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You've got this! Empowering and training parents in the role of parent as advocate

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About this Toolkit:

This toolkit was developed to accompany the workshop of the same title presented at the 2022 Society for Developmental and Behavioral Pediatrics (SDBP) Annual Meeting. This workbook represents the collaborative effort of the authors to enhance this workshop while providing attendees a small resource guide.

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Workshop Description:

Caregivers of neurodivergent children including children with identified disabilities often feel overwhelmed advocating for their children. This skill-building workshop aims to equip attendees with clinical tools, skills, and strategies to teach caregivers to advocate on behalf of their children and communities. The presenters will utilize hands-on teaching of motivational interviewing strategies, case examples, small group reflection, and role play. A toolkit will be provided to attendees providing support materials for families. Clinical cases highlight the intersectionality of federal special education law, state law/department of education regulations, and regional/municipal resource disparities experienced by children and families from underrepresented communities.

Workshop Goals:

- 1. Analyze caregiver self-efficacy as it pertains to self-advocacy skills.
- 2. Learn strategies providers can use to scaffold caregiver advocacy at the local level (with consideration for state and federal level needs).
- 3. Provide and implement a toolkit of resources to help providers and caregivers improve skills and confidence in advocating on behalf of children with disabilities.
- 4. Inspire attendees to act as experts in empowering caregivers to be advocates for their children and families, even under new and unusual circumstances.

Workshop Objectives:

- Recognize family and child-level factors related to inequities in social and educational outcomes for neurodivergent children including children with identified disabilities.
- Use an ecosystems-based framework to approach the intersectionality of special education law and social inequities at the clinical/family level.
- Use motivational interviewing skills with caregivers to: a.) Identify a child's barriers and needs; & b.) Increase caregiver engagement in advocacy of those needs.
- Employ strategies and language in written documentation that facilitate access to services in an equitable manner.
- Teach practical skills that providers can use to connect caregivers to and facilitate relationships with family advocates.
- Utilize toolkit to enhance training of caregivers as self-advocates and to engage in systems-level advocacy.

How to Use this Workbook:

This is a take-away for you to use during today's workshop. It is also designed to be used after the workshop to help you reflect on your advocacy activities and to use as a resource for families served in your practice.

Workshop Agenda

- Introduction and Welcome
- Icebreaker
- Part 1: Caregivers as Advocates
 Small and large group break outs
- Part 2: Setting Caregivers up for Success Small and large group break outs

BREAK

- Part 3: When the Going gets Tough, the Tough get Going (Advocating)
 Small and large group break outs
- Wrap Up and Final Q&A

Case #1: Caregivers as Advocates

You are a developmental-behavioral pediatrician at work on a busy Monday morning. Your last patient of the morning, Johnny, is a 3 year old boy. Your evaluation results in a diagnosis of Autism Spectrum Disorder requiring very substantial support (Level 3). Johnny's mother bursts into tears at the diagnosis and quickly tells you that these are tears of relief. She had suspected for some time that Johnny has Autism, but her family (including her spouse) and her son's previous Early Intervention occupational therapist (who has not consistently been able to work with Johnny during the pandemic) have told her that she is "wrong" and "overly worried." She has felt significant doubt in her maternal instincts until hearing your diagnosis.

Trusting in your assessment, she turns to you for advice. She is frustrated that no one has believed her so far, and she does not know how she is going to convince them of the diagnosis. Her county lost all of their Early Intervention therapists (due to staffing issues) before Johnny turned 3, so she did not have help in navigating the transition to preschool. She has called her local school district to see if Johnny could enroll in preschool, but no one has called her back. Johnny is not getting any services at this time, and she feels overwhelmed at the possibility that he is going to be placed onto years' long wait lists for services and Medicaid waivers. She is also admittedly exhausted, as she has been carrying guilt (she bumped Johnny's head against the crib by accident one time when he was a baby – is that why he has Autism?) and fear (what is going to happen to Johnny when she dies - who will love him and take care of him?) for some time.

What is Johnny's mother's role as advocate for her son?

What needs do caregivers (as parents and as advocates) have in cases like this?

Who may support her as she navigates the advocacy journey for her son?

Case #2 - Setting Caregivers up for Success

Rainbow Brite is a 3-year-old girl who lives with her foster family. She was diagnosed with Autism Spectrum Disorder (Level 3 for social communication and restricted/repetitive behaviors) earlier this year in your clinic. She returns because the family does not know how to go about getting extra services and needs some support with managing challenging behaviors and promoting her development.

You are certain that you provided them with a great deal of information about additional services in the community at her last appointment and highlighted those resources in the report you sent home with the family. However, they have not contacted any of the service providers that you told them about or even provided a copy of your report to the school.

Since then, Rainbow has also had a hospital stay for constipation, and it was a less-than-positive experience for her and the family. She was aggressive toward the staff, and since that time she has been increasingly dysregulated and irritable in the home. Foster mom tells you she has no idea how to help Rainbow but really wants to do what is best for her.

What MI strategies might you use to engage foster mom in a discussion?

How could you elicit some information about the foster family's values?

**Barriers:

- Insurance no places in town take her insurance through DCFS, but one has grant funding to cover services for youth with public insurance
- Consent for services local caseworkers have high turnover rates and are not always aware
 of all the additional consent forms that are needed; they have high caseloads and are often
 not able to follow through on things to provide the best care for their youth
- Lacking knowledge, strategies, and confidence
 - How to get started with outpatient services
 - How to get connected with public school services
 - How to manage challenging behaviors at home
 - How to communicate with hospital staff about Rainbow's behaviors and her sensory and communication needs

Rainbow returns 12 months later. She has been receiving ABA therapy that is funded by state grants at a local agency and has made excellent progress. Unfortunately, because the wait is so long, she is being graduated from those services to allow an opportunity for other youth to access them. She has also been attending a blended PreK/Early Childhood classroom in her local school district. Foster mom hopes they can access some other ABA therapy services but is also very pleased with the services she is getting through school.

Knowing that the other ABA therapy providers in your area will not take their insurance, what kinds of things might you offer to help empower foster mom?

Case #3 When the going gets tough, the tough get going (Advocating)

Part 1

You are seeing Joey, a 7-year-old boy with a genetic syndrome and mild intellectual disability, for a follow-up visit in your DBP continuity clinic today. Joey started 2nd grade in August and his parents just attended his annual ARD meeting last week. Parents are very upset because Joey has been placed in a Life Skills class, and they feel he will not be challenged academically in this setting. They also worry that he has started to pick up behaviors from some of the other children in his class, many of whom seem to be much lower functioning. Joey's mother asked to have Joey placed in regular education for part of the school day, but the assistant principal told her that would not be possible as he would require too much paraprofessional support. Mother is also concerned that Joey is not receiving the speech therapy services included in his IEP, and when she asked about that she was told that Joey is on a waiting list for speech because there are not enough speech therapists in the school district.

What are some questions you might have the family ask to learn more specific/nuanced information?

What are the opportunities for advocacy here?

How would you guide the family regarding next steps?

- Who is the next point of contact?
 - o Counselor?
 - Principal?
 - District special education director?
 - State agency?

Part 2

To wrap up your visit, you remind the parents about your recommendation to place Joey on the waiting lists for the Medicaid waiver programs, as these will provide important long-term wraparound services to help Joey as he gets older. Joey's father exclaims, "I called them after our last appointment and they told me the wait was 12-15 years! That's ridiculous – what's the point of signing up for this? Why can't this program help my family now?"

How might you respond to father's comments?

How would you guide the family regarding next steps?

What are the opportunities for advocacy here?

Advocacy: Back to the Basics

- 1. First and foremost, remember that advocacy begins with the ballot box, even for individual-level advocacy issues such as special education services. State and local elected officials make decisions about funding priorities and appoint people to boards and committees who influence curriculum and service decisions. Make sure you are registered to vote, preferably at your current address. Look up voter registration information for your current residence and fill out an on-line voter registration form or apply for absentee voting at www.vote411.org. Encourage others to register to vote!
- **2. Find your key players**. It is important to know whom to work with to make change. Elected officials are the key players to legislative change. Knowing names is not always enough. Block off some time and do some research. What are they passionate about? How have they voted in the past? Are they sitting on any committees? Use some of these tools provided to find out who your elected officials are. Then commit some web browser time to look them up and see where their thoughts, attitudes, beliefs, and values line up. Follow them on Facebook/Twitter!
- **3. Find your partners**. Our voices are stronger together, but sometimes it is hard to find similar voices among the cacophony of political advocates. There are often so many places to begin but we do not have to reinvent the wheel if there is already a team on the ground. Look for who is already working in your areas of interest; it could be:
 - Your workplace
 - Professional societies/organizations (i.e. SDBP, AAP, SPP, APA, NASW, etc.)
 - Disability-related organizations (i.e. Autism Speaks, AAIDD, CHADD, Zero to Three, etc.)
 - Child development and education organizations (i.e. Zero to Three, etc.)
 - Local grassroots coalitions.

Research them to see if their goals/values align with yours. If you think they are a good fit, sign up for their mailing list, donate, or consider joining.

Look for local chapters within larger organizations. This is the easiest and most efficacious way to get involved!

4. Engaging your partners.

Look in the right places. The best coalitions engage partners who have compelling relationships to either the problem or potential solutions and can add value by providing any of the following resources:

- Information
- Access to influencers (e.g. policymakers) and key messengers (e.g. press)
- Expertise and credibility
- Time
- Money
- Large base of support

Pitch your vision. Potential partners likely already understand the extent of the problem you're trying to address. They need to know the anticipated outcomes of your efforts so they can assess their willingness and capacity to contribute. Be descriptive, yet concise, and always do your research. Help potential partners draw explicit connections between their goals and the vision you've put forth.

Be mindful of equity issues. Those most significantly impacted by the problem you're trying to address, especially partners representing traditionally underserved (cultural and other identity) groups, must be "at the table" and positioned to drive collective decisions.

Proceed with flexibility and caution. Accommodating thoughtful changes to the collective vision based on the input of potential partners can encourage investment, but aligning too closely with the strategic priorities of some can cause friction and even derail efforts.

5. Stay informed. Continue to sharpen your skills and stay up to date on topics.

Subscribe to information about the topics that you are passionate about. You can use these websites. We also strongly recommend signing up through your professional societies/interest organizations.

You can also use this workbook as well as other online resources to help sharpen your skill set.

