

Caregiver's Workbook



**Caring
for Caregivers**



**For Groups of Caregivers of School-Age Children
with Autism Spectrum Disorders**

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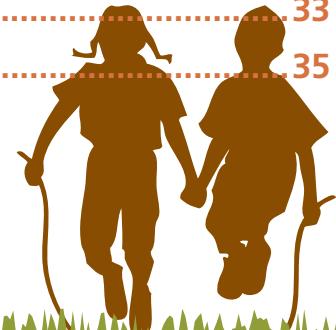
Caring for Caregivers is dedicated to the memory of Bruce Good, whose love and devotion to his family and son with autism continues to inspire us all.

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Introduction

Welcome

Welcome to the Caring for Caregivers (CFC) Workbook. This workbook has been designed to coordinate with the CFC program and to provide concrete, useable resources to help caregivers in their daily lives.

When you participate in a CFC group session, the facilitator will choose various activities from this workbook for the group to complete. Because of so many exercises, there will not be time to finish all of them. These exercises and handouts can also be used at home when you have free time. Flip through to see which exercises or handouts look helpful to you. Try to set aside a few moments during your day to read and complete one exercise. Most of the exercises should take about 20 minutes.

There are a number of exercises and handouts that can be used ove. Use this workbook as a starting point or a building block to find ideas, methods, and resources that can help you and your family.

Support Network

Throughout the workbook, there are references to the support network. As the facilitator of the CFC group session you attended explained, a support network is a group of people with common interests and experiences who listen and provide guidance and support. You may have joined a support network consisting of the members of your CFC group, you may find support on the Caregiver Community Web site, or you may have a group of people in your community. The prompts throughout this workbook are meant as reminders and ideas for ways to connect with the people in your life who can offer support.



Caregiving and Emotions

Exercise 1—Gratefulness

When we feel stressed and overwhelmed, it can be easy to lose sight of all that we have to feel grateful for. This feeling of gratefulness can sometimes help to bring more peace and joy into our lives. Use this exercise to think of things and that you are grateful for and lessons you have learned in relation to your child with ASD.



What positive qualities and/or characteristics has your child brought to your life?
(Examples: patience, love, involvement)

What lessons have you learned that you are grateful for? (Examples: appreciating individual differences, closeness of family)

What other things are you grateful for in relation to your child and/or your life?
(Examples: being a parent, finding support from your family, or everyday)



You may find it useful to keep a daily or weekly journal of the things you are grateful for. These can be specific to your child or to life in general.

*****Support Network Opportunity*****

Talk to your support network about the things you are grateful for. Maybe everyone in your network keeps a gratitude journal and can share their experiences, whether you connect online or in person.

Notes



Caregiving and Emotions

Exercise 2—Breathing relaxation

One type of relaxation technique is to focus on your breathing. This is a skill that can come in handy during stressful moments at work or home, or just when you need a few minutes of silence. Focusing on your breathing can help reduce anxiety and calm the mind. Physical stress responses, such as anxiety, tension, or shortness of breath, can be targeted by focusing on your breathing. You might notice that your breath lengthens, your heart rate decreases, and you feel more relaxed.



This exercise can last from 1 to 10 minutes (or more if you have time) and can be done anywhere.

Step 1: Sit or lay in a comfortable position.

Step 2: Close your eyes.

Step 3: Bring your attention to your breath as it moves in and out of your nose. Draw your attention to your nostrils for a few moments. Bring your attention to your breath as it moves in and out of your nose. Scan your whole body, inviting in relaxation, ease, and peace, then letting go to release your tension.

Step 4: Concentrate on sending your breath to your belly. Maybe place your hand just above your belly button. As you inhale, feel your abdomen expand into your hand. As you exhale, feel your belly move closer to your spine. Feel each inhale and exhale originate in the area below your ribs.

Step 5: Continue breathing in this way for up to 10 minutes or more if you have time” to match the top . When you are done, bring your awareness back to your breath at your nostrils. Sit for a few moments before opening your eyes.



Tip

Set a timer for the amount of time that you would like to sit and focus on your breath. This way, you won't be worried about when you need to stop and can truly focus on your breath.

Note: If you feel lightheaded, dizzy, or uncomfortable at all doing this exercise, then stop and just breathe naturally. Maybe try this exercise at another time or find another relaxation technique that may work better for you. Handouts 1, 2, and 4 have more ideas and information.

Notes

Caregiving and Emotions

Exercise 3—Mindful eating

It can be challenging to find or make time for yourself. Having a few moments of silence to be mindful can replenish and reenergize you.



For this exercise in the CFC group, you'll practice eating mindfully with a snack (almonds, raisins, chocolate chip cookies, etc). Mindful eating, like focusing on your breath or other techniques, can increase your attention on yourself, bring more oxygen into your body by breathing deeper, reduce muscle tension, and lower your heart rate. These are just some of the benefits. For more information on techniques like these, please see Handout 1 on page 27.

If you do this exercise outside of the CFC group, you can use this same technique for any meal. 2- Use the steps below to focus on the foods that you are eating and appreciate them, while finding quiet time for yourself. Maybe set aside one meal a week where you eat quietly and mindfully.

1. Sit quietly—without a TV on, without a magazine or newspaper, without work to do. Just sit with food in front of you.
2. Take a moment to look at the food in front of you. If it is a snack, maybe hold it in your hand. Examine all its characteristics, its textures, colors, etc.
3. Close your eyes and smell the food.
4. Open your eyes and look at it again.
5. Take your first bite and hold the food on your tongue. Notice what tastes come to mind. Maybe move the food around a bit on your tongue.
6. Taking your time, begin chewing your food. Feel the texture of the food in your mouth, hear the sound of your teeth chewing, and note the movement of your jaw.
7. Sit for a moment before taking the next bite. Let the previous bite settle into your digestive tract, maybe offering a silent gratitude for the food and its nourishment to your body.



8. Take your next bite, following steps 5–7.
9. Continue to eat slowly and mindfully during your meal or snack.

Optional:

After your snack or meal, you might like to write down your impressions of this mindful eating exercise. Use these questions as prompts:

What did you notice when you took the time to really look at the food you were going to eat?

How did it feel to take your time eating your food?

Did the food taste different?

After your meal, how did you feel?

*****Support Network Opportunity*****

Ask members of your support network to join you for a mindful meal or to share their experiences of eating a snack or meal slowly. What did they notice when they did this activity?

Notes

Caregiving and Emotions

Video 1

- As your child gets older, do you have similar concerns about the future the caregivers described on the DVD expressed? How are your concerns similar or different from theirs?



- In what ways do you make time for yourself—on a daily basis for a few moments or perhaps enjoying a favorite weekly or monthly activity?



Caregiving and Emotions

Handout 1—Mindfulness

Mindfulness is a technique where you pay close attention to your thoughts, feelings in the body, and emotions, and root yourself in the present moment. Over the years, mindfulness techniques have gained increased awareness and popularity. While this is not specifically a technique for relaxation, the practices for mindfulness can bring peace, relaxation, and a sense of space. Two techniques that are based on mindfulness practices include Exercise 2 (a breathing technique) and Exercise 3 (an eating technique). Practicing mindfulness—being aware of the present moment, what you are feeling/thinking/experiencing, without judgment—can give you skills to use in stressful situations and to bring more peace into your life.



