

# My Child at Home

A Champions Together Course for Parents

# Dealing with the Diagnosis

Session **1**





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NAME \_\_\_\_\_



...the splendor of the rose and the whiteness of the lily do not take away the perfume of the violet or the delightful simplicity of the daisy...if all flowers wanted to be roses, nature would lose her springtime beauty, and the fields would no longer be decked out with little wild flowers.

St. Therese of Lisieux



**Welcome to**

# **My Child at Home**

A Champions Together Course for Parents

Session 1  
Home

My name is \_\_\_\_\_, and I am your group leader. We will meet for three sessions in the My Child at Home course. In each session, you will receive a new manual that contains information and activities. I will guide our group through the activities.

You might think you could just read these lessons yourself instead of listening to me, but part of the value of the course will be learning together and participating in the activities and discussions in the manuals. I'll appreciate your support.

Each session lasts about 90 minutes. New information is presented in each session. After the first session, more time is devoted to discussion of the activities we complete between sessions. At the conclusion of the third session, we will hold a graduation ceremony. Those of you who attend all three sessions will receive certificates.

My Child at Home is a very practical, take-it-home-and-use-it course. Between sessions, you will complete activities with your families. Your work at home with your families is the most important part of this course.

## Getting Acquainted

Please write my name and telephone number in your manual. I want you to feel free to call me between sessions if you have questions.

Group Leader's Name: \_\_\_\_\_

Group Leader's Telephone Number. (\_\_\_\_\_)\_\_\_\_\_

### EXERCISE



### PARTNERS

To get to know each other better, I will assign each of us to a partner. If we have an odd number in the group, I will take two partners. Then we will talk with our partners for two minutes. At the end of that time, we will each introduce our partner to the group and tell the names of our partner's children. If we learn any other interesting information about our partner, we can tell that too.

**Group Leader.** Assign partners. Allow two minutes. Begin introductions.

Partner's name: \_\_\_\_\_

Names of partner's children: \_\_\_\_\_

### TELL THE GROUP



*I'll introduce my partner first and tell the names of my partner's children. Then my partner will introduce me. We will continue until everyone has been introduced.*

### APPLAUD



**APPLAUD AFTER EACH INTRODUCTION.**

### EXERCISE



### NAMES OF GROUP MEMBERS

Now write the first name of each group member below. Need help? Check the name tags. This list will help us remember everyone's name.

_____	_____
_____	_____
_____	_____
_____	_____

## Dealing with the Diagnosis

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Before any child is born, every parent has dreams for that child. Those dreams may include having the child grow up to be independent, have a good education and start a family. When children have disabilities, parents sometimes need to adjust these dreams. For most parents, this is a difficult process.

In this session we will discuss issues related to finding out about our child's diagnosis, dealing with the reactions of family and friends, and creating a system of support. Each of these is important in the process of dealing with the diagnosis.

Dealing with the diagnosis is the first step on the road to helping our children achieve their greatest potential. The activities in this book will help you to deal effectively with your own responses and those of others.

### EXPECTATIONS

EXERCISE

In what ways do you expect your family to benefit from your participation in this course?

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*Share with the group how you expect your family to benefit from this course.*



TELL THE  
GROUP

*Dealing with the diagnosis is the first step on the road to helping our children achieve their greatest potential.*

## Lesson 1: Acceptance

Most parents expect and look forward to a healthy child. When a child seems different from other children, parents begin to worry and wonder if there is something wrong with their child. When a medical professional confirms for the family that the child is indeed different, many parents go through a process of grieving that leads to acceptance.

What they are grieving is the loss of a dream.

### **Stages of Grief that Lead to Acceptance**

1. Shock/Denial
2. Bargaining
3. Anger
4. Depression
5. Acceptance

The length of time needed to move from one stage to the next varies with each individual. Sometimes parents can go back and forth between stages, or experience more than one at a time. For some parents, it can take years to pass from one stage to the next, with occasional regression. During times of anticipated milestones, such as graduations, parents may see their child lag behind, and may re-experience past emotions.

