Caregiver's Workbook

Caring for Caregivers

For Groups of Caregivers of Adolescents and
Young Adults with Autism Spectrum Disorders

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Introduction

Welcome

Welcome to the Caring for Caregivers' (CFC) Caregiver Workbook. This workbook has been designed to coordinate with the CFC program and 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 there are so many exercises, there will not be time to finish them all. All of these exercises and handouts can also be used at home in your own time. Flip through and see what 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 over again. 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, 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 CFC Caregiver Connection 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—Time for yourself

To be a successful caregiver, it is essential to make time for yourself to recharge your batteries and have some fun. Not only will this make you feel good, but it will also show your family and others that ASD does not run your life. Take charge, have some fun, and do something for yourself.

Complete the following questions quickly, without thinking too much about your answers. There are no right or wrong answers, just list whatever makes you feel good and would be fun for you to do.

1. When you were a child, what did you do for fun? List five activities that you loved as a child.

    a. ________________________________
    b. ________________________________
    c. ________________________________
    d. ________________________________
    e. ________________________________

2. If you had unlimited time and energy, what would you do with it? List at least five activities.

    a. ________________________________
    b. ________________________________
    c. ________________________________
    d. ________________________________
    e. ________________________________

3. What are 10 things you enjoy doing (even if you haven't done them in a while)?

a. ______	f. ______
b. ______	g. ______
c. ______	h. ______
d. ______	i. ______
e. ______	j. ______

4. What are five activities or hobbies you've never tried that sound like they would be fun?

   a. ______

   b. ______

   c. ______

   d. ______

   e. ______

5. Complete this sentence 10 times:

   I want to______.

Now, look back on each of these completed questions. Do they have anything in common? Are there any activities you listed more than once? Does anything jump out at you? Can you imagine doing any of these hobbies or activities? In the next week, pick one of these activities—just one—and set aside at least 30 minutes to do it. Decide now when those 30 minutes will be (date, time) and write it here:

Date:______

Time:______

On a separate piece of paper, post this activity in a central location as a reminder.

You can read more about it, actually start doing it, or make a plan, but those 30 minutes are all yours, and you should have no distractions and make no excuses. It is so important to make time for yourself. In the weeks that follow, try to build up the number of 30-minute time blocks where you are engaged in activities like those you listed. Set an ultimate goal of three times a week. You can do it!

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

This is a great opportunity to lend encouragement and support to the members of your network. E-mail the group after you have completed this activity. Discuss how it went, what you did, and how you felt after completing it. Your actions will provide encouragement to others.

Caregiving and Emotions

Exercise 2—Time management

The objective of this exercise is to have you think about your weekly schedules and then add in elements to help balance your lives. The goal is to have you add three things each week that give you more balance and are at least 30 minutes long. These three things should be related to yourself (hobbies, activities, downtime), your spouse or partner, and/or your family as a whole (activities everyone can participate in).

Take a moment to complete the weekly calendar on the other side of this page, filling in any relevant time commitments, such as work, appointments, treatments, and other scheduled activities. Look at your week. Do you see any moments when you could make time for yourself, your spouse or partner, and your family?

Now review this calendar again, adding in specific times when you plan to do one activity just for yourself, one for relationship time, and another for family time. Simply having these activities on your schedule will increase the likelihood that they occur. Try not to let another activity or commitment push your scheduled activity to another day; it likely will not get done then. You are an important person and must take care of yourself. Post this schedule in a prominent place as a reminder.

*****Support Network Opportunity*****
E-mail your network and let the members know how this activity is going for you. If you are having trouble scheduling time for yourself, get the network involved in brainstorming. A little encouragement goes a long way.

Scheduling Time for Self

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
6–7 a.m.							
7–8 a.m.							
8–9 a.m.							
9–10 a.m.							
10–11 a.m.							
11 a.m.–12 p.m.							
12–1 p.m.							
1–2 p.m.							
2–3 p.m.							
3–4 p.m.							
4–5 p.m.							
5–6 p.m.							
6–7 p.m.							
7–8 p.m.							
8–9 p.m.							
9–10 p.m.							

Caregiving and Emotions

Exercise 3–Relaxation techniques

Progressive Muscle Relaxation

If you find yourself in a stressful situation or are just feeling overwhelmed, the following technique(s) can help you relax. This exercise can last from 5–20 minutes, depending on your schedule. It's an easy-to-use technique that you can do anywhere.

Step 1: Sit in a comfortable position.

Step 2: Starting with your toes, relax all of your muscles. Envision your toe muscles relaxing, then your feet, then your heels, then your calves. Keep working your way up to the top of your head. Next, your knees and then your thighs relax. Your hips release tension and find more space. Then, focus on your abdomen and lower back, feeling ease seep into those muscles. Your chest and upper back then melt and open up more. Now, up to your shoulders, which sink down away from your ears. Your arm muscles let go of your arm bones, gently, to bring ease to your arms and then fingers. Bring your awareness now to your neck, and gently let go of tension here, inviting in space and relaxation. Moving up to your face, feel your facial muscles relax, with your eyebrows melting away from each other and any lines in your forehead smoothing out. Finally, move your attention to the top of your head and feel your scalp loosen and expand as tension seeps away.

Scan your whole body, inviting in relaxation, ease, peace, and letting go and releasing tension.

Step 3: Now, bring your awareness just to your breathing. Breathe naturally and fully. If random thoughts enter your mind, visualize them floating away. You can also think of a word, silently to yourself, as you breathe out, such as peace, calm, or any word that makes you feel peaceful.

Step 4: Continue this relaxation technique for 5–20 minutes.

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

Check in with your support network on this relaxation technique. How is it going for you? When have you used it? Did it help? Did you modify it in any way that made it more useful?

This relaxation technique is based on *The Relaxation Response* by Dr. Herbert Benson.

Belly Breathing

Another type of relaxation technique is focusing on your breath. This is a skill that can come in handy during stressful moments at work or just when you need a few minutes of silence. Focusing on your breath can help reduce anxiety and calm the mind. This exercise can last from 1–10 minutes and can be done anywhere.

Step 1: Sit or lie down 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.

Step 4: Then, 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 this area below your ribs.

Step 5: Continue breathing in this way for up to 10 minutes. When you are done, bring your awareness back to your breath at your nostrils. Sit for a few moments.

Caregiving and Emotions

Video 1

1. What fears or worries do you have related to having a teen or young adult with ASD?

2. Are the worries expressed by the caregivers in the video similar to your own (concerns about future, independence, accessing services when individual with ASD is an adult)? Why or why not?

3. What types of things (services, characteristics of teen or young adult, progress) give you hope for your teen/young adult's future?

Caregiving and Emotions

Handout 1—Exercise

If it's been a while since you've 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
- Scrapbook—this is a positive way to acknowledge your adolescent's or young adult'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

- Reconnecting with your sense of self
- 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
- Relaxation

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

Notes

Caregiving and Emotions

Handout 2—Web site

The Caregiver Community Web site has been created with you in mind. Ongoing guidance and support is essential in the life of a caregiver. The goal of the Caregiver Community Web site is to provide caregivers of individuals with autism with an opportunity to connect with each other, share ideas, and receive support and guidance from peers with experience.

The Caregiver Community Web site includes:

- Information and resources for coping with stress related to caregiving
- Tailored discussion areas on topics relevant to the lifespan of autism
- Shared documents to provide caregivers with a system to keep track of and share important documents related to caregiving
- Links to more information and resources

The Caregiver Community Web site is free and open to anyone with access to the Internet. The tailored discussion areas will require you to register and log into the Web site for each visit. In addition, there will be a secure discussion area on the Web site specifically for caregivers who participate in CFC support groups. In this way, you can continue to interact with and support members of your group online.

To begin using Caregiver Community:

- Go to **www.autismcaregiver.com**
- Click on a tab that interests you on the side bar
- Register in order to participate in the discussion area
- Visit often to review resources and connect with other caregivers

Caregiving and Emotions

Handout 3—Fact sheet

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

Caregivers encounter a variety of challenges and emotions as they navigate the teen and young adult years of the individual with ASD. It is often helpful to recognize these experiences, know that other caregivers have gone through similar things, and apply skills and/or solutions to help cope.

Guilt

Some caregivers of teens and young adults may struggle with feelings of guilt. This emotion may be caused by feeling that they:

- Are not doing enough for their teen or young adult to get transition-related services and supports
- Do not have the time, resources, or support to best help their teen or young adult
- Struggle to maintain daily family life and care for an adolescent or young adult with ASD

Grief and Sadness

Grief and sadness may occur at unexpected times, such as when a teen misses certain adolescent milestones like the prom or when a caregiver's vision of their adolescent's high school years does not meet his or her expectations.

Exhaustion

Caregivers often experience considerable physical and emotional demands that can make them exhausted, both physically and mentally.