For more information regarding mindfulness-based techniques:

Jon Kabat-Zinn

- Kabat-Zinn is the founder of the Stress Reduction Clinic at the University of Massachusetts and a teacher of mindfulness-based stress reduction.
- He has authored numerous books and papers related to mindfulness and mindfulness techniques, including:
 - *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness* (1990)
 - *Everyday Blessings: The Inner Work of Mindful Parenting* (with Myla Kabat-Zinn, 1998)

Local resources

- Conduct a search of your local area by using the search terms: “mindfulness,” “mindfulness resources,” and “mindfulness meditation.”
- There are often organizations and teachers in your local area that will offer more information and guidance on mindfulness.



Caregiving and Emotions

Handout 2—Take care of yourself

If it has been a while since you have done something fun for yourself, here is a list of potential activities you may enjoy. Keep in mind that the possibilities are endless. You are making a commitment to yourself and your health by making time for yourself.



- Play in a sports league
- Create a scrapbook—a positive way to acknowledge your adolescent or school-age child's and family's accomplishments
- Exercise—running, walking, biking, hiking
- Journal—buy a journal, find a comfortable spot, and spend some time just getting your thoughts down on paper
- Take a cooking class
- Attend a concert or play
- Take a knitting class
- Go to a museum
- Go to the park
- Bake cookies
- Go to a coffee shop
- Play cards with friends
- Go to the movies
- Call a friend you haven't talked to in a long time
- Take a dance class
- Get your hair cut
- Get a manicure
- Get a massage
- Read
- Listen to music
- Play board games
- Sing or do karaoke
- Watch your favorite sports team with friends
- Do a puzzle (crossword, Sudoku, jigsaw)
- Plan a trip or an evening out
- Invite friends over for dinner or coffee
- Start a garden
- Learn to woodwork



Benefits Of Taking Time For Yourself

- Recharging, building energy
- Lowering your stress levels
- Having things to look forward to
- Rewarding yourself for your hard work
- Building focus and increasing attention
- Maintaining a positive attitude
- Relaxing

All of these benefits help to make you a better caregiver—not to mention a happier person.

Notes

Caregiving and Emotions

Handout 3—Fact sheet

The following information is covered in the Caregiving and Emotions section of the CFC program.



Just when you start to have things under “control,” you are now getting ready to transition your child into school or maybe your child is already in school. This transition—along with many other types of transitions that you and your child may face—can bring along emotional reactions. It is common—at different times and for different reasons—to feel sad, embarrassed, worried, tired, or frustrated.

Being a caregiver of an individual with ASD is a full-time job, and helping your child learn, get services, and succeed can take up the majority of your time. At the same time, it is important to not let ASD take over. Time for yourself—taking care of yourself and exploring your personal interests and feelings—can create more balance in your life. It may seem hard to start, but you may have more time—even if it is a few hours—when your child is in school for part or all of the day. There may be some space opening up in your day for taking care of yourself.

Tips and Ideas to Help Caregivers Cope

There are a variety of options to help caregivers cope emotionally to reduce their stress. These include:

- Noticing the things that you are grateful for. These may be lessons that you’ve learned, daily events, or characteristics of your family that bring you happiness.
- Sharing experiences with other caregivers, whether online or in person, can provide a sense of support to caregivers.
- Finding time to dedicate to yourself can go a long way toward maintaining your emotional health. Finding and doing a favorite activity—even for 30 minutes—is important.
- Taking 10 minutes to just breathe and focus on your breathing can rejuvenate your mind, body, and spirit.
- Exercising is a great way to relieve stress and build energy.



Caregiving and Emotions

Handout 4—Resources for more information



- *The Organized Parent: 365 Simple Solutions to Managing Your Home, Your Time, and Your Family's Life* by Christina Baglivi Tinglof
This book offers tips and advice on managing and organizing your home and family life. It is written with all families in mind.
- Organized Families: <http://organizedfamilies.com>
This online resource features organization tips for busy families, with resources that can be used by any type of caregiver.
- *The Relaxation & Stress Reduction Workbook* (6th ed.) by Martha Davis, Elizabeth Robbins Eshelman, and Matthew McKay
This book is useful in assessing your stress level and provides tips on stress reduction and descriptions of relaxation exercises.
- Caregiver Community: www.autismcaregiver.com
This Web site is dedicated to connecting caregivers with each other and providing resources throughout the lifespan of ASD.
- National Caregivers Library:
www.caregiverslibrary.org/Default.aspx?tabid=130
This Web site offers information and tips about the importance of caregiving and exercise.
- *Cup of Comfort for Parents of Children with Autism: Stories of Hope and Everyday Success* by Colleen Sell
This book offers a collection of inspiring true stories that portray the strength, love, and devotion of families.
- Autism Speaks: www.autismspeaks.org/what-autism/autism-your-family/
This Web site provides advice and resources for grieving and the stages associated with grieving. It also provides guidance for the primary caregivers, siblings, and extended family members.



Notes

Caregiving and Relationships

Exercise 1—Asking for help

Caregivers of children with ASD do so much. It can be challenging to ask for help from others when you are used to doing things a certain way or by yourself. You might also be dealing with a complex situation that overwhelms you, and this might lead you to be uncertain about the type of help you need. Finding opportunities to ask for help with daily tasks or items on which you could use support can free up time for yourself, create a strong support system with the people in your life, and help you to accomplish more by doing less. Use this activity to think about mobilizing your support system.



1. What are some things that you have on your to-do list? List between 5 and 10 items here.

a. _____

f. _____

b. _____

g. _____

c. _____

h. _____

d. _____

i. _____

e. _____

j. _____

2. Could any of these items be done by someone else? Which ones? List them here.



3. Who could you ask to help with these items—friends, family members, community contacts?

4. Practice makes perfect when you learn how to ask for help for yourself. Write down a few ideas of how you can ask the people you listed in number 3 for help with your to-do list.

*****Support Network Opportunity*****

Talk to your support network about how they ask for help with daily tasks. How do they remove extra items from their to-do lists?

Caregiving and Relationships

Exercise 2—Nurture your relationships

As you focus on your child with ASD, it can be easy to let time get away from you. You may be too tired or not have enough time to connect with your significant other. Making the time is important to nurture your relationship as well as to have time together. Use this exercise to brainstorm easy, yet special things that you could do together with your partner to nurture your relationship.



When you and your significant other first met:

- What types of dates did you go on?
- What did you talk about?
- What questions did you ask?
- What tokens did you do for each other (e.g., notes, phone calls, e-mails) ?

Taking these things into account, let's think of ways to incorporate them back into your relationship:

- What would be a fun date that you listed above that you could go on?
- What types of things would you like to talk about now (unrelated to ASD)?
- What things would you like to ask your partner (about their day, world views, future plans)?
- What little tokens can you do for your partner during your day?

Support Network Opportunity

Use your support network to discuss how other caregivers connect with their partners. Local members of your network may have fun and easy local ideas for a great date night.



