

Caregiver's Workbook



Caring for Caregivers

For Groups of Caregivers of Adults
with Autism Spectrum Disorders

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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 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 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—Caregiver Community Web Site

At the Caregiver Community Web site, www.autismcaregiver.com, you will find a portal to connect with caregivers of individuals with ASD across the lifespan. Because it can sometimes be challenging to find other caregivers of adults with ASD, the Caregiver Community Web site provides a unique opportunity to ask questions, chat with, and share resources with other caregivers of adults throughout the nation.



If you are unfamiliar with using social networking media or are not sure how you would use the Caregiver Community Web site, let's brainstorm ways that you can use this Web site for help with support and access to information.

When you have questions about housing options or issues related to helping your adult with ASD find a supportive place to live, whom do you ask? Where do you look?

List here:

When you want more social opportunities for your adult with ASD, how do you find them?

List here:



You have now listed several ways that the Caregiver Community Web site could help. When you have questions, when you are looking for resources, or just want to connect with someone who understands, the Web site provides opportunities to receive answers from caregivers, like you, who are supporting the day-to-day needs of an adult with ASD.

In the space below, list a few questions that you could ask the caregivers on the Web site.

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

Whether you have done this exercise in a group or on your own, think about asking one or more of your questions at AutismCaregiver.com. Try it out and see how it might connect you in new ways to more resources, information, and support.

Notes

Caregiving and Emotions

Exercise 2—Journaling

Writing down thoughts, feelings, and experiences on paper can be a great way to let the pen (and your thoughts) flow. Often, we keep things bottled up and go over and over them in our heads. By writing down these thoughts, new ideas for approaching a situation, new ways of looking at feelings, and new understandings can come through.



For journaling, all you need is a pen and something to write on. You do not need a fancy notebook or even a specific time of the day to write. Whenever you notice you could use a break or have thought the same thing 100 times and need a new approach, consider sitting down with some paper even if only for 5 minutes. If the words hang in the air and you have trouble writing them down, use this exercise to get the pen flowing.

Where have you gone today?

What did you see?



Who did you talk to?

The goal here is to not think too much about what you're writing. Just jot down what you have done today to get yourself writing.

Now, what is on your mind? What situation have you been thinking about? What is the issue?

Just write...anything and everything. Get it down on paper. Write until you can't write anything else.

Now...leave it alone. Take the paper, or journal, and set it aside. The problem, issue, or feeling rests there. Give yourself a break and do something else.

Optional:

If keeping a journal does not interest you, another way to write down your experiences can be to start a Web log (blog). Using your computer and the Internet, you can type your feelings, daily thoughts, and experiences. There are a number of free options for blogs, and some can be more private if you do not want to share your experiences with others. To learn more, visit www.blogger.com or www.wordpress.com, or enter the words "free blog" into a search engine.

Caregiving and Emotions

Exercise 3—Turnarounds

It is easy to think negatively or talk to ourselves in a mean way. Use this exercise to think of new ways of looking at familiar things you might say to yourself. Be gentle and take care of yourself.



Examples

Negative thoughts	Turnaround
I don't have time to exercise.	I took the stairs at work instead of the elevator.
I'm not doing enough to help my family.	I am doing my best.
I don't have any friends who understand.	I spoke to my neighbor yesterday and that helped.

Think of a few self-judgments or negative thoughts that you might have about how you are feeling as a caregiver, maybe related to lack of time or to your self-attention. Then, turn them around into something positive, something that is also true about the situation or thought. Write your ideas below. The next time a thought pops up that makes you feel bad, see about turning it around into something that feels better.

Negative thoughts

Turnaround



Caregiving and Emotions



Exercise 4—Connecting with others

Having people in your life to talk to, laugh with, 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 adults with ASD feel isolated from other families or do not have time to nurture friendships.

Use this worksheet to think of ways to connect with people, such as other caregivers, friends, or community members. Finding an activity that you enjoy that also helps you to meet people can be one option. You may also 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?

Choosing one activity, who could you invite to participate in it with you next time?



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 have met or spoken with in the last couple of years.

Are there any friends with whom you have lost touch? Whom could you connect with again?

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

Plan a lunch or an afternoon activity with a member or members of your support network. You could even just chat on the phone. Find a time that works for everyone and mark it on your calendar.

Caregiving and Emotions



Exercise 5—Making a plan

Handout 2 explains what stress is, discusses the impact stress can have on your body, and gives ideas of ways to manage stress, like these:

- Stretching
- Yoga
- Deep or diaphragmatic breathing
- Progressive muscle relaxation exercises
- Exercise
- Eating well
- Walking
- Dancing
- Laughing
- Extra sleep
- Healthy friendships
- Sense of humor
- Creating and taking time for yourself

1. First, choose a stress management activity from the list above, in Handout 2, or another idea that you have. List just one below.

a. _____

2. Next, think of three specific and easy ways that you could implement this idea in the next week. For instance, if you would like to use dancing to manage some stress, you might dance to music as you get ready one morning, dance while making dinner one night, or dance as you take the dog for a walk.

a. _____

b. _____

c. _____



3. Take a look at your calendar or think of your schedule for the coming week. Find or create a 10- to 15-minute window for yourself, then choose one of the specific ideas from #2. Intentionally set aside this time in your schedule to practice your stress management idea.
4. After you have practiced, take note of how you feel. Maybe write down your thoughts or feelings here or on a separate piece of paper.

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

You may like to check in with your support network after doing this exercise. What types of things do they do to relieve stress? You can also support each other in practicing a stress management activity at least once a week.

Notes

Caregiving and Emotions

Video 1



1. What concerns do you have as you support and care for an adult with ASD?

2. What impact does caregiving have on your life? Can you think of both positive and challenging impacts like the caregivers in the video?



Caregiving and Emotions

Handout 1—Self-nurturing

Everyone, especially caregivers, needs time to take care of themselves. Taking time for the self to rest and renew can bring strength and more energy. With a busy life, it can be easy to postpone taking care of yourself until things “get better” or you have “more time.” Take the time now. It will help you feel better and help you to be a better caregiver.



- Take a few moments before getting out of bed to think of the fun things you will do during the day
- Set an intention for the day, write it down, and carry it with you
- Listen to your favorite music when getting dressed
- Read a poem
- Write a page in your journal
- Wear your favorite perfume or cologne
- Listen to an inspirational CD in the car
- Buy yourself flowers
- Sit down for a cup of tea
- Take a short walk
- Wear your favorite shirt
- Make a list of all you accomplished during the day
- Take a hot shower
- Soak a hand towel in water and microwave it for 2 minutes; place it on the back of your neck, then over your face
- Light a candle in your favorite scent
- Pick one thing that you love and put it on your schedule
- Make a list of what you are grateful for



Caregiving and Emotions

Handout 2—What is stress?

