



ADVOCATING FOR YOUR CHILD WITH A RARE DISEASE AT THEIR SCHOOL



Global Genes
The New England Genetics Collaborative
Genetics Education Materials for School Success
Parent Information Center on Special Education

This RARE Toolkit is being made available through generous support by



ADVOCATING FOR YOUR CHILD WITH A RARE DISEASE AT THEIR SCHOOL



Introduction

Children who have rare or undiagnosed conditions are members of neighborhood schools across the country. School can, and should, be a great place for everyone, including those with rare conditions.

Rare diseases can affect children differently, and children who have them can vary greatly in intelligence, behavior, medical issues, and educational needs. In this toolkit, we will offer general tips and strategies for children who have rare conditions that impact learning, whether diagnosed or undiagnosed. We will also describe specialized education supports and ways to work with your child's school to ensure an effective partnership is developed.



SECTION 1:

MEETING CHILDREN'S INDIVIDUAL NEEDS

The road to a diagnosis can be long and complex, and some children may never receive a specific diagnosis. Instead, they may have a general diagnosis like “global developmental delay.” A medical or genetic diagnosis may help open some doors for services and explain a constellation of symptoms and behaviors, but there does not have to be an official diagnosis in order to receive services, as long as the child meets eligibility requirements.

Testing Children’s Abilities

In order to ensure that a student has a comprehensive educational program, testing in the areas of each suspected disability is essential. If a specific diagnosis is made, it is important to become familiar with any cognitive and learning research that has been done to guide this process.

Not all areas of need are immediately obvious or typically tested by schools, and families should consider getting an independent assessment outside of the school. For either option, it is important to understand as much as possible the child’s condition and give input to the evaluation process. Some areas to consider when doing an evaluation include:

- Cognition;
- Academic Achievement;
- Executive Functioning;
- Adaptive/Daily Living Skills;
- Speech and Language;
- Fine/Gross Motor Abilities;
- Memory;
- Visual/Perceptual Skills; and
- Behavioral Concerns.

Whether or not a child has a specific diagnosis, it is important to have high learning expectations for all children with rare syndromes. Individualized, flexible, and appropriate educational strategies and supports are keys to success.

Schools need to understand that many children have more than one barrier to learning and that challenges have a compounding effect. For example, for a child with inadequate communication, a behavior may be perceived as “acting out” when in fact it is an attempt to express a need, pain, or another issue. It may be required, therefore, to be creative and employ different strategies in order to meet the individual needs. Here are some steps that you may take to ensure appropriate modifications are being made for your child.

- Track data over time to document educational growth;
- Keep a notebook at home and record the amount of extra time spent on school work outside of the school day;
- Keep records to document your child’s emotional well-being and whether there is a marked change;
- Record situations where services have not been delivered according to the special education support specifications (which are discussed further in the following sections); if, for example, therapy services are consistently cancelled or if promised services are sparsely provided, it is important to meet with the school; and
- Make sure teaching strategies being used are appropriate for the child. For example, if the child is already socially engaged, make sure the interventions are suited for someone who is socially engaged.

SECTION 1: MEETING CHILDREN'S INDIVIDUAL NEEDS

General Accommodations to Consider

“Accommodations, even those that are quite simple to provide, can make a big difference in the quality of life for a student,” says Marla Wessland, parent of a child with Noonan Syndrome. “For example, having short stature is common for those with Noonan syndrome, which my daughter has. Simple accommodations can allow those who are smaller than their peers to be more independent (e.g. a step stool at the sink) and perform to the best of their ability (e.g. seating that allows feet to be firmly on the floor for writing and other fine motor activities).”

Marla’s full story on her daughter can be found within the **Appendix** at the end of this toolkit. While some children may need significant support, including special education, your child may need minor adjustments and strategies to regular education. Some examples are:

- Extended time on tests and assignments;
- Preferential seating;
- Reduced homework or classwork;
- Structured learning environment(s);
- Repeated or broken down instructions;
- Use of verbal/visual aids;
- Behavior management supports, strategies, and/or plans;
- Adjusted class schedules;
- Verbal tests;
- Use of assistive technology;
- Modified textbooks or audio/video tape materials;
- Consultation with special education staff;
- One-on-one tutor, aide or note taker;
- Alternative food choices;
- Additional class personnel; and
- A services coordinator to oversee program and modification.

When advocating for your child, it is important to share any specific conditions he or she may have, whether they be medical, learning, behavioral, eating, or any combination of these with appropriate people at school.

It is also important to note that state laws vary on special education rules and regulations, so you should always make sure to explore the policies of the state. States can add to federal regulations but they cannot eliminate or reduce them. They often have different specifics about what is required in the special education support.



SECTION 2: STARTING THE PROCESS

If you think that your child is not developing at the same pace or in the same way as most children his or her age, a good place to start is with your child's pediatrician.

