
A SPECIAL EDITION OF *REACHING OUT* FOR OLDER INDIVIDUALS WITH CdLS AND THEIR FAMILIES

The Path Forward



INTRODUCTION

Welcome to

The Path Forward

Medical Transition is the planned movement of young adults from a child-centered to an adult-oriented medical system.

The goal of transitioning from pediatric to adult medical services is to maximize lifelong functioning and potential through the provisions of high quality, developmentally appropriate medical services and these services remain uninterrupted as the individual moves from adolescence to adulthood.

A smooth transition comes from the consideration and incorporation of the young adult's physical, psychological, and social development.

Transition from pediatric to adult healthcare is a critical stage of life for all individuals involved. This time can present many factors that can drastically change the daily lives of both the young adult with CdLS and their family. As a result, the transition period may be an especially stressful time. As a parent, it is important to consider using all available tools and resources to make the transition successful and to minimize potential stress.

For some parents of young adults with CdLS who have severe intellectual disabilities, little change may occur as the child grows into an adult. However, both legal and changing medical needs in adulthood will require parents to assume new responsibilities as the young adult begins the medical transition process. In addition to the medical transfer, some parents or caretakers may also take part in changes such as moving youth to adult daycare facilities or moving out of the home to a group home environment or other residential care.

Collaboration with the young adult, family, service provider(s), and community will be beneficial in creating meaningful outcomes for all who are involved in any transition.

This issue of the Path Forward will give you in-depth stories from individuals with CdLS who went through medical transition. It also includes helpful tools and resources that will assist you in planning for tomorrow.

In this edition, we dive into the topic of  **Medical Transition** and share resources that will assist on your journey.

Scan and let us know what you think of this issue.



THE PATH FORWARD

The Six Core Areas of Transition



EDUCATION



MEDICAL TRANSITION
(from pediatric to adult medical care)



LIVING ARRANGEMENTS



SOCIALIZATION



LEGAL ISSUES & GUARDIANSHIP



RESOURCES



Scan here to learn more
about the six core areas of
transition and other services
on these topics.





What Happens When Your Child Turns 18?

JEANINE GERACI, SPECIAL NEEDS SERVICES COORDINATOR FOR PROTECTED TOMORROWS

Your loved-one has turned eighteen, congratulations, they're now a legal adult! For families with children with special needs this time in their young adults' lives can lend a sense of uncertainty. There are a lot of choices to be considered: transition programming, benefits applications, future care costs, and of course the decision of guardianship. In some cases, this can be called conservatorship and your attorney will guide you in guardianship/conservatorship processes. If you are not your child's guardian or conservator upon them turning 18, legally they can refuse treatment from a doctor or a hospital, even as their parent, you no longer have the legal right to make decisions or be informed of their care or treatment plans.

The question often asked is 'do I need to be my child's legal guardian?' this question is often met with the answer 'it depends'. The standard for which guardianship is determined varies from state to state. A person with a disability is judged to need guardianship when they show lack of capacity to make their own responsible decisions.

Guardianship is a legal process, used when a person with special needs can no longer make or communicate safe or sound personal and/or financial decisions for themselves. Because establishing a guardianship may remove considerable rights from this individual, including medical, financial, and lifestyle decisions including the right to have a driver's license, it requires a great deal of thought and careful consideration. Choosing a guardian for your loved one should not be made lightly, as the guardian will take on the very important role of caregiver for your loved one and/or their assets.

There are four different types of guardianship:

- **Guardianship of the Person** the guardian is responsible for the well-being and care of the protected person, this is limited to making decisions which affect the physicality of the person. This includes medical treatment decisions, decisions about where the person will live and decisions regarding school (transition age included 18-22 and beyond).
- **Guardianship of the Estate** the guardian is responsible for managing the estate of the individual. This includes managing money, assets, inheritance, or other monetary benefits.
- **Guardianship of both the Person and Estate** the guardian is responsible for all personal, medical, and financial decisions of the protected person.
- **Limited Guardianship of the Person, Estate or both** the guardian makes decisions with the person with special needs who has demonstrated a rational decision-making process. The guardian is granted power to make only those personal and/or financial decisions that the court specifies.

Alternative to Guardianship:

- **Supported Decision Making** the person with a disability makes their own decisions with the support from a team of people they choose. The people involved in the team are often called Identified Supporters. Their role is to field questions and review options to help the person with a disability make their own decisions.

