



# CHARTING THE LIFECOURSE NEW JERSEY

## New Jersey Joins National Community of Practice to Implement the Charting the LifeCourse Framework

In 2019, New Jersey joined the National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities, a national initiative to develop systems of support for families across the lifespan of their loved one. The Charting the LifeCourse framework and tools are integral to this national effort.

Created by the University of Missouri-Kansas City Institute for Human Development in partnership with families, Charting the LifeCourse helps individuals and families of all abilities and ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want. Individuals and families may use the Charting the LifeCourse tools to focus on their current situation and stage of life or to think about life experiences that will help move them toward an inclusive, productive life in the future. The goal is to empower people with disabilities and families to communicate their vision for a good life and to help professionals and systems to ask the right questions, listen, and act on strategies that support reaching this vision.

The New Jersey Division of Developmental Disabilities, New Jersey Council on Developmental Disabilities, and The Boggs Center on Developmental Disabilities are collaborating to increase awareness in our state of the Charting the LifeCourse framework and tools. A cross-systems stakeholder group was convened to develop strategies for educating stakeholder communities and instilling the core principle that “all people have the right to live, love, work, play and pursue their life aspirations in their community.” Family leaders from the Regional Family Support Planning Council are supporting people



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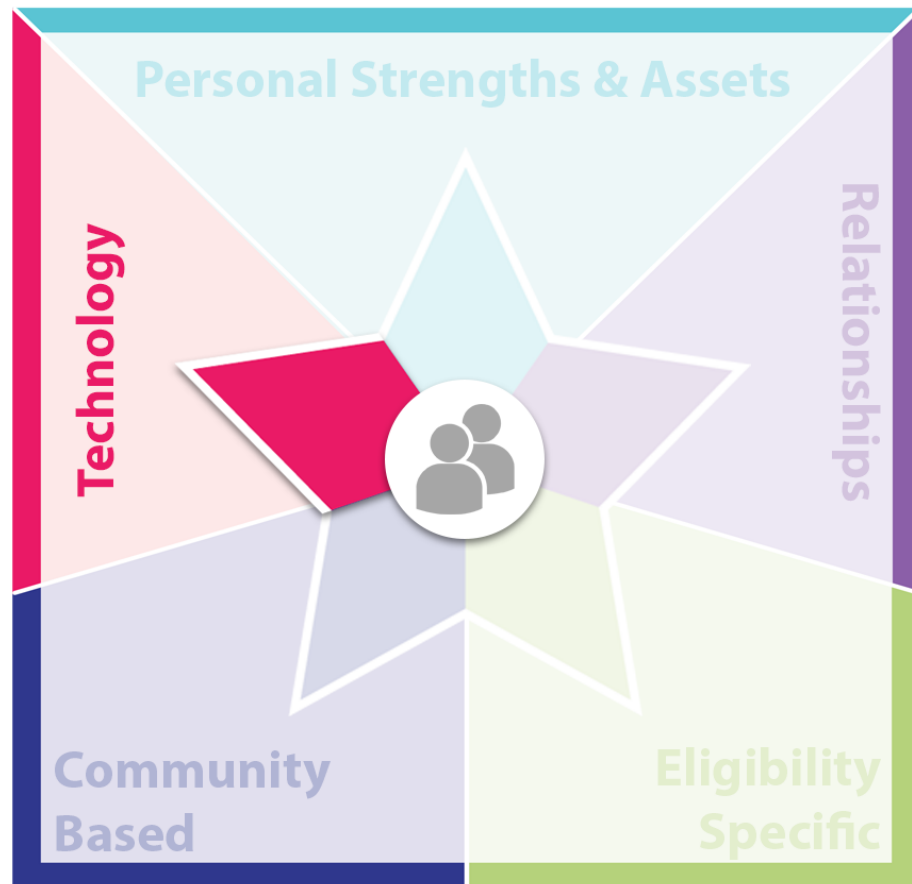
across the state in adopting this core principle and implementing the Charting the LifeCourse framework and tools.

As New Jersey’s Division of Developmental Disabilities completes its shift to a fee-for-service system, it will make strides to further develop community capacity, increase cultural competency, maintain the integrity of the person-centered planning process, and enhance individual and family involvement. People will be assisted to envision possibilities throughout the lifespan and plan for services that support individuals as contributing citizens in their communities.

Through participation as a member state in the Community of Practice, the Division and its collaborators have helped people envision what they want their life to look like and identify new and innovative supports to help them get there. Technology supports have taken on a critical role, with people discovering exciting new ways to use these resources. The Division and its collaborators look forward to highlighting such success stories, expanding knowledge and use of the Charting the LifeCourse framework and tools, and continuing our commitment to supporting people with disabilities and their families achieve their vision across the lifespan.