- Bill Tracking: https://www.govtrack.us/
- AAP Policy Page

https://www.aap.org/en-us/advocacy-and-policy/Pages/Advocacy-and-Policy.aspx; http://federaladvocacy.aap.org; www.aap.org/moc/stgovaffairs

- Sign up for the weekly email policy brief.
- They have excellent training modules.
- Follow your legislators on Facebook/Twitter!
- **6. Put your specific skill set to use!** Remember that we are not community organizers or event planners; use your team to round out your skill set.

Use your own skills in the most effective manner possible. Speak out on topics as they relate to your patients. Plan time to make a phone call to a legislator's office, write an op ed piece, attend a town hall, start/attend a committee, and/or teach others about how to be advocates.

Motivational Interviewing Tips for Providers

OARS

O - Open ended questions

- Allows parents to do most of the talking
- Gives insight into what is important to the parent
- E.g., "Tell me about how school is going" rather than "Is school going well?"

A - Affirmation

- Can be compliments or statements of appreciation and understanding
- Acknowledge their strengths and efforts for change
- E.g., "You have tried so hard to find the right resources for your child", "Wow, you have endured this year with so much strength"

R - Reflections

- Rephrasing information to capture the meaning and feeling of the patient's statement
- Encourages their personal exploration and helps them understand their motivations
- Can be used to reinforce motivation
- E.g., "You've seen so much progress with Johnny's interpersonal skills this year and see how school is helping to provide that support, but you're struggling to understand his IEP and what services have been put in place to help with his reading. You see how frustrated he gets during homework time and you feel desperate for help."

S - Summary

- Summarizing information helps patients to feel heard
- Allows for "check in" opportunities to ensure that you are on the same page
- Can point out discrepancies between current behaviors and future desires
- e.g., "OK, it sounds like you really want to use the reinforcement strategy we've talked about during our visits, but sometimes your emotions get the best of you and you're not able to use it in the moment. Is that right?"

Eliciting Change Talk

Change talk	Ougations to aligit abongs talk	Example of nationt's shange talk
Change talk	Questions to elicit change talk	Example of patient's change talk
Recognizing disadvantages of the status quo	 What worries you about your child's behavior? How have the problems at school impacted your lives? 	"I'm concerned that my child will be labeled as a 'bad kid' if they continue along this path and don't get the intervention they need."
Advantages of change	 In an ideal world, what would Johnny's school do to help? What would be different for you if you and his teacher had a positive relationship? What could happen in your school system or community if you address these concerns? 	"If we could get these concerns worked out with the school, Johnny would probably feel less stressed about going to school, and other children might benefit from how hard I am working to resolve these issues, as well."
Optimism for change	 When have you been an advocate for your child in the past? What did that feel like? What strengths do you have that would help you get this change done? 	"When he first entered preschool, I had to enroll him in several programs to help with insurance coverage. When we finally got the support we needed, I felt like I had done something huge. It was a great feeling."
Intention to change	 In what ways do you want your life to be different in 5 years? How do you think your work might impact others around you if you were to do what you've been considering? 	"I think I could make a big impact if I were able to take the next step into becoming a trained advocate. I've thought about it for years but the challenges sometimes seem insurmountable. When I think about the impact it could make for my son, I'm much more motivated."

Helpful Reminders

Express empathy - Use reflective listening skills and seek to understand the patient's perspective, thoughts, and feelings without judgment or criticism. Empathy doesn't mean that you condone a problem/ineffective behavior. Rather, it creates an open and respectful relationship and lays the foundation for future interactions.

Develop discrepancy - Helping to identify discrepancies between current behavior and future goals is a pillar of Motivational Interviewing. Exploring the pros and cons of change can help patients and parents develop and understand these discrepancies (e.g., on one hand, you feel anxious to discuss your concerns with your child's teacher, but on the other hand you think the problems won't be resolved unless you step in). These exercises help patients tease apart ambivalence and clearly understand their concerns.

Roll with resistance - A coercive or authoritarian style of intervention may cause the patient or family member to be resistant to change and recommendations. It may look like interrupting or arguing with the provider, excusing their own behavior or minimizing the effects of their behavior, blaming others, or overall pessimism toward change. When using MI, the practitioner is able to reflect back the patient's concerns and hesitancy without judgment. Emphasizing that change is "up to you" and aligning yourself as a partner can help refocus the conversation.

Support self efficacy - Many parents have tried to change in the past and been unsuccessful. They may have talked to school personnel, clinicians, and/or prominent figures and felt dismissed or belittled. By highlighting their strengths and resolve and reflecting on past <u>successful</u> attempts, you can promote self efficacy and increase motivation to change.

Addressing Resistance

Assess readiness to change

- Precontemplation: Does not recognize the need for change or is not actively considering change
- Contemplation: Recognizes the problem and is considering change
- Action: Has initiated change
- Maintenance: Is adjusting to change and is practicing new skills and behaviors to sustain change

Sometimes people aren't ready to change yet. *That's ok.* MI techniques are still useful to build rapport and help patients draw their own conclusions.

Motivational Interviewing Resources

- American Academy of Pediatrics
 https://www.aap.org/en/patient-care/mental-health-initiatives/mental-health-education-and-training/motivational-interviewing/
- Book Recommendation: Deliberate Practice and Motivational Interviewing (2022) https://www.apa.org/pubs/books/deliberate-practice-motivational-interviewing
- Center for Behavioral Health Integration
 https://healthandlearning.org/wp-content/uploads/2021/03/MI-Phases-Spirit-Acronyms-OARS-202
 1.pdf
- Motivational Interviewing Network of Trainers
 https://www.jcjc.pa.gov/Publications/Documents/JJSES/Motivational%20Interviewing%20Workbook.pdf
- Rutgers Motivational Interviewing Cheat Sheet
 https://rutgerstraining.sph.rutgers.edu/Fiveminutes/download/mi_strategies_cheat_sheet.pdf
- Texas Pediatric Society https://txpeds.org/motivational-interviewing

Clinician Resources

National Organizations to Know About

The Arc - https://thearc.org/

This is a national organization that has many chapters across the United States. They are highly engaged in policy and advocacy efforts at the federal, state, and local levels. Information regarding these efforts, how you can help with advocacy, and toolkits/resources for you as well as for families can be found on their website. In addition, many local chapters offer advocacy assistance for free to families. To locate your local chapter, visit this link: https://thearc.org/find-a-chapter/

The Center for Parent Information and Resources -

https://www.parentcenterhub.org/find-your-center/

This website allows you to find your local parent training and information centers (PTIs) and your local Community Parent Resource Centers (CPRCs). PTIs and CPRCs are endorsed by the U.S. Department of Education and work with families of children and young adults ages birth to 26. They also partner with professionals and policymakers to improve outcomes for children with intellectual and developmental disabilities.

American Civil Liberties Union (ACLU) - https://www.aclu.org/issues/disability-rights

This is an organization that works with the court systems, legislatures, and communities to defend and preserve the rights of people with disabilities. The ACLU website is a great place for providers to keep up to date on issues relevant in their immediate community, but also on a national level as well. The "take action" button on the ACLU website is also a great place to engage in quick advocacy action moments on a variety of different topics.

Easter Seals - https://www.easterseals.com/

This organization is working on the local, state, and federal level to expand access to healthcare, education and employment to individuals with disabilities. This organization offers many opportunities for providers to engage in advocacy on behalf of their patients

(https://www.easterseals.com/get-involved/advocacy/) and many local chapters offer direct services to clients such as help with educational guidance, respite care, assistive technology services, recreation, job training, etc. You can find your local Easter Seals chapter by visiting this link: https://www.easterseals.com/connect-locally/

Association of University Centers on Disabilities (AUCD) -

https://www.aucd.org/template/index.cfm

This is a network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families and communities. This is a great website to learn about current initiatives and advocacy steps you can take on behalf of your patient population.

Advocacy Resources

www.apa.org/advocacy

Advocacy page of the American Psychological Association (APA) website; includes information on APA advocacy initiatives and current legislation that affects practice.

www.kff.org

Website for the Henry J. Kaiser Family Foundation, an independent foundation that engages in research and education regarding national health issues.

www.childrensdefense.org

Website for the Children's Defense Fund, a nonprofit child advocacy organization that provides information and recommendations regarding legislation that affects children across all domains.

www.5calls.org

Provides a simplified framework for advocacy, encouraging individuals to make 5 calls to legislators regarding specific issues. This website does present issues in a partisan manner.

www.childrenshospitals.org

Website for the Children's Hospital Association, includes information regarding child advocacy with an emphasis on healthcare issues. The CHA's "Speak Now for Kids" campaign provides advocacy tools and guidance for professionals and families.

www.ncsl.org

Website for the National Conference of State Legislatures; includes a searchable bill tracking database for all 50 states (located under the Research tab on the home page).

www.congress.gov

Official website of the United States Congress (Senate and House), including links to contact your legislators, committee structure and membership, explanations of the legislative process, status of current legislation, etc.

www.wrightslaw.com

Detailed information and case law regarding special education, 504, education law and advocacy.

www.countable.us

Online resource for obtaining summaries of current legislation, an overview of public opinion regarding legislative issues, and links to directly contacting legislators through text or video messaging. A Countable app is also available.

www.govtrack.us

Online resource for tracking legislation (including predictions regarding likelihood of passage), identifying your legislators, tracking legislators' voting records, and other advocacy-related information.

www.icivics.org

Founded by Justice Sandra Day O'Connor, this interactive website offers free instructional tools, games and lesson plans designed to enhance civics instruction. Though intended for schoolteachers, the tools and games can be useful for medical learners and other audiences as well.

Collaborating with a Medical Legal Partnership (MLP)

A Medical Legal Partnership (MLP) is a medical-legal model that is becoming increasingly more common in healthcare settings nationwide. An MLP is a group of attorneys embedded within a healthcare system who function as part of the interdisciplinary team. MLP attorneys may be utilized for individual consultation with families but may also use their expertise to advance local and state policies that influence societal factors directly related to poor health outcomes. Building a relationship with your hospital MLP can be a great way to learn more about advocating on behalf of your patients.

