



Advance Your Advocacy: Techniques, Tips, and Technology

Dr. Melody Parsons, DNP, MS, RN, CNE
Westminster, Colorado
July 2024

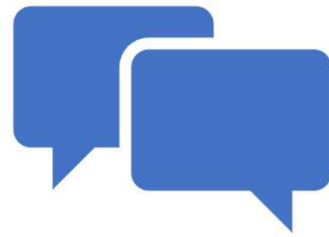


Please allow me to introduce myself a bit more and tell you why I'm here talking with you today. They read my bio and that gives you a bit more of an overview of my professional background, but when it comes to credentials. Through the years, despite the fact that I have inside knowledge of both the medical and the educational community, I have struggled to navigate the very complex world of disability advocacy, and I have often wondered how anyone who is not part of this world professionally could ever manage to get the services and treatments they or their loved ones need without an "inside guide". But everyday I meet parents, caregivers, and self-advocates who are doing that job well, and I have learned a lot from them along the way. But what really qualifies me to be up here talking to you about advocacy today is that I want you all to know that I have a PHD in Carter. Carter is 22 and, although we knew he had health and developmental concerns at birth, he was diagnosed with Sotos syndrome at age 3. As I look back at those early years, and even the massive advocacy steps that it took to get to that diagnosis in the first place, I often wish I would have had a handbook or a tutor to help me navigate the very complex world of medical specialists, tests, therapies, and educational evaluations that we had to go through in just the first few years. If those resources existed back then, I sure didn't have access to them. So, since I've spent 22 years becoming an expert in Carter, primarily through the school of hard knocks along with trial and error, I've learned a lot of things along the way. We've also, in the last 2 years, been through one of the biggest life transitions that a person with disabilities will go through when it comes to life planning and


funding and that was the transition out of the public school system, which in our state occurs on the last day of June following an individual's 21st birthday (unless they qualify for a traditionally earned diploma). Now I know that not everyone with Sotos syndrome will have the same or any level of disability but according to the New England Regional Genetics Network around 75-80% of individuals with Sotos will have developmental delays and require some additional accommodation in school, and nearly all will have some sort of motor developmental difficulties, especially early in life, so the vast majority of us who advocate for an individual with Sotos will have to navigate that world. I really enjoy meeting with and sharing some of those insights with other caregivers and self-advocates. Hopefully you will find some of this presentation helpful. I also want to let you know that we will leave some time for a Q and A and discussion at the end, but I want to keep this very conversation. Please feel free to ask your questions or offer your comments as we go as well.

Goals

- Discuss advocacy as a way of life for those in the Sotos community
- Introduce tools to promote advocacy using a person-centered framework
- Offer tips for use of simple technology to advance your advocacy



So, here's what we are going to focus on during our short time together today. The first goal I have is to continue that conversation about advocacy that we've already started and I hope to leave you thinking about advocacy as a way of life, rather than just something you do during appointments or IEP meetings. Secondly, I want to give a brief overview of tools to help frame the way to you advocate by keeping the individual and their unique needs at the center of every advocacy interaction. The person-centered framework is certainly not my invention, and we could honestly host a week-long workshop to go through all of the tools available on that subject, but I do want to leave you today with at least a basic definition and a common language to begin a person-centered discussion about yourself or your loved one. And finally, I will offer a few practical tips for using low cost or free technology to simplify, and enhance the work you do, especially to advocate for disability services and supports. If you attended my talk last year at the conference this last goal was the basis of that presentation, but I've got some updates and I hope that everyone here can find something useful to take away. So, with that we'll dive in.

