

OVERVIEW OF ADVOCATING FOR YOUR SPECIAL NEEDS CHILD

VISION * KNOWLEDGE * TEAMBUILDING * COORDINATION

VISION

Having a vision of the life that you desire for your child is extremely important. All parents have goals for their child's future. It is typically something that just remains an intangible thing. But for special needs parents it is imperative that we document these thoughts and share them with the team of people that will help us to make these visions a reality. Creating a Vision document ensures that your child remains humanized throughout this process and that the goals being created for your child are designed to propel your child's trajectory towards the ultimate goals for their life. They also provide valuable information that allows new team members to get a glimpse of your child and begin to know how to motivate them and manage challenges. As a child develops, within their capacity and abilities, they should begin to participate in their own vision for their lives. ALL TEAM MEMBERS SHOULD HAVE A COPY OF THE VISION DOCUMENT – Doctors, Therapists, Behaviors Supports, Teachers, Home Health Aides, Nurses, Social Workers, Etc.

Quick Version:

Name and A Picture

Strengths / Challenges

A short-term Vision for your child (this year)

Motivators

A long-term Vision for your child (life goals)

Behavior Challenges and Strategies

Long Term:

<https://www.lifecoursetools.com/charting-the-life-course-guide/>

KNOWLEDGE

Be knowledgeable about your child's rights, entitlements, and the services available to them. More importantly, be strategic in evaluating which of the supports and services available are appropriate and necessary for your child to achieve success. Simply because something exists, does not mean it is an appropriate or necessary support, service or strategy for your child. The goal is supports and services that are strategically designed to achieve the goals that will propel the vision for the special needs individual.

There are many books, online resources and conferences that can help you to navigate this. In addition, be sure to engage your entire team in designing supports and goals for your child based on the vision that you have created. Each member brings a different perspective or area of expertise. This is part of why developing a strong team is an important part of the process. But parents are the leaders of that team! So be sure to arm yourself with as much knowledge as you can.

Training and Learning Resources:

<https://disabilities.temple.edu/programs/leadership/c2p2.shtml>

<https://www.pattan.net/>

<https://adayinourshoes.com/>

<https://www.understood.org/en>

<https://www.wrightslaw.com/>

School Age Transition Quickguide :

<https://www.pattan.net/Publications/Pennsylvania-Parent-Guide-to-Special-Education-for>

Adult Transition Quickguide:

<https://drive.google.com/file/d/1mTJ-wt8kcdsk1W5Zml4i7h9TaC1xRL3-/view?usp=sharing>

Reach out to

ADVOCACY RESOURCES:

<https://pealcenter.org/>

<http://www.phlp.org/>

PARENTS WHO UNDERSTAND:

<http://www.parenttoparent.org/>

TEAMBUILDING

Persuasion

The art of persuasion will be an imperative skill for you to acquire. It will not be enough to simply present your child's rights and entitlements and expect that they will be met. You must learn how to persuade others to acknowledge and adhere to them while maintaining a strong team dynamic. Ideally you will be able to persuade the provider, school, or agency working with your child to meet their needs without a battle. Conflict will happen, but the goal is teamwork on behalf of your child. All parties working in unison will always result in the best possible outcome.

Persistence

Assert persistence without confrontation whenever possible. When the provider, school or agency will not submit to your request, be sure they understand that you will be persistent because it is your job to advocate for your child but try not to allow the emotions and stress of the situation to interfere with your assertions. There are times when you may need to assert your rights more forcefully or even seek the help of a professional advocate or attorney. However, the goal should remain to get others to support your position, solve problems, resolve conflicts, achieve positive outcomes, and keep the best interests of the child in the forefront of all conflicts to create an ongoing collaborative environment.

Negotiation

Know when and how to negotiate. Advocacy refers to the process of trying to persuade others to support your position. But in a negotiation, all parties are generally trying to work toward a mutually acceptable agreement. There is a time to consider a negotiation as a preferable way to achieve the best short-term and / or long-term outcome. When negotiating, both parties engage in discussion and bargaining, with the goal of reaching a settlement or compromise. Be prepared to compromise on something less important to achieve an item of bigger significance. Showing a willingness to compromise will go a long way in achieving your immediate goal and establishing a long-term collaborative relationship.

Appreciation

Sharing success and acknowledging the ongoing efforts of team members is a great tool to keep everyone motivated. People will always do more when they are appreciated!

COORDINATION OF CARE

One of the most challenging and most important pieces of advocating for your child is the coordination of care. The sheer number of people, services, meetings, documents and data that needs tracked and processed is overwhelming. But for most special need's individuals the ability for all providers and services to work in unison is often the key to making steady and substantial progress. Be sure to maximize the services of those on your team that are intended to help you to coordinate care. Parent Liaison, Social Workers, Case Workers can be valuable resources for your family. Have a key coordinator that attends all doctors' appointments and meetings. Have them take notes for you at those meetings and provide a second set of eyes and ears on the process. You cannot do this alone. You need help!

Tools:

Paper: Care Binder or Care Portable Filing Cabinet with Hanging Folders

Electronic / Online: <https://www.caringvillage.com/>, Project Management Apps, Google Drive

****Tip if you choose to coordinate care online or electronically be sure to ask your team to provide all documents via email and / or purchase a document scanner to download documents easily**