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Applying Lessons of Optimal Adolescent Health to Improve Behavioral Outcomes for Youth with Disabilities

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Introduction

Disability is a common part of the human experience. An estimated 25.6% of the adult population (age 18 years and older) of the United States has some type of disability (CDC, 2019), making people with disabilities the largest minority group in the country. Some disabilities are not acquired until middle age or later, while others are present from birth or occur during the developmental period (prior to the age of 22 years; Boyle et al., 2011). Approximately 15% of children ages 3-17 years have a disability (Boyle et al., 2011). The most common causes of disabilities present during the adolescent years are emotional and behavioral disorders, learning disabilities, mild intellectual disability, speech and language impairments, and autism (Gage, Lierheimer, and Goran, 2012). Lower incidence disabilities in this age range include blindness/low vision, deafness/hard-of-hearing, and mobility disabilities (Boyle et al., 2011).

I. Historical Overview and Background

The health needs of adolescents with disabilities have received relatively little attention historically. Up until the mid-20th century, people with disabilities were a population that was largely kept hidden and segregated from the general public. Most people with disabilities were institutionalized, regardless of their level of need for care, and many experienced abuse, neglect, trauma, and involuntary sterilizations within institutional settings (Francis and Silvers, 2016). Fueled by the eugenics movement of the 1920s and 30s, involuntary sterilizations without cause continued to occur until recently (Rowlands and Amy, 2019). In the 1960s, disability rights activists began demanding equal access to transportation, housing, and education (McCarthy, 2003). Activists behind the independent living movement in the 1970s began efforts to promote community integration of people with disabilities (Jones et al., 1984). Policies such as the Education for All Handicapped Children Act of 1975 (subsequently re-authorized as the Individuals with Disabilities Education Act) and the Americans with Disabilities Act of 1990 put into law the inclusion of people with disabilities. Current practices such as the use of supported decision-making as an alternative to guardianship, and funding to support community-based services have helped to improve the quality of life of people with disabilities (Blanck and Martinis, 2015; Leslie et al., 2017). Still, significant disparities in inclusion and well-being exist for this population.

Definition and measurement of disability in youth

Disability is a complex, multidimensional experience that is challenging to define succinctly. There are, in fact, multiple approaches to defining disability, including those based on: 1) specific diagnoses or conditions; 2) eligibility or need for services such as special education, rehabilitation programs, medical care, and income benefits; 3) limitations in certain types of body functions (e.g. mobility) or activities (e.g. bathing or dressing); and 4) the extent of misfit between an individual's needs and the accommodations available within the individual's environment (i.e., barriers within the environment create the disability; Iezzoni, 2011; Lollar and Horner-Johnson, 2016). The International Classification of Function, Disability, and Health (ICF) provides a conceptual framework for integrating these approaches and classifying multiple layers of characteristics and experiences that may be associated with disability. In this model, a health condition may precipitate changes in bodily structures, activities, and social participation; activities and participation are in turn influenced by both environmental and personal factors (World Health Organization, 2007). People with the same diagnosis may have differing levels of functioning and participation depending on variations in the characteristics of the condition itself and on differing levels of environmental support and opportunities. Conversely, people with very different diagnoses may encounter similar participation restrictions in their family, school, work, and social environments (Lollar and Horner-Johnson, 2016).

Many studies assessing youth health behaviors, risks, and protective factors rely on existing population-based data sources. Disability in such data sources is often operationally defined based on functional limitations (Horner-Johnson and Newton, 2012). These limitations can be grouped into broad categories based on the type of function impacted (e.g., mobility, vision, hearing, cognition, emotional regulation). However, the range of impact can vary widely. Moreover, youth may have more than one type of functional limitation. A further complication is that items used to identify functional limitations among youth have historically varied considerably from one survey to another (Hollar, 2005; Horner-Johnson and Newton, 2012).

Functional questions may focus on limitations in certain types of activities, need for assistance with activities of daily living (ADLs), or impairments in particular body parts. In self-report formats, questions of perception and identity may also be included. For instance, youth may be asked whether they think of themselves as having a disability or whether other people perceive them as having a disability (Horner-Johnson and Newton, 2012).

A broader approach employed in some surveys focuses on elevated health care needs resulting from ongoing conditions. This approach uses a standard 5-item screener to identify a group referred to as children with special healthcare needs (CSHCN), defined as follows:

> "Children with special healthcare needs are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998).

The CSHCN Screener assesses: (1) need for or use of prescription medications, (2) need for or use of specialized therapies (e.g., physical, occupational, or speech therapy), (3) above-routine need for or use of medical, mental health, or educational services, (4) need for or use of treatment or counseling for emotional, behavioral, or developmental problems, and (5) limited ability to do things most children of the same age can do (Bethell et al., 2002). Youth with functional limitations thus constitute a subset of the CSHCN population, but many analyses group together CSHCN with and without functional limitations (Houtrow et al., 2011).

Another consideration in case identification is the source of reports on youths' conditions, functional limitations, or increased health needs. Some surveys collect data about children from birth through age 17 years, typically relying on parents or other caregivers as informants for their children. These reports may or may not be verified by other informants or by medical or administrative records. Questions about children and youth are sometimes included in household surveys in which one respondent provides information about some or all of the individuals living in their household. Surveys of older children and youth -- usually in the middle school to high school age range -- often collect data directly from the youth themselves, sometimes supplemented with input from peers, parents, teachers, or other sources (Horner-Johnson and Newton, 2012).

Given the diversity of data sources and measurement strategies, this paper takes a broad approach and draws on available data pertaining to specific diagnoses, functional limitations, or special healthcare needs. We will highlight broad themes across disabilities, as well as addressing some specific considerations in relation to type of disability.

II. Aspects of Optimal Health and Normative Development

Historically, disability has often been perceived as equivalent to poor health (Krahn, Walker, and Correa-De-Araujo, 2015). However, in recent decades, there have been efforts to distinguish between the constructs of disability and health (Krahn et al., 2009). When these concepts are understood as separate, it logically follows that people with disabilities can be either sick or healthy; one can have a disability and also experience good or excellent health (U.S. Department of Health and Human Services, 2005). Important in this view is the recognition that many of the health problems experienced by people with disabilities are preventable (Krahn, Walker, and Correa-De-Araujo, 2015). Thus, addressing the health needs of individuals with disabilities is an important responsibility of public health, comparable to addressing health disparities experienced by other marginalized groups (Iezzoni, 2011; Krahn, Walker, and Correa-De-Araujo, 2015).

