

*Amazing Grace Advocacy  
2020 Guidebook*



*Every Life Has A Purpose™*

## **Brain Disorders include: Mental Health, Trauma, IDD, Autism, Substance Use and Neurological Disorders**

- 1 in 5 children ages 13-17 experience a mental health disorder
- 1 in 68 children are diagnosed with Autism
- 1 in 10 families have a child with Intellectual Disabilities
- 60.8% of Children (in a national study) were exposed to Trauma
- 37% of NC High School Students reported Marijuana Use (2017)

**You are not alone!**

### **Taking the Lead for your Child**

Take things one day at a time, don't get overwhelmed with the diagnosis and remember that your child is still your child, you know them best. No matter what, you love them the same way you did before that diagnosis, you have been doing this for a while and now it just has a name.

Amazing Grace Advocacy is your Central Resource to help navigate and connect you with the appropriate supports and services. Use this Guidebook as your starting point and reference.

Step 1-Reducing Crisis

Step 2-Get Organized

Step 3-Educate yourself

Step 4-Have a Plan

Step 5-Future Planning



### **Stay Connected with Amazing Grace Advocacy**

There are several ways to stay connected with us virtually

[www.amazinggraceadvocacy.org](http://www.amazinggraceadvocacy.org)

Follow us on Facebook, Twitter and Instagram

[connect@amazgraceadvocacy.com](mailto:connect@amazgraceadvocacy.com)

Engaging in our Programs will help your entire family learn skills to make your lives better now and the future. Through connections to the appropriate services, education, support, self care and having people who understand are essential to families.



A Crisis in an unexpected event that we are not prepared for.  
 Planning for the “event” enables you to react and know what to do.

Identify behaviors that require an action

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Are there any pre-warning signs to this behavior (body language, verbal, or trigger items)?

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What is your response? Does it work?

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Strategies to try when child is escalating

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When do you seek outside help and what do you think the outcome will be?

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Who do you seek help from?

Type	Contact info	Notes
24-hour Crisis Line/Cardinal	800-939-5911	Mobile Crisis can take 2 hours but can come to home
Clinical Home (Therapy)		Some therapists offer crisis calls
Emergency Room (not preferred and not 1 <sup>st</sup> choice)	Don't call ahead	Cabarrus not a good choice/use BHC or Levine in Charlotte
Law Enforcement	911	Ask for a CIT Trained Officer-explain diagnosis to dispatch

*Please note that Amazing Grace Advocacy is not a Crisis Response Service, any calls or texts outside of business hours will not be responded to-until next business day.*

# Crisis Plan

## Create a plan that works:

A Crisis Plan should be approached in the same way as a "Fire Escape Plan".

Who is involved, what do each of us do, where do we go in the house,  
what variables can change the plan?

Removing the child from home is sometimes necessary, however it should not be the first reaction. If the plan has no impact and outside help is needed-have your plan established.

*Remember that Hospital Visits are expensive and often you will be sent home!*

Names of Family Members	What can we do at home?	Places everyone?	Variables-life happens

### Plan for Emergency Actions:

Where is the preferred place to go? \_\_\_\_\_

Who can watch other siblings? \_\_\_\_\_

Can I transport safely or need EMS? \_\_\_\_\_

Do I have Child's Binder? \_\_\_\_\_

Am I prepared to be gone for up to 6 Hours? \_\_\_\_\_

## Why you Need Natural Supports



As you are probably aware, having a child with needs can be very isolating. Sometimes it is just easier to stay at home than venture out when behaviors, physical and mental needs and family struggles are present.

It is also very easy to become isolated when it feels that no one understands your situation, or you feel that your child is just too hard for a sitter, family member or a friend to care for. It becomes a bigger struggle to prepare for a night out or time away and so we resolve ourselves to just be home and care for our children.

Problems arise for parents, who are the caregivers for years and years, but have little social interaction or down time due to the constant, and never ending, needs of children with special needs. We often feel alone and struggle to connect with our own peers.

Also, in times of crisis it can become very hard to navigate life all alone. A sick child or parent, an emergency in the home or a time of loss can be extremely hard for families of children with needs. We need community and sometimes help, but don't always have those supports in place.

As a part of your "Natural Supports" section of your Guidebook it is going to be important for you to begin to think about those people around you, that you might be able to start a conversation with, regarding your need for community and support.

Who are the neighbors, family members, church members, pastors at your church, friends or special teachers in your life that might be able to begin to come along side you? What can you begin to do to help nurture some of those relationships so that you have a community around you that knows your needs, and the needs of your child, so that you could have some support?

