

Getting Ready For Transition

Rough Draft

By

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Thank you for agreeing to review this hand book on transitioning to adult hood. If you have any recommendations or ideas please contact me at 272-5296 or you may email at Jchimarusti@sauld.unm.edu with your comments. Thank you once again and if you have any questions please feel free to contact me. Version year 2017

Getting Ready For Transition

We all experience transitions throughout our lifetime. Your family is preparing for a very important transition that can be different for families who have children with unique challenges. There are several important steps that you as a family must consider over the next several months and years. This handout will give you some ideas, recommendations, and services that will assist you during this period of transition. Please remember that not every issue or resource will be available in this handout and you may need to adapt the information for your specific needs.

When does transition start:

There are several areas that you might want to consider over the next several months and years. This handout will break down important areas that need to be considered when your child turns 18. The most crucial time of transition is between the ages of 18 to 21. But, it is very important to start planning for their transition as early as possible. The federal government suggests that transition should start when a child reaches the age of 14. Many programs do not start talking about transition until the child reaches the age of 16. Hopefully, your child's school program has been working with you and your child regarding transitional issues when they were a freshman in high school. If you have questions or need assistance, please contact the social work department here at Carrie Tingley Hospital and we will support you through this very important time of your child's life and in your life. This is an important part of you and your child's life and should be an exciting part of the journey that your family is entering into. Please

let the Carrie Tingley Hospital team be a resource to support your family over the next few years.

The Three Stages of Transition

There are several stages of transition that you need to be prepared for. The First Stage of transition is the Emotional Aspects of Transition for you and for family. It is important to remember this is a major change of life and many services and programs that you and your child/young adult have been accessing may change over the next several years. The first major transition is that when your child turns 18, and legal adult, even if they have cognitive challenges, insurance and other programs will not speak with you unless you have the proper legal documentation (for example guardianship or Power of Attorney). This will be discussed later in this information packet. The Second Stage is school. For most people, graduating from high school is experienced between the ages of 18 or 19. However, depending on your child's condition or disability they may be able to continue receiving services from their school district until the age of 21. The Third Stage is medical transition.

Things to Consider During Transition

School Transition:

You and your family have been through many different transitions through the school system. This will be a very unique transition that your child should be working on over the next 4 years of high school and possibly until they are 21. This transition should begin their freshman

year of high school. Most schools will try to work with the student to determine their potential, dreams, and abilities. The school will work with the student and the family to access the potential and abilities of the student after they graduate from high school. Depending on the student's medical or physical condition they may be able to stay in school until they are 21 and continue to receive therapy through the school until they are no longer able to participate in their school program. Depending on when the student's birthday falls, they may be able to stay in school until they are 22.

If your student is able to academically participate in school and work they may be able to go to college. They can either go to a 4-year college or to a junior college. They will participate in all academic programs like all other students however, there are other supports to help them go to college and have funding resources such as SSI, DVR, and special academic services to mention a few. Your student's advisor should be able to help your student find what is appropriate for them. If your student is looking forward to going to college it is extremely important for you to help them become as independent as possible during the 4 years of high school. Please encourage them to participate in activities in and out of school. The more they are involved in their community the easier it will be for them to find financial support and scholarships. The more independent they become, the more opportunities will be available to them during college.

There are some students who may not be able to attend a 4-year college or a junior college. There are still employment opportunities and activities that are available to them. It is important to work with the school during the IEP process (Individual Education Plan) to determine what your child will be able to accomplish after high school. Also develop an

Individual Transition Plan (ITP) during your child's freshman year in order to help them find what would be best for them after high school and what your child and you would like to see from your child's educational experience in high school. Parents Reaching Out (PRO) 505-247-0192 or Education for Parents of Indian Children with Special Needs (EPICS) 888-499-2070 are good resources and have materials to help you and your student develop a great transition program. A good transition planning should be taking in their high school years that will follow them into their adult years. Do not wait until their junior or senior year to start developing a transition program for your child. Please understand transition from high school can be very rewarding if it is planned in advance and with a lot of thought. This can also be a very difficult time emotionally for you and your child. Your child should have a central part in developing their own transition program and have ideas of what they want to achieve after graduation.

Social Security (SSI):

If your child was receiving Social Security Income (SSI) or has not yet received SSI because of the parents' income, things are different once they are 18 years old. Prior to an individual turning 18, SSI is based on 2 areas: the individual's disability or medical condition and the family's income. Once a child turns 18 years old, the family's income no longer is considered and it is the individual's income and assets which are considered. Social Security will still need to consider the individuals disability, however, they now look at whether the individual has the potential of gainful employment. If the person's disability prevents them from maintaining a part-time or full-time job, or cannot work because of their disability, they can qualify for SSI. Their parents or family income will no longer be considered when applying for SSI. It is important to note that even if you were receiving SSI before your 18th birthday you need to

reapply as an adult. If you were not receiving SSI because of family income you may qualify now to receive SSI under the individuals own financial situation.

