

Alberta's Autism Alliance
Self-Advocates Panel

Adam G:

Before we start with the introductions, I would like to say a couple of things. I am on the planning committee for this event and have been working closely with Shino and Lyndon on all aspects of this event, not just this panel. From choosing the topic, and planning the panel, all the way through to the 4 of us presenting here today has been a great experience for me. As Maya Angelou said, when someone shows you who they are, believe them the first time. People know themselves much better than you do. That's why it's important to stop expecting them to be something other than who they are. This advocates panel is, as far as we can tell, the only panel in a gathering this large to be completely done by autistics in Canada.

Again I am Adam Glendon.

Aksana: Hi I am Aksana Kirton, and following compassion has lead me here, to you today, where I am privileged enough to identify as advocate, writer, and presenter for ASD mental health, and humanity in general

Michael: I am Michael Frost, an activist who is currently exploring issues in health care experiences for autistic people.

Adam K: And I'm Adam Kedmy and my passion in life is finding ways for everyone to be understood accurately, especially when autism is involved.

Introduction



Process management can include changing routine a bit, adding a technology, removing a "feature" or many other things. Many times it will be separation from a stimulus.

Adam G:

When working with the diverse group of people on this panel, it is natural to make accommodations. Whether it be "How we are encouraged to participate by another when we encounter a difficulty," or "enabled to perform without the expected unexpected hindrance," we can negate the detrimental effect or difficulties through process management to help continue the project.

Generalization of what we did: Boil your needs down to one or two important outcomes and facilitating the rest. We chose accuracy and visibility as our outcome goals. So some of you may be wondering why there is a Gold infinity symbol on this slide.

Aksana: Gold to symbolize Authentic Autistic voices. Gold's own elemental symbol on the Periodic Table of Elements, Au, is echoed in both the words Authentic and Autism. Authentically gold is real gold. The real voices relevant to Autism, speaking about our own selves. Our Authentic selves, not filtered through a loved ones eyes. Go gold in support of Authentic Autistic voices. Go gold in support of learning about someone else's voice.

Agenda

- How to advocate
- How can Autism organizations encourage & support advocates
- Inspiring action
- Q&A

Adam G:

We are 4 voices with the honour of speaking on behalf of the Autistic community today.

We will talk about How we advocate. How can Autism organizations encourage and support advocates and finally inspire action.

The Question and answer session will be split into 2 parts. The first will be only for Autistic adults to ask questions then we will open it up to everyone. For those that do not wish to speak, you can write down your question on the paper provided and, one of the volunteers with the microphones can ask the question.

You will note, our panel is not starting a working group but is here to inspire the 50 plus autistics in the audience to become equity stakeholders in the working groups or become involved in their local, provincial or national autism community.

Autism Advocate vs. Self-Advocate

- Self advocacy power dynamic is a hard one
- Advocating for others on the spectrum
- Disclose that you are on the spectrum
- We need to be flexible

Adam K: Self advocacy power dynamic is a hard one - people try to write us off for being autistic, and IF I'm not, they try to write me off for being no closer to autism than they are. Michael and I don't use "self advocate" in conversation when advocating for ourselves. As we start to expand and advocate for others on the spectrum, we need to make sure that it is known we are not just advocating for ourselves but for a larger group of those on the spectrum. It may be necessary to disclose that you are on the spectrum or clarify why you are advocating.

Michael: I consider myself an Artist, which is a combination of artist, advocate and activist: I call myself an artist because it enables me to create a safe environment where ideas are all potentially good ideas, and to lead to numerous potential solutions. It enables me to avoid the situations where misunderstandings hold negative social value, like when I have used the word, "advocate." I realized early on that it was up to me to attempt to facilitate mutually safe spaces for me to seek the accommodations I need to improve my quality of life. Too often, I have been in situations where I needed to explain myself to others but I had potentially offended them. I use art to bridge our understandings and help me start the conversation I have had to better myself.

Adam G: When describing myself, I will say I am a self-advocate. When I am actually advocating I let it be known I am Autistic but never really say the word advocate.

Adam K: I call myself an educator, speaking on behalf of autistic experiences. I will validate that I have the abilities to express an autistic experience when necessary. Typically either my presented privilege or a declaration of being autistic gives me the freedom to express my experiences to help educate.

