SCHOOL SUPPORT NEEDS

IN THE 8p COMMUNITY

PROJECT 8p FOUNDATION

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Introduction

Every 8p hero has a different set of strengths, challenges, and lived experiences. Recognizing no two journeys are the same, the support services that work best for one child can be entirely different for another. Learning how to identify and take advantage of those supports can feel overwhelming, especially when balancing complex medical information and new processes at the same time. Feelings of uncertainty are normal, as is experiencing a learning curve as you begin advocating for your hero in the school setting.

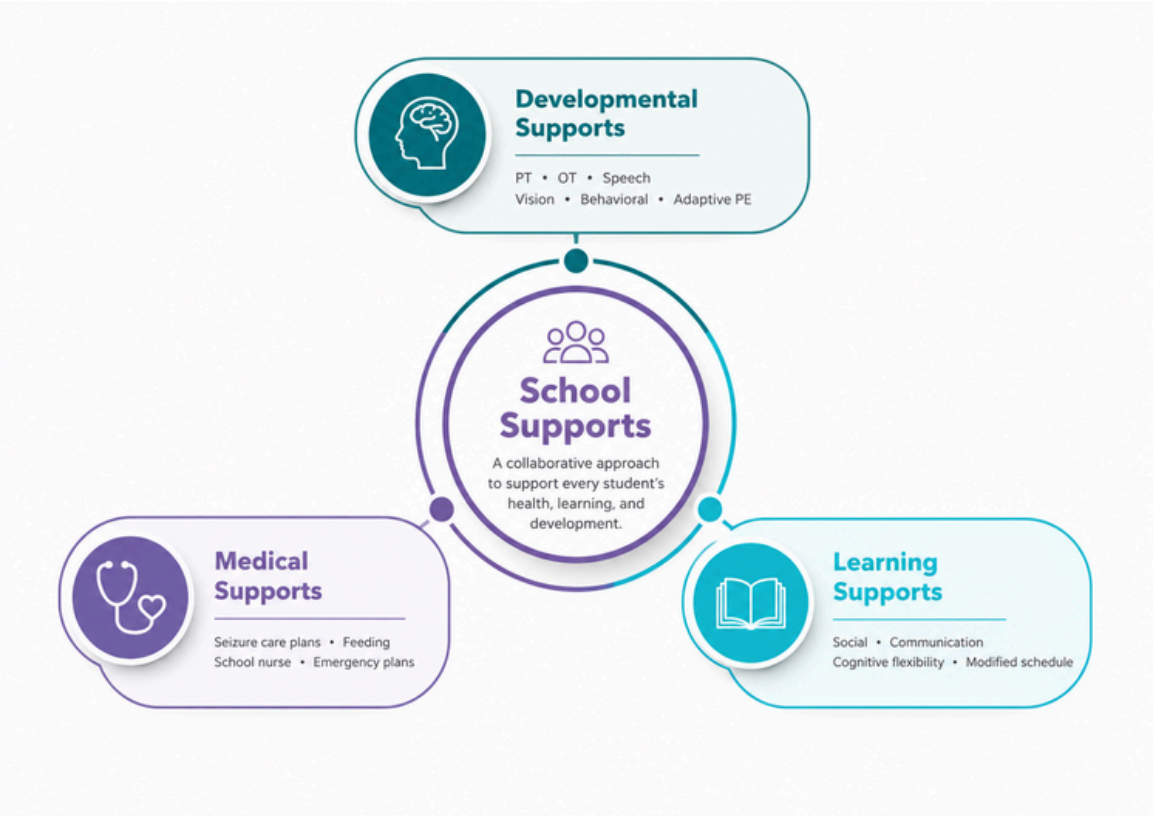
It's important to remind yourself as you progress through this journey, you are not expected to have all the answers immediately. Advocacy is a concept that develops over time, so getting comfortable with and learning to ask questions is a big part of the process. Above all else, you are your hero's strongest advocate; knowing the specific needs, personality, and story better than anyone provides you with the best perspective for advocating in a way that's most effective for your child. By combining this knowledge with available resources and tools, you can bridge the gap between your hero and an educational environment fit to truly meet their needs.

