



Federation of Families
of South Carolina

A voice for children's mental health in South Carolina.

866-779-0402 www.fedfamsc.org



800-578-8750 www.familyconnections.org

A Factsheet Series:

Parents Building Leadership & Advocacy Skills

Phase 1: You & Your Family

Phase 2: Local Involvement

Phase 3: State & Federal Level

About this Factsheet Series

Building advocacy and leadership skills is just like building skills for your job or career; it takes time and experience to get to the skill level you desire. In this factsheet series, you will be guided through three phases of developing leadership and advocacy skills.

We use the term “phase” instead of “levels” because you can move back and forth through “phases” while “levels” can imply that once you have completed one level you move on to the next level, never going back. As a Parent Leader, you may be advocating for your child (Phase 1) while serving on the school PTA (Phase 2) or working on a state advisory council (Phase 3).

Defining Leadership: a process whereby an individual influences a group of individuals to achieve a common goal.

Defining Advocacy: The act of pleading or arguing in favor of someone or something, such as a family member, cause, idea, or policy; active support.

Where do you begin?

As a parent, your first priority is to provide for the needs of your family. In order to be a leader/advocate on any level, you first need the ability to meet the needs of your own family. Phase 1 goals include:

- **Prioritizing your family's needs.**
- **Building relationships with those involved with family's needs.**
- **Finding and using resources for yourself or your own family.**
- **Speaking up for your family's needs.**

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Prioritizing Needs:

- It is helpful to actually write down a list of what you believe to be issues for your family. Having the chance to look at them on paper can give you a better perspective of what you need to tackle first.
- Once you have prioritized your family's needs, you can begin to focus on building relationships with the professionals who are directly involved in those specific areas.

Finding Resources:

- Once you discover agencies or programs that can provide you with the resources you are looking for, write down possible questions in advance. If you have recommendations, write your comments in a positive and constructive plan of action.
- Frame your messages and requests clearly so that you are understood.
- **Remember:** Stay positive when working with others to get the services and support you need. The more polite you are, the more likely someone will want to help you. The more someone wants to help you, the more likely you will get the resources you were aiming for.
- Ask questions and get information in a way that you understand. It is okay to ask again if you don't understand something.

Building Relationships:

- Communicating appropriately is vital to building relationships, navigating systems and problem solving. You are the expert on your family, be ready and willing to share your experiences and what works for your family.
- Let your child's primary care doctors, specialists, educators and providers know what you need from the relationship with them (i.e. how you would like to be treated, how you would like your opinion respected, the best way to communicate with you, etc.)
- Try your best to remain confident, yet in control of your feelings, during the meeting or conversation.
- Try to keep your comments and correspondence brief and to the point.
- Keep a notebook to write down notes from conversations, names of people or agencies, contact information, and questions you may have. It will be helpful to you in finding resources and helpful to others as well.

Speaking Up:

- Be assertive about what you need and believe you're child's rights are, without becoming aggressive.
- The professionals that work with your children also benefit from your feedback. They are better able to serve your child and other children with similar needs when they have your input.
- Learn how to share your story with others to meet your family's needs and potentially help others families as well. Speaking out about your experience in seeking assistance for your family is the first step in transitioning to Phase 2.



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How do I Partner to Help Others?

As you gain experience as a leader/advocate in Phase 1, you may consider thinking about how you can make a difference in lives outside of your family and build relationships that support others in your local community . We consider this next step as Phase 2 of becoming a leader/advocate. Phase 2 activities include:

- Identify gaps in services in your community and suggest possible solutions. Don't be afraid to seek out city council members or your Mayor.
- Participating in parent group and being willing to share information about a certain issue that impacts your family. You may be surprised that other families are dealing with the same issues.
- Consider mentoring others needing support. In this role, you can share information and resources with other families and serve as a listening ear to another person whose family is going through something you have experienced. For more information, call the Federation of Families of SC or Family Connection.
- Join a Family Connection Navigator Team in your county
 Parents joining together to bring activities and events to their communities for their children and families.. For more information, contact Family Connection at 1-800-578-8750.
- Organize or join a Federation of Families Parent or Youth Support Network
 These are local support networks that are organized by parents of children/adolescents with emotional/behavioral, mental health and/or substance abuse issues. For more information, contact Federation of Families at 1-866-779-0402.
- Talk to your pastor or Rabbi about how to improve your church's/synagogue's ministry to children with special health or mental health needs.
- You may also want to volunteer at your child's school to help teachers or other students.
- Contact SC Autism's All Are Welcome project at 1-864-241-8669 for more information on inclusion in the faith community.
- Some service providers have advisory groups, which allow you to provide feedback on policies, resources, and services.

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Parent Advisory Councils: Advisory councils, committees, and/or boards function better when they include parents/ family members input and perspectives. These are typically known as Parent Advisory Councils.

