



COLORADO

Department of Health Care
Policy & Financing

SUMMARY OF SB 18-231 TASK FORCE MEETING #3

Community First Foundation
5855 Wadsworth Bypass, Arvada, CO
October 1, 2018, 10:00 a.m. – 2:00 p.m.

Participants:

In-Person: Jennifer Martinez, Joan LaBelle, Rachel Tomlin, John Barry, Samantha Satchell, Gail Lott, Rhonda Berry, David Bolin, Jim Brennan (Parent)

By Phone: Abigail Negley, Colin Laughlin, Kelly Wilson, Katherine Duran, John Paul Burden, Matt Cook

Keystone: Lorez Meinhold, Cally King

Meeting Summary:

Welcome and Introductions

Lorez Meinhold of the Keystone Policy Center opened the meeting with round-room introductions, review of the agenda and housekeeping items.

Youth/Parent panels – What Works and Challenges with the Current System

Jim Brennan began the discussion sharing his story about his son, Ian, with down syndrome who has recently begun the transition process from school to adult services. His son is in Cherry Creek School District and the family has had the opportunity to be very active and participatory in his son's schooling from a very early age. Jim recognized he has had many supports to make their transition somewhat smoother than what others experience, but it was still difficult. He has seen a number of people in the system trying to do the best they can but still felt entirely unprepared once they reached the transition point. It is hard to discuss the transition in a meaningful way because it is so nebulous and there are many different factors that go into the process.

Group discussion:

- What would have made the transition better and work better for parents? What information would have been helpful in making the transition from school to the right adult services?
 - Two categories: 1) More collaborative approach earlier-on (middle school age) regarding the child's potentials. 2) Need better understanding of the logistics and reality of what the transition looks like and what it means (i.e., at age 21 Part B services are over and what this means).

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- There is a need to be more proactive about the potentials for people with disabilities and that once a path is determined at age 21, it shouldn't be the only path they are set on for the rest of their lives. It is important to understand the voice of the child and incorporate a sense of self advocacy. We shouldn't rule anything out and have someone say this is all you can do.
 - Need to understand the transition will be different for people based on the services available to them. Someone in La Junta will likely have a much different experience and support than someone in Metro Denver.
 - Parents need training (i.e., PEP Conference) more than they need more pamphlets, websites, etc. to help through the transition. Parents need frank conversations and peer support/mentor relationships from parents that have been through similar processes. This is something that should be in conjunction with other information. Other parents help you understand the value in a way other information might not.
- What agencies came in and who initiated the agency linkage when you started the transition process?
 - It was all done through the school district. We have a good relationship with our CCB but the transition was mostly done through the school district and we have not been approached by any other outside agencies.
 - At our last IEP meeting from middle to high school – the caseworker came in and wanted to start planning the transition process right away. There was a push on paper towards transition and life skills that the academic experience was forfeited in favor of life skills. As parents we pushed and collaborated to make sure our son was able to be exposed to regular academic classes and this was what provided him the most positive outcomes. My hope for Ian in the workforce is that he is surrounded mostly with people who don't have disabilities because this is the reality and will prepare him better for a real world social and work interactions.

Kate Duran, parent, shared her experience beginning to transition her 17-year-old son with autism and ADD at Littleton High School. She has also seen that people with a disability do not have a voice at the table. Her son doesn't say anything because he assumes someone was taking care of things and there were reasons why decisions were made, however, she doesn't want him to feel like he is relegated with whatever is left over. The family has been involved with ARC of Douglas and Arapaho and they are working with DVR. Her son has a job working at King Soopers where he is learning customer service skills and responsibility. They have run into issues getting faculty and staff on board with them that academic skills are just as important as life skills. They feel their son is missing basic academic courses that he would need to be college-ready



and will have to be backfilled once he is out of the public school system. As parents they are not advocates, but they have to do a lot of advocacy on their own time. They have to figure out how to track down information on their own so they can ask the right questions and know what is available or not for their son. They would like to see a single clearinghouse that could provide important information (academic and life skills - how to make and keep friends, driving classes that might be available, etc.).

