavior among children with ASD may contribute to the high incidence among this group. Advertisers' marketing of magnets to children with special needs for the purported purpose of learning enhancement may further compound this hazard. A website for an online magnet retailer reads: "Teaching children with special needs is an exceptional experience, and magnets can make learning even more rewarding for everyone!"

Burning

Although the pediatric population ages 1 to 15 years already sustains the highest burn risk injuries, research suggests that children with disabilities are at even greater risk of burn injuries than children without disabilities (G. Chen et al., 2007). The Government of Ontario reports approximately 1,700 home fires, especially in kitchens and cooking areas, involving individuals with mental disabilities (Government of Ontario, n.d.). Burn risks among individuals with IDD vary based on IDD diagnosis or severity of impairment. Specifically, children with ASD have a lower risk of burn injury than their general population peers. They are less likely to engage in potentially dangerous imitation play, such as cooking, than neurotypical children (Fredriksen et al., 2014; Fritz & Butz, 2007).

Burn risk increases as the IDD population ages. Attention and hyperactivity difficulties among adolescents and adults with ASD place them at a higher risk of burn injuries from fire-related activities than their general population peers (Chan et al., 2021). In addition, traits associated with ADHD—including novelty-seeking behaviors, poor reading skills, hyperactivity, cruelty to animals, and thrill-seeking temperament—place individuals with ADHD at a higher risk for burn injury than their non-ADHD peers (Chen et al., 2020; Fritz & Butz, 2007; Spitz et al., 1994).

Many burns have been found to be preventable. The most serious burn injuries occur in the shower (e.g., scalding) and of those reported, have all been deemed avoidable. Other avoidable burn incidents are due to use of electric irons, hair curling irons, and hand-held hair dryers.

Drowning

Drowning is a significant cause of childhood mortality worldwide (Handley, 2014). There is conflicting evidence of the association between IDD and increased risk of drowning. Some literature suggests that individuals with IDD are at greater risk for death by drowning than the general population (Franklin et al., 2017; Kemp & Sibert, 1993). However, this research has focused

primarily on epilepsy and has not demonstrated significantly increased risk for individuals with IDD in general (Robertson et al., 2015; Shavelle, Strauss, & Pickett, 2001). For example, a study demonstrated that epilepsy in children increases the risk of drowning to 4.1%, as compared to 0.7% to 1.7% among the general population (Franklin et al., 2017). Conversely, a study of individuals with IDD and asthma reported a lower risk of drowning than the general population due to reduced exposure to aquatic hazards and heightened supervision of children. One study suggested that deaths due to drowning are more common for those with ASD that live in California, a state with coastline and warmer weather that allows for greater exposure to aquatic environments (e.g., lakes, swimming pools) (Shavelle, Strauss, & Pickett, 2001).

Wandering

Wandering behaviors occur more often among individuals with IDD, especially those with dementia, ASD, and Alzheimer's, as compared to the general population (Barnard-Brak et al., 2018; Tilly, 2015; Wiggins et al., 2020). For instance, an online study demonstrated that about half of children with ASD ages 4 years and older have engaged in wandering behavior at least once. About one quarter of the children who wandered went missing long enough to cause concern for their caregiver (Anderson et al., 2012). An estimated one out of five individuals with dementia wanders off, and 40% of those may need assistance to return home (Barnard-Brak et al., 2018). Increasing awareness among family members and caregivers can help prevent wandering behaviors.

Managing Medication Regimens

Research indicates that the medication regimens of individuals with IDD are almost twice as complex as those of individuals taking medications who do not have IDD (Erickson et al., 2018; MacLeod & MacLure, 2020). Polypharmacy is common for individuals with IDD and a risk factor for adverse effects (O'Dwyer et al., 2016). Patients with IDD have a higher percentage of hospital admissions for adverse medication events (AME) as a principal diagnosis (1.61%) than the non-IDD group (0.7%) (Erickson et al., 2020). Individuals with IDD often have poorer health literacy than the general population and are vulnerable to experiencing clinical and practical problems with medication and/or serious errors in drug administration (MacLeod & MacLure, 2020; van den Bemt et al., 2007).

Because caregivers undertake significant responsibility for medication use by individuals with IDD, their health literacy is essential. One study showed that 70% of the caregivers of individuals with IDD in the study (*N* = 47) were intimately involved with medications. These caregivers obtained medication from pharmacies, reminded the individual with IDD to medicate and/or administered the medication to the individual, documented medication and health information, and accompanied the individual to the physician's office (Erickson & LeRoy, 2015).

Traumatic Brain Injury (TBI)

Because literature related to product safety information for individuals with IDD is sparse, FMG also included research on product-related safety hazards for individuals who acquire IDD due to a traumatic occurrence, such as a traumatic brain injury (TBI). While the literature on TBI and product safety is also scant, we did uncover some associations between TBI and significant health and safety risks.

