



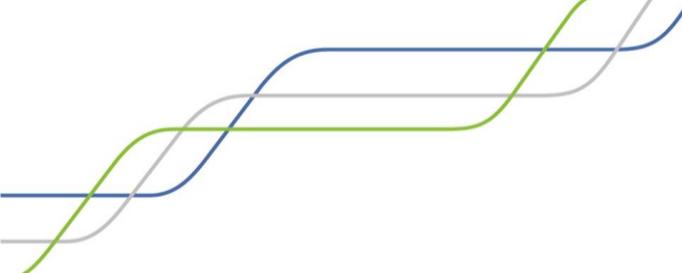
Center on Technology and Disability
www.CTDinstitute.org

Uncommon Communication Challenges Require Uncommon Sense

Re-published with permission from
Family Center on Technology and Disability
Technology Voices – September 2012



**Family Center
on Technology
and Disability**



Uncommon Communication Challenges Require Uncommon Sense

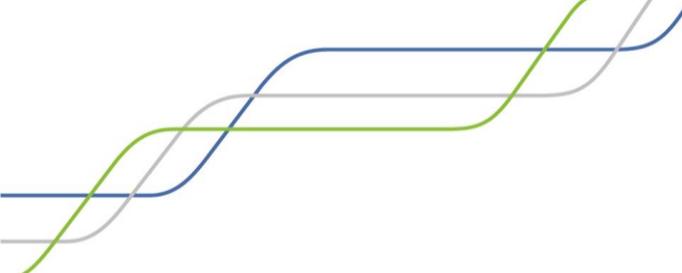
*An Interview with Dana Nieder of New York City,
parent of Maya, blogger and former teacher.*

The Mars Rover, with its mission to explore and help others understand an uncharted territory by collecting, analyzing and disseminating its findings, has nothing on Dana Nieder. Ms. Nieder, a former teacher, tends to the personal and education needs of four-year-old Maya while awaiting a diagnosis that would explain Maya's lack of vocal capability. Two years ago Ms. Nieder found herself in a similar position to the Rover: a stranger in a strange land where every foot of terrain overflows with new information, that must be sifted through and understood on the fly. Her journey has meaning for every parent of a child with a disability as they face a new school year, some receiving their first exposure to the world of special education, assistive technology (AT), and Individualized Education Programs (IEPs).



For Ms. Nieder, the first round of information gathering was aimed at defining Maya's disability, which takes the form of global developmental delays, especially an inability to vocalize. The first signs of Maya's developmental delays were not noticeable until she was between six and nine months old. Still undergoing extensive testing, so far to no firm result, Maya has a normal brain MRI, karyotype, FISH (fluorescence in situ hybridization) and microarray. She has experienced two surgeries during which her adenoids were removed and ear tubes were inserted. According to Ms. Nieder, "Maya's hearing raises questions – in behavioral testing she appears to hear normally, which contradicts a sedated auditory brainstem response (ABR) showing mild-to-moderate hearing loss."

Recently, Ms. Nieder explains, a gene mutation was found during genome sequencing that may be the source of the delays. At least six months of testing lie ahead before those findings are confirmed or discounted. In the meantime, she points out, it's time for another school year, Maya's last at her current school – a therapeutic two-year nursery



school -- before she must move on to a kindergarten environment and a new set of challenges.

Although Maya can speak only one or two words, she communicates through signs, gestures, sounds, communication boards and, increasingly, via an iPad app that allows her to construct complete sentences.

“I Was Totally Lost”

If medical information gathering has so far produced murky and inclusive results, the family's experience in assembling information to launch and navigate the earliest stages of Maya's education, including a quest for the most appropriate communication devices, has been far more rewarding, if equally stressful. Their initial experience with the school system and its myriad requirements and procedures, meetings and paperwork, was daunting. It was, unfortunately, an experience familiar to thousands of families of children with disabilities. Ms. Nieder says that she thought often of the families of the students she had taught in Baltimore and New York City. “So many were recent immigrants who spoke little or no English and here I was, a former educator, totally lost.”

