An Advocate’s Autism Action Kit

Want your government to make the right decisions for people and families affected by autism? Tell them how they can!

In this packet you’ll find:

Government info
- The State of Delaware’s legislative and budget processes
- State legislators’ contact information

Action Guides
- Writing to your legislators
- Writing to your local papers
- Meeting with your legislators- at their offices, constituent gatherings, or even in your home!
- Tips for people with autism on visiting Legislative Hall

For the most current information about policy issues Autism Delaware is working on, visit www.autismdelaware.org!
The Budget and Legislative Process - A Brief Overview

The Budget

Delaware’s fiscal year runs July 1 through June 30. In the executive branch, state agencies work over the summer and fall to develop their budgets and submit their requests to the Office of Management and Budget in October. In November, the agencies make formal presentations of their requests to OMB in a series of public hearings, at which the public is invited to testify. The information presented forms the basis for the governor’s budget, which they submit to the General Assembly in January.

On the legislative side, the governor’s budget is promptly introduced as two new pieces of legislation - the operating and capital budgets. The Joint Finance Committee, made up of six representatives and six senators, then holds six weeks of hearings at which the state agencies make their case for their requests in the operating budget, and again the public is invited to testify. The JFC works throughout the session on the operating budget, and goes into a formal “Mark-Up” process in May, meaning that they add or remove budget lines, or increase or decrease the amounts allocated. All of their deliberations are now open to the public as the result of a 2009 law. The Bond Bill Committee reviews the capital budget requests.

A final budget is presented to all legislators for their vote late in the session - until 2010, legislators typically did not see the budget until the last day when it had to pass. Because of that short time for all legislators to review, it is critical to advocate budget policy issues to JFC members as well as one’s own legislators.

The Legislative Process

How A Bill Becomes A Law

[Diagram of the legislative process]

This graphic may be found on the General Assembly’s website at www.legis.delaware.gov
Writing to Your Legislators

Writing to your legislators is an easy way to make sure they hear your message, and as a constituent, your words carry a lot of weight. Here is an easy outline to follow and a sample letter using it.

- **Introduction:** Tell them what you are writing about in the first or second sentence. Introduce yourself and your family. Tell your legislator that your child (or you) has autism (and/or other disability/ies) and explain what that means and the effects. Tell them about the future your child (or you) hope to have.

- **Middle:** Tell them what issue you are writing about, and how you and/or your family will be affected. If there is no funding for new grads, will a parent have to quit their job or go on public assistance? If there were insurance coverage for autism treatments, what do you believe it would accomplish for your child or family? Would you be able to get out of debt, save for college for other children, avoid bankruptcy, etc.? Be honest and clear.

- **Closing:** Close by repeating your request for their support of your position.

- In any of the above paragraphs, use numbers and dollar figures wherever appropriate, and put your main points in **bold**.

**SAMPLE**

The Honorable Jane Doe  
State Senate  
PO Box 1401  
Dover, DE 19901

Dear Senator Doe,

*I am writing to ask you to support funding for the Family Support Waiver, a program to provide support services for young adults with developmental disabilities who choose to live in their family’s home rather than a state-funded residential placement.* My wife and I have raised two wonderful children in <<neighborhood>>, Jane and Bob. Bob is 20 and has severe autism, a neurological disorder that affects his ability to communicate and interact with others. He cannot speak and finds it very difficult to be around crowds, but the services of the Delaware Autism Program (a public school) and the staff at <<provider>> have helped him to develop work skills like filing, shredding, and sorting to prepare him for a job in a local doctor’s office.

We look forward to both of our children going to work when they complete their education, but unlike Jane and most other young adults Bob’s age, even then he will continue to live year-round with us for the foreseeable future and require constant supervision. Caring for a grown man who can still have tantrums when we cannot understand what he tries to say or when his routine is upset is both emotionally and physically taxing.

Without the help of the Family Support Waiver to get more respite care, we will have to seek a residential placement through the State for Bob. We know a number of families facing similar dilemmas; their son or daughter is comfortable in the family home but just need a little more personalized help—maybe respite or behavioral therapy or transportation - for their families to continue to provide primary care for them.

We know that the State has difficult budget decisions to make. We will care for Bob as long as we are able, and the State is certainly better off spending a couple of thousand dollars to help us do that than spending tens of thousands on residential placements. Please help Bob and the many other young adults like him stay in their homes by funding the Family Support Waiver.

Sincerely,

Pat Smith
Writing to The Media

Writing letters to the editor is a little different. Not only do you have far fewer words available, but they can edit it even further. It’s important to focus on your message, and get just one to three points across as concisely as possible. Again, be clear and honest.

A good letter will catch the attention of legislators and members of the public who might not have known about the issue you’re raising—maybe you’ll inspire others to write too!

These samples are provided to give you ideas, but please do not copy them for your own; if papers get the same story from multiple people, chances are they won’t print them— and the best story to tell is always your own!

My son has autism, and has a better life than I ever hoped for; with the support of a job coach, he has a job he likes delivering mail on the campus of a major Delaware corporation. But his provider has had only a 4% increase in the past three years after eight years with no increase, even as gas and other costs went up. To save transportation costs, my son will soon work his hours over three days instead of five and be home the other two; we are scrambling to find someone to care for him those days so we can continue to work and prepare for when we’re no longer here for him. We’ll take care of him as long as we can, but the state needs to do its part too. Call your legislators and tell them providers of disabilities’ services need fair pay!