The laws of each state dictate the process of obtaining guardianship. Generally, the individual seeking guardianship must complete the following steps:

- File a petition for guardianship of the individual, naming themselves or another qualified person.
- Arrange for personal service of the petition, the rights of the individual, and a summons on the individual. The summons is usually performed by the sheriff of the county the petition was filed in unless by private service (could be subject to court approval.) This process must be completed within a certain number of days before the hearing date.
- Provide notice by mail to the individual's nearest relatives and obtain a medical report from a licensed physician detailing the reason guardianship is necessary.
- If guardianship is determined to be necessary, the guardian becomes an officer of the court and is subject to supervision by the court.

There are professionals state to state that can assist you through the process. An attorney who is familiar with guardianship issues, special needs law and estate planning is always advised. In need of an attorney referral or assistance in determining if legal guardianship or conservatorship is the right choice? Contact Protected Tomorrows at 866.544.6333 or email us at info@protectedtomorrows.com.



Helpful Tools for Medical Transition Planning

ADAPTED FROM: THE CdLS FOUNDATION'S NAVIGATING HEALTHCARE TRANSITIONS

Identify All the Key Players

The best place to begin when creating a Medical Transition Plan is to identify all key players in a young adult's current medical team.

Find an Adult Provider

Successful Medical transitioning requires the identification of an adult healthcare model. Once the young adult and parent or caretaker select an adult provider(s) (usually with the help or guidance of the pediatrician), it is the pediatrician's responsibility to ensure proper communication of all medical needs to the receiving provider(s). This is a critical step in the transition process, as the adult healthcare personnel may be unfamiliar with any pediatric conditions.

- Ask current doctor for a referral
- Consider current adult providers used by family/friends
- Call insurance company
- Check with local support groups
- Call large medical and specialty rehab hospitals to ask for referral line
- Ask case manager for suggestions
- Ask adults who have similar health needs for recommendations
- Call a Family Service Coordinator at the CdLS Foundation for resources

Seek Support From Social Workers

Given that the healthcare transition from pediatric to adult healthcare has many moving

parts, having someone on your team with the knowledge and understanding of these "processes" may relieve some confusion and stress.

Social workers can be a valuable resource when it comes to transition planning. Social workers are knowledgeable about community resources and can make necessary referrals for support in the transition to adult healthcare.

Culture and Transition Planning

Culture involves several elements, including personal identification, language, thoughts, communications, actions, customs, beliefs, values, and institutions that are often specific to ethnic, racial, religious, geographic, or social groups. As a result, culture plays an important role in defining the values, beliefs, and practices surrounding when and how young adults transition into adulthood.

Some transition policies, practices, and services may assume that all young adults with disabilities or special healthcare needs value similar outcomes. It is important to incorporate cultural values in transitional planning because it will help create goals and objectives that are meaningful.



Medicaid Tips for Families

ADAPTED FROM: REDTREEHOUSE.ORG

Having a child with serious illness or disability can be overwhelming, and the costs of medical care can be extraordinary. Even families that have private health care insurance can find themselves financially ruined when the treatment their child needs is not adequately covered by their policy.

Fortunately for many children with special needs, Medicaid may provide coverage for items such as: hospital stays, doctor visits, or medications. Medicaid as a secondary insurance can cover cost sharing expenses that would fall to the family in the form of deductibles, co-pays, and co-insurance.

Medicaid is the single largest source of health insurance in the United States and currently covers about 73 million Americans. Medicaid provides health insurance to low-income and needy people, including children and adults with disabilities. Medicaid became law in 1965 along with Medicare (insurance primarily for individuals 65+ or who are disabled) and can be found in Title XIX of the Social Security Act.

Although Medicaid is a joint federal/state program, it is administered by the states. Therefore, who qualifies varies from state-to-state. Both financial and non-financial criteria are considered.

The Affordable Care Act (ACA) gave states the opportunity to expand Medicaid coverage to most low-income Americans under age 65. This Medicaid expansion program allowed states to cover people with income up to 138% of the federal poverty level (FPL) regardless of whether they have a disability or not. The federal poverty level is determined annually by the Department of Health and Human Services and FPL data by household/family size.

