



DADVOCATES Welcome Packet

For The Fathers and Families of
Family Network on Disabilities

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Developmental Stages for Children

What if your child was found to have extraordinary skills in a sport? Recruiters were telling you “your child could really be someone awesome in this sport.” Wouldn’t you do everything you could to make sure they got all the help they needed to be great? You would practice with them making sure they had the best coaches so they could become the best ball player ever. It is important that our children hear from us that “We believe in them and they can do it.” All parents want the best for their children.

But what if they have special challenges? Wouldn’t they need all the help we could give them? Wouldn’t it be even more important that they got all the coaching they needed? Wouldn’t it be even more important for them to hear their dad say, “I believe in you and you can do it?” It is clear that no one has greater potential to speak into a child’s life and to help shape their identity than their father. If your child is struggling, you as their father can have one of the greatest impacts on their lives.

So how would I know if my child might need some extra help from me? Often times a pediatrician (child’s doctor), or the school may identify where your child might be struggling. They may recommend that your child be evaluated for a physical¹ or developmental delay². This is a good thing because if my child is struggling, the support of their dad will be crucial. Once we know of their challenge, we can begin to research and identify strategies that may help our child. If the evaluators turn out to be wrong, it just means that our child received extra help that they may not have actually needed. It is important that we err on the side of being overly cautious rather than taking a “wait and see” approach. Again, if we are wrong it just means that my child will get help to “kick a ball even sooner” than the other kids.

So, how do I know if my child may need to be evaluated? The next several pages will list what a child should be able to do during the first two years of life. There is also information on how we can intervene to help them. Each child develops differently and your child may not be developing like this material is describing. That is why it is so important that we get evaluations if we are at all concerned with their development.

1 The steps or stages in growth with regards to the use of bones, muscles, joints and nerves.

2 The steps or stages in growth and development before the age of 18.

What Your Baby Will Do At

MONTH 1

- Be sleeping a lot (16 hours a day is average, but it does vary. There is no set pattern).
- Drink mother's milk or formula every 2-3 hrs.
- Wet diapers often.
- Cry (and often times you may not know why).

MONTH 2

- Recognize mom/dad's voice and touch.
- Look at moving objects.
- Show some control of fingers (grip your finger).
- Begin to control movement of head (lift his/her head if lying on their tummy).
- Smile and make lots of sounds.

MONTH 3

- Hold head steady.
- Hold hands together.
- Smile.

MONTH 4

- Roll from stomach to side.
- Put everything in his/her mouth.
- Laugh, smile and coo.
- Enjoy baths and playing in the bath water (with a lot of supports).
- Sit with supports for a few minutes.
- Begin to make sounds when looking at toys or people.
- Lie on her back and bring her/his hands together over their chest.

MONTH 5

- Turn head to sounds.
- Reaching for a toy while sitting on your lap.
- Cry when angry or scared.
- Follows objects with their eyes.

3 Caring for Tomorrow's Children: Having a Healthy Baby Printed July 2003

What Your Baby Will Do At

MONTH 6

- Roll from back to stomach.
- Show emotion by making sounds.
- Bounce while standing with support.
- Enjoys lots of attention.
- Turn toward noises.
- Start teething.
- Cry to be picked up.
- Chew on toes and feet.
- Sit without support for short periods of time.

MONTH 7

- Creep along on stomach.
- Stand holding on to something.
- Act afraid of strangers.
- Sit up without support.

MONTH 8

- Play peek-a-boo.
- Pick up small things.
- Babble, shouts for attention.
- Start to eat with fingers.

MONTH 9

- Begin to crawl.
- Wave bye-bye.
- Looks at picture books.
- Push away things he/she doesn't want.
- Cry when separated from mom.
- Pull on something to stand up.
- Pass things from one hand to another.
- Like positive attention.
- Understand a few words, such as "no" and "bye."
- May say "dada" and "mama."

What Your Baby Will Do At

MONTH 10

- Be very curious.
- Walk when holding someone's hand.
- Be able to feed himself or herself finger foods.

MONTH 11

- Stand without help.
- Like to look at pictures in books.

MONTH 12

- Loves to play with toys, pots and pans.
- Crawl everywhere.
- Drink from a cup.
- Like to feed him/herself.
- Show love to family and favorite toys.
- Play games like peek-a-boo.
- Walk with support or take a few steps alone.

MONTH 15

- Walk better.
- Bend to pick up objects.
- Love to throw things.
- Stack 2 blocks.
- Like to put things into containers
- Use 3 or 4 words correctly other than "mama" or "dada."
- Imitate adult voices.
- Pull things out of cabinets, wastebaskets, and closets.
- Begin to use "no" to show independence.