For children under three years of age, your pediatrician may refer you to the early intervention program in your area to evaluate your child for a developmental delay or disability. You may also contact early intervention directly. To find the program in your area, ask your pediatrician or visit the **Early Childhood Technical Assistance Center website** <http://ectacenter.org/contact/ptccoord.asp>. Although the request doesn't have to be in writing, it makes sense to document who you spoke with and what was said for your own tracking purposes.

For children over three years old, if you suspect your child has any disability or challenge that impacts learning, including physical, behavioral, or a special learning need, you may ask the school for a meeting to determine if he or she is eligible for services or accommodations. Educators, therapists (physical, occupational, speech), or doctors can also request eligibility meetings with the school. Referrals should be made in writing and explain why you believe your child may have an educational or behavioral disability. See the **Supplemental Materials** at the end of this toolkit for a sample letter.

After the referral, a team, including key staff and parents, meets to determine if the child is eligible for an Individualized Family Service Plan (IFSP), Individualized Education Plan (IEP) or a 504 Plan; the child's needs and age will determine the direction. Sometimes children need further testing.

"Understanding IEP language can be confusing and it's made up of many parts," says Tanya Johnson, Special education teacher, parent of a child with Prader-Willi Syndrome and rare disease advocate. "It is driven from assessments, observations, and medical reports. But if there is one part you can become an expert in, it's the action plan and the goals you want your child to achieve."

Read more advice from Tanya Johnson through her RARE Daily series, "**Leading IEP Champions**" <http://globalgenes.org/author/tanyajohnson/>.

SECTION 2: STARTING THE PROCESS

See the **Supplemental Materials** at the end of this toolkit for some things to consider during an IEP meeting. These are similar for a 504 meeting.

If the child is found eligible, the team then develops the IEP or 504 Plan. The team will meet and review the assessment information available about the child, and design an educational program to address the child's educational needs that result from his or her disability. The team will determine the child's educational disability code:

- 01 Mental Retardation
- 02 Hearing Impairment
- 03 Deafness
- 04 Speech/Language Impairment
- 05 Visual Impairment
- 06 Emotional Disturbance
- 07 Orthopedic Impairment
- 08 Other Health Impairment
- 09 Specific Learning Disability
- 10 Multiple Disabilities
- 11 Deaf/Blindness
- 12 Traumatic Brain Injury
- 13 Autism
- 14 Developmental Delay

There is no requirement for parent participation in a 504 or IEP-planning group or for your written approval of the plan, like there is if your child qualifies for special education. However, many schools routinely involve parents in the 504 process as they would in special education.

Once the documentation is complete, the planning group determines the student's placement. The student is always educated in the least restrictive environment. That means that he/she would be taught in the regular classroom, unless they are unable to satisfactorily achieve in that environment, even with the use of aids and services. In that case, other locations, including alternate settings in the school and private (even residential) programs may be used.



SECTION 3:

SPECIAL EDUCATIONAL SUPPORTS IN MORE DETAIL - ISFPS

If a child is under age three and is found eligible for an early supports and services program or early intervention program (names vary depending on the state), an **Individualized Family Service Plan (IFSP)** is developed. This plan is created around the family's concerns, priorities and resources, not just the child's, and builds on family strengths. It is a process designed to facilitate the child's development and serve as a roadmap for the early intervention system.

Involvement of other team members will depend on what the child needs. These other team members could come from several agencies and may include medical people, therapists, child development specialists, social workers, child nutrition department (foodservice director) and others.

For more information on IFSPs, see the **Resource Guide**.



Note:

Some states continue IFSPs after age 3.



SECTION 4:

SPECIAL EDUCATIONAL SUPPORTS IN MORE DETAIL - IEPs

Individual Educational Plans (IEPs) are written for children ages 3-21 who are in special education programs. They:

- Include accommodations and modifications
- Can provide related services such as occupational therapist, physical therapist, and speech language therapist
- Allow the student to keep the same placement and stay in the regular classroom
- Include safe guards:
 - › Parental notices of evaluation or placement
 - › Parental review of records
 - › Impartial hearing for appeal
- Include possible accommodations categories, such as:
 - › Presentation of information
 - › Response
 - › Behavior
 - › Timing
 - › Test scheduling
 - › Organization
 - › Setting
 - › Classroom assignment
 - › Volume of work
 - › Worksheet testing
 - › Seating arrangement

The following will be documented in an IEP:

- The child's present levels of academic achievement and functional performance;
- The annual goals for the child to accomplish in the academic year;
- The special education and related services to be provided to the child;
- Notation of how much of the school day the child will be educated separately from other children and in the classroom;
- The modifications that will be made for testing, including state assessments;
- Description of when services and modifications will begin, how often they will be provided, where they will be provided, and for how long; and
- Documentation of how the child's progress towards his/her annual goals will be evaluated.

For more information on IEPs, see the **Resource Guide**.