- Become familiar with your organization's legislative priorities.
 - Does your organization have a Center for Policy and Advocacy?
 - What issues are important on an institutional level and do any of these align with your specific area of advocacy interest?
 - What are your organization's policies around employee advocacy participation?
 - On what levels of advocacy has your MLP been involved in the past and regarding what issues?
- Get to know your hospital's MLP program.
 - Where is the MLP located within your organization?
 - What types of issues does the MLP help with?
 - Are there lawyers within your organization that patients are assigned to or does your organization partner with other volunteer lawyer programs in the community?
 - Are there other providers you know who have utilized the MLP for their patients? If so, ask about their experiences.
 - Learn how to make a referral to the MLP.
- Build a relationship with your MLP.
 - Schedule a meeting to introduce yourself.
 - At this meeting, make sure you give them information about the types of patients and issues you see most common.
 - Get their insights into current legislative priorities and where you may be most helpful.
 - Make sure other members of your staff (particularly your social worker, if applicable) are receptive to the MLP and can foster trust between patients and the legal team.
- Prioritize education regarding social determinants of health within your clinic setting.
 - Hospital MLPs can be a helpful resource for education regarding social determinants
 of health and related effects within your practice setting. National MLPs have
 conducted a variety of educational seminars for providers nationwide including didactic
 education sessions, poverty simulations, case samples, etc.
 - Your MLP may also be interested in providing educational seminars for families as well. For example, some MLPs have provided group education to families regarding topics such as guardianship and alternatives, immigration issues, special education services, etc. Caregivers may be more open to legal consultation and education within a healthcare setting they know and trust.

- If you do not have an MLP at your institution, consider advocating for one using the resources below:
 - National Center for Medical Legal Partnership https://medical-legalpartnership.org/
 - Medical-Legal Partnership Toolkit
 https://www.medical-legalpartnership.org/wp-content/uploads/2014/03/MLP-Toolkit-Phase-I-FINAL-FILLABLE.pdf

Family Resources

Special Education Law Primer

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA) is a federal law that requires that all eligible children and young adults who are 3 to 21 years of age be provided a "free and appropriate public education" (FAPE) in the "least restrictive environment" (LRE). Eligibility is determined based on whether the child qualifies for one of the following 13 disabilities, and that disability must adversely affect the child's education:

- Specific Learning Disability (can include dyslexia, dyscalculia, dysgraphia)
- Speech or Language Impairment
- Autism
- Intellectual Disability
- Hearing Impairment
- Deafness
- Visual Impairment, including blindness
- Deaf-Blindness
- Emotional Disturbance (can include anxiety, depression, obsessive-compulsive disorder, schizophrenia, bipolar disorder)
- Orthopedic Impairment (can include cerebral palsy)
- Traumatic Brain Injury
- Other Health Impairment (can include ADHD)
- Multiple Disabilities

If you are concerned about your child and think they might be eligible for services under the IDEA, you can request an evaluation through your local public school district. The evaluation to determine whether your child is eligible for IDEA can include any of the following assessments:

- Psychological
- Psychoeducational (typically involves cognitive and academic testing)
- Neuropsychological (typically involves cognitive and academic testing, as well as behavioral testing)
- Speech and Language
- Occupational Therapy (evaluates fine motor skills, self-regulation, and visual and/or sensory processing)
- Physical Therapy (evaluates gross motor skills)
- Social History
- Medical or Psychiatric

Following the evaluation, you will be invited to a meeting to determine whether your child is eligible for special education services. The school district is <u>not</u> allowed to determine whether your child is eligible before the meeting. This is called 'pre-determination.' You have the right to participate in the meeting and share your concerns before any decision is made about whether your child is eligible for services. You also have the right to see the results of the evaluation <u>before</u> the eligibility determination meeting.

At the meeting, the team might decide that your child is eligible for an **Individualized Education Program (IEP)**. An IEP is a formal document that describes the special education supports and services that your child is entitled to, along with a list of educational goals for your child.

Based on data from the National Center for Education Statistics from 2018-2019, greater than 14% of students enrolled in public schools from ages 3-21 (a total of over 7 million students) were being served under IDEA.¹

If your child receives an IEP, they will have a meeting to review the IEP once a year, and a full re-evaluation every three years.

If your child is not found eligible for an IEP, they might be eligible for a **504 Plan**. A 504 Plan provides supports and removes barriers for a child with a disability, and is covered under a federal law, Section 504 of the Rehabilitation Act of 1973. A child with *any* disability (not only the 13 described above) can be eligible if that disability affects the child's ability to learn in a general education classroom. A 504 Plan details the accommodations your child will receive at school, but often does not include the same types of services provided to children with IEPs.

If you have additional questions about the evaluation process, or the types of services your child might be entitled to receive, www.understood.org has several articles detailing the answers to these questions. They also have articles detailing what to do if you disagree with the special education team's findings or decisions.

References:

https://www.understood.org/en/articles/conditions-covered-under-idea

https://www.understood.org/en/articles/different-terms-you-may-hear-for-evaluations? sp=5fefcd31-d 5ee-4e22-a235-857ae03240c9.1664405128314

https://www.understood.org/en/articles/the-difference-between-ieps-and-504-plans?_sp=6429979f-5d df-4038-86b5-945540932729.1665183565363

https://specialneedsanswers.com/idea-101-a-short-primer-on-the-law-for-students-with-special-needs-16143

¹ https://nces.ed.gov/programs/digest/d19/tables/dt19_204.70.asp Wallace, Keder, Cervantes, Godwin, Hickey, Perrin, Spector, Toomey, Tyner-Wilson. 10-21-2022. Please do not reproduce without permission from authors.

Cheat Sheet: Advocating For Your Child by Type of Problem

School Services	Other Local Issues	State and Federal Policies
School has not evaluated your child.	Problems with your child's Medicaid/CHIP, SNAP, SSI.	Eligibility requirements for programs such as Medicaid.
Your child has a 504 plan, but you feel they need more help.	Problems with housing. Problems with transportation.	Medicaid coverage for services.
The first step is to ask the school to do a Full and Individual Evaluation (FIE). Ask for this in writing (sample letter or email). The school should answer within a specific time frame (check your state's education website for this information). Your child has an Individualized Education Program (IEP), but they are not getting the services they need.	The best first step is to contact the local agency that provides these services or benefits. Examples: your local Health and Human Services office (Medicaid office, DHHR), Social Security office (SSI), housing agency, public transportation agency. Ask to talk with a supervisor about your problem. If this does not work, you can contact the offices of your local or state legislators to ask for help. Here are some steps to take:	Lack of access to behavioral health. Learn as much as you can about the reasons for these problems. Decisions about eligibility and coverage for services through Medicaid are usually decided at the state level. And states also make decisions about how much money goes into the budget for different programs, and those decisions affect waiting lists and access to services.
Your child with an IEP is having behavior problems in school. Your teen has an IEP and you are not sure what will happen after high school. Ask for an IEP meeting to talk about your concerns. You can have as many IEP meetings as you need to and do not have to wait for	League of Women Voters website (www.lwv.org) has a search tool where you can easily find your local, state and federal representatives. Contact city or county legislators for problems with local services (transportation, housing). Contact state legislators for state benefits (Medicaid, SNAP, etc.).	Here are some suggestions to help you find out more about your state's decisions about programs and budgets: Check out your state's legislative website (search your state's name plus "legislature"). This will give you information about laws being discussed, who serves on the committees that make decisions, etc.

an upcoming scheduled meeting.

If these first steps do not work, here are some next steps:

Contact the school district's special education department.

Contact your school board member. You may be able to speak at a public meeting about your problem.

Contact the state's education agency.

Find an advocate to help you.

Explain your problem briefly and ask for what you need help with.

Find a case manager to help you. Here are some ideas on how to find case management services:

- Your child's Medicaid plan
- Community agency for people with developmental disabilities
- Cultural or other community organizations
- Pediatrician's/specialist's office

Check out the websites for organizations that focus on children with developmental differences or disabilities.

National organizations can often direct you to their state/local groups. Examples: Autism Society of America, National Down Syndrome Society, National Fragile X Foundation.

Join with others. Parent support groups and other community organizations are a great way to discuss advocacy needs and ways to address gaps in services.

Ten Tips for Effective Policy Advocacy

- 1. Choose an issue that is very important for you and your family.
- 2. Learn as much as you can about the issue and decide on your "ask."
- 3. Decide whom you want to talk to and schedule an appointment with your legislator or one of their staff members.
- 4. Keep it clear and short legislators and their assistants may only have 10-15 minutes to hear your ask.
- 5. Know your facts, but tell your story. Stories (about your child and family) usually stick with legislators longer than statistics do.
- 6. Stay positive, pleasant and collaborative, not confrontational.
- 7. Follow up with an email to say thank you, and offer to be a resource if they need any other information.
- 8. If you can't meet with a legislator in person, contact them in other ways (phone calls, emails, social media). Same tips apply: be prepared, keep it short, tell your story, make your ask.
- 9. Follow your legislators on social media and subscribe to their newsletters so you know what they are working on.
- 10. Don't give up! Policy change can be slow and frustrating, but advocacy will make a difference. This process is a marathon and not a sprint.

Helpful Advocacy Websites and Resources for Caregivers

League of Women Voters - https://www.lwv.org/

National Center for Learning Disabilities – A Parent's Guide to Local Advocacy https://www.ncld.org/wp-content/uploads/2020/09/2020-Parent-Guide-to-Local-Advocacy_v4.pdf

Special Needs Alliance – Political Advocacy by Parents of Children with Disabilities https://www.specialneedsalliance.org/the-voice/political-advocacy-by-parents-of-children-with-disabilities/

Video - "Advocacy 101: Tips for Legislative Advocates" https://youtu.be/h0cUj6-uJjU

Although this video discusses resources and processes in Washington State, the advocacy tips are valuable regardless of where you live!

Wrightslaw - https://www.wrightslaw.com/

APPENDIX A: GLOSSARY OF SPECIAL EDUCATION AND LEGAL TERMS

Adapted from Wrightslaw (https://www.wrightslaw.com/links/glossary.sped.legal.htm)

Α

Accommodations. Include changes in presentation format, response format, test setting or test timing. Appropriate accommodations are made to level the playing field, i.e., to provide equal opportunity to demonstrate knowledge.

Americans with Disabilities Act of 1990 (ADA). Legislation enacted to prohibit discrimination based on disability.

Alternative dispute resolution. See mediation.

Appeal. Procedure in which a party seeks to reverse or modify a judgment or final order of a lower court or administrative agency, usually on grounds that lower court misinterpreted or misapplied the law, rather than on the grounds that it made an incorrect finding of fact.

