



A GUIDE FOR FAMILIES

The Family Journey

What to think about at every stage,
from diagnosis to the future

- 1 Diagnosis
- 2 Early childhood
- 3 School years
- 4 Transition
- 5 After graduation
- 6 A place to live
- 7 Work
- 8 The future



WELCOME

Your path, your pace

Every disability journey is beautiful and unique. No two families take the same road, at the same speed, or in the same order.

Think of this guide as a list of things worth knowing along the way, so fewer things catch you off guard. It isn't a schedule, and you can't fall behind.

It's built around eight stages, from diagnosis to planning for the future. Some families go through them in order. Others start in the middle, circle back, or skip one. A diagnosis can come at birth or at 40. Start where you are and use what helps.

Who this guide is for

Parents and caregivers, siblings and grandparents, self-advocates planning their own lives, and the professionals who walk alongside them.

With gratitude to Emily Perl Kingsley



In 1987, Emily Perl Kingsley wrote "Welcome to Holland" about raising her son, Jason, who had Down syndrome. She compared finding out your child has a disability to planning a trip to Italy and landing in Holland instead.

In her telling, Holland isn't a worse place, just a different one. It has its own beauty, and nobody hands you a map.

Emily also wrote for "Sesame Street" for decades and helped bring people with disabilities onto the show. We built this guide around her image, with thanks. We don't reprint the essay here, but you can read it on her website:

[Welcome to Holland by Emily Perl Kingsley →](#)

Some families feel the essay speaks for them. Others would describe their journey differently. Both are welcome here.

WHAT FAMILIES TOLD US

47,278

online posts and comments from families we studied in the Texas Disability Project

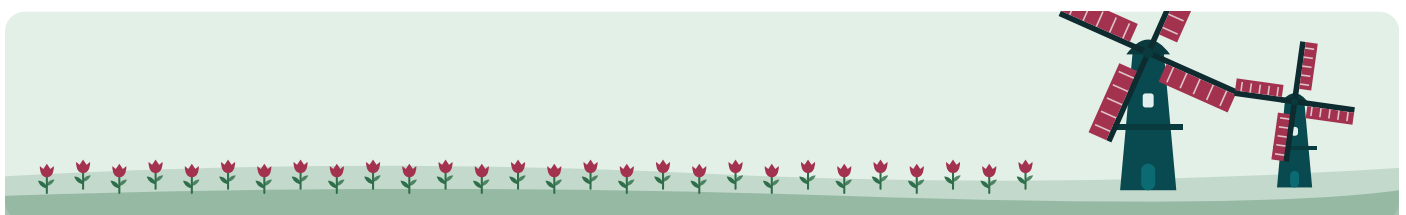
We wrote this guide to get that information to families sooner.

24 to 40

hours a week of unpaid care that parents described

78%

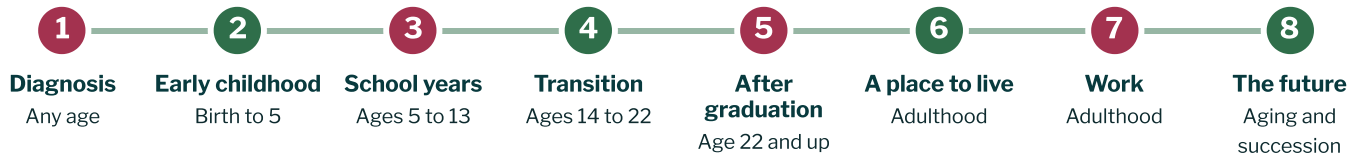
of conversations were about systems that did not work the way families needed



HOW TO USE THIS GUIDE

Eight stages, one map

This guide follows the way life tends to unfold, from the first diagnosis through school, adulthood, and the years ahead. Each stage covers what's happening, what to start, and what to ask. Read it straight through, or jump to the stage you're in now.



Five lenses at every stage

Each stage looks at the same five parts of life, so you can quickly find what matters to you.

- Health and Care
- Services and Funding
- Learning and Growth
- Family and Community
- Money and Legal

Watch for these marks

START NOW

Start now, even if it feels early. These things take time.

PLANK 1

This is a plank in your bridge. The planks come together in stage 5, After graduation.

?

Questions to bring to your next appointment or meeting.

[Link →](#)

Bold teal text with an arrow is a live link.

Look for 9 planks. They're spread across stages 1 through 5. Find them all, then check them off on the My bridge worksheet in the back.

A note before you begin

This guide shares general information to help you know what to ask and who to ask. It is not legal, financial, medical, or benefits advice. Rules differ from state to state and change over time. Before making legal or money decisions, talk with a qualified professional in your state.

Find help near you

ConnectIDD built three free tools to go with this guide. The links in these pages open them already set to the kind of help you need.

