# Navigating the Human Service System; Vocabulary Cheat Sheet

In an attempt to assist individuals with terminology and resources, be it those in the system or working in the system, I wanted to create a laundry list of information compiled and easy to navigate for people to keep and utilize as they navigate services. Also, I wanted to add realistic information and strategies to help as not everything is by the book and as stated on paper; you must advocate, fight, and strategize here as it is a human field which means it is dependent (*sometimes explicitly*) on whom you are working with or speaking to that makes the difference and if you are not educated, you are entrusting your care to someone, likely, equally as not educated or not having the motivation to actually learn – how someone is in the same field for five years and more, but still doesn't know even a fraction of this information is beyond me but hand to everything I hold dear, it is real and I am still at a loss on how to explain it.

This means that your power must be invested in yourself and I cannot reinforce this enough, track everything with documentation and report services for service waste – the only way to get funding to train these people properly is to force companies who state themselves as a service is hold them accountable and state agencies to follow through by cutting their funding and lobbying for better care.

You are your most viable and power asset here and if you're not fighting for yourself then you're already losing not only the battle, but the war and you will face a circus in this field.

I will attempt to track and update this list, as well as add links to specific write ups which require stationary posts due to the depth and encourage sharing and reaching out to me if you feel there is something to add or correct to it in this data set – I request permission as I would like to review and verify information before adding it and will give credits to added information. I feel collaboration is important and anything we can empower others with as fundamental to what we give and grow in our communities and each other.

This doesn't have to be a circus and funding spent should be allocated and held to a standard; we are the difference and together, we can redefine empowerment.

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# **Achieving a Better Life Experience (ABLE) accounts:**

An ABLE account is a separate, non-taxable account for SSI recipients that individuals declared blind or disabled before the age of twenty-six can obtain and are not counted as income at \$100,000 or below for Medicaid and SSI benefits.

This means a person can save money and not lose benefits, but those funds will go into an account managed through a service and can only be spent on certain needs – you will have to submit them as a Qualified Disability Expense and the categories are fairly broad here and different locations have different programming on how that is done. I am going to post two links with information and one location that handles ABLE accounts which states information on withdrawals and data sets.

Basically, these are wonderful because you can save and not lose benefits but the drawback is it is with conditions and in the event of a death, the state will funnel the money towards balances owed or burial services and anything else they deem credibly owed *before* it is initiated in the process of being awarded to a beneficiary – i.e., don't use this as a nest egg.

You can find information and resources on ABLE accounts on the SSA website here.

https://www.ssa.gov/ssi/spotlights/spot-able.html?tl=2

And you can find an ABLE service here with a version of guidelines here.

https://www.ableunited.com/

Different counties in your state contract with agencies, as well, that assist with ABLE account information and there is likely a local resource available you can find more information about by contacting your local MH/ID/DD agency or state HHS department.

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#### **Age of Consent:**

In Pennsylvania, the age of consent is 14 years old and older for mental health treatment (2020 Act 65) and it is absolutely being abused and misinterpreted. If you are running into issues, I strong recommend you read this piece by Parent and Family Alliance – they break it down and will assist with the language you need to succeed here.

I have had to argue and force hands here multiple times so let me state this clearly – **you, as a parent,** can abrogate their consent. That means, you can override their consent as a parent/caregiver and waive their rights to treatment.

Whenever your child begins any treatment, it is important when signing paperwork to request a Release Of Information (ROI) be completed between you and the adolescent, as well, due to the age of consent as they will not consult or speak to you about their treatment without it. *Now*, one would hope in good

faith you, as a support, do not manipulate or cause damage to their treatment and utilize this only in their best interests. There may be push back here, but overall, the goal is to be able to communicate and obtain documentation as needed.

- ✓ <u>Pros</u> Children can obtain treatment for their needs which they may not want to speak to their parents/supports about or may have a family with religious or social beliefs that conflict with the child's feelings, and they can obtain the support needed here.
- ✓ <u>Cons</u> Children *are* treated like adults who can manage their mental health needs I had a teenage client who physically and emotionally abused her family and could have had bodies stacked in a pit in the backyard and the therapist and psychiatrist wouldn't speak to supports or the family and simply asked how the teenager "was doing," to which the reply was "good," and that was that never mind an hour ago the client attacked the mother with a knife. **Get a ROI** and demand services and these *professionals* do their job as a large percentage do not and you have to argue them, too. Absolutely educate yourself on state laws and inform services of those rights as so many services do not know their own state's law and will tell you incorrect data and follow incorrect protocols. This is heavily seen at hospitals with intake and long-term mental health treatment for a psychiatric hospital.

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# **Alternative School:**

An alternative school is an educational institute that provides specialized settings and adherence to special needs children have been deemed necessary by approval of their local Education agency (*LEA*).

In Pennsylvania, they run under Alternative Education for Disruptive Youth (*AEDY*) and you can find more information on the guidelines and rules here <u>Education.pa.gov Alternative Education for Disruptive Youth guidelines</u>.

Alternative Educational centers and approval do not just focus on "disruptive youth," but those with special needs and must ensure that the individual is receiving a fair and appropriate education (FAPE).

I find two sides to alternative schools – they are amazing in accommodating to the high level of needs students may require, especially after the COVID pandemic and high surge of school refusals being seen; smaller classrooms, trained mental health staff, accommodations *but* they can also be destructive and limiting.

I am on the Autism scale and diagnosed, I am high sensory and have had to engineer a lot to function throughout my life, but I am not with an intellectual disability; I am actually on a higher scale that has placed me in honors and gifted classes. I am either exceptional, a potato sitting in a field zoned out or somewhere in the middle and those with ADD and Autism get this.

You know where alternative education will place you and everyone with diagnoses similar? In the same classroom with everyone else – so, yes, that means your high sensory child will have to manage their educational needs while say another child that is lower functioning is screaming or Mary, who would like to stab people, is staring everyone down while sharpening her blade.

Some alternative educational centers do not even separate by age; there was a nine year old in a classroom with an eighteen year old and this child had no real social opportunities or even someone to relate to, always stating how he felt depressed, alone and couldn't make friends – all because he was higher functioning but experienced extreme ADHD which placed him, in youth, at alternative education location and was never re-evaluated (we did get him replaced back into his school district).

Also, the school district will most definitely fight you because they are paying for these placements and it has to be agreed that they cannot accommodate; I am seeing schools opening their own programs within their location as a result.

The basic formula is this – child has issues at school, school attempts to accommodate, child still has issues which is now considered *unnecessary damage* and the school can be sued as they are suffering and not obtaining a fair and appropriate education and can place them for alternative education needs. You will do better to have an educational attorney if in this deep because the school will fight you and you will struggle if you do not know how to tango with them.

If your child does get approved for alternative placement, there are long waiting lists or time frames for enrollment and you will likely feel rushed to select whatever comes up.

Your strategy is this – you search and call every location yourself and inquire about a tour and current openings and if they will accept your child. Those referral packets the district is supposed to send out? I had another suburban school with a lot of money funneling to them that one would assume would complete tasks by the book and follow through that, in fact, did not send the packets out after calling to confirm. You will lose time, your child will suffer, and it will be a complete circus – call, confirm, inquire and tour to see the classroom settings to confirm it is right for your specific child's needs.

Some locations *do* separate behavioral needs from educational needs so inquire on what programs they offer.

I know this may seem common, but the school district absolutely is accountable to your child's rights under FAPE and placing them in an alternative location is a side route to mitigate issues rather than resolve them and could be more damaging if it is not an appropriate placement.

- ✓ <u>Pros</u> Trained staff, smaller classrooms, heavily focused on special needs, more accommodating.
- ✓ <u>Cons</u> Long waitlists, not educationally tailored to a student's realistic needs, kids grouped Randomly, poor staff training and service management.

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#### **Any Mental Illness (AMI)**

Any mental illness is defined as a mental, behavioral, or emotional disorder that can vary in impact that ranges from no impairment to mild, moderate and severe impairment.

You can find a lot of information and diagnoses break down on Drugwatch.com which offers a plethora of information here:

https://www.drugwatch.com/mental-health/mental-illness/

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### **Appeals:**

Appeal is a word you need to know because with services, there is almost always no definitive with a denial – you almost always can appeal and should.

Whenever you are denied a service or need you applied for, you can inquire with the service on appealing the matter which will lead to some paperwork and an official appeal process in which you can defend and negotiate their statements verse yours.

In social security alone, there are multiple appeals you can peel off that onion and go through in different layers.

Remember, sometimes you receive a denial simply because they did not get information that was needed and were *not* denied because you didn't qualify and if you didn't track or follow up, it got written as the service stated it. Appealing will find this critter hiding in the cracks and could be the difference between you succeeding at the outcome you hoped for.

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#### **Behavioral Health – Managed Care Organization (BH-MCO):**

BH-MCO's are county dependent and assigned to individuals with HealthChoices (Medicaid) and work fully with all mental and behavioral health management and planning – so, while your regular physical health is covered by X, any mental health services are managed by Y. In Berks County, the service is managed by Community Care Behavioral Health Organization (CCBH) while some counties are covered by Magellon, etc.

You can find your county specific provider <a href="here">here</a> or by searching for BH-MCO and county name.

- ✓ <u>Pros</u> Multiple services available for a wide scope of needs and planning, low or free in cost to recipients.
- ✓ <u>Cons</u> Only one provider available which means there are no other options than what is provided and you are working with what you are working with which isn't always negative, but not always positive either considering.

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#### **Behavioral Therapy:**

Behavioral Therapy is a blanket term for different forms of behavioral therapies available to individuals and I will briefly break some of them down; it is important to know what *kind* of therapy you are participating in because, as I have said in the therapy breakdown, it is important you are in the right therapy and this may be a reason it isn't working.

Behavioral itself indicates something more – you are working on behaviors versus solely cognitive needs so, this should include different elements with *actual* behavioral elements such as de-escalation, breathing techniques, grounding techniques and other forms of work with exposure, modeling, scaling and the like.

Cognitive Behavioral Therapy (CBT) is more popular and focused on current goals and needs with both behavioral and cognitive work and is similar to Cognitive Play Therapy which is utilized for children and involves monitoring and interacting with the child in play to learn the child, assist in strategy building and help the family learn to cope and manage behaviors.

Acceptance and Commitment Therapy (ACT) is a form of psychotherapy and is more centered on mindfulness and acceptance strategies.

Dialectical Behavioral Therapy (DBT) has also become popular and assisted many individuals which focuses on emotional regulation, mindfulness, interpersonal strategies, and tolerance with distress.

Psychotherapy has different approaches with psychanalysis and psychodynamic therapies, cognitive and behavioral work and focuses on thought processes and unconscious motivations, generally.

There are also other therapies available for Autism related needs such as food therapy and social integration therapies which are part of the behavioral element. Applied Behavioral Analysis (ABA) is a large one with children and offered in different services and referrals which has shown a lot of positive outcomes but can be intense with triggering to teach the child to cope through it. There is even Art Therapy, Music Therapy, Hypnotherapy, and even a computerized CBT Therapy.

The thing is, there are many forms that are used in therapy and for the behavioral approach, you should be getting strategies and tools to utilize – not just talk therapy, unless that is what you want. If you're not, you may need to find a different and more specific or generally available provider that does more than ask you how you are doing today (*I see so much of this*).

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### **Blended Case Management (BCM):**

Services intended to assist adults and children with diagnosis with service integrations and service overview for quality assurance, as well as day to day life management and assistance with finding solutions across a broad spectrum. Services paid for low-income families by BH-MCO. (See Case Management for adults.)

✓ <u>Pros</u> – Consistent in home and community support, funneling and monitoring of services, meet from twice a month to once a month or once every three months (services vary), referral ability, crisis intervention services.

✓ <u>Cons</u> – Low staffing, long wait lists, poor service output/untrained staff and service management.

Here is a link to a PDF breaking down blended case management services and criteria to assist with information and expectations.

https://www.dhs.pa.gov/docs/Publications/Documents/FORMS%20AND%20PUBS%20OMHSAS/d 006970.pdf

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#### **BrainSTEPS:**

BrainSTEPS (strategies teaching educators, parents, and students) is a program ran from adolescents who have suffered a brain injury (concussions/mild traumatic brain injuries, moderate and severe traumatic brain injury, non-traumatic brain injury) with transitioning back to school.

BrainSTEPS will provide education and training for individuals and families and assist with the individual re-integrating back into school and work on overall successful outcomes through graduation and can assist with support and interventions.

In Pennsylvania, you can contact the Bureau of Family Health, Division of Community Systems Development and Outreach at (717) 772-2763 or at 1-866-412-4755 and you can contact your local county assistance office.

You can find more information at the link, as well, which may provide more details.

https://brainsteps.net/home/

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#### **Burial Assistance:**

Recipients of TANF are qualified for assistance with burials (*this includes cremations*) up to \$750 – the Department of Human Services will not assist with burial payments if the countable resources is at \$1,500 or more.

These payments go directly to the approved funeral director and there are some discrepancies with the funeral director needing to have a written agreement of how funds will be applied, follow the Federal Trade Commission requirements, practice commonly accepted funeral practices and they cannot accept other supplemental payment from another source for the funeral being provided.

Eligibility for assistance is for those receiving TANF benefits or benefits that stopped when hospitalized and passed or within three months of admission, SSI recipients, those receiving State Blind Pension (SBP)

or State Supplementary Payment (SSP). This assistance is also extended to families receiving cash assistance and the family member who passed was living with them, applying or qualified for cash assistance. There is also a clause for nursing home residents who have received SSI or SSDI since 1973 that are eligible.

You can find more information by contacting your local county assistance office.

You can find resources and information with burial assistance by state here.

• <a href="https://www.funeralocity.com/blog/the-complete-a-to-z-guide-to-getting-state-government-assistance-for-a-funeral/">https://www.funeralocity.com/blog/the-complete-a-to-z-guide-to-getting-state-government-assistance-for-a-funeral/</a>

It is also worth noting that some funeral homes will provide free or reduced costs to assist with stillborn births. When I gave birth to my stillborn son at eight months pregnant, there was no real information or assistance given to me other than being told I had a short time to figure out what to do – it was traumatic enough and then, being given a day to figure things out with no help...well, it was a mess. I was suggested to by a nurse to contact a local place and Whelan Schwartz Funeral Home, Inc in Reading, PA provided me with a cremation for free and his ashes were given to me in a nicely done box – they really saved me there and the whole situation. Always call around and ask.

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#### **Case Management (CM):**

Services intended to assist adults with diagnosis with service integrations and service overview for quality assurance, as well as day to day life management and assistance with finding solutions across a broad spectrum. (See blended for children)

- ✓ <u>Pros</u> Consistent in home and community support, funneling and monitoring of services, meet from twice a month to once a month or once every three months (services vary), referral ability, crisis intervention services.
- ✓ <u>Cons</u> Low staffing, long waitlists, poor service output/untrained staff and service Management, services may be managed virtually/

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#### Case Worker (CW):

A case worker is someone assigned to your case in a service; they are responsible for managing your needs and program planning as assigned.

Case workers are your go to for needs and mitigating documentation so it is important to document who you are assigned and tracking everything if you have a particularly high level of needs as you'll

coordinate with this person more often and if you need to report due to the case worker not completing tasks and causing issues, it will fall on them.

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#### Cash Assistance (CA):

Cash Assistance is a collection of supplementary programs that have funding for parents/specified relatives with children or pregnant mothers (TANF), students, specified relatives, deprivation cases, and non-citizens who are migrants, special allowances for supportive services (SPALs), Emergency Shelter Allowances (ESA), as well as other programming with transportation needs and programs for interim assistance for those within the State Blind Pension (SBP) program.

