Autism™
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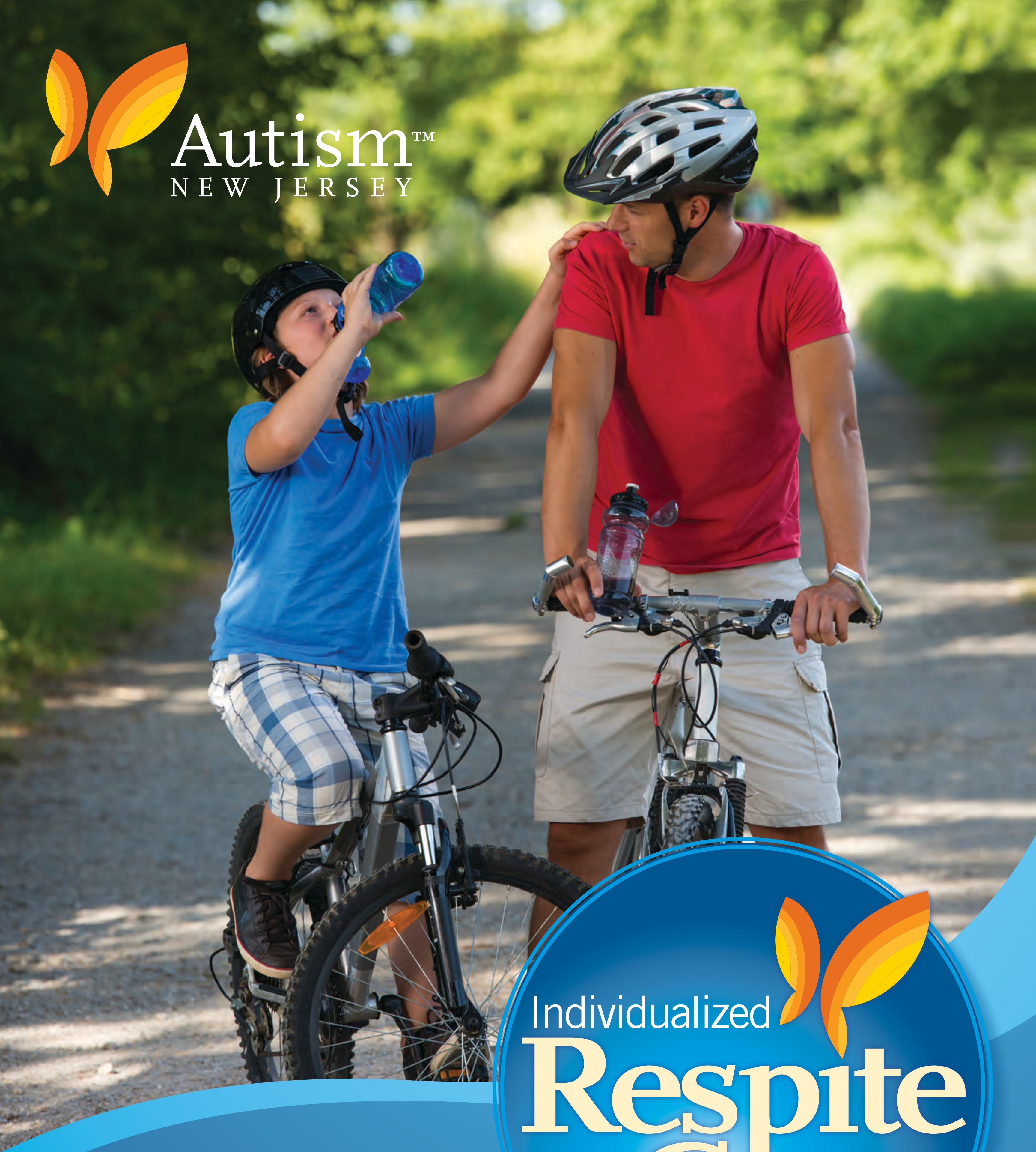

Individualized Respite Care Guide

A Resource for Families and Providers

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Individualized
Respite
Care
Guide