Scope of This Guide

Because educational systems and service eligibility can vary across the United States, this guide is intended primarily for U.S.-based families. Policies and procedures will differ by school district, state, and as time goes on. Families are encouraged to verify current rules, eligibility criteria, and procedural requirements within their hero's school system and relevant state education agencies when making choices about services and supports.

What Supports My Hero Might Need at School

Every 8p hero has a unique experience with 8p, meaning needs at school are highly variable. Some may need more comprehensive support, while others may need just a handful of accommodations. Due to the wide range of symptoms and severity seen within the condition, it can be helpful to think about support services in broader categories: developmental, medical, and learning needs. Although these areas often overlap in terms of goal setting and practice, breaking them down in this manner can help families and school teams decide how to build the best plan for each 8p hero.



The tables below highlight common school based supports your hero is entitled to, when they might be helpful, and how they benefit your hero's success in the classroom. Not every child will need every support, and the right combination is dependent on your child's individual strengths and needs.

Developmental Supports

Support Type	When It Can Be Helpful	Areas of Improvement in School
Physical Therapy (PT)	Low muscle tone, balance issues, motor delays, coordination difficulties	Balance, strength, mobility, playground activities, PE participation
Speech Therapy (ST)	Speech, language, and social communication challenges	Expressive/receptive language, social communication, class participation
Occupational Therapy (OT)	Developmental delays, sensory processing challenges, fine motor difficulties	Writing, drawing, sensory regulation, self-care, smoother transitions
Vision Therapy	Eye coordination, depth perception, visual tracking	Attention, reading, engagement
AAC Device	Significant communication challenges	Allows children to express needs, thoughts, feelings, and participate independently
Behavioral Support	Difficulty with attention, emotional regulation, or behavior	Focus, engagement, emotional regulation, participation
Adaptive PE	Difficulty participating safely in traditional PE	Modified activities that promote movement, fitness, and inclusion

Developmental supports often work alongside medical services to help children remain healthy, safe and able to fully participate throughout the school day.

Medical Support

Support Type	When It Can Be Helpful	School Benefits
Seizure Care Plans	Children with a history or risk of seizures	Clear instructions to recognize seizures and respond to episodes
Feeding Support	Swallowing difficulties, dietary restrictions, assistance with meals	Appropriate positioning, pacing strategies, supervision during meals
School Nurse	Routine health monitoring, medication administration	Coordinates care and responds to medical needs during the school day
Emergency Care Plan	Conditions that may require urgent intervention	Outlines how staff should respond to a medical emergency

Beyond therapies and medical care, many children also benefit from classroom accommodations and learning supports that help them access the curriculum and participate alongside their peers.

Learning Support

Support Type	When It Can Be Helpful	School Benefits
Social Support	Struggles to build peer relationships or participate socially	Peer buddies, social skills groups, guided peer interactions
Communication Support	Difficulty understanding or expressing information	Visual schedules, simplified language, extra processing time, AAC
Cognitive Flexibility Support	Difficulty adapting to changes or managing transitions	Predictable routines, transition warnings, structured supports
Modified Schedule	Fatigue, attention difficulties, or medical needs	Later start time, early dismissal, or gradual increase in school time

Developmental supports include therapies such as physical therapy (PT), occupational therapy (OT), speech therapy (ST), vision therapy, and adaptive physical education (PE), in addition to behavioral supports. Children with chromosomal 8p conditions can experience motor delays, low muscle tone, and complications with coordination, due to the genetic differences that impact the function of the musculoskeletal and neurologic systems.

Depending on your hero's specific situation, medical support throughout the school day may be required to uphold well-being and safety. Seizure care plans and emergency care plan outlines for staff can help caregivers at your school feel more confident and prepared, should any medical emergency arise.

Learning assistance can range from social support, reinforcement with cognitive flexibility, and communication accommodations. Implementing these strategies improves access to the traditional curriculum and supports engagement with both peers and academic content.

