

Advocating for Your Child with Disabilities

Being a parent of a child with disabilities brings many new experiences. Over time, we continue to improve our parenting skills. One important skill to learn is advocating for our children. This may include advocating within various systems that serve our children: health care, education, or Regional Centers. This may also involve advocating for your child to be included in recreational activities, the community, or family events. Building your advocacy skills will serve you well in many settings.

Skills take time to develop. Certain skills come easier to some of us than others. All of us have said or done things that we wish we hadn't. In hindsight, we may realize that these actions have not helped us help our child. Be patient with yourself, and keep trying. It has been said that we do the best we can with what we know, and when we know more, we do better.

This packet provides information on seven skills that you can learn to use to increase your ability to advocate for your child. Matrix Parent Advisors are also available to coach you and offer advice on your journey. You know your child best and are the one who is the constant from year to year. As a parent, your advocacy efforts reflect the values, hopes and dreams you have for your child.. You are your child's best advocate. Matrix can be your advisor in that process.

Our website has links to information from other agencies on this topic, and we have other information packets on specific disabilities, Special Education, and Regional Centers that relate to advocacy. The following packets have specific information on skills and tools needed for your advocacy:

Getting Organized
IEP Toolkit
Resolving Disagreements

Our library in Novato has books, DVDs/videos, magazines, and other materials that relate to this topic. We also offer workshops on Individualized Education Plan (IEP) issues, support groups, and one-on-one consulting with parents. Please visit our website, www.matrixparents.org, for more information.

Resources to Help with Advocacy

Websites



Advocacy Institute

www.advocacyinstitute.org

Alliance for Technology Access

www.ataccess.org

American Association of People with Disabilities

www.aapd.com

Calif. Dept. of Special Education

www.cde.ca.gov/sp/se

Center for Parent Information and Resources

www.parentcenterhub.org

Council of Parents, Attorneys and Advocates

www.copaa.net

Disability Rights California

www.disabilityrightsca.org

National Center for Appropriate Dispute
Resolution in Special Education

www.directionservice.org/cadre/

Office for Civil Rights, U.S. Dept. of Ed

www2.ed.gov/ocr

TASH: Equity, Opportunity and Inclusion
for People with Disabilities

<http://tash.org/>

Wrights Law

www.wrightslaw.com

Books or Pamphlets

All About IEPs

Wright

Beyond Reason: Using Emotions as you Negotiate

Fisher and Shapiro

Complete Guide to Special Education

Wilmhurst

Crucial Conversations: Tools for Talking When Stakes are High

Patterson, Grenny

From Emotions to Advocacy

Wright

Guide to Collaboration for IEP Teams

Martin

Negotiating the Special Education Maze

Anderson, Chitwood, Hayden

Special Education Rights and Responsibility

Disability Rights California

Special Needs Advocacy Resource Book

Weinfeld

The Everyday Advocate: Standing Up for your Autistic Child

Martin and Koegel

The Special Needs Parent Handbook

Singer

*Working Together: A Parent's Guide to Parent and Professional
Partnership and Communication Within Special Education*

Technical Assistance ALLIANCE



Resources to Help with Advocacy

You are your child's best advocate. Effective advocacy is a learned skill and one that can make a positive difference in services for your child with disabilities. Effective advocacy involves these seven skills:

1. Taking care of yourself
2. Learning about your child's disabilities
3. Learning about systems and laws that support families
4. Preparing, organizing and planning for meetings
5. Building your communication skills
6. Understanding yourself and others by gaining perspective
7. Contributing to creative problem solving



Ways to build your skills:

- Review our *Getting Organized* packet. Have someone help you sort papers and organize a binder.
- Use our *IEP Toolkit* to help organize your priorities and questions and to link the information you have to your concerns.
- Work on sorting out your interests versus positions.
- Take care of yourself. When people are tired or have strong emotions, it is hard to think clearly.
- Use books, websites, or trainings to learn key information and skills.
- Keep an open mind. Look for possibilities. Be creative.
- Instead of "Yes, but..." think "Yes, and..."
- 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 a 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, acknowledging good work and efforts. This means being assertive but not aggressive. Effective advocates are respected for their skills in communicating in a way that avoids making others feel defensive. 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.

Taking Care of Yourself

"Put your oxygen mask on first before helping your child"

Being a parent brings joys and worries. Being a parent of a child with disabilities can create additional challenges. When you face important decisions or have to deal with particularly challenging issues, it becomes even more essential to take care of yourself.