Appendix A. Appendix to the federal special education regulations that answers questions about IEPs, IEP teams, parental role, transition.

ARD- Annual, Review, and Dismissal meeting. Some states utilize the term ARD to describe the meeting that happens before the IEP is developed. See IEP for more information.

Assistive technology device. Equipment used to maintain or improve the capabilities of a child with a disability.

В

Basic skills. Skills in subjects like reading, writing, spelling, and mathematics.

Behavior disorder (BD). See emotional disturbance.

BIP. A plan of positive behavioral interventions in the IEP of a child whose behaviors interfere with his/her learning or that of others.

Brief. Written argument that supports a case; usually contains a statement of facts and a discussion of law.

Burden of proof. Duty of a party to substantiate its claim against the other party; in civil actions, the weight of this proof is usually described as a preponderance of the evidence.

C

Child find. Requirement that states ensure that all children with disabilities are identified, located and evaluated, and determine which children are receiving special education and related services.

C.F.R. Code of Federal Regulations

Complaint. Legal document that outlines plaintiff's claim against a defendant.

Confidential file. File maintained by the school that contains evaluations conducted to determine whether child is handicapped, other information related to special education placement; parents have a right to inspect the file and have copies of any information contained in it.

Consent. Requirement that the parent be fully informed of all information that relates to any action that school wants to take about the child, that parent understands that consent is voluntary and may be revoked at any time. See also Procedural safeguards notice and prior written notice.

Cumulative file. General file maintained by the school; parent has right to inspect the file and have copies of any information contained in it.

Curriculum-Based Measurement (CBM). A method to measure student progress in academic areas including math, reading, writing, and spelling. The child is tested briefly (1 to 5 minutes) each week. Scores are recorded on a graph and compared to the expected performance on the content for that year. The graph allows the teacher and parents to see guickly how the child's performance compares to expectations.

D

Damages. Monetary compensation that may be recovered by a person who has suffered loss, detriment or injury to his person, property or rights, through the unlawful act or negligence of another; damages are not generally available under the IDEA.

Disability. In Section 504 and ADA, defined as impairment that substantially affects one or more major life activities; an individual who has a record of having such impairment, or is regarded as having such an impairment.

Discovery. Term for methods of obtaining evidence in advance of trial; includes interrogatories, depositions and inspection of documents.

Due process hearing (impartial due process hearing). Procedure to resolve disputes between parents and schools; administrative hearing before an impartial hearing officer or administrative law judge. Called a "fair hearing" in some states.

Ε

Early intervention (EI). Special education and related services provided to children under age of 5.

Emotional disturbance (ED). Disability category under IDEA; includes depression, fears, schizophrenia; adversely affects educational performance.

EMR. Educable mentally retarded.

ESY. Extended school year services.

Exhibit. Anything tangible that is produced and admitted in evidence during a trial.

F

FAPE. Free appropriate public education; special education and related services provided in conformity with an IEP; are without charge; and meets standards of the SEA.

FBA. Functional behavior assessment.

FERPA. Family Educational Rights and Privacy Act; statute about confidentiality and access to education records.

FIE. Full and Individualized Evaluation; the evaluation the school does to determine if a child meets educational criteria for special education services.

G

General curriculum. Curriculum adopted by LEA or SEA for all children from preschool through high school.

Guardian ad litem. Person appointed by the court to represent the rights of minors.

н

Hearing impairment. Disability category under IDEA; permanent or fluctuating impairment in hearing that adversely affects educational performance.

Ī

IDEA. The Individuals with Disabilities Education Act.

IDELR. Individuals with Disabilities Law Reporter

IEE. Independent educational evaluation. This is an outside evaluation the family can request if they are unhappy with the evaluation done directly through the school.

IEP. Individualized Educational Plan. This is the plan that details the specific services the child receives and goals the child should meet for the year. This plan should be reviewed annually.

IFSP. Individualized Family Service Plan.

Impartial due process hearing. See due process hearing.

Inclusion. Practice of educating children with special needs in regular education classrooms in neighborhood schools. See also mainstreaming and least restrictive environment.

Interrogatories. Written questions served on a party that must be answered under oath before trial; method of discovery.

ITP. Individual Transition Plan

J

Judgment. Order by a court

L

LRE. Least restrictive environment; requirement to educate special needs children with children who are not disabled to the maximum extent possible.

LEA. Local education agency or school district

M

Mainstreaming. Practice of placing special needs children in regular classrooms for at least a part of the children's educational program. See also least restrictive environment and inclusion.

Manifestation determination review. If child with disability engages in behavior or breaks a rule or code of conduct that applies to nondisabled children and the school proposes to remove the child, the school must hold a hearing to determine if the child's behavior was caused by the disability.

Mediation. Procedural safeguard to resolve disputes between parents and schools; must be voluntary, cannot be used to deny or delay right to a due process hearing; must be conducted by a qualified and impartial mediator who is trained in effective mediation techniques.

Modifications. Substantial changes in what the student is expected to demonstrate; includes changes in instructional level, content, and performance criteria, may include changes in test form or format; includes alternate assessments.

Multiple disabilities. Disability category under IDEA; concomitant impairments (such as mental retardation-blindness, mental retardation-orthopedic impairment, etc.) that cause such severe educational problems that problems cannot be accommodated in special education programs solely for one of the impairments; does not include deaf-blindness.

Ν

Native language. Language normally used by the child's parents.

0

OCR. Office of Civil Rights

Occupational therapy. Related service; includes therapy to remediate fine motor skills.

OHI. Other health impairment.

Opinion. Formal written decision by judge or court; contains the legal principles and reasons upon which the decision was based.

Orientation and mobility services. Related service; includes services to visually impaired students that enable students to move safely at home, school, and community

Orthopedic impairment. Disability category under IDEA; orthopedic impairment that adversely affects child's educational performance

OSERS. Office of Special Education and Rehabilitative Services

OSEP. Office of Special Education Programs

Other health impairment (OHI). Disability category under IDEA; refers to limited strength, vitality or alertness due to chronic or acute health problems that adversely affects educational performance.

P

Physical therapy. Related service; includes therapy to remediate gross motor skills.

Precedent. A court decision that will influence similar cases in the future.

Prior written notice. Required written notice to parents when school proposes to initiate or change, or refuses to initiate or change, the identification, evaluation, or educational placement of the child.

Pro se. Representing oneself without assistance of legal counsel

Procedural safeguards notice. Requirement that schools provide full easily understood explanations of procedural safeguards that describe parent's right to an independent educational evaluation, to examine records, to request mediation and due process.

Progress monitoring. A scientifically based practice used to assess students' academic performance and evaluate the effectiveness of instruction; can be implemented with individual students or an entire class.

Public Law (P.L.) 94-142. The Education for All Handicapped Children Act; enacted into law in 1975

R

Reasonable accommodation. Adoption of a facility or program that can be accomplished without undue administrative or financial burden.

Recreation. Related service; includes therapeutic recreation services, recreation programs, and leisure education.

Rehabilitation Act of 1973. Civil rights statute designed to protect individuals with disabilities from discrimination; purposes are to maximize employment, economic self-sufficiency, independence, inclusion and integration into society.

Rehabilitation counseling services. Related service; includes career development, preparation for employment, vocational rehabilitation services funded under the Rehabilitation Act of 1973.

Related services. Services that are necessary for child to benefit from special education; includes speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, early identification and assessment, counseling, rehabilitation counseling, orientation and mobility services, school health services, social work services, parent counseling and training.

Remediation. Process by which an individual receives instruction and practice in skills that are weak or nonexistent in an effort to develop/strengthen these skills.

Response to Intervention (RTI). Use of research-based instruction and interventions with students who are at risk and students who are suspected of having specific learning disabilities.

S

School health services. Related service; services provided by a qualified school nurse or other qualified person.

SEA. State educational agency (state department of education).

Section 504. Section 504 of the Rehabilitation Act protects individuals with disabilities from discrimination due to disability by recipients of federal financial assistance.

Settlement. Conclusion of a legal matter by agreement of opposing parties in a civil suit before judgment is made.

Special education. Specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability.

Speech-language pathology services. Related service; includes identification and diagnosis of speech or language impairments, speech or language therapy, counseling and guidance.

Speech or language impairment. Disability category under IDEA; includes communication disorders, language impairments, voice impairments that adversely educational performance.

Statutory rights. Rights protected by statute, as opposed to constitutional rights that are protected by the Constitution.

Statute of limitations. Time within which a legal action must be commenced.

State education agency (SEA). State departments of education.

Statutory law. Written law enacted by legislative bodies.

Supplementary aids and services. Means aids, services, and supports that are provided in regular education classes that enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate.

SWD. Students with disabilities.

т

Technology (see assistive technology)

Testimony. Evidence given by a person as distinguished from evidence from writings and other sources.

Transition services. IEP requirement; designed to facilitate movement from school to the workplace or to higher education.

Transportation. Related service about travel; includes specialized equipment (i.e., special or adapted buses, lifts, and ramps) if required to provide special transportation for a child with a disability.

Traumatic brain injury. Disability category under IDEA; includes acquired injury caused by external physical force and open or closed head injuries that result in impairments; does not include congenital or degenerative brain injuries or brain injuries caused by birth trauma.

Travel training. See orientation and mobility services

U

U.S.C. United States Code

Visual impairment including blindness. Disability category under IDEA; impaired vision that adversely affects educational performance.

W

Weapon. Means a "dangerous weapon" as defined in the United States Code.

This Glossary of Special Education and Legal Terms is from <u>Wrightslaw: From Emotions to Advocacy.</u> <u>2nd Edition</u>.

APPENDIX B: Advocacy Letter Templates

Sample Letter Requesting Referral for Initial Evaluation

PARENT'S NAME ADDRESS CITY, STATE ZIP CODE TELEPHONE NUMBER

Date

(Name of Special Education Director) (Name of School District) (Address of School)

Dear (Name of Special Education Director):

My child, (child's name) (date of birth) attends (school name). I believe that s/he might have unidentified disabilities. The following difficulties support my concern:

(List your observations – here are some examples)

- S/he does not respond normally to sensory input;
- S/he shows no desire to explore her environment through touch;
- S/he has difficulty holding a pen or pencil with a mature grasp;
- S/he has difficulty when applying decoding skills when writing; and
- S/he has poor short-term memory.

