



AUTONOMY SUPPORT

toolkit

For Support Staff and Caregivers



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Jackie Ryan, PhD, Heather Brown, PhD,
and Sandy Thompson-Hodgetts, PhD



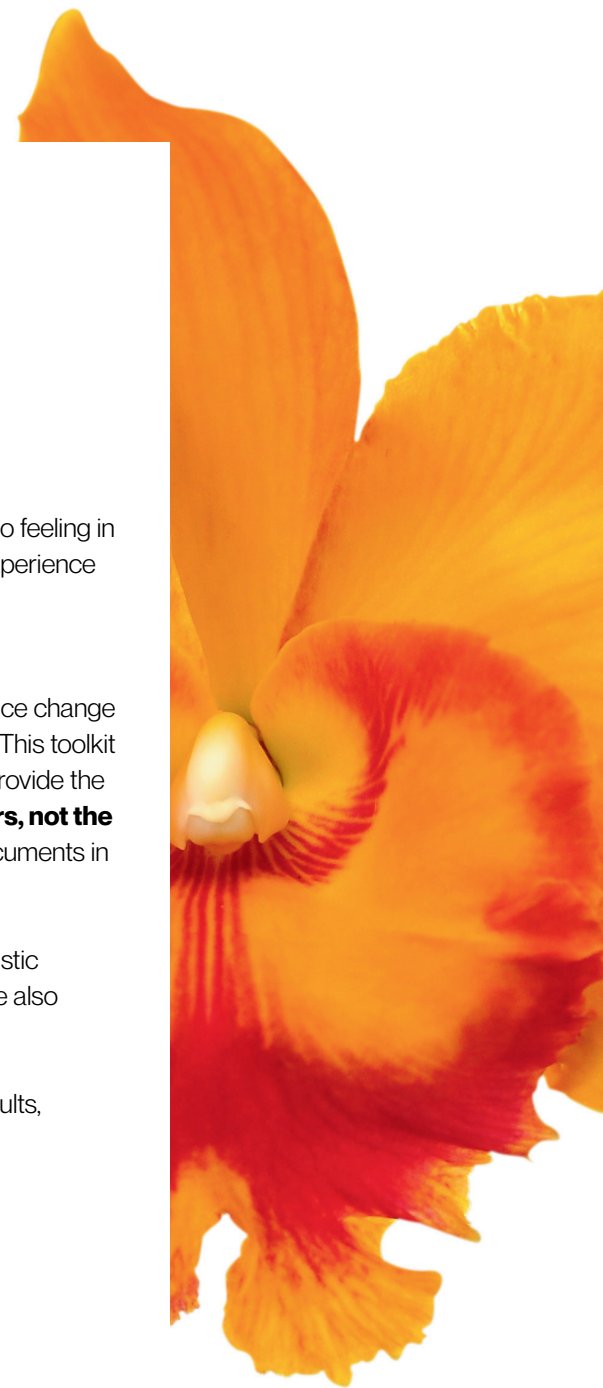
INTRODUCTION

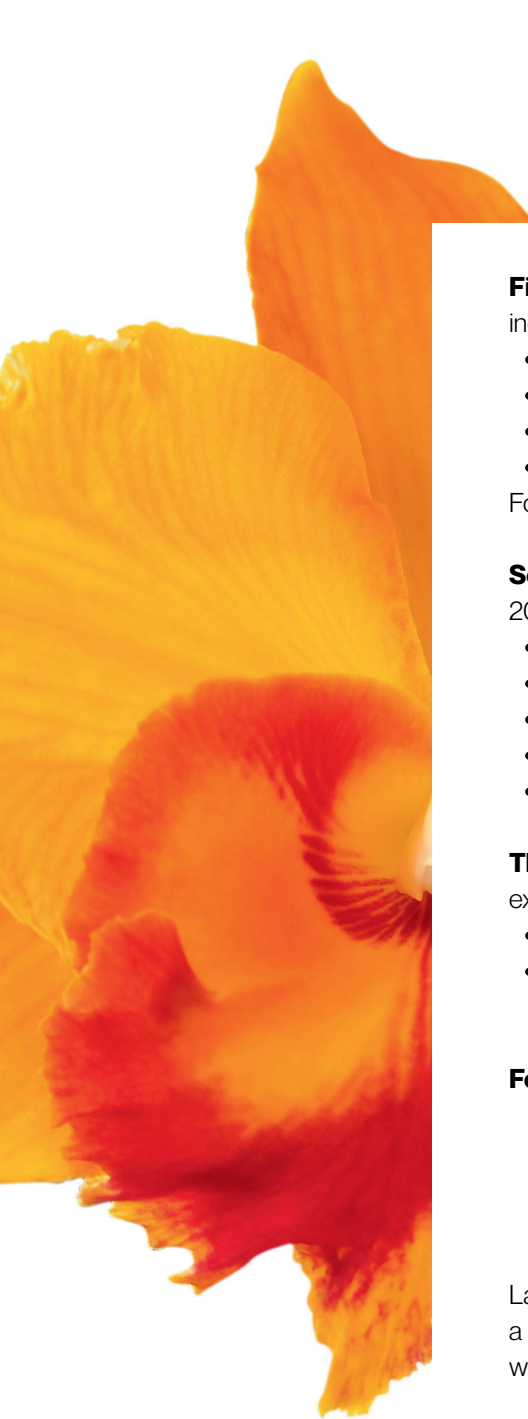
Autonomy is a fundamental human right regardless of disability and a key component of well-being. Autonomy refers to feeling in control of one's life, making choices, and acting voluntarily. Autistic people with and without intellectual disability (ID) experience decreased autonomy, perhaps due to having fewer opportunities and/or less support to act volitionally than others. Professionals often presume incompetence and limit opportunities for making choices.