The stage of acceptance is reached when parents are able to do the following:

- × Discuss their child's disability without becoming emotional
- × Encourage their child to be independent
- × Make realistic short-term and long-term plans
- × Make time for activities they enjoy, unrelated to their child
- × Discipline their child appropriately (regardless of the disability)



EXERCISE



EXERCISE

What was your initial response to your child's diagnosis?

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What stage of grief leading to acceptance are you in now?

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*We will each share our responses with the group.*



TELL THE  
GROUP

*The length of time needed to move  
from one stage to the next varies  
with each individual.*

## Lesson 2: Reactions of Family, Friends and Others

Once we have dealt with our own emotions and responses to the diagnosis, it is time to share the information with our family and friends. This can be an emotional experience. Dealing with their responses can cause parents to relive their own difficult emotions.

Some parents worry about the reactions of others and a possible lack of support from extended family and friends. They worry about whether their child will be accepted. It can be difficult when someone you care about doesn't respond in the way you hoped they would.

For some parents, the experience of having a child with a disability can impact their marriage. If the parents have different responses or different ideas about how to care for the child, they will need to find ways to resolve these conflicts.

The reactions of siblings are also important. The amount of time that needs to be devoted to the child with special needs impacts the amount of time and energy available for other children. The siblings may have increased responsibilities or take on a "caretaker" role. They can feel resentful, but may also feel guilty about this emotion.

The reactions of strangers can be difficult to handle. Sometimes strangers will say things such as:

"What's wrong with your child?"

"Can't you get him to stop that?"

"You must be a saint!"

*Once we have dealt with our own emotions and responses to the diagnosis, it is time to share the information.*

# Dealing with the Diagnosis

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DEAR ABBY



EXERCISE

*Dear Abby:*

*Well-meaning family members and strangers at the mall make hurtful comments about my child. Why do they say these things? What should I say to them?*

*Frustrated Parent*

*Each group member will share ideas about why well-meaning people sometimes say hurtful things to us about our children and how we might best respond to them.*



TELL THE  
GROUP

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## Lesson 3: Creating Support

One of the most effective coping strategies for dealing with our child's diagnosis is to identify and develop a network of support.

We all have people in our lives who are able to provide varying levels of support. This can include family, friends, religious leaders, other parents, support groups, organizations, doctors and other paid providers. Some parents have found that inspirational books of affirmations have helped them get through difficult times.

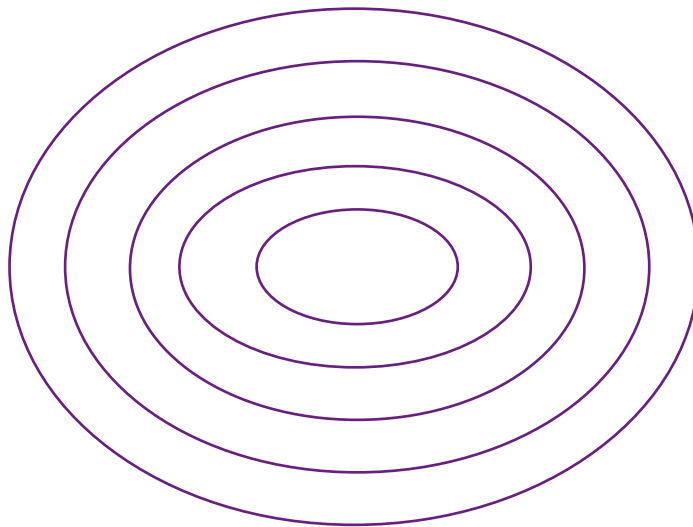
The individuals in your support network can listen when you need to talk, share your concerns and feelings, provide childcare, provide information and help relieve stress.

### EXERCISE



### IDENTIFY THE INDIVIDUALS IN YOUR CIRCLES OF SUPPORT NETWORK

Fill in the diagram below, with your name in the middle. In the first circle, list the names of people closest to you, such as spouse, family and closest friends. In the next circle list close friends and associates or others you feel would be appropriate at this level of support. In the next circle list individuals you may know through groups or organizations you may belong to. In the outer circle list doctors, paid providers and other acquaintances.



