

# A Journey Through The Maze: Service and Support for Your Child With Special Needs



...for Children

the region's leading resource  
in early education and care

## About 4C for Children

4C for Children, the pioneering leader, advocate and resource for early childhood education and care in this region since 1972, serves 23 counties from offices in Cincinnati, Dayton (Ohio) and Newport (Kentucky).

Each year this not-for-profit agency...

- assists over 8,000 families of all income levels in finding and choosing quality child care;
- enrolls over 20,000 child care providers in its workshops and trainings;
- works to increase the supply of high-quality early education and care in the region; and
- advocates for children and families at the local, state and federal levels.

For more information visit [www.4cforchildren.org](http://www.4cforchildren.org) or call 513-221-0033 or 800-256-1296.

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4C Central Office, 1924 Dana Ave., Cincinnati, OH, 45207

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*Special thanks to Diann Forbes, 4C staff member  
and parent of a child with special needs.*

# An Introduction

Having children is a wonderful experience, yet one that brings many changes to your life. If you return to work after having a child, you'll find that searching for child care can be a frustrating experience. However, if you have a child with a disability it becomes even more of a challenge.

As the parent of a child with a disability, you may find that early childhood educators or child care providers feel inadequate and unable to care for your child. This is due to the lack of proper training, information, or experience. They may also be fearful of a child's disability. Often, you may find providers have not had the opportunity to be with individuals with disabilities. Other barriers families face are a provider's concern about insurance liability and program changes to accommodate children's needs.

You can play a key role in your child's inclusion in a program. As parents, you have many roles; mother, father, therapist, employee, advocate, coach and teacher. When talking with providers, your role is critical in educating and advocating for your child. Here are some tips to keep in mind as you talk with providers about your child.

First, when interviewing providers, speak in a positive way as you describe your child. Focus on the child's strengths, then mention the child's needs. It's important to emphasize to the provider a description of the child that includes the every day "little kid" needs, likes and dislikes as well. Remember, all children are more alike than different. They like to play, eat, read books, etc.

It's important to find a child care provider who is excited and interested in adapting and making modifications to his or her child care program to meet your child and family's needs. The important thing for parents to note or observe is a provider's response and behavior. Does he or she seem motivated and willing to learn about your child? Do they seem sincerely interested in caring for your child? Emphasize that working with a child with a special need is an ongoing learning experience and that most parents themselves do not have prior training in special education.

# The Americans with Disabilities Act (ADA) And Child Care

The Americans With Disabilities Act (ADA) is a federal civil rights law that became effective January 26, 1992. The ADA states that individuals with disabilities have equal access to all public services, facilities, employment and public accommodations such as child care centers, family child care homes and preschools. Child care programs can no longer discriminate on the basis of disability, regardless of whether or not they receive public subsidies. Accommodations should be made based on the resources available to the child care program. This evaluation is done on a case by case basis. There is one exception to this rule, pertaining to two types of programs that are exempt from ADA public accommodations compliance:

- If it can be proven that the child care program is operated and financed by a church.
- If a church donates space to a child care center.

The ADA requires that all non-exempt child care programs consider making modifications in three facets of their program:

Reasonable modifications must be made in center policies, practices and procedures in order to accommodate the individual with the disability, unless the accommodations would greatly alter the nature of the program. Examples would be accepting a child into the program who is not toilet trained when that is a usual criteria for entrance into the program. Another example is the elimination and prohibitions against serving children with disabilities in the admissions policies.

Programs must provide "auxiliary aids and services" for those with disabilities affecting hearing, vision or speech. However, a program could be exempt from this modification if it alters the nature of the program or imposes an undue burden (a significant difficulty or expense) and there are no alternative steps available. Examples of some aids or services are the purchase of large print books or staff training in sign language.

- Architectural barriers must be removed if removal is readily achievable, able to be carried out without much difficulty or expense. If the barrier is not readily removable, services must be made available through alternative methods.

According to the ADA, a disability is defined according to the following criteria:

- a physical or medical impairment which substantially limits one or more of the major life activities, for example, self help skills, walking or talking.
- record of such an impairment.
- being regarded as having such an impairment.

Disabilities vary from one person to another and may include physical, medical and /or emotional impairment. Examples of disabilities are spinal cord injuries, seizure disorders, Tourette Syndrome, autism, and learning disabilities.

