

Medical Home Phone Conference  
August 28, 2007  
“Voc Rehab and the Medical Home”  
Guest Speaker: Diane Behl

**Dr. Samson-Fang:** We are meeting today with Diane Behl, her first title is Senior Research Scientist at the Center for Person’s With Disabilities and the Early Intervention Research Institute, her second title is Mother of a young man with special health care needs and she is going to talk with us about her experience in the transition process specifically with regards to her medical home plate and helping with that.

**Diane Behl:** Thank you Lisa. Let me give you some background information about my son Jack. He is now 21, now living in Portland and he’s realizing that the weather is a bit hard on his arthritis. Jack has had multiple health needs to deal with. When he was 12 he was diagnosed with Type 1 Diabetes and when he was 14 he started having severe back pain. The doctors tried to figure out what it was through numerous assessments and then finally diagnosed him with severe ulcerative colitis, ankylosing spondylitis - spinal arthritis. Jack had all kinds of health needs associated with his diabetes but also with medications that he was taking, he ended up having a colectomy for his ulcerative colitis and he’s doing quite well in terms of that. Because of these different health issues, we approached the school about developing a 504 plan. I sensed that the schools are not crazy about 504 plans but because of my own background, being in the field of disability and health care needs and working on the Maternal and Child Health Program, I was able to have a lot of input into the development of the 504 plan. As Jack was approaching the end of high school, through my work here at the institute I was worried more about the importance of transition into an adult life and the value of rehabilitative services. I had approached the school about connecting with Voc Rehab. As you know schools generally do a pretty good job at developing transition plans for children with developmental disabilities but when it comes to our children with chronic health issues without any intellectual disability, my experience was that the schools aren’t really attending to transition issues for this population so that is a critical place where the Medical Home can come into play- helping these schools in how to do transition efforts to meet the needs of our children with chronic health conditions. My experience then with the schools was to educate them that, yes, Jack is most likely a candidate and at least be referred to the Utah Office of Disability Services, so I in a sense held the hand of the counselors in getting that relationship going and really they were kind of on the sideline. In our efforts to approach Voc Rehab here in Utah, Patti Hackett, who is a Voc colleague of mine, was an incredible help. She helped me understand the process and ensured that we had appropriate documentation. I had been in touch with the local office of Rehabilitation Services, Deborah Bowen, who was very approachable and supportive, however it was a still a big crisis in terms of what the eligibility criteria was or how that was determined so Patti came into play for me and said “there are three things that are very important. One is that you have good documentation of the health issues for Jack, such as specifically stating the ICD9 codes. The second thing is to be specific in terms of how his health conditions impact his health and his daily routine.” Do you all have a copy of the letter Jack’s Medical Home provided to Voc Rehab and the accompanying documentation? If you note in that letter, what you see as an example is the ICD9 codes and then the health impact. What does that mean when you have diabetes, or for ulcerative colitis, how does that upset sustainable health and how does that impact your day-to-

day life. The third aspect is in terms of what accommodations are needed that would influence employment. So just because he has diabetes wouldn't suffice necessarily. What the Office of Rehabilitative Services wants to know is; how does that impact the kind of job he would have. For example he would need to have something that would ensure daily monitoring, being able to eat when necessary, use the restroom at not just a scheduled time, making sure that physical exertion would be limited – he can't be standing on his feet a lot. Those kind of things need to be spelled out. This letter was put together with the help of Patti Hackett, myself, and Dr. Odell. When this was done, 3 years ago, the experience of a lot of pediatricians was that they were not that familiar with Voc Rehab and the role that they play in supporting eligibility. Dr. Ruddell was very helpful, as well as the Medical Home coordinator, in supporting us: taking a look at this information and adding to it. It really was a team effort. Jack's experience was that we sent this letter with this documentation and then the voc rehab counselors called Jack and said, "come into the office and we'll get things rolling." Our experience was a very easy one, it didn't seem like we had a lot of hoops to jump through and I'm not sure if it was because of the documentation or if the relationships that I've had with my status at the Center for Persons' With Disabilities and people I knew had any influence on that. I think that is a real possibility. My personal experience was very successful, as an outcome Jack was able to get funding to go to college because there was that justification that said he couldn't get just any average job that someone would get with a High School Degree alone. We said one of the things he could benefit from is additional education to have a job that will address these accommodations, so in talking with his counselors, they decided that yes they would provide support for Jack to attend Utah State University. Because I got half off tuition being an employee here, Voc Rehab picked up the other half of the tuition as well as books.

That is my experience, can I answer any questions?