Caregiving and Relationships

Exercise 3—Connect with others

Use this exercise as a way to brainstorm different places, people, and/or activities that you could use to connect with others. Creating a support system, even in the simplest places (like at your local coffee shop), can give you a sense of belonging, comfort, and encouragement. Once you have identified certain things from this worksheet, trying them out.

Use the ideas below to jump-start connecting with people in your life. Circle the places where you often go, people you see, and activities you do. Feel free to add to this list, and then use the items that you circle to find people and places to connect with.

People

- Coworkers
- Parents from the child care center
- Spiritual center (church, temple, etc.) participants
- Neighbors
- Gym members
- Caregivers of Other school-age children with ASD
- Parents from school
- Caregivers at service offices
- Facebook friends
- Old friends (e.g., from high school, college)
- Community center members
- Support group participants

Places

- Coffee shop
- Park
- Grocery store
- Farmer's market
- School



- Therapist's office
- Gym
- Yoga studio
- Post office
- Community center

Activities

- Exercise
- Hiking
- School
- Work
- Accessing services for your child
- Birthday parties
- School events
- Organizations (ASD-related or community-related)
- Book club
- Sporting events or clubs
- Poker night
- Movie night

Notes

Caregiving and Relationships

Video 2

1. Have your friendships shifted as a caregiver of a child with ASD? How so?



2. In what ways have your romantic relationships been affected by being a caregiver of a child with ASD?

3. In what ways has your extended family, friends, and/or community supported you and your family?



Caregiving and Relationships

Handout 1—Respite resources

Every caregiver is in need of a break. Respite allows caregivers time away from caregiving—time to recharge, refresh, and regroup. However, many families have difficulty affording skilled people to help with their child with ASD. In addition, they may not feel comfortable leaving the responsibilities of caring for their children with someone else.



You may only need to find a babysitter—or you may need respite care. Respite care is short-term, temporary care. The amount and duration of services may vary, and there are a number of options that may be available. The resources listed below are a great place to start to find more information and programs that may help.

Autism Source (www.autism-society.org)—a service v the Autism Society of America. You can enter your city and state and select the specific type of service you are interested in (recreation, camps, medical information and support, and a number of others) and find services in your area.

The Arc (www.thearc.org)—a national, nonprofit organization for people with developmental disabilities and their families. The Arc's Web site has a variety of information on various topics and features an important paper on the importance of respite care and its benefits.

National Respite Locator Service (www.respitelocator.org)—helps caregivers find respite services in their area that meet their needs. While it is not an all-inclusive list of services in your area, it will give you a jump-start.

American Camp Association (www.acacamps.org)—allows you to search for camps related to your child's specific needs. You may search by price, services, activities, and other terms to fit your needs.



Keep in mind the following questions as you look into respite services:

- What kinds of services do I need?
- Do I want services in my home or at another location?
- Is there a cost for the service?
- What programs are available to help cover the costs of this service?
- What are the qualifications of the respite provider?
- Are the providers trained to deal with individuals with ASD?
- Can I set up meetings with these providers to discuss our family's needs?
- Will my insurance cover this?

Notes

Caregiving and Relationships

Handout 2—Fun and free activity ideas

Use the ideas below for fun (and free) date night or friend night out ideas:

- Play cards
- Work on a family or event scrapbook
- Exercise—walk, run, bike together
- Take a free cooking class at a local market/grocery store
- Attend a concert or play in a local park (often these events are free or offer complimentary tickets)
- Go to the library and find a great movie to watch together
- Visit a museum (local museums often offer free admission on certain days)
- Take your dog for a walk
- Go to the park
- Have a picnic
- Play board games
- Read together at a park
- Give each other manicures/pedicures
- Put together a puzzle
- Drive to a new area of town and explore
- Start a garden
- Paint or make a craft together from items on hand
- Practice taking pictures, being a photographer
- Create a playlist of music together
- Walk around the downtown area of your city
- Visit the mall and window shop
- Make dinner together
- Discuss a book that you've both read



Caregiving and Relationships

Handout 3—Communication

Connecting with other caregivers of school-age children with ASD is easy at the new Caregiver Community Web site (www.autismcaregiver.com). This Web site was designed to coordinate with the CFC product and includes sections for caregivers along the lifespan of their child with ASD.



On the Web site, you will find:

- A place to create a member profile
- Discussion boards divided by age group
- Additional resources for caregivers
- A links to AutismOnline, a comprehensive resource for information and tools for caregivers and other individuals

To best use the Web site:

- Visit www.autismcaregiver.com
- Click on “Members”
- Create your profile
- Then access the section most appropriate for you (school-age children with ASD)
- Post questions, reply to other caregivers, and even connect with caregivers in your local area



Caregiving and Relationships

Handout 4—Fact sheet

The following information is covered in the Caregiving and Relationships section of the CFC program.



Clear and open communication is especially important for maintaining relationships. Being clear about what you need, stating it effectively, and saying it in a manner that is open with others will make a big difference in maintaining relationships and getting help and support. Communication can take work and time. It can also improve with practice and help to strengthen your relationships.

You may find that your group of friends has changed over the years, either to those who also have kids on the spectrum or to the select few who really understand. Normal activities or play dates with friends can be difficult to coordinate with your child's needs, and you may feel embarrassed or judged by the curious stares or comments from others when you do participate in social activities. Nurturing relationships with friends and others who make up your support system can make you feel good and give you energy. Some caregivers find incredible support from other caregivers of individuals with autism. Others find that they would rather connect with friends without focusing on autism. Either option is great, with the importance being support and connection with others.

Tips and Ideas to Help Caregivers Cope

There is a variety of options to help caregivers nurture their relationships. These include:

- Asking your support system for help. Often, family and friends want to help but are unsure of how. Think of some items on your to-do list that someone else could help with to give you more time.
- Brainstorming easy, yet special ways that you can show your significant other how you feel. Set aside time for catching up, give him or her a note or e-mail during the day, or find ways to connect that are fun and easy.



- Creating a sense of community in your neighborhood and/or local area can build relationships and extend your support system. Getting involved in a local organization or even striking up a conversation at your local coffee shop can help build and support a feeling of being part of the community.
 - Access respite resources in your area to find qualified temporary care for your child with ASD.
 - Network with other caregivers on the Caregiver Connection Web site (www.autismcaregiver.com).

Notes

Caregiving and Relationships

Handout 5—Resources for more information



- *I Hear You, But...: Communication and Listening Skills. Tips for Improving All Relationships* by Rick Goodfriend
Focusing on communication and listening skills for all types of relationships, this book promotes quick and easy-to-implement tips that can help your relationships.
- Caregiver Connection, www.autismcaregiver.com
Connect with other caregivers of school-age with ASD on this interactive Web site.
- Organization for Autism Research, www.researchautism.org
The Organization for Autism Research offers links and information specifically to help family and friends understand ASD.
- Sitter City, www.sittercity.com
This Web site contains a database of respite caregivers and babysitters. A search tool allows you to search for local respite caregivers who have experience working with children with ASD. The Web site can help you find respite caregivers more quickly and with the experience you want.
- *The Relationship Cure: A 5 Step Guide to Strengthening Your Marriage, Family, and Friendships* by John Gottman
This book provides practical advice for transforming troubled relationships into positive ones.
- *The Friendship Factor: How to Get Closer to the People You Care For* by Alan Loy McGinnis
Readers learn how to be a warmer, more loving person; how to communicate better; and how to resolve tension in friendships, marital relationships, and family relationships.



