

Determining Services & Supports for Individuals with Cognitive Disabilities: Tools You Can Use RIGHT NOW



STETSON LAW | 2026 National Conference on
Special Needs Planning and Special Needs Trusts

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presented by

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Legal tools set the authority.

Services and supports deliver the outcome.

(Legal planning succeeds when support reaches the person)

A carefully drafted document can:

- establish authority/decision-maker
- preserve assets
- express preferences

Someone still needs to:

- arrange transportation
- support medication routines
- locate provider(s)
- ...and follow up on day-to-day well-being, etc.

Think of your last client/case involving a person with a cognitive disability...

Did the legal document or order solve the everyday problem?

Today's Objectives

- **Spot common unmet needs** through a structured conversation during the legal intake and review.
- Apply **person-centered planning principles** to legal work.
- **Match specific needs** to an appropriate assessment or service system (and interdisciplinary approach).
- Use existing tools to **explore decision-making options and supports.**
- **Navigate the major publicly funded and community-based service systems.**
- **Create a plan** with responsible people, deadlines, and follow-up.

Law Sets Authority, Supports Deliver Outcomes.

(Legal tools and daily supports work together)

Legal planning	Everyday implementation
Guardianship or decision-making alternatives	Support to understand and carry out decisions
Powers of attorney and advance directives	Health care access and coordination
Special needs trusts and estate plans	Someone to identify, arrange, and monitor funded supports
Representative payee arrangements	Benefit management and attention to daily financial needs



What Happens When the Support Piece Is Missing?

Common failure points:

- Plan funds sit unused while needs go unmet
- Loss of benefits through missed deadlines or redeterminations
- Crisis-driven placements (hospital, nursing facility, or jail)
- Isolation, neglect, or exploitation
- Guardianship used as a fix for a service gap

The Legal Framework Behind Supports

- **ADA** and the **Olmstead** decision address unnecessary segregation in public services (rights to services in the most integrated setting).
- Applicable guardianship law guides **consideration of less restrictive alternatives**.
- **Supported decision-making** recognition and legal effects vary by state.
- **Person-centered planning requirements** in **Medicaid home and community-based services (HCBS)**.



Cognitive Disability is *Not* One Thing

(Diagnosis $\neq$ Decision-Making Ability $\neq$ Support Needs)

A spectrum of conditions and origins:

- Intellectual and developmental disabilities (IDD)
- Traumatic or acquired brain injury
- Dementia and neurocognitive disorders
- Serious mental illness with cognitive effects
- Co-occurring conditions

Question	What we need to understand
What does the person want?	Preferences, priorities, and desired outcomes
What help does the person need?	Everyday functioning and available supports
What legal authority is necessary?	Applicable legal standards and decision-specific evidence

The Seven Life Domains Checklist

A checklist you can use at intake:

1. **Housing:** Where do they live? Is it safe and stable?
2. **Health:** Primary care, medications, dental, behavioral health
3. **Daily living:** Personal care, meals, hygiene, household tasks
4. **Money:** Income, benefits, bill-paying, vulnerability to exploitation
5. **Daily activity:** Work, school, day program, meaningful routine
6. **Relationships:** Family, friends, natural supports, isolation risk
7. **Safety:** Abuse or neglect risk, emergency plan, wandering, behaviors

Questions That Help Reveal Unmet Needs

- “What matters *most* to you right now?”
- “Who helps you on a typical day?”
 - “What happens if that person is sick or unavailable?”
- “What services do you receive now?”
 - What have you been told you can't get?”
- “What does a good day look like for you?”
- “What worries you most?”
- “What would you like help with, and what would you like to keep doing yourself?”
- “What is becoming difficult or going wrong?”
- “Who helps you now, and what happens if they are unavailable?”
- “Who or what helps you do the things you like to do?”

Participation Depends on Accessible Communication

(don't forget about effective communication supports)

- Ask how (and when!) the person prefers to communicate.
- Explain one idea at a time. Use plain language.
- Use concrete language, pictures, or written choices.
- Allow processing time and breaks.
- Offer a supporter the person chooses.
- Ask the person to explain the next step in their own words/way.

