



# Barriers and Facilitators to Healthcare Access in Adults with Intellectual and Developmental Disorders and Communication Difficulties: an Integrative Review

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## Abstract

This integrative review explores the barriers to and facilitators of healthcare access in adults with intellectual and developmental disorders (IDD) and communication difficulties (CD) using Levesque et al.'s conceptual framework of access to health. IDDs are a group of disorders that occur early in childhood and often involve language dysfunction. CDs are prevalent in adults with IDD. Several themes emerged as barriers to access for adults with IDDs and CDs including health literacy, understanding health information, and screening; fear and negative patient expectations; impaired autonomy; time; accommodation needs; insurance coverage and financial hardship; communication; coordination and continuity of care; and supporter presence and inclusion. Communication between providers, patients, and supporters is a significant barrier for adults with IDD and CD.

**Keywords** Health system access · Developmentally disabled adult · Communication disorder or difficulties

Intellectual and developmental disorders (IDDs) include diagnoses such as learning disabilities, Down syndrome, autism spectrum disorder (ASD), and cerebral palsy. These conditions typically manifest early in childhood and involve language dysfunction and slowed acquisition of new knowledge and skills, including limited self-care skills (*Definition of Developmental Disorders—Children's Health Issues*, n.d.; *DSM5 Diagnostic Criteria Autism Spectrum Disorder*, 2013; *Intellectual and Developmental Disabilities (IDDs)*, n.d.; *Intellectual Disability—Pediatrics*, n.d.). Individuals with IDDs often have mental and/or physical impairments as well, which lead to increased healthcare use (*Definition of Developmental Disorders—Children's Health Issues*, n.d.; *DSM5 Diagnostic Criteria Autism Spectrum Disorder*, 2013; *Intellectual and Developmental Disabilities (IDDs)*, n.d.; *Intellectual Disability—Pediatrics*, n.d.). Although definitions of IDD vary, in this paper, the term is used to refer to concurrent intellectual and developmental disorders. Individuals with IDDs often rely heavily on *supporters*, a term

that can refer to an adult with IDD's caregiver, family member, adult sibling, or other assistive personnel who acts as a support in any capacity, voluntarily or professionally. The term *supporter* emphasizes the autonomy of the individual with IDD and the role as one who supports.

While the significant impact of IDD on health is well established, overall IDD prevalence is not easy to ascertain. The Centers for Disease Control reported developmental disorder prevalence in 2020, showing an increase from 13.87 to 30.87% between 1997 and 2008, but did not report the overall intellectual disability rates or IDD rates (Anderson et al., 2013). IDDs are more common in males than females; however, prevalence by race and ethnicity remains unclear (Nicolaidis et al., 2013). A systematic review of IDD prevalence noted that three of eight studies reported statistically significant differences by race and/or ethnicity, with a lower prevalence of IDD for White children as compared to Black children; conversely, the prevalence of ASD, a developmental disorder and therefore subtype of IDDs, was found to increase with socioeconomic status among White, Black, and Hispanic children in a population study using US census data (Hillier et al., 2017; Zwaigenbaum et al., 2016).

Communication difficulties (CD) are prevalent among individuals with IDD; an estimated 57.9% of those with intellectual disabilities (ID) and 40% of those with ASD

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struggle with communication (*Autism Statistics and Facts*, n.d.; García et al., 2020). These difficulties involve challenges in sending, receiving, processing, and/or comprehending abstract ideas, verbal and nonverbal communication, and/or graphic symbol systems and range from mild to profoundly severe (Definitions of Communication Disorders & Variations, 1993). CDs are a significant barrier to healthcare for all patient populations, with ineffective communication acting as a barrier to care for individuals with IDD (Hoffman, Jeanne M. et al., 2005; Mason et al., 2019b; Stransky et al., 2018). Additional barriers to care include lack of provider education regarding the care needs of the adult IDD and CD population, and disparities in social determinants of health including stigma and discrimination, e.g. “ableism” (Anderson et al., 2013; Blaskowitz et al., 2019; Hillier et al., 2017; Lunskey et al., 2019; Nicolaidis et al., 2013, 2015b; Zwaigenbaum et al., 2016).

Individuals with IDDs use preventive care less frequently and report higher rates of unmet healthcare needs and increased use of emergency departments (ED) compared to neurotypical individuals (Ali et al., 2013; Blaskowitz et al., 2019; Doherty et al., 2020; Nicolaidis et al., 2013). Disparities in healthcare access contribute to shorter life spans in adults with IDDs (compared to adults without IDDs) due in part to their significantly higher rates of comorbidities, including sleep problems, diabetes, obesity, seizures, problems of the gastrointestinal, autonomic, nervous, immune, metabolic, and respiratory systems, skin conditions, and food allergies (Anderson et al., 2013; Nicolaidis et al., 2014). These complex health issues lead to increased