- The Family Journey** journey.connectidd.com →
This guide's home online. Pick your state and stage to see your state's facts and find help near you.
- Disability Search** disabilitysearch.connectidd.com →
A free directory of disability services in all 50 states and DC. Search by state, county, age, and service.
- State of Support** stateofsupport.connectidd.com →
Grades every state on disability services: waiting lists, community living, jobs, and more.



Diagnosis

You have landed somewhere new

A diagnosis can come before birth, in the NICU, at age 4, or at 34. However it arrives, this is where your new map starts. You don't have to do everything on these pages this month. Pick one or two things and start there.



Health and Care

- Ask your doctor for referrals to specialists who know this diagnosis, such as a developmental pediatrician, geneticist, or neurologist.
- Ask for a copy of every evaluation and report. You will be asked for them again and again.
- Start a care binder, on paper or on your phone. See the checklist in the back.
- Choose one doctor as your “medical home” to help coordinate care among specialists.

Services and Funding

- **▶ START NOW** **▬ PLANK 1** Ask your state's developmental disability agency how to join the Medicaid waiver interest or waiting list. In many states the wait runs for years. Signing up early costs nothing.
- Under age 3, ask for a referral to Early Intervention, or call your state's program yourself. Age 3 and up, contact your school district's Child Find office about a free evaluation.
- Ask whether your state offers Medicaid for children with disabilities no matter what parents earn. It may be called TEFRA, Katie Beckett, or a waiver.
- For adults diagnosed later in life, ask the state disability agency about eligibility for adult services.

Family and Community

- Connect with an organization focused on your family member's diagnosis.
- Ask for a Parent to Parent match with a family a few steps ahead of you.
- Find your state's Parent Training and Information Center. Every state has at least one.
- Make room for your journey and connect with others in a way that allows you to honestly express your thoughts and feelings.
- Think about how and when to share news with siblings, grandparents, and friends.

Money and Legal

Topics to explore with a qualified attorney or financial professional

- Wills, and who would care for a minor child if you could not.
- Whether a special needs trust could fit your family.
- How wills, life insurance, and retirement account beneficiaries can affect eligibility for SSI and Medicaid. Many families learn that money left directly to a person with a disability can affect benefits. Ask how this applies to you.

FIND HELP NEAR YOU

[Find early intervention providers →](#)

[Find family support and navigation →](#)

[See waiting lists in every state →](#)

Links open ConnectIDD tools. Add your state and county once you are there.

? Questions to bring

- Who else should evaluate my child, and how soon?
- How do we get on our state's waiver list, and how do we check our place?
- Which local families or groups do you recommend we meet?
- What should we be watching for in the next six months?

Early childhood

Learning the language of Holland

Holland has its own language: IFSP, Part C, OT, AAC. You'll pick it up faster than you expect, and the glossary in the back will help. These are the years of therapies, firsts, and finding your people.



Health and Care

- Therapies through Early Intervention or insurance: physical, occupational, speech, and feeding therapy.
- Ask your speech therapist about AAC (augmentative and alternative communication). Research shows AAC does not get in the way of speech.
- Track milestones without letting milestones run your life. Celebrate the inchstones too.

Services and Funding

- Early Intervention builds an Individualized Family Service Plan (IFSP) with you. Services often happen at home or in childcare.
- Ask what Early Intervention covers, what insurance covers, and whether your state charges family fees.
- Around 2 years 9 months, your team should hold a transition meeting to plan the move to public preschool at age 3. Ask for it if no one brings it up.
- Ask about respite: short breaks for caregivers, sometimes paid for by your state.
- Check your place on the waiver list.

Family and Community

- Ask your employer about leave and flexible schedules for appointments. The Family and Medical Leave Act (FMLA) may protect some of that time.
- Protect time for your partner, your other children, and yourself.
- Adaptive playgroups, library story times, and parent meetups.

Learning and Growth

- Look for inclusive childcare and preschool, where children with and without disabilities learn together.
- Early Head Start and Head Start set aside spots for children with disabilities. Ask your local program.
- Ask your state about childcare subsidies and inclusion support for providers.

Money and Legal

Topics to explore with a qualified attorney or financial professional

- **PLANK 2** Start a Letter of Intent: a plain-language guide to your child's routines, likes, health, and what works. It is not a legal document. See the starter in the back.
- If you have not yet, bring the topics from the Diagnosis stage to a qualified attorney.

FIND HELP NEAR YOU

[Find therapy providers for children →](#)

[Find childcare →](#)

[Find respite →](#)

Links open ConnectIDD tools. Add your state and county once you are there.