The dimensions of optimal health (physical health, emotional health, social health, intellectual health, and spiritual health) are applicable to youth with disabilities in much the same way that they are to youth without disabilities, with some minor variations (O'Donnell, 2017). For example, physical activity is important for youth both with and without mobility limitations, in order to maximize physical fitness and minimize occurrence of secondary health problems (Papas et al., 2016). Like other youth, those with disabilities also have needs relating to balanced nutrition, weight control, avoiding or quitting tobacco use, and prevention of alcohol misuse and abuse (Bandini et al., 2015; Krahn, Hammond, and Turner, 2006; Papas et al., 2016). However, medical self-care is a more central issue for youth with some types of disabilities than it is for youth without disabilities, and the focus on medical management of the disability may result in less attention to other aspects of optimal health (Lindsay, 2014). In the emotional health arena, youth with disabilities may need greater support in coping with stress and emotional challenges, which may be related to aspects of their disabilities and/or to the social stigma and marginalization disproportionately experienced by youth with disabilities (Anaby et al., 2013; Kramer et al., 2012; Lindsay, 2014; Tonkin et al., 2014). For similar reasons, attaining and maintaining social health may be more challenging for youth with disabilities, but these youth certainly have no less need of nurturing relationships with family, friends, teachers, and others. In fact, such relationships can serve as crucial buffers against the more negative forms of social interaction youth with disabilities may encounter (Kramer et al., 2012; Lindsay, 2014). For youth both with and without disabilities, key components of intellectual health (e.g. academic and career accomplishments) are considered important markers of development toward adulthood. Youth with disabilities may see achieving milestones in these areas as a particularly important aspect of being “normal” and attaining social status (Gibson et al., 2014). Less is known about spiritual health among youth with disabilities. However, similar to supportive social relationships, positive spiritual health may help protect youth with disabilities from detrimental effects of some of the health risks experienced by these youth.

Just as the dimensions of optimal health are applicable for youth both with and without disabilities, the developmental tasks of youth also are largely consistent regardless of disability (Greydanus, Pratt, and Patel, 2012). However, youth with disabilities may encounter unique barriers and/or need additional support with some of these developmental tasks (Murphy and Young, 2005). Thus, the physical and social environment of youth with disabilities plays a crucial role in facilitating or hindering normative development and optimal health. In the following paragraphs, we discuss particular issues faced by youth with disabilities in four key areas: 1) identity development and self-esteem; 2) participation in activities with peers; 3) understanding social cues, boundaries, and consent; and 4) coping with the changes that come with puberty.

Identity development and self-esteem among youth with disabilities

Several qualitative studies have explored identity development and self-esteem among adolescents with disabilities in the U.S. and other developed countries. In one U.S. study, teens with spina bifida described perceiving themselves as dissimilar to others in negative ways (Kinavey, 2007). They saw their bodies as differing from broader cultural images about physical ideals and attractiveness, and they consequently struggled with body image and self-esteem (Kinavey, 2007). The sense of being different in undesirable ways was reinforced by teasing and bullying from peers without disabilities -- experiences that were also reflected in other studies of youth with physical disabilities as well as youth with other types of disabilities (DePape and

Lindsay, 2016; Kinavey, 2007; Lindsay, 2014; Mejias, Gill, and Shpigelman, 2014). Although concerns about body image and social acceptance are common among adolescents in general, these concerns may be exacerbated for youth with disabilities (Kinavey, 2006, 2007; Mejias, Gill, and Shpigelman, 2014). The fact that youth with disabilities often have few or no peers like them in their classes or schools can contribute to a sense of isolation and otherness, and difficulty developing self-esteem and a positive identity (Brice and Strauss, 2016; Kinavey, 2006, 2007).

Adolescents and young adults with disabilities have also mentioned challenges in developing a sexual identity, both because of their own insecurities about sexual activity and because they were aware that others did not perceive them as sexual beings or potential romantic partners (Kinavey, 2006, 2007; Mejias, Gill, and Shpigelman, 2014). Moreover, while family members can be an important source of support, adolescents with disabilities have described parents as sometimes being overprotective (Lindsay, 2014; Mejias, Gill, and Shpigelman, 2014). Parental overprotectiveness makes development of independence more challenging in a variety of life arenas, and particularly hampers development of sexual identity (Ailey et al., 2003; Krupa and Esmail, 2010; Lindsay, 2014; Mejias, Gill, and Shpigelman, 2014). Individuals with disabilities are often viewed by parents and others as childlike and asexual, despite describing themselves as having the same sexual desires as people without disabilities (Ailey et al., 2003; Brown and McCann, 2018; Esmail et al., 2010; Greydanus, Pratt, and Patel, 2012). Lack of acknowledgement of the sexuality of youth with disabilities limits normative development and may contribute to poor self-esteem (Ailey et al., 2003; Esmail et al., 2010; Greydanus, Pratt, and Patel, 2012; Holland-Hall and Quint, 2017).

Despite the obstacles, many youth with disabilities develop a positive self-concept (Bellin et al., 2007; Brice and Strauss, 2016). According to parent reports, strategies that seem to be helpful include celebrating successes, encouraging their children to challenge their limits, and treating youth with the understanding that they have the same rights and worth as their peers (Antle, Montgomery, and Stapleford, 2009). For youth who are deaf or hard-of-hearing, clear communication at home and at school (facilitated by parents who sign and provision of sign-language interpreters at school) appears to be associated with higher levels of self-esteem (Brice and Strauss, 2016). Among adults with disabilities, valuing the experience of disability has been found to be associated with higher self-esteem (Nario-Redmond, Noel, and Fern, 2013). Thus, helping adolescents identify and appreciate the positive aspects of having a disability may contribute to self-esteem and a healthy identity.

Participation in activities with peers

Participation in group activities outside of school can help youth with disabilities explore and demonstrate different sets of competencies, establish friendships, attain a sense of belonging, and develop their own identity (Willis et al., 2017). Research from the U.S. and other developed countries indicates that children and youth with various different types of disabilities have low involvement in social and recreational activities compared to peers without disabilities (Bedell et al., 2013; King et al., 2010; Law et al., 2011; Lindsay, 2014; Orsmond, Krauss, and Seltzer, 2004; Shields et al., 2014; Taheri, Perry, and Minnes, 2016; Tonkin et al., 2014). When youth with disabilities do participate in such activities, they are more likely to do so with relatives rather than peers (Bedell et al., 2013; King et al., 2010; Shields et al., 2014; Tonkin et al., 2014). There is evidence, as documented in scoping reviews and metasyntheses, that social marginalization by peers and negative attitudes among community members constitute significant barriers to participation for youth with a variety of disability types (Anaby et al., 2013; Kramer et al., 2012; Lindsay, 2014; Tonkin et al., 2014). In addition, barriers in the natural and built environment (e.g., inadequate wheelchair accessibility) have been identified as one of the most frequent impediments to youth with physical disabilities participating in after-school and community activities (Anaby et al., 2013; Lindsay, 2014; Mejias, Gill, and Shpigelman, 2014; Tonkin et al., 2014). For youth with autism spectrum disorders, noise, bright lights, and crowds can make environments feel overwhelming or threatening (Krieger et al., 2018). Important facilitators of participation have also been highlighted, most notably social support from family and friends (Anaby et al., 2013; Bedell et al., 2013; Krieger et al., 2018; Willis et al., 2017).

