





Inclusive Provider Self-Audit Tool Companion Guide



Introduction

This tool is designed to support healthcare entities in assessing and improving their inclusivity of people with disabilities (PWD), specifically individuals with intellectual and developmental disabilities (IDD). The goal is for providers to set concrete action plans to make greater progress towards inclusion each year.

This tool is a product of the collaborative among the following entities:







Center on Disability

The Center on Disability (CoD) is a disability-led program that provides education, advocacy, and support to advance the full and equal participation of PWD in all aspects of society.

The Center to Advance Community Health and Equity

The Center to Advance Community Health and Equity (CACHE) supports strategic approaches to health improvement in communities where health inequities are concentrated.

Both CoD and CACHE are housed at the Public Health Institute.

Special Olympics Health

Special Olympics Health, made possible by the Golisano Foundation, and in the United States in collaboration with the U.S. Centers for Disease Control and Prevention, is creating a world where people with intellectual and developmental disabilities have every opportunity to be healthy. Special Olympics' health programming focuses on improving the physical and social emotional well-being of people with IDD by increasing inclusion in health care, wellness and health systems for Special Olympics athletes and others with IDD.

Note: If you need this document or the Self-Audit tool in a different format for accessibility, please email Info@CenterOnDisability.org.

Special Olympics Health activities are supported by many sources, including in the United States by Grant Number NU27DD000021 from the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS), with \$18.1 M (64%) financed with U.S. Federal funds and \$10.2 M (36%) supported by non-federal sources. The contents of this document are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

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How to use tool

Who should perform the assessment?

This tool is designed for a wide variety of healthcare clinics, offices, and facilities. Choosing which staff members should perform the audit depends on the staffing of your particular medical entity. Some entities may be small with few staff. Others may have a large number of staff in different departments, who are responsible for designated components of the tool.

When deciding how to perform the assessment, look at the tool's tabs (we refer to them as domains in this guide). Think about the person(s) on your staff with the most knowledge about those areas. One person may complete multiple or all domains of the assessment, or a separate department may handle each domain. When possible, a team approach is best. This approach builds accountability and ownership for completing the audit and implementing the action plan. You can upload the excel file to a collaborative program like Google Drive or Sharepoint if you want multiple staff to be able to work in the tool simultaneously. Regardless of who completes the audit, discussing the results and action plan with your full staff after completing the assessment helps build buy-in and align with the organization's commitment to accessibility and inclusion for people with IDD.

What are the tool's domains?

The tool consists of seven domains: Staff Training; Communication; Physical Space; Operations; Policies and Procedures; Autonomy and Support; and Specialty Areas.

What is the expected time commitment to complete the assessment?

There is no minimum number of days or hours to complete this assessment. Our providers who pilot tested the tool generally noted it took them 4-6 hours, with some less and some more. You do not have to do the assessment all in one sitting. You can take it domain by domain and break it up however works best for your organization. Understand that many items in the assessment may feel out of reach for medical providers that are only beginning to explore accessibility and inclusive practices. That's okay! This tool is thorough and meant to grow with your practice over many years. That's why the tool allows you to categorize items into short-range, medium-range, and long-range action items.

If you wish to break the assessment up over the course of a month, below is one potential extended schedule for using the tool:

Week one: Staff Training and Communication domains Week two: Physical Space and Medical Equipment domains Week three: Operations and Policies and Procedures domains

Week four: Philosophies of Support (and Specialty Areas if applicable)

What should I do if the audit tool feels overwhelming?

The goal of the tool and guide is to provide you with information and resources to make progress. If the number of questions feel too daunting, you can filter out the more advanced questions. Once you've downloaded the tool, simply click the dropdown arrow next to Effort Level, choose the Filter by values option, and uncheck Modest and Moderate. You will need to do this on each domain. You can always recheck these options when you are ready.

Figure 1.1 Filtering by Effort Level

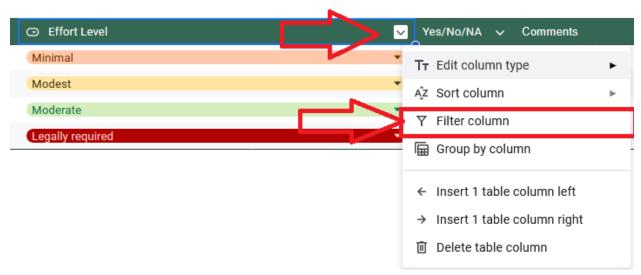
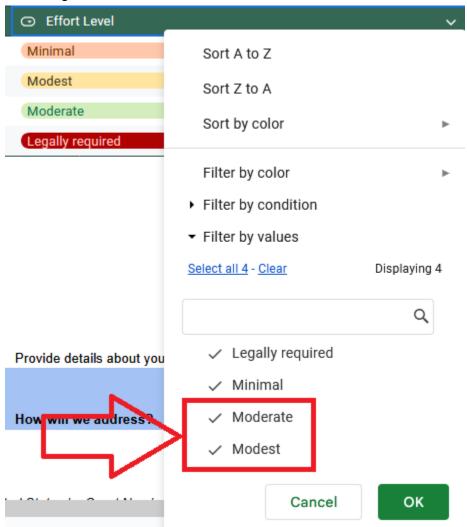


Figure 1.2 Unchecking Effort Levels



Domains and Categories

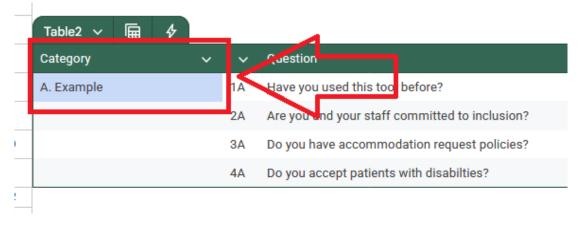
The domains are the main topic areas named on each tab of the excel sheet.

Figure 1.3 Location of domains in the tool



Each domain is divided into categories, denoted in the left-hand column (Column A) in light gray. The categories will have questions and a corresponding effort level next to each question.

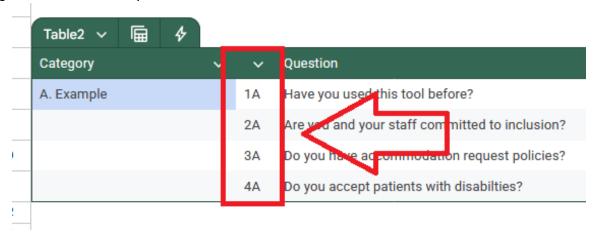
Figure 1.4 Location of categories in the tool



Questions

Each question is labeled with a letter-number combination in Column B. To make it easy to find the information related to that question in this guide, go to the Domain section in this document that matches the tab, then find the corresponding letter-number combo for more detailed information about what the question is asking and find resources or support for implementation.

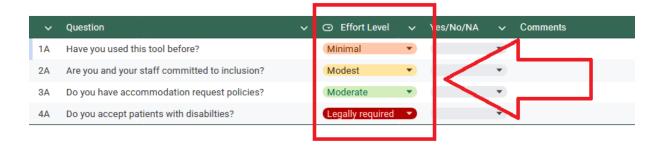
Figure 1.5 Location of question numbers in the tool



Effort Levels

The effort levels are found in Column D. The effort levels are based on estimated time and cost investment.

Figure 1.6 Location of the tool's effort levels



The effort levels are categorized as follows:

Minimal: This level requires a low time and cost investment. Resources are available to assist the provider.

Modest: This level requires a bit more staff time to develop or implement or takes more financial resources but is not a major undertaking.

Moderate: This level may take more financial planning. Some items may require a multi-year plan or external to achieve.

Legally Required: This item is likely required under the Americans with Disabilities Act (ADA). Some qualifying factors may exist, like the building's construction and last renovation date, historical significance, etc.

Answers and Comments

Next to each question, select Yes, No, or NA (not applicable). Record any comments next to the question that may be helpful for future use in determining what issues to address.

Timeframe to Address

The last column allows you to determine the timeframe to address the issue. The five options include within 6 months, 1 year, 3 to 5 years, or not a priority.

When you choose a specific timeframe, the tool automatically places that question onto the appropriate timeline tab. This breaks up the questions into the appropriate action plan tabs on the right side of the tool. Note: If you mark a legally required item as "Not a Priority," the box will turn red to remind you of the potential legal risks of not addressing it.

Action Plan

Once you have completed the self-audit, you will see the questions that have automatically populated in the Short, Medium, and Long term tabs based on your timeline responses. Starting with the Short-Term tab, look at each of the action items. Based on your staffing capacity and available resources, fill in the remaining columns next to each item. You can work directly in these tabs, but you can also print or save by "printing" to PDF if you want to share only these tabs with others.

Date to Complete

When would you like to address this issue? Setting clear dates helps ensure the identified issues remain a priority.

How will we address?

What needs to happen for this item to be addressed? If there are multiple steps, write them out here, include any supplies or resources needed.

Who is Responsible?

Which staff member(s) are most appropriately positioned to work on this item? Who has the authority and capacity to make this step happen?

Comments

Use this column as needed to remember relevant discussion items or take short notes from the guide about addressing the item.

Completed

You can mark items as "In Progress" once you have started them and switch them to complete once the item has been resolved.

Items in this tab can be adjusted at any time.

Domains

A. Staff Training

Staff training is vital to creating a welcoming, inclusive, and effective environment at serving people with disabilities (PWDs). A recent study shows that medical providers have bias and a general reluctance to treat people with disabilities, which contributes to their ongoing health disparities.¹

Training logistics

A1. Has your staff received disability awareness training?

This question refers to any level of disability training. More specific information on the topics of these trainings is covered in the next category. You can require disability training as part of your onboarding requirements to make sure staff are trained at the beginning of their employment.

A2. Is the training required for all staff that interact with PWDs?

Training all staff is important, including those who answer the phones, work at the front desk, and handle billing questions and appointment scheduling. Everyone your patients come in contact with impacts their overall experience and satisfaction.

A3. Was any part of training developed and provided by a disability-led organization, with actual stories from patients with IDD?

No one understands the disability experience and barriers they encounter better than those with disabilities. Hearing first-hand from trainers with disabilities helps minimize stigma and bias.

Some organizations that may be able to help with training include:

- Centers for Independent Living (CILs)- CIL programs provide tools, resources, and supports for integrating people with disabilities fully into their communities. The majority of the CIL staff are people with disabilities. To find out if a CIL serves your community, you can go to the <u>Statewide Independent Living Council website for your</u> state. Look for the section labeled State SILC Contacts.
- Local disability advocacy groups
- Your local Special Olympics chapter. To find if a Special Olympics chapter serves your community, you can go to the directory of Special Olympics North America

¹ Lagu T, Haywood C, Reimold K, DeJong C, Walker Sterling R, Iezzoni LI. 'I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities. Health Aff (Millwood). 2022 Oct;41(10):1387-1395. doi: 10.1377/hlthaff.2022.00475. PMID: 36190896; PMCID: PMC9984238.