Her initial exposure to AT occurred in January 2011 when Maya was nearly three years old. “I had never heard of assistive technology or augmentative communication. When I was discussing Maya's communication struggles, the leader of my support group referred me to Mark Surabian, an AT practitioner who is an instructor at Pace University's School of Education in Manhattan in the hope that he could enlighten me on communication issues and technology.” Mr. Surabian was able to direct Ms. Nieder to several researchers who had published material that might apply to Maya's need for augmentative communication.

That was the good news. The bad news, she recalls, “was that I located several speech therapists but none was an authority on AAC (augmentative and alternative communication).” This was, and continues to be, a surprise to her. “I live in New York City and I've yet to find a speech-language pathologist who specializes in AAC, who could guide us through the process of selecting appropriate AAC for Maya, and then could support us as we learn to use the device and incorporate it at home and school.” Last fall, however, Maya received an AT evaluation under the auspices of the New York City Department of Education. “At that point we'd been experimenting with Proloquo2go

<http://www.assistiveware.com/product/proloquo2go>). I brought that app to the evaluation to demonstrate that Maya was able to navigate through the folders. I'd researched communication devices and knew which ones I wanted her to experiment with to see which worked best for her."

Nevertheless, she continues, "I was told by the NYC DOE officials at the eval that Maya was not yet ready for a dynamic device. They said she was only ready for the 32-word/symbol set, in which she touches a symbol and says the word. I disagreed. I thought she was ready. For pre-schoolers, however, the official mindset appears to remain fixated on simple, static devices. During the evaluation, the evaluator,



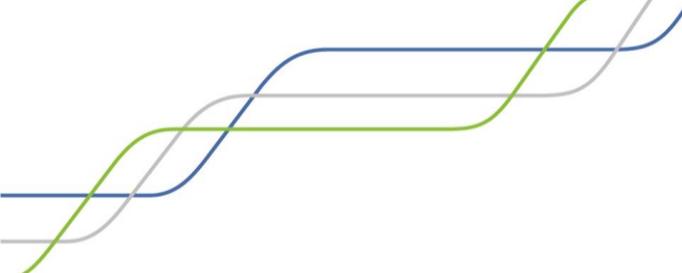
although very nice, was just not hearing what I was trying to explain. She said, 'I give this device to children when I meet with them in the evaluation. I sit the children down and show them where colors and verbs are and they then demonstrate to me that they can make sentences. If they're successful, this is the device for them to use.' My response was, 'That's never going to happen with a three-year-old. You can't do that in two hours. If she can handle a 32- symbol set at this meeting she'll need something bigger to grow into and last the school year. Finally, I just said to the official, 'Thanks, let's put that on the IEP' and I decided to figure out the rest myself. And that's what I've done, by trial and error, research and exploration."

The device finally approved for Maya (<http://www.enablemart.com/tech-speak>) holds 32 words. Her current device however, is her iPad with AMDi iAdapter iPad cover and Speak for Yourself app, which currently provides constant access to 496 words "and she can, and frequently does, turn on the 'babble' function which opens up all of the words (around 11,000)." Clearly, Ms. Nieder asserts, Maya was ready for more than 32 words.

"Imagine being a child like Maya sitting down in a classroom and having someone else choose the words that you were able to say – and there are only 32 words. How frustrating, and kind of insulting, that would be if you were capable of using more than the allotted words. Although this device is appropriate for some children, it's inappropriate for Maya."

The AMDi iAdapter iPad cover, she says, "is the best case that I've seen for a young child who is using the iPad as a communication device. We have a plastic keyguard for the app, attached to the





case with Velcro. Prior to the keyguard, we were using a made-at-home glove to prevent Maya from accidentally hitting the wrong buttons with her knuckles, which was impeding her ability to start effectively communicating with the iPad.” Maya began working with the app in January of 2012 when she was three years, seven months old.

This fall Ms. Nieder will meet again with the NYC DOE AT evaluators for a reappraisal. “I’ll tell them, ‘This is the device we are using and I want to add it to the IEP, and now I have plenty of video to support my desire.’”