## Integrated Supports Star: Spotlight on Technology

The Integrated Supports Star can be used by anyone to map current services, identify gaps, and brainstorm the variety of other supports and services that they may want to access. This tool can be used to problem-solve, address specific needs, or plan for next steps. The Integrated Supports Star encourages leveraging supports that reach across five areas: Personal Strengths and Assets; Relationships; Eligibility Specific Services; Community Based Places and Services available to everyone with and without disabilities; and Technology.



This edition of the New Jersey Charting the LifeCourse Newsletter brings focus to the benefits of **technology** through stories that had this method of support impact their lives for the better.

To learn more about the Integrated Supports Star and how you can use it in your life go to: <http://www.lifecoursetools.com/lifecourse-library/integrated-supports-star/>

## New Jersey's Regional Family Support Councils Champion Use of the Charting the LifeCourse Framework

New Jersey's Regional Family Support Planning Councils (RFSPC) are supported by the NJ Council on Developmental Disabilities (NJCDD) and provide a venue for family members of people with disabilities to exchange knowledge and information about supports, services, needs, and new ideas. The RFSPCs were a natural fit to champion and expand awareness and use of the concepts and tools within the Charting the LifeCourse (CtLC) Framework as a way to identify supportive resources throughout one's community, examine potential gaps, and help people with disabilities and families to achieve the visions they've set forth for their lives.

A RFSPC Family Action Group was introduced to the CtLC concepts just prior to the pandemic and widespread COVID-19-related restrictions and shutdowns. Together, they brainstormed ways the tools could be used to enhance local efforts to assist families in finding supports and services to help their loved ones achieve the lives they desire. Many in the Family Action Group started to use these tools with their family members to identify life goals, plan for potential emergencies, and discover new opportunities for support.

Over the past six months, the RFSPCs have incorporated the Integrated Supports Star into their virtual meetings. Guided by the Star's five main areas of support, the RFSPCs helped identify the personal strength-, relationship-, eligibility-, community-, and technology-based resources available within their local areas and across the state and created an evolving spreadsheet of collective resources. Those participating in conversations shared and reflected upon experiences and resources that helped their family members to be included, active, and engaged. Held throughout the pandemic, these conversations also focused on sharing virtual technology strategies, including using technology beyond the pandemic to empower their loved one and connect them with preferred activities. The families both contributed to the conversation and learned a concept that could help guide ongoing planning.

In the coming months, the groups will dive into using the trajectory to help create visions for their "good life" and pinpoint what needs to be put in place for this to be achieved. Anyone interested in learning more about the RFSPC can visit:

<https://njcdd.org/the-regional-family-support-planning-councils/>

*"My adult son with intellectual and developmental disabilities recently moved to a new day program. We used the Life Domain Vision Tool and the Life Trajectory Planning Tool as the basis for introducing Michael to the staff. It then became the foundation on which we built his program."*  
Cathy Tumbrello

*"The Integrated Support Star enabled me to see how resilient my son is and how he adapted to the dramatic changes in his life due to COVID 19."*  
Ann Martinelli

*"Together we can share our resources to help our families get the services they need to live their best lives."*  
Melanie Ayers

*"It reminds me to keep looking for what else my child can or is willing to do for a different person or in a different environment."*  
Neng Wang

*"Charting the Life Course provides an avenue to innovation, inclusion, community and enlightenment in creating the 'best life.'"*  
Eileen Hurley

## Using Technology to Share *Inclusive Views*

Johanne Mayer and Marlene Brockington recently set out on a new virtual venture together. The two are the proud hosts of a new podcast, *Inclusive Views*, which airs on Spotify and Anchor. They are working on getting it on iTunes as well to expand their base of listeners.

For years, Johanne had a dream of a podcast for people to come to understand that the lives of people with disabilities are not all that different than the lives of people without disabilities. Both graduates of the New Jersey Partners in Policymaking program, Johanne decided that she wanted to work with Marlene on this project because of her passion and her advocacy experience.