Where to start

- Find ways to get plenty of rest. While this may be easier said than done, sleep deprivation affects memory, thinking, emotions and more
- Exercise. This is a proven method to reduce stress
- Put enjoyable activities, just for you, in each week or day
- Eat healthy foods. This gives you the fuel you need
- Find people with whom you can share your thoughts and feelings - people who can help you decide what is really important

KEY POINTS

- ▶ Try not to feel guilty about taking time for yourself. As parents of children with exceptional needs, we become accustomed to putting our child first. Remember, taking care of yourself is an important part of being able to take care of your child.
- ▶ Sometimes taking care of yourself means finding others who can help you. It may feel strange asking for help from others. Practice asking!
- ▶ Frustration and anger can drain your energy. Find a good listener who will give you a chance to vent your emotions so you can move on.
- ▶ Be gentle with yourself. Hard work takes time. Being a parent is a life long journey. Pace yourself.
- ▶ Make self care a habit. Take a walk to a place that rejuvenates you. If you can't get out, try taking a few moments to do some deep breathing and imagine yourself in a restful location. Buy an issue of a favorite magazine to occupy yourself in waiting rooms. Every little bit helps! The important part is making it routine, so you plan to have the time to do it.
- ▶ We are role models for our children in how we manage stress, growth and change. Being the best we can be helps our children be their best.

Self care does not come naturally to many of us. Remind yourself often that you deserve the time for this important task. It benefits you and your child.

"Love yourself first and everything else falls into line. You really have to love yourself to get anything done in this world." —Lucille Ball

Learn About Your Child's Disabilities

For some disabilities there is so much information that it is hard to know where to get started. For other disabilities that are less common, it may require searching to find what you need. Keep in mind that each child is unique no matter what the disability. One role we play as parents is to learn how the disability shows up in our child. We then can be teachers to others just as others will teach us.

Good places to start

- Gather information from a variety of reliable sources: professionals, books, websites, and agencies
- Ask parents who have experience with the disability what they know
- Sometimes books with chapters on various disabilities can give you an overview and then lead you to more in-depth materials
- Many disabilities have national organizations with website information or local chapters that host meetings or trainings

Internet tips

When sorting through website information, pay attention to the sponsor of the website. Non-profits typically are noted by .org or .net, commercial/for profit groups by .com, educational organizations by .edu. A commercial organization may be selling a product through giving information. A blog is one person's information and opinions.

What should you know?

- Common characteristics of the disability
- How the disabilities may affect various aspects of life: school, social, daily life activities, home
- Treatments or interventions, and which are proven effective and which may be emerging or experimental
- What behavior is related to the disability and what may be related to typical developmental stages of childhood and adolescence

Learn About Systems and Laws that Support Families

Several service systems are available to help your family. Some are publicly funded, others are not. It is important to have a basic understanding of how these systems work so that you can successfully advocate within these systems. Public agencies are governed by laws and regulations which include consumer rights and appeal processes. Some of the most important disability laws are:

- **The Individuals with Disabilities Education Act (IDEA)** This federal law provides for Special Education through an Individual Education Plan (IEP) for eligible children birth to age 22. This law is implemented by Local Education Agencies (LEAs), better known as school districts.
- **The Lanterman Act** created Regional Centers in California. They provide services to people of all ages with developmental disabilities through an Individual Program Plan (IPP). These services include Early Start for infants and toddlers. Regional Centers are governed through the Department of Developmental Services.
- **Section 504** of the Rehabilitation Act of 1973 is an anti-discrimination law. Any agency that receives federal funds must provide equal access. Under this law schools are required to accommodate a student with a qualifying disability through a 504 Accommodation Plan.
- **Americans with Disabilities Act (ADA)** is an anti-discrimination law that applies to both publicly funded and privately funded settings: employment, transportation, public services and accommodations accessed by the public but operated privately.

Public Agencies that serve children with disabilities include: Local Education Agencies (public schools); Community Mental Health; Regional Centers; Head Start and County Health and Human Services. Our website has a directory of government and non-profit agencies in our area.

Health care is complex and ever-changing. Often hospitals have patient advocates who can guide you. Knowing how to communicate your concerns to your medical and insurance providers is essential. Find a reliable organization specific to your child's disability and stay connected to keep up to date on pertinent health care issues. California's Department of Managed Health Care has a Help Center for problems and complaints with your health plan.