With federal mandates in the form of ADA, families and their children with

special needs are now protected by law. It means that children can no longer be excluded from a child care setting based on a disability. The basis behind the ADA was to include all children with physical and mental disabilities into an inclusive setting. This enables them to participate in all activities, thus allowing them to benefit socially and cognitively from relationships with their peers.

If you have specific questions or concerns regarding the ADA and child care, call the U.S. Department of Justice at 1-800-514-0301, TDD 1-800-514-0383. This federal agency is responsible for the investigation and enforcement of possible ADA violations.

## Inclusion in Child Care Programs

Families and early childhood educators can work together to build inclusive child care settings. In an inclusive setting, children with special needs participate in activities along with children with typical development. Inclusion provides the opportunity for children to develop positive attitudes and values toward each other. It creates a sense of belonging which is essential for positive self-esteem and achievement in children who may be challenged by a special need.

According to experts in the area of special education, there are many and varied reasons for inclusive programs for children. Some of the major ones are categorized here.

- **Learning** - children with and without disabilities learn to celebrate similarities and differences when they are together in groups. This can result in positive relationships which often pave the way for diverse, rewarding relationships in adulthood. Children with disabilities learn from children with typical development in areas of problem solving, social and communication skills.
- **Establishment of friendships** - inclusion provides an opportunity for all children to form lasting friendships.
- **Acceptance of all individuals** - an inclusive environment provides for a cooperative community and society that accepts and values all people in the various aspects of community life.
- **Team building** - inclusion creates a collaboration between parents, educators and other professionals, challenging them to provide an inclusive community where all children are welcomed, valued and successful.
- **Parental involvement** - inclusion supports each parent's responsibility to be involved in their child's development and education. For parents of children with special needs, they become an instrumental part of inclusion. They can make it happen successfully by providing educators with existing resources and support.

The key to a successful inclusive program is to ensure that services and supports are in place. Parents, teachers and program administrators work together to assure that existing community resources are familiar and accessed as needed. Some key points that are part of a successful program are:

- Opportunities are provided for children to learn about each other's enhanced contributions.
- Teachers are supported with access to training, resources and strategies.
- Friendships between all children are encouraged.
- Children are taught to understand and value human differences.

### **Questions to Ask Directors/Teachers/Providers**

1. What diversity does the program offer? For example, 10% disability, 40% African American, 60% Caucasian?
2. What is the program philosophy on inclusion and diversity? What training has the staff had regarding these topics?
3. How does the staff respond to children with disabilities?
4. What accommodations, if any, has the center or provider made to prepare for children with disabilities in the classroom or the family child care home?
5. Describe the activities and transitions that occur throughout a typical day for all children.
6. What is your philosophy on the abilities of all children? Are all children encouraged to succeed?
7. How are children with varying abilities included in activities? Are they included in all activities or just selected ones?
8. Could you tell me how teachers, or you as a provider, bring out the positive qualities of every child?
9. Could you tell me how you would facilitate the inclusion of children and help facilitate friendships for all children?
10. Could you describe a situation in which a family needed understanding and support? How was this accomplished?
11. Have you ever cared for children with special needs/varying abilities? Could you describe your experience with the child(ren)?
12. How do you interact with the child with varying abilities versus the child who has typical development?
13. How do you foster each child's learning ability? How do you progress that child to the next developmental level?
14. How is success encouraged?
15. What role do parents play in the program?
16. If concerns arise, either by the parent, staff, or provider, how and when does communication take place? Is it via direct conversation, daily journal, or weekly conferences?
17. How many children are in one group or classroom?
18. What is the staff turnover rate?
19. Do staff have training in early childhood education and child development?
20. How often are fire drills conducted? How long does it take to get children out of the building?
21. How do you feel about unannounced visits?
22. How do staff provide for a child's changing needs?
23. What is the diapering policy? If a child is not potty trained yet, will he/she still move to a room with age-mates?
24. If a child is not walking, what's the program's policy? Will the child move to the advanced classroom?

25. How do teachers address the questions the other children might have about the child with varying abilities? Ask for examples.

### **Information Parents Should Share With Caregiver:**

- Offer the provider technical assistance regarding your child's disability, such as related articles/reading material. If your child is receiving other services, such as early intervention, physical, occupational or speech therapy, provide the caregiver with the goals for your child and other related information.
- Provide caregivers with the names and phone numbers of the people providing services so these professionals can serve as a resource to the care facility.
- Share other resources about disability related agencies that you are aware of, such as the ARC or organizations that represent children with disabilities and their family, such as the Child Advocacy Center.
- Locate other child care programs who are currently caring for children with disabilities. Refer the provider to 4C (Comprehensive Community Child Care) for this information.
- Problem solve with the provider when the need arises.