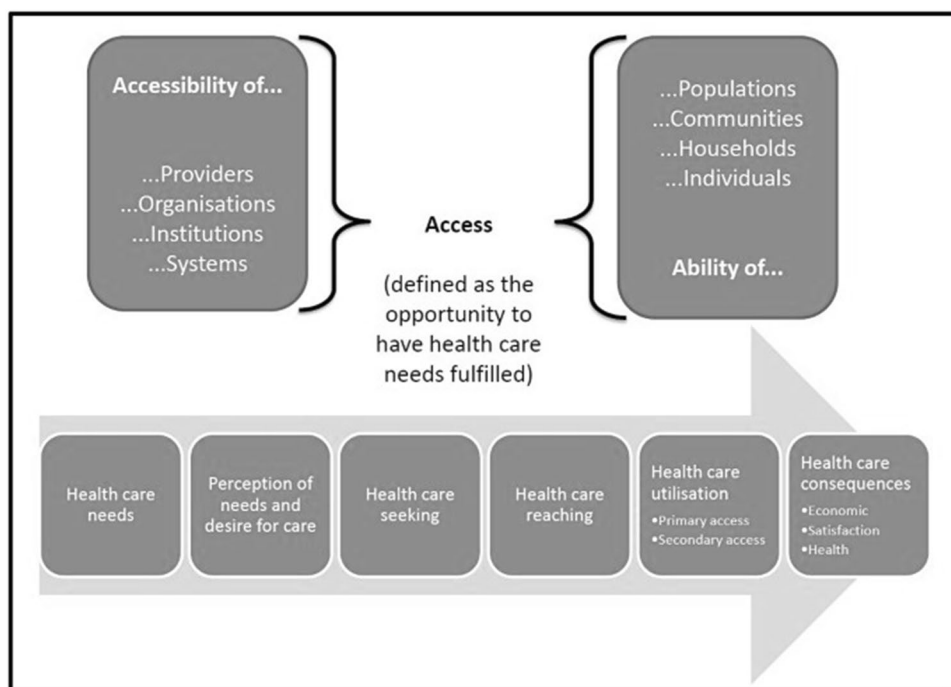
healthcare utilization needs. As a result, adults with IDD are estimated to have four times higher annual healthcare costs than individuals without IDD (Lunskey et al., 2019).

The relationship between healthcare access and factors affecting and associated with adults with IDD and their often inherent CDs warrants further investigation. Accordingly, the purpose of this integrative review is to analyze and synthesize current knowledge about the barriers to and facilitators of access to care in adults with IDDs/CDs through the lens of Levesque et al.’s conceptual framework of access to healthcare (Levesque et al., 2013). The findings of this review may inform further research and the development of interventions that alleviate barriers and/or leverage facilitators to access to care.

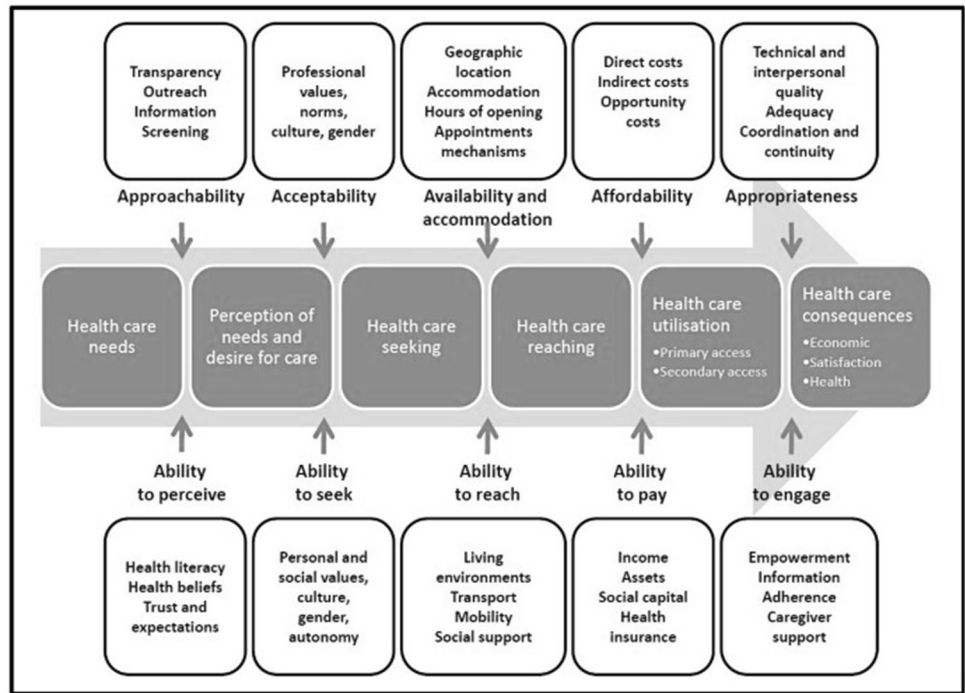
## Theoretical Framework

Levesque et al.’s (2013) conceptual framework of access to healthcare guided this integrative review (Fig. 1). The framework is patient-centered and defines access to care as “the opportunity to reach and obtain appropriate healthcare services in situations of perceived need for care” (Levesque et al., 2013, p. 4). A key aspect of this model is the interactions between the healthcare system/supply and the patient/demand sides of the model (Fig. 2). Factors affecting access pertain to three areas in this model: the system/supply side, patient/demand side, and process factors that describe the ways that access is achieved (Levesque et al., 2013). The patient dimensions

**Fig. 1** Defining Access to Healthcare (Levesque et al., 2013)



**Fig. 2** Conceptual Framework of Access to Healthcare (Levesque et al., 2013)



represent socioeconomic determinants, health literacy, physical or cognitive barriers, and potential facilitators. Each stage in Levesque et al.’s (2013) conceptual model with the corresponding patient and system dimension, as well as operational definitions of each dimension for the purposes of this review, can be found in Table 1. The

model’s linear structure leads from the perceived need of care to the receipt of care and having healthcare needs met. Each step in the model represents crucial transitions where barriers or facilitators to access may become apparent (Levesque et al., 2013).