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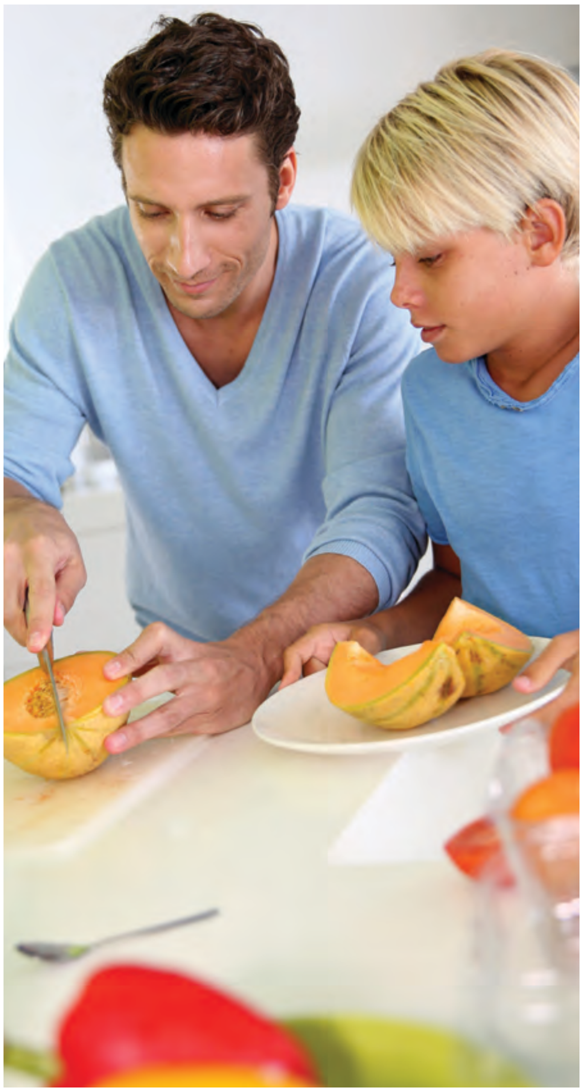
AUTISM SPEAKS™
It's time to listen

Foreword

Many individuals with autism spectrum disorder (ASD) require significant levels of support in home, school, and community settings. Due to deficits in social communication and interaction, compounded by restricted, repetitive patterns of behavior, many individuals need direct supervision throughout their lives. Individuals can make great progress when provided with specialized intervention, yet there are many who will not be able to keep themselves safe so need constant supervision, even as adults. This duty usually falls to already exhausted families who experience the stresses of intense caregiving demands and restricted daily activities. They may be unable to accept career opportunities, attend religious services, participate in activities with other family members, or enjoy community events due to special childcare issues. Parents also report a lack of time alone to relax and the virtual impossibility of family vacations. Not surprisingly, they are at risk of both physical distress such as poor sleep and psychological distress exacerbated by extreme stress, anxiety, fear, and guilt. Marital difficulties, fears about safety, and financial worries over autism intervention are just a few of the specific concerns frequently shared. These potentially damaging effects on both individual family members and the family unit point to the need to develop respite services geared specifically for individuals with autism and their caregivers. As these challenges often continue into adulthood, the information discussed in this guide pertains to individuals with ASD *of all ages*.

Respite services have improved over the years, but there are still far too few services available. Parents report the need for greater quality, quantity, variety, and flexibility in how these services are provided. They also request autism-specific respite so that providers are prepared to support the complex and unique needs of individuals with ASD. According to research, one of the most valued options by parents is formal in-home care. This guide is designed to prepare the parents and the provider for such care, whether the provider is a professional from an agency or an extended family member or friend. The critical nature of training for respite providers cannot be overemphasized. Services provided by those who may be well-intentioned but not well-trained can undo the potential benefits of the respite for both the family and the individual. In this guide, we will highlight important characteristics of autism that must be understood as well as best practices for addressing them. Research clearly suggests that respite is a lifeline for families, so it is vitally important that it provide the intended effects.

We sincerely hope this guide will help families continually improve the potential benefits of their respite experiences by providing a system for educating potential providers about autism and their unique loved one. Please contact us at 800.4.AUTISM or information@autismnj.org for any autism concerns pertaining to respite, early intervention, special education, transition, adult services, insurance, and more.



What is Autism?

Families want to know that anyone providing respite care has an accurate understanding of autism. The extent to which ASD affects each person varies greatly, and parents will provide those details in the separate form provided. But to make the respite experience more successful for everyone, the provider should at least know the basic facts about autism and best practices for interactions.

Autism is a neurological disorder characterized by impairments in social communication and interaction as well as restricted, repetitive patterns of behavior. Individuals with ASD have difficulty interacting with others: building relationships, using language, regulating their own emotions, and understanding others' points of view. Some prefer to be alone and do not seek social interaction, yet others clearly want to be social but may not understand how to do so effectively. Some develop fluent conversational speech, others speak only to get their basic needs met, and still others remain nonverbal but may communicate with pictures, sign language, or technological devices like smartphones or tablets. They may have repetitive physical mannerisms (rocking, pacing, waving) or vocalizations (using the same sounds or phrases over and over). Intense interests in certain topics, insistence on strict routines, and unusual responses to sensory input are also common. Because of these difficulties, there is an increased likelihood of frustration and therefore challenging behaviors including aggression and self-injury. Health and safety concerns include seizures, significant eating and sleeping problems, and eloping or wandering. Individuals with ASD often require specialized educational programs to learn how to do simple daily tasks as well as more complex skills. Many on the spectrum will also have an intellectual disability (IQ lower than average) that needs to be considered. But rather than being simply several years behind in their development, they may have some skills at or above their age level in addition to significant challenges. These unique traits are part of the reason why autism-specific intervention is so important. Conversations between the family and provider (such as those prompted by the forms provided in this guide) are crucial to painting a clear picture of how the individual is affected by autism so everyone can best meet his/her needs.