Assessments: An Often Unwieldy Means to an End

On the whole, she remarks, her opinion of the school system’s assessment process is not high. “Frankly, it hasn’t proven to be very useful -- yet.”

Admittedly, she concedes, “Maya is very difficult to assess, mainly because she is unable to vocalize, which makes many of the assessment questions irrelevant. I know parents who have been devastated by assessments because the results can appear to be very dire on paper and because assessments are often incapable of effectively evaluating children when the kids either can’t communicate or they are incapable of performing basic physical functions, such as independent walking. The result is that the assessment ends at the bottom of the first page of the PT [physical therapy] assessment.”

She regards assessments as necessary and blames her science background for her occasional low opinion of them. “My science training compels me to gravitate toward the flaws in any information gathering process, including assessments. To me assessments are just a means to an end. I know Maya needs therapy. Even if an assessment says she’s at a six-month level I know what she’s really capable of. I don’t let the process upset me.”



From a teacher’s perspective, she says, “the assessments provide only so much information, which is often very outdated by the time a teacher sees it. For example, Maya’s assessments were done in November before she started pre-school the following September. That’s a huge time span. Many teachers have similarly outdated assessment information about many of the special needs students in their classes. I can’t imagine that information that outdated could be very helpful when trying to plan for your class before the year starts.”

Maya's IEP? No Sweat. Getting After-School Services? A Challenge

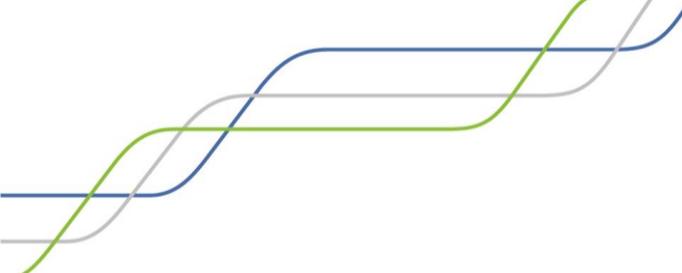
According to Ms. Nieder, Maya obtained an IEP before she began her two-year pre-school. "Surprisingly, the IEP wasn't our major challenge. Our focus was making sure she got into a good pre-school, which she did, thankfully – and then obtaining the after-school services I thought she needed."

Ms. Nieder began the IEP process with some apprehension. "The members of my support group – other moms with kids who have disabilities – cautioned that the content of an IEP is dependent on the personality of the school district official who is sitting in front of you on any given day." Initially, she said, "this was frustrating for us. Last year we were told, 'You can have the special school for your child but nothing else.' I could live with that at that stage because Maya was so



young. She was accustomed to taking a two-hour nap each day – but the school doesn't nap. She doesn't sleep on the bus so she would arrive home exhausted. I decided not to jeopardize her place at the school for services that she might be too tired to fully utilize." Ms. Nieder will meet soon with a different NYC DOE official "who we were randomly assigned to this year and who happens to be very considerate. When I first met with her she said, 'I see you want to add services. We just have to complete a few forms and evaluations and then we can meet again soon to make the appropriate arrangements.' We're lucky in this round but luck should not be a determining factor in this process, which becomes more complicated because Maya still doesn't have a diagnosis."

The Nieders had an Individualized Family Services Plan (IFSP) for early intervention before an IEP was obtained for Maya. "Our IFSP process was good. Maya was nine months old when the process began. At IFSP meetings we were told that Maya was allowed certain therapies. That was fine with me and my husband. A year later it was time to revisit the IFSP. I brought Maya with me to the meeting. I was unaware that it was not the norm to bring your child to these official meetings. I had a day off from work but no babysitter so I brought her. Fortunately, the official who was supervising the meeting had her eyes on Maya, and after watching her said to me, 'You should have more services than you've had.' My response was, 'How am I supposed to know that?' She asked if we needed any special instruction but I didn't even know what special instruction was. This exchange shows why the process is often an enigma to parents."



