

Communicating with Dylan - [A compilation of posts on the Communication Matrix Community Online Forum](#)

Jan 4, 2016

### **The Joy of Communicating**

I knew my son was Deaf at 5 days of age. I also knew he had blind spots in his eyes called colobomas, but he clearly saw something. Not yet knowing about deafblindness and the impact of the combined loss, our focus was on his hearing loss. How were we going to communicate with our son? How were we going to know what he wanted, what he felt, what he thought? How was he going to know us? I couldn't imagine how to do that without language. Feeling it would be easier for us to learn American Sign Language than for Dylan to learn spoken English, we jumped into ASL classes when he was only 3 months old. Desperate to make up for the time he didn't hear our voices in utero, I couldn't wait to share this visual language with Dylan. As time passed though, the significance of Dylan's vision loss and vision processing became clear to me, as Dylan did not sign back to us.

Now Dylan is 19 and is still what the professionals call an emergent communicator, a person who communicates without formal language. In spite of this, we have a rich, full, meaningful relationship that I would not have thought possible without language all those years ago.

Why? How do we communicate without words? How do we talk about the past, the present, and the future? How does Dylan learn new concepts? How does he express his preference?

As I moderate over the next month, I'll share more of what's worked for Dylan and would love to learn what's worked for you in sharing communication with someone who is an early communicator.

Kim



Image Description: Dylan is sitting next to me in his fancy clothes, a smile on his face, and his hand resting on mine, the wedding guests in the distance, as we co-sign a toast we have co-drawn for his brother and his bride. That is the joy of communicating.

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January 7, 2016

**The danger in doing the right things, while measuring the wrong thing.**

Have you ever felt like you were doing everything you possibly could to help your child or student communicate, and yet felt frustrated by the slowness of their language development? Have you ever felt like you weren't doing enough to help your child or student communicate?

I think at times, everyone on Dylan's team - including me - has felt both of these emotions; frustration with his lack of progress and self-doubt or self-blame. Clearly my son, Dylan, was a skilled communicator with those who knew him and what his body actions, patterns, and nuances meant. But naming things, initiating signs, and expressing choice were far more challenging, in spite of the team's focus on these very areas in each of his IEPs and related educational interventions.

When Dylan was 10, we completed the Communication Matrix for the first time. Ah ha, I thought. Perhaps we have been doing the right things, but measuring the wrong things. His Matrix showed mastery through Level 3, reflecting his skill as an unconventional communicator. When looking at his IEP goals, it was clear they were all focused at Level 7, Language. The mismatch was clear for us all to see. Yet, it also showed the vast array of language development skills in the levels between Unconventional Communication and Formal Language, with each providing an opportunity to support Dylan's expertise as a communicator.

Over the next nine years, the Communication Matrix has been our guide. It's shown progress, regression, and further progress, yet with each update, it has given us the opportunity to acknowledge and celebrate Dylan's communicative strengths and our successes in supporting his language development. These updates have also shown where Dylan can use more support and where we've been off track with our interactions, interventions, or expressive language goals, and helped us redirect our efforts.

Dylan's story is not unique, particularly for those who are Deafblind. As natural as it is to focus on formal language as our communication goals, it is easy for all to be frustrated when these goals are not met year after year. Why is the student not meeting their language goals? Are the interventions appropriate for the student's level, but the goals not? By using the Communication Matrix, teams can identify what level the child is communicating at, and explore where they can best target their supports, and measure progress. In this way, progress towards formal language is more likely to be seen and celebrated along the way, which is far more fun and rewarding for all.

January 13, 2016

### **Imitation or initiation of language**

I was talking with Dylan's Intervener this week about the Communication Matrix and how initiation is such a key aspect of expressive communication. We've found it to be so easy to get in the trap of counting all of Dylan's signed words as "language"—level 7 on the Matrix—but when we step back we find these signs are often imitations, even delayed imitations of something we had signed quite a bit earlier. Using the matrix helps us recognize when Dylan has moved from imitation to initiation with any of his forms of communication, although this post will primarily focus on the imitation or initiation of formal signs or words.

Now I'm not saying imitation is bad, it is an important, essential step in language development, and when Dylan finally got to the point where he was imitating anything and everything around him we (his school team) were ecstatic.