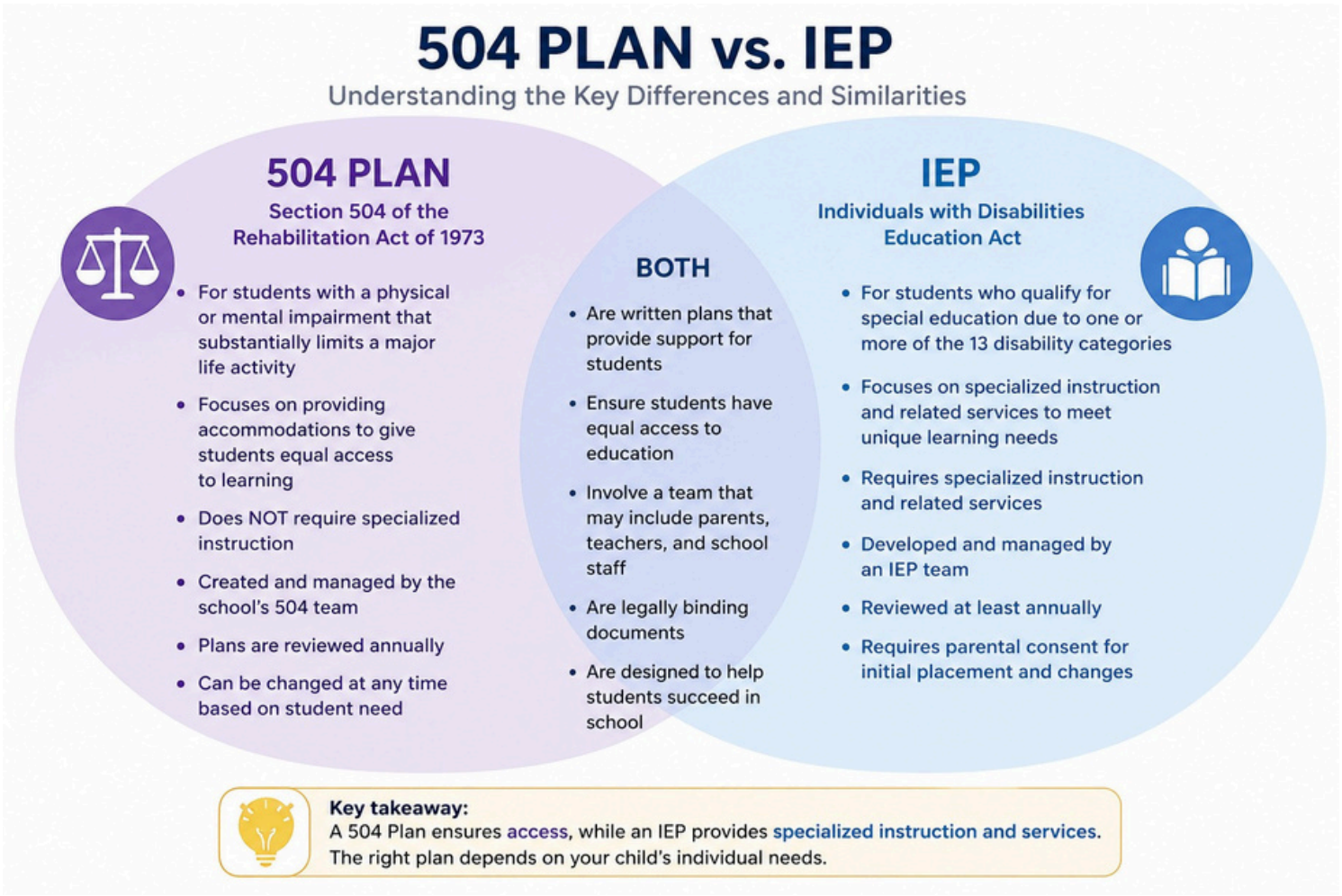
A school day that incorporates numerous supports can become demanding and contribute to fatigue, attention complications, and overall difficulty tolerating a full day. Modified schedules can help to better align the school day with a child's individual needs.