With the Natural Supports worksheet, you will also find a letter that might help you start the conversation. Being willing to share your needs with others is part of the journey and will make a big difference in your effort to gain community. Sometimes others are not sure how to approach the situation, but if we are actively seeking to make connections and open up about our lives others are usually willing to help.

We were made for community. Living life together is important and it keeps us connected. As a parent of a child with needs, you have a unique and different perspective on life than the parent that may have never walked the road you are on. You would be surprised at what you also have to offer others as you become a part of their community too!

<b>Name of Person</b>	<b>Have you communicated?</b>	<b>Ideas on how they can help</b>

Use our Sample Letter to start these conversations! Email, text and Social Media! You won't get help unless you ask! Think outside your family-neighbors, church, school aides, local college programs.

Dear Family and Friends,

As you are aware, our child, and consequently, our family deals with some special needs. Often families of children with special circumstances struggle to make connections with their community, family and friends due to the nature of the child's needs. Behaviors, academics, health and other aspects of the child can affect the entire family.

Recently our family began working with Amazing Grace Advocacy. We are working on a guidebook that is helping us plan for a variety of goals for the future. One of the goals that we have is to begin to look at those around us that might be a natural support for us. Natural supports are people who are just naturally around you who might offer help, love, encouragement and support in everyday life.

Some of the needs that we have are like any other family. We sometimes need a sitter for a date night or help with taking our child to the park. Sometimes we'd love to have a few hours just to run errands or catch up on things at home while someone spends time with our child. There may be times that we need some support during a time of emergency and we are just trying to make a list of names and contact information that we could easily access in time of crisis.

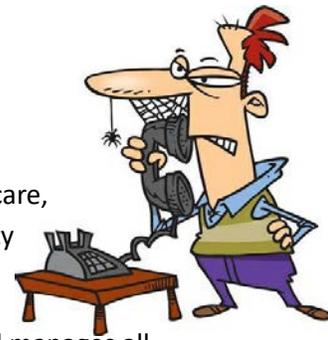
We would love to have better connections with our family and friends because having a child with needs can sometimes be very isolating, and building a supportive community could make all the difference for our family.

We consider you a natural support. As our friend, neighbor and family thank you for being someone that we feel we might be able to call on in time of need or just for fun. Would it be ok if we put your information in our guidebook as a Natural Support?

Thank you!

# Understanding your Insurance Benefits

Mental (Behavioral) Health is handled differently than medical coverage and especially for adolescents. It is essential that you learn what your plan covers and limits prior to seeking care, to avoid financial distress. Private Insurance companies use and contract an outside specialty health care management company/organization to process and approve services.



Medicaid uses “Managed Care Organization” (MCO) that specializes in behavioral health and manages all referrals, authorizations and that is provided by State Tax Dollars. Cardinal Innovations is the MCO for Cabarrus, Rowan, Mecklenburg, Stanly and Union Counties. Partners Behavioral Health manages Iredell County.

You will be dealing with these management companies, and not directly with your insurance (such as BCBS or Medicaid).

Locate your Behavioral Health Information/ Phone Number usually on the back of your insurance card.

**Here are the most common companies (click on links for direct access to websites):**



**Blue Cross/Blue Shield of NC: 1-800-359-2422** for Behavioral Health. **BCBS uses “Magellan Behavioral Health” management company (MCO).** Typically most plans require a “pre-certification/referral” for all mental health services. Pediatricians are usually used for the referral. Visit **Magellan’s website** for more info: <https://www.magellanassist.com/default.aspx>

**NC Health Choice (available through DSS, with a premium): Beacon Health Options**  
<https://www.beaconhealthoptions.com/members/beacon/>

## **Medicaid:**

**Cabarrus, Rowan, Mecklenburg, Stanly, Union-Cardinal Innovations (MCO) : 1-800-939-5911** handles all of Medicaid mental health and intellectual disabilities. <http://www.cardinalinnovations.org/>

*\*Cardinal Innovations is often given as the contact for all mental health crisis’; they can assist in referring to appropriate providers, but they are NOT a Private Insurance Company and cannot authorize if you do not have NC Medicaid.\**

**Iredell, Catawba, Cleveland, Gaston and Lincoln 1-800-235-4673** Partners Behavioral Management (MCO) handles all Medicaid mental health and intellectual disabilities. Visit [www.partnersbhm.org](http://www.partnersbhm.org)