- Let providers know when you appreciate them or when you are not satisfied. You might actually help them improve an area that would better serve families. Always offer a positive solution or suggestion to them.
- Federation of Families for Children’s Mental Health of South Carolina -
Parents of children/adolescents with or at risk of emotional, behavioral or diagnosed mental health disorders and/or substance abuse issues interested in participating on local boards or advisory councils with mental health, juvenile justice, education or drug and alcohol agencies should contact Federation of Families of SC at 1-866-779-0402.
- Family Connection of South Carolina -
Parents of children with special healthcare needs or disabilities that are interested in participating in advisory councils or boards, please call 1-800-578-8750 to learn about existing opportunities.
- Disability and Special Needs Boards (DSN) -
DSN boards are governed by a local board of directors. Contact your local board to see their process of appointing board members.
- Department of Disabilities and Special Needs (DDSN) Providers -
Providers who serve families receiving DDSN services are required to have family input through “Service Recipient/family groups.” Each provider may call their group something different. This should be the place you can provide input in the services your family receives. Contact DSN boards for a listing of service providers.
- Education - Each school district varies in how parents participate in committees. Contact your local school district for information on parent involvement on committees. The types of school committees may include:
 - School advisory Committee
 - School Improvement Councils
 - Parent Teacher Association (PTA)/Parent Teacher Organization (PTO)
 - Teacher Parent Advisory councils (most school districts)
 - Home School Associations may have Special Needs Advisory Committees. Contact your home school association.
- Faith Communities -
 - Deacon, Elder boards or synod
 - Education boards
 - Sunday school or Christian Education Board
- Local Non-profit Boards (typically an advisory/oversight and fundraising positions)
- Hospitals, mental health facilities, doctor’s offices, therapeutic and childcare service centers
- If an agency or organization does not have a parent advisory council, you can help create one. For more information, contact Family Connection or the Federation of Families.



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How do I partner at the state and federal level?

- Contact your state legislator and/or Congress member via mail, phone or email at any time to discuss an issue of concern. You can help improve legislation by letting your voice be heard. They want to hear from their constituents. Let them get to know your family and their needs. Go to <http://www.scstatehouse.gov/cgi-bin/zipcodesearch.exe> to find your legislators.
- Testify at legislative hearings and town hall meetings. Legislators often say that a parent’s story is what influenced their decision making.
- Find out what is happening with state agencies or non-profits that impact your child. See if they have an advisory or advocacy council you can serve on. Or, send the director a note or make a phone call, if there is an issue that concerns you or your child.
- For more information on federal legislation regarding children and youth with special healthcare needs, go to Family Voices (www.familyvoices.com)
- National Federation of Families for Children’s Mental Health - www.ffcmh.org - provides information on federal legislation. The Federation national conference holds Policy Day at the annual conference with visits to legislators on Capitol Hill.
- Engage in awareness events such as walks, rallies and observe awareness weeks. Examples include...
 - Participating in Disability Advocacy Day at the State House every March. Contact Family Connection at 1-800-578-8750 for more information.
 - Participating in Children’s Mental Health Awareness Day at the State House the first Tuesday of May during Children’s Mental Health Awareness Week. Contact Federation of Families for Children’s Mental Health of SC at 1-866-779-0402 to learn how you and your community can be involved.

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Advisory Councils - Federal and State advisory councils, committees, and/or boards function better when they include parents/family members input and perspectives. These are typically known as Parent Advisory Councils.

(some are by appointment from within the agencies or the Office of the Governor)

- **Parents Pulse** -
Family Connection's online parent advisory council. Help guide this organization in program planning and delivery and provide input to state agencies that serve your child. Input from the Parents Pulse is conducted through online surveys and does not require much time. Contact Family Connection to become a Parents Pulse member.
- **Federation of Families for Children's Mental Health of South Carolina** -
Parents of children/adolescents with or at risk of emotional, behavioral or diagnosed mental health disorders and/or substance abuse issues interested in participating on state level boards or advisory councils with mental health, juvenile justice, education or drug and alcohol agencies should contact Federation of Families of SC at 1-866-779-0402.
- **National Federation of Families for Children's Mental Health - Board of Directors** (www.ffcmh.org)
- **South Carolina Advisory Council on the Education of Students with Disabilities - State Department of Education Division of Children with Special Health Care Needs** facilitates -
The purpose of the "Advisory Council" is to provide policy guidance with respect to special education and related services for children with disabilities in an advisory role.
- **Commission for Minority Affairs** -
Advisory boards are provided for each population the Commission service but they would be minority specific rather than disability specific. Contact: Ms. Lauretha W. Whaley at 803-832-8161.
- **Department of Health and Human Services (DHHS) - Medical Care Advisory Committee**
(appointments made by the director of DHHS)
- **Division of Children with Special Health Care Needs DHEC - Maternal and Child health - Title V-** Contact Cheryl Waller at 803-898-0784.
- **State Interagency Coordinating Council (SICC)** -
Governs BabyNet, (Appointment by governor approval by Senate)
- **Department of Disabilities and Special Needs (DDSN) Commissioners** (Appointment by governor approval by Senate)
- **DDSN Advisory Council** -
(Which by SC legislation is to advise the Commission - has not yet been appointment by governor or approval by Senate).
- **Department of Mental Health State Plan Committee** -
Required membership of family members of children served by community mental health centers.
- **Continuum of Care for Emotionally Disturbed Children** -
Families served by Continuum of Care are invited to a annual meeting called Family forums held in each region. Contact Continuum of Care at 1-888-539-8863.
- **State wide non-profit boards (typical an advisory/oversight and fundraising positions)**
 - Family Connection
 - Federation of Families of South Carolina
 - NAMI
 - Pro-Parents
 - Special Olympics
 - Disability specific Non-profits (i.e. Autism Society, Down Syndrome Associations, Fragile X Association)