SECTION 5: SPECIAL EDUCATIONAL SUPPORTS IN MORE DETAIL - 504S

This is for children who have physical or emotional disabilities, are recovering from chemical dependency, or have an impairment that restricts one or more major life activities, which include:

- Caring for one's self;
- Performing manual tasks;
- Eating;
- Vision;
- Hearing;
- Speaking;
- Walking;
- Breathing;
- Writing; and
- Learning difficulties.

The 504 addresses the modifications and accommodations that will be needed for children to be able to perform without receiving discrimination from their peers.

For more information on 504s, see the **Resource Guide**.



SECTION 6: COMPARISON BETWEEN IEPS AND 504 PLANS

In summary, the differences between these two plans are detailed below.

The IEP

- Is for children who have a disability and need accommodations, modifications, related and special education services;
- Is written when the disability interferes with the student's education and performance;
- Includes safeguards:
 - › Written prior notice of all evaluations, changes to IEP and placement;
 - › Right to independent evaluations; and
 - › Arbitration or mediation with disagreement or complaint process;
- Allows for direct/indirect services with student or consultation services between special education teacher and classroom teacher; and
- Is designed to ensure that all children with disabilities have access to a free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living, while also ensuring that the rights of children with disabilities and their parents are protected.

The 504 Plan

- Is for children who have physical or emotional disabilities, are recovering from chemical dependency, or have an impairment or disability;
- Is for children who have a condition that impacts major life activities including caring for oneself, performing manual tasks, eating/nutrition, vision, hearing, speaking, walking, breathing, writing, and learning difficulties;
- Provides access to a learning environment that will ensure their academic success;
- Does not require written plans, goals or evidence of growth;
- Provides parents minimal rights;
- Has fewer procedural safeguards; and
- Follows students after they leave school.



SECTION 7: SPECIAL ACCOMMODATIONS WITH MEALS

The U.S. Department of Agriculture's (USDA) nondiscrimination regulation (7 CFR 15b), as well as the regulations governing the National School Lunch Program and School Breakfast Program, make it clear that substitutions to the regular meal must be made for children who are unable to eat school meals because of their disabilities, when that need is certified by a licensed physician.

Three federal legislative acts mandate that school food service programs will serve children with special dietary needs because of their disabilities:

- Section 504 of the Rehabilitation Act of 1973;
- Individuals with Disabilities Education Act (IDEA); and
- Americans with Disabilities Act (ADA).

In most cases, children with disabilities can be accommodated with little extra expense or involvement. The nature of the child's disability or diagnosis, the reason the disability prevents the child from eating the regular school meal, and the specific substitutions needed must be specified in a statement signed by a licensed physician. Usually, the substitutions can be easily made. When major modifications are needed, additional equipment, outside expertise, or specific technical training and expertise, it is important that school food service managers be involved in IEP or 504 process. They should be invited to attend the meetings where nutrition and dietary needs will be discussed.

To receive special dietary accommodations or meals, most schools will require you to complete a "Medical Statement for Children with Special Dietary Needs." Some states have a form that they require statewide. This varies from state to state. To see a sample form, turn to the **Resource Guide** of this toolkit.

Each special dietary request must be supported by a statement, which explains what is being requested. It must be signed by a recognized medical authority (physician, physician assistant, or nurse practitioner). The medical statement must include:

- An identification of the medical or other special dietary condition that restricts the child's diet;
- The food(s) to be omitted from the child's diet; and
- The food or choice of foods to be substituted.

If the child receives free or reduced priced meals, the school cannot increase the charge for the meal or start charging for the meal.

Although not required, it is especially helpful to have the physician complete a prescription for the meals that specifies a calorie goal and possibly other dietary goals. This holds the school accountable to meet not just the restriction, but to provide meals that support the child's entire nutritional needs.

SECTION 7: SPECIAL ACCOMMODATIONS WITH MEALS

If your child has a dietitian, it is helpful to have him or her talk with the foodservice department and help with menu development or nutritional analysis. Many schools have a dietitian, but these dietitians do not always understand the medical nutrition therapy required by your child.

If your child needs feeding assistance or has feeding equipment, the school nurse needs to be part of the IEP/ 504 process as well. Additional people on the IEP/504 committee could be a dietitian, occupational therapist and speech pathologist. An occupational therapist can help with the “big picture” approach to mealtimes. They will help select adaptive equipment, modify the feeding environment and address any mechanics of plate-to-mouth feeding. They will also address sensory deficits that limit mealtime participation. The speech-language pathologist will help with swallowing, safety issues, and may be needed to train school-based personnel.

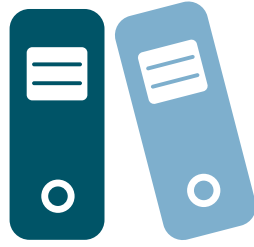
Food allergies are generally not a disability or defined under Section 504 of the Rehabilitation Act and the Individuals with Disabilities Education Act, Part B. The school is not required to make accommodations in this situation. When the food allergy results in a severe, life-threatening reaction, a child’s condition would rise to the level of a disability. The school would then be required to accommodate the prescribed diet ordered by a physician.