MONTH 16

- Say at least eight words besides "mama" and "dada."
- Climb on a chair to get something he wants.
- Turn the pages of a book by him/herself.
- Turn a bottle upside down to get something out.
- Ask for help when needed, such as winding up a toy.

What Your Baby Will Do At

MONTH 18

- Kick and throw a ball.
- Climb and run, may fall less often.
- Dance to music.
- Follow simple directions.
- Imitate what you do at home, like dusting, phoning, hammering.
- Like to have his or her own way.
- Come when called.
- Say about 10 words.
- Enjoy nursery rhymes.
- “No” may be a favorite word.
- Put toys away with help.
- Use spoon and fingers to eat, and use a cup to drink.
- Stack 3 or 4 blocks

MONTH 20

- Follow at least three simple directions like: “Close the door,” “Put the toy on the table,” and “Find your coat.”
- Walk up or down at least two steps by him/herself.
- Turn doorknobs, wind-up toys, twist tops, or jar lids.
- Find a chair or box to stand on to get something he wants.

MONTH 24

- Like to be pushed on a swing.
- Pedal a tricycle.
- Throw a ball into a wastebasket.
- Walk down stairs (be sure to stay near your baby).
- Ask and answer some questions.
- Like to run and play tag.
- Put some clothes on.
- Want to do things without help.
- Turn doorknobs, open doors, and slam/close doors.
- Like to pull things apart.

What Your Baby Will Do At

MONTH 30

- Tell you what's happening in pictures in a book.
- Stand on one foot for a little while without holding onto anything.
- Turn the pages in a book, one page at a time.
- Tell you about pictures he has drawn.
- Says "me" or her name when you ask, "Who's in "the mirror."

Each child is different. If you feel your child is not developing as quickly, you may want to get some advice on what you can do to help your baby.

A game Plan for Fathers Introduction

If you are reading this, you may be in complete shock. When I heard for the first time that my child might have special needs, it was like someone had given me a sucker punch to my gut. I wanted to run in the other direction. For me it was the words Down Syndrome. For all of us the shock is real. I felt I was forced into a ball stadium and told to play a game that I knew nothing about and really had no desire to play. I hadn't trained and wasn't conditioned for it. I didn't even know the rules. I had planned for a totally different game. But now, my baby boy was asking me to come out and play.

Men thrown into this game will play it very differently. Some want to go it alone. They just want someone to show them the court and give them the ball and get out of their way. That's OK. Others may want a coach. Not someone who thinks they're better than they are, but someone who has played the game before and can share the rules with them. The reality is coaches know they are usually in the presence of better ball players than themselves, but a coach knows the rules and how to work the field to your advantage. He may even be able to let you know where other sucker punches come into play. Some dads want a team, or a group of men who play the game together.

The choice is yours. I just know that when I chose to answer my child's call to "come out and play," I began to travel down one of the best roads I have ever traveled.
Family Network on Disabilities of Florida

Family Network on Disabilities (FND) is a national network of individuals of all ages who may be at risk, have disabilities, or have special needs and their families, professionals, and concerned citizens. FND was founded in 1985 and began as a grass roots organization in the living room of parents who were determined to make a difference. Our mission states that we are striving for complete integration and equality of people with disabilities in a society without barriers.

"Dadvocates" is a program of Family Network on Disabilities. It's a network of dads who want to train and support other volunteer dads in a father-friendly manner. The Dadvocates program will try to cater to your specific needs as a Father of a child with special needs, knowing that the issues and solutions will be addressed differently than the way a mother may address them.

Welcome to Holland

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this ...

When you're going to have a baby, it's like planning a fabulous vacation trip - - to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting!

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland".

"HOLLAND?!!" You say. "What do you mean, Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would have never met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills--Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever, go away...because the loss of that dream is a very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about HOLLAND.

- By Emily Perl Kingsley

A Note from Father's Network

When you arrive in Holland, most people find it very helpful to talk with people who have lived there for a while. May we introduce ourselves? We are a group of fathers who network together around the issues associated with our children's special needs.

We really see ourselves as coaches. It doesn't mean that we are better ball players than you. It's just that we have played the game a little longer. We encourage you to read this welcome packet thoroughly. Learn this game so you can take the ball and your child and run down the field as far as you can.

We did not have a welcome packet when our special needs child was born. So we thought it might be helpful, for your sake, to develop one. No single guidebook will have all the answers, because every journey is a bit different. Our hope is that these thoughts and resources will help you navigate through this journey to develop the best outcome for your child and your family.

We see that our children have introduced us to so many wonderful things. We have found portraits by Rembrandt and we have slowed down to even notice the tulips. Although the journey you are embarking on will be difficult, it will not be impossible.