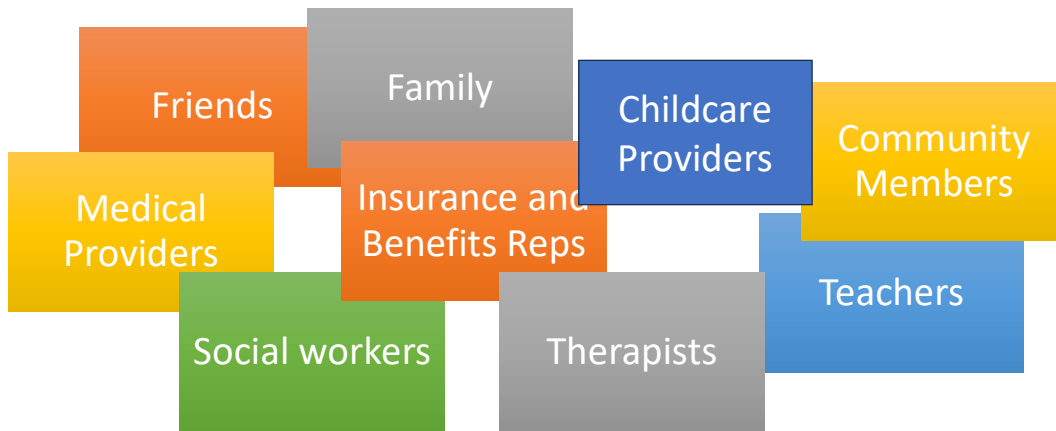


Your Role as Advocate

Self
Caregiver
Friend
Professional

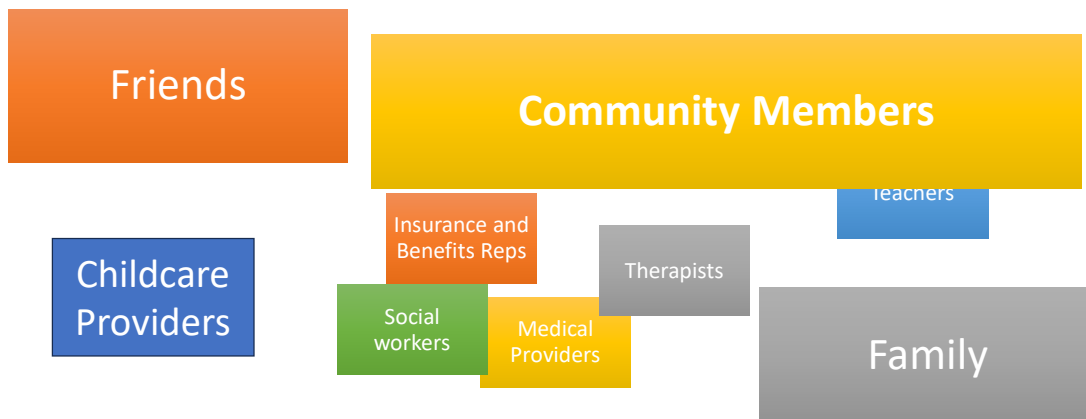
One of the things that I love about coming to these conferences and also about staying connected to our Sotos community online is meeting and interacting with Adults who have Sotos syndrome, some of whom are here in this session today. If you are a self advocate, then I hope then there may be some things that we discuss today that you will find helpful moving forward, and you may also have some wonderful insight to share during the discussion later on. However, I know that most of you are here because you are in the caregiver role and want to learn more about advocating for your child or a loved one with Sotos. When I say Caregiver Usually that is parents, but I know we also have a lot of grandparents, aunts and uncles, siblings, and others who are here to support a loved one with sotos, either an adult or child, and they may also fall into the caregiver role. The caregivers in this group know who they are. As a parent of a child, especially a young child with Sotos syndrome. So, this is just to say while a lot of responsibility for formal advocacy will fall to the parents or primary caregivers, if you here in a different role there are still things that you will do every day to be involved, and it can also be helpful to hear about some of the challenges and potential solutions for those primary caregivers so that you can care for the caregiver when they need that extra bit of back up.

Need to Know vs. Nice to Know



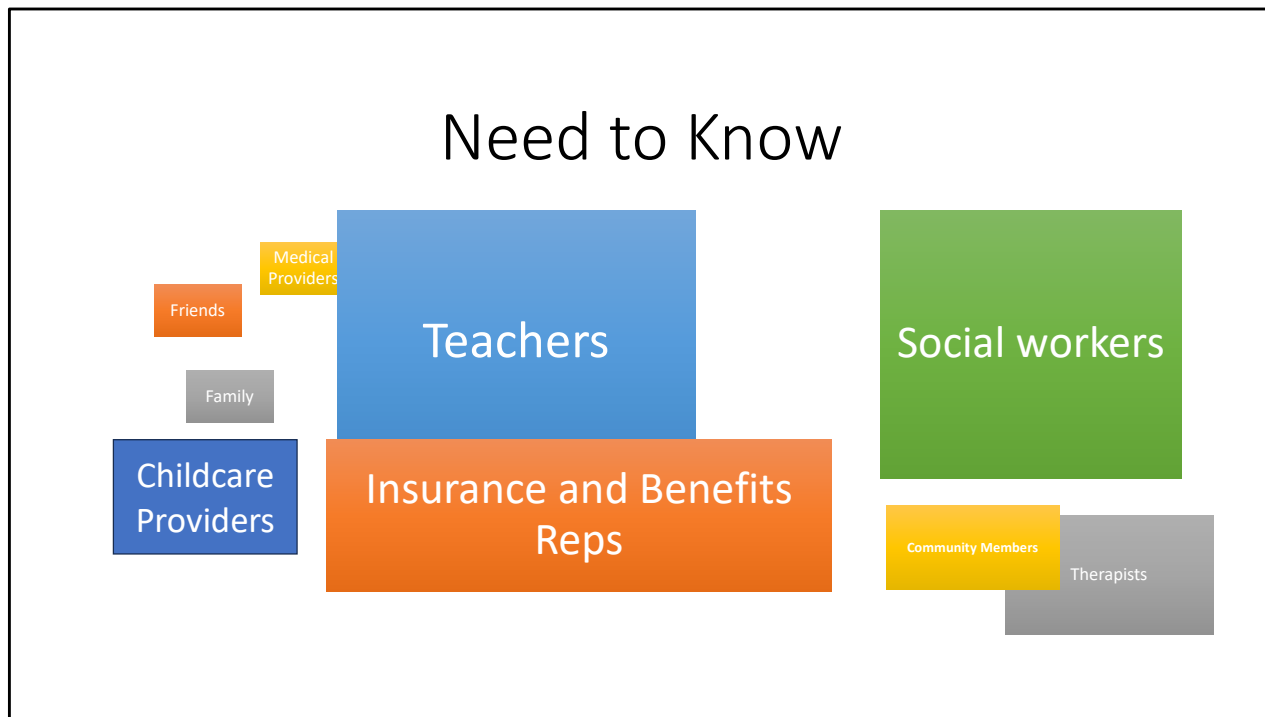
Let's talk a little bit about the many conversations you have probably already had and will need to have about your loved one with Sotos syndrome. These are all potential categories of people or agencies you will have the opportunity or responsibility to interact with as an advocate. Let's start by talking about those nice to know situations,