You see, for many years Dylan initiated topics by his actions, such as looking at light through a Dasani water bottle. To share in this topic with him, we would get a water bottle and move it and look through it the same way Dylan did. As time went on, we could make a change and he would follow us. But this new "monkey see, monkey do" stage of imitation was exciting because it showed the shift in his attention to what we were doing. My attention would be directed elsewhere, then I would notice Dylan looking at me and sitting in my exact position, including attempting to match my facial expression, and even my signs. As I moved, he moved. His gaze and imitation of me, invited me to "talk" with him through imitation games and copying fingerspelling and signs (American Sign Language.) The shared attention and reciprocity was, and is, fun and gives us the ability to share in "conversation" and relationship about topics that are present in the here and now.

Now Dylan can sign many words that he's learned through imitation. The trick is in the evaluation of his expressive language as he uses those signs. Is he answering a question, such as "more" or "finished" or modeling my signing of those words? Is he imitating my signing of a word, such as planetarium, without understanding what a planetarium is, or does he connect the sign for planetarium with the concept of planetarium? This connection of sign and concept is what allows Dylan to initiate the use of signs to introduce a topic, and allows us to "talk" about things that are not in the here and now.

Take the phrase, "want different movie." In attempting to help Dylan learn language, we paired a sign language model with his body movements that indicated he wanted help changing his VHS movies. Through imitation, he learned to sign, "want different movie," a three-word phrase. Then came the day shortly after when we were in the community doing something that Dylan didn't want to do, and he signed, "want-different-movie." Apparently to Dylan the phrase meant, "I want something different" and had nothing to do with movies. Many, many years later, Dylan can now get our

attention through vocalizing or hand motions, sign “want different movie” and point to the TV, clearly communicating, “I want a different movie.” (And yes, some days he even changes it himself, but that’s a different story.)

It’s important to remember that imitation is the model for formal language and provides a way to expand expressive communicative intent and interaction in the here and now, where as initiation allows the active use of communication in an ever changing, dynamic world. When the student is at the level of imitating signs, the adult is most often determining the topic of conversation. At the initiation level, the student has the ability to gain a communication partner’s attention and direct the partner’s attention to his or her own desired topics.

At 19, Dylan is just now beginning to initiate signs, such as ball to request a familiar item that wasn’t in it’s typical place, a person’s sign name as he gets ready to open the door to go see her, want finished as he was being offered an opportunity for more swinging. These initiations of signed words allow Dylan to let us know what or whom he is thinking about, so we can now talk about things that are not in the immediate here and now.

Through each stage we’ve moved from Dylan initiating at one level, and us modeling the next. Then he’d make the jump to initiating at that level and we would imitate the next. At each level relationship and reciprocity has been our focus, allowing us to enjoy each step along the way. And yes, when Dylan got up on his knees, reached his arm towards his Intervener, and signed ball, to ask her to go and get the ball from the other room, we celebrated the new level of control this new form of communication provides him, just as we’d celebrated each jump along the way.



#### Image Description

10-year old Dylan is lying on his back holding a new soccer ball. Roy, Dylan's Dad, is leaning over him signing ball as Dylan look looks intently on. With a hand on each side of the ball, Dylan's hands perfectly match his father's hands.

I'm sorry to say I don't have a photo of the moment, ten years later when Dylan first initiated a request for a ball.

January 15, 2016

### **From choice to voice**

Dylan's expressive language development has been a slow process filled with lots of patience and consistency, before suddenly a new way of communicating would emerge, sometimes even many years later. Can you relate?

One example is the use of Dylan's picture symbols. Dylan has receptively understood key symbols for years and they have been very effective as part of his anticipation calendar. Since his earliest IEP's, a routine has been incorporated into his calendar routine that allows for choice making, yet Dylan did not point to or hand us a symbol to express his choice. He did push away the symbol he did not want. (Yes, the Communication Matrix clearly shows that expression of refusal comes before expression of want.)

Then one day at home, when a choice was offered, he nonchalantly reached out, took the symbol he wanted and handed it to his Intervener. With our mouths hitting the floor, we quickly honored that choice, as we wondered if today was a fluke or if he would do it again. Over the next week it became clear that Dylan had made the jump. He was now consistently choosing the symbol he did want. We asked ourselves, what are we doing differently that he is now expressing his preferred choice? Is there something we could have done earlier that would have helped him make the jump sooner?