In addition to restrictions in participation outside of school, youth with disabilities have historically been excluded or excused from important components of school classes and activities related to health, including physical education and sexual education (Abells, Kirkham, and Ornstein, 2016; Mejias, Gill, and Shpigelman, 2014; Nosek et al., 1995). Such practices send the message that these aspects of life are not relevant or applicable to people with disabilities. Even when students with disabilities are included, the content is not necessarily adapted to meet their needs (Holland-Hall and Quint, 2017; Krupa and Esmail, 2010). Thus, youth with disabilities may be less knowledgeable about safer sex practices, health risks associated with tobacco and alcohol use, and strategies for maintaining and maximizing their health (Holland-Hall and Quint, 2017; Murphy and Young, 2005).

Social interactions and boundaries

Social interactions can be particularly challenging and more complicated for youth with disabilities compared to their typically developing peers (Hui Shyuan Ng et al., 2016). These challenges can be due to cognitive, physical, or external factors such as attitudes of non-disabled adults and peers. For example, youth with ASD may have challenges understanding social cues and non-verbal communication (Metcalfe et al., 2019). These challenges may lead to inappropriate or unusual social behavior or crossing of social boundaries, which may ultimately affect youth's ability to engage in healthy relationships. Similarly, youth with intellectual disabilities may have difficulty understanding the different types of touching that are appropriate with family members, friends, acquaintances, and strangers (Ailey et al., 2003). Confusion on this front may put youth at risk for sexual victimization or being accused of sexual perpetration. Privacy can also be complicated for youth with disabilities to understand (Advocates for Youth, 2016). Like social cues and boundaries, privacy is an abstract, contextual concept that can be difficult for some youth with cognitive needs to comprehend, putting them at risk of violating the privacy of others or exposing themselves.

Coping with changes during puberty

Adolescents with disabilities who are entering puberty experience many of the same physical and emotional changes as their peers. However, youth with disabilities may require additional support to adapt to these changes. Menstruation can be more challenging for youth with disabilities (Quint, 2016), in some instances due to functioning, or in others because of family or caregiver perceptions about youths' ability to manage their own menstruation. Youth with physical disabilities, for example, may have motor challenges that make hygiene more difficult, while youth with intellectual and developmental disabilities may face difficulties coping with menstrual pain and cyclical emotional and behavioral changes (Burke et al., 2010). The practice of managing menstruation with medication or surgical interventions raises medical, social, legal, and ethical concerns and The American Academy of Pediatrics has recommended alternatives for physicians to guide families in managing menstrual hygiene (Quint and O'Brien, 2016).

Emerging sexual desire can be complicated for both youth with disabilities and their families. Families may be concerned about their child's emerging sexuality due to abuse risk or to perceived or actual potential for concerning sexual behaviors. While many youth with disabilities seek more opportunities for sexual exploration, others may experience suppression of sexual feelings due to medications such as antidepressants and antispasmodics which can affect desire and arousal (Fouquier and Camune, 2015).

Puberty and adolescence is a time when youth can become more susceptible to peer pressure. Some studies suggest that youth with disabilities are more susceptible to pressure than their typically developing peers (Bexkens et al., 2019). This could lead to higher rates of sexual behaviors, alcohol use, and tobacco use among this population, but more research is needed on the linkages between disability, peer pressure, and these risk behaviors.

III. Risk Factors

Evidence of differences in risk behaviors and adverse outcomes

Attention to optimal health and improving behavioral outcomes of youth with disabilities is much needed. Numerous studies have shown that youth with disabilities are more likely to engage in risky behaviors and have adverse outcomes compared to youth without disabilities. Below, we summarize key findings from this literature, focusing on key sexual risk behaviors (number of sexual partners; use of contraceptives), adverse sexual health outcomes (sexually transmitted infections; unintended pregnancies), and tobacco and alcohol use. We have limited our summary to U.S. studies using population-based data gathered at the national, state, or metropolitan level.

Sexual Risk Behaviors

Understanding the extent to which youth with disabilities are sexually active provides important context for discussion of risky sexual behaviors in this population. Findings from population-based survey data in the U.S. suggest that most youth with disabilities are at least as likely to be sexually active as their peers without disabilities, although participation in sexual activity may vary by type and severity of disability. Two studies using national survey data found that youth with physical and/or sensory disabilities were as likely or more likely to be sexually active during high school as their peers without physical or sensory disabilities (Cheng and Udry, 2002; Jones and Lollar, 2008). A third study using a similar data source found that individuals with mild or moderate physical disabilities were as likely to have engaged in sexual activity by early adulthood as their peers without these disabilities (Kahn and Halpern, 2018a). However, those with more severe physical or sensory disabilities were significantly less likely to be sexually active (Kahn and Halpern, 2018a). Similarly, individuals identified as having low cognitive abilities during adolescence were less likely to be sexually active during adolescence or early adulthood compared to peers with average cognitive abilities (Cheng and Udry, 2005; Kahn and Halpern, 2018b). On the other hand, analysis of statewide data from high school students in a single state (Oregon) found that youth with disabilities – especially those with self-reported cognitive limitations – were significantly more likely to have had intercourse than high school students without disabilities (Horner-Johnson, Higgins Tejera, and Braun, 2018).

Among youth who are sexually active, those with disabilities appear more likely to engage in risky sexual behaviors (e.g. sexual activity with multiple partners; unprotected sex) than is the case among youth without disabilities (Horner-Johnson, Higgins Tejera, and Braun, 2018; Jones and Lollar, 2008). One study using national data found that high school students with physical disabilities or long-term health problems had significantly higher odds of having had intercourse with more than four partners during their lifetime compared to students without disabilities (OR=1.7; 95% CI=1.4-2.1; Jones and Lollar, 2008). A study using state-level data found that 11th graders with disabilities had significantly elevated odds of having had two or more partners within the past three months (OR=1.31; 95% CI=1.09-1.56; Horner-Johnson, Higgins Tejera, and Braun, 2018). A national study of college students found elevated odds of having had two or more partners in the past year among students with one disability (OR=1.33; 95% CI=1.24-1.43) and those with two or more disabilities (OR=1.57; 95% CI=1.42-1.73) compared to students with no disabilities (Bernert, Ding, and Hoban, 2012).