Aksana: I recognize myself as an Advocate. Now I say, Advocate rather than self advocate because for me, I got to this point by learning to understand natures of respect and relationships. So forth, I have learned it can become easier to respect and love another, when you respect and love the person you deal with most often, yourself. Valuing one's own self, can flow, into a value for the world, and that is among my reasons for being here. If we know how to hold values, can we stand by while values are erased?

AdamG: Reminder: We need to be flexible in many ways when describing ourselves, and with respect to other choices about disclosure. As a listener, as a speaker or as a third party.

Definitions

- **Self-advocacy** — Communicating to achieve more accessibility for yourself or an understanding that results in a more positive situation for yourself
- **Autism Advocate (Self-Advocate)** — Communicating to achieve better accessibility for a larger part of the Autism Spectrum or a positive understanding of ASD by others
- **Leader/Leadership** — In a position to be an integral part of making decisions (board member, executive position, trusted advisor)

Aksana:

These definitions are here to give us a common understanding for this panel as we have found that some may interpret these differently.

Self-advocacy is communicating to achieve more accessibility for yourself or an understanding that results in a more positive situation for yourself.

Autism Advocate (Self-Advocate) is communicating to achieve better accessibility for a larger part of the Autism Spectrum or a positive understanding of ASD by others.

Leader/Leadership — In a position to be an integral part of making decisions (board member, executive position, trusted advisor)

Definitions

- **Ally** — A person who is not autistic but uses their privilege to support autistic people and promote equality and accessibility. Allies stand up and speak out when the people they're allying for cannot communicate effectively alone
- **Accommodation** — A reasonable change from the norm to fit a need and equalize the situation for “the someone with a need”

Aksana:

Ally is a person who is not autistic but uses their privilege to support autistic people and promote equality and accessibility. Allies stand up and speak out when the people they're allying for cannot communicate effectively alone.

An accommodation is a reasonable change from the norm to fit a need and equalize the situation for “the someone with a need”

Self Advocacy

- Self-led & egocentric/Self-Referential
- I am the type of person who scripts to ask for accommodations without disclosing
- When advocating for accommodations & understanding, keep a positive spin
- We need to be our own meaningful dialogues
- Talk about issues in productive, general, nonthreatening terms

Adam K:

By definition, I am leading myself in Self Advocacy - that's what it means. It's Self-led and egocentric. It needs to be something that helps myself, and is directly linked to the centre of my need.

Adam G will give us an example of doing this while scripting without disclosure...

Adam G: I am the type of person that focuses intensely on the job at hand, if you need my attention please knock on my desk and I will finish my train of thought so I can give you the proper attention that you deserve.

Adam K:

Keep a positive spin. People are more apt to adapt to your accommodations when there's a benefit to them. Advertise it and assure and reassure that these answers will include the needs of everyone. Advocacy is easier when the other side is comfortable in an accommodating appeal for change.

For Example, I introduce my glasses by saying it makes me more comfortable-preventing migraines- and it means we're mostly done in that domain (but we can keep an eye on it).

We need to be our own meaningful dialogues. To be effective presenting our own needs, we need to be accessible to our helping listener. It often takes editing in partnership with someone trusted who hears like your listener will hear. With time and effort, a narrative forms as a template-like script for advocacy.

Talk about issues in productive, general, nonthreatening terms

Some of many examples that have worked:

"I react that way when...." or

"I know an answer that once worked, you might try..."

Things to Avoid	Ways to Avoid
Judgemental sentences	Describe actions & effects only
Direct or Indirect violent imagery & aggressive language	Peaceful language
Put downs slurs etc.	Omit words when they're offensive
Too much detail	Rehearse, each part points to the message
Creating Complex solutions when simplicity works	Suggest reasonable actions so people can commit
Frivolous accommodations	Realistic, low cost, justifiable goals - Prioritize accommodations by productivity

Adam K:
 Things to Avoid, Ways to Avoid. These are like best practices, and I wouldn't let us tell you what NOT to do without a "TO DO instead" complementing. People generally stop if all they know is what not to do.
 So my words are fourth wall breaking examples. I'm moving through this slide fast, with nice words. I _____ing hope you can all see that I practiced this. I could have listed all the books these strategies are from, but instead, it's just a chart.

The last point takes a bit more explanation, it's a negotiation and someone's well being is a commodity. If it's yours:
 Suggest actions the people you appeal to can commit to: realistic, cost effective, justifiable goals. Be willing to settle, while knowing your minimum, explain the extra costs of settling (emotional, physical, social, *whatever they are!* time?). Prioritize accommodations by productivity and be willing to get less than what you asked for.

And now, Michael will tell us about his current advocacy:

Michael: I am grateful for the ongoing collaborative work I am doing with others. I need them to help me articulate my ideas in writing. I first explore ideas in great depth using collage. I begin by taking and finding pictures, then creating a collage to sort my ideas, explore competing points of view, and pick out what is essential to discuss. Then I need an ally interpreter. With the help of an interpreter, I can create meaningful conversations for self-advocacy. Currently I'm creating for doctors and dentists. My goal is for my health care accommodations to be the least invasive possible for me and my care providers. These accommodations will be sustainable while they prevent hardship. For me, this will be an ongoing, long, mutually reciprocal collaborative process. I realize I must start this conversation from a point the other party is familiar with. That's easier with an interpreter who helps me build familiar conversations for my dentist. My activist process supports genuine dialog while maintaining emotional neutrality and encouraging creative, mutually respectful approaches to necessary personalized accommodations. I dream of a widespread, standardized response for self disclosing that would open meaningful dialog. While I think this is a long way off, it will apply to people who live with many conditions, including Autism. For now, I hope that by placing my self-advocacy art in a semi-public domain, others can avoid the struggles that are a daily part of my life. Finding health care and a community living options that work for me have not been simple, and I'm still looking. I know there will be a point where the frustrations which Autism causes me in the care system could be too great for me to keep working on overcoming them. Help from allies defers my end point.

How to Request Accommodations

- Phrase requests to assert action with universal appeal
- Be specific with requests & be results oriented
- Give benefits. Put a positive spin
- Have a corrective strategy
- Remember to respect anything you don't understand
- Clarify your tones & your message
- Know or learn others' interpretations of your presentation

Aksana:

How to request accommodations without sounding petulant or condescending.

Try to keep solid in your mind, that you are talking to a human being. With needs, and wants, fears and dreams. Empathizing with them will help them, and yourself, realize symbiotic possibilities. Possibilities where people benefit from talking to you, simply because you were kind. Not only can you achieve your goals with empathy, and understanding, but you can help people when you are in need. You can, by it's nature of respect, respect, and help yourself much more than achieved without affective compassion. Repetitively engaging in this affective compassion can even help your brain to release highly beneficial neurotransmitters.

When requests and demands are made, be sure to phrase them in ways that assert action and in ways that reinforce the universal nature of their human condition.

Asking for results and suggesting a process is necessary. Have multiple ways of asking for what you need. Other processes may be in place, which can address your needs

Using positive tones and words avoids sounding childish or condescending. When others feel things are helpful, they'll be more apt to help you.

If your listener does take offence because they interpret something differently than you mean, calmly saying, "I'm sorry you heard that, I didn't mean that interpretation, can I please try again to explain what I mean" can save the moment

Other points are valid and ask politely for clarity when needed. It's what you want from them.

Allies can help, so can others. It could be in the form of advice, to give you better talking points, or by being an outside advisor giving recommendations - or even mediating a discussion

Be prepared to adjust when others don't interpret your communication as you would like

Identity-first vs. Person-first Language

- Identity first – is a way of living that shows we are proud of who we are & autism is a big, inseparable part of us
 - People & life conditions we respect: Gay people, Muslim people, Christian people, alcoholic people, left handed people
- Person first – interests & personality is front & centre & your autism sounds to be an implicitly separable part of who you are
 - People we seek to separate from their condition: People with cancer, people with a cold, people with an anger problem, people with a drinking problem

Adam K:

I want my identity to be identity first. The real world consequences are the implicit rank of my personhood or humanity, and the way others treat me. Given this binary, I would rather be treated with religious respect than cancerous fear.

Identity first – Autism is a big, inseparable part of us. Be Proud, own it. Other options strip you of power.

I mean,

Is there anyone in this respected category you think you can separate from their condition? Do they all have legal ramifications if you try? Left handed might not.

I understand the history of this person first language, and I appreciate it. The medical system institutionalized person first for good reasons. It protected people from our society. Over time, society has shifted, and so must we if we want to continue protecting those same people. And it will protect everyone... Until it shifts again

When we are person first, we fall into linguistic neighbourhoods shared by people in that second category.

At its simplest, most accessible: according to AA, it's no longer a drinking problem if you're an Alcoholic.

So person first, "with" language implies that we can be cured or separated from the autism. This label is what communicates to the unlearned folk, and worse, "people with autism" internalize a dual self, one who is "me" and in control, the other that is "autism" which needs your assistance - or worse there is no assistance for that deficit, and we must give up!

On Being a Woman...

- Gendered nature of this question makes it difficult to answer
- I am a woman, is a great achievement, like never before
- Being a woman, involves foundational empathy
- Strength & frailty are within one another
- One must also rise to the defence of that reconciliation
- Research is required

Aksana:

What's my view on being a Woman and an Advocate?

After reconciling the gendered and thus deluded nature of absolutes in this genuine, question, I stayed in my belief regarding foundations, and I believed in the foundation enough to dig it up, at least a little.

I had to formally ask, "What is a Woman?" and thought it should stand representing the same sincerity and depth as it does to ask "What is a Man?" To speak of the former, I had to recognize that being able to say "I am a Woman," is a great achievement, like never before.

I believe that part of being a Woman, and thus being a Human being, often, involves what I believe, is a highly relevant reconciliation where in, strength and frailty are within one another. This reconciliation, in my opinion, can work in great support of advocacy. Where in, with advocacy I maintain, that one must also rise to the defence of reconciliations and ideas like such.

Naturally, more research is required especially when advocating for a niche as invisible as Autistic women. However when a group is so unnoticed, it can make the achievements that much more prominent.

... And an Advocate

- Illuminating your commonalities to reaffirm your leadership
- Willingly, consciously, & calmly assert that you have weaknesses
- Privileged in different ways than the people we fight for
- Challenge is fundamental to both legendary friendships, & rivalries

Aksana:

I have found that when advocating for someone with the same condition as yourself, illuminating your commonalities with the person you are fighting for, can allow you to reaffirm your leadership of the situation. When you willingly, consciously, and calmly assert that you have weaknesses and vulnerabilities - when you expose your own ignorance, with self awareness, it can lead people out of their own ignorances. This is not something that must be done, and that's why when we do it, it is best taken as an offering. A gift.

We as advocates have been privileged in different ways than the people we fight for, and to fight well, I believe we must always stay conscious of our own ignorance.

More ideally, being better would be a term relative to one's own life, not yours against others. To proactively, and without deluded implications, approach this ideal of "better" I strongly believe that, in many ways, people can already know what they need, and if we want to truly use our intelligence to help others achieve this state of betterment, then perhaps, we should be working to help people find, what they already know.

Challenge is fundamental to both legendary friendships, and rivalries, in my opinion, because to face a challenge, you must first face yourself. In this way, the challenge can act as your council. Effective council, being a well-touted foundation in the philosophical study of friendship. So then, thru the potentially counselling nature of challenge, you can gain something from everyone, even an adversary, and visa v. Everyone can teach you to save someone. Be that a stranger or simply yourself, and I find that that is why, bad experiences are so important to advocacy.

Communication ASD-ASD or ASD-NT

Pitfalls & Interruptions: How to correct them

- Communication problems: 2 people experience 2 different points of view, not known to both people at the time
- Assume you don't know everything
- Treat me like a tourist

Adam K:

How do we work with others When the pairing is two autistic people (ASD-ASD), or an autistic person and a not-autistic person (ASD-NT)?

THAT's a workable definition of communication error. Contexts involving more than 2 people are merely many pairs of 2.

A Universal solution which applies to both sides is to assume you don't know everything, and check on what the other person "knows" without negativity, or any portrayal which is perceived as negative. This means skills for navigating their offense when you do offend someone because it's you who doesn't know something. And vice versa. I suggest politeness and apologizing for doing things with explicitly communicated plans to avoid doing again.

In short, Treat me like a tourist - we're polite and explicit to tourists. When they miss a cultural signal, we tell them, no judgement.

How to be WE: ASD-ASD / ASD-Org.

- Represent needs for the advocated populations as accurately as possible (ASD-ASD)
- Take others' perspectives & traits into account (both)
- Act in good faith (both)
- Take ownership of failure & share credit for success (both)
- Share Accurately (both)
- Ask for help (both)

Adam K:

How to be a WE in relationships between ASD individuals and between the individuals and organizations

I'd like to start by saying that we CAN represent each other as individuals, even though autism is diverse. I have not witnessed any diversity that keeps two autistic individuals any further apart than two typical developing humans. When we lack interruptions in communication, either by experience or communication strategies, we have the same or better connectedness of experience as any successful pairing, and we cut to the chase.

"Represent needs" — This is about knowing each other to represent each other best. As a community, we need to connect and prioritize needs. We each have to know and assert our needs, then we can assess all of them together. Communication strategies are valuable in this step.

Taking others' perspectives and traits into account. — Differences are going to happen and need to be respected. If we're working to know each other, we both need to be mutually involved in listening and re-phrasing as needed to not overtax the other party. This comes with an ongoing balance of respecting the other person's needs so that dynamic processes can adjust to needs.

Example: If you're in a group requiring quiet, and you need to fidget, fidgeting with a click noise is inappropriate since it undermines the quiet needed by others.

Acting in good faith means being up front and honest, not just for what you want but also why you want it. Then we act on the commitments we agree to. Going after changes because you simply dislike doing the task makes it harder to get accommodations for things you are unable to do without help.

Take ownership of failure and share credit for success — I failed - When analyzing a failure, commit to and analyze the things you said or did in the context of the failure.

When you succeed, you succeed as a group, the success is context based, and your success is a shared success. This needs to be recognized socially.

Share Accurately: No one knows what the Other needs. Allies can only help if they know the need with information about context. That's the nature of other-ness. If there's a power imbalance, the More Powerful One needs to recognize and maintain explicitly that needs are to be addressed. Something like, "Please ask for things you need" as a reminder periodically.

Ask for help, when necessary, get a third party involved in your conversation about needs.

To Be Heard Best

- Issues are global speak
- Examples are personal speak
- Give possible solutions with benefits when changes are required
- Give examples of similar situations where accommodations are already in place
- Respect the purpose of existing rules, challenging only necessary parts

Adam K:

To be heard best:

Issues are global speak

Examples are personal speak

To avoid controversy: talk in terms of representing autism issues, not necessarily representing people. Ironically it's more political to specify that it is YOUR experience and YOUR best guess that the individuals are the way you perceived

Give possible solutions with benefits when changes are required.

The benefits are for the party that needs to change. "I will be more efficient" or "this allows me to be involved properly" are always possible benefits to give.

Adam G: Or energy saving with lights.

-Give examples of similar situations where accommodations are already in place

Smoke and coffee breaks are common. An overwhelmed break can have a code name "smoke break" if needed.

-Respect the purpose of existing rules, and only challenge necessary parts

Rules are there to keep order and help people. If you create a new rule, you want it respected that way. Challenging existing rules is necessary, and it needs to be done carefully

Ask for Appropriate Accommodations

- Emphasize the positives/outcomes
- Equal rights are not special rights
- Outcomes will not be equal

Adam K:

Ask for appropriate accommodations

-Emphasize the positives and outcomes. Wearing noise-canceling headphones helps increase concentration and accomplish tasks more efficiently while only affecting the wearer.

-Equal rights are not special rights.

We're asking to be able to perform to our potential. If we need accommodations to participate with the same ease as others, that's not a special right, it's ability focused equality, also known as equity.

-Outcomes will not be equal. Find something you're better at than everyone else.

If you can outperform others with accommodations, state it clearly. The cost-benefit ratio is important in money making businesses (all businesses)

How to Avoid Pitfalls When Being WE

- We need to accommodate the most needs without creating new detriments
- If you need accommodation for your unique trait use “I”
- Don’t demand, or make unreasonable claims
- Work toward compromises
- Be humble, we can all be wrong
- Be careful with words and validate them when necessary
- Don’t make false claims, or claims that look false

Adam K:

When speaking on others’ behalf, we need to accommodate the most needs without creating new detriments. In order to know their needs, learn as much as you can - Read blogs, listen to podcasts, experience as much of the spectrum as practical for your domain of advocacy (so all of them) Balance your effort with social expectations. This means you have to measure effort and remember your findings

- If you need accommodation for your unique trait use “I”

Be honest with who the accommodation is for.

-Don’t demand, or make unreasonable claims

When representing another, explain it as your best, and as close to their experience as possible - make sure to ask for validation

Work toward compromises by being honest with task costs and values from outcomes

-Be humble - we can all be wrong

Don’t act like you can’t be wrong

-Be careful with the words you use and Validate when you need to

Offense needs validation or correction

Miscommunication or Misunderstandings can happen from either side. As the minority, it is your obligation to explain the lesser known (your) experience to the other person

We take words differently than the majority culture (too literally sometimes) or apply definitions where others don’t

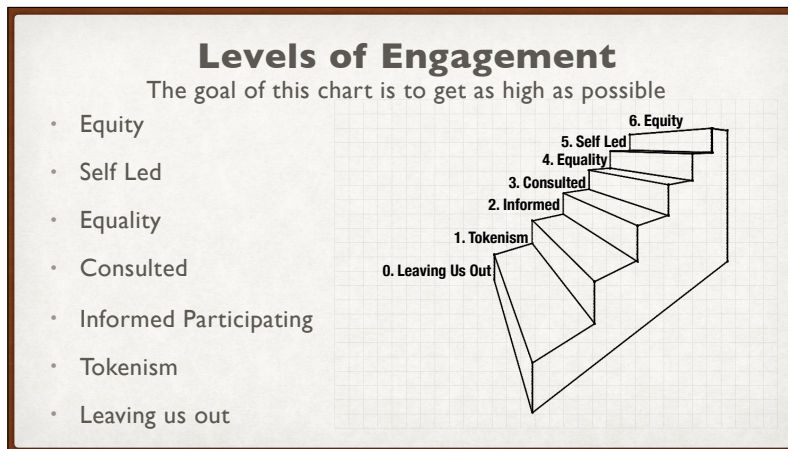
-Don’t make false claims, or claims that look false

Others can’t tell them apart.

Role of Autism Organizations



Adam G:
We will now shift our attention to the role autism organizations play.



Adam G:

Levels of engagement. The goal of this chart is to get as close to the top - Equity - as possible

Leaving us out – You just presume what we want or completely ignore us. We are absent from decision conversations

Tokenism – A symbolic gesture to include us but is done for appearance only, doing nothing of consequence for us. We are invited, but not listened to meaningfully, not asked directly.

Informed Participating - You tell us and make sure we understand, we're still not listened to.

Consulted – We are asked but our input is limited by the scope of the question or does not carry weight. False participation - no influential power.

Equality – Everyone is treated the same, regardless of needing assistance for micro tasks that make up self-determination in the context. This leads to situations where everyone is provided the same stimulus, opportunity or product, regardless of in-abilities to process or utilize the stimulus, opportunity or product.

Self Led - The ability to change environment or experience for ourselves - under the umbrella of equality. An individual with no contribution at an organizational level has no group endorsement, creating individual burden and social risk. Without group endorsement, the group might make rules against it, or atypical behaviour may be misinterpreted negatively. The strategies are worth it, as they increase quality of life.

Equity – Bringing all experiences (regardless of ability) to the same level. We as stakeholders, along with our Allies, have a responsibility to keep ability and contribution in mind during the decision making process and how it relates to those that need assistance in a subtask. From a business perspective, this means more to lose, more to gain. We know it is equity when we are the stakeholders making decisions and being invested in as directly as the rest.

Organizations & Meaningful Involvement

- Both sides need to share our respective points of view
- A team concept, each member has equity to realize common goals
- When dissension occurs, it needs to be dissected & evaluated
- All viewpoints are valid
- Autism organizations need to lead by example

Adam G:

Organizations and meaningful involvement

Both sides need to share our respective points of view and help the “other” to include us. The benefits of involving autistic people involves accurate input from both sides to communicate needs, capitalize on the flexibility of processes and engineer accommodations with optimization of involvement in mind.

An example of this is Autism Calgary’s “Non-hierarchical approach”:

A team concept for an organization with all team members have equity when decisions are made to realize the common goals of the group and to arrive at the collective good answer which the entire group can live with

When dissension occurs it needs to be dissected and evaluated with mutually reciprocal understanding and remember all viewpoints are valid

Autism organizations must lead by showing that minor changes for both how the organization does things and what is required by the autistic adult will result in greater productivity and a happier experience for all. When creating a job, list all the duties possible along with a few required skills then tailor the job to the candidate will give a better chance of success. This can be done for all jobs, shifting responsibilities to those who have the aptitude instead of just following a narrow job description. On the job, provide definitions that are results oriented, and be honest and accurate with desired results. Allow the employee dynamic ways of accomplishing results.

How Organizations Can Offer Accommodation

- Act in good faith with honesty
- Having options available before bringing an autistic adult into the situation helps
- Bring in outside self-advocates & allies to create & continually review accommodation options
- Do not pressure them. Instead, let them know accommodations are available if needed
- Discuss viability of solutions without judging the person for having to ask about viability/appropriateness
- Read books about “humanizing” your language
- Be dynamic & flexible

Adam G:

How organizations can offer or advertise accommodation without sounding condescending or ableist
“Don’t be evil” - like Google; Act in good faith, with honesty.

Having options available before bringing in an autistic adult to the situation helps

Bring in outside self-advocates and allies to create and continually review accommodation options - especially around communication

Do not pressure them. Instead, let them know accommodations are available if needed

If things do not go as expected: listen to understand the individual’s issues, knowing that they are real to the person talking, validating your understanding of their point of view and then work with them to solve the problem. Some may not be good with written communications. Others may not be comfortable on the phone.

Write guides and expectations that employees can follow. Have lists and procedures ready and available. Allow design input from the advocate.

Wait until the end of the conversation if you need to say that this is not something you will commit to beyond this conversation. Be willing to logically explain your decision

Discuss viability of solutions without judging the person for having to ask about viability or appropriateness

Read books about “humanizing” your language - Communication topic books

Be dynamic and flexible

Adam K has an example.

AdamK: When I applied to my latest respite position, my identity as autistic was explicit. In navigating my needs, the people hiring me listened to my needs - my light sensitivity is new to them. Accommodations started with offering to change the lights every time we were together. I don’t need that, as I am capable of handling many environments with my glasses on. But in offering these, it opened up a conversation for ~how~ they are interested in helping me. I led the conversation and we agreed that I could ask by starting with, "I would like..." followed by a direct request and an experience explanation. Such as "I would like to create airflow through this room because there are many smells in here and it is taxing for me to endure them." Now I am able to request any accommodation. While some may be answered with, "That’s a big request, what does it take to endure?" we have a system where we can value each of our efforts and accommodate needs with the least effort for everyone. Plus they can comfortably ask me to accommodate them in the same voice. It makes everything easy. It’s mutually beneficial.

Some Things Hurt Advocacy

- Talking about us in 3rd person when the person referenced is within hearing distance
- Talking down or oversimplified answers for dynamic problems or situations
- Not owning mistakes
- When someone talks about my autism as separate from my life
- Claiming to want results, while hindering progress
- and more

Adam K:

We prepared examples and an explanation for this slide. It's a REAL downer, so we can answer any questions about it after. Take pictures, I mean, we hope you never run into this but this is people stuff, so you will most likely experience it at one point or another.

Everyone good for pictures?

Good Intentions Aren't Enough in Advocacy

- Methods to avoid undermining the message with the action:
 - Do what you say you will
 - Communicate clearly
 - Include the needs of the people you're helping in design
 - Allow for the autistic person to accurately show you their needs
 - Validate your involvement accurately
 - Explicitly include how you will judge our performance

Adam K:

Methods to avoid undermining the message with the action:

Do what you say you will and

Communicate clearly - to the experience of your listener

Include the needs of the people you're helping in design, which means you have to...

