

Parents Reaching Out provides resources that focus on helping families make informed decisions about the care and education of their children. Keeping your family healthy means knowing how to navigate the health care system and talk with your doctor or other providers. We hope these tip sheets will give you the information you may need to access the best, most cost-effective medical and related services to meet the needs of your family.

Parents of children with special health care needs and disabilities need to plan, connect, advocate and find information on behalf of their child. Planning ahead is very important and makes a difference. There are important things to consider as you prepare your adolescent to become more independent in adulthood. Young adults need increased responsibility for their own health care. This means that it is important for families to plan for transferring health care from a pediatrician to adult health care providers. Here are some tips to consider:

- Begin by age 14 but plan over a period of time. Make a plan that is specific to your adolescent and his/her special health care needs.
- If your adolescent has a special health care need or disability significant enough to interfere with his/her ability to make financial and medical decisions, you will need to file a petition to the court six months before your adolescent turns 18 to maintain guardianship or to initiate conservator ship.



- Ask the provider how and when age-appropriate information will be shared with your adolescent about: his/her disability or chronic illness, sexuality, preparing for parenthood, genetic counseling, vocational awareness, work opportunities and leisure time.
- Suggest to the provider that he/she meet privately with your adolescent to discuss topics such as physical, emotional and sexual development, relationships and friendships, sexuality, alcohol, drug and tobacco use, and family issues.
- Ask the provider who on his/her staff can assist you in care coordination.
- Ask the primary care provider or nurse for help in identifying others such as school nurses and personal care attendants who can help manage your adolescent's care.
- Talk to your adolescent about his/her condition and or disability in a way that he /she can understand. If your adolescent has development disabilities, work with his/her primary care provider to choose the key points and figure out how to make them clear.



- Help you adolescent understand the importance of the medication he/she takes.
- Encourage your adolescent to make his/her health care appointments.
- Encourage your adolescent to prepare for doctor visits by writing down questions in advance. Young adults should learn how to keep their own health notes and records.
- Begin teaching your adolescent about his/her insurance coverage. Source: Institute for Community Inclusion at Children's Hospital, Boston, Massachusetts

For information about Transition Health Care Issues, contact Children's Medical Services 1-877-890-4692 or Parents Reaching Out 1-800-524-5176.

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