Understanding School Support Systems

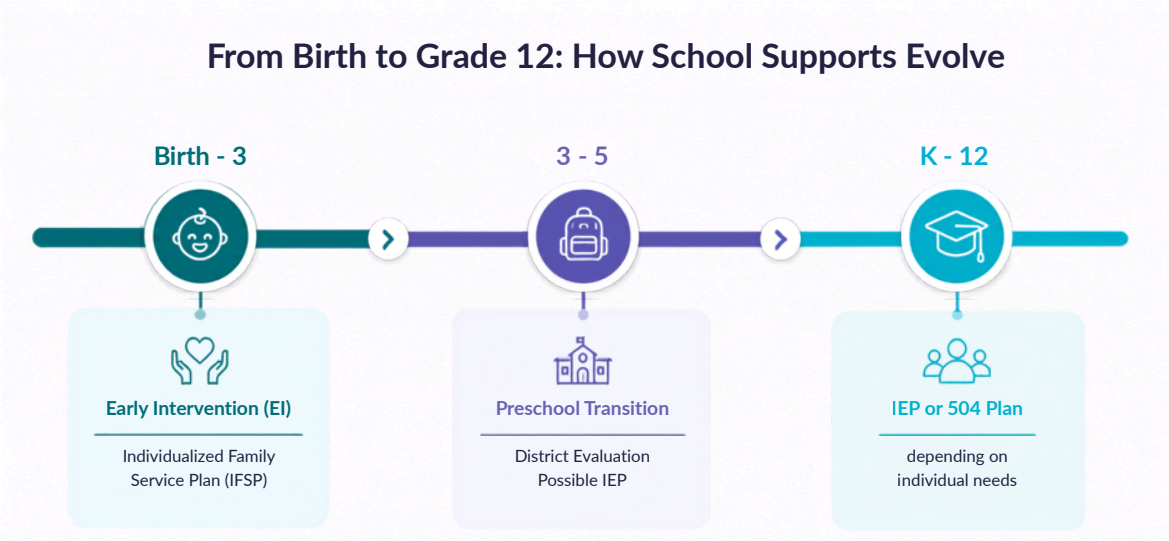
School support needs are not one size fits all, especially when it comes to our 8p heroes. As you begin to explore different options for your hero, terms such as IEP and 504 Plan may frequently come up. These are two ways schools provide support to help children with unique needs thrive in the learning environment. Although they seem quite similar, they serve very different purposes.

An Individualized Education Program, or an IEP, is created for those who require specialized instruction due to a disability that affects the ability to learn effectively in a traditional classroom. With an IEP, you have the opportunity to work with your school administrators and educators to create a highly individualized plan tailored to your hero's specific needs. This can include specialized classroom or teaching strategies, developing educational goals, and integration of related therapies into the school day, such as speech, physical, and/or occupational therapy. This approach is most appropriate for those that benefit from a more structured environment with continued interventions built into the schedule.

A 504 Plan is created for those who require specific accommodations that help a child succeed in the traditional classroom setting. Accommodations may include additional time on tests, taking tests in a separate space, priority seating, modified assignments, and/or access to technology that may assist with learning. Instead of focusing on specialized instruction, 504 Plans help to remove barriers to learning so children still have the ability to participate in the traditional classroom. This approach is most appropriate for those that benefit from accommodations and are able to follow the standard educational curriculum.



Obtaining an IEP or 504 Plan for preschoolers (Pre-K) can be different from the traditional process for those in grades K-12. For children under 3 years old, services are typically provided through Early Intervention (EI) programs, where in school support is coordinated through an Individualized Family Service Plan (IFSP) instead of an IEP. Beginning at age 3, when a child transitions to preschool, responsibility for service evaluation is shifted to the local school district to determine eligibility for an IEP if a child qualifies. In contrast to school-aged students, services for preschoolers have more emphasis on developmental milestones, functional skills, and play-based learning. Evaluations for services can take place in more natural environments such as daycare, preschools, or even at home to make children feel more at ease. Access to these services is dependent on whether the district offers a Pre-K program, impacting how, when, and where the supports are delivered. Although 504 Plans can be utilized in a preschool setting, they are less common, as most young children qualifying for support receive services alternatively through IEP's. Overall, the core principals of eligibility, evaluation, and individualized support remains consistent, the setting and structure of services in the Pre-K stage are much more flexible and developmentally focused.