TBI has been shown to increase an individual's health risks post-injury. Individuals with moderate and severe TBI have an increased risk of seizure (Annegers et al., 1998). Researchers have also found an association between moderate/severe TBI and neurological degenerative disorders, including Alzheimer's dementia and Parkinson's disease (Langlois et al., 2006). Individuals with TBI are also subject to an increased risk of binge drinking, depression, and choking/suffocation. Even individuals who are ambulatory post-TBI are at a higher risk than the

general population for seizure mortality and accidental death due to choking. TBI also increases long-term mortality, reduces life expectancy, and is associated with sexual dysfunction, bladder and bowel incontinence, and metabolic dysregulation (Langlois et al., 2006; Shavelle, Strauss, Whyte, et al., 2001). The literature reveals that individuals with TBI also experience psychosocial difficulties (Rapport et al., 2008). Additionally, those who have experienced a TBI have cognitive problems that have been shown to lessen productivity and to impede return to the workplace.

Due to the close association between some forms of TBI and various complicated health conditions, some scholars and health professionals argue that congenital brain injury (CBI) and TBI should be considered chronic diseases (Corrigan & Hammond, 2013; Masel & DeWitt, 2010). A chronic disease designation, they argue, would better describe the ongoing health difficulties such individuals encounter post-injury and would encourage ongoing health management of the condition.

Conclusions

Although they are at greater risk of injury and death than the general population, individuals with IDD rarely interact with consumer products entirely independently; they are often limited in mobility and may have assistance with daily activities. Nevertheless, product hazards are prevalent within the home. Uneven or slippery surfaces, as well as miscellaneous small parts (e.g., stray pen caps, loose change, refrigerator magnets), pose a risk for falls, ingestion, and choking, even in the most vigilant homes. For individuals with IDD who have greater personal independence, burns from water or kitchen appliances are a regular risk as well. Individuals with IDD, who often rely on others to manage complex medication regimens, also run the risk of toxicity from accidental medication mismanagement. Supporting individuals with IDD and their caregivers in managing risks inside the home is first and foremost a resources challenge. Most families are knowledgeable about what does or does not pose a risk to their children but have limited time and income to dedicate to managing those risks. This review shows that those with TBI face similar in-home safety challenges to individuals with IDD.

Outside of the home, drowning and wandering remain worrisome risks for individuals with IDD who have significant mobility or greater independence. An individual with IDD who is wandering or swimming may be unable to successfully communicate their distress to others. Such communication disconnects make it difficult to mitigate the risks of wandering and drowning incidents. Despite these challenges, greater public education and awareness about IDD is one way to better support individuals with IDD in their communities.

Limitations

The most significant limitation in this literature review is the gap in research on product safety for individuals with IDD. There are gaps in basic categories of information, such as comparative morbidity and mortality rates for common types of IDD, evaluation of safety interventions, and primary research conducted with individuals with IDD about their safety experience. This aporia is no great surprise, as research about individuals with IDD has historically lagged behind general population research and has been troubled by assumptions about the dignity of individuals with IDD. As such, this literature review also covers issues that may aid in indirectly addressing the original research questions.

Environmental Scan Findings

FMG conducted an environmental scan to identify organizations that have expertise in and/or insights to share about the characteristics of individuals with IDD that may put them at higher risk for injuries related to consumer products. The scan also sought to better understand how stakeholder organizations address these risks and to highlight gaps in current communications outreach from these groups.

Overall Findings

Findings from the environmental scan highlight the importance of caregivers as producers of important safety-related information for individuals with IDD. In addition, caregivers are also the central audience for organizations providing information about, or services related to, IDD. From a high-level view of the online resources revealed by the environmental scan, it was found that caregivers create much of the salient information about safety considerations for this population. Caregivers generate information about managing safety risks in the form of online day-in-the-life diaries that describe caregiving best practices and challenges related to caring for an individual with IDD. In turn, the majority of government and nonprofit organizations that support safety for individuals with IDD orient their information toward caregivers. Therefore, when considering the audience for reviewing safety guidelines for individuals with IDD, it may be useful to develop resources and communication materials for caregivers, as well as individuals with IDD.

The environmental scan also included relevant public-use data sets and news articles. In the last decade, questions about the experiences of individuals with IDD have been included with greater frequency in national surveys. Although more safety and injury-specific questions are needed to better understand national patterns, precedent is finally being set so that more specific questions can be asked in the future. In a similar vein, policymakers are only beginning to act more directly on the behalf of the IDD community. They are starting to ensure that sufficient protections are in place for individuals with IDD to be able to find and afford safe housing and support throughout their lives. It will be important for researchers and policymakers to collaborate more closely on improving the well-being of individuals with IDD as they continue to live longer and healthier lives.

Topline Findings

- Organizations focus their investment on a broad spectrum of IDD educational and advocacy resources.
- Organizations place the greatest emphasis on educational resources for caregivers of individuals with IDD and for professionals working with IDD populations.
- Caregivers focus more attention on safety practices that are specific to the needs of the individual with IDD and are not as concerned about the recommended guidelines for the general population.