# **Transportation:**

Transportation services may be provided by the CAO for TANF, MAGI, MNO and SSI recipients who have no means of transportation for necessary medical care and/or to obtain prescription drugs when no transportation is available – they are not available for participants of Healthy Horizons with cost sharing benefits and Family planning services, live in a county without MATP, not covered by MATP, or not covered by CHC-MCO if applicable. If such the case in which MATP could not assist, transportation services would be reviewed under medical transportation allowances.

See also Transportation Services for more information.

Here is a link to the PDF with all information on medical transportation services.

http://matp.pa.gov/PDF/MATPStandardsGuidelines.pdf (Program side)

# **Moving Allowance:**

Available to TANF and SSI recipients who need to move due to a health hazard or for employment opportunity; the max amount of grant is \$200, ran through the local CAO, and approved if they have not used a previous moving allowance within the year, are moving within the same state and have no other resources. For hazards, documentation will be needed by a housing inspector or observation with documentation and a provider statement (*Medical Verification of Residential Health Hazard PA 594*) on why the hazards are presenting harm or risk to you (*mental or physical*).

Moving companies will require two bids and be licensed by the PUC or a moving truck company from a commercial rental organization (*like U-Haul or Ryde*).

# Clothing and personal care Allowance:

Available to TANF recipients that are admitted to a rehabilitation facility or residential school and does not have any other resources to obtain specified items or clothing and items/clothing is required by the location.

# **Hearing aid batteries and Repairs:**

Available to TANF recipients and those on state blind pension, assistance can be reoccurring.

# **Emergency Shelter Allowance:**

This is a complex grant with maximum benefits for those twenty-one and over and living in a household with all members twenty-one and over at \$100 when providing the grant for a permanent living change and for eviction/foreclosure, the maximum is \$300 for the same group.

For a person under twenty-one or a family with a child under twenty-one, the maximum is \$400 if for permanent living quarters and \$300 if for foreclosure or eviction.

There is a maximum of \$100 for temporary shelter due to domestic violence, disaster, or when it is uninhabitable to stay living in conditions.

This is open to those receiving public assistance but can be completed by the local CAO if not currently receiving any public assistance which utilizes the PA 600 form.

There is income eligibility, and it goes by annual incomes of all in a budget group (*household*) and is considered at 80% FPIG.

### **Automobile and Automobile Repair:**

There are grants for Automobiles available for those who are on public assistance and live in an area where there is no public transportation; your local CAO can review and determine eligibility and assistance available to help you purchase a vehicle (*special allowance related to training and employment, code 261 and 861 for those on TANF and working*)

Automobile repairs are available under the same special allowance under codes 262 and 862 for those on TANF and working.

The allotted maximum amount is \$1,500 annually and for a purchase of a vehicle, \$1,500 in a lifetime. You can find all values and maximum amounts with codes on the SPAL Desk Guide – this will download a file you can view.

• <a href="http://services.dpw.state.pa.us/oimpolicymanuals/cash/SPAL">http://services.dpw.state.pa.us/oimpolicymanuals/cash/SPAL</a> <a href="Desk Guide.docx?rhhlterm=special%20">Desk Guide.docx?rhhlterm=special%20</a> <a href="mailto:alw20">alw20</a> <a href="ma

# **Childcare subsidies and allowances:**

This grant is available to TANF recipients and SNAP recipients in an employment and training program (ETP) and are engaged in a work-related activity/training. The program may be available to former TANF recipients if need is established, eligible and the person is 235% of the FPIG income level.

The child under care must be under thirteen years old or nineteen and under with a provider statement on why the child cannot care for themselves.

The provider has to be an approved location for childcare and there are co-payments possibly.

### Transitional Cash Assistance:

Transitional cash assistance is allotted for those moving off TANF due to employment, have a TANF qualified child and work according to the federal Work Participation Rate (WPR).

Payments are \$100 a month (\$50 twice a month) for up to three months.

Eligibility is run through a system that checks for SSI/ES qualifications with specifications for this program. If you moved off TANF and did not receive this and feel you should or do, you should contact your CAO to find out why you did not qualify as the system is set to check this – the CW does not manually check it.

#### Diversion:

Diversion is available to those who are applying or qualifying for TANF benefits and is a payment received in a lump sum payment.

You cannot have had a diversion payment in the last year or be receiving other cash assistance benefits, but there are exceptions here for domestic violence, unforeseen circumstances, disaster, child welfare agency services and expected employment falling through and they have to be approved by the Bureau of Policy (*BOP*) and Division of Family Assistance (*DFA*).

The diversion benefit is always equal to a full FSA of one, two or three months and is dependent on the length of the financial crisis.

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### **Cerebral Palsy:**

An advocate for Cerebral Palsy took the time to reach out and request information be provided for children and families in need of specialized support; after reviewing their website, I am so pleased to share it with you. There is a plethora of information available, written in an easy to understand form and had no issues navigating between the pages.

I hope this helps those in need of specialized information!

# https://www.cerebralpalsyguide.com/

I am also going to link to the United Cerebral Palsy foundation which has tools on their website to assist with finding local supports in your state.

https://ucp.org/resource-guide/

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## **Childrens Health Insurance Program (CHIP):**

Children's health insurance program is designed for uninsured children who do not qualify for medical assistance and is ran by private insurance companies that are licensed and regulated by the Pennsylvania Insurance Department (PID).

Free coverage by CHIP is available to children up to age nineteen whose family income is 208% or less of the federal poverty income guideline and low-cost CHIP is available to children up to nineteen years old whose family income is 208% to 314% of the federal poverty income guideline.

Full-cost CHIP is available to families whose income is over 314% of the federal poverty income guideline.

It is important to note that children with qualifying disabilities should qualify for Medical Assistance through the state which offers free medical insurance and if you are currently paying for CHIP, you should check into qualifying for MA despite income-limits if there is a disability with a child.

You can find more information and resources for Pennsylvania online at the Department of Human Services here.

https://www.dhs.pa.gov/CHIP/Pages/CHIP.aspx

You can find national information for different states on the Medicaid website here.

https://www.medicaid.gov/about-us/beneficiary-resources/index.html

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# **Complex Case Review:**

Complex case reviews are a secret weapon no one tells you about (*most do not know about them and the others who do know about them, don't want to do them*) – I watched an insurance staff member physically cringe and verbally attempt to escape this lasso when I mentioned it during a "*training*," and other staff in the field mimic the same behavior; that's when I knew *just* how much a weapon it was.

These services are for children and youth up to age 21 and there are two forms in Pennsylvania – County and Regional. They are intended to draw together all supports an individual has and come to a solution when nothing is working and the system is failing them (which it likely will) – this is how you force a hand and strike fear in the services you currently have; this is your last ditch effort and generally for more extreme cases or harder issues when you have an older adolescent denied for services, especially with repeated hospitalizations and emergency room visits with adolescents sent home due to being currently calm and no beds available (99% of the time).

<u>Pennsylvania Complex Case Review</u> – find forms and information here in for Pennsylvania residents. I strongly advise review for other states as there are likely supports similar or other interventions for high level needs.

- ✓ <u>Pros</u> Forces services to come together and find realistic solutions with county and state level Intervention, often the last resort for resolution due to age and service barriers with denials.
- ✓ <u>Cons</u> Intense level of intervention, you will have to argue and speak sometimes against current services which could hurt service relationships, but it is vital to be honest not nice.

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# **County Assistance Office (CAO):**

Your local county assistance office is the location that administers the states benefit programs, such as Medicaid, TANF (*Cash Assistance*) and SNAP (*Food Stamps*).

This is the first step, generally, in obtaining assistance from the state and onboarding programs to assist with special needs and state assistance programs. You'll fill out an application online or in person and will need copies of your income, housing situation (*Lease, living arrangement statement, deed*), a copy of your social security card and whoever is living with you that you are applying with (*children/spouse/etc.*) and a copy of your photo ID.

There are *A LOT* of discrepancies here which all need their own write up as there are far too many to put into this space, but for now this is where you start.

As an ongoing reminder, in Berks County at least, children (*up to* eighteen) qualify if they have a diagnosis despite overall income so you may be able to apply and obtain insurance benefits even if you think you make too much and have a child or children with special needs that may fit in the special needs category.

This is also true for certain physical health diagnoses.

As always, track your data whenever submitting information – there is a high percentage of denials and closure of cases all because you handed something in without tracking it and services are not wrong unless you can prove it.

In Pennsylvania, you can apply online here at the <u>Compass Pennsylvania</u> website. Different states have a department of human services, and you can find where to apply by searching for your state's overhead of the program.

A powerful tool is searching for your states county assistance handbooks; in Pennsylvania, you can find different online handbooks here at <u>PA Handbooks and Manuals</u>.

The PA SNAP program handbook here PA SNAP Handbook.

The PA TANF handbook here PA TANF Handbook

The PA Medicaid Handbook here PA Medicaid Handbook

<u>Disability Category</u> for children to qualify for MA outside income.

I am providing these links and encouraging you to read them, be it as a recipient or professional, because most staff working for the county assistance office do not even know half of the data and the most

powerful tool you have is your knowledge and ability to find the resolution needed. I have had to pull a lot of rabbits out of hats, and I was able to because I knew what they didn't.

You can report public assistance fraud in PA at 1-800-932-0582

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#### **Crisis Intervention Services:**

Crisis intervention services are available multiple ways, be it on phone lines (*national and* local) or in person (*mobile*), and they are meant to assist with a mental health crisis actively and respond with services as needed, such as actively working with the person in crisis and contacting the local emergency services if a person is a harm to themselves or others and cannot deescalate with intervention attempted. I am going to cover them as mobile and national and provide information to assist with finding what is in your area and different states have different models; a good portion of crisis intervention services are paid for by Medicaid funding resources and services are provided free to individuals. Whenever reaching out to emergency services (*911*), always affirm the situation is a mental health crisis to alert all parties of the situation and complex needs this means.

#### Mobile:

The mobile Mental Health Crisis Intervention service is county based and is contracted to provide crisis intervention services in person or on the phone, as needed. Services, per SAMHSA, should be available 24/7 and they can assist with crisis needs and planning through the process, be it in the home or community and at the hospital.

A major issue I have seen is low staffing; in Berks County, SAM (Service Access Management) was contracted as the crisis intervention provider and for the most part, services actually responded and came to the home. Holcomb Behavioral Health (CHIMES) took the contract and almost every time I placed a call for active crisis needs, they stated being low staff with inability to come to the scene as needed or offered very little in services and I've been told similar by others who have used the service, be it professional or clients. It is important you report services and the lack of them to assist with having a service in place that is contracted and can fulfill that contract as the lowest bidder cannot adjust for a blanket service in place, paid, with the cost to individuals receiving the service; it's irrational.

Ultimately, it is still a more positive step when available than contacting 911 who dispatches police services and the situation escalates from a mental health crisis to criminal activity – there are strategies here, as well, which will be under a different post.

Services are *intended* to come to your home and work on deescalating the individual and assist with further needs, such as potential hospitalization evaluation and can assist with information resources for ongoing needs or speak with the individual on the phone, if requested, and assist with de-escalation.

You can find your local mobile crisis intervention services in Pennsylvania here.

https://www.dhs.pa.gov/Services/Mental-Health-In-PA/Pages/Crisis-Intervention.aspx

You can find if you have a crisis center nationally and more information and resources here.

https://988lifeline.org/our-crisis-centers/

#### National:

National crisis centers assist with the same basis of crisis intervention and are generally available 24/7 to the public for free and work on de-escalation of crisis and can assist with support and resources available to an individual or families during the crisis and for planning after the crisis.

The National Suicide Hotline can be reached at 1-800-273-8255

You can also call or text 988.

There are a large amount of crisis services available nationally, but I am going to link to the National service here. To find other services available, you can search for national crisis interventions or local as you choose.

https://988lifeline.org/talk-to-someone-now/

The PA HHS website also offers a wide variety of national services that provide text, phone and online services which you can find here.

https://www.dhs.pa.gov/Services/Mental-Health-In-PA/Pages/default.aspx

You can review data sets and information on crisis management services throughout the state, guidelines and contractual agreements here.

• <a href="https://www.kff.org/mental-health/issue-brief/behavioral-health-crisis-response-findings-from-a-survey-of-state-medicaid-programs/">https://www.kff.org/mental-health/issue-brief/behavioral-health-crisis-response-findings-from-a-survey-of-state-medicaid-programs/</a>

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#### **Dedicated Account:**

A dedicated account is an account for children under the age of eighteen who are awarded social security insurance benefits that were held previously during the determination phase and have to be placed in a separate account and the account has to be shown to be owned by the child, if they are of age they should attend to sign with you as the caregiver, and funds can *only* be used for specific items.

Listen to me as I repeat this; funds can only be used for specific needs and items.

These back held funds tend to stretch a few months and at the maximum benefit payout in 2023, if determined, that can mean, \$914 held for seven months with a payout of \$7,312.

Past due payments have a formula, but generally, these funds will be released in installments over a course of six months with amounts divided if no other issues or variances to a case.

But and there is a but, you can request specific amounts of funds and be approved and obtain a specific deposit sooner. Most often, we have used this for rental/housing needs where there is potential for homelessness or loss of housing or for vehicles which can qualify due to need for a working vehicle to get to appointments (public transportation may be available, but if the child has PTSD/Anxiety/ Depression and/or other mental health barriers – it can be associated and approved as necessary and qualifying).

You cannot use these funds for purchase daily needs such as food or clothing *but* there is an emergency provision you can request to use the funds for with these things associated if you use the words emergency and can explain the relationship. If your child regularly soils their clothing, this becomes a qualified approval for use of funds for clothing items or bedding needs.

The magic here is in the writing and how you can associate it. You can spend funds without approval *but* I always recommend obtaining an approval and make sure it is in writing or some documentation of date, time, and person you spoke with that stated approval. If you are found to use funds inappropriately, you are required to pay them back.

These funds are not considered income but will be considered income if not spent within a period of time which is where an ABLE account can come in handy.

There is documentation needed for expenditures so you will want to keep receipts for everything and send only copies in to your local SSA (never send your copies because if lost by SSA case workers and you can't replace them or find a substitute showing what something was spent on, you misappropriated funds as far as they are concerned).

Funds do have time frames to be deposited as per SSA code and if you do everything right and things are dragging, report the SSA case worker or SSA office as needed. Those funds can be released quite literally in a day or two; I had a case where we put the request in early and months dragged by because a specific case worker wasn't completing this task (somehow he still has a job there after multiple reports), called into the local office to the head supervisor who knew my next call was the Office of Inspector General and the supervisor handled the situation and had funds released the next day. Always know the regulations – there are specific time frames for tasks to be completed and escalation measures if it is found to be service waste.

You can find dedicated fund breakdowns on the SSA website here.

- https://secure.ssa.gov/poms.nsf/lnx/0200602140
- https://secure.ssa.gov/poms.nsf/lnx/0502101010

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# **Department of Aging:**

The Department of Aging is ran by the state and you can find yours (or similar if setup) by searching for the department of aging and your state; services are intended to assist with older populations with programs directed to their age and specific needs, such as meals, Medicare Counseling, free Legal Services (60 or older/specific criteria), Caregiver/Aid needs, Employment, Health services, there is a

prescription assistance program, assistance with transportation and protective services to assist with potential abuse and safety needs and much more.

As of 2023, according to <u>OLR Research Report (This also breaks each state down)</u>, ten states have separate departments on aging - California, Florida, Illinois, Iowa, Kansas, Ohio, Pennsylvania, Rhode Island, Texas, and Virginia.