- *Making Peace with Autism: One Family's Story of Struggle, Discovery, and Unexpected Gifts* by Susan Senator

This is a personal narrative of a mother who demonstrates how families can find courage, contentment, and connection in the shadow of autism. The author offers valuable strategies for coping successfully with the daily struggles of life with an autistic child, including: grieving and acceptance, finding the right school program, helping siblings with their struggles and concerns, having fun together, and keeping the marriage strong.

Notes

Caregiving and Family

Exercise 1—Family mission statement

A family mission statement can create a cohesive vision for the future of your family. A mission statement outlines the values, goals, and qualities that are important to your family. It does not need to be a formal contract, but rather a guiding document. It should be created with all members of your family together, including your child with ASD, and it should define what is important to your family.



Use the beginning of this exercise to help you think about what you would like your family mission statement to be. Brainstorm using the questions below. Then, use these same questions as you work together with your family to develop a final mission statement that includes everyone's interests, goals, and hopes for your family.

What does your family aspire to be?

What are your overall goals for your family?

What responsibilities does your family have, to each other, and to others?

What qualities or characteristics are important to your family?

What are your top three goals/dreams for your family?

What are your top three goals/dreams for your children?

How do these responsibilities contribute to your family as a whole?

Your family mission statement should include these sections:



- Definition of your family (who are the members)
- Overall goals for your family
- Qualities/characteristics important to all members of your family
- How you will approach your goals and work as a family to fulfill your mission

Your mission statement can be as specific or as general as you like to be. After you have written it with your family, consider framing it and placing it in a prominent location.

When you have family meetings or discussions with your children, you can reference the mission statement as a guide.

Sample family mission statement:

We are the Jones family: Jessica, Ari, Evan, and Sarah. As a family, we are dedicated to supporting each other and creating a loving, fun, open environment in which to grow and prosper. We work together as a team, supporting each other's dreams. We are strong advocates for people with ASD and all work together to support Evan and create a comfortable environment for him as well as for the rest of the family. We work hard, yet we also play hard, having fun with each other and encouraging each other to pursue hobbies, friends, and interests outside of our family.

Notes

Caregiving and Family

Exercise 2—Explaining ASD to children

All families have different ways and approaches to talking about ASD as it relates to their child. Some of this is due to the characteristics of ASD that are unique to the child, beliefs about causes, and ways that ASD impacts the family. As siblings get older and have friends over or interact with their sibling with ASD at school, peers may have questions about their sibling with ASD. Siblings have grown up with their brother or sister and most often accept and love him or her for exactly who he or she is. They may not have the words to describe what makes their brother or sister a bit different from other peers when kids ask. Use this activity to help siblings and your family find positive, proactive ways to explain ASD to others.



Think about your other children as you do this exercise. If you do not have other children, perhaps think of a niece, nephew, or other child in your life who may need to explain what ASD is to others. Use age-appropriate words that kids would use with each other in your answers.

Begin by completing this exercise on your own, and then complete this exercise with your children.

- Using between 5 and 10 distinct words, describe your child with ASD (for example, smart, quiet, visual). Using these words, combine them into a general description of your child.

For example: Alex is smart and quiet and enjoys drawing robots.

- Now think of some additional words that would describe ASD. Make sure these are appropriate for kids to understand (for example: brain, senses, differences, friends, communication, repetition).



- Create a general description of ASD from these words. For example, someone with ASD senses things such as sights, sounds, and tastes differently. Everyone has something that makes them different from others. Someone with ASD may have trouble talking or saying what they want or need, yet they definitely want to be friends.

Work on this exercise with your other children to help them find their own words to explain what ASD is and how other children can understand their brother or sister.

*****Support Network Opportunity*****

Talk to your support network about how they explain ASD to their other children. What words do they use? How often do they talk about it? How do their other children answer questions from others?

Notes

Caregiving and Family

Exercise 3—Family calendar and activity chart

Yes, please change as follows:



This is a customizable activity that you can think about and plan for now and then complete with your family. It can be a fun and creative project for everyone. Creating one central place that lets every family member know what is going on that day—what appointments you have and what chores can be done—can not only create a schedule for the day, but also prepare your child with ASD for any upcoming activities or events.

Use the following categories to help plan your activity chart:

Materials

You can select

- Posterboard
- Bulletin board
- White board
- Paper
- Markers
- Stickers
- Sticky notes or Post-it® notes
- Magnets

What materials will you use? Are there others that you'd like to use that aren't mentioned?



Types of activities

Your activity chart can be a calendar, chore chart, reminder board, or all of the these. Choose from the options below or make it your own by adding other things.

- Calendar
- Chores
- Reminders
- Appointments
- Birthdays
- Activities

Family members

All of your family members should be represented on your activity chart. Consider the following ways of doing this:

- Color coding (with markers, fonts, Post-it® notes, push pins, etc.)
- Stickers
- Pictures of family member made into stickers

Using the above ideas, decide how you would like your activity board to look. You may have some of the supplies already at home. Gather your supplies and schedule an evening, a weekend, or several nights to work together with your family to customize your board. Add in birthdays, appointments, trips, and anything else you would like to create a useful, organized board. By creating it together, each member of your family will understand what it is, how it works, and be able to update it as new things come up.

Caregiving and Family

Video 3

1. How do you define balance for your family? How do you strive to achieve balance for your family?



2. What type of relationship does your child with ASD have with his or her siblings?



Caregiving and Family

Handout 1—Talking about ASD

Talking about ASD in your family can lead to approachable, open discussions where your other children feel they can ask questions, learn more, and support their sibling better. Consider these tips as you discuss ASD with your children.



- **Early and often.** Talking to siblings about ASD on a regular basis can help them understand their brother or sister with ASD. Start early, using words that siblings can understand. Demystify the symptoms of ASD in your child with ASD and help siblings learn how to develop a good relationship.
- **Age-appropriate.** Explanations of ASD should be relative to the age of the child you are talking to. A very young sibling will not understand a comprehensive explanation of possible causes of ASD. Yet, they will wonder if they can catch it, and the best way of playing with their sibling will be important to them. Teenage siblings will be better prepared for more in-depth explanations.
- **Explanations will change.** Additional information may be needed and explanations may change as siblings get older. The basic point that your child with ASD has differences and that everyone has something different about them may stay the same. As children get older, they can understand more about ASD in relation to the world.
- **Ask siblings.** Siblings may have concerns or questions. Involve them in the discussion, asking for their opinions and finding out what their understanding of their brother or sister with ASD is. Children will surprise you with their insightfulness and ability to accept and understand.
- **Understanding special qualities.** Explaining ASD to siblings is not about making your child with ASD appear different or challenged. It's about helping the sibling understand the unique qualities of ASD to enhance their relationship with their sister or brother. All children—all people—have unique characteristics that make them special. Understanding what each brings to the other's life is important.



Caregiving and Family

Handout 2—Creating a photo book about ASD

You can create your own family's book about ASD. You can use this book to explain to your other children, family, and even friends who your child with ASD is and how to support him or her.



