



#### **This Series**

This series is about you and your child with disabilities. Throughout the series, we will use the word parent to identify the adult(s) caring for a child with disabilities - even though, many times, that person may be a grandparent, foster parent or other relative. We know there are all kinds of parents and families.

Too often as a parent or caregiver, we all feel overwhelmed. As the parent of a child with disabilities, you probably have additional concerns. This series was developed with parents to help you understand some of the special issues you may face. Throughout the series, you will find exercises, examples, and success stories that may help you understand how to help your child be as independent as possible.

Each booklet is based on your child's age and covers 6 important areas: Community Involvement, Independence, Health & Wellness, Finance, Employment Skills and Self-Advocacy.

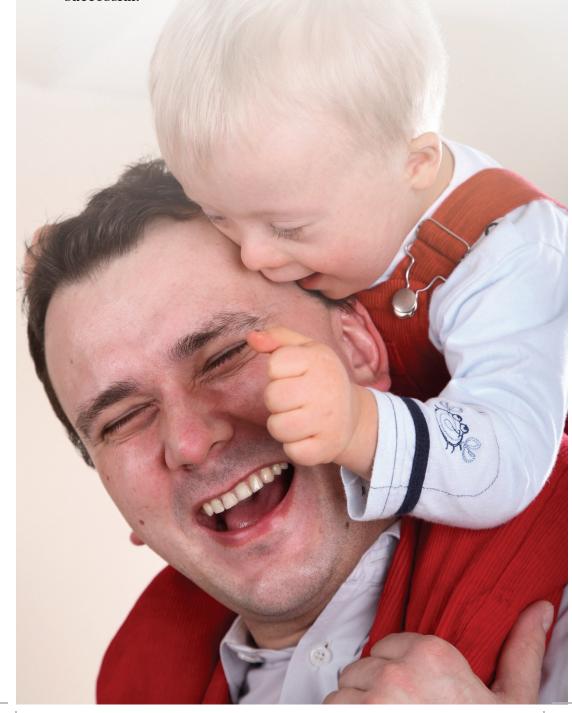
# Special Advice for Parents of Children with Disabilities

Your child may be ahead in some areas and need more specialized work in others. Since this series is designed to help children with all types of disabilities, your child may have excellent verbal skills but poor mobility – or in the case of autism, great mobility but poor interaction with others. Use the suggestions as a guide to think about the areas of development that you need to stress.

Your child's disability may make it difficult to follow all
the suggestions in this booklet. But just because
something may be harder than usual for you or
your child, doesn't mean you should give up.
Our goal is to help guide you in raising
a strong, independent, well-adjusted
child who happens to have a disability.

Success Story: Mike watched his older brother start taking the trash out to the curb. So, I started making a special, smaller bag of trash for him. When it was time, I put Mike and his trash bag in his little red wagon and pulled him out to the curb so he could put his bag beside the larger trashcan. Mike learned that we expected the same things from him as we did from everyone. Maybe he did it a little differently but he always got it done.

As you come to a crossroads, ask yourself, "Is this something my child will need to be able to do in the future?" If you say yes, then how can you adapt the situation so your child can be successful?





### **Getting Started**

To get started, you may need to do an assessment of where you and your child are. Children develop in different areas at different rates. Being aware of where you may need to concentrate your efforts can save you a lot of time. Your child's disability may greatly impact some areas more than others such as verbal skills, mobility, ability to concentrate, and how your child interacts with others.

This chart may be able to help. In each area, check the box if your child has this or if your child needs this. If you're unsure how your child would rate in each area, talk this over with your doctor or specialist. If your child needs help in this area, write down the local resource you could use and the contact information. The sooner your child gets help in this area, the more progress you will be able to see.

Age Appropriate Skill	My Child Has	My Child Needs Improvement	Where Will We Get Help?
Verbal			
Mobility			
Concentration/ Thought Process			
Interaction with others			
Vision/Hearing			
Diet/Nutrition			
Other			

<sup>&</sup>quot;Children are not the same but they should have the same opportunities."

#### For you:

One of the most important areas that is different for you as the parent of a child with a disability is that you need to reach out to other parents. Knowing that you're not alone can give you hope that your situation isn't that much different from others. There are parent support groups for most disabilities. Finding out what has worked for other families and connecting with specialized resources can be invaluable. Find out what professionals in your community specialize in working with your child's disability. Organizing with others to support community services for your child's disability will result in better services as your child grows up.

Coordinate care with your family, other families and friends to give yourself a break. Parenting is a 24-hour a day job under the best of circumstances. If you don't take care of yourself, you can't take good care of your child.

#### For your child:

Begin social skills training with your child. Playtime with other children and interaction with other people outside your family is important in developing social skills and expectations. Stress "please" and "thank you" as soon as your child begins talking.



# Independence / Self-Care

Good habits start early. Children mimic the behaviors they see. Let your child watch you get ready, see you combing your hair, brushing your teeth, etc. Talk about what you're doing and why; like "I brush my teeth every morning so my teeth are healthy and strong" or "we always put dirty clothes in the hamper so they can be washed". Your child will begin to mimic these behaviors and make your job a little easier.

Also, give your child lots of opportunities for self-expression. Very simple things can be strong learning opportunities. Banging on pots and pans may be annoying to you but it gives your child a feeling of control since he is making the noise, controlling the volume, listening to different pitches in the sound, etc. Coloring, describing the shapes of clouds, and building a fort in the living room can all be opportunities for your child to learn about his environment and exercise a sense of control.

