

Navigating School and Care Services

A practical guide for families: early help, school support, disability services, and planning for adulthood.

A diagnosis does not come with a guide for daily life. This page covers the practical things: early help for babies and toddlers, school support, disability services, and planning for adulthood. Most of it applies to any child with a developmental disability, not only UPF3B.

Before school age: Early Childhood Intervention

In Texas, **Early Childhood Intervention (ECI)** helps children from birth to age 3. Services can include speech therapy, occupational therapy, and physical therapy. They usually happen at your home.

- You do not need a diagnosis.** You can be referred as soon as you have a concern.
- You do not need a doctor.** A parent can refer their own child. So can a family member, a teacher, or a friend.
- No child is turned away for money reasons.** Families who can afford it may be asked to pay part of the cost on a sliding scale based on income. No child is refused because a family cannot pay.

Speech is one of the most common areas affected in UPF3B, so this is often the most useful early step a family can take.

To refer a child, find your local ECI program

<https://www.hhs.texas.gov/services/disability/early-childhood-intervention-services/make-a-referral-eci>

Or call the HHS Office of the Ombudsman: 1-877-787-8999, choose your language, then Option 3.

ECI ends at age 3. After that, your local school district takes over. Start planning that handover about six months early, not in the final week.

School age: IEP and 504 plans

There are two ways a school can support your child.

Type	What it does
IEP (Individualized Education Program)	For a child whose disability affects their learning and who needs teaching that is changed to fit them. Protected by federal law. The stronger of the two.
504 plan	Gives changes to the classroom, like extra time, but not changed teaching. Easier to get, gives less protection.

Most children with UPF3B-related disorder will qualify for an IEP.

How to start. Write to the school's special education office and ask for a full evaluation. Keep a dated copy of your letter. Asking a teacher in person does not start the legal timeline. A written request does.

A Texas difference worth knowing. In Texas the IEP meeting is called an **ARD meeting**, short for Admission, Review, and Dismissal. In other states it is just called the IEP meeting. It is the same thing.

Support that often helps with this condition

- Speech therapy written into the IEP as a service, not just offered informally
- Extra time, and instructions given both out loud and in writing
- Small group or one to one teaching for main subjects
- A communication device or picture cards if speech is very limited
- Movement breaks and support for sensory needs
- A daily notebook or log shared between school and home

One practical tip. Bring the genetic test result letter to the meeting. A named condition usually moves things along faster than a general description of delays.

Plain-language guide for Texas parents

<https://texasprojectfirst.org>

Free legal help and advice on disability rights in Texas

<https://disabilityrightstx.org>

Long-term disability services

Medicaid waiver programs. Texas has several programs that pay for long-term support at home instead of in an institution. They can cover respite care, an attendant, therapies, and housing support. The main ones are **HCS**, **CLASS**, **MDCP**, **TxHmL**, and **DBMD**.

This is the most important item on this page.

These programs have waiting lists, called **interest lists**, and they are very long. Often years. **Put your child's name on the lists as soon as you have a diagnosis, even if you do not need help right now.** It is free. You do not have to prove eligibility to join a list. Being on a list does not commit you to anything. Many families only find out about this years later, and by then they have lost that time.

There is no single number for all of them. You have to sign up separately.

Program	How to join the interest list
CLASS, MDCP, DBMD	Call 1-877-438-5658
HCS, Texas Home Living	Contact your Local Intellectual and Developmental Disability Authority (LIDDA). Find yours at https://apps.hhs.texas.gov/contact/search.cfm
STAR+PLUS	Call 1-877-782-6440

Ask for a confirmation letter each time. If you move house, tell every list your new address.

[Plain-language explanation of all the Texas waiver programs](https://www.navigatelifetexas.org/en/insurance-financial-help/texas-medicaid-waiver-programs-for-children-with-disabilities)

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SSI (Supplemental Security Income)

Monthly payments for children with disabilities in lower-income households, and for adults with disabilities. While your child is under 18, your household income counts. Once they turn 18, only their own income counts. This is why some people qualify at 18 who did not qualify before.

[Social Security Administration](https://www.ssa.gov/ssi)

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Planning for adulthood

Families often put this off. It matters more than almost anything else here.

Transition planning must be part of the IEP by the mid-teen years. It covers work, further education, and living independently.

At 18, your child becomes an adult in law, whatever their ability. Parents no longer automatically make medical or money decisions for them. Start this conversation at 16, not 18.

Option	What it means
Supported Decision-Making Agreement	The least restrictive choice. Your adult child keeps their legal rights and formally names people to help them make decisions.
Power of attorney	Covers specific areas only.
Guardianship	The most restrictive. It removes rights, and Texas courts expect you to show you considered less restrictive options first.

Job training and supported work is available through the Texas Workforce Commission's vocational rehabilitation services.

The hardest question: who cares for an adult after their parents are gone

- A **special needs trust** holds money for their benefit without making them lose Medicaid or SSI.
- A **letter of intent** describing their routines, likes, dislikes, and medical needs, so a future caregiver is not starting from nothing.
- **Naming a future caregiver clearly**, and talking to that person, rather than assuming a brother or sister will simply take it on.

For families in India

Support exists, but many families do not know about it.

UDID card (disability certificate). This is the document that unlocks most other benefits. Apply through a designated government hospital.
<https://www.swavlambancard.gov.in>

Rights of Persons with Disabilities Act, 2016. Recognises intellectual disability and learning disability. Covers access to education, and reserved places in government jobs and higher education.
<https://depwd.gov.in>

The National Trust. Runs schemes for people with intellectual disability, including the Niramaya health insurance scheme and legal guardianship arrangements.
<https://thenationaltrust.gov.in>

Disability pension. Rules differ by state. A disability certificate is normally needed first.

If you have been through any of this, please write to us. There is very little written guidance for Indian families dealing with rare genetic conditions, and what you learned would help the next family.

Please read this

This page gives general information. It is not legal or medical advice. Rules change, and every child's situation is different. Check the linked websites for current details, and talk to a professional about your own case.

Version 1, September 2026. If you spot something out of date or unclear, please tell us at support@upf3b.org so we can correct it.