You can do this with pictures and create a type of scrapbook, with handwritten explanations and captions. You can also use an online photo service. A number of services exist that make creating photo books easy and fun.

Steps:

- Gather photos (either digital or hard copy) of your child with ASD and your family.
- Decide which of your child's characteristics you would like to highlight. They might include his or her interests, routines, challenges with foods, ways he communicates, and/or strengths.
- Break your photos up into categories by the characteristics that you've listed.
- For each category, write a simple story to tell readers about your son or daughter with ASD. This may include captions with the pictures or it could be a paragraph explaining his or her favorite activity. It can be as simple or as complex as you would like. You get to use your creativity to put pictures and words together to tell a story about your child with ASD.



Caregiving and Family

Handout 3—Fact sheet

The following information is covered in the Caregiving and Families section of the CFC program.



Parenting partnerships take teamwork and compromise. A complicated juggling act takes place to make sure all of the balls in your life are kept up in the air. Caregivers of children with ASD feel vigilant and of course want to protect their child. As your child begins school, you need to learn to let go and help and support your child gain more independence.

Many autism caregivers mention that autism has brought their family closer; a sense of cohesiveness develops as they all work together to support the child with ASD and create a balanced family life. This does not mean that finding this balance is easy to do. Communication and teamwork are essential. Helping your family become involved in your community and finding family support and activities you can appreciate together can help.

Just as your child with ASD is unique, so are his or her siblings. All children have their own personalities and needs, and each sibling has a different relationship with his or her brother or sister with ASD. Some siblings may act out; they want more attention from you and resent the attention given to their sibling with ASD. Others may take on more of a parenting role, being the defender or protector of their sibling with ASD. Listening to your other children when they express themselves, either through words or actions, and acknowledging their feelings can help them.



Tips and Ideas to Help Caregivers Cope

There are a variety of options to help caregivers nurture their family dynamic. These include:

- Creating a family mission statement to highlight the goals your family has and the qualities and characteristics that are important to guide your family life.
- Discussing ASD in ways that are easy for children to understand, using age-appropriate words to answer questions, and having frequent conversations go a long way.
- Creating a family calendar together with all members of your family can be a fun family project and a creative way to stay organized.
- Talking about ASD on a regular basis with your other children to help them understand and interact with their brother or sister with ASD.
- Producing your own family book about ASD using family pictures and stories to create a photo book to explain ASD to children, other family members, or friends.

Notes

Caregiving and Family

Handout 4—Resources for more information



- *Empowered Autism Parenting: Celebrating and Defending Your Child's Place in the World* by William Stillman
Written by an adult with Asperger syndrome, this book offers parents a different perspective on relating to their child with autism.
- Organized Families: <http://organizedfamilies.com>
This online resource features organization tips for busy families, with resources that can be used by any type of caregiver
- Organization for Autism Research: www.researchautism.org/family/index.asp
This Web site offers support and resources for families and friends of an individual on the autism spectrum.
- Sibling Support Project: www.siblingsupport.org
The Sibling Support Project is dedicated to helping siblings of people with special health or developmental concerns. The Web site offers reading lists, information on local sibling meetings, and online resources for siblings.
- Autism New Jersey, Inc.: www.autismnj.org/SiblingPenPalProgram.aspx
The New Jersey Center for Outreach and Services for the Autism Community (NJCOSAC) to "Autism New Jersey, Inc."
- Photo books
Web sites such as kodakgallery.com, shutterfly.com, or snapfish.com all offer options to easily create a picture book, with text, that can be a great story book about ASD.
- *Playing, Laughing and Learning with Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Carers* by Julia Moor
This book shows how to break down activities into manageable stages, and looks at ways to gain a child's attention and motivation and to build on small achievements.



- *Autism Heroes: Portraits of Families Meeting the Challenge* by Barbara Firestone, Ph.D.

This book is an account of the experiences of 38 families from different walks of life confronting the challenges of ASD with courage, tenacity, and love.

Notes

Caregiving and the Individual with ASD

Exercise 1—Circle of support

A circle of support is a group of people who share a common interest in an individual—in this case your school-age child with ASD. A circle of support can involve a variety of people in the individual with ASD's life, and the main goal is to provide a group of people dedicated to helping the individual with ASD lead a successful, happy life.



What does a circle of support do?

A circle of support can work together with you and your child throughout the years on a variety of topics and needs. Some examples may include:

- IEP meetings
- Setting daily living goals
- Practicing social skills

Who can participate in a circle of support?

Members of a circle of support can vary. The two most important people are you and your child with ASD. It is helpful to have a variety of different types of people on the team. These people may include:

- Family members
- Friends
- Community members
- Individuals who participate in similar activities or share interests with children with ASD
- Professionals who work with teens with ASD
- Teachers
- Spiritual support leaders
- Coaches



By creating and routinely connecting with a circle of support, you gather a dedicated group of people to support you, your child with ASD, and your family. A circle of support can meet regularly and grow with your child as he or she gets older (in-person meetings may work, as well as conference calls or web chats). Having consistent people to encourage and assist your child can be a great help.

Think about this idea of a circle of support and how it might help you and your child using the following questions.

On what types of things could a circle of support advise or provide input for you?

Who would you invite to participate in a circle of support?

In what ways would having additional help support your goals and your child's goals for the future?

How often do you think it would be helpful for the circle of support to meet?

What would be an easy way for all members of the circle to communicate about various topics you need help with?

How would having a consistent group of support benefit you and your child as he or she grows up?

*****Support Network Opportunity*****

Touch base with your support network about this circle of support idea. Have they created a circle of support? In what ways have they used one? How do they anticipate using it in the future?

Caregiving and the Individual with ASD

Exercise 2—Independence journal activity

Encouraging and promoting your child's independence is an important part of being a caregiver. However, it can be difficult to let go and watch your child learn from his or her own experiences. For children with ASD who may need more guidance and support to learn from life experiences, it can be especially challenging to find ways to have more independence as he or she gets older. Use the questions below as a journal activity to think about how you feel about your child growing up and how you can support him or her to be more independent.



How do you feel when you think about your child getting older?

When you think about independence in relation to your child with ASD, what does it mean to you?

What things do you do for your child now that he or she could start learning how to do?

In what areas of his or her life could your child experience more independence?

What do you think the benefits of increased independence in your child's life would be for him or her?

Notes





Caregiving and the Individual with ASD

Exercise 3—Explaining ASD role-play

All children benefit from knowing about their diagnosis. By understanding what their strengths or challenges may be, they can learn more about themselves and their interactions with others. Explaining and providing information about ASD is not appropriate for all children, though. You know your child best and know what will help him or her.



If you do decide to talk to your child about his or her ASD, this exercise may help. It involves a role-play where you will have a discussion with your “child” (another CFC participant) about his or her strengths and challenges. If you are working on this activity outside of the CFC group, consider writing out your response or practicing with a friend or family member.

Scenario:

After a particularly hard day at school, Jeremy comes home very upset. As he tries to explain to his mom, Debra, the kids in his class were teasing him all day about how much he talks about the Civil War. He tried to explain to them the importance of understanding that time in history and its significance to what they were learning in school, which only seemed to make matters worse. Jeremy is very frustrated because he wants to connect with his classmates, but he can't seem to figure out how.