Parent to Teacher Back-to-School Information Flow

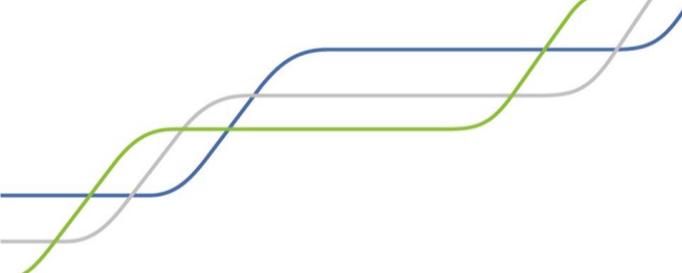
Each school year brings with it elements of newness, but when children with impairments enter a new school or a new phase of their education everything is truly new. Parents often find themselves with questions for which there are no easy answers, such as, 'What information ought to be conveyed to teachers about my child?' and 'Should that information be conveyed before the onset of the school year or after the school year begins?'

Says Ms. Nieder, "When I was teaching I had 140-150 students in a general education environment. I would have been swamped if every parent had called me before school and started to talk about their child, whether or not the child had special needs. Speaking as a parent of a child with special needs, however, I definitely want to communicate with my daughter's teacher before the school year begins."

This desire is especially pronounced among parents of non-verbal children, she notes. "Otherwise, without that parent-teacher orientation, the first day of school is too scary because a parent has no idea what will happen. To make a difficult situation even more difficult, some children, depending on their impairments, may not be able to tell their parents anything after the school day. This is especially true for a very young child. Maya is starting to use her talker to tell me some details about her day at school, but she's four years old, so who knows what really happened in school because I can't vouch for the accuracy of Maya's report."

Before the school year began last year – and again this year – Ms. Nieder provided much information to Maya's teacher. "I sent a booklet about her and about the signs she uses. I made a video dictionary of her signs. One of my major concerns on the first day of school was the sign she used for water, pushing her open hand against her cheek. The thirstier she is the more pronounced that motion becomes; I didn't want her teacher or school officials to think that she was hitting herself so I created a translation guide to help her teacher interpret Maya's sounds and gestures.

"Maya is very stubborn so I included a few tips on how we deal at home with her stubbornness. I included my email address, the URL for my blog and other contact information. I created another booklet providing information on how to use Maya's talker,



how to add words and how to turn it off if it's not working and other essential operational information.

“It can sometimes be touchy for a teacher to deal with a parent who is a former teacher. I want to be as helpful as possible without stepping on any toes or appearing too aggressive or demanding or obnoxious in any way. Each section of each booklet or information piece I prepared was prefaced by an explanation that the information contained therein had proven to be effective for us but also that we are happy to hear any teacher input about what other approaches might prove to be effective as well. It's important for parents to communicate with teachers but once a school is selected that school needs the space to fulfill its responsibilities without being micromanaged by parents.”

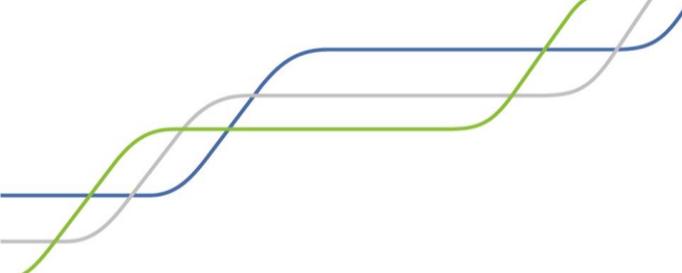


In short, she explains, “Information concerning the child's favorite color and her favorite subjects, for example, should be delivered to the teacher and school in the child's backpack after school begins. Other more pressing issues, like how parents communicate with their child and safety issues, should be addressed with the teacher before the start of the school year.”

Speaking as both a former teacher and as a parent, Ms. Nieder encourages teachers to seek useful information from family members. “The parents are most familiar with the child. If I am a teacher who for the first time has students with a range of disabilities in her class I would want to quickly contact the parents of those children. I'd ask about how the child's previous teacher resolved specific situations. I'd want to know how that teacher made a textbook more accessible. I'd ask about modifications that have been effective at home that might also be effective in a classroom environment.” That type of information, stresses Ms. Neider, helps teachers meet the education and skill goals of each child.

