

Understanding Support Roles: Who Has a Say in Healthcare Decisions?

*A Clinician's Tool for
Aiding Patients with IDD*



1. Understanding Support Roles

Support roles for individuals with IDD can have different responsibilities. Clinicians should assess the support's role to determine how they contribute to decision-making and support. The [National Disability Rights Network](#) is a great resource to reference when advocating for laws protecting the civil and human rights of all people with disabilities.

Support Role	Responsibilities	Legal Limitations
Family Member	Offers emotional support and assistance in communication.	Cannot make medical decisions unless designated as a legal guardian or holding a power of attorney.
Driver/ Transporter	Provides transportation for appointments.	No legally documented authority in decision-making.
Direct Support Professional	Assists with daily living tasks and logistical needs.	Cannot consent to medical treatment unless legally authorized.
Healthcare Proxy	Has legally documented authorization to make healthcare decisions if the patient is incapacitated.	Decisions must align with the patient's previously stated wishes.
Legal Guardian	Has legally documented authorization to make decisions for the patient.	Must act in the patient's best interest and respect their autonomy where possible.
Advocate/ Peer Mentor/ Chosen Buddy	Helps explain patient needs and rights to clinicians.	No legal authority to consent or make medical decisions.

2. Identifying the Decision-Maker

Clinicians should be aware of the legal age of medical consent within their state, and should ask clear, respectful questions to determine who has the authority to make healthcare decisions.

- **For the patient:**
 - *"Do you make decisions about your own healthcare, or does someone assist you?"*
 - *"Is there anyone we should include when discussing your care?"*
- **For the support person:**
 - *"What is your relationship to the patient?"*
 - *"Do you have legal authority to make healthcare decisions (e.g., power of attorney or guardianship)?"*
 - *"How can you best support the patient today?"*

3. Supporting Autonomy

All patients, including those with IDD, have the right to participate in decisions about their care. This tool helps ensure autonomy is respected.

- **Encourage Communication:** Use accessible communication aids (e.g., visual schedules, plain language, or picture cards) to engage the patient in decision-making.
- **Clarify Preferences:** Ask the patient directly about their comfort levels and preferences before assuming reliance on a support person.
 - **Example:** "Would you like to tell me about this, or would you like [support's name] to explain?"
- **Respect Legal Boundaries:** Only defer decisions to a support when legal documentation supports this authority.

4. Limits to Support Authority

Even when supports play an active role, their authority has boundaries:

- **Non-Legal Supports:** Cannot override the patient's expressed wishes without legal documentation.
- **Legal Guardians:** Must respect the individual's preferences to the extent possible and act in their best interests.
- **Professional Ethics:** Clinicians should advocate for the patient's rights and autonomy if a support's actions seem to contradict these principles.

5. Best Practices for Clinicians

- **Document the Role:** Clearly record the support's role and any legal authority in the patient's medical file.
- **Provide Accommodations:** Ensure the patient has access to communication supports and sensory accommodations to engage in discussions about their care.
- **Promote Team Decision-Making:** Collaborate with supports to create a shared decision-making environment where the patient's voice remains central.

6. Decision-Making Scenarios

Scenario 1: Patient with Independent Decision-Making

- **Situation:** The patient can make decisions but benefits from a support person.
- **Clinician Action:** Speak to the patient directly. Use the support team to clarify or reinforce information.

Scenario 2: Support Claims Legal Authority

- **Situation:** A support states they are the legal guardian during the initial visit.
- **Clinician Action:** Request and verify guardianship documentation before proceeding with any treatment beyond examination and diagnostic x-rays. If documentation is not immediately available, limit care to emergency services only until proper legal authority is confirmed.

Scenario 3: Conflicting Input

- **Situation:** The patient and support express differing preferences.
- **Clinician Action:** Prioritize the patient's expressed wishes unless legal guardianship documentation specifies otherwise. Consider involving a social worker or advocate for resolution.

National Organization Resources

The Arc

- National community-based organization advocating for and with people with intellectual and developmental disabilities
- Founded in 1950, with chapters in every state
- Key Resources:
 - Comprehensive policy guides for supporting individuals with disabilities
 - Training materials on rights, inclusion, and self-advocacy
 - State-specific resources and local chapter connections
 - Provides guidance on communication strategies
 - Offers legal advocacy resources
 - Supports inclusive healthcare access
- Contact: (800) 433-5255

National Disability Rights Network (NDRN)

- Protection and Advocacy (P&A) system for individuals with disabilities
- Operates in all 50 states and U.S. territories
- Key Services:
 - Legal representation
 - Individual and systemic advocacy
 - Rights protection and enforcement
 - Each state has a designated Disability Rights Center
 - Provides local legal support and resources
 - Offers training on disability rights in healthcare settings
- Contact: (202) 408-9514

Center for Independent Living (CIL)

- Community-based, cross-disability, non-residential private nonprofit agencies
- Mission: Supporting people with disabilities to live independently
- Key Functions:
 - Peer support programs
 - Skills training for independent living
 - Advocacy and systems change
- State-Specific Resources:
 - Local centers provide tailored support
 - Offer communication and accessibility workshops
 - Connect individuals with local healthcare resources

Practical Guidance for Verification and Communication

Legal Guardianship Verification

- Request official documentation
- Confirm guardianship through:
 - State court records
 - Direct communication with designated guardian
 - Verification with local social services
- Maintain confidentiality and respect patient privacy

Communication Strategies

- Speak directly to the patient
- Use clear, respectful language
- Provide multiple communication format options
- Offer communication assistance tools
- Respect patient's communication preferences

Practical Guidance for Verification and Communication

Ongoing Training

- Bi-annual disability awareness workshops
- Updated resources from national organizations
- Feedback collection mechanisms
- Continuous improvement of communication protocols

Communication Strategies

- Consult state dental boards for specific guidelines
- Review state disability rights legislation
- Coordinate with local disability advocacy groups
- Develop region-specific accommodation strategies