The only answer I can come up with is control. Many of you may be familiar with the adage, follow the child. At 17, an educational program was set up for Dylan with following Dylan's interests at the center. Our curriculum was created around his primary interest - Dasani water bottles. We incorporated the receptive modes of communication that were working for him, picture symbols, co-drawn symbols, visual American Sign Language, co-sign, and co-drawing, into our interactions. We set up the environment to maximize his vision and meet his sensory needs, established routines, and continued use of deafblind principles and practices that are essential for Dylan's learning.

Yes, we started with his likes, but our responses were dependent on what Dylan's body communicated was working for him and what wasn't. As we adapted an activity, or continued a theme, or accepted Dylan's need to lie down for continued productivity, based on these subtle communications, I believe Dylan learned that he did have a choice. Then came the day at home—where the communication routine had not been changed—when Dylan started using symbols to tell us what he wanted to do in his free time.

Everything we'd been doing at home and school before the new program had been effective communication strategies - we still use these strategies. Yet it appears that for Dylan, the increased opportunities for him to experience all levels of his communication being responded to, and the corresponding sense of perceived control gained from this,

have led to Dylan beginning to initiate the use of his voice in the world, in new and exciting ways.

In the next posts, I will talk more about Dylan's communication through co-signing, co-writing, and co-drawing and how those shared experiences, along with Dylan's new found self-determination, have helped expand Dylan's ability to communicate about the past, the present, and the future, and to explore new topics.

#### Description of Dylan's portable communication system

We found a blue plastic card to provide good contrast and to be sturdy enough for lots of use. The back has Velcro for attaching 2 or 3 symbols for Dylan to choose from. Once he has selected a symbol the card is turned over and Dylan adds the cue to the sentence strip on the front. The sentence consists of cues that depict how Dylan is traveling (Brown Truck), where he is going (his choice) and who is going with him (Deb and Mom.) A later version has symbols for first, second, and third. Underneath is Velcro for Dylan to place 3 symbols. For example it might say 1<sup>st</sup> horseback riding, 2<sup>nd</sup> park, 3<sup>rd</sup> home.

#### Image Descriptions

In the first photo Dylan's hand is posed over the sentence strip ready to pick. In the second he is pulling his hat down on his head with two hands - each also holding one of his favorite water bottles.



January 19, 2016

### **Tactile sign language to support visual sign language**

I remember the first time I felt Dylan's hands on mine as I signed to him, and how quickly his attention shifted to that signing and my face. He was three years old, and we were walking down the path outside of his preschool. At last there was shared attention with which to foster relationship and communication. I can't tell you the joy I felt in that moment.

We had been modeling visual sign language since Dylan was only a few months old, but he was not initiating signs on his own, or even copying our signs. I'd been advised to take my hand and form his into the proper hand shape and guide his hand and arm through the proper movement—my hand on top, my hand in control. Well, I don't know about your kids or students, but Dylan did not respond well to this. Each time I tried, he would withdraw his hands from mine and turn away. There he was with his hands fisted against his chest and his head turned away from mine. Not exactly the shared communication and relationship I was aiming for.

I've always been a follow Dylan's lead kind of mom. When he didn't relax into my shoulder to cuddle as my other babies had done, I learned to hold him facing out. When he didn't like to snuggle in my arms, I learned he responded better to my nurturing, with my sitting next to him and touching him rather than me holding him. (Who knows perhaps he needed to see me or see out where we were going.) The point being, if I had persisted in trying to parent him as I had my other children, we would both have been frustrated. Instead, we enjoyed a responsive, communicative relationship. Dylan's communications - cries, withdrawal, relaxation, smiles - were noticed and responded to, and I think he learned he could trust me to respond to his communication about what was working for him.

But how was I to help us move beyond touch and body language to communicating through words? Having Dylan withdraw and turn away as I tried to form his hands into signs or words did not fit at all with our existing communication style and relationship, but he wasn't responding to my visual sign even though it seemed he had adequate vision to see it. What was the answer?

At last, I asked Ed Gervasoni, Dylan's Orientation and Mobility Specialist, about tactile sign. I'd heard about it, but really had no idea how to start. Should I be beside him or across from him, how should I position our hands, how would he get a sense of what I was saying if his hand wasn't actually making the sign? Ed simply put his hands underneath mine and started signing. You mean it's as easy as that, I thought.

