FAQs

Commonly asked Questions from Parents/Guardians With Developmental Disabilities/Related Conditions

Note: *This general information has been compiled by Dana Norton (Executive Director of Covenant Enabling Residences of MN) and reflects her own experiences in the field. Because regulations and protocols vary from state to state and county to county, we recommend that you explore local sources for specifics related to your particular area.*

When should I apply for services for my child?
As soon as you know child has a disability, you should contact your local county and inquire about the procedure to access county services. Many times when a child is born with a disability, it is not identified. In fact, doctors/psychologists will not typically test a child for disabilities until four or five years of age. Doctors are hesitant to make a diagnosis with a developmental disability or mental illness and can take many years to do so.

What should I tell the case manager/doctor who assesses my child/young adult for services?
Parents often want to describe their child's abilities at a higher level than they are at realistically. Parents are hesitant and do not like to discuss a child's negative behaviors or their need for assistance. This will not benefit the child when trying to access services. Parents need to be brutally honest in their description of their abilities, level of independence, need for assistance, behaviors, medical needs, etc. Give worse case scenarios as examples of care and behaviors so all bases are covered.

How should I choose the best service/funding mechanism for my child/young adult?
It is possible for your child to qualify for one service or multiple services. There may only be one choice or many choices of services/funding sources, and there may be many different funding sources for different age groups. (Example: Early Childhood services for toddlers, transition monies/services for young adults, Residential services when adult age, etc.) When there are several choices, you want to choose the service/funding source that has the best chance of success (i.e., of not being cut and one that will carry the child into adulthood). (Example: In Minnesota, Waivered Service is a funding source that can be used for In-Home Services when a child or young adult is still at home. It will follow him/her when out of High School to pay for a transition Program or Work Program, as well as Residential Services when an adult (and in some cases children).

What does having a case manager mean?
A description of a case manager, when related to serving folks with Developmental Disabilities, TBI or related conditions, is a person who typically works for your home county and assists persons with the aforementioned issues, access and manage services (e.g., School, work, day program, residential, in-home service, respite, PCA, combination of services, but not limited to those). A county case manager can also help families with accessing other services that may or may not be related to a child or young adult with disabilities, i.e., physical therapy, occupational therapy, speech therapy, adaptations, psychological/psychiatric counseling for families and/or siblings.

The case manger is responsible for developing/creating an ISP or Individual Service Plan (there may be different names for this document—it is the plan/contract/agreement of services and goals to be delivered to the consumer, person/child receiving services).

The ISP is information that the case manager typically gathers from parents/guardians, siblings, teachers, doctors, sometimes jail/detention centers, hospitals and any other persons determined to have valuable information regarding this consumer. Then you have one document that has all the information needed and it is in one place.

The ISP is a legal document that contains historical, medical, behavioral, psychological, education records and any other pertinent information needed to complete the ISP.

The ISP also contains the long and short-term goals that are developed as related to educational and residential needs. These goals must line up/similar with the Educational, Vocational and Residential goals, in order for any individual to continue receiving financial services/funding.

This is also the contract for services between the county and/or state and paid programs (e.g., Vocational, Residential, In-Home, Transportation, Case-Management—but not limited too). The ISP usually states the service being provided, who is providing service, number of units, time intervals/increments/days and dollar rate per indicated unit.

Examples:
Vocational—Joe's Vocational daily rate, 280 days, $90 per day.
Residential—CER of MN Inc—daily rate-- 365 days $135 per day
In-Home Program –CER of MN Inc.—hourly rate—1235 hours--$21 per hour
In-Home Respite—CER of MN Inc.—daily rate-48 days--$65 per day
Transportation—usually the same as vocational—280 unit--$7 per unit

The ISP ***must*** be signed by the Case Manager and consumer and or parent/guardian, in order for it to be legal or effective.

What is Guardianship? When do I need one? Where do I access one? Why do I need one? How do I gain guardianship?
A Guardian is person/persons responsible for the care and safety of child or vulnerable adult (i.e., a person who is 18 years of age or emancipated by marriage who meets the category of vulnerable adult-person who is mentally disabled, TBI or related condition that meets the state's requirement.)