The main goal is to meet the child’s nutrition needs in the least restrictive environment, which includes having as much of a typical meal experience as possible, comfortable seating, not being secluded, and sitting with age related peers.

For additional information on policies regarding school nutrition, go to the FNS Instruction 783-2, Revision 2, **Meal Substitutions for Medical or Other Special Dietary Reasons** <https://education.alaska.gov/tls/cnp/pdf/783-2.pdf>.

If you encounter difficulty in obtaining specialized meals, you may want to talk with the USDA regional office for the Food and Nutrition Services. Information on this can be found on the **USDA website** <http://www.fns.usda.gov/fdd/fns-regional-offices-contacts-fd-programs>.

APPENDIX: PARENTAL EXPERIENCES



Marla Wessland, Noonan Syndrome

“Many children with Noonan syndrome (NS) have learning disabilities but Sara, my daughter, does not have any that are significant enough to be noticed at school,” says Marla. She describes Sara as a quirky kid who excels in her academics but “marches to the beat of her own drummer.”

For several years, my daughter received physical, occupational, and speech/language therapies at school as a part of her IEP. She no longer needs those services, but she now has a 504 plan that provides accommodations for some vision and GI issues. She has preferred seating, so she can see well in the classroom, and has access to the bathroom whenever she needs it.

Sara was diagnosed at about six months of age. Sara tested positive for a genetic mutation for Noonan that is present in about 50 percent of the people diagnosed with this syndrome. Over the years, Sara has had quite a few specialists in and out of her life. She sees an endocrinologist, ophthalmologist, gastroenterologist, orthopedist, and geneticist. She had supports to help her gain weight from nutritionists and speech/language pathologists, as well as her gastroenterologist.

Sara’s Mother Shared Some Useful Tips for Parents:

- Get all the early intervention you can! They really can catch up with this extra help and the feeding support can be so helpful.
- Because there is so much variation in each child, if you give any information (articles, etc.) about your child’s condition to the school team, highlight the items that affect your child.
- Work with the school system for any IEP/504 accommodations. There are many things that can easily be done.
- Teach your child to advocate for her/himself. If there is a substitute teacher who isn’t aware of your child’s needs, he or she may need to advocate for themselves.

APPENDIX: PARENTAL EXPERIENCES

Vanessa Rashid, William's Syndrome

Zhala (pronounced Jah-la) is an extremely friendly child and usually quite happy. She is much loved at school and is surely missed if she misses a day of school. In fact, her teacher described her as the “glue of the classroom” because she knows the name of every child, calls them by name, and greets each one.

Her school experience has been phenomenal. She is in typical classes and her therapists come into her class to administer therapy. “Math is her strongest subject, which is contrary to what children with William's syndrome typically experience,” says Vanessa, Zhala's mother. Reading comprehension is a top priority, as is strengthening her social skills, so that she has good solid friendships. “She is not isolated in any way,” says Vanessa who is very pleased at how her school team has supported her in the classroom.

Vanessa explains how the team has earned her trust. When Zhala's eating didn't go well on the first day of school, her case manager called home that very afternoon after receiving an email from Vanessa. They developed a communication notebook and started using it the very next day, and continued all the way through the end of the school year.

Zhala's Mother Shared Some Useful Tips for Parents:

- An invaluable tool is a daily communication log, which highlights any issues or news in her school or home routines such as eating, behavior, or toileting.
- Consider seeing teachers daily. If that is not possible, try emailing or writing them frequently.
- Go into school with a good game plan, be open about significant concerns, and make sure concerns are addressed in a reasonable amount of time.
- Discuss issues that could be big problems, like sensitivity to sound. For example, they had to have a plan for fire drills because Zhala is so highly sensitive to noises that a fire drill would scare her tremendously.
- If something doesn't feel right, be an advocate and don't worry about being a complainer. Also, approach the school nurse with special health concerns and make sure the school has up-to-date contact information if there is ever an important non-emergency issue.
- Music can be so beneficial to help with cognitive skills. For example, Zhala's teacher has had great success teaching math facts by singing them with Zhala. “Music is a great motivator and cognitive tool for lots of kids,” says Vanessa who has done a lot of reading on the topic.

APPENDIX: PARENTAL EXPERIENCES

Elisa Calderwood, Tuberous Sclerosis Complex

Sophia, who was diagnosed with Tuberous Sclerosis Complex (TSC) at 16 months of age, is in a regular classroom, has an IEP, and has paraprofessional support. In a regular classroom, Sophia gets to see how her peers act socially in many different environments. This approach has enabled Sophia to grow in many areas personally and socially.

At school and home, she uses an iPad and that helps with spelling and practicing writing. Sophia is quite social and seeks out certain people. She is included in regular class activities, and it works well when “everyone works together.”