We talk a lot about stress, but what exactly is it? What is our physiological response to stress that we experience in our body, and how does that affect our physical and emotional health?



Our physiological response to stress is regulated by our autonomic nervous system (ANS). The ANS is made up of the sympathetic and parasympathetic nervous systems. The sympathetic nervous system helps our bodies get ready for action, while our parasympathetic nervous system typically helps relax and restore the body after the source of stress or threat is gone. When we experience stress or a stressor, our bodies react with a “fight-or-flight” response (from the sympathetic nervous system).

When your fight-or-flight response is activated, you may experience or feel some of the following:

- Speeding up of your breathing
- Increasing heart rate
- Increasing blood pressure
- Sweating
- Moving more blood to the muscles
- Producing more “fuel” (glucose) to feed active muscles
- Increasing adrenaline levels in the body

In evolutionary terms, this stress response is how our bodies are programmed to react to a danger, demand, or change, whether the danger is real or perceived. In today’s world, rather than a threat from predators, threats may be something such as stepping off a curb to cross the street and having a car you did not initially see whizz past.

Once a threat has passed, your body should automatically (with the help of the parasympathetic nervous system) regulate this stress response to bring the body back



into balance. Adrenaline and cortisol levels return to normal, your heart rate goes down, and your breathing returns to a steady pace.

Yet, when we have chronic stress and our body keeps reacting in these ways (either in a smaller degree or over an extended length of time), these physical changes that were meant to protect us may cause harm to our physical and emotional health. In some people, chronic stress can lead to diabetes, obesity, heart problems, stroke, autoimmune deficiencies, immunity problems, or even cancer. Prolonged stress can also lead to anxiety, depression, or other mental health problems.

Learning to recognize, better manage, and ultimately reduce stress is very important for your physical and mental health. Here are some steps to help you do this.

First, we need to notice when we are feeling stressed. Symptoms that you may feel when stressed might be:

- Moodiness
- Worry
- Anger
- Feeling pressured
- Stomach problems
- Headache
- Problem sleeping
- Sadness
- Butterflies in stomach
- Sweating
- Tension in neck or shoulders
- General body tightness
- Shortness of breath
- Clenched jaw

While the stress response can be an involuntary reaction to a situation, feeling, or thought, we can take proactive steps to reduce or manage stress. Stress management may include:

- Stretching
- Yoga
- Deep or diaphragmatic breathing
- Progressive muscle relaxation exercises
- Meditation
- Exercise
- Eating well
- Changing attitudes about an event or situation
- Walking
- Dancing
- Laughing
- Affection

- Extra sleep
- Healthy friendships
- Sense of humor
- Creating and taking time for yourself
- Doing something you enjoy
- Cutting back on your schedule
- Making connections with friends, family or community
- Enjoying a hobby
- Seeking professional help (from a doctor or counselor)
- Positive thinking

Use these ideas as a starting point to see what activities or concepts might work for you when you feel stress.

Notes



Caregiving and Emotions

Handout 3—Fact sheet

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



The caregiving experience is long-term and full of ups and downs. Some caregivers of adults with ASD may be relatively new caregivers, such as a sibling or new guardian transitioning into more caregiving responsibilities. Other caregivers may have many years of experience under their belts. In whatever situation, every caregiver brings his or her unique life experiences and approaches to supporting an adult with ASD.

Whether an adult with ASD lives at home or more independently, caregivers of adults continue to play an active and important role in their lives. Often, caregivers spend all of their energy taking care of others and then run out of time for themselves. Making self-nurturing an important aspect of life can replenish, relax, and rejuvenate caregivers.

Tips and Ideas to Help Caregivers Cope

- Visit the Caregiver Community Web site (www.autismcaregiver.com) to connect with other caregivers of adults with ASD.
- Keep a journal to write down thoughts, feelings, and experiences as a caregiver.
- Pay attention to the negative thoughts that you may have and try to turn them around into something more positive.
- Get out and meet to reconnect with people in your life. Make dates with friends and join in new activities.
- Make time to nurture yourself, even if only for 5 minutes a day.



Caregiving and Emotions

Handout 4—Resources for more information



- Caregiver Community: www.autismcaregiver.com
Caregiver Community offers opportunities to connect with other caregivers of adults with ASD.
- *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.
- Family Caregiver Alliance: www.caregiver.org
The Family Caregiver Alliance provides information, education, services, and advocacy for caregivers of individuals with all chronic or disabling conditions, including autism. Its Web site has many useful fact sheets, resources, and events that may support you.
- WebMD: www.Webmd.com/fitness-exercise/default.htm
The Health and Fitness page of WebMD offers lots of advice and ideas for finding exercise options that work for you and ideas for healthy eating and lifestyles.
- *Asperger's Syndrome and Adults...Is Anyone Listening? Essays and Poems by Partners, Parents and Family Members* by Karen E. Rodman and Tony Attwood
The difficulties faced by people with Asperger syndrome (AS) cannot be underestimated, but the emotional problems experienced by those around them—partners, family, and friends—are often overlooked. This book gathers letters, thoughts, and poems to give voice to the loneliness, frustration, and love felt by many individuals who are close to one or more people with AS. This collection provides the emotional support, insight, and understanding needed to deal with the emotions that AS evokes within close relationships.



- YouTube: www.youtube.com
YouTube has a wealth of different videos to help you manage stress. Search the Web site using keywords such as relaxation, progressive muscle relaxation, yoga, deep breathing, and dancing. You can also find funny videos that will make you laugh. Remember, before you practice any specific relaxation techniques (such as deep breathing or muscle relaxation), be sure to watch the video first to see if you are comfortable with the techniques taught.

Notes

Caregiving and Relationships

Exercise 1—Making connections

Getting involved in activities, small or large, is always a great way to make connections with new people or strengthen relationships with old friends. Being involved does not need to be a huge time commitment in your already busy schedule. Having outside activities, besides supporting your individual with ASD, can build relationships, interests, and create a multifaceted life for you.



If you're not already involved in a community organization, volunteer activity, or other role that helps you make connections and nourishes things that are important to you, use this exercise to brainstorm a new activity to bring into your life.

List three things that interest you.

1. _____
2. _____
3. _____

List three things that help you feel relaxed.

1. _____
2. _____
3. _____



List three things that make you smile.

1. _____
2. _____
3. _____

List three things that you enjoy doing with others.

1. _____
2. _____
3. _____

Are there common threads between these lists? For example, maybe working with children makes you smile and you are interested in supporting children who have challenges.

Getting involved in another activity does not mean just adding another thing to your to-do list. The main goal is to find something that you truly enjoy so that it will nourish you and leave you feeling more energized and happy than when you started. An additional benefit will be that it might help you meet new people or make time to connect to others in your life.