Among sexually active adolescents, girls with low cognitive abilities were significantly less likely to have used contraception at both first and most recent intercourse compared to girls with average cognitive abilities (25.8% versus 49.3%; Cheng and Udry, 2005). Boys with disabilities were at least as likely as boys without disabilities to have used contraception at first intercourse (Shandra, Shameem, and Ghori, 2016). However, among those who used contraception, boys with learning disabilities or emotional conditions were significantly less likely to have used condoms compared to boys without disabilities (87.60% vs. 92.27%; Shandra, Shameem, and Ghori, 2016). Another study specific to adolescents found that high school students with disabilities were significantly less likely to have used condoms at most recent intercourse (55.3% versus 63.7% of high school students without disabilities (Horner-

Johnson, Higgins Tejera, and Braun, 2018). Studies that included both teens and adults found that women with physical or sensory disabilities were less likely to use long-acting reversible contraceptives (IUD or implant; Wu et al., 2017) or contraceptive pills (Mosher et al., 2018), and women with cognitive disabilities were less likely to use any contraceptive method compared to women without disabilities (Mosher et al., 2018).

Data on sexually transmitted infections (STIs) are limited, but two studies have indicated greater exposure among youth with disabilities. In a study using national survey data, sexually active boys and girls with low cognitive abilities were much more likely to have had STIs compared to sexually active teens with average cognitive abilities (Cheng and Udry, 2005). A study linking special education enrollment data to Medicaid claims found that higher proportions of adolescents receiving special education had been treated for STIs compared to youth not in special education (Mandell et al., 2008).

There has been little examination of unintended pregnancy in the context of disability, and even less that is specific to adolescents. Studies using data sources that include adolescents as well as adults have revealed higher proportions of unintended pregnancy in disability populations compared to those without disabilities (Bernert, Ding, and Hoban, 2012; Horner-Johnson et al., 2019; Mitra et al., 2015). There is some evidence that low cognitive abilities are associated with teenage pregnancy (Cheng and Udry, 2005; Shearer et al., 2002). However, it is not clear that teen pregnancies among girls with disabilities are necessarily unintended. One study found that girls with substantial and/or multiple disabilities who did not use contraception at first intercourse were more likely to want a pregnancy compared to girls without disabilities (Shandra and Chowdhury, 2012). A better understanding of pregnancy intentions and pregnancy planning among adolescents with disabilities is sorely needed (Shandra and Chowdhury, 2012).

Tobacco Use

National studies in the U.S. have found that, compared to high school students without disabilities, high school students with disabilities were significantly more likely to have smoked at least one cigarette within the past 30 days (31.0% versus 22.9%; Jones and Lollar, 2008) and significantly more likely to have smoked ≥ 1 cigarette/day for at least 30 days (26.6-32.8% depending on type of disability, versus 20.2% of youth without disabilities; Blum, Kelly, and Ireland, 2001). Similarly, school-based surveys in specific U.S. states have found significantly higher prevalence of smoking among youth with disabilities or chronic health conditions compared to other youth. In Minnesota, 38.5% of 7-12 graders with chronic health conditions had ever smoked compared to 30.7% of those without such conditions (Erickson et al., 2005). In Oregon, 11th graders with disabilities were more than twice as likely to have smoked within the past 30 days as their counterparts without disabilities (14.2% vs. 6.2%; Horner-Johnson, Higgins Tejera, and Andresen, 2017).

Although use of tobacco cigarettes among youth declined considerably between the time of the oldest study (2001) and most recent study (2017) cited above, use of e-cigarettes has increased dramatically in recent years (US Department of Health and Human Services, 2019). Like tobacco cigarettes, e-cigarettes appear to be disproportionately used by youth with disabilities. In pooled Oregon data from 2015 and 2017, 23.4% of 11th graders with disabilities had vaped within the past 30 days compared to 14.9% of youth without disabilities, a difference that remained statistically significant when controlling for age, gender, and race/ethnicity (Horner-Johnson, Higgins Tejera, and Andresen, 2017).

Alcohol Use

One study of youth (7-12 grades) with and without chronic health conditions found a statistically insignificant difference in the proportions of students who had ever had an alcoholic drink (40.2% versus 38.6%; Erickson et al., 2005). However, other studies have found that youth with disabilities were significantly more likely than youth without disabilities to be recent, regular, or heavy drinkers. A national survey study found that high school students with physical disabilities or long-term health problems were significantly more likely to have consumed alcohol within the past 30 days compared to youth without disabilities (48.4% versus 43.7%; Jones and Lollar, 2008). Similarly, recent data from a single state found that 11th graders with disabilities (including cognitive, physical, and sensory disabilities) were significantly more likely to have consumed alcohol within the past 30 days compared to those without disabilities (35.3% versus 26.8%; Horner-Johnson, Higgins Tejera, and Andresen, 2017). National-level data have also indicated that youth with emotional disabilities or mobility disabilities were significantly more likely to consume alcohol more than monthly (24.2% and 23.7% respectively) than their counterparts without disabilities (16.1%; Blum, Kelly, and Ireland, 2001). Among 12th graders with disabilities, those with learning disabilities or emotional disabilities were the most likely to binge drink: 58% and 62% of these groups, respectively, indicated they had consumed more than five drinks in a row within the past two weeks (Hollar, 2005). These proportions are considerably higher than a contemporaneous estimate of 28% for the general 12th grade population using the same data source (Crawford and Novak, 2002).

<u>Elevated exposure to risk factors for risk behaviors</u>

In this section, we discuss risk factors that may contribute to the observed differences between youth with and without disabilities in health risk behaviors and outcomes. In the general population, several factors have been identified as risk factors for engaging in risky sexual behaviors and for using tobacco and/or alcohol. Risk factors include early sexual debut (prior to age 15), experiences of sexual violence and abuse, being subject to physical violence and/or bullying, and having unmet mental health needs (Lara and Abdo, 2016; Santaularia et al., 2014; Vasilenko, Kugler, and Rice, 2016). There is compelling evidence that youth with disabilities are much more likely to experience sexual violence and abuse (Cheng and Udry, 2005; Higgins Tejera, Horner-Johnson, and Andresen, 2019; Horner-Johnson and Drum, 2006; Jones et al., 2012; Jones and Lollar, 2008; Kahn and Halpern, 2018a; Mitra, Mouradian, and McKenna, 2013; Sullivan and Knutson, 2000; Walters and Gray, 2018), physical violence (Horner-Johnson and Drum, 2006; Jones et al., 2012; Mitra, Mouradian, and McKenna, 2013; Slayter, Lightfoot, and Leisey, 2018; Sullivan and Knutson, 2000), bullying (Higgins Tejera, Horner-Johnson, and Andresen, 2019; Lebrun-Harris et al., 2018; Lindsay and McPherson, 2012; McGee, 2015; Twyman et al., 2010; Van Cleave and Davis, 2006), and unmet needs for mental healthcare (Higgins Tejera, Horner-Johnson, and Andresen, 2019).