One of the things I will allude to is another document that was emailed to you. That was a program I just became aware of in the state of Utah. That is a Client Assistance Program. My experience was a very successful one and I think it was due to the expert advice I had received. That is not true for the average family and they are really going to be looking to the Medical Home for support and maybe even a higher level of expertise in dealing with Voc Rehab in particular. So the Client Assistance Program is a service that is available and that could be a valuable resource with the Medical Home's working partnership with the families to help you understand this particular service.

**Dr. Samson-Fang:** Has anyone else on the line had some interaction with Voc Rehab?

**Kathi Hall:** I'm in Ogden at Intermountain Peds. I have a son with visual imparities who is currently going to school with Voc Rehab.

**Dr. Samson-Fang:** Has your experience been positive, and how has it helped your son and you out?

**Kathi Hall:** It has been very positive. My son is legally blind and so they were able to provide him with not only tuition but equipment – a closed circuit TV, so he could enlarge things and do his school work. Did Voc Rehab then help Jack to get a job?

**Diane Behl:** What they did was assisted him in getting the education so he was better able to get a job.

**Kathi Hall:** Then at that point his case was closed?

**Diane Behl:** Yes. What they did was provide training for employment in the form of money for college. My understanding is that support from Voc Rehab can have a wide range too: providing for assisted devices and money for any other specialized training as well as something traditional like going to a University.

**Kathi Hall:** They did indicate to me at the beginning of my son's process with Voc Rehab that they would then help him find a job in an area that would take someone with his disability. I didn't know if that process happened with your son.

**Diane Behl:** Jack isn't that far enough along in school, but you are making me think of other things like Job Mentoring and Job Coaching that they also provide.

**Dr. Samson Fang:** Anybody else with experience interfacing with Voc Rehab?

**Lynn Pease:** Did Jack transfer to Portland, since he started in Utah State University? Is he done with school and is he working?

**Diane Behl:** Actually Jack is a typical 21 year old. He went to the Utah State University for a year and a half and then decided he wanted to move to Portland. So he quit school here and has been working in Portland until he could get residency so he can go to school over there. He has talked about communicating with Voc Rehab Services in Oregon to see if he would be eligible for help there. He's been there for about 10 months now.

**Lynn Pease:** It will be interesting to see if he gets services in Oregon and what it takes for him to do that. I think it will be great for you to tell us about that in the future. It would be interesting to see what the availability in Oregon is in comparison to what is available here and if the process is any more or less involved.

**Diane Behl:** I will keep you posted.

**Dr. Samson-Fang:** I was fascinated that in the bottom of his letter, Dr. Odell outlined an actual definition of disability according to 504, it's certainly much broader than I envisioned. Did anyone else take a look at that? A medical condition like Cystic Fibrosis or Diabetes would come over 504.

**Diane Behl:** Exactly. I was well aware of that just because of my professional background, but it is something that the schools are not necessarily aware of or even when it comes to employers when you talk about the Americans With Disabilities Act it really is covering a very broad population, you're not just talking about people with developmental disabilities or significant physical disabilities, for example in a wheelchair, it really refers to a broad population like our children with special health care needs.

**Dr. Samson-Fang:** Diane, I am not familiar with the Division of Voc Rehab coming into play with a teenager in my clinic, who has a fairly significant disability, in job placement and job experience. I know they play other roles, some around transportation so one can be employed, or seek additional education. Obviously you've laid out their role in supporting additional education. Are there other roles we should be thinking about in Voc Rehab?

**Diane Behl:** I think you said some good ones. Essentially Voc Rehab will take a look at what would be needed to help employ this person. It could be in the form of some transportation assistance. I think they also could look at assisting with some adaptations at the job such as seating accommodations, changes at the work place, training like for Kathi Hall's son who was visually impaired, have something to enlarge documents-those kinds of assistive technology devices, they can look at those things.

**Dr. Samson-Fang;** I know there is often conflict about what age Voc Rehab should be pulled into to start with transition planning. I sense its very likely 16-18, but others feel it should be an earlier process. What sense did you get about that?

**Diane Behl:** The sense I got from Voc Rehab is they really like to wait until someone is 18, but again this was a few years ago and maybe that was based on the particular office. But one of the qualifications involved income, so when a person looks at age 18 they take a look at the income of that person. When Jack applied for Voc Rehab my income was not considered, it was Jack's income. It's an institute that is serving adults and so my understanding is that they are waiting until that person is 18. You could have conversations with them informally and start developing a relationship but there is not much they are going to be doing before that person turns 18.

**Lynn Pease:** To add to that, Voc Rehab also wants to avoid duplicating services that can be provided by the Public School if that is where the kid is attending. So if you have a young adult who is going to stay in a school program until their 22nd birthday, Voc Rehab is reluctant to get involved because they don't want to duplicate what can happen within the school system. The age of the traditional kid who graduates from High School is probably 18 or approaching 18 so it makes more sense. What is a little more critical is if you can start the process before they leave high school, because with each of the high schools in Utah there is supposed to be a Vocational Rehabilitation Counselor assigned to that High School specifically.