**Table 1** Levesque et al.’s (2013) conceptual model stages and operational definitions

Stage in Levesque model	Patient dimension	System dimension
<b>Healthcare needs</b>	Ability to perceive - Health literacy and beliefs - Trust and expectations that system has available and reachable services that will help	Approachability - Point at which patients perceive the need for care, see service <i>x</i> exists and is reachable, and can have an impact on their health
<b>Perceived need and desire for care</b>	Ability to seek - Personal and social values - Ability to be autonomous	Acceptability - Social factors and cultural norms within a health system/provider’s office - Impacts patients’ ability to access service and whether they feel it’s acceptable to seek care
<b>Healthcare seeking</b>	Ability to reach - Living environment, mobility, transportation, support through assistance in reaching care	Availability and accommodation - Physical, environmental, and time accommodations the system or provider makes to meet patient needs
<b>Healthcare reaching</b>	Ability to pay - Socioeconomic status of patient	Affordability - Direct costs related to providing care to patient(s)
<b>Healthcare utilization</b>	Ability to engage - Patient’s empowerment, interpersonal support, and information comprehension and adherence	Appropriateness - Continuity and coordination of care within health systems and between providers - Adequacy of services provided to patients (quality, timeliness, appropriateness of care)

## Methods

The Whittemore and Knafl five-stage framework guided this integrative review: (1) problem identification; (2) literature search; (3) data evaluation; (4) data analysis; and (5) presentation (Whittemore & Knafl, 2005). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were applied during the literature search (PRISMA flow diagram, Appendix 1) (Liberati et al., 2009; Moher et al., 2009). ProQuest, OVID SP, CINAHL Complete, CINAHL Plus, Health Source: Nursing/Academic Edition, MEDLINE, APA PsycArticles, Psychology and Behavioral Sciences Collection, APA PsycInfo, and SCOPUS were searched with the goal of identifying studies reporting on the barriers and facilitators to access to care for adults with CD or difficulties and ID, developmental disorders (DD), and/or ASD. Search terms used for each database included the following: “(autism spectrum disorder OR developmental disability OR intellectual disability OR autism)” AND “adult” AND “(healthcare access OR health services accessibility OR access to health services OR access to care)” AND “(communication disorder OR health communication OR communication barriers OR nonverbal communication).” Ancestral searches were also completed.

Inclusion criteria were as follows: publication date 2006 or later, English language, studies on barriers and/or facilitators of healthcare access in the population of interest, and studies focused on the type of healthcare of the target population. The population of interest was defined as individuals 18 years or older with autism or a developmental, intellectual, or cognitive delay who had a communication disorder, disability, or difference. The time frame for review was informed by the passing of the Autism Cares Act, entitled the Combating Autism Act, in 2006 (Corby-Edwards, 2012; Santorum, 2006). Exclusion criteria were as follows: studies focused on the diagnosis or risk of IDD/ASD; grey literature; literature reviews; text and opinion pieces; and articles that did not include patient or supporter perspectives.

The initial searches yielded 1,947 articles (see Appendix 1). After screening for eligibility, 28 articles were analyzed in-depth, all of which met selection criteria and were included in this integrative review.

Study quality of the 28 articles was assessed using the Johns Hopkins Nursing Evidence-Based Practice Research Tool (Dearholt et al., 2012). The tool provides a rating level of evidence (level I through IV) and study quality (A through C) (Dearholt et al., 2012). All study ratings can be found in Appendix 3 with a short rationale provided.

A literature matrix was used to organize and analyze the 28 articles (Appendix 3). Extracted data was organized into thematic groups within the patient and systems domains of Levesque et al.'s (2013) framework for analysis and synthesis.

## Results

Twenty-five of the 28 reviewed articles focused solely on adults with ID, IDD, learning disabilities (LD), or ASD. The remaining three articles focused on adults with CDs, with only some participants having IDDs. The majority ( $n=20$ ) of studies were conducted using qualitative methods. The remaining studies used quantitative methods ( $n=8$ ) (see Appendix 3). All studies were non-experimental, and the quantitative study designs were cross-sectional ( $n=4$ ), cohort ( $n=3$ ), and case-control ( $n=1$ ). Additionally, three studies used a community-based participatory research (CBPR) approach (Nicolaidis et al., 2013, 2015b; Raymaker et al., 2017). Studies were conducted in a variety of developed countries with differing healthcare systems, including the USA ( $n=11$ ), the UK, ( $n=9$ ), Canada ( $n=5$ ), Australia ( $n=2$ ), and Spain ( $n=1$ ). Ten studies collected data via supporters (Donner et al., 2010; Drainoni et al., 2006; Ferguson et al., 2011; Joseph-Kent, 2019; Koneru & Sigal, 2009; Lees et al., 2017; Perry et al., 2014; Stein Duker et al., 2019; J. Wilkinson et al., 2013; J. E. Wilkinson et al., 2011).

### Ability to Perceive/Approachability

#### Health Literacy, Health Information, and Screening

Adults with IDDs/CDs experienced challenges with health literacy, which affected their ability to perceive health information (Bogenschutz, 2014; Brown et al., 2017; Doherty et al., 2019; Drainoni et al., 2006; Hillier et al., 2017; Joseph-Kent, 2019, p.; Lum et al., 2014; Perry et al., 2014; Truesdale-Kennedy et al., 2011; J. E. Wilkinson et al., 2011; Wood & Douglas, 2007). This inability to perceive was recognized as a barrier across a variety of disabilities including ASD, LD, hearing disorders, and some physical disabilities (Bogenschutz, 2014; Brown et al., 2017; Doherty et al., 2019; Drainoni et al., 2006; Hillier et al., 2017; Joseph-Kent, 2019, p.; Lum et al., 2014; Perry et al., 2014; Truesdale-Kennedy et al., 2011; J. E. Wilkinson et al., 2011; Wood & Douglas, 2007). Patients repeatedly reported being unable to comprehend written information from their providers (Brown et al., 2017; Doherty et al., 2019; Drainoni et al., 2006; Durbin et al., 2016; Hillier et al., 2017; Perry et al., 2014; Truesdale-Kennedy et al., 2011; J. E. Wilkinson et al., 2011). Both patients and supporters noted that the use of medical terminology instead of lay language, and the lack of supplemental information such as pictures or diagrams in written documents were barriers (Brown et al., 2017; Doherty et al., 2019; Drainoni et al., 2006; Durbin et al., 2016; Hillier et al., 2017; Perry et al., 2014; Truesdale-Kennedy et al., 2011; J. E. Wilkinson et al., 2011). Verbal health

