

The Motivated Parent

Looking at all of the steps and procedures that need to be in place to help a deaf child communicate effectively, sometimes we do not think about the driving force that is required to make it all work. As parents we need to have the right mindset to face the challenges and hurdles and to climb the educational mountains all at the same time, doing numerous tasks while we might still be grieving over our young child's medical prognosis. As a father, I have been there. I have felt the lowest lows of helplessness, not knowing what to do, praying for a miracle to change my daughter's life. Not having any idea what the end result of oral education would bring. In this process there will certainly be emotional high points and low points. The following text will lay out, in my opinion, the mental mindset and tasks that need to be in place to truly be a motivated parent.

What is a "motivated parent?" What does a motivated parent do that other parents might not? Don't get me wrong, we all want the best for our children and we want our kids to succeed. If you read this text and measure yourself against what is written you will know if you are in the category of the "select few" who can truly use the word "motivated." Everything that is written here, I have done. I have walked the walk and I can relate to exactly what is needed to go through this process and have a successful outcome. This is not written to judge any individual. If you read this document along with the document on this website titled "How to Obtain the Absolute Best Medical Outcomes for Children Using Oral Education" and apply all that is written, there is no way your child could possibly fail. He or she will make great achievements and reach that all-important "brass ring" of excellent communication.

Let us look into the unstoppable drive and determination that is at the forefront of the "motivated parent." First off, we all must grieve and we all must come to the realization that our young son or daughter has a very serious disability that will affect their entire life. One of the purposes of writing the book titled "A Father's Love," which is free of charge on this website, was to give hope and promise to every parent who truly puts in the effort and time to help their child. Miracles do happen, and I have living proof in my family. In the beginning of our journey I never read anything about what the possible outcomes of oral education could be. All I heard from many professionals was the same old worn out "every child is different, there is no guarantee." What does this mean? I need something to hang my hat on and I need a goal to work toward. The purpose of this website is to explain what is possible and give parents a snapshot of what the future can hold when the right steps are taken.

You might not think that there is enough time in the day to do what is written in this document. This is why I emphasize strongly that one parent needs to have flextime or a flexible job. This is a must. Keep in mind that only two to four years of flexibility is needed, not your whole working career. I have been fortunate to have been in outside sales for the last fifteen years, which has given me the ability to make phone calls, go to therapies, speak to professionals, and deal with the insurance side of things during the daytime. The educational reading, the writing letters and teaching your young child how to speak can be left to the evening hours and weekends.

Let me now present the mindset and motivation that will give you the knowledge and ability to put all the pieces together. My wife and I were told many times by professionals, "oh you are great parents, I wish all parents were like you." I would not say that we were "great" parents going through this process, just parents who knew that we had one chance that God has given us to make a difference, one chance not to make any mistakes, and only one opportunity to give our daughter the precious gift of speech. I knew in my heart that I would NEVER look back and say to myself that I wish that I did something different. It had to be right the first time and every time. Time was too valuable to even make one mistake that could jeopardize our goals. Have the mindset that "I will find out everything possible about

this process, I will not let anything stand in my way, I will get my child on the right track to learn spoken language, I will do whatever is needed every day at home to help my child hear and speak.”

1) Being a parent with a newly diagnosed infant it may seem odd that the first thing I will say is to have a long-term game plan and a set of procedures to follow. Do not guess at things, do not go down the wrong path, do not get caught up in the various opinions that people will tell you. Just have a well worked out plan and move forward to put everything into place. I have written this road map of all the pieces that need to be in place to help young orally educated children learn language and audition. This step-by-step procedure can be found on this website under the link “How to Obtain the Absolute Best Medical Outcomes for Children Using Oral Education.” Read the document, follow what it says, and know that this is everything that my family has done to obtain great success with our daughter. If you want to check the validity of this document, give it to three different professionals and then let them tell you their opinion of it.

2) Build a reference library of essential books, and read every day. In my opinion the educational process should follow this format: first, learn everything you possibly can about your medical insurance plan. Do not say, “My daughter is deaf. Is XYZ covered?” Request your “Plan Summary” or “Benefits of Coverage” document. This document is the formal contract between you and the insurance company; it states precisely what is covered and what is not. Read the pertinent information regarding your son or daughter. I hate to say this; you do not want to get a track record started in an insurance company’s computer system where they would view you as a long-term financial risk. Do not give these people any opportunity to drop your coverage.

After you feel comfortable with the medical insurance side of things, read everything possible on the IDEA law and the special education services for your particular state. Simultaneously to this, contact the special education department or Early Start programs in your state to obtain services for your child.

Talk to numerous people and read everything possible on the oral education process. Like an arrow shot straight toward a bull’s-eye, know what you want in the oral process and go straight for it.

3) Start to build a remarkable and rewarding relationship with every professional you work with, Be courteous, easy to get along with, thankful, appreciative, and do whatever is needed to keep the professional happy and on your side. You are the collector of needed information, medical reports, hearing tests, IDEA documents, and educational documents. Make sure that every professional has copies of the needed information to do their job more effectively.

4) From infancy forward provide auditorily challenging toys to your child that will enhance their audition. Provide proper DVDs and CDs to help your child “hear.” Play with your child and love them like they are the most precious thing on this earth, because they are.

5) Go to every therapy session you possibly can. The format in our case was about two sessions per week in the beginning, then three sessions, and then four sessions per week. In reality the beginning therapy sessions are the most important, as time goes on you may end up going to fewer. Watch what the therapist does. Ask yourself what you can do at home to enhance your child’s audition and spoken language that coincides with those particular therapy sessions.