Evidence regarding timing of sexual debut among individuals with disabilities is more mixed. One recent study found that young adults with severe physical or sensory disabilities had a slower progression to first vaginal sex, first oral sex, and first sexual experience compared to young adults without these disabilities (Kahn, Suchindran, and Halpern, 2019). No statistically significant differences in timing of sexual experiences were found between individuals with mild or moderate physical disabilities and the comparison group of young adults without disabilities (Kahn, Suchindran, and Halpern, 2019). However, other studies have reported that high school students with various types of disabilities were significantly more likely to have had early intercourse compared to youth with without disabilities (Blum, Kelly, and Ireland, 2001; Horner-Johnson, Higgins Tejera, and Braun, 2018). Some research has indicated gender differences in sexual debut. For example, one study reported very similar mean ages of sexual debut for girls with and without disabilities (Shandra and Chowdhury, 2012), while a companion study using the same data source found that boys with disabilities were more likely to have had early sexual debut compared to boys without disabilities (Shandra, Shameem, and Ghori, 2016). Conversely, another study found that both boys and girls with disabilities were more likely to have had early sexual debuts compared to their counterparts without disabilities (Horner-Johnson, Higgins Tejera, and Braun, 2018). Of particular concern is the elevated prevalence of very early sexual debut (before age 12) among youth with disabilities, which can be interpreted as a proxy for sexual abuse (Blum, Kelly, and Ireland, 2001).

Disparities in exposure to risk factors may be compounded for youth with disabilities who also belong to other marginalized groups. For example, recent research has found experiences of abuse, bullying, and unmet mental healthcare needs to be particularly prevalent among lesbian, gay, and bisexual (LGB) youth with disabilities (Higgins Tejera, Horner-Johnson, and Andresen, 2019). Interestingly, youth with disabilities are also more likely than those without disabilities to report same-sex or both-sex attraction or identify themselves as LGB (Blum, Kelly, and Ireland, 2001; Cheng and Udry, 2002, 2005; Higgins Tejera, Horner-Johnson, and Andresen, 2019; Kahn and Halpern, 2018a). Similarly, youth with disabilities are more likely to belong to less affluent families, and some types of disabilities are more commonly identified in minority racial and ethnic groups (Higgins Tejera, Horner-Johnson, and Andresen, 2019; Kahn and Halpern, 2018b; Murray, 2003). We found one study that examined sexual debut at the intersection of race/ethnicity and disability but sample size in the subgroups was small enough that statistical power for detecting differences was limited (Kahn, Suchindran, and Halpern, 2019). Additional large scale studies are needed to build an understanding of how intersectionality may be associated with health risk factors among adolescents with disabilities.

Unique risk factors for youth with disabilities

In addition to the above risk factors, youth with disabilities face substantial barriers to normative sexuality development, as noted earlier. The failure to acknowledge sexuality of youth with disabilities and provide appropriate sexual education may increase their vulnerability to abuse and contribute to greater sexual risk behaviors and adverse outcomes (Abells, Kirkham, and Ornstein, 2016; Ailey et al., 2003; Holland-Hall and Quint, 2017; Murphy and Young, 2005; Walters and Gray, 2018). Further, research in the general population suggests that experiences of abuse may be associated with subsequent tobacco, alcohol, and other substance use (Elliott et al., 2014; Roberts, Klein, and Fisher, 2003; Santaularia et al., 2014). Thus the higher prevalence of abuse experienced by adolescents with disabilities may place them at greater risk for additional health threats via substance use.

In addition to socio-environmental risks, it is possible that biological characteristics of certain disabilities may be associated with increased risk of substance use. In particular, retrospective studies have identified associations of childhood hyperactivity with subsequent alcoholism and other substance abuse (Cosden, 2001). However, these associations may have socio-environmental components in addition to or instead of biological underpinnings. It may be, for example, that hyperactive youth use alcohol and other substances as a form of self-medication to cope with a misfit between their traits and their environments. If their environments were better adapted to meet their needs, the association between hyperactivity and substance use could perhaps be attenuated.

IV. Unique Needs Regarding Risk Behaviors

Compared to their peers without disabilities, youth with disabilities can experience unique learning and support needs. These needs may that affect access to the health education that is needed to mitigate risk behaviors related to sexual health, alcohol use, and tobacco use. These unique needs can stem from limitations related to their disability, as well as external factors such as parents, caregiver, teacher, and healthcare provider perceptions or knowledge of disability. We framed these issues to address both internal and external factors and capture needs that are often neglected in areas of health promotion research and practice: addressing complex communication and learning needs; supporting capacity to consent to sexual activity; parent, caregiver, and teacher education; LBGTQ-inclusive education and services; and addressing needs of youth who experience trauma.

Addressing communication needs

Youth with disabilities such as autism spectrum disorder, intellectual disability, learning disability, speech and language impairments, and hearing impairments may experience communication, comprehension, attention, retention, and behavioral challenges that affect their ability to learn (Treacy, Taylor, and Abernathy, 2018). Complex communication needs (CCN) are significant disabilities affecting speech, language and sometimes comprehension. Youth with CCN do not communicate in typical ways and often require augmented communication interventions or assistive technology (Swett et al., 2019). There is limited research in the US about how CCNs affect overall learning, however a study conducted in schools in Australia suggested that youth with CCN participated less in structured school activities and had fewer interactions with peers (Raghavendra et al., 2012). These limitations could affect how youth access health education to prevent sexual health, alcohol, and tobacco risk behaviors, though more research is needed. Youth who are deaf or hard of hearing may struggle to learn in hearing-oriented settings, and have been shown to have lower scores on academic assessments compared to typically hearing children (Lieu, 2004). Further, perceptions about the ability of young people with communication challenges to learn may affect whether they receive information or education about risks related to sexuality or other health behaviors. In a study of parents of youth with autism spectrum disorder, parental perception of their child's comprehension and learning ability affected whether they initiated conversations about sexuality (Ballan, 2012). Communication challenges can also affect interactions with professionals who provide services and education. Healthcare providers, for example, are important and trusted sources of information and education about healthy behavior. While little research has been conducted with youth populations with disabilities, adults with physical disabilities have reported low satisfaction with communication with healthcare providers. In particular, needed patient-provider conversations around reducing risk behavior were lacking (Kroll, Beatty, and Bingham, 2003).