In pairs, take turns role-playing the role of Debra and Jeremy. How would you explain why he has trouble socially at school? What tips can you provide to help him engage with a classmate?



Caregiving and the Individual with ASD

Video 4

1. What has the school experience been like for you and your child with ASD?



2. What issues in your relationship with your child create stress for you? In what ways do you manage this stress?



Caregiving and the Individual with ASD

Handout 1—Community activities

Helping your child get involved in community activities can help him or her meet new people, participate in activities in which he or she is interested, and learn new skills for independence. Community involvement can also give caregivers additional resources for helping your child 1. learn new skills, as well as an opportunity for you to interact with your child, perhaps in new environments with new people. Here are some ideas for getting your child involved in community activities. You may choose to participate in these activities with him or her or do some activities together as a family.



Interest activities

Your child probably has a number of topics or activities that he or she is interested in. Most communities will have opportunities available to support all different kinds of interests. For example, if your child likes music, he or she might enjoy music lessons. If he or she is interested in Egyptian culture, a museum or university might offer a kid-friendly class. Make a list of your child's interests and then do a quick Internet search to see what resources are available in your area to foster these interests. Some ideas for interest activities may include:

- Arts and crafts classes
- Sports, such as swimming
- History or science lectures
- Museum programs
- Pokémon leagues
- Animation or computer classes
- Drama programs
- Gardening class



Volunteer.

Volunteering is a great way for children and their families to get involved in their communities. It can be a way of learning new skills while also participating in an activity or organization that your child enjoys. Search your local community organizations online for possible volunteer opportunities. Your local paper may also offer ideas. You may even just talk to your local community center or an organization that you are involved with to see what opportunities they have available. The organizations listed below often have local volunteer opportunities.

- Habitat for Humanity
- Soup kitchen
- Ronald McDonald House
- Faith organization
- Neighborhood cleanup day
- Animal shelter

Notes

Caregiving and the Individual with ASD

Handout 2—Fact sheet

The following information is covered in the Caregiving and the Individual with ASD section of the CFC program.



It seems like your child just started school, and you already need to be thinking ahead to adolescence and beyond. Starting early with daily living skills, such as hygiene routines and getting dressed, can help them gain important skills and also support their continued independence.

Children who are in school are 1. want or are gaining more independence, which is an important part of growing up. You are your child's best advocate and best support to help him or her find options to become independent in his or her life. By encouraging this independence and supporting your child as the capable and talented individual who he or she is, you're helping him or her to grow into a successful adult. At times though, it can be difficult to allow your child to explore and learn from his or her mistakes; you always want the best for him or her.

Tips and Ideas to Help Caregivers Cope

There are a variety of options to help caregivers who support individuals with ASD. These include:

- Creating a circle of support for your child with ASD with the goal of providing a group of people dedicated to helping your child lead a successful, happy life
- Journaling or writing about your feelings and thoughts as your child gets older
- Finding appropriate ways to explain ASD to help your child understand his or her strengths and challenges
- Helping your child get involved in community activities



Caregiving and the Individual with ASD

Handout 3—Resources for more information



- *1001 Great Ideas for Teaching and Raising Children with Autism or Asperger's* by Ellen Notbohm and Veronica Zysk
This book covers tips, advice, and strategies for raising your child with ASD.
- *The Autism Answer Book: More than 300 of the Top Questions Parents Ask* by William Stillman
Presented in a question-and-answer format, this book provides answers to some of the main questions that parents of children with autism have.
- *Ten Things Every Child with Autism Wishes You Knew* by Ellen Notbohm
This is a short book that highlights the key characteristics of children with autism and how they are special.
- Evaluating Internet Information:
<http://guides.library.jhu.edu/evaluatinginformation>
Johns Hopkins offers a resource to help evaluate information found on the Internet.
- National Dissemination Center for Children with Disabilities (NICHCY):
<http://nichcy.org>
This Web site is a central source of information on disabilities in infants, toddlers, children, and youth; education laws; and research-based information on effective educational practices.
- AutismVision: Creating Classroom Connections: **<http://shop.danya.com>**
Explaining ASD to peers can promote a more welcoming classroom environment for your child with ASD. This video-based intervention can be used to educate peers about what ASD is and how to be a good friend to someone with ASD.
- Indiana Resource Center for Autism (IRCA):
www.iidc.indiana.edu/www2/index.php?pageId=411
IRCA offers information on creating a circle of support for an individual with ASD.



- *Yoga for Children with Autism Spectrum Disorders: A Step-by-Step Guide for Parents and Caregivers* by Dion E. Betts and Stacey W. Betts
This illustrated book offers a range of gentle and fun yoga positions and breathing techniques that are effective in dealing with the increased levels of anxiety, disorientation, and tactile sensitivity often found in children with ASD.
 - *The Unwritten Rules of Social Relationships: Decoding Social Mysteries Through the Unique Perspectives of Autism* by Temple Grandin and Sean Barron
The authors use their colorful life stories to explain the unwritten rules and patterns of social relationships. They create guidelines for living and working with others and illustrate their infinite applications in even the most complex situations.

Notes



Caregiving and Services

Exercise 1—Communicating with teachers role-play

Role-plays can be good ways to practice how you would say something or communicate an important point. Use this exercise to create a situation that you can role-play with a partner.



Scenario, part 1: Your child with ASD comes home from school with a note in his or her backpack from the teacher. The teacher indicates that your child had trouble participating in a classroom activity where classmates in groups of three were acting out a loud scene from a play.

Using the above scenario as a guide, think of a time when your child may have had trouble participating in a classroom activity.

What made the activity difficult for your child?

What environmental factors (e.g., lights, noises, touches) could have made the activity challenging?

What types of activities, in general, may be more challenging for your child in the classroom?

What ways could these types of activities be modified to help include your child and make it a positive experience for him or her?

Notes



Scenario, part 2: The next day, you meet with your child's teacher after school to discuss the note and the classroom activity. You want to be sure to explain what aspects may have been challenging to your child as well as appropriate ways the teacher could modify the activity to encourage your child's participation.

Using your answers to the above questions, role-play with a partner. Take turns being the caregiver and being the teacher. As the caregiver, be sure to emphasize the areas of the activity that may have been challenging for your child and how to modify the activity so your child is included. As the teacher, practice asking the caregiver questions, restating what the caregiver is saying, and using the information the caregiver provides to brainstorm new ways of interacting with children with ASD.

Notes

Caregiving and Services

Exercise 2—Caregiving roles

As a caregiver, you play many different roles in your child's life. You are his or her best advocate, parent, and teacher. Often, with so many roles to juggle as a caregiver and the inherent demands of each, it can be easy not to see all of the incredible skills, talents, and knowledge that you have. Use this exercise to list the roles that you play in your child's life and, with these roles, the different skills and knowledge that you've gained because of them.



1. Make a list of the different roles you play as a caregiver of a child with ASD. These may include parent, teacher, advocate, therapist, doctor, chef, maid, coach, and/or friend. Think of the many roles or labels that describe what you do on a daily basis for and with your child with ASD.