Functional Assessment Tools: What They Are

(we don't administer these, but we *should* know what they are)

Assessment type	What it may help describe
Adaptive behavior assessments such as Vineland or ABAS	Everyday adaptive skills
Supports Intensity Scale (SIS) Adult Version, for IDD	Pattern and intensity of support needs in IDD
Activities of daily living (ADL) and instrumental activities of daily living (IADL) screens	Personal care and household functioning
Cognitive screens such as MoCA, used by clinicians	Whether further clinical evaluation may be needed
State-specific functional or level-of-care assessments for Medicaid eligibility	Whether program criteria are met



The Interdisciplinary Team

(who can answer what questions)

Question	Potential professional
What explains a new change in functioning?	Medical clinician
How does cognition affect complex tasks?	Neuropsychologist or other qualified evaluator
What would help this person function at home?	Occupational therapist
What communication supports would help?	Speech-language pathologist
Which services fit, and how can the person access them?	Social worker or care manager
Does the person meet a program's criteria?	Program-designated assessor

The Service Landscape At-a-Glance

1. PUBLIC BENEFITS: INCOME AND HEALTH COVERAGE
2. LONG-TERM SERVICES AND SUPPORTS: MEDICAID WAIVERS AND STATE PROGRAMS
3. EDUCATION, EMPLOYMENT, AND REHABILITATION
4. COMMUNITY AND INFORMAL SUPPORTS



Service systems have different entry points

(The system is fragmented. Eligibility is based on a mix: age, diagnosis, income, & functional needs.)

Need or circumstance	Starting point
Long-term assistance with daily activities	State Medicaid long-term services and supports intake
Intellectual or developmental disability (IDD)	State or local developmental disability system
Aging or dementia	Area Agency on Aging or Aging and Disability Resource Center
Acquired brain injury	Rehabilitation team and applicable state brain injury resources
Employment support	State vocational rehabilitation agency
Community access and independent living	Center for Independent Living
Mental and behavioral health needs	Local public behavioral health system or treating team
School services or transition	School district's special education team

Public Benefits: The Foundation

- **SSI:** needs-based income, with strict asset and income limits
- **SSDI / Childhood Disability / DAC:** based on work record (own or parent's)
- **Medicaid:** health coverage, and often the gateway to long-term services and supports
- **Medicare:** after the qualifying period
- **SNAP, housing assistance, and other income supports:** food and housing support under applicable program rules

Home and Community–Based Services (HCBS)

Potential funding sources

- Medicaid state-plan services (“waiver”) and HCBS programs. Medicaid waiver programs include residential supports, personal care, supported employment, respite, behavioral supports, and more. Waitlists are common in many states. Eligibility usually requires:
 - a disability determination
 - a level-of-care assessment, and
 - financial eligibility
- Medicare or other insurance for covered care
- Aging, disability, and vocational programs
- Trust assets or private payment
- Community organizations and informal supports

ASK: Eligibility? Coverage? Provider? Start date?

Other Public Systems to Know: Community- Based & Informal Supports

- **Vocational rehabilitation:** job training and placement
- **Special education and transition services (IDEA):** through age 21 or 22, depending on state
- **Aging network:** Area Agencies on Aging, Aging and Disability Resource Centers
- **Mental and behavioral health systems**
- **Brain injury programs and waivers**
- **Adult Protective Services,** a safety net and also a resource
- **Disability advocacy organizations** (The Arc, Centers for Independent Living, Protection and Advocacy agency)
- **Faith communities, civic groups, and volunteer programs**
- **Peer support and family networks**
- **Technology:** medication reminders, GPS, remote monitoring, communication tools

Community and Everyday Supports Fill Specific Gaps

Need	Possible support to explore
Remembering tasks	Visual schedule, reminders, scheduled prompts
Managing bills	Accessible bill review, payment reminders, automatic payments
Getting to appointments	Transportation coordination, travel training, accompaniment
Preparing meals	Meal delivery, cooking instruction, adaptive equipment
Maintaining relationships	Peer support, chosen activities, transportation
Supporting a caregiver	Respite, training, emergency backup



Person-Centered Planning Principles

- The **person is at the center and directs the process** as much as possible
- **Focus on strengths, preferences, goals**, and what is important to and for the person
- Plans reflect **the person's own voice and desired life**
- **Supports are flexible and revisited over time**
- **Dignity of risk:** people have the right to make choices, including risky ones, with appropriate support