Nice to Know



Let's talk a little bit about the many conversations you have probably already had and will need to have about your loved one with Sotos syndrome. As a parent of a young child with Sotos syndrome, I can remember especially when Carter's challenges got in the way of him fitting in in an age appropriate classroom, or social group, or even play activity, I used to wish that he had a floating sign above him that would explain him a bit, especially for our loved ones who have invisible disabilities. (and just as a side note, that is one of the things I absolutely love about coming to these conferences. It is pretty obvious who the individuals with Sotos are and I love that they all look alike, but they're all different. But if you've been to one of these before, I wonder have you ever noticed that when you leave you start scanning the community for the person with Sotos? I totally do that. Being here is like being in a safe bubble where we totally belong.) anyways, back to the nice to know conversations.... There is a school of thought that says, "I don't owe you an explanation." And that is absolutely true. The mean lady in the grocery store who glares when he was throwing a fit doesn't have a right or need to know anything about him or why he is acting the way he is, but let's face it, sometimes it does make a difference when the general public has some awareness of an individual's disability. They tend to be kinder, more understanding, and more inclusive. So there are people on this list that don't need the full story, and don't have a right to the details, but doing a little "nice to know" advocacy work with them can make life a little better for your loved one. I'll give you a quick example of this, I remember when Carter turned 8 and he was finally eligible to participate in Special

Olympics. He started wearing his Special Olympics t-shirt a lot in public and I noticed that people treated him differently but not in a bad way. They might be a little more patient with him when he talked their ear off in line at the post office, or more understanding when he didn't sit still in a restaurant. I think that you can pin that down to a bit of awareness. If a person is aware that an individual has some sort of invisible disability, can even open doors to conversations. I can't tell you how many conversations I've had through the years that have started with a kind person trying to figure out a kind way of saying "what is wrong with him?". SO in those advocacy situations it's really all about giving a quick overview or an elevator speech (which we'll talk about more her in a bit) to help them see what is great about Carter while also having an understanding that he might act differently than a neurotypical person of his age, or especially when he was younger and was so big for his age, it helped people understand why this kiddo that looked 4 could barely walk and was really only 2 years old. He's still a big guy, but he has grown into his body a bit. So we don't get that one as much as we used to.



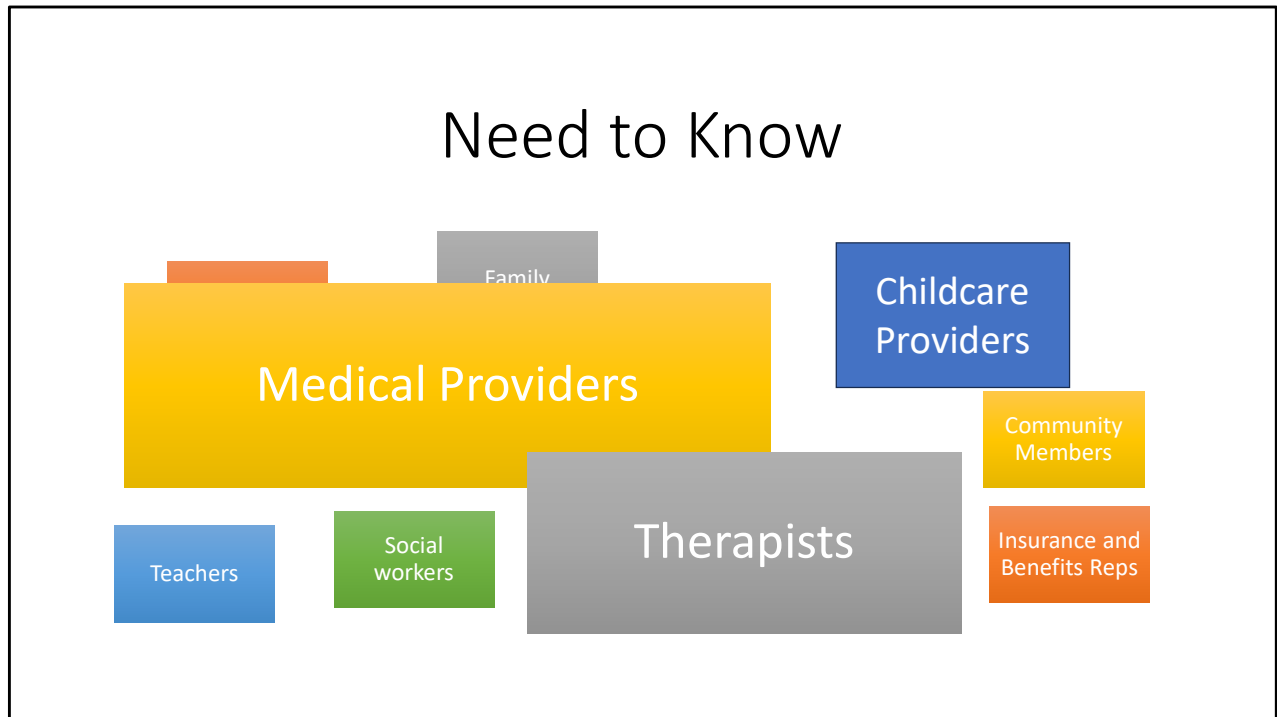
But those nice to know conversations that are intended to help the world around them a better place for them to live in, that are weighted in your loved one's strengths are unfortunately not the bulk of what we do as advocates. That is when we transition into those "Need to know" advocacy talks, where we have to weight our information differently. These are some situations where the information you share needs to be more specific, and you are likely to enter the room with may more knowledge of Sotos and your loved ones needs than anyone else in the room. We often have to learn more, say more, and do more than we feel comfortable with to make sure that our loved ones get the services and support they need. These are those conversations with teachers, insurance companies, government agencies like social security. These are the really difficult talks. When you have to talk about your loved ones' struggles and get the right people to see your child's needs so that they get the support they deserve. To me that's always the hardest part, having to talk about my son's struggles, and also educating people who are supposed to be the experts.