Remember, the goal of this exercise is not to create more stress. Using the above list of things, see if you can think of an activity that you already do that you could participate more in. Maybe you volunteer at your church, and you would like to be on another committee. Maybe you have heard of the local food bank and want to pitch in with some friends. Maybe you want to start a book club in your neighborhood.

Choose an activity that is easy for you to incorporate into your life and that involves seeing or interacting with others. Try it out at least once.

When you are done, ask yourself these questions:

- How did I feel while at the activity?
- Do I feel more energized now or tired?
- Was it challenging to make time for this activity?
- How could I incorporate this activity more into my life?

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

Ask your support network what types of activities they do that they enjoy. Maybe you could tag along one day, or you might use their ideas as inspiration to start a new activity in your life.

Notes



Caregiving and Relationships

Exercise 2—10 in 10

Connecting with your significant other, friend, or family member can provide an important time for yourself and your relationships. Caregivers often put themselves last on the list of things to do and can become tired and isolated. Giving yourself even 10 minutes of time with the people important to you can rejuvenate you and your relationships, keeping both strong and lively.



Use this activity to brainstorm 10 ideas that you can start or do in 10 minutes with the people important to you.

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____



Here are some ideas to jump-start your list:

- Making a quick phone call to catch up
- Taking a coffee break in the backyard
- Starting or making dinner together
- Sending an e-mail update to reconnect with old friends
- Getting an ice cream cone
- Taking the dog for a walk

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

Ask your support network ways that they spend time with people in their life. Share with them a few of your ideas from your list.

Notes

Caregiving and Relationships

Exercise 3—Caregiving story

Sharing your caregiving story with those close to you—such as a spouse, partner, friend, or relative—can be an empowering activity. Often, even those closest to you do not fully understand your caregiving role, how it has evolved over the years, and what it means today. Furthermore, by writing and/or sharing your story, you are giving yourself the opportunity to reflect on the past, noticing how things have changed over the years and paying attention to how the past has shaped who you are today.



This exercise will help you to begin writing your caregiving story. A key component to this is to then share it with someone in your life. This may be showing them the written form or talking through your story over time. The key thing is to share it.

Your caregiving story can take many forms, and you can be as creative as you like. If you are artistic, maybe you can express it through drawings, or maybe you just write down all of your feelings over the years. You could write it down, record it, draw it, or even create collage or scrapbook of your story.

Some tips and questions to get you started:

- Recall how you first felt when your child (or sibling) was diagnosed
- Remember how you juggled services, family life
- Share a key story from your child's younger years that was significant to you
- Share some key lessons that you have learned—how did you learn them?
- How has being a caregiver shaped your life?
- What qualities of being a caregiver do you think you do well? Which are challenging?
- Remember humorous or sad memories and how they played a role
- What would you like others to understand about your caregiving journey?

Remember to share your story with someone important to you.



Caregiving and Relationships

Video 2



1. How has being a caregiver impacted your relationships, either romantic relationships or friendships?

2. Do you feel like your friends can or are willing to support you as a caregiver? If yes, in what ways? If no, why not?



Caregiving and Relationships

Handout 1—Friendships

Friendships are so important in our lives, but it is not always easy to make or maintain friendships.

Take a moment to think of a few qualities that your friends bring to your life.



Friendships:

- Increase your happiness
- Give a sense of belonging
- Provide someone to share stories and experiences with
- Create laughter
- Give advice
- Share encouragement
- Support you during difficult times
- Share good moments
- Celebrate together
- Provide another opinion

There are many ways to maintain your friendships. Some ideas may be:

- Go for walks with your pet
- Go to the gym or work out together
- Have lunch or coffee together
- Say yes to invitations—get out there and have fun
- Volunteer together
- Get involved in a cause or with a local group that does something you're interested in
- Take fun classes
- Chat using Skype
- Play Internet games together
- Write each other notes



Caregiving and Relationships

Handout 2—Connecting with other caregivers

Connecting with other caregivers of adults 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 lifespan age group
- Additional resources for caregivers
- 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
- Access the section most appropriate for you (adults with autism)
- Post questions, reply to other caregivers, and connect with caregivers in your local area



Caregiving and Relationships

Handout 3—Fact sheet

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



Depending on your caregiving circumstances, you may have more time for your relationships now that your child with ASD is an adult. Sibling caregivers, however, may find that as they juggle their own family and caregiving responsibilities, they have little time for the relationships in their lives. Teamwork, community, and intention work together to help maintain relationships.

Across the lifespan, isolation can be a common experience among caregivers. With limited time and unlimited responsibilities, making time for friends or family can be hard. Family dynamics over the years also change; and as roles and responsibilities shift, your family relationships may change, too.

Tips and Ideas to Help Caregivers

- Find ways to get involved in things you enjoy
- Brainstorm ideas that you can do in 10 minutes to reconnect to important people in your life
- Write down or tell your caregiving story to someone close to you
- Find ways to connect with friends to bring more laughter and encouragement into your life
- Connect with other caregivers



Caregiving and Relationships

Handout 4—Resources for more information



- Volunteer opportunities: 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.
- AutismOne Web site: www.autismone.org/search_site
You can search for people who are caregivers and advocates for autism and individuals with autism who are interested in networking and friendships.
- *Life and Love: Positive Strategies for Autistic Adults* by Zosia Zaks with a foreword by Temple Grandin
This book is divided into two sections: Life and Love. In the Life section, the author describes and suggests concrete ways to deal with some of the issues and problems faced by those on the autism spectrum. In the Love section, instead of focusing on one topic, the author includes a broad spectrum of suggestions for different types of relationships and weaves these together with the core concept of self-esteem.
- *Social Skills Picture Book for High School and Beyond* by Jed Baker
- This book offers photos of actual students engaging in a wide variety of social situations to show (rather than tell) the right and wrong ways to interact in different circumstances. The photos visually illustrate positive and negative consequences of both ways of interacting. The book also offers instructions for students and families to create their own social skills booklets.
- *Social Skills for Teenagers and Adults with Asperger Syndrome: A Practical Guide to Day-to-Day Life* by Nancy J. Patrick
This resource provides practical strategies for helping teenagers and adults with Asperger syndrome to navigate social skills, friendships, and relationships at home and in the community. The chapters are structured around real-life scenarios and the challenges they present, followed by step-by-step solutions and suggestions.



- *Today's Man*, a film by Lizzie Gottlieb
Today's Man follows Nicky Gottlieb, a young adult with Asperger syndrome, as he navigates adulthood. Filmed by his sister, the movie showcases one individual's journey into adulthood with Asperger syndrome.

Notes

Caregiving and Family

Exercise 1—Storytelling

Family life expands as children, siblings, and relatives get older, move out, and do their own thing. Whether you are a sibling caregiver or parent caregiver, you may not see other family members often, or other family members may not be as involved in caregiving as you.



