

Advocacy Skills That Everyone Needs

Presented by:

Doreen Byrd, Lead Parent Educator

Christy Moore, Family to Family Health
Information Center Program Lead





What is ECAC?

Exceptional Children's Assistance Center

Non-profit organization dedicated to improving the lives of children and families in NC through a focus on children and youth ages birth-26 with special health care needs, disabilities or developmental concerns

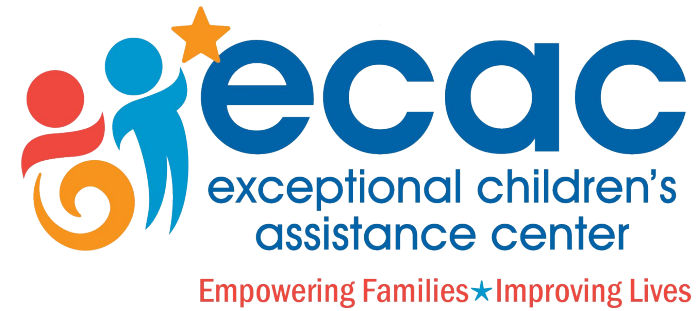
- Serve the whole state of North Carolina
- Provide one-on-one assistance, resources, education and training to families, youth and professionals on a variety of topics
- For families, by families
- All services are provided at no cost to families. We may charge a small fee to professionals for some services



Programs and Funded Partnerships

- NC's Parent Training and Information Center (PTI - OSEP)
- Family to Family Health Information Center (F2F - HRSA)
- NC State Improvement Project (NCSIP - NC DPI)
- NC DeafBlind Project (NC DPI & ECU)
- Pre Employment Transition Services (Pre-ETS) STAR Program
- Learning for Equity: A Network for Solutions (LENS-NC)





Our main goal is to provide families with support, information and resources so that they can become their child's best advocate and supporter.

We support families and professionals by providing:

- Individualized assistance
- Tools and resources
- Webinars and in-person training
- Advocacy on the national, state, local and individual levels for equitable and responsive services for families with children with disabilities/special health care needs

[ECAC FactSheet_05042022_English_Spanish_web.pdf \(ecac-parentcenter.org\)](https://ecac-parentcenter.org)



All services are provided at no cost to NC Families!

ecac...

- is committed to improving the lives and education of ALL children with a special emphasis on children with disabilities and special healthcare needs.
- affirms the right of all individuals, from all backgrounds and cultures to an appropriate education and needed services.
- helps families navigate systems such as early intervention, special education and the transition to adulthood.
- provides families and educators with information and resources to build partnerships.

Our services

- Provide information, support, and training
- Answer questions about early intervention, special education, and the transition to adulthood
- Specialized support to families & children with DeafBlindness
- Make referrals and connections to needed services
- Support family engagement in schools and communities
- Develop leadership skills in parents and youth
- Advocate for fair, equitable, and responsive services



We serve families with children, birth to age 26, with disabilities and special healthcare needs.

Today's Objectives

Participants will be able to:

- Provide a working definition of “advocacy”
- Describe at least three things that they can do to increase the chances of achieving a positive outcome within a system of their choice
- State at least two ways that data (information) can help advocacy efforts be more effective



A Word Before We Get Started

- The main message of this session is that many basic advocacy skills can be helpful in a wide variety of situations.
- We expect that the audience will consist of families at different life stages.
- Families interact with a lot of different systems, sometimes simultaneously.
- We don't have time to cover separate slides for every group or situation that all make the same point.
- We ask that you look and listen with an open mind.
- Please actively look for ways that the information can be applied broadly.



Key Words to know

- **Advocacy**
- **Systems**



What is Advocacy?



- Any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of self or others.
- Any action that increases the likelihood of achieving a desired outcome.

Three Types of Advocacy



Self-Advocacy - A person's ability to effectively speak up for themselves and push for their own interests, desires, needs and rights.

Individual Advocacy - A person or group speaks up for or works on behalf of one or two people. This can be formal or informal.

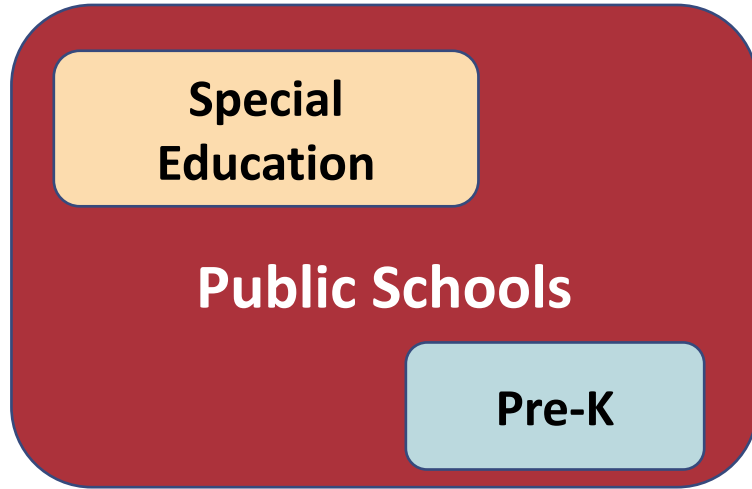
Systems Advocacy - Efforts to change laws, policies or rules that affect people's lives. This can happen at the local, state or national level.

