

CPAR



**Community Partnerships
in Autism Research**

Working Together Training



**University
of Vermont**



**UVM AUTISM
COLLABORATIVE**

This training was created by and for autistic and non-autistic research partners. This includes researchers and community members.

You will learn about creating a **welcoming and inclusive research team** to help autistic and non-autistic people work together.

The information presented is based on focus group discussions and on our experience.

There is no research yet to validate that this training works to create a safe space for autistic people.

Look up underlined glossary words as needed or access the optional resources for additional information.

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1 Team trust and safety

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Module 1 Introduction



Duration 0:30

[TRANSCRIPT](#)

Module 1 Introduction transcript

“Hi, my name is Matthew.

In this module, you will learn about the guiding principles for working together.

You will learn the importance of making a positive impact on individuals’ lives.

You will also learn about the benefits of being a research partner.

Finally you will be introduced to what helps build trust with research partners.

We have added optional resources.

Click on each lesson to learn more.”

Module 1

Team trust and safety



Lesson 1: Guiding principles



Lesson 2: Language considerations



Lesson 3: Knowing about ableism



Lesson 4: Respecting each other



Something to think about



Lesson 1: Guiding principles

Our [research partners](#) identified four (4) guiding principles for building trust within an autism research team:



Photo by [fauxels](#)

- Research has a real-life impact.
- [Group culture](#) is [inclusive](#) and accepting.
- [Focus](#) is on understanding [autistic](#) people on the team. Their ideas are given priority.
- [Accessible](#) practices support everyone's [participation](#).

Disclosure



Our project relied on word-based communications. Most interactions happened through video conferencing.

We did not offer other ways to communicate, like arts or movement activities.

Research teams should explore inclusive ways for research partners to communicate.

Optional resources

Making a real-life impact



Photo by Bailey Beltramo

People are interested in autism research because they want to make a positive impact on individuals' lives.



Time and effort are precious

Community partners have limited energy to engage in research.

Researchers and clinicians have a lot of demands on their time.



Photo by Bailey Beltramo

- The research work must focus on an important topic that has real-life impact.
- Flexibility and options for participation are critical so that working together is possible.

Collaboration is worth the time and effort



Photo by [fauxels](#)

Optional resources

Some benefits of participation include:

- Being connected to a community
- Developing friendships
- Following a personal interest and learning new skills
- Mentorship and support

Fair payment for expertise should be provided to community research partners.

Some forms of compensation



Photo by [Thomas Balabaud](#)

- Monetary payments
- [Recognition as author](#)
- Receiving [course credits](#)
- Opportunities to attend [conferences](#)
- Access to research tools and information such as:
 - Library
 - Full text of journal articles
 - Specialists knowledgeable on a topic

[Optional resources](#)

A non-autistic parent shares some of the benefits of being a research partner:



- Discussing topics she is passionate about
- Having an impact to support other families
- Learning skills she can add to her resume

Duration 1:53

[TRANSCRIPT](#)

A non-autistic parent shares some of the benefits of being a research partner transcript

“ I appreciated the opportunity to work with the UVM researchers, to learn about the research process. It was nice to get paid, and so I haven’t been able to work outside of the house or it’s been difficult for quite some time.

So just having this opportunity to, you know, do something meaningful, to connect with others, to learn about, you know, and discuss something that is so, I’m very passionate about because of my kids and our experience and, you know, I’ve learned so many... Just, you know, in terms of navigating the different computer systems or I’ve gotten a lot more proficient in the Google Docs and, you know, Zoom, I’ve learned, you know, I’ve gotten a lot of experience being part of Zoom meetings and how that process goes.

For the past several years, I’ve thought about, you know, the need to put a resume together and thinking, you know... 5, 10 years ago, I was like, “I don’t know what I would put on a resume.” And I actually now can, this is something I can put on my resume. It’s difficult navigating these systems when you have, when you’re supporting an individual with such high needs. And so to provide support that will help pave the way for other families is, you know, I think that, you know, I feel really good about that.”

Lesson 2: Language considerations



It is important to be aware of language preferences of autistic people on a research team.



Photo by [Cottonbro Studio](#)

- People on the autism [spectrum](#) have different preferences for how they describe themselves.
- Words they use for themselves may not feel right for others to use.
- There is no consensus on correct language.
- It is best to ask someone what they prefer.
- Respecting autistic people's preferences is important.

Ways to talk about autism



Disorder-Based Language	Person-First Language	Identity-First Language
		
Autism is a problem that needs to be fixed or cured.	<p>Puts the person front and center. The focus is on the person, not their disability.</p> <p>Helps fight stigma related to disability.</p>	<p>Some conditions make up a core part of our identity or culture.</p> <p>Influenced by Disability Culture and the Pride Movement.</p>
<p>Autism Spectrum Disorder (ASD)</p> <p>“Suffering from autism”</p>	<p>“A person with autism”</p> <p>“A person on the autism spectrum”</p>	<p>“An autistic person”</p> <p>“A person who is autistic”</p>
Avoid this language. Consider using Autism Spectrum Condition (ASC)	No consensus. Respect what an autistic person prefers.	No consensus. Respect what an autistic person prefers.

[Download this resource](#)



There is no consensus

Some people on the autism spectrum feel very strongly about person-first language.

Other autistic people want to use identity-first language.

When unsure, non-autistic research partners may choose to use:

- Autistic person
- Person on the autism spectrum
- Person who is autistic

In this project we say "autistic person" and "person on the autism spectrum."

It is important to respect the language an autistic person uses for themselves.



Autism and other experiences

The autistic experience is complicated by individual differences:

- **Disability:** Some autistic people identify as having one or multiple disabilities, while others do not.
- **Race:** Autistic people of color often do not get an early childhood autism diagnosis.
- **Gender:** Gender affects whether autism is recognized, overlooked, misdiagnosed, and, if diagnosed, at what age.



- **Gender identity:** Autistic people are 6x more likely to identify as non-binary, gender fluid or transgender.¹
- **Culture and religion:** Some cultures and religions may have different explanations for autism.
- **Language:** Autism may be missed in people who do not speak English as their first language.

Accepting and recognizing self-diagnosed autistic people is important.

Having a diagnosis is a privilege many people do not have.

[Optional resources](#)

Diversity in gender identity:



Photo by [Alexander Grey](#) on Pexels

[Optional resources](#)

Gender identity is someone's personal concept of self as male, female, a blend of both, or neither.

Someone's gender identity can be the same or different as their sex noted at birth.

- We cannot tell gender identity by how someone looks or acts.
- Teams can make it safe to share what [pronouns](#) people use.
- Some people may not be ready to share their pronouns.
- When unsure, it's always safe to use the person's name.

