

Exploring the Family Experience: Seeking Developmental Disability Supports

Megan Mutti, MA

Ligas Family Advocate Program

The Arc of Illinois

Ligas Family Advocate Program

- Provide education and advocacy for individuals and families who have received Early Notification of an upcoming PUNS selection or are selected for evaluation for funding under the Medicaid Home and Community Based Waiver
- Connect families and self-advocates to ISC
- Provide education regarding system navigation and options available under the MHCB Waiver
- Support families in navigating barriers

LFAP Partnership with Families

- Uniquely situated
- 2023 – 260+ 1:1 consults
- Provide long-term advocacy
- Families asked to provide feedback regarding experiences and challenges via survey (2022 - #22, 2021 - #25)
- Families receiving or seeking services asked to provide video and/or written interview regarding specific questions
- Review of all survey feedback from events, webinars, and consults



Note on Family Perspectives

- Limited to families who shared feedback via video or survey participation
- Not representative of all families
- Experiences vary significantly via region

Family Experiences – Focus

What aspect of service initiation has been most challenging to navigate?

How would you change the system to make it more person and family-centered?

What would you like professionals who work in I/DD supports and programs to understand about providing effective and meaningful support to families and individuals?

What has been most useful to you/your family in finding and utilizing I/DD supports?

Family Perspectives: Challenges

Lack of connection/familiarity with providers

History of difficulties in school system and services system navigation

Limited support networks

Difficult experiences that may have impacted ability to build relationships with new providers

Fear/anxiety about separation/safety/vulnerability

Personal challenges (physical/mental health, sibling support needs, employment concerns, financial pressures)

What does "funding" really mean?

We have had funding for awhile, but we have never been able to find reliable Personal Support Workers. I didn't know this would be so hard.

What do you mean I don't qualify? I have been waiting for years. Now what?

How long will it take until I can go to day programming?

I don't understand this Medicaid application and I cannot find help!

I have been waiting for a CILA opening forever! When will I be able to move?



Challenges – Core Areas

- Evaluation
- Autism as Primary Diagnosis
- Service Initiation & Communication with ISC/Providers
- Lack of accurate information about process
- Unclear process regarding contacts for concerns
- Lack of family input into process effectiveness
- Underfunded system
- Staff turnover

Difficulties in Evaluation

Lack of knowledge about what to expect

Surprised by requirement for evaluation (PUNS selection = funding?)

Communication challenges with key support providers

Inability to obtain Medicaid and/or difficulty with Medicaid application

Difficulty finding provider for psychiatric evaluation

Delay in being able to access provider psychological evaluation

Perceived delay in psychological evaluations being sent from provider to ISC

Autism Diagnosis – Evaluation/Access

Families often misinformed about Autism being a primary qualifying diagnosis

Surprised by need for Psychiatric evaluation; difficulty finding provider to complete evaluation in timely way

Families have operated on assumption that the challenges brought on by their loved one's autism diagnosis, regardless of lack of intellectual disability diagnosis, will be enough to qualify for HCBS funding

Difficulties in Services Initiation

Delay in award of funding

- What is reasonable amount of time from PUNS selection to access to funding?