The Children's Health Insurance Program (CHIP) became law in 1997 under Title XXI

of the Social Security Act. Like Medicaid, it is a joint program between the federal and state governments. CHIP allows states to use federal matching funds to provide health coverage to children whose families have income too high to qualify for Medicaid, but who can't afford private insurance. This program is for children through age 18.

To apply for Medicaid, you must check with the agency that administers Medicaid in your state. Thirty-two states and the District of Columbia have begun automatically enrolling individuals in Medicaid once they have been approved by the Social Security Administration (SSA) for Supplemental Security Income (SSI).

Medicaid waivers allow states to use federal Medicaid funds to provide community-based services to people with disabilities who would need to be in a nursing home, hospital, or other residential setting without them.

Each state offers its own waiver programs which are not transferable state-to-state. Some state waivers are available for those whose income is too high for Medicaid. Some states have waivers that provide wrap around services for those with Medicaid to help them remain in the community.

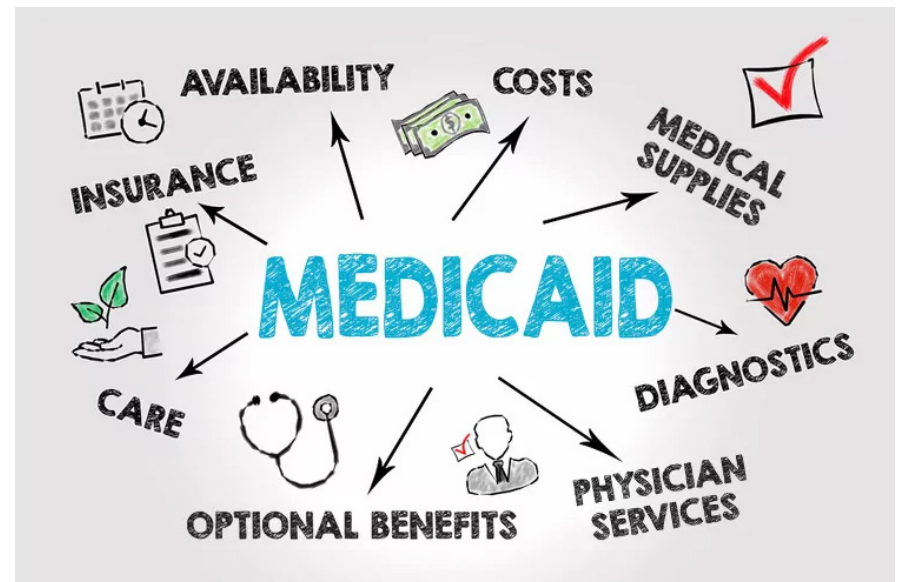
Medicaid is the only type of health insurance (public or private) to pay for long-term care. For families with children who have disabilities or serious chronic illness, this means that Medicaid is essential, even if the family has private health insurance.

People are sometimes surprised to learn that Medicaid does not cover everything. Although states are required to cover many services and procedures (mandatory benefits), other services and procedures are classified as optional. That means Medicaid in some states may cover them and others may not.

Some states have elected to provide Medicaid to children with severe disabilities regardless of their family income. Because rules for eligibility are different in each state, it is important for families to understand the rules in their own state.

Many people who have Medicaid also have private health insurance and/or Medicare. Many people who need long-term services and support, which are typically only covered by Medicaid, or who have extensive medical needs that are not adequately covered by other insurers require both. Medicaid is considered the “payer of last resort”. This means that for people who have Medicaid and either private health insurance or Medicare, Medicaid will pay only after those programs have paid as the primary insurance.

All Medicaid programs must follow minimum federal guidelines, the programs are managed by the states and do vary from state-to-state. Families with children who have special needs need to understand this because a move from one state to another can impact eligibility, coverage, and waiver status.



Scan the QR Code to learn more about **Medicaid Tips** for Individuals with CdLS.

4 Steps to Medical Transition

1 Talk to your child's pediatrician.

Ask when your child will need to move to a new primary care provider, and other expectations for the healthcare transition.



Note, if your child needs ongoing support in medical decision making, explore options for guardianship or conservatorship.

THIS SHOULD BE
DONE BETWEEN THE
AGES OF 12-14.

