

## Visiting your Senator or Congressman: Script

### PART A

*F2F Director Green:* Good morning, Ms. Allen. Thank you so much for agreeing to meet with us today. We know you are very busy and we really appreciate your time.

*Ms. Allen/Legislative Aide:* I'm sorry Senator Jones couldn't be here but he had a prior engagement that he couldn't get out of.

*FV Coordinator Brown:* We know that you will share our concerns and recommendations with Senator Jones.

*F2F Director Green:* Before we start, I'd like to introduce the people who are here with us. I'm Tomasina Green, the Director of the State Family to Family Health Information Center at the Statewide Parent Group. This is Linda Brown, longtime Family Voices coordinator for the state (Family Voices is a national organization that speaks on behalf of families of children with disabilities and special healthcare needs); Violet Azure, a parent volunteer for our Family to Family Center; Redina Anderson, a parent; and Amanda Blue, another parent. All of us are parents of children and youth with special healthcare needs.

### PART B

*Ms. Allen:* I am so happy to meet all of you. I'm Rebecca Allen and I work on health and disability issues for Senator Jones. Of course, I'm familiar with the Statewide Parent Group, but what exactly does your Family to Family Health Information Center do?

*Volunteer Azure:* At the Family to Family center, we help families of children and youth with special healthcare needs get health and other services. We have a toll-free telephone number that parents and professionals can call to get answers to their questions; we do workshops all over the state on things like Medicaid, the State Children's Health Insurance Program, transition, early intervention, and partnering with healthcare professionals; and we work one-on-one with families who need the most help. Last year, we helped over 5,000 parents and 2,500 professionals.

*Parent Blue:* If it wasn't for the Family to Family Center, I wouldn't have the nursing services my child needs to be able to stay living at home and going to our neighborhood school. I would have had to send him to live and go to school in an institution. Because of the Center's help, I was also able to go back to work.

*Ms. Allen:* What exactly is your child's special healthcare need, Ms. Blue?

*Ms. Blue:* Well, he has cerebral palsy and chronic lung problems. He has to be on a ventilator all the time and he also has to take medication intravenously, or he could die.

*Ms. Allen:* That must be a lot for you to deal with.

*Ms. Blue:* Oh, it is! Before I found out about the Family to Family Center, I was at the end of my rope. I had to quit my job, I was having trouble paying my bills, and I was angry all the time. They really helped me and my son! It made such a difference to be able to talk to another parent of a child with special needs who knew what I was going through and who worked so hard to help me get what my child needed. And he's such a great kid.

## **PART C**

*Ms. Allen:* Thanks for giving me that information about your Center. How can I help you?

*F2F Director Green:* Ms. Allen, Ms. Blue's story is just one of thousands of stories of families of children with special healthcare needs that our F2F Center has helped in the last year. With a grant of less than \$100,000 from the U.S. Maternal and Child Health Bureau, we provided information, training and support to over 7,500 parents and health professionals. We helped them navigate the very complicated healthcare and other systems for children and youth with special needs with really positive results. We help families of children with all kinds of special needs, from diabetes, allergies and asthma, to intellectual disabilities, to autism and emotional disabilities. Unfortunately, the funding for the Family to Family Centers ends in less than a year and unless we can get funding restored, all the families we have helped and the many more families who haven't found us or needed us yet will have nowhere to turn.

*Mr. Anderson:* Before the Family to Family Center, I was on my own dealing with my daughter's insurance company. They kept turning me down for the services her doctor said she needed. The Family to Family Center helped me understand my insurance policy, what was covered and what wasn't, and they worked with me to find the right primary care doctor and specialists in our network. They also helped me file an appeal of the insurance company's denial of coverage and win! My daughter is still quite young, and even though I'm learning about how to advocate for her from the Family to Family Center, I can't imagine what it would be like without their support. They even helped my doctor understand how to do a better job in coordinating her care, which is really great for us but also more cost efficient.

## PART D

*Ms. Allen:* So if this program is so wonderful, why is its funding running out?