For example, let's talk about IEP meetings. I can't tell you how many times teachers have made assumptions and wanted to cut back on services just when we are starting to see a little progress and that sort of thing. While I do want to celebrate every small success that my son has, I know that it is usually because of the tremendous support and that by cutting back services we will likely lose ground and have a lot of make-up work to do. In short,

progress should not mean discharge.

I have another example of how this often works. I mentioned that we recently went through a big life transition and Carter went through an application process that took us almost a year for a state program that will manage his funding and support services for medical care, day services, employment support, etc. Well, after this major process we finally got accepted and he had a 15 minute meeting with the case manager who is supposed to facilitate this program, in which Carter talked to her about sports and Food network the whole time. Well, if you've met him you know he's very verbal and has a ton of knowledge about his preferred topics, so in a short meeting he can come across as very independant, and in those ways he really is, but I'm afraid knowledge of who won the 1976 Heisman trophy does not equate to the ability to follow all of the steps of brushing your teeth independently or making change from a 5 dollar bill. So after this short meeting the case manager said to me "I'm sure he won't qualify for much." But then, we went through all of the testing and I presented her with 20 years worth of records as well as copies of medical records, psychological tests, and educational and day program records and she was like "wow, I guess I was wrong." In that case, it was my job as an advocate to make sure that she had access to documentation about all of his challenges and needs, because that is what He needed to get and keep the supports for his every day life.