What are Systems?

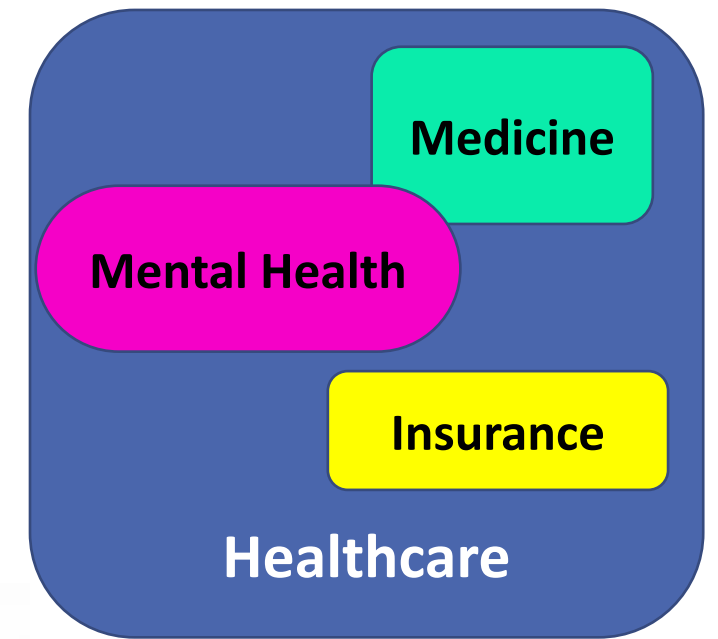
- A set of things that connect and work together as a whole in order to achieve something
- A way of working, organizing or doing something which follows a fixed plan or set of rules. System can be used to refer to an organization or institution that is organized in this way.



We Are Surrounded By Systems!



Transportation



Social Security

Division of Employment & Independence for People with Disabilities

Juvenile Justice

Think about...

A situation when you tried to advocate, or were afraid to do so, and things did not go well.

- What do think went wrong?
- What could you have done differently that may have had a positive effect?



“Knowledge is Power!”



Learn How the System Works

State and District

- **District Website**
 - School Board Policies
- **NC Dept. of Public Instruction**
 - Standard Course of Study
- **State Board of Education**
 - Graduation Requirements

School

- **Parent/Student Handbook**
 - Student Code of Conduct
- **Grade level curriculum**
- **Principal's Authority**
- **Teacher expectations**




Federal Law: IDEA '04 –

The Individuals with Disabilities Education Improvement Act of 2004
Provides for special education services for all children who qualify



Federal Regulations: 34 CFR 300 are the “rules” of IDEA
and define specific and detailed processes for carrying out the law



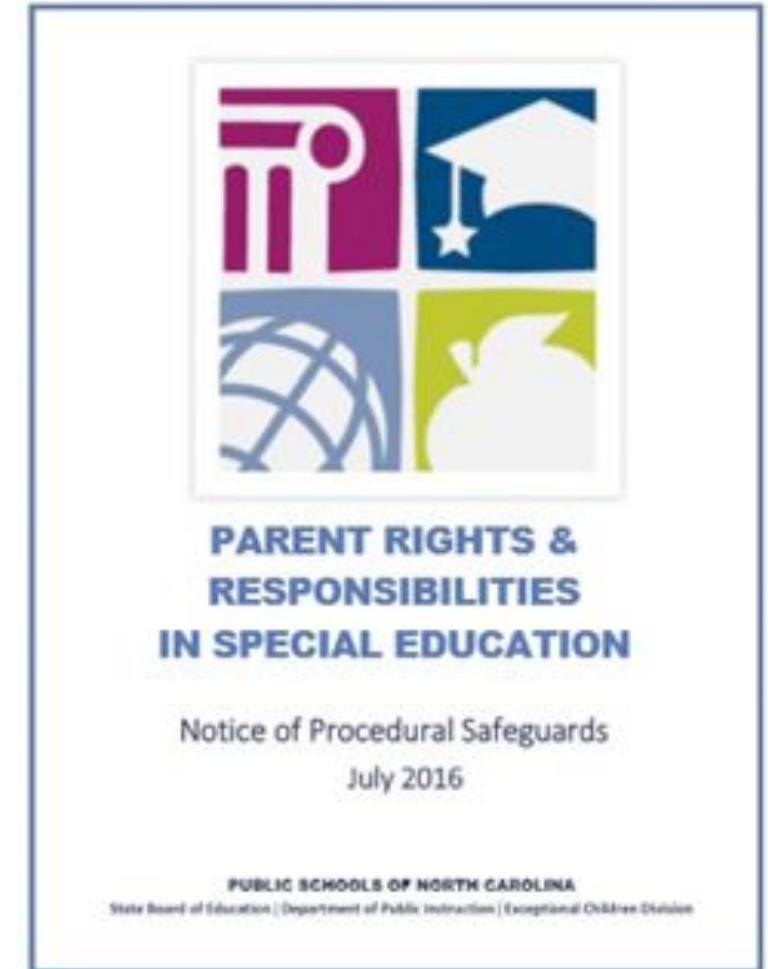
State: State law and Policies dictate “how” special education
“works” in NC – each is aligned with IDEA '04 and the Federal
Regulations

