



Advocacy and Communication for Parents

Parenting a child with special needs brings challenges as well as rewards. Besides nurturing and loving your child, parents need to navigate complex systems on the journey of finding the help a child needs. Professionals bring vital information and expertise AND parents bring continuity over the years along with expertise and information. As parents we need to develop the skills to effectively speak up for our child, balancing our heads and hearts. Through collaboration, caring, organization and knowledge, parents can be successful advocates to pave the path for their child's future.

Matrix Parent Advisors are available to provide information and guidance as you develop your advocacy skills. You are your child's advocate and we can be your advisor in that process. We help you gain the tools you need to advocate for your child, understanding that parents know their child best and are the continuity in their child's life from year to year.

In this packet you will find information to help you communicate effectively, advocate for your child collaboratively, and learn how to be assertive rather than aggressive.

Other Information Packets Available:

ADHD/ADD
Assessment
Behavior
Bullying
Emotional Difficulties
Getting Organized
Individual Education Plans (IEP)
Learning Disabilities
Resolving Disagreements
School Discipline
504 Plans

New! HELP Sheets

Suggestions and tips answering frequently asked questions

Our libraries in Novato and Fairfield have articles, books, DVD's/videos, magazines and other materials that relate to this topic. We also offer workshops on IEP issues, support groups, and one-on-one consulting with parents. Visit our website for more information.

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Resources on Advocacy and Communication

Books

The Art of Possibility – Zander
Beyond Reason: Using Emotions as You Negotiate – Fisher and Shapiro
Better IEPs – Bateman
Crucial Conversations – Patterson, Grenny, McMillan and Switzler
From Emotions to Advocacy: The Special Education Survival Guide – Wright
Getting to Yes – Fisher, Ury and Patton
Getting Together: Building Relationships as We Negotiate – Fisher
A Guide to Collaboration for IEP Teams – Martin
Negotiating the Special Education Maze – Anderson, Chitwood and Hayden
Nonviolent Communication, A Language of Life – Rosenberg
Parents Guide to Special Education – Wilmhurst
Special Education Rights and Responsibilities - CASE and PAI (1-800-766-5746)
Special Needs Advocacy Resource Book – Weinfeld

Web-based Articles

“Special Ed Advocacy: Mistakes People Make” – Crabtree www.familyeducation.com
“Special Ed Advocacy: Nine Rules of Thumb” – Crabtree www.familyeducation.com
“Collaboration with Other Adults to Address Your Child’s Learning Difficulties” –
www.greatschools.net
“Parents’ Top Tips: Partnering with Your Child’s Teacher” – www.greatschools.net
“Advocating for Your Child – Getting Started” – www.wrightslaw.com
“Communicating with Your Child’s School” – www.directionservice.org/cadre
“Collaboration and Conflict Resolution in Education” – www.directionservice.org/cadre

Websites Special Education & Advocacy

California Dept of Education, Special Education	www.cde.ca.gov/spbranch/sed
Disability Rights California	www.disabilityrightsCA.org
Families & Advocates Partnership for Education	www.fape.org
Disability Rights Education & Defense Fund	www.dredf.org
Wrights Law	www.wrightslaw.com
Office for Civil Rights US Dept of Education	www.ed.gov/about/offices/list/ocr/504faq.html
Coalition of Parents, Attorneys and Advocates	www.copaa.net
Technical Assistance Alliance for Parent Centers	www.taalliance.org
Parents Engaged in Education Reform	www.fcsn.org/peer
National Dissemination Center for Children with Disabilities	www.nichcy.org

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Effective Advocacy – An Overview

You are your child's best advocate. Advocacy is a skill that parents can learn and can make a positive difference in services for your child with special needs. Effective advocacy involves:

- Gaining Information
- Preparing, organizing and planning
- Communicating in a way that others listen
- Willingness to solve problems

Specific ways to build your skills:

- Focus on key areas of concern, an **interest** versus a **position**. Interests are broadly defined needs or motivation and can be met in several ways. Positions have a narrow focus and one way to solve a problem.
- Prioritize areas of concern
- Take care of yourself. When we are tired or have strong emotions we may not think clearly. Find outlets through exercise, friendships, hobbies and manage your diet and sleep.
- Learn about your child's special needs, the requirements and rights your child has in the various the systems that serve your child and how decisions are made.
- Work on communicating clearly and in a short concise manner
- Take notes on key conversations or information.
- Create a binder with all key documents on your child
- Keep an open mind. Look for possibilities. Be creative. "Yes, but..." thinking limits what can be done.
- Bring in other people to help you with perspective, to problem solve or to give you support.
- Ask questions and listen for answers—it's ok to not know something
- Identify problems/barriers - be a problem-solver instead of blaming or accusing others
 - Use the facts, not speculations
 - Brainstorm options as an IEP team
 - Find common interests and build upon small agreements
 - Don't rehash the past—focus on what can be done today

It is always important to communicate respectfully, without being aggressive or blaming others. By being assertive, your concern will be the focus and others in the room will be less defensive. Finally, acknowledge good efforts and good intentions, and thank those who work with you. You are building a relationship with those who educate your child.

As an equal member of your child's team, you can help set the tone for collaboration while advocating for your child.

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Coordination, Collaboration and Communication – Strategies for Success

IEP meetings are like all other important meetings, the better prepared you are, the better the outcomes are likely to be. Remember, you are a full partner in this process!

Preparing for the IEP meeting:

- Collect all relevant information; include information that the school may not have, such as work samples. An organized binder can be a very helpful (see our handout: Keeping Records – an IEP Notebook). Review current reports and last year's IEP (if applicable).
- Prioritize. Bring a written list to remember what's most important to you. List your child's strengths, needs, interests, vision for the future and your major concerns — what has and hasn't been working – reach high, but be realistic! If needed, get letters from professionals to support your positions. Use the **Matrix IEP Planning Worksheet** to provide a framework to organize your thoughts. You may want to share this with members of the IEP team ahead of time.
- Build a positive relationship with one or more persons on your IEP team (i.e. teacher, administrator, school psychologist) to help you feel more comfortable and also help ensure that your ideas and perspective will be heard.
- Know the purpose and format of the meeting and who will be attending. Find out how much time is allotted for the meeting. Speak up if you think more time or another meeting is needed.
- Get materials ahead of time so you can formulate your suggestions and questions, be more emotionally prepared, and perhaps save time at the meeting. Early on, let the school know that you want copies of any written documents that at least several days before the meeting. Learn about your Parents Rights in special education.
- Send the school copies of private assessments, if applicable, so that they can be familiar with the data before the meeting as well.
- Get feedback from your child, your child's teachers or others who work with your child, both in and out of the school setting. It's your choice to have your child at the meeting or part of the meeting: consider what will be discussed and if it is appropriate for your child. If your child will attend, prepare him or her in advance.
- Arrange to have someone you trust come to the meeting with you (a spouse, partner, friend, relative). Having support, as well as another set of ears, can be important. You can bring anyone to the meeting who has knowledge of your child. Best practice is to let the school know ahead of time, who will attend with you.

- You can tape record the meeting if you feel it would be helpful. Notify the school at least 24 hours before the meeting of your intent to do so. The school will then likely tape as well.

During the meeting:

- If IEPs should be pre-written they should be considered a “draft”. You have input as a team member and changes and additions should be made during the meeting as needed.
- It is important to understand what people think and why. Don't hesitate to ask questions, including clarifications and explanations. You're not expected to know all the jargon. Ask!
- Share your thoughts, knowledge, insights, and concerns as an equal team member. Your perspective on your child's strengths and concerns both at home and at school are invaluable. You should be given enough time to present your information and perspective. The team must consider your comments.
- The team will have a designated note taker. Make sure your comments are accurately reflected. Your additional statements can be attached. You or your support person may want to jot down your own notes.
- BEFORE writing goals, all information about your child's current levels of performance and progress should be reviewed and considered (assessments, grades, standardized test results, teacher and parent observations, work samples). Placement and/or related services should be discussed only after the Goals & Objectives are completed. Services should address individualized needs in all areas of suspected disability.
- Sign wisely. You don't have to sign in agreement, partial agreement or disagreement at the meeting. Even in the most cooperative and positive meeting you may want to consider your decision in private. Know your signing options, or ask. Never be pressured into signing. If you take the papers home, return the signed form in a timely manner.
- Communication in an IEP meeting should be respectful, safe and open. If you feel uncomfortable ask to take a break or reschedule when you'll have more support available. If you feel rushed, ask the leader to slow the pace down or ask to schedule another meeting with more time.
- Stay focused on your child's needs. If necessary, remind the team that the meeting is about a real child — your child. Find a way to personalize him or her. Sometimes telling your child's story can help. Share both your long and short-term visions for your child.
- Develop rapport and treat people with dignity. Praise the positive actions of others. A good participant is a respectful listener! People are often better listeners after first being heard and acknowledged.
- The school's input and direction may be different from yours, but may also be valid. When the team disagrees, try thinking outside the box. Brainstorm. Keep an open mind. Seek and build on common ground. If needed, find a solution that improves on the current situation, with the understanding that the “best” solution is not guaranteed by law.