**Mental Health Parity** Act of 2013 stated that Mental Health Disorders had to be treated/covered the same as Physical Health with Private Insurance companies. Despite the law, insurance companies have continued to discriminate and get away with not covering all services. However, the Affordable Care Act did improve some aspects with preventing the pre-existing condition exclusion and other small benefits. With the pending repeal and replace of the ACA; Amazing Grace Advocacy has become vocal advocates at the state and national level to protect Mental Health Parity. To learn more about this and our efforts visit:

**Insurance Claim Assistance:** Mary Kathryn Ewart at Time Agency 704-786-8131  
This is a fee based service; but is incredible in fighting claims for you with private insurance companies.

## Contacting Your Insurance Company or MCO

***Before you make phone calls; complete your parent binder. Have it with you when you make phone calls to insurance or any provider. Be sure to get all names, direct phone numbers and emails of all insurance contacts and quoted benefits.***

Insurance Company (Behavioral Health) Phone # \_\_\_\_\_

Subscriber ID or Medicaid # \_\_\_\_\_

Contact Info \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Questions to ask:**

**Record answers:**

What mental health or Autism benefits do I have for Out Patient services? Who are the providers?	
Are Psychological Evaluations a covered benefit? Who are the providers I can go to for this?	
Can we be assigned a Care Coordinator or Case Manager? If so, how?	
What is the co-payment for Out Patient Therapy?	
Do we have a limited number of visits?	
Do we have higher level of care coverage? Intensive In Home? Day Treatment? PRTF?	
Do you cover Autism related therapies? Speech Therapy? Applied Behavior Analysis (ABA)? Occupational Therapy (OT)?	
What is the mental health deductible or maximum benefit?	
Do mental health costs contribute to the same deductible as medical costs?	
Can you send me a list of covered (or non-covered) medications?	

***Notes of more specific questions:***



# What is Trauma?

When a child feels intensely threatened by an event he or she is involved in or witnesses, we call that event a trauma. There is a range of traumatic events or trauma types to which children and adolescents can be exposed.

**It can include: bullying, parental separation/divorce, community violence, family member with mental illness, abuse, neglect, family member with substance use/alcoholism, sexual abuse, natural disasters, racism, domestic violence, medical conditions/surgeries, loss of a loved one and ongoing poverty.**

## **How it affects families:**

Trauma changes families as they work to survive and adapt to their circumstances and environment. Research demonstrates that trauma has a range of impacts on individual family members, their relationships with each other, and overall family functioning.

Individuals can experience a range of reactions to a traumatic event. Initial distress is likely. Subsequent responses range from resilience to thriving, or on the other end of the spectrum, short-term to chronic physical health concerns (e.g. headaches, sleep problems, digestion problems, high blood pressure) or mental health problems (e.g. acute stress, post-traumatic stress disorder, depression). In both children and adults, these symptoms can inhibit developmental growth and cascade into changing the course of one's life.

The adult intimate relationships in a family can be a source of strength in coping with a traumatic experience and its aftermath, but when coping resources are stretched too thin and the stress is too high, partners can have problems communicating, managing emotions, and remaining close, which increases the chances for separation or even interpersonal violence.

Even in the closest of families, it is sometimes hard to remember that family members may have different reactions to the same traumatic event. Reactions will differ depending on each family member's age, developmental level, trauma history, as well as his or her relationship with the child, and personal exposure to the event. For example, one family member may have shared the child's experience, another may have witnessed it, and another may have heard about it after the fact. While all family members may be upset, only some will have traumatic stress reactions and each will take a different amount of time to recover from the experience.

## **What parents don't know:**

Sometimes your child is being exposed to trauma outside of your home and family. Children tend to be embarrassed and do not open up to anyone about traumatic events. Sudden changes in behaviors, performance in school, depression, aggressive or substance use are red flags that a trauma may have occurred.

Amazing Grace Advocacy staff has trained by the North Carolina Center for Child and Family Health to screen and respond to trauma in children and families. We use a questionnaire for children and parents that asks basic questions without re-traumatizing the child or parent. If we discover any trauma, we will guide parents through steps and referral to a Trauma Focused Therapist.

*“There are wounds that never show on the body that are deeper and more hurtful than anything that bleeds”*

*Laurell K. Hamilton, Mistral's Kiss*



## After the AUTISM diagnosis....

It's normal to feel very overwhelmed by getting an Autism Diagnosis; take a minute to yourself to process your feelings. It is important to take that step back and regroup so that you can be the best you can be to help your child. While there are many unknowns about the Disorder, learning as much about it will give you power to advocate for your child.