Table 2. Matching Findings and Findings Specific to Literature Review and Environmental Scan

Literature Review Specific Findings	- Literature focuses on heightened safety risks for the IDD community, particularly regarding increased mortality and falls. - Increased attention has been paid to specific risks faced by children with IDD, including products such as magnets and choking hazards.
Environmental Scan Specific Findings	- Organizations tend to lean toward caregivers and professionals to use communication strategies to work through trauma and safety concerns with the IDD community. - Resources focused on public education regarding the IDD experience, advocating for the IDD community, and trauma-specific safety guidelines. - Additional resource emphasis placed on integrating the IDD community into the wider community living model. - Resources focused on family and caregiver education, particularly related to fire safety guidelines. - Additional resource emphasis placed on increased IDD research into injury prevention.
Matching Findings	- Both the literature and intervention/planning guides focus on systematic, behavioral approaches for working with children with IDD. - While limited, both the literature and environmental scan indicate video-based approaches for fire safety prevention are the most effective. - Resources focus on children with IDD, rather than the IDD population as a whole.

Types of Organizations

The organizations that are the most trusted and valued by the IDD community include government-affiliated groups, nonprofit groups, children-focused groups, hospital groups, and safety groups. The trusted organizations that were identified in the environmental scan include:

Government Affiliated Groups:	Children Focused Groups:
• Administration for Community Living • National Alzheimer's and Dementia Resource Center • National Child Traumatic Stress Network (NCTSN) • MDQuit • Safety First Initiative • U.S. Fire Administration	• The Center for Discovery • Center for Parent Information and Resources • KidPower • Safety Kids Worldwide • Youth Organizing Disabled and Proud

Nonprofit Groups:	Hospital-Based Groups:
• The ARC • Autism Speaks • Center for Disability Services • The Center for Discovery • Disability Visibility Project • National Autism Association (NAA) • National Fire Protection Association • Prevention 1st	• Children's Hospital of Philadelphia: Center for Injury Prevention Research • The Ohio State University's Nisonger Center

Safety Groups:
• Sandy Spring Volunteer Fire Department (SSVAD) • Rave Mobile Safety

Outreach Channels

All organizations primarily disseminate information online through their websites. Although most of the organizations primarily engage with their audiences via digital channels, some organizations also use other mediums such as print, local and national events. Not surprisingly, almost all organizations disseminate content via their websites by developing or curating fact sheets, guidelines, curricula, videos, toolkits, PowerPoint presentations, and blog posts, whereas only a few organizations also disseminate information via print (e.g., flyers).

Target Audience

Organizations place the greatest emphasis on educational resources for caregivers of individuals with IDD as well as professionals working with IDD populations. Specifically, the content developed by organizations reviewed is geared toward two specific sub-groups of individuals:

1. Caregivers of individuals with IDD, and
2. Professionals who work with those with special needs in different contexts of health, policy, education, and professional services (e.g., HCPs, teachers, advocates, public safety officials).

Websites for toy manufacturers likewise target caregivers with information about age-based appropriate use.

Organizational Mission

Of all the organizations identified, three broad overarching organizational missions emerged:

1. Educate families, caregivers, and communities with credible information and resources (e.g., toolkits, curriculum, safety guidelines);
2. Encourage and provide a platform to generate action—behavioral engagement, advocacy, and empowerment—within the IDD community (e.g., social and professional networking platform for youth with disabilities); and
3. Engage in dialogue on best practices among practitioners and experts (e.g., HCP-generated blogs).

Most organizations' materials that were reviewed offer expertise in certain niche IDD-focused domains. Notably, several organizations provide injury-prevention strategies and interventions—especially fire-safety geared toward preventing fire-related injuries among children. However, fewer organizations have materials that provide the same for home safety, choking, or drowning, even though the incidence of these types of injuries is common among those with IDD. Other organizations offer materials on the following:

- Caregiving skills and communication strategies,
- Educational materials for children and educators,
- Resources on trauma and mental health issues,
- Literature on clinical approaches,
- Tobacco-cessation strategies and programs, and
- Materials for advocating, empowering, and generating awareness.

Education Tools and Advocacy

Organizations focus their investment on a broad spectrum of IDD educational and advocacy resources. Organizations either play a more active role as an instigator of action (i.e., "pull") or a more passive role as an education/informational tool that only offers information/facts (i.e., "push"). Most of the websites identified in the scan act as an informational repository for visitors. A limited number encourage a variety of action among visitors; fewer still do both.

Websites that play the role of an informational repository offer educational tools/toolkits to better support individuals with IDD in a variety of contexts (e.g., at home, educational settings, health care settings). On the other hand, the few websites that do engender action do so in a variety of ways, such as:

- Using online materials to educate children with IDD,
- Asking individuals to record their stories for the Library of Congress,
- Encouraging individuals to be a more active part of research communities for individuals with IDD, and
- Generating greater awareness of fire safety and general safety for children with IDD.

Furthermore, a handful of websites provide educational tools and encourage actions to get involved in advocacy and education efforts.