<u>United States Programs</u>. Scroll to the bottom of the page and click on your state for local contact information. You may also contact <u>inclusivehealth@specialolympics.org</u>.

A4. Do staff have to take the training each year as a refresher?

It's always good to take the training each year to keep knowledge and skills sharp.

A5. Do you track which staff have taken the training?

Without a tracking mechanism, it's easy to miss when staff haven't taken the training or if it has been a while since their last training. Tracking can be a simple spreadsheet. An administrative staff member or the staff member responsible for disability-related issues can put a reminder on the calendar to check the tracking sheet every 6 months and send reminders to staff whose training may be outdated.

A6. Does the training offer a way to measure understanding of the concepts?

If possible, training programs should offer quizzes or surveys after modules to measure staff understanding and knowledge retention.

Training topics

One training likely will not cover all of the topics listed in the tool. Several different training sessions may be needed to provide a thorough understanding of disability and how to competently serve persons with disabilities.

Note: Some suggested trainings and topics they cover are presented below and in Figure 2.1.

B1. Does the training cover provider legal requirements under the ADA?

All staff need to understand their legal obligations under the ADA. The ADA is not only about the physical space but also has requirements about effective communication for those with a communication disability (e.g., speech and/or hearing disability) and modifying policies and procedures on a case-by-case basis when needed to accommodate a specific person with a disability.

B2. Does the training cover the different models of disability, specifically the medical versus social models?

Typically, medical education and training are focused on the medical model of disability – i.e., identifying a diagnosis and a treatment or intervention. The social model of disability examines how a person accesses their lived environment and the barriers they encounter. Societal attitudes and physical and programmatic barriers can limit PWDs from fully participating in their communities. Understanding these environmental barriers helps

medical providers understand the importance of using a holistic service approach and the supports an individual may need in the community. Medical providers can lessen the impact of environmental barriers, by connecting PWDs to community resources or services.

B3. Does the training cover communicating in plain language and Easy Read?

Individuals with IDD may need information broken down or delivered differently, particularly if it is complex medical information. Plain language and Easy Read are two different ways to provide written communication. The use of plain language and Easy Read can be helpful for all patients, but are particularly important for individuals with IDD in helping them understand their medical services.

The National Institutes of Health (NIH) has helpful training <u>resources on plain language</u>.² The Center on Disability provides virtual <u>plain language and Easy Read training</u> for businesses and organizations.³ Special Olympics provide an <u>Easy Read resources</u>⁴ and an Easy-to-Read Writing Basics Course on its <u>learning portal</u>.⁵

B4. Does the training cover supported and surrogate/substitute decision making?

Individuals with IDD have the right to participate in decisions about their healthcare. Supported Decision-Making helps them do so with assistance from trusted individuals. Training on this topic ensures providers understand alternatives to guardianship and how to honor a person's preferences while meeting their healthcare needs.

B5. Does the training cover guardianship and healthcare/medical power of attorney documents?

Healthcare providers must be aware of the legal rights of individuals with IDD, including when a guardian, agent, or proxy is involved in decision-making. Proper training helps staff recognize the limits of these roles, ensuring they involve authorized decision-makers, as appropriate, and respect the individual's autonomy.

² Plain Language: Getting Started or Brushing Up. (2015, February 17). National Institutes of Health (NIH). https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/plain-language/plain-language-getting-started-or-brushing

³ Training. (2024, February 9). Center on Disability. https://centerondisability.org/training/

⁴ Special Olympics. (n.d.). *Easy read & accessibility*. Retrieved May 28, 2025, from https://resources.specialolympics.org/easy-read-accessibility

⁵Special Olympics. (n.d.). *Online Learning Portal*. Retrieved May 28, 2025, from https://learn.specialolympics.org/

The U.S. Department of Justice provides some helpful information on the scope of guardianship.⁶ It states, "Recent trends in law and practice reflect the idea that courts should remove only those rights that the adult is incapable of handling (i.e., limited guardianship). The court order appointing a guardian should specify the scope of the guardian's authority."

B6. Does the training cover use of the Teach-Back Method to ensure understanding of communication?

The Teach-Back Method is a simple and effective way to confirm the individual with IDD understands healthcare instructions.⁷ Training in this approach equips providers with strategies to communicate clearly and adjust explanations based on the individual's ability to process and recall information. The Stanford Center for Continuing Medical Education has a short YouTube series on the Teach-Back Method⁸.

B7. Does the training cover how to recognize and document informed consent?

Informed consent ensures that the individual understands the provided information and can make a voluntary decision. Training helps providers recognize when the individual needs additional support to provide consent, how to assess comprehension, and how to document the process. The Health Care for Adults with Intellectual and Developmental Disabilities Toolkit for Primary Care Providers provides helpful information on informed consent for individuals with IDD.9

B8. Does the training cover how different cultural and racial backgrounds may necessitate different healthcare and communication approaches?

Cultural beliefs and experiences shape how individuals with IDD engage with healthcare providers. Individuals from different cultural backgrounds may have differing views of disability and how community resources are used. Training on this topic helps providers deliver respectful, inclusive care by recognizing diverse communication styles, traditions, and potential barriers to trust in medical settings.

⁶ *Guardianship: Key concepts and resources*. (2021, May 20). Www.justice.gov. https://www.justice.gov/elderjustice/guardianship-key-concepts-and-resources

⁷ Yen, P. H., & Leasure, A. R. (2019). Use and effectiveness of the teach-back method in patient education and health outcomes. *Federal Practitioner*, 36(6), 284–289. https://pmc.ncbi.nlm.nih.gov/articles/PMC6590951/

⁸ Stanford Center for Continuing Medical Education. (2023, November 1). *MedEd Mastery Series: Mastering the Teach-Back Method for Patient-Centered Care*. Stanford Medicine. Retrieved May 28, 2025, from https://stanford.cloud-cme.com/course/courseoverview?EID=47382&P=0

⁹ Informed Consent in Adults with Intellectual or Developmental Disabilities - Health Care for Adults with Intellectual and Developmental Disabilities. (2024, April 12). Health Care for Adults with Intellectual and Developmental Disabilities. https://iddtoolkit.vkcsites.org/informed-consent/

B9. Do you have staff trained on how to transfer an individual from a wheelchair to the examination table?

Safe and dignified transfers are essential ensure quality healthcare access for individuals who use wheelchairs. Proper training helps staff use the right techniques and equipment to prevent injury while promoting comfort and respect during medical visits.



A Hoyer lift, as shown in the picture above, makes it easier for staff to transfer individuals from their wheelchairs to the exam table.

Figure 2.1 List of Training Resources and Assessment Topics Covered

| Training Name | B1 | B2 | В3 | B4 | B5 | В6 | В7 | В8 | В9 |
|---|----------|-------------|-------------|----------|----|----|----------|----|----|
| ADA And Healthcare webinar series, Northwest ADA Center and Oregon Health Authority ¹⁰ | / | ~ | | | | | | | |
| Healthcare and the ADA, Rocky Mountain ADA Trainings ¹¹ | \ | | | | | | | | |
| Health Risk Screening Tool ¹² | | > | | | | | | | |
| Green Mountain Self Advocates (GMSA) Plain Language Training Series 13 | | | > | | | | | | |
| Pre-Service Health Training Series ¹⁴ | | > | | | | | | | |
| How to Develop Products for Adults with Intellectual and Developmental Disabilities and Extreme Low Literacy A Product Development Tool ¹⁵ | | | > | | | | | | |
| Surrogate Health Care Decision Making Course ¹⁶ | | | | \ | | | | | |
| Care of the Patient with Intellectual and Developmental Disabilities ¹⁷ | | | \ | | | | | | |
| NGA Fundamentals Series ¹⁸ | | | | | > | | | | |
| MedEd Mastery Series: Mastering the Teach-Back Method for Patient-Centered Care 19 | | | | | | > | | | |
| Informed Consent Process for Adults with Intellectual and Developmental Disabilities ²⁰ | | | | | | | / | | |
| Cultural competence in lifelong care and support for individuals with intellectual disabilities (article) ²¹ | | | | | | | | > | |
| Health Care for Adults with Intellectual and Developmental <u>Disabilities Toolkit for Primary Care Providers</u> ²² | | | | > | | | | | |

¹⁰ OHA Healthcare Webinars. (2024). [Webinar Series]. Northwest ADA Center and Oregon Health Authority. https://nwadacenter.org/oha-healthcare/

¹¹ Healthcare and the ADA (2025). Rocky Mountain ADA Center. https://rockymountainada.talentlms.com/plus/catalog/courses/185

¹² IntellectAbility Academy. (n.d.) Health Risk Screening Tool from https://replacingrisk.com/health-risk-screening-tool-overview/

¹³ Green Mountain Self Advocates (GMSA) Plain Language Training Series. (n.d.) from https://gmsavt.org/gmsa-to-teach-a-series-of-free-training-on-plain-language

¹⁴ Human Development Institute, University of Kentucky, PreService Health Training Series. (n.d.). From https://hdi.uky.edu/learn/preservice-health-training/#

¹⁵ Centers for Disease Control and Prevention. (2023). How to Develop Products for Adults with Intellectual Developmental Disabilities and Extreme Low Literacy A Product Development Tool. Created in partnership with Research Triangle Institute, and Communicate Health and the Centers for Disease Control and Prevention. from https://www.cdc.gov/ccindex/pdf/idd-ell-product-development-tool-508.pdf

Special Olympics offers <u>additional training on its learning portal</u> that may be helpful for medical staff.²³

Cross disability training

Cross-disability training helps providers understand and meet the needs of people with all types of disabilities including physical, sensory, intellectual, developmental, and psychiatric. Instead of assuming one approach works for everyone, this training provides staff with the tools to assess an individual's different needs, communication styles, and accommodations to make healthcare more accessible and effective.

C1. Does the training cover individuals diagnosed with IDD and a dual diagnosis of a mental health disability?