- Article 9, Chapter 115C (NC General Statutes)
- Policies Governing Services for Children with Disabilities

“Parent Rights Handbook”

Must be given to parents at certain times:

- One time per school year
- Upon initial referral or parent request for evaluation
- Upon receipt of a State Complaint
- Upon receipt of Petition for Due Process
- Upon request by a parent
- Upon any revision to the content



Pop Quiz:

1. Who is in charge of deciding if kids move to the next grade?
2. How long can students with disabilities stay in high school?
3. Where can you learn about your school's bullying policy?



Information is Everywhere: Use it!

Backpacks (Check them!)

Websites

Parent/Student/Consumer Portals

Handbooks

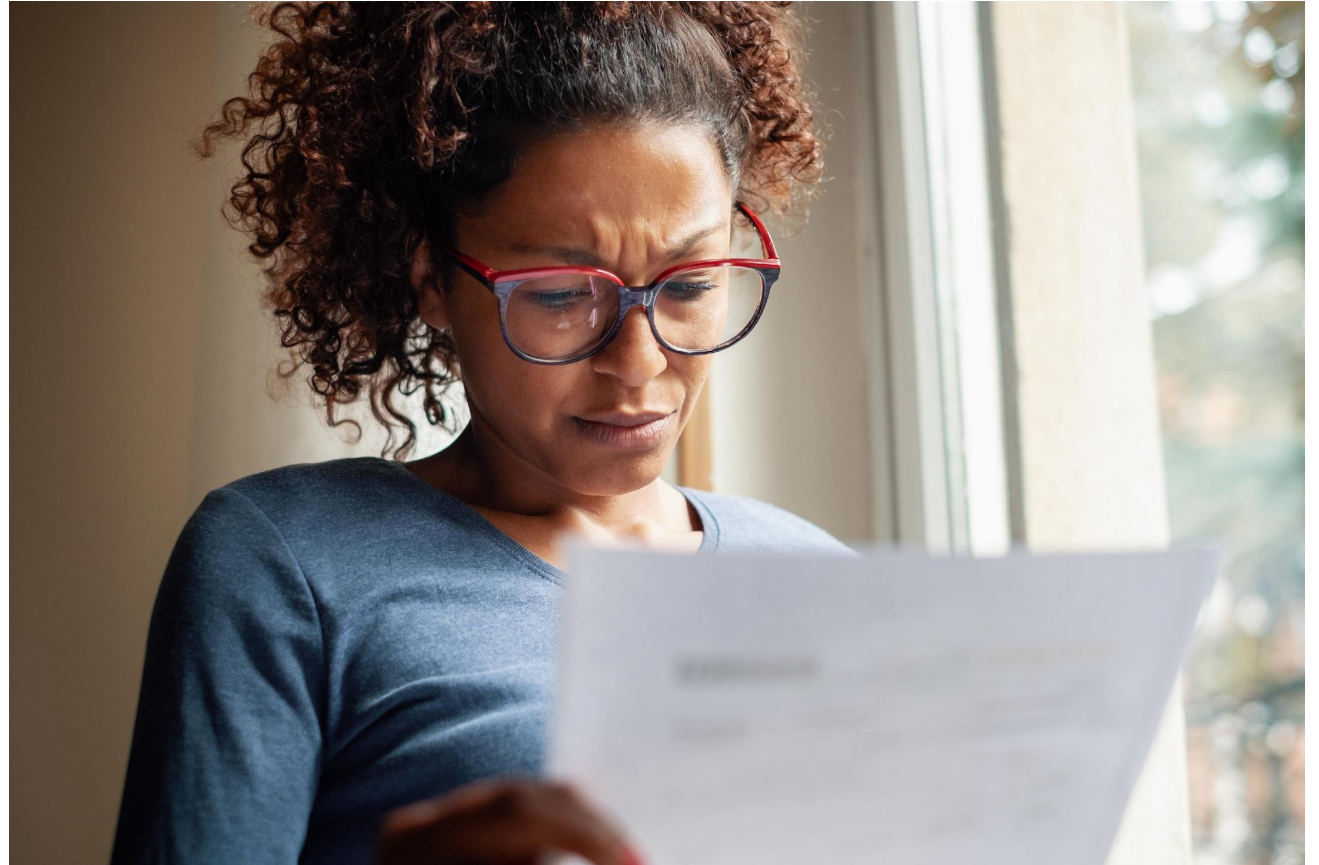
Mail (USPS)

