## Family Education Sheet

## Moving from Pediatric to Adult Care: Top Things I Wish I Knew About Transition to Adulthood



childrenshospital.org/ autismspectrumcenter

This Family Education Sheet was created by the Family Advisory Council (FAC) at the Autism Spectrum Center. The FAC is made up of parents and caregivers of children like yours, and many of them have helped their own children transition from adolescence to adulthood. This sheet is for a parent/care giver of children 14 or older.

- 1 Remember that autism is a spectrum disorder. The transition to adult care looks different for every family. Not all information that you may come across about transitions for a child/person with autism may be relevant for you and your child. Look for <a href="check lists and time lines">check lists and time lines</a> offered by autism resource agencies to help you stay focused.
- 2 Listen to others and build a network of people you can talk to and ask questions. This could be friends or people associated with your child's medical team.
- 3 Before the transition process starts, step back and think about your family's vision for your child's future, including needs and goals.
- 4 **The path toward transition looks different for each person.** Some may head for <u>college</u>, while others need <u>more support</u>. Avoid the comparison trap.
- There is a lot of information about transition out there, and it can be hard to sift through and find the <u>most relevant information for your family</u>. Don't be afraid to speak up or be the "squeaky wheel". **Take your time,** see what matters most for your unique situation and save it.
- Organize all of the information you get about resources for transition. Binders are a great tool.
- 7 **Keep track of all the forms you submit for services,** such as Supplemental Security Income (<u>SSI</u>), <u>MassHealth</u> and Department of Developmental Services (<u>DDS</u>). You may need them again down the road. Make photocopies or scan and save them just in case!
- 8 Create an email just for your child, so you can store all communications in 1 place.
- 9 Get legal advice about financial questions. Other parents are a great resource for learning which legal experts are skilled in this area.
- 10 **Pay attention to <u>laws</u>** because they can change.
- 11 Attend information <u>trainings</u> and seminars early on. Even if you hear the same information many times, it will help you feel more prepared when your child reaches 16-18.
- 12 **Plan ahead.** Services and supports related to transition, such as <u>guardianship</u> and Social Security, are often a multi-step process. Start thinking about these services ahead time to stay on track.
- 13 It may not be easy, but **you** can do this.

## References

- · Checklists and timelines
  - o <a href="https://www.mass.gov/files/documents/2018/02/15/resource-quide-transition-aged-youth-and-young-adults-14-22-years-with-autism-spectrum-disorder.pdf">https://www.mass.gov/files/documents/2018/02/15/resource-quide-transition-aged-youth-and-young-adults-14-22-years-with-autism-spectrum-disorder.pdf</a>
- E-mail
  - o <a href="https://www.google.com/gmail/">https://www.google.com/gmail/</a>
- · Most relevant information for your family
  - https://www.childrenshospital.org/centers-and-services/programs/a- -e/autism-spectrum-center-program/resources/transition-to-adulthood
- College
  - o <a href="https://thinkcollege.net/college-search">https://thinkcollege.net/college-search</a>
- More services
  - o <a href="https://www.mass.gov/orgs/department-of-developmental-services">https://www.mass.gov/orgs/department-of-developmental-services</a>
- Support
  - o <a href="https://www.mass.gov/orgs/massachusetts-rehabilitation-commission">https://www.mass.gov/orgs/massachusetts-rehabilitation-commission</a>
- SSI
  - o <a href="https://www.ssa.gov/locator/">https://www.ssa.gov/locator/</a>
- Masshealth
  - o <a href="https://www.mass.gov/topics/masshealth">https://www.mass.gov/topics/masshealth</a>
- DDS
  - https://www.mass.gov/dds-eligibility-services
- Laws
  - o <a href="https://thearcofmass.org/post/category/news">https://thearcofmass.org/post/category/news</a>
- Trainings
  - o https://thearcofmass.org/webinars
- Guardianship
  - o <a href="https://www.mass.gov/lists/probate-family-court-forms-for-guardianship-and-conservatorship#informative-and-instructional-materials-">https://www.mass.gov/lists/probate-family-court-forms-for-guardianship-and-conservatorship#informative-and-instructional-materials-</a>