Find a good Support Group or a Person you know you can count on to support you during your journey through the ins and outs of Autism Spectrum Disorder

### Support Groups: (in-person)

- [Amazing Grace Advocacy](#) - Support Groups in Cabarrus and Rowan Counties monthly.
- [Autism society-NC](#) -Support Groups in Cabarrus and Rowan Counties.

### Support Groups: (on-line)

- [www.myautismteam.com](http://www.myautismteam.com) – This sight may help you connect with other families in your area.

## There are different names for Autism Spectrum Disorder along with varying levels.

### Terms you will hear:

- **AU**- this is an Acronym for Autism
- **ASD**- this is an Acronym for Autism
- **Severe, Mild, Moderate**- these are the different levels of Autism
- **PDD-NOS**- this is a form of Autism also known as Pervasive Developmental Delay- Part of the Autism Spectrum also known as Mild Autism but according to the new DSM5(Diagnostic Statistical Manual of Mental Disorders 5<sup>th</sup> edition/DSM V) this is now known as part of the Autism Spectrum Disorder and rarely used, but you will hear other parents talk about this.
- **Asperger's** – this form of Autism is known as High Functioning but according to the new DSM5(Diagnostic Statistical Manual of Mental Disorders 5th edition/DSM V) this is now known as part of the Autism Spectrum Disorder.
- **ID**- also known as an Intellectual Disability, some children with autism also have an intellectual disability.
- **Dual Diagnosis**-Refers to have more than one brain disorder (can be Autism with Intellectual Disability or Mental Illness)

Make sure that you use reliable information when researching information about Autism, there are a lot of webpages that will present you with unreliable information along with unreliable resources.

### Good web pages with valuable and Reliable information...

- [www.autismspeaks.org](http://www.autismspeaks.org)- this webpage contains some very valuable information along with a 100-day tool kit, they also have providers listed which would include dentist, doctors and much more.
- [www.teacch.com](http://www.teacch.com) - this is not only an amazing website they also have several amazing programs for children with special needs. They are the go to for Autism. They serve children and adults.
- [www.autismsociety-nc.org](http://www.autismsociety-nc.org)- The Autism Society has many chapters around and you may find one in your area and they also have a lot of Valuable information
- [www.myautismteam.com](http://www.myautismteam.com)- this is a network of parents from all over, while some of the information may not be the most reliable the parent connection is very powerful and very helpful after first getting the Autism diagnosis.



## Understanding the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

Mental health professionals use the manual to determine and communicate a patient's diagnosis after an evaluation; hospitals, clinics, and insurance companies require a DSM diagnosis for all patients treated. The DSM is updated frequently and is now in its fifth edition as of 2013 “**DSM-5**”.

Types of Professionals to treat Brain Disorders can be confusing, here are the most common titles and descriptions for those working with our children. They are often referred too as "providers"

Therapy	Therapist, Clinician, Social Worker, Counselors, ABA and Psychologists
Medication	Psychiatrist, Medication Management, Nurse Practitioner and Physician Assistant
Related Services	Speech Therapy, Occupational Therapy, Physical Therapy
Specialists	Developmental Pediatrician, Neurologist
Testing and Evaluations	Psychological Evaluation, Comprehensive Clinical Assessment (CCA), Trauma Screening, Autism Screening, Psychiatric Evaluation, School Psychological Evaluation



## Intellectual and Developmental Disabilities

There are two categories for Intellectual Disabilities:

**Intellectual Disabilities (ID)** are significant limitations in both intellectual functioning and in adaptive behavior, which includes everyday social and practical skills. This disability originates before the age of 18. However the child does not have any physical limitations.

**Intellectual Developmental Disability (IDD)** are disorders that are usually present at birth and that negatively affect the functioning of the individual’s physical, intellectual, and/or emotional development. They also affect multiple body parts or systems that limit the child’s physical capabilities.

There are Four degrees of severity are solely related to the individual’s level of intellectual impairment:  
**Mild, Moderate, Severe and Profound:**

Mild Intellectual Disabilities: IQ level 50-55 to approximately 70

Moderate Intellectual Disabilities: IQ level 35-40 to 50-55

Severe Intellectual Disabilities: IQ level 20-25 to 35-40

Profound Intellectual Disabilities: IQ level below 20 or 25

## What is Dual Diagnosis?

Dual Diagnosis is a term applied to the co-existence of the symptoms of both intellectual or developmental disabilities and mental health problems. Children with Dual Diagnosis have an IQ score below 70 and had onset of mental health symptoms before age 18.

