

PROOF Alliance

Parent Advocacy Toolkit

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Self-Advocacy for Young Adults and Children with FASD

School and Employment Supports

Self-Advocacy can mean many things to different people. Here's one definition: "acting to represent yourself and your views or interests." This may sound easy, but to be an effective self-advocate, here are several things you can do to reach your goals.

1. Know yourself!

Knowing your strengths, weaknesses, and needs is very important. This means that you can do research on how FASD impacts you, how others think of you, and what strategies or supports have worked for you in the past. Medical and school evaluations can help too. Also, other trusted people (family, teachers, friends, and others) can give you honest feedback and suggestions.

2. Know the systems and players!

When you work with a school or state vocational rehabilitation services, there are rules, forms, meetings and specific ways to do things. It is important to know who is going to be at the meetings and what rules will be followed. If you know the people and rules, you'll be able to know what to say, when to say it and how to say it.

3. Have a game plan and goal!

It usually doesn't work to just go into a meeting and get what you want. You may have to explain why there's a problem, how the problem might be solved, and why your suggestion makes the most sense. Also, it is important to have a specific goal, clearly express your goal, and be willing to try alternatives and solve problems.

4. Don't give up and try again!

Self-Advocacy can be challenging and it sometimes doesn't work the first time. Don't get discouraged. Patience and dedication are often required to get to your goals. Keep at it! Oftentimes, smaller steps over time can make bigger changes faster. Setting a meeting time in the future to check in about a plan or decision also makes sense.

Top 10 Self-Advocacy Tips for the Special Education (IEP) Process

1. Become Familiar with the Special Education Process, Acronyms and Lingo.

The special education process can be confusing and complex. Fortunately, there is help available for you to learn about what the process looks like and what different words and phrases mean. Knowing what is happening and what people are talking about will help you feel more comfortable participating in the process. Check out the links at the end to find resources to help you become familiar with the process.

2. Have a Plan and Ask Questions

You know your student better than anyone and know what works and what doesn't. An IEP team meeting is an opportunity for you to share your knowledge. Think about what you want to say and what outcome you'd like to achieve BEFORE the meeting. During the meeting, ask questions when you don't understand something or about why the school is suggesting something and if other options have been explored.

3. Find a Staff Person Who Knows and Cares About Your Student.

There is usually at least one (and hopefully more!) school staff person who seems to really understand and care about your child. This staff person could be a paraprofessional, a teacher, a school case manager, a principal, or someone else. Identify the staff people who seem to work with your student the best and ask that they be involved in your student's IEP planning. A positive working relationship with a trusted and caring adult can be key to your student's success in school.

4. Get Prepared and Organize Records.

The special education process involves a lot of documents. You will likely receive a lot of documents so it's important to keep them organized. Documents can also help you advocate for your student. You can share documents that support your requests with the IEP team. These documents may include IEPs, evaluations, notices from the school, and other information about your student.

5. Focus on Successes, Skill Development and Progress

If a student can find areas of success in school, he or she is likely to be more confident and happy at school. Try to identify these opportunities for success, and focus on increasing a student's academic, social, and life skills. You can also ask for more frequent written updates on student progress.

6. Ask the School for Written Notices.

Schools are required to give parents written notices about important decisions and the reason for those decisions. Ask the school to put their decisions and explanations in writing – or in what’s called a “Prior Written Notice” or PWN. This can be a powerful way to understand what the school is doing.

7. Know your Rights, and know that you have 14 calendar days to respond to a school district’s proposed plan.

As a parent of a child with a disability, you have many rights – ranging from getting notices from the school, having a copy of your student’s educational file, getting the school’s proposals in writing, and, for example, being able to agree or disagree to certain services and steps. For example, parents generally have 14 calendar days from the date of a proposed IEP to either agree or disagree. And, remember, if you do not respond in writing to the proposal within those 14 calendar days, the school’s proposal can automatically go into effect (whether you like it or not!).

8. Know that you can challenge a school’s decision or proposal.

There are many different ways to challenge a school’s position, decision or proposal. These options include: having an IEP meeting; doing a “conciliation conference;” participating in a mediation; requesting a “facilitated” IEP meeting; filing a complaint with a state agency; and, among other options, requesting a hearing by a judge. You can find out more about these options from the resources listed below.