Below are email addresses to which you can send your letter(s) to the editor.*

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*Thanks to Douglas Marshall-Steele at www.towardequality.org for collecting these addresses and permitting their use here.
Hosting A Legislative Visit to Your Home

This is a great way to bring the message about how policies affect people and families home to your legislators. By visiting your home, legislators get a firsthand look at why autism-friendly policies are so critical to their constituents.

Inviting Your Legislator
You can invite them by email, phone, or postal mail and be specific about what you would like to discuss. It does not have to be about a specific bill or budget item; if there is a problem you believe state government should be addressing or aware of, that is the kind of thing to keep your legislator informed of.

We suggest you invite their family for two reasons: 1) the opportunity to not have to choose between their service (which is 24/7/365 and often a second job) and time with their family is a kindness and 2) if they are not themselves affected by disability, the visual comparison of your family to theirs may be compelling. If you prefer to meet only with them, that still accomplishes the core goal of making sure they are aware of their constituents’ needs. Inviting other families from their district may also increase the chance of their accepting the meeting because they will be able to address a number of constituents at once.

Offer your legislators a choice of a few different dates and times if you can, and invite them to make their own suggestions. Remember that they are in session Tuesday-Thursday during many weeks between the second Tuesday of January and July 1.

During The Meeting
As host, take the lead in explaining why you invited them. If there is more than one family at the visit, take turns telling how they are (or would be) affected, though it would be best to keep each story to just a few minutes, and then open it up to questions from the legislator.

When politics gets down to such a personal level, it can be easy for the dialogue to go in a direction that makes people feel angry, upset, or defensive. These meetings are intended to raise awareness and secure their support; the latter may take more than one evening and more voices than just those in the room. Focus on keeping the discussion positive and constructive. And of course at the end, thank them for taking the time to meet with you.

After The Meeting
Send your legislator a personal thank-you note for meeting with you, and repeat your request or thanks for their support. Before your guests leave, ask them to write thank-you notes too, and share the legislators’ contact information with them. While your communications with your legislator are of course personal, Autism Delaware does find it helpful to our own advocacy efforts to know how legislators respond to autism issues so if you’d like, let us know how it went!

How Autism Delaware Can Help
If you want to address issues with your legislator that we are working on or support, we can:

- provide talking points;
- identify and invite other families in your district to join you
Meeting a Legislator in their Office or Local Constituent Hour

Personal contact with legislators is very effective. Some host open meetings in their districts on a regular basis, many are willing to set up a personal meeting or call with a constituent, and all have offices at Legislative Hall where they can receive visitors.

Arranging the Meeting
If your legislator does not have a regular meeting in your district or you cannot attend that, you can call or email them to ask for an appointment either in the district or at Legislative Hall when they are in session.

Some people may feel intimidated at the idea of asking for an appointment. Remember that it is their job to represent you and your input helps them do that job. Legislators genuinely like hearing from you!

At the Meeting
You may only have a few minutes with your legislator. Introduce yourself and tell them about your family member with autism or why you are concerned about someone with autism. Explain how existing or proposed policies affect or could affect your family or others that you know. Ask them for their support.

Keep in mind that elected officials are responsible for a wide variety of policies and agencies and may not know the fine details of DDDS adult programs, insurance, or autism. Answer their questions as best you can, and don’t be afraid to say “I don’t know, but I will try to find that out for you.” Then contact Autism Delaware with those questions and we will do our best to get the information.

After the Meeting
Thank them for their time, and follow up with a thank-you note or email. While your communications with your legislator are of course personal, Autism Delaware does find it helpful to our own advocacy efforts to know how legislators respond to autism issues so if you’d like, let us know how it went!

How Autism Delaware Can Help
If you want to address issues with your legislator that we are working on or support, we can:
- provide talking points;
- help secure an appointment in Legislative Hall or find out when your legislators are holding constituent meetings
- send a staff member or volunteer to Legislative Hall to go with you or provide moral support in advance or after your meeting.
Helpful Tips for People with Autism on Visiting Legislative Hall

⚠️ There is a cafeteria in the basement for snacks and to take a break.

⚠️ All adults will need a photo ID.

⚠️ To enter the building, you will have to put your possessions through an X-ray machine and walk through a metal detector. It will beep if it senses metal such as a belt buckle or bra underwire. If it beeps, security guards will stop you. Follow their instructions on where and how to stand. They will pass a wand by your torso, arms, and legs to identify what is causing the beep.

⚠️ There are often delays.

⚠️ There are often crowds and a lot of people talking at once.

⚠️ The upper galleries of the House and Senate (accessible by stairs and elevators) face hanging lights near eye level. There is usually some limited seating in the main chamber if you don’t like bright lights.

⚠️ A sound system is used in the House and Senate and there are speakers at the gallery level and on the main level.

⚠️ The main areas of Legislative Hall and the offices use fluorescent lighting.

⚠️ The House, Senate, hallways, and main foyer have marble floors and high ceilings. There are a lot of echoes.

⚠️ Bells may ring to summon legislators to start working in their chambers. It rings once for the Senate, twice for the House. These bell patterns will ring multiple times once begun.

⚠️ Legislators may talk to you or want to shake your hand. Do the best you can, but if it makes you uncomfortable, you or your parent or companion can politely explain your boundaries to them.