Email

Medical documents

“My Chart” portal

Insurance Plan Information





Organize your Information

- Phone call log & emails
- Other communications
- Test results

- School records
 - Special Education documents
 - Report cards
 - Work samples
 - Observations notes

- Medical records
 - Insurance information
 - Service Plans
 - Receipts



**Use an organization system
that works for you!**

ECAC Care Notebooks in [English](#)
and [Spanish](#)

Parents Pay Attention!

- Check out PowerSchool for grades, missing assignments
- Look at your child's class schedule and test score reports
- Monitor communications from school staff
- **Read** the IEP, Evaluation and Progress Reports carefully
- Attend parent-teacher conferences
- Look for change in your child's mood, behavior or health
- Keep your eyes open in general
- Make notes on your thoughts and observations



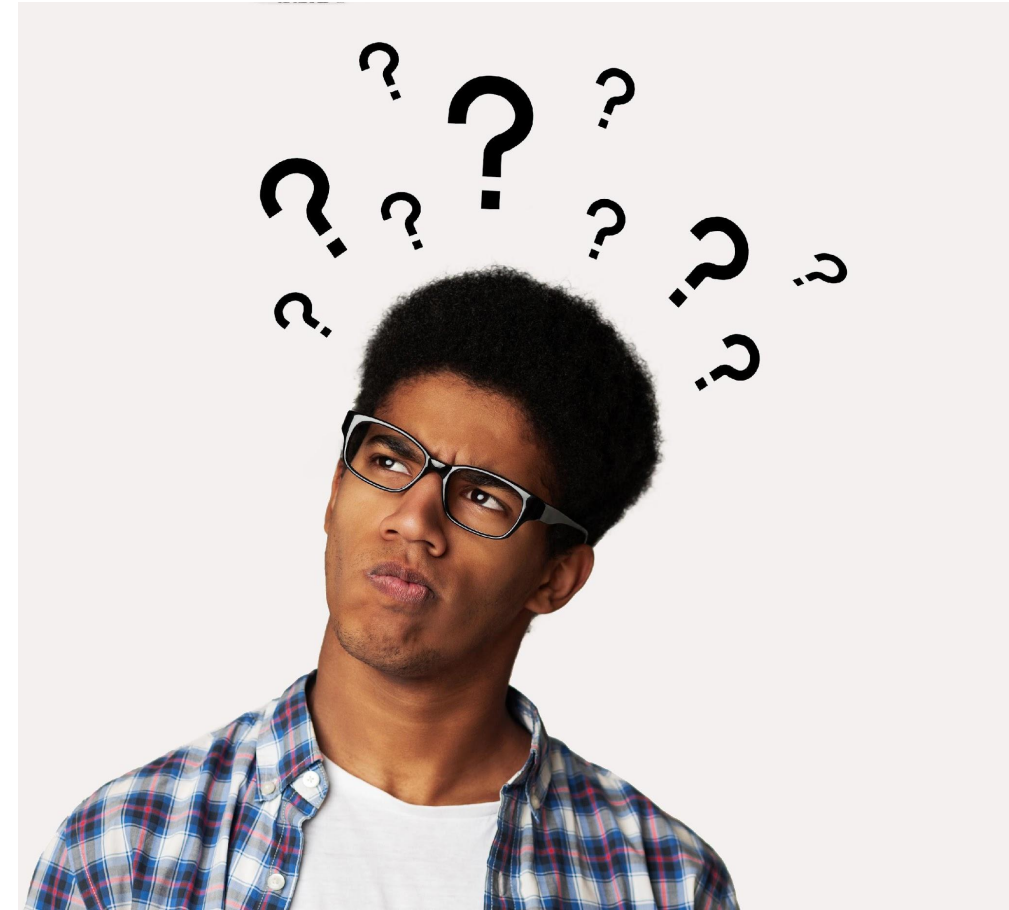
Put It In Writing!