Tools YOU Can Use: Make YOUR State List

- Use the seven life domains at intake and review
- Ask questions to uncover unmet needs
- Request existing assessments before commissioning new ones
- Identify the right service door (disability, aging, brain injury, mental health)
- Get on waitlists early, and appeal denials on time
- Build interdisciplinary input into legal decisions
- Align legal tools with person-centered goals
- Social Security Administration (SSI/SSDI information)
- State Medicaid and IDD / developmental disabilities agency
- Aging and Disability Resource Center / Area Agency on Aging
- The Arc [YOUR state chapter], Center for Independent Living, Protection and Advocacy agency
- Charting the LifeCourse Nexus (UMKC)
- ABA Commission on Law and Aging
- National Resource Center for Supported Decision-Making
- Brain injury association [YOUR state chapter]

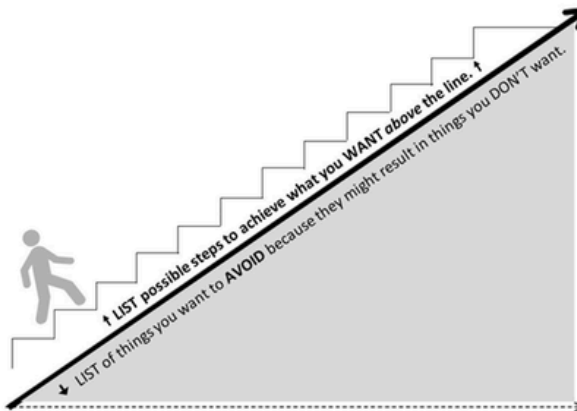
Tools YOU Can Use: Local Resource Contact Worksheet

Resource	Local agency and intake contact
Medicaid long-term services and supports	[Agency, intake number, website]
Developmental disability services	[Agency, intake number, website]
Aging and caregiver navigation	[AAA or ADRC, number, website]
Brain injury and rehabilitation resources	[Program, number, website]
Vocational rehabilitation	[Agency, number, website]
Independent living and advocacy	[CIL, Arc chapter, number, website]
Protection and Advocacy or benefits legal assistance	[Organization, intake number, website]

Supported Decision-Making (SDM) is at the heart of ensuring “liberty and justice for all” “the pursuit of happiness” and honoring an individual’s civil and human rights.



Name: _____
Today's date: _____



What I WANT

What I DON'T Want

This tool was originally developed by the UMKC Institute for Human Development, UCEDD (Missouri) (2010, 2016), and modified by The Arc of Colorado (thearc.org, 2022).



IDENTIFYING DECISION-MAKING SUPPORTS

This tool is designed to assist with identifying an individual under the age of 18 years-old's ability to make decisions and manage key areas of life. It is intended to assist with exploring options for integrated decision-making services & supports.

Name of Individual: _____
Name of individual completing this form: _____
Relationship to individual (circle one): Self Family Friend Guardian Other: _____
How long have you known the individual? _____

Step 1: If yes, put a checkmark in the GREEN column – this means the individual is good to go. If NO, put a mark in the yellow column.

Step 2: When you have completed all the questions, explore integrated services & supports options for supported decision-making for all questions marked in the yellow column.

Step 3: ONLY if NO integrated services or supports can be identified should substitute decision-making be considered for those specific areas of need.


Can individual decide or direct this activity independently most of the time?


Can individual decide or direct this activity with assistance most of the time?


Does the individual require substituted decision making support?

DAILY LIVING at HOME

Can the individual make and communicate choices in regard to getting dressed in the morning (what to wear, appropriate attire for weather/event, etc.)?			
Can the individual make and communicate choices in regard to bedtime and/or morning routines (i.e. what time to go to bed, when to get up, bathroom, etc.)?			
Is the individual able to decide and direct what kinds of support they need or want and select who provides those supports?			

HEALTHY LIVING

Does the individual make decisions about where, when, & what to eat?			
Can the individual follow a prescribed diet and/or take medicines as directed?			
Does the individual understand the need to maintain individual hygiene and dental care?			
Does the individual understand health consequences associated with high-risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?			

Modified by The Arc of Colorado (5/5/2025) from UMKC Institute for Human Development, UCEDD (11/2015).



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Thank You!

Questions?

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