

Melynda Ross

*Listening to David--Draft*

## **Introduction**

Theoretically, *disability* is amorphous--it means different things to different people. What one researcher references as *disability*, another may label *handicap*. Likewise, another theorist may use the term *disability* to describe *impairment*. The term *disability*, is now (in American education and social work) synonymous with *impairment*, and is acceptable if used in conjunction with person-first language. Consequently, there are disparate differences between the connotations *having a disability*, as in having a functional impairment of a body system that results in some degree in restricted activity, and *being disabled*, which implies an undesirable state of functioning, or less-than-well-being (Vehmas, 2004). It is in this connotation that this author will use the term *disability*.

There is no canonized model of disability theory in the literature, but there are several commonalities to the multiple models that co-exist (Michailakis, 2003; Thomas, 2004; Vehmas, 2004;). How the concept of disability functions in a society is determined by many complex forces, from archaic traditions and mores, to simple numbers--the oft subscribed "majority rule." Historically, injustices occur when a majority of individuals can identify a subgroup individuals that do not fit the socially accepted concept of normality. Silvers (1994) supposed that perhaps it is not the disability that is the issue, "they are inferior not because they are too defective, but because they are too few," (as cited in Vehmas, p. 169). Because social structures--conceptual and tangible--result from the collective assumption of the way the "normal" members of society function, disability (as an attitude--not used in lieu of the word impairment) exists within the parameters established by society and operates according to the meanings given to it by the majority (Oliver, 1992; Thomas, 2004; Vehmas, 2004).

The social model of disability has evolved into a political identity combatting oppression and ignores the realities of functional differences (Koch, 2001). In 1999,

Williams examined the concept of disability from a critical realist perspective and claimed that it is not purely social construction that determines what disability is, but rather, the “interplay between the biological reality of physiological impairment, structural conditioning (i.e. enablements/constraints), and socio-cultural interaction/elaboration,” (Williams, 1999, p. 810). Shakespeare and Watson (2001), though not subscribing to critical realist philosophy per se, took Williams’ model one step further and rejected Oliver’s (1992) seminal social model of disability because of the conceptual separation of *impairment* from *disability*: “People are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial,” (Shakespeare & Watson, 2001, p. 17).

Undoubtedly, there is a combination of factors that converge to form a collective consciousness that permeates a society and creates an institutional perception of people who have disabilities. Thomas’ proposed *social-relational* theory of disability recognizes the causality of impairments, “socially marked as unacceptable bodily deviation,” that (unjustifiably) lead to social oppression, presumed limitations and restrictions on people “...and the socially engendered undermining of their psycho-emotional wellbeing,” (Thomas, 2004a, p. 15; Thomas, 1999, as cited in Thomas, 2004b). Thomas chose the term “impairment effects” to conceptualize and describe the restrictions, exclusions, and disadvantages that people with disabilities experience as a result of socially defined norms (Thomas, 2004a, p. 17). Theorists still debate what gives initiates and sustains societies’ maltreatment of people with disabilities. However, in my experience, this prejudice is like most others--not present in young children, but grows with age--and can be overcome with education, good examples, and experience in the real world with real people (some of whom may have disabilities).

## **Meet David**

David is a twenty-eight year-old African-American man. Like most men his age, he scowls when he thinks his mother is a little too much “in his business.” He prefers the company of his brother, Steven, although he seems a little less fond of his sister-in-law, perhaps because he associates the decrease in he and Steven’s time for “man stuff” with her. David is artistic and likes to impress those around him by constructing “flip books”--books of line drawings that equate primitive animation when shuffled. David has always enjoyed playing and listening to music and watching movies. Over the past year, he has become quite a “techie”: listening to music on his ipod and surfing the ‘Net on the computer. Although David enjoys playing on the Wii, he prefers adult company to children.

David is hard-working, doesn’t mind getting his hands dirty, and can’t stand to be late. These traits are especially desirable to employers, but like many Americans, David was laid off due to the declining economy and has been out of work for over a year. Since then, David has attended Inverness, a center that provides supported employment, day habilitation, and pre-vocational services for adults with disabilities. In April, 2009, David’s service provider contacted the primary researcher, a professional acquaintance, to ask for assistance with understanding some of David’s challenging behaviors and developing a plan to discover potential employers for David. This researcher suggested a Person-Centered Planning meeting with multiple stakeholders, and a relationship began.

## **Methods**

A case study approach was used in this investigation to capture rich descriptions of David and his interactions with others, notably his primary caregivers, in an attempt to determine how these experiences functioned in the development of his sense of self. Additionally, as the planning and implementation of strategies developed over a year-long period, it became important to also consider what function technology served for David’s ability to communicate.