*Please share with the group the names in your circles of support and how you can count on them.*



TELL THE  
GROUP

Identify organizations that are available to provide support to parents of children with the same disability as your child. This can include parent groups, organizations specific to your child's disability, internet groups or others.



TELL THE  
GROUP

I cried a lot and prayed a lot and yelled at God a lot. Then, I said, "So be it. You're sorry for yourself, but look at that child. Just look at him. Not what he might have been, but what he is. Grow up, lady.

Exceptional Parents, June, 1982

## Lesson 4: What Makes Parents Smile?

EXERCISE

Our children are a great source of joy for us. Sometimes it is good to remind ourselves of the things our children do that make us smile.



**WHAT DOES YOUR CHILD DO THAT BRINGS A SMILE TO YOUR FACE. LIST A COUPLE ITEMS BELOW.**

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*We will each share our child's smile-making behaviors with the group.*

## Key Points

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### Let's review the key points from this session:

- × Parents go through stages of grief when they find out their child has a disability.
- × Parents reach the stage of acceptance when they are able to discuss the disability without becoming emotional and discipline their child appropriately.
- × Dealing with the reactions of family and friends can be a difficult experience.
- × There are many ways to respond to strangers who make inappropriate comments.
- × An effective coping strategy is to identify and develop a network of support.
- × There are many individuals and organizations available to provide support.

## Taking it Home

You have learned about dealing with your child's diagnosis. You have learned about accepting the diagnosis and dealing with reactions of others around you. You have learned the importance of a support network. Now it is time to put your learning into practice. Listed below are the activities for the week.

### ACTIVITIES FOR THE WEEK

Parent's Initials:

- \_\_\_\_\_ 1. I will talk with someone in my life who reacts to my child in ways that concern me. I will listen carefully to better understand the person. I will express my feelings and offer suggestions.
- \_\_\_\_\_ 2. I will list all members of my "support network" and keep the list as a handy reference. I will contact one person on my list this week to visit and give them an update on my child.
- \_\_\_\_\_ 3. I will make a list of organizations, parent groups, and internet groups that provide support to parents of children with the same disability as my child.
- \_\_\_\_\_ 4. I will connect with my child in a special way and enjoy my good feelings and those of my child.



## Closing the Session

You will take home this manual to remind you of your activities for the week. You have my name and telephone number so you can call me during the week if you have questions. I will collect the pencils so we will have them at the next session.

**Group Leader.** Collect pencils.

The next page in this manual is a tear-out page. You can place the tear-out page in a prominent place in your home (like on the refrigerator). You can check each activity as we complete it.

The lessons you have learned in this session are just the beginning of *My Child at Home*. In the next two sessions, you will continue to build on what you have learned. We will also take time to talk about your activities.

