

# Your Patient with Intellectual and/or Developmental Disability (IDD): Accessibility, Decision-Making, and Consent A Resource Guide

## Programs that Support People with IDD

### Primary Care Guidelines for Adults with IDD

The Canadian College of Family Physicians has created primary care consensus guidelines for adults with IDD, including recommended resources for health providers.

Sullivan WF, et al. Primary Care of adults with intellectual and developmental disabilities. *Canadian Family Physician*. April 2018, 64 (4) 254-279.

<https://www.cfp.ca/content/cfp/64/4/254.full.pdf>

How to use and understand the guidelines:

<https://ddprimarycare.surreyplace.ca/guidelines/guidelines-about/guidelines-how-to-use/>

The Vanderbilt Kennedy Center created a resource called Healthcare for Adults with Intellectual and Developmental Disabilities, Toolkit for Primary Care Providers. The toolkit includes general guidelines for working with people with IDD, physical health issues, health watch tables, and behavioral and mental health issues.

Healthcare for Adults with Intellectual and Developmental Disabilities, Toolkit for Primary Care Providers: [iddtoolkit.vkcsites.org](http://iddtoolkit.vkcsites.org)

### Models of Interprofessional Team-Based Primary Care for Adults with IDD

- Medical homes with a primary care provider serving in a coordinating role.
- Providers included in interprofessional teams can include: physicians, nurse practitioners, nurses, social workers, mental health (psychologists, counselors, behavior therapists).
- An interprofessional team can also refer out to specialty services such as speech-language pathology, occupational therapy, physical therapy, or pharmacy.
- Outcomes of these programs included lower emergency room use, fewer inpatient admissions, and lower hospital readmission rates compared to standard care.

**For more information, visit:**

Interprofessional Health Care:

Bobbette N, Ouellette-Kuntz H, Tranmer J, Lysaght R, Ufholz L-A, Donnelly C. Adults with intellectual and developmental disabilities and interprofessional, team-based Primary Health Care: A scoping review, JBI Evidence Synthesis. 2020;18(7): 1470-1514. <https://doi.org/10.11124/JBISRIR-D-19-00200>

Canadian Family Physician, Vol 64 (suppl 2): S1-78, April 2018:

<https://ddprimarycare.surreyplace.ca/guidelines/general-health/inter-professional-health-care-teams/#1517951029720-750e1bda-99b81520613751594152063085957815208786635751522167452277>

Medical Home for People with IDD:

[https://sonoranucedd.fcm.arizona.edu/projects/medical\\_home](https://sonoranucedd.fcm.arizona.edu/projects/medical_home)

### **Resources for Community Living**

The main source of funding for community-based individualized supports for people with IDD is through the **Medicaid Home and Community Based Services Waivers program through the Centers for Medicare and Medicaid Services.**

### **Long Term Services and Supports**

- Long-term services and supports (LTSS) include assistance with activities of daily living, such as getting dressed, taking medication, preparing meals, job coaching, residential support, and managing money.
- There is no national coordination of long term services and supports, so there is no comprehensive approach, each state can define services to include as LTSS for individuals with IDD.
- A variety of professionals are involved in providing LTSS including (but not limited to): Home Health Aides, Direct Support Professionals, Habilitation Professionals, Case Managers, Supported Employment Coaches, Home Nursing, Behavioral Health.

**For more information, visit:**

LTSS by State:

<https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/state-resources-map#newmexico>

A description of community-based LTSS provided by The Arc of the U.S.:

<https://thearc.org/policy-advocacy/community-based-long-term-supports-and-services/>

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A description of LTSS provided by the Association of University Centers on Disabilities: <https://www.aucd.org/template/page.cfm?id=1109>

Medicaid and LTSS:

Reaves E, Buscumeci M. Medicaid and long-term services and supports: a primer. Kaiser Family Foundation. 2015.