Sometimes, Sophia gets frustrated when things don't go as planned, and she has behaviors that might frighten other children, such as screaming when she is upset. This might particularly happen after a seizure. Her behavior can make it harder to get out in the community. As more supports are put in place, life gets easier for Sophia and those around her. For example, a behavior specialist has been visiting with Sophia's family to teach everyone how to deal with the negative behaviors, keep people safe and provide strategies to avoid or lessen these occurrences in the future. A weighted vest at school has also been a good sensory support for her. There is also a Seizure Action Plan in place that is supported by her medical community.

Sophia's Mother Shared Some Useful Tips for Parents:

- It is important to remember that not everyone knows about TSC or how it affects your child. I have learned over the years that educating others regarding TSC is a non-threatening approach.
- Talk with your school staff about changes, new ideas, and proposed plans. For example, having Sophia carry a big backpack full of supplies on an outing really would stigmatize her as no one else would have to carry a pack. Talking it through helped the team come up with acceptable alternatives.

APPENDIX: PARENTAL EXPERIENCES

Christine Brown, National Phenylketonuria Alliance

Connor and Kellen were diagnosed with phenylketonuria (PKU) at birth and require medical foods and a very restricted diet in protein to help them grow and develop normally. Both boys are in elementary school and part of their 504 plan is that the public school provides them with a hot lunch each day.

Each school will vary in what it provides in terms of meals or cafeteria food. Regulations that require schools to provide school lunches for children with special dietary needs differ from state to state. However, several federal regulations provide the legal basis for requiring schools to offer nutrition services to children with special needs.

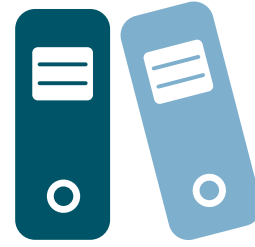
In Connor and Kellen's case, the school provides each boy with a hot lunch modified to be low in protein. I, their mother, am emailed the monthly lunch menu. I circle the fruits and limited vegetables the boys can eat and in what quantity. Then, the school provides a low protein food item that they specially order each day to supplement the boys' meals. One cafeteria worker prepares their food, weighs and measures it and then serves it to the boys in the lunch line. Afterwards, the boys return their trays to the same worker, who then weighs each item food leftover so that an accurate record can be emailed to me at the end of the day for effective management of their PKU.

Connor and Kellen's Mother Shared Some Useful Tips for Parents:

- Get to know the Food Services Director and staff, and request that one worker be in charge of your child's meal each day.
- Encourage food services staff and teachers to contact you about questions with your child's diet.
- Provide the school with appropriate items that your child can have when there is a special celebration or birthday in the classroom so that your child has something to eat.
- Keep other appropriate snacks at school as necessary.
- Make sure there is a "no-swapping" rule in the classroom to prevent children from trading or sharing food.

SUPPLEMENTAL MATERIALS:

THINGS TO CONSIDER AT AN IEP MEETING



General Questions to Ask the School Include:

- › Do the evaluation and assessment results make sense with what you know about my child and his/her abilities?
- › Do they describe my child's strengths as well as areas of need?
- › Compare all the areas of need identified and recommendations listed in the evaluations and assessment with goals, objectives, modifications or accommodations and strategies that addresses that area of need. Are they all addressed?
- › Are the recommendations being used in the IEP?

Questions to Consider Regarding Present Levels of Academic Achievement and Functional Performance:

- › Are all academic areas covered?
- › Are social, emotional and other functional skill areas covered?
- › Does it describe how your child's disability affects his/her involvement and progress in the general curriculum?
- › Does it describe specifically what your child can and cannot do today?
- › Does it take into consideration your child's strengths and learning styles?
- › Is it based on current information, and does it state more than test scores?

Annual IEP Goals Questions to Ask:

- › Are they based on assessment of your child's present academic achievement and functional performance?
- › Are the goals reasonable and attainable?
- › What changes are expected in your child's skills or behavior?
- › Are positive behavioral supports included?
- › Given your knowledge of your child, are the goals appropriate?
- › Can your child's progress on each goal be measured?
- › Could you tell if your child has mastered a goal?

Short-term Instructional Objectives or Benchmarks to Consider:

- › Do they describe the steps and how your child will reach their goals?
- › Can your child's progress on each objective be measured?
- › Could you tell if your child had mastered an objective or reached a benchmark?

How will your Child be Reviewed and How will the Progress be Reported:

- › How will your child's progress towards meeting their goals (and objectives) be measured?
- › What kinds of tools will be used to measure progress?

SUPPLEMENTAL MATERIALS: THINGS TO CONSIDER AT AN IEP MEETING

- › How and when will you be informed of progress?
- › How will you know if the progress is enough so that they will achieve their goals by the end of the year?
- › When will the IEP team meet to review the IEP?

Special Education and Related Services to Consider:

- › What types of specialized instruction or services does your child need?
- › Where will they be provided (individually, in a group, in a classroom, etc.)?
- › Who is responsible for providing them?
- › When will the services begin and end?
- › How often will they be provided?
- › Does your child need extended school year services?

