



TRANSITION GUIDE

The transition to adulthood is a unique journey for every 8p hero. This guide offers the essential tools, resources, and community connections needed to help caregivers and providers navigate this change with confidence. From healthcare structure to peer-to-peer support, Project 8p is here to ensure no family walks this path alone.





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Introduction

The Project 8p Foundation Adult Transition Guide serves to support caregivers and healthcare providers as they help their 8p hero transition into adulthood. Transition into adulthood requires thoughtful planning, informed decision making and access to tailored resources. This guide addresses many areas of life that may be impacted by transitioning into adulthood and will serve as a resource that you can revisit at any time. This guide will also provide structure for conversations with healthcare providers and forms to fill out as you make progress in your transition journey.

In addition to our Transition Guide, we encourage you to seek support from other community members. Many families in the 8p community have made the transition into adulthood and are willing to help other families as they do so too. Some hospital social workers can also help connect you with resources helpful for the adult transition. We encourage you to ask 8p community members, teachers and medical professionals for additional support during your transition.

This guide is tailored to services and programs available in the United States. While some information will not apply in every country, other information can be useful regardless of location.

It is important to remember every 8p hero is different and aspects of the transition will be different for everyone. The Project 8p Foundation is here to support you as you navigate this transition. Please reach out to engagement@project8p.org if you need assistance or have questions about the information in this guide.

School Transition

IEP Transition Plan

Adding a transition plan to your hero's IEP is an important step in the transition process. A transition guide helps create specific and attainable goals for your hero to work on leading up to graduation from high school. Transition plans can be started as early as middle school but should be started no later than when the hero turns 14.

When working on the transition plan, your hero should always be included in the process. The transition guide should be made to reflect their interests and skills they can build before graduation to help them become more successful in adulthood. The transition plan sets goals for after graduation, such as living in the community, attending postsecondary education or a community day program. You can ask questions about what programs are available for your hero in the community. Outlining these long term goals can help refine the educational plan while still in high school, for example, if the goal is to attend a day program, the hero could work on daily living skills, like getting ready independently for the program. If a hero's goal is to get supported employment, they can set goals for how to communicate effectively with team members or how to navigate public transportation. Some students may need significant support in the community, and this can be discussed during the transition planning.

Transition guides are a legally required part of an IEP. However, the family may also decide to have a person centered planning meeting. Since these are not legally required, they can be a more casual and informal plan for goal setting. These meetings can include similar discussions as an IEP meeting as they aim to address questions about the student's future but the meetings are welcome to family members and community members who may have more information about community support. This meeting will help address preferences for future community involvement, address future medical needs and help the student brainstorm future preferences. This meeting can primarily focus on community involvement options after the student graduates high school.



You can learn more about transition plans and person centered planning meetings here:

<https://www.understood.org/en/articles/iep-transition-planning-preparing-for-young-adulthood>

<https://acl.gov/programs/consumer-control/person-centered-planning>

<https://www.perkins.org/resource/the-power-of-person-centered-planning/>

Community Based Activities

Under the Individuals with Disabilities Education Act, people with disabilities have access to free public education and supports until the age of 22. After 22, they are no longer entitled to support and need to consider involvement in adult activities and supports. The IEP transition document will no longer be in place but should have prepared you for this change.

As covered in the medicaid section, you can choose to apply for the Home & Community Based Services (HCBS) waiver which will grant you access to day programs and community support options. Even if you are on the waiting list for the HCBS waiver, you can still look for other opportunities for your hero; some states have additional medicaid waivers that cover other community involvement opportunities.

Employment

The Ticket to Work program was developed to help people receiving social security benefits find meaningful employment. Ticket to Work will give adults with disabilities access to career coaching, benefits counseling and assistance with the job search. To get started with Ticket to Work, you can call 1-866-968-7842 to verify eligibility and begin the application process.

Each state has a State Vocational Agency and many have a local Center for Independent living to help connect adults with disabilities to resources in the community.



You can also find more information about job opportunities and job hunting for adults with disabilities here:

<https://www.usa.gov/disability-jobs-training>

<https://www.understood.org/en/articles/how-to-help-your-young-adult-hero-with-the-job-hunting-process>

<https://Idaamerica.org/info/get-your-hero-ready-for-work/>

<https://Idaamerica.org/job-resources-by-state-for-adults-with-learning-disabilities/>

Housing Options

As your 8p hero grows, it is important to consider their housing options. There are many choices from living at home to residential living. What works best will be unique to your hero and their strengths. This can be a difficult decision to make and preplanning can help alleviate some stress.

Housing Choice Voucher

The Housing Choice Voucher, also known as Section 8 housing, provides housing assistance to low income individuals, people with disabilities and the elderly. Eligibility for the program varies based on family income. You can apply for a voucher through your local Public Housing Agency. Many states have a waiting list for Section 8 housing so it is important to apply early. Once you have been accepted and received a voucher, you will be responsible for finding a unit to rent. In most cases, the rent will be 30-40% of the resident's income but this can vary depending on which unit you rent.



You can learn more about section 8 housing here:

<https://www.hud.gov/helping-americans/housing-choice-vouchers-tenants>

Section 8 housing is a great choice if your 8p hero is ready to live independently while working or receiving SSI.

Group Homes

A group home is a great option for adults with disabilities who want to live in a home environment away from family but cannot live independently. Group homes can provide support with daily living tasks, like personal care, cooking, transportation and some even offer medication management. Some group homes are covered by federal medicaid but some states offer additional waivers to cover the cost of group homes. It is important to consider that each group home is different and it may take time to find one that is best suited for your hero. When looking for group homes you can ask questions like:

- What is the skill/training level of support staff in the home? Do you regularly go on outings outside of the home?
- How many people live in the home?
- What level of medical care can you provide?
- How can my hero contact family?
- How long is the waiting list and how do I join?

Assisted Living Facilities

Assisted living facilities are geared towards adults with disabilities with complex medical needs who need more specialized care. These facilities provide 24/7 support for residents. Many assisted living facilities have recreational activities for residents to participate in throughout the day and allow families to visit when they wish.



It can be difficult to decide which housing option is the best for your hero. These resources provide a more comprehensive overview of available options:

<https://www.egglestonservices.org/blog/how-to-choose-the-right-group-home-for-adults-with-disabilities/>

<https://www.specialneedsalliance.org/blog/a-place-of-her-own/>

Living at Home

For some families of 8p heroes, living at home may be the best fit. 8p heroes can still be connected to resources and the community when living at home. Caregivers should look for day programs and supported employment or volunteer opportunities. Families can also look for in-home support covered by medicaid.

Medicaid and Medicare

Health Insurance Considerations

Most private insurance companies will stop child coverage at age 26. However, some carriers have exceptions to this rule if your hero has a disability and will extend coverage past age 26. Filing for an extension requires preplanning before your hero turns 26. Companies who offer extended coverage will have different criteria your hero must meet and will require medical documentation of your hero's disability. If your employer will not continue coverage after 26 or if your hero does not meet the company's requirements, you should consider enrollment in medicaid. Even if the private insurance company will provide indefinite coverage, you may still be eligible for medicaid enrollment to use as a second insurance. If you meet the requirements for medicaid, you can apply for it at any time. You do not have to wait until the adult transition process starts to apply for medicaid.

What is Medicaid?

Medicaid is a program that provides healthcare coverage to low income families, children, seniors and people with disabilities. Medicaid can be used as the main health insurance plan or can be dual coverage for people already enrolled in private healthcare which can help cover costs not paid for by the primary insurance. The program is funded by both federal and state governments and coverage, eligibility and administrative processes vary by state.

What Does Medicaid Cover?