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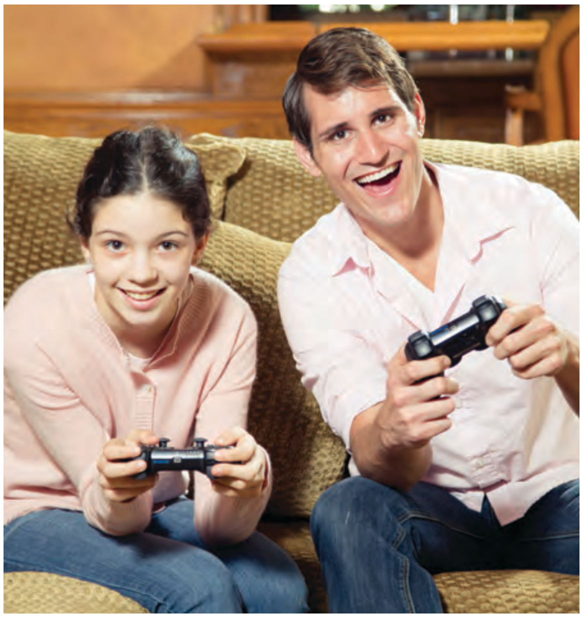
How Can Autism Affect Families?

For many, autism has a significant effect on every aspect of the family. Living with and caring for an individual with autism requires extreme patience, and the experience will have its ups and downs. Initially, it can take time for families to adjust to the diagnosis, address their emotions, and become knowledgeable about autism, intervention, and advocating for their child. Parents may have had certain hopes and expectations for themselves and their children that were altered after the diagnosis. They may be unable to return to their careers as planned, their circles of friends may change, community activities may become too difficult, and finances could become an increasing concern. Specific stressors may include excessive caregiving demands, extraordinary concerns about the child's well-being, difficulties in obtaining services, supporting their other children, and planning for the future. Living with constant stress can have physical effects as well; recent studies have shown that mothers of individuals with autism have physiological profiles similar to combat soldiers and those with posttraumatic stress disorder. It is essential that respite providers understand the stress experienced by families so that they can assist in a compassionate manner.

What Do Families Look For in Respite Providers?

Families entrust respite providers with the ultimate responsibility: the sole care of their loved one. No matter the age of the individual with ASD, the family's concern over placing this trust in someone else must be respected. Due to the unique challenges associated with autism, parents typically have certain expectations of their respite providers. Above all else, safety is the primary objective. Parents have repeatedly shared how desperately respite services are needed, but only if they feel that their child will be safe in the provider's care. Understanding the traits of autism, knowing the individual well, and appreciating potential dangers in the environment can help ensure the safest conditions. Flexibility, staying calm during stressful situations, and good problem solving skills are all essential qualities of respite providers that relate directly to keeping everyone safe.

Beyond the clear focus on safety, certain professional characteristics are also important when providing respite. Being reliable and punctual are mandatory so the family can count on the services being provided when expected. Confidentiality is another required professional attribute; families are trusting providers to be in their homes and expect that their personal information is kept private. Providers should support the individual's development by learning how to engage him or her and following the plans the family has in place to increase independence. It is crucial to be as consistent as possible with the family's instructions. The role of respite provider takes energy, enthusiasm, and creativity as well as a willingness to learn new skills.



Another vital trait that families look for in providers *and* providers need in the families they serve is clear and open communication. Expectations of what will happen during respite must be clearly expressed and understood. Details about the individual and the activities to take place should be shared in advance (using the forms in this folder as a guide) as well as information about the respite time after the family returns. Accepting feedback in a professional manner is an important aspect of this communication. Oftentimes, the needs of the individual with autism are complex and may require very specific procedures. Providers should be open to learning about different approaches that might work better when interacting with the person. Therefore, when parents or other professionals provide feedback, the respite provider should take time to listen, willingly accept the feedback, and ask any clarifying questions. Providers should also share what they did with the individual that was successful so the parents can try it as well. This two-way respectful communication will benefit everyone.

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How Should Providers Interact with Individuals with Autism?

Getting to know someone with limited social communication skills can take time, but developing a positive relationship is fundamental to a successful respite experience. To begin to establish rapport, providers should find out about his or her interests. Many individuals with ASD are very passionate about certain topics or activities, so learning what these are (by asking the individual, the family, and just by observing) is key. Joining in these preferences may help the person with autism to engage with the provider and enjoy the respite time even more. Many people with ASD have great anxiety about change, so following the usual routines and being consistent with what the family does can greatly increase their comfort level. By communicating these details in advance, the family and provider can work as a team to ensure a quality respite experience.