<https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>

A research article summarizing home and community-based Services in the United States, for more recent information you can download reports from the Kaiser Family Foundation (<https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>)

Rizzolo M, Friedman C, Lulinski-Norris A, Braddock D. Home and Community Based Services (HCBS) waivers: A nationwide study of the states. Intellectual and Developmental Disabilities. 2013; 51(1):1–21. <https://doi.org/10.1352/1934-9556-51.01.001>

### **Centers for Independent Living Provide Independent Living Services for People with All Types of Disabilities in All 50 States.**

Centers for Independent Living:

<https://acl.gov/programs/centers-independent-living/list-cils-and-spils>

#### **FYI: Living Arrangements for Adults with I/DD**

- While the majority of adults with IDD live in their family's home\* (Larson et al 2020). Many live in other more formal living settings.
- Group homes – many disability agencies who receive funding from Medicaid and other sources have group homes where 4-6 individuals to live together with staff to support needs. Some homes accept residents with high medical needs.
- IDLA (Individually Designed Living Arrangement) - individual apartments or homes where individuals receive supports to live.
- ADH (Adult Developmental Home) - Licensed residential home with a family setting.



**For more information about living options for people with I/DD in Arizona, visit:**

**Group Home:**

[https://des.az.gov/sites/default/files/media/DDD\\_Complete\\_set\\_of\\_all\\_Policy\\_Manuals\\_011619.pdf](https://des.az.gov/sites/default/files/media/DDD_Complete_set_of_all_Policy_Manuals_011619.pdf)

**IDLA:**

[https://des.az.gov/sites/default/files/00\\_habilitationinddeslivingar\\_v2011.pdf](https://des.az.gov/sites/default/files/00_habilitationinddeslivingar_v2011.pdf)

**ADH:**

<https://des.az.gov/services/disabilities/developmental-disabilities/certification-licensing/developmental-home-licensing>

**ADH Licensing:**

<https://des.az.gov/sites/default/files/media/Arizona-Administrative-Code-Developmental-Disabilities-Article-11-Adult-Developmental-Home-License.pdf?time=1630424765633>

**For more information about living options for people with IDD in the United States:**

Larson SA, Taylor B, Pettingell S, Sowers M, Bourne ML. In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2020. <https://publications.ici.umn.edu/risp/2017/state-profiles/arizona>

**State Developmental Disabilities Programs**

- Depends on need, state/federal guidelines, and funding.
- Provides support and services provided to individuals with developmental disabilities in-home and community-based settings.
- Disability eligibility and services vary from state to state.
- A variety of professionals are involved in providing services through state developmental disability agency approval including (but not limited to): Case Managers or Support Coordinators, Home Health Aides, Home Nursing, Direct Support Professionals, Habilitation Professionals.

**For more information, visit:**

State Agencies:

<https://www.nasdds.org/state-agencies/>

**Employment Services**

- The Vocational Rehabilitation (VR) program provides a variety of services to persons with disabilities, with the ultimate goal to prepare for, enter into, or retain employment.
- State VR programs are funded and overseen by the federal Rehabilitation Services Administration.
- The person with IDD works with a professional called a Vocational Rehabilitation Counselor.

**ELIGIBILITY**

- You have a physical or mental impairment
- Your physical or mental impairment constitutes or results in a substantial impediment to employment
- You require VR services in order to prepare for, secure, retain, or regain employment

## ELIGIBILITY (continued)

- You can benefit from the provision of VR services in terms of achieving an employment outcome.

### For more information, visit:

VR Contact Information for Every State:

<https://rsa.ed.gov/about/states>

Federal Policy: <https://www.nad.org/resources/civil-rights-laws/rehabilitation-act-of-1973/>

### Community-based treatment, training services, and recreational programs

- **The Arc** has chapters throughout each state that provide advocacy and also supports and services.
- **The Arc's Center for Future Planning** aims to support and encourage adults with I/DD and their families to plan for the future.
- **Special Olympics** has programs in each state. In addition to athletic programs for children and adults, state Special Olympics organizations offer health screening and education, as well as leadership development and other programs.
- **Best Buddies** has programs in most states that provide social, living, and employment resources.
- **United Cerebral Palsy** has affiliate locations throughout the U.S. providing support and services.