A Special Perspective on Fatherhood

I have talked with hundreds of dads. One thing we all have in common is the sense of loss of the dream we had of what our child may do and be. Yet, the reality is that few, if any of us, met the expectations of our own fathers. I never became the engineer that my father expected, and you may not have been the ball player your dad anticipated. But our parents had 20-30 years to discover that their dreams would be re-directed. I had to digest this reality in the time it took someone at the hospital to say “Down Syndrome.”

The loss of this dream is real, and it is quite natural to be upset. I can also say that although I am not the engineer my dad wanted me to be, my parents (especially my dad's) encouragement has been the most significant factor in realizing the dreams that I have created for myself. Your role is even more significant now.

I have learned to take life at a little slower pace. I understand so much better the stages of development and how each builds on the next. You will hear a lot of us say that our child has made us much better fathers than if we had not experienced this world of special needs.

Please understand your child will succeed at the thing they choose to accomplish. Some of our children are holding down full-time employment, attending college, authoring books, and even getting married. Others may take longer, or struggle to meet these goals.

Will my child reach these aspirations? I really do not know and “having to wait and see” for me this is the hardest part of being a dad. Our children may amaze us with the things they are interested in and the dreams they will create for themselves. A realistic goal is helping them to walk through all the developmental stages to achieve the dreams they will create for themselves. You have the opportunity to learn and understand all of the developmental stages that it takes to fulfill their dreams. Information is power, and you and your child can succeed in any endeavor you take on.

Telling Family & Friends

There is no doubt that one of your most difficult tasks will be telling friends and relatives, particularly grandparents, that your child has special needs. Give grandparents, aunts and uncles, siblings and friends time to process this unexpected information. They will need time to adjust, just as you will.

It is natural for families and friends to feel awkward. Many do not know what to say or do to help you deal with this stressful situation. Human nature causes us to want to pull away or “shut down” from uncomfortable situations. This is the body’s natural mechanism to extreme stress. It is not uncommon for people in shock to say the wrong thing at the wrong time. A technique you may find very helpful is simply called “applying grace.” Often times someone will say something that could be construed as inappropriate. They often feel terrible about what they have said or the situation they now find themselves in. This may cause them to pull away from you or your family, creating a greater sense of loneliness for you. Our goal as parents is to pull people back into our circle of family and friends by saying something like, “You know that dumb thing you just said five minutes ago? I know you’re kicking yourself in the head for saying it and it’s OK. We are all trying to figure this out and I know this is difficult, but you have no idea how much your friendship and support means to us during this time.”

On the other hand, you may find that many people are drawn to your child and have a genuine concern for them and for you. Creating a team/support network for your child will help tremendously in your child’s future. As your child’s number one advocate, helping people feel like they belong on your child’s team is one of the single best things you can do to strengthen relationships and build a foundation of support. We will discuss this in more detail under the section Family/Friends.

Get the Information You Need

Read books and research, but be careful with what you read. Older and outdated material may still be available on library shelves. Seek out current information about your child's diagnosis whenever you can. Your child's future is much more positive than it would have been just 5-10 years ago. Great progress has been made in helping children with special needs achieve the best possible future. Talk with parents and professionals about reading materials. Meet with your Parent Resource Specialist of Family Network on Disabilities (PEN or POPIN projects), these are parents of children with special needs trained to help other parents of children with special needs. They will be able to provide support, training, resources, and information that will help guide you through the evaluation, diagnosis, and special education processes.

How Networking Works for Men & Women

If you've been with your significant other for a long time, you know that the way men and women approach a new situation can be very different. For issues very important to us, it can be even more difficult. There is no issue that we, as parents, are more intense about than the care of our children. Issues of parenting styles, medical approaches, and interactions with family and friends will force us to communicate about topics we may never have discussed otherwise. These intense discussions are even more heightened when a child with special healthcare needs is involved.

Needless to say, the way we go about gathering information may be very different. Typically, a woman's form of networking is very social and men may only want the nuts and bolts.

The important thing to realize is that each approach has its advantages and neither is wrong. "My wife and I approach our child very differently. We never use the same approach, but choose to talk it out to become one minded on the way we care for our son" (quoted by a father of a child with special needs).

Several fathers have commented that the greatest stressor of having a child with special needs is not the child itself, but rather dealing with their spouse being stressed. If you are finding it difficult to communicate about these issues, realize that you are not alone. Family Network on Disabilities has tools to help.

The Effect of a Disability on the Family

Family members each cope with a child's disability or illness in their own way. Each member must adapt to the new situation. Relationships within the family, along with previously defined rules, values and roles, must be adapted, also. Such tremendous changes on everyone's part can cause stress on the family unit, as well as on individual members.