- Focus on what your child needs, not the specifics on how to get there (interests versus positions). Examples - Interest: "I want my daughter to progress in the 3rd grade curriculum and have opportunities to be with and socialize with other non-disabled classmates." Position: "I demand a one-on-one aide for my daughter in a regular 3rd class."

After the meeting:

- Review the IEP papers at home. If the papers aren't clear, find someone to explain them (someone who understands special education or one of your IEP team members).
- Return the signed IEP as soon as you've made your decision. Do so in a timely manner. After your review, if you have serious doubts or concerns, you may want to request another meeting. Other options are to request Alternative Dispute Resolution (ADR) or formal methods to resolve conflicts.
- Talk with your child about the meeting. Speak in terms he or she will understand. Share what you learned about his or her progress, any new goals and what the child should expect in the coming year regarding services and placement. Your child's "buy-in" can be very important. Your student's understanding of his/her disability may help your child better accept and utilize IEP services, as well as lead to your child advocating for him or herself.
- For further reference, put all documents related to the IEP & personal notes in your binder.
- If appropriate, follow up with a thank you note or email. An on-going collaborative relationship benefits everyone. Express appreciation for positive efforts.
- Track and monitor your child's progress. Regular contact with your child's teacher(s) and instructor(s) may be necessary. Sometimes a notation on your calendar to check in with staff can be helpful. The IEP must state how often you will receive progress reports as well as the frequency and duration of the services. Watch for those reports and request a progress report if you do not receive one.
- Sometimes volunteering in the classroom or on field trips or other school activities is a way to reinforce your relationship with the teacher. This can also be an opportunity to observe your child in his classroom or school social setting.
- If you're not satisfied with your student's progress and think changes/additions are needed in the IEP, request an IEP meeting. Do this in writing. The team must meet within 30 days of your request. Your child's IEP must be reviewed at least once a year (annual review), but it may be necessary to meet sooner.

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Communication Techniques ...to use in school meetings

- **Build small agreements** – *We all agree that Sam's grades are poor partially due to incomplete homework. Knowing that Sam's ADHD makes it hard for him to focus at night, can we also agree that Sam needs strategies to use study hall time more wisely? Look & listen for consensus.*
- **Write it down** – *So my notes accurately reflect this discussion, I want to confirm you said...*
- **Take a break/focus** – *I am feeling overwhelmed right now and would like a short break. A break may also refocus us on how to help Sam be more productive in study hall.*
- **State a fact/redirect to the agenda** – *It is my understanding the IEP can include goals for any area impacted by the disability. Can we direct our discussion to a goal on homework completion and later talk about accommodations?*
- **Set a deadline** – *Can we meet in 2 months to see if Sam's work output has increased?*
- **Repeat/reflect to confirm** – *Do I hear you correctly that you think Sam is choosing not to do his work and that if he tried harder and we disciplined him at home, this issue would resolve?*
- **Use and ask for facts/data/references** – *Who can provide some data or a reference on motivation in children with ADHD? Who on the team, district or county has extensive training in this area?*
- **Ask and/or name what is going on** – *It is very quiet around the table. What does this silence mean? OR My sense is that not everyone agrees with the way we're making this decision. Does anyone else have that feeling?*
- **Reminder on ground rules** – *Let's step back and remember one of the ground rules we agreed to –no interrupting. Would you mind holding your thought until Dr. Smith finishes?*
- **Refer to an outside expert** – *Let's refer back to the evaluation we accepted – to the part in which Dr. Smith talks about ADHD and fatigue and its impact on homework.*
- **Request to hold judgment** – *Could you wait until I explain what Sam's doctor has told us before you decide...or internally you acknowledge you disagree with the speaker BUT you listen to their rationale.*
- **Be creative** – *Maybe this is a good time to discuss how we can use Sam's love of art to support work completion.*
- **Use body language** – *Lean forward to convey interest, open palms, un-cross your arms.*
- **Friendly, light comments** - *The school garden is really looking great OR What a wonderful bulletin board display for the California missions. At the beginning of an IEP meeting these comments can create positive tone.*
- **Defer** – *Would you be willing to wait until we analyze the data before we finalize this present level of performance?*