### For more information, visit:

The Arc:

<https://thearc.org/find-a-chapter/>

The Arc's Center for Future Planning:

[https://futureplanning.thearc.org/?\\_ga=2.226357338.1534051602.1630359568-570306696.1630359568](https://futureplanning.thearc.org/?_ga=2.226357338.1534051602.1630359568-570306696.1630359568)

Special Olympics:

<https://www.specialolympics.org/>



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Best Buddies:

<https://www.bestbuddies.org/>

United Cerebral Palsy

<https://ucp.org/find-us/>

## The Principles of Person-Centered and Patient-Centered Approaches

### Overview of Person-Centered Planning

- An individualized, strengths-based approach to life planning.
- Guided planning process assists people in:
  - Bringing together important people to provide input and support around the health of the individual.
  - Identifying health goals.
  - Creating a vision for the future.
  - Identifying formal and informal supports is needed to keep the individual happy, healthy, and safe.

#### For more information, visit:

Person-Centered Planning:

[https://sonoranucedd.fcm.arizona.edu/sites/default/files/publication/PCPToolkit\\_Final.pdf](https://sonoranucedd.fcm.arizona.edu/sites/default/files/publication/PCPToolkit_Final.pdf)

UCEDD Person-centered planning slides

Arizona Board of Regents. (2020). A Person-Centered Arizona.

### Person-Centered Methods to Develop Supports and Services

- Where should the person live?
- What supports need to be in place?
- Who can they live with?
- How does the person want to spend their time?
  - At home?
  - During the day?
- What are the characteristics of those who can best support the person?

#### For more information, visit:

Person-Centered Planning:

<https://sonoranucedd.fcm.arizona.edu/person-centered-initiative>

UCEDD Person-centered planning slides

Arizona Board of Regents. (2020). A Person-Centered Arizona.

### **What Should Primary Care Providers Know to Support Patients with IDD in a Person-Centered Way?**

- How does the person communicate?
- Are there critical issues to be aware of?
- What helps the person have good days and avoid bad days?
- What things should be considered about where the person lives?
- How should healthcare-related supports be provided?

#### **For more information, visit:**

Person-Centered Planning:

[https://sonoranucedd.fcm.arizona.edu/sites/default/files/publication/PCPToolkit\\_Final.pdf](https://sonoranucedd.fcm.arizona.edu/sites/default/files/publication/PCPToolkit_Final.pdf)

UCEDD Person-centered planning slides

Arizona Board of Regents. (2020). A Person-Centered Arizona.

### **Best Practices for Communicating with Patients with IDD Tips on Communicating with People with IDD**

- Establish Rapport
  - Speak directly with the patient
  - Avoid talking to an adult as if they were a child
- Choose appropriate language
  - Use concrete language
  - Avoid shouting
- Listen
  - Listen to what the patient says
  - Allow enough time
- Explain clearly
  - Explain what will happen before you begin
  - Tell and show what you are going to do and why
- Communicating without words
  - Use visual aids
  - Act or demonstrate

#### **For more information, visit:**

Vanderbilt Kennedy Center site's Toolkit: <https://iddtoolkit.vkcsites.org/general-issues/communicating-effectively>

Tips and Strategies to Promote Accessible Communication Booklet from The North Carolina Office on Disability and Health: [https://fpg.unc.edu/sites/fpg.unc.edu/files/resources/other-resources/NCODH\\_PromoteAccessibleCommunication.pdf](https://fpg.unc.edu/sites/fpg.unc.edu/files/resources/other-resources/NCODH_PromoteAccessibleCommunication.pdf)

## Provide Opportunities for Information Sharing

Here's an example from Vanderbilt Kennedy Center site's Toolkit:

<https://iddtoolkit.vkcsites.org/resources/>

TODAY'S VISIT	
<p><b>Main Reason for Today's Visit to the Physician or Nurse (To be filled out by the Patient and/or Caregiver)</b></p> <ul style="list-style-type: none"> <li>• Please bring an updated form for each visit to the physician/nurse.</li> <li>• Bring an updated medication list, or all medications being taken.</li> <li>• Bring any monitoring forms being used (i.e., sleep or behavior charts).</li> <li>• Keep a copy of this completed form for the patient's home medical files.</li> </ul>	<p>Last/First Name: _____</p> <p>Address: _____</p> <p>Phone: _____ DOB <u>   </u>/<u>   </u>/<u>   </u> Gender: _____</p> <p>Medical Record Number: _____</p> <p>Date of Visit: <u>   </u>/<u>   </u>/<u>   </u></p>
<p>Up-to-date Medication List attached? <input type="checkbox"/> No <input type="checkbox"/> Yes</p>	
PATIENT / CAREGIVER	
<p><b>What is the main health problem that the patient or caregivers are concerned about?</b></p> <p>_____</p> <p>When did it start? <u>   </u>/<u>   </u>/<u>   </u></p> <p>List any new symptoms:</p> <p>_____</p> <p>List possible contributing factors:</p> <p>_____</p>	<p><b>Any recent visit to the dentist or other doctor?</b></p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p>_____</p> <p><b>Any recent medication changes or additions?</b> <i>(Include antibiotics, creams or herbal medicines)</i></p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes _____</p> <p>Any recent physical or emotional changes? If yes, check and briefly describe.</p> <p><input type="checkbox"/> Activity level: _____</p> <p><input type="checkbox"/> Mobility: _____</p> <p><input type="checkbox"/> Sleeping habits: _____</p> <p><input type="checkbox"/> Pain or distress: _____</p> <p><input type="checkbox"/> Eating patterns/Weight change: _____</p> <p><input type="checkbox"/> Swallowing: _____</p> <p><input type="checkbox"/> Bowel routine: _____</p> <p><input type="checkbox"/> Mood or behavior: _____</p> <p><input type="checkbox"/> Other: _____</p>
<p><b>Circle or list other needs</b> — (e.g., prescription renewals, test results, forms to be filled out, appointment for annual exam)</p> <p>_____</p>	<p><b>Caregiver Needs</b> — Write down or tell doctor or nurse whether there are issues regarding caregiver fatigue or burnout:</p> <p>_____</p>
<p><b>Any Recent Changes or Stressors?</b> (e.g., staff changes, family illness or stress, changes in living or social environment)</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p>If yes, please describe:</p> <p>_____</p>	<p>Caregiver Name: _____</p> <p>Position: _____ Contact #: _____</p> <p>Signature: _____</p>

OR My Health Report from University of South Florida's Center for Inclusive Communities: [http://flfcic.fmhi.usf.edu/docs/FCIC\\_My\\_Health\\_Report\\_Fillable.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_My_Health_Report_Fillable.pdf)



# My Health Report



Please prepare and share this information with your doctor

About Me

My full name is: \_\_\_\_\_ I like to be called: \_\_\_\_\_

I am a person with (Down syndrome, cerebral palsy, etc.) \_\_\_\_\_ Date of Birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Communication Preferences: (e.g., Interpreter, etc.) \_\_\_\_\_

I have a legal guardian  No  Yes, and their name is \_\_\_\_\_

You can talk to this person about my health: \_\_\_\_\_ Relationship: \_\_\_\_\_

The Reason for My Visit Today

Check:  Need form  Need prescription  Annual physical  New problem or pain

Describe the problem(s) or pain(s): \_\_\_\_\_

If pain, it feels like:  Burning 🔥  Aching 📌  Sharp 📌  Dull 📌  Other

When did it start? \_\_\_\_\_ Have you had this issue before? \_\_\_\_\_

What makes it better? (e.g., rest, medication, etc.) \_\_\_\_\_

What makes it worse? (e.g., eating, activity, etc.) \_\_\_\_\_

Since My Last Visit

I have (list any major medical events, hospitalizations or any other information you feel I should know):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