# Psychological Evaluations

A psychological evaluation is a set of procedures and tests that are administered by a licensed psychologist to obtain information about a student's learning (IQ), behavior, and mental health. Also known as "Neuropsychological Evaluation".

**Most higher level of care programs will require a Psychological Evaluation that is less than 24 months old as a requirement for admission.**

*\*These evaluations, typically takes months to get an appointment and at least 8-12 weeks to be completed; so it is best to be proactive in attaining and keeping them current every two years.*

*\*Evaluations provided by the public schools are not accepted by programs, you will need a full evaluation by a licensed psychologist.*

**Typically, the evaluation is done in two sessions (usually a week apart) and each session takes 1-2 hours.**

Parent's should be prepared to spend the first session giving the psychologist the following info:

- Description of present problems and symptoms
- Information about health, illness and treatment (both physical and psychiatric), including current medications
- Parent and family health and psychiatric histories
- History of child's development
- Educational records and school information
- Family and social relationships

**The second session is typically spent testing the child and parents are not present in testing room.**

**There are multiple page assessment's that are given to parent to fill out about the child and also an assessment is sent to the child's teacher to complete.**

**Sometimes laboratory studies such as blood tests, x-rays, or special assessments (such as speech and language or occupational) or also ordered to gather more information.**

Once the evaluation is completed; the Psychologist will schedule a follow up appointment to go over the findings and they will give recommendations for treatment and educational settings.



# Programs

## Programs to start immediately if your child has been diagnosed with ID/IDD

**NC Innovations Waiver** is a Medicaid program for individuals with intellectual/developmental disabilities or dual diagnosis; designed to enable individuals and their families to plan, obtain and sustain community based services. This is an alternative to placement in a care facility; giving individuals of all ages to live as independently as possible in their community.

- Must have a Psychological Evaluation that is less than 3 years old from a Psychologist (not school).
- There is a waiting list to receive the Innovations Waiver called the “Registry of Un Met Needs”. The typical wait is 7 years. All children that fit the diagnosis criteria should apply for the waiver as soon as possible.
- Contact Cardinal Registry Department by **phone and email** 704-939-7980 and [registry@cardinalinnovations.org](mailto:registry@cardinalinnovations.org) to start the application process, which can take months to complete. Visit [www.cardinalinnovations.org/nc-innovations-waiver](http://www.cardinalinnovations.org/nc-innovations-waiver) for info

**Social Security Disability Income-** You will need to complete an Application for Supplemental Security Income (SSI) AND a Child Disability Report. [www.ssa.gov/disabilityssi/apply-child](http://www.ssa.gov/disabilityssi/apply-child) The report collects information about the child’s disabling condition and how it affects his/her ability to function. At this time, only the Child Disability Report can be completed online. Please contact Social Security by phone (1-800-772-1213) or in person to schedule an appointment to complete the SSI application. They will help you in person or by phone. See directory for Attorney Info (you will probably need help if you are turned down and need to appeal).

No matter the age of your child; it is never too early to start planning for a successful transition into adulthood. By age 14 families should have educated themselves about options for high school and have a plan for what happens at age 18.

## Areas to explore:

**Guardianship** is a person lawfully invested with the power, and charged with the obligation, of taking care of and managing the property and rights of a person who, because of age, understanding, or self-control, is considered incapable of administering his or her own affairs. (Dictionary, 2015) Guardianship is handled by the Cabarrus County Clerk of Courts (704-262-5500) to contact them.

**Alternatives to Guardianship** are a great way for parents to give their child independence, while preserving some legal rights to the decision making for financial and medical issues. These alternatives can be creating, “ Power of Attorney, Psychiatric Advance Directives, and a Health Care Power of Attorney”. More information can be found at : [www.nrc-pad.org](http://www.nrc-pad.org) and also at [www.arcnc.org](http://www.arcnc.org)

**(b)(3) Medicaid Services** are additional community based services for all ages with mental health and ID/IDD diagnosis. They include: In-Home skill building, Respite, Supported Employment (ages 16+), Transitional Living and much more! Visit [www.cardinalinnovations.org \(b\) \(3\)](http://www.cardinalinnovations.org(b)(3))

**College and post-secondary education-**planning and preparation can be researched through these great resources: [www.wrightslaw.com](http://www.wrightslaw.com) [www.ahead.org](http://www.ahead.org) [www.heath.gwu.edu/](http://www.heath.gwu.edu/)



## Therapeutic Interventions

For some children, outpatient therapy, medication management and specialized classrooms aren't enough and a higher level of care is needed. Often, the decision for more intensive care is determined by insurance and limited by, as well. Sadly, a child and family usually reach an urgent crisis level in order to receive appropriate care.