Parents are typically the guardian of their children. If you have a child/young adult with a disability or related condition, it would be important to ensure that you have guardianship in place before the child/young adult reaches the age of eighteen. If you do not have this guardianship document in place, your child/young adult has all the rights as an adult and can make his/her own decisions whether or not they are in the best interest. Example: If they wanted to get married, legally no one can stop them. They are also free to participate in alcohol consumption—especially not a good idea if they are on medications or they can decide how they want to spend their money (loans credit cards, etc.). These situations can be very concerning for a parent/guardian.

If you know that you have a young adult that is at risk (i.e., not able to take care of himself/herself and/or does not make good decisions), you should be gathering documentation and information that supports your decision. By doing so, you are recognizing that your loved one has limitations that would put him/her at risk if acting as his/her own guardian. This type of paper trail is usually achieved with copies of medical records and psychiatric evaluations. You will have to re-establish guardianship yearly at no or minimal cost. Parents/guardians should be aware that a ward (person you are seeking guardianship for) can also contest the guardianship at this time.

It is also a good idea, as parents age, to have someone in mind to take over guardianship when they are no longer able. Family members are usually given priority over guardianship rights and are preferred by the state. If no private guardian is appointed at the time of parent's or current ward's dissolution, the county may appoint a public guardian—a person who is paid by the state or the county.

As a guardian, you are able to keep your loved one safe establishing rules and guiding them through life and the decision-making processes, e.g.: financial, medical, choosing appropriate living situation—etc.

Again, your county case manger or Advocates for Special Groups serving persons with developmental disabilities/related conditions, can help you through the process or direct you to someone who can help you through the process.

When is a child eligible for services? When can he/she start school? What do School Services and IEP mean?

A child is eligible for services at birth.

A child/young adult with disabilities has a right to access school services just like children who do not have disabilities. As mentioned earlier, as soon as you notice that there is a delay in your child's development you should consult your pediatrician/physician and have your child assessed by a professional who can help you access county and/or state services.

It is typical that children are tested at the age of four, sometimes three. Physicians/psychologists like to see a child with developmental disabilities or related condition enter the school system as soon as possible, because the sooner the services are accessed the better the chance that the child has to reach his or her potential.

When in the Early Childhood Program or grade school, a plan is developed called IEP (Individual Education Plan) or IPP (Individual Program Plan). Data on the adolescent is compiled every six months and reviewed to discuss strengths and weaknesses. In the beginning of the school year, your child's team meets to develop potential goals. The team consists of the child, parent/parents/guardian, teacher/teachers, county case manager, paraprofessional or anyone who works directly with the child/young adult. This could include: PT, OT, or ST, especially if the child is receiving services outside the home. A parent/guardian can invite other individuals they believe could advocate/support their child/young adult in receiving the best services available.

Parents should ensure that they understand the system/systems of which their adolescent is a part, and parents should not feel shy about seeking out clarification of information. Parents should ensure that their child/young adult receives the services that they are entitled to by maintaining ongoing relationships with county case managers. It is important to understand that the county will not seek out

your child to provide them with services. As parents, it is your job to advocate for your child and speak to legislation about services that should be provided and needs that are not being met. Parents need to be persistent in getting services for their child. This can be uncomfortable and seem forceful, but it is sometimes the only way to be heard.

After the IEP is completed, it MUST be signed by parent or legal guardian—or young adult if serving as his/her own guardian—case manager, a school representative and any providers or therapists listed as a team member. This is a LEGAL document and it must be signed. If not signed, there is nothing binding the county, school or guardians to the agreement. If parents have concerns about the completed IEP, they can opt not to sign it and to meet with mediation services through their local school district. It is important that all parties are in agreement with the IEP. The goal is always that the needs of the student be met.

This Team will meet again about half way through the year to assess and discuss progress. If changes need to be made, this is the time to do it—and again the plan MUST be signed for it to be binding.