Lesson 3: Knowing about ableism



- It's often hard to see ableism because we learn it from our daily lives.
- Internalized ableism:
 - is when people with or without disabilities are not aware that they have ableist beliefs.
- Systemic ableism:
 - is everywhere in society. It's part of all systems and institutions.
 - It makes us think there is a right way to be or do things.

Optional resources

A note on systemic ableism



Photo by [KEHN HERMANO](#) on Pexels

Ableism prioritizes behaviors that society recognizes as “normal.”

This is when the ways of doing things work for common abilities.

- Most people do not see in the dark, so cities have street lights.
- If most people were blind, street lights would not be a common accommodation.

When ableist norms are in place, some people’s strengths don’t have room to come out.

[Optional resources](#)

What internalized ableism looks like:



- Having internal negative self-talk:
 - “I can’t do this.”
 - “I should be able to do this without help.”
- Thinking you need to “fake it until you make it.”
- Fear of being exposed as a fraud.
- Valuing unrealistic independence, like the expression “picking yourself up by your own bootstraps.” This means doing something impossible.

[Optional resources](#)

What systemic ableism looks like:



- Payroll systems to enter time online require many steps and are difficult to navigate.
- Fluorescent lighting that cannot be adjusted.
- A person needs to request “special [accommodations](#).”
 - They may not know what accommodation to ask for.
 - Someone has authority over the person and can refuse what they need.
- Research “about us without us.”
 - For example, thinking all autistic people want to cure autism when many people see it as their identity.

[Optional resources](#)

Lesson 4. Respecting each other



Inclusive group norms that are supportive and accommodating:



Photo by [cottonbro studio](#) on Pexels

- Provide options for participation
- Make time to hear everybody
- Read [video conference](#) chat input in a timely manner
- Check for understanding
- Have a process to address missteps and [misunderstandings](#). They may raise important issues
- Have meetings for people with similar identities but also meet in mixed groups
- Review group norms at the beginning of meetings

[Optional resources](#)

Meeting facilitation



A good meeting facilitator needs to support the group's meeting norms.

- The facilitator addresses and follows up on emerging conflicts or concerns.
- Some virtual platforms allow private chat. It can be used to:
 - Alert the facilitator about concerning situations
 - Reach out to a supporter
- It is important to balance the needs of the group and the needs of the individual.

[Optional resources](#)

Inclusion and acceptance



Within the autism and the research communities, people have different experiences and opinions.

Some important topics include controversial aspects:

- Autism as neurodiversity or a condition to cure and prevent
- Respectful language and fear of making mistakes
- Disability, accessibility, and support needs
- Interventions and traumatic experiences

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- Interventions and traumatic experiences

Learning together



For participatory research to succeed:

- It is important to create a safe space to learn from each other.
- People may be uncomfortable at times as they learn.
- It is important to respect and support different levels of understanding.
- Autistic people face a lot of difficult and traumatic experiences. Their safety should be prioritized.

Everybody should feel safe

Working together helps everyone

How to be supportive



Ask and respect everyone's [identity preference](#).



Use a person's correct pronouns, or use their name if unsure.



Be patient. Take time to hear and understand everyone on the team.



Make it safe to be different.

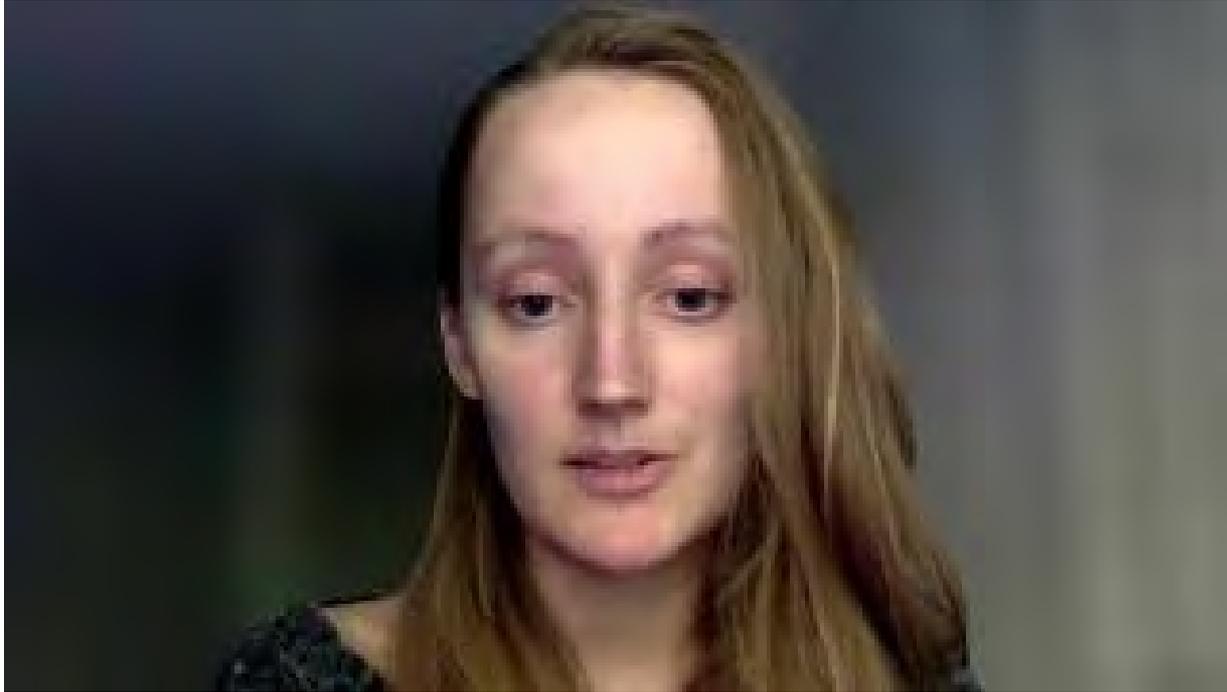
Something to think about



What makes you feel comfortable joining a new group?
(Check all that apply)

- Having enough time to share
- Being understood
- Being able to be myself
- Other:
- Having common interests
- Having common experiences
- Being respected
- Being supported

Module 2 Introduction



[Duration](#) 0:30

[TRANSCRIPT](#)

Module 2 Introduction transcript

“Hi, my name is Fiona.

In this module you will learn about different experiences of autism.

We have organized this module into 5 areas that are important to autism research partnerships: communication, [sensory and motor](#) experiences, interests, thinking patterns and some of our experiences with emotions.

We’ve added optional resources for you to learn more. Click on each lesson to get started.”

Module 2

About autism



Lesson 1: [Autism awareness](#)



Lesson 2: [Communication](#)



Lesson 3: Interests



Lesson 4: [Sensory and motor](#)



Lesson 5: Thinking patterns



Lesson 6: [Emotional expression](#)



Something to think about

Lesson 1: Autism awareness



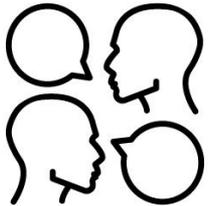
- This module uses the first-person voice (“we, us, our”) because it was created by [autistic](#) people.
- The information presented is only an overview of how autism is experienced by different people.
- Autism features occur on a [spectrum](#):
 - Each person is different.
 - We have complex lives.
- It is [important](#) to take time to get to know us.