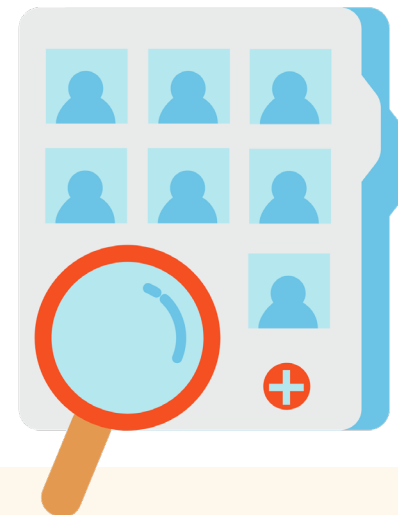


2 Develop a healthcare transition plan.

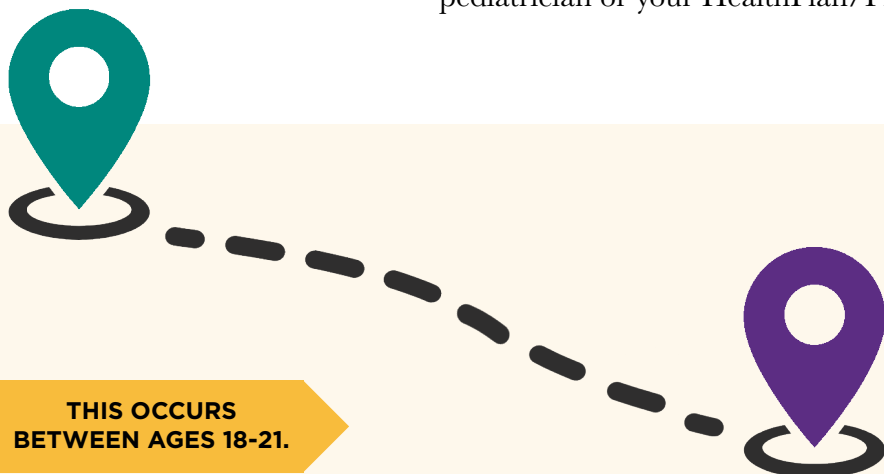
This written plan should be updated annually, showing your child's progress.

3 Locate an adult provider*.

Request recommendations from your pediatrician or your HealthPlan/Program.



*BE SURE THE
ADULT PROVIDER IS
IN YOUR NETWORK.



THIS OCCURS
BETWEEN AGES 18-21.

4 Coordinate a smooth transition.

This happens between pediatric and adult providers. Make sure the pediatrician transfers important medical records to the adult provider.

TRANSITIONS REQUIRE TIME, DISCUSSION AND PREPARATION. THE CdLS FOUNDATION FAMILY SERVICE TEAM CAN HELP YOU AND OFFER SUPPORT DURING THIS JOURNEY. PLEASE CALL 860.899.9391 IF YOU ARE IN NEED OF ASSISTANCE.

On *The Path Forward* Together

Welcome to our third edition of *The Path Forward*. We hope you have found the articles you have read so far informative.

The topic detailed in this issue is medical transition. Each story is unique and offers insight, as well as guidance of what worked and challenges encountered along the way.

Some questions parents/caregivers should think about are:

- Have I identified all the key players in the process?
- Have I begun to discuss the transition with my child?
- Is my child eligible for Supplemental Security Income (SSI)?
- Is my child receiving service coordination services (case management) through the Medicaid Waiver?
- Is my child involved in recreational/leisurely activities?
- Are medical needs being addressed? Have I identified transition barriers?

The CdLS Foundation is working on the *CdLS Care Notebook* which will be helpful in this process. Be on the look out in the near future.

In the next few pages, you will find some of this information in detail from individuals with CdLS who have already gone through their medical transition.

If you have thoughts or suggestions you would like to share on how we can best serve our rapidly growing adult population, please contact me at Outreach@CdLSusa.org.

Warmly,



Bonnie Royster

Executive Director

A last thought...

Here is a helpful medical transfer checklist:

- ☐ Transfer letter (including date of transfer to adult provider)
- ☐ Final transition readiness assessment
- ☐ Healthcare Transition Plan and Plan of Care (including transition goals and pending actions)
- ☐ Updated Portable Medical Summary*
- ☐ Guardianship or healthy proxy documents, if needed
- ☐ Medical records

*A Portable Medical Summary is written information about a patient's health history to help medical professionals quickly learn more about the patient.