### **Special Considerations**

When seeking child care, consider the following:

- Training level of caregivers.
- Attitudes of caregivers.
- Willingness to be trained.
- Number of children with special needs in care.
- Level of accommodation in the environment.
- Recognition of the benefits of integrating children with special needs into the program.

Be aware of some of the following reasons for denying child care services because they are not legitimate reasons for exclusion of your child:

- Insurance risk
- Child not walking
- Child not toilet trained
- Placement in an age-inappropriate setting
- Diabetic, insulin-dependent

As a parent, you may experience feelings of insecurity, "Am I making a mistake placing my child in an inclusive setting?" Most children with special needs have wonderful experiences in integrated child care settings. It not only benefits your child, but other children in the setting, the staff/caregivers, the other parents and yourself.

# Advocacy

Are you intimidated easily by others, especially those in authoritative positions such as a center director, teacher or physician? Are you unaware of your rights? Or are you too busy just trying to survive? Do you accept only a "parent" label? As parents, one of the most important roles you have is that of an advocate because no one knows your child better than you. Learn how to become an advocate. What is advocacy and what does it mean to become an advocate?

Effective advocacy takes place:

- When an individual knows how to communicate assertively.
- When an individual can communicate effectively, he/she is better able to advocate for a child's needs in a way that's effective.

Advocacy is defined as people who speak out on behalf of their children and their rights. The three key characteristics to becoming an effective advocate are:

- persistence
- commitment
- the desire to be actively involved

When dealing with professionals, whether they are providers, doctors or teachers, as an advocate, it's important to be well informed and clear on your child's rights and needs and your own goals. Being an advocate requires involvement and taking an active role in your child's life. Do not let professionals tell you what to do for your child without careful consideration. You have choices, and should base these choices on information you gather from many available resources.

Parents are responsible for managing the child's services. It's important to get as much educational information as possible so you are able to make an informed decision. Parents need to be aware of their rights and responsibilities to play a primary role in determining the nature and extent of services provided for them and their child.

## As You Begin:

- Trust your instincts. If a physician or other professional minimizes your concerns and you feel the issues need to be addressed, be assertive and insist that they be addressed now. The same thing applies to an authority figure at your child's school.
- Encourage collaboration with support systems for **mutual** support in the best interest and developmental needs of your child, whether it be with providers, therapists, or physicians.
- Research information before meetings with a care provider or center staff, come prepared with a list of questions and information.
- Challenge the professional if you disagree with what is being said to you.
- Ask questions; it's critical to your understanding. Ask that information be explained in layman's terms, not medical terms. Do not be afraid to ask for clarification, several times, if necessary.
- Respect those individuals involved in your child's care and expect that same level of respect in return.

- Prepare and plan a strategy, based on information you have acquired.

### **Working with Professionals:**

As parents, your role is critical due to your direct impact on your child's development. As parents, you have a right to be fully informed in decisions affecting your child and your family. The role of the professional is to provide the knowledge, skill and expertise that is needed for diagnosis and necessary services to help your child reach his/her potential.

Both parents and professionals bring a wealth of experience that can be shared. You know your child better than anyone; the professional brings expertise based on theory and practice. Open communication, mutual respect and trust can provide for a positive exchange of ideas regarding intervention, education and family needs.

As you begin to work with a team of professionals involved in your child's care, learn as much as you can about your child's disability. Knowledge is power and this will help you become an active participant on the team of professionals.

Write down any questions you have prior to meetings with therapists, doctors or counselors. It's also helpful to record the responses for future reference. It's important that you as a parent be included in the process of collecting and sharing information, and in the decision making process. It's okay to disagree with the professional's recommendations. Be prepared to be specific with reasons why you disagree, whether it's based on personal or family values or specific knowledge of your child, etc.