Need to Know

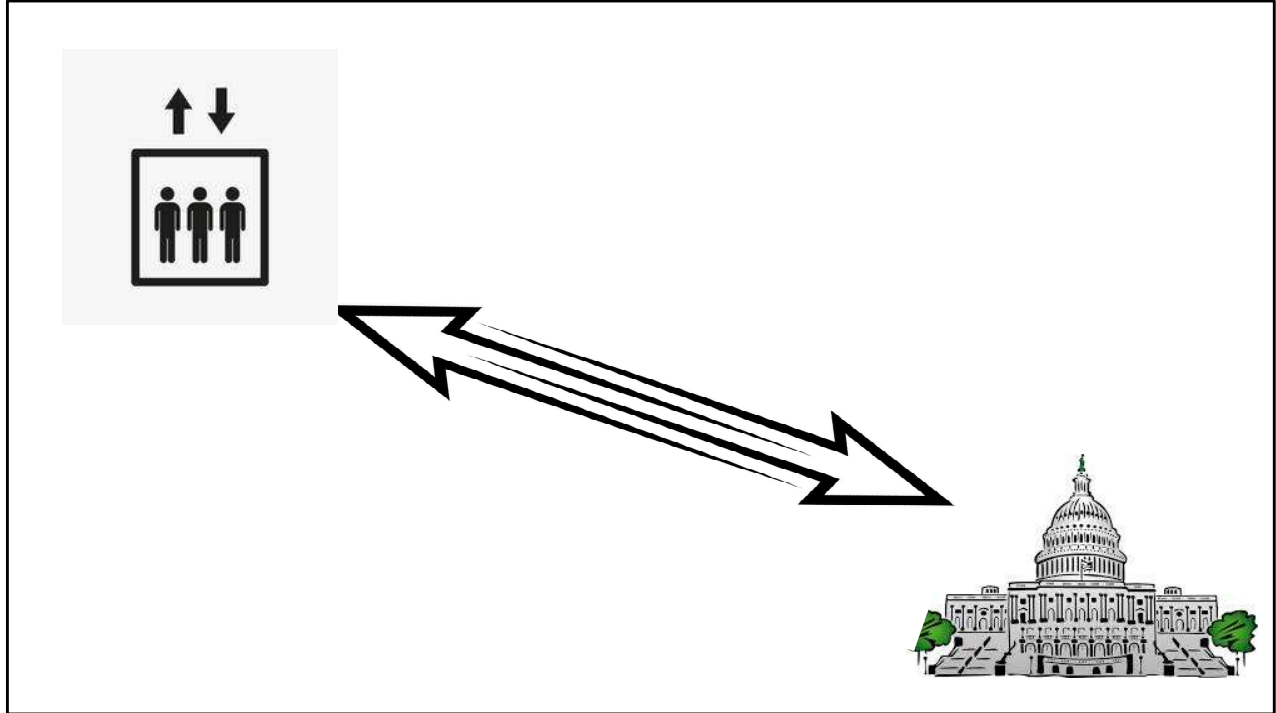


This last category that we're going to talk about within the need to know, is very essential, but can also be the most difficult. Here is another way that I can guarantee you will have to advocate in a need to know setting, and I'm sure many of you have already experienced this. You have a new primary care provider, or a new GI specialist, and they walk into the room and say "What is Sotos syndrome?" Or worse, "I looked it up and I see that they often grow out of it." Yes, I actually heard that one. I think that the top hit on google discussed something about how the gaps in their myelin in the brain often fill in somewhat in the adolescent years and with therapy a lot of kids with sotos do reach milestones, if just a bit later than average. While that is true, it is far from the whole story. So it has been left to me, and it will often be left to you, to educate the professionals about Sotos. Just the fact that you are here means you are already on that path. You don't have to be a nurse or a doctor or a professor to do that. But with some of the tools we are going to talk about here is you can go into those situations with a bit of a plan and some resources to help back you up.

In fact, unless you are in a doctor consultation here at the conference, it is highly unlikely that you will encounter any provider that has knowledge or experience in treating more than one individual with Sotos. Even genetics specialists who are good at diagnosing Sotos, don't usually have the opportunity to follow an individual through all of their specialty care. This is where it is so important to have a standard approach, and a plan. It used to make

me very angry when I encountered a doctor or provider who had no clue what they were dealing with, but now I look at those encounters as a way to build Carter's team, and educate them, while also drawing on what they do know, and what their professional strengths are to build the right plan of care.

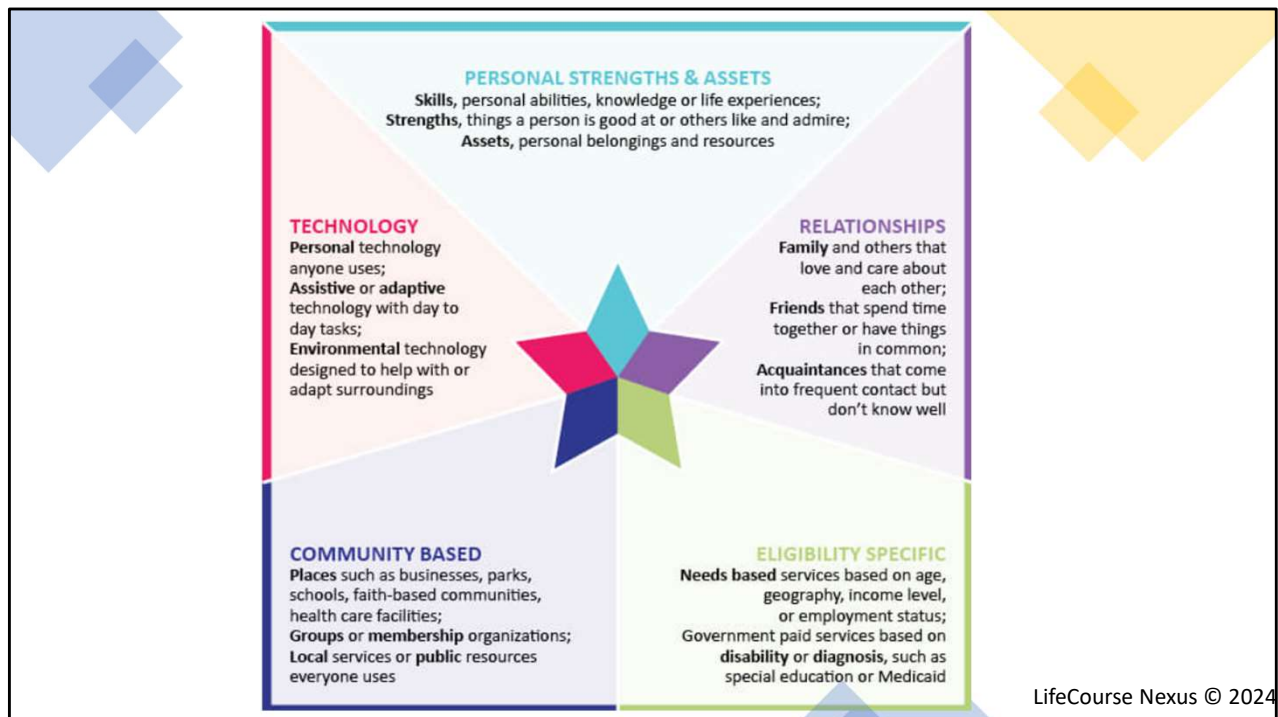
We'll briefly talk about how you might do that as well, but in short, please try to go into these situations with the right tools. Watch out for key words from your provider like "typically, and usually". With all due respect, Dr Zuess, "Typical doesn't really apply to Carter. Refer your providers to the SSSA website. Tell them about the medical board and the resources page that has a list of journal articles outlining the specifics of Sotos and, this one is my biggest pet peeve, if you can learn it in the first 3 hits on Google, it's probably not going to be helpful because that is likely what they looked up right before your appointment. And by all means, if you deal with a provider who is offended by your involvement or lets their ego get in the way, please try to find another provider. I know that is not easy. I've been there with you on those long waiting lists, and I'm not saying it will happen overnight, but please don't let that get in the way of persung what your loved one needs to have the best health, and the happiest, most full life possible.