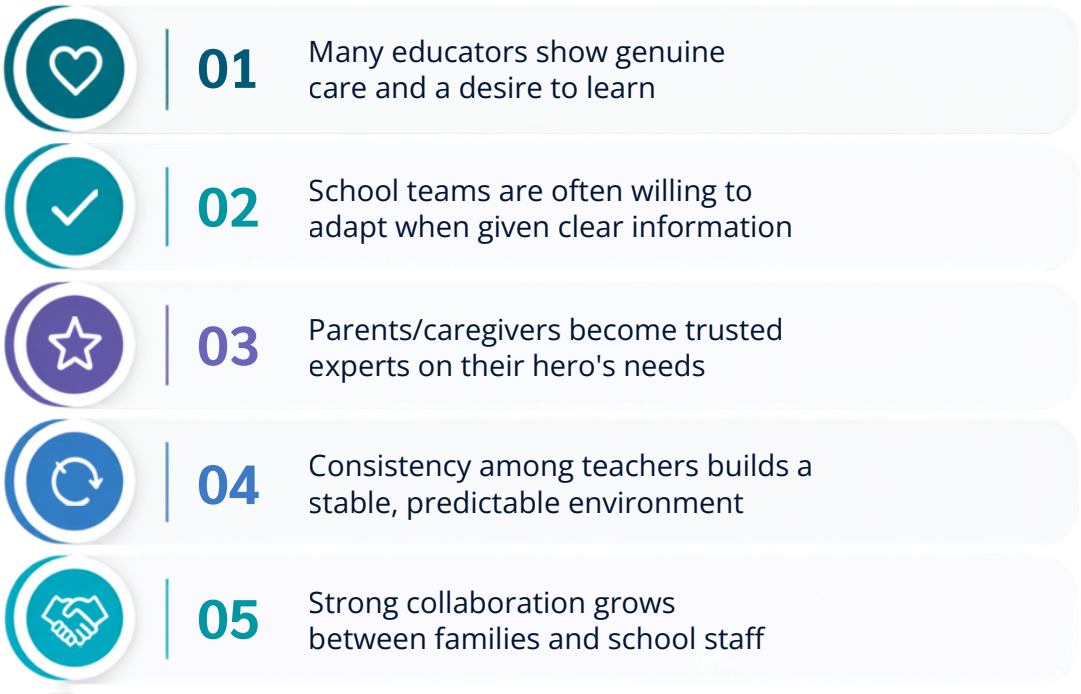
Choosing an option that is most appropriate is highly dependent on your child's individual needs. If you're not sure where to begin, requesting an evaluation through your child's school administration can aid in getting a better understanding as to what supports may be most beneficial. Being open with your school's educators, specialists, and your child's medical care team can go a long way in ensuring the chosen plan is tailored to support your child's success. It is also important to remember your child's needs may change over time; what works for your child in elementary school may not work the same as in middle school, and making adjustments to these plans as your child's needs develop is crucial to the learning process.

What Families Told Us - Common Strengths and Challenges

Families have shared a wide range of experiences when working with school systems, highlighting both strengths and challenges that impact their advocacy journey. Although many describe positive collaboration between school teams eager to assist, there are notable gaps in resources, knowledge, and consistency that can influence access to appropriate support. A recurring, and inevitable theme is the distinct role families and caregivers serve as both an advocate and expert in their child's care, something that can be both empowering and demanding. Understanding the background of these encounters can promote a well informed, individualized, and thoughtful approach to supporting 8p heroes in the school setting.

One of the most meaningful strengths within school systems recognized by families is that many educators have a genuine care and desire to work with you to support your child as a student under their supervision. Even in cases where school teams are not familiar with rare conditions, the lack of prior knowledge can create space for you to build relationships with the school team through orientation of the day-to-day logistics of supporting an 8p hero. When teachers and other staff members are provided with clear, accessible information, they are often happy to learn from you as a parent or caregiver and adapt typical protocols to what best benefits your child. A significant difference has also been observed when consistency among teachers and continued communication is established, as this can create a more regimented and stable environment for the child. The ability to educate the educators, by translating complex medical knowledge into easily digestible language, is another factor that can empower school teams to better grasp and respond to a child's unique needs. As previously mentioned, many parents and caregivers often become the expert on both the condition itself, and the child's needs, placing them in the ideal position to be a key partner to the school team.