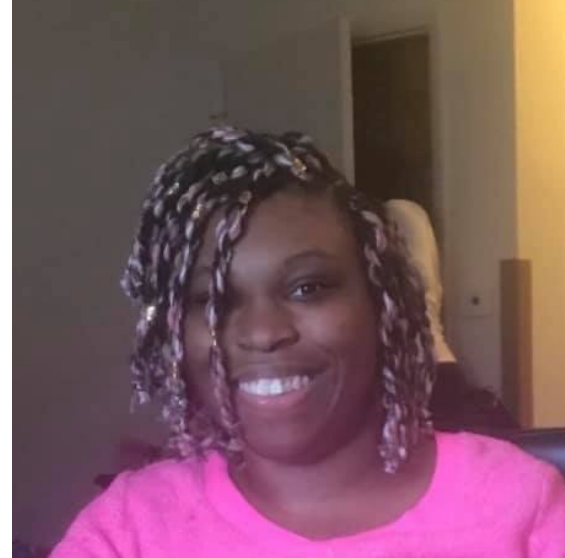
The duo met at Mercer County Community College (MCC) a number of years ago through the Mentorship program that MCC has for people with disabilities. Johanne, a graduate of the school, works as a mentor to current students attending college. Through this role, she assists current students with assignments, registering for classes and navigating college life. Marlene is a current student, working on a liberal arts degree and hopes to pursue a career where she can be of service to others in some capacity.

*Inclusive Views* tackles topics that affect the day-to-day lives of people with disabilities. Some of the topics that the podcast has covered thus far are COVID and how it's impacted the lives of people with disabilities, and how to advocate for good medical care during the pandemic. One episode covered making toys inclusive and representative of people with disabilities, and another discussed disabilities in Hollywood. The topics of representation are of particular interest to the podcast hosts because they align with making sure the world is more inclusive for all people. As many of their episodes remind us, inclusion starts with being represented.

Here's what Johanne and Marlene had to say about *Inclusive Views*:

### **Johanne, what was it that made you decide to pursue this project with Marlene?**

Johanne: I felt that we worked well together and that showed true in my relationship with mentoring her. Also, when I found out that she was in the NJ Partners in Policymaking program, I thought that would be a good fit.



Johanne Mayer (top) and Marlene Brockington (bottom), advocates and hosts of *Inclusive Views* podcast

**What things have you two learned about in Partners that you feel has lent itself to the success of your Podcast?**

Marlene: So Much! But to pinpoint one or two things, it would be making sure that our voice is heard. Also, another main thing is the idea of using social capital to our advantage for advocacy and supports.

**What’s a general takeaway that you’d like your listeners to gain from the podcast?**

Johanne: That things need to be more inclusive, and the world needs to be more understanding of disability issues.

Marlene: Exactly and that’s why I like our name so much. We want to have everybody included, representing all different kinds of disabilities. And not just people with disabilities, we want to get like people and family members on, to talk about their experiences too. We just want a wide range of people to share their experiences because that can help somebody else.

**Johanne, what kinds of things do you want to see improved for people with disabilities in the future?**

Johanne: Just to change the narrative in the disability community and how people with disabilities are looked at and the terms that are used about people with disabilities. Things like that.

**Familiarize me, as I don’t have any experience with how podcasts work, are you able to interact in real time with people who listen to the podcast? If not, what ways are you able to interact with people who are listening in?**

Johanne: No, so people aren’t able to interact directly with us on the actual podcast, but we can interact through our Facebook page and Twitter and Instagram.



PODCAST  
**Inclusive Views**  
Johanne and Marlene

Marlene and Johanne are always open to new ideas for topics they can explore. They can be reached on their Facebook Page, “Inclusiveviewspodcast,” Twitter “@InclusiveViewsPodcast” or through email, [inclusiveviews.85@gmail.com](mailto:inclusiveviews.85@gmail.com)

## Transition and Technology from COVID and Beyond

Last March, Erica Cohen, like many high school students, suddenly found herself attending school virtually, as the COVID-19 pandemic suddenly impacted the lives and future plans of every New Jersey citizen. Erica attends Hunterdon Central High School, where she is in her second to last year of her educational entitlement. She has been successful with attending school online through the virtual supports from her school and help from her parents.

Erica is pursuing all of the supports available to her related to employment, pursuing driving, planning for college, and even exploring social opportunities for herself. One of the most memorable experiences that Erica had was of job sampling she did through a program at her local Independent Living Center. Through the job sampling, she was able to try different employment settings, each on a short-term basis. This helped her solidify some ideas around where she sees herself in the future. While it was a great experience for her, Erica learned she does not want to work at a fast-food restaurant!

After she's completed high school, Erica plans to pursue a career in elementary education. Also, through her local Independent Living Center, she has been able to do some tours and other planning around what college will look like for her and what types of supports are available. She plans to attend Raritan Valley Community College, but is still keeping her options open, as she may consider other colleges. At Raritan Valley, there are a number of educational supports that Erica would take advantage of through the disability services office, such as note-taking and extra time on tests.