2. Using the roles that you listed in item 1, brainstorm the skills, techniques, talents, and/or knowledge that you have gained from each role. List at least three skills that you've gained with each role.

- a. _____
- b. _____
- c. _____
- d. _____
- e. _____
- f. _____
- g. _____
- h. _____

Example

Role: Advocate

- Communication skills
- Knowledge about ASD-specific laws
- Understanding the IEP system

3. Now, take a look at this incredible list of talents, skills, and knowledge that you have and that you gained as a caregiver of a child with ASD. Give yourself a huge pat on the back for all of the hard work that you do!

*****Support Network Opportunity*****

Discuss with your support network all of the roles that you play as a caregiver. How do you juggle all of these roles and still have time for yourself?

Caregiving and Services

Exercise 3—Resource binder

Creating a resource binder can be a great way to organize all of the information for your child with ASD related to school, interventions, and other services. Think of it as a one-stop resource for all of the information you may need. This resource binder can help you by keeping everything in one place and is easily portable when you need to take paperwork or other information with you.



Your resource binder may include these sections:

- Medical history—specific information and/or paperwork regarding diagnosis, allergies and, other important medical information
- Research—articles, pamphlets and, printouts about the latest news you have found on ASD
- Reports—Results from assessments, interventions, and school reports
- Interventions—homework assignments from providers and, activities or other related items to work on with your child
- Questions—Blank pages to write down questions to ask doctors, teachers, and therapists (and then answers)
- Calendar—a copy of your family calendar to keep track of appointments and important dates
- Contacts—contact information for service providers, teachers and, other important people in your child’s life
- Inspiration—photos of your family, your child, affirmations, quotes, or other encouraging items



Take a moment to think about what sections your resource binder will include. Add as many sections as would be helpful, and list them here:

In what ways would you use a resource binder? How could it help you?

Would it be helpful to create a binder for each member of your family?

On your own, use this exercise to help you create your own resource binder (or binders). Materials that you might need include:

- Large, 3-ring binder
- Page pockets
- Tabs
- Blank paper
- Pens
- Copies of reports, medical history and, other documents

Be sure to personalize your binder with photos, poems, or other sources of inspiration.

Caregiving and Services

Video 5

1. What advice have you found to be useful as you work with the school system?



2. What advice would you give to other caregivers about accessing services for a school-age child with ASD?



Caregiving and Services

Handout 1—Daily report

It can be helpful to get a daily progress report from your child's teacher. Some teachers may have a system they use to give caregivers information about each student's day. If your child's teacher does not, consider talking to him or her about using the brief checklist below to provide you with additional information on your child's school day.



Subject	Successes	Challenges	Notes/Reminders
Language arts			
Social studies			
Physical education			
Math			
Science			
Art			
Lunch			
Recess			
Other			



Caregiving and Services

Handout 2—Advocates

Caregivers are also advocates—they are the best advocates for their child with ASD. Being an advocate can be challenging and frustrating, but it can also be fulfilling. Use this handout as inspiration when you need to advocate for your child and his or her rights. Feel free to also add your own words to describe what an advocate means to you.



An advocate is:

- Strong
- Informed
- Courageous
- Knowledgeable
- Clear
- Committed
- Hard working
- Dedicated
- Supportive
- Understanding
- Friendly
- Mindful
- Steadfast
- Caring
- Loving
- Sharing
- Open
- Active

Notes



Caregiving and Services

Handout 3—Fact sheet

The following information is covered in the Caregiving and Services section of the CFC program.



With a school-age child, you are now interacting with the school system, accessing benefits, and perhaps receiving school-based interventions. It can be overwhelming to feel empowered during this process when you are learning and trying to access new information and learn the system. Caregivers have indicated that knowing the laws, understanding their child's rights, and having a basic understanding of the process for accessing services can help. Yet, it is daunting.

It is always important to remember that you know your child the best and are his or her best advocate. Being put in this advocacy role can feel intimidating and confusing. By getting involved in school, either through school activities, advocacy groups, or working with teachers and administrators, you can become an integral part of the process. You may need to educate your child's teachers and school about your child and his or her unique strengths and challenges. Helping out in school can also help you to get to know your child's peers and other parents, and to become an active part of the school community.

Tips and Ideas to Help Caregivers Cope

There are a variety of options to empower caregivers in maintaining services. These include:

- Educating your child's school, teachers, and peers about what ASD is as it relates to your child.
- Receiving daily feedback from your child's teachers so you understand his or her day, what happened, and how he or she performed.
- Appreciating and acknowledging all that you do as a caregiver. You wear a lot of hats and have a lot of knowledge!
- Developing a resource binder to contain all of the relevant information about the services your child receives. By keeping all of the paperwork and questions in one place, it will help you stay organized.



Caregiving and Services

Handout 4—Resources for more information

- Wrightslaw, www.wrightslaw.com/info/autism.index.htm
Wrightslaw offers a variety of resources on autism; specifically, it can educate caregivers about the rights of parents and children with autism. This resource also offers a lot of information about becoming an advocate for a child with ASD as well as learning about the IEP process.
- National Association for the Education of Young Children (NAEYC), www.naeyc.org
NAEYC offers resources to parents and professionals who care for young children with ASD.
- Autism Speaks, www.autismspeaks.org
Autism Speaks has a special initiative dedicated to helping caregivers and other interested individuals advocate on behalf of children with ASD.
- Autism Society of America (ASA), www.autism-society.org
ASA offers a wealth of resources about services and advocacy for individuals with ASD.
- Organization for Autism Research (OAR), www.researchautism.org
OAR offers a variety of free resources for parents and teachers about autism through their *Life Journey Through Autism* series.
- *Special Needs Advocacy Resource Book: What You Can Do Now to Advocate for Your Child's Education* by Rich Weinfeld and Michelle Davis
This is a Special Needs Advocacy Resource Book for helping and empowering parents to work with the school system to learn about and access resources and services for their child.
- Disability.gov, www.disability.gov
This is a U.S. government Web site that connects the disability community to information and opportunities. Type “autism” or another key word in the search bar to find resources and information.



- The Autistic Self-Advocacy Network (ASAN), www.autisticadvocacy.org
ASAN is a nonprofit organization run by and for people with autism. ASAN's supporters include adults and youth with autism, cross-disability advocates, family members, professionals, educators, and friends. ASAN was created to provide support and services to individuals on the autism spectrum while working to change public perception and combat misinformation by educating communities about persons on the autism spectrum.
- Georgetown University's Maternal and Child Health Library,
www.mchlibrary.info/KnowledgePaths/kp_autism.html
This Web site offers a variety of information and resources to help you advocate for your child and learn about updated research and information about autism.
- Autism Today, www.autismtoday.com/classifieds/classifieds.htm
This Web site offers a resource directory of professionals, organizations, events, and more related to autism.

Notes

Caregiving and Finances

Exercise 1—Financial planning questions

Financial planning is an important activity to begin when your child (or children) are young. Planning for your and your child's financial future can be overwhelming without the proper information and tools. Use the questions below to think about what financial planning resources you have and what questions you have. The resources section has additional information on finding financial planning resources.