Features of autism



In this training, we focus on features of autism that may be important to research partnerships.

These features can be grouped into five (5) general areas:



Communication



Interests



Sensory and
Motor



Thinking
Patterns



Emotional
Expression

Every autistic person experiences these features differently.
Think about it as a unique balance of different features:



Autism and co-occurring conditions



Multiple areas of health challenges can complicate our lives, including:

- Other conditions like Attention Deficit Hyperactivity Disorder (ADHD)
- Mental health conditions like Anxiety Disorder and Complex Post-Traumatic Syndrome (CPTSD)
- Allergies and immune conditions
- Brain and nervous system issues like migraines
- Digestion and gastrointestinal conditions
- Sleep disorders
- Muscle and joint pain

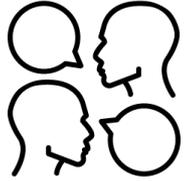


[Optional resources](#)

Autistic strengths that benefit the research process



- Pattern recognition
- Passion for diving deeper
- Noticing things that others don't
- Unique [perspectives](#)
- Seeing the big picture as well as the details
- Curiosity informed by our life experiences



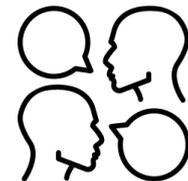
Lesson 2: Communication

We use a variety of ways to communicate:

- Some people talk in short sentences; others use many words.
- Some of us use [Alternative Augmentative Communication or AAC](#).

Examples of AAC include: signs, picture boards, spelling boards, computers, or speech devices.

Understanding



- Many of us like direct and precise language.
- We may be unable to speak when we are overwhelmed.
- We may understand everything but not be able to show it.

Masking

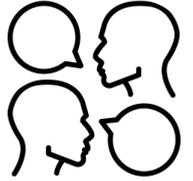


Masking is when we work really hard at hiding our autism.

- Masking takes a lot of energy.
- Some of us are not able to mask.

Being accepted for who we are is important for our mental health.

Influence



Some minimally speaking people get physical support or prompts from another person.

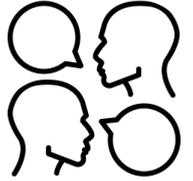
Examples:

- [Facilitated Communication](#) (FC)
- Rapid Prompting [Method](#) (RPM)
- Spelling to Communicate (S2C)

There is evidence that the supporter may influence what the person types.

[Optional resources](#)

Ways of including someone who gets physical communication supports



Duration 2:58

[TRANSCRIPT](#)

This training is not endorsing Facilitated Communication.

Provide other ways to confirm, agree, or protest:

- Speech
- Typing on their own
- Gestures
- AAC

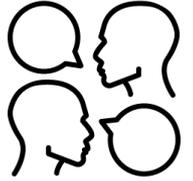
[Research partners](#) should receive support to communicate on their own.

This video shows Facilitated Communication.

Including research partners who get physical communication supports video transcript

- [Narrator] Including someone who gets physical communication supports.
- [Device] Independent.
- Independent.
- [Interviewer] Yeah, and for recording, was that yes or no?
- Yes.
- [Interviewer] Okay, and- Turn your volume up.
- [Device] Yes.
- [Interviewer] You were telling me that verbal is not always reliable, but and you are saying that when it's, like, repeated, like-
- Yes, if you ask him the same question multiple times and you get the same answer twice, then it's verbally reliable.
- [Interviewer] Okay.
- To just ask him once, he might be repeating what you said the last time.
- [Interviewer] Okay.

- Or that he's saying something else instead, but when you get that same answer more than once, then that tends to be very reliable.
- [Interviewer] Okay, so Thad, the other thing I wanna ask you is, because we did that interview and I created the video and I want you to look at it again, and then tell me with your voice or with your independent typing if you agree that this is really what is your experience, okay? Let's watch it, and then you tell me if you're good with that, if it's really what you want. Thank you so much for joining me and being willing to answer some questions about your experience of being on the autism spectrum. So my first question is, how old were you when you were diagnosed with autism?
- [Device] It was just before my fourth birthday.
- [Interviewer] How did you communicate with your...
- [Narrator] Provide other ways to confirm, agree, or protest, like speech, typing on their own, gestures, or AAC.
- [Interviewer] Okay, so is that okay? Is that really what you wanted to say? You have to tell me by yourself, because I wanna know, like, if you're good with what you said, so you can just say yes or no, and if it's no, then you tell me more about it. Is that yes?
- Yes.
- [Interviewer] Okay.
- Yes.
- [Interviewer] Can I hear it with your sound there?
- [Device] Yes.
- [Narrator] Research partners should receive support to communicate on their own. This video shows facilitated communication. We are not endorsing facilitated communication.



Our experience with communication:



Duration 3:16

[TRANSCRIPT](#)

- People assume we're not intelligent or we're incapable of learning based on how we communicate.
- We often change the way we communicate to be more in-sync with others.
- People don't show [tolerance](#) for things they don't understand.

Communication video transcript

- [Narrator] Using alternative augmentative communication, AAC.

- [Automatic Voice] When I was younger, it was even more challenging than now, as I could not talk very much. It was one or two words at most. I sometimes used pictures until I learned facilitated communication in the first grade that I could start to express myself. Then in middle school, my SLP helped me to become more verbal. It was possible for me to speak some basic sentences and could read books out loud with a clear voice.

- [Narrator] Authenticity.

- [Person 1] I want to just be able to have my autistic way of like speaking and moving and doing everything that's just easier and more comfortable. And if I have to try and like really monitor myself and really like try to control exactly the way I'm speaking, and it's like, I'm not even really capable of that to like, I can pull it off for maybe a couple minutes, but like people, it's like they just think, that based on the way that I'm talking, that I'm not actually that perceptive or that I like don't know what's going on or don't know how to interact,

- [Narrator] Translation and masking.

- I have certain levels of translation of my communication that I'm mostly doing, whether it's verbal or nonverbal, to be more in sync with other people or be able to meet people where they're at or that kind of thing. People assume that there's one real self or something, and I don't think it's as simple as that.

- [Narrator] Being misunderstood by non-autistics.

- [Person 2] And to me it's like, you know, with the children, you know, I'm easier to connect with than an adult because adult may think that, you know, and sometimes they call me a freak. I been called that many times. It doesn't hurt my, it doesn't hurt me sooner. It does not hurt me, literally, because I dealt with that.

- [Person 3] You've grown a thick skin maybe, right?

- [Person 2] Not just a thick skin, but thick and protective skin. But I don't use that as, you know, they're trying just purposely trying to get under my skin or trying to be mean to me. It's just they don't understand.