Creating a sense of camaraderie and teamwork among family members can strengthen your bonds and give a sense of support to you and your individual with ASD. Try one of the following the next time some members of your family are together.

Family pictures

- If you have family picture albums, get them out. You can also get out a pile of pictures from when you or your kids were little.
- Sit down together to look at the pictures.
- Take turns telling stories, remembering what was going on.
- Share favorite childhood memories with each other.

Family charades

- If you would like to, build from the picture activity by creating family charades. Maybe there is a favorite moment from childhood you want to recreate or you want to share a feeling you had from long ago. Charades can get everyone involved and can be a fun, lighthearted way of sharing experiences.
- Choose a memory, situation, or time from years ago that you would like to remember fondly with your family.
- Act it out and ask your family members to guess either what the memory is or what is going on, or see if they can build off of your charade with their own.



Before doing the following activities, think about the following questions:

- Do you think your family would be open to these activities? Why or why not?
- What could another type of family activity be that would encourage talking and sharing?

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

Ask your support network about ways that they spend time with people in their life. Share with them a few of your ideas from your list.

Notes

Caregiving and Family

Exercise 2—Online family connections

With family members potentially spread out and not able to interact or share in caregiving roles, it can be tough to stay in touch and feel a sense of family support. At the same time, family members who understand the family situation can offer new insights, perspectives, and humor in the face of challenging times.



The Internet provides a fast and easy way to connect with others, especially family members. By keeping family members up to date on what you are up to, asking them for support, or just sharing funny stories, you can easily access and nurture a family support system.

Some ideas for connecting with family members include:

- E-mailing—maybe once a day or once a week
- Sharing pictures (e-mail, via a photo sharing Web site)
- Telling funny old family stories
- Connecting with extended family on Facebook
- Using Skype to talk to each other via the Internet
- Asking questions, getting encouragement

How do you think connecting on the Internet might work for your family?

Would it be useful to you or just another thing to do?

How do you stay connected with your family?



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

If you feel overwhelmed by the online options available to you, ask a member of your support network for help. Maybe a particular member is really good with technology and can help you get set up.

Notes

Caregiving and Family

Exercise 3—Family dynamics

As a caregiver, it can certainly be challenging to take the primary role in supporting an adult with ASD. You are dedicated, hard-working, and committed to always helping your adult with ASD. It is completely natural to have good and bad days. Family dynamics can be tricky; and if you have other siblings or family members who are not as involved as you in caregiving activities, it may bring up conflicting feelings.



Use this activity to process some of your feelings toward other family members and their involvement in caregiving.

What are some ways that other family members have supported caregiving activities?

What has their help meant to you?

How could you ask them for more help?



How can you tell them what you need?

After you have had a moment to write down a few ideas, you can role-play or practice a few things you might say or ask of other family members. In this group environment, other caregivers can give you a safe place to practice and figure out the way that will work best for you to receive what you need from your family.

Notes

Caregiving and Family

Video 3



1. In what ways is your extended family involved with your adult with ASD?

2. If family members are uninvolved in caregiving responsibilities, how does that make you feel? If family members are involved in caregiving activities, in what ways?



Caregiving and Family

Handout 1—In the loop

Caregiving responsibilities may fall to one or two members of the family. Often, other members of the family may be unsure of what types of activities are going on, feel out of the loop, or be unsure of how to help. Here are some ideas for keeping family members or close friends up to date on what's going on with you and your adult with ASD.



- Send short update e-mails
- Blog
- Use free online video communication sites, such as Skype
- Communicate on Facebook
- Send text messages
- Have lunch meetings once a month
- Have family dinners
- Divide up chores/responsibilities
- Share videos on sites such as YouTube
- Make a list of funny things that happen during the day to share
- Ask the adult with ASD to correspond with them
- Share pictures every month or every few months
- Share a calendar to coordinate activities/appointments



Caregiving and Family

Handout 2—Sibling support

Whether taking on caregiving responsibilities or not, siblings play an important role in the life of an individual with ASD. Even if distance separates siblings, they often mention that they want to be involved. Keeping siblings up to date on the daily life of their brother or sister with ASD is one way. Asking for their support in daily activities is another idea. Other ideas to help siblings be involved and supported might be:



- Sibling Leadership Network: www.siblingleadership.org
The Sibling Leadership Network gives siblings of individuals with disabilities information and resources for themselves and to advocate for their brother or sister.
- Sibling Support Project: www.siblingsupport.org
The Sibling Support Project is a national organization for brothers and sisters of people with health, developmental, or mental health issues. The organization organizes peer support opportunities and information for siblings. They run Sibshops for younger siblings and host online groups for adult siblings.
- Waisman Center: www.waisman.wisc.edu/family/study_autism.html
The Waisman Center conducted a longitudinal study with families of adults with ASD to understand their experiences. Reports from their study are available online for free and provide reflections, perspectives, and insights from all family members, with a focus on siblings.
- *Today's Man*, a film by Lizzie Gottlieb
Today's Man follows Nicky Gottlieb, a young adult with Asperger syndrome, as he navigates adulthood. Filmed by his sister, the movie showcases one individual's journey into adulthood with Asperger syndrome.



Caregiving and Family

Handout 3—Fact sheet

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



Supporting an adult with ASD is less about parenting and more about helping him or her lead a happy, healthy life. As a caregiver, you are working together to find resources and opportunities for the adult to meet his or her goals. Family teamwork, compromise, and support between caregivers and the other adults in your individual's life are important.

Like any challenge, caregiving can bring you closer together or may sometimes create resentment and tension. You may find that supporting an adult with ASD may bring you closer to members of your family—over time or as you take on more of a caregiving role. On the other hand you may find tension between family members as caregiving roles change and concerns about the future become more pronounced.

Your family is figuring out each other's roles, how to help each other, and especially how to help the adult with ASD. You may find that family activities can still be challenging, like going to dinner or on vacations. Roles may change but the needs, strengths, and challenges of an individual with ASD may not.

Tips and Ideas to Help Caregivers

- Share family stories with siblings, relatives, and other family members. Use this sense of camaraderie to give you a sense of support.
- Connect or reconnect with family members online. Use e-mail, Skype, or other online tools to stay in touch and keep family in the loop.
- Talk with other families and caregivers about their experiences with adults with ASD.
- Support siblings in staying involved and connected with their brother or sister with ASD.