**APPLAUD FOR A GREAT FIRST SESSION! COME ON, A BIG,  
HEARTY ROUND OF APPLAUSE.** 

APPLAUD

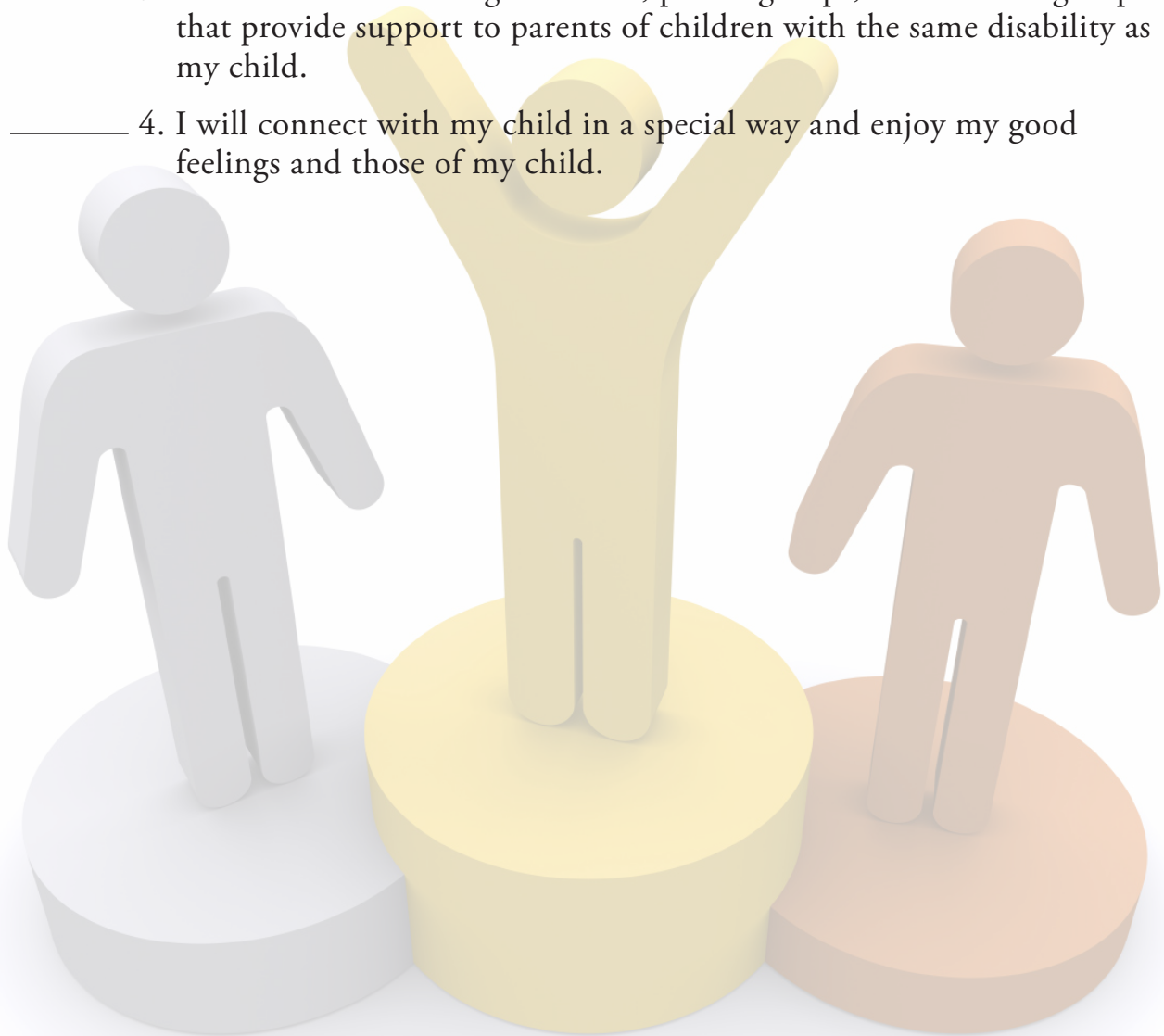


# Activities for the Week

## ACTIVITIES FOR WEEK #1

*Check (√) when completed*

- \_\_\_\_\_ 1. I will talk with someone in my life who reacts to my child in ways that concern me. I will listen carefully to better understand the person. I will express my feelings and offer suggestions.
- \_\_\_\_\_ 2. I will list all members of my “support network” and keep the list as a handy reference. I will contact one person on my list this week to visit and give them an update on my child.
- \_\_\_\_\_ 3. I will make a list of organizations, parent groups, and internet groups that provide support to parents of children with the same disability as my child.
- \_\_\_\_\_ 4. I will connect with my child in a special way and enjoy my good feelings and those of my child.





# **Academic Development Institute**

**Founded in 1984**

The Academic Development Institute (ADI) works with families, schools, and communities so that all children may become self-directed learners, avid readers, and responsible citizens, respecting themselves and those around them. ADI's vision is of an American landscape filled with distinct school communities reflecting the hopes and dreams of the people intimately attached to them. To this image of the school as a community, ADI is devoted. When the school functions as a community, its constituents (students, parents, teachers, staff) associate with one another and share common values about the education of children. At the root, members of the school community assume responsibility for one another. Those children become our children, and parents are not external agents, but full partners in the education of their children and of each other's children. Teachers are not isolated practitioners of pedagogy, but professionals integrated into the web of community and buoyed by common purpose.



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