Medicaid is required to cover many procedures including therapies, hospital stays and doctors visits. All states are required to cover mandatory benefits but some states may elect to offer additional benefits, such as covering costs for longer hospital stays. In some states, medicaid also offers the Home & Community Based Services (HCBS) waiver which provides in-home or in community coverage, supported living homes, supported employment opportunities and transportation. to medicaid recipients. With proper documentation, your hero may be eligible for long term in home healthcare, day programs, or day rehabilitation programs with the HCBS waiver.

How do I enroll my hero?

Enrollment processes will vary by state. You can choose to apply directly to your state's medicaid office or you can start by applying for federal insurance. Once you qualify for medicaid after completing the federal application, your information will be passed along to your state's office who will contact you with further instructions for enrollment. Once you have completed all of the enrollment requirements, you will begin receiving medicaid coverage. If your hero was receiving medicaid prior to turning 18, they may need to transition into adult coverage with a new application.

It is important to note that additional medicaid services like the HCBS waiver require an additional application once qualified for medicaid coverage. Additional services provided by waivers may have longer waiting periods before you can be admitted and start receiving services covered by the waiver. You should apply for HCBS as soon as possible to ensure faster acceptance into the program.



More information on medicaid coverage and basic information about medicaid can be found online at:

<http://www.medicaid.gov>

<https://www.macpac.gov/>



<https://www.usa.gov/medicaid-chip-insurance>
<https://www.youtube.com/watch?v=OIHoGUQCAzM>
<https://www.partnersbhm.org/1915i-services/>

Check your state's medicaid office website for additional resources.

Transitioning to Medicare

Your hero will receive benefits through Supplemental Security Income (SSI) and medicaid as long as they remain eligible. However, benefits may shift when one parent retires and starts receiving Social Security payments.

If you are applying for Social Security for retirement, your adult disabled hero will be eligible for the Disabled Adult Child (DAC), also known as Social Security Disability Insurance (SSDI). Under this provision, the adult hero will receive a payment that is equal to half of their parent's social security, which is usually larger than their SSI payment. This counts as unearned income under SSI and will disqualify them from the SSI program but they will remain eligible for DAC. Federal law ensures that even if the adult hero makes the switch from SSI to DAC, they will remain eligible for medicaid but a new application to the state office may be required. When the parent is applying for social security, they must specify that they have an adult disabled child in order for the hero to start receiving DAC.

Once your adult hero has been receiving DAC benefits for a 24 month period, they will become eligible for medicare. Medicare is insurance from the government that is available to adults 65 years and older, some disabled adults and people with some specified health conditions. Medicare is split into two main parts, Part A, which is hospital insurance that most people don't pay for and Part B which is medical insurance that you have to pay for monthly. The amount you pay for Part B depends on which plan you select and on your monthly income. After 24 months of receiving DAC, your hero can apply for medicare. If they maintain medicaid eligibility, they can have medicare as primary insurance coverage and medicaid as a secondary which will cover costs medicare does not.



You can learn more about medicare and how to apply here:

<https://www.usa.gov/medicare>
<https://www.ssa.gov/disabilityresearch/wi/medicare.htm>



You can learn more about medicare and how to apply here:

<https://www.fletchertilton.com/continued-eligibility-for-medicaid-for-a-disabled-adult-hero-when-a-parent-retires-or-dies/>

https://asaga.info/wp-content/uploads/2017/01/SSA-for-Guardianship-Conference-PDF.pdf?utm_

Legal

Transitioning into adulthood has many legal implications that require careful review. For some matters, individual review of your state's laws can be enough. However, it is important to consult a lawyer if you have any questions or need help filing paperwork. Lawyer and legal fees can be expensive. Plan ahead and start saving as soon as possible to make the transition more comfortable.

This guide serves as a reference but is not legal advice.

Health Care

Health Insurance Portability and Accountability Act

Under the Health Insurance Portability and Accountability Act (HIPAA), healthcare providers cannot share health records or information to anyone other than the patient unless there is written authorization in place. This means that once your hero turns 18, you will not be able to access their health information unless you are a designated proxy or guardian.

Health Care Proxy

A health care proxy is a trusted person you select to make medical decisions for you if you are unable to do so yourself. Once you select a healthcare proxy, you can sign a legal document called an advance directive that will legally appoint them to make decisions if you are unable to. This process can be completed without an attorney.



You can find the paperwork for an advance directive here:

<https://www.caringinfo.org/planning/advance-directives/by-state/>

A healthcare proxy is a good option if the 8p hero can make medical decisions for themselves but wants to have someone appointed in case they can't.

Decision Making

A person regardless of disability should keep as many rights as possible as they transition into adulthood. This means they should maintain as much control as possible over decision making. Each 8p Hero will need a different amount of support in decision making. When determining the amount they need, ask yourself:

- What type of decisions do they need help making?
- How much help do they need?
- Who will provide support?

Each answer will be different depending on the hero. There are various options to assist with decision making from supported decision making to full guardianship. Not all options require a judge or court ruling but many will require legal expertise, so it is important to consult a lawyer when needed.

Supported Decision Making

Supported Decision Making is a newer alternative to full legal guardianship. In Supported Decision Making, the adult with a disability maintains full autonomy over important decisions around healthcare, finances, etc. with help from a chosen supporter. The supporter will help guide and assist the adult with decision making but does not make choices for them. In some states, supporters of the person with a disability sign a support plan but the requirements vary by state.



You can find more information here:

<https://supporteddecisions.org/about-supported-decision-making/>

Durable Power of Attorney

A power of attorney is someone you choose to make decisions on your behalf. This legal document can give decision making power to a trusted adult and can give them authority over decision making in one area, like finances, or in many areas, like finances and medical decisions. The durable power of attorney ensures the person appointed to make decisions can make them even if the person becomes incapacitated. You do not need to go to court to file a durable power of attorney.



You can fill out durable power of attorney paperwork here:

https://legaltemplates.net/form/lt/power-of-attorney-forms/?utm_source=google&utm_medium=cpc&utm_campaign=%7B16-Power%20of%20Attorney%7D&utm_term=durable%20power%20of%20attorney%20form&utm_campaign_id=21242175059&utm_adgroup=%7BPower%20of%20Attorney%7D&utm_adgroup_id=165294763081&utm_content=697965167416&device=c&gad_source=1&gad_campaignid=21242175059&gbraid=0AAAAADmNoOSgTMu5UuKnY7LHwsY22gNTj&gclid=Cj0KCQiAlczLBhDhARIsAIEc7uhkfq9-zJm6JcvfMLQY5KKocZWpiuxpETwnvON9PXWwuIhnuZ6iTQQaAvcxEALw_wcB

A durable power of attorney is a good choice for a hero who can make some decisions in one area but not in another.

Conservatorship

A conservatorship gives an appointed adult control over someone else's finances who cannot manage them by themselves. The appointed person has the power to make decisions regarding savings, budgeting, spending, taxes etc. Conservatorship requires a court date.

Conservatorship is a good option for an 8p hero who can make personal choices but cannot make financial decisions independently.

Guardianship

Some 8p heroes will require more support and will be unable to make any important decisions for themselves, including financial, medical and personal decisions. In these cases, the parents need to apply for full guardianship. Guardianship is a legal process that occurs in Probate Court and once approved grants full decision making responsibilities to a designated guardian. Guardianship can be transferred to another person through a petition to the court. There are two main types of guardianship:

Limited guardianship: The guardian can only make decisions in specific areas as designated by the court. This allows the person with a disability to maintain ownership over decision making in specified areas.

Plenary guardianship: If the court finds that an individual is not capable of making any decisions independently, they will grant full guardianship. Under full guardianship, the guardian takes over all decision making.

Once guardianship paperwork is filed and approved, it may need annual review and resubmission. Talk to your lawyer and review state requirements to make a plan for future filings.