Caregiving and Family

Handout 4—Resources for more information



- *Families of Adults With Autism: Stories and Advice for the Next Generation* by Jane Johnson and Anne Van Rensselerer
This book is a collection of real-life stories of people on the autism spectrum growing up, as told by their parents and siblings. The individual accounts explore the challenges that families of people with autism have faced. This book offers practical and heartwarming advice to families who are affected by autism spectrum disorders and provides insights for professionals working with people with ASD.
- Blogs: A Weblog or blog can be a great way for family members to stay up to date on daily life events. Consider these free sources for creating a blog:
www.blogger.com
www.wordpress.com
- National Institute of Mental Health: www.nimh.nih.gov
This link provides information to families regarding different options for living arrangements for adults with autism.
- Autism Society of America: www.autism-society.org
At any age, it is imperative that families of individuals with autism create a plan for the future. This Web site gives information and guidelines for making a plan for your loved one with autism.
- *Adults on the Autism Spectrum Leave the Nest: Achieving Supported Independence* by Nancy Perry
This book provides a guide for parents on how to prepare their children for adulthood and describes in detail the kinds of services people with ASDs need to live independently, away from the parental home.



Caregiving and the Individual with ASD

Exercise 1—Circle of Support

For adults with ASD, it is often difficult to maintain relationships. They may have only a few people they are close to, yet many want the ability to have meaningful relationships with others.



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

Who Might Be In a Circle of Support?

Members may vary, but there will be a main leader, maybe you, and your adult with ASD will be involved, too. Other members may be:

- Other family members
- Siblings
- Friends
- Community members
- Support staff
- Professionals involved with the adult with ASD
- Spiritual support leaders

What Can a Circle of Support Do?

The members of a circle of support can work together with the adult with ASD to help him or her implement his or her goals, remain active in community life, and participate in enjoyable activities. Some ways a circle of support may help an adult may be:

- Going on day adventures to favorite locations or activities
- Spending time together
- Practicing independent living skills
- Finding or maintaining a job
- Cooking together



Use this exercise to brainstorm ways a circle of support may enhance your caregiving life and the life of your adult with ASD.

Who could be in the circle of support?

What types of activities would your adult with ASD like support with?

What key talents do people in your adult with ASD's life have to offer?

How would you like the circle of support to stay in touch (e-mail, meetings, phone)?

Who is your adult with ASD most comfortable with?

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

Ask your support network how or if they use a circle of support with their adult with ASD. How do the members work together to support the adult with ASD?

Notes

Caregiving and the Individual with ASD

Exercise 2—Journal activity

Supporting independence with an adult with ASD is exciting and challenging. Whether they are living on their own or with support, they have things in life they enjoy and people who care about them. As a caregiver, some of your support responsibilities may be transitioning to others—whether staff in a housing setting, professionals at work, or other places your adult with ASD frequents.



Caregivers say that it can be difficult to allow others to help, to have others share in this support role. Caregivers may worry that others may not do as good a job or may not do it like they would.

If your adult with ASD has other support in his or her life or if you are thinking of receiving additional support, use these questions to reflect or journal on your thoughts and ideas about letting go.

- How do you feel about the supporting players in your adult's life?
- Do you feel like you constantly check in or want to check in on them?
- What things would make it easier for you to trust that their services are being done well?
- In what ways would you like more support in your adult's life?
- In what ways might you like less help so you could do things on your own?

Support Network Opportunity

Talk to members of your support network about how they use others to help in their life. Did they have trouble letting go of some of the control? What have they done to make it easier for themselves?



Caregiving and the Individual with ASD

Exercise 3—Safety concerns and ideas

Some caregivers of adults mentioned that one of their biggest areas of concern is safety. Issues of safety may involve:

- Using the Internet and connecting with strangers
- Living on their own
- Misunderstanding social situations
- Aggression
- Misunderstandings by police



Day-to-day issues may raise safety concerns, such as cooking on one's own, or larger issues, such as potential victimization.

Because this can be a big topic for caregivers, let's discuss your concerns together and use each other as references to brainstorm ideas for helping keep our adults with ASD safe.

Take a moment to complete these questions:

What types of daily situations might create safety concerns in your adult with ASD's life?



What types of activities might create safety concerns?

Can you remember a time or experience when something happened to or with your adult with ASD? If so, what happened and how was it resolved?

What are your biggest concerns for safety?

How are you addressing these concerns right now?

Let's discuss these questions and your answers. We can then brainstorm ideas together that might help alleviate or help you manage some of these concerns.

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

Talk to members of your support network about experiences or situations that they worry about in terms of safety. What are some ways they've worked with their adult with ASD to manage these concerns?

Notes



Caregiving and the Individual with ASD

Video 4



1. How is your relationship with the individual with ASD different now than when he or she was younger?

2. In what ways do you connect with your adult with ASD?



Caregiving and the Individual with ASD

Handout 1—Physical activities

Physical activities and exercise are important for a healthy lifestyle. Exercise can help maintain weight while also preventing disease; it can also help alleviate tension, anxiety, and sadness. In addition, relieving stress can help to prevent problem behaviors. Exercise also gives more opportunities to socialize and be involved in the community.



Being active can be challenging for individuals with ASD because of lack of motivation, coordination, monitoring of self, and slower reaction time. Some physical activities in adulthood involve more social activities, such as team sports. Social activities may be fun for some individuals, or more independent physical activities may be a better fit. Your local YMCA, fitness, or community center may offer activity options.

Depending on the sensitivities and coordination of individuals, different exercise activities will be better fits than others. Consider these options when supporting an individual with ASD to get more into physical activities:

- Swimming
- Walking
- Hiking
- Dancing
- Jogging
- Hula hooping
- Yoga
- Treadmill
- Basketball
- Kickball
- Biking
- Trampoline
- Golfing



Caregiving and the Individual with ASD

Handout 2—Volunteering

Volunteering can be a great way for adults with ASD to be involved in their community and offer their skills and talents to a good cause. It can also be a way to establish and maintain relationships and continue to build skills.



Your local autism organization may have contacts for organizations with volunteer opportunities. Other volunteer opportunities that may be of interest to adults with ASD may include:

- Habitat for Humanity
- Local library
- Neighborhood clean-up day
- Animal shelter
- Local autism organization events
- Museums
- Local nonprofit organizations
- State or local parks
- Senior centers
- Salvation Army
- Local community centers
- Faith-based organizations or communities

To support an adult with ASD as he or she volunteers, the following things may be helpful:

- Make sure there are clear expectations for what the volunteer task will be. Have specific instructions, a specific timeframe, and maybe an assigned helper.
- The volunteer organization could create a visual schedule or checklist to help be clear about what needs to be done.



- Other volunteers can be made aware of an adult with ASD’s sensitivities (perhaps to noise, smell, touch) to make the environment more comfortable.
- Make sure needed supports—including help with transitions, a helper volunteer to support adult (if needed), and breaks—are put into place.

Volunteer Match (www.volunteermatch.org) can also connect you with other opportunities to volunteer in your local area.