Nine states have a separate agency, office, board, or commission on aging that has substantive program functions and is designated the state unit on aging under the federal Older Americans Act – Alabama, Idaho, Maryland, Massachusetts, New Mexico, New York, Minnesota, Tennessee, and West Virginia.

Connecticut is independent but is in the Department of Social Services (DSS) for administrative purposes only and works as an advocacy.

In the other 30 states, aging programs and issues are handled either by (1) a division of a larger department, most often the human services or social services department, or (2) an office or division within the Governor's Office itself that performs the advocacy and sometimes the administrative functions of certain elderly-related programs.

You can find the Pennsylvania website here

Pennsylvania Department of Aging

You can find more resources and information nationally on the Administration of Community Living.

- https://acl.gov/about-acl/administration-aging
- ✓ <u>Pros</u> Free or low-cost services for older populations, multiple areas of assistance offered between health, community, assistance with safety and welfare needs and program assistance with new integrations.
- ✓ <u>Cons</u> Programs are available for specific ages and needs, so to qualify, you would need to fall within the specifications and some programs may be income dependent, state level interventions vary.

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### **Department of Health and Human Services (HHS):**

The department of health and human services is a federal ran department and oversees CMS which administers programs for individuals for Medicare, Medicaid, children's health insurance program (*CHIP*), the marketplace and other similar needs assistance planning.

You can find a lot of resources and information on their website here.

https://www.hhs.gov/

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### **Disability Advocacy Program (DAP):**

The disability advocacy program (DAP) is a program developed by the Department of Human Services and assists individuals with applying for SSI and SSDI and through any appeal process when applying.

The DAP advocate is a case worker who can step in and assist at any time during the initial or appeal process and can also assist with representing the client at an Administrative Law Judge (ALJ) hearing.

Services are referred by your local county assistance office which you can call to find more information.

You can also visit the Department of Human Services here for more information and resources.

https://www.dhs.pa.gov/PA-Community-Care/Pages/Advocacy.aspx

And you can find some information and resources at Disability Rights PA's website.

https://www.disabilityrightspa.org/get-help/

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# **Dual-Eligibility:**

Dual Eligibility is a term used for low-income individuals who are covered by Medicare and Medicaid as they qualify for both. There are different types of beneficiaries, as stated on the MLN Fact sheet PDF from CMS.Gov, which you can find here.

- https://www.cms.gov/outreach-and-education/medicare-learning-network-mln/mlnproducts/downloads/medicare\_beneficiaries\_dual\_eligibles\_at\_a\_glance.pdf
- Qualified Medicare Beneficiary (QMB) Program:

Pays Part A and Part B premiums, deductibles, coinsurance, and copayments.

• Specified Low-Income Medicare Beneficiary (SLMB) Program:

Pays only the Part B premiums.

• Qualifying Individual (QI) Program:

Pays only Part B premium (Medicaid/CAO side) and may not qualify for other Medicaid coverage.

• Qualified Disabled Working Individual (QDWI) Program:

Pays only Part A premium for certain individuals under age 65 with disabilities who have returned to work – having Medicaid, the CAO has a program that pays for B or at least, part of it.

Dual Eligible individuals usually fall in one of these categories and it just means this person qualifies between both state MA and Medicare. Medicare is always the primary insurance and Medicaid picks up where Medicare doesn't pay the rest.

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### **Durable Medical Equipment (DME):**

Durable medical equipment are equipment and supplies ordered by a health care provider and different plans have different benefits and income variances but are generally covered and work with items related to oxygen machines, wheelchairs, diabetic blood test strips or things like crutches or CPAP machines.

You would be surprised with what some things covered or can be implemented as DME and covered so it is always important to review your insurance information and know the specifics as you may be purchasing items out of pocket that could be paid for by your insurance company or at least covered by some degree."

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# **Early and Periodic Screening, Diagnosis and Treatment (EPSDT):**

Early and periodic screening, diagnosis and treatment services is a federally funded service that is free and open to adolescents from birth to twenty-one who qualify for MA and focuses on primary care.

This is also part of the waiver program for in home health aides or in home care with a paid family member for adolescents under the age of twenty-one; if you are caring for a individual under the age of twenty-one and contracted through a service to be their aide or have aides in the home, the individual is part of the EPSDT waiver.

Before they turn twenty-one, the individual will transition to another waiver such as community choices (*generally*), unless they qualify and/or choose a different waiver which there are quite a lot, but they are specific and some dependent on a lot of other factors or long waitlists.

You will want to transition and prepare for leaving the EPSDT waiver, so everything transitions smoothly without losing care in the home.

You can contact your local county assistance office for general needs or programming with ESPDT onboarding, but generally a child is receiving care from MA and is part of the process here.

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<u>F</u>

# Fair and Appropriate Education (FAPE):

All children with special needs are entitled to a fair and appropriate education by law and it is a powerful word you need to know and utilize during meetings with schools and interactions with planning to assist in obtaining it.

It guarantees the work put in to accommodate for children to be able to have their educational needs met just the same as atypical students, which means everything when negotiating with schools. If they do not provide this in a meaningful way, they are causing unnecessary damage to the child and can be sued.

If you have a child or work with children with special needs – this word you need to know and understand these words and how they function and know the school *is* responsible for ensuring this.

You can read about FAPE and order copies online here.

https://www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

Here is another link with Section 1415 from IDEA which overviews information with FAPE and procedures by statute law.

https://sites.ed.gov/idea/statute-chapter-33/subchapter-ii/1415

And here is a PDF which breaks this down even more.

https://www2.ed.gov/about/offices/list/ocr/docs/504-discipline-guidance.pdf

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# Family Based Mental Health Services (FBMHS):

Family based mental health services are services that meet with you in the home or community and provide family and individual therapy, crisis management, and assist with developing solutions on a more intense level.

Services generally meet twice a week, are *supposed* to be paired in groups of two certified staff members and are obtained by a referral for FBMHS by a licensed psychiatrist.

They are intended for adolescents twenty-one and younger with a diagnosis who are at risk for psychiatric hospitalization or residential placement and at least one caregiver in the home must be agreeable to the program.

Some may also have funding for community activities such as summer camp or family/individual activities in the community or for in home items to assist with special needs and overall functionality an item may provide and assist with behaviors up to a certain amount.

You can find more information by contacting your department of human services, an office of mental health or the bureau of children's behavior health; also, you can speak to the child's medication management provider (*Psychologist/psychiatrist*) and inquire about FBMHS to review for a referral for services.

In Pennsylvania, you can call (717) 705-8289 for more information, as well.

✓ <u>Pros</u> – Intensive in home and community treatment and support with licensed staffing to assist with a higher level of behavioral needs, family intervention and training with managing ongoing needs, treatment planning, crisis support and intervention.

✓ <u>Cons</u> – Poor staff training and service management, too intense for some individuals, poor crisis crisis management (*falls back to poorly trained staff*), child needs a higher level intervention, long waitlists/lack of staffing to assist.

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# Federal Poverty Income Guideline (FPIG):

The federal poverty income guideline is similar to the federal poverty level (FPL), but classes differently and is issued by the Department of Health and Human Services (HHS) for determinations.

Both the FPL and FPG identify and place different numbers of people below the same poverty threshold, but the FPG tends to place more people under the line than the FPL.

Different programs follow FPG and FPL which may make the determination different.

You can find some breakdown here and 2023 numbers here, if interested.

 https://www.shadac.org/news/fpg-vs-fpl-whats-difference-2023#:~:text=Ultimately%2C%20FPL%20and%20FPG%20identify,lower%20poverty%20categorie s%20than%20FPL.

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#### Federal Poverty Level (FPL):

The federal poverty level is a definition based on money income before taxes and doesn't include any capital gains or non-cash benefits, the official FPL is calculated annually and assists with reflecting inflation by the Census Bureau.

The federal poverty level influences a lot of programs and how you qualify – states generally follow by this formula or the federal poverty income guideline (FPIG).

These numbers can change yearly and are formulated between individuals and families.

You can find the current federal poverty level here and always check whenever for updates to get an idea of where you or you and your family fall currently to assist with understanding what qualifications you may fall under.

√ <a href="https://www.healthcare.gov/glossary/federal-poverty-level-fpl/">https://www.healthcare.gov/glossary/federal-poverty-level-fpl/</a>

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# **Free Clinics:**

Free clinics are clinics available to those without insurance free of charge or income-based charge – you can be seen for general health needs, and some have services for dental needs, as well.

There are free clinics throughout the states and finding care may require a bit of digging, but I am going to provide a link to search nationally for free clinics near you.

You can find this here.

https://nafcclinics.org/find-clinic/

You can also find information and resources here, as well.

https://www.freeclinics.com/

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### **Grants:**

When someone mentions grants, one can easily assume that grants are intended for more researchers or monetary figures someone is awarded, be it for a school or project. However, there are individual grants and in mental health, you will want to keep the word *grant* in your vocabulary.

This will be an individual write up with resources posted as there are far too many and for purposes here, I want you to use this as a strategy; go to your search engine and type in the specific diagnoses and grants. That's it. You will start your journey on multiple different grants available to individuals and families from vehicle modification needs, summer camps, specific assistive technology, and much more.

I will update this post with a link to a write up once complete, but for now – absolutely, there are a ton of grants available to assist with specific diagnosis needs through-out the states and national grant services that assist wherever you live.

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#### **Head Start:**

Head Start is an early intervention program for children birth to age five that centers around education with early learning and development, health and wellness and family planning.

Services are free for qualifying families – this is income at or below 100% of the Federal Poverty Line (FPL).

Head Start also has pre-school services for children aged three to five and again, are provided at no cost to eligible families.

You can learn more about Head Start Programs here.

√ https://www.acf.hhs.gov/ohs/about/head-start

And you can find a national Head Start program locator here.

√ <a href="https://eclkc.ohs.acf.hhs.gov/center-locator">https://eclkc.ohs.acf.hhs.gov/center-locator</a>

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# **Health Insurance Portability and Accountability (HIPPA):**

The health insurance portability and accountability act of 1996 is a federal placement of rules and regulations with a recipient's private information ran by the Office for Civil rights (*OCR*); you will hear this term frequently and goes hand in hand with release of information (*ROI*) documentation.

Remember all the documentation tracking in place? When you can prove items sent and confirmed and the office mismanages them, stating they never received them, you can actually make a HIPPA complaint – especially when it happens often, and mentioning your HIPPA rights to the service has an advantage on expediting your case needs when they mess up and you can prove it for this reason.

There are some variances on *who* has to follow HIPPA laws, but for the most part – for physical and mental health needs, you are covered.

You can review information and obtain resources about your HIPPA rights here.

√ https://www.hhs.gov/hipaa/index.html

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#### Home and Community Based Services (HCBS):

Home and community-based services are provided by Medicaid to assist individuals and families with services in the home and community – I will put in home health aid services separately with some breakdown on how to complete steps, as these are part of HCBS.

These are long term care (*LTC*) services that assist with care in the home or living facilities, as well as different waivers pertaining to those and other services with Autism waivers with similar goals and are a IDD service.

Obtaining these services follows the IDD services with having a PCP complete the MA-51 Form (ICF/MR box for Autism) and again, these are IDD services, so you would complete different assessments such as the such as the ABAS-3 (Adaptive Behavioral Assessment Scale), a support intensity scale assessment (SIS) and a goal assessment form.

To qualify, there are factors in life domains and for Autism, there must be diagnosis with certain assessments completed and same with intellectual, actual testing.

You will also obtain a service coordinator with HCBS services.

You can find more information on the Pennsylvania Department of Health website here.

√ <a href="https://www.dhs.pa.gov/Services/Assistance/Pages/Home-and-Community-Based%20Services.aspx">https://www.dhs.pa.gov/Services/Assistance/Pages/Home-and-Community-Based%20Services.aspx</a>

Other states have waiver programs, and you can find yours here on the Centers for Medicare and Medicaid website.

✓ <a href="https://www.cms.gov/training-education/partner-outreach-resources/american-indian-alaska-native/ltss-ta-center/information/ltss-models/home-and-community-based-services">https://www.cms.gov/training-education/partner-outreach-resources/american-indian-alaska-native/ltss-ta-center/information/ltss-models/home-and-community-based-services</a>

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### **Home Health Aid Services:**

Services intended to support individuals in the home with physical and/or mental health needs; services are provided in the home and hours vary based on need and level of insurance approval. These services can provide assistance with general cleaning, cooking, basic needs with laundry and shopping (some will provide transportation, but most will not or only allow special circumstances which means they do the shopping and will not take you to appointments) and can assist with personal hygiene needs such as bathing and toileting.

These services can be applied for yourself or someone else, but we'll use *you* as a template and define it as yourself, the person in need of services or those with authority to act on another's behalf.

This is for an adult, but children can be applied for and is similar in which case you start with your family doctor.

The first step for home health aide services, at least for those on Medicaid, is the MA-51 Form which must be completed and signed off by a licensed professional who agrees you need services, or is at least willing to refer you for home health aide services.

Once this is completed, you have three months (*form valid*) to complete the next steps with a state provider – in Pennsylvania, there are independent enrollment brokers, such as Maximus.

It gets tricky here because, realistically, it is not smooth and they will likely mess something up. You need to track every statement and call made – maybe you will get lucky, but this is doubtful. In the same day, I have called Maximus Independent Enrollment Brokers multiple times and received different statements each time – I mean hours on the phone and complete chaos; trust me, track and confirm.

You will complete an initial application, and this will signal other services to begin their end:

County services will request x number of years of financial statements – you will call your bank and request a printout of three years, I believe (they will tell you), of account statements which they will do for you and likely schedule a pickup time as they will need time to do this. You will turn this into the local county assistance office either by fax (keep confirmation of fax statement) or in person (in person is free and you obtain a confirmation number stating you handed documentation in. DO NOT drop it off in the drop box as you may receive a statement of never getting the documentation.)

You will also schedule a meeting with the Office of Long-Term Living – they will call you and visit you at your home to go over your needs and planning.

There will also be an in-home visit from Maximus IEB, as well, in which you will sign documentation and go over general needs and planning.

Between these steps, you may call Maximus IEB to confirm on documentation or check in and be told your application was denied; do not stress this as, likely, county services are still working on your financial approval, and something wasn't received or coordinated appropriately by services and it will be considered approved once finalized.

You will also need to pick a service coordination provider, change your insurance to a provider that works with home health aide services if the current insurance provider does not (you'll receive mail with options to choose from), and you'll want to choose a home health aid agency which will be assisted by the service coordinator.

If you have a family member who is willing and able to provide the home health aide services, they can contract through a home health aid agency; most now require training which the family member will be provided and paid for. You must specify this to assist with appropriate service transitioning.

If any steps are missing or not coordinated appropriately, there could be a denial or delay, so it is important to track and document everything, as well as check in on the application status to confirm on tasks completed.

Once all steps are completed and you are approved, services will begin; you'll be approved for a select number of hours (*units*) and an agency can begin working with you. You can apply for more hours if you feel you need more time in the home, but this will have to be reviewed and approved.

There are likely a large amount of home health aide services available for your location and you may need to change providers if you are receiving services you feel are not working; you can call your service coordinator and request to change and have the right to do so. I have actual photos of a home health aide sleeping on a person's sofa so who you receive as an aid is unpredictable and remember, these services do not pay their employees well and there is a lack of funding to them which means there is a high turnover rate and people calling off work.

There can be some issues with services sending over monthly unit approval requests which is something handled by internal services, *but* if a family member is providing services – it could affect their paycheck and it's important to note and call the agency they contract with to the issue immediately, no matter how many heads you must go above.