**Out Patient Therapy (in an office) is the most widely used and covered by both Private Insurance and Medicaid. There are different types of out patient therapy and we will help determine and refer you to the best fit for your child and family.**

- **Other Types of more Intensive Therapies (typically only covered by Medicaid)**
- **In Home Therapy** is a home and community based treatment designed to meet the needs of families who are having a difficult time managing the behavior of a child with a diagnosed mental health need. It provides concentrated treatment to address a current crisis and/or to decrease the risk of a youth being removed from their home. In some cases, a child may have already been removed from their home and this type of therapy can assist with successful reunification with their family. Therapists and clinicians will travel to the family home at least 2-3 visits per week over the course of 3-6 months.
- **Partial Hospitalization Program (PHP)** is a type of program used to treat mental illness and substance abuse. In partial hospitalization, the patient continues to reside at home, but commutes to a treatment center 5-7 days a week for about 6-8 weeks.
- **(b)(3) Medicaid Services** are additional community based services for all ages with mental health and ID/IDD diagnosis. They include: In-Home skill building, Respite, and much more! Visit [www.cardinalinnovations.org](http://www.cardinalinnovations.org) (b) (3)

## Out of Home Placements

- **Hospitalization Inpatient care** involves hospitalization of a youth in need of around-the-clock care. Carolinas HealthCare System's child and adolescent behavioral health programs provide a safe, nurturing environment where young patients can work with our trained clinicians to focus on functional skills and behaviors. Inpatient care is usually 7-14 days.
- **Psychiatric Residential Treatment Facility (PRTF)** for severe emotional, behavioral and psychological problems who need a highly structured, therapeutic environment. All services are provided under the direction of a board-certified child and adolescent psychiatrist with nursing on site 24-hours a day. Individualized treatment plans are designed by an interdisciplinary team along with family members and other stakeholders. PRTF is typically a 4 to 6 month program.
- **Therapeutic Foster Care** Trained foster parents provide a highly supervised, therapeutic environment in their home for children and teens from throughout the state who are receiving treatment for emotional challenges. All of the Treatment Parents in our program are fully screened, trained, and supervised by our on-staff Treatment Coaches, and are licensed by the state to provide treatment in their home environment.
- **Group Home** is a private residence for children or young people who cannot live with their families, due to severe mental disabilities. Typically there are no more than six residents and there is at least one trained caregiver on staff 24 hours a day/7 days a week.
- **North Carolina State Operated Health Care Facilities** are residential centers for youth with serious mental illness and disabilities. They are typically reserved for children and teens that have not been successful in other residential placements.

# Education



Educational needs often require accommodations and support for kids diagnosed with Brain Disorders. Parents and educators working together will help determine the extent of services the child needs to succeed. It is very important for parent to understand that schools are not mental health facilities and have very limited resources to accommodate children presenting with severe behaviors.

Accommodations for children with Brain Disorders:

- **Individualized Education Plan (IEP)** is a program and document to ensure that a child who has a disability (identified under the law) and is attending an elementary or secondary schools, receives specialized instruction and related services.
- **504 Plan** is developed to ensure that a child who has a disability identified under the law and is attending an elementary or secondary educational institution receives accommodations that will ensure their academic success and access to the learning environment. They do not require special instruction for intellectual disabilities.
- **Functional Behavior Assessment (FBA)** a problem-solving process for addressing student problem behavior. It relies on a variety of techniques and strategies to identify the purposes of specific behavior and to help IEP teams select interventions to directly address the problem behavior. A FBA looks beyond the behavior itself; the focus when conducting a functional behavioral assessment is on identifying significant and specific social, affective, cognitive, and/or environmental factors associated with the occurrence (and non-occurrence) of specific behaviors. This broader perspective offers a better understanding of the function or purpose behind student behavior.
- **Behavior Intervention Plan (BIP)** are a useful classroom management tool for students having inappropriate classroom behavior. They teach and reinforce positive behaviors and document the success of the intervention.
- **Resource Classroom** is a separate classroom in a school where students with educational disabilities, such as specific learning disabilities, are given direct, specialized instruction and assistance with related assignments as individuals or in groups.
- **The Behavior Focused Self Contained (BFSC)** classroom is typically for the student who struggles with severe behavioral or emotional issues that keep them from being able to access the general curriculum in a less restrictive setting. These are students who require a higher teacher-to-student ratio. Students typically enter the BFSC classroom with an FBA (Functional Behavior Assessment) and a BIP (Behavior Intervention Plan). Students focus primarily on improving their behavior at school through social skills and behavior strategies with the goal of eventually returning to the regular education classroom setting. (Downs, 2015)
- **Self-Contained Special Education classrooms** are available for students with intellectual disabilities and documented IQ score below 55.
- **Day Treatment (only available to children with Medicaid)** is a highly individualized treatment option for children who have social and behavioral problems that create challenges for them in traditional classroom settings. In addition to tutoring, therapists and qualified professionals provide therapy; therapeutic recreation and stress management to help children better manage their emotions and behaviors. Children who experience success with this therapeutic option can be integrated back into their regular classrooms. (AYN, 2015)