Notes

Caregiving and the Individual with ASD

Handout 3—Internet safety

The Internet can be a wonderful place for individuals with ASD to create a community for themselves. To help keep individuals safe from possible victimization on the Internet, consider sharing these ideas listed below:



Things NOT to do on the Internet

- Do not share your first and last name.
- Do not share your address.
- Do not share your phone number or cell phone number.
- Do not share your Social Security number.
- Do not agree to meet people you meet online, in a face-to-face place.
- Do not share other family members' personal information, such as names, addresses, or Social Security numbers.
- Do not share bank or monetary information.

Things TO DO on the Internet

- Remain as anonymous as possible.
- Use only your first name or a nickname.
- Only use your credit card number when buying from a reputable, secure shop.
- Keep your passwords private.
- If you feel uncomfortable or upset online for any reason (in a chat room maybe), tell a trusted adult.
- If you do not recognize the sender of an e-mail, delete it.
- If you post pictures online, use only pictures that you would also show to your mother.
- Use an anti-spyware and anti-virus program.
- Adjust your privacy settings on social networking sites so that you share only information you want to share.



Work together with your individual with ASD to develop a list of Internet safety rules. That way, you can customize them based on how they use the Internet and their individual needs

Notes

Caregiving and the Individual with ASD

Handout 4—Fact sheet

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



Adults with ASD can and do live full lives. With support from caregivers and other individuals in their life, adults with ASD work, live at home or independently, maintain community relationships, practice hobbies, and live well-rounded lives.

Caregivers help to coordinate opportunities for adults with ASD to be as independent as possible. Most caregivers work as a team with their adults with ASD, supporting, encouraging, and championing them, as always.

Tips and Ideas to Help Caregivers

- Establish or maintain a circle of support—a group of people who are involved with your adult with ASD.
- Use a journal to write about the challenges of supporting an adult with ASD.
- Participate with your adult with ASD in physical activities that can help him or her lead a healthy, active lifestyle.
- Volunteer together with your adult with ASD or find opportunities for volunteering for your adult.



Caregiving and the Individual with ASD

Handout 4—Resources for more information



- The Daniel Jordan Fiddle Foundation: www.djfiddlefoundation.org
A national organization dedicated to adults with ASD.
- Temple Grandin: www.templegrandin.com
Temple Grandin, Ph.D. is an incredibly accomplished and perhaps the most well-known adult with ASD. Her Web site includes more information about her, her various books, and her intriguing descriptions of leading a successful life with ASD.
- *Asperger's From the Inside Out* by Michael John Carley
This book, written by an adult with Asperger syndrome, offers insights into leading an enriched adult life.
- *Getting to Grips with Asperger Syndrome: Understanding Adults on the Autism Spectrum* by Carol Hagland
This book explains common situations and behaviors in adults on the spectrum as well as offers practical strategies to help adults on the spectrum.
- *Life and Love: Positive Strategies for Autistic Adults* by Zosia Zaks
Written for adults with ASD, this book provides detailed information to navigate day-to-day life as an adult on the spectrum.
- The National Autistic Society: www.autism.org.uk/living-with-autism/adults-with-autism-or-asperger-syndrome.aspx
This Web site provides a variety of resources and information for adults with autism or Asperger syndrome.
- Autism Society of America, Autism Source: www.autismsource.org
Find an online resource database, autism information and local resources, providers, services, and support.



- John Elder Robison
John Elder Robison is a bestselling author sharing his life and experiences with Asperger syndrome. In addition to his books (*Look Me in the Eye: My Life with Asperger's*, *Be Different: Adventures of a Free-Range Aspergian with Practical Advice for Aspergians, Misfits, Families & Teachers*), he keeps a blog where he shares insights on being a successful adult with Asperger syndrome.
- Wrong Planet: www.wrongplanet.net
Wrong Planet is an online community for individuals with ASD, as well as their caregivers.

Notes

Caregiving and Services

Exercise 1—Information about adults with Autism Spectrum Disorders



Finding a respite caregiver or service is important to give primary caregivers time for themselves as well as for the adult with ASD to have additional support in his or her life. Every adult with ASD is unique. While some may need more vigilant supervision, other adults may live completely independently without the support of a caregiver. In the former situation, for respite caregivers, it can be helpful to share information about the adult with ASD to make the respite time as comfortable and routine as possible.

Complete this worksheet and share it with the respite caregivers who work with your adult with ASD. You may add other relevant information that is important to your adult with ASD, too.

Name: _____

Enjoys these activities:

Helps with these chores:



Does not like these things:

Has routines for:

Is very good at:

Is challenged by:

These things are important to him or her:

Enjoys these foods:

Has these hobbies:

Communicates by:



Caregiving and Services

Exercise 2—Workplace tips

Many adults with ASD enjoy rewarding jobs in various types of employment. The following tips can help to create an accommodating environment that promotes success in the workplace.



- Provide a regular work area with designated work supplies.
- Give a clear description of each task to be completed. This might include pictures, a flow chart, a checklist, or other visual device that the individual finds useful.
- Offer a regular schedule for each day so the individual becomes familiar with the daily routine.
- Create a quiet workspace with optimal lighting and noise levels for the individual.
- Help the individual transition from one task to another.
- Assign jobs or projects that can be completed once started.
- Make it clear what the individual should do once a task is finished.
- Provide awareness training about ASD to other employees.
- Role-play social situations with the individual with ASD that are common in the workplace.
- Provide consistent supervision.
- Communicate directly and clearly. Avoid using slang words, acronyms, or metaphors. Give concrete instructions that are easy to follow.
- Offer positive feedback routinely.
- Explain any changes in protocol or schedule to the individual directly. Provide a written or visual explanation of the new schedule.

Using these tips as a starting point, list 5–10 important things that an employer should know about your adult with ASD to create a successful workplace.



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

Ask your support network about the opportunities their adults with ASD have found for work. What types of education or advocacy have they used in the workplace environment that have supported their adult?

Caregiving and Services

Exercise 3—Contacting representatives

Caregivers are amazing advocates. You have always been the best advocate for your adult with ASD. Voicing your concerns and needs is a way to help improve services and access to services for you, your adult, and other adults with ASD.



Adults with ASD continue to need more services than what are easily and affordably available. Use your voice and your experience to tell your local, state, and federal representatives ways they can help you and your adult with ASD.

Ways to Contact

- Letters
- E-mail
- Phone
- www.usa.gov makes it easy to contact an elected official. Go to the Web site, click on “Contact Government,” and you can contact the President, senators, representatives, state governors, and state legislators, as well as local government agencies. You can easily find e-mail addresses, district offices, and phone numbers in this way.

Writing Letters

Individually written letters often make the most impact. When writing a letter to a representative, consider these tips:

- Focus on only one issue per letter
- Keep your letter to one page
- State your purpose for writing a letter in the first paragraph
- Establish why you are an expert or credible to comment on this issue
- Give specific examples, from your experiences and life, to support your purpose for writing the letter



- Ask for a response from the representative
- Provide your return address

Practice

List one to three topics that you could write to your representative about.