Caregiver Blogs and Diaries

Some caregivers of individuals with IDD have developed blogs about their experiences. Fifteen blogs written by caregivers of children with special needs or disabilities from the United States, Canada, and the United Kingdom were identified. These blogs cover a wide range of content on caring for children with special needs or disabilities. These blogs show both caregivers of children

with IDD and the public the great diversity of experiences that children with IDD needs have. These blogs include:

- Finding Cooper's Voice (https://www.findingcoopersvoice.com/)
- Different Dream (https://differentdream.com/)
- Child Bright Network (Canada) (https://www.child-bright.ca/)
- Tiptoeing Through (Canada) (http://www.throughthetulips.ca/)
- Wonders Within Reach (https://wonderswithinreach.com/)
- Special Happens (https://specialhappens.com/)
- Love that Max (https://www.lovethatmax.com/)
- Noah's Dad (https://noahsdad.com/)
- Embracing Imperfect (https://embracingimperfect.com/)
- Down's Side Up (United Kingdom) (http://www.downssideup.com/)
- Atypical Familia (http://atypicalfamilia.com/)
- Parenting Special Needs Magazine (https://www.parentingspecialneeds.org/)
- Tumble into Love (https://tumbleintolove.blog/)
- Ellen Stumbo (https://www.ellenstumbo.com/)
- My Loveable Pest (Canada) (https://mylovablepest.com/)

Guidelines versus Child-Specificity

Most toy manufacturers include some information on their website about toys for children with disabilities (physical, intellectual, and developmental). The manufacturers also commonly provide age-grading information, or guidelines intended to help caregivers understand what toys are safe and developmentally appropriate for their children. Most toys curated for children with IDD meet the same safety guidelines for children within the same age grading. Experts recommend that caregivers of children with IDD take age-grading information into consideration but ultimately make their own assessments of what is developmentally appropriate, regardless of the child's age. Experts also indicate that caregivers need not purchase toys made specifically for children with IDD. Instead, everyday toys like puzzles, balls, books, and blocks can be safe, fun, and developmentally appropriate options for children with IDD (21 Best Toys for Kids with Autism, n.d.).

Websites that are written by caregivers also focus attention on child-specificity for safety practices rather than on recommended guidelines.

Target Audience

The blogs are geared to family and friends as well as to an audience of other caregivers of special needs children. Most of the blog authors create content about their daily lives and give family updates to readers. All the blogs seek to provide other caregivers of special needs children with advice and tips for navigating life's challenges.

Caregiving Guidance

These blogs provide support to the IDD community through content that offers a mix of practical strategies for parenting children with special needs and first-hand stories from daily life. The parenting strategies discussed range from recipes to recommended products to accessible travel to sleep strategies. Some blogs provide tips and tricks for working (including single) caregivers of children with IDD who may face additional challenges due to their type of employment.

Three of the blogs have specific sections devoted to recommended products for children with special needs/disabilities. These sections are designed to give caregivers a sense of what products help children like theirs in their daily lives. Accessibility is a major theme throughout these blogs.

Several blogs also emphasize the importance of self-care for the caregivers themselves. Self-care for the parent is seen as an important part of being able to take care of the child. The blogs that mention self-care offer strategies for managing stress and making time for oneself even with having responsibilities as a caregiver. One blog includes a post about the isolation that caregivers of children with special needs face.

Health Care Advocacy and Experience

The diagnostic process and health-care-related IDD informational sources are two major medical topics that appear in the blogs. In general, writers of the blogs see other caregivers of children with special needs and health/occupational professionals as good sources of information. However, one blog, Embracing Imperfect, rejects the medical model of care and claims to be a source of information for "what your doctor won't tell you." In a post on toxins, the author urges followers to "only go to the doctor when you need to." The post highlights the fact that some caregivers of children with IDD may be hesitant to trust medical professionals.

The process of coming to terms with an IDD diagnosis is a frequently discussed topic in several of the blogs. One caregiver expresses relief in having answers and a diagnosis that helped her understand her son's challenges. However, several blog authors mention the grief that often comes with a special needs or disability diagnosis. The caregiver behind the blog Finding Cooper's Voice explains that "dreams don't die, they change." Accepting reality and the challenges that their family will face is a theme in several of the blogs.

Ableist Language

The blog writers describe the challenges that caregivers of a child with a special needs or disability diagnosis may experience. The blog writers also express ambivalence about the social impact of a child's diagnosis and the language others may use to characterize individuals with a special needs or disability diagnosis. One blog author explains that the commonly used phrase "more alike than different" minimizes her child's experiences and is an example of ableism. She emphasizes that it is okay that her child was different from other children. The author of Finding Cooper's Voice makes a similar point about labeling children as "high-functioning." This is a frequently used term that lacks real meaning and fails to acknowledge the struggles children with special needs may face even if they function at a certain level.

COVID-19 Pandemic Concerns

COVID-19 is understandably a frequently discussed topic for blogs that have been recently active. Individuals with IDD are a group particularly vulnerable to COVID-19 infection. Posts about the pandemic tend to focus on education and the challenges of distance learning for children and their mental health. One post from Ellen Stumbo's blog discusses the stress of having a child at high risk for COVID-19. All the posts about the pandemic emphasize the importance of keeping children both mentally and physically healthy during COVID-19.

Relevant Secondary Data Sources

The environmental scan located data sources related to IDD and safety. Several of the relevant data sources are surveys that pertain to children with IDD. For example, the National Health Interview Survey (NHIS), which has been conducted since 1957, is a household survey of children and adults (National Center for Health Statistics, n.d.). Questions include whether any of the children

have been diagnosed with IDD and detailed questions about injury (e.g., if they have been injured, cause of injury, whether it required hospitalization).