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### **Housing and Urban Development (HUD):**

The department of housing and urban development is a federal agency that manages policy and programs involved in housing needs in America and helps develop, monitor and fund housing programs through-out the states.

You can find information and resources on their website here - <a href="https://www.hud.gov/">https://www.hud.gov/</a>

HUD also has information available for home purchasing and other housing related services available in the community and is a good first stop with finding county services.

Subsidy housing is managed by HUD and if experiencing extreme issues, at times you can reach out to HUD for information, assistance, and some advocacy if programs are not following rules and regulations.

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# **Individualized Education Plan (IEP):**

An individualized Educational Plan is a powerful tool for adolescents with their educational needs and can get complicated fairly fast and treated as less valuable but rest assured that *this* is the front of the war families and students often face with educational institutes because this plan defines and holds those institutes accountable (*you can sue the school for unnecessary suffering*) – *unless* they are an alternative school which has loopholed their way through as state ran program which presents different discrepancies to suing or if they attend a private school which does not have to follow the same laws with an IEP, but private schools *do* have to follow some state guidelines.

First and foremost, an IEP evaluation can be requested at any time by a support or caregiver, *but* there are discrepancies they must meet to qualify for an IEP. There are 13 qualifying disabilities categories and there needs to be a "thought to be," in need for a special education – for details on this, see Pennsylvania IEP and 504 Service Agreements which can assist with specifics.

Educational institutions have an obligation to support the learner; if they are failing, it is the school's responsibility to provide accommodations and assistance to help that learner succeed. That's right, all those calls they deliver informing you of your child's behaviors or failing to succeed and looking to you to fix it with no solutions or aid on their end? Yes, incorrect.

I once sat in a room with a family member (the student), the school psychologist and the school social worker who, even in body language spoke refusal to assist with her legs crossed, body positioned away and her facial expression blank as both of them stated there was "nothing they could do," to help — a child who they determined did not need an IEP after a request for review with severe anxiety and associated behaviors, eloping and fighting at the school. The Governor Mifflin High School is certainly deserving an award for that one (among other incidents at the same location with different students) and unfortunately, there are more like them. You may have to fight this one out and unfortunately, obtain an educational attorney from the door to get results.

On the positive side, most schools *actually* want to help and are not like some locations, tending to assist and implement positive accommodations. However, the caveat is they won't tell you *exactly* how much they really can accommodate or assist.

Often, implementations can assist with different educational variants such as more multiple-choice options, going to different rooms in the building for tests, having questions read or explained better when needed, speech therapy, hours (*Units*) for one on one educational support with reading interventions and supports with mathematics, as well as mental health supports with behavioral needs such as breaks or ability to request to go to a support when feeling overwhelmed or anxious during instruction, and many other integrations to add and create accommodations.

These assists can extend to children with school refusal, changing school hours for the student to come in for shorter day periods or even for a few hours (*I've seen a child come for an hour a day*) and a lot of schools are beginning to create and run their own alternative option with smaller classrooms which they run as a program.

The plan is considered agreeable by all parties and is binding which means it overrides general practices and all teachers and staff are expected to follow that plan; if they do not, the child is not held as accountable as the staff who did not follow the plan and behaviors and needs are considered within the school's ability to accommodate them as stated in the plan – so, calling you weekly should stop.

IEPs are reviewed annually and amended as needed and if the school is unable to prove they can accommodate by incidents still occurring, you can request an alternative school placement and sue the school district for unnecessary damages if they refuse alternative placement and the child continues to suffer setbacks and barriers. You can find more information about alternative placement in this write up in section A and there is more depth here to review for IEPs which will be in a future write up or linked here when complete about IEP navigation.

IEPs also extend to age 21, which means the learner *can* receive educational services until they are twenty-one.

Educational Attorneys are a great resource with assisting with IEP and student needs for educational institutions that fail to accommodate or assist with actual solutions – some are provided free and only take payment if the school is sued, in which they take a percentage of the award and you will complete an intake for review to see if they feel you are a good candidate for services due to this.

I am providing a link for Pennsylvania which is a helpline where you can speak with special education advocates about any questions or concerns with assistance in pointing you in the right direction.

- https://www.education.pa.gov/K-12/Special%20Education/Complaints/Pages/ConsultLine.aspx
- ✓ Pros A binding agreement which states accommodations and ability for the educational institute to be able to support the child and their specific needs, powerful tool to assist with individualized needs and planning and avoid ramifications with treatment or being labeled as a "bad," student, assist with physical and mental health supports and help qualify learners for other programs and family assistance.
- ✓ <u>Cons</u> School refusal to assist or deny students for services, complex regulations which require a lot of time to learn and become familiar with, full range of capabilities more difficult to discern as different locations have different results in what they offer, lack of funding.

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# **Individuals with Disabilities Education Act (IDEA):**

The individuals with disabilities act will come up often – it is a federal program that governs the states and protects the right of individuals with disabilities to obtain a fair and appropriate education (*FAPE*). IDEA also does grants for programs through-out the states (*State Formula grants*) ran through the Office of Special Education Programs (*OSEP*) and discretionary grants which are more competitive and selective to those applying for the specific grant and managed by OSEP, as well.

Children birth through two years old receive early intervention services under part C and children three to age twenty-one receive special education and related services under IDEA part B, which is just an age breakdown and how services are considered.

You should become familiar with IDEA and read over policies and the law to familiarize yourself with terminology and a child's rights as this is your power.

You can find laws and regulations and other resources on the IDEA website here.

✓ <a href="https://sites.ed.gov/idea/">https://sites.ed.gov/idea/</a>

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# **Inpatient:**

Care that is received after being admitted to a hospital or mental/physical health facility.

When you hear inpatient, it just means you or an individual has been admitted for a period of time and will receive care at the location.

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#### **Intellectual Disability Services (IDD):**

Intellectual disability services are services provided in the community and home and are part of a waiver which is most often completed by the PCP with the <u>MA-51 Form</u> - you will need to check off a box, the **ICF/MR** box for Autism related services but other boxes depending on which the individual is qualifying for – they can tell you at your local MH/DD/ID office (*In Pennsylvania*, at least).

The Office of Developmental programs is an entity of the Department of Human Services and your local county MH/ID's role is to verify your information and eligibility.

I have seen a psychiatrist complete this form, but more often – the PCP is your go to.

You will need a psychiatric evaluation with specific Autism related testing if applying for IDD services with Autism specific needs and IQ testing related evaluations for MR specific needs.

You will send these forms to your county Intellectual Disability Service location (*MH/ID*) who will review and complete intake needs, you are assigned a service coordinator and assessments need to be completed which you'll have assistance with, such as the <u>ABAS-3</u> (*Adaptive Behavioral Assessment Scale*), a support intensity scale assessment (*SIS*) and a goal assessment form.

From there, they can review services available to you with community integration and life skill building – services tend to be more intensive; this means meetings generally twice a week for longer periods. Services are meant to assist with community integration, life skill development, employment training, adult day care services, case management, mobility training and even have assistance with transportation for education and work.

You can find more information about Pennsylvania IDD services here.

✓ https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Intellectual-Disabilities-Services.aspx

You can also reach out, in Pennsylvania, to the Office of Developmental Programs at 1-888-565-9435 which is the intellectual disabilities service customer service number.

You can find your local or states agencies worldwide here:

√ https://www.nasddds.org/state-agencies/

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#### **Juvenile Justice Services:**

Services within the juvenile justice system can sometimes be more, unfortunately, adequate for youth that are aggressive physically; they may have underlying diagnoses and environmental factors and need more intervention services, but the mental health sector is limited to availability, programs, diagnosis needs, referral needs and a wide range of letdown which makes treatment difficult and families ultimately suffer. Turning to the juvenile justice system is sometimes a last ditch effort to obtaining results for certain cases to get the child into treatment but alas, it also is human run and can come with restrictions and cause more trauma or even no results, all the same, as I've seen it happen.

Let's examine this.

In Pennsylvania, the Bureau of Juvenile Justice Services (BJJ) is meant to ensure services based on criminogenic risk, needs, and responsivity factors that work with private and public services in the state. They can be a first step in obtaining information and resources when services are failing to support the youth and are a good starting point. I've been to court cases enough to know they are never mentioned to families and most times, the family or youth is simply fined and sent on their way.

There is information you can find on the Youth Development Center/Youth Forestry Camp System here.

https://www.dhs.pa.gov/Services/Children/Pages/Forestry-Programs.aspx

You can find more information about the department, as well as other entities and programs here.

https://www.dhs.pa.gov/Services/Children/Pages/Juvenile-Justice.aspx

There are many county-based services and state-wide services available for the Pennsylvania Academic, Career and Technical training (PACTT) services and I am going to link to a list of them all. You will find

names of locations with signatures of being community based, open residential, secure residential or a mix. Community based is in the community and residential is on-site and secure or open signifying the level of intensity and treatment – open is with close supervision while a secure site is considered locked doors. If you follow this link and click on locations, you will pull up PDFs with breakdowns to each center and you can always reach out and ask questions on how a facility does intakes or how referrals come to assist with actual data and how to go about getting the treatment.

https://www.dhs.pa.gov/Services/Children/PACTT/ layouts/15/formspubs/formsandpubs.aspx

You can find national information and resources online on the Office of Juvenile Justice and Delinquency Prevention (*OJJDP*) website here.

https://ojjdp.ojp.gov/model-programs-guide/home

And tons of guides and programming under implementation here.

https://ojjdp.ojp.gov/sites/g/files/xyckuh176/files/mpg-iguides/index.html

NAMI also has a large of amount of information and resources with handling mental illness and intervention be it both for adults and youth.

- https://namimainlinepa.org/info-resources/criminal-justice-resources/
- <a href="https://namimainlinepa.org/info-resources/mi-help/#youth">https://namimainlinepa.org/info-resources/mi-help/#youth</a>

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### **Keystone Education Yields Success (KEYS):**

The Keys program is a program in which the Pennsylvania Department of Human Services (*DHS*) works with the Pennsylvania Commission of Community Colleges to assist individuals on TANF and some SNAP recipients with continuing their education. The program also has assistance with GED support and classes.

Individuals interested can speak with their CAO.

I am providing a link with a break-down for TANF recipients that covers a lot of details as it is required for TANF recipients; I was part of the Keys program myself during my associate degree while on TANF and the program was *actually* nice despite some of the hour requirements and checking in. You have a lot of support here and opportunities available to you being a part of it.

✓ https://www.palawhelp.org/resource/the-keys-program-things-to-know

You may find more information, as well, by searching your local community college and the Keys program to find more information on services available, such as GED and if not on TANF but SNAP. The referral will be completed, and the CAO will confirm on SNAP and TANF benefits during this with the coordinator of the program at the community college.

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# **Local Education Agency (LEA):**

The local education agency is the school district and at IEP meetings, the person attending the meeting is the individual representing the school district.

They are important for approvals and during IEP meetings, you actually want the LEA to be part of this as they can answer questions about funding and mitigate approvals *and*, by IDEA, if they were not part of the IEP meeting – the IEP meeting didn't happen.

I have been on many IEP meetings and the IEP representative was not there and staff could not answer some questions and even utilized this fact to stall requests and needs.

Here is a site you can read more about LEAs and other special education information on

✓ https://adayinourshoes.com/who-is-the-lea-at-iep-meeting/

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### **Managed Care Organization (MCO):**

A MCO is a managed care organization is a health plan or company that offers services are low and reduced prices in agreement with managed care needs.

There are four types of MCOs or plans: Preferred Provider Organization (PPO), Health Maintenance Organization (HMO), Point Of Service (POS), and Exclusive Provider Organization (EPO).

These terms would need a write up alone as they can be complex, but for the most part they are more relevant with Medicare or private insurance contracting while Medicaid chooses a MCO and it is your physical health side of insurance, while the *BH-MCO* is more mental and behavioral health.

MCO's are different in counties, and you usually have at least three or more choices in who you select. You and your family can *choose* different MCOs, also, under the same case. Sometimes this has benefits,

such as in Berks County in Pennsylvania – I find Amerihealth Caritas more positive for mental health and UPMC more positive for physical health needs.

You can find more information about your MCO and other MCOs (you can change) here.

https://enrollnow.net/index.php/

And resources in PA's Department of Human Services website for those qualified and exceptions for some qualifications outside of income here.

https://www.dhs.pa.gov/Services/Assistance/Pages/Medical-Assistance.aspx

You can search for similar exceptions and information on your state's department of human services website or call your local county assistance office.

You can also find information about prior authorizations or limitations at the MA MCO's toll-free number on the back of your insurance card and for information on Fee-For-Service information, the Fee-For-Service Recipient Service Center at 1-800-537-8862.

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# **Medical Assistance (MA):**

Medical Assistance (*MA*) is a qualifying insurance program from the state for low-income families, also known as Medicaid. You may qualify for other programs not defined by income levels such as certain diagnoses and conditions which will enroll you and children with disabilities that meet the special needs <a href="Category">Category</a> are separated by income dependent guidelines.

See Medicaid.

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# Medical Assistance for Workers with Disabilities (MAWD):

Medical assistance for workers with disabilities is a program setup for individuals who have a disability but make over the state breakdown amounts for earned income to qualify for Medicaid – the amount over is capped at \$10,000 in resources and there *has* to be some form of income.

The nice part is this means, at bare minimum if the individual does not hold an atypical job, you can write a note stating the individual comes to your home once a month and washes the dishes for \$5 and it counts.

There is a monthly premium that must be paid – this goes by your income after deductions and if you are under or equal to 250% of the FPL, you will pay 5% of your countable income. There is a 7.5% premium of your countable income if you are in the Workers with Job Success program, while the total premium is \$948.00 if none qualifying in brackets.

Anyone with a disability, as defined by SSA standards but you do not have to be obtaining SSI or SSDI to qualify and it is for those 16 years old to 65 years old; these include mental health diagnoses which is why it is important for have your psychological evaluations completed.

You can apply online or by contacting your local county assistance office. This is Pennsylvania specific, however there are other states with similar programs, so the goal is to find what your state offers — doing a quick search with MAWD and different states brings up different programs and is a good starting point for anyone not in Pennsylvania.

You can find the Pennsylvania MAWD program information here.

https://www.dhs.pa.gov/Services/Assistance/Pages/MA-for-Disabled-Workers.aspx

And here is a link to a PDF with a PA state flyer breaking information down on MAWD.

https://www.dhs.pa.gov/Services/Assistance/Documents/INDIVIDUAL%20PAGES/MAWD/MAWD %20FAQ.pdf

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# Medicaid:

Medicaid is insurance for low-income families run through state programs that implemented the program. Medicaid is income dependent and applied for through your county assistance program; once approved, you'll be able to choose between different providers as part of the freedom of choice that was put in place to allow families to choose, if you do not actively choose a provider will be selected for you. You can change providers and are not locked in, and services assist with mental health, medical, dental and vision, as well as specialists with referrals.

- \*Special note Adolescents with a diagnosis that fits the special needs <a href="Category">Category</a> qualify for Medicaid (*up to* eighteen) and cannot be removed due to income limits being too high. Also, adults with diagnosis and income barriers can qualify for program extensions such as MAWD with some out-of-pocket expenses.
  - ✓ <u>Pros</u> Full coverage with generally little to no co-pays or out of pocket payments, no cost for coverage itself, offers insurance solutions for low-income individuals and families.
  - ✓ <u>Cons</u> Income dependent potential acceptance with program knowledge and ability to navigate it, work barriers if your job location offers insurance and needs to work out coverage.

You can find the PA Health and Wellness Manual in PDF form (this view with providers showing what is expected), which has specific guidelines and time frames for services to complete tasks and is a good source of information and staying in control of your healthcare and making sure needs are met.