information was also reported as difficult to understand, with autistic adults noting specific difficulty comprehending healthcare provider's (HCP) instructions regarding, for example, self-care and medication regimens due to unclear explanations and instructions (Hillier et al., 2017; Joseph-Kent, 2019; J. E. Wilkinson et al., 2011). Furthermore, patients with IDD who were unable to easily access information were less able to follow their provider's instructions, resulting in poor preparation for future testing and interventions (Hillier et al., 2017; Truesdale-Kennedy et al., 2011; J. E. Wilkinson et al., 2011). Patients expressed a significant lack of understanding of procedures and diagnoses, as well as notable feelings of incompetence despite feeling generally competent in their everyday activities (Truesdale-Kennedy et al., 2011; J. E. Wilkinson et al., 2011).

When communications about preventive screening needs were unclear, patients experienced a barrier to approachability. Patients were unsure of the purpose and importance of screening because invitations were poorly designed and discussions with providers did not validate patients' comprehension of relayed information (Lum et al., 2014; Nicolaidis et al., 2013; Truesdale-Kennedy et al., 2011; J. E. Wilkinson et al., 2011; Wood & Douglas, 2007). For example, high-functioning autistic women reported receiving inadequate information from HCPs during pregnancy, and women with LDs encountered non-adapted screening invitations as barriers to routine cervical cancer screening (Lum et al., 2014; Wood & Douglas, 2007). Similarly, women with IDD who received mammography both preventively and post-cancer diagnosis reported poor understanding of the purpose and importance of screening (Truesdale-Kennedy et al., 2011; J. E. Wilkinson et al., 2011). Primary care providers (PCPs) noted that they rarely proactively considered the screening and information needs of patients with LDs (Wood & Douglas, 2007). Although PCPs, nurses, and practice managers described contingency plans for patients who missed screenings, they also reported a preference for individualized follow-up if patients did not respond to screening invitations instead of adapting their standard invitations (Wood & Douglas, 2007).

### **Fear, Stigma, and Negative Patient Expectations**

Adults with IDD/CDs who experienced negative interactions with providers in the past reported expectations of future negative interactions (Drainoni et al., 2006; Joseph-Kent, 2019, p.; Nicolaidis et al., 2015b). Negative experiences included perceptions that providers ignored their needs or failed to make accommodations, waiting rooms that were sensory-inappropriate, or being stigmatized or labelled in negative ways (Brice et al., 2021; Drainoni et al., 2006; Nicolaidis et al., 2015a; Vogan et al., 2017). The expectations that resulted from negative healthcare experiences

were associated with patient-reported lower quality and less effective healthcare (Brice et al., 2021; Drainoni et al., 2006; Nicolaidis et al., 2015a; Vogan et al., 2017). Both autistic adults and their supporters reported that a lack of provider knowledge of ASD contributed to negative healthcare experiences in adult hospitals, which caused them to seek healthcare elsewhere such as in pediatric facilities; however, others noted an increased likelihood of ED use when they felt their regular providers were poorly equipped to care for their specific needs (Joseph-Kent, 2019; Nicolaidis et al., 2013).

Patients who expected negative encounters feared being stigmatized for their disability through insensitive or disrespectful actions of HCPs; this expectation made patients less likely to access preventive care and to show up for appointments (Brice et al., 2021; Drainoni et al., 2006; Joseph-Kent, 2019; Lum et al., 2014; Navas et al., 2019; Nicolaidis et al., 2013, 2015a). Older adults with IDD/CDs reported fears of stigmatization based on disability and age (Drainoni et al., 2006; Navas et al., 2019). In addition, patients expressed a general fear of being judged and stigmatized in a way that might affect the treatment they received and/or how providers communicated with them (Drainoni et al., 2006; Joseph-Kent, 2019; Lum et al., 2014; Navas et al., 2019; Nicolaidis et al., 2015a).

## **Ability to Seek/Acceptability**

### **Patient Autonomy**

Adults with IDD/CDs experienced decreased and/or impaired autonomy as a common barrier to the ability to seek healthcare (Hillier et al., 2017; Nicolaidis et al., 2015a; Stein Duker et al., 2019; Stransky et al., 2018). Patient autonomy was limited during interactions in which HCPs communicated directly with supporters instead of the adult with IDD/CD, and decisions were made without the involvement of the patient (Doherty et al., 2020; Hillier et al., 2017; Kripke, 2018). To counteract this barrier and foster patient autonomy, some researchers and clinicians advocated for supported decision-making with direct patient communication and balanced supporter involvement (rather than supporter-dominant interactions) to increase patient satisfaction and autonomy (Brown et al., 2017; Donner et al., 2010; Ferguson et al., 2011; Jones et al., 2008; Mason et al., 2019b; Navas et al., 2019; Nicolaidis et al., 2015a; Perry et al., 2014; Stein Duker et al., 2019).

Autonomy was also diminished among adults with IDD/CDs when providers held misconceptions about the individual and assumptions that they were cognitively impaired (Donner et al., 2010; Drainoni et al., 2006; Navas et al., 2019; Nicolaidis et al., 2015b; Sue & Mar, 2021; J.

Wilkinson et al., 2013). These misconceptions occurred when HCPs did not take a patient's attempt to communicate seriously (Drainoni et al., 2006; Jones et al., 2008; Perry et al., 2014; Stein Duker et al., 2019). Patients and supporters also noted misconceptions when providers offered and/or performed preventive screening on patients who were unable to give consent (Wood & Douglas, 2007). An additional barrier was noted in discrepancies found between parent proxy reports and young autistic adults' self-report of autonomy where young adults reported higher rates of autonomy than their parent proxy (Hillier et al., 2017). This discrepancy in assessments, and possibly false perception, could act as a barrier to care by limiting young adults' understanding of what accommodations they needed and giving them a false sense of autonomy.