You can find more information about guardianship here:

<https://www.justice.gov/elderjustice/guardianship-key-concepts-and-resources>

https://www.americanbar.org/groups/senior_lawyers/resources/voice-of-experience/2010-2022/understanding-guardianship/

If you are not sure which decision making plan is right for you, the below can assist in your planning:

<https://www.specialneedsalliance.org/the-voice/sometimes-less-is-more-alternatives-to-plenary-guardianship/>

<https://eji.courtims.org/catalog>

Important note: some states use conservatorship and guardianship interchangeably, so in some states there may not be two distinct choices. It is important to check your state's laws when deciding what legal process is best for your family.

ID Card

Your hero will need a state issued ID card. This is not a drivers license but rather a form of identification for adults. The federal government now requires a Real ID to travel and for some legal processes. To obtain a Real ID card you will need to present your hero's birth certificate or a valid passport or an official document with complete name and social security number. They will also need to provide two documents with proof of address. You can take these documents to your local motor vehicle department. It is important to make sure your hero obtains this when they turn 18.

Selective Service

If your hero is a male over the age of 18, they must legally enroll in the selective service, also known as the Draft. Just because they are registered does not mean they will be called or be eligible to serve in the military.



You can register here: <https://www.sss.gov/register/>

Voter Registration

If you do not have full guardianship of your hero and they can make decisions independently, they are eligible to vote.



They can register here:

<https://www.eac.gov/voters/register-and-vote-in-your-state>

Financial Considerations

There are many financial considerations to make when planning for the future. It may be helpful to work with a financial advisor as you work through the financial transition aspects.

Supplemental Security Income

What is Supplemental Security Income and what does it cover?

Supplemental Security Income (SSI) is government assistance provided to low income adults and children, adults 65 and older and people with disabilities. SSI provides a monthly payment to support the cost of living for recipients.

Eligibility & Enrollment

An application for SSI can be submitted at any time. However, if your hero is already receiving SSI before age 18, they may need to fill out a new application on their 18th birthday, depending on state regulations. Regardless of individual state policies, a new medical review must be conducted when the recipient turns 18 and you will be asked to provide updated medical records and information.



You can begin your application online:

<https://www.ssa.gov/ssi/eligibility>

After submitting the application, it must be reviewed by state offices. It may take up to 6 months to begin receiving payments, although some payments are processed immediately depending on your hero's condition. When you are applying, you will be asked to provide original documents. Make sure to make copies of these documents before submitting them.

Other Important Considerations

The amount of SSI benefits your hero receives will depend on their living conditions. Benefits will vary if the recipient lives at home with family and their rent and living expenses are paid entirely by family, if they are in a hospital or nursing home that is paid for by medicaid or if they live independently but living costs are paid for by someone else. Benefits will also fluctuate if the recipient has a job, and will change depending on the amount of earned income.

To get the maximum SSI payment, you may need to charge your hero for rent and living expenses. You can think of this in two ways:

Fair share: SSI will require you to document all household expenses, like rent, electricity, groceries, gas and property taxes. You will divide this amount by the number of household members. If the amount is below the SSI payment and the recipient can pay their share, they will receive the full SSI payment. If the household payment amount exceeds SSI, the benefits will be reduced by $\frac{1}{3}$.

In kind: You may choose to list your hero as a tenant. You will be required to charge them rent at a rate that is consistent for what one room would cost to be rented in your neighborhood. In this arrangement, the SSI recipient would be responsible for paying their other living expenses like groceries. The recipient would receive full benefits if their housing cost does not exceed their SSI benefits.

Regardless of which way you decide to charge the recipient for living expenses, it is important to note that there are restrictions on the amount of assets in the recipient's name. Generally, the SSI recipient cannot have their total assets exceed \$2000 at any time while receiving benefits.

The SSI requires that all income is reported monthly.



You can find more information using the following links:

<https://www.ssa.gov/ssi/eligibility>

<https://www.ssa.gov/ssi/text-income-ussi.htm>

<https://www.ssa.gov/pubs/EN-05-10026.pdf>

<https://farley1.com/maximizing-ssi-by-charging-rent-to-your-disabled-hero.html>

Supplemental Nutrition Assistance Program

The Supplemental Nutrition Assistance Program (formerly known as food stamps) is a program that will help pay for groceries, and is available to low income individuals or people with disabilities. Application processes vary by state but after submitting an application, you will be asked to provide copies of supporting documentation and complete an interview. SNAP may take up to one month to be approved after which you will start receiving benefits. The amount of benefits varies depending on the number of people in the household and amount of household income. Recipients are sent an electronic benefits transfer card (EBT card) that will automatically be loaded each month. EBT cards can be used as debit cards to pay for groceries, however, some restrictions exist.



For more information you can visit the following web pages:

<https://www.fns.usda.gov/snap/recipient/eligibility>

<https://www.fns.usda.gov/snap/state-directory>

Special Needs Trusts

A Special Needs Trust is a type of trust that can be set up if you want to provide support to your hero with a disability without jeopardizing their access to government support programs like medicaid and SSI. With a special needs trust, you can give your hero assets like money or property and still ensure they won't lose access to their benefits.

There are two different types of special needs trusts:

First party trust: If the hero with a disability receives money, property or stocks, as part of inheritance or settlements, they will need to move it into a special needs trust. By moving their assets into a trust, they ensure access to benefits. However, after the hero passes away, the government will use remaining assets to pay back medicaid.

Third party trust: Parents and other family members can put assets into the trust for the hero with a disability to use. These provisions should be used to enhance the quality of life for the hero and do not require medicaid payback.

It is important to note that your hero should never be listed as the beneficiary in a trust. To avoid the risk of losing benefits, the special needs trust should always be listed as the beneficiary. When creating the special needs trust, you will have to name a trustee who will help your beneficiaries manage the trust.

Creating a special needs trust can be a complicated process. It is best to consult an attorney to ensure the proper creation and completion of the trust, but you can learn more about the trust using the following links:



<https://www.actec.org/resource-center/video/understanding-special-needs-trusts/>

<https://www.fidelity.com/learning-center/life-events/what-is-special-needs-trust>

<https://www.youtube.com/watch?v=JtVo4tKXYC8>

Achieving a Better Life Account

The Achieving a Better Life (ABLE) Act established a way for people with disabilities to save their own assets without losing access to public programs. Under the ABLE act, people with disabilities can set up a tax free savings account.



The amount that can be saved varies by state. To set up an ABLE account, check your state regulations. For more information, you can visit:

<https://www.ablenow.com/learn/basics/>

<https://www.ablenrc.org/what-is-able/what-are-able-accounts/>

Puberty

A big part of transitioning into adulthood is the beginning of puberty, a time where adolescents experience social, emotional and physical changes caused by fluctuations in hormones. Like all adolescents, 8p heroes will go through puberty, though timing for children with disabilities can be slightly different from their peers. It is important to start discussions about puberty before it begins with your child. These conversations should be approached with sensitivity and with age appropriate language. We encourage you to seek support from healthcare providers or counselors if needed.

Puberty is different for every family. Project 8p has a community of caregivers who have helped their 8p hero navigate puberty. If you would like to be connected to a family support, please email engagement@project8p.org

This section briefly covers navigating puberty with your 8p Hero. For additional resources, we encourage you to explore our [Patient Navigator](#) and resources at the end of this section.

How to Navigate Puberty with Your 8p Hero

Puberty can be confusing for your 8p hero and your family. As a caregiver, you can help your hero learn so they are prepared for when changes start to occur. Here are some areas to focus on when preparing your hero for changes:

- Use clear language. Use anatomically correct names to avoid confusion. You can use whatever communication style is best for your 8p hero, including visual aids or repetition.
- Discuss changes. It is important to clearly discuss all aspects of life that may be changing. You should include physical body changes, emotional and mood changes and how they might experience differences socially.
- Discuss private and public places and behaviors. You can teach your hero about private spaces, such as the shower or bedroom. Then you can help your hero understand what behaviors are safe for public areas and behaviors that should be reserved for private places.
- Encourage good hygiene. Help your hero make a hygiene plan for the day. This can include showering, changing clothes, brushing hair and teeth, and wearing deodorant. Help them maintain a clear schedule to reduce poor hygiene habits. Females will need information about menstruation products, including how and when to use them.