From 2001–2010, the National Survey of Children with Special Health Care Needs (NS-CSHCN) fielded three times to better understand the population's physical, emotional, and behavioral health care needs (Child and Adolescent Health Measurement Initiative, 2012). The survey collected information from caregivers about reported diagnoses and the severity of any IDD. It also provided information regarding the prevalence of children with special health care needs. The survey included questions about how many school days a child missed due to injury/illness and about difficulty swallowing.

From 2018–2019, the National Survey of Children's Health (NSCH) collected data from nearly 60,000 parents of children and youth on many dimensions of a child's life. Data collected from the NSCH includes physical health, mental well-being, access to health care, education, and psychosocial environment (Child and Adolescent Health Measurement Initiative., 2019). Survey data were adjusted to reflect the demographic composition of non-institutionalized children and youth ages 0–17 years in each state. One percent of the sample (ages 3–17) reported being diagnosed with an IDD. Of children ages 3–17, 4.7% currently have a developmental delay and 1.6% did have a developmental delay, but no longer have it. One-third (33%) of the caregivers of children diagnosed with IDD reported that their child's current condition is mild, and two-thirds (67%) reported their child's condition is moderate/severe. Just under half (46.1%) of caregivers of children with a developmental delay noted their child's condition is mild and 53.9% of caregivers reported their child's current condition is moderate/severe.

Conducted in 2011, the Survey of Pathways to Diagnosis and Services (Pathways) is a nationally representative survey about children ages 6 to 17 with special health care needs who are, or have ever been, diagnosed with IDD (i.e., autism spectrum disorder, developmental disabilities, or intellectual disabilities; CDC, National Center for Health Statistics, State and Local Area Integrated Telephone & Survey, 2011). The survey included questions on:

1. Whether an injury affected the child's development or existing condition any further,
2. Whether the child is at risk to wander and get lost, and
3. If any wandering prevention strategies were implemented to minimize risk.

Over one-quarter of children surveyed (26.7%) wandered or became lost in the year before the survey, a risk factor for injury. Over one in five (21.5%) experienced an incident, injury, or illness that the caregiver felt affected the child's behavior or development.

Other surveys collected data on adult individuals with IDD. The 2017–2018 National Health and Nutrition Examination Survey (NHANES) is a research program involving interviews and physical examinations that studies the health of adults and children in the United States. In the 2017–2018 survey, IDD-relevant questions include whether a respondent has an IDD that impairs their ability to complete physical tasks (CDC, 2018). The survey did not gather data specifically on the incidence of injuries among the IDD population. Moreover, the questions related to falls or injuries exclude children, a significant population among individuals with IDD.

Last conducted in 2010, the National Survey of Residential Care Facilities (NSRCF) collected data from residential care communities, which included "residential care facilities; assisted living residences; board and care homes; congregate care; enriched housing programs; homes for the aged; personal care homes; and shared housing establishments…" (CDC). Around five percent of the residents at the care facilities (N = 8,094) reported being diagnosed with an intellectual or developmental disability, such as mental retardation, severe autism, or Down syndrome. Eight percent of residents with an IDD have fallen and injured something other than their hip in the past

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12 months. One percent of residents with an IDD have had a fall that caused a hip fracture within the past 12 months (CDC, 2011).

Product-Specific Incident Reports

CPSC's Clearinghouse Online Query Tool includes reports made related to product-specific injuries and deaths of individuals with IDD. These include such incidences as:

- Choking from ingestion of a product;
- Drowning in a pool or bathtub;
- Falls due to uneven or faulty flooring;
- Electric shock from a malfunctioning stove; and
- Concussion suffered by a child with ASD who was injured in a swing.

IDD In the News

President Biden has announced plans to enact and implement policies that support people with disabilities in their communities (Americans with Disabilities: Joe Biden,2020). These plans include facilitating access to good jobs in competitive, integrated employment; affordable, accessible, and integrated housing; affordable transportation; inclusive voting processes; and any needed long-term services and supports.

Two states are taking steps to improve safe housing conditions for individuals with intellectual disabilities. Connecticut is working with communities to provide affordable, safe, and secure apartments for adults who have intellectual disabilities (Moody, 2021). An apartment complex in Canton, CT, has designed units with walk-in showers and technology-controlled stovetops to help prevent food from burning. Lawmakers in Washington state are proposing a replacement of large residential facilities designed for individuals with disabilities with housing communities across Washington due to years of safety issues, reported deaths, and serious accidents (O'Sullivan, 2021). They are also recommending building a new skilled nursing unit at Fircrest School, a state-run center for developmentally disabled individuals, to keep the campus open.