An important part of working with individuals with autism is reinforcement. When someone engages in any behavior, the likelihood of it occurring again increases when it is followed by a pleasant consequence. In other words, if James finishes his homework and gets to play his favorite video game, he may be more likely to complete his assignments the next night if he knows he can play that game afterwards. Without that motivation, he may not cooperate when told to do his homework. What each person finds reinforcing is different and changes over time, so this is more information families should share before respite. If Ashley doesn't want to go to bed on time, reminding her that she can read her favorite book once she is ready and in bed may motivate her to complete her nighttime routine. If the provider doesn't know that Ashley really likes reading that particular book before going to sleep, it may be difficult to motivate her to follow basic directions to prepare for bed. Note that reinforcement only happens after the behavior is done; letting her read the book before she has done what was asked is not the same thing. Reinforcement is especially important when asking someone to do something they are really not interested in or find particularly difficult. Individuals with ASD have difficulty learning from their environment, so when a fun consequence is earned for a specific behavior, they can more likely see the connection between their actions and the results. They may not understand yet why it is important to eat their vegetables, but if they get their favorite ice cream after they do, they will be more likely to finish their dinner tomorrow. For some people, praise or a high-five is reinforcing enough to motivate them, but others will need more concrete examples that they are doing what they are supposed to do. For example, Ashley might get a sticker as she completes each step of brushing her teeth, putting her pajamas on, and getting into bed to show her progress towards being able to read her book. Whatever form the family has established, providing positive reinforcement helps to clarify and reward what the individual *should* do rather than punishing what he or she *shouldn't.* At the same time, the provider becomes associated with positive experiences which may encourage the individual to look forward to the time spent together.

There are several strategies to address the communication challenges of individuals with ASD, both in expressing themselves and

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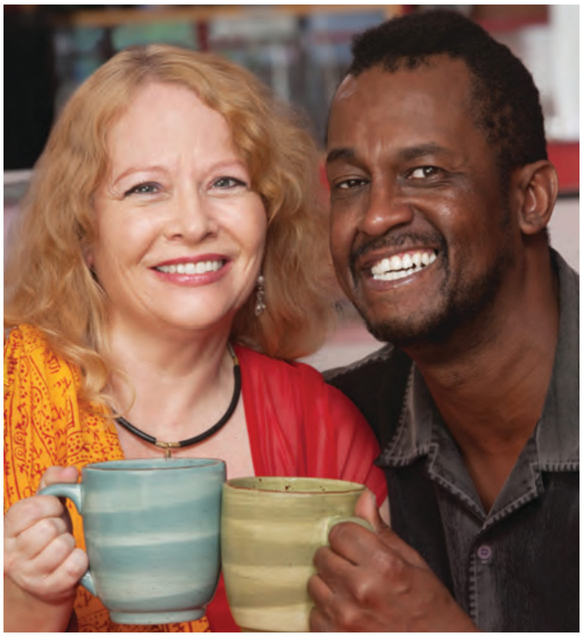
Providing positive reinforcement helps to clarify and reward what the individual should do rather than punishing what he or she shouldn't.

understanding others. The way questions are phrased greatly affects the person's ability to respond. Open-ended questions with an infinite number of possible answers may be too confusing, so start with simple yes/no or short-answer questions. Instead of asking, "What do you want to eat?" try, "Do you want pizza?" Some individuals may respond yes or no when they do not really understand what is being asked; thus it is important for parents to share how they understand what their child wants. Whenever possible, offering choices promotes independence and respects the individual's preferences. Suggest only two or three options so as not to be confusing. Some individuals with autism repeat the last words they heard. If this seems to be the case, to be sure they are answering as they intend, reverse the choices. For example, first ask, "Do you want to ride your bike or scooter?" and then "Do you want to ride your scooter or bike?" If they consistently choose the last option, show the two items to make the choice clearer. In some cases, it takes a little longer than usual for an individual to respond, so allow extra time before moving on or repeating the question. Although sometimes it may be obvious what the person wants, encourage him or her to request it in whatever form they are capable (attempting the sound, giving a picture of it, signing, using a full sentence, etc.) before providing it. If Jayden says, "Outside," but the family has said that he can say, "I want to go outside," prompt him to say that before going out. This will help him to learn that he needs to speak fully with everyone he encounters. Whenever the individual communicates appropriately, be encouraging and provide positive reinforcement so he or she will be more likely to do so again.

Perhaps the most important thing providers can do to help the individuals they are caring for to understand them is to choose their words carefully. Speak as simply and clearly as possible. For example, break activities down into small steps, give one direction at a time, and avoid expressions that could be confusing ("What's up?" or "That's cool!"). Phrase directions as what *to* do instead of what *not* to do: "Sit, please," instead of "Stop jumping on the couch!" Praise should be frequent and specific, such as "Thank you for cleaning up!" or "Good reading!" (depending on their comprehension level) rather than a vague "Good job!" Also, keep in mind that their understanding of language is likely very literal; if a provider states that she will do something "in a minute," the individual may get upset if more than sixty seconds go by and it is not done yet. Explaining what will happen at each stage of the respite time may also help reduce anxiety, and visual supports can be a great way to do this. They can be written lists if the person can read or pictures if something even clearer is required. Families may already have visual supports in place, or providers can create schedules for the day, choice boards (pictures of available options), or instructions for completing activities like making lunch or getting ready for bed. Getting the person's attention before speaking to him or her and keeping a calm yet firm tone of voice may also help. Providers may be surprised and pleased to learn how interactions with individuals with ASD can improve when they deliberately focus on interacting in ways they can more easily understand.