Additionally, do not assume that behavioral issues are necessarily a mental health disorder. Behavior is often a form of communication for those who have may have difficulty expressing themselves verbally. The video <u>Behavior is Communication</u> provides a good summary of how behavior may be a voluntary or involuntary indication of fear, pain, or stress

The documented percentage of individuals who have both an IDD and a mental health diagnosis varies, but a general consensus among professionals is that about 35% of individuals with IDD have a mental health condition.²⁴ Your staff should have training about how to work with individuals with a dual diagnosis. A low-cost series of trainings available online are the <u>Healthcare for Individuals with Intellectual and Developmental Disabilities modules.²⁵</u>

Office of Developmental Programs (ODP), Pennsylvania Department of Human Services. My ODP Resource Center. Surrogate Health Care Decision Making Course. From https://www.myodp.org/course/view.php?id=385

¹⁷ CEUfast. Nursing CEUs. Care of the Patient with Intellectual Disabilities- Accredited for assistant level professionals only. From https://ceufast.com/course/care-of-the-patient-with-an-intellectual-disability

¹⁸ National Guardianship Association (NGA). (n.d.). NGA Fundamentals Series.# From https://www.guardianship.org/education/webinars/

¹⁹ MedEd Mastery Series: Mastering the Teach-Back Method for Patient-Centered Care - Stanford Center for Continuing Medical Education - Continuing Education (CE). (2023). Stanford Medicine. https://stanford.cloud-cme.com/course/courseoverview?P=5&EID=47382

²⁰ The Vanderbilt Kennedy Center. (2024). The Informed Consent Process for Adults with Intellectual and Developmental Disabilities Toolkit. From https://vkc.vumc.org/assets/files/resources/informed-consent.pdf

²¹ van Herwaarden A, Rommes EWM, and Peters-Scheffer NC. (2021) Cultural competence in lifelong care and support for individuals with intellectual disabilities, #Ethnicity & Health, 26:6, 922-935, DOI: 10.1080/13557858.2019.1591348

²² Health Care for Adults with Intellectual and Developmental Disabilities-Toolkit for Primary Care Providers. (n.d.) https://iddtoolkit.vkcsites.org/contact-us/23

²⁴ National Association for the Dually Diagnosed (NADD). (n.d.). *ID/MH diagnosis*. Retrieved March 31, 2025, from https://thenadd.org/idd-mi-diagnosis/.

²⁵ Modules for Healthcare Professionals - MHW-IDD. (2024, October 16). MHW-IDD. https://training.mhw-idd.uthscsa.edu/healthcare-professionals/

C2. Does the training cover how to interact with individuals with communication disabilities (both speech disabilities and hearing disabilities)?

Training that includes people with lived experience is recommended. Check with local Deaf organizations and Centers for Independent Living to see if they may provide training.

Trauma-informed care

D1. Does the training include a trauma-informed approach to care?

Relias Academy's <u>Trauma-Informed Service Programs</u>²⁶ and <u>A Trauma-Informed Toolkit for Providers in the Field of Intellectual & Developmental Disabilities</u>²⁷ from the Center for Disability Services are two resources that cover trauma-informed care.

D2. Does the training include de-escalation techniques?

As medical settings can be stressful, helping staff learn how to de-escalate is a worthwhile training investment. The Cypress Resilience Project offers Mental Health First Aid and De-Escalation training.²⁸

Ongoing Learning

Ongoing learning ensures that healthcare providers continue to improve their understanding of disability, accessibility, and inclusive practices. As disability rights, medical advancements, and best practices are consistently evolving, staying current helps providers provide equitable care. Continuous learning helps challenge negative assumptions on PWDs and fill in knowledge gaps that might otherwise go unnoticed.

One way to address questions E1 - E4 is to provide staff with an electronic survey that asks about their involvement and engagement in these areas.

E1. Does your organization have a relationship with a disability-led organization to obtain ongoing input on policies, practices and procedures?

Working with disability-led organizations helps ensure policies and practices are shaped by people with firsthand experience. These partnerships provide valuable insight into what is working, what is not, and how to make services more accessible and inclusive. This approach results in more effectively meeting the needs of the disability community. Below are some ideas on how to locate these connections:

²⁷ Marcal, S., & Trifoso, P. (n.d.). A Trauma-Informed Toolkit for Providers in the Field of Intellectual & Developmental Disabilities.

 $\frac{\text{https://pacesconnection.crowdstack.io/fileSendAction/fcType/0/fcOid/468137553002812476/filePointer/468137553002812517/fodoid/468137553002812512/IDD%20TOOLKIT%20%20CFDS%20HEARTS%20NETWORK%205-28%20FinalR2.pdf}$

Harvey, K. (2025). *Trauma-Informed Service Programs* Relias Learning.
 https://reliasacademy.com/rls/store/courses/trauma-informed-service-programs/ /A-product-c1368632
 Marcal, S., & Trifoso, P. (n.d.). *A Trauma-Informed Toolkit for Providers in the Field of Intellectual &*

²⁸ Our Trainings | Cypress Website. (2024). Cypress Resilience Trainings. https://www.cypressresilience.org/ourtrainings

- Centers for Independent Living (CILs) provide tools, resources, and support for
 integrating persons with disabilities fully into their communities. The majority of CIL
 staff are persons with disabilities. To find out if a CIL serves your community, go to the
 Statewide Independent Living Council website for your state
 and look for the section labeled State SILC Contacts.
- Local disability advocacy organizations and coalitions- You can google "disability advocacy group" or "self-advocacy group: for your city or state to identify what currently exists, as these organizations vary by location.
- Local <u>Arc chapters</u> or <u>Special Olympics program</u> may have persons with disabilities in leadership positions who provide input and support.
- **E2.** Do staff sit on disability-related committees or councils to stay current on new disability-based developments?

Being part of disability-related committees or councils help staff stay connected to disability-based current issues, best practices, and policy changes. These connections provide an opportunity to directly learn from advocates, stay ahead of emerging trends, and make sure the provider's organization continuously improves how it serves PWDs. Examples include city disability commissions, State Councils on Developmental Disabilities, advisory boards for state Protection and Advocacy systems in the National Disability Rights Network, and Arc Chapter Boards. Furthermore, if you are on any committees or councils that discuss healthcare and don't have members with disabilities, you should encourage representation from that population.

E3. Do staff subscribe to mailing groups or listservs with other medical professionals that include attention to disability-related healthcare issues?

Subscribing to disability-based mailing lists, list servs, and/or professional forums helps staff exchange ideas, ask questions, and stay current with new research and strategies that support healthcare provision for persons with disabilities. Examples of this recommendation are the Down syndrome medical interest group listserv; the Center for Inclusive Health newsletter, and the general Special Olympics Health Newsletter.

E4. Does the healthcare team have additional knowledge and understanding of health conditions common to individuals with IDD?

Individuals with IDD may experience certain health conditions at higher rates or in ways that require a different approach to care. When providers have the right training and knowledge, they are better equipped to diagnose, treat, and prevent health issues, leading to better outcomes and a more positive healthcare experience for PWDs.

These <u>Health Watch Tables</u> are a helpful resource to "highlight particular health problems that occur more frequently among adults with intellectual and developmental disabilities compared with the general population."²⁹

B. Communication

Materials

A1. Are your forms written in plain language?

People with intellectual and developmental disabilities often need forms and instructions in plain language that is easy to read. Try to reach a 6th - 8th grade reading level with any written materials and forms.

For more information about how to write in plain language and Easy Read (discussed below), check out the Center on Disability's Inclusive Communication Guides³⁰.

A2. Do you convert forms to Easy Read if requested?

Easy Read materials are typically written at a 3rd-5th grade reading level and contain pictures to help with comprehension.

The Autistic Self Advocacy Network's <u>One Idea Per Line: A Guide to Making Easy Read</u>
<u>Resources</u> provides guidance on how to make Easy Read materials.³¹

A3. Do you offer both written and verbal information about treatment, medications, and follow up steps after each visit?

After each health care visit, offer both written and verbal information about the individual's treatment, medications, and follow-up so that individuals with IDD can understand how to maintain their health and their medication schedule.

A4. Do you provide all information to both the individual and the caregiver or guardian (in accordance with HIPAA and the individual's wishes)?

Make sure you are clear on what information can and should be shared with an individual's caregiver/guardian and others in the individual's support network.

²⁹ Health Watch Tables - Health Care for Adults with Intellectual and Developmental Disabilities. (2024, September 18). Health Care for Adults with Intellectual and Developmental Disabilities. https://iddtoolkit.vkcsites.org/health-watch-tables/

³⁰ Plain language and Easy Read. (2025, March 4). Center on Disability. https://centerondisability.org/plain-language-and-easy-read/

³¹ One Idea Per Line: A Guide to Making Easy Read Resources - Autistic Self Advocacy Network. (2021, July 27). Autistic Self Advocacy Network. https://autisticadvocacy.org/resources/accessibility/easyread/

Review HIPAA releases, guardianship/conservatorship documents, and healthcare/ medical power of attorney documents. Document who has access to information clearly in the individual's electronic health record (EHR). Make sure both the individual and others who have access to the medical information receive separate copies of written documentation.

A5. When speaking with the individual and the caregiver (in accordance with HIPAA and the individual's wishes), do you avoid complex language and medical jargon?

Breaking information into smaller pieces/segments makes it easier for individuals with IDD to understand and retain important details. Use short sentences with one idea per sentence. Pause often to allow for questions. This approach reduces confusion and supports improved decision-making.

A6. Do you have alternative tools to communicate information with individuals with IDD (charts, pictures, videos, models)?

Individuals with IDD may understand healthcare information better when it is presented visually or interactively rather than only verbally. Tools like charts, pictures, videos, or models about procedures, parts of the body, pain levels, etc. can make explanations clearer, reduce confusion, and help the individual make informed decisions. Make sure you use captioning for videos. Offering multiple ways to communicate ensures that healthcare is accessible and patient-centered.

Alternative formats

B1. Do you know how to take existing materials and make them large print (PDFs, copies, etc. where the original Word version isn't available)?

Any written materials should be available in print that is at least 18-point font for people who need large print. Some individuals may need larger print, so it's always best to ask. Always use sans serif fonts such as Calibri, Arial, or Verdana. There are some free online programs that can convert PDFs to Word documents so you can adjust the font size. You can also enlarge the print size on photocopiers.

B2. Do you know how to make materials in electronic format that can be read by a screenreader? Learn how to make your health care materials and forms accessible for those using screen reading software. The documents typically need properly marked headings, and any images must have alternative text that describes the image. If you don't know how to make materials and forms accessible to a screen reader, ask your <u>regional ADA Center</u> for assistance or a referral.

Interpreting services

C1. Do you provide American Sign Language interpreters or captioning services when requested?

If a person is deaf and requests a sign language interpreter, the medical provider must secure and pay for a qualified interpreter that interpreter. Be sure to ask what type of interpreter the person needs – i.e. American Sign Language or a Certified Deaf Interpreter.

Some Deaf individuals may not know ASL so it is important to find out their preferred method of communications.

Another common request for individuals with hearing disabilities is live captioning. You should seek out captioning services, also known as CART (Communication Access Realtime Translation), ahead of getting a request so you are prepared. Live captioning is more accurate than auto-captioning software.

C2. Do you have contact information for an American Sign Language Interpreter or captioning/CART readily available if requested?