Not understanding specific role of each agency

Difficulty in paperwork exchanges between ISC and family

Lingering Covid related barriers

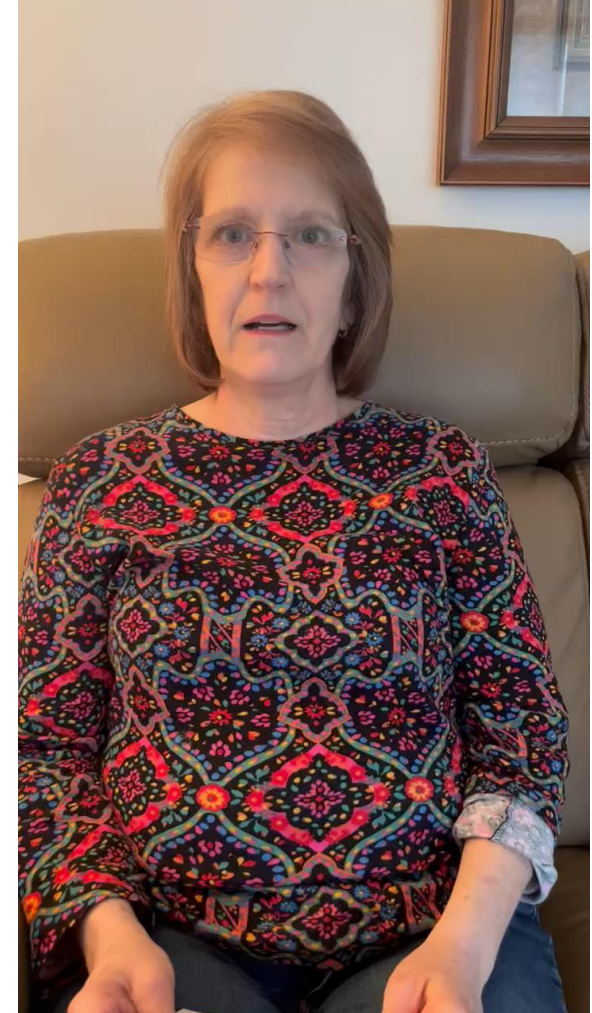
Misinformation about availability of services in region

Inability to find supports matching individual's needs

- CDS
- CILA Group Home
- Identifying/hiring PSW in Home-based services

Common areas of confusion shared by families

- Guardianship – Need? Options? Alternatives?
- Work hours allowed & impact on Medicaid
- Parents as PSW's
- Maintaining private insurance
- Impact on SSI and SSDI
- Regional expectations – What are families experiencing near where “we” live?
- Misinformation



Barriers in Support Access - Information



Family perspective - snapshot

- *"Being able to manage all of this. I'm a single mom who works a 40+ hour a week job downtown. Medicaid, SSI, etc. It's so overwhelming. I hope to find a day program with transportation that fits my schedule so I can even get my son to a program."*
- *"My most significant concern is that my family member will not be eligible."*
- *"Getting the correct help we need in a timely fashion. Getting answers to questions."*
- *"The most challenging experience is being completely in the dark or what is going on."*
- *"We have been waiting for over a year for psychological eval"*
- *"We are now over 1 year into this process and still do not have approval or funding of any services."*
- *"PATIENCE is key with this process. We started this journey in 2013 and was picked last year for funding. It has taken six months to get the ball rolling and we have everything (paperwork) done and now once again we wait until next month is what's been guesstimated for actual services to start be funded. Now, I'm not by any means trying to complain about this program and I'm very grateful that my son was accepted for it. I'm just simply saying hopefully all of this will be paying off soon because the waiting is very hard to explain to somebody that doesn't grasp the concept of it."*
- *"Communication, Communication !!!"*
- *"Our case manager was wonderful and explained the process. The follow up was very positive."*

Common Misconceptions

- PUNS selection is a “lottery”
- PUNS selection = funding for services awarded
- PUNS selection = “Golden Ticket”
- The services that we need will be available once we are funded
- No reason to be listed on the PUNS list until age 18
- Funding and services will be available quickly after PUNS selection



Critical Highlights

- Process is not friendly to families/individuals who are not primarily English speaking
- Not provided accurate timeline regarding when to expect award of funding and initiation of services
- Inconsistency in accuracy information provided

"Very little contact and consideration given the importance of this decision with no certainty of the financial planning piece. LIMBO" - family seeking supports

"This process of making online accounts and it being in English is a huge barrier to non-English speaking families as well as non-techy families."

What do families tell us they want?

- Frequent, consistent communication from ISC
- Accurate and realistic timelines around service initiation
- Sense of urgency
- Flexible and individualized services
- Choices in Community Day Programming & access to day supports outside of traditional programming
- Ability to adjust services easily and quickly
- Support in finding Personal Support Workers
- Access to information about resources - early

What do families want other families to know?



How can we better support families in the process of Service/Support Initiation?

