

## **Transition Planning with Sharon Butterfield**

**Hosted by Elim Christian Services via zoom- 9/19/24**

Notes taken by Sarah Dillon Elim Transition coordinator (not recorded)

### Medicaid Waiver:

- Name of a disability service
- Children and adults can be eligible
- Must have Medicaid to be eligible for the program- can get after selected from PUNS
- Usually abbreviated “HBS”
- Services do not have to happen in the home, just means the person does not live in a residential setting that is funded by Department of Human Services
- Home Based Services is funded by IL DHS
- Federal government reimburses the IL DHS for 50% of what they pay out to individuals
- Monthly allotment of money that can be used for services
- DHS holds the money, and families decide how to use it
- Money must be used monthly; it will not roll over if the person is an adult
- Child waiver allows more flexibility- can use more hours during the summer months for example
- \$1,886 is the monthly allotment for a child
- \$2,829 is the monthly allotment for an adult- more because they are out of school and can cover day program services
- \$15,000 allotment is available to be used over a 5 year period for home modifications, vehicle modifications, etc.
  - This must be pre-approved by DHS and have a physician’s order stating this is a “needed” addition
  - Resets every 5 years
- Home-Based Services last forever
- Can have private insurance as well as the HBS waiver along with Medicaid

### Getting on the PUNS list:

- To apply for HBS a person must complete the PUNS
- PUNS stands for the Prioritization of the Urgency of Needs for Services
- There is a 10 page questionnaire that is used to be put on a waitlist
- The waitlist is used to select people for the HBS program
- You must have your son or daughter on the waitlist to be selected
- This database is through the DHS
- Who can enroll?
  - Children and adults that have developmental disability (DD)

- DHS defines DD by saying it is an individual that has an Intellectual Disability which means they have an IQ of 70 or under and that diagnosis was given to them prior to the age of 18
- If the person has a higher IQ score but are diagnosed with a comparable disability by the time they are 22, they may still be eligible (Autism or Cerebral Palsy for example)
- If they have a higher IQ, they must have significant delays in 3 of the 6 following areas:
  - Self-care
  - Language
  - Learning
  - Mobility
  - Self-direction
  - Capacity for independent living
- How to get on the PUNS list:
  - Must reach out to your local Independent Service Coordination Agencies (ISC)
  - They are assigned to people geographically
  - Chicago- Community Service Options
  - Cook Suburbs- Suburban Access
  - Call them and say you would like to get your child on the PUNS list
  - You may need to call them every single day to get a response
  - The caseworkers are still working remote and are not in the office daily to see messages
- 2 sections in the PUNS- Seeking Services and Planning for Services
  - You must get your child in the Seeking Services section
  - If your child ends up in the Planning section they will not be placed in the waitlist
  - No one from the ISC will tell you this
  - Make sure your child fits the criteria for Seeking Services
- DHS has stated that individuals on the waitlist will not wait more than 5 years past their 18<sup>th</sup> birthday, putting the selection date around the 23<sup>rd</sup> birthday
- Children's waiver selection- have stated they will select individuals based on how long they have been on the list and in seeking services, have not defined a waiting time, the number of selected is not always the same
- Until about 2.5 years ago only adults were being selected
- Less children are selected annually compared to adults
- You must update your child's case annually
- You should also update the caseworker if any circumstances change with your child
- Services starting, once a person is selected, can take a year to complete
- Your child will not receive the money directly- the money goes directly to services or family members caring for the child if they become the Personal Support Worker
- The 5 year wait time truly doesn't start until they are 18 and in the seeking services section
- Switching from child to adult waiver:
  - You can have the adult waiver when your child turns 18 and still in school, but you will still get the child allotment.
  - The main benefit of this is that the parent can become the worker and get paid from the allotment.

- You can tell your caseworker you would like to switch but you do not need to complete an extra paperwork or get back on a waiting list
- You can also wait until the child turns 22 and you must show proof that they exited school. Then they will receive the adult allotment.
- May 2019, Reasonable Pace – no individual on the waitlist will wait more than 5 years past their 18<sup>th</sup> birthday to be selected from the PUNS list.

#### Medicaid:

- Funding source for HBS program
- Is a medical insurance
- Do not have to use it as a medical insurance
- Do have to secure it to use the HBS program
- You can get on the PUNS list and not have Medicaid
- You can be selected from the PUNS list and not have Medicaid
- Once you get the letter stating you have been selected, you should start the process of securing Medicaid
- Once your child gets their “award” letter, they should have Medicaid in place
- Adult children, aged 19 and older can apply for adult Medicaid
- Parklawn staff can help families apply for Medicaid, saving them from having to go into the Blue Island office
- Present the child is a household of one, do not include parents income, etc.
- Parents assets and income are considered when the child is under 19 years of age
- Once your child is selected from the PUNS list that waves the eligibility criteria, parents income will not prevent the child from being eligible for Medicaid and Medicaid services
- In IL a child is an adult when they turn 18 but under Medicaid it is when they turn 19
- The first letter parents receive will say they are missing documents, this is to buy themselves time, this happens around 3-4 weeks after the applications was put in. They are usually approved by the second month. It can be random who is approved and who is not.
- Your child cannot have over \$2,000 in their name. It doesn't matter if it has the child's name and a parent's name.
- This will disqualify them from Medicaid
- You can put it into an Able account or SNT

#### Supplemental Security Income (SSI):

- You are not applying for Social Security Disability Services- this is for people that have worked and paid into the system
- You are applying for SSI which is for individuals that have a disability that is approved by Social Security
- Learning Disability or Speech delay are not approved
- Intellectual Disability and Autism (with certain conditions) are approved by Social Security

- The disability must be severe enough to prevent employment in adulthood
- This doesn't mean that they cannot or will never work
- This means that the disability is so severe they cannot currently be employed
- Your child can gain employment after being approved for SSI
- You want to focus on their limitations
- Under 18 will look at activities of daily living
- This should be comparing your child to a neurotypical child of the same age
- \$2,000 limit applies to SSI as well
- Current maximum monthly SSI amount is \$943
- Adults will only receive the full amount if the parents are charging the child rent. If parents do not want to say they are charging their child rent, they will receive 1/3 less ~\$629
- Sometimes the worker helping with the application will do this automatically for the parent but not all of them will, parents need to make this clear during the application process
- Under the age of 18, the parents income will be considered
- SSA cannot talk to a parent unless they are a court appointed guardian or the adult child gives permission
- If the child is under 18, parents must provide documentation their income every month, this will decide what the next payment will be
- When parents are applying for SSI on behalf of their child, they can complete the application online. They will then receive paperwork in the mail sent to the child to make them aware someone applied on their behalf and make sure the information is accurate. The adult child will need to "sign" off on the application themselves and may need to happen in person at the local social security office so it can be witnessed "

#### Guardianship:

- When a child turns 18 they become a legal adult according to the law, regardless of their disability
- A participant fell at Parklawn and went to the hospital with her brother. He was not the guardian. She refused a needed surgery and the doctors would not operate. A guardian ad litem needed to be appointed temporarily
- There will be a court hearing, your child does need to be present as well as the people that want to be appointed as the guardian
- The child's physician must agree that the person needs a guardian
- Do guardianship of guardianship first? Do guardianship first at 18 since you lost ability to make decisions, do Medicaid at 19 so your income and assets will not be included

#### Other Notes:

- Sharon meets often with families and would be happy to meet with parents one on one to discuss specific questions or assist with applying for Medicaid
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