Your Advocacy Plan

From Elevator Speech to Testifying before Congress – Most of our time as advocates will be spent on that arrow in between. When were trying to be sure that a doctor, teacher, or therapist understands our loved ones needs. Let me ask, how many of you have an elevator speech? You know, that quick response you try to give when someone asks you “What is Sotos?” Now keep in mind I’m talking about an elevator speech, so not necessarily trying to get a doctor to help you, or telling a teacher everything they need to know to support your child, but more for those casual or early interaction. Mine is something like this “Soto is a genetic overgrowth syndrome. Since it affects every system there are often a lot of medical concerns with Sotos and he’s always required a lot of support from medical specialists and therapies such as speech and OT. Sotos effects his growth and development and most people who have Sotos have some learning difficulties. Many people with sotos are on the autism spectrum like Carter. A lot of people hear that and assume he struggles with social interactions but Carter is very social. He has a great memory and he loves to talk to people, especially about sports.....” (end Speech). Do you see that last little part, I’m talking about the elevator speech, so I gave a little glimpse into his challenges but steered towards his strengths and what is good

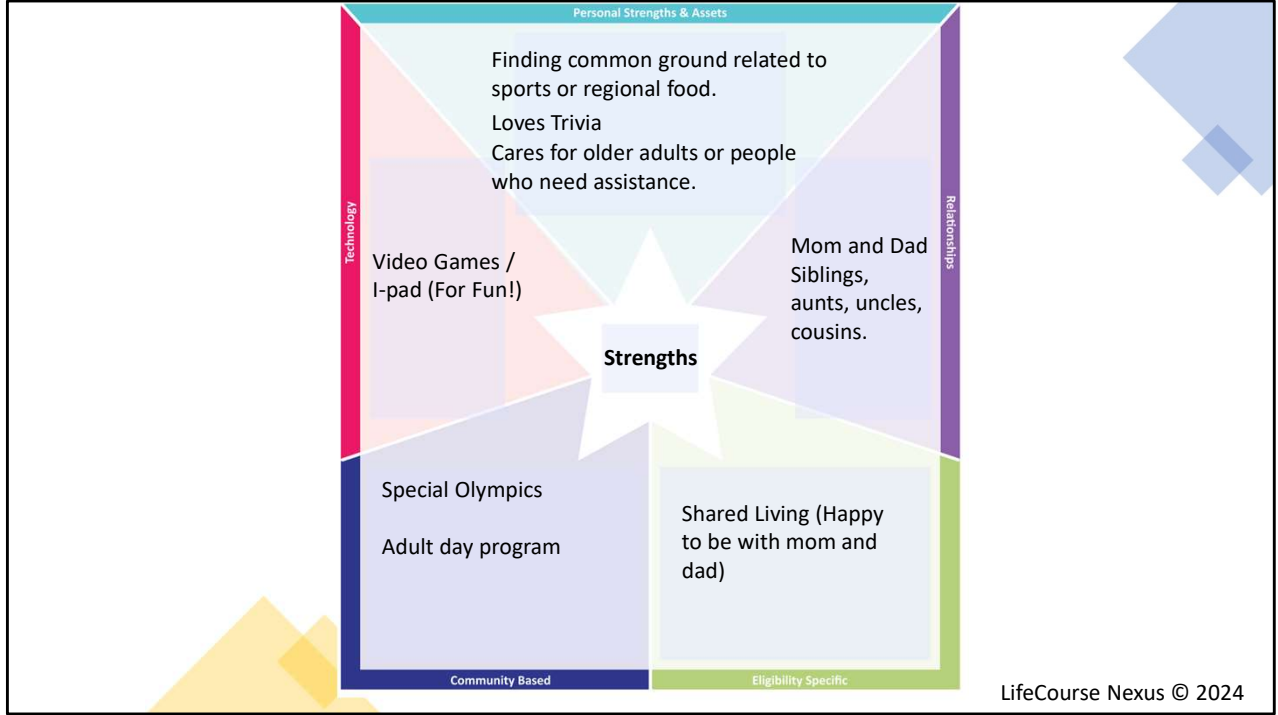
about him. That is where I left it. Now if I was testifying before congress, this would be a lot longer, and the biggest thing I would want to highlight, or at least where I would want to leave it, is unfortunately, I would have to emphasize the challenges. That is what we so often have to do as advocates in order to get our loved ones the support they need, whether it is from a medical provider, a teacher, or a government social worker who determines what benefits they qualify for. I would love it if every conversation I had about my son could be about his strengths, because he is a wonderful person with so many great qualities, but as his advocate, I have to be able to talk about and outline the hard stuff too. So, that is where this next goal for our presentation comes in, were going to talk about the integrated supports star, which is a tool to organize our advocacy efforts using a person-centered framework, so that you can continually identify and community what your loved one really needs to have a full and meaningful life.