We used a four-cycle Experienced Based Co-Design (EBCD) to share agency and focus on evidence-informed practice change to design a toolkit grounded in the real-world experiences of autistic people and the professionals who support them. This toolkit is to provide support staff and caregivers with information about the autistic person they are supporting so they can provide the best help for the autistic person to have autonomy. **That is, the targets of change are support staff and caregivers, not the autistic person.** The autistic person, with support from staff and/or caregivers, if necessary, should complete the documents in the toolkit.

Our research team comprised eight people: 4 autistic community partners, 2 with ID; 2 autistic researchers; a non-autistic researcher; and a non-autistic occupational therapist. We recruited 20 participants: 14 autistic people (5 with ID, 2 were also support workers); and 6 non-autistic clinicians, support workers and caregivers.

This group of 28 people co-designed this toolkit to help support staff and caregivers support autonomy for autistic adults, particularly those with intellectual disabilities.





First, the research team conducted an organized internet search to identify existing tools relevant to supporting autistic individuals. The review highlighted a wide range of resources, categorized as follows:

- In-the-Moment Choice-Making Tools: Supporting immediate decisions.
- Longer-Term Goal-Setting Tools: Aiding in planning and achieving personal goals.
- Training Resources for Staff: Educating support workers and caregivers.
- Training Resources for Autistic People: Empowering individuals in self-advocacy and autonomy.

For the toolkit, we were interested in the “In-the-Moment Choice-Making” tools.

Second, participants highlighted five critical principles from earlier research (see Ryan, et al., 2024; Thompson-Hodgetts, et al., 2023; & Ryan, et al., in review):

- Get to know me: Build an understanding of each individual.
- Don’t make assumptions: Avoid preconceived ideas about abilities or preferences.
- Clear communication: Use direct, accessible, and consistent communication.
- Advocate with me: Empower autonomy by standing alongside the individual.
- Always be kind and respectful: Foster relationships based on empathy and dignity.

Third, participants explored the implementation of strategies using the in-the-moment choice-making tools from our resource exploration:

- Existing tools align with the five themes identified in Workshop 1.
- There was a notable gap: no tools identified from our search were specifically for helping supporters communicate clearly with autistic people with ID.

Fourth, participants reviewed and provided feedback on four prototype tools:

1. One-Page Profile: A concise summary of the individual's preferences, needs, and communication style.
2. Communication Chart: A guide for understanding and responding to the individual's communication methods.
3. Personal Environment Needs and Supports: A tool to understand an individual's needs and supports within environments.
4. Exploring Choice-Making Supports: A resource to help individuals navigate and make informed daily choices.

Lastly, the research team used this feedback to finalize this toolkit. Together, the research team and participants co-developed a neurodiversity-affirming toolbox of practical resources to equip support staff and caregivers to empower autistic individuals with ID to make choices.

WHAT ARE HUMAN RIGHTS?

Human rights refer to the ways you can expect to be treated because you are human.
Having a disability does not mean that you lose your human rights.

You have the right to be treated with dignity.

You have the right to be treated with respect.

You have the right to be treated fairly.

You have the right to have a say over your life.

You have the right to be involved in decisions about your life.

**You do not have to earn these rights.
They are your rights like they are the rights for everyone.**

RIGHT TO MAKE CHOICES

- ✓ **I have the right to make choices throughout my day.**
- ✓ **Let me make choices without support if I can.**
- ✓ **Support me if I need help making my choices.**
The [Exploring Choice and Choice-Making Supports for Daily Life](#) document will give you more information about the support I may need to make different choices.
- ✓ **My choices may be limited by money, experience, or what is possible, but don't make assumptions.**
Help me to understand why my choices are limited.
- ✓ **I have the right to be who I choose to be.**
- ✓ **I have the right to choose my hopes, goals, and dreams.**





WHAT IS NEEDED FOR REAL CHOICE?

- ✓ **Options to choose from¹.**
- ✓ **An understanding of what those options involve¹.**
I need to have lots of experiences to understand various options (e.g., if I have never been to a bowling alley, I may not understand that the environment can be noisy; if I have never eaten chocolate, I may not know that I like chocolate).
- ✓ **A way to communicate the choice¹.** My *One-Page Profile* will tell you how I make choices. The *Exploring Choice and Choice-Making Supports for Daily Life* document will give you more information about the support I may need to make different choices.
- ✓ **A history of having choices respected¹.** This means that most of the time when I make a choice, I get to do or have that choice.

¹ Murphy, B., Bradshaw, J., & Beadle-Brown, J. (2017). Person-centred Active Support Training Pack (2nd Edition). Pavilion Publishing and Media Ltd.
<https://pavpub.com/learning-disability/person-centered-practice/person-centred-active-support-training-pack-2nd-edition>

CLEAR COMMUNICATION

Tips from Autistic People for Staff/Caregivers

- ✓ Provide clear instructions (e.g., numbered task list, clear communication of delegation).
- ✓ Tailor communication to my preference (see my [Communication Chart](#)). Consider various means of communication such as written, simplified (yes/no), charts/checklists.
- ✓ Start instructions from the beginning.
- ✓ Don't gloss over steps quickly and send me on my way.
- ✓ Ask if I need instructions repeated or even say them twice.
- ✓ Verify understanding of information or task. You could ask me if I understand. You could ask me what I am going to do.
- ✓ If I am confused, start with context.
- ✓ Pause between ideas and instructions.
- ✓ Let me know ahead of time what you want me to do, not just on the spot.
- ✓ Be patient; give me time to absorb the information.
- ✓ Help me process things when I need to work through it with someone.
- ✓ Write the information down.
- ✓ Provide information in multiple ways, some of which I can go back and reference later (such as instructions on whiteboard).
- ✓ Create visual cues to remember important information.
- ✓ Follow up verbal communication with written overview/notes (e.g., in-person meeting, then email).
- ✓ Speak slowly and clearly.
- ✓ Talk to me as an adult.
- ✓ Limit lengthy explanations and provide only important detail.
- ✓ Accept all forms of communication as valid.
- ✓ If I am not answering, then you need to figure out my communication (see my [Communication Chart](#)). It could be the answer requires me to have more energy than I have, but I want to talk. Try simple yes or no questions.

_____’s One Page Profile

Date: _____

Instructions: You may want to have someone else help you to complete the document. You may complete the form over several sessions. You may fill in the boxes in any order. This document will be used by support staff to understand you better. This is a working document and can be changed or updated anytime.

Staff/Caregivers: If you are completing this document, please fill it out from _____’s perspective.

Things and activities I like:

How I like to be supported:

How I make choices:

Environmental needs and supports:

- Noise and Sounds
- Visual
- Smell
- Touch and Feel

What is important to me:

What do people (including me) like and admire about me:

Communication Chart for _____

Instructions: The purpose of this chart is to help your support staff/caregivers understand you so they can meet your needs.

Staff/Caregivers: Fill out this document from the perspective of _____. Fill this out with what you know about _____ so far. This will be an iterative process of trial and error. Try to put yourself in _____'s shoes. This is not an ABC chart. This is to help everyone understand _____'s communication.

What am I doing?	What is happening around me?	Staff/caregivers thinks it means...	Do staff/caregivers need to do anything? If yes, then what do they need to do?
Example 1: I am bouncing in my seat.	Everyone is playing a video game except me.	I want to play the video game.	Yes, invite me to join the game.
Example 2: I am flapping my hands.	Everyone is watching a movie.	I am happy.	No.
Example 3: I am pacing.	Everyone is watching a movie.	I don't like the movie.	Yes, ask me if I would like to choose another activity.

Communication Chart for _____

What am I doing?	What is happening around me?	Staff/caregivers thinks it means...	Do staff/caregivers need to do anything? If yes, then what do they need to do?

Exploring Choice & Choice-Making Supports for Daily Life

Instructions: The purpose of this chart is to help support staff/caregivers know what choices you need support for, and choices you can make by yourself. Your one page profile has information on how you like to be supported. You can add more choices to this document. You can change this document anytime.

Staff/Caregivers: Support can look different for each person. Some people need support thinking through options and consequences. Some people need emotion regulation support or other co-regulation. Support needs can change over time so this document should be updated regularly.

I Choose...	I want to choose by myself.	I want some support to choose.	Some days I want support to choose.	Usually I want support to choose.	I want someone to choose for me.
how I communicate.					
who interprets for me.					
what to wear each day.					
how much I can be observed.					
what to eat.					
when to eat.					
what I will drink.					
to have a shower.					
where I will go for the rest of the day (e.g. work, volunteer, day program, etc.).					

Exploring Choice & Choice-Making Supports for Daily Life

I Choose...	I want to choose by myself.	I want some support to choose.	Some days I want support to choose.	Usually I want support to choose.	I want someone to choose for me.
who to hang out with.					
my activities.					
how to get to the activity.					
who to do activities with.					
when to stop an activity.					
how long I engage in an activity.					
when to take a break or rest.					
which stimuli I seek when I need/crave sensory stims.					
what exercise I do.					
my groceries.					

Exploring Choice & Choice-Making Supports for Daily Life

I Choose...	I want to choose by myself.	I want some support to choose.	Some days I want support to choose.	Usually I want support to choose.	I want someone to choose for me.
to buy groceries for myself.					
how to pay for my groceries.					
what will I buy.					
how I will pay for what I buy.					
what video games to play.					
who to play video games with.					
where to play video games.					
when to go to bed.					
my faith activities.					
who to share information about me with.					

Exploring Choice & Choice-Making Supports for Daily Life

I Choose...	I want to choose by myself.	I want some support to choose.	Some days I want support to choose.	Usually I want support to choose.	I want someone to choose for me.
who can share information about me.					
what information about me gets shared.					
when to go home.					
an exit strategy.					
to accept criticism.					

Exploring Choice & Choice-Making Supports for Daily Life

I Choose...	I want to choose by myself.	I want some support to choose.	Some days I want support to choose.	Usually I want support to choose.	I want someone to choose for me.



Personal Environmental Needs & Supports

Instructions: The checklist is a starting point. You can add additional needs and supports. You can have someone help you complete this form. If you have different needs depending on the environment, you can note that on the document.

Staff/Caregivers: Some people will be sensory seekers and some sensory avoiders so the ability to adjust as necessary is key. Not everyone will need every suggestion. Complete this form using the perspective of the autistic person.

's Personal Environmental Needs and Supports

Noise and Sound

Staff/Caregivers: Most autistic people have trouble filtering out different sounds and focusing on the ones that are the most important.

PERSONAL NEEDS

- I need a quiet environment
- I have trouble filtering out different sounds and focusing on the ones that are the most important.
- I process all the noises I hear. This takes a lot of energy.
- I like auditory input.
- Loud unexpected noises are hard.
- Misophonia – extreme sensitivity to certain sounds such as chewing, yawning, breathing, that causes a physiological fight or flight response.

SUPPORTS

- Noise-cancelling headphones available.
- Ability to listen to music or white noise on headphones.
- Quiet room available for access.
- Give advance notice where possible for loud noises (e.g., scheduled fire drill).
- Doors closed to minimize noise from other rooms.
- Doors open.
- Windows closed to minimize noise from outdoors.
- Windows open.
- Windows soundproofed where possible and necessary (i.e., when the building is near a busy road).
- Electrical devices switched off when not in use to avoid hum.

_____’s Personal Environmental Needs and Supports

Noise and Sound

Staff/Caregivers: Most autistic people have trouble filtering out different sounds and focusing on the ones that are the most important.

PERSONAL NEEDS

SUPPORTS

's Personal Environmental Needs and Supports

Visual

Staff/Caregivers: In addition to differences between people, this is one area where people may seek sensory input at times and avoid it at others as well as a combination of the two.

PERSONAL NEEDS

- I like it bright but not too bright.
- I like dim lighting.
- I dislike bright contrasting primary colours.
- I like bright contrasting primary colours.
- I need organized wall displays
- I need important information to be clearly displayed.
- I dislike patterns on carpets and rugs.
- I like patterns on carpets and rugs.

SUPPORTS

- Dimmer switches.
- Covering put over lighting, so it is less "sharp."
- Allow sunglasses to be worn inside.
- An area with minimal visual distraction for working is available.
- Liquid timers.
- Sand timers.
- Visual apps on tablets (e.g., lava lamps, slime apps, visual stim videos of waterfalls, plants growing in time elapsed videos etc.).
- Fluorescent lights that do not flicker.

_____’s Personal Environmental Needs and Supports

Visual

Staff/Caregivers: In addition to differences between people, this is one area where people may seek sensory input at times and avoid it at others as well as a combination of the two.

PERSONAL NEEDS

SUPPORTS

_____’s Personal Environmental Needs and Supports

Smell

Staff/Caregivers: Some autistic people are aware of smells, but they don’t necessarily register as good or bad smells. Some smells can be very difficult. Some traditionally soothing smells (e.g., lavender), are not relaxing for all. Some autistic people will adjust to the smell over time.

PERSONAL NEEDS

I like these smells:

-
-
-
-
-

I dislike these smells:

-
-
-
-
-

- I smell everything very vividly.

SUPPORTS

- Allow autistic people to use accessible toilets.
- Be aware of any difficulty some autistic people may have near kitchens while food is being prepped.
- Glue, paint, cleaning stuff, etc. to be non-scented where possible.
- Perfume, aftershave, etc. to be avoided.
- For sensory seekers, allow scented stationary or aromatherapy oils, and ensure sensory avoiders are not seated next to them.

_____’s Personal Environmental Needs and Supports

Smell

Staff/Caregivers: Some autistic people are aware of smells, but they don’t necessarily register as good or bad smells. Some smells can be very difficult. Some traditionally soothing smells (e.g., lavender), are not relaxing for all. Some autistic people will adjust to the smell over time.

PERSONAL NEEDS

SUPPORTS

's Personal Environmental Needs and Supports

Touch and Feel

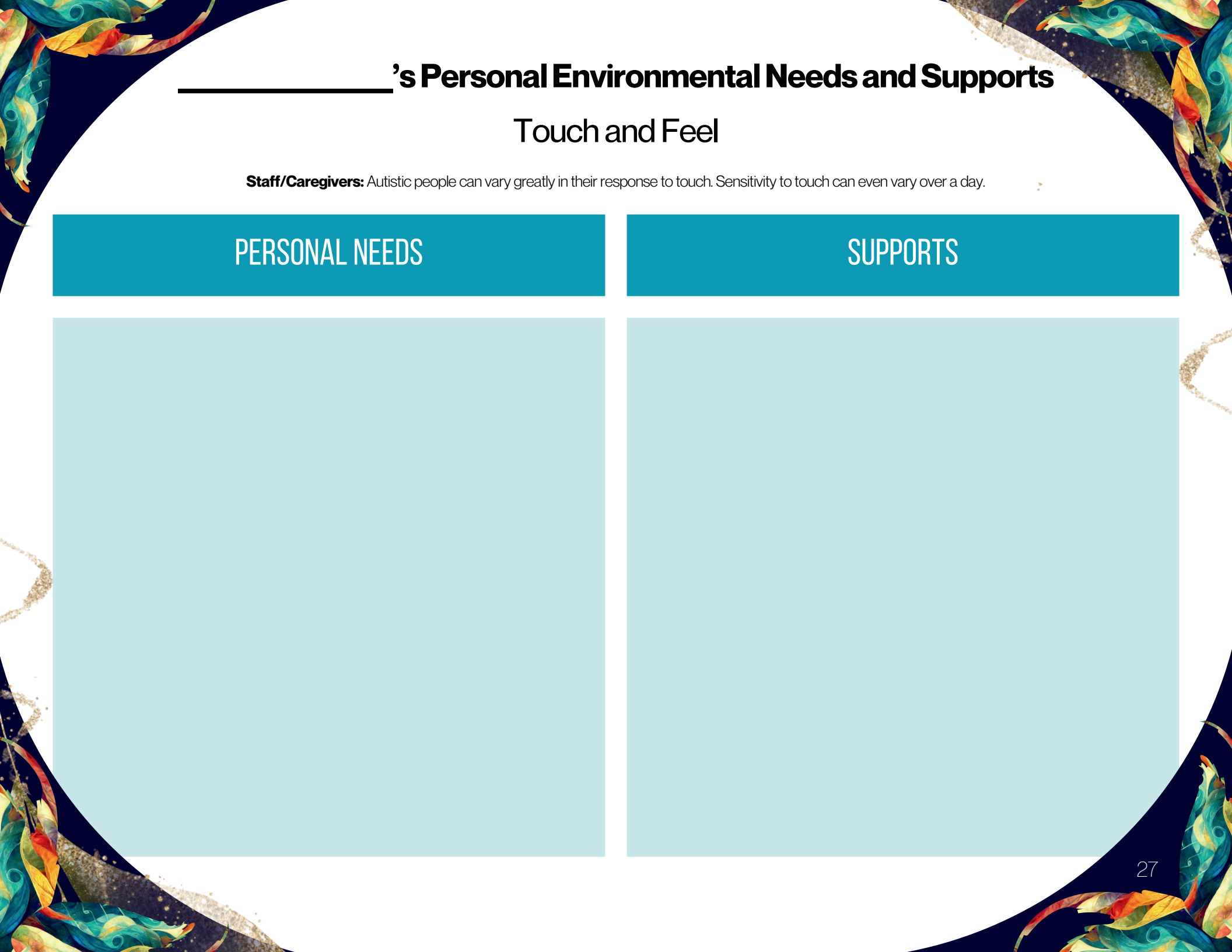
Staff/Caregivers: Autistic people can vary greatly in their response to touch. Sensitivity to touch can even vary over a day.

PERSONAL NEEDS

- I like touch.
- I hate touch.
- I like light touch.
- I like firm touch.
- Seams and labels on clothing are difficult for me.
- Formal shirts are uncomfortable.
- I need comfortable seating with appropriate sensory feedback
- I like bean bags or other soft options in the library/quiet area.

SUPPORTS

- Clothing may be able to be identified by lack of label as well as name on the label.
- A polo shirt with a collar may be acceptable.
- Clip-on ties or loosely tied ones may be easier.
- Wobble cushions may be good for those who are sensory seekers.
- Blankets or other comfort/fidget items available.
- Allow fidget items to aid concentration.
- Pencil grips available.
- People are allowed to type work on a computer or tablet as opposed to writing.
- Adaptive scissors made available.



_____’s Personal Environmental Needs and Supports

Touch and Feel

Staff/Caregivers: Autistic people can vary greatly in their response to touch. Sensitivity to touch can even vary over a day.

PERSONAL NEEDS

SUPPORTS

_____’s Personal Environmental Needs and Supports

Ensuring Autistic People are Supported

Staff/Caregivers: Even with all sensory needs catered to, an autistic person’s confidence that they are understood and respected may need to be bolstered and maintained. Many autistic adults report being told that they were too sensitive as children, which they have internalized into adulthood to think that their way of experiencing their environment is not okay. The following will help guide staff/caregivers to ensure the autistic person’s well-being is respected.

PERSONAL NEEDS

- I know I can discuss my concerns with staff.
- I am confident my concerns will be taken seriously, and action will be taken promptly when necessary.
- I am treated with respect by all staff who are aware of my sensory needs.
- I have the option to take breaks at times other than colleagues when I want to.
- I can take sensory breaks, as necessary.
- I am notified in advance of any changes to staffing and other important changes.

SUPPORTS

- Clear contact person for concerns.
- Clear system in place for when the autistic person needs to withdraw from sensory input.
- Clear system in place for when the autistic person needs to sensory seek (e.g., using desk toy/fidget, listening to music on headphones).
- Aware that both sensory seeking and avoiding are ways autistic people self-regulate emotions and their nervous system, deal with stress and cope with demands placed on them.
- Notify Autistic person in advance of any changes.

_____’s Personal Environmental Needs and Supports

Ensuring Autistic People are Supported

Staff/Caregivers: Even with all sensory needs catered to an autistic person’s confidence that they are understood and respected may need to be bolstered and maintained. Many autistic adults report being told that they were too sensitive as children, which they have internalized into adulthood to think that their way of experiencing their environment is not okay. The following will help guide staff/caregivers to ensure the autistic person’s well-being is respected.

PERSONAL NEEDS

SUPPORTS