Like most high school students, Erica loves to hang out with her friends. During the pandemic, she has managed to maintain most of her social contacts through the use of technology, natural, and family supports. The summer months were definitely a lot more conducive to safe gatherings. Erica is hopeful that next school year will have more of the normalcy that she was used to pre-pandemic as she works to pursue her dreams for herself beyond high school.

## Tablet Leads to Much Needed Social Connection

When the COVID-19 pandemic started in March of 2020, Bonnie Tinsman knew she needed to do all that she could to keep her sister-in-law, Beth, healthy and safe. Beth's late sister, Lisa, was her primary supporter since the two moved to the US from Puerto Rico when Beth was in her late 20's. When Lisa passed away, Bonnie took over as Beth's primary caregiver.

Prior to the pandemic, Beth attended Abilities Day Program for most of the past two decades. Additionally, she attended many events through the local county Arc. Between her program and other activities, she made numerous friends and social contacts in her community. When the pandemic shutdowns went into effect, she lost many of the social opportunities and connections she once enjoyed.

Beth was in the hospital right at the beginning of the pandemic with some considerable health

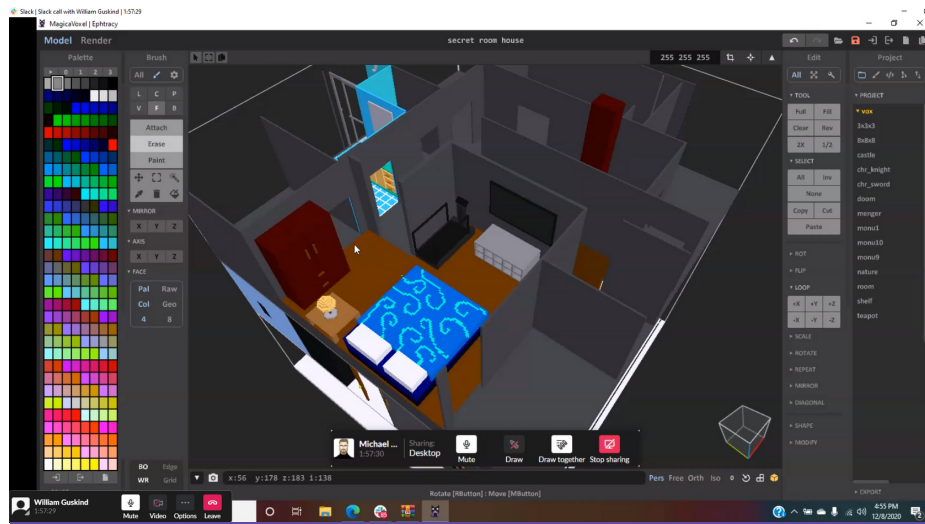
problems, not thought to be related to COVID-19. She was released only the week before the mandated statewide shutdown of DDD-funded day programs. The pandemic also put a long pause on visits with family for Beth and Bonnie, creating months of being homebound and isolated with few opportunities to see other people.

By the early spring, a tablet was purchased through Beth’s DDD funding, which was a welcome relief to both Beth and Bonnie. Beth had a tablet before, but it was dated and not fully functional for the purposes that Beth needed it to be. It was essential that she be able to virtually rejoin planned activities. Her day service provider was able to get a virtual option created within a few weeks of the shutdown, even when many people thought we might be going “back to normal” soon. Beth’s tablet has become a lifeline for her, helping to regain important constants in her life: relationships, social interaction, and learning opportunities.

## Career Building Through Technology

William Guskind, like many young men, is not entirely sure what it is he’d like to do as a career in the future. Regardless, he knows that using technology is something that will play into whatever he chooses to pursue.

Until this past July, William worked at a local supermarket for about 2 years before deciding to resign so that he could pursue other endeavors. As part of William’s journey, he attended community college and completed an Associate Degree in General Education Studies. For the past 2 years, he’s also been working on building his professional portfolio through learning he’s been doing at Game-U. Game-U is an educational business which specializes in teaching numerous web-based platforms to create art, models for 3-D printing, and even video game design. Through the availability of self-directed service options, William uses his DDD individual budget to access integrated goods and services like Game-U. This opportunity has led him to take an interest in creating designs and model layouts of interior design for homes. He hopes that in the future the skills that he is gaining can assist him in pursuing employment that is meaningful and exciting to him.



3-D model of interior design for home created by William Guskind



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