Tips and Ideas to Help Caregivers Cope

There are a variety of options to help caregivers cope with stressful feelings and challenges. Here are some ideas:

- Find one activity that is fun or a hobby to do at least once a week.
- Develop a weekly schedule for the family and be sure to schedule time for yourself.
- Talk to other caregivers about how they are feeling.
- Exercise.
- Start a journal to write down thoughts and experiences.
- Practice deep-breathing exercises or other relaxation techniques.

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Caregiving and Emotions

Handout 4—Tips on time management

The following tips may be useful as you organize your weekly or daily schedule to help accommodate balance in your busy life.

Tips on Time Management

- Your day is not just about getting things done and moving on to the next activity. Be mindful of every moment and appreciate each activity or appointment as you do it. This will keep you in the moment and reduce any anxiety about the rest of your day.
- Find something good about whatever you are doing.
- If you have two conflicting activities scheduled for the same time, prioritize. Which is more important? Which one will you and/or your family and/or your adolescent or young adult get more out of?
- Keep your calendar handy when you are not at home.
- At the beginning of each week, make a list of three to five goals for the week. These could include things such as spending 30 minutes reading, taking the kids to the park, or reviewing the calendar with your spouse or partner. Put these goals on your planning calendar, and then post them somewhere where you'll see them often.
- Delegate. Ask others to help you with specific day-to-day chores. For example, your teen or young adult with ASD may like to wash dishes. Find something specific he or she can help with. Make sure your other children have chores too. Then reward everyone for a job well done. If you have a spouse or partner, ask them for help, too. Planning ahead can help everyone prepare for their chores instead of feeling as if they were thrust on them when they had other plans for their time.
- Make a monthly calendar and post it where all the members of your family can see it. Plan one time a month to go over the calendar, asking all members of the family to add one or two specific things they would like to do.

- Take tasks one at a time.
- Prioritize tasks.
- Set deadlines for yourself, if applicable, and put them on your calendar.
- Set reasonable goals for your week. Remember, you are only one person. If you don’t think another person in your shoes could get it all done, then you probably shouldn’t expect it of yourself.

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Caregiving and Emotions

Handout 5—Resources for more information

Time Management

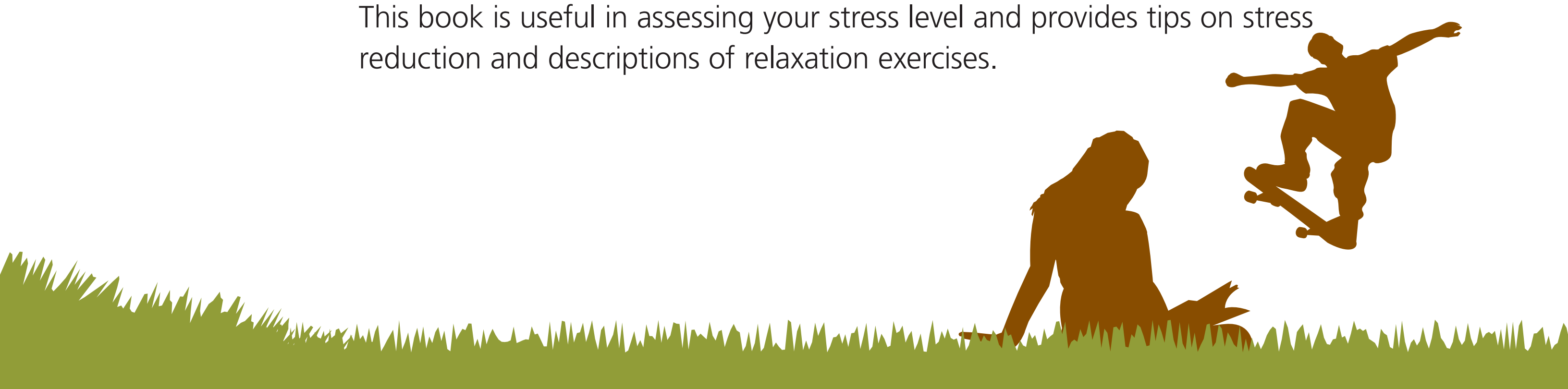
- *The Organized Parent: 365 Simple Solutions to Managing Your Home, Your Time, and Your Family's Life* by Christina Baglivi Tinglof
  This book offers tips and advice on managing and organizing your home and family life. It is written with all families in mind.
- Organized Families: **http://organizedfamilies.com**
  This online resource features organization tips for busy families, with resources that can be used by any type of caregiver.

Interests

- Quizilla: **www.quizilla.com**
  This fun Web site offers quizzes on just about everything. Take a quiz just for fun or find one on hobbies to get some ideas of activities you might enjoy.
- *The Artist's Way* by Julia Cameron
  This book provides many activities and ideas for finding things that you enjoy while also encouraging you to reconnect with yourself and your creativity.

Relaxation

- Local Yoga studios: **www.yogafinder.com**
  Use this link to search for a yoga studio in your area for trying yoga for relaxation.
- *Guided Mindfulness Meditation* by Jon Kabat-Zinn
  This audio CD, from the founder of the renowned Stress Reduction Clinic, offers tools to help deal with stress and promote awareness and clarity.
- *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.



Support

- Caregiver Community: **www.autismcaregiver.com**
  This Web site is dedicated to connecting caregivers with each other and providing resources throughout the lifespan of ASD.
- Autism Society of America: **www.autism-society.org**
  In addition to online resources, the Autism Society of America has local chapters throughout the United States that offer information and support to caregivers. You can find a local chapter through their Web site.
- AutismWeb: **www.autismweb.com**
  AutismWeb is a Web site created by parents for parents. It offers a message board to connect with other caregivers, ask questions, and find resources.
- Online Asperger Syndrome Information and Support (OASIS): **www.aspergersyndrome.org**
  OASIS offers resources for families such as articles, links to local and national support groups, and a moderated message board to connect with caregivers.

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Caregiving and Relationships

Exercise 1—Connecting with others

Having people in your life to talk to, laugh and have fun with can lift your spirits, give you something to look forward to, and provide you with friendships and support during challenging times. Often, caregivers of adolescents or young adults with ASD feel isolated from other parents or do not have time to nurture friendships.

Use this worksheet to think of ways to connect with people, such as other caregivers, friends, and community members. Finding an activity that you enjoy that also helps you to meet people can be one option. Or you may choose to cultivate relationships that you already have, but have not made time for. This worksheet can be a springboard of ideas for finding connections to others in your life.

Activities

Make a list of the types of activities that you enjoy doing.

Of these activities, which ones are done with other people? Which ones could be done with other people?

Places

Make a list of the types of places that you visit on a weekly basis.

Do you see some of the same people each week at these places? Could you connect with someone there? Could a friend join you in any of these places?

People

Make a list of friends who you've met or spoken with in the last couple of years.

Are there any friends who you've lost touch with? Who could you connect with again?

Caregiving and Relationships

Exercise 2—Relationship communication skills

Elements of Good Communication In Relationships

- **Be clear.** Your partner cannot read your mind. When you have a problem or need help, be up front and open so you can work as a team to find a solution. If an issue is important to you but maybe is not as important for your partner, make sure he or she understands its importance. Speak up.
- **Listen actively.** Let your partner talk, and make sure you understand what he or she is saying. Do not interrupt. If something doesn't make sense, ask for clarification. Repeat or paraphrase what he or she has said to confirm your understanding and show that you were listening carefully. ("So, I hear you saying that you are overwhelmed and would like some help cooking meals.")
- **Express your feelings, not your judgments.** If you feel sad when your partner does not remember your birthday, express it. ("It makes me sad when you do not remember my birthday.") Judgments cloud effective communication and result in hurt feelings and communication blocks. Refrain from statements such as: "I think you are a jerk for not remembering my birthday."
- **Avoid absolutes.** When discussing issues with your partner, try to avoid the words always and never.
- **Use "I" statements.** Express how you feel instead of focusing on what your partner has done. Instead of: "You are always late for dinner," try: "I feel hurt when you arrive home late for dinner."
- **Take a timeout.** If you or your partner need a break or some time to regroup to avoid getting angry or frustrated, it is okay to take a timeout. This will give each of you time to clear your head. Specify when you'd like to resume your conversation.

- **Ask questions.** If you do not understand your partner's point of view, ask. Make sure you are clear on what he or she has to say.
- **Reach closure.** At the end of your conversation, summarize what you have talked about and make sure you and your spouse are on the same page. Check in on how you are both feeling.
- **Follow up.** Check in with each other after a few days to see how things are going and whether you need to talk about anything else.

Activity

Discuss with the group how you might approach the following scenarios using the communication skills we have discussed.