Recent COVID-19-related news has highlighted considerations being made for the IDD community during the pandemic. The Occupational Safety and Health Administration (OSHA) issued a COVID-19 National Emphasis Program (NEP) on March 12, 2021. The policies help to ensure that employees in high-hazard industries, including residential and developmental disability facilities, are protected from contracting COVID-19 (Wright, n.d.). This action reaffirms that the IDD community is continually at high risk for contracting the virus due to increased potential exposure to COVID-19 in their own facilities. New data also suggests that COVID-19 infections among individuals with an IDD drop significantly once they are eligible for vaccines (Heasley, 2021). In Tennessee, the first state to make COVID-19 vaccines available to residents with developmental disabilities, infections have declined by over 80% among this community and their staff between December 2020 and February 2021.

Conclusion

In the absence of meaningful guidance from the scientific community until relatively recently, caregivers of individuals with IDD have done the majority of the work themselves to gather, verify, and share meaningful safety information specific to IDD. Blogs, online forums, and community profiles have served as a treasure trove of information for caregivers looking for guidance about how to support the safety of their family members with IDD. Although the work that has been achieved in this grassroots space is astronomical, many questions remain that ought to be addressed by the research community and policymakers. Significant gaps remain in the following areas:

1. The realm of safety intervention evaluations,
2. Primary research with individuals with IDD about the types of safety support they are interested in receiving, and
3. Available safe and accessible housing for those with IDD throughout their lives.

Limitations

This environmental scan was limited only by the relative recency in which the experiences and rights of individuals with IDD have become a focus for reporters, policymakers, and community leaders. Caregivers have been dedicated to developing resources for those with IDD for years, but more comprehensive information from other industries and stakeholders only became more significant in the last 10 years or so.

In-Depth Interview Findings

Overall Trends

After reviewing the literature and conducting an environmental scan, FMG conducted individual interviews to further develop our understanding of product safety experiences for individuals with IDD. The following section summarizes findings from the interviews with stakeholders who have expertise in the areas of education, caregiving, health care, manufacturing, and play. Overall, many of those interviewed articulated some of the same product safety concerns revealed in the literature review and environmental scan, including falling, choking, and safety risks associated with communication difficulty.

Education Specialists

FMG spoke with two education specialists who work with individuals with IDD. Education Specialist 1 has direct experience teaching students with special needs. Education Specialist 2 has focused on behavioral coaching and skill-building for those with special needs in classroom settings. Both Education Specialist 1 and Education Specialist 2 discussed the opportunities and limitations they have as educators in influencing the safety education that individuals with IDD receive in the classroom. Both specialists spoke generally about the individuals with IDD they have seen in their working life overall.

Although Education Specialist 1 has worked with students who are more independent, and Education Specialist 2 has worked with students who rely on others for basic functioning, they both shared similar tactics in helping their students learn new safety skills. For instance, they both use visual depictions to convey safety messages. Education Specialist 1 advised that illustrations used in safety instructions should not be too cartoonish, as this can feel infantilizing for individuals with IDD. Conversely, Education Specialist 2 pointed out that for certain individuals with IDD, simpler imagery is best.

Both education specialists also identified classroom products that can be dangerous to individuals with IDD. Education Specialist 2 talked about the challenge of finding the right headphones for her students. Air pods, or similarly sized devices, can be choking hazards, and larger headphones with long cords can be hazardous as well. Some individuals may try to put paper in their mouths or may get paper cuts; laminating documents can be helpful in avoiding those incidents. Education Specialist 2 noted that some individuals with IDD can't go outside in the rain with their wheelchair and recommended that wheelchair manufacturers develop all-weather products. Education Specialist 1 shared that markers and small writing implements can become projectiles and highlighted the importance of removing all writing or drawing tools with sharp edges from the classroom.

Education Specialist 1 and Education Specialist 2 acknowledged that they work hard to build safety skills and awareness in their students. However, both noted that safety education in the classroom can only go so far if caregivers are not reinforcing similar skills at home. In cases where caregivers have reached out to them, both education specialists have provided insight and resources. Ultimately, these two interviews reinforce that developing safe environments for individuals with IDD requires the investment of stakeholders throughout their communities.

Play Specialist

FMG interviewed a specialist in inclusive play and play spaces. A parent of a child with a disability, she is an expert in indoor and outdoor play space design. Years ago, she was the executive director of a nonprofit formed by parents raising children with IDD. More recently, the specialist has formed her own consulting business, Let Kids Play. Let Kids Play provides communities and businesses with recommendations for creating inclusive play spaces.

The play specialist notes that elopement, falling, and choking are significant safety hazards for children with IDD at play. Wandering or elopement is a safety hazard experienced by children with ASD. She reports that a fence installed around a playground goes far in mitigating the risk of elopement and in helping both parents and children feel more secure. Non-unitary playground surfaces like mulch are hazards for children using wheelchairs and are potential choking hazards. She particularly likes tiles, turf, and pour-in-place as unitary surfaces for inclusive play. Unitary surfaces should be installed properly and maintained well to prevent injury and to enable wheelchair access. She also advocates for use of the specialty swings which can carry a wheelchair much more safely than the typical metal swing set can.

The specialist also noted that a manufacturer of playground equipment, has published an inclusive play design guide online (https://response.playworld.com/inclusivedesignguide).