WORD OF WISDOM: MEDICAL TRANSITION

Rachel Busch (Age 36)

MICHIGAN



I was around 18 years old when I started medically transitioning from a pediatric to an adult doctor. Both parents really helped me when I was going through this process. I currently see about 17 doctors. I thought it would be more of a difficult process with all the specialists I see, however I was surprised to have a simple transition. It was simple because I was able to move from the pediatric care to the adult care doctors in the same practice. I also think having the support of my parents really made me feel safe and secure during this big change in my life.

My advice is to remember to tell your new adult doctor you have pediatric organs because some of the adult equipment or treatments won't work.

There was a period where it was difficult to find a few different doctors. I had gone through several different specialists, GI, neurologist, OBGYN, because a few I met with did not work with patients with special needs and I knew it was important to feel comfortable with a doctor and have my needs met. It was a frustrating time.

When my needs weren't being met, I researched doctors in my area or got a referral from the doctors I liked. Very recently, back in January one of my doctors told me that my body was too difficult to work with and I had to find a new doctor and would not help me anymore. This is my body, and I can do whatever I want with it. I took it upon myself to find a new doctor. I found a new doctor who respects me for me and my medical decisions that I can make for myself.

I am happy that I was able to find a doctor who doesn't judge me for having CdLS and special needs and treats me the way I want to be treated. I hope this experience empowers other adults with CdLS to advocate for themselves when they feel like they are being mistreated.

Remember! No doctor can tell you what you can or cannot do with your body. If a doctor tells you that – find a new doctor immediately. Ask a doctor you trust for a referral.

“

I hope this experience empowers other adults with CdLS to advocate for themselves ...”

WORD OF WISDOM: MEDICAL TRANSITION

Fermina Lopez (Age 23)

OREGON



My transition to adult care has been a long process. In my early teens my doctors and I started discussing how it would look when I transitioned to adult care. During my teens, I had a primary care doctor and an OB/GYN. My doctors explained how health care would be provided as an adult. My primary doctor explained to me how to discuss my health care to an adult care provider. I was lucky because my primary care doctor knew

that it would be a challenging process transitioning into adult care, so she connected me with my OB/GYN that was also a primary care physician and was allowed to see young adults until the age of 21.

At 18 my primary doctor released me to my OB/GYN so I would still be seen by a pediatrician until 21. My OB/GYN explained how health care would change as an adult women and procedures that I might experience. One concern was that I wouldn't be able to see doctors that specialized in CdLS health care because there were not a lot of doctors in my area that knew about my CdLS conditions so my doctors explained how I should explain my condition and how to ask for special services.

I started transitioning to adult care around 21. Unfortunately, my transition to adult care was during the COVID pandemic so I was not able to see a doctor in-person which made the transition difficult. I really didn't get the care I needed and now I have relocated to a new state it has been very hard to find another doctor in my current location that understands CdLS. I am currently trying to get care for certain conditions and asking for help with special accommodations but because the local doctors are unfamiliar with CdLS and symptoms I feel they are ignoring my requests. In my new location I do not feel like I am getting the services I need from the adult care providers. When I try to explain my problems, the local doctors treat me as I am just complaining.

The adult care providers don't understand there are some issues that I have due to CdLS. Some of my medical conditions do not give me problems all the time but flare up sometimes and I need referrals to specialist but because the local doctors are not familiar with CdLS they say I look healthy and that all adults have health issues, and those adults don't need special care so I shouldn't need special care. If I could do



it all over, I would have prepared better by doing more research on adult care providers that have experience with CdLS. I also should have asked other adults that have CdLS how they found the right care. Dental care is another issue I have because as a teen I had a lot of dental work done but

I was seen by a pediatric dentist, so the office was more understanding when it came to dental care. My recommendation to anyone with CdLS that is thinking about transitioning to adult care is to start the discussion early with their current provider and explore all their options to find the right care.

Conversation with...

The CdLS Foundation Family Service Team

As our children grow into adulthood, we are faced with many transitions to navigate. One of the largest transitions is securing health care services with an adult rather than pediatric provider. As with all large transitions, planning and preparation help ensure success. Here's how to create a Healthcare Transition Plan.

When should I create a healthcare transition plan?