- Encourage independence and social interactions. Help your hero get involved in school or community activities to build new friendships and social skills. You can also teach them about safe communication online. Help your hero understand what healthy relationships look like and help them practice healthy boundaries.



For more information about puberty and development for children with disabilities, please review the resources below:

<https://vkc.vumc.org/HealthyBodies/girls.html>

<https://vkc.vumc.org/HealthyBodies/boys.html>

<https://www.uwhealth.org/news/puberty-teens-special-needs>

<https://www.michiganmedicine.org/health-lab/preparing-puberty-girls-disabilities>

<https://amaze.org/what-is-amaze/>

https://teenpregnancy.acf.hhs.gov/sites/default/files/resource-files/IDD_Adolescent_Dev_Snapshot.pdf

Healthcare Transition

Family Healthcare Transition Planning

There are many considerations to make when transitioning healthcare. Below are important healthcare considerations to begin working through before your hero turns 18.

Questions to Ask BEFORE Transferring Care

Begin integrating these questions into your hero's appointments as early as 12 years old.

Transition Planning Process

- Can we schedule a transition planning visit specifically to review next steps?
- Can I work with you to prepare a medical summary and emergency plan for my hero?
- What have other families in similar situations struggled with during this transition?
- Are there any red flags or warning signs I should watch for once we transition to new providers?

Medical Records, Privacy and Consent

- Before my hero turns 18, what information about privacy, consent and access to Electronic Health Records (EHR) do we need to learn about and what actions need to be taken?
- Will you send my hero's medical summary to the new adult doctors and may I also have a copy?
- Who should new providers contact if they need clarification on our hero's history?
- Do you have any suggestions for adult doctors for my hero to transfer to who have experience in 8p syndrome or similar neurogenetic conditions? Neurology? Physical/occupational/speech therapy? GI/Nutrition? Psychiatric/behavioral health?

Medical Continuity During Transition

- If you, as the pediatric provider, continue to see my hero after age but our insurance changes, will we still be able to see you?

- Before the initial visit can be made to the adult doctor, will you still refill their medications and treat them for acute care needs?
- Will you be available for questions after we have transitioned out of your care? If so, how do we contact you?

Medications, Devices and Authorizations

- Will any of our hero's medications or medical devices require new authorizations in adult care?
- Are there any medications or treatments that adult providers may be unfamiliar with?
- What Durable Medical Equipment (DME) support will need to be renewed or transferred?

Insurance, Financial and Support Services

- Do you know if our state offers transition case management or care coordination services for adults with disabilities?
- Can you connect us with a hospital social worker to help with adult medicaid, waiver programs or SSI planning?
- Are there any parent networks or support groups you recommend for transition age families?

Emergency and Hospital Care Planning

- Can we discuss a planned hospital admission versus an emergency situation during the transition at specific ages (18, 21, 22+)? Where do we go and who do we call?

Questions After Transferring Care

Questions to Ask When Selecting New Providers

- Have you ever worked with individuals with 8p syndrome or similar neurogenetic or developmental disabilities before?
- Do you accept Medicaid and/or our private insurance? Are there services you commonly provide that are not covered by our insurance?
- How do you handle communication - do you offer email, patient portals, or phone calls for non-urgent questions?
- What hospital or health systems are you affiliated with in case of emergency inpatient needs?
- Do you offer longer appointment times for patients with complex medical or communication needs?

- Will you help coordinate referrals to adult neurologists, GI specialists or others as needed?
- Is there a social worker, case manager or care coordinator in your office or network who can support patients with disabilities?
- How do you prefer to receive outside care summaries (from pediatric providers, therapists etc.)?

When Scheduling New Appointments

- Ensure all paperwork is completed prior to your appointment.
- Request the first appointment of the day or right after lunch as these times doctors are less likely to run behind, thus decreasing wait time.
- Suggest things that will help regulate your hero like removing white coats.
- Request one room to have all activities done if possible (i.e intake, scheduling appointments etc.)
- Request additional time to allow transfers from wheelchairs, removing braces, etc.

Before Your First Visit with a New Provider

- Ensure receipt of the transfer package including Provider guide, Provider Master List, Medical Summary, Goals of Care, Emergency Plans, About Me and Legal Documents.
- Ensure receipt of any clinical records shared.
- Share the 8p Patient Passport, particularly for providers less familiar with 8p.
- Write down a list of questions and concerns you have before seeing your new doctor.
- Keep your hero's health insurance card with you always.
- Keep copies of your legal caregiver documentation with you at all appointments.

Questions to Ask at First New Provider Appointments

- Have you had a chance to review our Passport and Transition of Care Toolkit?
- Are you familiar with our current medications or treatment protocols? (i.e seizure medications, sleep aids etc.)?
- Will you continue to prescribe the same medications if they are effective or do you follow a different prescribing approach?
- Can you help coordinate or re-establish PT/OT/ST services if needed?

- What is the best way to schedule routine and urgent appointments?
- Can you help us connect with local or regional services for adult with disabilities (i.e day programs, respite or residential facilities)?

Children's Hospital Colorado Multidisciplinary Clinic

Project 8p's partnership with Children's Hospital Colorado (CHCO) is a great resource for 8p heroes of all ages. The multidisciplinary clinic is designed to support patients with rare diseases of all ages. At CHCO, you will see different specialists who will help draft a care plan that you can share with your providers at home. Providers at CHCO also offer provider to provider support and can offer guidance to your local healthcare providers. Please email engagement@project8p.org if you want to connect your providers.



You can find more information about clinic scheduling, providers and insurances accepted on our website:

<https://project8p.org/step-3-multidisciplinary-neurogenetic-clinic/>

Provider Guide

How to Use this Toolkit for 8p Heroes

Thank you for your commitment to supporting individuals with 8p disorders. Your willingness to learn, listen and provide compassionate care makes a profound difference in the lives of your patients and their families.

If a caregiver has shared the Project 8p Transition Care Toolkit with you, it likely means you're working with someone who is not only deeply invested in their 8p hero's wellbeing but also eager to partner with you. Caregivers of 8p heroes often serve as the primary coordinators of care, advocates, historians and communicators for their hero. By choosing to engage with this resource, you're taking an important step in building a collaborative, person-centered care plan- one that honors the caregiver's knowledge and the patient's unique needs.

The transition of care from pediatric to adult-based healthcare is a critical phase for 8p heroes, their families, caregivers and providers. The Provider Guide is designed to support healthcare providers in how to use the toolkit effectively to ensure a smooth, informed, and well coordinated transition. The toolkit effectively centralizes essential information and serves as a resource to streamline communication.

Purpose and Scope

This toolkit is designed to be a comprehensive resource managed by the caregiver with the support of their providers. It has been created to help guide both parties through the complexities of transitioning from pediatric to adult care by centralizing crucial data including:

- An extensive review of the patient's medical history including all diagnoses, medications, allergies and past surgeries or procedures
- Emergency care plans
- Past and current provider details

How Providers Should Use the Toolkit

Before Transition

- Use the toolkit to review important patient information and specific needs related to the care of the patient.

- Engage in family and caregiver education. As a provider, it is essential to ensure the family, caregivers, and the patient (as much as possible) are involved in the transition process. The toolkit includes sections designed to help caregivers understand what to expect during the transition, how to manage ongoing care, and when to reach out for specialized help.

During Transition

- Pediatric providers use this toolkit as a prompt to help caregivers create a centralized document to pass medical information to the adult care team. It should be shared by caregivers with their loved one's new adult providers to help them understand the patient's unique needs and ongoing treatments or therapies which need to be continued and/or adjusted.
- Help caregivers keep care plans updated and reflective of adult-specific needs by reviewing and documenting necessary information (i.e medication adjustments, changes in care protocols, or a specialized approach to symptom management in adults with 8p disorders).