This qualitative project is the offspring of what began as a service project at the request of a professional acquaintance. The year-long interactions between David, his caregivers, and the Person Centered Planning Team provided valuable data, and with the permission of family, I transitioned from a role solely based on advocacy to that also of researcher. I continued to participate as an advocate for David and his family on the Person Centered Planning Team, while gathering all the documents spanning one year, such as Person-Centered-Planning Meeting documents, researcher observation logs, emails, and Customized Employment Profiles.

Multiple data sources and collection methods triangulated the data. In addition to the PCP documents, informal interviews were also conducted with direct support professionals (DSPs; American version of the U.K.'s "Carers") and the Inverness Center Director, P.M. Selected quotes were written during these conversations, and I journaled immediately following each meeting. (Because I, nor the PCP team, had audio recorded and interviews prior to the addition of the research component to the project, later interviews were not audio recorded to preserve the authenticity of these conversations.) Additionally, I had informal conversations and one-on-one interactions with David, as well as observed him in group interactions (which I had done prior to the start of this research project). After compiling and interpreting all of the data, I asked four core PCP team members, including David's Mother, Danielle, to give feedback for respondent validation to provide further validity to the study (Maxwell, 2005).

## **One Year of Data**

### *A Primer on Person-Centered-Planning*

Person-centered planning (PCP) is a values-based best-practice that transforms the transition process from a generic deficit-oriented program to one of individualized services and supports based on abilities, choice, and self-determination (Kohler & Field, 2003). Unlike typical planning and service coordination for people with disabilities, PCP does not rely on or support any type of professional authority hierarchy (Holburn & Vietze, 2002). Instead, the foundation of person-centered planning is collaboration, shared decision making, and equality among all stakeholders (Wehmeyer, 2006). Therefore, the PCP process mobilizes and empowers students, families, and community

members (C. L. O'Brien, O'Brien, & Mount, 1997; Michaels & Ferrara, 2003). Person-Centered Planning documents are especially useful for case-study methods, as they inherently capture the perspectives of multiple people. All team members' personal and professional backgrounds are different, as are our relationship or association with David, therefore individually, we see him through unique lenses, and with different biases (Baxter & Jack, 2008).

There are five "essential accomplishments" of person-centered planning: (a) student's increased community presence, (b) development of student autonomy and choice-making, (c) building competence for functional, age-appropriate, and meaningful activities, (d) receiving respect (e) community participation and development of relationships (J. O'Brien, 1984, 1987). According to Wehman (2006), there are basic steps to implementing person-centered transition planning. Because David is past the typical age of transition to post-school outcomes, his PCP plan is a bit different than what one might see if they were going through the transition process in the last year of high school, but the basic steps are the same:

1. The team must convene--family, friends, Local Education Agency (LEA) representatives, community members, agency representatives and service providers--and roles must be clarified.
2. A transition statement should be formulated and a transition coordinator chosen or identified. ***(In this case, because David attended Inverness, his case manager/job coach acted in this capacity.)***
3. Assessment data is then reviewed and needed assessments are conducted; this ensures that the right experts are on the transition team. ***(While no formal assessments were conducted by Inverness, many observations and interactions were used in place of informal assessment data.)***
4. The transition coordinator develops a profile of the student with information provided by the student, family, and friends (i.e. relationships, places, background, preferences, dreams/hopes/fears). ***(David's profile was initially built from information***

***captured during that first PCP meeting and is updated as the team discovers new pertinent information.)***

5. The student and family, with the support of the transition team, develop outcome goals. The student, family, and support providers should then work backwards to ensure that the student has the opportunities, experiences, services, and supports that will provide skills, knowledge, and experiences to attain the goals.
6. The culmination of these steps is the production of the transition Individualized Education Plan (IEP)—a comprehensive plan explaining plans for future employment, post-secondary education, living arrangements, finances, socialization, transportation, medical and health choices, advocacy and legal options. ***(David's plan is an electronic document developed from PCP meeting minutes, emailed to every team member, and updated by LB, an ARC employee, after every PCP meeting.)***

The transition planning process is not over after the transition document is created; the team must modify the plan if or when it needs to be updated. Team members must also facilitate implementation of the plan and monitoring must occur to ensure accountability (Williams & O'Leary, 2000). Fortunately for David, his PCP team is composed of state and national leaders in the field of adult services; excellent practitioners, as well as scholars; and those whose professional qualifications are buttressed by the years-long friendships that many of the team members share. David's core group of team members are committed to his success; they are committed to the field, and they hold each other accountable.

