

Issues

Down Syndrome Advocacy Day
NC General Assembly
16 West Jones Street
Raleigh, NC

The goal of Down Syndrome Advocacy Day is to come together to share a common message.

We will address two issues that cover the life span of all individuals with Down syndrome. Please choose a topic that relates to your loved one with Down syndrome and craft a personal story based on the topic. Examples are provided below.

Education and Medicaid – both hot topics, not only in NC, but nationally.

Important advocacy tips:

- Be brief
- Remain non-partisan and respectful
- Remain on topic
- Rehearse your personal story
- Be prepared
- Do not use disability specific language, jargon, or acronyms

Issues related to Education

- Early intervention (birth to age three)
- School age (3-21)
- Post-secondary education
- Vocational Rehabilitation

Issues related to Medicaid

- If your child/self-advocate has Medicaid – share the benefits or drawbacks
- If your child/self-advocate is waiting for services – how has your child/self-advocate suffered
- If you anticipate your child/self-advocate qualifying for Medicaid – what will that mean them or your family

In three minutes or less, tell your personal story as it relates to either education or Medicaid. Your story can either be informative or it can present a problem that includes a solution that you are asking for. A simple solution for Medicaid and education is funding. You can make a point such as: The Medicaid Innovations waiver provides supports so your loved one can live as independently as possible. You have seen the benefits of the program for other families, but your child has been on the waitlist for X years. We need to increase funding for the Innovations waiver.

Choose only one topic, as your time is limited. Highlight successes or limitations and failures as they relate to one topic of education or Medicaid policy.

Examples of how to tie your personal story to one of the topics:

These examples are a starting point. Include more details or explanations of the issue you are discussing.

Use your child's name as often as possible to make it personal.

Early intervention – child with significant health issues or feeding problems – how services through early intervention allowed your child and family to overcome those challenges and now you have a happy, healthy, five year old getting ready to start kindergarten next school year.

School age education – your child is flourishing being fully included in family life and out in the community. However, every day your child goes to school only to be sequestered away in a self-contained, separate setting classroom with no opportunity to have relationships with their typically developing peers, no opportunity to have positive role models, and no access to the traditional school experience. Best practices have proven the benefit to all students when children with Down syndrome are included in regular educational settings. We must move away from discriminating against children with Down syndrome.

Post-secondary education – how devastated you were when you received your child's diagnosis of Down syndrome and how your hope for the future was crushed. Instead, you have experienced a wonderful life and you are proud of and have celebrated your child's many accomplishments. Now you are filled with the anticipation of your child attending one of the state's post-secondary programs. Share how this will improve your child's life and future.

Vocational Rehabilitation – as your child was growing up, you prepared him/her for adulthood and the opportunities that would include. However, your adult child sits idle many hours of the day because of the lack of employment options and job coaches through Vocational Rehabilitation. Although ABLE Accounts now allow your adult child to earn money without losing necessary benefits, there are no options for sustainable employment.

Medicaid is not an easy issue to address. It is a complicated, multi-faceted program. Parents barely understand how it works. Legislator's knowledge will likely be limited. Medicaid is in the process of being reformed.

Innovations waiver – which may need explaining – if you are lucky enough to have it, you could tie it to your personal story if your family faced challenging times when your breadwinner was unemployed, but the waiver paid for services that benefited your child who reached certain milestones. Without the waiver, you would not have been able to meet those needs. Thousands of families are without the Innovations waiver because lack of funding keeps them on the waitlist for years.

Medicaid for an adult – again tying it into your personal story about your relief to know that as an adult, your child, who would no longer be covered on your health insurance policy, will have access to health care and a healthy future to live out his/her dream. Medicaid reform must take into account individuals with Down syndrome and the long-term consequences of removing or limiting services or funding.

Medicaid for a child - Explain your family's situation that qualified your child with Down syndrome for Medicaid. Without Medicaid, your child would not have access to adequate health care or therapies.

Alternative to addressing one issue:

If you do not want to address one of the issues specifically, you can discuss education and or Medicaid in general as programs that do or will benefit your child. Stress that individuals with Down syndrome are often overlooked when decisions on policies regarding education and Medicaid are made. Express your concern about the national dialogue surrounding reforms to both programs and that you fear safeguards protecting your child and programs that benefit your child are in jeopardy.

You can talk in more general terms:

Our children are not leaving school prepared to enter the workforce. The workforce that is not welcoming to individuals with Down syndrome. Without adequate employment opportunities and a sustaining income, adults with Down syndrome rely on Medicaid to maintain their health. They are forced to remain living at home with parents or siblings. They sit idle many hours of the day because of lack of opportunities for employment and social connections.