After Transition

- Attempt to maintain clear and open channels of communication between the pediatric and adult care teams. The toolkit is designed to help maintain continuity of care and facilitate ongoing discussions about the patient's evolving needs.
- Prompt caregivers to update the toolkit with changes in the patient's medical condition. New treatments or emerging symptoms in order to maintain a current record that both pediatric and adult teams can rely on as the patient's care evolves.

Successful transition requires collaboration among a team of healthcare providers. Providers should encourage dialogue amongst all involved aiming to address all aspects of the patient's healthcare, The toolkit is not a standalone solution, but a collaborative tool that should be used in conjunction with discussion among:

- Pediatric specialists
- Adult providers
- Multidisciplinary clinic providers
- The patient and their caregivers

Advice from Caregivers: What We Wish Providers Knew

Caregivers are experts in their hero's care—and they want to be treated as respected partners on the healthcare team. Here's what they want you to know:

- **We know our hero best.** If something seems off—even subtly—we often notice it first. Please take our instincts to heart, even if tests or vitals seem normal.
- **We want to work with you.** At home, we're juggling medications, feeding schedules, insurance paperwork, adaptive equipment and more. We've had to become experts in 8p and we're here to collaborate—not to control.
- **We want to build a relationship, not just get through an appointment.** Compassion, flexibility and curiosity from providers go a long way. When you speak directly to our hero, ask questions and show a willingness to learn, it builds trust.
- **We're in this for the long haul.** This isn't just a transition— it's a part of the journey. When you show you're in it with us, it gives us strength and hope.

The transition of care for patients with 8p syndrome requires thoughtful planning, clear communication, and an ongoing commitment to high-quality care. By using this toolkit, healthcare providers can help ensure that the patient's journey from pediatric to adult care is as seamless and supportive as possible. This guide should be used alongside the toolkit to help healthcare providers navigate the process with confidence, providing the best care for the patient while addressing the needs of their families and caregivers.

Clinician Resources and Support

- Training and Education: The [Project 8p Foundation](#) offers educational resources for providers just learning about 8p syndrome. Providers should take advantage of training opportunities related to 8p syndrome to stay up to date with the latest research and best practices in care by subscribing to relevant newsletters and becoming familiar with the resources available.
- Emergency Care Planning: One of the critical components of this toolkit is ensuring providers are aware of emergency care plans. These should be reviewed regularly to ensure they are appropriate for the patient as he/she ages and care needs to change.
- Current Best Practices: The Project 8p Foundation, Lab Partners and CROs are leading the charge for 8p research. Below are selected publications to assist you in learning about 8p, but a [full list of publications](#) can be found on the Project 8p Foundation website.

- Clinical Presentation
 - Chromosome 8p Syndromes Clinical Presentation and Management Guidelines (Santucci et al., 2024) [PMID: 39390634](#)
 - Clinical and genomic characterization 8p cytogenomic disorders (Okur et al., 2021) PMID: 34282301
 - Neurodevelopmental phenotype in 36 new patients with 8p inverted duplication-deletion: Genotype-phenotype correlation for anomalies of corpus callosum (Vibert et al., 2021) PMID: 34866188

- Symptom Studies
 - Evaluation of epilepsy in 8p-related disorders (Abott et al., 2026) PMID: 41506120
 - Cortical Vision Impairment Across a Range of Neurodevelopmental Disorders (NDD): Clinical Characterization, Diagnostic Tool Evaluation, and Association with Developmental Outcomes (Abbott et al., 2025) PMID: 40767165

Transition Readiness Assessment

Intent

This Transition Readiness Assessment is designed to assess a young adult with 8p Syndrome and their caregivers' readiness for transition from pediatric to adult healthcare. It aims to:

- Help caregivers, providers and patients navigate the tools provided in the Project 8p Foundation Transition Guide
- Identify what caregivers and providers already know about the health and healthcare needs of patients with 8p syndrome
- Bring to light potential gaps in knowledge, services or resources that may be needed for a successful transition to adult healthcare
- Encourage discussion about the differences in the models of care between pediatric and adult providers

Instructions

This assessment should be maintained and updated annually by the parent or caregiver with input from your 8p hero and with the support of their healthcare providers. Expert 8p providers and caregivers of adults with 8p suggest building your Transition of Care Plan, beginning with this assessment, as early as 12 years old with the goal to complete it by age 18.

Suggested Timeline

Age 12-13

Initiate transition of care conversations with your providers.

- Do your providers have Transition policies in place? Age cutoffs? A system in place for adult referrals? Etc.
- Talk with your providers about the expectations of both caregivers and providers during the transition.

See questions in caregiver guide for more suggestions.

Age 14-15

Begin to develop your Transition of Care Toolkit.

- Start with pieces of the Provider Master List, Provider Transfer Plans and Medical Summary.
- These tools will likely not be done in one visit, but rather updated and added to every year.

- Take the Transition readiness Assessment annually to identify any potential gaps in knowledge, services or resources needed.

Age 16-17

Review and update your Transition of Care Toolkit.

- As your loved one nears 18, begin finalizing earlier Toolkit pieces, begin working on Goals of Care, Emergency and consider consulting a lawyer or learning more about guardianship, medical decision making and financial planning.
- Begin establishing relationships with adult providers.
- Continue taking the Transition Readiness Assessment annually.

Age 18+

Finalize and begin implementing your Transition of Care Toolkit in Adult Care,

- Use the Toolkit to ensure continuity of care as you transfer to adult providers, ensuring they receive all necessary information from both the pediatric provider and the caregiver.

Last Update: _____

Patient Name: _____

Date of Birth: _____ Current Age: _____

Primary Diagnosis: _____

Primary Caregiver Name: _____

Relationship to Patient: _____

Email: _____ Phone: _____

Transition Confidence Scale

Please circle how confident you feel in your ability to take care of your 8p hero's health care.

- Not Confident
- Somewhat Unconfident
- Neither Confident nor Unconfident
- Somewhat Confident
- Confident

Supporting Caregiver(s)

Having supporting caregivers that can support the primary caregiver when needed helps ensure continuity of care. They should receive up to date copies of your Transition of Care Plan as they are made. Supporting Caregivers may be good Emergency Contacts when asked in new provider paperwork.

Name	Relationship	Contact (Email/Phone)	Transition of Care Toolkit Shares (Date)

Transition of Care Master Checklist

	In Progress	Completed
Provider Master List	<input type="checkbox"/>	<input type="checkbox"/> Date:
Medical Summary	<input type="checkbox"/>	<input type="checkbox"/> Date:
Provider Transfer Plans	<input type="checkbox"/>	<input type="checkbox"/> Date:
Goals of Care	<input type="checkbox"/>	<input type="checkbox"/> Date:
Emergency Plans	<input type="checkbox"/>	<input type="checkbox"/> Date:
Legal Documentation	<input type="checkbox"/>	<input type="checkbox"/> Date:
Communicated with Pediatric Provider about End of Service Date	<input type="checkbox"/>	<input type="checkbox"/> Date:
Communicated with Adult Provider about Transfer	<input type="checkbox"/>	<input type="checkbox"/> Date:
Immunizations Send to Adult Provider	<input type="checkbox"/>	<input type="checkbox"/> Date:

Understanding Young Adult's Health

Please check the box that applies to you right now. Note that "We" refers to the primary caregivers and the individual with 8p.