Sign language interpreters typically work through private referral services. Research which referral services serve your area. You may need to sign an interpreter contract before you hire a sign language interpreter, so it is best to communicate with preferred companies prior to a request.

C3. Do you provide foreign language interpreters when requested?

Research foreign-language interpreter providers in your area. You may need to sign a contract, so it is best to communicate with providers before you need to hire a foreign language interpreter.

C4. Do you have contact information for Spanish language interpreters and other common foreign languages spoken in your geographic area readily available when requested?

Have this contact information readily available for those working at the front desk, answering the phones, and scheduling appointments.

C5. Do you have funds identified in your budget for interpreting costs?

Set aside funds in your budget each year to make sure you can pay for foreignlanguage and sign language interpreters. Get the provider rates ahead of time for accurate cost estimates.

Nonverbal communication

D1. Do you have communication cards or a communication board available to help facilitate communication with individuals with IDD who may need them?

Communication cards provide pictures in place of commonly used words or phrases to facilitate communication. For example, a picture of a plate of food could be used to represent "are you hungry?" or a glass of water could represent "are you thirsty?" These visuals can be represented on a communication board for easier navigation.

Research and print or purchase communication cards you can use to communicate with individuals with IDD. These cards show pictures in addition to words, which are easier to understand. The <u>PAMI</u> communication cards³² and Widgit Health's communication resources³³ are examples of free options.

D2. Do your staff communicate with individuals with IDD using their assistive or augmentative communication devices when that is their standard or preferred method of communication?

Many individuals with IDD may bring their own communication devices to medical visits. It is important to try and communicate with the individual using the method most comfortable to them.

D3. Do you have visual pain charts to ask patients about their pain level?

Research and purchase pain charts that show different pain levels with images in addition to words. The typical pain level images with the round faces may not be expressive enough to show more severe pain. Think about how your patient can express how severe their pain is.

C. Physical Space

When completing this section of the tool and deciding which items to address first in your action plan, consider which items may prevent your facility from being safe and usable by people who use mobility devices.

³² *Communication Cards* (n.d.). University of Florida College of Medicine. https://pami.emergency.med.jax.ufl.edu/resources/communication-cards/

³³ Widgit Health - Communication boards and easy read sheets for professionals. (n.d.). Widgit Health. https://widgit-health.com/downloads/for-professionals.htm

Parking

A1. Does each of the parking facilities (lots or garages) have at least one van accessible parking space with a short route to the accessible entrance?

If a medical office, clinic, or hospital has a parking lot, at least one van accessible parking space should be available. The more parking spaces provided, the more accessible spaces are needed. There should be one accessible space for every 25 total parking spaces. One of every 6 **accessible** spaces needs to be a van accessible space.

See Figure 2.2 below.

Figure 2.2 Table of Minimum Accessible Spaces

| Total Number of Parking Spaces Provided in Parking Facility | Minimum Number of Required Accessible Parking Spaces | |
|---|---|--|
| 1 to 25 | 1 | |
| 26 to 50 | 2 | |
| 51 to 75 | 3 | |
| 76 to 100 | 4 | |
| 101 to 150 | 5 | |
| 151 to 200 | 6 | |
| 201 to 300 | 7 | |
| 301 to 400 | 8 | |
| 401 to 500 | 9 | |
| 501 to 1000 | 2 percent of total | |
| 1001 and over | 20, plus 1 for each 100, or fraction thereof, over 1000 | |

A2. Is the ground of the parking space firm, stable, and slip-resistant with no level changes, and generally flat with no slopes more than 2% in any direction?

The ground in the accessible parking area should be paved and smooth, with no gravel or dirt surfaces. You can measure the slope by following these directions³⁴ under the Accessible Slopes heading.

A3. If this is a van space, is it at least 12 feet wide? *a van space width can be 9 feet if the access aisle is increased to 8 feet.

Figure 2.3 lists the stall and access aisle dimensions for car and van spaces.

³⁴ How to Use This Checklist - ADA Checklists for Existing Facilities. (2016). New England ADA Center. https://www.adachecklist.org/howto.html

Figure 2.3 Table of Accessible Parking Stall and Access Aisle Dimensions for Cars and Vans

| Type of Space | Stall Dimensions | Access Aisle Dimensions |
|---------------|---|--|
| Car | 9 ft wide x 18 ft long | 5 ft wide x 18 ft long |
| Van | 12 ft wide x 18 ft long or 9 ft wide x 18 ft long | 5 ft wide x 18 ft long or 8 ft wide x 18 ft long |

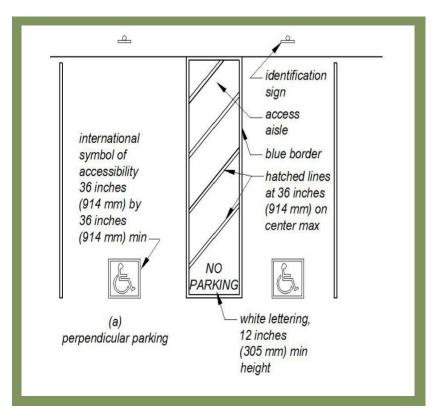
A4. Are accessible car spaces at least 9 feet wide?

See Figure 2.3 above.

A5. Is there a striped access aisle next to any accessible parking space that is firm, stable, and slip-resistant with no level changes, and a generally flat surface with no slopes more than 2% in any direction?

Accessible parking spaces should have access aisles next to them. These access aisles should have diagonal stripes with the words NO PARKING at the bottom. The access aisles should be paved, have no level changes, and be basically flat in all directions except a 2% slope that allows for water to run off and not puddle as identified in Figure 2.4 below.

Figure 2.4 Accessible Parking Stall and Access Aisle Dimensions



A6. Is the access aisle at least 5 feet wide and as long as the vehicle space? *an 8 foot wide van space requires an 8 foot wide access aisle

Parking space access aisles should be at least 5-feet wide and as long as the accessible parking space they are next to. See Figure 2.4 above.

A7. If this is a van space, is the access aisle on the passenger side?

Most wheelchair accessible vans have the exit ramp or lift on the passenger side.

A8. Is there a sign at the head of the parking space or immediately next to the space it identifies that displays the International Symbol of Accessibility (wheelchair symbol)?

The accessible parking space should have a sign with the International Symbol of Accessibility (the wheelchair symbol) at the top of the space on a pole or on a building as shown in Figure 2.4 above.

Passenger drop-off areas

B1. If a passenger drop-off area is provided, does the drop-off area provide a vehicle pull-up space that is at least 20 feet long and at least 98 inches wide?

Passenger drop-off areas allow the person driving a vehicle to safely drop off an individual with a disability who uses a wheelchair or other mobility device, or who cannot walk from the parking area to the building entrance. These drop-off areas or loading zones must be at least 20 feet long and at least 98 inches wide and must connect to an accessible route or path that leads to the building entrance.

B2. Is there an access aisle adjacent to the pull up space that is at least 60 inches wide and as long the vehicle pull-up space?

Passenger drop-off areas allow the person using a vehicle to safely drop off an individual with a disability who uses a wheelchair or another mobility device or who cannot walk from the parking area to the building entrance. These drop-off areas or loading zones must have the measurements explained in the Self-Audit Tool and must connect to an accessible route or path that leads to the building entrance.

B3. Is there a staff member that can meet the individual at the drop-off area if needed?

If a person cannot be left alone when dropped off or waiting to be picked up at a site, staff should go to the passenger drop-off area when notified that a person needs to be escorted between the dop-off area and the office, or to wait with the individual until the caregiver parks the car and meets them.

Accessible routes

Use the following information for C1 through C7:

When people arrive at a building using the sidewalk, parking spaces, or passenger drop-off area, there must be an accessible path that leads from these arrival areas to the entrance of the building. The accessible route or path must be at least 36 inches wide, and the surface of the path must be firm, stable, and slip resistant. The path must also have a forward-facing slope of 5% maximum and a side or cross slope of 2% maximum with no level changes. You can measure the slope by following these directions³⁵ under the Accessible Slopes heading.

- **C1.** Can you get to the building from each of these areas: the city sidewalk, accessible parking, or drop off area?
- **C2.** Is the ground firm, stable, and slip-resistant?

 The ground should be easily accessible using surfaces such as concrete or asphalt. It should not be unstable or slippery like gravel or mud.
- **C3.** Is there a continuous accessible route that is at least 36 inches wide?
- C4. Is the running (forward) slope of the walking surface no greater than 1:20 or 5%?
- **C5.** Is the cross slope no greater than 1:48 or 2.08%
- **C6.** Are there any changes in level no greater than 1/2 inch on the walking surface? Changes in level can happen when trees push up sidewalks and other walking surfaces.
- **C7.** Are there clear signs along the path that direct the person where to go?

Signage that is clear and easy to read should direct individuals from the parking lot to the office lobby. Be mindful of the path a person needs to take and take care to provide helpful signage at turns along the way to help them avoid confusion or frustration. Providing directions via email or voice recording prior to the visit can be helpful.

Ramps

Use the following information for D1 through D5:

³⁵ How to Use This Checklist - ADA Checklists for Existing Facilities. (2016). New England ADA Center. https://www.adachecklist.org/howto.html

If there are ramps along the accessible path, they must meet the requirements of the Self-Audit Tool. It is important for ramps to be 48-inches wide, have a forward slope of 8.33% maximum and a side or cross slope of 2% maximum. If the forward slope is too steep, someone that uses a mobility device will not be able to use the ramp. You can measure the slope by following these directions³⁶ under the Accessible Slopes heading.

- **D1.** Are there any ramps on the accessible route?
- **D2.** Is the running slope of the ramp between 1:20 and 1:12 (5%-8.33%)?
- **D3.** Is the cross slope no greater than 1:48 (2.08%)?
- **D4.** Is the width of the ramp at least 48 inches?
- **D5.** Does the ramp have landings each time the height or rise of the ramp is at least 30 inches?

Use the following information for D6 through D8:

Each time the ramp rise or height off the ground is at least 30 inches higher than the last ramp section, the ramp must have a landing that is at least 60 inches deep and the same width as the ramp.

- **D6.** Is the landing at least 60 inches long?
- **D7.** Is the landing at least as wide as the ramp?
- **D8.** Does the landing include a door?
- **D9.** Does the ramp provide edge protection (wall or barrier at least 4 inches high to prevent rolling off the ramp?)

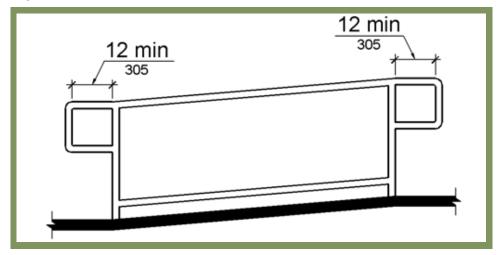
At the top landing of the ramp, the ramp must provide enough clearance for the door to open and allow an individual who uses a wheelchair to be safely on the landing outside of the door swing.