? Questions to bring

- What will our transition meeting at age 3 cover, and when will it happen?
- Which inclusive preschools near us have worked with your families?
- What is one thing we can practice at home this week?
- Who can we call between visits when we have a question?

School years

You have a seat at the table

There's a seat for you at every IEP meeting. You're an equal member of the team, and nobody at that table knows your child better than you do. These years are about learning, belonging, and speaking up.



Learning and Growth

- Learn the difference between an IEP (special education services) and a 504 plan (accommodations).
- You can ask for an evaluation in writing at any time. If you disagree with the school's evaluation, ask about an Independent Educational Evaluation (IEE).
- Ask how your child will learn alongside classmates without disabilities. The law calls this the least restrictive environment.
- Ask about related services, behavior support plans, and extended school year (summer) services.
- **PLANK 3** By middle school, ask how course and diploma choices affect options after high school. Some tracks can close doors to college programs or jobs later.

Advocacy

- If your school district is not meeting your child's needs, look for a local professional advocate for your child and family. Your Parent Training and Information Center can help you find one.
- Your state's Protection and Advocacy agency can explain your rights.
- Bring someone with you to meetings, ask for a draft before the meeting, and put requests in writing.

Services and Funding

- Check your place on the waiver list.
- Ask your school about health services it can bill to Medicaid.
- Respite, for you and for siblings.

Family and Community

- Friendships, belonging, and a plan if bullying happens.
- Adaptive recreation, Special Olympics, camps, and faith communities.
- Support for siblings, such as Sibshops.

Money and Legal

Topics to explore with a qualified attorney or financial professional

- Update your Letter of Intent.
- Review your plans with a qualified professional when life changes: a move, a new job, a new baby.

Health and Care

- Plan ahead for dental care, including sedation if your child needs it.
- Body safety, puberty, and consent education, at a pace that fits your child.

FIND HELP NEAR YOU

[Find schools and education supports →](#)

[Find recreation, sports, and camps →](#)

[Find advocates and family navigation →](#)

Links open ConnectIDD tools. Add your state and county once you are there.

? Questions to bring

- How is my child doing on each IEP goal, and how do you measure it?
- Where does my child spend the school day, and with whom?
- What diploma options exist, and what does each one lead to?
- What supports help my child most at school, and can we use them at home?

Transition

Build the bridge before the bus stops coming

One day the school bus stops coming. School services end, and adult services work differently. You have to apply, qualify, and often wait. Use the years from 14 to 22 to build the bridge to what comes next.



Learning and Growth

- **PLANK 4** Transition planning must be part of the IEP by age 16, and many states start at 14. Ask for it.
- Students in special education can often stay in school until 21 or 22, depending on your state.
- Explore inclusive college programs for students with intellectual disabilities. Think College lists them.
- Build self-advocacy and life skills: leading part of their own IEP meeting, making choices, travel training, and money skills.

Work

- **PLANK 5** Ask your state's Vocational Rehabilitation (VR) agency about Pre-Employment Transition Services (Pre-ETS) for students. Many states start at 14.
- Apply for VR services before graduation.
- Work experiences, internships, and programs like Project SEARCH.

Health and Care

- Plan the move from pediatric to adult doctors (Got Transition has free tools). At 18, providers may need a signed release to share health information with you.

Family and Community

- Relationships and sexuality education, and friendships outside of school, since the daily school network ends.

Before the bus stops coming

- **START NOW** **PLANK 6** In the last years of school, research and visit adult programs: day programs, community-based programs, and day services. Ask about waitlists and get on them early.
- At each visit, ask what a typical day looks like, how much time is spent in the community, staffing, transportation, and how it is paid for.

Services and Funding

- **PLANK 7** At 18, Social Security stops counting parents' income for SSI and reviews eligibility under adult rules. Ask Social Security how this applies to your family member.
- Ask how your family member will keep Medicaid as an adult.
- Ask about free benefits counseling (WIPA) before your family member starts working.

Money and Legal

Topics to explore with a qualified attorney or financial professional

- **PLANK 8** Decision-making supports. At 18, your family member becomes a legal adult. Options range from least to most restrictive: supported decision-making, powers of attorney, and guardianship. Many families explore these before 18.
- ABLE accounts, which let many people save without losing SSI or Medicaid, within program rules. Starting in 2026, people whose disability began before age 46 may qualify.
- State ID, voter registration, and Selective Service registration for young men at 18.