Be in synchronicity with the speech therapist; buy the AusPlan book, which explains in detail how natural language is acquired. This book will also let you know if your child is making sufficient progress in speech, language, and audition goals six months out, twelve months out, twenty-four months out, etc. (Buy this book from Children’s Hospital Oakland’s Audiology department. Call 510-428-3885.)

6) Learn all of the terminology of language (chapter 5 in “A Father’s Love), and let the therapist know what is happening at home and be able to hold a substantive conversation with the therapist. Once you know how language is acquired and where your child is on the speech, language, and audition hierarchies there are numerous things that can be done at home to help.

7) You will learn through attending numerous therapy sessions that there are plenty of tasks that can be done at home to help your young child, such as: point out every sound, i.e., the phone rings and you say “I hear that, that is the phone” and point to your ear. If she is eating, say “You are eating apples,” etc. Everything, all the time, narrate what your child is doing and what they are playing with. “You are playing with Elmo. Elmo is red.” Narrate what you are doing. “Look, Mommy is cooking. I take the pan and put it on the stove...” Repeat the words dozens and dozens of times throughout the day. Whether it be the phone, door, birds, car, vacuum cleaner. Whatever the sound is, point to your ear and say “I hear that, that is the _____.”

Explore the world outside every weekend. Go to the store, the park, the zoo, building vocabulary and letting your child see the actual object or item while you name it. Keep in mind that children need to learn to listen before they can speak. This goes back to proper therapy. A lot of time needs to be spent on listening before they can graduate to spoken language. Do not go too fast or explain things in a complex manner. Work at the level your child is at.

8) Keep names simple, one name for each item. Many items have numerous synonyms, but choose one name for each item. Stick with it until they fully understand that name. (A pair of shoes is SHOES, not sandals, boots, slippers, tennis shoes, etc. They are all shoes for the first six months. Same with plates, cups, etc.) Make a list of 40 - 50 items and write down one name for each item and have the entire family use this one name. Hand a copy of this list to your therapist. As time progresses and your child understands more, you can move on to the next synonym.

8) Do not take “NO” as the final answer, go to the top. What this means is since you are the motivated and well-educated parent, you will and should exhaust every effort possible to get what your child needs. If a procedure is not covered, have the insurance company show you in writing where it is not covered. If services are not granted, then find out specifically why and make an argument why those services are crucial to the success of your child. A well-drafted letter with strong points can bring great rewards if written correctly and put into the hands of the right person.

9) Find out from at least three professionals what is right. It is your job to continually become more and more educated on every aspect and procedure that will affect your child’s success. With this said, talk to numerous professionals and parents about whatever question you may have, roll it around in your mind for a few days and since you are already well-educated on the process go off your gut feeling and do what is right. I have seen too many mistakes made by parents who listen to one opinion, move forward, and do not search for additional answers.

10) The IDEA law and the IFSP / IEP process are the backbone of every service and educational program that your child will be involved in. With this said, it is vitally important that as a parent and advocate you understand all aspects of this law and the procedural aspects of the IFSP / IEP process. Talk to lawyers, read books, go to conferences and understand your rights as a parent. Become well versed in these topics and you will be in control of your child’s destiny.

When going to an IFSP / IEP meeting know what you want from that particular meeting. Have professionals on your side and have a well thought out explanation for every point you are trying to make. Do not sit back and attend these meetings as a “spectator.” You and your child are the primary

focus. These meetings are the one and only chance you will have to obtain the services that your child deserves. Be prepared.

11) Understand how cochlear implants and hearing aids work. Talk to the manufacturing companies, talk to your audiologist, and read the owners' manuals for these devices. Since these high tech programmable devices help your child hear, it is vitally important to be knowledgeable and to be able to hold a substantive conversation about the functionality, problems, care, and maintenance of these devices. You should also understand the hearing thresholds and the audiogram to convey this information to all parties concerned.

In addition to this, attend as many conferences as possible. Most conferences are supported by the major manufacturing companies and this is a great opportunity to discuss any problems or concerns with a factory rep who works for the company you have chosen, i.e.: Cochlear, Advanced Bionics, Med El, Widex, etc.

12) Do not make mistakes that will cost precious time. Going through this process I had two thoughts in my head: I needed to provide everything possible that my daughter needed to succeed at oral language, and I could not make any mistakes. Each and every mistake costs precious time. This is why my wife and I consulted with numerous professionals, read everything possible on a particular subject, and obtained one of the best books written on language development. We did this so we would be involved, be active members of this process and be knowledgeable to make changes to a particular program or recommendation if needed.

This concludes what I feel is essential to becoming a "motivated" parent. By putting everything you have into this process for the next three to five years you will feel a sense of accomplishment which is unmatched by anything else you will ever achieve in your life. I look back on the effort, the ups and downs and the commitment that I and my family put into this process, and to this day, there is no bigger achievement, no bigger accomplishment, nothing that I could be prouder of than the ability to give my one and only daughter the precious gift of speech and hearing. There is no business success or personal success that could ever compare to the accomplishments I feel when I hear my beautiful daughter speak.

To look back now five years later and think of myself as "an expert in providing speech and language to deaf children" is amazing. This process of becoming an "expert" just fell in my lap based on necessity. Yes, the word "expert" is pretty strong and yes, I am just a parent, but with the tools and books listed on this website it will provide everything needed to help a deaf child or hard of hearing child graduate to excellent spoken language. I never imagined that teaching deaf children to speak and oral education would ever be part of my life, until we were told our little one was deaf. At that point I knew it was the most important part of my life.

Take this document and the other educational material provided on this website, absorb it, think about it, but most importantly, act upon it.

Good luck.

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