Yes, we know this

We'd like to learn more

	Yes, we know this	We'd like to learn more
We know their medical needs.	<input type="checkbox"/>	<input type="checkbox"/>
We can tell other people what their medical needs are.	<input type="checkbox"/>	<input type="checkbox"/>
We know what to do if they have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>
We have an emergency care plan documented.	<input type="checkbox"/>	<input type="checkbox"/>
We know what medications they take and what they are for.	<input type="checkbox"/>	<input type="checkbox"/>
We know what they are allergic to, including medications.	<input type="checkbox"/>	<input type="checkbox"/>
We can name and have documented 2-3 people who can help them with their health goals.	<input type="checkbox"/>	<input type="checkbox"/>
We and 2-3 people know and can find their doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>
We and 2-3 other people have access to this Transition of Care Toolkit including their medical summary, emergency plan and goals of care.	<input type="checkbox"/>	<input type="checkbox"/>
We and 2-3 other people can find necessary health information (i.e insurance card, allergies, medications, provider list, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, we think about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>
We have a way to get to their doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>

Yes, we know this

We'd like to learn more

We know how to ask for a form to be seen by another doctor/therapist.	<input type="checkbox"/>	<input type="checkbox"/>
We know where their pharmacy is and what to do if they run out of medications.	<input type="checkbox"/>	<input type="checkbox"/>
We know where to get a blood test or x-rays if the doctor orders them.	<input type="checkbox"/>	<input type="checkbox"/>
We have a plan so they can keep their health insurance after 18 or older.	<input type="checkbox"/>	<input type="checkbox"/>
We know what we need to do to establish legal guardianship and/or conservatorship to ensure they have support with healthcare decisions.	<input type="checkbox"/>	<input type="checkbox"/>

Additional Comments/Notes

Provider Master List

Intent

This document is intended to keep up to date on all current and future providers.

Patient Name: _____ Date of Birth: _____

Primary Caregiver Name: _____ Last Updated: _____

Medical Providers		
Specialty	Current Pediatric Provider	Adult Provider
Primary Care Provider (PCP)	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Neurology (epilepsy, movement, sleep)	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Dietician/Nutrition	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Gastroenterology	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Rehabilitation Medicine	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Orthopedist/Orthopedic Surgeon	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Psychiatry	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Dental	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____

Ophthalmologist	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Other:	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Other:	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Other:	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____

Therapists		
Specialty	Current Pediatric Provider	Adult Provider
Occupational Therapy	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Physical Therapy	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Communication/AAC	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Behavior Therapist/BCBA	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Other:	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Other:	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____

Other Important Contacts		
Specialty	Current Pediatric Provider	Adult Provider
Social Work	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Care Coordination	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Respite Providers	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Other:	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Other:	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____
Other:	Name: _____ Role: _____ Phone: _____	Name: _____ Role: _____ Phone: _____

Provider Transfer Plan

Intent

The Provider Transfer Plan is designed to ensure clear communication about transition policies and protocols between pediatric providers and caregivers.

Instructions

Caregivers should request each relevant provider (i.e. pediatrician, neurology, gastroenterology etc.) help complete a Provider Transfer Plan to ensure they have clear expectations of how the process will work and identify key information each provider wants to be passed along to future adult providers.

Specialty: _____

Provider Name: _____

Clinic/Location: _____

Email: _____

Phone: _____ Fax: _____

Patient Information

Patient Name: _____ Date of Birth: _____

Current Diagnoses Treated: _____

Former or Resolved Diagnoses Treated: _____

Transition Complexity: Low Moderate High

Notes:

Transition Policy & Planning

- Practice policy on transition discussed/shared with caregivers and youth.

Date: _____

Notes:

- Communicated with caregivers and youth transition goals and prioritized actions to include in their Transition of Care Plan.

Date: _____

Notes:

- Discussed with caregivers the level of support we provide after the patient has started care with their adult provider (i.e answering new provider's questions, consult with caregivers if they have concerns about their new provider, etc).

Date: _____

Notes:

Timing of the transition has been discussed.

Date: _____

Notes:

Adult provider has been selected.

Provider Name: _____

Contact Information: _____

First Appointment Scheduled For: _____

Date: _____

Notes:

Additional Comments/Notes:

Medical Summary

Intent

This Medical Summary is intended to provide a consolidated, yet comprehensive, summary of a person with 8p syndrome's most important medical history highlights.

Instructions

With the support of their primary care and specialty providers, caregivers should update this document regularly. This can be shared with healthcare providers and supporting caregivers as needed to ensure a person with 8p syndrome's entire care team is aware of these very important components of their health care needs.

About 8p syndrome

8p syndrome is a rare neuro-genetic disorder that occurs in 1 in 10:000 live births. People with 8p syndrome have developmental problems noticeable in infancy or early childhood. Other common signs and symptoms usually appear in early childhood like walking and balance disorders, gastrointestinal issues, seizures and little to no speech. Despite these symptoms, people with 8p syndrome have an overall happy and excitable demeanor.

Patient Name: _____ Date of Birth: _____

Primary Caregiver Name: _____ Last Updated: _____

Diagnoses & Management

Pertinent Active Diagnoses:

Prioritize list of active issues for 8p hero (epilepsy, behavior, constipation, sleep, etc.)

[Transition Guide](#)

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Inactive or Currently Resolved Diagnoses:
E.g kidney stones, sleep apnea, pneumonias, etc.

Primary Care Provider

Name and Contact Information

Emergency Contact(s)

Name and Contact Information

Important Details or Recommendations

A brief summary of the most important things one would need to know about managing this person's health.

Current Medications

Medication Name	Dose	Frequescy	Pharmacy

Prior Medications

Medication Name	Dose	Frequescy	Pharmacy

Functional Information

Below is a general information to better understand this person with 8p syndrome's strengths, challenges, communication methods and preferences

Cognitive Skill Level:

Adaptive Skill Level:

Communication Skill Level:

Communication Method:

Type of Adaptive Equipment:

Diet:

Food Texture:

Food Intolerances:

Ambulatory (fully, with assistance, non-ambulatory etc.)

Sleep Concerns:

Sleep Concerns:

Safety Concerns:

Behavior Concerns:

Shower/Bath/Hygiene

Dental Hygiene:

Best Learning Method:

Things That Make Me Happy:

Things That Frustrate or Upset Me:

Additional Information:

Allergies	
Allergies:	Reactions:

Medications & Procedures to Avoid	
Medications/Procedures (List)	Why to Avoid:

Prior Surgeries, Procedures, and Hospitalizations	
Date:	Details:

Vaccine Administration Record		
Vaccine:	Administer Date:	Details:

Goals of Care

Intent

Goals of Care has been designed to ensure your healthcare team understands what is most important to you and your 8p hero. It is essential for your providers to know your 8p hero's medical needs but also the values and priorities you hold for their care now and in the future.

Instructions

Use the prompts below to help think beyond standard medical care while establishing your "Top Goals" list. Consider overall quality of life and what health and wellness goals will help your individual with 8p syndrome thrive, not simply survive their journey with 8p syndrome. This document may be edited often as new goals arise and former goals are achieved.

Example Goal

Goal	Issues/Concerns/Potential Barriers
Maintaining seizure control. For this patient, this means we only tend to see breakthrough myoclonic seizures in time of illness. Historically, a bridge medication during illnesses has prevented the return of grand mal seizures.	Prior to gaining control of seizures at the age of 14, the patient experienced dangerous grand mal seizures that often resulted in falls, injuries, and regressions that significantly affected the patient's overall wellbeing. Caregivers can often see signs of increased neurological behavior before actually seeing breakthrough seizures appear. It's critical that providers trust caregiver instinct on this and help us establish an emergency seizure action plan and regular plan for medication/dosing assessments.

Actions Needed	Progress/Notes
<ul style="list-style-type: none"> • Ensure provider is aware of seizure history, medications that did/did not work, and signs of increased neurological activity often identified by caregiver. • Understand provider process to receiving a timely appointment/request for medication adjustments if needed. • Ensure all caregivers and medical providers are aware of the EMergency Seizure Action Plan and, if needed. Post seizure recovery expectations (e.g. physical therapy may be needed to address potential mobility regressions due to a fall, etc.) 	<ul style="list-style-type: none"> • New adult neurologist appointment scheduled for: _____ • Pediatric neurologist has prepared a comprehensive seizure history and seizure action plan to share with new provider. • Caregiver has prepared notes and questions for new provider.

