Life is full of firsts. Do you remember when you first went to see a physician without your parent? What about your first job interview? How did you prepare for these new experiences?

The answer for many of us is that we didn’t prepare. It just happened! We may have practiced a few interview questions beforehand, but in general we take for granted that we often do not prepare for these momentous life events. When we hit roadblocks, we then reach out to those around us for assistance.

Our loved ones with Down syndrome and other special needs are constantly in transition - developing new skills, facing new challenges and transitioning from one stage of life to another. As a parent, you may be asking yourself questions such as: Will he be able to live alone? Will she be able to hold a job? Will he be able to advocate for his own medical care? These are simple questions about complex issues, and the answers are very specific to your family and child.

Experts debate what age physicians should start discussing transitions with patients and their parents. Many parents who have successfully navigated this road recommend that transition discussions and planning should start around age 12. To succeed, transition involves creating a network of support between parents, school system, service providers, and health care professionals. To get you started, I’d like to recommend that you next think about the following considerations:

• IDEA: The Individuals with Disabilities Act (IDEA) is a federal special education law that ensures that all individuals with disabilities are entitled to a “free appropriate public education.” What you may not know is that the IDEA requires your child’s school to focus on transition planning! Starting at age 16, you can incorporate transition goals into the IEP. Your child’s participation in this IEP meeting is really important. Some suggested additions to the IEP may include a stronger emphasis on independence with daily living, self-help skills and advocacy.

• Turning 22 Law: Massachusetts has a second law, which is commonly referred to as the “Turning 22 law” or the Chapter 688 law. Young adults who are receiving Social Security Income (SSI) and/or Social Security Disability Insurance (SSDI) are eligible for Chapter 688. You should consider asking your school to submit a 688 referral for your child at least 2 years before they are expected to turn 22. The school will then connect you and your child with a local human service’s agency such as Department of Developmental Services (DDS) or Department of Mental Health (DMH). The agency will then assist you and your family in creating an Individual Transition Plan (ITP), which focuses on vocational, residential and ancillary support services. These are all free services.

• Guardianship: It is important to remember that when a young adult turns 18 years of age, they are considered their OWN legal guardian. If you feel like your child is unable to provide informed consent, you may want to pursue guardianship. There are also less restrictive alternatives to guardianship, which consist of limited guardianship, durable power of attorney, etc. This topic can be very overwhelming to families. Massachusetts has numerous resources that can assist families through this process. (Some are listed at the end of this piece.)

• Finding a New Adult Doctor: Your child’s pediatrician should help you and your child with the transition from pediatric-based care to adult-oriented care. At the MassGeneral Hospital Down Syndrome Program, we prepare young adults for the eventual movement to an internal medicine practice. All individuals should ask their primary care physician for a health summary document that summarizes all of their medical care. It is also reasonable to ask the pediatrician to speak with the new internist about your son or daughter prior to the initial visit.

All children should be encouraged to advocate for their own needs. Parents can role play a medical visit with their children and slowly but surely your child will feel more comfortable talking to the doctor as opposed to having his or her parent speak on their behalf. Here is one parent’s comment on her experience with healthcare providers:

“Preparing your kids to become adult patients doesn’t have to be complicated. Just start giving them lots of tiny chances to practice, and they’ll surprise you. Before you know it, adulthood will be here and they’ll be ready. Even if we’re not!”

–Cristin Lind

Got Transitions, Why Transition Matters.

Transitions can definitely be overwhelming but parents and guardians have an incredible opportunity to help their loved one to become a successful, fulfilled adult. This is really exciting! Continue to dream big and set achievable goals. Remember you are not alone. The Massachusetts Down Syndrome Congress (MDSC) is here to support you, and you can rely on your local school system, community programs, and health care providers as well.

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The Ins and Outs of Transition continued

Transition Resources

1) Mass General Hospital Down Syndrome Program’s adolescent and young adult clinic focuses on medical wellness and transition planning.  
   www.massgeneral.org/downsyndrome

   Jo Ann Simons: Woodbine House Publications  
   www.woodbinehouse.com

3) Got Transition: National Health Care Transition Center  
   www.gottransition.org

4) Think College: College options for people with intellectual disabilities  
   www.thinkcollege.net

5) Guardianship and Alternatives to Guardianship

   • Massachusetts Guardianship Association: Useful information and resources regarding guardianship and alternatives to guardianship within Massachusetts.  
     www.massguardianshipassociation.org

   • Disability Law Center  
     www.dlc-ma.org  
     800-872-9992

   • Mental Health Legal Advisor’s Committee  
     www.mass.gov/mhlac  
     800-342-9092

6) For more information about Chapter 688 and transition requirements of IDEA:  
   www.doe.mass.edu/sped/links/transition.html  
   The Parent Training Information Center at the Federation for Children with Special Needs  
   1-800-331-0688

7) Social Security: The process of applying for Social Security benefits as an adult with a disability starts at age 18. For information on SSI/SSDI, go to  
   www.ssa.gov/disability

8) The Arc of Massachusetts:  
   www.arcmass.org