Common Strengths Families Have Shared



Conversely, families described a handful of challenges commonly faced when navigating school systems. Although parents and caregivers stepping into the role of the "expert" can feel empowering when teaching staff about rare conditions like 8p, the same responsibility can feel logistically and emotionally taxing. The expectation to simultaneously educate the school team and advocate for appropriate supports can weigh heavily on families, and highlights how advocacy can exist as both a strength and a challenge.

Access to support is also influenced by broader systemic factors. Limited resources within schools, such as funding, staff shortages, lack of adequately trained specialized providers, and time constraints within the daily schedule affects consistency and availability of services. Geographic location plays a factor, as families in different regions have varying levels of access to school based supports, specialized care, and external resources. For example, families in rural areas tend to have less access to paraprofessional support, specialized classrooms, or services they are entitled to (such as music therapy and mental health counseling) within the school setting. The type of school your child attends can also further influence access to services. Public schools are required to provide a wide range of special education support, while private and charter schools have limited resources or less opportunities for built in services. As a result, some students may receive more comprehensive and consistent care in the school setting, while others may experience gaps in services or rely heavily on generalized support.

Broadly grouping rare conditions under umbrella terms such as "disability care and inclusivity" is another challenge families have faced. Recognizing these systems are thoughtfully designed to be supportive, they don't always capture the specifications or complexities of an 8p hero's needs, which can cause mismatched or generalized supports and contribute to underlying inconsistency. Additionally, not all medically necessary services are offered within certain schools or districts, requiring families to seek outside support or go without support all together. Even when the correct supports are identified and approved, families still experience obstacles. Delays in evaluations and initiation of services are common barriers and interfere with having services implemented into the routine school day. Collectively, these challenges can cause a significant amount of frustration, unequal care, and fatigue in families working hard to secure consistent and individualized attention at school.

If these experiences feel familiar to you, you are not alone. Many families have shared similar journeys while working to balance advocacy, education, and respectful collaboration to ensure the child is receiving the support they deserve. Although the process is not always smooth, these shared experiences bring light to the importance of connection and persistence. With the right support, meaningful progress is achievable and each step forward adds to a more responsive and informed system for all children with a rare diagnosis.

Turning Knowledge into Advocacy

While it may feel overwhelming at first, acquiring a solid understanding of how your hero learns best and what supports might help them succeed can make it easier for all parties involved when communicating with your hero's school system. Many families may find that what once felt unfamiliar becomes much more achievable as confidence navigating the diagnosis is gained, medical system, language, and the overall process that goes into their 8p hero's care. Over time, you will learn more about your hero's diagnosis, strengths, and challenges; which is knowledge that can be turned into a powerful tool for advocacy.

"Advocacy is not about having all the answers; it is about asking questions, sharing your journey, and openly collaborating with your school team to determine what is the best fit for your hero."

As a caregiver, you bring a unique and essential perspective to these discussions; you observe your hero in all settings and across all time periods of development, providing the insight needed for guiding decisions about what support services and accommodations would make the most positive impact on your hero's learning experience. Therefore, your lived experience with your hero is just as important, if not the most important, piece of support service evaluations.

Making connections within your hero's diagnosis and their day-to-day routine is a great way to begin advocating for your child within the school system. For example, if your child experiences difficulty with communication and attention, sharing a specific scenario that you have observed *outside* of the classroom can help your school team better understand how these challenges might present *inside* the classroom. This approach can lead to more tailored and meaningful support, while also building trust with your school team. When you share what you're observing and work together with your school team, it helps create a true sense of partnership. Over time, this trust can make for smoother and more productive communication with your educators, as well as develop a safe space to problem solve when challenges occur. Conversely, highlighting your hero's strengths, such as their interests and motivations, can help in the same way. Doing so allows your school team to build on what your child already does well and enjoys, leading to more effective and engaging learning strategies that promote a positive and confident educational experience.

Coming well prepared to meetings with questions, ideas and observations can go a long way as well. Asking what supports are currently in place, what supports are planned to be implemented (if not already), how progress is measured, and what additional strategies could be utilized are great topics to begin these discussions. You may also want to establish how often progress reviews will be done, who will be responsible for implementing and administering support services, and a method of communication between home and school.