Please evaluate (child's name) under the Individuals with Disabilities Education Act [IDEA] and Section 504 of the Rehabilitation Act to see if s/he has a disability and if related services are necessary. Please consider this letter my consent to evaluate (child's name) for special education needs and services. It is my understanding that the District must complete the evaluation and determination process within 60 days from the date of consent. If the District requires consent in addition to the consent given in this letter, please provide me with the required consent form within 3 business days so that we can move forward expeditiously. Please call me at home to arrange times and places. I will need my copies of all written evaluations at least three school days before the IEP Team meeting. I will advise you of my IEP Team meeting availability dates by separate letter.

Thank you for giving (child's name) evaluations your immediate attention. I will work with you to address and achieve (child's name) educational goals.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample Letter Requesting an IEP Team Meeting

PARENT'S NAME ADDRESS CITY, STATE ZIP CODE TELEPHONE NUMBER

Date

(Name of Special Education Director) (Name of School District) (Address of School)

Dear (Name of Special Education Director):

My child, (child's name) (date of birth) attends (school name). My child's IEP Team has not yet met for this year.

Please schedule an IEP Team meeting as soon as possible to write my child's IEP. Please contact me so that the meeting can be scheduled at a mutually agreeable time and place. Before the meeting, please send me a copy of the school's IEP form.

Thank you for your help. I look forward to hearing from you soon on this matter.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample Letter Requesting an IEP Team to Review and Revise a School Program

PARENT'S NAME ADDRESS CITY, STATE ZIP CODE TELEPHONE NUMBER

Date

(Name of Special Education Director) (Name of School District) (Address of School)

Dear (Name of Special Education Director):

I am the parent and guardian of (child's name) (date of birth) who attends (school name). My child is experiencing difficulties at school (List the difficulties your child is experiencing).

I am writing to request that an IEP Team meeting be convened to address these difficulties and revise (child's name) IEP. Please ask the following people to attend the IEP Team meeting: (List the people you think are important to have at the meeting).

Please contact me to discuss a date and time for the IEP Team meeting.

Thank you for your help. I look forward to hearing from you soon on this matter.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample Letter Requesting an Independent Evaluation

PARENT'S NAME ADDRESS CITY, STATE ZIP CODE TELEPHONE NUMBER

Date

(Name of Special Education Director) (Name of School District) (Address of School)

Dear (Name of Special Education Director):

My child, (child's name) (date of birth) attends (school name). I disagree with the results of the school district evaluation of (child's name) on (date) because (reason why you feel the tests were invalid, inadequate or not an accurate measure of your child's performance).

I request an independent evaluation to obtain the valid and reliable information I believe is needed to plan an appropriate educational program for my child. Please send me information on:

- Criteria for qualified examiners;
- Suggested sources and locations;
- Procedures for reimbursement;
- Reasonable and expected costs.

I understand that the school must pay for the independent evaluation unless it can prove in a due process hearing that its assessment is appropriate. Please inform me in writing within seven days whether you intend to honor my request or to request a hearing on the issue.

I will forward the results of the evaluation to you since, as I understand it, the results of an independent evaluation must be considered in any future decisions about my child.

Thank you and I look forward to hearing from you soon.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample Letter Requesting Re-Evaluation

Date

(Name of Special Education Director) (Name of School District) (Address of School)

Dear (Name of Special Education Director):

My child, (child's name) (date of birth) attends (school name). I recently reviewed my child's evaluation and it is (out-of-date, incomplete, inappropriate due to change in seizure control, time for a three year evaluation). I request that my child be re-evaluated. Please tell me in writing who will be doing the evaluation and when it will be scheduled.

Thank you for your help. I look forward to hearing from you soon.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample Letter Provided by Family Resource Network, Inc.

Sample Letter Requesting Functional Assessment of Behavior and Positive Behavior Support Plan

PARENT'S NAME ADDRESS CITY, STATE ZIP CODE TELEPHONE NUMBER

Date

(Name of Special Education Director) (Name of School District) (Address of School)

Dear (Name of Special Education Director):

My child, (child's name) (date of birth) attends (school name). I believe that (child's name) behavior is beginning to interfere with his/her ability to learn and to reach his/her IEP goals and objectives.

The following difficulties support my concern:

(List your observations – here are some examples)

- S/he does not know how to respond constructively to name calling or teasing;
- S/he is not cooperative in groups;
- S/he needs assistance to distinguish between socially acceptable and unacceptable behavioral responses to various situations and environments;
- S/he does not recognize situations in his/her self-control is needed;
- S/he does not know how to cope with stress-provoking situations he/she cannot avoid;
- S/he does not understand the consequences of appropriate and inappropriate expressions of his/her feelings.

Please provide (child's name) with a functional assessment of behavior as is required by the Individuals with Disabilities Education Act [IDEA]. Please consider this letter my formal request for and consent for the school district to provide the functional assessment. I understand that a positive behavior support team will be assembled to review the functional assessment of behavior and develop an appropriate behavior intervention plan. I expect to be included in the functional assessment of behavior and as active participant on the team developing the behavior intervention plan Please provide me with copies of all FBA data and results as soon as they become available to you. I hope that this request can be expedited as (child's name) already has been suspended in/from school on (number of times) for a total of (number of days) days.

Thank you for giving this request for a functional assessment of behavior your immediate attention. I will work with you to address and achieve (child's name) educational goals using positive behavior support and an effective behavior intervention plan.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample Letter Provided by Family Resource Network, Inc.

Sample Letter Requesting Extended School Year

• • •
PARENT'S NAME ADDRESS CITY, STATE ZIP CODE TELEPHONE NUMBER
Date
(Name of Special Education Director) (Name of School District) (Address of School)
Dear (Name of Special Education Director):
As I promised, I have enclosed some material, which will be helpful to you in explaining to IEP Team why it is critical that receive summer services at the district's expense.
As we discussed, it is likely that the district will focus on the regression/recoupment standard based upon their belief that this is the only standard utilized in determining whether extended school year services are justifiable. However, as you will read in the attachment, regression is not the only factor that can be relied upon in the ESY decision. Courts have identified six factors that may be relied upon to make this determination.
While regression/recoupment is an important consideration, the Team must also consider: – degree of progress towards IEP goals and objectives; – emerging skills or breakthrough opportunities that will be lost over the long summer months; – any behavior that would interfere with the child's ability to benefit from special education. – the nature and severity of the disability; and – the child's ability to benefit from special education.
Because's needs are extensive, based upon his diagnosis of autism, it is critical that he receive consistent instruction 12 months a year without interruption's future independence is wholly based upon his ability to effectively communicate. His speech and language deficits unquestionably necessitate summer instruction, so that he not only maintains the skills that he has acquired during the school year, but continues to progress in an effort to catch up to his typical peers.
Thank you for your help.
Sincerely, (Your name) (Your address) (Your telephone number)
Sample Letter Provided by Family Resource Network, Inc.

Sample Letter Requesting Organizational Evaluation

Dear (Name of Special Education Director):

My child, (child's name) (date of birth) attends (school name). I am concerned that he lacks self-management skills as a result of his disability. I believe the lack of these skills is having a devastating effect on his academic performance. Here are some of the symptoms he exhibits that support my concern.

- He has poor time-management skills;
- He does not know how to take classroom notes;
- He does not know how to organize his notebooks;
- He has test anxiety and "shuts down" due to fear of failure.

Because (child's name) has great difficulty paying attention he is not able to focus on new information long enough to make it a part of his working memory. He has problems handing in homework on time and getting to class on time. Because of his organizational difficulties he has trouble remembering what he has read and difficulty writing a satisfactory report.

I read that self-management skills are considered to be part of the brain's "executive functioning" and that the frontal lobe of the brain is the "command center" for goal-directed behavior. I understand that executive functioning is a complex process that enables the student to see a task through from beginning to end by coordinating multiple processes, starting and stopping mental operations, and maintaining motivation and persistence.

Please evaluate (child's name) under the Individuals with Disabilities Education Act [IDEA] and Section 504 of the Rehabilitation Act to see how his disability is related to the above problems, to see what goals and objectives are recommended to address those problems in light of his disability, and to see what, if any, related services are necessary.

Please consider this letter my consent to evaluate (child's name) for special education needs and services. Obviously (child's name), the school district and I will feel much better once we understand what is going on with him. I would appreciate it if you would schedule the evaluations as quickly as possible. Please call me at home to arrange times and places. I will need my copies of all written evaluations at least three school days before the IEP Team meeting. I will advise you of my IEP Team meeting availability dates by separate letter.

Thank you for giving (child's name) evaluations your immediate attention. I will work with you to address and achieve his educational goals.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample Letter Provided by Family Resource Network, Inc.

Sample Letter Requesting Records From School District

Date

(Name of Special Education Director) (Name of School District) (Address of School)

Dear (Name of Special Education Director):

My child, (child's name) [date of birth] receives special education services at (school name). Please provide me with a complete list of all education records you have on my child. Please tell me where those records are kept, and whom I should contact so I can look at them and have copies made.

If (name of schools district) has produced any written material about access to student records pursuant to the federal Family Education Rights and Privacy Act, I would request that you send me a copy of that as well.

Thank you for your help. I look forward to your prompt response.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample Letter Provided by Family Resource Network, Inc.

REFERRAL/REQUEST FOR ASSESSMENT FOR SPECIAL EDUCATION SERVICES

DATE:			
DELIVERED VIA:	Fax	Registered Mail	In person
FROM:			
Parent/Guardian Name	(s):		
Street Address:			
City/State/Zip:			
Telephone Number(s):			
E-mail (if applicable):			
TO:			
Mr/Ms/Dr:			
Director of Special Edu	cation		
School District Name:			
District Street Address:			
City/State/Zip:			
Telephone Number (if k	nown):		
Fax Number (if known):			
E-mail (if known):			
ON BEHALF OF:			
Child/Student Name:			
Student Birth Date:			
Student School:			

My child has not been functioning well in school and I am concerned about my child's educational progress. I am writing to make a parent referral for assessment for special education services as allowed under the Child Find obligations of the Individuals with Disabilities Act (IDEA) and California Education Code Secs. 56029, 56301, 56302, and 56321(a) and 5 California Code of Regulations (C.C.R.) Sec. 3021. My child may be eligible

for special education assistance. I am requesting that my child be given a comprehensive assessment by the school district in all areas of suspected disability, and that an IEP meeting be scheduled.