Patient Name: _____ Date of Birth: _____

Primary CaregiverName: _____

Relationship to Patient: _____ Phone: _____

Last Updated: _____

Please consider the following questions as you develop your Goals of Care to share with your providers.

- **What are your primary goals for your 8p hero's care as they transition into adulthood?**

This may include things like maximizing quality of life, managing specific symptoms, or ensuring independence and autonomy in certain areas.

- **What are your 8p hero’s most important values and preferences?**

For example, are there specific activities, comforts or routines that are particularly meaningful to them? Are there things they enjoy or want to continue as they grow older?

- **Are there any medical or care priorities that you feel are particularly important?**

This could include managing certain health conditions, minimizing discomfort or pain, or focusing on mental or emotional well-being.

- **How involved would you like to be in your 8p hero’s care decisions moving forward?**

Do you prefer to be the primary decision-maker or are you comfortable with your 8p hero being involved with decision making or working with a healthcare team to make decisions together?

- **Are there any cultural, religious or personal beliefs or practices that should be considered when making family decisions about your 8p hero’s care?**

We want to ensure that care is aligned with your family’s values and beliefs.

- **Do you have specific wishes or concerns about end-of-life care planning?**

If you would like, this can include preferences or interventions or comfort care if the patient reaches a terminal stage.

- **What support or resources would be helpful to your family during this transition?**

Your providers are there to give guidance and ensure you have the resources you need, whether it's emotional, logistical or financial support. Think about what might be helpful to ask prior to your appointments.

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Emergency Care Plan

Intent

Emergency Care Plans are a critical resource designed to ensure the primary caregiver, any supporting or secondary caregivers, and health care providers have clear communication and understanding of what must be done in case of an emergency.

Instructions

Caregivers should work with their healthcare team to establish emergency care plans for any major risks to the 8p hero's health.

Example

Emergency Care Plans	
Symptom or Diagnosis	Special Precautions
Patient has an allergic reaction to tree nuts which may be found in some nut milks, nut meals and nut oils.	<p>Allergic Reaction Action Plan: Mild symptom's can be an itchy or runny nose, few hives OR mild nausea or abdominal cramping. If there are mild symptoms from one system, give an adult dose of oral antihistamine such as Benadryl, Zyrtec or Claritin or their respective generics. Closely monitor for worsening symptoms. If there are mild symptoms from more than one system, give epinephrine as soon as possible and call EMS.</p> <p>Severe symptoms are shortness of breath, wheezing, persistent cough, pallor or blue coloring, feeling faint, lightheaded or weak, difficulty breathing and/or large areas of redness on the skin, repetitive vomiting or severe diarrhea. If severe symptoms, inject epinephrine immediately and call 911 and alert the dispatcher that you are witnessing an anaphylactic reaction. Wait with the person until responders arrive. Alert caregivers/emergency contacts.</p>

<p>Patient has an increased risk of aspiration where food and fluids enter the lungs rather than the stomach after being swallowed.</p>	<p>Aspiration symptoms: Choking, difficulty breathing, wheezing, pallor or turning blue. Aspiration action plan: If any of these symptoms are present after eating, check for a pulse and listen for breathing. Do not do a blind sweep. If you know how, perform the Heimlich. If you do not, call 911 immediately and stay with patient until responders arrive.</p>
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Patient Name: _____ Date of Birth: _____

Primary CaregiverName: _____

Relationship to Patient: _____ Phone: _____

Last Updated: _____

Emergency Care Plans	
Symptoms or Diagnosis	Special Precautions

Emergency Care Plans	
Symptoms or Diagnosis	Special Precautions

Legal & Planning Documents

Intent

The Legal & Planning Documents section is a critical component of the 8p Transition of Care Toolkit, designed to help caregivers and families centralize and organize important legal paperwork that ensures the continuity of care and supports the hero's legal and financial needs as they transition into adulthood. This section is intended to provide a comprehensive, easy-to-access place for storing key legal documents that may be required by healthcare providers, guardians and financial advisors. Proper legal planning is vital to ensuring that the hero continues to receive appropriate care and support, especially as they move to adult services.

As 8p heroes transition from pediatric to adult care, the role of caregivers and family members often shifts. Legal documents help ensure that caregivers have the authority to make critical decisions on behalf of the hero, particularly in areas of healthcare and finances. This section of the toolkit is designed to make it easier for caregivers to organize and manage these important documents.

Instructions

Use this resource to help keep track of key legal and planning processes, documentations, links, points of contact, key dates and notes. Consider using a calendar reminder system to keep track of annual renewals and determinations.

It is crucial you keep documents suggested in this section in secure locations, whether that is as paper copies, digital scans, or both. Consider fireproof safes for paper documents and secure password-protected files for digital files. Do not include critical information (i.e social security numbers) in this resource to prevent identity theft in the case your toolkit is shared with other caregivers or providers.

Essential Identification

	<i>We have this on file</i>	<i>Person Responsible for Safe Keeping</i>
Social Security Card	<input type="checkbox"/>	
Birth Certificate	<input type="checkbox"/>	

Photo ID	<input type="checkbox"/>	
Insurance Card	<input type="checkbox"/>	

Guardianship and Alternatives to Guardianship

- If the 8p hero has a legal guardian, a copy of guardianship paperwork should be included.
- For those who do not have a formal guardianship in place but may need it as the patient transitions to adulthood, include notes/documents related to alternatives such as power of attorney to support decision-making arrangements.

Healthcare Proxies and Advance Directives

- If the 8p hero or their family has designated a healthcare proxy or decision- maker for the medical decisions, include copies of these documents. This ensures that the adult healthcare providers can follow the hero's wishes and consult the designated individual in the event the patient is unable to make decisions independently.

Medicaid, Medicare, Social Security (SSI/SSDI) & Waiver Documentation

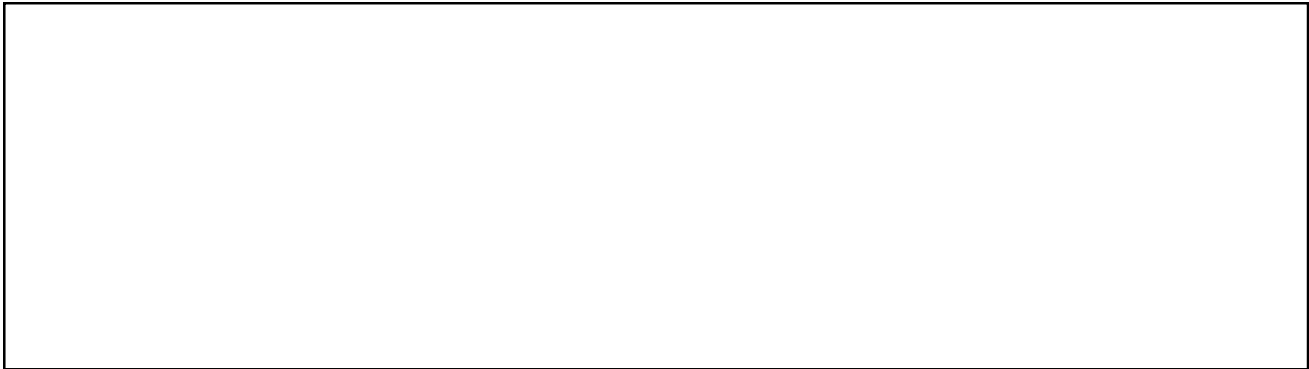
- Social Security (SSI/SSDI): Award letter and benefit determination, recent annual renewal or redetermination forms, payee designation (if you are the representative payee), income and resource documentation (for eligibility purposes)
- Medicaid/Medicare: Approval letter and member ID, enrollment documents, Explanation of Benefits (EOBs) and notices, eligibility letters, service plans or individualized support plans (ISP), managed care provider assignments (if applicable), prior authorizations for durable medical equipment (DME), therapies, etc.
- Medicaid Waiver & Long-Term Services: Waiver enrollment confirmation and case manager contact, waiver service authorizations (e.g. Respite, day programs, therapies etc.), individualized service plans (ISP) or person-centered plans, service provider contracts or care agreements. Receipts or records of waiver-related services (important for audits).