Accommodations and Modifications that May be Required:

- › Does your child need accommodations such as preferential seating arrangements or extended time for tests?
- › Does your child need modified homework assignments?
- › Does your child need assistive technology to assist them with class work, homework, or long-term assignments?
- › Do the modifications lessen the expectations of your child?

Participation in Statewide/District-wide Assessments Questions to Consider:

- › Will your child participate in statewide/district-wide assessments?
- › Are modifications required? If so, how will the assessment be modified?
- › If your child will not participate how will her progress be assessed?

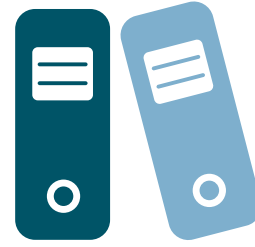
Transition Services (to be Included in the IEP in Place When a Child is 14):

- › Are your child's interests and preferences for life after high school reflected in their annual goals?
- › Is your child participating in the development of their transition plan and IEP? If not, how is their input being gathered and included?
- › What transition services are necessary to assist your child in meeting their post-secondary goals?
- › What services is your child going to need after high school, and what connections to adult service agencies are needed?
- › Who will provide the transition services?

Placement Recommendations:

- › Is this the least restrictive environment where the supports and services described in the IEP are delivered?
- › What makes this placement appropriate to meet your child's needs?
- › How will your child participate in the general education curriculum?
- › What modifications and/or accommodations are needed in regular education classes for your child to be successful?

SUPPLEMENTAL MATERIALS: IEP SAMPLE LETTER



Date

Dear [Name of School Principal]:

I am making a formal request for a complete educational evaluation for my child, (Name of Child), who is a student at (name of school) in (grade/class).

I am making this request because I believe that my child may have educational disabilities. (Make a brief listing, such as ADD, short attention span, vision problems, speech or language problems, physical issues, failing most classes, inability to get along with others, unsatisfactory performance on group achievement or accountability measures, multiple behavioral or academic warnings, suspensions/expulsion from childcare or after school programs, inability to progress or participate in developmentally appropriate preschool activities, receiving services from Family-Centered Early Supports and Services, etc.)

I understand that you will contact me in writing to set up a team meeting date so that the team can make the necessary decisions about my concerns within 15 days.

Please let me know if I can provide any additional information to assist you in better understanding (my child's) needs. I look forward to hearing from you.

Sincerely,

(Your name, address, telephone number and email address)

cc: (List of other people to whom you are sending a copy of this letter, i.e. Superintendent of Schools)

RESOURCE GUIDE



504 Plan

Center for Parent Information and Resources <http://www.parentcenterhub.org/repository/section504/>: There are many sources of information on Section 504. Rather than repeat the work of others, this page connects users with it! Use the links included on this page to find out more about Section 504 and what it means for students with disabilities.

Great Schools! **“A Parent’s Guide to Section 504 in Public Schools”** <http://www.greatschools.org/special-education/legal-rights/868-section-504.gs>: Written by Mary Durham, this article covers Section 504, key terms, and the types of accommodations a child can receive if determined eligible.

WrightsLaw’s **“Discrimination: Section 504 and ADA”** <http://www.wrightslaw.com/info/sec504.index.htm>: This page covers frequently asked questions on 504 Plans.

Assistive Technology

AbleData <http://www.abledata.com/>: AbleData is the premier source for impartial, comprehensive information on products, solutions and resources to improve productivity and ease with life’s tasks. They provide a wealth of information to assist domestic and international customers and their family members, vendors, distributors, organizations, professionals and caregivers in understanding assistive technology options and programs available.

AssistiveTech.net <http://assistivetech.net>: This national public website provides access to information on assistive technology devices and services as well as other community resources for people with disabilities and the general public.

Augmentative and Alternative Communication

American Speech-Language Hearing Association <http://www.asha.org/public/speech/disorders/aac.htm>: Augmentative and alternative communication includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas. This Association wants to make effective communication accessible and achievable for all.

International Society for Augmentative and Alternative Communication <https://www.isaac-online.org/english/home/>: This Society works to improve the lives of children and adults who use Augmentative and Alternative Communication, which helps millions worldwide who cannot rely on their natural speech to communicate.

RESOURCE GUIDE



United States Society for Augmentative and Alternative Communication <http://www.ussaac.org/>: This organization is dedicated to supporting the needs and desires of people who use augmentative and alternative communication, as well as the family members, professionals and manufacturers making up this community. At USSAAC, members join forces to improve the services, resources and products used by children and adults who turn to AAC methods in order to communicate.

Genetic Conditions

GEMSS – Genetics Education Materials for School Success www.gemssforschools.org: The aim of GEMSS is to ensure all children with genetic health conditions succeed in school-life. GEMSS explains over thirty genetic conditions and offers helpful strategies for use in classrooms. These include ideas for emergencies, field trips, diets, communication, instruction, and more.