Supporting capacity to consent to sexual activity

Capacity to consent to sexuality activity is of concern with regard to the health of youth with intellectual disabilities, particularly in the realm of sexual abuse prevention. Age of consent laws vary from state to state, however, as with youth without disabilities, discussing and teaching consent before sexual decisions can be legally made can help youth take fewer sexual risks. US-based studies on consent capacity of youth with intellectual disabilities are lacking, but research with adults suggests that people with intellectual disabilities can learn to consent despite historical assumptions to the contrary (Dukes and McGuire, 2009). Using a tool to assess capacity to consent among adults in the UK, researchers found that many of the adults who were determined to be unable to consent had received little or no sex education. Comprehensive sex education, beginning in childhood or adolescence, with opportunities to learn what is involved in consent, could help youth and adults with disabilities protect themselves from sexual abuse and make informed sexual decisions (Murphy and O'Callaghan, 2004). Some literature from the US has addressed the sexual rights of people with disabilities, particularly the right to make their own sexual decisions (Farmer, 2000). This literature has argued for person-centered approaches to supporting people with intellectual disability to consent to romantic or sexual relationships (Glicksman et al., 2017).

Parent, caregiver, and teacher education

Due to various support needs in home, community, and educational settings, youth with disabilities rely more on parents, family members, and paid support staff than youth without disabilities. Adults who support youth with disabilities are potential health educators in the lives of youth. The education or lack of education of adult supporters can affect what information youth receive to reduce risk. A needs assessment conducted in Oregon on the sexual health education of youth with intellectual and developmental disabilities found that adults who support youth need skills-based training that addresses the rights of youth with disabilities, provides tools and resources to support unique learning needs, and provides opportunities to collaborate with members of a young person’s support and services team (Multnomah County, 2019). Parents and caregivers may not be informed about the rates of tobacco and alcohol use among youth with disabilities, assuming that education about reducing risk factors doesn’t apply to their child. A study that surveyed parents of youth and young adults with intellectual and developmental disabilities found that small numbers of parents reported needs for counseling services for their children in smoking, alcohol and substance abuse (1%) and sexual health screening (16%; Woodward, Swigonski, and Ciccarelli, 2012). Similarly, parents of CSHCN whose children were offered a human papillomavirus vaccine (HPV) were less likely to accept the vaccine than the general population (Cody and Lerand, 2013). Paid support staff may also have little or no knowledge of sexual health and may need training how to best support the individuals with disabilities for whom they work (Saxe and Flanagan, 2016). Teachers may not be adequately equipped to deliver health education, particularly sex education, to youth with disabilities. A study on special education teachers in Florida found that while many identified the importance of delivering sex education to their students, few had the necessary training to do so (Howard-Barr et al., 2005).

Needs of youth with disabilities who identify as LGBTQ

Youth with disabilities who are lesbian, gay, bisexual or transgender may have specific needs regarding risk behaviors related to sexual health, alcohol and tobacco use. There is very little literature available on risk factor prevalence data for youth with disabilities who are LGBTQ, or on interventions, programs, best practices or recommendations on how to support the unique needs of this population. A survey of Oregon youth found that youth with disabilities who identified as LGB were twice as likely to experience suicidal ideation compared to youth without disabilities who identified as LGB and heterosexual youth with disabilities (Higgins Tejera, Horner-Johnson, and Andresen, 2019). Though more research is needed, this disparity suggests these youth are at high risk for mental health crises as well as the possibility of engaging in higher rates of sexual risk behaviors, alcohol use, and tobacco use.

Addressing the needs of youth who experience trauma

As discussed, youth with disabilities experience much higher rates of sexual trauma than youth without disabilities. Professionals who interact with youth with disabilities need to be made aware of the high incidence of victimization and provide trauma-informed care and services (Berg et al., 2015). Unfortunately, research from the US on how to best address the needs of youth with disabilities through trauma-informed services, care, and education is very limited. A few studies with adults with disabilities, and studies conducted outside the US, provide some recommendations for practices that could inform future research with the youth population. One study on adults with disabilities who accessed services for survivors of sexual assault found that survivors with disabilities were more likely to be referred from agencies and received more services than survivors without disabilities, suggesting that integrating screening and referrals into existing services could be effective methods of helping survivors access treatment (Grossman and Lundy, 2008). Qualitative interviews with healthcare providers in the UK who serve adults with intellectual disabilities found that interventions for post-traumatic stress disorder can be effective and that training for healthcare staff can improve services for people with intellectual disabilities (Truesdale et al., 2019). A study of adults with psychiatric disabilities in institutional care found that current interventions were traumatizing for survivors of sexual trauma. The study's authors recommended that trauma be addressed in mental healthcare settings and that additional mental health treatments be trauma-informed (Carr, Hamlett, and Hillbrand, 2019). A review of the literature on trauma for patients in healthcare settings discussed the importance of trauma screening, provider-patient relationships, minimizing distress and maximizing autonomy, and multidisciplinary collaboration and referrals (Reeves, 2015). Trauma is linked to alcohol and tobacco use in youth without disabilities (Perepletchikova, Krystal, and Kaufman, 2008); research is needed on how trauma affects the prevalence of these risk behaviors in youth with disabilities, as well as on trauma-informed interventions to reduce risk.

V. Effective Elements of Programs that Reduce Risk

While youth with disabilities experience higher rates of sexual risk behaviors, alcohol use, and tobacco use and have unique needs regarding risk, there is limited research on evidence-based health promotion programs that reduce risk behaviors in these areas. In this section we will discuss key considerations when adapting current programming or developing new interventions for youth with disabilities: employing universal design for different learning needs; addressing gaps in sexual health education curricula for special education students; taking an ecological approach in health promotion; and effective programming for youth who are non-verbal, LGBTQ, and/or survivors of sexual violence.

Employing universal design for different learning needs

Effective health promotion programs and interventions for youth with speech and language, learning, intellectual, and developmental disabilities must be accessible and tailored to their diverse learning needs. Universal Design for Learning (UDL) is an approach to the development of educational curricula and materials that are accessible and meet the diverse learning needs of students regardless of ability (Vitelli, 2015). Educational programs employing UDL support multiple means of presentation, expression, and engagement and utilize various instructional strategies such as visual media, behavior modeling, role play, field trips, and interactive activities (Bowe, 2000; Jiménez, Graf, and Rose, 2007). In addition, some youth with disabilities may require more specific adaptations tailored to their disability. Providing translations of audio or video health education material in American Sign Language, for example, is a way to adapt existing material to be accessible and more effective for deaf audiences (Pollard et al., 2009). The use of tangible models has been found to be effective for teaching sexual health content to blind youth, compared to using lecture-only formats (Krupa and Esmail, 2010). Social stories and cooperative learning are teaching tools that can help youth with autism spectrum disorder learn social behavior (Grenier and Yeaton, 2019; Karayazi, Evans, and Filer, 2014). While there are some recommendations (though not a comprehensive body of research) for employing UDL in sexual health education (Grove et al., 2018), there is little research on how these methods could be used to develop effective health education interventions for youth with disabilities that address risk behaviors related to tobacco or alcohol use. With regard to reducing risk behavior in general, more research is needed to identify evidence-based practices that are effective for youth with disabilities.