In essence, our PCP team provides four types of supports: resource, moral, technical, and evaluation (York, Giangracio, Vandercook, & Macdonald, 1992). We provide information to David's family on who to contact for financial assistance for some of David's extra expenses and, potentially, for future needs like supported living or transportation. We also try to be a support for Danielle, to hear and address her concerns, and just be a group of friends. Because of our collective knowledge, and the

purpose of our meetings, we certainly provide technical support to Danielle and to Inverness. The group as a whole brainstorm to develop new ideas and strategies; individual team members teach David's caregivers many things according to our individual strengths (technology, transportation, best-practice in DSP education, etc.). Lastly, the PCP team continues to meet regularly (every 60-90 days) to provide evaluation support. Inverness staff collects data by observing David, recording any extraordinary behaviors or significant events, and the team monitors and adjusts as necessary.

### *Initial Meeting: April 2009*

The first meeting was held on the second floor of a satellite campus of a southern research university. To preserve a feeling of neutrality, it was held in an empty classroom, with long tables, arranged in a square. The meeting facilitator, L.B., had a large easel set up, with blank 2x3 paper and markers waiting to capture the information we would discover during the meeting. There were plastic cups and napkins, a cooler filled with ice, and soft drinks and cookies arranged on a side table: "textbook" PCP meeting environment.

The professionals who were attending arrived around 9am, and David and his mother, Danielle, shortly thereafter. We began by introducing ourselves to David's Mom, explaining why we were there, and what each of us had to offer her and David [supports included a parent advocate, 2 ARC staff, and Dr. Mark Yeager from TEAAM (Together Enhancing Autism Awareness in Mississippi)]. Despite our best intentions, Danielle initially appeared nervous, and understandably so, with nine "professionals" staring at her, asking questions about her child and life story. We explained the Person Centered Planning process, explained that anything she felt was "off limits" would not be discussed, and proceeded by saying, "Tell us about David..." The answer to that first probing question evolved into a 90 minute conversation about David--from birth to the present--his likes, dislikes, skills, and limitations.

Some things we already knew, of course. David had a diagnosis of autism. He was primarily "non-verbal," though to what extent, we were unclear. And, within a few

minutes into the meeting, we all knew he had a strong affinity for Coke and chocolate chip cookies, as he repeatedly returned to the table saddled with refreshments.

We learned about David's childhood. He was an "Army Brat." His mother rarely got very good advice from the doctors or special ed teachers. The family moved around a lot, but eventually his dad "couldn't handle it": "it" being day-to-day life with David, and his parents divorced. Danielle and the two boys finally settled here when David was a teenager, and he finished with a "Certificate of Attendance," when he was 21 from a local high school. Until now, he had jobs that people with disabilities commonly fall into --janitorial work at restaurants and pizza chains.

As the team was discussing David, we modeled best practice and attempted to bring him into conversation, but he seemed uninterested. (He only responded to my offers of more Coke.) David was doodling on a piece of paper while we talked. He drew, and drew, and seemed perfectly oblivious that every minutiae of his life was being dissected, transcribed on those 2x3 sheets of paper, and taped to the wall.

In trying to get more information about job possibilities, I asked if David could sequence things. Inverness employees said he liked to organize DVDs on the shelf, so they thought perhaps, but had not pursued any type of formal or informal assessment. Later during the conversation, a team member asked if David could read. Mom said no, Inverness staff said no, and David suddenly became very, very interested in our conversation. He then wrote random words on a piece of paper and--without making eye contact--nodded, and slid the paper across the table to a team member as if to affirm that he could read. He had just never been asked! Because he did not speak, no one who currently supported him, even professionals who should have known better, thought that he was actually reading the books he liked to look at. Like many people in mainstream society, they equated *speaking* with *intelligence*.

Toward the end of the meeting, it became more clear that communication was a pervasive issue throughout all aspects of David's life. His caregivers were frustrated, because he was hitting others for (what seemed like) no reason. Dr. Yeager took the lead as other team members explained that every behavior serves a function. We explain to his Mom and his DSP's that if their yelling is hurting his ears, and he has no other way to tell them, then he will have to hit to make them go away if he can't move himself.



Danielle said this made sense now, and she reflected on a time that she made David furious. He stormed off down the hall, turned around and said, “Make me sick!” and slammed his bedroom door in her face. She said she was so stunned she just quizzically said, “I thought you couldn’t talk?” while she meekly knocked on his door for a few minutes, but he refused to open it for the rest of the evening. We all laughed at her bewildered expression, imagining all the times she had probably prayed for him to answer her or say something--anything--and then when he finally did it reflected typical teenage angst!

We then talked about various possibilities for “quick and dirty” picture communication books. As we were discussing David’s long-term options for assistive technology and possible communication strategies, he began “flapping,” and his DSP pushed his hands down and told him to be still. Because of the expertise in the room, it took about five instances to determine that the “flapping” was primitive sign language. Obviously, his mom and his DSPs did not know sign; they just thought he liked “getting on their nerves” with his “crazy hand motions.” As it turned out, David had been taught a limited amount of American Sign Language (ASL) when he was five years old, but it never occurred to Danielle that any traces of it still remained. (The family was not taught ASL, nor did they use it in the home at the time.) That pseudo-flapping was David’s attempts to tell us that he wanted another Coke and a cookie using ASL he learned almost twenty-five years before.