## What is an IEP?

The IEP, Individualized Education Program, is a written document that's developed for each public school child who's eligible for special education. The IEP is created through a team effort and reviewed at least once a year.

Before an IEP can be written, your child must be eligible for special education. By federal law, a multidisciplinary team must determine that:

- (1) he/she is a child with a disability
- (2) he/she requires special education and related services to benefit from the general education program.

## Who is on the IEP Team?

**You, the parents, who have valuable insights and information about her strengths and needs, and ideas for enhancing her education**

- Regular education teacher(s) who can share information about classroom expectations and your child's performance
- A special education teacher who has training and experience in educating children with disabilities and in working with other educators to plan accommodations
- An individual who can interpret the results of your child's evaluation and use results to help plan an appropriate instructional program (usually School Psychologist or Social Worker)
- A representative of the school system who knows about special education services and has the authority to commit resources (Administrator)
- Individuals with knowledge or special expertise about your child that are invited by you and/or the school district (Navigator from Amazing Grace Advocacy)
- Representatives from transition services agencies, when such services are being discussed (therapist, Vocational Rehab or other community agencies)
- Your child, when appropriate, and whenever transition is discussed (start attending in middle school and must after age 14)

## What is discussed and written?

All North Carolina Public Schools use a software system called "ECATS" to capture all of the meeting discussions, decisions and plans. You will be provided a copy at the end of the IEP Meeting.

The content of an IEP is:

- Present Levels of Educational Performance
- Goals for the Student
- Additional Related Services for the Student

At the completion of the IEP Meeting, everyone on the IEP Team will be asked to sign the final page. If you do not agree with the decisions, you are not required to sign the document and another meeting can be scheduled. If you do sign the document, a "re-evaluation" of the IEP can be requested at any time with no limitations within the school year.

IEP Meetings should not exceed 2 hours; if they do, we need to be doing more work ahead of the meeting to resolve issues and collect data.





## Other Educational Interventions

### What is a 504 Plan?

504 plans are formal plans that schools develop to give kids with disabilities the support they need. That covers any condition that limits daily activities in a major way.

- 504 plans aren't part of special education. So, they're different from IEPs. 504 plans and IEPs are covered by different laws and work in different ways. But the end goal is the same: to help students thrive in school.
- One way 504 plans do that is through accommodations. For example, they might give extended time on tests or the ability to leave the classroom for short breaks. It's less common, but some may also provide services like speech-language therapy or study skills classes.
- Schools typically create written 504 plans. But they're not required to. There are no set rules for what a 504 plan should look like, or what it should include. The only things schools have to put in writing are their policies on 504 plans.

### MTSS-Tiered Interventions

Cabarrus County Schools is committed to implementing and sustaining a Multi-Tiered System of Supports (MTSS). MTSS is a multi-tiered framework which promotes school improvement through engaging, research-based academic and behavioral practices.

- 3 Tiers of interventions within the school to promote positive behaviors.
- Tier 1 is put into place when a teacher recognizes a repetitive negative behavior (parents may or may not be notified)
- Tier 2 is used when 1<sup>st</sup> intervention is not making an impact. Parents are notified and increased interventions take place; might be things like "small group counseling" during the school week.
- Tier 3 when 1&2 have not been effective; more intensive supports are put in place through the entire school day. Parents are involved in the planning of what this will look like.