What do I do when my young adult is done with school?
Children with developmental disabilities or related conditions may qualify for Transition Services. Consumers (the child/young adult/adult) typically are in the transition program between the ages of 18-21. (Availability and funding may vary from state to state and county to county.) This is a service that provides additional education, usually vocational. Sometimes a Transition Program is a separate program and other times it is a part of the high school programming. When admitted to a Transition Program, an assessment is completed that is based on vocational or volunteer skills and individual interest. Staff then assess the individual's skill set and what his/her areas of interest are which consist of either paid or volunteer opportunities for consumers. Most of the time the transition program will work with your child to find the best job fit—and several jobs or volunteer opportunities can be tried before one is found. The consumers are evaluated in each opportunity to see which ones might be a good fit. When the Transition Service in completed, they complete a report with their findings and pass it on to potential Vocational Programs. If the consumer is good fit and does the job well, he/she will continue working at the site. Depending on need for supervision, a Vocational Program may take over paid supervision—or if the consumer is doing well, perhaps the natural supports (e.g., the job supervisors and co-workers) will take that role on and there would be no need for a vocational program.

What do I do after High School and/or Transition Program? What is available?
After High School graduation and/or Transition Program, it is time to pursue a Vocational Program. As mentioned above, if your High School/Transition Program /Case Manager are proactive and have relationships with Vocational Programs, you may have a smooth transition into a Vocational Program. The key is always to be seeking the services that are next.

Vocational Services are programs that complete an assessment with a consumer and evaluate abilities, skills, and interest for employment. Vocational Programs also provide job training, job-seeking skills, resume development, other work readiness skills, and assistance in finding and keeping a job.

Because we serve a wide variety of consumers, there are a few different types of Vocational services/sites. DAC's (Day Achievement Centers) is a site where consumers mostly work on-site/in the building. DAC's typically bring work into the site, typically work for groups, such as labeling, shredding, recycling, mailings, etc. Some DAC's also have Community Employment sites. This is when consumers

work off site, sometimes individually with a job coach. Examples include: working at McDonalds, a car wash, or an enclave (several consumers and one or more job coaches). Additional examples include: Hotel cleaning, laundry, general cleaning, etc. Another type of Vocational Program is Community Employment. This is a program that focuses on employment or volunteer opportunities in a community. Jobs and volunteer opportunities may be specific to individuals or enclaves. Some examples are: Hotel cleaning or laundry, factory work, cleaning or working at restaurants, flower shops. Volunteer opportunities may include nursing homes, assisted living, library, hospital, etc. Jobs vary from state to city, and it depends on how aggressive your vocational providers are and how open the community is to job development for people with developmental disabilities/related conditions.

For folks that have multiple disabilities/needs of the aforementioned, Vocational Programs may individualize a program that meets the needs of a specific individual.

You must be an adult of age 18 to receive vocational services, although there have been situations when the State has issued a variance and has approved a younger person for services.

What is a Vocational Program? How old do you have to be to access this service? How do I access this service?

Like all the Services, a Vocational Program requires funding. Funding will vary based on level of supervision and skill sets/abilities, similar to other services provided to persons with developmental disabilities/related conditions. Parents/guardians will have to advocate to the county case manger to see if funding is available and which Vocational Programs have openings/availabilities. If you are lucky enough to have a Transition Program or School System that has a relationship with the county, they will help you with this process and probably be able to recommend a Vocational Program that best suits the consumer.

When your adolescent is accepted into a vocational program, a written plan is required (similar to the school system). A Vocational Program Plan must contain the consumer's abilities, needs, risks, goals, supervision, and progress. This Plan is required to ensure that the consumer is safe, successful, and that the appropriate services are being provided.

This IPP meeting should involve the Intradisciplinary Team, which includes: consumer, parents/guardian, county case manger, vocational supervisor, residential supervisor, job coach (person who works directly with the consumer), PT, OT, ST, and any other people the team feels necessary to invite to ensure that the best plan is written, developed, and implemented.

This meeting is held twice a year at the request of the parent or guardian—more often, if requested. This plan should be signed by the team members and the goals should be reflected in the County ISP (i.e., the plan the parents and county case manger develop), to ensure implementation. Unfortunately, if any significant event or discussion is not in writing, it is considered non binding and doesn't or didn't happen.