1. You and your significant other have been planning a date night for over a month. When the night arrives, he or she is too tired to go out and would just like to go to bed early.
2. You have a busy week ahead of you at work and need help getting the kids to their appointments.
3. You would like to enroll your child with ASD in a special afterschool program. Your spouse thinks it would be too much for the child and that it costs too much.
4. Extended family members are planning a visit and want to stay with you. You would prefer they stay at a hotel to keep in your normal family routine.
5. With your schedules, you and your significant other haven't really talked in more than a week. You keep passing each other as you go to the kids' activities.

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Caregiving and Relationships

Exercise 3—Relationship inventory

Pick a person in your life. You may choose your husband or wife, a friend, a neighbor, another caregiver, or family member. On the Inventory template provided on the following page, write down 10–20 things you like and respect about this person. These might be individual qualities that make him or her a good friend, funny memories, or ways that he or she has supported you. The goal of this inventory is to help remind yourself of of why this person is important to you and what he or she brings to your life. After completing this activity for one person, you may choose another two or three people to do an inventory on.

After writing down your inventory, you may wish to use it in the following suggested ways:

- Write a note to the person using a few of the qualities that you listed and thank him or her for being in your life.
- Invite the person out for coffee and share a few of your insights about your relationship.
- Post your inventory on a bulletin board or in a place you will see it.

Template for Relationship Inventory

Individual's Name:

Qualities that I like and respect about this person:

Characteristics about this person for which I am grateful:

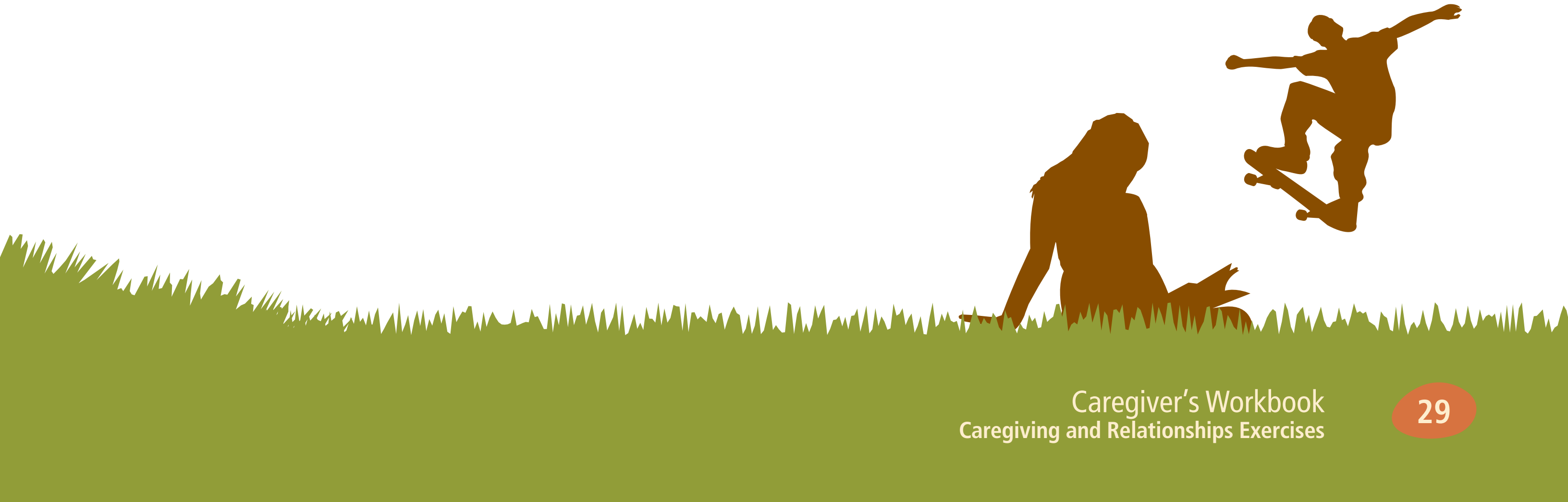
Caregiving and Relationships

Video 2

1. What types of things do you do to keep your marriage/partnership/relationships healthy and strong?

2. How has your extended family supported you and your teen or young adult with ASD? How have you helped them to get to know your teen's or young adult's interests or ways they could support your teen or young adult?

3. If your extended family has not been involved, how have other relationships supported you?



4. What roles do other caregivers of individuals with ASD play in your life?

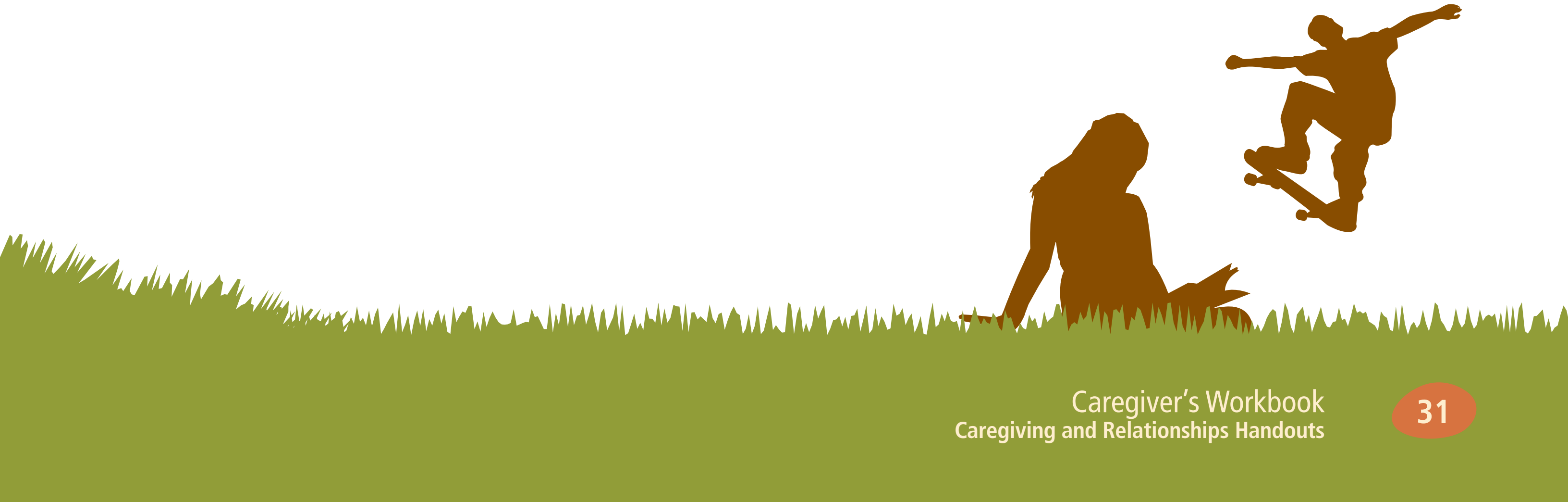
Notes

Caregiving and Relationships

Handout 1—Relationships

Relationships with friends, a partner, a spouse, or the community can create a foundation of support for you as a caregiver. Relationships provide you with outlets to talk, laugh, share, and receive help along the way. Time constraints, stress, and lack of communication are just of the some circumstances that can hinder relationships. This handout provides some ideas for maintaining and strengthening the relationships in your life.

- **Gift of intention.** Doing something nice for another person with no strings attached can bolster your feelings of gratitude for the relationship in your life and create a positive atmosphere for this relationship. The purpose is not to buy an expensive gift, but rather to do something with an intention, such as an intention of love, gratitude, respect, or offering. You might cook dinner for a friend, or you could pick some wildflowers for your partner. You might drive a friend to the airport. The goal is to do something for another person in your life with the intention of supporting them.
- **Making time.** The gift of time can be a big boost to relationships. Even 15 minutes spent with a member of your community can give you time to check in and talk. Look at your schedule and find a time (any length, from 15 minutes to an hour) to spend with someone in your life. You might choose to go for coffee or maybe take a walk. Spending time together is an important way to maintain relationships.
- **Check in.** Sometimes it is difficult to find time to spend with the important people in your life. At work, when you have something important to discuss, you schedule a meeting. Why not do the same for your relationships? Try scheduling a time with your spouse or a friend to check in. In this way, you have a definitive time to talk and catch up on important things.



- **Joint activities.** You lead a busy life and are probably on the go a lot. By inviting a friend or partner along with you to run errands, cook dinner, or garden, you can spend time together while also accomplishing something that will support you in your daily life.
- **Meal time.** Everyone needs to eat, so why not enjoy a meal together? Evening activities can often make dinners together difficult. Try scheduling at least one meal a day to eat together with your family. If it can't be dinner, try for breakfast or lunch, or even have dessert together. You may like to invite a friend over, too. You could even make it a small potluck dinner. The goal is not for you to cook a fancy meal, but to enjoy a meal and time together.
- **Time alone.** Time spent on your own, giving yourself some space and rest, can really help to rejuvenate and restore you and your relationships. It gives you time for yourself and can help you to appreciate the relationships in your life even more.