### *Out of the Manual and Into Practice*

We concluded the first meeting by prioritizing and developing an action plan and assigning responsibilities. We agreed to meet in 60 days. Several days after the first meeting, David’s job coach asked him what he wanted to do that day and he typed in “troy.” (Troy T. runs a nationally-recognized inclusive sports program and David really enjoys spending time with him.) The staff at Inverness finally saw with their own eyes what we were telling them in the meeting--Give him ways to communicate and listen.

In the two-month interim between the meetings, David was permitted to get on Inverness' computer<sup>1</sup>. His DSPs soon discovered that he could, in fact, sequence, read, and use the computer. He soon knew how to "Google" things and search for clips of his favorite movies on You Tube.

### *Meeting Two: June 2009*

We held the second PCP meeting held just two months later, to build on the momentum of the first and re-address communication and employment concerns. It was in a smaller classroom this time, with less refreshments. David still came, though, with his mom, new job coach, and DSPs. ARC staff and this researcher were present as advocates, and Troy T. and David's brother, Steven, who would both turn out to be phenomenal assets to the team, came as well.

Danielle was encouraged by what Inverness DSPs had discovered about David's computer abilities, but this was overshadowed by her concerns about his unemployment. She told Inverness people that if he did not get a job soon she was pulling him out because "He can watch movies at home!"

The PCP team believed that following the Customized Employment (CE) process developed by Marc Gold & Associates was the best way to assure David would find appropriate employment--not just take the first thing that came along. The CE process begins similarly to PCP--with Discovery--that is, learning as much as possible about the person (Callahan, Shumpert, Condon, and Mast, 2005). A portfolio is then created based on the evidence gathered during discovery. During the subsequent employment planning meeting, decisions can be made (what employers to approach, what locations or situations to avoid) based on this data. Only after the documents were finished could the team truly have a CE planning meeting and develop a blueprint for employment that clarified David's preferences, conditions of employment, and specific employer leads (Callahan et al., 2005). An ARC employee agreed to take Inverness' Director, P.M.,

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<sup>1</sup> The Director of the Inverness Center where David attends, PM, was subsequently terminated after human resources learned that David was allowed to get on the computer. The HR attorney said in a phone call that he was shocked that a person with a disability could "even figure out how to do it." Nonetheless, it was against company policy because Inverness' confidential records were kept on the same network.

under his wing to finish up David's Customized Employment documents within the following weeks.

Keeping Danielle's concerns at the forefront was paramount, however, it seemed more distressing that Inverness DSPs had made painfully slow progress in the effort to establish a reliable method of communication. I felt our discussion was quickly becoming akin to long committee meetings where lots of things are discussed, but no decisions are ever made. I tactfully stressed that David's quality of life (encompassing behavior, employment, independent living--all of Danielle's expressed concerns) would not change until he had a way to communicate. I showed examples of hard-copy Picture Exchange Communication System (PECS), but emphasized that what I thought would be really great would be if David got an ipod touch with a PECS program built-in. However, I was careful to emphasize to the job coach and DSPs that if they were not willing to learn the technology to support David so he could utilize it, we would be better off just sticking to a PECS board. They all expressed enthusiasm, so we made it a goal to try to secure funding for an ipod and PECS app.

During the meeting the special educators on the team explained the characteristics of autism to Danielle, Steven, and David's DSPs. They had no idea that loud sounds probably hurt David's ears, or that keeping a schedule is critical--not because David is difficult, but because he is likely "wired" for routine. Although, everyone is different, some of the fundamental characteristics of autism explain much of David's angst when routines change or his niece and nephew (toddlers) come around--they are loud and unpredictable. Steven seemed relieved to have a possible answer for what appeared as David's dislike for his children; he now understood that it was not personal--just painful!

*October 2009*

One step forward; two steps back. After many phone calls and documents justifying the purchase of such an innovative device (by Vocational Rehabilitation standards), Voc Rehab (hesitantly) agreed to purchase an ipod touch for David to use as a communication device to aid in employment. It could not have come at a better time. We had just learned that instead of taking it step-by-step, some of the Inverness staff

bypassed the rest of the PCP team and got David a job at a fast-food restaurant. This went against every tenet of PCP and Customized Employment. The PCP team was not in agreement (including Danielle). Some of us were not even notified. The CE process was not yet complete, but still, we knew that David could not tolerate loud noises. His new job was to clean up the lobby of the restaurant--not a good match. He made it 5 days, until he was cleaning during the middle of a children's birthday party and a little boy would not stop screaming at him. So, David told him to stop--the best way that he knew how--he hit. Our team decided this would be documented as a "paid work experience" rather than "terminated employment."