It is most important for respite providers to be incredibly vigilant when responsible for someone with ASD. No matter their age, they may not recognize basic dangers such as a hot stove, busy parking lot, or deep water or realize they could be hurt if they suddenly run into traffic, climb onto the roof, or hide in a tight place. What providers learn from parents about the person's functional level is much more important than their actual age. The form in the back of this guide can help families share these types of details and prepare the respite provider.

How Should Providers Handle Challenging Behaviors?

One of the biggest concerns about respite care is shared by both families and providers: what will happen if the individual with ASD exhibits any challenging behavior? Because of the social, communication, and behavioral difficulties, individuals may resort to inappropriate behavior to communicate, express frustration, or get what they want. This will not apply to everyone, but some may engage in aggression, self-injury, or other dangerous actions. When patterns emerge that predict when challenging behaviors are likely to occur, families and providers can take steps to minimize or even prevent them from happening at all. This proactive approach is a great way to reduce their likelihood, but it is also important to have a plan in place if they do happen. Families should explain these strategies to providers in advance of the scheduled respite.

Addressing challenging behaviors is best accomplished through a functional behavior assessment (FBA), often conducted by a Board Certified Behavior Analyst (BCBA). This includes documenting what happens right before and after the behavior so the team can look for patterns to suggest *why* it is happening. Although it can be difficult to determine in some situations, providers must understand that behavior serves a function, or purpose, for an individual. If new challenging behaviors develop suddenly, a medical evaluation may be necessary since the individual may not be able to communicate that he or she is in pain. Other simplified functions are to get something (an item, activity, or attention), to avoid something (a task or location), or for sensory stimulation or relief. Once the reason for the behavior is understood, everyone involved can begin the process of teaching safer alternatives.

For example, when Anthony is told to clean his room, he runs into the bathroom and slams the door. His parents allow him to stay in the bathroom, time passes, and he never ends up cleaning the mess. The next time he is told to clean his room, he is likely to hide again. Although not an appropriate response to his parents' direction, this behavior was effective because it enabled him to avoid the task. By analyzing these consequences, the family can try alternate ways to handle the situation, such as initially starting with a smaller task (asking to just make the bed), planning positive reinforcement, and exploring other proven strategies to motivate Anthony to follow that instruction.

Although many challenging behaviors can be prevented, the following are general tips to keep in mind if they do occur. Instead of reacting in frustration, take some time to consider why the individual may be having difficulty. For example, if Emma wants to go outside at a time it's not allowed, let her know when she can and suggest other activities she enjoys. If Caleb throws away his homework and refuses to work on it, consider why he may be trying to escape the task; maybe he needs help or would like to take a brief break every ten minutes, choose the order in which he completes the assignments, or have quiet music on while he works. If Ben misbehaves to get attention, be sure to give plenty of attention to his appropriate behaviors and demonstrate better options. If these types of responses don't help and the individual's agitation becomes a safety concern, the provider should follow the guidelines set by the family as to who to contact. Safety is always the number one priority.