FIND HELP NEAR YOU

[Find transition supports →](#)

[Find job training for transition-age youth →](#)

[Find guardianship and decision-making help →](#)

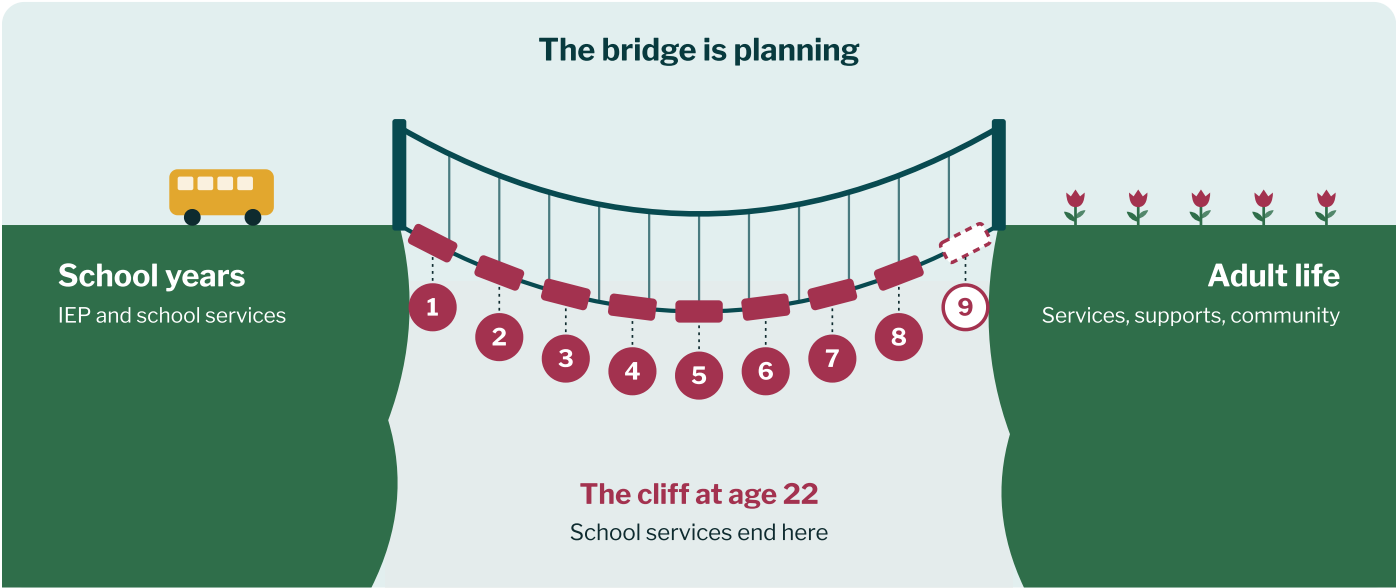
? Questions to bring

- What are my family member's goals for work, learning, and living, in their own words?
- Which adult programs have your graduates moved on to, and how long were the waitlists?
- When should we apply for VR, SSI, and adult Medicaid?
- Who will be at the table to plan the last year of school?

After graduation

Planning is the bridge over the cliff

Families call it the cliff. On the last day of school, services, routines, and often friendships can all end at once. Planning is the bridge across. Each plank you laid in earlier stages helps carry you over, and if one is missing, you can still lay it now.



Each plank is a planning step from an earlier stage. Look for the matching plank badges on those pages. If one is missing, you can still lay it now. Track them all on the My bridge worksheet in the back.

- | | | |
|--|---|---|
| 1 Waiver interest list
Diagnosis | 2 Letter of Intent
Early childhood | 3 Diploma track choices
School years |
| 4 Transition plan in the IEP
Transition | 5 Vocational Rehabilitation
Transition | 6 Adult program visits
Transition |
| 7 SSI and Medicaid at 18
Transition | 8 Decision-making supports
Transition | 9 Transportation and a day plan
After graduation |

After graduation CONTINUED

Planning is the bridge over the cliff

Services and Funding

- Activate the waiver services and adult programs you applied for.
- Ask how adult day services differ from community integration services, and which fits your family member's goals.
- Meet the service coordinator or case manager, and ask how often you will meet.

A week that works

-  **PLANK 9** Line up transportation: paratransit, travel training, or rides from family and friends.
- Sketch a typical week on paper: work or volunteering, a day program, classes, exercise, friends, and rest. Look for the empty spaces.
- Mix paid supports with natural ones: neighbors, faith communities, clubs, and family.

Money and Legal

Topics to explore with a qualified attorney or financial professional

- Childhood Disability Benefits (sometimes called DAC or CDB). Adults whose disability began before age 22 may qualify on a parent's Social Security record when that parent retires, becomes disabled, or dies. Ask Social Security.
- Review decision-making documents now that school is over. Are they still the right fit?

Learning and Growth

- Continuing education, community college classes, and adult learning programs.
- Hobbies, volunteering, and clubs that build skills and friendships.

Family and Community

- Daily routines change for the whole household. Parents' work schedules may need to change too.
- Loneliness is a real risk after school ends. Plan for social time the way you plan for services.