### *November 2009*

The ipod arrived. I spent many hours talking to David's DSPs about giving him every opportunity to make choices using picture software. During the first several weeks, David's DSPs gave him a camera and let him take pictures of all of his favorite places to eat, favorite foods, and favorite places. Six months prior, when asked where he wanted to go eat he would just give P.M. a blank stare. Several times this month, when asked what he wanted to eat, he picked up his ipod, scrolled through the pictures until he found the establishment he wanted, and off he went.

David was enjoying the ipod, and showed frustration when he discovered that Inverness did not have wireless internet access. Within the first week, David began typing on the "notepad" (to ask and answer simple questions). David loves listening to music, and quickly attempted to set-up a playlist of his favorite songs. (At the request of the PCP team, I seeded it with 100 songs of various genres until we could determine what type of age-appropriate music he liked.)

### *December 2009*

Lexus, David's DSP, describes their Thursday outing:

...When we got there, we watched a movie and ate dinner. When David acted like he was ready to go, I said okay, told everyone 'bye,' and started to leave. My cousin ran up and gave me a hug and David jumped over me and tried to hit

him to get him away from me. I was so mad. I said, "David! Go get in the car! Why would you go on an' do that?"

When we got in the car I told him that his behavior was totally uncalled for. I explained that he can't be doin' that. That I am his friend, but that he has to understand that I also have other friends and family and if he is going to be all jealous than he will have to find someone else to hang out with. I really let him have it-- 'cause, you know--I talk to him, just like I am talking to you. He understands what I'm sayin'--I looked at him and said, "I can't believe you...Now what do you have to say for yourself?"

"Sorry...." He said, as he looked out the window.

"Now that's all you had to say. Now, we're cool, but you can't be doin' that again."

### *January 2010*

When I went to Inverness for a visit, David greeted me at the door and shook my hand for the first time. I was shocked. He had never willingly touched me before. Later, when I spoke to P.M. (Inverness' Director) she told me that she told David he needed to "Thank Melynda for that ipod." I reminded her that it was a team effort, but assured her that he had.

David continued to use the ipod to make choices throughout the day (what to eat and what activities to participate in). He continued to use Inverness' computer for entertainment-mainly for entertainment, but would type simple answers to questions if asked. David was isolating himself less, as there was a new Nintendo Wii at the Inverness Center and he began taking turns competing in sports games with other men.

In January, David had 4 hitting episodes. Every episode's antecedent was easily identifiable. Twice, another person who receives supports from Inverness was incessantly screaming. And the other two times, the computer froze; David knew that he must push "Ctrl-alt-del" to unfreeze it, but could not physically do it. In all four instances, P.M. and David's DSPs were otherwise occupied and did not get to David in time. While this did not excuse his behavior, it did offer encouragement to the team that we are on the right track. (In the next meeting we planned for local law enforcement to

go to Inverness to discuss legal consequences of inappropriate behaviors with some of the people who receive supports there.)

Several times there was not an ipod, picture book, or computer access available when David has needed P.M. or Lexis' assistance, he has tried gesturing without success. In these instances, David used paper and pencil drew what he needed often a picture of batteries (for his headphones) and, once, a picture of the Wii (he wanted to play).

### *February 2010*

Another PCP team meeting was held, with new advocates for David in attendance. His pastor, R.W., came and spoke to the team about David's involvement with the church. According to R.W., David was a founding member of their church, and the church body wanted to be a better support for David.

The focus of this meeting was to continue to discuss employment, but also to specifically discuss independent living, as this is an option that the team thinks that David would like to possibly try in the future. The team decided that with the limited knowledge of Inverness staff (including senior-level directors), they should accompany David and his family to a neighboring state to see best-practices in supported adult living.

At Inverness, David continued to use the ipod. I continued to advocate for him to take it home to use there, as well. However, until the communication and trust is strong enough between David and all Inverness employees and David and his mother, there is a fear amongst the team that he will hide it to make sure that no one will take it away. David is used to things be taken away as punishment; therefore, when he treasures something, he will often hide it to make sure that it cannot be punitively removed from his possession.

Danielle also expressed concerns about David's growing frustrations and anger toward her. She explained that he had not hit her, but was fearful that he might. This usually happened when she told him it was time to go to bed, and turned off the TV or the computer. After listening to Danielle's concerns, the team discussed communication again, and explained the importance of negotiation. Whereas a typical adult would say,

“Just a second,” or, “Hold on, please,” and a typical mother would not just walk by and turn off the TV that her adult son was watching and tell him to go to bed, David is somewhat “at Danielle’s mercy” when it comes to her behavior towards him. The team plans to secure a speech app for the ipod and hopes that as David’s communication improves, he will be able to negotiate. Until then, he cannot negotiate, only comply--or not.

