



Poster Presentation

Sharing Information with Caregivers

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Presenter Information

My name is Sarah Cawthon and I am a mother of an 18 year old boy with CHARGE who is totally blind and deaf. I am also a practicing MD of 25 years and work as an emergency OB/Gyn taking care of acute life death events on a daily basis. When I compare the two callings I would say mothering my son has been by far the most challenging. There are many areas in our life that I could share, but the ones I am most passionate about are communication and securing a community to assist us in raising these special children.

Presentation Abstract

Frequently our complicated children baffle the educators as well as caregivers in their lives. This can result in minimizing interactions with our children thereby missing opportunities for meaningful relationships. This presentation demonstrates using various mediums to share information about our children with educators/care providers who will hopefully increase successful interactions with your child. This will not only increase the quality of your child's life but yours as well.

SHARING INFORMATION WITH CAREGIVERS

Sarah Cawthon

Fortunately we live in an amazing country that supports our special needs children. This ranges from access to academic programs at school to caregivers that teach our children community-based education.

Because of the complexities of our children with CHARGE, communication can be an issue and our kids might not be able to verbally advocate for themselves. Also their physical needs can be so complicated that it could take weeks to properly orient caretakers....not the 5 minutes that reality allows.

Because of our kid's special demands, they frequently require extensive support from numerous agencies and within these systems turnover and natural attrition occur. These communities might consist of:

| | |
|----------------------------|--------------|
| Teachers | Therapist |
| Community Support Liaisons | Work Coaches |
| Family | Friends |

As a parent of a special needs child you are an expert on your young one's abilities. Many times your children have capabilities that far exceed expectations of those who work with your child. Also, our kids will sometimes play "possum" with new caregivers adding to the low assumption of their capabilities. Teachers and caregivers frequently underestimate their potential; there is a very real danger that they will lapse into a custodial relationship. Because this could lead to missed opportunities for learning, I recommend sharing information with the support team, allowing them to know what your youngster can do so they can take off from a higher expectation.

For the above reasons, I think it behooves us to share information in as a ubiquitous and efficient manner as possible. I wanted to share a few of the strategies my family has used to help us orient new teachers and caregivers to increase the quality of my son's life as well as give both the support team and us, the parents, peace of mind.

Over the years we have been fortunate enough to have a state program that pays folks to care/support/stimulate our son out in the community. We primarily use OT (occupational therapy) students from a local college. They are graduate level, independent, and already dedicated to health promotion. They tend to be upbeat and willing to think outside of the box. They are quite professional and you can set a clock by their promptness. This steady stream of high quality "friends" keep the relationships fresh, unique and stimulating to my son. Only one problem: they tend to matriculate every 2-3 years, making it a constant chore to find and orient new talent. But because of the quality of their care, we have considered it well worth our effort. The following are processes we have developed to orient any new teacher or caregiver that enters my son's life.

FIRST: FINDING TALENT

When we need another caregiver, I have a Word document that I can quickly update and send to my contact at the local Occupational Therapy (OT) college. He is the resource man that helps students find jobs outside of school. He emails it to the students who then self-select as to whether they would like to apply for the job. The students get experience and a bit of coin. It is a win-win situation! In the letter we try to incorporate the following...

Short narrative describing your child

- He is a 19 year old boy who is deaf blind but loves walking, music and swimming

Emphasize the positive

- He only weighs 75 lbs
- The job pays almost 20 dollars an hour

List traits that are important to you for the potential employee
knowing sign language is a plus or willingness to learn

Leave preferred contact information

Typically, we will get several responses where I interview them over the phone (experience, availability, expectations etc.). They then come in person to our home where I will introduce them to my son and if they have not been scared away, present them with the paperwork necessary to become registered to work in this government sponsored program.

SECOND: THE PAPER WORK

1. I have pre-made folders
 - The right hand pocket has the required paper work they need to complete for the state. I highlight the specific parts they need to sign/fill out(the number of sheets is over 35 pages and appears daunting for a part time job.)
 - The left hand pocket has a written "autobiography" reviewing Max's life, challenges and interests. Here is where I try to explain a lot of what Max can do. Also there is his official care plan from the state(developed by myself and the social worker for this program) with specific goals that should be the focus of the employee. For example independent dressing, grocery shopping or community experiences. Remember keep the bar high! This is your chance to further along your child's abilities. I always keep a few folders ready to go in case we need to find another caregiver.
2. I have notes to myself reminding me of what checks are required for the security clearance and who I need to fill them out to.
3. Anytime there is new technology I write a brief summary of what it is and how it works. Frequently I'll draw pictures as to where the buttons are that need to be pushed. For example, my son just got a microphone for his Cochlear Implant (CI). I drew a picture of the microphone and remote and how they need to be synced. Always make copies as you'll want to share this with all people who will be responsible for working with your child.
4. We also encourage our workers to orient each other. As one is graduating from their program (and leaving us), we will ask them to orient the "new recruit."

THIRD: EDUCATING TALENT

Videos have been instrumental in orienting folks to my son's ways. Because he is totally blind and deaf he requires tactile signing, which can sound impossible to do, but we made several videos with the help of a free app called "Videoshop." I'm not a computery person but this App is very intuitive and after a bit of trial and error easy to use. I actually had one of my workers tape my son and me as we made our way through the day to show them how it's done. I've made 8 videos thus far that cover everything from how we communicate to G tube feeding. If you are curious you can look them up on YouTube under Max deaf-blind. This way the workers can review the tapes, learn at their own speed and review as necessary. We compensate our workers for the hours that are required to fill out the paper work as well as to watch the videos. I usually expect people to bill for about 7-8 hours. That way they are even more vested once they start the process as we soon owe them compensation thru the program.

FOURTH: HOW TO KEEP THESE FOLKS STRAIGHT

Another invaluable tool we've used is a free app called FamCal. This is an online calendar that you can set up for your workers to sign up for desired days that they are able to work with your child. It is limited to only the people that are invited to join and anyone of us can notate on it. For example I'll put when Max is going to be out of town or when he is in school. Therefore the caregivers know not to sign up for that time. We go by first come first served in that who ever signs up first to work with my son on this calendar will get that time. They also will communicate with each if schedules have to be changed to circumstances of their school or personal responsibilities. It's also nice for my husband and I to look ahead and see when childcare has been secured so we can make plans as well.

Final thoughts are the importance of enriching your child's life by these types of relationships. It'll also give the parents a break from the chronic grind of caring for these complicated children and you can have peace of mind knowing you have a well educated support team. And lastly, God forbid, but if something were to happen to us, the primary care givers, then we would be leaving behind a blueprint how to properly educate and care for your child.