

15 Tips for Parent & Family Member Advocates

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Your goal is to best prepare your child or family member for adulthood and to ensure they have the services and supports to reach their goals. For many families this means communicating with agencies and systems that offer services to people with disabilities. It can also mean attending meetings and advocating on behalf of your loved one. This fact sheet includes tips to help you prepare for meetings, develop the best plan for your child or family member, and resolve conflicts that may arise in the process.

1. Start with the Individual

The most important person in the planning process is your child or family member. Begin the process by thinking about the individual's goals, rather than a list of services. This will help you be in a better position to develop a more individualized and effective plan. Start with the big picture and work backwards. What are the individual's goals? Where are they now? What would it take to achieve those goals?

Talk with your child or family member about these topics. Encourage them to participate in the planning process and empower them to make decisions and have ownership of their plan and services. In doing so, you will be supporting the individual's choices. You will also allow them to have a better picture of what is needed to achieve their goals.

Once you have answered these questions, you will be better able to determine the timelines, services, agencies and organizations that should be included in the planning process.

2. Keep Records

It is good practice to keep copies of documents, assessments, letters and notices related to your child or family member. You can keep them in a folder or notebook. You may even save documents electronically so that important papers don't get lost.

Most agencies are legally required to provide you with copies of your child's records. If you need records that you do not have, you may ask for additional copies of your/your child's records at any time.

If you speak to someone over the phone, get the name and title of the person that you spoke to and the agency they work for. Follow up with a letter or e-mail about the conversation you had and the information they shared with you. If needed, ask them to send you the information in a letter or by e-mail.

When determining what records are helpful to share with an agency, consider: Is this record an accurate representation of my child or family member? Is it relevant to the service(s) I am requesting? If you have records that will assist you in your advocacy efforts, take them with you to the meeting or attach them to your meeting request. It is also important to keep a record of who you gave information to, when and what you gave them.

3. Ask for What You Need

Although many agencies have planning meetings annually, you can ask for a meeting or request services at any time. We recommend that you make your request in writing and explain what you would like to discuss at the meeting. It may be helpful to include in your request when you are available to meet. The request should include the people that you would like to be present at the meeting. You can also include a reasonable deadline by which you would like the agency to respond to your request. A reasonable deadline should allow the agency enough time to consider your request and should meet your child or family member's needs.

4. Primary Language

You have the right to receive information in your primary language. You have the right to request an interpreter in your primary language, including American Sign Language (ASL). If you have a disability, you have the right to receive information in alternative formats such as, Large Print, Braille, etc. You may request the agencies provide an interpreter for meetings and/or written documents in your primary language or in an alternative format.

5. Know your Rights

There are many different agencies that assist people with disabilities. Some individuals may need services from many different agencies, while others may only need services from one or two.

Each agency may have different laws, policies and procedures that govern who they serve, what type of services they provide and what their process is for providing services to people with disabilities. Disability Rights California provides advocacy and information about the agencies that provide services to people with disabilities in California. To view our publications or request assistance please visit, www.disabilityrightsca.org or call (800) 776-5746.

Many agencies post links to relevant laws on their website. For information about special education, see California Department of Education: www.cde.ca.gov. For information about services for people with intellectual or developmental disabilities/Regional Center services, see California Department of Developmental Services: www.dds.ca.gov. For information about pre-employment transition services and vocational rehabilitation programs see California Department of Rehabilitation: www.dor.ca.gov.

6. Prepare

Before a meeting, give yourself time to review documents, assessments and records. If the agency you are meeting with will be reviewing new assessments or reports with you at the meeting, you can ask for a copy in advance. Consult with other parents, teachers and professionals about their experiences and suggestions. Make sure relevant team members and decision makers will be present at your meeting.

7. Plan

Talk with your child or family member before the meeting about their goals, needs and preferences. Make an outline of things you would like to discuss at the meeting. If you are requesting a service, it may also be helpful to make notes about why you think the service is needed. You can bring documents with you that help to support your request. For example: medical records, assessments, records produced by other agencies, labor market information and online research. You may also write down a list of questions you have to ensure that you remember to discuss them at the meeting.

8. Participate

The individual should be the focus of the meeting. It is important that they share information about their goals, abilities, interests, capabilities and challenges. Encourage your child or family member to participate in the meeting as much as possible. If your child or family member needs accommodations in order to participate in the meeting, ask for these in advance.

At the meeting, be sure to ask questions, share information and propose ideas. If you do not understand what is being said or what is given to you in writing, ask questions.

You and your child or family member have the right to ask as many questions as you need to in order to clearly understand what is happening. If you have information, reports, assessments, or records that help support your request, it is important that you share the information with the relevant people or agencies.

If you have asked for a service or asked a question, listen to the other party's response and what they have to say. Make sure they answer your questions. Ask for the reason for their decision. You may request they provide you with an explanation for their decision in writing. If they are citing law, policies or procedures, ask for a copy.

9. Be Creative

Arranging services and planning for your child or family member's future is NOT "one size fits all." Be open to try a new approach. Be innovative! Encourage others to explore different strategies especially if the current strategies are not working. Instead of thinking about how it has been done, think about what is possible.

10. Collaborate

Each agency and staff person have a unique skill set and knowledge base to share. Be willing to listen to differing perspectives and ideas. Ask about resources, services and success stories. Where there are disagreements, remind the team of the common goal – supporting your child or family member's success.

11. Be Assertive Rather than Aggressive

Everyone, especially you and your child/family member, are invested in the planning process. Be clear about what you want. Ask for clarification about what the agencies can and cannot do.

Sometimes reasonable minds disagree. In deciding how you want to address disagreements, keep in mind that you and your child or family member will most likely have a long relationship with the agencies providing services. It's important to state your disagreements. If you find that the discussion about the disagreement is no longer productive or the agencies are firm in their position, you may decide to challenge the decision rather than continue the discussion.

If a request is denied or if information shared at the meeting does not seem right to you, ask for a copy of the law or policy that the agency is using to support its rationale or denial. Generally, individuals with disabilities and their parents have the right to receive a written notice or a letter explaining the reason a request has been denied. You have the right to know why you are being denied a service or why services are being reduced or terminated.

12. Your Right to Appeal

You have the right to challenge a decision if you disagree. You have the right to ask what the process is for challenging a decision you disagree with. You have the right to have that information provided to you in writing. Most appeal processes have timelines related to how much time you have to challenge a decision.

13. Interim Solutions

You may have an issue or request that cannot be resolved at the meeting. For example, disagreements about which agency is responsible to fund a service or which provider is available to provide a service to your child or family member. If there are issues that cannot be resolved at the meeting, discuss a short-term plan of action that ensures the individual will have the service/be able to participate in services while the dispute is being resolved. For example, agencies can agree to share funding for a service while

the dispute is being resolved. Or you can agree to a start date for services even if you are unsure of the provider.

14. Confirm Agreements and Action Items

Before the close of the meeting, read back your notes about the agreements and action items you have discussed to ensure everyone has the same understanding of the meeting. You can also send a follow-up email or letter to the team that documents what you discussed at the meeting. By doing so, you will have also created a physical record of your meeting that you can keep for your records.

15. Signing Documents

Be sure to read documents before you sign them. You and your child or family member have the right to review the documentation in its entirety. You do not have to sign a plan or other documents at the meeting. You can ask to take a copy with you to review at home. You may consider discussing the document with other parents or professionals before you sign. If you disagree with a document or would like to make changes to it, you can ask the agency to make changes before you sign. Sign only what you agree to and make a note of what you disagree with on the same document or in a cover letter that you attach to the document.

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