✓ <a href="https://www.pahealthwellness.com/content/dam/centene/Pennsylvania/pdfs/2023%20CHC%20">https://www.pahealthwellness.com/content/dam/centene/Pennsylvania/pdfs/2023%20CHC%20</a>
PHW%20Provider%20Manual%20FINAL.pdf

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## **Medically Necessary:**

The term "medically necessary," has a large of amount of break downs for different services, however it is generally a service or device that is considered necessary to assist with avoiding further onset of illness/diagnosis/disability, will alleviate the condition, and will assist with helping the individual main maximum functional capacity in life and social sectors.

It is important to know breakdowns for potential needs you have because sometimes it is all in the wording and a lot of times, it is just in the wording, and knowing how to word or point the arrow is the major difference in obtaining services by a provider with insurance approval and being denied.

I am putting a link here from the Centers of Medicare and Medicaid which lists conditions and various breakdowns on treatments, tests, and therapies and how they qualify. It may be tedious, but it *is* your power to know.

√ <a href="https://www.cms.gov/medicare-coverage-database/search-results.aspx?keyword=medically+necessary&keywordType=starts&areald=all&docType=NCA,CAL">https://www.cms.gov/medicare-coverage-database/search-results.aspx?keyword=medically+necessary&keywordType=starts&areald=all&docType=NCA,CAL</a>
<a href="https://www.cms.gov/medicare-coverage-database/search-results.aspx?keywordType=starts&areald=all&docType=NCA,CAL,NCD,MEDCAC,TA,MCD,6,3,5,1,F,P&contractOption=all</a>

And here is a link to the Pennsylvania code website which briefly defines it and you can go back and review more specifics on the site with code and law put into place.

✓ <a href="https://www.pacodeandbulletin.gov/Display/pacode?file=/secure/pacode/data/055/chapter110">https://www.pacodeandbulletin.gov/Display/pacode?file=/secure/pacode/data/055/chapter110</a> 1/s1101.21a.html&d=reduce

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#### **Medicare:**

Medicare is the whole devil, and his details are extensive, but it can be easier once you relearn the alphabet; I will write up a Medicare specific post to assist here but we can briefly explain it here.

Medicare is a federal program ran by the Centers for Medicare & Medicaid Services and is provided to those on SSDI (*after two years*), those retired and 65 and older, those with End-Stage Rental Disease, and some younger people with disabilities that qualify for Medicare. It does *not* cover dental and vision.

If you have Medicaid, you can be dual covered with Medicare as your primary and Medicaid secondary in picking up payment where Medicare does not.

With Medicare, you can only be seen by providers licensed to see Medicare patients which means a *large* gap happening in the mental health field; most services only have one clinician with ability to see Medicare patients which means no availability. It is a completely ridiculous situation currently in which Medicare recipients are highly limited now to mental health care due to credentials needed to be seen and they lose almost all access to treatment.

There are many letters which mean different services and parts of this insurance – let's digest some.

Part A – This is for inpatient hospital care, skilled nursing facilities, hospice, lab tests, surgery, and home.

- health care. There is no cost here associated with the plan payment for Part A. (*Hospital Insurance*)
- <u>Part B</u> Services from doctors and other health care providers think general treatment, visits to providers. There is a Part B cost that is a flat fee currently at \$164.90 (2023) and this payment is and can be waived for those income qualifying by county assistant programs. (*Medical Insurance*)
- Part C Medicare Advantage Plans that combine A, B, and D into one whole insurance plan with dental and vision often covered as part of it. There are *a lot* of advantage plans available and a lot have no cost and come with perks such as utility assistance, food cards, transportation services and other advantages. It is crucial that you verify your current providers accept the advantage plan you choose as some take only straight Medicare or a different advantage plan; staff assisting with plan setup are *supposed* to verify if the providers you see do or do not accept their plan and will during the call, but if you forget a provider you see they cannot verify this.

  There are time frames for open enrollments and an open enrollment time of six months from the time you begin part B which means changes do not go into effect instantly at times.
- Part D Part D is your prescription plan and you can choose who you would like to manage your services here as there are different providers, as well. If you get a Part C plan, you will still select a prescription management provider but it will be wrapped up in Plan C.

  If you do not have Part C, you will have A, B and D and select your Part D provider all the same.

  Services range here, as well as costs, and differences with dual coverage which may cover more.

  Medications run under tiers which class medications under different cost brackets and are influenced or can change in cost with length on Part C plans you can work with agents to review your medications and potentially obtain a generic or variation that is covered to avoid out of pocket costs. There is also a *Medicare prescription drug donut hole* in which Medicare part D only covers X amount of prescription costs and you'll have to pay, up to a yearly limit, out of pocket costs until the coverage gap ends and they pay again.

# Part F, G, and K-N

• These plans are known as Medigap coverage and are supplemental. Part F was stopped and only those who have had it before 2020 will continue with it due to the premium rising substantially

each year. If you do not have Part C, you would choose one of these for vision and dental needs and you will pay out of pocket costs for each plan and there are, again, multiple providers. This means you could have A, B, D and say G Dental and possibly N for Vision if qualifying and available.

- Medigap Breakdown here is a chart that is somewhat confusing, likely, but does tell you
  different plans and coverages to assist with understanding.
- ✓ Pros Medicare provider a federal ran coverage to assist with an individual's insurance needs at a lower cost than paying out of pocket or for a private insurance company, many options to assist with a specific plan that works for you as an individual, Medicare Advantage options which substantially cover more and provide more options for individuals, with less need for referrals.
- ✓ <u>Cons</u> High costs associated with straight Medicare, lack of providers with Medicare credentials to see Medicare patients in the mental health field, no vision or dental coverage due to the government declaring vision and dental *not* medically necessary, excessively confusing to navigate.

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# Mental Health/Developmental Disabilities (MH/DD) Intellectual Disabilities (ID) – MH/DD/ID

The office of mental health and developmental disabilities/intellectual disabilities in Pennsylvania manages and funnel a plethora of programs and waivers, as well as can help with information regarding those programs.

The MD/ID act of 1996 established the MH/DD program and is funded through federal and state grants and managed by the Department of Human Services, OHMSAS, the office of child development and early learning.

You may hear MH/ID or MD/DD or MH/DD/ID in terminology and I've seen other lettering attached – for the most part, the main key words are mental health, development disability, and intellectual disability and you can find your states center by searching MH/DD or MH/ID and your state name.

In Pennsylvania, you can find the county office information here.

https://www.countyofberks.com/departments/mental-health-developmental-disabilities

And a list of MH/DD centers by county here.

<a href="https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/ODP-County-MH-ID-Office-Contacts.aspx">https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/ODP-County-MH-ID-Office-Contacts.aspx</a>

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## **Midpenn Legal:**

In Pennsylvania, Midpenn Legal is a service assisting with legal aid for a broad range of needs outside of criminal (they assist with expungement and sealing of records), traffic or DUI tickets, personal injury and workman's compensation – they are a great resource and I have worked with them multiple times.

The service can be two-fold as I have seen some provide counsel on cases but not representation (*i.e., I had to represent my client in court with signed representation*) and I have seen them in action in court and win cases.

It can also be dependent on availability as I have called during a period of time and was told there were no staffing, but this seems to have gotten better since then.

You can find their website and intake information here.

https://www.midpenn.org/

There are also resources worldwide for free legal assistance that is provided pro bono, as well as likely free services similar in your state if not in Pennsylvania. I am providing links for pro bono resources worldwide.

- https://www.justice.gov/eoir/list-pro-bono-legal-service-providers
- https://www.americanbar.org/groups/legal\_services/flh-home/flh-free-legal-help/

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# **Multi-Systemic Therapy (MST):**

Multi-Systemic Therapy is a service provided for youth with intensive mental health needs, substance abuse and/or juveniles with associated issues with the law and maladaptive behaviors. The services meet more regularly, weekly to bi-weekly, and will work with the youth and family of the youth.

Services tend to be more focused on the family to assist with developing treatment and safety plans which can help the family when behaviors are active. MST services can also assist with referrals to other programs, but again – you are faced with staff that may not be trained appropriately and, as with all services, you are limited to their ability to assist. I had one who did absolutely nothing and I'm not sure what their point in being there was other than as another service to assist with showing the extreme level of need and solutions for the client. You can report issues and request new staff if having issues.

Services are covered by insurances, fully by BH-MCOs (children with diagnoses qualify for Medicaid despite income limits and Medicaid will pay for this service fully – in Berks, that's CCBH).

- ✓ <u>Pros</u> Intensive service centered on the child and family needs with planning to help with behavioral planning and mental health needs, meets consistently and in the home or community, ability to obtain referrals through services, extra support when needed to assist with high level referrals.
- Cons Untrained staff and poor service management, inability to obtain higher level of need

referrals such as RTF placement, more focused on in home plans that sometimes are not realistic or effective, families/supports at times are the bigger issue with following through on plans so service planning is not effective for the youth.

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<u>N</u>

# National Alliance on Mental Illness (NAMI):

NAMI is an amazing advocacy service with national services and state branches; they are your ally and a great support when you are uncertain or need more information about a particular issue or barrier. They also have support groups and walk in centers at locations which both adults and youth can utilize as needed.

I can sincerely say that I have never had any issues with NAMI and they *always* pulled through for me when called on; I had a case in which a client was hospitalized (Self Admission) for psychiatric care and the location was actually suggesting and hinting to my client about needs to "behave," and threatening to keep my client longer despite no need, attempting to coerce agreeance and even went as far as to state everyone stays longer as part of their care (*sadly, this can* happen) and conditions and staff behaviors at the location were highly questionable – I called on NAMI and together, we had my client discharged. Educational discrepancies? NAMI was there, even reading over the IEP and detailing everything noticed and outside of law and rights. Behavioral barriers and youth age related service barriers? NAMI assisted with multiple resources and information to assist with finding solutions.

NAMI is an incredible resource and support for any barriers or questions you may have or face with services, community needs, and mental health services.

# **NAMI National Website**

You can also call the NAMI Helpline at 1-800-950-6264 or text "HelpLine" to 62640.

- ✓ <u>Pros</u> Extra support and resource available in the community for free to assist with navigating through and with services, educated staff able to assist with informative needs and guidance, support groups, local centers available to visit and obtain services from.
- ✓ <u>Cons</u> Services are an assist and guide, limiting ability to assist like that of a case manager or other more intensive, long-term service.

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#### National School Lunch and Breakfast Program (NLSP):

The national school lunch and breakfast program was signed into law by President Truman in 1946 and has assisted families with free and reduced lunch prices since.

Free lunches are provided to children whose families qualify as earning at or below 130% of the federal poverty income guideline (*FPIG*) and reduced for families who earn at or below 185% of the federal poverty income guideline (*FPIG*).

The School Breakfast Program (SBP) is administered by FNS in public and private schools and residential facilities and is similar to the NLSP in which families receiving SNAP and TANF and/or at or below 130% of the FPIG receive free breakfast and those between 130% and 185% are eligible for reduced breakfast.

There is also an Afterschool Snack Program (ASP) which is income dependent and provides snacks to eligible children.

Children may be categorically qualified, also, if qualified for SNAP, TANF, or are homeless, a foster child, runaway, or migrant.

You can find more information nationally here.

https://www.fns.usda.gov/nslp

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# Office of Inspector General (OIG):

The office of the inspector general is a powerful tool to utilize when a service is failing you, especially with the social security office, but their powers *are* limited in some areas when dealing with a business as they are not a legal service and more a mitigation effort to help both parties come to a resolution.

Now, there is an OIG Social Security department, but this is more related to fraud with social security — do not listen to staff if you call the incorrect number that will tell you to contact someone else or that they do not handle those complaints. You'll likely get lucky or play some phone tag here without knowing the specific information — I had a particularly rude staff at the OIG SS redirection I was put on inform me completely incorrect information despite actively correcting him and it ended with him giving me a national social security number and hanging up on me. Your best bet is to complete an online form here, but calls will get you to the right place when you have options for service waste of the employee.

The OIG handles various complaints, and you can find some breakdown here - Office of Inspector General website - types of cases handled.

You are told you will be contacted when any complaint is submitted, but I have rarely seen this happen – eventually an e-mail comes from staff with statements of reaching out to the other party and the results of that outreach, but there are times when more information is requested. It's important to follow up and keep data in writing, as well as present as much information as possible.

I have mostly utilized the OIG to report service waste in the social security department when cases were not being handled appropriately, which is quite often. I had cases that a case worker did not complete a task for almost a year (there are time limits between different tasks) and didn't return calls, as well as cases with staff not completing tasks which were holding up funds being released or finalizing on needs

to move forward during different application steps, and one particularly ugly case with the service continuously causing overpayment issues and errors on one client's case and then stated she did not return documentation, then stated she agreed, then attempted to go back to old periods of data which made no sense and it was a constant pit of crazy which the OIG completely overrode and she hasn't had issues since nor was she determined need to pay back anything due to errors on the social security side.

You can choose to report anonymously or with your information – in most cases that are specific, you will need to have some identifiable information for them to correct the situation and look into it.

You can submit a complaint online on their website here - https://oig.hhs.gov/fraud/report-fraud/

You can submit service waste, fraud and service abuse online here on the SSA OIG website here.

https://oig.ssa.gov/report/

In Pennsylvania, you can report government misconduct at 1-855-372-8372

You can call the OIG report line at 1-800-447-8477 nationally.

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## Office of Long-Term Living (OLTL):

Services are targeted to assist individuals with long term care needs such as those with home health aides and in nursing/long term care facilities which may require care and service supports. They also offer information to assist with planning and support, work with individuals with self-directed care needs and have individual services with care managers and service coordination, work with waivers and assist and can be a support when reporting services for abuse, neglect, and service waste.

- Office of Long-Term Living Information and Forms
- Long Term Care Handbook

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# Office of Mental Health and Substance Abuse Services (OMHSAS):

OMHSAS oversees the behavioral health program that provides behavioral health and substance abuse services that are provided in your county and assist with oversight, reporting, and creating and managing programs with services provided by county Mental Health and Developmental Services (MH/DH) in Pennsylvania.

You can reach out when needing information or oversight and potential reporting information needs if one of the programs/services is not appropriately fulfilling their role.

OMHSAS Information

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# Office of Vocational Rehabilitation (OVR):

The office of vocational rehabilitation is a service targeted to assist individuals with mental and physical disabilities with employment assistance *and* so much more.

All 50 states have one designated vocational rehabilitation (VR) agency and 22 states have established two VR agencies; one that services individuals with who are blind or have visual impairments (*Blind VR agencies*) and a separate VR agency that serves individuals with all other types of disabilities (*general VR agencies*).

You can find more information about your state on the Rehabilitation Service Administration website.

Services work with children and adults with a wide range of disabilities and assist with IEP meetings for children, as well as diagnostical assessments and testing to support an individual with their goals which are low cost or free depending on income – those with SSDI and SSI do not need to complete a Financial Needs Test (*FNT*) as service fees are waived (*free*).

Some of the services provided are transportation, assistance with housing needs to assist an individual with employment (*repair/remodeling with disability and employment needs factoring together*), job shadowing, skill training and certifications, assistance with driver's licensing services, and in Pennsylvania there is even a college program with different options that works with OVR.

You can find a handbook copy online at <u>PAAutism.org VR Handbook</u> and a more detailed VR college and employment written one at <u>PAProviders.org (PDF)</u>.

To apply in Pennsylvania, you can find resources and links on the <u>Department of Labor and Industry</u> website.

Generally, in the beginning, you can call and complete an initial registration which will lead to some basic information and assessments to assist with review and assignment then, you'll get a letter in the mail with who you are being assigned to for a case worker with their contact information and you will reach out to begin scheduling.