How can I get a break and help with my child/young adult/adult with developmental disabilities?
There are services available to families that have children/young adults with developmental disabilities and related conditions. Each state or county has a budget that is specified for these services; however, funding, services, and availability may vary.

In order to access services you must have a case manager for your child/young adult, and they must have a screening document. (A screening document is a tool used to determined if and what services are needed. This document is usually completed on the onset of services and re-done every six years—or more frequently, if there is a change to the document. For example: If a child is going from High School to Vocational Program, this document can be compared to an order form). It is important for parents/guardians to be totally honest when completing a screening. This is not a time to shed a bright light on your child, but instead give examples of worse case scenarios. This could be the first document and it may set precedent of services in the future.

Services available:

PCA(Personal Care Assistants) Services or In-Home Waivered Services are services provided to children/young adult in their family homes—or it could be adults with mild developmental disabilities who can live on their own in their home/apartment but need minimal supports. PCA or In-Home Waivered services are determined via the screening document; a number of units/hours are determined and designated to an individual/consumer. The consumer/parent/guardian with the help of the case manager chooses an agency to provide services. The agency assigns and trains a staff person to work with the consumer. Sometimes there are more than one staff person assigned. Before services can start, a meeting must take place, similar to the school and vocational system. The meeting includes the consumer, parent/guardian, county case manager, agency representative, school/vocational representative and any other people the team feels necessary to invite to ensure that the best plan is written, developed, and implemented. At this meeting, an IPP (Individual Program Plan) must be developed and signed. The plan typically contains goals regarding independent living skills, behavior management, money management, health and safety, medication administration, community integration—but is not limited to these topics. In lay terms, staff will help/train/teach the consumer in learning how to do their laundry, make a small meal, take or identify medication, pick out appropriate clothing, etc. Again, this plan is signed by all appropriate parties, and this team meets usually 2 times per year—more, more if the guardian requests.

SILS (Semi-Independent-Living-Situation) - This service is also determined via the screening document when a specific number of units/hours are determined and designated to an individual/consumer. A consumer who typically receives this service is semi-independent. They are living in the community in a house or an apartment by themselves or with a roommate, sometimes with an overnight staff and sometimes not. The consumer/parent/guardian chooses an agency to provide services. The agency assigns and trains a staff person to work with the consumer, and sometimes there are more than one staff person assigned. Before services can start, a meeting must take place that is similar to the school and vocational system. The meeting includes the consumer, parent/guardian, county case manager, agency representative, school/vocational representative, and any other people the team feels necessary to invite to ensure that the best plan is written, developed, and implemented. At this meeting, an IPP (Individual Program Plan) must be developed and signed. The plan typically contains goals regarding skills that need to be developed, e.g.: independent living skills, money management, health and safety,

medication administration, OT, PT, community integration, and potentially other goals. In lay terms, staff will help/train the consumer with independent living skills, such as: budgeting, balancing a checkbook, making sure the consumer has medications and is taking them, medical appointments etc. Again, all appropriate parties sign this plan. This team usually meets 2 times per year—more, if the guardian requests.

SLS-(Supported Living Situation) Group Home - This service is also determined via the screening document, and the level of help and number or units/hours/daily rate are determined and designated to the individual/consumer. A consumer who typically receives SLS services needs 24-hour supervision or 24-hour plan of care. Consumers typically live in a house with others. The number of maximum roommates varies from state to state and county to county. The consumer/parent/guardian chooses an agency to provide services. The agency develops a living situation to ensure a good match of consumers/residents, develops a staffing pattern that meets the needs of those that live there, and hires and trains staff. Before services can start, a meeting must take place, similar to the school and vocational system. The meeting includes the consumer, parent/guardian, county case manager, agency representative, school/vocational representative and any other people the team feels necessary to invite to ensure that the best plan is written, developed and implemented. At this meeting an IPP(Individual Program Plan) must be developed and signed. The plan typically contains goals regarding independent living skills and community living with roommates, behavior management, money management, health and safety, medication administration, OT, PT, ST, and potentially other goals. In lay terms, staff will help/train the consumer with independent living skills, such as: meal prep, laundry-cleaning, banking- budgeting-handling money-cashing checks, balancing a checkbook, medication administration, health and safety-exercise and diet, etc.