#### For you:

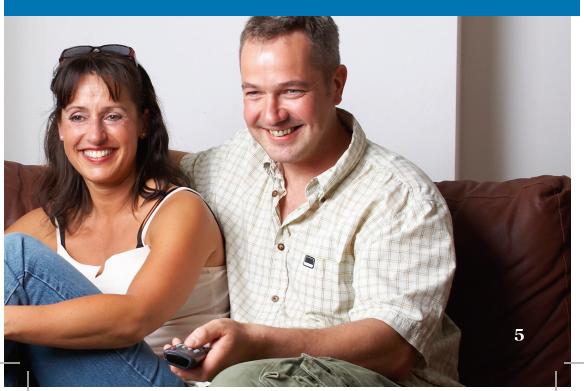
- Managing your child's medical condition may be a fulltime job by itself. Medications, medical visits, and treatments may all require a lot of planning. Reach out to others for support when you need it. Very often, friends, neighbors and relatives would love the chance to be supportive but they don't know what you need - unless you ask.
- Examine your emotions about having a child with disabilities. Common emotions are denial, fear about the future, guilt, confusion, powerlessness, and disappointment. Mild or fleeting emotions like these are common. But if the feelings are persistent or severe, seek assistance from another parent in understanding your situation or find a professional counselor.
- Work to maintain or strengthen your relationships.

  Parenting a child with a significant disability can be a strain on a relationship.



Make time for each other, getting away for a little time together or a special activity you both enjoy. Honest communication about your feelings, frustrations and hopes can strengthen the relationshipsyou have. Allow your partner, parents, and friends to be open about their feelings and don't feel that expressing your feelings will make them think you're a bad parent. If they are close to you and your child, they will see your commitment. If they're not that close, find someone else-maybe another support group parent.

Don't forget your other children. siblings of a child with a
disability may feel jealous, neglected or rejected because of
the time and attention you need to spend dealing with your
child with special needs. Make special time for them if you
can, and help them to understand the special care needed
to help the child with a disability do the things other kids
do without help.





# For your child:

If appropriate, begin helping your child to understand the disability and any special situations. Use simple terms that your child can repeat to others, like "I don't eat peanut butter because of allergies" or "I use a wheelchair because my legs aren't strong". If your child has severe allergic reactions, seizures or other complicated medical conditions, be sure that medical information is readily available to babysitters, friends, family or neighbors that might be caring for your child. Caregivers should be aware of your child's usual reaction and when to get medical help.

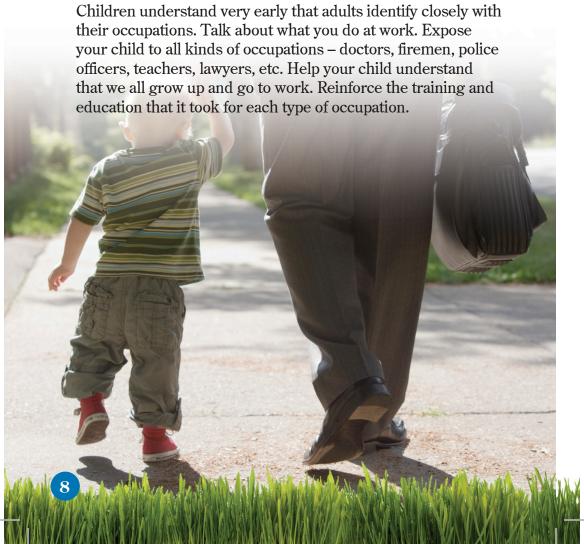


**Example:** "Our child has dozens of small seizures throughout the day. Our day care was extremely concerned until we spent some time working with them. Now they know to make sure she is safe and comfortable if she has a seizure - but to only call the doctor if it lasts more than a few minutes."

#### **Finances**

It may seem too early, but this is the time to start giving your child impressions about money. Little brains begin interpreting how you feel about things by your expressions and verbal tone. Be open but non-specific about money and finances. You can say things like "that's a lot of money, maybe we can save for that" or "this is a special, we can afford it". Your child begins forming concepts about spending, saving, and delayed reward. Later, when your child is older, these will be important concepts in trying to develop financial literacy.

# **Employment Skills**



The Americans with Disabilities Act and changing attitudes make it more likely than ever that your child will be able to work at a job they enjoy. Even individuals with severe medical conditions are working at jobs they love. It can be easy to imagine a future where your child will always be totally dependent on you, but try harder to imagine a future where your child reaches a higher level of independence. Many other parents in similar situations have faced many of the same problems and have been able to help their children become independent adults.

Start early to reinforce responsibility – like expecting trash to go in the garbage can or the sippy cup placed upright on the table.

"The great enemy of the truth is very often not the lie - deliberate, contrived, and dishonest, but the myth - persistent, persuasive, and unrealistic." John F. Kennedy

# **Self-Advocacy**

This is also the time to begin working with your child on self-advocacy skills. Encourage your child to express needs appropriately, such as "I want ..." instead of grabbing. Help your child to think why and state the case "I want a glass of water because I'm thirsty" is the beginning of self-advocacy. Also remember that good manners and self-advocacy can go hand-in-hand.

Let your child begin making personal decisions – choosing which shirt to wear, or which DVD to watch. Making choices and accepting responsibility for them can begin early. You could give your child the choice of picking up toys first or having an evening snack – just be sure your child understands that both will have to be done.

# **Great Expectations Series:**

Book 1 - Age 0 to 3

Book 2 - Pre-school

**Book 3 - Grade School** 

Book 4 - High School & Beyond

Additional web resources including community supports and disability-specific organizations to support parents of children with disabilities are available at: www.illinoisworknet.com



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