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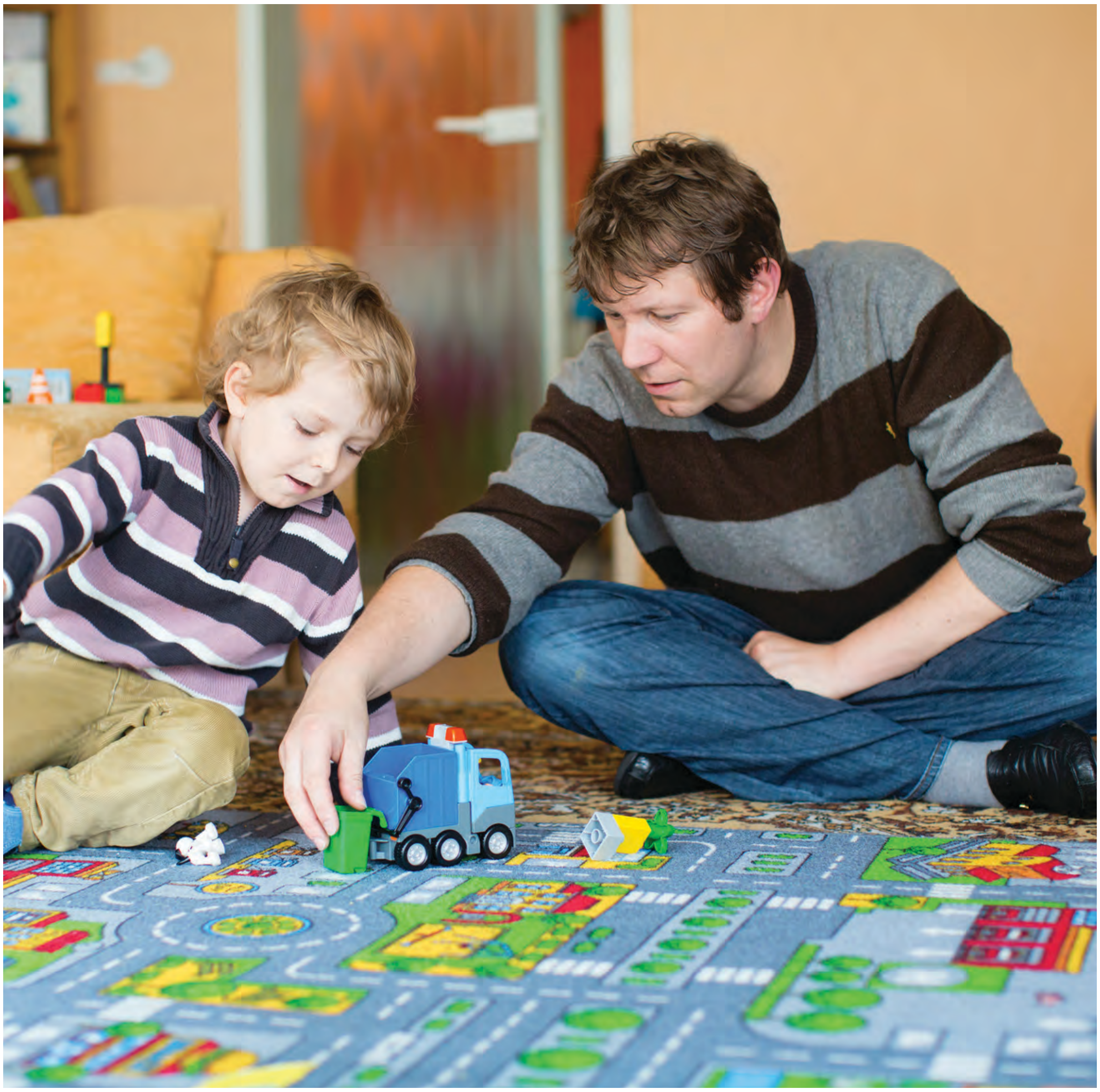
Taking Care of Yourself as a Caregiver

Whether you are caring for someone in your family or doing so as your profession, caregiving is a unique job that requires a lot of patience and energy. While it can be extremely rewarding, it may also produce stress and fatigue. These side effects of the role may impact relationships between respite providers, families, and individuals with autism as well as other aspects of your lives. Although it may seem there is never enough time, taking care of yourself should be considered a priority or you may not be able to care for anyone else. Making time for yourself, participating in stress reduction activities like exercise, and communicating the need to take a break when necessary are a few ways to stay strong and committed to this important role. It is our hope that the communication prompted by this guide will enable individuals with autism to be effectively supported, families to take advantage of respite opportunities, and providers to be compassionate and skilled when serving those with ASD.



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About Autism New Jersey

Autism New Jersey is the largest statewide network of parents and professionals dedicated to improving the lives of individuals with autism spectrum disorders. Self-advocates, their families, the professionals who work with them, government officials, the media, and concerned state residents all turn to Autism New Jersey for information, compassionate support, and training. Our public policy work in Trenton, annual conference, and information line (800.4.AUTISM) are just a few of the ways we make a difference for New Jersey's autism community.