Next thing I knew there I was with Dylan; I put my hands under his and started to sign

something and he didn't pull away. Even better, his eyes came towards my face and to our hands, giving me that sense of connection and relationship I wanted. It was much later that I learned that touching the palms of both hands triggers an orienting reflex. It is a protective reflex that says pay attention to what is touching your hands. So for the first time, as I signed, Dylan's brain was tuned in to what was happening. I knew then that this would be the way that we could continue the touch and body language driven relationship and communication we had and help move his language development to a higher level. And as is true with hand-under-hand used for other purposes, the hands have helped Dylan to see, and allowed him control of the input and movement.

Over the years, the hardest part about tactile sign has been the impression that Dylan gets adequate information visually to learn language and concepts so doesn't need tactile sign. When we adults see him navigate the world as a sighted person, it is easy to think that he can understand what we are signing to him the same way he visually knows when the sidewalk ends and the grass starts or how to find his way around on a very large campus. We forget that the brain needs information from two or more senses to form concepts. We forget that pairing touch and vision help Dylan's brain hold onto what he has seen, so he can use that information and learn from it. Then over time with enough repetition, Dylan does learn the visual sign and with familiarity of the sign and use of it in routine, the touch can be faded away. As with everything else with Dylan, it is a fine line in expecting him to rise to the challenge of using his vision, and recognizing that sometimes he still needs the tactile support to use his vision more effectively and with less fatigue.

My older children had bedtime songs that I sang to them every night. For Dylan, I signed the same songs. This was a very familiar part of our routine, and he seemed to be connected with the process. Then one day I needed a photo or video of tactile sign as an example for a presentation the next day. I asked Roy to video the bedtime songs that night and for the first time offered my hands to Dylan before I started. Reaching out and placing his hands on top of mine, Dylan accepted my invitation and together we started signing, hands to hands, eyes to eyes, and heart to heart. Part way through, Dylan lifted his left hand off of mine and began to sign with me. There it was, from passive to active through the simple act of pairing touch with the vision, even in familiar routines, with familiar signs. I was reminded of how often I thought his vision was enough.

Even now, as Dylan is so into watching and imitating signs, tactile sign is woven throughout the day. In the past, I had to remember to offer tactile sign. Now, by reaching for my hand, Dylan lets me know when he needs the touch to get more information or to rest his eyes. Talk with me this action says, and I do.

#### Image Description

Dylan's hand is on Kim's as they finish co-signing Christmas tree. Both are smiling as Dylan looks to the tree with a shiny round Dylan ornament on it.



January 27, 2016

## **Co-drawing and Communication**

In my last post, I shared my experience of talking with Dylan through tactile sign using a hand-under-hand technique. Often when we think of hand-under-hand, we think of using it to teach someone how to do a task, use scissors, zip their coat, or write their name. It is an alternative to hand-over-hand, where the helper's hand is on top, making the student's hand perform tasks, they aren't yet doing on their own. Hand-under-hand in contrast involves an invitation for the student to rest their hands on yours, so they can "see" through your hands; "see" what you are doing, "see" the object of discussion, "see" aspects of the environment, or to even "see" how to do something. It is an approach that allows the child to maintain control of their body, and to be an equal partner in exploration and interaction. When, I started signing with Dylan in this way, he did not resist, because we already had a history of sharing relationship through touch. Information about hand-under-hand and resources for helping students get familiar with this type of touch are readily available through a simple search of the Internet. But now I want to share a less familiar practice called co-drawing.

Dylan was only four when I first heard Dr. Stephanie McFarland share an overview of Dr. van Dijk's Curricular Approach, including "Drawing Instructional Strategies." If you're like me, you might have thought, "But I can't draw," and then left that strategy for someone else. At the time of her talk, I was focused on modeling American Sign Language and exploring what type of symbol, such as object, photograph, or line drawing made sense to Dylan. It never crossed my mind that co-drawing was something I could use at home, as a "language." Using hand-under-hand to co-write has been a part of our home life, but co-drawing? Not me.

Co-drawing was something that was done at school, with Dylan's fabulous communication specialist, Megan Mogan, and his incredible Intervener, Doe. I loved hearing the stories of how some amazing breakthrough happened during these co-drawing exchanges and I loved looking at the co-drawn experience stories that came home every day. Dylan and I shared a brief glimpse of his day through these stories.

Even better were the videos; videos that showed the connection and engagement that occurred as Dylan and Megan or Dylan and Doe wrote together. You can see this process in action as Megan was helping Dylan grasp the concept of up in connection with the sign for up through co-drawing. [Dylan learning about "up" with Megan video](#). As great as that was, it still didn't occur to me, that I could draw with him like they did.