- Important communications should be put in writing
 - Requests, concerns, bullying reports, absence excuses, etc.
 - Your email gives you a record of what you send
 - You can send a follow-up email to document a conversation or meeting
 - You can also ask for things to be put in writing



“Show me that in writing.”

- The power of the written word can help distinguish fact from fiction
 - Determine what a reported policy or law actually says
 - Clarifying misunderstandings should lead to change in behavior



Become an Expert in Your Child's Disability

- Learn about the disability
- How does YOUR child's disability look?
- How does the disability affect their communication, learning and participation?
- Learn to describe your child's strengths and needs.
- Write down observations



Share What You Know With Others



Painting the BIG Picture!

Children benefit when the adults in their lives are able to see "the big picture" by understanding them as unique individuals. Parents and other family members help to "paint the big picture" when they share who their child is, what she can do, and how others can relate and respond to the

Parents know many things about **who** their children are and what their children can do. In fact, all parents are their children's first teachers! When parents share what they know about their children, school staff are better able to support their students to learn, participate and

Parent input can be shared for many reasons:

- To introduce the child to a new teacher, coach or caregiver
- To offer guidance, to prevent unwanted behavior and/or to encourage positive relationship with the child
- To describe the child's learning style, communication challenges or needs
- To contribute to the child's IEP (Individualized Education Program) or Medical/Healthcare Plan

This worksheet has been created as a way for any adult to help "paint the big picture" of the child they care about and know well. The worksheet guides each writer to provide "tips" on what works best. The tips allow you to make what **YOU** know and what others can do to help him/her to be successful.

Other people in your child's life may also have valuable information. If you have been successful working with your child, consider including therapists and others.



907 Barra Row, Suites 102/103 • Davidson, North Carolina 28036 • (704) 892-1321 (Voice/TDD) • Fax: (704) 892-5028

Parent Information Line: 1-800-962-6817 • www.ecac-parentcenter.org

Painting the BIG Picture

big picture - the whole story of something; a complete view of something.
(*Typically: get ~; have ~; give someone ~; know ~; see ~; show someone ~)

Painting the big picture of...

Describe your child as a person and within your family. Share information you love about your child. What does he/she say about himself/herself?

Tips/What Works: Share any suggestions or insights that would improve the relationship with your child.

Strengths and Successes: What skills, activities or settings work best with? Think about a variety of settings both in and out of school.

Tips/What Works: Are there any supports or strategies to help your child succeed?



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Challenges: List the areas in which your child has the greatest challenges. What are you currently working on? What are you most concerned with?

Tips/What Works: Share any supports, strategies or accommodations that you find helpful addressing these challenges. Reward systems, charts, schedules, etc.

Dreams and Visions: Describe your vision for your child's future. What are your child's dreams and goals? Include short-term goals and long-term visions.

Goals for the next 12 months:

Long-term Visions:

Tips/What Works: List any tips or suggestions that you believe will assist your child in achieving these dreams.

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Build Positive Relationships

- Establish ongoing communication
- Be proactive
- Have a collaborative mindset
- Assume good intentions



Prepare for Meetings and Appointments

- Make sure you understand the purpose
- Ask about what to expect
- Bring or submit requested documentation
- Write down your questions and concerns
- Write down anything that you plan to propose
 - Be prepared to offer explanations or examples (This is useful data)
 - If your solution to a problem is rejected, ask for another option
- Arrive on time to reduce unnecessary stress