Below are some of my concerns related to my child's educational progress, and information about my child's known and/or suspected disabilities:

[List or describe concerns here related to the child's suspected and/or known disabilities and adverse educational performance impact, which may include any of these, for example: academic performance, learning challenges, health impacts, memory, psychological processing, social, behavioral, expressive or receptive communication, social skills, fine and gross motor, mental health, or other areas of concern.]

As part of the assessment process, I also request that my child be assessed under Section 504 of the Rehabilitation Act of 1973 to determine whether he should be identified as handicapped pursuant to that law and to determine what, if any, accommodations might be required in his educational program in the event that he does not qualify for special education services, or in addition to special education services. I also request that the school district's 504 Coordinator be present at the IEP meeting to discuss the results and recommendations of assessment.

In addition to the typical school district evaluations, I specifically request that the school district conduct the following evaluations of my child if listed here:

[List specific evaluations requests here if you have some]

I understand that Response-to-Intervention (RTI) is now allowed under IDEA 2004 as one evaluative tool that may assist in determining the presence of specific learning disability (SLD) but that, according to the U.S. Department of Education (DOE) Office of Special Education and Programs (OSEP) memo of 1/27/2011, "it would be inconsistent with the evaluation provisions at 34 CFR Sections 300.301-300.111 for an LEA [school district] to reject a referral and delay provision of an initial evaluation on the basis that a child has not participated in an RTI framework," and that the school district has an "obligation to ensure that evaluations of children suspected of having a disability are not delayed or denied because of implementation of an RTI strategy." https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/osep11-07rtimemo.pdf

If the school district asks to conduct a Student Study Team (SST) process in response to my parent referral for IDEA evaluation, I will consider such a request so that my child can receive help and intervention while the IDEA evaluations are ongoing. Understand, however, that if I give my approval for a SST, I will not and do not waive my child's right to comprehensive assessment under the district's "Child Find" mandate.

I understand that schools are required only to "consider" general education interventions before delivering special education services, and that evaluation is not services. I also understand that the school district is not required to "exhaust" general education interventions; that there is no exhaustion standard in IDEA; and that IDEA Child Find requires evaluation when there is suspected disability.

I look forward to receiving an Assessment Plan within 15 calendar days for my review and consent so that evaluations can proceed. If the district refuses to evaluate I expect to receive Prior Written Notice (PWN) that meets the requirements of the IDEA. I look forward to evaluations being completed promptly and an IEP meeting held, at a mutually agreeable time and place, within 60 calendar days of my consent to the Assessment Plan, to discuss results and plan for my child's supported education.

Please ensure that we schedule an IEP meeting to ensure that I receive copies of all assessment reports at least 5 business days before the IEP meeting that will be scheduled to discuss them so that I will have adequate time to review and prepare any questions or parent concerns I may have for the IEP team.

Sincerely,

[signature]

Parent/Guardian Name

Copies to: [School Principal and other members of child's educational team as needed]

Enclosed: [list attachments to this letter you may want to include to help the district understand child's suspected disabilities, needs, diagnoses and/or disability(ies) if known]

Sample provided by Disability Rights Education and Defense Fund

REQUEST FOR SECTION 504 DETERMINATION AND 504 PLAN (INCLUDING REQUEST FOR ASSESSMENT IF NECESSARY)

Parent/Guardian Name Address City, State, Zip Code Telephone Number / Email

DATE:	[NOTE: process	is driven by timelin	es. Get a receipt to show proof of delivery
DELIVERED VIA:	Fax	_Registered Mail	In person
1) Administrator Name: Director of Student Ser School District: District Office Address: City, State, Zip:	vices / District 504	4 Coordinator	
2) Administrator Name: School Principal School Name: School Address: City, State, Zip:			
Student Name: Name of School:			Date of Birth: Grade:

I am writing to refer my child for determination of eligibility under Section 504 of the Rehabilitation Act of 1973 and to develop a formal documented 504 Plan of necessary educational services, which may require accommodations, program modifications, or services in order to enable my child to benefit from public education to the extent that students without disabilities do and to provide a free appropriate public education (FAPE) under Section 504 in the least restrictive environment (LRE).

My child has disabilities which substantially limit(s) major life activities, adversely impacting my child's learning and preventing equal access to educational opportunities and programs.

[Briefly describe your reasons for concern, child's disability, needs, etc.]

Dear District 504 Coordinator and School Principal:

We have documentation from *[list independent evaluations, or doctor or therapist reports]* that would qualify my child for services under Section 504 and would like to submit that information for review. We believe this information is more than sufficient for the Section 504 planning team to immediately make the determination of Section 504 eligibility and to develop necessary accommodations and/or services in a formal 504 Plan to remove discriminatory barriers and to provide my child a FAPE. We request a 504 team meeting without delay to develop a 504 Plan to meet my child's unique needs.

[Attach documentation or pertinent reports or say that you have such evidence of need and can make it available to the district upon request.]

I request that the Section 504 Coordinator for District be present at the initial 504 team meeting to discuss findings, results and recommendations with the Section 504 team. [You may ask that specific 504 team members be included who could contribute information about your child's needs – FOR EXAMPLE:]

I also request that my child's physical education teacher, his principal, and an Adaptive P.E. specialist attend the 504 meeting. My child will also participate in the 504 meeting and will need to be excused from class to do so, if the meeting is scheduled within the school day.

Should the District believe that the information I have provided is not sufficient to determine 504 eligibility and needs immediately, let this letter serve as my formal written request comprehensive evaluation in all areas of suspected disability under the Individuals with Disabilities Education Act (IDEA), as best practice, to make the 504 (and/or special education determination) and to identify 504 needs (and/or IEP needs should my child be found eligible under IDEA) within the timelines and processes that IDEA requires.

[If you have specific areas you think need to be assessed regardless, or know specific tests your child needs, you might add specific requests – EXAMPLES:]

I request that the School District also conduct the following evaluations of my child to assist in determining all 504 needs, regardless of whether or not the team decides it is necessary to conduct full IDEA evaluation:

- (1) An assistive technology (AT) assessment to determine appropriate tools and program modifications that may be necessary to assist my child in accessing and benefiting from his educational program.
- (2) An Adaptive Physical Educational (APE) assessment to determine the appropriate accommodations or program modifications that may be necessary to assist my child in accessing and benefiting from his educational program.

Thank you for giving (child's name)'s needs your immediate attention. I will work with you to address and achieve his educational goals.

Sincerely, (Your name) (Your address) (Your telephone number)

Sample provided by Disability Rights Education and Defense Fund

Please confirm in writing that:

- 1) I have provided sufficient information, that a 504 Planning meeting will be scheduled without delay with proposed mutually agreeable dates/times for the 504 meeting to develop the 504 Plan, or that
- 2) I will receive an Assessment Plan within 15 calendar days for my review and consent so that necessary district evaluations can proceed within the timelines IDEA requires (within 60 calendar days of my consent). Also that upon completion, an IEP team meeting will be held to discuss the results to make an eligibility determination and develop an appropriate 504 Plan or IEP (if eligible) to meet my child's unique needs and provide a FAPE in the LRE, and that
- 3) I will be provided copies of any and all assessment reports and other documentation that will be presented at a 504 or IEP meeting, at least 5 business days in advance of the meeting, so that I may adequately prepare for the meeting and so that my parent participation is ensured.

I understand that I must receive a written response and information about my Due Process rights if refused. Thank you.

Sincerely,

[Signature]

[Parent/Guardian Name]

Enclosed: [list attachments you may like to include to help the district understand child's disabilities, diagnoses, or needs.]

Sample provided by Disability Rights Education and Defense Fund

INSTRUCTIONS/NOTES

REGARDING A REQUEST FOR

INDEPENDENT EDUCATIONAL EVALUATION (IEE) AT PUBLIC EXPENSE

REQUESTING AN INDEPENDENT EDUCATIONAL EVALUATION (IEE) AT PUBLIC EXPENSE

If you disagree with any completed school district evaluation(s), and believe your child needs an objective "2nd opinion," you have the right to request an "Independent Educational Evaluation (IEE) at public expense." This means that you request that the school district pay for an independent, qualified examiner to conduct an evaluation in the same area of evaluation that the school district completed, but that you disagree with.

You have the option to explain why you think this is necessary, and the district may ask you, but you are not required to say why. You are not required to come to a meeting to say why, either. However, it can further understanding to say why. It may serve to explain some of your position upfront, if the problem goes to a Due Process hearing. If you do not say why, the district cannot use this to delay responding to your IEE request.

Some reasons why an IEE may be necessary, for example:

- District staff was not sufficiently or appropriately qualified to perform their evaluation.
- The evaluation was not sufficiently comprehensive to determine the needs of your child.
- The evaluation was rushed.
- Another child's name or gender is used in the evaluation report instead of your child.
- Critical areas of suspected disability, or critical sub-tests in areas of concern for your child, were left out
 of the evaluation.
- Testing tools selected were not appropriate to your child's needs.
- The mode of communication of your child uses/needs was not provided in testing.
- School district results are at odds with other testing done on your child, so clarification is needed.
- District relied on insufficient testing when it made recommendations at the IEP meeting.
- Testing protocols (strict rules the test publisher requires to ensure validity) were not followed.
- Testing findings did not result in meaningful recommendations to meet your child's needs.
- Your child did not qualify for special education eligibility, or was exited from special education, and you believe the evaluations do not support this conclusion.

When you request an IEE, the school district can respond in only 2 ways:

- 1. Grant the parent request for IEE and set up a process for payment.
- 2. File for a Due Process hearing to prove to an Administrative Law Judge (ALJ) at the CA Office of Administrative Hearing (OAH) that the school district evaluation(s) were appropriate.

If the District refuses the IEE request, it bears the burden of proof at Due Process since they are the party who is required to file to defend the evaluation(s) with which the parent disagreed. The ALJ, decides whether the district must pay for the IEE, based on the evidence presented.

A parent does not need to choose an evaluator from a school district list. However, a school district may need to know more about evaluator(s) you select, in order to determine whether he/she meets the qualifications to administer the IEEs. If an evaluator the parent selects does not meet district criteria, parents must be given full opportunity to explain/request why this person, with this particular expertise is necessary to conduct the IEE. Determinations must be made on an individualized, case-by-case, basis.

Submit a WRITTEN LETTER to the school district Special Education Director. You may copy (cc) the Program Specialist, Principal, teacher, or others involved with your child's education, as necessary.