Notes

Caregiving and Relationships

Handout 2—Fact sheet

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

All relationships take time and energy to keep them healthy and cohesive. Unfortunately, caregivers of teens and young adults with ASD may find that they have limited time and resources to give to relationships, however much they would like to.

Marital/Partnership Relationships

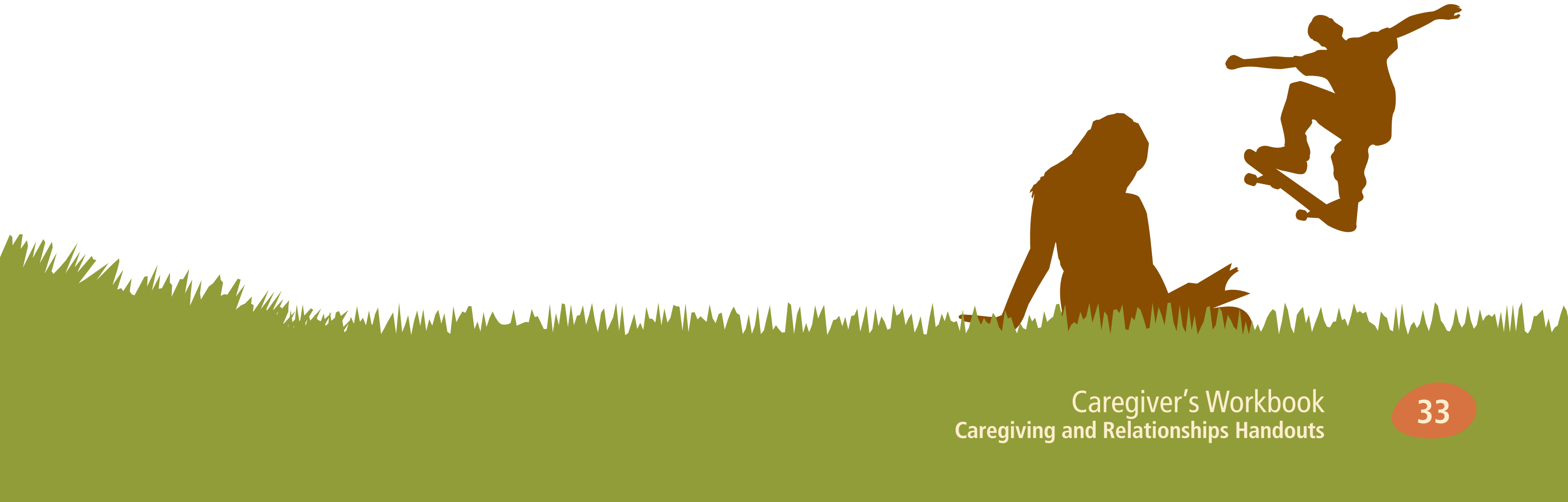
Marriages and partnerships can thrive by setting aside some time, even 15 minutes, to sit and connect with one another. Just as fixing your child dinner is important to support your child and his or her growth, time to connect and be with your significant other is just as important, for both you and your child.

Relationships with Friends and Social Support

It can be difficult to see other parents, with a child the same age as yours, running to soccer games and dances, while you run your teen to appointments or therapy. Having friends and a support system in your life can give you people to talk to, help you find balance in your life, and allow you to have some fun.There are ways to connect with others, especially other caregivers of teens or young adults with ASD.

Relationships with Extended Family

Some caregivers find that their extended family is incredibly supportive and understands the unique needs of their son or daughter. Other caregivers may have trouble connecting with extended family members or their relationships may be strained.



Tips and Ideas to Help Caregivers Cope

There are a variety of options to help caregivers cope with relationship challenges. Here are some ideas:

- Set aside a time, each week, for just you and your partner.
- Find activities that you enjoy, and invite your partner or friends along.
- Connect with other caregivers, either online or through local support organizations.
- Practice open communication skills in order to effectively communicate your needs and desires with others.
- Give thanks for the people who support you.
- Check in with the important people in your life. Let them know how you're doing and find out how they are doing.

Notes

Caregiving and Relationships

Handout 3—Resources for more information

Marital/Partnership Relationships

- Respite Services:
  www.iidc.indiana.edu/index.php?pageId=552
  This link offers more information on how to access respite services so that you and your partner can have time together.
- 29 Day Giving Challenge: **www.29gifts.org**
  Take the challenge from this organization of offering gifts to the person you love for 29 days. Gifts can be acts of kindness, tokens of love, spoken words. The goal is to open yourself up to all of the good things in your life. Maybe take the challenge together!
- *I Hear You, But…Over 101 Effective Communication and Active Listening Skills and Tips* 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.

Relationships with Friends and Social Support

- Facebook: **www.facebook.com**
  Connect with old and new friends through this popular social networking site. Join groups especially for caregivers of individuals with ASD.
- Caregiver Community: **www.autismcaregiver.com**
  Connect with other caregivers of teens and young adults with ASD on this interactive Web site.
- Volunteer: **www.serve.gov**
  Volunteer your time to a local organization dedicated to individuals with ASD and their families. In addition to giving to your community, you may meet and connect with other caregivers of individuals with ASD.

Relationships with Extended Family

- Organization for Autism Research: **www.researchautism.org**
  The Organization for Autism Research offers links and information specifically to help family and friends understand ASD.

Notes

Caregiving and Family

Exercise 1—Role-play

Scenario: *Your 14-year-old son, Sam comes home after school, and you can tell he is angry and upset. You ask what is wrong, and he blows up. Apparently, his friends had asked if they could come over and play video games on his new Xbox. Sam knew that after school his brother Mike (who has ASD) always plays on the Xbox and that Mike gets very agitated and upset if he cannot. Sam is mad that he doesn't have a "normal" brother and that he can't have his friends over after school.*

Role-play this scenario in the group. Then discuss the following questions.

Discussion questions.

How would you explain to Sam why Mike needs to play on the Xbox after school?

What alternatives can you give Sam so he can have his friends over?

What activities can Sam do to connect more with his brother?

Notes

Caregiving and Family

Exercise 2—Vignette

Scenario: *Tasha (or Ramon) just got home from a long day at work and needs to make dinner. Her (his) 12-year-old daughter comes into the kitchen needing help with her homework, while at the same time, her (his) 15-year-old son with ASD enters the kitchen and wants a snack. The phone starts ringing, a pot of water boils over on the stove, and the dog starts barking.*

Discussion questions.

What is Tasha/Ramon feeling?

How should Tasha/Ramon respond to this situation?

What are ways to address the needs of both the daughter and the son?

What suggestions do you have to help Tasha/Ramon keep peace of mind during these types of interactions (count to 5, take deep breaths)?

Notes

Caregiving and Family

Exercise 3—Family activities

Activities done as a family are an important aspect of family life, but they can be challenging when you have an adolescent or young adult with ASD. The goal of this exercise is to brainstorm different activities that would be fun for your family as well as find potential ways to make the activities easier for everyone.

You can answer the following questions in the group. It is important to do this activity with your family. After some initial brainstorming, please take these questions home and set aside an hour of time for all of your family members (including your adolescent or young adult with ASD in the group) to come up with more ideas and solutions.

In the past, what have been some fun family activities?

Currently, what are some activities you do as a family?

What would you like to do as a family? (Write the list of potential activities down on paper.)

If an activity might be difficult for the adolescent or young adult with ASD, what are some ways your family could make it easier? Could you modify the activity in some way?

Once you have made a list, pick one or more activities and schedule a time to do them with your family. Make sure everyone has them on the schedule (you might even consider putting them on the schedule from the exercise on page 24). In the days or weeks leading up to the activity, create some excitement around it. Prepare the teen or young adult with ASD for it. You also can do this as a family. For instance, if you are planning to go out to a restaurant, designate one evening's dinner at home as a practice run. When you have your normal family dinner, have everyone pretend to be at a restaurant. Have a sibling act as a waiter, maybe have the radio on, and set the table a bit differently than usual. Discuss the typical restaurant experience with your adolescent or young adult with ASD.

Ideas

Here are some ideas for fun family activities:

- Go to the movies or have a movie night at home
- Go to the park
- Go to a museum
- Play a board game
- Have a craft night
- Take a bike ride
- Play hide and seek

Be creative. Your family activity does not need to be extravagant or expensive. The key is to spend time together.

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

E-mail your support network about this activity. How did it go? Did you discuss activities with your family? What did you end up doing? How did it make everyone feel? What activities do you have planned for the future?

Caregiving and Family

Video 3

1. The Good family mentions that Mrs. Good is in charge of the interventions and services that their son receives, and Mr. Good provides the financial stability for the family. What roles do you and your partner have? How do you find balance in these roles so you are both involved and informed?

2. Differences in opinion and stressful relationships between parents or other family members can be extremely challenging when supporting an individual with ASD. How do you navigate challenging relationships in your life?

3. What roles do your other children have in relation to their sibling with ASD? What things do you do to support your other children?