## Ability to Reach/Availability and Accommodation

### Special Accommodations for Adults with IDD/CDs

Adults with IDD/CDs reported reliance on the accommodations that addressed their needs; thus, lack of accommodation was a frequently described barrier to healthcare. PCPs reported providing healthcare for adults with IDD/CDs regardless of their use of accommodation strategies and reported minimal use of accommodations to improve the care of autistic adults (Stein Duker et al., 2019). Preventive care was challenging for both HCPs to deliver and the adult IDD/CD population to receive, particularly in the case of invasive examinations or tests such as Pap smears, blood draws, or vaccinations (Nicolaidis et al., 2013; Wood & Douglas, 2007). Sensory concerns, insurance limitations, and/or ineffective communication and/or care coordination contributed to poor rates of preventive care (Nicolaidis et al., 2013; Wood & Douglas, 2007).

Both patients and providers cited the need for time accommodations (Bogenschutz, 2014; Brown et al., 2017; Doherty et al., 2019; Drainoni et al., 2006; Hemsley et al., 2012; Jones et al., 2008; Lees et al., 2017; Perry et al., 2014; Raymaker et al., 2017; J. Wilkinson et al., 2013; Wood & Douglas, 2007). Patients described additional health education time during visits as essential for effective and appropriate information delivery by providers, as well as for processing information (Drainoni et al., 2006; Nicolaidis et al., 2015a). Adults with IDD/CDs also reported a need for shorter wait times in waiting rooms because prolonged wait times increased anxiety that subsequently impaired their ability to communicate effectively (Joseph-Kent, 2019; Lum et al., 2014; Navas et al., 2019; Perry et al., 2014; Stein Duker et al., 2019; J. Wilkinson et al., 2013; Wood & Douglas, 2007).

While patients and supporters noted a need for more time with providers and staff, in two studies, HCPs described feeling frustrated with the additional time required during interactions with patients with IDD/CDs (Hemsley et al., 2012; J. Wilkinson et al., 2013). Physicians identified no specific potential solutions to this problem, whereas nurses either indicated that they were not able to allocate extra time due to the needs of other patients, or that they did allocate the extra time which saved time overall in the end (Hemsley et al., 2012; J. Wilkinson et al., 2013). This time saving occurred when nurses sought alternative or augmentative communication (AAC) methods or strategies rather than waiting for a supporter and eased communication frustrations of the patient (Hemsley et al., 2012). The use of AAC methods was a facilitator of access when used.

While the need to use AAC methods among the IDD/CD population is significant, patients and supporters reported that providers rarely communicated via the patient's preferred method of communication and/or were perceived to be unwilling to use AAC methods (Brown et al., 2017; Drainoni et al., 2006; Hemsley et al., 2012; Joseph-Kent, 2019; Nicolaidis et al., 2015a; Perry et al., 2014; Stein Duker et al., 2019). Beyond the use of AAC methods, communication accommodations included the use of concise, clear explanations and written instructions; communication with the adult with IDD/CD's supporter to ascertain the patient's communication skill level and needs; and development of services, systems, and policies to support improved communication in this population (Brown et al., 2017; Drainoni et al., 2006; Joseph-Kent, 2019; Nicolaidis et al., 2015a).

In addition to requiring communication accommodations, adults with IDD/CDs described a need for physical accommodations to address concerns stemming from sensory processing disorders, a hallmark trait of some IDD/CDs such as ASD (*Definition of Developmental Disorders—Children's Health Issues*, n.d.; Hillier et al., 2017; Nicolaidis et al., 2015a). Patients and families described sensory discomfort as an impediment to positive and productive healthcare interactions (Brice et al., 2021; Jones et al., 2008; Nicolaidis et al., 2015a; Raymaker et al., 2017; Stein Duker et al., 2019). Patients reported the need for accommodations such as dimmer lighting and less crowded seating, which decreased anxiety levels (Jones et al., 2008; Joseph-Kent, 2019; Lum et al., 2014; Nicolaidis et al., 2015a; Perry et al., 2014). A lack of accommodation for sensory needs was observed in certain areas of healthcare such as dentistry, where providers were reluctant to treat adults with IDD/CDs and significant sensory sensitivities (Drainoni et al., 2006; Joseph-Kent, 2019).

## Ability to Pay/Affordability

### Insurance Needs, Lack of Coverage, and Resulting Financial Hardship

Adults with disabilities described challenges related to insurance coverage, including Medicaid (Drainoni et al., 2006; Joseph-Kent, 2019; Stransky et al., 2018). Both adults with IDD and non-IDD adults noted issues with Medicaid coverage for basic services such as dental care and preventive care (Joseph-Kent, 2019). Insurance company *determinations* of necessary or rehabilitative services qualifying for coverage were particularly problematic, as was a lack of coverage for providers specializing in low-incidence conditions (Drainoni et al., 2006; Joseph-Kent, 2019).

When patients experienced frequent problems with public or private insurance, they reported significant financial hardships. Consumers with disabilities reported difficulties with over-the-counter medication reimbursement, limits on prescription coverage, prior authorizations for equipment, and limited return and repair policies on defective equipment (Drainoni et al., 2006). Adults with IDDs/CDs described significant rates of unmet healthcare needs due to problems with cost and struggles with the need to “spend down” to be eligible for Medicaid, and experienced insurance issues that caused other financial hardships such as large out-of-pocket expenses (Joseph-Kent, 2019; Koneru & Sigal, 2009; Raymaker et al., 2017; Stransky et al., 2018).