*FV Coordinator Brown:* The Family to Family Center funding was in the 2005 Deficit Reduction Act in the Family Opportunity Act, championed by Senators Kennedy and Grassley and Representative Pete Sessions. It started with 20 centers being funded two years ago, another 20 being funded last year, and the final 10 being funded just this past June. The authorization language itself contained a specific amount of funding, but there was no funding identified after the end of the third year. Because of this, there will be no funding for the F2Fs after this coming year unless Congress acts this year.

*Ms. Allen:* What is the cost of funding the F2Fs?

*F2F Director Green:* This year there is \$5 million allocated. Each Center receives the same amount of money, \$96,500, regardless of the size of the state. We're a big state so we have to do a lot with a little money. Also, we know that the territories and native American tribal organizations have requested money to start F2F for their families as well. That's why Family Voices and our Center are asking Congress to increase funding to the Family to Family Centers to \$12 million. That way, states with larger populations can get additional funds to help more families. We also want to make sure that Family Voices continues to get funds to provide us with support so that we can do the best job possible to help children and families. Can we count on Senator Jones to support funding for Family to Family Health Information Centers such as ours?

*Ms. Allen:* Well, obviously I can't speak for the Senator. I can tell you that he has supported the idea of a patient navigator in previous discussions.

*Volunteer Azure:* Ms. Allen, the Family to Family Health Information Centers *are* the patient navigators for families of children and youth with special healthcare needs. It doesn't make sense to set up a national network of 51 centers, staffed by experienced, committed and compassionate parents of children with special needs who know how to navigate the healthcare system, only to dismantle it one year after the final group of 10 centers has been funded! Our Center, like most of the centers, helps every family who contacts us for help, no matter what their child's disability or healthcare need. It would make more sense to give us additional funding and just use us as the patient navigator for children's healthcare than to stop funding us and start with a whole new "patient navigator" system.

## PART E

*Ms. Allen:* What kind of support is there in Congress for Family to Family Center funding?

*F2F Director Green:* Senators Bingaman from New Mexico and Snowe from Maine got 12 Senators to sign a letter to the Senate leadership in favor of F2F funding, including Senators Menendez and Lautenberg from NJ; Bernie Sanders and Patrick Leahy from Vermont; Stabenow from Michigan; Gillibrand from New York; Ted Kaufman from Delaware, Tim Johnson from South Dakota, and Kent Conrad from North Dakota. Senator Menendez' aide Megan Moreau is working with Family Voices and would be happy to talk with you. Many Congressmen also support F2F funding.

*Parent Anderson:* We really need Senator Jones' help and support. I have a copy of my story and the stories of 10 other parents from across the state who have been helped by the Family to Family Center for you to share with Senator Jones. Their contact information is on their letters asking the Senator to please support F2F funding.

*Parent Blue:* I also have an information packet about the F2F program across the country, including information on all the families who have been helped. This fact sheet summarizes information on the families we've helped here in our state. This program is so cost-effective and efficient. We help families for an average of \$24. It saves the system money in the long run and helps children and families. It's a win-win for everyone! Do you think Senator Jones needs any other information to support our request?

*Ms. Allen:* I think I have all the information I need right now. I will definitely share your request and this information with Senator Jones as soon as I can. I want to thank you again for coming and giving me this information for the Senator to consider.

*Volunteer Azure:* If I didn't think this Family to Family Center was valuable, I wouldn't be volunteering here. But it gives me the opportunity to help parents and their children with special needs. I want to be able to continue to help, especially with all the changes that are happening in healthcare right now! We will contact you in a week or two to see how your conversation with Senator Jones went and whether you need any additional information.

*FV Coordinator Brown:* I've been working with families of children with special healthcare needs in our state for over 15 years. The Family to Family Center funding has made such a big difference! I want to thank you on behalf of our center, our Family Voices network in this state and nationally, and families of children with special healthcare needs for taking the time to meet and listen to us. We are really counting on Senator Jones.

*F2F Director Green:* Yes, thank you so much. We'll be in touch soon. And don't forget that if you have any constituents who have children with special healthcare needs who are having difficulties you or they can just pick up the phone and we will be happy to help.