Get PROOF of the letter's delivery:

- Consider sending the IEE letter "certified return/receipt requested" from the post office.
- Or hand-deliver the IEE letter and ask that your letter be date-stamped and a copy of this provided to you before you leave, as a receipt.
- Or fax your letter and print your "successful transmission" fax report. Then follow up by phone to be sure all pages were received. Write down who said they received all pages of your fax.
- If you deliver an IEE letter in an IEP meeting, be sure the IEP notes reflect that you requested an IEE, and for disagreement with what school district evaluations.

For more information on IEEs, see:

ED.GOV - U.S. Department of Education: http://idea.ed.gov/explore/view/p/,root,regs,300,E,300%252E502,

Disability Rights CA - How to Obtain an Independent Educational Evaluation at Public Expense http://www.disabilityrightsca.org/pubs/547601.htm
Updated June 2009, #5476.01

SAMPLE LETTER BELOW TO TAILOR TO YOUR NEEDS

REQUEST FOR INDEPENDENT EDUCATIONAL EVALUATION (IEE) AT PUBLIC EXPENSE

DATE:	
Deliver	y Information: by FAX (number used) () by Registered/Certified Mail Delivered In Person (receipt obtained)
From:	Parent/Caregiver(s) name:
	Address:
	City/State/Zip:
	Best Day phone number(s): ()
	Parent Email:
То:	Special Education Director:
	School District:
	Street address:
	City, State, Zip:
	District Contact Phone #: ()Fax #: ()
	District Contact Email (if known):
RE:	Student Name:
	Student Date of Birth:
	Student's Current School:

Dear Director of Special Education:

I/We are requesting Independent Educational Evaluation(s) (IEE) at public expense for our child (named above). We understand that IEEs are to be provided at no charge, according to state and federal law.

Below, we/l have checked the evaluations/assessments that the school district COMPLETED that we disagree with, and for which we request IEE(s). We/l believe the evaluations were not comprehensive and/or appropriate to determine the unique needs of this student. We/l request IEEs at public expense with appropriately qualified examiners who meet district criteria, and with the understanding that requests for qualified examiners outside or exceeding district criteria, shall be considered and determined on an individualized, case by case basis, and may include qualified medical providers for diagnostic purposes.

Academic Achievement	
Psychological / Psycho-Educational	
Speech/Language/Communication (SLP)	
Gross Motor - Physical Therapy (PT)	
Fine Motor/Sensory - Occupational Therapy (OT)	
Health	
Functional Behavioral Assessment (FBA)	
Adaptive Physical Education (APE)	
Assistive Technology (AT)	
Alternative/Augmentative Communication (AAC)	
Orientation and Mobility (OMB)	
Educationally Related Mental Health (ERMS)	
Vision (VI)	
Hearing	
Transition-to-Adulthood Skills –	
Independent Living, Post-secondary Education/Training, Vocational	
Other (Describe):	_
Other (Describe):	

You've got this! Empowering and training parents in the role of parent as advocate
(If known at this time) We/I have selected the following qualified evaluator(s) to complete the above requested IEEs and request that the District provide contract(s) to authorize payment for IEE examinations without delay.
(If unknown at this time) We/I will inform the District later which evaluator(s) we/I have selected.
We/I understand that the District may ask the parent/Educational Rights holder for an explanation of their disagreement, but that it is not required under the IEE process to provide an explanation. If we/I include some explanation below, this is provided to further understanding and to help us work together toward resolution. We/I understand that if we/I do not include an explanation, that this may not delay the IEE process.
(Optional) Reasons why District assessment(s) were not appropriate to identify my child's unique needs and necessary specialized instruction and related services:
We/I request that INDEPENDENT EVALUATION AT SCHOOL DISTRICT EXPENSE include but not be limited to payment for any expenses and fees associated with completing the IEE(s), such as: testing; interviews; observations; interpretation and translation for non-English speakers and/or other alternative means of communication necessary for those who necessary to evaluation (such as, individuals with blindness, hearing impairment, or who communicate with AT/AAC), report writing, and attendance of the evaluator at any IEP Team meeting where the IEE results will be discussed.
We/I look forward to receiving a response to the IEE request without unnecessary delay. We/I understand that the school district, when approving an IEE request, shall provide a list of qualified assessors/examiners for selected IEE evaluations, and district IEE criteria. We/I understand that parents are not required to select evaluators from a district list of providers, so long as examiners selected by parents are qualified and meet IEE criteria provided that District criteria are not so restrictive as to result in preventing the parent from exercising their right to IEEs and that determination of evaluators must be made on an individualized, case-by-case basis. We/I understand that refusal or approval by the district requires provision of Prior Written Notice that meets the requirements of IDEA. We/I understand that if the district refuses the IEE request including selected evaluators that the district is required to file for a Due Process Hearing without unnecessary or unreasonable delay.
We understand that the independent evaluators will forward the completed evaluation report to the school district since the district is paying for the IEEs, that the district will schedule an IEP Team meeting to discuss the results of the IEEs, and that any IEE evaluation must be considered in any future decisions about my child and his/her educational needs.
Sincerely,
Parent/Caregiver Signature Date
Copies (cc) to:

Sample provided by Disability Rights Education and Defense Fund

REQUEST FOR FUNCTIONAL BEHAVIORAL ASSESSMENT (FBA)

Parent/Guardian/Education Rights Holder Name Address

City, State, Zip Code

Telephone Number / Email

Date:	[NOTE: This p	rocess is driven by timelin	nes. Get receipt to show pr	oof of delivery.]
Delivered via:	Fax	Registered Mail	In person	
Administrator Name:				
Director of Special Edu	cation			
School District:				
Street Address of Spec	ial Education Of	fice:		
City, State, Zip:				
Student Name:			Date of Birth:	
Name of Current School	ol:		Grade:	

You've got this! Empowering and training parents in the role of parent as
advocate
Dear [Administrator Name]:
I am writing to refer my son/daughter for assessment to determine the needs for additional special education services and supports. He/she currently has an IEP and has been experiencing ongoing challenges in the area of behavior.
[List some of the student's behavioral concerns impeding learning and ability to benefit from his/her education]
I request that the Unified School District conduct a Functional Behavioral Assessment (FBA) performed by a qualified Behaviorist to determine these needs and to develop a Positive Behavioral Intervention Plan (BIP) and other related services in order to benefit from his/her public education in the least restrictive environment (LRE).
I look forward to receiving an Assessment Plan within the next 15 calendar days for my review and consent. I understand that I may take at least 15 additional calendar days to ask any questions I may have about the Assessment Plan, including proposed qualified evaluators, to ensure that I am provided with necessary informed consent.
I look forward to our IEP team meeting within 60 calendar days from my consent to the Assessment Plan to discuss the findings so that we may develop an appropriate and individualized plan to meet my child's unique educational needs. Please contact me to schedule the IEP team meeting with adequate advance written notice so that we may schedule the meeting at a mutually agreed upon time and place.
Please provide all assessment reports to me at least 5 business days in advance of any IEP meeting that will be held to discuss these findings so that I am provided with adequate time to prepare for the IEP meeting and fully participate as a member of the IEP team.
I understand that if evaluation is refused that I am required to receive Prior Written Notice (PWN) that meets the requirements of IDEA.
Thank you in advance for your prompt action regarding this request. If you have any questions or concerns, please feel free to contact me.
Sincerely,
[signature]
Parent/Guardian/Education Rights Holder Name
Copies to: [School Principal, and other members of child's educational team as neede

REQUESTING AN INDEPENDENT EVALUATION

Today's Date (include month, day, and year)

Your Name Street Address City, State, Zip Code Daytime telephone number

Name of the person to whom you're writing Title Street Address City, State, Zip Code

Dear (person's name),

My son/daughter, (child's name), is in the (_) grade at (name of school), in (teacher's name) class. He/She was evaluated for special education services in (month/year). I am writing to request an Independent Educational Evaluation at public expense, for the following reasons: (BRIEFLY list your reason(s). Be very specific. For example,)

"I disagree with the evaluation results because . . ."

"The evaluation should have included . . . "

"Evaluation should have been done in the area of . . . "

I would like this Independent Educational Evaluation to be done as quickly as possible so that we can fully address (child's name) needs. Please respond as soon as possible and send me copies of the school's guidelines for this. My daytime telephone number is (give your phone number). Thank you.

Sincerely, (Your name)

cc: your child's principal your child's teacher(s)

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.

REQUESTING AN EVALUATION FOR SPECIAL EDUCATION SERVICES

Today's Date (include month, day, and year)

Your Name Street Address City, State, Zip Code Daytime telephone number

Name of Principal or Special Education Administrator Name of School Street Address City, State, Zip Code

Dear (person's name),

I am writing to request that my son/daughter, (child's name), be evaluated for special education services. I am worried that (child's name) is not doing well in school and believe he/she may need special services in order to learn. (Child's name) is in the (_) grade at (name of school). (Teacher's name) is his/her teacher.

Specifically, I am worried, because (child's name) does/does not (give a few direct examples of your child's problems at school).

We have tried the following to help (child's name): (If you or the school have done anything extra to help your child, briefly state it here).

I understand that I have to give written permission in order for (child's name) to be evaluated. Before the evaluation begins, I have some questions about the process that I need to have answered (list any questions you may have). I would be happy to talk with you about (child's name). You can send me information or call me during the day at (daytime telephone number). Thank you for your prompt attention to my request.

Sincerely,

(Your name)

cc: your child's principal (if letter is addressed to an administrator) your child's teacher(s)

Note: If your child has been identified as having a disability by professionals outside the school system, add the following sentence to the end of the first paragraph: "(Child's name) has been identified as having (name of disability) by (name of professional). Enclosed is a copy of the report(s) I have received that explains (child's name) condition."

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.

REQUESTING A MEETING TO REVIEW THE IEP

Today's Date (include month, day, and year)

Your Name Street Address City, State, Zip Code Daytime telephone number

Name of Your Child's Teacher Name of School Street Address City, State, Zip Code

Dear (Teacher's name),

I am writing to request an IEP review meeting. I would like to discuss making some changes in (child's name)'s IEP. I am concerned about (state your reasons, but don't go into detail about the specific changes you want to make—save those for the meeting).

I would also like to have (names of specialists or other staff) attend. I think his/her/their ideas about the changes we may need to make will be valuable.

I can arrange to meet with you and the other members of the IEP team on (days) between (give a range of time, such as between 2:00 and 4:00). Please let me know what time would be best for you.