Use the following information for D10 through D12:

Ramps must have handrails on both sides. The handrails must have returns at the top and bottom of the ramp so that someone can steady themselves as they reach the top or bottom (see Figure 2.5 below). Ramps must also have protection on both sides so that wheelchairs or other mobility devices cannot slide off either side of the ramp. This edge protection can be a railing that prevents a 4-inch wheel from going under the railing, or a low wall.

³⁶ How to Use This Checklist - ADA Checklists for Existing Facilities. (2016). New England ADA Center. https://www.adachecklist.org/howto.html

Figure 2.5 Accessible Ramp Handrail Dimensions



- **D10.** Does the ramp have handrails on each side?
- **D11.** Is the gripping surface of the handrails between 34 and 38 inches off the ground?
- D12. Do the handrails extend an additional 12 inches minimum beyond top and bottom runs?

Curb ramps

Use the following information for E1 through E5:

Curb ramps help individuals who use mobility devices like wheelchairs and walkers get to another level of the walking surface that is up a curb. Curb ramps must be the same slope and cross slope as a ramp and must have a 48-inch deep landing at the top that is at least as wide as the curb ramp.

- E1. Are curb ramps provided?
- **E2.** Is the slope of the curb ramp a maximum of 1:12 or 8.33% slope?
- **E3.** Is the cross slope of the curb ramp no greater than 1:48 or 2.08%?
- **E4.** Is the curb ramp at least 48 inches wide?
- **E5.** Is there a landing at the top that is at least 48 inches long and as wide as the ramp?

Doors

For this section, think about all doors the individual may need to use, including the entrance, cafeteria, bathroom, exam room hallway, exam room, testing and diagnostic rooms.

Use the following information for F1 through F5:

Doors must have a level area or "landing" on both sides. Doors must be at least 32 inches wide measured from the door jamb on the latch side to the face of the door when it is open at 90 degrees. If a door is recessed or set back from the wall 24 inches deep or more, the door must be 36 inches wide. Thresholds at doors must be ½ inch high maximum measured from the ground or floor to the top of the threshold. The threshold must be sloped or "beveled" on both sides. Door knobs are difficult to open for individuals with limited hand dexterity. Levers are the accessible alternative, and those levers must be mounted between 34 inches and 44 inches above the ground or floor. Doors should not be too heavy when they open. You can use a door pressure gauge or fish scale for measuring door-opening force. Doors should open with no more than 5 pounds of force. To measure the force required to open the door, first push down on the handle, unlatch the door, and open it a few degrees. Then, place the tool for measuring opening force just above the door handle. Open the door slowly, applying force to the pressure gauge until the door is open to about 70 degrees. This <u>fact sheet</u> shares how to measure the door-opening force and how to correct the issue if too much force is required.

F1. Is there a level landing on both sides of the door?

The area next to a door on both sides is called the landing. All door landings, both outside and inside of buildings, must be level, with no more than a 2% slope in any direction.

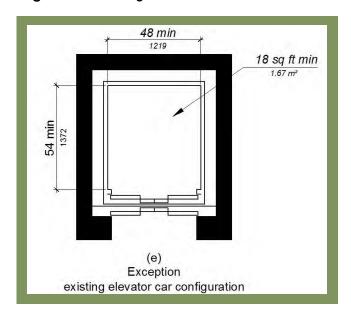
- **F2.** Are door openings at least 32 inches wide measured from the face of the door to the door stop?
- **F3.** Are thresholds a maximum of 1/2 inch vertical?
- F4. Is the door hardware a lever handle mounted between 34 and 44 inches off the floor?
- **F5.** Can the door be opened with no more than 5 pounds of pressure?

Elevators

Use the following information for G2 through G7:

The important accessibility features of elevators are that the buttons outside and inside each elevator car are within the reach range of 15 inches to 48 inches off the floor; that each elevator car has sufficient space for an individual in a wheelchair; and that the buttons and/or jambs are marked with signs that contain raised letters and symbols and are in Braille so that individuals who are blind know what floor they are on and what buttons they are pushing. Ideally, elevators have auditory floor announcements to accommodate individuals who are blind and visual floor announcements to accommodate individuals who are deaf. See below Figure 2.6 for a visual understanding.

Figure 2.6 Existing Elevator Car Measurements

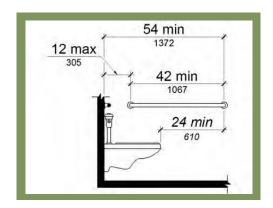


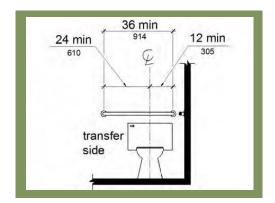
- **G1.** Are the elevator call buttons no higher than 54 inches above the floor?
- **G2.** Is there a sign on both door jambs at every floor identifying the floor?
- **G3.** Is there a tactile star on both jambs at the main entry level?
- **G4.** Are text characters raised on the elevator buttons? Are the buttons in Braille?
- **G5.** Is the interior of the elevator at least 54 inches deep by at least 48 inches wide with at least 18 sq. ft. of clear floor area?
- **G6.** Are the controls inside the elevator between 15 and 48 inches off the floor?
- G7. Are the car control buttons designated with raised characters?

Bathrooms

- **H1.** Is the centerline of the toilet between 17 and 18 inches from a side wall?
 - Measure the centerline of a toilet from the nearest sidewall to the middle of the toilet seat.
- **H2.** Does the toilet compartment provide a minimum clear floor space of 59 inches from the rear wall to the front of the toilet compartment and 60 inches from the side wall to the side wall of the toilet compartment partition?
- **H3.** Is the top of the toilet seat between 17 and 19 inches above the finished toilet room floor?

Figure 2.7 Side and Rear Grab Bar Placement Around a Toilet





Use the figure above for a visual representation of grab bar placement for questions H4 - H5.

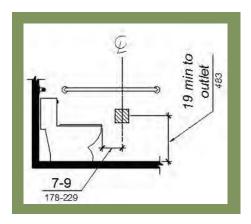
- **H4.** Are grab bars provided along the side and back walls?
- **H5.** Are both grab bars installed at a uniform height between 33 and 36 inches off the floor?

Use the following information for H6 through H8:

It is important that the grab bars have exactly 1 ½ inches between the bar and the wall or partition on which the bar is mounted. This is to make sure that someone's arm does not go all the way through the gap between the wall/partition and the grab bar when they are trying to stabilize themselves using their entire arm and not just their hand. No objects or shelves should protrude from the wall for 12 inches above either the side or rear grab bar. You can have items like toilet seat covers in that 12-inch space if they are completely flush with the wall and do not stick out at all. This is to allow people to hold onto the grab bar then slide toward the toilet and turn without encountering any items on the wall.

- **H6.** Are the grab bars exactly 1 1/2 inches from the wall or partition on which they are mounted?
- **H7.** Is there at least 1 1/2 inches free of any obstructions below the grab bar?
- **H8.** Are there at least 12 inches free of any obstructions above the grab bar?
- **H9.** Is the toilet paper dispenser located between 7 and 9 inches in front of the toilet? See Figure 2.8 below for a visual representation of toilet paper dispenser placement.

Figure 2.8 Toilet Paper Dispenser Placement



Use the following information for H10 through H12:

The flush control should be on the open side of the toilet where a person transfers, not against the wall. You should be able to flush the toilet by pressing the flush valve with your hand closed and making a fist. The flush valve should operate using no more than 5 pounds of force when you press it. To measure the force, you can use the same pressure gauge you used to test the opening force of doors in the Doors section.

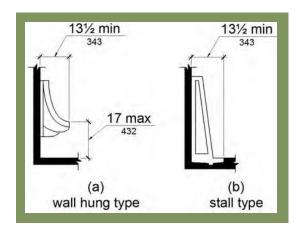
- **H10.** Is the flush control on the open side of the toilet?
- **H11.** Can the toilet be flushed with a closed fist?
- **H12.** Can the toilet be flushed using no more than 5 pounds of pressure?

Use the following information for H13 through H17:

A urinal must be able to be approached from the front with the person facing forward with a clear floor space of 30 by 48 inches in front of the urinal. Wall hung urinals must have a rim no higher than 17 inches above the floor. The urinal must be 13 ½ inches deep minimum. The flush control of the urinal must be mounted at 44 inches maximum above the floor and must be able to be operated with a closed fist and using no more than 5 pounds of force. To measure the force, you can use the same pressure gauge you used to test the opening force of doors in the Doors section.

- H13. If the urinal is wall hung is the rim no higher than 17 inches off the floor?
- **H14.** Is the urinal at least 13 1/2 inches deep?





- **H15.** Is there a clear floor space of 30 X 48 inches provided for forward approach to the urinal?
- **H16.** Is the flush control mounted no higher than 44 inches off the floor?
- **H17.** Can the urinal be flushed with a closed fist using no more than 5 pounds of pressure?

Use the following information for H18 through H24:

Lavatories (sinks) must provide room for wheelchair users to approach facing forward with a clear floor space of 30 x 48 inches and the ability to get their knees and toes under the lavatory rim and any pipes or drains under the lavatory. Clearance for a person's knees needs to be at least 27 inches above the floor and clearance for a person's toes needs to be 17 to 19 inches deep under the lavatory. The rim of the lavatory must be no higher than 34 inches above the floor. A person who has paralysis in their legs cannot feel hot water traveling through the lavatory pipes. Therefore, the lavatory pipes must be covered or insulated to prevent burns. The faucet must be able to be operated with a closed fist using no more than 5 pounds of force. To measure the force, you can use the same pressure gauge you used to test the opening force of doors in the Doors section.

- **H18.** Does the sink provide a clear floor space 30 X 48 inches positioned for forward approach?
- **H19.** Does the sink provide toe clearance that extends between 17 and 19 inches under the sink?
- **H20.** Does the sink provide at least 27 inches of knee clearance?

Lavatories must provide room for someone who uses a wheelchair to get their knees and toes under the sink and any pipes or drains under the sink.

- **H21.** Is the rim of the sink no higher than 34 inches?
- **H22.** Are exposed water and drain pipes insulated or wrapped to prevent contact?

- **H23.** Can the faucet be operated with a closed fist?
- **H24.** Can the faucet be operated using no more than 5 pounds of pressure?

Waiting rooms

J1. Is the check-in counter 36 inches high maximum and 36 inches long maximum?

If the counter does not meet this requirement, you need to find an alternative way to serve individuals in wheelchairs until the desk can be altered or a new one can be purchased.

Exam rooms

K1. Does the exam room have a clear floor space of 36 inches wide by 48 inches deep on at least one side of the examination table?