Advocacy Skills and Strategies

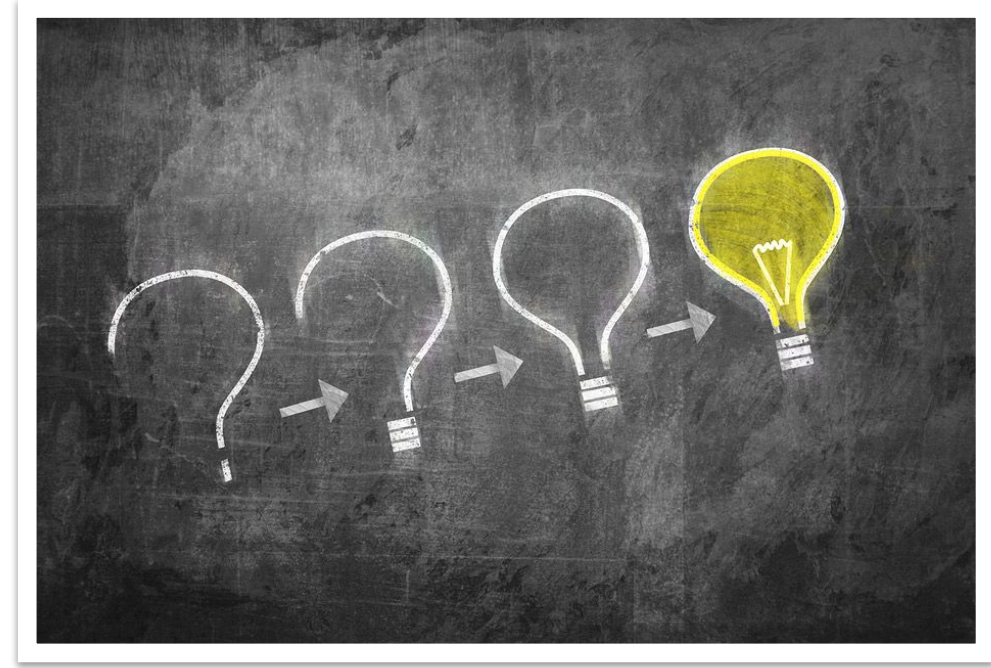
Effective advocacy may involve multiple steps- Be strategic!

- Check the facts before taking action
- Lay the groundwork for a “win” later
- Find out who has the authority to do what you want
- Follow the chain of command
- Play by the rules so that there is no excuse to shut you down



Questions can be Powerful Tools

- What does the data show?
- What are our options?
- What will the recommended intervention or treatment look like as it is implemented?
- What are the pros and cons?
- How will we know if it's working?
- What are the next steps?
- What other ideas do you have to meet my child's needs?





A tip to avoid the



- Do not ask questions that allow folks to say “NO” without adequate consideration of your point or request.
- Instead of ***asking***, “Can we do an assistive technology evaluation?”
Make a statement :
 - “I want to have an evaluation done to see if there is any assistive technology that could help (my child) communicate more effectively.”
 - “I need to have an accommodation so that I can do my job well.”
- Basically, don’t ask yes/no questions if “no” is not an acceptable response



Dig on Data!

Types of data

Quantitative Data

- Typically numbers
- Answers the questions:
 - How much? How often?

Qualitative Data

- Typically descriptions
- Answers the questions:
 - What is it like? What was observed?

- Data helps you be prepared to back up requests
- Plan on what you want to collect and why
- Have a method for collecting, organizing and sharing data
- Do you have an example of data collection that helped you be successful in advocating?



Important Advocacy Tips to Remember

- Decide on and prioritize issues you are trying to address
- Collect data (It matters!)
- Asking for clarification on something you don't understand
- Know how to find relevant policies and procedures
- Learn about dispute resolution or appeals processes
- Utilize trustworthy resources to research topics
- Remain calm and focused on the desired outcome
- Focus on facts, not feelings
- Plan what to do if someone tells you “no” or “I can't help you” (What are other options? Who else can I talk to? Where can I find more information?)

**What are some of your
top advocacy skills or
tips that we didn't
mention?**





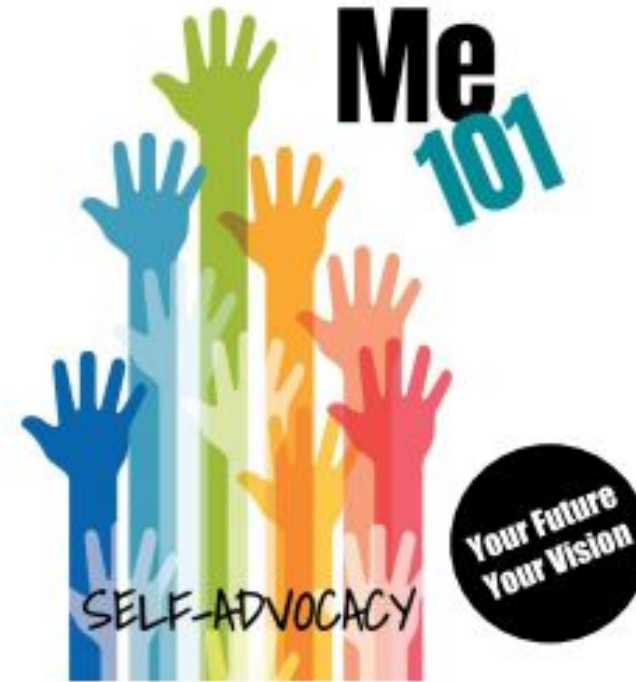
Expand Your Advocacy Reach

- People with lived experience should be at the table when important decisions are being made.
- Opportunities to do this range from the PTSA, speaking at public meetings to serving on advisory boards and statewide councils.
- Stay connected to stay informed!
 - Meetings of government are open to the public
 - Follow disability organizations and trusted groups on Facebook
 - Subscribe to get notices and newsletters
 - Local news outlets