1. What types of financial planning activities do you already do (savings account, 401(k), etc.)?

2. What types of financial planning options would you like to learn more about (e.g., special needs trust,)?

3. What questions do you have about planning for your child with ASD's financial future?



4. Who, in your life right now, could you talk to about your financial planning questions (other caregivers, family members, advocates)?

5. What three action items can you set right now to move forward with financial planning?

a. _____

b. _____

c. _____

6. What types of support or information do you need to achieve these action items?

*****Support Network Opportunity*****

Financial planning can feel overwhelming when you first start out. Talk to your support network about what they have done, who they have used, and what types of planning options they've explored to learn more.

Caregiving and Finances

Exercise 2—Fun and affordable activities

Finding fun, affordable, and accessible activities for you and your family to do can be really challenging. As a group, let's discuss the types of activities that you each do with your families. In this way, we can get ideas from each other about great activities to do at home or in our local area.



Take a moment to think about these questions and maybe write down a few answers. Then we will share our ideas as a group.

What types of activities does your family like to do together?

Where do you go in the community for different family activities?

Have you found free or low-cost activities in the area that are fun for your family? If so, what are they?



How do you afford family activities?

How do you get ideas for new activities?

*****Support Network Opportunity*****

This is a great activity to do with your support network. Pose these questions to other caregivers (maybe even on the Caregiver Community Web site) and get even more ideas.

Notes

Caregiving and Finances

Exercise 3—Thoughts about money

Money and finances may add significant stress to your life, especially when you are caring for an individual with ASD who requires many specialized services and resources. Sometimes, attitudes or beliefs about money add to the stress associated with it.



Take a few minutes to answer the following questions:

When you were a child, what did your parents teach you about money?

What do you think of people who have a lot of money?

If you won the lottery, what would you do with the money?



Does money bring happiness? Why or why not?

What do you think about money? Is it good or bad?

What would change your views on your financial situation?

How could you look at your finances differently?

After you finish answering the questions for yourself, consider asking your spouse or significant other to answer them, and then discuss your answers and your thoughts about money together to better understand each other's perspectives.

Caregiving and Finances

Video 6

1. What approaches have you used to try to alleviate financial challenges?

2. What types of activities does your family enjoy that are easy to access and relatively low cost?



Caregiving and Finances

Handout 1—Special needs trust

It can be helpful as you begin or prepare for future financial planning to establish a special needs trust. This handout does not give a full account of what a special needs trust is or how to establish one. It is intended to give a general overview to help you think about your child's financial planning needs.



What is a special needs trust?

- A way to provide financial support to your child when he or she is older
- A method of providing financial support that helps your child remain eligible for other government benefits
- Provides money to provide for your child's supplemental or extra needs
- A person is appointed a trustee to the special needs trust to administer the money

Who establishes a special needs trust?

- Caregivers should work with an experienced lawyer who is familiar with estate planning for individuals with disabilities.
- There are many technicalities when establishing and using a special needs trust. It is important to create it and use it correctly so your child retains all of his or her other benefits.

How do I put funds into a trust?

- Funds for a special needs trust can come from a number of resources, such as stocks, mutual funds, IRA, 401(k), real estate, home equity, life insurance, and others.
- A financial planner can help guide and organize funds for a trust.



Caregiving and Finances

Handout 2— Saving game

There are a lot of different ways to save money. Any little bit of change can add up. Consider the follow options to start a “saving game” with your family. Making saving a family activity can be fun, especially when some of the funds go toward extra family activities.



- Commit to setting aside a certain amount of money each week in a savings account.
- Set up savings accounts for each family member. See who can save the most money.
- Set a jar next to the washing machine. All of the coins from pockets will go into the jar.
- Place a piggy bank or jar in a prominent location in your home. Ask that any spare change be put into the jar by all family members.
- Make one night a week a “savings” night. Rather than going out, recreate an “out on the town” experience at home. Have a movie night and make popcorn together. Put the money that you would have spent going out in your savings jar or account.
- Have a family yard sale. Contribute the money you earn to your savings account.
- Cut coupons together out of the weekend paper. See who can save the most money on groceries.
- Go to the library—save the money you would have spent on purchasing a book. You can do the same thing with DVDs—many libraries have great DVD selections.
- Pack school lunches.
- Stick to just the items on your grocery list.
- Make handmade gifts for your family.



Caregiving and Finances

Handout 3—Fact sheet

The following information is covered in the Caregiving and Finances section of the CFC program for caregivers of school-age children with ASD.



Money is a difficult subject for many people. There are financial planning options available to help you, and accessing services or information through the school or your community may be an option. For many caregivers though, it can be a challenge to balance a job, with paying for services that aren't covered by insurance, and feeling like they are providing all of the different types of services that their child needs.

Now is also the time to begin thinking about and planning for your child's financial future. It can be hard to even think about your child being an adult and what types of resources he or she might need. By being prepared, planning early, and laying the groundwork for a solid financial future, you can make this process much more manageable and successful in the long run for your child's future.

Tips and Ideas to Help Caregivers Cope

There are a variety of options to empower caregivers in relation to financial planning. These include:

- Figuring out what questions you have about financial planning and finding multiple contacts to talk to about your questions.
- Taking inventory of the types of savings options that you have available to you.
- Setting easy to achieve tasks related to financial planning to get you started.
- Working with reputable and experienced financial planners with knowledge of the needs of families of children with disabilities.
- Finding fun, affordable, and accessible activities for your whole family to enjoy.
- Understanding how your thoughts about money may create stress.
- Developing, as a family, fun and easy ways to save money together.



Caregiving and Finances

Handout 4—Resources for more information



- Household Planning worksheet: www.kiplinger.com/tools/budget/
A budget planning worksheet
- *How to be the Family CFO: 4 Simple Steps to Put Your Financial House in Order* by Kim Snider
This book explains personal finances in an easy-to-use-way that will help you plan and save for your family's needs.
- *First Comes Love. Then Comes Money. A Couple's Guide to Financial Communication* by Bethany and Scot Palmer.
This is a book on communicating about money and achieving financial goals.
- Coupons: www.coupons.com
This Web site offers a lot of great ways to save money.
- Easter Seals and Autism: www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles
Visit this Web site for state information on autism demographics and state insurance coverage of autism.
- Wrightslaw: www.wrightslaw.com
This Web site offers a variety of information and resources to learn more about special needs trusts and other financial planning options for your child's future

SSDI and Autism Waivers

- Supplementary Security Income (SSI): www.ssa.gov/ssi/
This U.S. government Web site is a handy site for finding helpful information about SSI payments for children with disabilities.
- U.S. Social Security Administration: www.socialsecurity.gov and www.socialsecurity.gov/pgm/links_disability.htm



- Access these U.S. government Web sites to find helpful information about Social Security Disability Insurance (SSDI) benefits for adults disabled since childhood.
 - Social Security Online: www.ssa.gov/disability/
This is a U.S. government Web site with forms and information about SSDI and SSI.

Notes



For more educational products and programs, visit www.autismonline.com. AutismOnline is the only Web site of its kind devoted to providing research-based, effective, high-quality resources, products, and information on autism, across the lifespan. The mission of AutismOnline is to provide helpful products for all individuals affected by autism, including individuals with autism, caregivers, advocates, teachers, and professionals. AutismOnline is a unique and extensive resource for the autism community.



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