## Ability to Engage/Appropriateness

### Communication

Lack of provider education and training for communicating with patients with CDs was a common barrier to healthcare access among those with IDDs/CDs. Both HCPs and patients/supporters reported communication barriers occurred as a result of providers’ reliance on communication with a supporter rather than with the patient, or HCPs’ disinclination to allow a patient to communicate in their preferred AAC method, such as by writing (Brown et al., 2017; Drainoni et al., 2006; Hillier et al., 2017; Joseph-Kent, 2019; Lum et al., 2014; Nicolaidis et al., 2015b; Stein Duker et al., 2019; Stransky et al., 2018; Wood & Douglas, 2007). Providers, adults with IDDs/CDs, and their supporters consistently noted that all hospital staff (not just HCPs) needed additional education, improved competence, more

time to communicate, and improved access to AAC methods to make interactions successful (Bogenschutz, 2014; Brown et al., 2017; Doherty et al., 2019; Donner et al., 2010; Ferguson et al., 2011; Hemsley et al., 2012; Lees et al., 2017; Navas et al., 2019; Nicolaidis et al., 2015b; Perry et al., 2014; Raymaker et al., 2017; Stein Duker et al., 2019; Stransky et al., 2018; Sue & Mar, 2021; J. Wilkinson et al., 2013; J. E. Wilkinson et al., 2011). When office staff were not properly trained, communication became a barrier at various checkpoints in the system. Patients noted issues related to office staff’s impatience with speech difficulties, difficulties with check-in, and general feelings that HCPs and staff did not take communicating with them seriously (Drainoni et al., 2006; Jones et al., 2008; Perry et al., 2014; Stein Duker et al., 2019).

### Communication and Empowerment

Healthcare providers who recognized the strengths of adults with IDDs/CDs and interacted with them accordingly were able to facilitate communication and empower patients (Brown et al., 2017; Hemsley et al., 2012; Jones et al., 2008; Lees et al., 2017; Navas et al., 2019; Perry et al., 2014). Facilitating empowerment included accepting, allowing, and utilizing the most effective communication method for the individual and attempting to minimize the distress experienced by patients, as distress often led to a significant reduction in verbal communication abilities (Bogenschutz, 2014; Hemsley et al., 2012; Lum et al., 2014; Nicolaidis et al., 2015a). Patients who reported not feeling empowered did not disclose their IDD diagnosis to new HCPs who were unaware of the diagnosis, particularly when not previously noted in the patient’s medical record (Lum et al., 2014; Wood & Douglas, 2007). Therefore, HCPs who provided communication assistance empowered patients who were already placed in vulnerable situations (Doherty et al., 2019). One implementation study noted significant improvements in communication with increased staff training, provision of centralized scripts, and adaptive care approaches, which empowered patients through the implementation of proactive health checks (Durbin et al., 2016).

### Coordination and Continuity of Care

A lack of continuity of care for adults with IDDs/CDs acted as a significant barrier to access to and receipt of quality healthcare (Bogenschutz, 2014; Brown et al., 2017; Donner et al., 2010; Drainoni et al., 2006; Jones et al., 2008; Joseph-Kent, 2019; Lees et al., 2017; Navas et al., 2019; Nicolaidis et al., 2015a; Perry et al., 2014). The issue of continuity of care and coordination was threefold: (1) patients and providers noted a need for increased provider communication across disciplines; (2) patients and providers reported

a need for offices to improve coordination of services; and (3) patients and providers described a need for providers to coordinate with other, more experienced providers who could suggest strategies to care for adults with IDD/CDs (Drainoni et al., 2006; Joseph-Kent, 2019; Navas et al., 2019; Nicolaidis et al., 2015b; Stein Duker et al., 2019). Additionally, patients and supporters desired HCPs with a greater understanding of the individual's medical history and communication style, as well as providers willing to learn the patient's behaviors (Joseph-Kent, 2019; Stein Duker et al., 2019). This improved understanding was particularly important as illness often presented as a change in behavior or function in patients in the IDD/CD population; thus, establishing rapport with the patient prior to illness was described as monumentally important to care (Jones et al., 2008; Perry et al., 2014). Because patients with IDD/CDs had an increased likelihood of being incorrectly triaged secondary to atypical presentations of illness, a carefully documented record of the patient's behavior at baseline and a well-maintained patient-provider or patient-provider-supporter relationship was vital to the patient receiving proper treatment (Jones et al., 2008; Joseph-Kent, 2019; Stein Duker et al., 2019).

In maintaining continuity of care and coordination, HCPs treating the adult IDD/CD population had a significant need to coordinate with the patient's supporter (Brice et al., 2021; Doherty et al., 2020; Ferguson et al., 2011; Hemsley et al., 2012; Hillier et al., 2017; Joseph-Kent, 2019; Nicolaidis et al., 2015a; Perry et al., 2014; Sue & Mar, 2021; Truesdale-Kennedy et al., 2011; J. Wilkinson et al., 2013). For this group of complex patients, the incorporation of the supporter allowed HCPs to learn the patient's behaviors, obtain information regarding the patient's preferred methods of communication or sensory needs, and fostered patient-centered care (Doherty et al., 2020; Hemsley & Balandin, 2014; Hillier et al., 2017; Joseph-Kent, 2019; Nicolaidis et al., 2015a; Stein Duker et al., 2019).