You can start the process by contacting Social Security at 1-800-772-1213 or go to www.socialsecurity.gov. It is recommended that you begin the process about 4 months prior to the individual turning 18. If the person is capable of making their own decisions that they work on this process themselves with your support. If they are capable of doing this, do not do it for them but guide them on what they need to do. (A copy of the brochure is attached to the back of the folder for further information.)

Another recommendation is to charge people rent if they are over the age of 18 and are still living at home so that they can receive their full benefits. If they are living at your home and not going to school they will not receive their full benefits and their Social Security check will be reduced. Some families may charge rent and then give it back to the young adult or put it in a small savings account for the young adult without their name associated with that account. Please remember that an individual over 18 can only have assets no greater than \$2,000.00. This does not include a home, vehicle, or items which are required for daily living.

There are several agencies that can assist you while applying for Social Security (please see resource information at the end of this information packet). Also, if your young adult is able to work, there are programs that will allow them to have Social Security Income and maintain all of their benefits. There are resources in the community that can assist in this situation such as Division of Vocational Rehabilitation (DVR), Independent Living Resource Center (ILRC), Parents Reaching Out (PRO) and some other community resources which are listed at the back

of this folder. Please ask for further information if you find yourself in this situation and we can assist you in finding the right resources that will meet you and your child's situation.

Medical Transition:

Another major transition that families need to consider when their child turns 18 is dealing with the medical community and changing doctors. Many families have had the same pediatrician or doctor for many years. Your Primary Care Physician (PCP) or specialists will only see your child until they are 18. Here at Carrie Tingley Hospital (CTH) we provide services until your child/young adult is 21 years old. Most pediatricians begin asking you to find another doctor once your child is 18. We have been recommending that families start looking into adult providers one year before they need to transition medical care. You might want to speak with your PCP or specialists to ask who they would recommend for your young adult so you can interview them prior to their 18th birthday or in the case of CTH, their 21st birthday. This way both of you can find a primary doctor or specialists that will meet your young adults needs when they need to transition to a new provider. This way if the provider that you have interviewed cannot meet your young adults' needs, you can always go back to his/her PCP, or the specialist at CTH, to view other options or ideas. In some cases there may not be many options available. This can take a lot of time; therefore the sooner you look into your options, the better your chances are for your needs to be met.

Guardianship

In the United States, when a person turns 18 they become their own legal guardian and can start signing official documents for themselves. However, there are some young adults that are not able to understand or able to make decisions regarding their life. There are situations

that are important to file for some level of guardianship to protect your young adult who is unable to make decisions or understand the legal situation that they find themselves in. Some of the terms that you need to be aware of and consider for your young adult when they turn 18 are:

Payee, this is a person who can be financially responsible for a person's Social Security but allows the person to make all other decisions in areas other than finances.

Power of Attorney, this is a person that can speak for another person regarding medical issues or other situations that they cannot speak for themselves. However, the individual who gives the Power of Attorney to another person can take it away at any time if the person who gives the Power of Attorney chooses to not have another person speak for them. Power of Attorney can also be only for 6 months to a year at a time and must be renewed at least once a year. This also allows the person to make decisions independently or reverse decisions that someone has made for them.

Partial or Full Guardianship, this is a legal process that gives full or partial decision making to another person for a person that is not capable of making decisions for themselves. This is a legal process that can take 6 months to year and can cost up to \$3000-\$5000 depending on how complicated the case is. It is important to try to start this process when the individual is about 17 1/2 years old. It is important to note that you the parent who is asking for guardianship will need to have a lawyer and your young adult will also have a lawyer. There will also be a court appointed evaluator who is usually a psychologist, social worker or case worker that can independently evaluate your child's ability to make decisions. There are some financial resources that are available to help you through this process. If you financially cannot afford to

apply for guardianship you can call the UNM Legal Alliance for children at the UNM Law School at 505-277-5265 (for Bernalillo County residents only). You can also contact the following resources to see if there are other opportunities to help you through this process:

- NM Guardianship Association www.nmgaresourcecenter.org
- Law Access New Mexico – Volunteer Attorney Pool 505-944-7167 ext. 124
- New Mexico Developmental Disability Planning Counselor Office of Guardianship 800-331-2229 or 505-476-7321 (families have indicated it's difficult to get a hold of this program. It is recommended that you start as early as possible.)
- Disability Rights NM 505-256-3100 or 800-432-4682

Division of Vocational Rehabilitation (DVR)

Many young adults with special needs have the opportunity to have a part-time or full-time job or even go to college/trade school depending on their ability. There are different financial programs that can help an individual succeed. One of those programs is Division of Vocational Rehabilitation (DVR). DVR can help with supporting an individual to go to a college/trade school or find employment that is suitable for their abilities. It is a process to get in to the DVR program and not all individuals are able to get in the first time. DVR counselors will consider individual's needs and abilities and work with the individual to develop a program which is appropriate for them.