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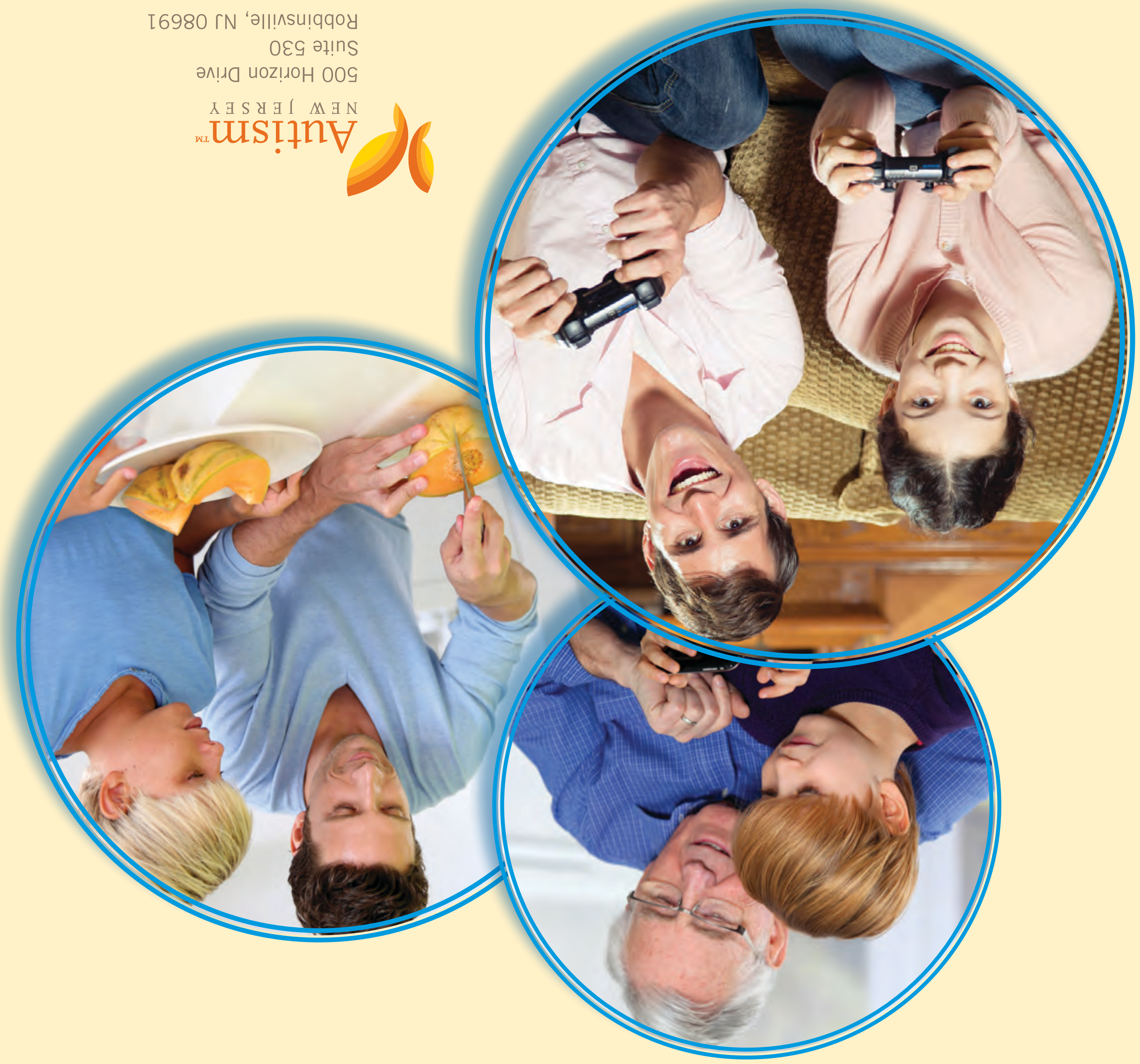
We’d Love Your Feedback!

Parents and respite providers, please let us know what you like about the *Individualized Respite Care Guide* and how the guide and/or forms could be improved. Email information@autismnj.org or call 800.4.AUTISM. Thank you for your help in developing future editions of this resource.



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Individualized
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Family Form

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This guide is designed to help you describe your child (of any age) in detail by spurring thoughts of the little tricks that you've learned lead to more successful interactions. Sharing this with potential respite providers in advance should help them to feel more prepared and make the time with your child more successful.

Additional copies of this form can be downloaded at www.autismnj.org.

Suggestions for Completing the Guide

- Be specific! The more detailed information, the better.
- Update the information as your child grows.
- Keep a copy in an easily accessible place.
- Encourage providers to bring this guide if they leave the house with your child.
- Although you are offering as much information as possible, remind providers to still expect the unexpected!

EMERGENCY INFORMATION

- **Phone numbers**

Name ________________________________ Number(s) ________________________________

Name ________________________________ Number(s) ________________________________

- **Under what circumstances to call (check all that apply)**
  - ☐ Only in case of emergency
  - ☐ If (s)he becomes upset and can't be consoled
  - ☐ If (s)he becomes aggressive
  - ☐ If the provider is unable to locate something (s)he wants/needs
  - ☐ General questions
  - ☐ Other reasons: ________________________________

- **Emergency contacts if parents/guardians are not available**

Name ________________________ Number(s) ____________________ Relationship: ________

Name ________________________ Number(s) ____________________ Relationship: ________

- **Preferred hospital**

Doctor's name, office address, and phone number ________________________________

____

Insurance company, name of policy holder, and policy number ________________________________

____

Medical release form (if needed) ________________________________

- **Medications**

  Names ____

  ____

  Times ____

  Amounts ____

  How the medications are taken (with meals, mixed in applesauce, etc.) ______________________

  ____

- **Allergies**

  List ____

  Signs of an allergic reaction ____

  How to respond ____

- **Seizures**

  Signs of a seizure ____

  How to respond ____

  How long it usually lasts ____

  How (s)he usually acts afterwards ____

  Who to contact (parents, doctor, 911) ____

- **Other medical conditions**

  ____

  ____

- **Dangerous behaviors to be aware of** (check all that apply, describe, and advise how to prevent or intervene)

  ☐ Eloping/wandering (leaving the designated area without telling anyone)

  - Places (s)he might go or hide ____

  ☐ Strong interest in pools or bodies of water

  - Can (s)he swim? ____

  ☐ Eating nonfood items or putting them in his/her mouth ______________________

  ☐ Aggression ____

  ☐ Self-injury ____

FOR COMMUNITY OUTINGS

- **What to bring** (check all that apply and describe any specifics)
  ☐ Change of clothes
  ☐ Visual schedule
  ☐ Reinforcers ______________________________
  ☐ Other: ______________________________
  ____
- **Transportation plan** (should car doors be kept locked, where (s)he should sit in the car, etc.)
  ____
- **Toileting plan** (ladies' or men's room, alone or with provider, diapers/pull-ups, etc.)
  ____
- **Notes for specific locations within the community** (go into restaurant or use drive-through, favorites, etc.)
  ____
  ____
- **Level of supervision needed in various environments** (hold hands, be at his/her side at all times, stay back if with friends, etc.)
  ____
  ____