9. Keep Calm as Possible and Use Different Ways of Addressing a Problem.

Sometimes problems happen and parents and school staff get upset. Be sure to think through what you want to see happen, consider different ways to communicate your concerns and goals, speak professionally and firmly, and try to actively engage the school team in a problem-solving process. If this doesn’t work, see the next Tip!

10. You can seek help from the Minnesota Disability Law Center.

Our office may be able to help. We take cases based on legal merit, office priorities, and available resources. We have attorneys and advocates that have a wide range of experience in special education. Contact the Minnesota Disability Law Center (MDLC) for free legal help statewide by calling our new client intake number:

1-800-292-4150 (Statewide) • 612-334-5970 (Twin Cities) • 612-332-4668 (TTY)

Top 10 Self-Advocacy Tips for Receiving Services from Vocational Rehabilitation Services (VRS) or State Services for the Blind (SSB)

1. You can apply for services as many times as you want.

You can receive VRS or SSB services as many times as you need. You can always reapply even if you received services before or if VRS/SSB closed your file.

2. You can give VRS or SSB more evidence about your disability if you are placed on the waiting list but think your disability is more severe than the agency realized.

As of May 2017, VRS and SSB are only able to serve some of the people who have applied for services. You may be able to get services sooner if VRS or SSB know about all of your physical and mental impairments, and how severe they are.

3. You have the right to informed choice while you are working with VRS or SSB.

You will choose a job goal after talking with your counselor about your interests and abilities and what jobs would be a good match. Your counselor should tell you about how they can help you achieve your job goal, what services are available, and from which service providers you can choose.

4. You must have a written employment plan to receive services and VRS or SSB must approve services before you receive them.

You and your counselor will develop an employment plan within 90 days of being determined eligible for immediate services or after coming off of the waiting list. VRS/SSB will **not** pay for services that happened before the date of the employment plan, and VRS/SSB will **only** pay for services that they approved.

5. Make sure all of the services that you and your counselor agree on are listed in the written employment plan.

It's important that the employment plan include everything you and your counselor think you need to meet your job goal, so everyone is on the same page about the services you will receive and for which services VRS/SSB will pay. The employment plan must include a deadline for you to reach your job goal and for VRS/SSB to start providing services. You may ask to include other benchmarks in the plan if you think that would be helpful. Your employment plan can be changed later if you and your counselor agree you need more services or different services.

6. Attend scheduled meetings and complete the tasks you agreed to do.

You will play an important role in your employment plan and will have some responsibilities, such as attending meetings with your counselor, writing a resume or completing applications. It's important that you meet your responsibilities.

7. You can ask for a different counselor if things aren't working out with your current counselor, but you don't have a legal right to a different counselor.

If you are having difficulty working with your counselor and can't resolve the problems, sometimes asking a supervisor to change counselors can help. However, you don't have a legal right to a different counselor.

8. If you disagree with your counselor's decision, you have the right to appeal in writing before the agency's deadline. You can also try mediation.

Your appeal may be resolved after a supervisor's review, mediation or an impartial due process hearing. Be sure to request an appeal within 120 days if you are working with VRS or 60 days if you are working with SSB. Keep a copy of your appeal request for your records. Mediation may be an effective way to resolve problems.

9. You have the right to see most of your VRS or SSB file.

You have the right to see most of the information in your file or get a copy of your file. You may be charged copying fees. If you are denied access to some information, you can appeal the denial.

10. You have the right to seek help from the Client Assistance Project.

The Client Assistance Project (CAP) at the Minnesota Disability Law Center (MDLC) provides free assistance and advocacy for people receiving rehabilitation services in Minnesota. CAP helps people with disabilities make sure they have the services they need from VRS/SSB. CAP is not a part of VRS or SSB and we do not provide rehabilitation services.

Self-Advocacy Resources

This is a compilation of websites that contain examples and starting points for various aspects of self-advocacy. Inclusion on this list is not an endorsement of content or scope, but they offer a sampling of the variety of what resources are available.