My overall health is (better, worse or about the same as my last visit):

\_\_\_\_\_

I have generally felt:



happy



sad/depressed



anxious

Medications I'm Taking

Name	Dose	Freq
<input type="checkbox"/> e.g. Amlodipine	5mg	1x day
<input type="checkbox"/>		

If it is new, please check box.  
Attach medication list if more space is needed.

My Medical/Surgical History

I have been diagnosed with (diabetes, depression, etc.):

\_\_\_\_\_

\_\_\_\_\_

I have been hospitalized for (bronchitis, an injury, etc.):

\_\_\_\_\_

I have had surgery for (an injury, heart condition, tonsils, etc.):

\_\_\_\_\_

## My Health Report

### My Daily Life

I live:

  
  
At home

  
  
Group home

  
  
Nursing or assisted living facility

I live with *(alone, family, friends, other)*: \_\_\_\_\_

I have recently moved:  Yes  No

My work status:

Employed  Not employed  Student

My job is: \_\_\_\_\_  
 full time  part time

Location: \_\_\_\_\_

I get around by *(walking independently, using a power or manual wheel chair, walking with an assistive device, etc.)*: \_\_\_\_\_

Any change in mobility status?  Yes  No

Please describe \_\_\_\_\_

### My Abilities

	On My Own	With Help
Eat/drink	<input type="checkbox"/>	<input type="checkbox"/>
Use the restroom	<input type="checkbox"/>	<input type="checkbox"/>
Wash/shower/bathe	<input type="checkbox"/>	<input type="checkbox"/>
Get dressed	<input type="checkbox"/>	<input type="checkbox"/>

### My Sexual Health

I am sexually active:  Yes  No

I practice safe sex:  Yes  No

I need more information about how to practice safe sex:  Yes  No

I have questions about periods:  Yes  No

I have other questions about sex/sexual concerns:  Yes  No

### My Health Maintenance

My last physical: \_\_\_\_\_

My last eye exam: \_\_\_\_\_

My last hearing test: \_\_\_\_\_

My last dental appointment: \_\_\_\_\_

My last flu shot: \_\_\_\_\_

My last colonoscopy *(if over 50)*: \_\_\_\_\_

My last prostate exam & PSA Test *(if over 45)*: \_\_\_\_\_

My last mammogram/breast exam *(if over 40)*: \_\_\_\_\_

My last pap smear *(if between 21-65)*: \_\_\_\_\_

Recent vaccinations *(i.e., flu shot)*: \_\_\_\_\_

### Recently, I have been...

Eating more or less

Losing interest in things I liked to do

Feeling tired

Feeling like hurting myself or others

Not able to focus

Having trouble sleeping

Other \_\_\_\_\_

### Additional Comments for My Doctor

*E.g., Questions about other concerns, about my medication, or activities, etc.*

\_\_\_\_\_

\_\_\_\_\_

**This form was completed by** *Print Name* \_\_\_\_\_

**Signature** \_\_\_\_\_ **Date** \_\_\_\_\_ 



**Please cite this document as:**  
Perkins, E.A., & VanZant, S. (2015). *My Health Report*. Florida Center for Inclusive Communities.  
For more information visit [www.flcic.org](http://www.flcic.org), or contact Dr. Elizabeth Perkins at [eperkins@usf.edu](mailto:eperkins@usf.edu)



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Adults with IDD may indicate a health issue (pain, discomfort, etc.) through behaviors. Dr. Tom Cheetham, MD created a list of things to consider if a person is displaying new or concerning behaviors.

**For more information, visit:**

Cheetham's Checklist for Understanding Behavior Changes:

<https://iddtoolkit.vkcsites.org/physical-health/cheethams-checklist/>



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