Organizing thoughts ahead of time, or bringing notes to meetings will help ensure concerns are clearly outlined and reduce the chance of forgetting specific discussion points. Prioritizing your concerns can be helpful as well, especially when time becomes limited. Keeping an up to date log of evaluations, reports, emails and meeting notes can aid in tracking progress and identifying new patterns over time. With all the information in one place, it becomes much easier to reference previous discussions, follow up on recommendations, and advocate for support adjustments when applicable.

Building collaborative relationships with the individuals in your school system is another extremely important piece to advocacy. Asking questions and expressing concerns is always encouraged, and approaching conversations with a shared goal of supporting your child in mind creates a productive and positive experience. When families/caregivers and school teams view each other as partners, it can shift discussions from feeling overwhelming and challenging to more solution focused and supportive.

Understanding how your state and school system function in regards to educational procedures, available services and eligibility criteria is another crucial piece of advocacy. School district policies can be widely variable depending on location, so it is important to be familiar and up to date with what is applicable to your specific situation. Identifying your state and using targeted search terms, such as “IEP/504 Plan eligibility in [state]” or “Special education evaluations in [state]” can help families better understand what supports are available and how to go about accessing them. From there, you may feel inclined to search more about your child’s unique needs. Researching topics like “School nursing requirements in [state]” and “Medical accommodation guidelines in [state] school districts” can provide clarity in terms of medical support policies that may be applicable to your child’s care. In regards to behavioral supports, terms such as "Functional behavior assessment process in [state]”, or “In-school counseling services offered in [state] districts” can be beneficial as well. Additionally, you may be interested in exploring therapy related supports, using terms like “Speech/occupational/physicial therapy protocols in [state] schools.”

Although all 50 states follow the Individuals with Disabilities Education Act (IDEA), each state implements its own timelines, terminology, and procedures for evaluating students and delivering special education services. As a result, the process for accessing supports may look different depending on where you live. The examples below illustrate just a few ways states may vary. They are not meant to be comprehensive, but rather to demonstrate why it is important to become familiar with your own state's policies and use them as conversation starters with your child's school team.

State	Example	Purpose
Texas	Admission, Review, and Dismissal (ARD) Comittee	Create and review IEP In public scool setting
New York	Comittee on Special Education (CSE)	Consist of multidisciplinart team that arranges evaluations and supports for those In public and private schools
California	Specific Guidelines for Extended School Year (ESY) policies	Specific Guidelines for Extended School Year (ESY) policies

If a requested support or service is not approved for your hero, it is important to know the school must legally provide documentation elaborating on the decision and reasoning behind it, including what information was reviewed, and why the evaluating team determined the service is not currently needed. This explanation can help you as the parent or caregiver better comprehend the decision making process and acknowledge multiple perspectives were considered. If after reviewing documentation you have additional questions regarding the decision, it is absolutely appropriate to request further clarification. You may want to meet with your school team to learn how the evaluation for support was conducted, what criteria the school adheres to, or if additional documentation or observations can be gathered. Sharing additional information on your hero's diagnosis, requesting further evaluation, or requesting to revisit the conversation in the future are all great ways to continue advocating. If you feel your hero's needs are not properly being accommodated, you can request your concerns and disagreement be documented as well. This makes sure your point of view is part of the official record, and supports future discussions when revisiting the conversation. If you feel further escalation is needed, there are additional steps and ways to take action.

Advocacy is a process that evolves over time. As your hero develops and needs change, the role of an advocate will develop and change alongside them. At times, you may feel a sense of confidence and at other times, you may feel a sense of uncertainty, both of which are completely normal. With time, support, and experience, you'll begin to feel stronger and find your voice in being an effective advocate for your hero. Remember you know your child best, your voice matters, and your input plays a crucial role in your child receiving the proper support they need to thrive in the school setting.

"Turning Knowledge into Advocacy Checklist" guides you through turning knowledge into action. This tool is meant to break advocacy into manageable steps and provide practical methods.

