

A Good Life

Planning Summary notes from Pat Hemlock

Presentation given at the 2022 Glut1 Deficiency Foundation Family Conference

Life Planning varies with Stage of Life.

All stages need an Advocate.

Get Guardianship before 18 years old after 18 need to go before a judge.

Keep Records

- Plastic file Tub, colored hanging folders,
- Keep a list of all terms and acronym definitions
- Keep all Notes, letters and Documents (date, name who talked to)

Life after school planning needs to start before Freshman Year

Keep in mind child's Love and Interests. Plan a HAPPY and Productive LIFE.

Talk to everyone about work opportunities, volunteer opportunities, social opportunities and school opportunities. Talk to everyone...ASK

Join Peer groups, Special Olympics, YMCA , church groups, start your own group

STAY INVOLVED and ACTIVE in your Community. ASK others for ideas or help with job, volunteering, or mentoring opportunities.

Work with your transition team plan at the IEP meetings

Learn the lingo of the Waiver Services, BDDS, SSI, SSDI, SNAP, Medicaid, and MEDICARE.

BE Prepared. Get guardianship before 18 years, or limited guardianship

Keep INFORMED.

Get on your State's email Bureau of Disability for updates . Get involved. Talk with your states representatives about the handicapped community needs for housing and transportation.

Get on the ARC email list...it helps inform what is happening at the Federal level

Ask transition team to give you all kinds of ideas of what life after school life paths could look like. Housing, work , transportation, cooking, life skills. Ask how often you will meet with transition team and be sure you keep in contact as your child's hopes and dreams change.

Ask about the different WAIVERS your state uses. And remember they will change on you! Our state waiver changed when our son was just out of high school and he was put on a waiting list and it took us 14 years to get him into supported living in our town and even then we were not on the waiver he had originally qualified for.

BE DILIGENT when you sign forms! You may not realize how that will affect you years later when you want and need the services.

The waivers are managed for your child by a case manager you select. You can change if your manager is just a pencil pusher. Ask other families who they use. You want someone who knows what programs are in your area, recreational, therapy, work support, dance therapy, music therapy.

AFTER SCHOOL

Socialization so important. Self-worth so important. If your child only works part time be sure to fill the rest of the week with volunteer jobs. Companionships are so important. Hire someone to be with your child and even see if they could spend the night with them if you need to go out of town.

Transportation thru public service for the elderly / disabled or private pay someone even uber.

Just because formal school has ended your child's education continues in day-to-day life skills, reading, buying items, money management, and work around the house.

Let them DREAM of what they would like to do and help them learn about it. Never say they cannot do something...let them try and let someone else disappoint them (as parents it's hard to be the one to always say no), however work for a solution. For instance, instead of being a teacher have them help in the school system, instead of being a life guard while they are reading the manual and studying have them volunteer at a pool to watch swimmers.

Housing options vary with your state. At this time in Indiana you have a choice of a Group Home where your child has a roommate and 4-6 other house mates...a CIH waiver home. Your child has their own bedroom with other house mates. Private Homes are beginning to form with parent involvement. CASS housing is another model which is a combination of using SSI and private pay. www.casshousing.org

YOU want your child to be Happy and YOU want to be Happy for them.

RETIREMENT

When you apply for your social security be sure to TELL them you have a handicapped dependent. Your child's social security will then increase to ½ of the higher earner. We

did not know and it was in closing when my husband mentioned our situation and they helped us. SO be sure to tell them at time of applying!!!

Where will you be, where will your child need to be? Due to State Waivers they will need to be in the state where you signed them up...this doesn't mean they cannot stay some extended time out of their home state but they do need to be serviced by that state so many days out of the year. Also their state insurance (Medicaid) is not always accepted out of state. If they have MediCARE then you can use that in all the states.

Plan for LIFE without you.

Set up a TRUST. It can always be changed. Be sure to have someone who is a disability lawyer. They will set it up so you child will not have any direct money but would be able to access it as needed. Thereby keeping your child's assets under the amount the government allows them to keep.

Write out a WILL. We set up ours so our son's portion would be used for family vacations. Drew would be able to take them on a family togetherness trip.

The government food stamp program is called SNAP. This benefit is for low wage earners. They take into account your child's SSI and SSDI benefits and any earned income and calculate it based on expenses. Have your child pay rent. A simple document and the limit of what they calculate as a fair rental agreement is all you have to write out. It is another thing you have to apply for and keep records for. The amount is not that great but it gives your child the chance to buy food stuffs of their liking.

Keep that file system accurate and save everything.

LIFE Planning varies with the stage of life.

ASK....LISTEN....PLAN....Make a few different plans. ADJUST plans. Talk with your other children...

REMEMBER... LIFE is the SUM Total of your experiences...

No decision is the wrong one and all decisions can be changed.

Ask and Listen to others.

Remember to enjoy and celebrate your child's JOY and Accomplishments.

Feel Free to contact us if any questions my cell:
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We hope this information is helpful.