Good Morning,

We appreciate you registering for tomorrow’s virtual, focused discussion entitled: *Ensuring a Meaningful Engaged Life: A National Discussion*, scheduled for Tuesday, August 1, 2023, from 11:00 AM – 3:00 PM (Eastern) and look forward to engaging with you throughout next week’s meeting.

After registering you should have received an email from NTACT:C/Zoom with your login information, we also resent this email to you this morning.

If you didn’t receive this email in your inbox please check your spam folder.  If you haven’t received a login email please let Michael Stoehr – mstoehr@charlotte.edu know as soon as possible.

As a reminder, the purpose of this event is to move beyond the “why not” to the “how to” in order to create sustainable changes that will improve meaningful engaged lives for young adults with the most complex support needs. Below are two case studies of real young adults that provide a description of the students/youth that we are focusing on for this event. Please review these narratives and come prepared to add to our discussion regarding potential action steps for change.

The invited participants for this meeting include stakeholders at the national, state and local levels representing youth, families, education, vocational rehabilitation, health, intellectual/developmental disabilities, university staff, political leaders, and other individuals who are engaged in supporting students and youth who have the greatest need of complex supports to successfully transition to a meaningful and engaged life.

To help foster an open, meaningful and collaborative discussion throughout next week’s meeting, time has been built into the agenda for you to get to know the other participants’ background, experiences and contributions that they can provide to creating action steps that will lead to sustainable changes to improve meaningful engaged lives for young adults with the most complex support needs.

The following is an outline of the agenda for the day.

Several short breaks are scheduled throughout the meeting and we encourage everyone to plan accordingly regarding how to best accommodate your lunch and self-care needs.

Ø  11:00 AM – 12:35 PM - Opening remarks from family members Jody and Carrie Roberts, establishing our  meeting’s purpose and engagement in collaboration building activities.

Ø  12:35 PM – Break

Ø  12:40 PM - Breakout Discussion – Topic - Meaningful Life: Community Engagement/Employment (Strengths, Barriers, Dreams/Actions)

Ø  1:10 PM – Breakout Debrief

Ø  1:15 PM – Youth Engagement Discussion- Erin Black, Connor Archer, Helena Roberts, Shannon Ward

Ø  1:45 PM - Breakout Discussion – Topic - Accessible Life: Communication/OT/PT/AT/Accommodations – maintaining and supporting -(Strengths, Barriers, Dreams/Actions)

Ø  2:05 PM – Breakout Debrief

Ø  2:10 PM – Break

Ø  2:15 PM - Breakout Discussion – Topic - Healthy Life: Personal Care and medical/physical support challenges - (Strengths, Barriers, Dreams/Actions)

Ø  2:45 PM - Breakout Debrief

Ø  2:50 PM – 3:00 PM – Next Steps and Closing

If you have any questions or need additional information contact Michael Stoehr – mstoehr@charlotte.edu

Thank you,

***The Ensuring a Meaningful Engaged Life: A National Discussion Planning Team***

Case Study #1

Shannon is a 23-year-old woman diagnosed with cerebral palsy (spastic quadriplegia), seizure disorder, gastroesophageal reflux, cortical visual impairment, osteoporosis, esotropia, and intellectual disabilities.  Shannon enjoys learning new things and graduated from a class focused on functional academics.  She is a good friend and loves volunteering with organizations like the YMCA and Alex’s Lemonade Stand.  Shannon continues to practice driving a power wheelchair via head array which she also uses to access her communication device.  She is dependent on others for all activities of daily living as well as medical management of seizures, g-tube feeds, and general monitoring for health and wellness.  She’s had significant hospitalizations and unfortunate physical and emotional setbacks around these admissions.  Shannon’s goal post-graduation was to volunteer at a variety of community organizations in her neighborhood including the children’s hospital where she received all of her care, go to the mall, hang out with friends, and receive ongoing therapies to maintain her progress.  Due to her need for a 1:1 nurse, she is not eligible for any traditional day programs or habilitation programs such as art and music because her waiver will not pay for both.  Shannon also does not qualify for vocational rehabilitation because she is unable and not interested in holding down a paid position due to her multiple medical issues and the level of flexibility she requires to tend to those needs.  The children’s hospital where she received care is close to her home, but across state lines which her county’s transportation won’t cross.  Her 1:1 nurse supports her with pursuing some of her interests, but does not have the specific training nor is it in his job description to provide vocational or habilitative support.  Shannon lives at home with her mother and grandparents.  She often visits her father on the weekends.  Both parents are well-educated on the systems, strong advocates, and have always connected Shannon quickly with all that her professional teams recommend.  Shannon worked hard for 16 years in school and now has a post-grad program that is not the robust life she was working towards.  Her post-grad program has not met her goals of keeping busy doing what she loves, but rather involves some trips to visit family members, occasionally going to the mall or movies, and remaining at home.

Case Study #2

Eric lives at home with his two parents who both work outside of the home and his college-aged brother who cannot be home consistently due to his own education and work.  Eric is about to graduate from high school at 21 years old.  Eric is diagnosed with cerebral palsy, gastroesophageal reflux, congenital glaucoma, asthma, scoliosis (corrected with posterior spinal fusion surgery), and intellectual disabilities. He enjoys music and movement such as rocking, power mobility and swinging. Eric is in a sensory-based classroom where he explores movement and the world around him.  He receives his nutrition through a combination of oral meals with thickened foods and tube feedings using his gastrostomy tube. Eric is fully dependent on others for all of his care and activities of daily living. He receives home nursing services to assist with his care needs but staffing has been heavily affected by the nursing shortage.  Again, because of the need for a 1:1 nurse, Eric does not have local options of programs that will accept him because they will not allow him to bring his own nurse due to funding conflicts.  Eric and his family would be interested in exploring the world of work, but have not found a program that provides the level of support Eric requires to be successful.  Eric’s parents are both psychologists working outside the home and cannot change their work schedules.  They are strong advocates and extremely knowledgeable of their state’s systems.  Eric received the highest-level waiver in the state.  However, they are struggling to find a way  for Eric to be engaged in what he enjoys outside of the home, receive necessary therapies to maintain his skills, and be with individuals trained on his care needs.  There are programs that exist, but they either have waitlists or do not allow for 1:1 nurses.  If the family agrees to send Eric to programming without that level of support, they then wouldn’t have the nurse when they need them on days the program is closed, on transportation, or upon arrival home when both parents are still working.