- [Narrator] Asking for clarification.

- [Person 4] Sometimes I have challenges because I don't always get the support and the direction I need at work to understand the aspects of work. But I do pretty well of asking for clarification. I ask like, what needs to be done next? Like I try to interact as much as I can to understand what to do at work.



Lesson 3: Interests

Some of us are very passionate (and smart!) about specific topics.

This is how we like to spend our time and connect with others.



Some of our interests or passions:



Duration 2:11

[TRANSCRIPT](#)

- Accessibility
- Technology
- Autism
- Languages
- [Advocacy](#)
- Sports

Interests video transcript

- [Narrator] A passion for accessibility,

- So you understand the individual needs of the person. That's priority number one in my, you know, my work, because their access needs, it's essential to their daily lives. No if, and, or but. I wanna make sure that the information we give you, the resources we give you, the technology, the advancement, et cetera, that we give you, that it works for you and you alone, nobody else.

- [Narrator] A passion for technology.

- My biggest sort of like, I'll call it semi-hobby interest now is electronics. And so I think that's an interest that I'm gonna pursue more in various ways that I hope to sort of do some things related to technology and support for people with neurodevelopmental differences, and also just disabilities in general.

- [Narrator] A passion for autism and languages.

- Someday, at some point, in some way, write a book about autism. I mean, I'm an anthropology major, It just kind of feels like I'm constantly doing autoethnography of autism. It's kind of interesting to be able to look at it and just be able to see like what autism is for me personally. Another thing I would like to do is become fluent in Scottish Gaelic because I'm learning that right now.

- [Narrator] A passion for advocacy.

- I'm very interested in self-advocacy and helping others learn how to advocate for themselves.

- [Narrator] A passion for sports.

- [Speech Synthesizer] It is great to do activities with others such as sports, like basketball and bowling. It is wonderful to ride horses at adaptive riding programs and go swimming at summer camps. It is great to make friends, watch football, and hockey.



Lesson 4: Sensory and motor differences

- Our brains may struggle to process some sensory information.
- Too much input through the senses can be overwhelming.
- Our bodies may not move when and how we want to move.
- Spontaneous, unwanted actions or words may get in the way and be misinterpreted. Some examples include:
 - Echolalia
 - Hand flapping



Some of our sensory and motor experiences:



Duration 2:17

[TRANSCRIPT](#)

- Saying words we don't want to say
- Flapping our arms or hitting our ears when [overstimulated](#) or stressed
- Having to avoid environments that are overstimulating
- Wanting people to recognize and respect our limitations and needs

Sensory and motor experience video transcript

- [Presenter] Echolalia.

- [Automated Voice] Some sounds echo in my head and are very loud so that you constantly try drowning out those sounds with other words. Sometimes words get stuck in my head, I call them words of annoyance, but technically the term is echolalia. When this happens, I say the words out loud and end up sounding foolish.

- [Presenter] Stimming.

- [Automated Voice] It sometimes causes me to do an activity called flappy where I flap my arms up and down or hit my ears at times, especially when I am overstimulated or am stressed.

- [Presenter] Overstimulation.

- People just don't really realize, how much is happening and how much it's affecting me in every waking moment of every day. Because, I'm really sensitive. I don't express it very much because, it's not like I can just go around complaining about everything all the time. Like now that I'm an adult, I can control a lot better how much I expose myself to on a daily basis and the kinds of environments that I'm in. But when I was a kid, I did not have very much control over that, and so I would just get so overstimulated, so quickly.

- [Presenter] Adaptation.

- In preparation for a surgical procedure. A couple years ago during the height of COVID, I put myself on lockdown before, the month before the procedure and I found that a lot of my chronic pain went away, and I realized that forcing myself to go out into the world was actually increasing my chronic pain. And so, my adaptation unfortunately, is I've, I've become agoraphobic. It's made me recognize that I have legitimate limitations and I need to honor those limitations, and if I don't, my functioning gets worse.



Lesson 5: Thinking patterns

It can be difficult to describe differences in thinking.
It can be complex to understand.

- Each brain works differently.
- Some of us can be really good at understanding details and how things are connected.
- It can be hard for us to understand social situations.



Information processing



- It may be hard to remember everything and the order things should be done.
- It may be hard to change between topics or tasks.
- Too much information can be overwhelming.



Getting things done



It can be difficult to start or complete a task.

- Pressure or anxiety make it even worse.
- Some of us need complex tasks and information broken down to process them.
- Others may need to have all the information and details before starting a task.

How we think, [process information](#), and understand the world:



Duration 2:15

[TRANSCRIPT](#)

- Having a spectrum of skills and knowledge
- Seeing details but also the big picture
- Thinking in terms of systems
- Experiencing increased awareness
- Being overwhelmed when getting started with a task

Thinking video transcript

- [Announcer] Spectrum of knowledge.

- Social communications and processing visual information are both really, really hard for me. And I may understand very complicated things, I can see patterns very easily, I can see the big picture and the small picture at the same time, which is something that not a lot of people can do. But the things that I'm good at, I'm really, really good at, and the things that I'm bad at, oh, do I really suck at.

- [Announcer] Systems thinking.

- I tend to be a fairly analytical person. I tend to kind of look at things in a very systems-oriented lens. So I'm both a big-picture and small-picture person in that way. I have to learn by really seeing how things integrate with my overall knowledge of reality and the world, and make it make sense while I'm learning it.

- [Announcer] Heightened awareness.

- I think things differently, do things differently. I have different skill sets differently. But it makes me more aware of my surroundings and it makes me more aware of what I'm doing, but also makes me have more insight.

- [Announcer] Executive skills.

- It's like, because the way that my executive dysfunction works, it's not that I don't know that I'm supposed to do something and it's not even, sometimes I forget, but it's not even necessarily that I've forgotten, it's just that initiating things and then not knowing exactly how it's gonna go or how I'm going to approach it is so overwhelming that I just don't start. So it's like, "I know I need to do this, but I'm overwhelmed by the prospect of doing it and therefore I'm delaying it until I feel more regulated and I'm able to just do this."

Lesson 6: Emotional expression



- We can express emotions differently.
- Our faces may not match our thoughts.
- Pay more attention to the words we say than our facial expressions or actions.

We are happiest when we feel loved and supported and we can do the things we enjoy.



- We may have trauma from bullying or failures due to not being supported.
- Some of us can act out when overwhelmed or upset even though we don't want to.

Acting out may look like yelling, screaming, or hitting.

- Sometimes, we have had bad experiences with research.

Building trust takes time.

Some of our experiences related to emotions:



Duration 2:45

[TRANSCRIPT](#)

- [Emotional awareness](#):
“there is more coming in than there is going out.”
- Expressing feelings can be difficult.
- Being more aware of people’s feelings.
- Wanting to be part of the community, respected, and valued.

Emotions video transcript

- [Narrator] Emotional awareness.

- [Person 1] There's a lot more coming in than there is going out, and that's something I think is pretty universal across all autistic people. Just because someone's not speaking or being super expressive to you, and really engaging with you, it doesn't mean that they're not aware or that they don't understand what's happening.

- [Narrator] Expressing feelings.

- [Automated Voice] Autism makes it difficult to express my thoughts and needs such as when things are frustrating and I need to convey my feelings, such as being angry or when someone says something hurtful. It is easier to show love by hugging someone than I love or trying to help them, especially my mom or other family members.

- [Narrator] Empathy.

- [Person 2] Being autistic, it makes me be more aware of people's feelings too as well, and I can feel that. For me, it's trying to understand the gifts that I have, the empowerments that I have, and also the insight that I have. How can I best utilize them?

- [Narrator] Being valued in the community.

- [Person 3] Just because I'm on the autism spectrum and I have a disability, it does not mean I don't have ideas, I don't have thoughts, I don't have the ability to make my own decisions and figure things out. I like to be part of a community and do things just like anyone else would in the community.

- [Person 4] I would just like to see a world where, like Data on "Star Trek," the entire community there understands that he is not a typical quote unquote human being. He is an Android. I'm not saying that autistic people are androids, but his lack of social ability definitely highlights part of the autistic experience. But what's interesting is that on "Star Trek," everyone understands this and tries to help him understand and bring him along, whereas out in the real world, you never know what you're gonna get.

Summary

- Autism is a spectrum condition. It affects different people in different ways.
- We all have different accessibility needs. Those needs may change based on the task and the environment.
- Our needs are not related to how we look or how we communicate.
- Having strength in one area does not mean also having strengths in other areas.
- Accommodations and supports should be [individualized](#).

Something to think about



What features of autism would you like to learn more about? (check all that apply)

 Communication

 Interests

 Sensory and Motor

 Thinking Patterns

 Emotional Expression

 Co-occurring conditions

Module 3 Introduction



Duration 0:32

[TRANSCRIPT](#)

Module 3 Introduction transcript

“Hi, my name is Liliane.

In this module, you will learn about what makes collaboration accessible for diverse research partners.

We will give you tips for materials, meetings and flexible work practices so everybody on the team can participate and be their best.

We’ve added optional resources for you to learn more. Click on each lesson to get started.”

Module 3

Accessible collaboration



Lesson 1: Accessibility



Lesson 2: Materials



Lesson 3: Meetings



Lesson 4: Flexibility



Something to think about



Lesson 1: Accessibility

Accessibility is about removing barriers so everyone can be included and have equal opportunities.



Pexel by [Adi April](#)

Barriers come from:

- The physical environment
- The social environment
- The way that we do things and share information

Accessibility is influenced by policies and politics.



Accessibility is not optional

The Americans with Disabilities Act (ADA) is a law.

It applies to most businesses with more than 15 employees and to organizations serving the public.

The ADA mandates accessible environments including:

- Transportation
- Entrances
- Parking
- Restrooms
- Routes with clear and wide paths



The ADA mandates accessible communication including:

- Plain language
- Closed captions
- Descriptive text for images

The ADA also mandates accommodations and **supports** including:

- Service animals
- Compatibility with assistive technology
- Reasonable accommodations

Accessibility is a civil right.

[Optional resources](#)

Universal Design



Universal design is when we do things in a way that is easy for everybody.

- Any team member may need accommodations.
- All team members have complex lives and could benefit from flexibility and options for participation.

The whole team will be more successful if everybody can participate.

[Optional resources](#)

Identify needs and preferences



Identify what team members need to be their best.



Consider an onboarding interview or survey that includes:

- Identity and language preferences
- What technology a person uses
- Accessibility and support needs
- Participation preferences

[Optional resources](#)

[Download onboarding survey](#)



Accessible collaboration

What it looks like:



- The environment makes people feel welcomed, comfortable, and safe.
- Materials are shared in many formats that are easy to access and understand.
- There are options for participation to meet your schedule and other needs.
- Supports are provided to remove barriers to participation.

[Optional resources](#)

Lesson 2: Materials



- Provide options for accessing different levels of information.
- Use accessible language addressing the needs of team members.

Example:

Sharing a research article with a plain language summary.

[Optional resources](#)

Lesson 2: Materials



Provide options for accessing different levels of information.



Photo by [Tara Winstead](#) on Pexels

Use accessible language addressing the needs of team members.

Example:

Sharing a research article with a plain language summary.

[Optional resources](#)

Plain language



Plain language can include:

- Literal, common words
- Short sentences
- Bullet points
- Topic headings

There are trainings and tools to help teams with plain language.

[Optional resources](#)

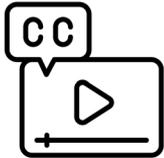
Multiple formats



Use multiple formats to share information including:



- Writing



- Video with closed captions



- Auditory recordings

Ways of sharing information



Share materials in different ways:



- Online options like:
 - Website
 - Microsoft Teams
 - Google Docs
 - Dropbox
- Email or text
- Hard copies sent by regular mail



Visual information

Images and icons can help with understanding. Visual information can also be distracting for autistic people.



- Seeing materials before meetings can help to prepare.
 - It can also help with being less distracted by the visual information.
- If using text on slides, the text should match what is said.
 - Processing different information at the same time can be overwhelming for autistic people.
- Avoid infantilizing or stereotypic images and cartoons.
- Use underlined words only for active links.

Visual formats



- Provide a PDF version of the materials.
 - PDFs may be easier for people with visual impairments to work with.
 - PDFs can be printed to follow along during meetings.



- Also provide the original editable document so each person can adapt it to their needs.
- Remember, people using small mobile devices or regular phones may not be able to see materials shared on the screen.





- Make sure electronic materials are accessible to screen readers and add “alt text” to pictures.
 - Ask an accessibility specialist for support in making PDFs accessible to screen readers.



- Use a colorblind palette.

Lesson 3: Meetings



A comfortable environment is important for in-person meetings.



Photo by [fauxels](#) on Pexels

This includes:

- Lighting and sound management
- Options for seating, standing, and location in the room
- Ability to adjust temperature
- Allowing food, fidgets, support animals, etc.
- Support for transportation needs and parking

[Optional resources](#)

Virtual meetings



Accessibility considerations for video conferencing:

- Live closed captions by a person are more accessible
- Choice of cameras on or off
- Option to speak or use the chat
- Support for internet access

Other types of virtual meetings:

- Over the phone
- By text or chat

[Optional resources](#)

Schedule



Photo by [Leeloo The First](#) on Pexels

- Offer meeting times when community partners are available, like at night or on weekends.
- Send calendar invitation with reminders.
- Schedule meetings on the same day and time.
- Meet in the same room or use the same virtual link.

Group size



Smaller group size (5-10) can be more comfortable and accessible.

- Provide the size of the group in advance.
- Let people know in advance if breakout rooms will be used.
 - Very small groups can be uncomfortable and force people to participate.
 - Larger groups make it hard for everybody to have time to contribute.
- Allow time for people to meet with others with similar experiences so they can share more candidly.

Processing information



- Provide agenda and materials in advance.
- Offer support to prepare for meetings.
- Slow down:
 - Allow time for people who use Augmentative Alternative Communication (AAC) to respond.
 - Allow time for people who need time to process information.
- Plan frequent breaks.
- Check understanding frequently.



- Be precise and avoid questions that are too broad or vague.
- Offer a support person as needed.
- Use Artificial Intelligence (AI) to take notes or provide a summary.
- Provide ways to communicate and share ideas after each meeting (e.g., survey, emails, chat apps, shared documents).
- Provide a written summary of the meeting.

Lesson 4. Flexibility



Build in flexibility for the unexpected within grant budgets and project timelines.



- Abilities of autistic and non-autistic partners to complete tasks may change based on their daily lives.
- Use creativity in addressing barriers to participation. Solutions may include:
 - Assistance with caregiving
 - Transportation
 - Household support

Task support



People want to be involved but may be afraid of letting the team down if they cannot complete their tasks.



Photo by [Fauxels](#) on Pexels

- Consider assigning the same task to 2 people and combining their work.
- Co-lead projects.
- Have regular individual meetings.
- Use these strategies:
 - Body doubling: working on different tasks.
 - Co-creation work sessions: working on the same task.

Hiring support



New employees on a US research team will need to fill out the Federal I-9 form for identification and [work authorization](#).

In rural areas, when [research partners](#) will collaborate remotely, it may be more accessible to complete the form:

- Remotely using E-Verify
- In their community with a notary public as the employer's Authorized Representative

[Optional resources](#)

Employment support



Using payroll systems can be difficult for community partners. Most time-keeping portals are not accessible.

Solutions:

- Adopt a fixed schedule for a research partner's work.
- Assign someone to enter community partners' time.
- Update team members' schedules as needed.

Paying research partners can impact the benefits a person receives. Project managers may need to fill out paperwork to support their benefits.

Something to think about



What accessibility strategies would be helpful for you to participate on a research team?

(check all that apply)

- Live closed captions
- Video off
- Typing in the chat
- Sharing tasks with someone
- Regular individual meetings
- Materials shared in video format
- Materials printed and mailed to me
- Getting support with internet access
- Assistance with caregiving
- Other:

Module 4 Introduction



[Duration](#) 0:19

[TRANSCRIPT](#)

Module 4 Introduction transcript

“Hi, my name is Emily.

In this module, you will learn about the importance of [communication](#) to support positive experiences within a research team that includes autistic and non-autistic people.

We include considerations for clear [expectations](#) as well as [self-care strategies](#).

Finally we’ve added optional resources for you to learn more. Click on each lesson to get started.”

Module 4

Communications



Lesson 1: Responsibility for connection



Lesson 2: Clear expectations



Lesson 3: Self-care strategies



Something to think about



Lesson 1. Responsibility for connection

Team members have different communication styles and ways of thinking.



Photo by Joshua Defibaugh

[Optional resources](#)

- These differences can lead to misunderstandings.
- Non-autistic people need to try to understand autistic partners.
- Team members can help “translate” and support mutual understanding.

Advice to researchers



Duration 1:53

[TRANSCRIPT](#)

- Have contact with autistic people.
- Develop personal relationships and explore a variety of topics.
- It's not easy to get it right and have a positive relationship.
- Be sensitive of ethical and power issues as well as boundaries.

Advice to researchers video transcript

- So I think one of the first things to me is that if you're gonna be a researcher and you haven't had a lot of contact with autistic people, have some contact with people and, you know, have a sense, some balance of personal and contact and, you know, exploration of topics and subjects and stuff maybe before it's even a formal research thing. And you have to be careful with the ethics of, you know, how to do that appropriately and in healthy way. And you know, at least, I can't give very quick advice to that, but I think you keep that in mind. In my first relationships, no, and I mean that in a casual sense of relationships with autistic people, other autistic people were tricky and different and stuff. Interacting with people with different sorts of social skills and ways of doing things and stuff, even though I have different ways of processing things, is different. And so even as an autistic person, it's not automatically simple or easy to really get it right and have those positive relationships. And then the other thing with that piece is to be really, really careful and sensitive to the consequences of those relationships and how to, definitely, I mean, it's important not to use things against people in those relationships too, and that can be hard because there's a lot of sense of dual relationship to this kind of work where we're being supportive to people, and we have our own lives, and we have our own needs.

Advice to community partners



Duration 1:33

[TRANSCRIPT](#)

- There are multiple priorities that need to be balanced for research to be feasible.
- Understand that not all of your ideas can always be implemented.
- Work in a collaborative way to achieve the best outcome for the project.
- Understanding has to go both ways.

Advice to autistic partners video transcript

- I think the biggest piece of advice I would have from a researcher to an autistic research collaborator, if that's okay. Can I shift the question a little? Is kind of looping back to things that Michael has kind of touched on already about this balance between kind of wanting to go deeper on these different avenues, but then also realizing that that's not always feasible. I think researchers are often tied in a lot of ways to, you know, the institutional bureaucracy or you know, the funding mechanisms, requirements and things like that. And so if there's, in a collaboration, if you put forth an idea about, "Oh, I think we should study this, or we should do it this way," just being open to the idea that we might not always be able to do that, right? Just because... Which is not to say that it's not a fabulous idea or, you know, we wanna do that in the future, but sometimes we do need to balance that kind of the needs of multiple different agencies and inputs with the feasibility, with, you know, where it can go in the long term. So just kind of recognizing that, and working in a collaborative way to kind of reach the best possible outcome for that particular project.

- I think that's a really good message. It really suggests that in research it has to go both ways for it to work. Both the researcher has to understand the unique needs and differences that an autistic partner brings, as well as the autistic partner understanding what the expectations are from our end.

Balancing different needs



Different communication styles and accessibility needs can create challenges.



Photo by Joshua Defibaugh

- Some people's communication needs can get in the way of other people's needs.
- Balancing individual needs and the needs of the group can be difficult.
- Mutual respect and understanding improves as team members get to know each other.



Example 1

Someone may interrupt a team member to add their thoughts to the conversation.

- They may have memory challenges and are afraid to lose their idea.

The team member who is interrupted may become upset.

- They have learned that it is rude to interrupt.
- They may be upset that someone is breaking this conversation rule.

It's important to be tolerant.



Example 2

A team member describes their experience in detail.

- They want non-autistic people to understand what they mean.

Another team member cannot process a lot of verbal information at once.

- Without pauses to process, this team member may be left out of the conversation.

Summarize, check in for understanding, and plan enough time for discussions.

Self-advocacy



Sometimes, parents and their child or adult relative are on the same team.



- Each person should have space to communicate for themselves.
- It's important not to speak for someone else unless they ask for support.
- Let research partners share their own ideas first. Then, it might be okay to add more about their situation if they agree.



Lesson 2. Clear expectations

People may enter a research team with different ideas about:

- The goal of a project
- How the tasks will be shared
- The flexibility of the timeline
- How decisions will be made

What a person expects when joining the team can influence the group dynamics.

Clear, common expectations contribute to a sense of fairness and satisfaction.

It is also important to know about team members' personal goals.

Important information to have



- The goal of the research study
- Your personal goals
- Who is in charge
- A clear, detailed job description
- Payments and impact on taxes and benefits
- Supports and accommodations available
- Timeline with important dates
- What is flexible and what is not (e.g. deadlines, work environment)
- Who are the other people on the team
- How information is shared
- How decisions are made
- Who pays for the project

Including research partners' ideas



Photo by [fauxels](#) on Pexels

- Discuss the project with community partners to understand their vision and ideas.
- Be ready for the ideas to change with people's input.
- Consult with people who are experienced in engaging research partners in similar projects.

Staying on track



- **Review the goals of the project at the beginning of each meeting:**
 - People may change course or lose track of the initial goal.
 - Create space for people to share their ideas.
 - Take time to figure how these ideas may be used in the project.
 - When people disagree, review the goals and limits of the project.
- **Check in regularly on how things are going:**
 - Discuss and reassess expectations.
 - Apply what is learned through the experience of working together.

Work style



Photo by [Ivan Samkov](#) on Pexels

- People may have different work styles.
- Team members may approach the project in different ways.
- A person's role or experience can change the support they ask for or expect.
- Reach out and offer support and flexibility with the timeline when possible.



Autistic communication

Autistic people may face challenges expressing expectations:

- This may affect sharing about sensory issues and inclusion challenges.
- They may share only what they believe will be accepted. This may impact their overall experience.

Transparency:

- Autistic individuals may be transparent about some aspects but protective about others. They may not disclose certain expectations.
- Transparency in one aspect doesn't guarantee openness about everything.

Lesson 3. Self-care strategies



Even when everybody is doing their best, tense situations will happen. People may have different reactions and emotions:



- Be upset
- Disagree
- Feel unheard
- Feel overwhelmed
- Be stressed
- Not feel respected
- Become dysregulated

Awareness



Consider using these strategies:

- Reflect about your situation.
- Recognize your emotions: frustration, anger, boredom, despair, etc.
- Recognize your physical reactions: breathing, lump in throat, jaw getting tight, sleepiness, stimming, etc.

Trust yourself



- Decide what you want to communicate in the moment and what to keep for later.
- Take a deep breath and speak up about how you feel.
 - Address the meeting facilitator directly or the whole group.
 - Always be respectful.
- Ask for what you need: more time to process, change deadlines, etc.

Or, step back and take a break.

Being honest



Sometimes, we may not treat other team members honestly.

Examples



Photo by [Tirachard Kumtanom](#) on Pexels

A researcher may worry that a community partner will be upset that their idea is not feasible.

- They do not provide the information and change the topic.

A meeting facilitator may assume that what a person is saying is “off topic.”

- They move on with the conversation without asking clarifying questions.

Communication strategies



Clashes can happen where 2 people do not understand each other.

- Tell someone that you care about the relationship and that you have concerns.
- If a topic comes up again and again, try to understand what about it is important to the person.
 - Ask for clarification.
 - Say what you understand.
 - Ask if there is something else that you haven't understood.
 - Try to find out if there is a piece of information the other person has that they might assume you understand.

Be patient and take time to understand.

Be brave



Community partners, trust yourself and believe in your capacity to share your “voice.”

Non-autistic partners, trust that you can understand and make autistic people feel safe.

Contribute positively to resolve conflicts and bring closure.

Put the relationship first.

[Optional resources](#)

Something to think about



What is hard for you to do in a conversation where you disagree?

- Feel my body
- Feel my emotions
- Take a deep breath
- Ask clarifying questions
- Speak up
- Step back and take a break
- Trust that it can be resolved
- Stay in the relationship



You can now download your certificate of completion.

Return now to the PDF
download page and click “finish”
to download your certificate.

Resources

[Glossary](#)

Disclosure

Other ways to communicate

- Augmentative and Alternative Communication (AAC)

Beukelman, D. R., & Mirenda, P. (2013). *Augmentative & alternative communication: Supporting children and adults with complex communication needs*. Brookes Publishing Co.

Schlosser, R.W., & Koul, R. (2023) *Advances in augmentative and alternative communication research for individuals with Autism spectrum disorder: moving research and practice forward*, *Augmentative and Alternative Communication*, 39:1, 2-6, DOI: 10.1080/07434618.2023.2181214

- Co-creations using arts, movements and interactions

Wilson, C., Brereton, M., Ploderer, B., & Sitbon, L. (2019) *Co-design beyond words: 'Moments of interaction' with minimally-verbal children on the autism spectrum*. In Cox, A & Kostakos, V (Eds.) *CHI 2019 - Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, United States of America, pp. 1-15.

<https://eprints.qut.edu.au/130556/1/Wilson%20et%20al.%202019%20CoDesign%20Beyond%20Words.pdf>

- Visual Methods and Photovoice

Prosser, J., & Loxley, A. (2008). Introducing visual methods. ESRC National Centre for Research Methods Review Paper. <https://eprints.ncrm.ac.uk/id/eprint/420/1/MethodsReviewPaperNCRM-010.pdf>

Gerlach, J. (2024) Connection Across a Lens: Expression Through Photography. Psychology Today. <https://www.psychologytoday.com/ca/blog/beyond-mental-health/202403/connection-across-a-lens-expression-through-photography>

Catalani, C., & Minkler, M. (2010). Photovoice: a review of the literature in health and public health. Health education & behavior : the official publication of the Society for Public Health Education, 37(3), 424–451.

<https://doi.org/10.1177/1090198109342084>

<https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=51c1e96e62d82f1aa0174d5d1da4d00eef7d0d21>

Do, P.L., Frawley, P., Goldingay, S., O’Shea, A. (2021). The Use of Photovoice in Research With People on the Autism Spectrum: A Meta-Synthesis of the Literature. *Research in Autism Spectrum Disorders*. 87, 101828, ISSN 1750-9467, <https://doi.org/10.1016/j.rasd.2021.1018>.