1. _____
2. _____
3. _____

What has been your experience with these topics?

What would you like your representative to address regarding these topics?



Caregiving and Services

Video 5



1. What types of community activities is your adult with ASD involved in?

2. What challenges have you experienced accessing services for your adult with ASD? How have you managed these challenges?



Caregiving and Services

Handout 1—Finding respite services

Finding time for a few hours to yourself or an evening out can be difficult without dependable, quality care or support for your individual with an ASD. Over the years, you may have accessed various services through local organizations, family, or friends to help provide yourself with some respite or additional care for your individual with ASD. Respite services can be challenging to find for adults with ASD. The resources below may provide more information and/or opportunities for respite.



Easter Seals (www.easterseals.com)—Offers services for individuals with ASD, including respite services for caregivers.

Autism Source (www.autismsource.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 (respite, services for adults with ASD) 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 local chapters exist throughout the country. Some chapters of the Arc employ advocates that can help families access respite services.

ARCH National Respite Network and Resource Center (www.respitelocator.org)—helps caregivers find respite services in their area that meet their needs.

Autism Speaks (www.autismspeaks.org)—Autism Speaks offers a searchable database for state and local resources. Respite and day program services can be found here.

Eldercare (www.eldercare.gov)—Eldercare Locator is a service of the U.S. Administration on Aging. You can search for local community resources online, in an online chat, or call representatives to find services for older adults and their families. They can help you find home- and community-based services in your area.



Caregiving and Services

Handout 2—Talking to service providers

Your adult with ASD may work with different service providers for living, work, hobbies, and community involvement. As you support your adult in achieving independence, it can still be helpful to check in with these service providers, see how things are going, and address any needs that arise. Using these tips can create a productive meeting for everyone.



- **Prepare questions ahead of time**—Set an agenda for your meeting beforehand. This will help you to be clear about what you want to talk about, and the providers will be able to prepare as well.
- **Set goals for meeting**—Decide what you would like to accomplish at the meeting. This might be put on an agenda, or a goal for a specific topic you'd like to discuss.
- **Ask for what you need**—If you are feeling out of the loop, ask for an update on services. If you have questions, let them know. As a caregiver and supporter of an adult with ASD, you need to be upfront about what you need.
- **Remind ahead**—E-mail or call with a reminder about your appointed meeting time.
- **Talk to someone**—If you are concerned about providers or want to talk before a meeting with providers, get together with a friend or family member. Talking through issues can take the “personal” out of it. Getting a new perspective can always help.

Here are some other tips for positive communications:

- **Be clear.** Speak up and be clear about what any issues or challenges are.
- **Listen actively.** Let providers talk, and make sure you understand what they are saying. If something does not make sense, ask for clarification. Repeat or paraphrase what the provider has said to confirm your understanding and show that you were listening carefully.
- **Avoid absolutes.** When discussing issues, try to avoid the words “always” and



“never.”

- **Use “I” statements.** Express how you feel instead of judging them. Instead of: “You aren’t doing enough,” try: “I feel upset when X isn’t getting enough exercise time.”
- **Ask questions.** If you do not understand the provider’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 or meeting, summarize what you have talked about and make sure you are on the same page. Check in on what the next steps are.
- **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.

Notes

Caregiving and Services

Handout 3—Fact sheet

The following information is covered in the Caregiving and Services section of the CFC program for caregivers of adults with ASD.



There are more resources and services available for adults with ASD than in previous years. While this is true, it can still be challenging to find the right services that are the right fit. Caregivers may find their adults on wait lists or with few real opportunities that might support them as well as hoped.

Caregivers frequently express a need for more day programs, social networks, housing options, job opportunities, and transportation solutions for adults with ASD. Caregivers want help finding these types of options in their local area.

With career or job opportunities, employers may need some education about ASD. Job support and mentorship is always something that there could be more of. An adult with ASD is navigating not only the work world, but the social aspect of the work world, which can be the most challenging.

Helping an adult with ASD be involved in the community is another way of staying active and meeting people. Support for community activities may be scarce, and caregivers may find that they are the coordinator and supervisor of many outings and experiences.

Tips and Ideas to Help Caregivers

- Provide specific information about your adult with ASD to service providers. Help providers get to know your adult's strengths, routines, and challenges.
- Providing employers specific information about the optimal work environment for an adult with ASD can create a more comfortable and accepting workplace.
- Respite services exist to help give caregivers a break.
- When meeting with service providers, plan ahead of time the questions you have and goals for your meeting.



Caregiving and Services

Handout 4—Resources for more information



- The Foundation for Autism Support and Training (FAST): www.foundationforautismsupportandtraining.org/
This Web site offers information on lifespan planning and other ideas and opportunities to help adults with ASD thrive.
- Aging with Autism: www.agingwithautism.org
Aging with Autism provides programs and services for adults with ASD.
- Advancing Futures for Adults with Autism: www.affaa-us.org
Advancing Futures is a national organization dedicated to adults with ASD. Through the Web site and organization, you can receive updates on opportunities to advocate on behalf of adults with ASD, as well as updates on policies and laws that impact adults with ASD.
- Jobs4Autism: www.jobs4autism.com
Jobs 4 Autism is a Web site that shares job success and challenge stories for individuals with ASD and their families. The Web site can provide ideas for job opportunities and tips for working with employers.
- U.S. Government-sponsored Web site: www.disability.gov
This U.S. Government-sponsored Web site connects the disability community to information and opportunities.
- *Adult Autism & Employment: A Guide for Vocational Rehabilitation Professionals* by Scott Standifer, Ph.D.
This guide discusses aspects of ASD that can affect a person's job performance and how the job and work environment can be adjusted to accommodate the individual with ASD. Available online at www.dps.missouri.edu/Autism/Adult%20Autism%20&%20Employment.pdf
- *The Job Developer's Handbook: Practical Tactics for Customized Employment* by Cary Griffin, David Hammis, and Tammara Geary
Internationally known for their innovative, proactive job development strategies, the authors motivate readers to expand the way they think about employment opportunities and develop creative solutions.



- University of Missouri Disability Policy and Studies: www.dps.missouri.edu
The Web site provides advice, training, and support to agencies and groups that provide services related to employment, independent living, community integration, and access for people with disabilities.
- Vocational Rehabilitation Service Models for Individuals with Autism Spectrum Disorders: www.autism.sedl.org
A research project to identify best practices in vocational rehabilitation for people with ASD, this site also acts as a clearinghouse for a variety of adult ASD resources.
- The Institute for Community Inclusion (ICI): www.communityinclusion.org
ICI offers training, clinical, and employment services; conducts research; and provides assistance to organizations to promote social inclusion of people with disabilities in school, work, and community activities.