Caregiving and Family

Handout 1—Teamwork

It is common for caregivers to find effective ways to manage all of their day-to-day responsibilities. In two-parent households, one caregiver may take on the tasks of figuring out how to help their teen transition out of high school, while the other caregiver may focus more on helping the siblings. Single parents may take on all of these tasks themselves or may have support from family and friends. In any situation, it is always imperative to work together as a team—caregiver to caregiver, caregiver to family, etc. So that everyone is on the same page with daily activities, feels part of the process, and can help each other to the best of their ability.

You can use this handout as a prompt for daily or weekly check-ins with those who support you. Try to set aside 10 minutes a day or maybe 30 minutes a week to meet with or check in with those who help you, your family, and your teen or young adult with ASD. By regularly checking in, everyone will be well informed about the week's activities and future events and even brainstorm ways to address any new situations.

Possible Check-in Topics

Tasks

- Example: How did the things on your to-do list go today/this week? How can I support you with them?

Siblings

- Example: How are the other children doing? How is school going for them? Do they have anything big going on this week?

School

- Example: Has the teacher given any new reports or updates? Are there upcoming school events?

Transition

- Example: What type of transition activities are you working on? How has [teen or young adult with ASD] been helping with these activities? What is the next step
  in the process?

Daily skills

- Example: Has [teen or young adult with ASD] been practicing certain daily living skills? Like what? How can we support him or her with these?

Feelings

- Example: How are you feeling this week? Would you like to talk?

Upcoming events

- Example: Do you have any upcoming meetings this week? Is there anything on the schedule for the kids?

Appointments

- Example: Do the kids have any appointments this week? How did appointments from this past week go?

Time for self

- Example: Have you been able to take some time for yourself this week? How can I support you to find more time?

Additional Ideas for Check In Topics:

____

____

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Caregiving and Family

Handout 2—Fact sheet

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

Partner/Spouse Relationships

Relationships with partners may take a back seat when all of your time and energy go into supporting your adolescent or young adult with ASD. Some caregivers may have hoped that when their child reached adolescence, they would have more time for themselves and their relationships. If this is not the case, or respite care is difficult to find or afford, there can be a strain on relationships.

Siblings

Sometimes, siblings may feel jealous of the attention and time that the individual with ASD receives. However, their experience of living with and loving an individual with ASD can also enhance their ability to express compassion, patience, and understanding for others.

Extended Family

Depending on the experiences of different caregivers, extended family members may be extremely supportive or may play a limited role in supporting the family and individual with ASD. Misunderstandings, differences in opinion, and limited knowledge of ASD may hinder extended family relationships. It is important for caregivers to be able to find support, whether from extended family or from other resources.

Tips and Ideas to Help Caregivers Cope

There are many ways to nurture caregiver-family relationships:

- Be clear and open in your communications with your family.
- Actively listen to your partner and other family members.
- Ask questions to clarify another person’s point of view.
- Plan activities that can be done together as a family.
- Feel gratitude for the relationships in your life.
- Make time—even 15 minutes a day—to spend with someone important in your life.

Notes

Caregiving and Family

Handout 3—Resources for more information

Parenting/co-parenting

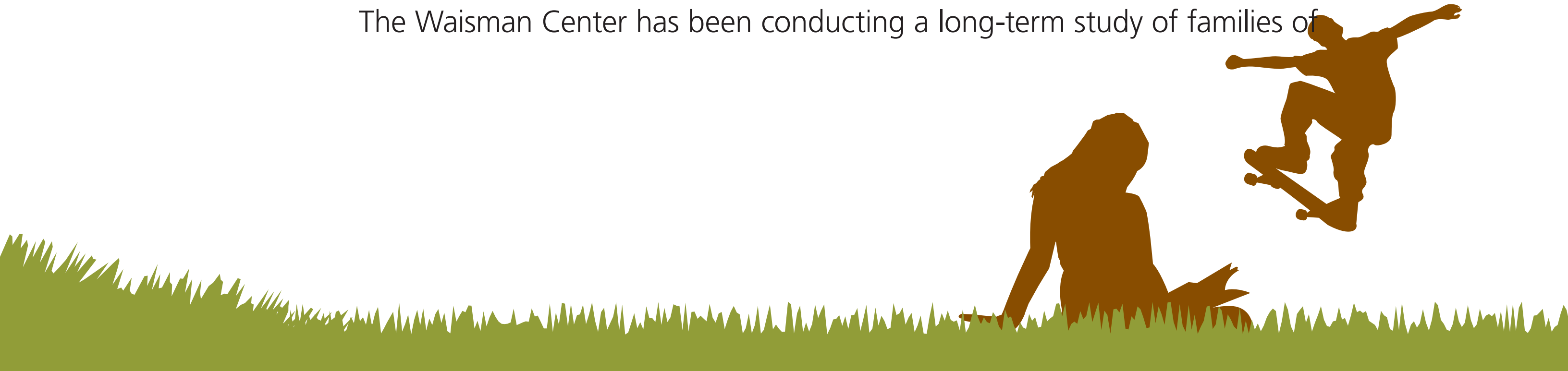
- *Parenting Across the Autism Spectrum: Unexpected Lessons We Have Learned* by Maureen Morell and Ann Palmer
  Two mothers of individuals on opposite ends of the autism spectrum offer insights into parenting individuals with ASD.
- *The Autism Mom's Survival Guide (for Dads, too!): Creating a Balanced and Happy Life While Raising a Child with Autism* by Susan Senator
  This is a book for parents—not about how to parent an individual with ASD, but instead focusing on the parents themselves, their needs, and ways to care for themselves and their children.

Family Activities

- Family activity ideas: **http://familyfun.go.com**
  This Web site offers ideas for fun family activities.
- Family communication tips: **www.healthychildren.org**
  This Web site, from the American Academy of Pediatrics, has many resources for families. When you search for "communication", you will find a number of helpful articles for your family.

Siblings

- *Sibling Stories: Reflections on Life with a Brother or Sister on the Autism Spectrum* by Lynn Feiges and Mary Jane Weiss
  This book includes first-person accounts of sibling relationships with individuals with ASD.
- Waisman Center, A Study of Family Caregiving:
  www.waisman.wisc.edu/family/study_autism.html
  The Waisman Center has been conducting a long-term study of families of



adolescents with ASD. Its Web site offers several reports on the experiences of siblings of individuals with ASD.

- Sibling Support Project: **www.siblingsupport.org**
  This national organization's Web site offers workshops and retreats for siblings of individuals with special needs.

Notes

Caregiving and the Individual with ASD

Exercise 1—Strengths

When you care for an adolescent or young adult with ASD, you may often worry about the future, feel stress or worry associated with puberty and sexual changes, and find yourself continually dealing with treatments and appointments. These day-to-day challenges are sometimes all you can think about, and you may lose focus on your main goal: to raise your son or daughter to be a happy, healthy adult. To keep you focused on the important issues in your life, this exercise asks you to list the strengths of your adolescent or young adult with ASD. Post this list on your bedroom mirror, keep it in your bag, or put it somewhere else near at hand. If you keep it handy, whenever you are feeling overwhelmed or need some extra encouragement to advocate for your teen or young adult with ASD, you will have your reasons in the palm of your hand.

What does your adolescent or young adult like?

What is his or her favorite activity?

What accomplishment are you most proud of?

What is your favorite thing to do with him or her?

At school, what is his or her favorite subject?

What other strengths does your adolescent or young adult have?

What have you learned from your son or daughter?

What personality trait does your adolescent or young adult have that you wish you had?

Once you have a list, type it up or write it on a good piece of paper. Make sure you refer to it every day.

Caregiving and the Individual with ASD

Exercise 2—Positive reinforcement

Positive reinforcement can go a long way as you work with your adolescent or young adult with ASD. Research shows that a ratio of three praise statements or rewards for every command or correction is the ideal number to increase desired behaviors. You may already be familiar with this behavioral technique, and it can be applied to many situations during adolescence and young adulthood to support your teen's or young adult's independence and life skills development. Positive reinforcement occurs when you reward the adolescent for a certain behavior. This makes the hard work of learning new skills easier for your teen. You may want to make sure you are adhering to the ratio by tracking your statements in a notebook or writing tic marks on the palm of your hand. Eventually, the ratio will be more automatic and feel more natural. It is important to reinforce all positive steps toward a particular goal until that goal is achieved. Small, incremental steps that are reinforced and rewarded continually work best as you work to achieve a goal with your adolescent or young adult. You may want to have your teen earn points toward a desired reward, and you can easily track this on a point sheet or other simple accounting system. Devise a system that is simple, flexible, and easy to use so that you can stick to it.

The following exercise will ask you to break down a particular goal into small steps. You will then determine appropriate rewards for your adolescent or young adult. (Things that would be rewardi for one teen or young adult may not be reward for another.) Using these steps and rewards, you can build toward your intended goal.