Best Practice Highlight

The <u>Jefferson FAB Center for Complex Care</u> in Philadelphia has exam rooms that provide plenty of space for wheelchair users, caregivers, and service animals. The exam room lights can be dimmed for a more calming environment. The walls have additional soundproofing for privacy and to avoid overstimulation. The staff store fidgets and stress balls in the cabinets to help individuals.



Medical diagnostic equipment

L1. Does your medical diagnostic equipment (MDE) meet the technical requirements of MDE Accessibility Standards? (*Legally required for all equipment purchased on or after October 2024)

MDE used while lying down must comply with the technical requirements of M301.

MDE used while seated must comply with the <u>technical requirements of M302</u>.

MDE used while in a wheelchair must comply with the <u>technical requirements of M303</u>.



Example: A wheelchair accessible scale located at the <u>Jefferson FAB Center</u> <u>for Complex Care</u>.

MDE used while in a standing position must comply with the technical requirements of M304.

MDE used with communication features must comply with the <u>technical requirements of M306</u>.

MDE used with patient-controlled operable parts must comply with the <u>technical requirements of</u> M307.

D. Operations

Scheduling

A1. Do you offer an online option to schedule an appointment (in addition to calling the office to schedule)?

Providing an online scheduling option makes booking appointments more accessible and convenient. Some individuals may have communication disabilities, experience anxiety with phone calls, or simply prefer the ease of scheduling on their own time. It is recommended that the provider's recorded phone message reminds the caller to speak slowly, especially for items like menus, website and physical addresses, and office hours.

A2. Do you send reminder alerts for appointments?

Appointment reminders help reduce no-shows and makes it easier for persons with disabilities to stay on top of their healthcare. A quick text, email, or call can be a simple way to provide extra support, especially for those who may have trouble keeping track of appointments.

A3. Is the reminder alert in plain language?

If a reminder is full of medical jargon or complicated instructions, it can be confusing and unhelpful. Keeping the reminder short, clear, and in plain language helps ensure that persons with disabilities understand when and where their appointment is without unnecessary stress.

A4. Is calling the person with a disability part of regular operations who may need appointment

reminders?

Some persons with disabilities need extra reminders to make it to appointments, and a simple follow up call can make all the difference. Taking the time to check in shows that the provider cares and helps prevent missed visits that could impact the person's health and waste valuable practice resources.

A5. If the provider's practice serves both individuals with IDD and their caregivers, are appointments scheduled back-to-back for the caregiver's convenience?

Coordinating appointments for both the individual with IDD and their caregiver can make scheduling easier and reduce stress. Offering back-to-back appointments minimizes the need for multiple trips and ensures caregivers can focus on the individual's care without added logistical challenges.

A6. Do you ask about accommodation requests and communication needs in advance of the appointment?

Special Olympics Health has an <u>About Me form</u> that provides for some basic information about the person prior to an appointment, including accommodation needs, communication preferences, and decision-making supports.³⁷

Referrals

B1. Do you have a list of IDD-friendly providers for referral purposes?

Finding a provider that understands the needs of individuals with IDD can be difficult. Maintaining a list of known IDD-friendly providers ensures that these individuals are referred to professionals who are knowledgeable about accessibility, communication needs, and inclusive care.

B2. Do you have a process to contact providers prior to a referral to create a smooth transition process for the patient with IDD?

Referrals should be a coordinated process that supports continuity of care. Contacting the receiving provider beforehand allows for preparation, ensuring that the individual's needs are understood and any necessary accommodations are in place.

B3. Do you communicate, collaborate, or do joint consultations with the individual's other providers to gain a better understanding of their full medical picture?

Individuals with IDD often have multiple healthcare providers managing different aspects of their care. Collaboration between providers helps create a complete picture of the patient's health, avoids gaps in treatment, and ensures that all medical decisions are made with the full context in mind. While this is true for all persons, individuals with IDD may have a more difficult time remembering or explaining relevant details of their medical treatment.

Appointments

C1. For individuals who may be easily overstimulated, do you have an alternate space for them to wait until the exam room is available?

Crowded or noisy waiting areas can be overwhelming for individuals with sensory sensitivities. Offering a quieter space to wait helps reduce stress and makes the healthcare experience more comfortable and accessible.

³⁷ About Me For My Health Team. (2024, April 11). Center for Inclusive Health. https:// inclusivehealth.specialolympics.org/tools-resources/about-me-form

C2. If a person is fearful of the exam room, will the provider see the individual in a private waiting area or in the individual's car?

Some individuals with IDD may have anxiety about medical settings, making traditional exam rooms difficult for them. Being flexible about where care is provided, such as in a private waiting area or even in their car, can help reduce fear and improve the individual's experience during visits.

C3. Are the health staff supported in making reasonable adjustments as needed for individuals such as longer appointment times or minimal wait times?

Individuals with IDD may need extra time for exams, communication, or processing information. Allowing staff to adjust appointment lengths or prioritize minimal wait times ensures that patients receive care in a way that meets their needs.

C4. Do you have sensory kits (headphones, sunglasses, fidgets) available for individuals who are overstimulated?

This <u>Sensory Toolkit for Adults</u> provides some ideas of how to create a sensory kit for your practice.³⁸ These items can provide a sense of calm in stressful situations and help the visit go more smoothly.

Understanding and consent

D1. Are staff documenting understanding and consent in EHRs?

Individuals with IDD are presumed to have the capacity to make decisions unless a court has stated otherwise. If you are working with an individual whose capacity, or ability to understand the information and make an informed decision, may be questioned, it is important for staff to document the consent process for procedures in the individual's health record. Understanding the steps involved in the consent process is important.³⁹

Continuous quality improvement

Creating a more inclusive healthcare setting for individuals with IDD is an ongoing process that starts with looking closely at how care is delivered. As individuals with IDD often face barriers to care, improving factors such as wait times, communication, and staff training can positively impact the individual's experience.

³⁸ Samford University. (n.d.). *Creating sensory toolkits for adults*. Retrieved May 28, 2025, from https://www.samford.edu/worship-arts/files/sensory-sensitivity/Creating-Sensory-Toolkits-for-Adults.pdf
³⁹ Surrey Place. (n.d.). *Informed consent in adults with intellectual or developmental disabilities*. Health Care for Adults with Intellectual and Developmental Disabilities. Retrieved May 28, 2025, from https://iddtoolkit.vkcsites.org/informed-consent/

Collecting feedback from individuals with IDD and caregivers helps identify what is working well and what needs improvement. Understanding the individual's experiences allows providers to make meaningful changes that create a more accessible and supportive healthcare environment.

Individuals and caregivers should feel confident that they understand their healthcare options and can make decisions that are right for them. Gathering feedback on this helps ensure that information is being communicated clearly and that individuals with IDD are truly being included in their care.

Consider how accessible the survey is for individuals with IDD. Think about creating easy-read versions, reducing the number of questions, adding pictures, or recording videos that explain the survey questions in more depth. The evidence indicates that these items may improve comprehension and engagement from both the individual and their caregivers.⁴⁰

Examples of questions you may want to include:41

- Did the staff treat you with respect?
- Did the staff give you the information you needed to help you make choices about your medical care?
- Did the staff support you in making your own decisions (with help from people you chose)?
- Did the staff listen to what you had to say and what was important to you?
- Did the staff provide you with any supports or accommodations you needed?
- Did the staff make you feel welcome?
- Did the staff talk to your other medical providers about your care?
- **E1.** Are you measuring individual and caregiver satisfaction?
- **E2.** Are you measuring whether the individual and caregiver felt they could make informed decisions?

⁴⁰ Harrison, R., Adams, C., Newman, B., Mimmo, L., Mitchell, R., Manias, E., Alston, M., & Hadley, A.-M. (2024). Measuring Healthcare Experiences Among People With Intellectual Disability: A Rapid Evidence Synthesis of Tools And Methods. *Value in Health*, *27*(11). https://doi.org/10.1016/j.jval.2024.05.018

⁴¹ Pham, H. H., Benevides, T. W., Andresen, M.-L., Bahr, M., Nicholson, J., Corey, T., Jaremski, J. E., Faughnan, K., Edelman, M., Hernandez-Hons, A., Langer, C., Shore, S., Ausderau, K., Burstin, H., Hingle, S. T., Kirk, A. S., Johnson, K., Siasoco, V., Budway, E., & Chin, D. (2024). Advancing Health Policy and Outcomes for People With Intellectual or Developmental Disabilities. *JAMA Health Forum*, *5*(8), e242201–e242201. https://doi.org/10.1001/jamahealthforum.2024.2201

The questions in this section (E3 - E10) are designed to help providers take a closer look at clinical processes that impact an individual's care, experience, and outcomes. These questions prompt providers to consider the clinical data that is collected, how it is used to identify gaps (or pain points) for staff and/or the individuals served, and the changes that can be made to improve care for individuals with IDD.⁴²

Continuous quality improvement (CQI) works well when it is part of a culture where both staff and the individuals served have a voice to identify challenges and help improve care. When healthcare leaders support a CQI culture, individuals, particularly those with disabilities, experience higher quality of care through more efficient clinical processes such as reduced wait times, easier appointment processes, and accessible office visits. ⁴³

Research shows a need for data and tools that accurately represent individuals with IDD. Building in CQI methods to collect IDD data can help disaggregate patient data and inform actionable and meaningful change. 44

To find more ideas about tools to support your clinic or office's efforts, please visit:

- <u>Institute for Healthcare Improvement (IHI)</u> Practical guides and frameworks for improvement care and advancing health equity.
- <u>National Committee for Quality Assurance (NCQA)</u> Standards and resources for delivering high- quality care.
- **E3.** Are you routinely surveying staff to assess their confidence level at working with individuals with IDD?
- **E4.** Are these data used to evaluate care delivery specifically for the IDD population and identify areas for improvement?

⁴² Wyatt R, Laderman M, Botwinick L, Mate K, Whittington J. Achieving Health Equity: A Guide for Health Care Organizations. IHI White Paper. Cambridge, MA: Institute for Healthcare Improvement; 2016. (Available at ihi.org)

⁴³ Scoville R, Little K, Rakover J, Luther K, Mate K. Sustaining Improvement. IHI White Paper. Cambridge, MA: Institute for Healthcare Improvement; 2016. (Available at ihi.org)

⁴⁴ Pham HH, Benevides TW, Andresen M, et al. Advancing Health Policy and Outcomes for People With Intellectual or Developmental Disabilities: A Community-Led Agenda. JAMA Health Forum. 2024;5(8):e242201. doi:10.1001/jamahealthforum.2024.2201

E. Policies and Procedures

Note: You may notice similarities in questions in this domain to questions answered in other domains. This is intentional. The goal is to make sure the item is both part of regular practice and is documented in written procedures for sustainability purposes.