### *March 2010*

Mid-month, the author arrived at Inverness to demonstrate a new ipod picture to speech app for David (Voice4U). I brought my six-year-old daughter (she had been to Inverness before prior to this research project and was aware that David did not like children), and introduced her. After a second’s hesitation, David’s face lit up, and he gave her a big smile and waved. When she immediately went off to talk to some other folks, he looked relieved. I said, “Don’t worry, she won’t scream or make any loud noises.”

I then introduced the speech program to David, I expected him to be excited, but he was indifferent. He attended long enough to watch me demonstrate it. But, when I asked him to say, “Be quiet” (using the program) he just stared at me. I said, “David, if you will use this program, more people will be able to communicate with you.”

David continued to stare at me like my three-year-old daughter does when she is trying to decide how far she can push me.

“I just want to practice. Will you try it one time?”

He cocked his head to the side, grabbed the ipod, found the program from the main menu, scrolled through the picture icons, and pushed the button for...socks. He then thrust the ipod back at me and stormed off.

I asked David if he would practice just for one more minute. He looked at me like I was the devil, set his jaw, shook his head and said, “Uh-uh.”

I smiled and said, “Okay. If you just don’t feel like it, maybe next week.”

### **Findings and Interpretations**

Throughout the past year, David's self-determination and quality of life have significantly changed, as evidenced by the increase in the number of choices he makes on a daily basis, and the decrease in inappropriate behaviors. During this time, best-practices were implemented for planning and decision-making (*Person-Centered Planning* and *Customized Employment*). The PCP team met several times throughout the year and developed and prioritized both short- and long-term goals. The team also integrated technologies (Ipod Touch and the Internet) to facilitate communication, appropriate future employment, and offer entertainment and leisure options.

This author, and the entire Person-Centered Planning team, learned many life lessons by listening to David:

1. *Do not mistake silence as indifference or ignorance.*

One primary characteristic of people with autism is communication difficulties. Because of these communication difficulties, little is often known about an individual's "sense of self" or internal locus of control. In order for a person with a significant communication disability, like David, to develop a recognizable sense of self, he or she must first have a method of functional communication (Brown, Gothelf, Guess, and Lehr, 1998, as cited in Dennis, 2002). During our first PCP meeting, it was evident by David's "flapping" (which turned out to be long-remembered ASL) and the discussion with his caregivers that he did not have any *consistent* method of appropriate functional communication. Therefore, this was the PCP team's immediate priority.

As we observed with David, after a more reliable form of communication was established, he could more confidently communicate his choices, and when problems arose, he had alternative, appropriate methods of communication to get his point across. David's caregivers more easily recognized the nuances of David's personality and self-expression. He became more like "just one of the guys." Over the span of one year, David matured from not communicating any preferences, to choosing to take control over many aspects of his life including what to wear, what activities to participate in, and what to eat. While this may not be at the same level of decision-making that a typical adult David's age usually engages in, it is leaps and bounds beyond



where David was one year ago. However, it is not that David did not have the will or the mental capacity to *make* these choices last year, he just did not know how to *communicate* them. He was making the choices, but his caregivers were not recognizing or respecting them.

## 2. *Not everyone speaks with their mouth.*

The PCP team did not use any sophisticated assessments or elaborate interventions. We watched and listened. We discovered David's talents and strengths and showed him how to use those to communicate and make things happen in his life (Ward, 2006). What began as a conversation about PECS and picture communication quickly evolved to sequencing, reading, and sign language. David had ways to communicate, but he did not have the appropriate communication partners. Razack (1993) contends that in communicative exchanges the listener is as important as the *teller* and, in fact, has a *moral obligation* to hear what the teller has to say. Further, the roles of listener and teller are ever in flux, dependent upon different environments and audiences, as individuals contemplate whether they choose the role of the listener or the teller (Razack, 1993). David was not neglected or abused. He was loved and cared for, but had not been valued as a potential *teller* with curiosity, or genuine interest, and with the acknowledgment and recognition that he might have something to say (Dennis, 2002).

During the very first PCP meeting, David had been drawing quietly until I asked if he could read. When he heard all of his caregivers say no, he chose to join the conversation. Using art, he became a *teller*. Until then, when we were all in that room explaining the person-centered planning process, I believe that David did not realize his knowledge was useful or important--*because he had never been asked*.

## 3. *Give People Tools that Build on Strengths and Interests.*

From the start, it was clear that David's immediate need was for a method of communication, in lieu of speech, that would work across multiple environments. Alternative communication skills take many different forms: single words or limited phrases, pictures or signs, gestures, or the use of augmentative devices (Kaiser & Grim,

2006). During the first PCP meeting, we learned that David liked high-tech gadgets, movies, and music. One of his caregivers even (grudgingly) commented on the amount of money Inverness spent on batteries each month for his headphones.