Goal: Make a new friend.

Goal: Learn to cook a meal.

Goal: Commute to a job.

Goal: Learn grooming techniques.

Goal: Keep track of expenses.

Ask your adolescent or young adult with ASD to choose a goal, such as one of those listed on the previous page. Then, divide this one goal into 5–10 smaller, incremental steps. Next, ask what reward your teen or young adult would like to earn for successfully completing each step. This technique can be used for any behavior you and your teen or young adult are working on.

In addition to choosing a goal and breaking it down into steps, you and your adolescent or young adult should discuss potential barriers to achieving his or her chosen goal and ways to overcome them. Addressing barriers before they happen also supports successful achievement of the goal.

Example:

Goal: Participate in an afterschool activity.

Have your adolescent or young adult:

Step 1: Discuss different activities that interest him or her.

Step 2: Go over a list of activities the school provides.

Step 3: Choose an activity that sounds interesting.

Step 4: Go to this activity with a friend or parent to see what it's like.

Step 5: Attend this activity again with a friend or parent and meet a few people.

Step 6: Attend this activity alone.

Potential barriers and possible solutions:

- There are no activities at school that are of interest. Instead, maybe look at a community organization's activities or other programs offered in your local area.
- The afterschool activity only meets once a month, which is not enough time to meet and make friends with other participants. Instead, consider asking if another meeting each month could be added to the schedule or invite participants in the activity to your house to get to know each other.

Support Network Opportunity

If you decide to implement a goal using positive reinforcement, share that with the group. Follow up with support network members to let them know how it is going. If things are moving slowly, brainstorm with the group on ways to improve the reinforcement technique or change the rewards. Remember, other caregivers are a great resource for you!

Notes

Caregiving and the Individual with ASD

Exercise 3—Puberty and sexuality

A key issue as an individual with ASD reaches adolescence and young adulthood is puberty and sexual maturity. While this is an in-depth topic, we want to give you some tips and skills to use when approaching this subject with your adolescent. For more information, please see the handout that accompanies this exercise.

Tips for Talking About Puberty and Sexuality

- Use pictures or visual representations of the topic you are discussing. For example, you could show pictures of yourself as a young child, an adolescent, and an adult to convey the changes your body goes through.
- Relate explanations from the point of view of your teenager's interests. For instance, if he or she collects action figures, use an action figure to explain puberty and bodily changes.
- Be aware of your attitude and tone when having these discussions. Keep the mood light, open, and positive.
- Start these discussions early and have them often. Adolescents with ASD often need a lot of preparation time to get ready for changes in their lives.
- Follow the individual's cues. If he or she seems overwhelmed, take a break and resume at another time. If he or she begins asking questions or repeating things heard at school, it is time for a talk. Ignoring these signs could potentially place your teen or young adult in embarrassing or dangerous situations.
- Be patient. Your teenager may have a lot of questions. If you do not know the answers, find them together at the library or on the Internet.
- Stress the positive aspects of puberty: becoming an adult, attaining more independence, taking on more responsibilities.
- Stress that everyone's body is unique and may change at different times.

Discussion

Take a few moments to write down your ideas for approaching the following topics with your teen or young adult.

Your body: Highlight the general changes your teen will experience and how this may make him or her feel.

Boys: Explain what an erection is and why he might experience one.

Girls: Explain menstruation, what it is, and what will happen each month.

Social context: Highlight what is appropriate behavior in public versus in private. For example, explain when it is appropriate to talk about issues surrounding puberty and sexual maturity.

Reproduction: In matter-of-fact, simple terms, explain how a baby is made.

In the group, discuss how you would approach these topics with your teen or young adult. Keep in mind that these areas of discussion can be difficult. Use the group to brainstorm ideas for explaining different topics.

Notes

Caregiving and the Individual with ASD

Video 4

1. In what ways have you talked about puberty with your teen or young adult with ASD?

2. How have you helped him or her practice personal care and hygiene skills?

3. How has your relationship with your teen or young adult with ASD changed as he or she has gotten older?

Caregiving and the Individual with ASD

Handout 1—Puberty and sexuality

For more information on how to explain puberty and sexuality to your adolescent or young adult, please look at the following resources:

Books

- *Autism-Asperger's & Sexuality: Puberty and Beyond* by Jerry and Mary Newport
  This book was written by a husband-and-wife team, both of whom have Asperger syndrome. It takes an in-depth, honest look at the sexual challenges and issues facing individuals with ASD. It is a resource for the caregiver as well as the adolescent or young adult.
- *Taking Care of Myself: A Hygiene, and Personal Curriculum for Young People With Autism* by Mary Wrobel
  Using visual aids, stories, and activities, this book covers topics such as hygiene, health, modesty, growth and development, menstruation, touching, personal safety, and masturbation. It does not contain an explanation of sexual intercourse or reproduction.
- *Asperger Syndrome in Adolescence: Living with the Ups, and Things in Between*, edited by Liane Holliday Willey
  This book covers all topics that are important to individuals with Asperger syndrome during adolescence, such as sexuality, friendships, and transition to adult issues.
- *Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorder*s by Chantal Sicile-Kira
  This book offers an in-depth look at the cognitive, social, physical, and transitional needs that face adolescents along the autism spectrum. Topics such as teaching strategies, puberty, self-care, social skills, teenage emotions, and sexuality are presented with important advice and examples.

Web Site

- The National Autistic Society, **www.nas.org.uk**
  This UK site offers a good overview of puberty and sex education.

Other

General parenting books on puberty and teens may be useful to you as well. These books can provide language, pictures, and other reproductive information that could be used as you discuss this topic with your adolescent or young adult with ASD.

Notes

Caregiving and the Individual with ASD

Handout 2—Community activities

Getting your teen or young adult involved in community activities can help him or her meet new people, participate in activities that he or she is interested in, and provide him or her with new skills for independence. Helping your child become more active in the community can give you time for yourself and may also put you at ease that your adolescent or young adult with ASD is learning skills for independent living. Here are some ideas for getting your teen or young adult involved in community activities.

Interest activities.

Your teen or young adult 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 teen or young adult likes music, he or she might enjoy music lessons. If he or she is really into computers, an advanced programming class through a local computer center might be good. Make a list of your teen's or young adult'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 teens and young adults with ASD 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 teen or young adult enjoys. Search your local community organizations online for possible volunteer opportunities. Your local paper may also offer ideas. You could even just talk to your local community center or an organization that you are involved with to see what opportunities they have available. Ideas for volunteer activities are listed below. The organizations listed often have local volunteer opportunities.

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

Walk for a cause.

Different organizations often have walks to increase awareness of an issue and raise money. Your teen or young adult may have a cause that is important to him or her, or may wish to get involved with a local autism group.Your teen or young adult could join a team to train for an upcoming walk, and then they could complete the event together.

Notes

Caregiving and the Individual with ASD

Handout 3—Fact sheet

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

Aggression and Behaviors

Individuals with ASD in adolescence and young adulthood are often bigger, stronger, and may exhibit more aggressive behaviors than when they were younger. Aggressive behaviors can make caregivers feel fearful, worried, and concerned for their safety, the safety of the individual with ASD, and the safety of others.

Puberty

Teenagers with ASD, like all teenagers, are dealing with changing bodies and feelings. Caregivers often wonder how to explain these physical and emotional changes in ways appropriate for individuals with ASD. Educating adolescents and young adults about sexual development and relationships can be challenging.

Independence

Like other teens or young adults, teens and young adults with ASD want independence and more control in their lives. Caregivers want to provide opportunities to practice these skills while also ensuring the individual with ASD's safety.

Tips and Ideas to Help Caregivers Cope

Challenges during adolescence and young adulthood may be helped by:

- Making a list of your teen or young adult with ASD's strengths
- Practicing positive reinforcement with your teen or young adult to help him or her build independence and life skills
- Accessing books on puberty and ASD

- Practicing explaining sexual development before talking with the individual with ASD
- Having sexuality discussions early and often
- Practicing patience
- Encouraging your teen or young adult to get involved in community activities

Notes

Caregiving and the Individual with ASD

Handout 4—Resources for more information

Information About Teens and Young Adults with ASD

- A Guide for Transition to Adulthood from the Organization: **www.researchautism.org**
  The Organization for Autism Research offers a free resource about transitioning to adulthood for parents of teens and young adults with ASD.
- *Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders* by Chantal Sicile-Kira
  A practical book written by an experienced mom that offers strategies for understanding teens and young adults with ASD.
- *Growing Up on the Spectrum* by Lynn Kern Koegel and Claire LaZebnik
  A book addressing the unique issues facing caregivers of teens and young adults with ASD.
- Autism Society of America: **www.autism-society.org**
  The Autism Society of America offers a resource, "Growing Up Together," that explains ASD to peers of teens with ASD.
- *Girls Growing up on the Autism Spectrum* by Shana Nichols, Gina Moravcik, and Samara Tetenbaum
  This book offers information and resources for helping caregivers of teenage girls on the autism spectrum.
- Puberty and Children on the Autism Spectrum: **http://support.autism-society.org/site/DocServer/LWA_Puberty.pdf?docID=4182**
  This is a printable handout about how puberty affects both boys and girls with ASD.