Inclusive Education

Center for Patient Information and Resources <http://www.parentcenterhub.org/find-your-center/>: Families with a child who has a rare disease often need information on early intervention (for babies and toddlers), school services (for school-aged children), therapy, local policies and transportation. Every state has at least one Parent Training and Information Center or Community Parent Resource Center to offer families just this kind of information. Use this interactive map on this site to find each in any given state or territory.

The Council of Parent Attorneys and Advocates, Inc. <http://www.copaa.org/>: This independent, nonprofit offers a peer-to-peer network of attorneys, advocates, parents and related professionals who are dedicated to protecting and enforcing legal and civil rights of students with disabilities and their families at the national, state and local levels.

Kids Together, Inc. <http://www.kidstogether.org/>: This nonprofit's goal is to promote children with disabilities, so they can just be kids. They also want other people to understand that having a disability is one small part of the children they serve, and that they are more similar to all children than they are different.

National Center for Inclusive Education http://www.iod.unh.edu: The National Center on Inclusive Education at the University of New Hampshire's Institute on Disability is a leader in the transformation of schools, so that students of all abilities are successfully learning in their home schools within general education settings.

RESOURCE GUIDE



PACER Center <http://www.pacer.org>: The mission of PACER Center (Parent Advocacy Coalition for Educational Rights) is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents.

Individualized Family Service Plan (IFSP)

Center for Parent Information and Resources' "**Module 5: Procedures for IFSP Development, Review, and Evaluation**" <http://www.parentcenterhub.org/repository/partc-module5/>: This module takes a detailed look at what the Part C regulations require in terms of the procedures used to develop, review, and evaluate a child's IFSP.

Center for Parent Information and Resources' "**Module 6: Content of the IFSP**" <http://www.parentcenterhub.org/repository/partc-module6/>: This module takes a detailed look at the content that must be included in each child's IFSP, according to the Part C regulations.

Center for Parent Information and Resources' "**Writing the IFSP for Your Child**" <http://www.parentcenterhub.org/repository/ifsp/>: The IFSP is a very important document, and you, as parents, are important members of the team that develops it. This webpage focuses on the IFSP—both the process of writing it and what type of information it will contain.

IFSP Web <http://ifspweb.org/>: This site offers an online assistance program designed to help families and professionals develop Family Service Plans for young children with disabilities.

Improving Early Learning Outcomes Webinar <http://www.parentcenterhub.org/repository/webinar-earlylearning2014/>: Hosted by the Center for Parent Information and Resources, handouts and materials also are available for those interested.

Parent Information Center on Special Education <http://nhspecialed.org/>: Since 1975, the Parent Information Center on Special Education has been providing information, training and support to families who have a child with a disability, so that they may participate effectively as team members in the Special Education process. This Center provides information on developing an IFSP and its components.

Special Education Guide <http://www.specialeducationguide.com/>: This guide is an online resource for parents and educators who want to master the terminology, procedures and best practices in special education. The writers are special education experts who cover everything from early intervention to ISFPs; IEPs and RTI, inclusion, classroom and behavior management; disability profiles for each category under IDEA and a Special Education Dictionary to master "SPED" jargon.

RESOURCE GUIDE



WrightsLaw's Early Intervention (Part C of Individuals with Disabilities Education Act of 2004, or IDEA) <http://www.wrightsLaw.com/info/ei.index.htm>: This resource answers many questions about Early Intervention – what does it include, does my child qualify, what if I'm not happy with the services – and explains Part C of the IDEA legislation.

Individual Education Plan (IEP)

Center for Parent Information and Resources' **"All About the IEP"** <http://www.parentcenterhub.org/repository/iep/>: This webpage includes an overview of the IEP, the IEP team, the contents of an IEP and other important and pertinent information.

"IEP Essentials for Parents" <http://www.parentcenterhub.org/wp-content/uploads/2015/04/IEP-Essentials-for-Parents.pdf>: This article discusses the initial IEP process as required by the federal IDEA.

U.S. Department of Education's **"A Guide to the Individualized Education Program"** <http://www2.ed.gov/parents/needs/speced/iepguide/index.html>: The purpose of this guide is to assist educators, parents, and state and local educational agencies with implementing the requirements of Part B of the Individuals with Disabilities Education Act (IDEA) regarding Individualized Education Programs (IEPs) for children with disabilities, including preschool-aged children.

WrightLaw's **"IEP Tips: Taping Meetings"** <http://www.wrightsLaw.com/info/iep.tips.taping.eason.htm>: Written by Anne Eason and Kathleen Whitbread, this article includes tips about taping and what to do if you encounter resistance from school administrators.

WrightLaw's **"IEP Tips: What to Do at an IEP Meeting"** <http://www.wrightsLaw.com/info/iep.tips.eason1.htm>: Written by Anne Eason and Kathleen Whitbread, these IEP tips are strategies for becoming a more effective, advocate participant in the IEP process for your child. The strategies offer common sense approaches about how to effectively advocate for your child, while learning how to provide input and build positive relationships with the school personnel who work with your child.