Advocacy and Leadership Training for Parents/Guardians & Youth

- Telling Your Story and Telling Your Story for Families of Color
- Me 101 Self-Advocacy
- Student Led IEPs
- Family Leadership Conferences



Self-Advocacy Training Event

Deciding what **YOU** want, speaking up for **YOURSELF**, making **YOUR** own choices, solving problems on **YOUR** own, setting goals that matter to **YOU** – these are all important components of Self-Advocacy. **Me 101** is an opportunity for youth with disabilities to learn more about taking an active leadership role in their own lives by identifying a circle of support, creating a vision statement for themselves, establishing post-secondary goals and recognizing the benefits of sharing information about their disability with others. This training leans on the premise of **“Nothing About Me, Without Me”**.



LEARNING OBJECTIVES

Upon completion of this training, students and their families will be able to

Summarize Self-Advocacy and why it is important

Recognize who could be included in a circle of support

Develop a Vision Statement for the student's future

Create goals for life after high school

List the benefits of disability disclosure

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Do you want to share?

A situation when you tried to advocate, or were afraid to do so, and things did not go well.

- What do think went wrong?
- What could you have done differently that may have had a positive effect?





Tools and Resources

- [Accommodations to Consider for Students with Problems in Organization](#)
- [Adaptations and Modifications](#)
- [Supplemental Security Income / Supplemental Security Disability Income](#)
- [Medicaid Waivers in NC](#)
- [IEP Checklist](#)
- [Student Snapshot](#)
- Painting the Big Picture [English](#) and [Spanish](#)
- Family to Family Health Information Center flyer [English](#) and [Spanish](#)



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- To describe the child's learning style, communication challenges or healthcare needs
- **To contribute to the child's IEP (Individualized Education Program), 504 Plan or Medical/Healthcare Plan**

This worksheet has been created as a way for any adult to help "paint the big picture" of a child they care about and know well. The worksheet guides each writer to describe the child and to provide "tips" on what works best. The tips allow you to make a connection between what **YOU** know and what others can do to help him/her to be successful.

Other people in your child's life may also have valuable information to share about how they have been successful working with your child. Consider including caregivers, former teachers, therapists and others.





WAZE To Adulthood Fact Sheet Series

(Available in English and Spanish)

- **Heading to High School: Choosing a Course of Study**
- **Life's a Journey: Learn More! Do More! Be More!** - Learn about career exploration and training in high school, as well as postsecondary education and training
- **NC High School Graduation Requirements**
- **Secondary Transition in NC** - Learn about transition planning and services
- **Ways to Support Your Adult Child** - Age of Majority and ways a parent can support their child once they turn 18

The Path to Adulthood

Life's a Journey. Learn More! Do More! Be More!

Many options are available to North Carolina students with and without disabilities to help them prepare for their adult lives. Whether teens and young adults want to work, attend college, or need support to figure it out, many programs are in place across the state. This fact sheet offers a sampling of opportunities that are currently available as well as resources where you can get more information and keep up with new developments.

If you can't fly, then run. If you can't run, then walk. If you can't walk, then crawl. But, whatever you do, you have to keep moving forward.
—Martin Luther King, Jr.

The options in the left column are available to high school students, while those on the right are available once students leave high school. Unless noted otherwise, the opportunities listed below are open to people with and without disabilities.

Career Exploration and Training in High School:	Postsecondary Education and Training:
<ul style="list-style-type: none">• Career and Technical Education (CTE) courses are offered by almost all NC High Schools. These courses count as elective credits toward meeting graduation requirements. CTE courses introduce students to career fields including business, information technology, automotive, horticulture, health sciences, cosmetology, photography, culinary arts, carpentry and more. Consult your school system's high school planning guide or guidance counselor for more information.• Internships, Apprenticeships and Service Learning offer work-based learning experiences in real-world settings. Students spend time working in local businesses, non-profit organizations, medical centers, or government agencies, including the National Guard. They get to see and participate in work activities and learn about jobs from people who actually do them. Your school's Career Development Coordinator or guidance counselor should have more information about opportunities in your local area.• Pre-Employment Transition Services are offered by the NC Division of Vocational Rehabilitation Services to students with disabilities between ages 14-21. NCDVRS works with schools and a variety of community partners to provide these <u>Pre-ETS services</u>: training in self-advocacy and workplace readiness skills, job exploration, work-based experiences and postsecondary counseling.	<ul style="list-style-type: none">• Community Colleges - North Carolina has a very strong community college system that offers a variety of programs that range from Basic Academic Skills, High School completion/ GED preparation to Associate Degrees. Some students later transfer to 4-yr colleges or universities. Other students earn certificates or diplomas in a specific career field or skilled trade. Many community colleges partner with local employers to teach job skills that are needed in their particular industry.• Vocational or Technical Schools - Some of these schools train students for a specific occupation, such as cosmetology, barbering, truck driving or diesel mechanics. Other schools may have multiple programs that teach skills needed for entry-level jobs in particular career fields.• Traditional Colleges and Universities - These schools can be private or publicly funded. They also range in size from very small to extremely large. They offer programs that lead to Bachelor's or graduate degrees. Students select a "major" area of intensive study, but coursework is usually designed to provide a broad base of knowledge across many content areas.• College Experience Programs for Students with Developmental Disabilities - There are currently at least 14 programs for students who have intellectual and/or other developmental disabilities located on community college or university campuses in North Carolina. These programs differ in terms of length, primary focus (e.g., vocational vs. independent living), and the extent to which students are included in the