Then Dylan's school placement was changed to home, and I became Dylan's day-to-day teacher. "Umm, now what?" I thought, "I can't draw." I clearly recalled my struggles in 7<sup>th</sup> grade art class. Nope. Drawing wasn't for me. But as with everything we do in our School-Home, I learned from Dylan.

Fortunately Dylan “got it” with my rough stick figures and real objects traced on to the pages of his stories as I ventured into co-drawing with him. His engagement as we drew, led me to try basic drawings, such as a house or a tree, to provide more information. I began to let go of my need to be “good” at drawing in favor of the connection with Dylan and his learning.

The beauty of co-drawing, as with any hand-under-hand technique, is Dylan has a “voice” in it. The feedback between our hands constantly guides the story or lesson that emerges before us. Dylan is able to direct me to a part of the page as a request to elaborate. After just a couple of exposures, his hand can guide the direction of mine, expressing his knowledge of how to draw a rough outline of the United States for example. He also lets me know when I am starting to draw something he doesn’t want to talk about or doesn’t understand by either guiding my hand in a different direction, or taking the page, crumpling it up and throwing it in the trash.

Starting in school as a way to illustrate a concept or create an experience book for the day, co-drawing has evolved to a dynamic communication form wherever we are. I no longer have to worry about having the right picture communication symbol with me, when we leave the house. As long as we have paper and markers, Dylan and I can communicate about anything. It allows for spontaneity of topic, easy adaptations to our schedule, and best of all the opportunity for us to just “talk.”

If you saw Dylan on the Young Adult Panel at the 2015 International CHARGE Syndrome conference, you saw us co-drawing together as we waited his turn. You might have wondered what we were drawing together. Quite simply, I was interpreting for him, in the form of co-drawing, letting him know who was talking, key points of her talk, when his turn was, and what he was going to do. What you couldn’t see as he and I co-signed his presentation, was his “speech” lying there on the table, written out in co-drawn form for him to “read” from as we went along.

For a recent presentation, I looked up information on co-drawing, and found Dr. McFarland’s article, which was written about the time I first heard her talk about Dr. van Dijk’s Curricular Approach. As I read anew the key benefits of “drawing instructional strategies,” I thought about Dylan. Yes, co-drawing does promote the use of his residual vision, as placing his hands on mine draws his eyes to the page. Yes, co-drawing does allow Dylan and I to have communication that is clear to him and to me. Yes co-drawing does encourage Dylan to be an active participant in learning, and life. Yes co-drawing does provide a static communicative referent; that is it provides communication in a form that he can hold onto and refer to again and again. What the article doesn’t list is the benefit of competence and self-determination for Dylan and contentment for me, as we “talk” together through this shared media. I encourage you to give it a try.

Overview of the van Dijk Curricular Approach, Dr. Stephanie Z.C. McFarland, NCDB, Nov. 30, 2000

<https://nationaldb.org/library/page/1969>

Sample hand-under-hand resource.

<http://gsap.coe.uga.edu/resources/instructional-strategies/hand-under-hand/>

## Images

### Co-drawn Dylan Dad Mom

The first image shows a completed co-drawing of 3 stick figures holding hands with smiles on their faces. The figures are labeled Dad, Dylan, and Mom. The bottom of the page says 3-of-us Happy. This is the last page of the first book we co-drew and wrote at home about Dylan and Dad putting the tables together for School-Home.



### Dylan Mom co-draw buy water bottles

The second photo shows Dylan and I shoulder to shoulder facing his slant board. The paper on the board has a co-drawn water bottle vending machine with co-drawn figures labeled as Dylan and Deb. Dylan's right hand is resting on my right wrist as we complete the text "buy water bottles."

### Co-drawing list at Target

I am sitting at a table in Target with Dylan standing beside me, his right hand on mine, as I begin to draw a square, which will become his symbol for batteries. Our paper rests on top of a page that has photographs taken from a video of the simplest electric train, which he enjoyed watching again and again. With each viewing we talked about needing to buy the 3 objects shown on screen, batteries, copper wire, and magnets, so we could make our own. In the store, Dylan wanted nothing to do with the photographs. (I agree they are horrible contrast, but sometimes with familiarity it is enough.) More often though co-drawing our own representation has more meaning for Dylan, as it did on this day, where we stopped what we were doing to co-draw his list.