- ✓ Pros Large number of programs available to assist with employment and disability needs, low cost or free, works with waiver programs and can assist with onboarding to potential waivers, consistent support, assists youths and families with IEPs and employment training.
- ✓ <u>Cons</u> Poor staff training and service management potential, communication and coordination barriers, not all services available are out right stated so an individual may miss opportunities if not informed, potential waitlists/specific program availability.

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# **Outpatient:**

Outpatient care is registering and being onboarded at a physical or mental health facility, but receiving services without staying at the location long-term, i.e., you attend treatment then go home.

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<u>P</u>

# Partial Hospitalization Program (PHP):

Partial hospitalization is an outpatient facility treatment center where you receive therapy and medication management on site, but while still living in the community and is more intensive than general therapy and medication management.

For adults, treatment is daily, and you will attend between specific hours or as in your treatment plan.

For children, they will attend a program daily instead of school (*School services will provide transportation and be considered waived for educational needs due to mental health needs*) – often the school will provide an online option to complete schoolwork and slowly integrate back to full time educational services.

Services are generally obtained by referral from another mental health provider, *but* do not need a referral necessarily from a licensed provider – this can come from a service, parent, or other support involved. Service and length in time for treatment varies, but generally can range from a month to three months.

- ✓ <u>Pros</u> Daily therapy and medication management, step-down planning management for ongoing service needs, serves children and adults, paid for by insurances completely by the BH-MCO (*CCBH in Berks County*), transportation services provided by school services (*youth*) and some services provide transportation for adults.
- ✓ <u>Cons</u> Limited availability (*there are only two in Berks County for children*), long wait lists, costs associated with insurance, transportation barriers, obtaining referral for service.

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#### **Peer Support Services:**

Services intended to assist individuals with support from other individuals who have experienced similar barriers with mental health and substance abuse. Services meet regularly and more intensively with weekly to monthly scheduling and are intended to assist with general recovery and finding solutions with barriers and needs. There are multiple services here in Berks County who offer PSP and are generally covered by insurances and fully by BH-MCOs.

- ✓ <u>Pros</u> More intensive services designed to assist with rebuilding your goals and skills by others who have had similar experiences, staff are trained and certified, positive support and community building, consistent support.
- ✓ <u>Cons</u> Poor staff training and bad service management, time barriers with required program hours and ability to meet, may be too intense for some individuals.

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# Pervasive Developmental Disorders (PPD):

Pervasive Developmental Disorders are characterized by delays within the social and communication development of an individual.

You may see this term in passing with autism spectrum disorder (ASD) as individuals tend to display mild ASD symptoms, but do not necessarily meet all the criteria and PDD is often termed as atypical autism.

There are five disorders identified with PDD – autistic disorder, Rett's disorder, childhood disintegrative disorder, Asperger's syndrome and pervasive developmental disorder not otherwise specified/PDD no other symptoms (*NOS*).

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## **Pregnant and Parenting Teen Program (ELECT):**

The pregnant and parenting teen program ELECT (*Education Leading to Employment and Career Training*) is a program funded by DHS and administered by the PA Department of Education.

The goal of the program is to assist with graduation planning and success, transitioning to employment or higher education, assist with parenting skills, life skill training, domestic violence, and even assist individuals who dropped out return to school that are pregnant.

Services are for individuals under twenty-two, expectant or custodial parent receiving TANF or at or below 235% of the federal income poverty guideline (*FPIG*) and in an educational program or intending to return. *This program is also available to males whose paternity has been verified.* 

You can find more information by contacting the Centers for Schools and Communities at (717) 763-1661 in Pennsylvania.

You can find more information on the Department of Education here.

<a href="https://www.education.pa.gov/Policy-Funding/FederalPrograms/ELECT/Pages/default.aspx">https://www.education.pa.gov/Policy-Funding/FederalPrograms/ELECT/Pages/default.aspx</a>

Some states do have an ELECT program similar, like Delaware – I would search for your state's programming and visit the department that manages human services.

You can find some resources here.

https://americanpregnancy.org/unplanned-pregnancy/getting-help/

And the federal program for reproductive health services has search resources here.

https://reproductivehealthservices.gov/

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#### **Pre-K Counts:**

A lesser-known program for families who may not qualify for Head Start or other programs, the Pre-K Counts program provides full or half day pre-kindergarten services for free for at risk children ages three and four for families that make up to 300% of the FPL.

I am going to assist here with 300% of the FPL – you can find a breakdown here that has a guide and information as this is a bit dependent on congress and complex.

https://taxfoundation.org/research/all/federal/what-300-percent-poverty-level/

As of February 2023, only Florida, Oklahoma, Vermont, and Washington D.C provide free preschool services and most states have programs.

You can find nationwide free preschool programs here.

https://www.freepreschools.org/

And in Pennsylvania, here is a link to a Pre-K Counts PDF flyer with information and resources.

• <a href="https://www.education.pa.gov/Documents/Early%20Learning/Pre-K%20Counts/Pre-K-Counts-Brochure.pdf">https://www.education.pa.gov/Documents/Early%20Learning/Pre-K%20Counts/Pre-K-Counts-Brochure.pdf</a>

You can also find information on the PA Compass website or by contacting your local county assistance office.

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# **Primary Care Physician (PCP):**

When you hear the term PCP, this is your primary care physician which is your main general health doctor i.e., not a specialist but your primary doctor or so to speak, your local doctor's office you see for general health.

A good strategy with your PCP, as with all doctors, is that they are a good fit for you – you can change who you see in the same office or even find a different office to be seen at.

I have witnessed doctors who do not think Autism is real, doctors who refuse to prescribe medicine and recommend herbal supplements, doctors who prescribe high levels of medication for pain that are irrational (one prescribed Methadone for pain – no, the person doesn't have cancer and no, the person is not a severe pain case) and even doctors who have hands in with local services and threaten CYS with pushing services despite irrationality of diagnosis at a young age (I am tracking and documenting one currently with a family) – unfortunately, this is a real situation, like the others.

Advocate for yourself and your family – you have options and if something isn't right, the services questionable or not appearing to work for you, call your health care provider or go online to their website and review other providers in your area, as well as report questionable behaviors to the insurance and above the insurance to the state to assure nothing is swept under the rug in the matter.

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# **Psychiatric Evaluation:**

A mental health evaluation performed by a licensed provider (**Note:** the school diagnosis does not count) – you obtain these by scheduling an evaluation with a facility or individual which you can find on your insurance provider websites or pay out of pocket for as you choose.

These tend to be done yearly and *are* needed for certain programs and are a part of beginning medication management.

You have a right to a copy of the evaluation, which is good to keep on file if needed for referrals.

These are also completed during intakes at mental health facilities with long term management such as PHPs, psychiatric hospitalizations and RTFs.

If you want a specific evaluation, you want someone specialized – there are Neuropsychologists, Autism specific assessments (*some programs require specific testing for approval*), and other variants so be sure to ask questions and confirm on needs. It is always better, if for a specific program, to inquire on what testing is needed if looking to qualify for a specific thing.

Psychiatric Evaluations are also a part of obtaining specific needs – they can complete an evaluation and recommend RTF placement or so many hours a week for behavioral therapists for children in schools, etc. Be sure to inquire, also, if obtaining in school or home supports on specific languages needed and hours as some programs must have the evaluation with specific recommendations written into it.

- ✓ <u>Pros</u> Ability to obtain official diagnosis, you don't have to begin medication and can decline it
  and still obtain your evaluation, covered by insurance if you have it.
- ✓ <u>Cons</u> If you don't have insurance, there are high fees associated and at times, long wait lists for the Evaluation (*Always call around to obtain different wait times and fees*).

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# **Public Housing:**

Public Housing is overseen by HUD and managed by your local housing authority; they are similar to subsidy housing in which rental costs are significantly lower and based on your income but differ by having specific locations and all being managed by your local Public Housing Authority.

You can find your local public housing authority here - HUD Public Housing Authority Search.

To apply for a location, you will have to wait until the waitlist is open which is announced on their website; you will have to monitor, generally, but you may often find an announcement on social media or in the news.

Once the waitlist is open, you can apply and will be put on the waitlist and notified of all updates. I have seen some locations where there is little to no waitlist, but more urban and suburban areas tend to have a long wait (think at least two years+) depending on which location you are applying for. Most individuals do not move out once in so the list stalls unless there is an eviction, death, or someone chooses to move.

If selected and next on the list, you'll complete intake assessments to confirm eligibility and move forward with moving in.

Here is a good link that assists with information - PA Law Help - Public and Subsidized Housing

- ✓ <u>Pros</u> Affordable rent, no credit checks, long term housing solution, on-site laundry facilities, on-site maintenance, special need accommodation, income based.
- ✓ <u>Cons</u> Stricter rules, overcrowding, unnecessary billing (they will bill you to change a lightbulb).

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R

#### Referral:

A referral is a request for services often sent from another practitioner such as your PCP (doctor's office), specialist, mental health provider, etc.

Medicaid recipients will generally need a referral to be seen by a specialist, while Medicare recipients have more flexibility in which they can call and schedule without a referral.

You don't always need to be seen for this and can often call in with a request for a specific referral and reasoning why, as long as the specialist provider is covered by your insurance and you are regular with the provider you are requesting the referral from and it makes sense for them to send the referral – they often will do this.

In mental health, you'll need referrals for services such as behavioral therapists or for different programs to be seen.

The rule of thumb here is that you need to follow up on referrals as there is often miscommunication or issues with the referral getting to the provider – never assume all is well once granted, always check in and confirm.

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# Release of Information (ROI):

Documentation that provides release for services to speak about your treatment to others or send documentation between services with your consent. ROIs are generally made for a year but can be limited to specific time frames and what is released is specific to what is granted on the ROI.

✓ <u>Pros</u> - Your data is considered protected and limited to only who and what you consent release to.

✓ Cons — This can hold services up and you have to make certain releases are completed, such as applying for SSI or SSDI who will create a release you sign *but* some services require you complete one on their end and won't send documentation until done and no one will tell you this issue until you get a denial due to information not being received.

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#### **Representative Payee:**

A representative payee is an individual or service provider that receives an individual's benefit money and assists with budgeting, paying the individual's bills, and general money management.

Social Security services offer a representative payee program or can find qualified providers in the area that work as representative payees.

Rep payees will generally have to keep records of payments, but a new law does not require natural or adoptive parents, spouses or legal guardians residing in the same household to complete annual reports for SSI recipients.

If you have a representative payee and feel you do not need one and are of adult age, you can contact your local social security office and request a meeting to review benefits. To be your payee, you have to meet certain factors with being able to count money and manage financial needs which is more a set of questions you answer (*I have assisted with changing rep payee status*). You may also need a review and signed statement from your mental health provider to assist with stating you are mentally competent to manage your own finances.

With state benefits with TANF, a payment may go to a protective payee that is not a legal guardian or trustee or if support payments are not being made regularly and as contracted, the individual may be appointed a protective payee.

You can find more information on the SSA side here with representative payees here.

https://www.ssa.gov/payee/index.htm

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#### Residential Treatment Facility (RTF / RTFA):

#### RTF:

Services available for children and adolescents with severe mental health and behavioral needs; placements are on site and provide daily therapy and medication management with family integration and step-down planning.

**You need a psychiatric evaluation or referral for services** – this means it *must* come from a recommendation from a licensed professional and getting this can sometimes be a complete

circus. Your child could have a pile of bodies sitting behind them and they'll still fight recommending RTF. You will have to fight for this, unfortunately, at times and without insurance, it will be costly.

Statistically, children *do* do better in the home and it is better long term to integrate with in home treatment, but this is not true for all families and even more – sometimes the families are the issue, sadly. Insurances also like to fight RTF placement, but you can force hands here and battle them out. Insurances have departments for specific needs – call them and start a paper trail of treatments to assist with building needs and getting placement when needed.

Another con is the child's age – some RTF services will take up to 21 (*they won't tell you this*) and will often deny anyone aged seventeen. **Appeal** and force a meeting on denials. At this age, it is increasingly difficult, *but* there is a save here with county and state intervention with a **Complex Case Referral** – there is county and regional which will allow you to state your case, lack of support/success and force services to come together and find solutions.

Magellan does a great job breaking information down for RTF criteria which is similar and general to most mental health managed care providers and you can find the PDF here.

- https://www.magellanofpa.com/documents/2021/07/provider-performance-rtf-irtf.pdf/
- ✓ <u>Pros</u> Consistent and daily treatment in a facility with trained professionals, active monitoring, step- down planning with ongoing managed care to assist with recovery and ongoing treatment when back home, covered by mental health insurance for low-income families.
- ✓ <u>Cons</u> Difficulty obtaining recommendations, insurance company will fight this, RTF location has poorly trained staff and service management, lack of coordination.

#### RTFA:

A residential treatment facility for adults, which is similar to a RTF for adolescents, who require inpatient treatment. There are more RTFs for adults than children, which offers more availability, but similar barriers with waitlists and referral needs, as well as service management issues.

You can view Pennsylvania statute here with definition and intake criteria to assist with information on criteria here.

 https://www.dhs.pa.gov/providers/Clearances-and-Licensing/Documents/MH%20Residential%20Licensing/RTF-A%20Bulletin%201995.pdf Another PDF with a write up from Community Behavioral Health can be found here.

 https://dbhids.org/wp-content/uploads/2017/12/Residential-Treatment-Facility-for-Adults-RTFA -.pdf

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S

### Serious Mental Illness (SMI):

A serious mental illness is defined as a mental, behavioral, or emotional disorder that results in a serious functional impairment that substantially interferes with or limits one or more major life activity.

SMI is more commonly referred to diagnosis of psychotic disorders, bipolar disorder, and major depression with psychotic symptoms or treatment-resistant depression. It can also include anxiety disorders, eating disorders and personality disorders where the degree of functional impairment is severe.

SMI's are considered long term disorders that impair function across different life domains and interfere with a person's ability to maintain employment, housing, social and safety needs, and ongoing crisis situations with hospitalizations and co-existing disorders or substance abuse.

You may hear this term or be labeled as having SMI – it is just coding and certain programs require specific language to assist with the level of care needed and provided for programs.

You can find a lot of information and diagnoses break down on Drugwatch.com which offers a plethora of information here:

https://www.drugwatch.com/mental-health/mental-illness/

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# **Service Coordinator (SC):**

Services intended to assist with new service integrations and assistance with current services – similar to case management, but less integrated with focus on services specifically intended. Services covered and provided by mental health services in the county for low-income families and/or offered by programs you may be enrolled in already.

(See Case Management and Blended Case Manage for more overall needs with assistance)

✓ **Pros** – Services work with children and adults, assist with referrals and program enrollment,

assist with focus on individual needs and planning.

✓ <u>Cons</u> – Meet less frequently, untrained staff and poor service management, services are intended to focus on more specific service integrations to the program intended, less broad.

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## **Severe Emotional Disturbance (SED):**

Severe Emotional Disturbance is referenced for individuals under the age of eighteen with a diagnosable mental, behavioral or emotional disorder with sufficient duration that meet diagnostic criteria within the DSM-V which result in functional impairment that substantially interferes with or limits the child's functioning with family, school, social or community integration.

These usually include Schizophrenia, conduct disorders, affective disorders (anxiety/depression/bi-polar), disruptive behaviors (ODD), and self-destructive behaviors.

Part of a child's diagnosis/diagnoses may come with a SED statement which is there to, again, code and signify a level of intensity and needs which assist with service integrations and goals within the treatment plan.