Disability coordinator

A1. Do you have a designated staff member to handle disability rights and access-related concerns and issues?

Having a specific person responsible for disability rights-related concerns ensures that accessibility and inclusion are not overlooked. The disability coordinator role helps individuals with IDD and other disabilities and caregivers navigate accommodations, address barriers, and improve overall healthcare experiences.

A2. If you answered "Yes" to A1, are they a senior member of staff with decision-making authority?

A disability coordinator with decision-making power can implement impactful changes rather than only flagging issues. When this role is held by someone in leadership, it signals a commitment to accessibility and inclusion.

A3. If you answered "Yes" to A1, do they have opportunities (paid time) to receive additional training on best practices?

Providing paid time for training ensures the disability coordinator stays current on the best practices in accessibility and inclusion.

A4. If you answered "Yes" to A1, is there a designated budget for this person to receive additional training and resolve disability rights and access-related issues?

A dedicated budget allows the disability coordinator to access high-quality training and address accessibility challenges as they arise. Without financial support, efforts to improve disability inclusion may be limited or deprioritized.

Accommodations

Use the following information for questions B1-B6.

Having written procedures ensures that accommodation requests are handled consistently and fairly. This also provides clear guidance for staff, making it easier to provide the right support without unnecessary delays. The questions below provide items that you should consider including in your written policies to assist staff in

complying with the ADA. You can find helpful examples in Disability Rights Education and Defense Fund (DREDF)'s Model Policies and Procedures for Primary Care Practices.⁴⁵

- **B1.** Do you have any written procedures about handling disability accommodations/modifications requests?
- B2. Do these policies include sign language interpreter requests?
- **B3.** Do these policies include alternative formats for written materials (large print, Braille, electronic, audio recording)?
- **B4.** Do these policies include interpreters in other languages (e.g, Spanish, Vietnamese, Mandarin, etc.)
- **B5.** Do these policies include procedures for staff to facilitate communication with patients who may need alternative tools to communicate?

Policies and processes

C1. Do you have a policy about providing information both verbally and in writing to individuals with intellectual, cognitive, or learning disabilities (or for all patients)?

Make sure these policies cover how to document who should receive the instructions in the individual's record and any other communication needs.

C2. Do you have a process to convert materials into Easy Read?

Include which staff member should receive requests and the length of time they have to fulfill requests.

C3. Does your practice or clinic have a standard process to provide post-visit instructions and treatment plans?

Discuss how post-visit instructions and treatment will be covered and ways to promote follow through with the individual.

C4. Do you have documented policies for staff training required for disability awareness and maintaining quality care for individuals with disabilities?

Having clear written policies for training staff regarding individuals with IDD increases the likelihood of implementation. The policies should cover both onboarding training for new staff

⁴⁵ Accommodating Seniors and People with Disabilities: Model Policies and Procedures for Primary Care Practices*. (2010). Disability Rights Education and Defense Fund. https://dredf.org/wp-content/uploads/2015/02/P-and-Ps-4-1-10.pdf

and refresher training for all staff. Be specific about what topics should be covered in the training.

C5. Do you have documented policies to handle longer appointment visits when requested or needed by individuals with disabilities (e.g., staff coverage, schedule availability)?

Make sure your policies are clear on the protocol is for allowing staff longer appointment times for individuals with IDD who may need longer appointment times and how to document those needs for scheduling and billing purposes.

C6. Do you have a designated staff or senior leader charged with frequently reviewing and updating policies & procedures?

It is important for a staff member who is tasked with staying up to date on best practices for individuals with IDD in healthcare settings to review and update policies and procedures at least yearly as research and new practices emerge.

C7. Do staff have an opportunity to provide input when updating policies & procedures?

At least yearly, seek input from staff about what's working and what could be improved to update policies and procedures related to serving individuals with IDD.

Understanding and consent

D1. Do you have a policy about documenting the individual's consent or nonconsent in EHRs?

Make sure your policies discuss the expectations and protocol for documenting consent and nonconsent in EHRs, including what procedures require documentation of consent.

F. Autonomy and Support

Patient autonomy

A1. Do you speak directly to the individual to fully inform them about their treatment options, including risks and benefits, so they can make autonomous decisions about their care?

Under the ADA, individuals with IDD must have their healthcare explained to them directly in a way they can understand. Giving individuals full information empowers them to make their own decisions about their health. IntellectAbility Academy eLearning Courses provide great information on person-centered care.⁴⁶

⁴⁶ IntellectAbility Academy. (n.d.) eLearning Courses. Direct Support Professionals (DSP) Training. from https://replacingrisk.com/idd-staff-training/

A2. Do you involve individuals in setting their care goals and making decisions that align with their values and preferences?

Individuals should have a say in their own care. Involving them in decision-making ensures that their treatment aligns with what matters most to them.

A3. Do you supplement your verbal instructions with decision aids as strategies used to identify and address barriers that might limit the ability of an individual with IDD to make independent decisions about their care?

Individuals process verbal instructions in different ways, and some may benefit from additional support. Decision aids like charts, videos, or written materials can provide clearer explanations, helping individuals with IDD better understand their options and make informed choices.

A4. How do you involve an individual's team of chosen supporters in meetings about their care?

When thinking about setting health goals, treatment follow through and healthy daily habits with individuals with IDD, consider their support network and who they choose to assist them in different aspects of their lives. For visits that include action items that may trigger this additional support, discuss how best to involve the individual's support network.

A5. Does your practice assist individuals with using digital apps designed to help individuals with IDD manage their healthcare?

Technology can be a great tool for helping individuals with IDD process information and take a more active role in their healthcare. Digital apps with daily reminders or schedules can improve independence and help patients feel more in control. One example is <u>iMHere 2.0</u>, specifically designed for those with chronic health care conditions.⁴⁷ This app also has a caregiver version to help supporters stay up-to-date on the individual's progress.

Community support

C1. Do you have a social worker or community health worker to assist individuals with navigating community services and support?

In addition to accessing healthcare, individuals with IDD also often need help connecting to services like housing, transportation, and in-home support. A social worker or community health worker can make a big difference in ensuring they get the help they need.

⁴⁷ University of Pittsburgh. (n.d.). *iMHere*. https://www.imhere.pitt.edu/

C2. Does this individual assist with writing accommodation letters for school or work?

Navigating accommodations in school or work settings can be complicated, and individuals may need official documentation to get the support they are entitled to under the ADA. Having a dedicated person on staff to help with this removes a major barrier.

C3. Does this individual understand and help navigate community support systems (e.g., Supplemental Security Income (SSI), home and community based services under Medicaid waivers, service providers, food assistance programs, low income or disability housing, paratransit eligibility)

Understanding how to access community-based services can be overwhelming, especially for individuals with IDD and their caregivers. A knowledgeable staff member who can guide them through these systems can be a major support.

Caregiver support

D1. Do staff discuss respite planning and options with caregivers?

Caring for someone with IDD can be exhausting, and caregivers need breaks to avoid burnout. Discussing respite care options helps ensure they have the support they need to continue providing quality care.

D2. Are caregiver respite plans a part of the EHR of the individual with IDD?

Including respite plans in the patient's electronic health record ensures that providers recognize the caregiver's needs as part of the overall care plan. This helps facilitate conversations about support options and prevents gaps in care.

G. Specialty Areas

This domain applies to providers of certain specialty areas and providers where inpatient stays are typical, such as rehabilitation facilities, recovery centers, and certain inpatient mental health facilities that have on-site sleeping rooms and cafeterias for for individuals with IDD.

Dentistry/Orthodontics

A1. Does your practice schedule longer or more frequent dental appointments to accommodate the individual's needs?

Some individuals with IDD may need extra time to feel comfortable during dental visits. They may be anxious in a new environment or have sensory sensitivities about having someone examine their mouth or use unfamiliar equipment. They may also need more

time for explanations of procedures. Offering longer or more frequent appointments can help reduce stress and ensure they receive proper care. <u>Several strategies may help individuals with IDD feel more comfortable during dental procedures.</u>

A2. Does your practice offer sedation or anesthesia options for patients with IDD who experience severe anxiety, distress, or difficulty tolerating dental procedures?

For some patients with IDD, dental procedures can be overwhelming due to communication barriers, anxiety, or sensory sensitivities. Some may require sedation for procedures, although other less intrusive methods, like desensitization visits should be attempted first. Offering these options ensures that individuals with IDD can get necessary dental care without undue stress or discomfort. Additional strategies include using adjustable-speed equipment (slow-speed handpieces, vibration-dampened tools), alternative positioning (e.g., wheelchair-compatible chairs, bean bags for support); and behavioral strategies such as clear visual schedules, countdown timers, and "stop signals" like hand-raising.

Ob/Gyn

B1. Does your practice have a network of specialty providers that includes Ob/Gyn physicians to whom women with IDD who are 21 years and older can be referred for services?

Women with IDD need access to routine OB/GYN care just like anyone else, but finding providers who understand their unique needs can be difficult. Having a trusted referral network makes it easier for individuals to get the care they need.

B2. Does your practice have a system in place to ensure that all female individuals aged 21 and older are routinely informed about the importance of annual Ob/Gyn care and are referred for a timely appointment, with appropriate follow-up to confirm that the referral was completed?

Many women with IDD miss out on essential OB/GYN care due to lack of information or barriers to access. A system that reminds, refers, and follows up ensures that they receive preventive screenings and necessary care.

B3. Does your practice routinely assess whether female individuals with IDD aged 21 and older face any barriers to accessing annual OB/GYN care?

Even when referrals are made, some individuals may still struggle with transportation, insurance, or communication barriers. Checking in on these challenges allows providers to help problem-solve and ensure individuals do not miss out on critical care.

⁴⁸ University of Washington School of Dentistry. (n.d.). *Oral health fact sheet for dental professionals: Individuals with intellectual disability*. Retrieved May 28, 2025, from https://dental.washington.edu/wp-content/media/sp_need_pdfs/Intellectual-Dental.pdf

Substance use recovery services

<u>This article</u>⁴⁹ from Current Psychiatry provides some basic information about providing substance use recovery services to individuals with IDD, as it applies to questions C1 & C2 below.

- C1. Do you modify your programming to fit the needs of the specific individual?
- C2. Do you provide extended support and referrals for individuals with IDD?
- **C3**. Have the program staff received training on addressing substance use disorder in individuals with IDD?

This training through the American Association on Intellectual and Developmental Disabilities explores the co-occurrence of substance use disorder and IDD.

Sleeping rooms

D1. Is the facility a licensed medical care, rehabilitation, psychiatric, or detoxification facility where the length of stay is more than 24 hours?

