Family Needs Assessment: Easing Access to the Adult Services System

Susan Colacello, Family Fellow, NJLEND
Amy Kratchman, Family Discipline Coordinator, NJLEND

1. Where are Families Finding the Best Information?

Families primarily look to other families for the most useful and accessible information. Groups they found most helpful include; The Arc of New Jersey, New Jersey Council on Developmental Disabilities, their school district and The Boggs Center. NOTE: The gap in quality, resources and training among school districts is cited as a significant challenge.

2. What Are Families Experiencing?

The majority of families responded that they are overwhelmed and do not have the time the process requires. Even if they understand the information, they still need help navigating the complex and complicated systems. Time and availability are critical factors with 66% saying attending meetings and devoting time to this during the day is not possible or very difficult. Also noted, 64% said there are too many resources and it is hard to know which to choose. And, 91% felt there are too many people and that they need one point person to help them navigate access.

3. The Greatest Challenges to Accessing Help

Families responded that time, availability and complexity of the system were their challenges. Notable for families of students transitioning was the profound differences in the way the school and adult systems operate, inadequacy of school transition programs, and the absence of any bridge between the two.

4. Outcomes, Recommendations and Next Steps

This study was a first step in bringing the voice and lived experience of families and individuals with ID/D to improving access to the adult system of care. Bridging school to adult transition, reducing the profound negative impacts on families and young adults.

Outcomes: Although families felt there are too many resources and they can be complicated and redundant, the real issue for families is the complexity of the system, the number of agencies and people and the fact that none of them are coordinated or talk to one another.

Recommendations: Establish an office focused on Disability Services Navigation and Support to serve both families and adults with ID/D. 91% of respondents agreed that they needed a “clearinghouse” and one person trained as a support person to bridge the school to adult services transition and serve as a one-stop navigator for the complex, multiple agency systems.

Next Steps: The survey potentially reached hundreds of in-boxes, with only 53 responses. The next step will be to build off of the information found here to engage a more diverse group of parents through partnerships and in person and virtual focus groups.

Outreach and Advocacy: The data will be shared with the NJ Legislative Disability Caucus, disability agencies, education organization, parent groups and all that supported this project.

Background and Purpose

While many resources are available to support families of young adult and adult children with ID/D in accessing the adult system of services and supports, most continue to find the process overwhelming and complex.

Through this needs assessment survey, we seek to identify gaps in support and suggested solutions to improving the process and experience for families and young adults that can be put into action.

The Data

- **Step 1: Research and Discovery Consultations** with families, service providers and agencies, individuals with ID/D, NJLEND faculty and mentors to inform the study.
- **Step 2: Development of Needs Assessment Survey** - 16 multiple choice and open-ended questions. A number of questions included a “select all that apply” option and all had an “other” or “comment” option.
- **Step 3: Survey Dissemination** - over 10 family support organizations and groups, including SPAN, New Jersey Council on Developmental Disabilities, The BOGGS Center and school districts shared the survey with members statewide.
- **Step 4: Data Analysis** - data here comes from the 53 responses. All respondents completed the 10 multiple choice questions, over 50% answered the 6 additional comment questions.

The Families

91% having kids with ID/D, with 23% mental/ emotional health disabilities; 51% employed full-time; 15% part-time; 69% some college, with 42% having graduate degrees, all with children ages 18-25.

Most Helpful Information

- **Families and Support Groups**
- **School District**
- **The Arc of New Jersey**
- **The Boggs Center**
- **New Jersey Council on Developmental Disabilities**
- **Other**