FASD Information: *General information on FASD*

Proof Alliance <https://www.proofalliance.org/support-and-resources/>

National Organization on Fetal Alcohol Syndrome: <https://www.nofas.org/>

American Academy of Pediatrics: <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>

US Center for Disease Control and Prevention: <https://www.cdc.gov/ncbddd/fasd/index.html>

Olmstead: *“Olmstead” refers to a US Supreme Court Decision that discusses the rights people with disabilities must be integrated into the community*

Olmstead Rights advocacy organization: <https://www.olmsteadrights.org/>

State of Minnesota Olmstead Plan: <https://mn.gov/mdhr/news-community/partnerships/olmstead.jsp>;
<https://mn.gov/dhs/general-public/featured-programs-initiatives/olmstead-plan/>

Student Self Advocacy: *General Self Advocacy Resources for K-12 Students*

The Arc: <http://www.thearc.org/what-we-do/resources/publications>

Great Schools: <http://www.greatschools.org/gk/articles/self-advocacy-teenager-with-ld/>

Parent Center Hub: <http://www.parentcenterhub.org/repository/priority-selfadvocacy/>

Autism Speaks: <https://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit/self-advocacy>

York University: <https://teachingselfadvocacy.wordpress.com/>

Transition Age: *Resources for students ages 14-12 who are transitioning from school to community settings*

PACER: <http://www.pacer.org/transition/>

MOFAS: <https://www.mofas.org/resource/transition-plan/>

Wisconsin Community of Practice on Transition:

<http://www.waisman.wisc.edu/cedd/pdfs/products/health/THCL.pdf>

K-12 Educational Strategies: *Specific educational strategies to use in the classroom to help children with FASD*

Emory University: <http://www.psychiatry.emory.edu/PROGRAMS/GADrug/Edfas.htm>

Sanford School of Medicine of The University of South Dakota:

<http://www.usd.edu/~media/files/medicine/center-for-disabilities/fasd-educational-strategies-handbook.ashx?la=en>

US Center for Disease Control and Prevention: <https://www.cdc.gov/ncbddd/fasd/educators.html>

MN ADOPT: <https://www.mnadopt.org/wp-content/uploads/2014/03/FASD-Strategies-and-Intervention.pdf>

Worksheets/Planners: *Starting points to develop strategies and plans for self-advocacy*

National MS Society:

<http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Paper-Self-Advocacy-Worksheet.pdf>

Pennsylvania State Education Association:

<https://www.psea.org/uploadedFiles/TeachingandLearning/SelfAdvocacy.pdf>

Idaho Council of Developmental Disabilities:

https://icdd.idaho.gov/pdf/parent_league/secondary_transition/Self%20Advocacy%20Checklist.pdf

Connecticut Parent Advocacy Association: <http://cpacinc.org/wp-content/uploads/2009/12/Self-advocacy-checklist1.pdf>

Olmstead Rights advocacy organization: <https://www.olmsteadrights.org/self-helptools/>

Toolkits: *Longer and more comprehensive self-advocacy planning tools*

Disability Rights Wisconsin: <http://www.disabilityrightswi.org/wp-content/uploads/2008/02/advocacy-tool-kit-2007.pdf>

CBM: http://www.cbm.org/article/downloads/54741/The_Self_Advocacy_Toolkit_-_For_Mental_Health_Service_Users.pdf

Policy Advocacy: *Ways to learn about and get involved in policy advocacy*

Minnesota Governor's Developmental Disability Council: <http://mn.gov/mnddc/pipm/>

MOFAS: <https://www.mofas.org/public-policy/advocacy-toolbox/>

Minnesota Olmstead Plan: <https://mn.gov/mdhr/news-community/partnerships/olmstead.jsp>;
<https://mn.gov/dhs/general-public/featured-programs-initiatives/olmstead-plan/>

Minnesota Organizations with Information on Self Advocacy

Self-Advocates of Minnesota: <http://selfadvocacy.org/programs/self-advocates-minnesota-sam/>

Links to other self-advocacy groups: <http://www.selfadvocacyonline.org/find/state.asp?state=mn>

Self-Advocacy Webinars for parents with children or young adults with an FASD.

FASD and Special Education. This webinar includes the fundamentals of special education law, processes, and principles and is available here: <https://youtu.be/uBrdCi4OWxA> .

Hello from the Other Side: Employment-Related Options for Transition Age Youth. This webinar provides information about different supports and services to promote complete integrated employment and is available here: <https://youtu.be/z5CUFZL-5H8>

Want to Find out More?

- MDLC's Fact Sheets: <http://www.lawhelpmn.org/issues/disability/>
- Minnesota Department of Education FAQs: <http://education.state.mn.us/MDE/dse/sped/caqa/>
- PACER Center Publications: <http://www.pacer.org/publications/>
- Glossary of Terms and Acronyms: <http://www.specialeducationguide.com/special-education-dictionary/>
- MDLC webinar on special education basics: <https://youtu.be/uBrdCj4OWxA>