### Supporter Presence and Inclusion

Supporters were often highly involved in the healthcare of adults with IDD/CDs, making effective collaboration and communication with them central to successful healthcare provision (Drainoni et al., 2006; Hillier et al., 2017; Joseph-Kent, 2019; Nicolaidis et al., 2015b). Additionally, communicating effectively with the supporter and with the assistance of the supporter was highlighted as particularly important for those with more severe IDD/CDs (Brown et al., 2017; Ferguson et al., 2011; Hemsley et al., 2012; Hillier et al., 2017; Lees et al., 2017; Perry et al., 2014; Stein Duker et al., 2019; Sue & Mar, 2021). However, when HCPs and other staff relied completely on communication with supporters rather than the patient, the patient was

disempowered. Instead, supporter assistance by sharing patient communication preferences or needs was identified as a strategy to preserve patient empowerment and improve care (Brown et al., 2017; Hemsley et al., 2012; Jones et al., 2008; Lees et al., 2017; Navas et al., 2019; Perry et al., 2014). This guidance and information provided by supporters needs to be incorporated into the patient's care while maintaining respect for the patient themselves (Hemsley et al., 2012; Hillier et al., 2017; Navas et al., 2019; Nicolaidis et al., 2013, 2015a; Perry et al., 2014; Stein Duker et al., 2019; Sue & Mar, 2021).

### Quality of Care

A significant barrier to high-quality care by HCPs and facilities was a lack of provider and specialist training that resulted in significant knowledge gaps among adult HCPs regarding care of patients with IDD/CD (Brown et al., 2017; Doherty et al., 2019; Donner et al., 2010; Drainoni et al., 2006; Durbin et al., 2016; Hemsley et al., 2012; Hillier et al., 2017; Joseph-Kent, 2019; Navas et al., 2019; Nicolaidis et al., 2015a; Perry et al., 2014; Stein Duker et al., 2019; Stransky et al., 2018; Sue & Mar, 2021). This training deficit presented as a lack of awareness regarding the breadth of issues faced by the IDD population, inadequate communication with patients and supporters, and/or a failure to make adjustments such as allowing for written communication (Doherty et al., 2019; Donner et al., 2010; Drainoni et al., 2006; Ferguson et al., 2011; Hemsley et al., 2012; Jones et al., 2008; Joseph-Kent, 2019; Navas et al., 2019; Nicolaidis et al., 2015a; Perry et al., 2014; Stein Duker et al., 2019; Sue & Mar, 2021; J. Wilkinson et al., 2013; J. E. Wilkinson et al., 2011). In addition, some HCPs had insufficient knowledge about medical issues related to disabilities, where to refer patients, chronic disease management, and end-of-life care in older adults with IDD/CDs (Doherty et al., 2019; Drainoni et al., 2006; Jones et al., 2008; Sue & Mar, 2021). Patients and families reported that a lack of provider knowledge resulted in subsequent incorrect assumptions based on IDD diagnosis (Brice et al., 2021; Nicolaidis et al., 2015b). Providers similarly reported a knowledge deficit, with one study finding that 77% of PCPs received no specific ASD education and 92% received inadequate training to work with autistic adults (Stein Duker et al., 2019).

### Literature Quality

Of the 28 studies in this review, none were randomized control trials or tested interventions. Using the Johns Hopkins Evidence-Based Practice Research, all articles were rated at level III, with four graded as level IIIA, 21 as level IIIB, and three as level IIIC (Appendix 3). The lack of level I



and level II grade studies highlights the significant need to advance the research in higher levels of evidence, including intervention development and testing for adults with IDD/CD, specifically regarding healthcare access, improved provider education, and increased availability of AAC devices. Only one implementation study was found, further highlighting the need to advance intervention research with efficacy/effectiveness testing, as well as the implementation of evidence-based interventions.

## Discussion

The purpose of this integrative review was to analyze and synthesize current knowledge about the barriers to and facilitators of access to care in adults with IDDs/CDs through the lens of Levesque et al.'s (2013) conceptual framework of access to healthcare. Application of this theoretical lens resulted in a more comprehensive understanding of the interplay between healthcare access and key barriers faced by adults with concurrent IDD and CD such as ineffective communication that ultimately contributes to lack of continuity of care, patient's need for autonomy, fear of stigma and negative experiences with healthcare.

Ineffective communication between providers and patients and supporters was the most prevalent and significant barrier affecting healthcare access in the adult with IDD/CD population. Communication challenges inherent in this population include difficulty understanding abstract language, strict linear thinking, and a need for alternative methods of communication such as text-to-voice applications or the use of writing (Nicolaidis et al., 2015b). These challenges can result in slower cognitive processing, making the comprehension of complex medical situations or diagnoses difficult. As noted throughout this review, communication between adults with IDDs/CDs and their HCPs directly affects healthcare experiences, which often in turn affect future service use (Mason et al., 2019a; Nicolaidis et al., 2013, 2015b). Within communication challenges, negative experiences and expectations were most commonly described by patients and supporters as relating to problems with communication and fear of stigmatization, and lead to increased ED use and health system strain (Hall et al., 2015; Liu et al., 2017; Raymaker et al., 2017; Vohra et al., 2016, 2017). In most instances, providers, patients, and supporters attributed communication problems between adults with IDDs/CDs and their providers to a lack of provider training and/or competency.

While communication may seem an obvious barrier for those with CDs, the lack of HCP training and education on accommodation of CDs, as well as reliance on supporters for communication, is concerning. Findings from a previous integrative review concluded that poor communication

had a negative impact on patient safety, yet there is little evidence to suggest that HCPs and/or healthcare systems have addressed these communication barriers to decrease their negative effects on access or safety (Hemsley & Balandin, 2014). Gaps in education regarding IDDs and the importance of communication of all types have not been sufficiently addressed for new or existing providers.