Caregivers

FMG interviewed two caregivers of individuals with IDD. Caregiver 1 works as a professional caregiver and has a long working relationship with an individual with Down syndrome. Caregiver 2 is a caregiver to her adult son, who has been diagnosed with Klippel-Feil syndrome and has some developmental delays. Caregiver 2 lives with her son in their home and accompanies him out in the community. Caregiver 1 and Caregiver 2 described safety risks similar to those cited in the literature, such as falling, burning, choking, and "stranger danger."

Caregiver 1 explained that the individual she cares for experiences a risk of falling, as this individual has seizures. Physical alterations, such as a hospital bed with guard railing and soft rugs/furniture, have been made in the individual's bedroom to mitigate the risk of falling out of bed. Caregiver 2 recalled an incident of her son falling during childhood; he was physically unable to jump on the trampoline, and when he attempted to do so he broke a small bone.

The caregivers reported other safety risks, such as the risk of burn from hot water and risk of burn or fire from use of the stove. Caregiver 1 helps the individual she cares for regulate water temperature in the bathtub to avoid injury by scalding water. Caregiver 1 explained that a temperature gauge attachment for the bathtub would be useful, as she could instruct her to recognize a safe temperature range. Caregiver 2 was also aware that there are products that can help regulate shower temperature, and she expressed interest in learning more about these.

Additional health hazards noted by the caregivers include choking and stranger danger. Because he has difficulty swallowing, Caregiver 2's son eats many of his meals in the form of a liquid supplement to mitigate choking risks. Caregiver 1 also recalled safety risks associated with internet

use. One of Caregiver 1's clients who has a developmental delay had been exchanging messages with adult men online, interactions that led to some conflict in the home.

Caregiver 2 noted that others' assumptions about her son's abilities have posed a potential safety issue in the community. Caregiver 2 characterized her son's abilities as "in-between," as he does many things independently, such as moving and eating, but he cannot meet his daily needs independently without Caregiver 2's presence. When her son was in school, the school assumed he could take the school bus independently and Caregiver 2 had to advocate for her son. Her son also worked briefly at Goodwill. There, the trainers also assumed a level of independence in work tasks that did not reflect his abilities.

Caregiver 2 explained that she communicates about safety (e.g., crossing the street) with her adult son just as she would with her children or grandchildren without an IDD. Caregiver 2's continued concerns about her son's safety are related to general emergency preparedness, such as responding to an emergency in the home.

Physicians

FMG spoke with two internal medicine physicians, Physician 1 and Physician 2, about their experiences treating patients with IDD. For both physicians, comorbid health conditions are top-of-mind. Physician 1 described obesity as a potential comorbid health hazard for individuals with IDD, many of whom may have limited mobility. He also explained that he sees IDD patients who experienced a fall related to ambulatory deficits associated with type 2 diabetes. Physician 2 similarly cited type 2 diabetes as a comorbidity frequently seen in individuals with Down syndrome.

Aside from identifying the health risks associated with comorbid conditions for individuals with IDD, both physicians also cited mobility challenges and falling as potential safety hazards. Physician 1 identified failing personal health technologies, including broken canes, walkers, hearing aids, or eyeglasses, as safety hazards in individuals with IDD. Physician 2 also described falling, seizures, and impaired judgment in the individuals with IDD he has treated in the past. Physician 2 underscored falling as a particular risk for those individuals with IDD who work in a factory setting. He also added that non-IDD populations would have a similar risk in such an employment setting. Both physicians noted falling as a safety hazard, which aligns with findings in the literature review and environmental scan.

Both physicians also articulated concerns about the safety of an individual's social environment. Physician 1 believes that the state of disrepair in group home settings, along with elder abuse, which he understands to be present in such settings, may present a risk to individuals with IDD. Physician 2 also cited elderly caregivers who lose the capacity to provide adequate care as a potential health risk for individuals with IDD.

Both doctors described additional medical- or treatment-related challenges in caring for patients with IDD. Physician 1 reported that challenges in communication, particularly if an individual with IDD is nonverbal, can make assessment of a patient's baseline status difficult. In such instances, he relies on the caregiver, if present, to fill in the gaps. Physician 2 takes steps to educate caregivers and individuals with IDD about appropriate medication usage.

The two interviews also revealed that neither physician actively seeks out information about individuals with IDD or the IDD community. Internal medicine and/or primary care physicians like Physician 1 and Physician 2 may therefore benefit from receiving education or information relevant to caring for individuals with IDD.

Entrepreneurs Supporting the IDD Community

FMG also spoke with an entrepreneur supporting the IDD community, who is an award-winning entrepreneur and designer whose work with her start-up, ABL Denim, inspired major retailers to begin making clothing for people with disabilities. The entrepreneur has been a clothing designer for 30 years and spent nine of those years creating clothing for individuals with an IDD. She grew up with a brother with an IDD, which motivated her to create clothes that are non-harmful for the IDD community.