AT HOME

- **Any areas that are off limits** ______________________________
- **Doors/windows** (lock, keep closed, okay to open) ______________________________
- **Telephone** (answer or let it go to voicemail) ______________________________
- **Directions for operating TV, DVD player, computer** (password)**, and anything else (s)he might want to use**
  ____
  ____
- **Favorite items and activities (indoor and outdoor)** ______________________________
  ____
  ____
- **Items and activities (s)he does NOT like** ______________________________
  ____
- **Activities that (s)he might want but are not recommended** ______________________________
  ____

- **Any concerns related to spending time outside** ______________________________

____

INTERACTING

- **General communication level** (check all that apply)
  ☐ Verbal (can express self clearly)
  - If highly verbal, favorite topics to discuss ______________________________

  ☐ Limited verbal (small vocabulary or difficult to understand)
  - Unusual phrases (s)he might use ______________________________

  ☐ Nonverbal (no or extremely limited spoken vocabulary)
    ☐ Uses PECS (Picture Exchange Communication System)
    - Location of book and how to use it ______________________________

    ____

    ☐ Uses sign language
    - Most frequently used signs ______________________________

    ____

    - Any modified signs ______________________________

    ☐ Uses an iPad or other device
    - Location of device and charger ______________________________

    - Specific instructions on how (s)he uses it ______________________________

    ____

- **Communication strategies that may be effective** ______________________________

____

____

- **Communication strategies that are less likely to work** ______________________________

- **What (s)he calls others who live there** (Mom/Mommy, siblings' names, pets) ______________________________

____

- **Ability to follow directions**
  ☐ Independently
  ☐ Independently but needs extra time
  ☐ Needs a reminder or cue
  ☐ Needs significant assistance

- **Signs that (s)he is happy** ______________________________

- **Signs that (s)he is becoming upset** ______________________________

- **Signs that (s)he needs to use the bathroom** ______________________________

- **Signs that (s)he is hungry** ______________________________

- **Signs that (s)he is tired** ______________________________
- **Signs that (s)he doesn't feel well** ______________________________

UNUSUAL BEHAVIORS

- **Repetitive sounds** ______________________________
- **Repetitive movements** (rocking, pacing, waving) ______________________________
- **Activities** ______________________________
- **How to address these behaviors** (if at all) ______________________________
- **How not to address them** ______________________________

FUNCTIONAL SKILLS

- **Eating**
  - Set meal/snack times or whenever (s)he likes? ______________________________
  - Where can (s)he eat? ______________________________
  - Any particular utensils and dishes? ______________________________
  - Favorites foods (and how to prepare) ______________________________

    ____
  - Foods (s)he will not eat ______________________________
  - Dietary restrictions ______________________________
- **Toileting**
  ☐ Can do independently
  ☐ Needs assistance with (and how) ______________________________
- **Bathing/hygiene** (bath or shower?)
  ☐ Can do independently
  ☐ Needs assistance with (and how) ______________________________
- **Dressing**
  ☐ Can do independently
  ☐ Needs assistance with (and how) ______________________________
- **Bedtime routine**
  - Time ______________________________
  - Lights on/off, door open/shut ______________________________
  - Favorite book, activity, or item needed ______________________________
  - What to do if (s)he gets up ______________________________

- **Schedule**
  - Daily schedules or routines ____
  - Best way to transition to different activities ______________________________

☐ Provide advance warning ("In 5 minutes we will…")

☐ Use a picture schedule

☐ Use a written schedule

☐ Use a timer

  - How to respond to difficulties transitioning ______________________________

- **Sensory Sensitivities**
  - Preferences ____
  - Sensations (s)he finds upsetting ______________________________
  - How to accommodate ____

Any Other Potentially Upsetting Experiences

- Describe ____
- What may prevent them ____
- How to react if they occur ____

Behavior Plan

- What the problem behavior looks like ______________________________
- How often it typically occurs ______________________________
- How long it usually lasts ______________________________
- Triggers ____
- How best to respond ______________________________
- How NOT to respond ______________________________

ADDITIONAL COMMENTS

Individualized Respite Care Guide

Provider Form

Autism™ NEW JERSEY

Providers can record the following information here, or it can be used as a guide for a follow-up conversation.

Provider’s name ____

Date and time of respite ____

How the time was spent ____

____

____

Activities that were successful ___________________________________

____

Any challenges ____

____

What (s)he ate ____

____

Time (s)he last used the bathroom _______________________________

Time (s)he went to bed ____

Any safety concerns ____

____

____

Any additional information to share _______________________________

____

____

____