Group discussion:

- Want to look at this issue with families not being contacted directly by resources – would it be helpful for school districts to supply information to HCPF about IDD students who are there and possibly in need of services that are coming down the pipeline and may need access to services? CDE could aggregate data by region without providing personal identifying information. Would still need to look at student privacy concerns.
 - Great idea from the parent perspective
 - From CCB perspective, thought this would be beneficial but found each school district had different hurdles to navigate. One school district was able to create an internal system which was helpful in identifying and helping families earlier on.

Sam Lawrence, an adult with autism, shared his experience from his transition and was joined by his DVR job coach, Chris White. Sam began his discussion with a video he produced titled "The First Step is the Hardest" about young adults with autism. Sam emphasized that it is important to see the potential of people with developmental disabilities as they make transitions.

Group Discussion:

- When you were getting ready to find work – what do you think was the best quality about yourself that you think was overlooked?
 - Sam's first job was at a local grocery store who insisted they had the proper training and skills for Sam; however, after a few months it was determined that all they provided Sam for development was pushing a broom and turning cans so they faced out. This wasn't real development for Sam. Sam has started his own company that allows him to do his own work at his own timing. He specializes in color correcting and has lots of vision but needs some support to execute his vision.
- What would you like the task force to know about the challenges making the transition?
 - Many people with autism are poorly educated, just over half graduate from high school and only about 12 percent attend college.
 - Sam lacked some of the important academic courses and training in high school, like math skills.



- The earlier we can work with a client and figure out the skills that are needed through a discovery process, the better. Sharing of information is extremely important. The plan needs to be adaptable and grow with the client.

Alignment Conversation – Education Transition Services between 18 to 21 years old

The task force needs a better understanding of where the medical responsibility lies when students are enrolled part time in school - how do services look different for the student from school district to CCB to DVR? What services do kids receive and what is missing?

Discussion:

- Because school boards have a limited amount of funding, how do we help leverage services?
- Some school districts will provide services in a student's IEP regardless of the student's status, but other school districts will not and refer to the payer of last resort to meet those needs. There is a need for clarity and accountability on who is responsible for the service – what is the school district responsible for and what is the CCB responsible for?
 - There is no baseline standard for schools and there likely won't ever be one put in place. This is a conversation that should be addressed at the local level.
 - Need to consider what is in the IEP and have a better process and more active partnerships between school districts and CCBs to understand who is responsible for the services being provided.
 - When supports overlap, need a better understanding of who is responsible for payment of that particular service.
- It takes both agencies to come together collaboratively to make sure it is an effort from both perspectives and shouldn't be one or the other. The crux is to figure out what is the best service for the individual and how do we make sure they are receiving the needed service. This needs to be a collaborative process to ensure smooth transitions.
 - Need a matrix that shows "if I have a certain need, what is the resource I should reach out to"
- How do we engage and handle families that are resistant to and do not want to put together an IEP or other testing for a child we know have developmental disabilities? This places them at a disadvantage in the future when trying to access services and also leads to them to needlessly being put on waitlists for important services.

Emerging Recommendations

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Commented [CK1]: Lorez – this should be cross-checked with your list. I'm not sure I captured everything you had read off to the group.

- Parent-Peer and Student-Peer Mentoring program or network
- Setting the right expectations with regards to academic rigor with an eye towards future opportunity. There is a lack of academic expectations placed on children with IDD in the schools and providing a real high school experience (social skills, dealing with conflict, etc.).
 - Conversations need to start earlier and need to determine when it should happen (early intervention, elementary school, middle school)
 - School districts need a checklist on when and what information should be shared
- Data collection and dissemination of data. Understanding HIPPA and FERPA considerations.
- Creation of a collaborative agency approach
- Transition Liaison approach and what are the right components to include
- Adequately funding and supporting systems of support

Next Steps

- Other groups/voices for the task force to hear from:
 - Youth Leadership Services – a week-long conference that teaches youth with disabilities leadership lessons through different learning opportunities and activities.
- Final Task Force recommendations due to the JBC by January 2, 2019
- Lorez to provide task force with a document that frames the emerging task force recommendations.
- Next meeting scheduled for October 29 from 10 AM – 1 PM at The Colorado Trust