I'll preface this with saying that this next part is not my creation, we're going to talk a little bit about the charting the lifecourse integrated supports star for person-centered advocacy, that was developed by the University of Missouri Kansas City Institute for Human Development. I'm going to give you just a brief glimpse into their framework and at the end I will be sure to share more information about how to access a ton of free to use training resources that you can go through on your own or share with your small advocacy groups in your own communities if you find this might be useful to you.

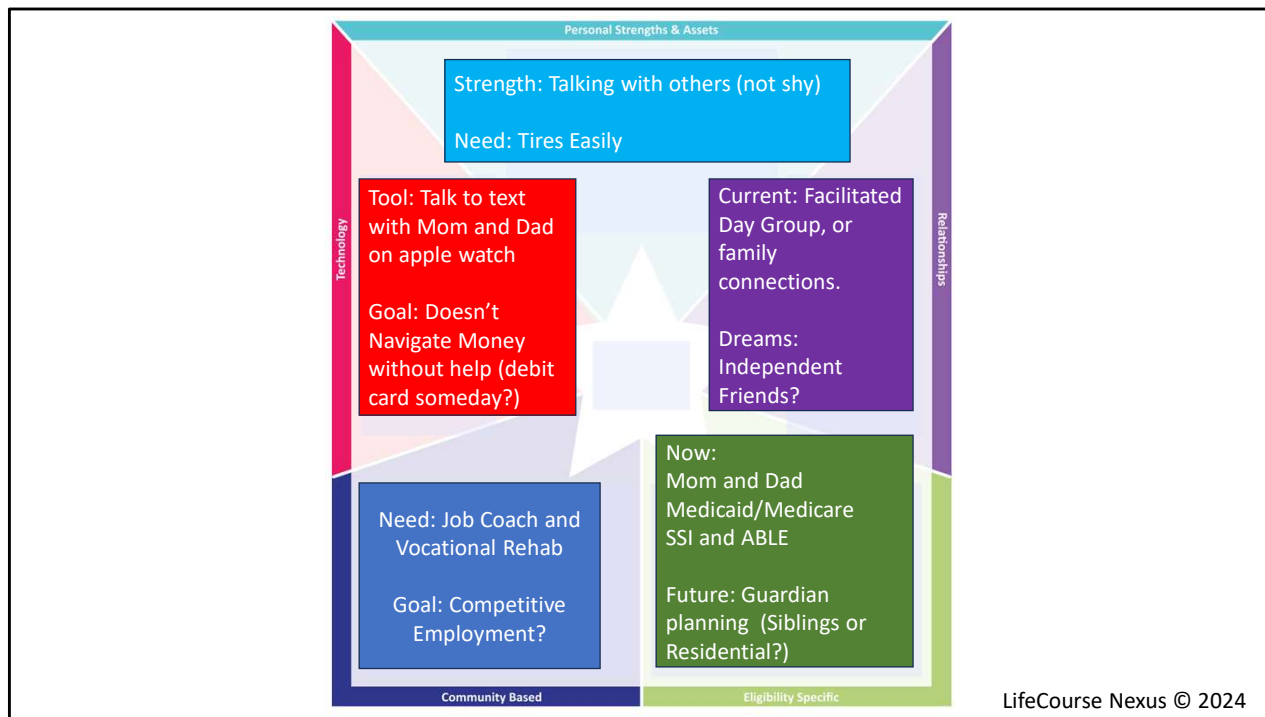
So the framework, in a nutshell is.....very helpful in mapping or charting the various little aspects that make up the life of a person with a disability. It allows you to think about and jot down some notes about how those different things fit into making up the full picture of their strengths and needs. When you are advocating for yourself or someone with a disability, it will pretty much always fit into this framework in one way or another. The other thing that can be useful here is to determine the weight or percentage of each aspect in day to day life, or in the particular situation you are working on at that time. So, you should all have a blank sheet with this same sort of framework on it. We're going to walk through this together in a little bit so that you can start developing your elevator version, or if there is another goal you want to work on first that is okay too, but I like to keep it simple at first, so let's say you just had to put a small bit about each one of these aspects into a short description of the person in your life who has sotos, what would you include?

Pick up here.....





Think about percentages (90% of my day is spent navigating the bottom right hand corner, but he cares most about the left side or the top of the page.



Split Star has current and future goals or hopes integrated,

Consider how this changes on weekends, summers, holidays (Example: Technology is much different)

Consider best case scenario, but also consider other options. (When Carter was 5 I was just thrilled that he was finally talking and our biggest goal of toilet training. People used to ask me, even back then, will he ever live on his own. I know that some of you do, and some of your loved ones will, but my answer then was I don't know, and my answer now is no. That doesn't need to come with an explanation. I know he will always need some support and even if he were to have an independent apartment or something like that he will always need help with his medical needs, bills, personal care, etc. But that is not the most important thing to him, and it is not the most important thing to me either. I would be lying if I said that didn't make me sad sometimes, and dealing with those emotions and self-care, well, that is a whole different presentation, isn't it? But the important thing is that Carter has what he needs and that we enjoy life together.