Mothers

In the initial crisis period, mothers may react differently from fathers or significant others. Mothers may be more emotional and may voice concerns about their ability to cope with the additional tasks of childcare. Usually, mothers are more encouraged socially to express their feelings, and they also receive the majority of support offered to the family.

Because mothers are usually the traditional caretakers in the family, they assume most of the additional work in caring for their child with special needs. They must learn how to make it all work together within the existing household routine. And, because they are doing much of the daily care, mothers may recognize and feel the reality of their child's special needs earlier than the father. Sometimes, along with the responsibility for daily care, comes the additional role in the medical world. This includes taking your child to clinics, evaluations, consultations, and other medical related services. Thus, mothers become the primary source of information for their family.

Fathers

Fathers may respond less emotionally at first than their partners, concentrating more on long-term concerns, such as prognosis, social stigma, financial effects and the child's future as an adult. It is not unusual for fathers, because of cultural and family beliefs, to cope by trying to be what society expects men to be: "strong and silent." As a result, dads are discouraged from confronting and expressing their feelings. Fathers may be expected to assume the role of family leader, "the fixer," and the person in control. These roles and expectations may be difficult to live up to and maintain, adding more pressure to the existing stress of your child's diagnosis. Fathers traditionally are the "breadwinners." That is, their primary role in the family is making money to provide the family with what it needs. They may feel a tremendous responsibility for the financial burden that may accompany the disability, especially if the mother must quit her job to care for their child. More hours working means more hours spent away from the child, less time for receiving information, and less opportunity to initiate professional and/or supportive relationships.

Mother-Father Relationship

The relationship between the mother and father usually is the initial bond within the family. That relationship is a partnership, one that sets the rules and roles for the family. Still, each parent is an individual who reacts uniquely to the crisis, and in fact, each may define the loss differently. These individual responses or reactions alone may cause a crisis in the family.

When a parent utilizes his or her own coping skills in the crisis, the other parent may misinterpret this behavior. He or she may judge the partner's response as inappropriate because it is different from the way they reacted. At times, mothers may label their partner's behavior as "cold" or "uncaring." Fathers may judge their partners as "overly-emotional" or "weak." Fathers may feel that they must take care of their partner in spite of having unmet needs of their own. Mothers may feel the same way. Each partner may be unable to see beyond his or her own needs. Each can be unaccepting of the other's way of coping. Each may become angry with the other for adding to the stress in an already-stressful situation.

The Effect of a Disability on the Family

Parents may have difficulty communicating with each other about their child's disability. One parent may want to share his or her feelings, but the other parent may be unable to, or unwilling to do so. This difference may set up a communication block and one-sided discussions. Fathers may have to rely on their partners to relay information from professionals, but the information they need may not be forthcoming. Mothers may understand what they heard but are unable to explain it fully. At times, parents may be reluctant to express their concerns to each other, fearing that such concerns only will add to the worry or depression for their partners. Consequently, each may attempt to protect the other by avoiding such discussions.

Each parent has his or her own value system, which was learned from his or her childhood, and/or family. Differences in value systems may contribute to conflicts within the relationship, this includes all decisions made with regards to your child's care, education, and future planning. Thus, the parental unit may become overwhelmingly burdened, and it may take much compromise to keep it intact. The mother-father relationship can survive the many changes it must endure, but parents must work to:

- Find a way to communicate feelings and concerns in a productive manner. They may need to seek guidance in this area, especially if effective communication has not been well established.
- Develop a respect for each other's coping style. This too, may require professional guidance.
- Re-examine individual roles and rules within the family. Develop a new plan together to meet the child's needs as well as needs of the other family members.
- Maintain their relationship as partners, apart from their relationship as parents. Parents need to have quality time together.

The Three-Legged Stool

As new dads, there are three areas that you may want to focus on for the next several weeks, and like a three-legged stool, each should be worked on equally to keep our lives balanced.

Financial (Contact Family Network on Disabilities for tips on how to plan ahead).

How do we provide for our child, especially if there may be added expenses such as extra medical expenses or therapies? You may need to reconsider questions about your resources, such as insurance. What new special issues need to be considered in long-term planning for my child?

Interventions/educational and medical

What we mean by intervention is how we can intervene (get involved) in the life of a child with special needs to improve their outcomes. One example is the use of specific targeted therapies to help an infant or young child. This can greatly improve a child's outcome later in life.

Family Concerns and other Resources

How do you use the natural support your child already has around them to improve the future outcomes for your child? Contact Family Network on Disabilities, our staff will assist you with information, training, and our list of resources.

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