After the first meeting, when Inverness allowed David to use the computer, he could quickly find the movies and music he desired. No longer was he at the mercy of other people served by Inverness and what they wanted to watch on the shared television. These Google searches alone probably contributed to much of his independence; he chose search terms, scanned the results, and chose the best matches. However, the computer was a stationary object. Although he could type notes on it, it was not a portable method of communication, and was therefore unreliable.

During our second meeting, the PCP team discussed more options and it became clear that we should try to get David an ipod touch to use for an AAC device. There were several reasons that led the team to agree to this; it seemed like a natural fit. The ipod touch had both keypad and microphone input options. It could also play both movies and music, and so be used for entertainment, as well as education and communication. The ipod's seamless integration with itunes meant that applications (programs) could also be easily purchased--either on the ipod itself with a wireless network, or on a computer and then downloaded via USB port. The ipod touch was also relatively inexpensive (\$300) compared to other high-tech AAC devices. The team also thought that it was critical that David's AAC device was portable and age-appropriate. We knew that he could take the ipod anywhere and fit in with every other adult and teenager using an ipod, smartphone, or other mp3 player.

After he received the ipod, the team knew we had made a good decision. As expected, David quickly learned how to operate the ipod, because he was motivated by high-tech gadgets. Without prompting, he quickly found the notepad feature and began to write simple one- and two-word requests to P.M. (*e.g.* "batteries?"). He also used the music features and played the games on the included apps. (David has still not mastered the speech program, and prefers to write instead of "talk." But that is still okay--*we are listening.*)

The computer and ipod empowers David and contribute to his growing senses of independence and self-determination. Although he does have a binder of pictures,

paper and pencil for back-up communication, he does not enjoy communicating this way; it is strictly when the ipod or computer are unavailable. However, because he is more empowered, he is now more apt to use any AAC--ipod or paper and pencil--than before. He still uses gestures, but will more quickly switch to AAC, rather than get frustrated. He has very few behavioral incidents, and when he does, the antecedent and functions of the behavior are readily identifiable (therefore, later preventable).

#### *4. The Road to Hell...*

...is probably paved with PCP plans that were never completed. David's team is highly committed to him. Some members work together on other projects, some members see each other socially, some team members are family (besides David's family), and there are a myriad of other connections. However, we have yet to have a meeting where every single person completed every task on the list for that time period. It is no wonder that people fall through the cracks. Especially when teams include both people who are PCP team members as terms of their employment and those who are simply giving of their time and expertise. Perhaps, admittedly, in the latter case it is a trade--passion (these people really want to be there) for time (but it cannot always be a priority).

### **Implications**

#### *Family-Centered Care is Essential, but Family Education Comes First.*

In practice, family-centered planning means focusing on the family as the unit of attention, collaborating with family while considering family strengths and addressing family needs. Facilitating family-centered care includes giving family members information they need to make informed choices, assuring families have their voices heard and needs met, and focusing on family strengths in decision making and service-delivery (Allen & Petr, 1996). In David's case, Danielle was included in decisions, but had never heard of many of the things the team discussed in everyday, layman's terms (such as sensory overload being a typical characteristic of autism). We spent time in every meeting educating David's family on adult services and possibilities they might want the team to explore (*e.g.* supported living options for some time in the future).

For family-centered care to work, professionals must trust families as capable decision-makers, and for this to happen families must first know the services and supports that are available for their child. Keeping parents in the dark is unquestionably unethical. In addition, when transition goals are created according to the priorities and perceptions of professionals instead of student and family preferences, it is unlikely that the outcomes will be achieved (Wehman, Moon, Everson, Wood, & Barcus, 1988). Professionals must incorporate family information and strengths into the assessment and evaluation process, provide information to enable families to decide among a menu of alternative choices for care, and defer to wishes and preferences of the family in cases of differences. The resulting family-centered services are guided by fully informed choices made by the family, individualized for each family, and structured to ensure accessibility and minimal disruption of family integrity and routine.

*Direct Support Professionals (Carers) Must Share the Philosophy.*

It initially takes significant support for people with communication difficulties to express preferences, make choices, and have autonomy (Guess, Benson, & Siegel-Causey, 2008). One problem with the socially-constructed perceptions of disability, is that they almost single-handedly hold-up outdated--or just bad--social service systems. Some employees are mean or power-hungry. Some employees are well-meaning, but do not know how degrading or demeaning they sound when they refer to adults as “Sweet Angels” or “Darlings.” Others have been in “the system” since it was acceptable to have an Angel Unaware outlook on disability. All of these employees must be untrained, retrained, retired, or redirected into another profession. These DSPs (carers) must be taught to honor an individual’s choices and respect his or her decisions--often a paradigm shift that creates new challenges (Algozzine, Browder, Test, & Flowers, 2001).