Webinar Recordings on Website and YouTube Channel



- Registry of Unmet Needs: AKA The Innovations Waiver Waiting List
- NC Able Accounts
- The Exceptional Experience Podcast Series
- Introduction to Assistive Technology
- Transitioning to Adult Healthcare: How Students and Families Can Prepare
- A Guide to Guardianship
- **NEW!** Self-Advocacy is for Everyone

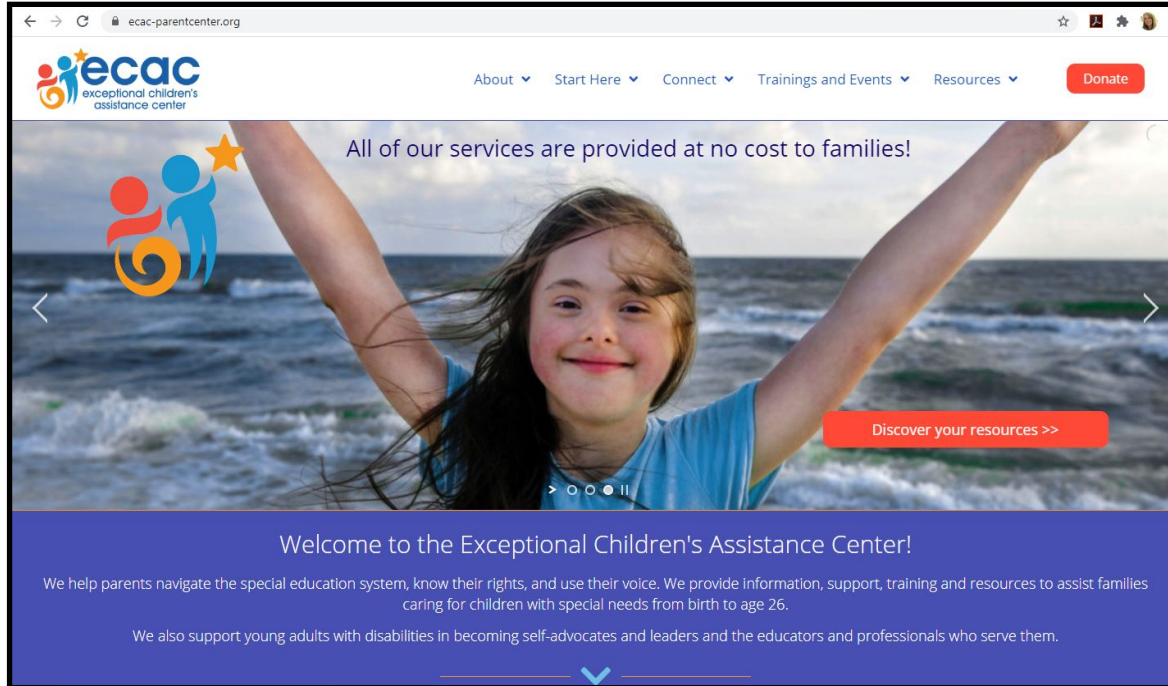
Please Take A Moment to Fill Out This Evaluation

ECAC is funded largely by grants. We collect data on our activities for grant reporting purposes and to make improvements to meet the needs of families and professionals across NC. We appreciate your feedback!





Where To Find Us



<https://www.ecac-parentcenter.org/>

Website is available in 6 languages



<https://www.youtube.com/user/ECACorg>



<https://www.facebook.com/ecacparentcenter/>

<https://www.facebook.com/CentroDeAsistenciaaNinosExcepcionalesEcac>

Please Ask Questions!

Call: 1-800-962-6817

www.ecac-parentcenter.org

Email: ecac@ecacmail.org



Empowering Families★Improving Lives