- Hands-on support in completing Medicaid application
- Family-to-family mentorship specific to region
- Frequent ISC check-in regarding where case is in process
- Education about likely barriers; setting of realistic expectations

• "Would like better support for finding local services. There has been no follow up or anything as of yet from the agencies we have been assigned to. It has been upsetting to say the least."

How can we better support families

- Introduce Adult DD Services/Support process early and often (school/transition)
- Improved process to assist families in identifying and connecting with local providers
- Assistance hiring PSW's



What has
worked for
families?

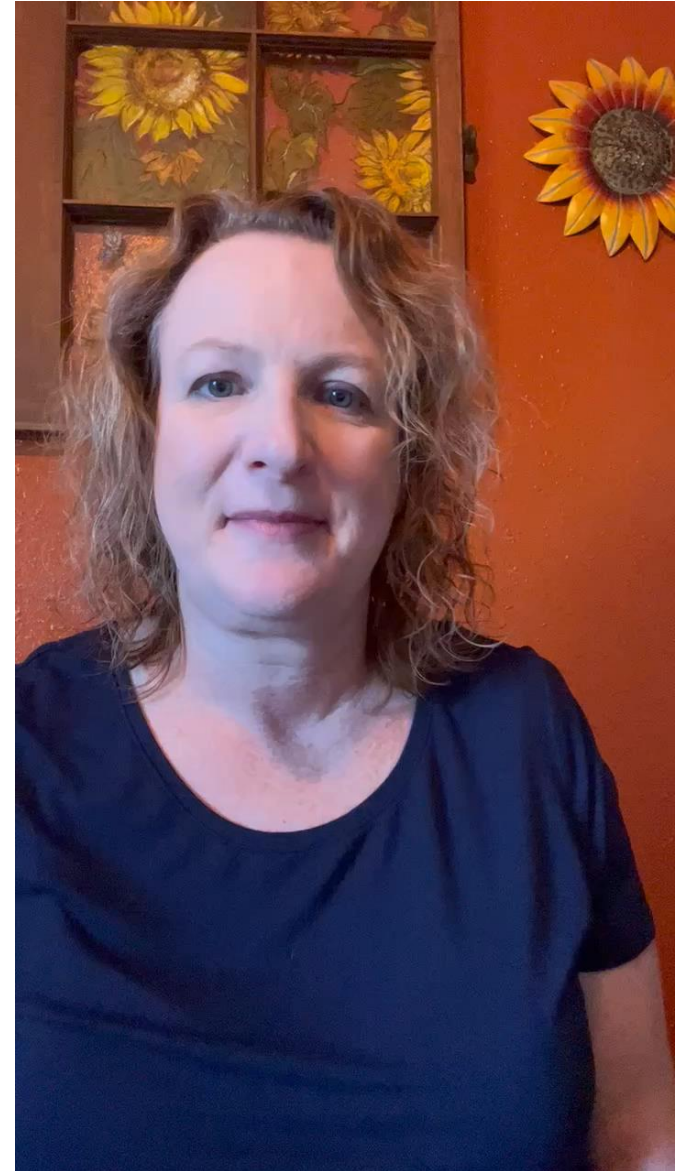
What do you want professionals to know?

- System navigation and accessing services place significant stressors on families



Parent-to-Parent Guidance

- Provide resources early and often
- Provide ongoing support
- Acknowledge the difficulties in system navigation that families are likely to experience
- Do not gatekeep information or “protect” families from needed resources



Family- to- Family: Why?

- Tried and tested navigation strategies
- “Let me get in the hole with you” – relationship
- Transparent guidance
- Reminders to set aside guilt about being “difficult”
- Validation of family experience

Potential Systemic Improvements for Consideration

Embedded family-to-family support in service navigation

Transparency about common barriers

Required school-based engagement by DD system at start of, and throughout, transition process

Exploration of PUNS listing process – are we doing all we can to ensure that those who are listed will ultimately be eligible for service funding?

Family/Self-Advocate Advisory Boards – ISC specific

What role can families play beyond recipients of service?

Advisors

Mentors

Volunteers

Reviewers

Educators

Thank you

- Contact:
 - Megan Mutti
 - (815) 464-1832 (ext 1022)
 - megan@thearcofil.org