**Dr. Samson-Fang:** The reason I asked about that is that I have a 16-year-old girl, who could drive, but she had Muscular Dystrophy, and who wanted to take early college placement courses at the University. The issue was she wanted to start on her college career like many teens do and she wanted to build her CV to make her more competitive for University placement when she turned 18, yet we couldn't get Voc Rehab to consider helping her with transportation, even though she was of driving age. I'm wondering if that is appropriate or whether we just didn't push Voc Rehab hard enough.

**Diane Behl:** That is an interesting question and Lynn you may have some insight into that.

**Lynn Pease:** Actually that is very interesting, and I don't know what the answer would be to that. Was she not able to take college placement classes at her high school?

**Dr. Samson-Fang:** Not the ones she wanted to. It was over the summer and she wanted to take some at the university here. Being a teenager she had a big aversion to having her parents transport her for that- she did not want her parents to transport her.

**Diane Behl:** Did you say she was 17 at the time?

**Dr. Samson-Fang:** I think she was 16 ½ or 17. She was of driving age.

**Diane Behl:** Lynn, do you think the age could have been a stumbling block.

**Lynn Pease:** It could have been a stumbling block with parental income included. That could have been a factor. They could have said parental income doesn't qualify her and so they would have to figure out a way to get to the school. Does she drive?

**Dr. Samson-Fang:** No that is what she needed- accommodations to be able to drive such as hand controls.

**Lynn Pease:** Oh and she wanted Voc Rehab just to help with hand controls?

**Dr. Samson-Fang:** Yes and to help with being able to learn to drive.

**Lynn Pease:** I might have pushed Voc Rehab a little bit harder on that.

**Diane Behl:** Again those key points I learned that you need to have in a letter, is that you need to document how her Muscular Dystrophy is impacting her health, for example not being able to use public transportation because of any health reasons and why it was important for that specific accommodation for her employment in the future.

**Dr. Samson-Fang:** I was going to turn the conversation just a little bit, unless someone has some questions, and ask you Diane, what other programming or philosophy or things you were referred to that helped you in this process. As we all have patients moving through the transition process, what are the things we could recommend or connect families to or even just say that could help that process move along better?

**Diane Behl:** The thing that comes to mind, and I'm sure you've heard this before, is that transition from pediatric care to adult care was a bit on my radar. Some doctors, like Jack's endocrinologist was much more flexible and willing to continue to see him for a couple more years until he knew where he would be living after school. Whereas other doctors, like his Gastroenterologist said no, Jack was not able to get services from him and there was no support for helping him connect with an adult doctor. The other thing that Jack made me aware of was that when he turned 18 he said that I was no longer welcome to come to his doctor's appointment because he could see that when I would be there with the rheumatologist, the rheumatologist

would talk to me rather than Jack. I had become too good of an advocate for Jack's health care and had not prepared him. Jack is very articulate and could communicate with the doctors fine himself, but I did not provide him with the opportunity and the doctors did not tell me to shut up and that they needed to be talking to Jack. I think, as a Medical Home, being able to help parents and youths to pass that baton so youths are competent to talk to doctors themselves, giving youths that role. At this point, Jack makes his own appointments; he has to find his own doctors in Portland himself. He doesn't attend his medical management, his diabetes management, as well as I'd like to see, however it's me having to come to the realization that he is an adult and he is the one who is deciding how all of that is going to be played out, its not me.

**Dr. Samson-Fang:** Is there anything that helps you get to that realization, other than time?

**Diane Behl:** Jack would let me know and I think probably a lot of time. Also me realizing that the more that I ask him about his health the less effective that seemed to be. That whole sense of a parent with a child with disabilities, is that so much of the relationship can be built around those health needs. I found that I really had to work on the idea of when I talk to Jack I am going to bite my tongue and not ask how his blood sugar management going, how his back pain is, to not always have that as part of the conversation. Since you want to build a relationship with this adult, you want to show that your role as mother is backing out of that.

**Dr. Samson-Fang:** Anyone else with a question for Diane as we come to a close? Any announcements Barbara?

**Barbara Ward:** Our next call will be on September 25<sup>th</sup>, we'll have Susan Denney from the school system, she is nurse, and the topic will be "How to Communicate With The School Nurse."

In attendance:

Lisa Samson-Fang, Barbara Ward, Al Romeo, Bob Terashima, Chuck Norlin, Walt Torres, Diane Behl, Clinic 6 U of U, Dinosaurland Vernal, Montezuma Creek, Balinda at Redrock, Cathy Hall, with Ogden Peds, Summit, UVP American Fork, UVP Cherry Tree.