I look forward to hearing from you soon. My daytime telephone number is (give your phone number). Thank you for your help.

Sincerely,

(Your name)

cc: specialists or other staff

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.

REQUESTING A CHANGE IN YOUR CHILD'S PLACEMENT

Today's Date (include month, day, and year)

Your Name Street Address City, State, Zip Code Daytime telephone number

Name of Principal or Special Education Administrator Name of School Street Address City, State, Zip Code

Dear (Principal's or Administrator's name),

I am writing to request a meeting to discuss a change in placement for my son/daughter, (child's name). He/she is currently in the (___) grade in (teacher's name) class. I feel he/she needs to be in (name of alternative, if you know; otherwise describe the type of placement you feel is more appropriate for your child, such as your neighborhood school, a center-based program, general education class, or special class).

I am most concerned about (keep this paragraph brief and mention your child's unmet needs, not problems with individual people).

I would also like to have (name of teacher(s) and/or any specialists you would like from the current and/or requested placement) attend this meeting.

I can arrange to meet with the rest of the IEP team on (days) between (give a range of time, such as between 8:00 a.m. and 10:00 a.m.). Please let me know what time would be best.

I look forward to hearing from you soon. My daytime telephone number is (give your phone number). Thank you for your time.

Sincerely, (Your name)

cc: your child's principal (if letter is addressed to an administrator) your child's teacher(s) specialists or other staff

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.

REQUESTING PRIOR WRITTEN NOTICE

Prior Written Notice

Today's Date (include month, day, and year)

Your Name Street Address City, State, Zip Code Daytime telephone number

Daytime telephone number
Name of person to whom you're writing Title Street Address City, State, Zip Code
Dear (Person's name),
At our meeting (or) during our phone conversation on (date), we discussed my child's (evaluation, eligibility, placement, IEP, services, etc.). I requested () and was denied (or) I was told the school intends to () but I have never received any information about this decision in writing. In accordance with the IDEA regulations, I am requesting prior written notice regarding (be very specific about the issue/decision you want the school to respond to. Bullet or number the items.)
According to the IDEA, at 34 CRF §300.503, prior written notice must include the following:
1. A description of what the school is proposing or refusing to do;
2. An explanation of why the school proposes or refuses this action;
3. A description of any other options the school considered and the reasons why those options were rejected;
4. A description of each evaluation procedure, test, record, or report the school used as a basis for this decision;
5. A description of any other relevant factors that went into this decision;
6. Information on how I can obtain a copy of procedural safeguards available to me under the law and a full explanation of the safeguards, and
7. Information on sources I can contact for help in understanding IDEA's regulations.
I look forward to receiving a detailed response to my request as soon as possible. Thank you for your assistance.
Sincerely, (Your name)

cc: the principal, supervisor, or special education administrator other members of the meeting

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.

REQUESTING MEDIATION TO RESOLVE A CONFLICT

Today's Date (include month, day, and year)

Your Name Street Address City, State, Zip Code Daytime telephone number

Name of person to whom you're writing Title Street Address City, State, Zip Code

Dear (Person's name),

My son/daughter, (child's name), currently attends (name of school) and is in the (____) grade in (teacher's name) class. I am writing to inform you that the school and I are in disagreement concerning (BRIEFLY state what the disagreement is about). We have been unsuccessful in resolving this dispute, and I am requesting mediation so that we may resolve our differences.

I would like the mediation to be done as soon as possible. Please let me know when this can be arranged and send me a copy of the school's guidelines on mediation. My daytime telephone number is (give your phone number). Thank you for your assistance in this matter.

Sincerely,

(Your name)

cc: your child's principal your child's teacher

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.

REQUESTING A DUE PROCESS HEARING

Today's Date (include month, day, and year)

Your Name Street Address City, State, Zip Code Daytime telephone number

Name of person to whom you're writing Title Street Address City, State, Zip Code

Dear (Person's name),

I am writing to request a due process hearing on behalf of my child, (child's name), whose address is (give your child's address, even if it is the same as your own). (Child's name) attends (name of school).

I have met with school personnel in an effort to resolve our differences concerning my son's/daughter's (IEP, placement, testing, or . . .) and have been unable to do so. The nature of our disagreement is as follows:

Explain the problem with BRIEF statements of fact.

Consider listing the facts with bullets or numbers.

An acceptable resolution of the problem would include . . . (To the extent that you know how you want the disagreement to be resolved, state these facts here, again bulleting or numbering the items if possible.)

Please advise me as soon as possible as to the date and time of this hearing so that I can make the necessary arrangements. My daytime telephone number is (give your phone number).

I also request that this hearing be (open/closed) to persons other than those directly involved. (Child's name) will/will not attend the hearing. Thank you for your assistance.

Sincerely,

(Your name)

cc: your child's principal your advocate or attorney

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.

FILING A COMPLAINT WITH THE STATE EDUCATION AGENCY

Today's Date (include month, day, and year)

Your Name Street Address City, State, Zip Code Daytime telephone number

Name of person to whom you're writing Title Street Address City, State, Zip Code

Dear (Person's name),

I am writing to file a complaint on behalf of my son/daughter, (child's name), regarding his/her education in the (name of school district). The nature of my complaint is as follows:

Explain the problem with BRIEF statements of fact. Consider listing the facts that support your complaint with bullets or numbers.

For the above reasons, I believe the school district is in violation of certain requirements in the Individuals with Disabilities Education Act, specifically: (list the requirements of IDEA you feel the school system has violated. For example, "The school system has violated the following requirements of the IDEA:

- to consider whether my child needs assistive technology services or devices, as required by Section 300.324(a)(2)(v);
- to include in my child's IEP a statement of the special education, related services and supplementary aids and services, including assistive technology, that he/she needs as required by Section300.320(a)(4)."

Enclosed are copies of relevant documents and correspondence I have sent to and received from the school district concerning this matter. These documents are (List the documents you have enclosed, giving the date sent, by whom, to whom, and the issue discussed.) Please provide me with copies of any information you obtain in the process of investigating my complaint. If you need further information or clarification on my complaint, I can be reached at (give your phone number). Thank you.

Sincerely,

(Your name)

cc: school district special education director your child's principal your advocate or attorney

Note: The "cc:" at the bottom of the letter means you are sending a copy of your letter to the people listed after the cc.

APPENDIX C: Who makes the education decisions in your state?

Special education advocacy differs from federal policy advocacy in numerous ways. While it's still important to know who your legislators are (and the next section addresses how to find those individuals), there are many other players involved in decision making at the state, local and school district levels. Below is a link to help you understand the education system in your state:

https://www.ecs.org/50-state-comparison-k-12-governance/

There are many key stakeholders to consider when determining your course of action with regard to education. States, counties/parishes, cities, and school districts may all be involved in education decision making and implementation, although all of these may not apply in your area. As a general rule, start your advocacy efforts at the local level (your "local education agency," or "LEA") and escalate higher as needed.

Use your favorite internet browser to search for "K-12 education system" in your state, and look up the following agencies as appropriate:

State Education Agency:	
Superintendent/Director:	
Special Education Director:	
Commissioners/Board Members:	
_	
County/Parish Education Department:	
Superintendent/Director:	
Commissioners/Board Members:	
_	
City Board of Education:	
Superintendent/Director:	
Special Education Director:	
Commissioners/Board Members:	

School District:	
Superintendent/Director:	
Special Education Director:	
Commissioners/Board Members:	
Finding your elected officials:	
Use these resources to list your elected officials and their contact information. Maspecific legislative aide who is the contact for issues of a certain type (i.e. aide for	•
• https://www.usa.gov/elected-officials	
• https://www.commoncause.org/find-your-representative/	
LOCAL:	
Mayor:	
Term ends/next election:	
Phone/email:	
Address:	_
Political Interests:	
Aide/Assistant:	
Contact:	
Alderman/County/Parish Exec:	-
Term ends/next election:	
Phone/email:	

	Address:
	Political Interests:
STATE:	
S	State Senator:
	Term ends/next election:
	Phone/email:
	Address:
	Committee involvement:
	Political Interests:
S	State Representative:
	Term ends/next election:
	Phone/email:
	Address:
	Committee involvement:
	Political Interests:
G	Governor:
	Term ends/next election:
	Phone/email:

Address:
Political Interests:
Aide/Assistant:
Contact:
FEDERAL:
US Representative:
Term ends/next election:
Phone/email:
Address:
Committee involvement:
Political Interests:
Aide/Assistant:
Contact:
US Senator (1):
Term ends/next election:
Phone/email:
Address:
Committee involvement:

Political Int	erests:	
US Senator	(2):	
Term ends	next election:	
Phone/ema	ail:	
Address: _		
Committee	involvement:	
Political Int	erests:	
Aide/Assist	tant:	
US Preside	nt:	
Contact:		os://www.whitehouse.gov/contact/
	Phone:	White House switchboard: 202-456-1414 White House comments line: 202-456-1111 (regular business hours)
Political Int	erests:	

Appendix D: Finding Your Advocacy Partners

Please, please, do not reinvent the wheel if it already exists. Take some time and reflect upon the following:

Which professional societies are you a member of? Are you connected to their advocacy committee/division/workgroup? If they do not have one, are you interested in starting one? Whom should you contact? Are you subscribed to their advocacy briefings/mailing list?

Organization:	Active member? (i.e. Dues Paid)	Is there an Advocacy Cmt/ Div/ Group?	Registered with group?	Subscribed to listserv?	Contact person:	Personal goals:
SDBP	(Hope so!)	Yes!	Please do!	Did it!	Rob Keder / Jenna Wallace	

If your list is a little on the empty side or if you are looking to expand, take some time to map out

O	organizations that exist.
	 Your workplace: Does your institution have a Medical-Legal Partnership (MLP)? If splease check out the next section for tips on engaging with this great resource. Who you contact for more information about your MLP?
	Professional societies/organizations (i.e. SDBP, AAP, SPP, APA, NASW, etc.) Who can you get involved with that has goals that align with yours?
,	• Education/child development and disability-related organizations (i.e. Council for Exceptional Children, Zero To Three, Autism Speaks, AAIDD, CHADD, Learning Disabilities Association of America, etc.). Whose goals align with yours? Do they alig with your clinical/research work? How much time/talent/donations will you need to contribute?
	 Local grassroots coalitions. Similar to above. Grassroots coalitions can be effective can also be a big time commitment (literally herding cats and also moving at a glacia pace, even for advocacy).