Home-School Communication: “Everyone Should Have Reasonable Expectations”

After school begins Ms. Nieder recommends that a balance be struck between parents' desire to communicate with teachers and the teachers' heavy communication responsibilities. “We were so lucky this past year because Maya was in a tiny class and the



teacher was excellent. Her teacher wrote in Maya's communication notebook four times a week. She responded to emails quickly and thoroughly. As a result, the communication flow was easy from both directions. Maya had a different teacher for summer school and the communication flow was more constricted."

Maya's class has increased to 8 students this year, Ms. Nieder explains, and she's concerned about how difficult the transition may be for Maya. "The class is more advanced and the teacher will have more on her plate because there are not as many aides in the room. Maybe my husband and I will make a chart to tape to Maya's notebook every day, a checklist, or some other method to enhance the parent-teacher communication flow. We certainly understand the burden on the teacher to try to communicate with everyone, but our child can't talk so teacher-parent communication in certain areas is critical. For example, if Maya experiences a normal day at school we don't need to know the details, but we do want to know if she used her device or was able to communicate in another way."

Remembering that what's best for the child is also best for parents and teachers, she says, eliminates or at least reduces the potential for an adversarial relationship between families and school personnel. The objective, she emphasizes, "is to help streamline the relationship and the flow of communication so that teachers feel as if their communication responsibilities are manageable and that parents can acquire enough information to support the teacher at home."

Dana's Favorite Tech Tools

Having spent several years investigating AAC options for Maya, Ms. Nieder knows, at this point, what she likes. She shares her family's experience with a number of communication devices and apps (applications) on her blog Uncommon Sense.

Initially Maya tried Proloquo2Go on an iPad before moving on to other tools, including Boardmaker (<http://atclassroom.blogspot.com/2008/12/boardmaker-and-other-picture-symbol.html>). In chronicling her experience with Boardmaker, Ms. Nieder has posted photos of some of the boards she created. She felt it was important to mimic the format of the boards that Maya's teachers used in school. She also created theme-specific boards for use on class field trips. In a blog post about the "Word Book" Ms. Nieder created for Maya, she provides step-by-step instructions along with photos, that describe

how she made the book using the Boardmaker program, a laminator, a 3- ring binder, and Velcro (<http://niederfamily.blogspot.com/2011/10/introducing-word-book-or-how-to-make.html>).

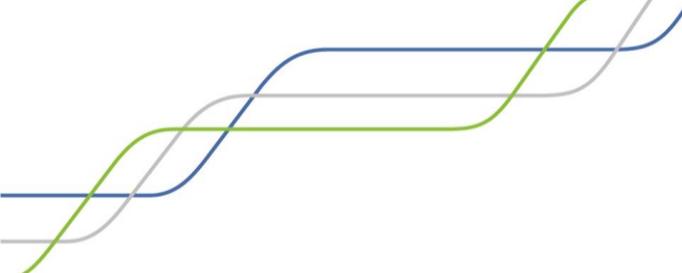
Ultimately, the AT tool that worked best for Maya was an iPad AAC app called Speak for Yourself. To adapt the tablet for the hands of a then-3 year old with fine motor limitations, the Neiders purchased an AMDi iAdapter (a protective case) and a plastic keyguard. In her January 9, 2012 post, Ms. Neider describes why Speak for Yourself works so well for Maya

(<http://niederfamily.blogspot.com/2012/01/search-is-over-weve-found-our.html>). Among the reasons are the program's core word organization, its ease in programming, and the stable navigation system. Readers of Uncommon Sense are treated to regular video updates of Maya's progress in communicating increasingly complex sentences with the device.



To bolster her own research Ms. Nieder attended the 2012 ISSAC (International Society for Alternative and Augmentative Communication) conference and came away agog. “I saw all sorts of devices, like wheelchair mounts, eye-gaze technology, switches and other gadgets that I don't know much about but which appeared to be very cool. I was surprised by the accessory devices that aren't very technical. For example a company produced bracelets with the AAC symbols for 'eat', 'drink' and 'bathroom'. That was clever. I saw various iPad stands that I'd never seen before in mainstream use.