So how does this translate to your advocacy conversations, well let's think about percentages. If you have a good overview of a) what his current strengths and future goals and needs are, along with a realistic understanding of how important that point of the star

is to the current situation, then it helps to break it down and focus on what is really needed. Example for community, Focus is on relationships and tech, example, for medical: insurance company wanting to send his meds to a mail order pharmacy instead of a local pharmacy. It took 4 phone calls and 3 letters and 2 months, but we got it done! I do want to come back and talk more as we get to our third and final goal of this presentation about that eligibility box, or that green box down here in the corner, which is where a great deal of our advocacy work tends to lie.



lifecoursetools.com

LifeCourse Nexus © 2024



But first I want to be sure that you all have access to some additional information about the charting the life course, person-centered integrated supports star training.

How do you keep it all straight?

Phone calls

Appointments

Records

Photos

Medications

Specialists

Multiple Diagnoses and Therapies

Financial support

Insurance

Individualized Education Plans (IEPs)





Transition



This is where the technology piece is going to come in to our discussion. Having a team means nothing if there is not a way to keep it all straight. This is just a snapshot of the many encounters and details you will need to keep straight as you advocate for your loved one with Sotos. Of course, all individuals with Sotos are unique and some have more needs than others. You'll meet many individuals this weekend who live quite independent lives and some who will need full time support for the rest of their lives. There is just no single pattern, but regardless of your loved ones unique needs I would bet that everything on this list has or will be a part of your journey at some point. I have some simple ideas, some tips I'd like to offer that have helped me learn to manage and cope with this long list of things that I do as my child's champion.



If you are serving as a primary caregiver for a loved one with sotos, make sure that you have a dedicated email address that is used for that purpose. Yes, even for an infant so many services will be tied to email for a username. Or secure communication, and this is a simple way to make sure that you keep your own records separate and that hopefully, you don't miss an important email that gets lost in a long list spam.

		<h2>Medical Records and Patient Portals</h2> <ul style="list-style-type: none"> • Legal Rights • HIPAA • Guardianship • Responsible Use • Practical Tips
		

So, why do you need an email address? Well, you need to read and keep things. What things, EVERYTHING! HIPAA is probably the last thing on your mind if you have a toddler, but if you are advocating for an adolescent or an adult, you may have already encountered a situation where HIPAA got in the way of you having a conversation with a medical professional that you should have had. If you are a legal guardian or conservator, you have those rights to information, but even if you are not, I encourage you to ask your adult children to sign HIPAA releases, not so that you can be nosy, but so that you can be involved as a partner in their care. I also strongly encourage you to decide what you need to know and what you don't. For example, I am a guardian and conservator for my son, and I have HIPAA permission to access all of his records and I do read every word in the after visit summaries and reports of operation, etc. But I don't go in and read notes from his Mental Health counselor. She knows me and I trust that she will call if she is concerned, but I want him to have a place where he can talk about anything he wants and have his privacy. But let's talk a bit about those patient portals and record systems. Don't count on them to keep the records you may someday need. In most states agencies are only required to keep records for 10 years. There is also no guarantee that those records might not "accidentally" be lost. SO, if it is important, I download or screenshot records and save a copy.

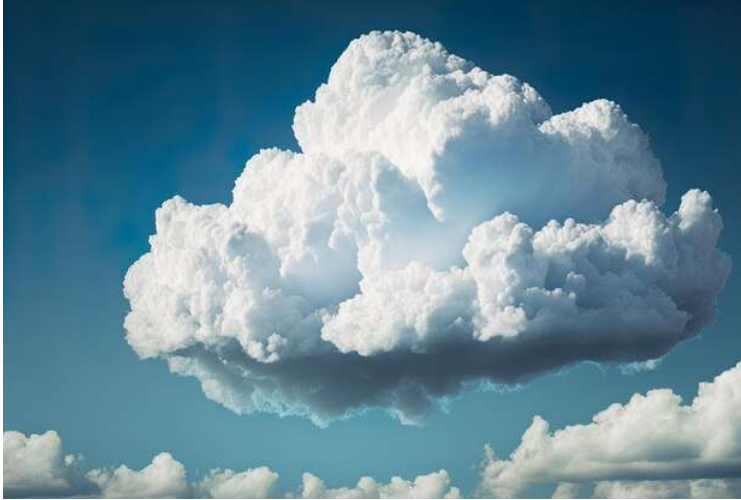
Multipage Document Scanner





External Hard Drive

Western Digital 4 TB It is estimated that **over 85 million pages of Word documents** would fill one terabyte. Now you are going to save more than Word docs, such as PDFs, screenshots,



Using the cloud
for storage
and
communication

Most of it is good, but it can be a little stormy. Security – back-up-

Why We Advocate

- Understanding, Inclusion, and Acceptance
- A Full Life Experience
- Future Planning



Goes back to the elevator speech (organize your own speech to help advocate for your loved one in any situation)

Full Life (person-centered, thoughtful approach)

Ultimately we have to be planning for the future now.

Discussion

lifecoursetools.com

*Developed by the Charting the LifeCourse Nexus -
LifeCourseTools.com
© 2020 Curators of the University of Missouri | UMKC IHD*

