

TIPS FOR A SUCCESSFUL MEDICAL TRANSITION

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Transition Medicine Clinic

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GIVING LIFE TO POSSIBLE



Texas Children's
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Healthcare Transition

- The planned process for adolescents and young adults to transition from pediatric to adult healthcare providers, facilities, and framework.

Objectives

- Learn to plan for transition early alongside your doctor
- Recognize barriers to a successful transition
- Identify important components of healthcare and life post transition

Transition Medicine Clinic

- I have no financial disclosures
- Patient-centered medical home for adults (>18yo) with Intellectual and/or Developmental Disabilities (IDD)
 - primary care
 - social work services
 - case management
 - Assist with transition to adult subspecialists as needed and to adult life
 - Provide interprofessional education to a multitude of healthcare learners
- 1200 patients (Down syndrome, spina bifida, cerebral palsy, autism, other genetic syndromes)



Phases of “transition”

Changing from adult to pediatric healthcare is more than just making a doctor’s appointment....

- **Birth to 17 – planning!**
 - **Waivers**
 - **Self management skills**
 - **Getting organized – medical summary, healthcare team**
- **Ages 17-19**
 - Social security determination
 - Consent and guardianship
 - Transfer to adult providers?

Phases of “transition”

- Ages 20-22
 - Insurance, insurance, insurance!
 - Nursing hours
 - Education and Employment
 - Dental care
- Ages 25 and beyond
 - Insurance (again!)
 - Long term planning
 - Stay Informed

Medicaid Waiver Programs

- A Medicaid Waiver provides additional money for services not covered by Medicaid.
 - There are multiple waivers, each with their own qualifying criteria, interest lists, and budgets.
 - Centers for Medicare and Medicaid Services lists programs in your state that can help provide services that allow those who need care to remain in their homes or communities.
- Waiver tips
 - Enroll today!
 - Ask for written confirmation that your child is on the interest list.
 - Call annually to verify your child's status on the wait list.

Getting Ready for Transition

- Start talking transition!
- At age 12-14 ask your doctor about the transition plan:
 - At what age will you stop seeing my son or daughter?
 - Do you have recommendations for adult doctors?
 - How can we help my son or daughter become more independent in their self-care and during office visits?
 - Can I meet with a social worker to talk about services and funding?
- Self-Management Skills
 - Medications, therapy, dietary skills
 - Practice having your child actively participate and manage their daily care as much as they are able



Getting Organized for Transition

- Make a list of your healthcare team (name, number, and what they do):
 - Emergency contacts
 - Insurance
 - Supplies/Equipment providers
 - Doctors and therapists
 - Nursing agency
- Make a medical summary
 - Life story of your child
 - Medical problems (date, current treatment)
 - Surgeries (date, doctor)
 - Major hospitalizations
 - Medications (dose, time)
 - Allergies
 - Vaccine record
 - Supplies needed



Review this with your doctor and teen. Carry a copy with you!

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Social Security Disability Determination

- **Make an appointment at the Social Security Office**

- Disability determination is based on the individual's ability to work and the individual's assets at age 18.
 - Parental income is excluded at age 18.
 - Disability determination provides Supplemental Security Income (SSI) and Medicaid health insurance.
 - The Blue Book at www.SSA.gov provides disability criteria.
 - For questions, contact the Social Security Administration (SSA): 1-800-772-1213
- Since there is an individual income limit for SSI, families may want to set up a **special needs trust** to help their loved one with financial support.
 - Contact your local ARC for more information.

Consent and Guardianship

- By law, a person who is 18 or older can give full permission or consent.
- **Informed consent** means that someone can:
 1. Understand their medical problems.
 2. Discuss their test and treatment choices.
 3. Understand the risks and benefits of their tests and treatment.
- Options for decision making support and protection include: **medical power of attorney, guardianship** and a **supported decision-making agreement**
- Contact your local ARC or The National Disability Rights Network at www.ndrn.org for more information.

Transfer to adult providers

- Ask again how long your primary care doctor (general pediatrician) and other subspecialists will continue to see your child
 - Insurance
 - Hospital privileges
 - Practice policy
- You may want to stagger transfer to adult doctors over the course of several years if your child has multiple doctors
- Discuss what hospital your child will go to if they become ill (pediatric or adult)

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 - **Insurance, insurance, insurance!**
 - **Nursing hours**
 - **Education and Employment**
 - **Dental care**
- **Ages 25 and beyond**
 - Insurance (again!)
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Medicaid Changes

- Be aware that Medicaid can change as the patient ages.
- For instance, currently in Texas, there are two major changes to a patient's Medicaid eligibility and plan based on age.
 - At age 19, the patient will lose their Medicaid if they do not qualify for Social Security Disability Determination.
 - At age 21, the patient's Medicaid changes from a pediatric managed Medicaid to an adult managed Medicaid.

Nursing Hours

- Medicaid requirements for nursing change from pediatric to adult
 - **What care does your son or daughter need?**
 - Write down everything that they need during the day and night.
 - Be specific about how many times per day!
 - **Who is your current nursing care company?**
 - Does this company provide adult care?
 - What adult insurance do they take?
 - **How many hours do you get per week? What about respite?**
- Need help with getting more nursing hours?
 - Contact National Disability Rights Network at www.ndrn.org to help ensure accountability in health care for individuals with disabilities.

Education & Employment

- Per the IDEA, everyone has a right to an education.
 - While in school, those that qualify should have an annual Individualized Education Program (IEP), which should include a transition plan.
 - Obtain copies of all testing (i.e. neurocognitive testing) from the school system prior to graduation.
 - In some states, those that qualify can even remain in school beyond age 18, or the traditional age of graduation.
 - Contact the National Disability Rights Network at www.ndrn.org with any questions.
- After graduation
 - While not everyone can have traditional employment, every patient needs a plan for after graduation.
 - Depending on the patient's diagnosis and capability, families should work with one of the three following resources:
 - The case manager with their Medicaid Waiver program
 - The service coordinator with their insurance plan
 - Or the local state employment training agency
 - In Texas, we have the Texas Workforce Commission (www.twc.state.us)

Dental Coverage

- Dental coverage through Medicaid can be reduced at age 21.
- Medicaid Waivers can help with dental coverage.
- If the patient needs a dentist who provides sedation, potential resources are the following:
 - The patient's pediatric dentist.
 - The local dental school.
 - The patient's insurance service coordinator.

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Private Insurance

- Adults with disabilities can remain a permanent dependent on their parents' health insurance.
 - Call the employer's human resources department for the adult disabled form **before age 26!**
 - Call your state Medicaid to find other resources.

Medicare

- The Social Security Disability Insurance (SSDI) program pays benefits to adults who have a disability that began before they became 22-years-old. It is considered SSDI benefit as a “child’s” benefit because it’s paid on a parent’s Social Security earning record.
- The SSDI funds may be more than the person with a disability can have to receive SSI/Medicaid. If they lose SSI, they will lose Medicaid.
- Disabled Adult Children (DAC) states that someone with a disability can be dual eligible for both Medicaid and Medicare. After receiving SSDI/Medicare, they have to re-enroll in Medicaid.

Long Term Planning

- Discuss options with your family early and often for where your child would live and who would support them if you as a parent or primary care-giver were no longer able to
 - Group home?
 - Own home with supports?
 - Move in with a different family member?

Stay Up-to-Date

- Visit the resources below to view their site and get connected:
 - The National Arc: <https://www.thearc.org/>
 - The National Rehabilitation Association: www.nationalrehab.org
 - The National Disability Rights Network: www.ndrn.org

Thank you!