“Each time I spied an intriguing gadget I asked myself, Why haven't I heard of this device before? There are many parents who would want to know about these devices. Even a list of the manufacturers participating in the conference would be helpful to parents if the company URLs were supplied so that parents could easily access those sites. But when I'd visit a company's booth I was asked, 'Are you a speech therapist?' No, I'd reply. Then I was asked, 'Do you work in a school?' No again. I'm just a parent. The company reps were very nice. They'd give me a catalogue. I'd ask, 'Do you sell privately?' They replied, 'Normally, we don't – but we're happy to sell to anyone; private orders can be placed.' I asked, 'How do parents find your company?' Through the school systems, I was told. If there's no storefront for these devices, if parents only recognize the four most popular iPad cases, for example, and they don't know that this company also makes a range of



disability-related educational products then parents will never make the connection and selling opportunities will be lost as well as opportunities for parents and children to acquire very useful but less mainstream equipment. It should not be so difficult to find these devices.”

In a marketplace where technology proliferates, she comments, “It’s difficult for parents on their own to know where to look for the most appropriate devices. I’m not a novice at Internet research. I know how to google and find what I need to find when I need to find it. But it’s often difficult to figure out where to go. It’s also time- and energy- consuming when I have many other child-related responsibilities.”

A Parent Sums Up: “There Must Be a Balance”

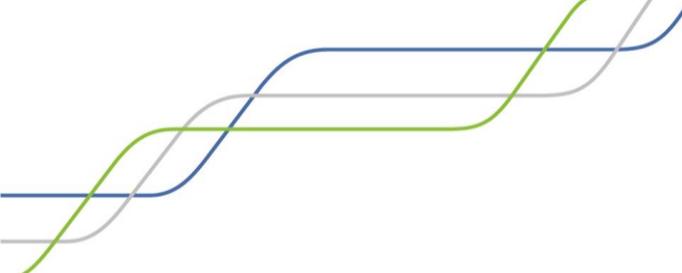
Thinking of parents setting out on the journey in which she has become immersed, Ms. Nieder says, “It is very easy to become overwhelmed by it all. I asked myself thousands of times in exasperation, ‘How am I supposed to figure this out?’ There are 400 iPad apps to sort through and 20 kinds of speech therapy. What’s the most appropriate? It’s a daunting way to begin what can be, and often is, a precarious journey along a rock-strewn path.”



Her message to parents for whom this adventure is brand new is the following: “Everything you are doing right now is more productive and easier than what you were doing earlier in the journey because of the knowledge that has somehow been acquired along the way. In other words, do not hold yourself to a ridiculous standard or think, ‘I won’t be able to do this.’”

She has more advice: “Parents should be aware that sometimes it’s fine to do nothing too! Parents do not have to be in a state of constant frenzy. I know there are some parents who believe they can’t do anything because everything is so overwhelming. And other parents throw themselves into doing everything, causing perpetual anxiety. There has to be a balance.”

She says that friends and other parents often tell her, “You’re always doing something and I’m not – and you’re blogging about it.” Her response is, “I don’t blog about the nights I’m watching TV! “ After all, she says, “I’m not doing this 24/7. There are moments, sometimes many moments, where I am actually sitting quietly, doing little or nothing.”



However, she admits, “I feel better when I’m busy pushing ahead. I want to feel as if I have some control over this process. If a parent feels more productive and more abreast of the process by staying busy then by all means keep busy. On the other hand, if a parent has reached the point where she says to herself, ‘I can’t do this; I’m burning out. I need to just be a mom.’ Then be a mom. Most of us have periods of both, including me and my husband. For months I’ll keep a feverish pace, and then I come to a stop because I know I need a break.”

For now, Ms. Nieder is able to research speech and AAC issues primarily while Maya is at school. By October, however, she is scheduled to give birth to a son. “After that,” she laughs, “all bets are off!”