Caregiving and Services

Exercise 1—“Go-to” people

It is important for your adolescent or young adult to feel that a variety of people are available to provide help and support. The situation may vary, but having a list of people in different places will be useful to your teen or young adult in navigating his or her way through young adulthood.

Use these prompts to compile a list of people from whom your teen or young adult with ASD can feel comfortable seeking advice in various environments. Then, make a copy of this list for your teen or young adult. In addition, speak to these people with your teen or young adult present and let them know that they may be asked for help in certain situations.

- Teachers
- Counselors
- Aides
- Friends
- Afterschool workers
- Relatives
- Neighbors
- Classmates
- Siblings
- Extracurricular activity leaders
- Religious organizations or faith-based contacts

It may also be useful to compile a list of potential topics that these "go-to" people might be able to help with. That way, if your adolescent or young adult has a question but is unsure who to ask, the list will serve as a prompt.

Caregiving and Services

Exercise 2—Transition process

The Individuals with Disabilities Education Act (IDEA) is a federal law that guarantees services to children with disabilities. It is a requirement of IDEA that schools create educational and behavioral goals for students with ASD. Schools are obligated to provide support and resources as students transition through high school and beyond, up to age 21. Beginning when ASD students reach age 14, schools must help them prepare for the transition from high school to postsecondary living. The transition process begins in middle school and continues throughout high school and involves the IEP team, teachers, and caregivers. Often, it will be necessary for you to initiate this process and to be sure that the school keeps up with it. Unfortunately, some school systems will not approach you about all of the services that can be placed in an IEP or that are available. You will need to be well informed and advocate actively for your teen or young adult.

Because you may have already started this transition planning process, this activity will allow you to focus your thoughts on one or two important transition topics. In this way, you can create an action plan to keep the process flowing smoothly for yourself and your adolescent or young adult.

Transition Issues

Some of the transitional issues or topics you encounter may include:

- Developing a transition plan with the school
- Accessing agency help and/or legal information
- Deciding the postsecondary plan—e.g., educational versus vocational
- Working on advanced social skills
- Teaching life skills
- Learning about estate planning

Take a moment and discuss with the group where you are in the transition planning process. Because this process can be overwhelming and time-consuming, use your group as a potential resource for more information and tips.

Transition planning is a long-term process and one that is made easier by taking small, easy steps along the way. After your initial discussion with the group, think about where you are in the transition planning process. What is one area or topic you would like to take on in the next few months?

This exercise cannot provide you with all of the resources and information you need on transition planning. However, your support group can be an important source of information and encouragement at this time. Use this resource now, discussing your concerns about transitioning your adolescent or young adult. Share your knowledge and ask questions of others.

*****Support Network Opportunity*****
Since transition planning is a long-term process, you can use your support network to access information and further support along the way. E-mail the group when you have questions or need guidance. They may have the exact resource you need.

Notes

Caregiving and Services

Exercise 3—Assertiveness and advocacy

Assertiveness and advocacy skills are important to have as you continue to work to obtain appropriate services for your adolescent or young adult in school, in transitional situations, at work, in medical care, and in all other arenas. This activity will highlight these skills and give you a chance to practice them.

Key Assertiveness Skills

Assertiveness is a key part of your ability to express yourself and your (or the individual with ASD's) rights. Being assertive does not necessarily mean being aggressive. Assertiveness involves open, honest communication that allows you to remain true to your beliefs and needs. At the same time, you must be respectful of the other person's rights.

Assertiveness is characterized by:

- **Specific and clear ideas, feelings, and thoughts.** You are specific about what you want or need for your adolescent or young adult, you are direct and up front, and you speak to the appropriate person for the situation.
- **"I" statements.** You want to be clear that your opinions and needs are your own. Keep it personal and own your opinions.
- **Reciprocity.** Ask for feedback and get reactions from the other party. Make sure your message is clear, and provide elaboration if necessary. Make sure you understand the other person's point of view.
- **Nonverbal communication.** Your body language, tone, eye contact, expressions, and posture will also convey your level of assertiveness. Visualize how you want to appear in a situation and practice before you have your discussion.
- **Calmness.** Keep your cool and do not deviate from your message. Take a few deep breaths if you need to.

Key Advocacy Skills

Being able to advocate for your adolescent or young adult is an important part of being a caregiver. Most likely, you have been doing it all of your child's life. There are several key elements you need to be an effective advocate.

- **Familiarity with the topic.** You need to be familiar with the topic in question or with the problem you are trying to solve. For instance, if you are meeting with a teacher about transition needs post-high school, do some research on your child's rights under IDEA and learn what the transition process requires from the teacher. In addition, be familiar with your child's specific needs.
- **Clear communication.** You will need to be able to express yourself clearly, succinctly, and effectively. This ties in well with your assertiveness skills. You may want to plan what you will say and the various points you want to make—and practice ahead of time.
- **A support system.** You do not need to advocate on your own. Your partner, friends, support group, extended family, and many others may be able to help you. You can brainstorm ideas with them, practice your communication skills, and learn about the various aspects of the system that interest you.
- **Knowledge of your rights.** Be familiar with laws and policies that affect you and your child.
- **Education of others.** Use your knowledge and skills to make others aware of the situation, including parents and teachers. You are a valuable resource for others.

These assertiveness and advocacy skills are not only important for you as a caregiver, but they can be taught to your adolescent or young adult with ASD. You can also both advocate on his or her behalf.

Role-Plays

Using the above skills, spend some time figuring out how you would approach each of these situations. Then, role-play the situations in the group.

1. You and your teen or young adult with ASD have a meeting scheduled with a local community college to learn about their programs and services for individuals with disabilities.
2. Your daughter's IEP meeting is coming up, and you'd like to start planning for her transition after high school.

3. You are interested in learning what support services your school offers for afterschool programs.

Notes

Caregiving and Services

Exercise 4—Living arrangements

There are different types of living arrangements or options that may be appropriate for your young adult with ASD. Below is a description of several types of accommodations:

- **Independent living.** Some young adults with ASD may live outside of your home. However, they may need assistance on some day-to-day tasks, such as getting to work or managing finances. This assistance could be provided by a variety of people, including you, an agency, or a hired caregiver.
- **Living at home.** There are some government programs that provide support to families that have their young adults living at home with them. These programs may include Supplemental Security Income, Social Security Disability Insurance, and Medicaid waivers.
- **Community group homes or supported apartments.** In this situation, a young adult with ASD lives in a home or apartment with several other individuals with varying needs. Trained staff at the home offer training and support in many areas, such as self-care, behavioral skills, and communication. Young adults who are higher functioning may not live with a staff member but may instead have someone who visits a few times a week.
- **Skill development homes or host family homes.** Similar to a supported apartment (see above), a skill development or host family home allows a young adult with ASD to live with a family that has been trained in the specific needs of the individual. Independent living skills continue to be taught, and support to the individual is provided on a continual basis.
- **College programs.** Some colleges now offer special programs and supported living arrangements for students with ASD. The services depend on the college or technical program. A little online investigation into the colleges or technical programs in your area might yield more information. In addition, your son or daughter's school guidance counselor might have more information.

Not all residential programs are alike, just as no young adult with ASD is the same as another. It will take time as you work with your young adult with ASD to find the appropriate living situation. Below are a few guiding questions to get you started with this process:

Where would you like your young adult to live? Where would he or she like to live?

What would be the ideal living situation for him or her?

What independent living skills does he or she have?

What level of self-care does he or she have?

What skills do you think would be needed for each type of residential setting?

*****Support Network Opportunity*****
Because this is a difficult topic and one that requires a lot of consideration and information, your support network may be able to help. As you begin this process, brainstorm with support network members on options they are looking into and other resources that may be available in your area.

Notes

Caregiving and Services

Video 5

1. How have you worked with your teen or young adult with ASD to plan for his or her future?

2. What are your teen's or young adult's dreams for the future? How are you working together to achieve them?

3. What types of information and/or resources have been helpful to you and your teen or young adult as you support his or her transition out of high school?

Caregiving and Services

Handout 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 teen or young adult 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, quality life.

What Does a Circle of Support Do?

A circle of support can work together with you and your teen or young adult with ASD on a variety of topics and needs. Some examples may include:

- Transition plans
- Setting goals for after high school
- Developing skills for independent living
- Finding a job

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 teen or young adult 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 belong to similar activities as your teen or young adult with ASD
- Professionals who work with teens or young adults with ASD
- Teachers
- Spiritual support leaders
- Coaches

How Does a Circle of Support Meeting Work?

