Research to Practice

Supporting Parents of Transition Age Youths with Intellectual and Developmental Disabilities: Findings from a Facebook Group Using Tools from Charting the <u>LifeCourse</u>

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Introduction

Family engagement is an important part of fostering full and meaningful lives for youths and young adults with intellectual and developmental disabilities (IDD). In particular, parents can influence expectations for successful employment and life planning by serving as role models for work ethic and behavior. With an in-depth understanding of their children's interests and experiences, parents can support the development of life goals and participate in creating plans for achieving them.

There are many resources for professionals supporting parents during transition planning from school to adult life. One such resource is Charting the LifeCourse ™ (CtLC), developed in 2017 by the Institute for Human Development at the University of Missouri at Kansas City. CtLC is the framework for a series of tools to help individuals and families solve problems, advocate for supports, and plan in all areas of life.

This brief shares findings from a research study conducted with parents of youths with IDD who participated in a six-month transition planning intervention. This intervention was based on content from CtLC's Daily Life and Employment Toolkit and was delivered via a private Facebook group. The purposes of the brief are to:

- 1. share parent perspectives about the impact of their participation
- offer considerations to transition professionals as they support parents engaging in effective transition planning

The Research Study

We recruited parents of youths with IDD ages 12-18 for a six-month study using tools from CtLC to plan for their children's future employment. Then, we invited the parents to join the study's private Facebook group. During the study, the research team used this Facebook group as a platform to introduce parents to tools and share other resources related to the transition from school to a future job or career. Parents also had the opportunity to connect with each other in the private Facebook group, use the tools, and participate in online chats with experts on employment, transition, and CtLC. Twentysix parents participated in the six-month study and eight agreed to be interviewed about their experiences in the study. This brief presents themes from the eight interviews.

Findings

By participating in the research study and using tools and resources from CtLC, parents learned to:

- Use knowledge of their young adult's skills and interests as a basis for planning
- Understand that they can start planning for future employment without having all the answers
- Take small steps so planning could happen every day
- Solidify their values about the importance of inclusion
- Think more broadly about supports that are available to help them plan and meet goals



Using knowledge of their young adults' skills and interests as a basis for planning.

Parents recognized how their young adults' skills and interests could help organize their planning for employment. CtLC's One-Page Profile and Trajectory Worksheets created a platform for developing goals. Parents realized they could use these worksheets as they work with professionals to align current employment experiences with future goals. One parent said,

"I wish I had known about it long ago. It is a way to organize all my hopes and dreams for [my son]...I like the way the [CtLC] tools organize the information so then you can share it with others. When I show [the school] the trajectory, they will say 'oh, this is what you want..."

Another parent used this exploration of skills and interests to focus on her daughter's natural connection to babies and how that could turn into an opportunity to explore work in the childcare field:

"It just kind of put a lot of thoughts into motion. And it was most helpful for me...just trying to get a little bit more focused about what her interests are, and thinking about what her abilities are, and ... what she's good at, and what she's not so good at yet. And maybe give us some direction."

Starting to plan without having all the answers.

Parents reported that participating in the study helped them realize it was important to "just start planning", irrespective of where they were in the process. They understood that they did not have to have all the answers about their youths' future employment but needed to "just start somewhere." One parent commented about how participating in the study and working with the CtLC materials helped her understand that creating employment goals did not have to mean finding a permanent job or choosing a career.

"I don't need to pick her career at six...she doesn't need to pick her career at 16 or 18 or

even 20...[instead] just kind of go out and try out new things. But that was liberating. And that took a lot of stress off."

Taking small steps so planning could happen every day.

Parents commented that participation allowed them to see how every activity is an incremental step toward a future goal. One parent reported having a greater willingness to take advantage of small opportunities when they arise. Using the example of supporting her daughter's participation in an employment-related conference, she said,

"I thought, well, there's an opening and we're just going to start this now."

Solidifying their values around inclusion.

Participants commented on how taking part in the study reinforced their views about their youths' value and ability to contribute.

"I've always had a belief that [people with disabilities] have a valuable role in our society. ... That wasn't a new thought for me...I don't think it changed my thought about that...I always felt that they would be valued members of society. That was my goal, like (not) how much they made or what they did."

Besides adding value, parents want their children to have meaningful lives. One participant commented that she had always believed everyone should do something they consider meaningful. Participation in the study strengthened this view. Another participant said the study experience did not change her view because she already believed that with the right supports, people with IDD can achieve a great deal more than others expect.

Thinking more broadly about supports that can help.

Parents were able to think more broadly about finding support and exploring new approaches to planning for their youths' future. Working with the CtLC Integrated Supports Star in

particular showed them they could tap into a number of new personal resources, including family, school, friends, and other community members (in addition to disability service programs).

...[The Integrated Supports Star] helped me think about a lot of different categories of supports that [my daughter] either has or that she may need in the future. You know, some of the technology and community supports and that sort of thing that I just kind of hadn't really thought about...at least to that extent. So I think it was positive in that sense."

Considerations for those supporting parents:

Parents reported that their participation in the study and exploration of CtLC content helped them organize their thoughts and plans, consider the full range of possible sources of support, and focus on planning earlier. It also encouraged parents to take small steps each day to increase the likelihood of achieving future goals. We offer the following considerations to those who support parents in transition planning.

Consider timing

Begin conversations about planning as early as possible. Building a vision of future employment takes time. Be prepared for some families' reactions that the planning seems premature. The idea is not to plan the youth's long-term career or permanent job, but to help families build and maintain the expectation that their child will be employed in the future.

Offer information in small doses

Deliver information in smaller, less overwhelming amounts. Encourage families to plan at their own pace. It may be easier for busy, preoccupied families to take in regular, small doses of information, rather than be expected to attend lengthy meetings for formal transition planning trainings.

Encourage Incremental Actions

Encourage families to take small steps. Parents envisioning the future can feel easily overwhelmed and think they need to have all the answers. Several parents reported feeling some initial anxiety about their youth's future as they considered the material. But they also reported the importance of starting somewhere. Examples of incremental actions that parents took included having their young adult jobshadow someone at work or pursuing a lead through school that became a summer job. Support families to continue taking small steps such as these toward the future with ongoing, but gentle nudges.

Consider social media

Social media platforms such as Facebook are a low-cost, low-effort way to reach a large group of people. These platforms facilitate connections between people in similar contexts. The ability to upload resources or record informational videos means you can tailor the breadth of knowledge you wish to share. Moreover, since these platforms are online, conversations and connections between people are asynchronous; individuals with busy lives can access resources or contribute to conversations at their own convenience. Consider using social media as a tool to help families engage with each other and professionals, and to find the supports and information for future planning.

Conclusion

Parents of youths with IDD know a great deal about their children and can spend significant time and energy considering what their children's futures will look like. Since their modeling and expectations can powerfully influence the future plans for their youths and young adults, it is important to engage them throughout the transition process in ways that are most useful for them. Transition professionals can engage families at a pace that works for them, using resources and platforms that help them formulate and maintain the expectation of successful employment outcomes.



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