### School Based Mental Health Services

Students requiring more intensive behavior modification to address behaviors that are occurring within the school environment can be offered "School Based Mental Health" services. This is an outside contracted therapist that comes into the school and pulls the student for a therapy session within the building. This is billed to your private insurance, Medicaid or it is the parent's financial responsibility. There are only certain providers contracted for this service.

## Alternative School Options

### Homeschool

Is sometimes a great option for families that cannot find the support needed for their child in public schools. We offer a “how to get a homeschool started for students with Brain Disorders” session if you would like more information. To explore, visit:

<https://ncadmin.nc.gov/citizens/home-school-information>



### Charter Schools

While Charter Schools are required to provide Special Education; most don't have qualified staff or classroom settings to serve your child in the same capacity as a public school. Therefore, we do not recommend this avenue for children needing an IEP. For behavioral concerns, they most often are not able to provide the mental health supports needed. We urge parents to reconsider this educational placement for a child with any Brain Disorder.

### Private Schools (Tuition Based)

Private schools are not required to provide Special Education; IEP or 504. They also can set their own rules and can expel your child based on behaviors. We do not recommend Private Schools for children with Brain Disorders.

### Melmark School-Charlotte

Specializes in serving those students who require a more specialized special education and clinically sophisticated environment than is available in a public school setting. Our 1:2 teacher-to-student ratio allows us to focus on each student's personal growth and development, shaping a learning environment that fits each child's specific needs enabling progress on his or her Individual Education Program (IEP).

Students with severe Brain Disorders that have been placed on Homebound and Modified Day are candidates for this program. It is funded by Public School funds, but is very costly to a school district and therefore difficult to get approval. Amazing Grace Advocacy partners with Melmark to help families have access to this school. Initial steps are to:

1. Student needs are considered (diagnosis and current school setting)
2. IEP Team at Public School needs to make the referral
3. Melmark comes to observe student and interview parents to determine if qualifying
4. School district reviews the case and denies or refers
5. The process of a Melmark referral can be 6-9 months.

Melmark The logo for Melmark, consisting of the word 'Melmark' in a teal serif font, followed by a stylized hand icon. The hand is green and blue, with fingers pointing upwards and to the right.



# Life Domain Worksheet

Life Domains are an individual's needs, broken down into categories.

<b>Social Relationships</b> Friends	<b>Mental Health</b> getting appropriate treatment	<b>Education</b> getting support and succeeding	<b>Safety/Crisis</b> individual is causing harm to self and others	<b>Recreation</b> hobbies, sports and activities
<b>Employment</b> is there a need for any family member	<b>Legal</b> any open investigations or court dates	<b>Behavioral</b> Behavior is interfering with everyday life	<b>Communication</b> any problems with verbal skills	<b>Values &amp; Culture</b> what traditions are important to family
<b>Independence</b> Transition into adulthood	<b>Parenting</b> parents are struggling	<b>Financial</b> needs for family to prosper	<b>Spirituality</b> Your family's beliefs and participation	<b>Basic Needs</b> Food, Clothing and living expenses.
<b>Family/Permanent Relationships</b> is your family together	<b>Language</b> need for bi-lingual assistance	<b>Transportation</b> does family have access	<b>Physical Health</b> any health concerns	<b>Housing</b> permanent housing for family

Can you list the top 5 Life Domains that are most important to your child and family today?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

Can you list 5 more that are going to be important in the future for your child and family?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

Our goal is to find a realistic solution for all Life Domains that have a need; and to prepare for future Life Domains, so that the child and family is successful in making it happen and continuing to thrive.

List any specific concerns or goals that apply to your family:

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## Adulthood Planning Starts at Age 14

## Schedule an Adult Transition Meeting with your Navigator

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### Steps with Transition Planning:

1. In Middle School, learn about the High School Options
2. Determine High School Path by December of 8th grade
3. Things to discuss BEFORE age 16
  - a. At 18, will they be in school still? \_\_\_\_\_
  - b. Will they be eligible for Social Security Disability? \_\_\_\_\_
  - c. Will you need to seek Guardianship or Power of Attorney? \_\_\_\_\_
  - d. Living arrangements? \_\_\_\_\_
  - e. College or Job Skills? \_\_\_\_\_
4. By age 17 parents should have a solid transition plan in place.
5. Begin process at age 17.5 for Guardian and Social Security Disability if applicable.

### Thoughts about Guardianship:

### Child's Strengths and Interests:

How could Strengths be used in a career path?

What does an adulthood vision look like to parents? And teen?