Allow for the autistic person to accurately show you their needs AND

Validate your involvement accurately - active listening will go a LONG way.

Explicitly include how you will judge our performance. We often don't think you expect "what you actually DO expect" until you've told us, whether it's the correction phase or as we start cooperating

Changing the Environment vs Coping to Fit The Mould

- Coping does not work long term
- There are known common accommodation starting points
- Most changes are low cost, & benefit more than just those on the spectrum
- Assess what resources are available to include autistic people in work culture
- Accommodations are a journey
 - Interim accommodations may be needed

Adam K:

Coping does not work long term. Coping is stressful - it leaves us exhausted physically and run down emotionally. It's not a good way to live life. To include us long term, we need environmental mediation so coping is not the only strategy. Coping can include not knowing what's being coped with.

Those in power can benefit everyone by learning the common autistic experiences.

The hard one - We may not realize right away that something in the environment is causing distress or overstimulating us.

Lighting, such as from office lights, noise or smells are common major stressors.

An easy catch all to start, is having a quiet room that can be darkened. Or having dimmable lights or task lighting in the work area might work, although different people will have different needs. This will help start the conversation, showing us that there is a real chance to be accommodated.

Low cost solutions can benefit everyone, even people who coped easily before.

Most work spaces were created without much design (think the Cubicle). Creating a space that is safe for both the individual and an organization by design will lead to better working relationships and ultimately be more productive in mutually beneficial ways

Organizations need to assess what resources they are willing to contribute to include autistic people in their work culture - in the same way we need to know our accommodations, we need to know what resources are available to our influence. To appeal for more resources, sensible arguments will be presented.

Accommodations are a journey.

Balance is a finish line, but also something to care for and maintain after it is created. Usually, dynamics of need will be understood by both parties in the maintenance part of the journey. We identify environmental sensitivities, and the organization can help, then we both contribute solutions which only the individual can validate is a solution that works.

Coping strategies may be a necessary part of the journey, but should not be the endpoint "balance" created and maintained.

If coping is present (for a small duration), "how intolerable it is" needs to be shared knowledge, and interim accommodations may be needed while long term accommodations are implemented

For autism service providers: Creating approaches to accommodations, especially those which prove successful, will show other organizations that there is a solution, and they can do it too, maybe even better. This is something that will make jobs more available to our people. With 15% employment rate and widespread under-employment, this is a real issue at hand. We need to do better.

How to Inspire Others to Get Involved

- Work with the system
- Respect your allies, show them their impact
- Learn to recognize others
- Show benefits of advocacy
- Encourage them to find their voice
- Present a manageable experience

Adam G:

Advocates are leaders. As a leader, you need to work within the system. Show by example of what can be done. If we alienate our allies you not only screw up your chance to make a difference but it will be harder for the next advocate to make a difference.

Remind people that you are learning from them while they are learning from you.

Recognize who the potential self advocates around you are, that you can invite. This is the first step to get others involved to help

Remember to show them the benefits of advocating. Appeal to their sense of social justice.

Encourage them to find their voice. Give encouragement and be ready to give advice when things do not go as planned. Remember, there are no stupid questions.

Present an experience they can handle. Listen to what they need. It often helps to start with small projects or break larger projects into small chunks so progress can be seen to give a sense of accomplishment. This, however, does not work for everyone.

What Traits Are Helpful for Success?

- Passion
- Willingness to work
- No idea is a bad idea, idea starts as good potential idea
- Willingness to be wrong/fail & learn from your mistakes
- Cooperation
- Listening skills
- Research skills
- Ability to let go of grudges
- Preparation skills
- A method for self-measurement & reflection
- Prioritizing
- Delegation
- Being able to let it go when you do not get what you want
- Awareness of others' state
- Emotional fortitude
- Confidence

Adam G:

As we go into our Q&A portion of our presentation, we will leave you with some skills and traits that are helpful for success when advocating.

We will now take questions from the audience. First from Autistic people, 20 minutes or as long as there are questions, then we will open it up for everyone. As a reminder, you can write down your question and have one of our volunteers ask for you.