A circle of support meeting should be designed to meet your and your teen's or young adult's needs. Each meeting might be different. Here are some guidelines for circle of xupport meetings:

- **Select a facilitator.** This might be your teen or young adult with ASD, you, or another member.
- **Decide on a time and location.** You might choose to meet at your house, a library, spiritual center, or at a restaurant.
- **Decide on an agenda for the meeting.** Working together with your teen or young adult, create a list of topics to discuss at the meeting. Send these agenda items to the members of the team prior to your meeting so they can think about them.
- **Hold the meeting.** The facilitator will run the meeting and follow the agenda, allowing enough time to talk about each topic. Each meeting should last between 1 and 2 hours. For each agenda item, a plan for action should be created to help meet the individual's goals.

Members of the circle of support are there to help and support your teen or young adult with ASD. Each meeting might lead to different members helping your teen or young adult implement various strategies to meet his or her goals. While the focus of each meeting might be different, the underlying goal is the same: to support your teen or young adult so his or her can be successful in his life.

Notes

Caregiving and Services

Handout 2—Fact sheet

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

The focus on services during adolescence and young adulthood shifts to:

- Transition planning
- Achieving skills for independent living
- Accessing adult services
- Working together with the adolescent or young adult with ASD

Transitions

Individuals with ASD need to prepare and plan for the transition out of high school early. Services during adolescence or young adulthood may focus on helping the individual with ASD develop independent living skills. Person-centered planning, to the extent possible, creates teamwork between caregivers and individuals with ASD to the meet challenges and to effectively address the desires of the individual with ASD.

Services

School and academic services may focus on daily living, hygiene, social skills, communication, and behavior management skills. After high school, young adults with ASD must transition to adult services and find appropriate environments and accommodations that are a good fit for them. Individuals with ASD may pursue and flourish in jobs, independent living, and/or college environments.

Tips and Ideas to Help Caregivers Cope

Many resources and areas of support exist to help caregivers transition individuals with ASD through adolescent and young adult services.

- Create a list of "go-to" people who provide help and support to the individual with ASD in various aspects of life.
- Become familiar with the transition process as required by IDEA and begin transition planning in the IEP process.
- Practice assertiveness and advocacy skills.
- Be clear about your and your adolescent's or young adult's legal rights.

Notes

Caregiving and Services

Handout 3—Resources for more information

- Circle of Support,
  www.iidc.indiana.edu/index.php?pageId=411
  This Web site includes information on creating a circle of support for individuals with ASD.
- Person-centered Planning, **www.ilr.cornell.edu/edi/pcp/**
  This Web site offers information on the importance of person-centered planning.
- *Realizing the College Dream with Autism or Asperger Syndrome: A Parent's Guide to Student Success* by Ann Palmer
  This book offers information and resources for helping individuals with ASD transition to college.
- Wrightslaw, **www.wrightslaw.com/info/advo.index.htm**
  Wrightslaw is a great Web site for all types of special education issues. This Web page offers a variety of links about parent advocacy.

Caregiving and Finances

Exercise 1—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. Paying for treatment may sometimes be a challenge when certain services are not covered by insurance. Sometimes, attitudes or beliefs about money add to the stress associated with it.

Participate in a discussion using the following prompts and/or questions as guides:

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?

If you could spend $500 on anything, what would it be?

Do you ever buy something just for yourself to enjoy?

What would change your views on your financial situation?

How could you look at money differently?

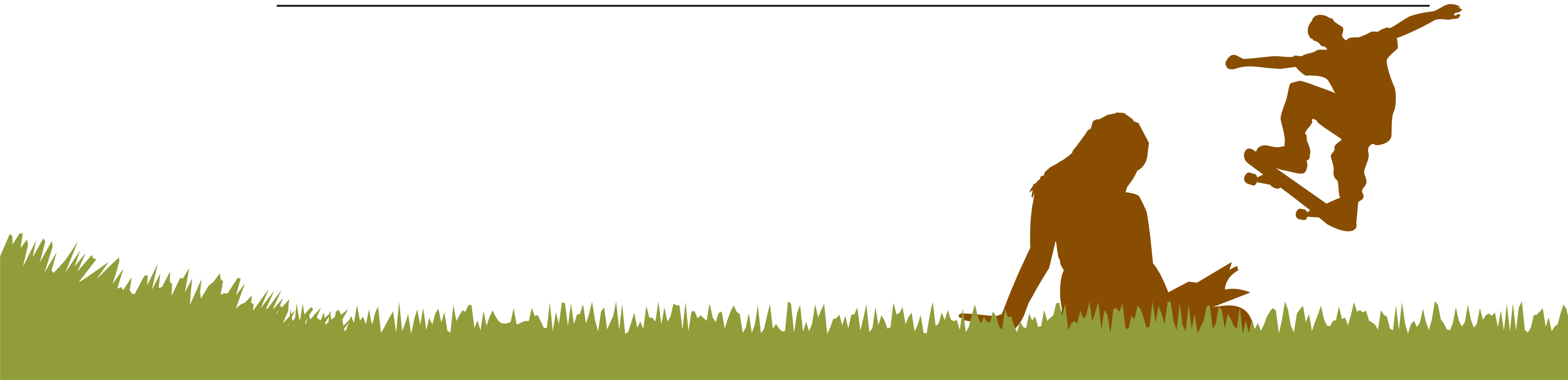
Caregiving and Finances

Exercise 2—Role-play

Using the assertiveness skills discussed in Caregiving and Services Exercise 3, page 115, practice being assertive and expressing yourself in these situations:

1. You are trying to talk to your insurance representative about coverage for your young adult with ASD. He never calls you back, and you feel like you are getting the runaround.
2. You are doing a monthly budget with your spouse, who says, "We are spending too much money on family activities; we should cut back." You feel like these activities really enhance your family relationships and do not want to cut back on them.
3. You are trying to coordinate payments for respite care between you and your ex. Your ex does not want to contribute as much as you.

Notes



Caregiving and Finances

Exercise 3—Budget

Creating a monthly budget can help you deal with financial stress. Complete the following worksheet with your spouse/partner and regroup to see how you did at the end of each month. Be sure to note the "For Fun" categories. These are included to make sure you are balancing your responsibilities with special activities for yourself and your family.

Category	Monthly Budgeted Amount	Monthly Actual Amount	Difference
INCOME:			
Salaries			
Miscellaneous income			
INCOME TOTAL			
EXPENSES:			
Mortgage or rent			
Electricity/gas			
Water			
Home repairs/maintenance			
Other household expenses			
Groceries			
Toiletries			
Clothing			

Telephone (landline)			
Cell phone			
Category	**Monthly Budgeted Amount**	**Monthly Actual Amount**	**Difference**
EXPENSES:			
Cable/satellite TV			
Internet service			
Health insurance			
Car payments			
Gasoline			
Auto insurance			
Other transportation			
Misc. loan payments			
Daycare			
Pets (food, vet)			
Gifts			
School-related costs			
Savings deposits			
FUN EXPENSES:			
Dining out			
Movies			
Gym membership			
Hobbies			
Vacations			
Other fun activities			
TOTAL EXPENSES			

Caregiving and Finances

Video 6

1. In what ways have you addressed financial challenges related to supporting your individual with ASD?

2. In general, what types of resources or budget techniques have helped you and your family?

3. In general, in what ways have you planned for your teen or young adult’s financial future?

Caregiving and Finances

Handout 1—Respite

Every family 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 individual 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. As you are researching, keep in mind that Medicaid service-approved providers can provide respite services, and some state programs may cover respite programs as well.

Autism Source (www.autism-society.org)—a service of 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 a 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 Finances

Handout 2—Fact sheet

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

Worry and anxiety about money can cause considerable stress for caregivers. Treatments and services for adolescents or young adults with ASD can be expensive, and some caregivers must balance the best services with their ability to pay.

During this life stage, caregivers must also begin thinking about future support for their adolescents or young adults with ASD. Caregivers begin to update their wills, learn about special needs trusts, and become knowledgeable about other financial planning resources. In addition to planning their financial support, thinking about the future for their adolescents or young adult with ASD can be overwhelming.

Tips and Ideas to Help Caregivers Cope

- Explore your thoughts and beliefs about money. Long-held attitudes about money can cause stress.
- Keep a monthly budget for your family.
- Find ways to access respite services.

Notes

Caregiving and Finances

Handout 3—Resources for more information

- Household Planning worksheet:
  www.kiplinger.com/tools/budget
  This Web page consists of a budget-planning worksheet.
- Autism After 16: www.autismafter16.com
  This Web site covers many topics relevant to the transition to adulthood for individuals with ASD. A search for "financial planning" will yield useful articles.
- Wrightslaw, www.wrightslaw.com/info/future.plan.index.htm
  Wrightslaw provides in-depth information to help with future financial and estate planning for those with special needs.

Notes

autismonline
Connecting Community and Resources

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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