If your child is in a special education program and planning to look into DVR, it is recommended that a DVR counselor be present at the students last IEP, 3-4 months prior to graduation. If your child has not been spoken to about DVR, it is recommended that your

student start looking into the program their senior year. For information go to the DVR website:

<https://www.dvr.state.nm.us/NMDVRLocations/NMDVRLocations.aspx>.

There are other programs and opportunities for individuals with special challenges to have the opportunity to work. If the individual is on SSI there are possibilities for them to work and still be able to receive their SSI. Both the counselor from DVR and programs with and Social Security can help determine what the best opportunities are for your young adult and be able to keep their Social Security and be able to work.

Agency and Phone Numbers

The following information may be able to assist you in the transition process. Please understand this is not all of the programs, but these agencies are good starting points to find the right support that your family needs. Many of these agency programs can refer you to other programs as well.

Social Security: 1-800-772-1213 (If you believe that you or your child may be disabled and qualify for Social Security Income) Call between 7 a.m. & 7 p.m.

Developmental Disability Waiver : (DD Waiver) 1-877-696-1472 (this is a waiver to provide financial support for individuals with developmental disabilities that have occurred before the person turned 22 years old. This provides financial support for services a person may need in their daily lives.)

Medically Fragile Waiver: 1-877-696-1472 (This is for children who are under age 22 and has a medical fragile condition with a developmental disability)

Brain Injury Association of New Mexico: 292-7414 (They can provide information regarding programs for individuals with a head injury)

Parents Reaching Out (PRO): 505-247-0192 1-800-524-5171 (They provide assistance with school issues, parent support, information regarding waiver's and SSI. They can also provide information on waivers and insurance related issues.)

ARC of New Mexico: 505-883-4630 (They provide support to individuals and families with developmental disabilities (DD), with advocacy in school matters, legal issues, and guardianship)

Department of Vocational Rehabilitation (DVR): 1-800-224-7005

Independent Living Resource Center: (ILRC) – Albuquerque 505-266-5022

San Juan Center for Independence : SJCI – Farmington (505) 566-5827 - 1-877-484-4500

(Both the ILRC and SJCI can provide information and financial support for home and vehicle modifications, guaranteed loans for handicap accessible vehicles and home modifications. They also can help with peer support. Both programs can serve individuals throughout the State of New Mexico)

Department of Senior Affairs (Home Retrofit Program): 764-6400 (Can help with home modification and ramps in Albuquerque city limits only)

New Mexico Technology Assistance Program (NM TAP):

505-841-4464 / 1-877-696-1470 (Can sometimes help with assistive technology, provide used computers for free and can loan adaptive equipment)

Back in Use: 505-341-7171 or www.Backinuse.com

(Recycle assistance with technology and durable medical clinic equipment)

There are several Work Programs, Supportive Employment Programs, Dayhab programs, volunteer programs and other activities for individuals with unique challenges. It is important to work with the school transition team, community programs, and other community resources to find the right program and services for your young adult. Also attached are some worksheets

that may help in the transition process or provide some ideas on what you need to do during this transition period.

Middle school to High school. (Ages 12 to 18).

Life is a constant transition for any person no matter how old or young they are. For some families, who have a teenager with special health care needs, transition may have challenges that may need to be considered. Many decisions during transition periods have to be made that will affect the life of everyone involved. There are several issues you, as parent (s), might want to consider regarding the needs of your teenager. Not all issues will be appropriate for all families or for all teenagers with special needs. You may want to discuss some of these issues with your teenager, teenager's primary doctor or a social worker.

Personal/Family Relationships:

- Take time for family outings.
- If appropriate look for appropriate accessible activities for the entire family.
- Start preparing for your own transition (preparing yourself for when your child might leave home, or for when your moves to a new level of independence).
- If your teen is interested give his/her the opportunity to meet with adults or older teens who have experienced challenges and can be role models.

Medical services:

- Find out what your teen perceptions and baseline knowledge is of his/her special healthcare needs. Fill in the gaps in their understanding of their medical issues.
- Begin helping your teen keep a record of his/her medical history, including diagnosis, operation, and treatments (date, doctors, recommendations, medications).
- Begin having the older teen's speak with the medical professionals about their medical history and learn how to ask questions about how they are doing and what are the next steps in their care; fill in the gaps when appropriate.
- Begin helping the older teen learn about his his/her insurance provider (how to access the insurance).
- Help your young adult, at about the age of 18, to find adult health care providers who are appropriate to the teen's healthcare challenges.