You can find a lot of information and diagnoses break down on Drugwatch.com which offers a plethora of information here:

https://www.drugwatch.com/mental-health/mental-illness/

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#### Social Security Disability (SSI):

SSI is intended for low-income individuals without work credits and can be applied for by adults and for children with disabilities – payouts are based on income and have a set amount for maximum benefits which you can find here (SSI Payments).

Adult applications can be applied for online or by scheduling a phone interview and a children's application is separate and can be scheduled both ways, as well.

# Apply for child or adult here

- ✓ <u>Pros</u> Positive option for those without work credits or children with special needs for low income families, most qualified for SSI qualify for state Medicaid and are not usually forced into Medicare.
- ✓ <u>Cons</u> Must fit certain income requirements, strict income guidelines and less ability to earn extra income (you can save with ABLE accounts and other sideways) the fact they think

people can survive on \$943 a month is incredible. Similar to SSDI, difficult to be approved for without consistent proof of condition and mental health conditions are even more difficult.

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# **Social Security Insurance Disability (SSDI):**

SSDI is intended for adults with a work credit history of 40 or more with 20 being earned in the last ten years with the last year being the time your disability began.

(You can find your work credits on the social security administration's website by creating an account)

## **SSDI Information**

- ✓ <u>Pros</u> You can work and earn income up to a <u>substantial gainful activity(SGA)</u> monthly, less restrictive, can be dual eligible with Medicaid and Medicare and programs available to low-income individuals to pay for Medicare supplemental part B payments, more payout.
- ✓ <u>Cons</u> SSDI is considerably hard to get approved for under the age of 50 with no surgeries or consistent medical care, you need work credits, after two years Medicare will become your primary insurance and Medicare is...insane, but navigable.

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#### **Special Education Advocate:**

A special education advocate is similar to the attorney in which they can help you navigate and funnel through the special education system and advocate for you and your child's needs with education and the school district, but they differ because an advocate does not need specialized training or a law degree as they do not practice law nor cannot provide legal assistance.

Some work for free through services or charge specific rates.

A special education advocate *can* point you in the right direction for suing the school if there are a lot of issues with the district and they are a powerful asset by your side.

You can find a good breakdown with information here.

https://www.research.chop.edu/car-autism-roadmap/using-a-special-education-advocate

And in Pennsylvania, there is a helpline to assist with information from Advocates (your state may have one similar).

- https://www.education.pa.gov/K-12/Special%20Education/Complaints/Pages/ConsultLine.aspx
- ✓ <u>Pros</u> IEP and LEA knowledge, specialized in assisting with special education needs and FAPE rights, powerful ally and advocate for needs.

✓ <u>Cons</u> – Cannot provide legal assistance, potential for poor training and service management, no license or credentials needed which may mean the person is less skilled or knowledgeable so it is important to ask questions and verify their ability.

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# **Special Education Attorney:**

An educational attorney is an amazing resource when dealing with schools and special needs because they can advise and sue the school – this comes back to a powerful word with children and special education; Fair and Appropriate Education (*FAPE*).

You want to see school staff choke on their words? Say FAPE.

Listen, I do not intend to make monsters out of people but I have been witness to so much stupidity that there is no rational sense behind actions – this system is written in nice little frames, but it does not follow them and you are battling these monsters.

I had a behavioral specialist tell myself, client and her mother to reach out to programs to assist with mental health and social behaviors with school refusal and reintegration and I just smile, look at this professional and exclaim how wonderful that is that they know programs *ACTUALLY* available (*there are none*) and inquire on which ones they were writing in as actionable tasks in this meeting to address school refusals and how they would help the family onboard and she looks at me and admits she doesn't know and will have to reach out to the social worker and follow up (*she never did after multiple calls*). She basically told the mother to find a unicorn, and on top of it offered no assistance or responsibility on their end. Luckily, my client had me to draw the line at the stupidity they were selling and an educational attorney that stepped in and forced an actual program enroll which was in a different county over an hour away, but a real unicorn (*unfortunately*, that program was just as much as a joke with how it was handled).

There are special education advocates which are a good asset, too, *but* they cannot legally advise or sue whereas the special education attorney *can* and schools change their behaviors real quick because now any unnecessary damage is being documented and lined up so when they say they can accommodate, it better accommodate or they will be in court paying. *That* is how powerful FAPE is.

You can onboard a special educational attorney without paying costs until the school is sued so there is less stress here in obtaining one with those who practice this way.

Here is another post from Adayinourshoes.com which break down information and is a great resource

- https://adayinourshoes.com/iep-attorney/

I will say, in Pennsylvania, I have worked with a lot of free special educational attorneys, so they are out there.

✓ <u>Pros</u> – Can practice law and advise, strong ally with special education needs and FAPE rights, can sue, schools tend to work with you more positively.

✓ <u>Cons</u> – Poor training and service management, costly if service is not provided for free until sued.

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# **Specialist:**

A specialist is a provider who manages and focuses on specific health and who you will see for specific health needs and management.

For Medicaid recipients, you will likely need a referral and for Medicare recipients, you have a little more leeway here as you do not always need a referral.

I have seen, more often, individuals continuing to see their primary care physician (PCP) attempting to get results which tends to be the issue; you likely need to see a specialist and should inquire on a referral to one, you can get an idea by reviewing symptoms and learning who handles or manages that area.

I'll tell a story of someone I work with that had ongoing symptoms of intense sweating, potassium deficiency and experienced muscle cramping/locking with a PCP who continued to push hormone imbalance and treatment that wasn't helping. I am aware of the potassium and sodium channels (this is taught often in psychology courses), as well as symptoms combined which appeared similar to hyperhidrosis and put together — a lot made sense. I suggested she request a referral to a dermatologist or find someone in the network that specializes, review with them and then request referral. Now, this person could continue with general medicine and hormone treatment or advocate to see specialist who could rule out potential other factors and obtain a long term solution.

If you have specific needs, you see a specialist in that area and you have rights to request referrals and branch out and sometimes, that can mean the difference. If your PCP fights the referral, call advocacies. Know your rights.

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#### Special Kids Network Helpline (SNK):

The special kids network helpline is a resource available to families and children and youth (*birth thru twenty*-one) with special health care needs as an information source meant to assist in not just identifying needs, but assuring they are obtaining the services they need and are qualified for.

Generally, think assistance and guidance with education, assistive technology, advocacy, and healthcare and a great power source overall.

The service can also provide referrals to services with permission from the caregiver.

You can reach them at 1-800-986-4550

And you can find information online available on the PA DOH here.

• <a href="https://www.health.pa.gov/topics/programs/Special%20Kids%20Network/Pages/Special%20Kids%20Network.aspx">https://www.health.pa.gov/topics/programs/Special%20Kids%20Network/Pages/Special%20Kids%20Network/Pages/Special%20Kids%20Network.aspx</a>

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# **Specialty Care Programs:**

Specialty care programs cover specific diagnoses/diagnosis:

Cooley's Anemia, Child Rehabilitation (*array of neuromuscular and osteopathic conditions*), Cystic Fibrosis, Hemophilia, Sickle Cell Anemia, and Spina Bifida.

The specialty care programs are intended to provide support for family participated health planning, care coordination, and multi-disciplinary clinics that are to bring together full medical team treatment and planning for the individual's health care needs. There are also community-based organizations that work with the sickle cell population that assist with education, outreach and support with daily living and community integration needs.

You can find more information by contacting the Department of Health, Bureau of Family Health, Division of Community Systems Development and Outreach at (717) 772-2763 in Pennsylvania.

Nationally, you can contact similar or the same agencies and/or inquire with your local county assistance office.

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## **Specific Developmental Disorders (SDD):**

Specific Developmental Disorders are characterized by delayed development in one or more specific areas.

There are four main developmental disorders – nervous system disabilities, sensory related disabilities, metabolic disabilities, and degenerative disorders.

You will see SDD more with communication, motor skill, and learning disorders and is generally identified in youth.

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# **State Blind Pension (SBP):**

The state blind pension is a program that pays individuals twenty-one and older with vision acuity in the better eye with the best correcting lens that is not better than 3/60 to 10/200 and some individuals who are considered medically blind due to severe tunnel vision up to a maximum of \$100 a month.

There are income requirements of the individual's combined real and personal property value at \$7,500 or less and annual net income limits are at \$4,260.

The program does not qualify if an individual chooses Healthy Horizons over Medicaid or those on MAWD.

You can find more information by contacting your local county assistance office and online at the Department of Human Services website here.

https://www.dhs.pa.gov/Services/Assistance/Pages/State%20Blind%20Pension%20Program.asp
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## **State Supplementary Payment (SSP):**

The state supplementary payment is for SSI beneficiaries and was created to assist with differences in cost of living across the state where the maximum SSI benefit amount may not be enough.

SSP payments can range in amounts and be awarded to families who did not qualify for SSI due to income limits as long as their countable income does not exceed the combined federal benefit rate and SSP, which will be eligible for department administered option SSP.

Some states do not offer a SSP, other states are administered through SSA which you would need to contact to review for eligibility and other states have a program administered by the state.

You can find more information here on the SSA website.

https://www.ssa.gov/ssi/text-benefits-ussi.htm

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#### **Step-Down Planning/Discharge Planning:**

I am writing step-down planning as the main go to due to the words often being used more over discharge planning, but know that step-down is a plan of discharge, or a transition from current services that have successfully managed one area of need and the individual is prepared to move on to less intense services and really, it begins day one of treatment by beginning assessments and treatment plans and finalizes on discharge. The goal of any service is not a continued and lifetime service as it is meant to succeed; if it didn't, the service wouldn't exactly be successful.

All services have a window for re-assessments with time frames, so a blended case management service is every six months to re-evaluate for service need while a PHP isn't usually longer than a few weeks *but* can be pushed to a few months, etc. Step-down planning is critical for children and adults to have services in place that are appropriate when leaving one service and *legally*, given the CARE Act and HIPPA requirements, it is *suppose* to be complete by protocols.

Do services *always* complete this step appropriately? Well, let's just say I had to make emergency calls to an inpatient psychiatric hospital and go over multiple heads to halt them sending a child home with no services in place nor meetings held to even review discharge at the last minute when we found out, *surprise*, the same person who followed no protocols the entire process was just going to release her. Oh...and that one meeting with the BH-MCO stating they call after hospital discharges to follow up and review for services which they must've left out in addendum that they do it in another realm, which is

why neither clients or co-workers have ever seen this happen. Right, right, right...and the multiple other services that fancy similar discharge or general statements on positive planning after but do *not* actually complete referrals to actual treatment as if the family or individual can obtain some services themselves and having to poke them with a hot stick to actually put services in place. I say this pointedly and with some frustration – *know your treatment is limited to the person writing it.* You have to know because there's a good chance that person is overloaded on cases, has developed an algorithm and general knowledge and will follow their patterns and if the management shapes patterns that lack actual functionality to that behavior, everyone loses.

Step-down planning should involve a team meeting with the individual or the family corresponding to the individual's care that basically states treatment for when they leave the service – if it is general therapy and they don't have a therapist, it should come with information and referrals to locations that have availability. For children, if this means a specialized mental health treatment with a behavioral therapist than it should come with a referral from a licensed professional who can signed off on that statement (*PHPs and Psychiatric hospital have a licensed professional they see weekly as part of that program in house*). There is also documentation with everything discussed and agreed upon in discharge that states the planning and actions in place to assist with the transitioning.

I am going to link some resources here you can read up on to assist, but know whenever you are leaving a service that there should be key elements in place — diagnosis, review on services, referrals if needed, and placement that will assist with moving from one element to another. If it is not in place, get on the phone and internet and contact advocacies such as NAMI and even your state human services office, the AARP (who has advocated heavily and pushed for the Care ACT to be put in place through all states), disability advocacies local and national — respond and demand services follow through as expected, not as they've followed when the case is such.

Another factor with hospitals and discharge, which can be given the same day; you can appeal and onboard with this and fight with it. They will fight you, but you can fight them with knowledge and the right strategy and linguistics using key terms to push back. Appeals fall into a QIO process which will halt the discharge and a series of steps must be completed. You can read more on the Medicare Advocacy's website here and it does follow similar patterns outside of Medicare.

#### https://medicareadvocacy.org/medicare-info/discharge-planning/

I have utilized this on a case I helped with and had a lot of push back with hospital staff stating the QIO process is not regulated to individuals who are in the emergency department – the child came in the ER for mental health crisis and was in the hospital for days, but not "inpatient," due to not beds being available. They fought everything and just wanted to get rid of the child because the child was "calm," now – no discharge planning, no concerns addressed, just here is your highly unstable child and good luck and we'll likely see you in two weeks when another crisis develops. With push back on the fact it was the weekend coming up with no services available to assist in planning needs and inability to review with mental health team such as therapists and the like, we got an extension of stay. Even I have more to learn here and I feel something irrational about their statements, which is how I even learned about the QIO review – I always tell people if it feels irrational, it likely is and it means we're missing information. Follow your hunch and dig.

You can find a general breakdown on caregiver.org that covers a wide breadth of information here.

<a href="https://www.caregiver.org/resource/hospital-discharge-planning-guide-families-and-caregivers/">https://www.caregiver.org/resource/hospital-discharge-planning-guide-families-and-caregivers/</a>

You can find a PDF from AHRQ.gov that overviews an IDEAL strategy with discharge and step down planning in attempts to create a skeleton strategy for all services intended.

<a href="https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfami">https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfami</a>
 lies/strategy4/Strat4 Implement Hndbook 508 v2.pdf

Here is an OMHASAS bulletin post release by the PA Department of Public Welfare on RTF discharge.

 <a href="https://www.dhs.pa.gov/docs/Publications/Documents/FORMS%20AND%20PUBS%20OMHSAS/">https://www.dhs.pa.gov/docs/Publications/Documents/FORMS%20AND%20PUBS%20OMHSAS/</a> d 005453.pdf

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# **Subsidized Housing:**

Subsidy Housing is housing catered to low-income individuals/families and is funded and monitored by the U.S Department of Housing and Urban Development – rent is based on income and ran by a formula which puts you in a bracket of a percentage of income you will pay towards rent and they will pay the other half.

Locations are spread throughout the states and there is no particular list for this group (do not confuse this with your local public housing authority) – you will have to call the locations and inquire on applications. For the most part, you will have to call and inquire on availability, but I have seen one or two that will tell you to check their website daily for openings.

There are often long wait lists (1 year and up) and there is no guarantee of acceptance. Once you apply, you'll go on the waitlist and when there are openings and your slot is up, you'll receive a call and an interview will be completed to review income, background information, etc. If approved, you'll sign a lease and there is no time frame limits to stay so as long as you follow the lease, you'll continue renting until you choose to leave or whatever the case may be.

*Now*, if you get denied – know you can appeal and have a formal meeting to review. I have done this for a client and got them into the location this way; do not just accept denials, know appeals are a thing.

The kicker is they can deny due to poor credit history or previous rental legal matters — never mind the program is for low-income individuals and as someone who has lived through this life, the last thing we are taught is credit and we live day to day which means there's almost always some legal rental history. Top this with people on SSI who barely have income to support current rent costs who can't work or they lose SSI benefit income, despite disability that they *actually* can't and shouldn't be working, who should be served by the subsidy housing locations as, no brainer, the housing is exactly what they need to survive and you have another program that throws another wall up to the population it is meant to serve.

If there is one thing I learned across all services, it is that denials are relative to you accepting it. Always inquire on the appeal process and complete the steps; it can be the difference.

You can find broad information on the <u>HUD Website</u>, but I recommend sites like <u>lowincomehousing.us</u> or doing google searches with your county and subsidy housing – the reason for this is HUD will direct you to your local housing authority and they tend to deal with their own housing groups and will not know specific information about the plethora of privately owned locations. Even if you're familiar with some in your neighborhood in which there are groups of similar appearing townhomes and usually some location name on a large plaque at the entrance– check it out and look for an office, go in and inquire if it is subsidy and ask for an application if it is.