It is noteworthy to add that, for the most part, usually there were two or three people from Inverness present at a PCP Meeting. When the team made a decision or decided to emphasize a particular area (such as making sure David always had extra money for the Coke machine), these team members returned to Inverness, and it was up to them to make sure that everyone else followed the team’s recommendations.

Some of the Inverness staff thought we were allowing David too many luxuries, giving him too much autonomy, or just “making dumb decisions” and took it upon themselves to continue to tell him what to do and when to do it. Because of this, not only did P.M. have many managerial issues to contend with, in addition to providing adult services, but David’s plan was being undermined. It was not until Lexus and Hope were hired that David found two DSPs that spoke to him respectfully and allowed him the dignity to make decisions. With their support, David made his own choices and was allowed the *dignity of risk* (Perske, 1972, as cited in Ward, 2006).

*“The best way to prepare for the future is to create it.” -Peter Drucker*

Research has discovered that self-determination outcomes result from consistent, individualized opportunities to participate in activities that offer choice- and decision-making in various environments (Zhang, Katsiyannis, Zhang, 2002; Ward, 2006). Because we individualized David’s plan (the purpose of the PCP meetings), and emphasized generalizability (for example, choosing a mobile ipod touch instead of a cumbersome PECS binder), David and his caregivers had many opportunities to practice communicating across various settings. This had multiple advantages: David’s rapid understanding of the ipod touch’s functionality, increased autonomy, and decreased episodes of problematic behaviors (primarily hitting). In retrospect, we are now able to discover the antecedent for every inappropriate behavior or outburst that has occurred in the last year, and every time it leads back to the fact that David did not have fluent functional communication.

*The PCP Team will not be around forever. David will likely live longer than Danielle. There will come a time when Inverness will not be the place that meets David’s needs, or where he chooses to be.*

All of these inevitable situations are why the PCP team plans for both the short-term and the long-term. Every skill that David learns is being taught across activities, environments, and with as many different people as possible. His caregivers are following his lead and being careful not to place him in situations with too much new stimuli, but David is learning to generalize his skills. He is learning to make choices and

communicate in many different environments, with many different types of people--not just choosing to have pizza or chicken at Inverness at lunch time.

David could have been taught to simply put on noise-canceling headphones every time there was a loud noise. Or, he could have simply been allowed to set-up a “quiet room” at Inverness. However, David is an adult, who is looking for a job, and yearns for more independence. Therefore, he must learn to communicate his discomfort with loud stimuli and cope. Certainly, leaving the room or putting on headphones may be an option, but not the only option--and not every time. Likewise, David could have been taught simply to use a desktop computer for communication, but that is not mobile, not *generalizable* to new environments.

In addition, sometimes uncomfortable conversations must be held. People are not always comfortable discussing death and what happens to loved ones left behind; however, “Hope is not a strategy,” (General Thomas McInerney). Many who have worked in this field have shared story after story of parents who refused to discuss the possibility of their deaths, and the adult child who was then “placed” in a nursing home because there was simply no where else to go. Long-term planning is essential. The PCP team can provide information and expertise ensure that the person receiving supports will continue to receive services in the event of a caregiver’s death. Perhaps more importantly, the PCP team can inventory the skills that the person will need if they should find themselves without a caregiver, and diligently work on building those skills *across multiple environments, activities, and with various people* so when the time come, he or she is prepared and the supports are in place.

## **Conclusion**

By observing and listening to David-*however he chose to communicate with us*-we began to discover who David was, on his own terms, and how this David differs from the man who has been culturally constructed in response to his disability (Couser, 2000). One year ago his caregivers began to listen to David, and a conversation began. At first, his caregivers encouraged David to communicate simple choices like which foods to eat. But very quickly, David realized someone was listening, and he had a lot to say. As David began to learn how to express his feelings and thoughts, his caregivers

learned to resist the urge to make choices for him--a hard habit to break. It has been a unique journey for the PCP team, the DSPs, Danielle, and David.

Some things still have not changed. Most of the time, David chooses not to “speak” in the traditional sense. But, he gets his point across. He has still not decided if he wants to use the ipod app that vocalizes words and sentences. He would rather type, write, or draw. But, it’s his choice--the app is there, and we will still encourage him and ask him to practice it--or not. David still has autism and still gets overwhelmed by too much stimuli. Inverness still employs DSPs who think that David has too much freedom and we members of the PCP team are all crazy. They think he should just, “Sit down and eat his peas.” But he doesn’t want to, and that’s okay. Adults do not have to eat their peas.

David is a real person: “If we were real people, people would see us as individuals, rather than heroes, tragedies, inspirations, or representatives of our entire impairment group,” (Baggins, 2010). I hope this research may inspire other teachers, family members, and “real people” to look beyond the label of disability and find the human being beneath.

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