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Advocacy Guidelines (When We are Tempted to Go Too Far)

Because we care deeply about our children with special needs, sometimes we become so angry or upset that we go too far. We abandon all efforts at being tactful, burn our bridges, and leave broken relationships in our wake.

Being an advocate for your child with a disability is a long term-term project. Parents have to figure out ways of getting along with educators, school administrators, medical staff, and human service agency personnel. Here are some suggestions for keeping your cool while making your case for services for your child:

- Before you say anything to anyone, ask yourself three things:
 - (a) Is it true?
 - (b) Is it kind?
 - (c) Is it necessary?
- Make promises sparingly and keep them faithfully.
- Never miss the opportunity to compliment or to say something encouraging to someone.
- Refuse to talk negatively about others; don't gossip and don't listen to gossip.
- Have a forgiving view of people. Believe that most people are doing the best they can.
- Keep an open mind; discuss but don't argue. It is possible to disagree without being disagreeable.
- Forget about counting to 10. Count to 1,000 before doing or saying anything that could make matters worse.
- Let your virtues speak for themselves.
- If someone criticizes you, see if there is any truth to what he or she is saying; if so, make changes. If there is no truth to the criticism, ignore it and live so that no one will believe the negative remark.
- Cultivate your sense of humor; laughter is the shortest distance between two people.

Adapted from PLUK NEWS, November 1994

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School Records

Accurate and complete records ensure that school personnel and parents have access to the same information. In reviewing your child's records, you may find that you are missing a document or the school is missing something from your records. School records are so important in planning and serving students with special needs that this issue has been addressed in federal law. The law governing school records is called the Family Educational Rights and Privacy Act (FERPA). For more information, ask for your district's school records policy.

Where are School Records Kept?

There are several types of records that may be located in different places: a cumulative file (cum. file) maintained at the school, a confidential file which often is maintained by the school psychologist, and a compliance file kept at the school district's office.

How Can I See or Get a Copy of School Records?

Call or make a written request to the school principal or special education director. You may request copies (you may be asked to pay the reproduction cost for the copies), or you may ask simply to review them at the school at which time you can make copies of only those documents you need. California law states that schools must give you access to your child's records and/or copies within **5 DAYS** after your written or oral request.

What Records Can I See?

Parents can see all records, files, documents and other materials that are maintained by the school system and contain information relating to their child. This includes all records that refer to your child in any personally identifiable manner. Records including information about other students will not be given to you due to confidentiality laws.

Are there Records I Can't See?

Personal notes of teachers, counselors, and or school administrators made for their own use and shown to no one else (except a substitute teacher); records of school security police when they are kept separate from other records and used for law-enforcement purposes; personnel records of school employees.

May I Make Changes to School Records?

If you feel that a document is inaccurate or misleading, you have a right to request that it be removed or corrected. If the school disagrees, you may submit a written response to the document and it must be included in the file. If the school does not want to comply with your request to correct the information, you may ask for a formal records hearing.

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IEP Planning Worksheet

Child's Name _____

Date _____

Filling out this form will help you give the IEP team an understanding of who your child is as a whole person. This form can help you organize your thoughts and ensure that you remember to discuss your concerns as well as what you know about how your child learns best. It is important to refer to assessment results or data in order to support your concerns and the requests that you make. You may want to share this information with IEP team members ahead of the meeting.

Name three or four areas of strength for your child:

1. _____
2. _____
3. _____
4. _____

Name three or four areas that your child needs help with:

1. _____
2. _____
3. _____
4. _____

What data or assessment results support the concerns you have identified?

1. _____
2. _____
3. _____
4. _____

Think about what you know about your child, what you have been told and the assessments that you have been given, what goals for your child should be addressed in the educational setting?

1. _____
2. _____
3. _____
4. _____

If you know of adjustments (accommodations) or situations that help your child learn, list them here:

What incentives or rewards are helpful with your child?

Other information that the school should know about your child:
