

Handbook For Parents to Assist in the Support and Training of a Respite Worker



**For Families who have a Child who has Autism
Spectrum Disorder.**

March 2008

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What is this booklet all about?

In 2007, representatives of the Ministry of Children and Youth Services (ON), South West Region, hosted meetings to talk to parents about respite services for families who have children and youth who have autism spectrum disorder (ASD). The purpose of this discussion was to understand more about the needs of these families, how respite services can offer support and gathering suggestions and recommendations from families. There were three major recommendations that came from these discussions.

First, the Ministry heard that respite care is a major support to families who have children with ASD. Respite care helps to sustain, “recharge” and support families so that they can continue to care for their child. Secondly, the families reported that they wanted the people that provide respite care for their child to have the opportunity to have training so that they will understand the particular needs of children with ASD and ways to provide support to them. ***Finally, participants said that families would like training and support to help them find people to provide respite care for their child and family, to develop effective ways to train their respite care provider and help them find ways to retain their workers.***

The Ministry of Children and Youth Services invested funding to increase resources for respite care for families across Ontario. Developing training opportunities and resources for workers was a part of this initiative. This booklet is part of the training support requested by families, with a goal of providing resources to help families to train and support their workers.

Respite care is intended to be a time when families can entrust the care giving of their child to someone they trust, giving them a time to reenergize. It is designed to be a service that empowers and strengthens families. That being said, we know that it is also complex having someone else come into your home on a regular basis and care for your child. We hope that some of the tips in this booklet give some suggestions that will assist families.

Many families who have children with ASD have people who are implementing specific therapies and strategies with their child such as ABA. Respite workers are not therapists. That being said, if there are particular goals that you are working on, the respite worker can often incorporate these things in their time with your child.

The time you take to prepare, train and support your respite care provider will be time wisely invested.

Section One:

Thinking about what makes your child and family unique

Take some time to think about your child and your family and what their special characteristics are. This will help you to talk about your child with a potential caregiver. It will also help you to think about what is most important for your child and for your family. It's sometimes difficult to do this, but the more specific you can be the more likely you will be to find someone who is a good match for your family.

Your Child's Unique Personality and Needs:

We know that children with ASD have particular kinds of needs. It usually means that they have particular challenges related to communication and social interaction. It often means that they have very specific kinds of reactions to the world around them, including sensory issues, making it hard for them to interpret what's happening. Usually, as a parent, you and other people who know your child well can tell about the way your child communicates. You have come to know the "cues" that something is happening. It might be confusion, anxiety, anger, frustration or excitement. Someone who does not know your child might read these signs incorrectly and inadvertently set off a chain of events that set your child up for failure. The more information caregivers have, the more likely they are to assist your child to be successful.

There has been a lot of media coverage about autism and autism related disorders over the last decade. The positive part of this is that a respite worker is likely to have information about ASD. The negative part is that they may also have preconceived ideas about your child, misinformation and ideas about strategies that don't fit with your child or your family. Therefore, discussing how ASD affects your child in particular is really important.

Make notes for yourself about these things. Parents find it hard to "tell their story" over and over. Putting things in writing often makes it easier to do this. Sometimes it is easy to get distracted in the conversation and a written guide helps to focus on the things that are important. Sharing information at the time you are interviewing and screening a new worker helps you both to decide if the worker's skills, interests and personality fit with your child.

In consulting with parents about the development of this booklet, parents said that they wanted the respite worker to have knowledge about autism, but it was just as important that the worker think about their child as an individual and get to know their child as a unique individual and understand how autism affects their child. Your child is a person first who has a particular syndrome that affects how they interact with the world. Help the worker to understand the person your child is, not just the labels.

Reflecting on How ASD Affects your Child:

As a parent who has a child affected with Autism Spectrum Disorder, you will be aware that the diagnosis of ASD is made because your child indicates particular traits. Therefore, they are likely to show some of these characteristics. Think about how you might describe your child's needs to someone who is meeting him. These terms seem clinical, but looking at them may help you to see how you want to explain in more specific terms how autism affects your child.

Communication Impairments:

- Delayed language development or no speech at all
- May not use words with meaning
- Communicates by taking your hand and guiding it to object
- Has a short attention span
- May repeat words or phrases back to you
- May have unusual speech patterns or tone of voice

Social Interaction Challenges:

- Prefers to spend time alone rather than with others
- Shows little interest in making friends
- Less responsive to social cues such as eye contact or smiles
- May relate better to adults than peers
- Doesn't understand or share the interests of others

Sensory Impairment:

- Unusual reactions to typical actions
- Strong over or under reactions to pain, sound, smell, taste or other sensations

Unusual Play Choices:

- Lack of spontaneous or imaginative play
- Poor imitation of other's actions
- Difficulty initiating games or play
- More interest in playing with parts of toys or doing things such as lining up toys instead of playing with them

Challenging Behaviours:

- May be overactive or very passive
- Throws tantrums "for no apparent reason"
- Shows an obsessive interest in an item, idea, activity or person
- May show aggression to others or self
- Has difficulty with transitions or changes in routines
- Performs behaviour such as rocking, spinning, flapping hands, making noises, toe walking

Develop a Profile of Your Child:

- What are the things your child really loves to do?
- Who are the people that your child really loves to be with?
- What does a really successful day look like for your child?
- What is a successful outing like for your child?
- What kinds of assistance or support does your child require? Think about different kinds of settings- personal care, social outings, social situations, stressful situations, loud settings, crowded settings, etc.
- What kinds of things make your child more comfortable in stressful situations?
- How does your child communicate? Do they use special programs such as Picture Exchange Systems, signing, written information, etc.
- How would you describe your child's personality?
- Does your child use any kinds of special assistive devices?
- What are the signs that your child is upset?
- How do you modify activities for your child?
- What kinds of activities does your child like to do?
- What kinds of activities does your child not like to do?
- What are the medical needs of your child- including medications, allergies, sensitivities
- What are your child's needs regarding personal space?
- What are the signs that your child is trying to communicate with you?

Based on your experience, what are the characteristics of the person who fits best with your child?

Develop a list of traits that you hope to see in a respite care worker.

Some different examples are:

- comfortable helping my child participate in community activities,
- relaxed- not too rigid, open to new things, calm demeanor during stressful times
- structured- has an organized approach
- willing to implement specific kinds of activities, responses and techniques
- is a real problem solver- has an open mind about how to solve problems without getting flustered
- is committed to having my child be included in the community
- has a warm and happy disposition

If you define what is most comfortable for you and your child it will assist you in recruiting and screening a respite care provider for your child.

Write out the profile of your child. Have the information in a binder that you can update as the needs of your child and family change. Having it written will help you keep things organized and not overlook information. It also helps to keep things positive and balanced on your child's strengths, interests and challenges.

This is one example of what a parent prepared for caregivers who are getting to know her son and be involved in supporting him. It reflects the role of the respite provider from her son's point of view.

My Personal Assistant

A Personal Assistant is someone who can assist me while I live a full life that is rich with opportunity, personal choices, and responsibility; having an Assistant in my life means having help while I am in control of my life, making my own choices and achieving my goals. I must be able to depend on, trust and feel safe with my Personal Assistant.

My Personal Assistant must be able to create every opportunity possible for me to communicate, take the time that allows me to communicate and respect my choices. I want my Personal Assistant to be extremely motivated, creative and supportive so that I can be as independent as I can be while I carry out my responsibilities, contribute as a citizen in the community and experience the effects of each decision I make in my day and in my life.

These are some of the things **I find myself needing assistance** with from day to day, but this is not the limit of my goals and the things I dream about.

At Home

- Use my communication tools to get your help, say how I feel and make choices
- Make my breakfast
- Choose my clothes/accessories
- Change my clothes
- Clean up my room
- Do the dishes
- Make by bed
- Do some laundry (operate machines, change loads, fold and hang)
- Cook my lunch/supper
- Do some baking
- Do some light yard work
- Do some light house keeping
- Visit with a friend or family member
- Work at the computer
- Sit on the porch/backyard
- Do some crafts
- Spend time enjoying my music

- Finding time for a rest
- Sensory activities
- Reading
- Board Games
- Puzzles
- Spelling games (“a” is for)

My Personal Time and Health

- Have a Shower
- Use the washroom facilities as often as I need to
- Change and apply personal hygiene products
- Wash my hands
- Brush/comb my hair
- Style my hair
- Brush/floss my teeth
- Take my medication
- Put on skin care lotions, like sunscreen
- Exercises
- Get out side for walk/run
- Private Time

My Time

- Horseback riding
- Skating
- Seasonal/holiday activities
- Visiting the family fun centre
- Going to community events/festivals
- Swimming at a local centre
- A road trip out of town to places like Point Pelee, museums, water parks
- Picnic at the river/park
- Going out to enjoy an evening of entertainment
- A walk along the river/trails
- Shopping for the things I need or want
- Visiting a family member
- A walk in the rain/snow
- A walk in my neighbourhood

- Participating in activities offered by Windsor Parks and Recreation- fitness, leisure
- Try new activities
- Meeting new people
- Reading
- Puzzles
- Board Games

My Responsibilities and Community Involvement

- Volunteering in the community
- Going to my personal appointments
- Packing my clothes for trips
- Doing my laundry
- Helping my family by doing my part of cooking, cleaning
- Eating healthy
- Helping me work on my goals
- Using my calendar to help plan my life
- Using my communication to speak for myself
- Attending meetings I am involved with
- Making my own decisions about what I want
- Learning about home and community safety
- Learning about my rights
- Educational goals
- Employment goals

Leisure/Travel

- Packing for vacation/weekends away
- Using a transit bus or train (in the city, small community or tourist setting)
- Trying out theatres that I am comfortable with
- Finding and going to the places that I like where I will be encouraged to socialize
- Trying new experiences like boats, remote cars, tri-biking, horse shows
- Find options that help me plan for outings, trips and activities put them on a calendar

My Assistant must be aware of the ways they can help be of great help to me even if I am taking time to rest or enjoying some private time alone. My Personal Assistant must be willing to support me when I become sensitive to things that over stimulate and trigger my sensory responses. My Personal Assistant must be willing to accept that every day is a new day, changes in my life and new experiences can mean I need less or more assistance. It works best for me if my Personal Assistant's stay open minded, work as a team and stay connected and up to date with what is happening in my life.

I Want You to Know

- I like to learn
- I like to have the choice of a break while doing a task or activity
- I like water
- Small pieces of lint or other pieces makes me react obsessively
- I prefer light colour clothing on people
- I am more comfortable around quiet and less distracting environments

Include things in the profile that will assist the worker and you as a parent. For example, some children with autism may have good verbal skills, but may react to things differently than another child because of how they see the world. It is sometimes challenging for respite workers to see that children with autism do not understand how others think even if they are quite verbal. This is really important so that the worker does not blame your child for reacting in certain ways or expect that they are going to teach your child empathy or other kinds of emotional reactions. They may also find it helpful to know if your child is not likely to tell them if they are upset about something.

Section Two:

Tips about Recruiting and interviewing respite care providers.

Faced with the challenges of caring for a child with special needs, the thought of having to recruit a respite care provider can seem overwhelming. Many parents think that they don't know how to go about it and don't have connections to make it possible. There may be agencies in your community that assist families to recruit and screen workers for families. That being said, in many cases, the workers that families recruit themselves often turn out to be the most suitable and lasting relationships. That is because as you get involved in looking for the person that suits your family, you seek out people that you have a "good feeling for". Your involvement also means that you will usually find someone quicker than an agency will, because the agency is faced with so many requests. Developing the confidence and skills to recruit people to support your child and family will reap many real benefits.

Where do you look for a worker?

- Talk to your friends- word of mouth is absolutely the best way of recruiting
- Ask a friend or someone you trust to help you develop a flyer that describes what you want. The flyer should reflect your most desired traits of a worker, outline the basic hours of work needed and have a brief profile of your child.
- Post the flyer at community centers, universities, colleges, daycares, churches, libraries, your workplace, child care centers, secondary schools
- Talk to the people that support your child at school
- Think about any "natural connections" such as friends, neighbours etc.
- Talk with any agencies that assist families in your community to recruit and support respite workers.

Here is one example of an ad. Some families are comfortable having their phone numbers on the ad. Others have an email address or a mailing address. Be sure to follow up to make sure that the ad gets posted and take it down when you don't need it anymore.

POSITIONS AVAILABLE:

Part time – Central Windsor

Caring, confident person is needed to assist in home with a beautiful young woman who has multiple challenges and is living with autism. The successful candidate will have good problem solving skills, be able to work independently, have a positive attitude, exhibit good common sense, be hard working, flexible and enjoy being part of busy environment. Evening and weekend hours.

Please submit resume to: your@emailaddress.com or (519) – 555 – 1212

Your Name, Family Respite Services

Screening and Interviewing a Worker:

Before you interview a respite care provider it is important to be clear about what the person's employment status will be. In most situations, respite care providers are self employed. What does that mean? Self employed people are responsible to keep track of their own earnings and report these earnings to Revenue Canada. This is similar to when you hire someone to come into your home and provide a service such as painting your house. The person does not receive a "T4" slip from you. They are not covered by Workman's Compensation- meaning that if they are injured on the job they do not receive replacement income. You may receive financial payments from an agency to cover the costs of the respite care, but you are not the employer. It is really important that this is discussed with your worker. ***An agreement should be signed with any worker to clearly outline the roles, responsibilities and employment status.***



If you are working with an agency to assist you with organizing your respite care they may have an agreement that you can use. However, if you are doing this on your own, the following is one example of an agreement that you might use.

Self Employed Worker/Family Agreement

This is an agreement between:

_____ **Self – Employed Worker**

and _____ **Parent/Guardian**

for the provision of support services on behalf of

_____ **Name of Child**

Terms of Agreement

This Agreement for providing personal support will begin on _____ **Date**

and will be finished on _____ **Date**

The hours of service will be _____ **Hours per Week**

However support requirements may change from time to time depending on the needs of the child and or family. The service provided will be paid at a rate of \$ _____ **Dollars/Hour**

- This agreement includes a probationary period from my start date for three months. If for any reason, the family does not feel that you have met the skills and abilities required for this position and/or feel that you are not a good match this agreement will be immediately cancelled.
- The worker must provide documentation of \$1,000,000 automobile insurance if they will be transporting the child. The service provider will ensure that appropriate child restraints and seatbelts are used when transporting the child.
- The worker agrees to follow the responsibilities listed in this agreement and agrees to follow the support plan that has been developed by the family.
- The worker will work with the child on a one-to-one basis to ensure the safety of the child. Including other children must be discussed and agreed upon with the parent.
- The worker will ensure that all information will be kept private and confidential.
- If any information is released without the consent of the family/caregiver, these would be grounds for immediate dismissal.

Terms of Payment

The worker is responsible for keeping a record of the hours worked on a supplied timesheet. This timesheet/proof of service is to be submitted to the family contact for signing every two weeks beginning _____

Date

THE WORKER WILL MAINTAIN FULL RESPONSIBILITY FOR KEEPING A RECORD OF EARNINGS AND DECLARING HIS/HER INCOME TO REVENUE CANADA FOR INCOME TAX PURPOSES. THE WORKER IS NOT AN EMPLOYEE OF ANY AGENCY OR THE FAMILY/GUARDIAN. NO T4 WILL BE PROVIDED.

We have the right to change this agreement with written notice. This agreement may be finished without notice, if at any time this contract cannot be completed, or you did not do what you signed on to do or you do not meet the skills/abilities necessary for the well-being of

Name of Child

I agree to provide support services as outlined in this agreement.

Self Employed Worker

Date

Signature of Parent/Guardian

Date

Copy to the parent
Copy to the worker

Interviewing the Worker:

If you are going to be interviewing a worker it's good to find ways to keep it business-like yet friendly. You want to be able to get to know the potential worker's abilities, but also a bit about their "style" and personality to see if it fits with your child and family. You might find it helpful to talk to the worker on the telephone first to see if your first impression is that there might be a good match. When you are going to meet with the person parents have reported that these things help:

- Have a friend, relative or someone you trust with you during the interview. It's an extra set of eyes and ears for you.
- Have written interview questions.
- Take notes so that you can remember things you have talked about.
- Be clear about what your expectations are.
- When you're sure that you think the person's qualifications are right, ask the person to meet your son or daughter and spend some time with the two of you.
- Ask the person to think about the position and call you back to confirm that they are interested. That gives you both some breathing room to think.
- Be clear that there is a "trial" period so that you both can make sure that it is a good match.
- Ask for three references.
- Require an up to date police clearance
- Discuss the strict requirement for confidentiality. Sign an agreement about this.



Here is an example from a parent of the questions asked during the interview.

Welcome and Introductions –

Introduce (child) personally and briefly present information that you would reveal on his profile. (Address, educational, community involvement, aspirations in life, social interests and activities, strengths and skills, why you are seeking a respite worker - personal assistant.

Ask and fill in

Name: _____ **Date:** _____

Phone: _____ **Cell:** _____

Availability: _____

Certificates: _____

Can provide:

- | | |
|-----------------------------------------------|--------------------------------------------------------------|
| <input type="checkbox"/> Suitable Attire | <input type="checkbox"/> Proof of Valid Automobile Insurance |
| <input type="checkbox"/> Police Clearance | <input type="checkbox"/> Availability for team meetings |
| <input type="checkbox"/> Driver's License | <input type="checkbox"/> CPR / First Aid |
| <input type="checkbox"/> Driving Record Check | <input type="checkbox"/> References |

Review Process:

- This is a behaviour based interview; please do not rush as we are interested in the content of your answer so that we can truly reflect on what your experience, values and strengths are.
- You may ask us to repeat the question or ask to back to a question to add to at any time. Please attempt to answer all of the questions.
- We will welcome any of your questions about the position at the end of the interview.
- Following your personal interview you will be invited to go with _____ and his Assistant to be introduced to the community and the some of the activities _____ is a part of.
- If you can, consider making your child part of the interviewing/screening process.

WORTH MENTIONING – This interview is to bring out the skills, abilities, traits and past behaviours so that we can obtain a clear picture of you and your service in a short period of time.

Respite Worker/Personal Assistant Interview Questions

- 1) Describe why you can see yourself in this position as a self employed Community/Personal Assistant. What skills and experience do you have that makes you a good match based on the requirements of the service.
- 2) Name four things that are important to you in a work environment.
- 3) Briefly describe your knowledge or experience working with a person who has a disability such as Autism or other disabilities has prepared you for this interview.
- 4) Reflect and identify the work, volunteer or school position you have stayed involved with the longest. Explain the reasons why you may have for staying committed so long.
- 5) Identify the way you will manage any other work and personal commitments you have while providing this service. Are you able to offer a small or large time and interest commitment to this position?
- 6) What personal values and professional qualities do **you have** that you may have noticed **are not common amongst others** that you may have worked with.
- 7) From what you have learned about our request for service for our child, what do you feel might be the most challenging for you to provide. How will you work through these challenges?
- 8) Briefly tell us about your short term employment/educational goals and long term employment/educational goals. Describe how working with our child fits into your short term and long term goals.
- 9) With out using names or personal information; Describe a time when you reacted to or witnessed a situation that was questioning some one else's safety. What was it about the situation that made you react or consider it to be a safety concern?
- 10) Tell us about a time when you had to deal with a person who was frustrated and unhappy. What did you do to comfort or help them?
- 11) What jobs or tasks have you had that you have found to be mundane and boring? What did you do to keep them or make them more interesting?
- 12) Please identify all of the qualities of a team player that you possess. How will you use them while working for our child?
- 13) Without names or personal information describe people's personality types, habits or personal routines that have caused you to be physically uncomfortable, embarrassed, frightened, nervous or ill.
- 14) How will you support and encourage my child's independence and encourage his participation in making choices about his life, new experiences, opportunities and goals?

Written Interview Task: Please develop a quick sketch about the service you provide, qualities, experience, your availability, how you provide the service, how you would like us to promote you and your support service to others. Have fun and be creative. (Provide paper designed layout and creative tools) This gives time for interviewers to get ready for tour)

Next Steps:

Once you've finished the interview process and decided on the person you wish to engage as a respite provider

1. **You'll want to talk more specifically about your expectations and what works best in your home.** While you certainly don't want to be inflexible, this is a good time to let the respite provider know about your family's values and what will make a good working relationship. Demonstrating mutual respect starts early in the relationship for both of you.
2. Be realistic about your expectations. The role of the person is to give your family a period of respite. They will be working together with you to decide on meaningful activities for your child to make the time fun. They are not there to be a therapist, to provide ABA/IBI or speech and language therapy....
3. Talk more specifically about activities that your child enjoys and what the respite provider might be expected to do.
4. Have some pictures of your child doing activities that they enjoy. This helps to make the plan real.

What follows is an example of an agreement that one family uses with their worker to express the family's expectations.

Family Expectations

What works best: (As expressed by the child being supported)

😊 Be at my house and ready to assist me when you are scheduled to be here. In the case of an emergency please call to let us know where you are and when to expect you.

😊 Be very aware of all safety concerns that my family has for me, since there are many in my home, in my yard and in the community if I don't have your assistance.

😊 Be sure to review the communication book and my calendar as soon as you get in to my house so I can make choices and get to the things I have planned.

😊 If you are not sure of your role or a task we need to do check the communication resources, ask my family.

😊 Keep my tools for communication with us at all times, encourage me to use my tools to communicate and make my own choices.

😊 Keep an open mind about what can be changed in case I am not feeling well or if I am having second thoughts about my day.

😊 Help me understand what to expect by showing me what comes next.

😊 Build a trustworthy working relationship with me and my family that includes respect for each other and confidentiality.

😊 Remember even when I want to be alone you always have to be aware of my safety, be sure to let me know where you are so I can find you.

😊 Spend your time you are working for me with me and not too much time chatting with my family or the other family members. I have my life to live and they have theirs.

😊 Give my family their privacy and space to live their life while you assist me in our home.

😊 Make your personal calls and do your personal tasks during the personal time we have agreed on.

😊 Be considerate- call if you are going to be late.

😊 Let's agree not to share information with other people about me or my family.

😊 Be sure to speak to my family if you have any concerns, suggestions or important community information to share that will open up new opportunities for me.

😊 Please be flexible and work together with my family to provide support when my family needs it. It is important for my family to have the break that they need so that they can continue to support me in my home.

I have had the opportunity to read and clearly understand the expectations of _____ and his family.

Name of Child

Signature of Respite Provider/ Personal Assistant

Date

Section Three:
Orientation with your respite provider

Like any new role or position, orientation is a really important part of getting off on the right foot.

The first part of orientation is for the worker to get to know your child.

Some of the information you share will likely need to be done when your child is not there. This would include:

- Your dreams for your child
- Medical information
- Specific information about your child's diagnosis, school program
- Review the profile you have completed about your child

Once you've had a chance to talk, you'll want to involve your child in the process.

- Expect to spend some time together with the worker and your child.
- Engage in an activity that your child enjoys. It's important for your child to be able to show their best side first as they get to know a new person.
- Focus on the most important things first. That may be communication, sensitivities, or behaviour. You know your child best.

The next part of orientation will be establishing how you are going to be communicating on an ongoing basis.

- Knowing what activities your respite provider and your child are doing is important. You'll want to know how the day went, any surprises and any concerns. However, talking about that at the time the worker is bringing your child home may not work for you if your child has trouble with transition. You might want to have a communication log that they can quietly do when they bring your child home. They might also email you if that works for you. An example of a communication sheet is included.
- You'll also want to plan in advance for any expenses. Let the respite provider know that if they wish to do an activity that they are asking you to provide money for that it is discussed in advance. Some families establish a budget for this so that the worker can plan ahead, while others deal with this as requests come up. Don't expect that your worker will pay for meals, tickets, etc. for your child, but don't expect your worker to do activities all the time that don't cost money.
- Expect to pay entry fees to activities for both your child and the worker if you are asking the worker to take your child to activities in the community.
- Talking and planning together about what the respite worker will be doing with your child is critical to the success of the respite time. Once you've set up some general guidelines, respite workers can then come with a plan for the day. However, you need to have input because you will know if your child is not having a good day, if they aren't feeling well or if they have a real need to do a particular activity.

COMMUNICATION IS KEY



NOTES: (_____ mood, activities, new experiences, positive and negative responses, communication used, things that need follow up, health)

Medication Given	Amount	Time

Menu:

Break Fast:

Snacks:

Lunch:

Snacks:

Supper:

Snacks:

Section Four: Keeping Things Safe

Any parent leaving their child with someone else wants to know that their child will be safe. This is even more critical if your child does not communicate with words or if there are concerns about their behaviour. You want to know that the worker has a clear plan about supporting your child, knows how to respond to emergencies and has some tools to help them solve problems.

Establish a clear support plan for your child. This means thinking and talking with the worker about what contributes to the success of your child, what leads to problems and how to plan ahead.

- Plan for success. Your support plan should include thinking about what triggers are difficult for your child. For example, if you know your child doesn't like crowds, develop a plan for swimming at a local pool when people are doing laps. It will require that you do homework ahead of time, but will ultimately let you relax.
- Be creative - Help the worker to identify simple things that might help divert your child's attention during a stressful time. It might be certain words, toys, food, touch (or not) etc.
- Be honest - Don't worry that if you tell the worker what might go wrong that they will leave. It's best to face things together than to have the worker on their own being surprised by a stressful situation. Talk about what you do when your child has a "meltdown", when they get aggressive, when they are hurting themselves, when they get "stuck" on a certain idea or activity and when they get over stimulated. Help the worker to learn to analyse triggers for problems, things that motivate your child to do well and ways to avoid problems.
- Be specific - While you need the worker to solve problems, you also want to identify specific signs that they should watch for and share your experience about what has worked for you. Identify what decisions they can make, when you want to be contacted, who to call in case of emergency.
- Think about all the places the worker will be with your child and train them in each situation. Go with them and show them how it is best to handle things in different environments, or have another worker do this. Children with autism often rely on a sense of security knowing that things must go a certain way. Help the worker to clearly know what that involves.
- Have a backup plan- Spell out what the worker should do if someone is in danger, if there are medical problems or if your child is in distress. Who do they call, what do you need to be called about, when is a supporting agency to be called etc.

An Example of a Safety Awareness Checklist

Factors of Obsessive Compulsive Disorder will cause _____

to act or respond impulsively in ways that can compromise his safety and challenge other peoples comfort level. While this disorder can cause a person to act impulsively in a variety of ways these behaviours can never be predicted and can change often.

_____ has demonstrated some of the following impulsive actions;

taking another people's food or drink, a burst of physical activity in a wide open space, reaching out to get other person's attention for a variety of reasons, eating large pieces of food fast, demonstrating an over exaggeration of cleanliness or opening or closing doors,

and windows. It is important to be aware of all _____

surroundings and to assess all situations for any elements or safety hazards that may

Prevent _____ from being active and independent in his life.

It is important to know about _____ likes and dislikes

so you can help him find opportunities and make choices that will involve him in lots of safe and stimulating activities.

Safety Tips and Suggestions

Always have the "urgent pictures" on the clip board available for _____ to use. They include but are not limited to bathroom, take a break, alone, stop, home...

Be aware of the "positive response" plan used by the family reduce _____ anxiousness and work through the agitation he may experience;

❶ When _____ demonstrates anxiousness – use a calm voice, use the "urgent" pictures on the clip board, redirect _____ by playing spelling or words game and reassure him

❷ If _____ mood escalates to a level of agitation – use a calm voice, if he wants to reach out for you put hands out open palm for _____ to rest his hands against and remind him to be gentle, ask him to take a break, suggest a shower, ask him if he is in pain then wait for agitation to settle.

❸ If you have concerns or you need other suggestions to help you work through a situation while assisting _____ ask his family, if you are out in the community call the family at _____.

Food should always be checked for temperature and cut into bite size pieces to prevent choking.

Be aware of _____ special diets and allergies listed in his support plan.

Security of _____ surroundings at all times so that _____ does not get hurt if he moves impulsively i.e. runs out on to a street, gets burned from an appliance or hot water.

_____ will not safeguard him self from bugs or the harm they can cause so you must be aware of his surroundings, use repellent, or leave areas where there are bugs.

Do not leave your hot drink or food out where _____ can reach it and take impulsively.

Keep all medications out of _____ reach in the intended designated area of his home.

Remain aware of any potential areas where there might be cleaning agents or poisonous chemicals left out, while _____ is in his home, visiting others and in the community.

When going to the car from the house or while in the community stay with _____ until he is safely and comfortably seated in the vehicle.

Visit familiar, enclosed and structured parks to control more of the safety risks that may occur when _____ impulsively walks or runs ahead of you.

Be aware that _____ responds positively to surroundings where noise levels are not in excess. _____ prefers to be with adults not with children. _____ is not comfortable in public areas that are filled with loud noises and screaming children.

Try to stay calm and speak in a clear, voice that is not loud.

Positive Response Plan

- 👉 When _____ begins to demonstrate anxiousness; be sure to redirect _____ to his communication pictures, keep a calm voice and reassure him.
- 👉 Calmly help him use his pictures, suggest time for a break; if in the car pull over, drive to a park or ask him if he is all done or wants to go home.
- 👉 Use _____'s pictures to ask if he has personal needs; if he is hungry, thirsty or needs to use the washroom.
- 👉 If you think you need other suggestions call, his home to speak with his family using the number _____ or _____.
- 👉 If you have questions or if you are looking for tips after an outing or new experience with _____ be sure to make notes in the communication and bring them forward at the following team meeting for so others can learn from your experiences.

A Note about the use of Physical Restraints

Respite providers usually work in situations where they are working alone without other staff persons around them. They are not supervised during their time with your child. Therefore **they are not authorized to use restraints, even if they have training.** If they are providing respite through an agency, there may be very specific guidelines that your worker must follow. This usually means that the worker cannot hold your child except in an emergency (e.g. running out on the road). Therefore, planning ahead is best. In an emergency the worker will need to think about getting out of the way if they are in danger, getting others out of the way and responding in a calm and patient manner. Talk with them about how to respond in a way that will help make things go well and what things will lead to the situation escalating.

Section Five:

Training your Worker to Communicate with your Child:

For children with ASD, communication is one of the biggest issues that they must face. Your respite worker is often the voice of your child when they are out together, so the worker will need your help to communicate effectively with your child.

Things to talk about with the worker:

- Body language - what are the cues that are important to observe. Think about bathroom needs, hunger, upset, anxiety, happy, sad, etc.
- What techniques do you use to support your child? Do they use a Picture Exchange system, signing, etc? If they are not familiar with PECS, you will need to work with them to learn the most critical pictures that your child uses and outline a plan for how they will continue to build on their knowledge.
- What are the most important things to communicate about with your child in a new environment?
- What is the best way to plan for transition times?
- How can you include your child in making choices about activities and his day? Even at an early age you want to clearly let the worker know that your child is an individual who has choices to make. The level of choices will depend on the age of your child.
- How do you plan activities but still listen to and observe the child's reaction to the plan?

Letting your Worker know about all that ASD “Lingo”:

Have you ever been in a meeting where people were using terms and acronyms that you didn't understand? As a parent, you've gradually learned a lot of names, initials, titles, programs and language that is just plain confusing to people who aren't familiar with it. While you don't want to overwhelm your worker, take the time to explain the basics of terms that you might use to explain services, programs, goals, needs and plans with your child. Some parents find it helpful to develop a tip sheet about this.

Section Six:

Keeping the Relationship Going with your Respite Provider:

Like any relationship, there are some key ingredients to keeping it healthy.

- ***Have clear boundaries.*** The respite worker is there to give you some time to yourself. Be friendly, but don't treat them as "your friend". Because they share a very special bond with your family, it's tempting to share your problems with them and talk about things happening in your family. Keep those conversations for your friends and share information with them that is important for them to know to support your child. Similarly, let the worker know politely, that you are concerned about them, but it's not a good idea for them to talk about the problems they may be having with their roommate, friend, husband, career planning, finances, etc.
- ***Don't expect more than is reasonable.*** Their role is to support your child who has special needs. Taking care of other children in your family is not part of their role unless that is something that you have discussed ahead of time, agreed upon and are compensating them for.
- ***Treat them with respect and expect respect in return.*** If your schedule is changing give the worker advance notice. Emergencies happen, but they will appreciate being able to plan their time.
- ***Agree upon a method of payment and make sure that you pay them on time.*** If you want your worker to treat this as a job you need to do that as well. Do not expect the person to work without pay or wait for longer than you've agreed upon for their pay. You would not be willing to do that at your place of employment.
- ***If things change with your child arrange a time to discuss it with them.*** Keep your workers up to date about things happening in your child's life.
- ***Arrange a time to meet regularly to talk about how things are going.*** This is a good time to review any support plans, talk about activities to arrange and talk over any issues or problems. Most of all, it is also a time to talk about success. You may think of this as "cutting into your respite time", but it is an investment in making the relationship successful.
- ***Find ways to express to the worker that their contribution to your family is appreciated.*** We all like to know that our work is meaningful. Your feedback is really important so that the worker understands that respite makes a difference in your family and that you appreciate that they care for your child.

Section Seven: Helping the Worker Learn about Modifying Activities for your Child

Sometimes people who work with children with special needs are tempted to treat them as little children no matter what their age. It is particularly challenging for workers who are caring for children who have difficulty communicating what their wishes, likes and dislikes are.

- ***Use activities to build on your child's skills.*** Help the worker to think about what same age children who don't have ASD like to do. From there, you can think about how to modify or structure experiences that will build on your child's social skills, independence and ability to model what other children are doing.
- ***Build on your child's understanding.*** Your child may have difficulty with time concepts. Have the worker use some concrete tools to assist them. As an example, an inexpensive timer from a game might be used. One worker was able to help the child know that after three songs from their favourite CD he would be home. Another worker was able to communicate the concept of waiting for a turn at going down the slide by having the child hang onto a simple ball until it was time for them to go.
- ***Plan the appropriate level of support:*** Outline that when teaching new skills they may need to start by using hand over hand, but the goal is to gradually fade out, perhaps encouraging other children to provide support and encourage independence.
- ***Adapt the goals of an activity to make it attainable.*** For example, the worker may use a board game with the intent to assist the child to learn to take turns while having fun, but the goals of the game will need to be modified. Your child might help to be the scorekeeper or to assist with the equipment or materials.
- ***Make it possible to be included with other children.*** Substitute different instructions or materials. The child may participate in an activity at a program or with other children, but may have different goals that are appropriate for his abilities. Think creatively about how to reduce sensory problems in ways that still allow them to interact. For example, one worker brings headphones to the library. The child is able to spend time on the computer, but "tune out" the distractions of the people around him. Your child might help to be the scorekeeper or to assist with the equipment or materials.

- ***Encourage your child to have fun.*** Your child has a right to have fun too. Don't expect that your worker and child are going to be using every minute to "keep on task". One parent commented that when the pressure was off of her child the "behaviour" disappeared. Let the worker and your child develop activities that they will enjoy together.
- ***Plan activities that do not require communication to be successful.*** Going for walks, watching the house league hockey games, swimming and volunteering at the local Humane Society are a few activities that don't require verbal communication to participate.

***Section Eight:
Helpful Resources***

Autism Ontario Children Diagnosed with Autism: Strategies and Information for Ontario Families and Care Providers.

Living with ASD- Adolescence and Beyond

Website: <http://www.autismontario.com/>

Janice Adams Autism - PDD: Creative Ideas During the School Years

Aiding the Vision - Skill Assessment Sheets, checklists, Leisure Skills, Personal Skills, An individual Profile Booklet and best practice inclusion strategies for parents and professionals.

Website: <http://www.adamspublications.com/>

CAIRN Canadian Autism Intervention Research Network – Generating and disseminating evidence based information on Autism.

Website: <http://www.cairn-site.com/>