### **Collaboration**

Collaboration between parents and professionals is crucial to the success and development of your child. Collaboration can begin with a meeting. Keep in mind the following:

- Be prepared, write down questions you want to ask.
- Consider bringing a support person with you. Be sure to talk to the person ahead of time regarding your goals for the meeting. This person will be more objective and help you make your point.
- He/she can also help you to decipher the information from other people and the general feelings and/or tone of the meeting.
- Ask the child care director, provider, teacher or doctor to explain further if you are unclear about what is being said.
- Write down the strengths and needs of your child. In the meeting, ask the teacher what strengths and assets they see in your child as well as the weaknesses. By writing down these points, you will then be able to focus your attention on helping your child to find activities for which he/she can experience success.
- End the conference with mutual understanding of what was discussed. Make sure the teacher agrees to follow through with a plan of action and that you have told the teacher what you will do at home. If necessary, schedule another appointment for the purpose of reviewing your child's progress.
- Remember that you have a right to speak up if you disagree with what is being said about your child or the recommended course of action.

- Join a parent's organization that helps advocate for children's rights. Talking with other parents who have experienced what you are going through will be helpful as you listen to their resources and feedback.

Maintain accurate records of all written information about your child. You should regularly request copies of professional recommendations for your child, so that you have a cumulative record of progress, milestones, successes, etc. These will be helpful as you consider your child's strengths, specific needs, and goals for him/her in one year, five years and as an adult.

## **Finding Support and Information**

Finding support from someone who has experienced similar feelings and situations can be beneficial to you. The purpose of support groups is to provide information and friendship to families of a child with special needs.

Exchanging information on issues such as your child establishing friendships with others, selecting preschools, developing IEP's (Individualized Education Plan) or forming partnerships with the school can be helpful to parents trying to figure out the maze.

It helps parents realize that they are not alone and encourages them to seek the experience of others. If a support groups does not exist in your area that meets your needs, you may want to consider starting your own.

These are some tips about how to begin:

- Call Children's Hospital Medical Center about other children with the same disability as your child. Due to confidentiality, they will not be able to release families names, however, you can leave your name and number and explain your desire to establish a support group.
- Make contacts and share your vision with family, friends, doctor and your child's teacher.

The more people that you tell, the more ideas and contacts you will have.

- Share ideas with other individuals who have an interest in forming the group.
- Pool your resources and talents to establish a partnership.
- Choose a format and meeting place; groups are as small as three people, as large as twenty.
- Converse over dessert or have a formal program with guest speakers.
- Promote the group with public relations, Discuss the group and its purpose in community newspapers, newspaper/television community calendars, welcome wagons, church bulletins, schools, or hospitals.
- Remain positive. It may take some time to establish a core group of individuals to attend your group.

## Conclusion

Parenting a child with special needs is an incredible and joyous experience. As a parent, it is remarkable to watch a child reach those precious developmental milestones that would otherwise be taken for granted. It is truly a celebration.

However, parents become involved in a maze - weaving in and out of systems (medical, educational, etc.) stumbling and hitting walls and yet also finding open doors. As parents become more aware of the available resources, agencies and services, they become more informed and confident in their abilities in advocating for their child.

Parents and children before us were the pioneers that paved the way for you and your child. Your family and many others have now benefited from such laws as Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). These families may have been discouraged but did not quit the fight.

Your child deserves the same opportunities for child care as children that are developing typically. As parents, you need to demand quality, accessible and affordable child care for your child. Your role is critical in creating a welcoming environment for all children now and for future generations. One hundred years from now your grandchildren and others will have reaped the benefits from your efforts as a trail blazer for creating quality child care for all!

## **Additional 4C Publications**

Available for download at [www.4cforchildren.org](http://www.4cforchildren.org) or by calling 800-256-1296 x1330.

Individual copies of all 4C publications will be sent by mail at no charge.

A fee will be charged to mail multiple copies of the same title.

### **Building a Partnership: You and Your Child's Caregiver**

A guide to creating and maintaining a successful family child care arrangement.

### **Using Relative Care: A Guide for Working Parents**

Explores the advantages and advises how to avoid the possible disadvantages of using relative care.

### **In-Home Child Care: Exploring the Possibilities**

Helps you decide whether in-home child care is best for your family and examines all aspects of locating and evaluating an in-home caregiver.

### **Is My Child Ready? Self-Care Assessment & School-Age Resources**

Suggests guidelines to help assess your child's ability to self-care and gives tips for preparing your child and your home for this important step. Provides a list of community resources concerning a variety of school-age related issues.

### **A Journey Through the Maze—Service and Support for Your Child With Special Needs**

Provides tips to keep in mind as you talk with providers about your child.

### **The Resource Guide to Babysitting Co-ops, Mother's Groups, Playgroups**

Offers information on informal groups—especially for getting one started in your area.