FIND HELP NEAR YOU

[Find day programs →](#)

[Find transportation →](#)

[Find arts and creative programs →](#)

Links open ConnectIDD tools. Add your state and county once you are there.

? Questions to bring

- What does a full week look like for my family member right now, and what is missing?
- Who is the service coordinator, and how often will we meet?
- What happens if a program has a waitlist?
- Who can my family member call when something goes wrong?

A place to live

A home that fits the person

Some adults live with family their whole lives, and that's a real choice too. What matters is a plan that fits the person, made before a crisis forces one on you. Most families weigh three main paths.



Three common paths

THE FAMILY HOME

Living with family

An adult child, sibling, or relative lives in the family home, often with day services, respite, or in-home help.

WHAT WORKS WELL

- + Familiar people, routines, and neighborhood
- + Lower housing cost
- + Family knows the person best

WHAT TO WEIGH

- ! Depends on caregivers who are aging too
- ! Can limit independence and friendships
- ! Hard to plan the next step in a crisis

WHAT IT ASKS OF THE PERSON

The person may do less on their own, since family often fills the gaps. Build skills anyway: chores, money, and making choices.

PROVIDER-RUN HOMES

A group home

A home run by a provider agency, often with 3 to 6 residents and staff on site. Larger settings, such as ICFs, offer 24-hour care.

WHAT WORKS WELL

- + Staff on site, often around the clock
- + Built-in housemates and community
- + Support for medical and daily care

WHAT TO WEIGH

- ! Less choice over roommates, schedules, and staff
- ! Staff turnover can be high
- ! Waitlists and limited openings

WHAT IT ASKS OF THE PERSON

The person follows a shared house routine. Staff help with daily tasks, so the person can need more support and still live well.

WITH SUPPORTS

Living on your own

The person rents or owns an apartment or home, alone or with roommates, with supports that come to them.

WHAT WORKS WELL

- + The most choice and control
- + Builds independence and confidence
- + Supports can grow or shrink with needs

WHAT TO WEIGH

- ! Takes planning, money, and backup plans
- ! Risk of isolation without a social plan
- ! Coordinating supports takes work

WHAT IT ASKS OF THE PERSON

The person handles more daily decisions: cooking, money, safety, and getting around, with help where they need it.

Many people move between these paths over a lifetime. There's no single right answer, just the right fit for this person right now.

A place to live CONTINUED

A home that fits the person

Whichever path you choose, the planning looks a lot alike. The first box below is for people living on their own, and lists the supports that make that possible. Everything else on this page applies to all three paths: paying for housing, practicing skills before a move, and the legal questions to sort out.

Supports for living on your own

- Supported living services: staff who come to the home for a few hours a week or a few hours a day, often paid for by a Medicaid waiver.
- Host homes or shared living: the person lives with a trained host family or companion who is paid to provide support.
- Remote supports: technology such as sensors, two-way video, and check-ins that let staff support someone from a distance. Companies such as SimplyHome offer these tools.
- Personal care attendants, meal programs, and paratransit can fill specific gaps.
- Build a backup plan for nights, weekends, and staff call-outs.

Housing options and funding

- Ask your state disability agency which home supports the waiver can pay for.
- Ask your local housing authority about vouchers, including Mainstream vouchers for adults with disabilities. Waitlists can be long, so apply early.
- Ask about home changes for access, and programs that help pay for them.

Skills and trial runs

- Practice independent living skills: cooking, money, chores, and safety.
- Use overnight respite or a short stay as a trial run.
- Try roommate matching before signing a lease.

Money and Legal

Topics to explore with a qualified attorney or financial professional

- How trusts and ABLE accounts can help with housing costs, and how each choice affects benefits.
- Who signs the lease, and what decision-making support is in place.

FIND HELP NEAR YOU

[Find housing and residential providers →](#)

[Find independent living supports →](#)

[Compare how states support community living →](#)

Links open ConnectIDD tools. Add your state and county once you are there.

? Questions to bring

- Who chooses roommates, and how are conflicts handled?
- How is staffing scheduled, and what happens when someone calls out?
- What does my family member want home to feel like?
- What happens if this home is not a good fit?

Work

Finding work that fits

In Holland, windmills turn wind into work. A job can bring purpose, a paycheck, and friends. Many adults with intellectual and developmental disabilities want to work, and with the right supports, they do.



DO THE RESEARCH FIRST

Before the job offer: understand benefits first

Work almost always leaves people better off, but a paycheck can change SSI, Medicaid, and sometimes housing. Do this homework with an expert before a job offer comes along, so nothing catches you off guard.