Licensed medical care, rehabilitation, psychiatric, or a detoxification facility where the length of stay is more than 24 hours must meet certain accessibility requirements for their sleeping rooms.

Use the following information for D2 to D8:

Medical facilities that specialize in conditions that affect mobility and/or provide long-term care must provide sleeping rooms with certain accessibility features like a 60 inch turning radius within the room and a 30 x 48 clear floor space on both sides of the bed.

- D2. If yes, does the facility specialize in conditions that affect an individual's mobility?
- **D3.** If yes, does the facility provide 100 percent of its sleeping rooms with the mobility features described below in D6 to D8?
- **D4.** If the medical facility does not specialize in conditions that affect someone's mobility, does the facility provide at least 10 percent of its sleeping rooms with the mobility features described below in D6 to D8?

⁴⁹ Allen, J. (2019). Addressing substance use in patients with intellectual disability: 5 Steps. *Current Psychiatry*, *18*(3), 49–50. https://cdn.mdedge.com/files/s3fs-public/CP01803049.PDF

- **D5.** If the facility is a licensed long-term care facility, does it provide at least 50 percent of its sleeping rooms with the mobility features described below in D6 to D8?
- **D6.** Does the sleeping room have a door that meets the requirements in the doors section?
- **D7.** Does the sleeping room have a wheelchair-turning space that is a 60-inch circle or T-shaped space?
- **D8.** Does the sleeping room have a clear floor space of 36 inches wide by 48 inches deep on both sides of the bed that allows someone to transfer from a wheelchair?

Cafeteria

For questions E1-E7 refer to the ADA National Network Factsheet <u>Food Service</u>: Accommodating Diners with Disabilities.⁵⁰

- E1. Does the cafeteria have a door that meets the requirements in the doors section?
- **E2.** Does the cafeteria have at least one 36-inch wide clear path that goes all the way from the front to the back of the room?
- **E3.** Do at least 5 percent of the seating spaces at tables or counters have a clear space with no chair or other item blocking the space that allows someone in a wheelchair to sit at the table facing forward?
- **E4.** Are the tops of the tables or counters between 28 inches and 34 inches high above the floor?
- **E5.** Is the top of the food service counter between 28 inches and 34 inches high above the floor?
- **E6.** Are the self-service dishes, utensils, napkins, condiments, and food and beverage dispensers located a maximum of 24 inches back from the front edge of the counter?
- **E7.** Are the self-service dishes, utensils, napkins, condiments, and food and beverage dispensers located a maximum of 46 inches above the floor?

⁵⁰ Food Service: Accommodating Diners with Disabilities | ADA National Network. (2017). ADA National Network. https://adata.org/factsheet/food-service

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Appendix A

Important Acronyms

Augmentative and alternative communication device (AAC)

Americans with Disabilities Act (ADA)

American Sign Language (ASL)

Communication Access Realtime Translation (CART)

Center for Independent Living (CIL)

Community Health Worker (CHW)

Electronic Health Record (EHR)

Healthcare Power of Attorney (H-POA)

Home and Community-Based Services (HCBS)

Intellectual or Developmental Disabilities (IDD)

Medical Diagnostic Equipment (MDE)

People with disabilities (PWD)

Appendix B

Key Definitions

Accommodations - See Modifications

Americans with Disabilities Act (ADA) - "The Americans with Disabilities Act (ADA) is a federal civil rights law that prohibits discrimination against people with disabilities in everyday activities. The ADA prohibits discrimination on the basis of disability just as other civil rights laws prohibit discrimination on the basis of race, color, sex, national origin, age, and religion. The ADA guarantees that people with disabilities have the same opportunities as everyone else to enjoy employment opportunities, purchase goods and services, and participate in state and local government programs." 51- U.S. Department of Justice Civil Rights Division

Caregiver - "[A] caregiver is a person who tends to the needs or concerns of a person with short- or long-term limitations due to illness, injury or disability."⁵² - Johns Hopkins Medicine Caregivers can be family members, but they can also be paid staff if an individual lives in a congregate setting like a group home or nursing facility.

Center for Independent Living- "Designed and operated by individuals with disabilities, CILs provide independent living services for people with disabilities. CILs...work to support community living and independence for people with disabilities across the nation based on the belief that all people can live with dignity, make their own choices, and participate fully in society. These programs provide tools, resources, and supports for integrating people with disabilities fully into their communities to promote equal opportunities, self-determination, and respect." 53

- Administration on Community Living

Communication Cards - Communication card or communication boards "help people communicate with others by using symbols, pictures, or photos. They can be used by people to express their needs, preferences, and decisions."⁵⁴ - Ohio Department of Developmental Disabilities

Community Health Worker - "A community health worker is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary

⁵¹ U.S. Department of Justice Civil Rights Division. (n.d.). Introduction to the Americans with Disabilities Act. ADA.gov. https://www.ada.gov/topics/intro-to-ada/

 $\underline{\text{https://www.hopkinsmedicine.org/about/community-health/johns-hopkins-bayview/services/called-to-care/what-is-a-caregiver}$

⁵² What is a Caregiver? (n.d.). Johns Hopkins Medicine.

Administration for Community Living. (n.d.). Centers for independent living. U.S. Department of Health
 Human Services. https://acl.gov/programs/aging-and-disability-networks/centers-independent-living
 Communication Boards. (2024). Ohio.gov. https://dodd.ohio.gov/communication/Communication-Boards

between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.

A community health worker also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy."⁵⁵

- American Public Health Association

Conservatorship - State law determines the rules for guardianship. Typically, a guardian is "a person appointed by a court to manage the care and well-being of another person, and conservator for a person appointed by the court to manage the property of another person." However, different states use different terminology, and in some states a conservator is responsible for the care of the person.⁵⁶

Easy Read - "Easy Read is a way of making written information easier to understand. Easy Read documents usually combine short, jargon-free sentences with simple, clear images to help explain the content.." - AbilityNet

Guardianship - State law determines the rules for guardianship. Typically, a guardian is "a person appointed by a court to manage the care and well-being of another person, and conservator for a person appointed by the court to manage the property of another person." However, different states use different terminology.⁵⁸

Health Care Power of Attorney (H-POA) - "A medical or healthcare power of attorney is a type of advance directive in which you name a person to make healthcare decisions for you when you are unable to do so. In some states this directive also may be called a durable power of attorney for healthcare or a healthcare proxy." 59 - Mayo Clinic

Home and Community-Based Services (HCBS) - "Home and community based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own homes or communities rather than institutions or other isolated settings. These programs serve a variety of targeted groups, such as older adults, people with intellectual or developmental disabilities, physical disabilities, or mental health and substance use disorders." - Centers for Medicare & Medicaid Services

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⁵⁵ American Public Health Association. (n.d.). Community health workers. APHA. https://www.apha.org/apha-communities/member-sections/community-health-workers

⁵⁶ https://www.justice.gov/elderjustice/guardianship-key-concepts-and-resources

⁵⁷ What is Easy Read? | AbilityNet. (n.d.). Abilitynet.org.uk. https://abilitynet.org.uk/factsheets/what-easy-read

⁵⁸ https://www.justice.gov/elderjustice/guardianship-key-concepts-and-resources

⁵⁹ Mayo Clinic Staff. (2022). *Your guide to living wills and other advance directives*. Mayo Clinic. https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303

⁶⁰ Home & Community Based Services | Medicaid. (n.d.). Www.medicaid.gov. https://www.medicaid.gov/medicaid/home-community-based-services/index.html

Large Print - "Large-print materials have a type size that is easier to read for individuals with low vision. Most adult books are set in 10- to 12-point type, newspapers are often 8-point type, and some editions of the Bible are in 6-point type.

Type size is measured in points from the bottom of the lowest letter (for example, the tail of the letter "y") to the tallest capital...Large-print materials are most commonly available in 16- to 18point type. The minimum size for large-print materials as defined by the US Postal Service Free Matter for the Blind mailing standard is 14-point type."61 - Library of Congress

Mental Health Disability - "A mental or psychological disorder or condition, such as intellectual disability, organic brain syndrome, emotional or mental illness, or specific learning disability, that limit a major life activity."62 - California Department of Human Resources

Modifications - Also known as Reasonable Modifications of Policies, Practices, and Procedure. "Health care providers are required to make reasonable modifications (or changes) to policies, practices, and procedures to provide equal access to facilities and services to people with disabilities. The term "reasonable modification" is a broad concept that covers every type of disability."63 - ADA National Network

Paratransit - "[A] fixed route system...or other special service to individuals with disabilities that is comparable to the level of service provided to individuals without disabilities who use [a] fixed route system."64 - Federal Transit Administration

Plain Language - "Plain language is communication that is clear and easy to understand for your target audience, regardless of the medium used to deliver it. PlainLanguage.gov defines it as communication your audience can understand the first time they read or hear it."65 -Digital.gov

Respite - "Respite is used to relieve family members from the responsibility of providing care to their loved ones with intellectual and developmental disabilities (I/DD). Services can be

63 ADA National Network. (2020). Health Care and the Americans With Disabilities Act | ADA National Network. Adata.org. https://adata.org/factsheet/health-care-and-ada

⁶¹ Large Print Materials. (n.d.), National Library Service for the Blind and Print Disabled (NLS) | Library of Congress. https://www.loc.gov/nls/services-and-resources/informational-publications/large-print-materials/ 62 Impairments. (n.d.). Eservices.calhr.ca.gov. https://eservices.calhr.ca.gov/Survey/Disability/Impairments

⁶⁴ Part 37--Transportation Services for Individuals with Disabilities I FTA. (2020), Dot.gov. https://www.transit.dot.gov/regulations-and-guidance/civil-rights-ada/part-37-transportation-servicesindividuals-disabilities#subpartF

⁶⁵ An introduction to plain language. (2023, May). Digital.gov. https://digital.gov/resources/an-introductionto-<u>plain-language/</u>

intermittent or regularly scheduled supervision."⁶⁶ - California Department of Developmental Services

Supported Decision Making - "Supported decision making (SDM) is one alternative to guardianship. With SDM, individuals retain their right to make decisions for themselves, with the support of trusted friends and/or family members they choose." - Administration for Community Living

Surrogate Decision Making - "A patient may designate an adult as a surrogate to make health care decisions by personally informing the supervising health care provider or a designee of the health care facility caring for the patient. The designation of a surrogate shall be promptly recorded in the patient's health care record." 68 - California Legislative Information

⁶⁶ Respite. (n.d.). CA Department of Developmental Services. https://www.dds.ca.gov/services/crisis-safety-net-services/respite/

⁶⁷ Supported Decision Making Program | ACL Administration for Community Living. (n.d.). Acl.gov. https://acl.gov/programs/consumer-control/supported-decision-making-program

⁶⁸ AB-2338, 2022 Secretary of State (Cal. 2022) https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=202120220AB2338