Addressing gaps in sexual health education curricula for special education students

There is evidence that youth with disabilities do not receive adequate sexual health education in schools. Data from the 2014 National Longitudinal Transition Study found that less than half of students receiving special education services received sex education. The percentage of students with moderate to profound ID that received sex education was significantly lower

(16.18%; Barnard-Brak et al., 2014). In the same study, analysis of teacher opinions about whether students would benefit from sex education found that most teachers indicated that students without ID or with mild ID would benefit (60% and 68%, respectively), but only 25% felt students with moderate to profound ID would benefit. Literature points to a lack of evidence-based, comprehensive sex education curricula that are adapted for audiences with disabilities (Treacy, Taylor, and Abernathy, 2018). One curriculum, Family Life and Sexual Health (FLASH), is evidence-based and has an adapted version for youth in special education. The special education version is undergoing a longitudinal, randomized, behavioral evaluation but the results have yet to be published (Winges-Yanez, 2014). One method of filling the gap in available curricula is to adapt current sexual health curricula for audiences without disabilities to be accessible for audiences with disabilities. Grove et al. (2018) for example, used an online UDL curriculum self-check tool to assess HIPTeens, a curriculum recognized by the Department of Health and Human Services Office of Adolescent Health. Their assessment found the tool useful in identifying strengths and weaknesses in the curriculum for meeting the needs of youth with disabilities, providing a framework for adapting the curriculum for pilot testing with this audience (Grove et al., 2018). Wolfe and Blanchett (2003) developed the Sexuality Education Protocol tool to assess whether curricula meet the learning needs of youth in special education, yet there is little research available about this assessment and its reliability. A number of trainings have been developed for adults with disabilities, including the Friendships and Dating Program (Ward et al., 2013) and Sexuality Education for People with Developmental Disabilities (McLaughlin, 2018). It is possible these programs could be useful in transition classrooms with youth who are 18 years of age or older, or adapted to meet the needs of youth who are minors.

As yet, these programs have not been studied with transition audiences, and no literature exists on whether they have been adapted.

Taking an ecological approach in health promotion

Many youth with disabilities rely on support from organizations and systems. An ecological approach to delivery of health promotion may be an effective theoretical framework for the development of interventions for youth audiences with disabilities (McLeroy et al., 1988). We have discussed the roles of families, teachers, caregivers and other paid staff in providing important health information to youth with disabilities. Organizations and systems play a role as well, but there is a lack of evidence on the health promotion efforts of organizations that specifically serve youth with disabilities. For adults with disabilities, health promotion could be better incorporated into the functions of community organization that serve them. A nation-wide survey of directors at Centers for Independent Living (CILs) — organizations that provide independent living resources to adults with physical, intellectual, and developmental disabilities — found a lack of onsite tobacco cessation programs at CILs. The study authors recommended CILs incorporate tobacco cessation and other health promotion interventions that are tailored specifically to people with disabilities into their organizational core functions (Moorhouse et al., 2011). Organizations can support the health of youth with disabilities by building capacity within their core functions to provide health education services. For example, the Healthy Sexuality Capacity Building Program is an approach to training professionals, developing organizational policies and practices, and providing community based organizations with materials and messages supporting youth and adult sexual and reproductive health (Colarossi et al., 2017).

School-based health centers (SBHCs) also can be ideal for delivering health promotion programming. These centers provide basic health services to youth and have demonstrated effectiveness in delivering health promotion messages and services to young people (Parasuraman and Shi, 2014). Research is needed on whether SBHCs are effective at reaching youth with disabilities, and whether efforts to make their services more accessible to youth with disabilities would improve health behavior.

Effective programming for youth who are non-verbal, LGBTQ, and/or have experienced trauma

We have discussed the unique needs of youth with communication challenges, youth with disabilities who are LGBTQ, and youth with disabilities who have experienced sexual trauma. Effective programming should be tailored to meet the needs of these particularly vulnerable sub-populations of young people with disabilities, who may need specific modifications or special considerations for their support needs. Though it is not well-researched, individuals who do not use words to communicate appear particularly vulnerable to sexual assault and exploitation. A study of people with intellectual disability in Taiwan found that those with speech and language difficulties were more likely to experience sexual abuse (Lin et al., 2009). However, effective health promotion programming for youth who do not communicate with words is underrepresented in the literature.

For the general population of youth who are LGBTQ, schools that make environments welcoming for sexual minority students provide a safer and more positive educational experience for students. A study found that LGBTQ students at schools that implemented LGBTQ-inclusive curricula throughout subjects had fewer experiences with bullying and felt safer than students at school who did not implement such curricula (Snapp et al., 2015). Similarly, educational models have been developed for trauma-informed instruction that could be applied in special-education settings or with students with disabilities in mainstream classrooms (Brunzell, Stokes, and Waters, 2016).

VI. Protective Factors

Similarities and differences in protective factors for youth with and without disabilities

In the general youth population, factors at multiple levels have been identified as protective against adverse outcomes. These include community factors (e.g., social support from adults, involvement in prosocial community activities); school factors (e.g., school quality, positive relationships with peers and teachers, sense of belonging); family factors (e.g., effective parenting styles, emotionally supportive relationships with parents); and individual characteristics (e.g., optimism, internal locus of control, high self-esteem; Fleming et al., 2019; Murray, 2003; Sieving et al., 2017). Among racial and ethnic minority youth, cultural connectedness can also be an important protective factor (Henson et al., 2017).

Considerably less research has examined factors that may be protective for youth with disabilities. One of the few studies to do so found that similar factors were associated with lower odds of unhealthy behaviors among youth both with and without disabilities (Blum, Kelly, and Ireland, 2001). These protective factors included family connectedness, parental presence in the home at key times of day, living with both parents, school connectedness, and higher grade point average (GPA; Blum, Kelly, and Ireland, 2001). There was some evidence that appearing young for one's age was also protective, although many of the associations did not reach statistical significance, likely due to limited power. Religiosity was associated with reduced risk among youth with emotional disabilities and the comparison group of youth without disabilities.

