Families & Caregivers

Supporting safety, autonomy, relationships, decision-making, and a life beyond the family

Evidence-informed • person-centered • rights-respecting • implementation-focused

THE FAMILY ROLE

Strong support does not mean making every decision or eliminating every risk. The goal is to help a person build knowledge, relationships, skills, access, and safeguards so that their life can become larger - not smaller - over time.

1. Start with the person, not the diagnosis

Person-centered planning is directed by the person receiving support and organizes services around strengths, goals, preferences, culture, relationships, community life, and desired outcomes. Family knowledge matters, but the person's own voice should remain central to the maximum extent possible.

- Ask what matters to the person before deciding what is best for them.
- Separate what the person cannot yet do from what they have never been taught, allowed, or supported to practice.
- Describe support needs specifically instead of using broad labels.
- Revisit old restrictions. A rule created during childhood or crisis should not automatically become permanent.

2. Supported decision-making and least-restrictive support

Supported decision-making (SDM) allows a person to retain decision-making authority while receiving help from trusted people they choose. ACL describes SDM as one alternative to guardianship. The empirical literature is growing, but it does not justify treating SDM as risk-free or universally appropriate; support arrangements should be individualized and monitored for undue influence.

- Identify the decision: health, money, housing, relationships, work, transportation, education, or another area.
- Ask what kind of help is actually needed: understanding options, remembering information, communicating a choice, comparing consequences, or carrying out the decision.
- Use the minimum level of substitution necessary under applicable law.
- Build more than one trusted relationship so one supporter does not become the only source of information or access.

- Document the person's preferences and successful support strategies.

3. A practical decision-support conversation

- ☐ What decision are we making?
- ☐ What does the person already understand?
- ☐ What information needs to be made more accessible?
- ☐ What does the person want?
- ☐ What are the realistic benefits and risks of each option?
- ☐ Can the risk be reduced without taking the choice away?
- ☐ Who does the person want involved?
- ☐ What backup plan would make this safer?
- ☐ When will we review whether the support is still needed?

4. Relationships, consent, privacy, and boundaries at home

Families can protect people from harm while still making room for age-respectful privacy, friendships, dating, sexuality education, and ordinary social learning.

- Teach consent as both a right and a responsibility: how to say no and how to respect another person's no.
- Teach body privacy, digital privacy, money boundaries, healthy and unhealthy behavior, coercion, grooming, and help-seeking in accessible ways.
- Do not make obedience the safety strategy. A person taught never to question adults or helpers may have fewer tools for resisting inappropriate requests.
- Create private ways to communicate with trusted people outside the immediate household or paid-care relationship.
- Use age-respectful language, activities, and expectations.

5. Build a circle of trusted people

A resilient support network should not depend on one caregiver. Identify people who know the person in different contexts and can notice change, provide practical help, or be contacted privately.

- Family and chosen family
- Friends and peers
- Healthcare and behavioral-health professionals
- Teachers, coaches, faith/community members, or employers when appropriate
- Advocates, case managers, Centers for Independent Living, or disability organizations
- Emergency and backup supports

NETWORK TEST

If the primary caregiver were unavailable tomorrow, who would know the person's communication style, medications or health needs, routines, rights, preferences, safety plan, important relationships, and how to reach the people they trust?

6. Reasonable risk: plan instead of defaulting to restriction

ACL's person-centered planning guidance explicitly includes appropriate risk and emergency planning. The practical question is not 'Can we eliminate all risk?' but 'What support would make this choice reasonably safer?'

- Name the specific risk rather than using vague fear.
- Estimate likelihood and seriousness separately.
- Ask what the person understands and what they want.
- Add safeguards: check-ins, transportation plan, emergency contacts, accessible phone, money limits chosen with the person, medication backup, or another support.
- Use time-limited trials when appropriate.
- Review what happened and adjust. Do not treat every mistake as proof that autonomy failed.

7. Family wellbeing matters too

Systematic reviews show that family quality of life is shaped by factors at the individual, family, service, and systems levels. Caregiving burden can affect physical health, mental health, finances, employment, relationships, and the ability to sustain care. Asking for respite, information, peer support, or practical assistance is part of a durable support plan.

- Map tasks that only you can do versus tasks that can be shared.
- Create written backup information before a crisis.
- Ask providers for clear roles, contact points, and follow-up responsibilities.
- Include siblings and extended family only in ways that respect their own roles and boundaries.
- Plan for future housing, finances, healthcare, decision support, and community connection before an emergency forces the issue.

8. Transition to adulthood and long-term planning

- Start early with daily choices, money skills, transportation, healthcare participation, self-advocacy, and household responsibilities.
- Build experience with work, volunteering, recreation, friendships, and community participation.
- Teach the person how to describe their disability and request accommodations if they choose.
- Review benefits, insurance, education/employment services, and legal options with qualified professionals.
- Create a portable 'what helps me' profile with the person's permission.

- Plan for caregiver aging, illness, or death without treating the person as a passive recipient of the plan.

9. Family conversation guide

- What do you want more control over?
- What makes you feel safe?
- Who do you trust when something is wrong?
- Is there anything we do for you that you want to learn to do yourself?
- What support helps without taking over?
- What relationships or activities do you want more of?
- What rules feel unfair or too restrictive?
- What should happen if I am unavailable?

10. Family support plan - one page

Plan area	Write your plan
Communication & access	_____
Health/medications	_____
Decision support	_____
Trusted people	_____
Transportation	_____
Money/benefits	_____
Relationships & privacy	_____
Work/education/community	_____
Emergency backup	_____
Review date	_____

IMPORTANT

Educational resource only. It is not individualized legal, medical, mental-health, emergency, or case-specific advice. Guardianship, mandatory reporting, consent, education, Medicaid, employment, and disability-rights requirements vary by jurisdiction and setting.

References & trusted sources

Source hierarchy: current federal/public-health guidance and rights standards; systematic reviews and evidence syntheses; then supporting peer-reviewed studies. Legal requirements vary by setting and jurisdiction.

1. Administration for Community Living. Person-Centered Planning. Source
2. Administration for Community Living. Supported Decision Making Program. Source
3. Aston P, et al. Everyday decision-making in adults with intellectual disabilities: systematic review (2023). Source
4. Dean EE, et al. Self-Advocate and Family Member Experiences With Supported Decision Making (2024). Source
5. Barratt M, et al. Parental experiences of quality of life: meta-aggregation systematic review (2025). Source
6. Luitwieler N, et al. Family quality of life variables: systematic review (2021). Source
7. National Council on Disability. Beyond Guardianship (2018). Source

EVIDENCE INTEGRITY

Where evidence is mixed, emerging, or primarily qualitative, this resource says so. Rights-based standards and legal requirements are not presented as randomized-trial findings, and associations are not presented as causation.

Prepared for Oklahoma Child Wellbeing • Disability, Safety & Autonomy

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