Introduction and Background

Health insurance is very important for youth with special health care needs.

- A person with special health care needs has a higher risk for long-term physical or mental health conditions. This means that they also need more health care services than other people usually would need.

- Many youth with special health care needs have a developmental disability (DD).

Youth aging out of public aid and private health insurance must find other coverage.

- Most youth have insurance coverage. Coverage is usually subject to age-related cutoffs.

The Affordable Care Act will help young adults with DD get continued insurance coverage.

- Youth who rely on Medicaid need to plan for the future.

Adults with DD must go to self-directed care.

- When youth go to adulthood, many think that they will begin managing their health care. As legal adults, they usually can make their own treatment decisions. They can enjoy privacy about their medical appointments and records. Youth with I/DD must not be an exception.

Adults with DD have changing health care needs.

- Children and adults have different health care needs. Adults need to go to adult-based doctors.

Youth with DD need health care transition support services to go to adulthood.

- Health care transition services help to make sure youth keep access to health care, can take control of their own care as adults, and transition well to adult providers.

- Youth with special health care needs may need preparation and support to keep insurance.
**Recommendations**

1. **Expand funding for medical “homes” and transition services.**
   - The medical home model involves a personal doctor who leads a team of providers.
   - Youth who receive care through medical homes are more likely to receive transition services.
   - Evidence shows that the medical home model increases access to planning for youth. We recommend that more states include refunds for “health home” services.

2. **States must expand Medicaid to adults with incomes below 133% of the Federal Poverty Line.**

3. **Increase education on transition planning.**
   - Education for parents and doctors should focus on the importance of going to an adult model of care.

4. **Further research on outcomes of transition support programs**
   - Research should focus on the outcomes of services. Research has only focused on rates of services.
   - Youth with I/DD may have unique needs. Research must occur to find the best ways of supporting these youth as they reach adulthood.
   - Studies have focused on reports by parents. This is rather than the youths and young adults themselves. Youth and young adults have their own views.
   - Research on more transition support services, including nutritional and sexual health
   - Research on health care transition support through non-medical providers
   - Places like public schools should include health care in transition plans. A high school student may be getting transition support from a doctor. They should work with the student’s Individualized Education Plan team.