However, the magnitude of the association was smaller for this variable than for other significant protective factors. No association between religiosity and risk behaviors was found for youth with mobility disabilities or learning disabilities (Blum, Kelly, and Ireland, 2001).

A study conducted in Canada found that youth with disabilities who had a strong sense of belonging to their local communities had higher life satisfaction than youth with a weaker sense of belonging (Daley, Phipps, and Branscombe, 2018). Moreover, a strong sense of belonging appeared to protect youth from negative effects associated with discrimination. Youth who experienced disability-related discrimination overall experienced lower life satisfaction. However, those who experienced high levels of discrimination but also had a strong sense of belonging to their community did not differ in life satisfaction from youth with a similar sense of belonging and low levels discrimination (Blum, Kelly, and Ireland, 2001). Although the study did not examine associations between sense of belonging and sexual risk behaviors, tobacco use, or alcohol consumption, the findings suggest that a sense of belonging could buffer youth with disabilities from negative impacts of socio-environmental factors that might otherwise increase their risk.

The study above did not specifically define community, allowing adolescents to respond regarding whatever community they identified with (e.g. neighborhood or town; school community; disability community; Blum, Kelly, and Ireland, 2001). While all of these types of communities are likely important, connection with a disability community may be especially key. A qualitative study examined the experiences of young adult women with a variety of disability types who were members of an ongoing support group for teen girls and young women with disabilities (Mejias, Gill, and Shpigelman, 2014). The women in this study reported numerous benefits of feeling connected to the disability community, including increased confidence, disability pride, a strong sense of belonging, and expanded awareness of their rights (Mejias, Gill, and Shpigelman, 2014). Research with adolescents who are deaf or hard of hearing has suggested that those who develop a bicultural identity – feeling connected to both the culturally Deaf community and the hearing community – tend to have the most positive outcomes (Brice and Strauss, 2016). These findings regarding (bi)cultural connectedness mirror those from studies of racial minority and biracial adolescents (Henson et al., 2017; Lusk et al., 2010).

Differential exposure to protective factors among youth with disabilities

Although Blum et al. (2001) found that the same protective factors were generally applicable to youth regardless of disability, they found that youth with disabilities had significantly lower exposure to these protective factors. Across disability types (learning, emotion, mobility), youth with disabilities reported significantly less school connectedness, lower GPAs, less family connectedness, and were less likely to live with both parents (Blum, Kelly, and Ireland, 2001). Additionally, although not all of the following factors were significantly associated with engagement in risky behaviors, youth with disabilities indicated lower parental expectations for school completion, fewer activities with parents, lower religiosity, and poorer self-esteem (Blum, Kelly, and Ireland, 2001). In a similar vein, Daley et al. (2018) found that Canadian youth with disabilities were less likely than their counterparts without disabilities to have a strong sense of community belonging. A study of Swedish teens with chronic conditions likewise found fewer protective factors present in this population than among teens in the comparison group (Nylander, Seidel, and Tindberg, 2014).

VII. Conclusions and Recommendations

Youth with disabilities have the ability to achieve optimal physical, social, emotional, intellectual, and spiritual health. They are, however, at risk for higher rates of STIs, unplanned pregnancies, sexual abuse and violence, alcohol use, and tobacco use. Youth with disabilities have unique differences from their non-disabled peers that affect their engagement in risk behaviors, such as differences in identity, self-esteem, activity participation, social learning, and coping with puberty. Policy makers, public health professionals, and educators need to take into account these differences and provide specific learning accommodations or modifications in health promotion program planning and school curricula. More research is needed on strategies for effectively improving behavioral outcomes among youth with disabilities.

Health education and programming needs to be made available and accessible to youth with disabilities. Youth with disabilities are sometimes excluded from sex education in schools and rarely receive adequate interventions tailored to their learning needs. We recommend the following strategies to ensure youth with disabilities receive relevant and accessible education: 1) Align special education standards with general sex education standards to ensure all students with disabilities are receiving sex education in schools; 2) Develop and implement health promotion curricula that employ Universal Design in Learning; and 3) Pilot-test curricula that have been adapted for youth with disabilities to develop an evidence base for education and programs that reduce risk behavior in these youth.

Ongoing data collection is crucial for monitoring disparities between youth with and without disabilities. In 2011, the Department of Health and Human Services (HHS) adopted a set of six functional disability questions as the minimum standard for disability ascertainment in population-based health surveys (Dorsey and Graham, 2011). These questions are now included in adult health surveys (e.g., the Behavioral Risk Factor Surveillance System) and in child health surveys for which parents are the respondents (e.g., the National Survey of Children's Health). In the latter survey, this set of questions provides an additional means of identifying children and adolescents (ages 6-17 years) with functional limitations beyond those captured by the single functional limitation question with the CSCHC Screener; the difference in proportions identified is substantial (17% versus 6%; Child and Adolescent Health Measurement Initiative, 2018).

The standard 6-item disability question set has not yet been included in major health surveys utilizing youth self-report, such as the Youth Risk Behavior Surveillance System (YRBSS). The YRBSS is conducted by the Centers for Disease Control and Prevention and by state, territorial and local education and health agencies (CDC, 2018). Although the YRBSS questionnaire does not currently include disability identifiers, at least one state (Oregon) has added the 6-item set to their state-level YRBSS-like survey (Higgins Tejera, Horner-Johnson, and Andresen, 2019). There has been some concern that the items have not been cognitively tested with youth (i.e., for youth responding to the items themselves as opposed to an adult responding on the adolescent's behalf). With the exception of one item about independent living activities that is only intended to apply to individuals 15 years of age and older, we have no reason to believe the items would be problematic for youth self-response. Nonetheless, we recommend that the items be cognitively tested with adolescents. If cognitive testing reveals no concerns, we recommend that these items be included in population-based youth health surveys, consistent with HHS minimum data standards and in compliance with section 4302 if the Affordable Care Act, which requires implementation of the data standards in national population health surveys as a means of monitoring health disparities (Dorsey and Graham, 2011).

In addition to ongoing monitoring of disparities via cross-sectional surveys, longitudinal research is needed in order to elucidate temporal associations. An important limitation of some of the research on abuse experiences of youth with disabilities is the cross-sectional nature of certain data sources. Although there is evidence of increased vulnerability to abuse among children and youth with pre-existing disabilities, it is also possible that some disabilities may have been caused by abuse. Once a disability exists, this may further exacerbate exposure to subsequent health risks. Additional study is needed of longitudinal associations between disability and exposure to risk factors. Such studies would inform strategies for interrupting cycles of risk and reducing threats to optimal health throughout adolescence.

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