Postsecondary Education

- Discuss and encourage educational options after high school when appropriate.
- Work with school staff to explore with them school program's that support your child's educational goals.

Employment/Job-training

- Help the teen work with the middle school and/or high school in developing a transition program that looks at adult life and career (this should actually start at the age 14 and should also include health related issues).
- Help the teen find volunteer programs or possible summer or part-time employment.
- Discuss possible employment options with the teenager, which also considers physical as well as medical abilities and challenges.
- Start working with the school provider regarding employment transition.

Financial Concerns

- Consider letting the teenager have a summer or after school job when appropriate.
- Start having the teenager manage their money for activities and appropriate personal items.

- Have the teenager start learning about Social Security benefits that are available to them.
- If appropriate develop Trust/Wills that will not affect financial benefits.

Independent Living Skills

- Help your teen identify his/her strengths.
- Continue teaching your teen normal self-help skills as well as skills related to their special healthcare needs.
- Start discussing living arrangements for after the teen graduates from school (Independent living, staying at home, supported living, group homes, etc.).
- Start having the teenager become independent living skills (cooking, cleaning, laundry, etc.).

Leisure/Recreation

- Continue to encourage hobbies and leisure activities that are appropriate to the teen's interest, abilities and talents.
- Support the teenager developing in social skills away from the family.
- Encourage the teenager to develop relationships outside the family.
- Help your teen explore support and/or summer activities groups, that he/she is interested in, (This could include but is not limited to: Boy/Girl Scouts, Boy/Girls clubs, 4-H clubs, wheelchair basketball teams, Special Olympics, church programs, camp and other youth programs).

Transportation

- Help the teenager explore what transportation will be appropriate for them (driving a car, bicycle public transportation, etc.).

Advocacy/Legal Services

- If appropriate start preparing for guardianship when your is 18 (this is important if you do not believe they can manage some or all aspects of their daily life).
- Receive legal advice to develop Trust/Wills that will not affect financial benefits.
- Encourage the teenager to develop self-advocacy skills.
- Talk to your teen or young adult about programs they can contact for assistance in their community: Department of Vocational Rehabilitation (DVR), Youth Leadership Programs, Governor's Committee on Disabilities, Independent Living Resource Center. These programs can help with employment, educational opportunities and advoca the cy.

(Depending on your child's disability and abilities, it may be important to consider the following.)

- By the age of 16, depending on your child's cognitive ability, it is important to start considering guardianship and the needed funding to file for this. (There are different levels of guardianship. It is important to find the least restrictive form of guardianship, which is appropriate to the teen's abilities.)
- If the teen is already on SSI, at the age of 18. They will they need to reapply as an adult and become their own payee (unless they are unable to manage their own money).
- Have DVR be a part of the individual transition plan at school as early as possible.
- Include the teen in the individual transition program in school and make sure that he/she reminds everyone that they must be aware of the medical issues relating to their transition needs. (Their dreams should not be disregarded based on their medical needs. However, they should learn what expectations or assistive technology could help them make their dreams possible.)

High school to adulthood (Ages 18 to 21, or according to your young adults developmental abilities.)

- It is important to act as a resource and support your young adult and their decisions (if you agree with them or not).
- Encourage your young adult to participate in support groups and/or organizations relevant to his/her special healthcare needs.
- Finalize healthcare financing (insurance companies) with your young adult.
- With your young adult to finalize transferred to medical care to adult providers.
- Programs that your young adult should be aware of, or have access to: SSI for adults, SSI Work Initiatives (PASS), Independent Living Resource Centers (ILRC), Post Educational Programs (Junior College, College or Technical School) and educational supports in school. Encourage your young adult to apply for DVR services and explore some form of employment.
- Most important let your young adult be an individual and live an independent life as possible.
- Please remember if your child is over 18 and is an able to make decisions or care for themselves you may need to consider some level guardianship for them. If you go through a lawyer this may cost up to \$3000.00-\$5000.00. You can also contact the programs mentioned under guardianship for possible financial support.

Final Thoughts

You and your family have gone through many transitions over the years. Some of the transitions may have been very challenging while others may have gone smoothly. Hopefully, all have been rewarding. The transitions for you and your family have its unique challenges, rewards and hopes that you may have not thought of before. It is important to work on these transitions over the next several years and be on. Here at Carrie Tingley Hospital we would like to support you and your family in this transition period. This small booklet cannot answer all of the transition questions we hope that he can give you some ideas and provide a starting point for discussion regarding transition. If you need more information or further support in the transition process in a the areas mentioned above please feel free to contact the social work staff John Chimarusti (272-5296) or Vicki Habersky (272-5274) and we will try to provide further resources and support during your child's transition to adulthood and in their medical journey in to the adult world.