Financial and Special Needs Planning Documents

- Trusts: Copies of any special needs trusts, which are designated to protect the 8p hero's eligibility for government benefits while allowing assets to be managed on their behalf.
- Wills: If applicable, include any wills that outline the 8p hero's wishes for the future, including provisions for care or financial support after reaching adulthood.
- ABLE Accounts: Include documentation of any Achieving a Better Life Experience (ABLE) accounts, which allows individuals with disabilities to save money without affecting eligibility for government benefits.

- Other Financial Planning Documents: Any documents related to long-term care planning, such as life insurance policies, government benefits eligibility, or financial support plans.



A Checklist For Transitioning to Adulthood

Prior to 12 Years

- Join a local advocacy or parent group to help educate yourself.
- Review the Individuals with Disabilities Education Act.
- Create a will and talk to someone about estate planning.
- Consider a Special Needs Trust and/or an ABLE Account.

12 - 14 Years

- Begin looking into vocational and/or recreational opportunities for your child.
- Consider a Vocational Assessment.
- Understand the Medicaid Waiver and learn about Long Term Care in your state.
- Write/develop a person centered plan.

16 Years

- Apply for a nondriver ID card for a form of government ID.
- Create an extensive IEP Transition Plan.
- Consider options for guardianship, legal planning and financial planning.

17 Years

- Prepare to assume guardianship or conservatorship.
- Apply for SSI for your hero.
- If the hero is male, register for the Selective Service.

18 Years

- Apply for Adult Services with the supporting Federal Agency.
- Take necessary steps to enact a guardianship plan.
- Carefully track SSI funding received monthly.
- Apply for Section 8 Housing.
- Begin transitioning from pediatric to adult healthcare providers.

26 Years

- Find out if your hero can stay on your private insurance plan.

Conclusion

We understand this process maybe overwhelming and confusing. This guide and checklists do not need to be completed at once. If you start the process early, you can work your way through the guide at a pace that is comfortable for you.

The adult transition is complicated for every family and can be an emotional time for 8p heroes and their families. It will take time for everyone to adjust to changes made in the transition journey. We encourage families to find support in their local community through providers, social workers and teachers. We at the Project 8p Foundation are here to support you through the transition process. The 8p community has many families and heroes who have made the transition to adulthood and are willing to offer support to those early in their journey. If you would like to be connected to another family, please email us at engagement@project8p.org.

This transition guide is our most comprehensive transition resource. As we work together and learn more, we will be able to grow this resource for families.

Any feedback or questions are always welcome.

Quick Reference Links

School Transition

<https://www.understood.org/en/articles/how-to-help-your-young-adult-hero-with-the-job-hunting-process><https://www.understood.org/en/articles/how-to-help-your-young-adult-hero-with-the-job-hunting-process><https://www.understood.org/en/articles/when-your-hero-with-an-iep-turns-18-your-parental-rights><https://www.understood.org/en/articles/how-to-help-your-young-adult-hero-with-the-job-hunting-process><https://rsa.ed.gov/about><https://sites.ed.gov/idea/about-idea/#ADA><https://www.usa.gov/disability-jobs-training><https://lumindidsc.org/transitioning-into-adulthood-what-to-do-when-your-loved-one-with-down-syndrome-becomes-an-adult><https://idaamerica.org/info/get-your-hero-ready-for-work/><https://idaamerica.org/job-resources-by-state-for-adults-with-learning-disabilities/>

Housing

<https://www.specialneedsalliance.org/blog/a-place-of-her-own/><https://www.egglestonservices.org/blog/how-to-choose-the-right-group-home-for-adults-with-disabilities/>

Medicaid/Medicare

<https://www.autismspeaks.org/blog/home-and-community-based-services-hcbs-waivers>
<https://www.medicaid.gov/medicaid>
<https://www.medicaid.gov/about-us/where-can-people-get-help-medicaid-chip#statemenu>
<https://massairc.org/factsheets/healthcare-coverage-for-adults-with-asd-frequently-asked-questions-for-parents/#page-content>
<https://www.ssa.gov/ssi/eligibility>
<https://www.ssa.gov/ssi/text-income-ussi.htm>
<https://www.ssa.gov/pubs/EN-05-10026.pdf>

<https://www.usa.gov/medicare%20https://www.ssa.gov/disabilityresearch/wi/medicare.htm><https://www.fletchertilton.com/continued-eligibility-for-medicaid-for-a-disabled-adult-hero-when-a-parent-retires-or-dies/><https://shepherdelderlaw.com/federal-law-on-medicaid-continuation-after-disabled-adult-hero-eligibility/>

Legal

https://asaga.info/wp-content/uploads/2017/01/SSA-for-Guardianship-Conference-PDF.pdf?utm_source=google&utm_medium=cpc&utm_campaign={16-Power%20of%20Attorney}&utm_term=durable%20power%20of%20attorney%20form&utm_campaign_id=21242175059&utm_adgroup={Power%20of%20Attorney}&utm_adgroup_id=165294763081&utm_content=697965167416&device=c&gad_source=1&gad_campaignid=21242175059&gbraid=0AAAADmNoOSgTMu5UuKnY7LHwsY22gNTj&gclid=Cj0KCQiAlczLBhDhARIsAIEc7uhkfq9-zJm6JcvfMLQY5KKocZWpiuxpETwnvON9PXWwuIhnuZ6iTQQaAvcxEALw_wcB
<https://www.caringinfo.org/planning/advance-directives/by-state/>
<https://www.nia.nih.gov/health/advance-care-planning/choosing-health-care-proxy>
https://legaltemplates.net/form/It/power-of-attorney-forms/?utm_source=google&utm_medium=cpc&utm_campaign=Consumer%20PoA&utm_campaignID=12170691591&utm_adgroupID=114323587902&utm_partner=googlesearch&g_acctid=207-817-4230&g_campaign=Consumer_PoA&g_campaignid=12170691591&g_adgroupid=114323587902&g_adid=699213223835&g_keyword=durable%20power%20of%20attorney&g_keywordid=kwd-89407051&g_network=g&g_type=search_display&gad_source=1&gad_campaignid=12170691591&gbraid=0AAAAADIKzre7IZXiLQGbkVRt3LY7R9ML1&gclid=Cj0KCQiAlczLBhDhARIsAIEc7ujVrwWjIIZO3t-gQpEwoWscm5Erm9CPWfIBxMndBIX4NHsdvuliRhYaAsUtEALw_wcB
<https://www.youtube.com/watch?v=X9IS7u2-22g>

Financial

<https://farley1.com/maximizing-ssi-by-charging-rent-to-your-disabled-hero.html><https://foodstampsnow.com/food-stamps-and-ebt/><https://www.fns.usda.gov/snap/state-directory/><https://www.youtube.com/watch?v=JtVo4tKXYC8><https://www.actec.org/resource-center/video/understanding-special-needs-trusts/><https://www.fidelity.com/learning-center/life-events/what-is-special-needs-trust/><https://www.ablenow.com/learn/basics/><https://www.ablenrc.org/what-is-able/what-are-able-accounts/>

Transition Guides From Other Foundations

<https://angelman.org/resources/transition-care-toolkit/><https://angelman.org/resources/transition-to-adulthood-checklist/><https://breaking-down-barriers.org.uk/t-kash-transition-tools/>https://www.viprarecare.com/sites/default/files/2024-07/UCB_CARE_Binder.pdf<https://ndss.org/resources/transitioning-school-adulthood>