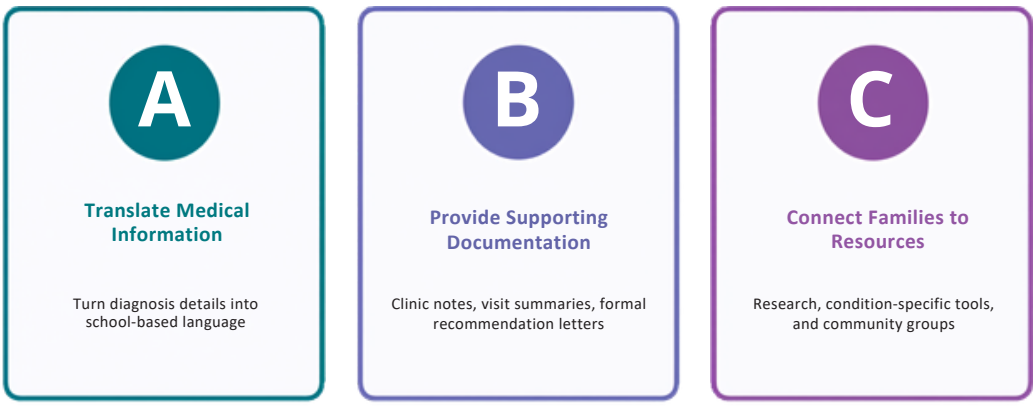
Ready-to-Use Language for School Communication

You may feel one of the hardest parts of advocating for your hero is knowing how to put their needs into words. These templates are starting points that can be adapted to fit your child's needs. Anything in brackets can be edited to best reflect your child's specific situation.

Below, you will find a communication hierarchy that can serve as a practical visual tool when deciding who is best to turn to with current concerns. Beginning with the staff member closest to the issue at hand, such as a teacher or case manager, and moving downward through other levels of support when concerns remain unresolved or input from higher authority is required. This framework encourages problem solving in a collaborative way, helps identify appropriate points of contact, and can make the process of advocacy more organized.

How Genetic Counselors and Advocacy Groups Can Help

Families can successfully advocate within school systems using tools like those above. If additional support is needed, members of your child's care team, including genetic counselors, may be able to help translate medical information into educational needs or provide documentation for school teams:



Turning to your hero's care team, including genetic counselors, is a wonderful place to look to for guidance when searching for ways to explain the diagnosis in a manner that is digestible for school systems to comprehend and apply in the classroom. Given medical information focuses mainly on treatment and diagnosis, school staff may need assistance when working to understand how the condition can impact a child's ability to learn and participate. Providers are fantastic resources for helping to describe how the diagnosis can affect communication, mobility, attention, behavior, and social interactions. By presenting information in this way, educators can better support your child's unique needs.

Verbal guidance is not the only effective method of communication between care teams and your school system. Genetic counselors and other healthcare providers part of your care team can distribute written documentation to support school-based needs. Clinic notes, visit summary letters, or formal recommendations that clearly outline your child's diagnosis and unique needs, can all serve as another way to advocate for services. These are especially beneficial during evaluations as they provide professional insight into the reasoning behind why specific supports and accommodations are required for proper learning and development. This information in writing can make a family's efforts towards advocacy stronger, and ensure medical recommendations are properly communicated to the school team.

Advocacy organizations and genetic counselors have connections to additional information and support networks. They can guide toward accurate research, condition specific resources, or community groups where they socialize and learn from others with similar stories. Advocacy groups commonly offer practical tools, such as educational guides and opportunities to connect with other families. With access to these resources, you can feel more supported, informed, and confident as you begin to navigate advocating for your child within the school system.

Conclusion

Overall, advocacy is an ever-evolving process that grows alongside a child's strengths, needs, and lived experiences over time. As needs change, support plans may need to be adjusted to optimize continued success in the school setting for your hero. Learning from and building relationships with those from a larger community, such as other families, healthcare providers, and educators, can be a very powerful resource for knowledge, reassurance, and support. Through access to information, willingness to collaborate, and persistence, you can create a strong sense of hope and agency, empowering you to confidently and effectively advocate for your child.

Advocacy does not have to happen all at once.

Over time, knowledge, support, and persistence can help you build the tools needed to advocate for your child with confidence.

Connect with Other Families

You don't have to walk this path alone. Reach out to engagement@project8p.org to be connected with the Peer Support Network and other 8p families who understand your journey.

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