Legislation and Governance

Besides advocating for your child, parents are always needed to advocate to our elected officials. These include your school board trustees and legislators, all of whom develop budgets, policies or laws that affect children with disabilities. Our website provides information on current hot topics and ways to communicate with your elected officials. It can seem daunting to become involved in legislative advocacy, but there are plenty of ways to make a difference with small efforts: Sign online petitions, send an email or a letter to a legislator, or make a phone call.

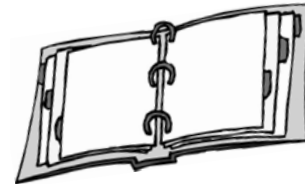
Learn the facts, get involved, and let your voice be heard!

Prepare, Organize, and Plan for Meetings

IEP Meeting Checklist

Preparing for the meeting

- ☐ Build positive relationships — this is an ongoing process
- ☐ Ask for any written reports ahead of the meeting
- ☐ Organize all information (see IEP Tool Kit and Getting Organized)
- ☐ Know the purpose and format of the meeting
- ☐ Depending on the age of your child, decide if/how she or he should be included in the meeting or planning
- ☐ Discuss your ideas and approaches with someone



During the meeting

- ☐ If no agenda is provided at the beginning, help create one
- ☐ Clarify any time constraints
- ☐ Ask who is the note-taker and request key comments be recorded
- ☐ Use core communication skills to clarify and share information, listen, and acknowledge other's point of view
- ☐ If your student is present for any part of the meeting, make sure team members speak directly to your child and are sensitive when sharing information
 - 1. Student strengths and parent concerns
 - 2. Assessment information
 - 3. Areas of need and student's present levels
 - 4. Annual goals
 - 5. Accommodations/modifications
 - 6. Services needed for goals
 - 7. Locations of where services will take place
- ☐ During the meeting, remember the discussion should follow this order:
- ☐ Build small agreements
- ☐ Show appreciation for others on the team
- ☐ Decide if you need to take the document home to review before signing in agreement

After the meeting

- ☐ If you didn't sign at the meeting, review the documents and then sign shortly thereafter — noting whether you agree or do not agree with the school's offer of services
- ☐ Talk with your child about decisions made at the meeting
- ☐ Put on the calendar any next steps, including key check-in points on progress
- ☐ File your paperwork

Other Meetings

Most meetings where services are determined for your child follow similar steps. Try to keep these in mind:

1. Review assessments
2. Determine needs
3. Decide on services

Build Your Communication Skills

Communication is complex. How we communicate is influenced by our emotions, thoughts, background, values, and culture. It is also influenced by how others communicate with us and the setting in which the communication is taking place. Our communication patterns form early in life. We can see this in how our children communicate. It is not easy changing long standing communication practices or styles. But it can be done! Sometimes just changing one way we communicate can make a big difference in how we advocate for our child.

Where to start

Evaluate yourself by thinking about how effective you are when you communicate. Seek feedback from others. Ask what skills are strong and which you might need to improve. Set small reasonable goals as you learn new skills.

KEY POINTS


- ▶ Most communication is non-verbal. What we say without words can be more powerful sometimes than the words we use. For example, watch out for eye-rolling, abruptly crossing your arms, or turning away from the person speaking.
- ▶ Our emotional state can affect how we communicate. Some parents use the phrase "H.A.L.T." to remind them to be mindful of communication around important issues if H-hungry, A-angry, L-lonely or T-tired
- ▶ Effective communication is a reciprocal conversation: listening to the other person, checking for understanding and then sharing our thoughts.

"Seek first to understand, and then to be understood" —Stephen Covey

- ▶ Trust and respect is the base for most successful communications. With trust each person can gently discard things that may have been said in error. Building trust includes positive conversation, often having nothing to do with your child. It involves communicating around areas of mutual interest and showing positive regard for the person. If we do not view someone in a positive light...or the reverse, they do not view us in a positive light, it can be hard to listen with an open mind and have effective communication.
- ▶ Sometimes less is more. Long emails are challenging for busy people to read and to capture the main points. Talking on and on about something also may result in losing the listener's attention.
 - » Calm, concise communications that stick with facts not opinions often can be most effective.
 - » A short question can also result in moving a conversation forward

"Communication Techniques" offers a variety of strategies that can be used in different situations. Building a new skill takes practice, so keep trying!