The entrepreneur is well known for a line of jeans she created for the IDD community. The jeans are easy to get in and out of, use textiles that are soft, and include seams, which can be irritating, on the outside only. The jeans lack tags and pockets, which can also be bothersome to those with an IDD. Because risks to the community include scratching and the pressure of the clothing, the entrepreneur's jeans reduce these risks; they have material over the zippers to prevent scratching and are also loose enough to avoid pressure sores, which can potentially hospitalize an individual. The jeans do not include buttons, which can present difficulty for individuals without full functionality in their hands and fingers. Zippers go all the way down the front of the jeans to allow the individual to use the restroom by themselves if they are able. She also created an aesthetically pleasing weighted vest for children with sensory issues.

The entrepreneur advertises her business by attending major disability trade shows (e.g., Abilities Expo), disability sport events, and charity events, and the use of direct mailings and advertisements in disability magazines. The entrepreneur cited capital as the biggest barrier to creating and promoting her product for the IDD community. She would like to see the government create programs and grants that provide entrepreneurs the necessary funds to create products to help the IDD community.

Conclusions

As findings from these interviews indicate, efforts to improve safety outcomes for individuals with IDD must engage a spectrum of stakeholders. The stakeholders interviewed have developed their own strategies for managing safety risk. They have a wealth of information to share with the other categories of stakeholders and with the broader community. For example, caregivers need regular conversations with health care providers, and educators must have a line of communication with families. While manufacturers already enlist the input of the IDD community, members of the community do not always have a great sense of the types of modified technologies and products that are available to them. In short, facilitating connections among stakeholders might improve product-safety management measures and improve communication about relevant resources.

Interviews also filled in gaps found in the literature review and environmental scan. In particular, the stakeholders interviewed provided indispensable information about current hazards and preventative modifications in the home and in school settings. Wearable items, such as clothing and headphones, pose unique inconveniences and risks to individuals with IDD; hems, zippers, cords, and buttons can all be difficult or dangerous. Meaningful adjustments for these personal technologies can significantly improve the quality of life and safety of their wearers. Many individuals with IDD end up spending a lot of time sedentary and having comfortable and safe clothing to wear can be important for creating sustainable daily routines. Clothing and other personal technology might not be top-of-mind for product safety researchers, but these items directly impact the quality of life for individuals with IDD and should be given fuller attention.

Limitations

These interviews were, by design, intended to fill in a range of gaps encountered in the literature review and environmental scan. As such, participants were recruited for their unique professional

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perspective rather than to capture patterns among a similar group of participants. Questions in the moderator guide were tailored to each participant and not all participants were asked the same question. Therefore, although these interviews provide important insight into our overall understanding of an incomplete (although growing) field of research, they do not lend themselves to more complex forms of thematic analysis.

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Appendix A: Literature Review and Environmental Scan Search Terms

Literature Review: Search Terms and Keywords	
Intellectual disability (/developmental disability) [IDD] safety hazards/constraints	[IDD] communication and prevention efforts/interventions
[IDD] safety dangers/risks/risk factors/warnings	[IDD] continuum of harm
[IDD] product (e.g., weighted blanket, toasters, etc.) warnings/accidents/injuries	[IDD] out of home risks (e.g., workplace risks, school or community safety risks)
Other products to consider: •Water safety (e.g., in-ground pools, above ground pools, including portable pools) •Appliances (e.g., stoves)- Many consumers with IDD have housing and independent living opportunities. •Medications – focus on the containers (e.g., childproof)	[IDD] health hazards (e.g., medications or supplements on the population for usage instructions and/or behavior on medication)
[IDD] home hazards/household hazards/household risks/in-home risks	[IDD] Residential care, group home, community services, long- term care, immediate care facilities (ICF)
[IDD] safety interventions	[IDD] safety implementation/usage issues
[IDD] safety continuum of care/health care provision/supportive non-family care support	[IDD] safety risk assessment compared to the larger population
[IDD] safety outcomes/indicators	[IDD] Perception of product hazards
[IDD] safety barriers and facilitators	[IDD] Hidden hazards in the home (e.g., tripping hazards)
[IDD] injuries/accidents/morbidity/mortality	[IDD] Product instructions
[IDD] wounds/injuries	[IDD] Safety interventions
[IDD] Safety interventions/medicine	[IDD] Risk/medication poisoning
[IDD] Medication hazards/polypharmacy/ Adverse Medication Events/AMEs	Choking hazards for children with [IDD]
[IDD] Fire safety/hazards	Fire hazards for individuals with [IDD]
[IDD] Kitchen burns/stoves/kitchen appliances	[IDD] Burn safety/interventions
[IDD] Scalding/Water burns	[IDD] Injury data
[IDD] Choking on products	[IDD] Drowns/drowning

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Environmental Scan: Search Terms and Keywords
Intellectual Disability Organizations" (alternative: IDD organizations)
Intellectual Disability Safety Organizations (alternative: IDD safety organizations; developmental disability safety organizations)
Top Intellectual Disability Organizations (alternative: top IDD safety organizations; top developmental disability organizations)
Intellectual Disability Resources (alternative: IDD resources; IDD accident resources; IDD safety resources; communication strategies used for IDD community in relation to product risk and safety; Teaching safety skills to students with IDD)
Intellectual Disability Injury Prevention Resources (alternative: IDD injury prevention resources; IDD accident prevention resources; blogs about IDD injuries; warning labels specific for individuals with IDD; IDD burn prevention resources)