Again, all appropriate parties sign this plan and this team usually meets 2 times per year--more, if the guardian requests.

ICF-MR (Intermediate Care Facility) This is a group home which serves persons with very intensive needs. This service is also determined via the care plan screening document, as well as the level of help and number of units/hours/daily rate determined and designated to the individual/consumer. Consumers who may need one-to-one staffing more often (e.g., awake overnights, nursing on site, higher level of behavioral needs—perhaps a behaviors specialist or similar staff) may need this type of facility. States usually hedge away from these, as they feel consumers do better in community living group situations; but these are sometimes the most effective and efficient regarding budgetary concerns. The agency develops a living situation to ensure a good match of consumers/residents, develops a staffing pattern that meets the needs of those that live there, and hires and trains staff. Before services can start, a meeting must take place similar to that of the school and vocational system. The meeting includes the consumer, parent/guardian, county case manager, agency representative, school/vocational representative and any other people the team feels necessary to invite to ensure that the best plan is written, developed, and implemented. At this meeting an IPP (Individual Program Plan) or Care Plan must be developed and signed. The plan typically contains goals regarding independent living skills and community living with roommates, behavior management, money management, health and safety, medication administration, OT, PT, ST, and potentially other goals. In lay terms, staff will help/train the consumer with independent living skills, such as: meal prep, laundry-cleaning, banking-budgeting-handling money-cashing checks, balancing a checkbook, medication administration, health and safety-exercise and diet, etc.

Again, all appropriate parties sign this plan, and this team usually meets 2 times per year—more, if the guardian requests.

How do I prepare my child or young adult for a move to a Group Home?
It is very important to help your child /young adult with the transition into a group home. We find that taking them to visit their friends who have successfully transitioned into a group home is great preparation. This way, they can see how first-hand much fun their friend is having and the independence that can be achieved.

When a group home is chosen, you should ask the home if there could be a plan developed for the move. This plan could be visits, short at first – dinner and game night (you should ask the home if they could engage in an activity that you know your child/young adult would enjoy, such as bowling, movie, music etc.) After a period of time, the visits would be longer—perhaps a full day of activities. Again, plan it with activities your child/young adult enjoys and add some household responsibilities, such as baking/making a meal, etc.

When decorating your child/young adult's room, decorate it similar to his/her room at home. This would give them a sense of consistency and feel like home. It typically helps the adjustment.

How do I prepare for my child/young adults move to a group home?
It seems that more often than not, parents/mothers struggle the most with the move. Their identity has been the parent, and this identity goes on for years. When their child moves away from the family home, their identity changes and their free time is significant. They start to wonder: What is my purpose now? How do I fill my free time? Sometimes they might become depressed. It is just as important for the parents/mothers to prepare themselves for this move. Options might include: building relationships with other parents whose children are in group homes, support groups, meet with a pastor/counselor, perhaps get involved in the community, part-time job, volunteer, etc.

Will I have to pay for services?
State to state and/or county to county funding varies. Programs may also differ. Some states have private funding programs for families who can afford to pay for services. Other may have programs that have "sliding fee scales." This is when families pay a per diem based on their income. Some states/counties fund the whole program. It is important to know what is available and how to access these services. If you need help accessing services contact your county case manager.

Privacy Information
When services are being provided and information needs to be shared (which is very important to provide consistency), you will need to sign releases of information and the information that can be shared. This is important so that information that needs to stay private does.

Choosing Service Providers
Parents/guardians should shop around and ask other parents you know about the services they are using and if they like them. You should interview companies and ask questions that are important to you and explain the services you expect. When your child/young adult is visiting a potential site/group home, you should observe them in that situation to see how they respond and how others respond to them. Listen to your "gut" and choose the service you feel will best fit your child/young adult. Don't be forced into a service you do not want.

If you have questions or need more information please contact Dana Norton, Executive Director-CER of MN (Office)218-624-3097, (Cell) 218-391-9203 or e-mail @ ourplace@cerofmn.org.

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