Start early! (Age 12)

View this transition is a process, not an event. Successful transition requires research, discussion, decision making and a period of adjustment. A good starting place is to ask your child's pediatrician at what age will they no longer be able to serve as your child's Primary Care Provider. The answer may depend on the provider's choice, credentialing or contractual requirements from a payer source or the organizational structure within a large practice or hospital-based clinics. Be sure to ask.

Make sure the right people are involved in creating your plan. A health care transition plan involves parents/guardians, a child's pediatric provider, important caretakers and the child impacted by this change. Preparation can begin when your child is about 12 years old with things like:

- Having your child's primary care provider allocate time during the office visit where they meet with your child without a parent/guardian present
- Helping your child learn the name of their primary care provider
- Helping your child ask or answer questions (start with one question!) during a doctor's visit
- Helping your child learn to identify their medical conditions and concerns
- Helping your child learn the names of the medications they take and any allergies they have

Transition Readiness (Ages 14-18)

Together with your "team," regularly assess your child's readiness to transition to an adult provider. Several formal Transition Readiness Assessments exist. Your child's pediatric provider may use one of them. If your child's provider does not use a standard Transition Readiness Assessment, you may want to share these with them and review it together.

- bit.ly/CdLSassessment
- bit.ly/CdLSassessment2

Assessing readiness includes figuring out which parts of their health care your child can manage independently, which parts of managing their health care they are willing and able to learn to take on themselves and which parts, of managing their own health care, if any, will require ongoing assistance.

This includes things like managing medications, tracking health issues, contacting providers when needed and speaking with health care providers during an appointment. Together with your team, regularly update your Transition Readiness Plan. Prioritize items your child shows the most interest in developing independence.

Practice skills with your child prior to a doctor's appointment. One technique you can use is helping your child form a 3-sentence summary explaining what is important to address during this appointment. The 3-sentence summary can be something like this:

- Sentence 1: My age, my diagnosis
- Sentence 2: My current treatment plan
- Sentence 3: My question/concern to talk about during this visit

Finding an Adult Provider

Your child's pediatric provider may be able to refer you to an adult clinician with whom they are familiar. Be sure to check with your Health Insurance Health Plan/Program to be sure the adult provider participates in your Health Plan. Your Health Plan is also a resource for finding an appropriate adult provider. Check your Health Plan's provider



directory or contact them to ask for assistance finding a local provider accepting new patients.

If contacting Customer/Member Services at your Health Plan does not lead to a satisfactory result, ask to speak with a clinician, such as a Nurse Care Manager for additional assistance. When an adult provider is located, ask the adult practice to share any welcome and orientation materials they may have. These may also be available on the provider's website.

Transition to an Adult Provider (Ages 18-21)

Typically transfer to an adult centered provider occurs between the ages of 18-21. Your child's pediatric provider should transfer important information to the new provider. This should include things like:

- A Transfer letter that includes the date of transfer
- A final Transition Readiness Assessment
- Plan of care including any pending actions
- Any needed provider records such as test and laboratory results or consults received from specialists
- Updated medical summary and emergency care plan

Keep in mind worrying about leaving a provider who you have worked with for years is normal. This is especially true where complex medical issues, behavioral health conditions and other disabilities are present. Allow yourself adequate time and resources to plan and adjust to this transition.

Ask if your child can see a new doctor for a trial period. Then, follow up with the pediatric specialist to let them know how things went. Plan the transition with both doctors. Allow time for this process. That way, if there is an issue with the new provider, your child can continue seeing the pediatric provider until you find an adult provider who is a better fit.

We can also help you find local medical and behavioral health care and community resources. When you speak with us, we may ask you questions about your family and social supports. We do this to help you find resources that may be helpful to your or your family. We can also connect you with other CdLS families and help you advocate to obtain the care and services the person with CdLS in your life requires. You can reach us Monday – Friday from 8:30 am to 5:00 pm EST at 1.800.753.2357 and select option 1 for family service or via email at FamilyServicesTeam@CdLSusa.org. We look forward to working with you!



word search

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- Social Security Income
- Awareness
- Medicaid
- Happy
- Hope
- Family Service
- Community
- Support
- CdLS
- Adult
- Path Forward
- Medicare
- Syndrome
- Rare
- Cornelia de Lange
- Transition
- Strong
- Help

The Funnies

SOMETHING TO MAKE YOU SMILE.