<https://www.sciencedirect.com/science/article/abs/pii/S1750946721001033?via%3Dihub>

Module 1

Lesson 1: Guiding principles

Compensation

- Children and Youth with Special Health Care Needs National Research Network: [A Standard Compensation Guideline for Youth, Family, and Patient Partners](#).
- UVM Autism Collaborative: [Autism Research Partner Compensation Guideline](#)

Lesson 2: Language considerations

Ways to talk about autism

- UVM Autism Collaborative visual: [Ways to talk about autism](#)
- Wooldridge S. (2023) [Writing respectfully: person-first and identity-first language](#). National Institute of Health.
- Dwyer P. (2022) Stigma, Incommensurability, or Both? Pathology-First, Person-First, and Identity-First Language and the Challenges of Discourse in Divided Autism Communities. *Journal of Developmental & Behavioral Pediatrics*. 43(2), 111-113. doi: 10.1097/DBP.0000000000001054. PMID: 34984993. https://journals.lww.com/jrnldb/fulldtext/2022/03000/stigma,_incommensurability,_or_both_.7.aspx

Ways to talk about autism (continued)

- Bottema-Beutel, K., Kapp, S.K., Lester J.N., Sasson, N.J., & Hand, B.N. (2021), "[Avoiding Ableist Language: Suggestions for Autism Researchers](#)," *Autism in Adulthood*, 3(1)
- CommunicationFIRST, The Words We Use. <https://communicationfirst.org/the-words-we-use/>

Gender identity

1. Warrier V, Greenberg DM, Weir E, et al. Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nat Commun.* 2020;11(1):3959.
- The Human Rights Center: <https://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions#>
 - [Pride Center Vermont: Education resources](#)
 - [The Trevor Project: Understanding gender identity](#)
 - LGBTQ+ Glossary from PFLAG: <https://pflag.org/glossary/>

Lesson 3. Knowing About Ableism

Internalized ableism

- All Brains Belong VT. Brain Club educational series:
 - Internalized Ableism & Identity (May 7, 2024): <https://www.orcamedia.net/show/brain-club-internalized-ableism-and-identity-572024>
 - Shame and Internalized Ableism (November 8, 2022): <https://www.orcamedia.net/show/brain-club-shame-internalized-ableism-1182022>

Systemic ableism

- Green Mountain Disabilities Stories. Monthly podcast of the UVM Center on Disability & Community Inclusion (CDCI)
 - Episode 11: on ableism in medical training: <https://cdci.w3.uvm.edu/blog/cdciresources/2023/01/31/cdci-connects-on-ableism-in-medical-training/>

Lesson 4. Respecting each other

Meeting norms

- UVM Autism Collaborative [meeting slides](#)
- [UVM Community Advisory Board Meeting roles](#)

Module 2

Lesson 2: About autism

- All Brains Belong VT co-occurring conditions resource: [Everything is connected to everything](#)
- Autism Self-Advocacy Network (ASAN) [Welcome to the Autistic Community](#)

Influence

- ASHA position statement on Facilitated Communication and Rapid Prompting Method <https://www.asha.org/policy/ps2018-00352/>
- ASAN's response to ASHA's position statement <https://autisticadvocacy.org/2018/08/asan-response-to-asha-position-statements/>
- Schlosser, R.W., Prabhu, A. (2024) Interrogating Neurotypical Bias in Facilitated Communication, Rapid Prompting Method, and Spelling 2 Communicate Through a Humanistic Lens. Current Developmental Disorders Reports. 11, 41–51. <https://doi.org/10.1007/s40474-024-00296-w>
<https://link.springer.com/article/10.1007/s40474-024-00296-w>
- Heyworth, M., Chan, T., Lawson, W. (2022). Perspective: Presuming Autistic Communication Competence and Reframing Facilitated Communication. Frontiers in Psychology. Mars 10;13:864991. doi: 10.3389/fpsyg.2022.864991. PMID: 35360599; PMCID: PMC8960292. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8960292/>
- [United Nations Convention on the Rights of Persons with Disabilities](#)

Videos of autistic experiences

[Michael's autism experience](#) (12:46)

[Zeph's experience of being autistic](#) (12:17)

[Eden's experience as an autistic person](#) (14:45)

[Matthew's experience as a person on the autism spectrum](#) (7:00)

[Nicole's experience of autism](#) (6:13)

Module 3

Lesson 1: Accessibility

The American with Disability Act

- <https://www.ada.gov/>

Universal design

- Center for Excellence in Universal Design: [7 principles](#)
- [Universal Design for Learning \(UDL\) Guidelines](#)

Identify needs and preference

- [UVM Autism Collaborative onboarding survey template \(PDF\)](#)
- [UVM Autism Collaborative onboarding survey template \(RedCap\)](#)

Accessible collaboration

- [UVM Center for Disability and Community Inclusion Accessibility Resources](#)
- Academic Autism Spectrum Partnership in Research (AASPIRE): [Practice-Based Guidelines for the Inclusion of Autistic Adults in Research as Co-Researchers and Study Participants](#)
- Nicolaidis C, Raymaker DM, McDonald KE, et al. Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations. *Autism Adulthood*. 2020;2(1):61-76. doi:10.1089/aut.2019.0074 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7188318/>

- Autism Intervention Research Network on Physical Health (AIR-P): [Resource for Researchers](#)

Lesson 2: Materials

Plain language

- <https://www.plainlanguage.gov/training/>
- <https://readable.com/>

Accessible meetings

- Autism Self-Advocacy Network (ASAN): [Plain Language Inclusive Meetings Guideline](#)

Hiring support

- Remote I-9 process: <https://www.uscis.gov/i-9-central/form-i-9-related-news/new-form-i-9-now-includes-alternative-procedure-for-e-verify-employers-to-remotely-examine-employee>

Employment support

- Department of Labor: <https://www.dol.gov/agencies/whd/fact-sheets/21-flsa-recordkeeping>
- Social Security Administration: [Working While Disabled. How We Can Help.](#)

Module 4:

Lesson 1: Responsibility for connection

Dual empathy problem

- Milton, D. E. M. (2012) 'On the ontological status of autism: the 'double empathy problem'', Disability & Society, 27(6), pp. 883–887. doi: 10.1080/09687599.2012.710008.
https://www.researchgate.net/publication/254245139_On_the_ontological_status_of_autism_The_'double_empathy_problem'
- Who Lacks Reciprocity? Challenging Precarious Assumptions about Autistic People. [Dr. Morton Ann Gernsbacher speech at NJ Autism Center of Excellence](#) in Sept 2021

Lesson 2: Clear expectations

CPAR research team development

- PCORI: [Building Effective Multi-Stakeholder Research Teams](#)
- Society of Clinical Research Associates (SOCRA): [Team science principles](#)
- PCORI: [Leading and Contributing to Team Decisions](#)
- PCORI: [Valuing All Voices Checklist](#)

Lesson 3: Self-care strategies

Advocacy tools

- Penn State College of Medicine's [Faculty Guidelines for responding to inappropriate comments](#)
- GMSA [self-advocacy training](#)

Disclaimer

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