How earnings affect SSI

- In general, Social Security does not count the first \$65 of monthly earnings, plus a \$20 general exclusion. After that, SSI goes down \$1 for every \$2 earned.
- Earnings must be reported to Social Security every month. Missed reports can lead to overpayments that must be paid back.
- SSDI and Childhood Disability Benefits follow different rules, including a trial work period.

Savings and asset limits

- SSI has a resource limit, currently \$2,000 for an individual. Saving paychecks in a regular bank account can push someone over it.
- The first \$100,000 in an ABLE account does not count toward that limit. Earnings can be saved there.
- A person's own earnings or savings may go into a first-party special needs trust or a pooled trust. These have their own rules, including Medicaid payback.

Keeping health coverage

- Many people keep Medicaid even when earnings stop their SSI check, under a rule called 1619(b).
- Some states offer a Medicaid Buy-In for working adults with disabilities.
- Ask how a raise, more hours, or a new job would change coverage before saying yes.

Who to ask: a free WIPA benefits counselor through Ticket to Work, a VR benefits counselor, and a qualified special needs attorney for trusts. Bring every Social Security letter you have.

Rules and dollar amounts change. Check current figures with Social Security or a benefits counselor.

Work CONTINUED

Finding work that fits

Paths to work

- Competitive integrated employment: real jobs in the community, at minimum wage or higher, alongside coworkers without disabilities.
- Supported employment and customized employment, which shape a job around a person's strengths.
- Self-employment and small businesses.
- Vocational Rehabilitation for job coaching, training, and placement. Ticket to Work is another free option.

Good questions to ask

- Some settings pay less than minimum wage under a federal certificate called 14(c). Ask any program how it pays and what its path to community jobs is.
- Accommodations at work under the ADA, and when and how to share a disability with an employer.
- What kind of work brings your family member joy? Start there.

FIND HELP NEAR YOU

[Find job training and employment services →](#)

[Find benefits and financial counseling →](#)

[Shop at businesses that hire and are led by people with disabilities →](#)

Links open ConnectIDD tools. Add your state and county once you are there.



SEE IT WORKING

Inclusive businesses near you

Cafes, bakeries, greenhouses, car washes, and shops across the country hire, train, and are led by people with disabilities. Visit one. It's a good way to see what's possible.

[Browse Shop Inclusive →](#)

? Questions to bring

- What kind of work brings my family member joy?
- How will earnings affect SSI, Medicaid, and housing?
- Who is our benefits counselor, and when should we meet?
- Where will savings go so they do not affect benefits?

The future

Who will be there next?

Many parents carry the same question: who will be there when I can't? No one person should have to hold the whole answer. This stage is about building a circle of people around your family member, and a plan that will outlast any one of them.



Build a circle of support

A circle of support is a group of relatives, friends, neighbors, people from your faith community, and professionals who know your family member and care about their future. The work gets shared, so the plan doesn't depend on one person.



Roles to fill

- **Someone who visits** and notices how things are going
- **Someone who handles money** or works with the trustee
- **Someone who advocates** at meetings and with providers
- **Someone who knows their health:** their doctors, medicines, and history
- **Someone for fun:** outings, holidays, and friendship
- **Your family member**, at the center, making the choices

Keep it active

- Write a long-term life plan together, built around what your family member wants.
- Meet at least once a year. Share the Letter of Intent with everyone in the circle.
- Talk with siblings and relatives early and openly. Ask what they want, not only what they will agree to.
- Add younger members over time, so the circle grows as parents age.

The future CONTINUED

Who will be there next?

Money and Legal

Topics to explore with a qualified attorney or financial professional

- A successor trustee, and a successor guardian or decision-making supporter.
- Parents' own retirement and estate plans, and how they connect to your family member's plans.
- Advance directives that include your family member's voice, using supported decision-making.

Health and Care

- Adults with intellectual disabilities, especially people with Down syndrome, can face a higher and earlier risk of dementia. Ask the doctor about a baseline check of thinking and daily skills around ages 35 to 40.
- Find doctors who know aging and disability.

FIND HELP NEAR YOU

[Find legal services →](#)

[Find special needs trust and planning help →](#)

[Find aging supports →](#)

Links open ConnectIDD tools. Add your state and county once you are there.

Master pooled trusts

Topics to explore with a qualified attorney or financial professional

- A pooled trust is run by a nonprofit. It holds money for many people in one investment pool, with a separate account for each person.
- It can be an option when there is no family member to serve as trustee, or when the amount is too small for a standalone trust.
- Depending on the trust, it may hold the person's own money, money from family, or both. Fees, payback rules, and services vary.
- Ask a qualified attorney whether a pooled trust fits your family.

Home and the next chapter

- A plan for where your family member will live when parents can no longer provide care, tried out before it is needed.
- Grief and end-of-life planning, including support for your family member through loss.