Notes

Caregiving and Finances

Exercise 1—Financial planning questions

There are many ways and options that should be taken into consideration as you prepare for your adult with ASD's financial future. Use the questions below to think of questions you may have. If in a group setting, ask these questions of the group to start brainstorming answers. If you are on your own, consider asking your support or online network.



Have you started financial planning for your adult with ASD?

What resources do you currently have?

What information do you wish you knew?

What experts in this area have you heard about or connected with?

What books have you read?

What Web sites have been helpful?

*****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 the types of planning options they've explored to learn more.



Caregiving and Finances

Exercise 2— Life plan binder

Creating a binder that includes all of the relevant documents and information can be a huge help to you now and in the future. This life plan binder may include anything from contact information for your financial planning to a monthly bills statement to particular goals and future wishes that you and your adult with ASD have.



Take a moment to envision the different sections you would include in such a binder. Write them here:

Examples: bills, banking, trusts, Supplemental Security Income benefits

Then, for each section, what types of information would you include?

Examples: copies of statements, lists of contact information, account numbers, copies of documents



Who would you like to know about this binder and have access to it?

Examples: other children, other guardians, individuals in adult's life

Once you've brainstormed ideas for this binder, think about creating one at home. All you need is a binder, a 3-hole punch, and a bit of time. By compiling all of this information in one place, it will help you stay organized and make your adult with ASD's life plan easy to continue for others.

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Exercise 3—Vision statement

A vision statement (also called a letter of intent) is a non-legal document where you can write down specific hopes, plans, and goals for the future of your adult with ASD.



This vision statement can be updated regularly. Revisit it at least every few years, work with your adult with ASD and others involved in his or her life, and revise it to be as up to date as possible.

For this exercise, complete these questions to jump-start your ideas for the vision statement. The guidelines in Handout 3 will be helpful as you develop a complete draft of this vision statement. You will begin creating a draft of the vision statement, but you also should work with your adult with ASD and other invested individuals (like siblings) to complete a well-rounded, detailed document that represents the plans and goals for your adult with ASD's future.

When you visualize your adult with ASD's future, what do you see that will create a full life for him or her?

What types of goals do you have for your adult with ASD's future?



What things do you NOT want to see in your adult with ASD's future?

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Video 6



1. What types of financial planning options have you explored or implemented?

2. What types of financial planning options have you explored or implemented?



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Handout 1—Budget

Creating and maintaining a monthly budget with your adult with ASD can help him or her manage finances and track his or her job or financial support. Use the following worksheet to develop a monthly budget together with your adult with ASD. Encourage him or her to keep track of receipts; then, at the end of the month, go back and see the expenses for the month. Revise the next month's budget as you both see fit.



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

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Handout 2—Choosing a financial planner

Even if you have a plan in place, checking with a financial planner who specializes in special needs adults can be useful when laws change or situations change. Use these questions when choosing a financial planner who will be the best fit for you and your adult with ASD.



- How long have you been specializing in special needs financial planning?
- How many years of experience do you have working with families with adults with ASD?
- What is your approach to working with families with adults with ASD?
- What types of financial planning resources do you usually recommend to families?
- After we establish a plan, how often would we meet to review or make updates?
- How long have you been working in the financial planning field?
- What are your educational and professional qualifications?
- What financial planning certifications do you have?
- How are you paid for your services—flat fee, hourly rate, commission?
- Can you provide three references from other families with adults with ASD who you've worked with?



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Handout 3—Vision statement guidelines

A vision statement can specifically highlight the goals, plans, and hopes for an adult with ASD's future. You can include as many topics as you want, with as much information as you want. In the end, the vision statement can be kept in a safe place, where individuals involved in your adult's life know where to access it.



Areas to Cover in the Vision Statement

- Names, addresses and, phone numbers of important contact people (not only family and friends, but also professionals)
- Biography of adult with ASD—likes, dislikes, strengths, challenges, history
- Wishes and goals—For each of these areas, detailing goals for the future as well as specific resources in place for each topic area:
 - Housing/residential
 - Education
 - Employment
 - Medical
 - Social
 - Faith/religion
 - Leisure
 - Finances

Remember that you can add other topic areas. Be as detailed as possible.

The Vision Statement Team

The vision statement can be a team effort. You can work on it, actively involving your adult with ASD through each step of the process as much as possible. Other team members may be siblings, Circle of Support members, or other trusted individuals active in the adult's life.



Living Document

A vision statement is not set in stone and can be revised frequently to reflect any changing plans, goals, or needs. At a minimum, it should be revisited every few years to make sure it is up to date.

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Handout 4—Fact sheet

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



Future planning is often thought of as a financial planning process. Yet, future planning also involves planning for legal, residential, employment, retirement, leisure, and advocacy needs. Just thinking about all of these things might feel overwhelming and make it difficult to even get started formulating a plan. Many caregivers mention that they are just getting through the day-to-day stuff and have a hard time getting started planning for their adult's future.

Future planning is an ongoing process that you do not have to do on your own. There are resources and professionals available. Furthermore, because planning should reflect everyone involved—you, siblings, other caregivers, and especially the individual with ASD—you can use teamwork to create a vision for the future. Revisiting and revising your future plan should happen at least every few years to keep it up to date and relevant to the needs of the adult with ASD.

In addition to future planning, caregivers also mention their difficulties balancing their own career needs with the needs of caring for their loved one. Because many adult services are not covered by insurance or the fit of services to the individual might not be optimal, often caregivers face the tremendous decision of deciding between their job or staying home to support their adult with ASD. Even if your decision is not this drastic, you probably continue to feel pressures to find and pay for appropriate services.

Tips and Ideas to Help Caregivers

- If you have questions about financial planning and it seems daunting to get started, write them down. See what information you already know and what you still need to find out.
- Ask other caregivers for references to financial planners who specialize in families with adults with ASD.



- Create a life plan binder to hold all your relevant documents and information on financial planning and monthly expenses.
- Develop a vision statement together with your adult with ASD.
- Help the adult with ASD to create and maintain a monthly budget.
- Interview financial planners to be sure they provide the specific services that you need.

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Handout 5—Resources for more information



- Organization for Autism Research: www.researchautism.org
OAR offers an annual scholarship to qualified individuals with ASD for postsecondary education.
- Autism Society of America: www.autism-society.org
ASA offers information on future planning on its Web site. On the homepage, search for “future planning.”
- Autism Speaks: www.autismspeaks.org
On the AutismSpeaks Web site, you can search for state resources specific to financial or future planning.
- Benefits.gov: www.benefits.gov/benefits/browse-by-category/category/DIA
Benefits.gov (formerly GovBenefits.gov) is a U.S. government-sponsored Web site about disability assistance benefits that was launched in an effort to provide citizens with easy, online access to government benefit and assistance programs.





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