Here is a good link that assists with information - PA Law Help - Public and Subsidized Housing

- ✓ <u>Pros</u> Affordable housing, low rental amounts, utility assistance at some locations with electric, long term solutions, on-site maintenance, accommodation for special needs, on-site laundry facilities.
- ✓ <u>Cons</u> Credit history checks, background checks with rental history, stricter rules, cramped living conditions.

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# **Substance Abuse and Mental Health Service Administration (SAMHSA):**

SAMHSA is a federally ran program which assists with program development, monitoring and funding for mental health and substance abuse programs. Services are intended to assist with directing individuals to services available to them, as well as provide oversight and ongoing analysis of programs and may be a location to report service abuse, neglect or waste to if appropriate for the specific program.

This program also integrates with other programs and centers, as well as health a large amount of information on their website to assist with multiple resources and information related to public and community needs.

The program also has grant opportunities and other support available for those in the field.

**SAMHSA Website** 

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#### **Summer Food Service Program (SFSP):**

The summer food service program is funded through the USDA and administered by state and local agencies.

Meal are served at location sites and facilities for low-income families.

You can find location sites nationally here and contact 1-866-348-6479.

https://www.fns.usda.gov/sfsp/summer-food-service-program

And in Pennsylvania, you can contact the Pennsylvania Department of Education Child Nutrition Programs at (717) 787-3186.

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## **Supplemental Nutrition Assistance Program (SNAP):**

The supplemental nutrition assistance program is designed to assist qualifying individuals and families with food assistance to prevent malnutrition and hunger associated and is overseen by the United States Department of Agriculture (*USDA*) Food and Nutrition Services (*FNS*) and the state overseeing the benefits for participants.

Benefits are issued on an EBT card and can be used at all participating locations; benefits loaded on a card and if the card has no debit activity, benefits will be returned to DHS and the case will be suspended.

EBT cards *must* be replaced within five days by the CAO if the card is lost or stolen and reported. The first card will be replaced for free and a fee of \$2.50 is charged for the second and any additional card replacements.

SNAP Benefits can also be used for authorized meal delivery services, communal dining services for SSI recipients and elderly communities, and authorized restaurants for the elderly, homeless and disabled. Homeless individuals can use SNAP benefits at qualified restaurants which is issued under PA 2SP.

Applicants must have a chance to participate within thirty days of the application to eligible individuals which means, you should be issued a card no later than 29 days of initial application. If there is a delay due to CAO or the individual filing, the case can be re-opened within a thirty-day period and if CAO fault, must be corrected within another thirty-day period. This is why you track and document.

You can receive expedited SNAP benefits which must be provided within five days if you qualify by having \$100 or less in cash or liquid assets. Weekends and holidays are a part of that five-day count from initial application, and it must be issued sooner if holidays or weekends fall during the initial application and five day card issuance needs. You will have an interview and be reviewed for expedited benefits when applying and should state expedited needs if needed and qualifying.

There are categorically eligible households such as those with SSI recipients, TANF, SBI and/or have a FPIG at 200% or below.

For those who do not qualify because of income (*exceeding 200% of the FPIG*) and have someone elderly or disabled in their home and care, there is still a chance to receive benefits under a net test which many qualify for the minimum benefit.

There is a program for Able-Bodied Adult without Dependents (ABAWD) who falls between eight and fourth-nine years old, has no minors and is fit for employment. SNAP benefits may receive SNAP benefits in a three-year period for a total of three months, after which they will need to be in a federal ABAWD work program, be in a work program or complete community service for a total of 80 hours in a 30 day period or is exempt due to location or other factors qualified.

You can find more information about income limits and application on the DHS website here.

https://www.dhs.pa.gov/Services/Assistance/Pages/SNAP-Income-Limits.aspx

You can also apply online on the Compass website or contact your local CAO office.

In Pennsylvania, you can find your compass website here.

https://www.compass.state.pa.us/compass.web/Public/CMPHome

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## **Targeted Case Management (TCM):**

Targeted Case Management is similar to Case Management by providers but is more intense and assists with more chronic needs, such as long-term homelessness or reoccurring crisis interventions due to instability.

Meetings will be more frequent, and services will focus on stability needs and planning.

To find more information about targeted case management, you can contact your local MH/ID/DD service or mental health provider for assistance on referrals and information.

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## <u>Technology Assisted Children's Home Program (TACHP):</u>

Technology assisted children's home program is a Pennsylvania program designed to provide comprehensive non-medical services to families and individuals and aid them in navigating the system for children who are dependent on assisted technology.

The service is a positive resource and advocacy to help empower families with obtaining, keeping and understanding services, what's available to them and building a long-term framework for independence. Service is provided in the home and paid for by MA; you would need to complete a referral.

You can reach services through the Department of Health, Bureau of Family Health, and Division of Bureau Operations at (717) 346-3000 in Pennsylvania.

You can find more information here, as well, at the link that services Eastern PA and Philadelphia.

- https://www.findhelp.org/health-promotion-council--philadelphia-pa--technology-assisted-children%2527s-home-program-%2528tachp%2529/4612608370540544?postal=18043
- https://www.hpcpa.org/programs-services/family-services

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# Temporary Assistance for Needy Families/Extended TANF (TANF / ETANF):

Temporary Assistance for Needy Families is a supplemental cash assistance program that provides some income and other work training opportunities for low-income qualifying individuals with children and pregnant women.

Applications must be provided the same day requested, the individual applying must receive an interview within thirteen calendar days of the application dated and signed and have an eligibility determination within thirty calendar days. Individuals, believe it or not, can even have a home visit made if the person cannot come to the CAO office as per <u>Section 104.41</u>. You have a right to appeal any decision, as well.

Individuals applying for TANF will need to provide proof of paternity and work with DHS and DRS in establishing support or provide good cause on why you are unable to do this.

Good cause is considered eligible for children born from incest or rape, legal proceedings are pending for adoption, the parent is working with a social service pending adoption and has continued for less than three months, domestic violence situations in which engaging with the other parent may cause distress and safety risks. Good cause claims need to be filed within thirty days from when the claim is made except in domestic violence cases which falls under different criteria and documentation completion.

It's important to note some verification can come from individuals who witnessed the domestic violence aspect or health provider statements that are aware of situations.

Good cause waivers are reviewed every six months.

A person can receive cash assistance through TANF for a period of sixty months (*five years*) over the course of an individual's lifetime and to qualify, you must have resources of \$1,000 or less.

There is an extended TANF (ETANF) program someone may be eligible for if their contingency period utilized and they fall under Hardship Track through domestic violence, Maximizing Participation Project (MPP), Deferral, referral to or enrolled in a approved Employment and Training program (E&T), Work Plus, working but not meeting hourly requirements, working and meeting hourly requirements; six month determinations are made here if qualifying under a track and re-assessments are completed with other contingencies and guidelines.

TANF programming also works with domestic relations and has a program participants enroll within which works with support payments and TANF payments.

As part of the TANF benefit, able bodied adults will have to participate in the Road to Economic Self-Sufficiency Through Employment and Training (RESET) program or the KEYS program as part of the assistance requirement. There are exceptions here and you can file for an exception request; some families have qualified due to taking care of a disabled family member in the home which had to be signed off by a provider and submitted.

See cash assistance for other programs and related TANF benefits.

You can find more information and resources on the Department of Human Services website here.

https://www.dhs.pa.gov/Services/Assistance/Pages/TANF.aspx

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# **Therapist:**

A therapist denotes more a term with a licensed professional with a field in which they specialize and treat individuals with, for physical health needs you may see a physical therapist and in the mental health field, a psychotherapist.

For mental health, therapist is interchangeable with counselor, psychologist, a mental health counselor or someone defined as a psychotherapist which denotes the psychological aspect.

More important in terminology is the specialty you seek, as in the mental health field there are a large and broad number of specialties and techniques.

I've found the largest gap with clients is they often are involved in talk therapy and a large percentage need more defined therapy such as behavioral work or even trauma therapy and when they speak about their barriers with the service, I explain the difference and needs to find what therapy is right for them.

If you are seeing a specialist and not satisfied or feeling positive results, you may need to ask yourself if you are in the right kind of therapy first and call your provider with a request to change who you are working with or find a new facility more defined to your needs.

You can find more information on what's available in your area and by your provider by contacting your insurance provider or resources available in the community by contacting your local MH/ID/DD office, State HHS Department, and advocacies such as NAMI.

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# **Transportation Services:**

#### Medical Assistance Transportation Program (MATP):

Funded by Title XIX, not CAO, and provided in most counties in Pennsylvania - MATP provides transportation to and from appointments, has a token/ticket system, reimbursement to a person for a trip, and this can include meals and lodging. You can find your local MATP program here and speak with a CAO for assistance or more information.

You will need a verbal or written verification of need from a provider.

MATP can provide reimbursement to providers by paying for mileage of your own vehicle or a "volunteer," who drives you that does not live in the same household and is not related or an organization and at least twenty-one (child clearances if driving children), so you may see a provider. There are escort and attendee allowances (an escort stays with individual; the attendee stays with the vehicle during appointment).

There are reimbursements for urgent care visits, as well, but you would need a statement from a provider on why you need to see the urgent care.

Paratransit has a door-to-door policy and fifteen-minute window for pick up before or after scheduled time.

Exceptional transportation requests go to your local CAO and this is for distance further than your regional transport is able to assist with, such as flight and lodging/meals needed for visitation.

Here is a direct link with resources and information to assist.

http://matp.pa.gov/

I am providing a link to the actual handbook for CAO with information on MATP here.

• <a href="http://services.dpw.state.pa.us/oimpolicymanuals/cash/138">http://services.dpw.state.pa.us/oimpolicymanuals/cash/138</a> Allowances and Benefits/138 4 T ransportation Allowances.htm

# Free Transit Program for Senior Citizens:

Seniors aged sixty-five and older are eligible to ride for free on the transit system. You would need to contact your local public transit service and complete an application and obtain a senior citizen transit card, which is free as well.

Find your local public transit service in Pennsylvania here.

https://gis.penndot.gov/transitmap/

You can find your public transit office by contacting your states human services department or driver's services department.

# **Shared-Ride Program:**

The shared ride program is available to seniors aged sixty-five and older and provides shared-ride, demand-responsive (*generally curb-to-curb*) services which the senior pays only a small portion of the regular shared-ride fare.

You have to register and call specific numbers to schedule if your county participates.

In Berks County, you can find more information on the BARTA site with ride-share programming here.

https://www.bartabus.com/service-information/senior-shared-ride-program

You can contact the U.S Department of Transportation for more specific information, as well.

https://www.transportation.gov/mission/health/ride-sharing-programs

In Pennsylvania, the Department of Aging has transportation programs, as well, which you can find information and resources on here.

https://www.aging.pa.gov/Pages/default.aspx#

# **Disabilities:**

Individuals with disabilities also qualify for reduced costs and ride-sharing transportation services, as well as some waivers that offer and assist with transportation to employment or educational programming which can be from OVR services, IDD services and other state programs.

You can contact your local CAO for the MATP program and local MD/ID center for more information, as well as advocacies.

You can find more information here, as well, for seniors and disabled individuals on the National Aging and Disability Transportation Center.

https://www.nadtc.org/

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# **Treatment Plan:**

Treatment plans are a data set of information on an individual which includes their base data with general information, their diagnosis/diagnoses and an outline of general management and goals that are tracked through service time and updated by program standards.

Treatment plans should follow the individual's needs which means they may change during the course of treatment, this changing treatment planning in place as previous intervention may not be realistic or befitting of the individual due to those needs changing.

Whenever with a service, always inquire on your treatment plan or the individual you are responsible for treatment plan as this should come with a breakdown of what is in place and currently being worked on as part of a stepdown plan with discharge.

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#### **Triangle of Care (TOC):**

I always educated my clients on what I call the triangle of care due to a lot of confusion between providers they see, especially psychiatrists and their appointments with medication management. Almost everyone always says, "but the appointment lasted five minutes, it was barely anything."

Here's the breakdown; that psychiatrist is likely scheduled back-to-back on specific time frame increments, much like the other specialists and providers you see. When you meet with them, in person or virtually, and they make the statement, "How are you?" — they are not necessarily asking how you are in general, they are asking what is wrong. It's a very, maybe, American thing to open dialogue this way and a question I have conflict with due to our very natural response to downplay everything and simply state "Oh, I'm good," or "You know, still living!"

The triangle I speak of is to think of a fifteen-minute interval – your first five minutes is not to answer with a "Ohwowow, I'm still alive!" but to specifically state what your issues are, the next five minutes is for the provider to digest and review with you on those issues and the last five minutes are the resolution you and your provider come up with. The second, say with the psychiatrist, you state you are

fine – they assume all is well with your medication and all is good so they can finalize and move on, which makes absolute sense given their schedule and difficulty to probe you deeper given this.

This is not the same for a therapist whose time is ran much longer and their job is to actually probe you or a service that comes into the home with actual time to work with you fully on goals or assessments, etc.

The strategy here is to know your goal with the provider you are seeing and organize needs into data sets which you can address issues, assess, and have a resolution at the end.

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# **Unnecessary Damage:**

This is a term that can be used with any special needs planning and utilized as a statement to speak that any treatment planning or steps to goals being taken are not causing more psychological or physical damage in the process to the individual.

I would use this term during IEPs more often, but you can really use this for any service you are working with to state your concerns when completing goals and actions with a program. It intentionally speaks to a cause and assists with affirming in an assertive way of your intentions when damages do occur, especially if you are in disagreement with the service and a linguistic tap to give the service pause given this.

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#### **Veterans Services:**

It is important to note that there are a large amount of services for veterans both nationally and different states have different programs; these services can range from meals, healthcare, grants, programs and services specific to criteria and broad.

If you are a veteran or caring for a veteran, there are resources available and this area could use a write up in it's own, which will be coming, but for now I am going to provide some links to assist with sourcing information.

In Pennsylvania, you can find more information on the Department of Military and Veteran Affairs (DMVA) here.

• <a href="https://www.dmva.pa.gov/dmvaoffices/Pages/default.aspx">https://www.dmva.pa.gov/dmvaoffices/Pages/default.aspx</a>

And nationally, you can find local and nation services and information on the Veteran Affairs website here.

https://www.va.gov/

#### And here.

https://www.usa.gov/agencies/u-s-department-of-veterans-affairs

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## **Waivers:**

There are a plethora of waivers across services in this field and they are your best friend when it comes to getting into specialized care and needs met.

Autism related programming and home health care alone have multiple waivers in multiple programs, each specific to each program as far as qualifications and intake to them.

I will try to cover some here as possible, but some may be specific write ups to assist with more details.

Just know, waivers are a door in for specific needs and programming that often have a lot of support and funding to assist with those specific needs and planning.

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# Women, Infants, and Children Supplemental Food Program (WIC):

The women, infants and children supplemental food program is a program available to pregnant, postpartum (*one year if breastfeeding and up to six months if not*), and breastfeeding women with infants and children (*under five*) who fall 185% of the federal poverty income guidelines (FPIG).

Services include lead screen, social and community assistance with needs-based referrals and provide assistance with formula payments and supplemental food items which are more specific such as milk and other dietary based items.

Services are available across the states and you can find more information nationally here.

https://www.ers.usda.gov/topics/food-nutrition-assistance/wic-program/

In Pennsylvania, you can call the statewide number at 1-800-946-9467 (1-800-WIC-WINS)

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