WrightLaw's **"Starting a New IEP Advocacy Year: Back to School Tips"** <http://www.wrightsLaw.com/info/advo.school.tips.krizman.htm>: Written by Lisa Krizman, this list of tips can be used as the new school year approaches.

WrightLaw's **"Individualized Education Programs"** <http://www.wrightsLaw.com/info/iep.index.htm>: This page includes articles, law and regulations, and tips about how to get quality services in your child's IEP. You'll also learn how to use tactics and strategies to negotiate with the school.

RESOURCE GUIDE



Positive Behavioral Interventions and Supports

Center on the Social and Emotional Foundations for Early Learning <http://csefel.vanderbilt.edu/>: CSEFEL is focused on promoting the social emotional development and school readiness of young children birth to age 5. CSEFEL is a national resource center funded by the Office of Head Start and Child Care Bureau for disseminating research and evidence-based practices to early childhood programs across the country.

Positive Behavioral Interventions and Supports <https://www.pbis.org/>: The Technical Assistance Center on Positive Behavioral Interventions and Supports is established by the U.S. Department of Education's Office of Special Education Programs (OSEP) to define, develop, implement, and evaluate a multi-tiered approach to Technical Assistance that improves the capacity of states, districts and schools to establish, scale-up and sustain the PBIS framework. Emphasis is given to the impact of implementing PBIS on the social, emotional and academic outcomes for students with disabilities.

School Nutrition Program

Example of a “**Medical Referral for Special/Modified School Meals**” found through New Albany-Floyd County Consolidated School Corporation School Health Services <http://prosser.nafcs.k12.in.us/wp-content/uploads/2014/08/modified-diet.pdf>: If dietary modifications are necessary for the student, a completed medical statement is needed. This is an example of a form you may have to fill out.

Parents Learn About the School Nutrition Program <https://schoolnutrition.org/AboutSchoolMeals/Parents/>: This page provides answers to many of the frequently asked questions from parents on how benefits are provided under the school meal programs.

School Nutrition Program FAQ's <http://www.fns.usda.gov/school-meals/faqs>: The School Nutrition Association is a national, nonprofit professional organization representing more than 55,000 members who provide high-quality, low-cost meals to students across the country. This page provides information on school meals.

United States department of Agriculture Food and Nutrition Service: Accommodating Children with Special Dietary Needs in the School Nutrition Programs: Guidance for School Food Service Staff http://www.fns.usda.gov/sites/default/files/special_dietary_needs.pdf: This document provides information on the process of obtaining specialize and modified meals in the school environment. It has references on forms that need to be completed to obtain specialized nutrition services.



**LET OTHERS BENEFIT
FROM YOUR KNOWLEDGE
BY SHARING YOUR TIPS
AND TRICKS!**

If you would like to contribute your experience
or have a comment/suggestion,
please enter it online at <http://globalgenes.org/toolkits>.

Global Genes Would Like to Thank All of This Toolkit's Contributors and Participants

Leah Burke, MD

Vermont Regional Genetics Center/University of Vermont
www.uvmhealth.org

Christine Brown

National PKU Alliance
<http://www.npkua.org/>

Elisa Calderwood

Parent of a Child with Tuberous Sclerosis Complex

Donna Cutler-Landsman

M.S. Educational Consultant and Advocate

Vince Donnelly, Ed.D.

Associate Professor of Education, University of New Hampshire
<http://www.unh.edu/>

Ann Donoghue Dillon, M.Ed., OTR/L

*Clinical Assistant Professor, Institute on Disability/
University of New Hampshire*
www.iod.unh.edu

Evan Farrar

*Crisis Intervention and Family Support Counselor at
Prader-Willi Syndrome Association*
<http://www.pwsausa.org/>

Christine Giummo

*Genetic Counselor, Vermont Regional Genetics Center/
University of Vermont*
www.uvmhealth.org

Debra Geary Hook, MPH, RDN

Nutrition Consultant to Ultragenyx Pharmaceutical
<http://www.ultragenyx.com/>

Tanya Johnson

Special education teacher, Rare Parent and Advocate
<http://globalgenes.org/author/tanyajohnson/>

Monica McClain, PhD

Co-Director, New England Genetics Collaborative
<http://www.negenetics.org/>

Vanessa Rashid

Parent of a Child with Unique Challenges

Karen Smith

Project Coordinator, New England Genetics Collaborative
<http://www.negenetics.org/>

Marla Wessland

*Parent of a child with Noonan syndrome and active
member of the online Noonan syndrome community at
"Noonan Syndrome Family" and "New England (USA)
Noonan Syndrome Community"*

The New England Genetics Collaborative is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant no 46UMC24093, New England Genetics Collaborative, total award amount \$3,000,000 (100% governmental sources). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.



<http://globalgenes.org/toolkits>

Global Genes
The New England Genetics Collaborative
Genetics Education Materials for School Success
Parent Information Center on Special Education