? Questions to bring

- If something happened to me tomorrow, who would know what to do?
- Has the person named in our plans said yes, and do they have the Letter of Intent?
- Who is in our circle today, and who should we invite next?
- What does my family member want their life to look like in 20 years?

AT EVERY STAGE

Threads that run through the whole journey

Stages come and go, but some things stay with you the whole way. These show up at diagnosis and are still there at 60. Check in on them once a year. A birthday or the start of a school year works well.



● Waiver list status

Check your place at least once a year and update your contact information. Missed mail can remove you from some lists.

● Respite

Caregivers need breaks to keep going. Plan for them the way you plan for appointments.

● Siblings

Brothers and sisters have their own journey. Give them information, a voice, and their own time.

● Your state's rules

Waivers, school ages, and benefits vary by state. Check your state's facts on The Family Journey and State of Support.

● The care binder

Keep it current. Add every new evaluation, plan, and provider.

● Caregiver wellbeing

Your health counts. Families in our research described 24 to 40 hours a week of unpaid care.

● Their own voice

At every stage, more of the choices belong to the person. Ask what they want, and keep asking.



A yearly check-in

Pick a date. Pull out the care binder, check the waiver list, update the Letter of Intent, and ask your family member what they want next. Then look at the facts for your state.

[See your state on State of Support →](#)

[Find respite near you →](#)

My bridge

Check off each plank as you lay it. Write the date and one note.

DONE	PLANK	STAGE	DATE AND NOTES
☐	1. Waiver interest list	Diagnosis	
☐	2. Letter of Intent	Early childhood	
☐	3. Diploma track choices	School years	
☐	4. Transition plan in the IEP	Transition	
☐	5. Vocational Rehabilitation	Transition	
☐	6. Adult program visits	Transition	
☐	7. SSI and Medicaid at 18	Transition	
☐	8. Decision-making supports	Transition	
☐	9. Transportation and a day plan	After graduation	

Contacts log

NAME AND ROLE	ORGANIZATION	PHONE	EMAIL	NOTES

Care binder checklist

Check each section once it is in your binder. Use the lines for the details you reach for most.

☐ **Diagnoses and evaluations**

- ☐ Diagnosis and date _____
- ☐ Who evaluated _____
- ☐ Most recent evaluation _____
- ☐ Where reports are kept _____

☐ **Waiver list**

- ☐ State agency _____
- ☐ Date applied _____
- ☐ Confirmation number _____
- ☐ Last checked _____

☐ **Medicines and allergies**

- ☐ Medicine and dose _____
- ☐ Medicine and dose _____
- ☐ Allergies _____
- ☐ Pharmacy _____

☐ **Benefits**

- ☐ SSI or SSDI letters _____
- ☐ ABLE account _____
- ☐ Benefits counselor _____
- ☐ Next review _____

☐ **Care team**

- ☐ Primary doctor _____
- ☐ Specialists _____
- ☐ Therapists _____
- ☐ Dentist _____

☐ **Legal**

- ☐ Will _____
- ☐ Trust and trustee _____
- ☐ Decision-making documents _____
- ☐ Attorney _____

☐ **Insurance and Medicaid**

- ☐ Insurance plan and member number _____
- ☐ Medicaid number _____
- ☐ Waiver program _____
- ☐ Where cards are kept _____

☐ **Letter of Intent**

- ☐ Last updated _____
- ☐ Copies given to _____

☐ **Plans**

- ☐ IFSP, IEP, or 504 plan _____
- ☐ Transition plan _____
- ☐ Service plan _____
- ☐ Next review date _____

☐ **Emergency**

- ☐ Emergency contact _____
- ☐ Emergency contact _____
- ☐ Preferred hospital _____
- ☐ Emergency plan location _____

Letter of Intent starter

A plain-language guide to your family member, for anyone who may support them someday. Write it with them when you can. Update it every year, and give copies to your circle of support.

All about me

Name, nicknames, how I communicate, what people love about me.

A good day

Daily routine, morning to night. What helps, what to avoid.

Health

Conditions, medicines, doctors, signs that something is wrong.

Likes and dislikes

Food, music, places, people, sensory needs.

Relationships

Family, friends, and people who matter, with contact information.

Hopes and wishes

Work, home, faith, and dreams, in their own words when possible.

If something happens

Who to call first, and where documents are kept.

Other comments and thoughts

Anything else someone should know to support this person well.

Glossary

504 plan

A school plan for accommodations under Section 504 of the Rehabilitation Act.

14(c)

A federal certificate that lets some employers pay people with disabilities less than minimum wage.

1619(b)

A Social Security rule that lets many people keep Medicaid when earnings stop their SSI check.

AAC

Augmentative and alternative communication: tools like picture boards and speech apps.

ABLE account

A savings account for people with disabilities that many benefit programs do not count, within limits.

CDB or DAC

Childhood Disability Benefits, paid on a parent's Social Security record.

Child Find

A school district's duty to find and evaluate children who may need special education.

Circle of support

A group of family, friends, and professionals who help a person plan and live their life.

Early Intervention

Services for babies and toddlers under 3 with delays or disabilities. Also called Part C.

Host home

A home where a trained host family or companion is paid to support an adult with a disability.

ICF

Intermediate care facility: a licensed home with 24-hour care and services.

IEE

Independent Educational Evaluation, done by someone outside the school.

IEP

Individualized Education Program: the plan for a student's special education services.

IFSP

Individualized Family Service Plan: the Early Intervention plan for a young child and family.

Letter of Intent

A plain-language guide to a person's life, needs, and wishes. Not a legal document.

Medicaid Buy-In

Lets working adults with disabilities keep Medicaid by paying a premium.

Medicaid waiver

State programs that pay for home and community services. Many have waiting lists.

P&A

Protection and Advocacy agency: every state has one to protect disability rights.

PASS plan

Plan to Achieve Self-Support: lets a person set aside money for a work goal.

Pooled trust

A trust run by a nonprofit that pools money for many people, with a separate account for each.

Pre-ETS

Pre-Employment Transition Services from VR for students with disabilities.

PTI

Parent Training and Information Center: free help for families on special education.

Remote supports

Technology that lets staff support a person at home from a distance.

Respite

Short-term care that gives caregivers a break.

SSI

Supplemental Security Income: monthly payments for people with disabilities and low income.

Special needs trust

A trust that can hold money for a person with a disability. Rules vary; ask an attorney.

Supported decision-making

Choosing trusted people to help you make your own decisions.

Supported living

Staff who come to a person's own home to help with daily life.

Transition plan

The part of an IEP that plans for life after high school.

VR

Vocational Rehabilitation: the state agency that helps people with disabilities get and keep jobs.

WIPA

Work Incentives Planning and Assistance: free benefits counseling for people who want to work.

More plain-language definitions: [State of Support words to know](#) →

WHERE TO START LOOKING

National resources

Each of these can point you to help in your state. Every link below is live. Listing an organization here is not an endorsement.

Parent Center Hub

Find your Parent Training and Information Center

parentcenterhub.org →

Family Voices

Family-to-Family Health Information Centers

familyvoices.org →

National Disability Rights Network

Your state's Protection and Advocacy agency

ndrn.org →

Think College

Inclusive college programs

thinkcollege.net →

ABLE National Resource Center

ABLE accounts by state

ablenrc.org →

Social Security

SSI and Childhood Disability Benefits

ssa.gov →

National Resource Center for Supported Decision-Making

Alternatives to guardianship

supporteddecisionmaking.org →

Sibling Support Project

Sibshops and sibling resources

siblingsupport.org →

Parent to Parent USA

Get matched with an experienced parent

p2pusa.org →

ECTA Center

Early Intervention contacts by state

ectacenter.org →

NACDD

Your state's Council on Developmental Disabilities

nacdd.org →

Got Transition

Moving to adult health care

gottransition.org →

Ticket to Work

Work, benefits counseling (WIPA)

choosework.ssa.gov →

Center for Future Planning, The Arc

Planning for the future

futureplanning.thearc.org →

ARCH National Respite Network

Find respite

archrespite.org →

National Task Group on ID and Dementia

Aging and dementia resources

the-ntg.org →



About ConnectIDD

ConnectIDD is a Disability Empowerment Agency. We work alongside people with intellectual and developmental disabilities, their families, and the organizations that serve them, and we build free tools so every family can find what they need.

The Family Journey

journey.connectidd.com →

This guide's home online. Pick your state and stage to see your state's facts and find help near you.

State of Support

stateofsupport.connectidd.com →

Grades every state on disability services: waiting lists, community living, jobs, and more.

hello@connectidd.com

Disability Search

disabilitysearch.connectidd.com →

A free directory of disability services in all 50 states and DC. Search by state, county, age, and service.

Shop Inclusive

shopinclusive.connectidd.com →

Find cafes, shops, and other businesses that employ, train, or are owned by people with disabilities.

PLEASE READ

This guide shares general information only. It is not legal, financial, medical, or benefits advice, and reading it does not create a professional relationship with ConnectIDD. Program names, ages, dollar amounts, and rules vary by state and change over time. Talk with a qualified attorney, financial professional, benefits counselor, or medical provider in your state before making decisions. Mention of an organization or company is not an endorsement.

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