Communication Techniques

- **Build small agreements** — We all agree that Alisha's grades are poor partially due to incomplete homework. Knowing that Alisha's ADHD makes it hard for her to focus at night, can we also agree that she needs strategies to use study hall time more wisely?
- **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.
- **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 talk about a goal on homework completion and talk later about placement?
- **Set a deadline** — Can we meet in two months to check on Sam's behavior? 
- **Repeat/reflect to confirm** — Are you saying that Maria is choosing not to do her work and that if she tried harder this would not be a problem?
- **Use and ask for facts/data/references** — Who can provide some data or a reference on motivation in children with learning disabilities? Does anyone have training in this area?
- **Ask and/or name what is going on** — It's very quiet around the table, why is that? 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 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, where Dr. Johnson writes about ADHD, fatigue and its impact on school.
- **Request to hold judgment** — Can we wait until the speech therapist finishes her report before a decision is made?
- **Be creative** — Maybe this is a good time to discuss how we can use Michael's love of art to support work completion.
- **Use body language** — Lean forward to show interest, open hands, un-cross your arms.
- **Use humor** — I'm so sorry to be a bit late, but you know what they say: the early bird might get the worm, but the second mouse gets the cheese! Remember, humor should never be at the expense of another person.
- **Defer** — Would you be willing to wait until we look at the data before we affirm this present level of performance?

Understanding Yourself and Others — Getting Perspective

An important skill in advocacy is gaining an understanding of yourself and others. This involves putting yourself in the shoes of the other person – to understand their view of the situation as well as how they may perceive your views. This also involves taking an objective look (as much as we can) at ourselves.

Where to start

Think about the other person or people and what factors may influence their views. Some compare this to looking at an iceberg. You can see part of it above the surface, but most of the iceberg is underwater, out of view.

With educators, some factors that may be unseen are:

- A desire to help your child mixed with frustration that there may be 30 other children also needing help
- Past experiences with your child's disability are influencing how your child is viewed
- Lack of knowledge about your child's particular challenges or confidence about what to do
- When someone isn't a parent, it can be harder to appreciate parenting challenges, let alone disabilities parenting

Concerns that may be below the surface for parents are:

- Worry about your child's long-term future
- Your insecurity or lack of confidence about knowing what to do
- Past experiences with how you were parented or your past experiences with education
- Unresolved grief over your child's limitations

KEY POINTS

- ▶ Share openly what may be under the surface for you. You may be surprised that this can make others more empathetic.
- ▶ We want others to have an open mind and understand our child with their strengths and challenges. This is what every person wants – to be understood and respected.
- ▶ In order to learn what is below the surface for others, make a simple statement or ask a question, such as: It must be challenging to teach a child who often is off task and not paying attention.

Pause, observe, and listen to others. Their actions and words will tell you about themselves and will give you clues to their views on educating your child. People like to be asked about their views. It can only help to learn another person's perspective.

Creative Problem Solving

When anyone who is part of a team arrives with a fixed position, we can guess how that affects their ability to be flexible. In the ideal world, the purpose of a team is that many people together can be more creative in finding solutions. How can you tell if you or someone else is being a fixed or flexible participant?

Where to start

Understand the difference between a position and an interest.

A fixed position:

- is one way to solve a problem
- has a narrow focus

A flexible interest:

- is a broadly defined need
- can be met in several ways

An interest may be: wanting your child to be respected, master skills, or be safe. A position could be: wanting a one on one aide, a particular reading program, or a specific amount of time in speech therapy. When the team can identify interests the result will be more flexible and creative problem solving.

KEY POINTS

- ▶ To help brainstorm, have someone write down all ideas in a way that others can see them, without passing judgment.
- ▶ Describe situations as if you are describing a photograph. This keeps your descriptions objective. Instead of saying "Susan hates to write" say "During free writing time, Susan sits at her desk and looks out the window. She will write no more than one sentence."
- ▶ Ask questions to help others be more specific. Often when others use general statements such as "Ben is a delight," we miss an opportunity for more detailed information. By asking follow-up questions the other person may then give a more descriptive answer about how Ben is successful in the classroom.
- ▶ Listen carefully to the ideas of others and keep an open mind. Let others finish speaking.
- ▶ With a common interest in your child's needs, look at ways to agree to some ideas, rule out others or combine parts of two ideas into one.
- ▶ Work hard to avoid "Yes, but..." thinking. Instead, try "Yes, and..." For example, say "I like that idea. Can we also...?"

In these times of scarce resources, creative problem solving and respectful communication are free valuable resources that can result in new and innovative ideas for your child.