Time was a consistent barrier for HCPs and patients and their supporters. Nurses described time constraints as decreasing their likelihood of using AAC methods and/or impeding their ability to empower their patients by prioritizing communication (Hemsley et al., 2012). This overall time shortage in the healthcare profession has become increasingly apparent during the COVID-19 pandemic, with growing daily stressors like the reality of time constraints of nurses and HCPs who are already understaffed and overworked. When time is scarce and providers are stretched to accomplish more in less time, time becomes increasingly precious and hard to come by. Many HCPs cited an inability to justify "wasting" limited time using AAC when it may not result in a successful communication attempt (Desroches et al., 2021; Hemsley et al., 2012). While patients with IDDs/CDs should have support for their autonomy and a positive healthcare experience, HCPs are also burning out and experiencing compassion fatigue (International Council of Nurses, 2021). These feelings can affect their desire to "go the extra mile" by applying a range of adaptive strategies to communicate directly with a patient when speaking with a supporter is perceived to be more efficient (International Council of Nurses, 2021). Conversely, the pandemic did result in increased availability of tablets to patients in large health systems such as Mayo Clinic and Johns Hopkins. These tablets provide a means for AAC access to adults with IDDs/CDs in the future, pending software installation and user training (Moore, n.d.; *Patients Stay Connected to Family, Friends, and Providers with Bedside – Mayo Clinic News Network*, n.d.).

As a consequence of these cumulative communication barriers, patients with IDDs/CDs do not have consistent, reliable access to safe and effective healthcare. The current culture in healthcare appears to be one where rules set forth by the Americans with Disabilities Act (ADA) seem to be viewed much more as guidelines than an actual law (*ADA Requirements: Effective Communication*, n.d.; Agaronnik et al., 2019). This viewpoint was reinforced by multiple studies that found that HCPs did not take an adult with IDDs/CD's communication seriously, declined to accommodate their communication preference, or communicated solely with the supporter (Drainoni et al., 2006; Ferguson et al., 2011; Hemsley et al., 2012; Jones et al., 2008; Nicolaidis et al., 2015a; Perry et al., 2014; Stein Duker et al., 2019; J. Wilkinson et al., 2013). Although alternative communication allowance and the use of AAC are provider dependent, there is a clear trend of both a lack

Fig. 3 FR<sub>2</sub>A<sub>4</sub>ME<sub>2</sub> Framework

<b>F</b>	<b>Familiarize</b> yourself with how the patient best communicates, first
<b>R</b>	<b>Reduce</b> your speaking rate and the amount of information <sup>1</sup> <b>Respect</b> the patient's autonomy
<b>A</b>	<b>Assist</b> the patient with communication and acknowledge what they've told you <b>*Accommodate</b> the patient's needs for AAC strategies and sensory processing <b>*Allow</b> the patient extra time for communication exchanges <b>*Affirm</b> education using modified teach back methods
<b>M</b>	<b>Mix</b> communication modalities for both understanding and expression
<b>E</b>	<b>Engage</b> the patient directly, using supporter/interpreter/AAC when needed <b>*Empower</b> the patient by using their preferred communication strategy

Adapted by K. Shady, 2022 from Burns et al., 2012.

of accommodation and failure to allow AAC use (Drainoni et al., 2006; Mason et al., 2019b; Nicolaidis et al., 2015a; Stein Duker et al., 2019).

This review explored a novel view of healthcare access by adults with IDD/CDs by narrowing the focus to those who also have CDs. Existing research on this specific topic is limited; however, recent literature reviews reflect comparable findings (Doherty et al., 2020; Hemsley & Balandin, 2014; Malik-Soni et al., 2021; Mason et al., 2019b). These recent reviews did not focus on adults with IDD/CDs or their overall access to healthcare; rather, existing reviews highlighted only primary healthcare access, physical access to care, access of patients with severe CDs, or access of those with ASD (Doherty et al., 2020; Hemsley & Balandin, 2014; Malik-Soni et al., 2021; Mason et al., 2019b).

### Strengths and Limitations

The selection of search terms may have excluded relevant literature, although a medical reference librarian was consulted during the search process. Levesque et al.'s (2013) framework may have limited some of the findings by highlighting specific areas of access and grouping of themes to fit into existing domains of the framework. The use of Levesque et al.'s (2013) model, however, was particularly appropriate for adult patients with IDD/CD because this population relies heavily on patient-centered care to have the best possible healthcare experience (Appendix 2). Levesque et al.'s (2013) model also highlights different types of barriers and facilitators to healthcare that this population experiences, such as accommodations and appropriateness of a healthcare system, as well as the patient's ability to perceive, seek, or engage in healthcare.

### Implications for Future Research

The findings of this review establish an initial body of evidence to identify the current numerous barriers to access to care for the adult with IDD/CD population. Communication serves as a monumental barrier to healthcare

access for the adult IDD/CD population, yet none of the articles reviewed offered evidence-based recommendations for overcoming communication barriers beyond provider education and increased competency.

The FRAME framework, as proposed by Burns et al. (2012), uses the mnemonic FRAME to present providers with appropriate strategies to “frame” their conversations with patients with CDs. Each letter in the mnemonic represents an essential strategy across various CDs; however, based on the findings of this review, there are several key strategies that patients and supporters reported as considerably important that are not included. Thus, a modified version of the FRAME framework, the FR<sub>2</sub>A<sub>4</sub>ME<sub>2</sub>, is proposed to incorporate elements identified as instrumental to successful, quality healthcare experiences by individuals with CDs and IDD/CDs and their supporters (Fig. 3). This enhanced framework will be evaluated in future research exploring the barriers and facilitators to care provision by adult in-hospital HCPs in the USA caring for adults with CDs and IDD/CDs.

Given the high healthcare utilization rate, increased cost of healthcare, and an increasing number of adult patients with IDD/CDs as they transition or age out of the pediatric healthcare system, more research is needed. With an estimated 50,000 children with ASD turning 18 each year and adding to the existing population of adult patients with IDD/CD, the urgency of additional research, implementation projects, policy changes, and increased HCP education and training will only continue to grow (*Coming of Age: Autism and the Transition to Adulthood | Interactive Autism Network*, n.d.).

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## Declarations

**Conflict of Interest** The authors declare no competing interests.

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