

## 2024 KT Online Conference

### Can a Video Intervention Improve Independent Living Skills of Autistic Young Adults?

*Presenters:*

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Sponsored by AIR's Center on Knowledge Translation  
Disability and Rehabilitation Research (KTDRR)  
<https://ktdrr.org/conference2024/index.html>

Transcript for audio/video file on YouTube:  
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Regina Firpo-Triplett: So I'm Regina, and I have mainly gray, but some brown and some pink in my hair with pinkish glasses. A white woman and a maroon top. And I guess Lane, do you want to describe yourself before we get started?

Lane Edwards: Yeah, I'm Lane. I'm a white person with shoulder length purple hair, and a black striped button up.

Regina Firpo-Triplett: Alright, while we're going to talk about Can Video Intervention Improve Independent Living Skills of Autistic Young Adults, we were hoping to be able to answer that question, but we're still involved in the evaluation now, so we don't have all of our results. But we will share with you what we have, and we're happy to be here. Next slide please. And as was mentioned, dFusion is a small business. We use science and technology to develop innovative products to advance health and wellbeing. We're mainly on the west coast, but our small team does reach out in different parts of the US. Okay, advance please. And so during this short presentation, we realized it's a very short amount of time. We're going to talk about our skill flakes for autistic young adults, our video-based training, our community engagement and development. We're going to highlight some of our learnings from the development.

We are going to describe the study itself, share what we have for qualitative results at this time, and have time for discussion and questions. Advance. And so skill for autistic young adults. So some of you if you were at this last year, may remember a little bit about it, but it's a video library of one to three minute videos that model different skills for young adults as to learn how to communicate in relationships, learn about skills to use in employment, coping with stress in different situations, advocacy, whether it's in a medical office or with a police officer, and more. You'll learn more about that from Lane. And the skill flex technology itself, it's mainly videos. There's some supporting printable resources that are really, really helpful, but 90% of the site is all about these micro skills videos that are clustered into larger skills. So we take a skill that's really important, break it down into micro skills, and then folks watch those and learn from these models. And most of them are live action, but we do have some that are animated for a special reason. But as

an example of a skill and a micro skill, an example of a skill is using emotional regulation strategies. And three of the several micro skills in that under that skill would be identify emotional dysregulation triggers, use a plan to prevent meltdowns and make a plan to manage burnout. So they all relate to the bigger concept. Okay. You can advance please and I'll hand it over to Lane.

Lane Edwards: Yeah, so this should be hopefully playable. One of the videos as an example, a portion like Gina said, of our videos are animated like this one, particularly those that are more about internal processes or more informational or in settings that would've been hard for us to access. Another large portion are live action videos demonstrating interpersonal communication skills. So this large collection covers a wide variety of topics and skills. It follows these 10 main characters, all autistic young adults with diverse needs, backgrounds, and experiences. And here is one that we made for navigating medical settings.

*Video Speaker A:* Um, I really don't want to know my weight right now. I'm going to stand backward on the scale. Could you please hide the number and make a note to avoid sharing it with me?

*Video Speaker B:* Sure thing, Sweets. Is there a reason?

*Video Speaker A:* I'm just really uncomfy in my body right now and don't want another thing sloshing around in there.

*Video Speaker B:* Okie dokie. Well, I'll let the doctor know. She may refer you to someone else about this too. Also, they may want to discuss if your weight is out of average range.

*Video Speaker A:* Okay, fine.

*Video Speaker B:* Alright, sweets, we're just going to get some personal and family history. Alright?

*Video Speaker A:* Yes.

*Video Speaker B:* Do you drink?

*Video Speaker A:* Yes.

*Video Speaker B:* How much?

*Video Speaker A:* Like by volume? Could you be more specific?

*Video Speaker B:* How many drinks per week do you have?

*Video Speaker A:* Like two to three over the weekend mostly, sometimes wine with dinner if my girlfriend's in town.

*Video Speaker B:* Your girlfriend, huh? Are you sexually active?

*Video Speaker A:* Sometimes.

*Video Speaker B:* Do you use birth control methods?

*Video Speaker A:* She doesn't. I use condoms. This is a lie. I need like a 20-second break from sharing with you.

*Video Speaker B:* You got it, sweets. What triggers your vasovagal, syncope, fainting spells?

*Video Speaker A:* A bunch of stuff. I don't really know how else to describe it.

*Video Speaker B:* What triggered your most recent episode?

*Video Speaker A:* Ah, the bus stop. Super cold time. I think what was from a combo stressing about being late, being super hot outside, and standing for a long time,

*Video Speaker B:* How do you feel before you faint?

*Video Speaker A:* Could you be more specific? Sometimes I find it hard to describe how my body feels. Maybe use yes or no questions.

*Video Speaker B:* Sure thing, sweets. Do you feel any pain?

*Video Speaker A:* No.

*Video Speaker B:* Nausea?

*Video Speaker A:* Yes.

*Video Speaker B:* Okie dokie, Eric. Time to take your blood pressure and temperature.

*Video Speaker A:* Sure. Would you mind doing them at different times? I don't like having everything touch me at once.

*Video Speaker B:* Sure thing.

*Video Speaker A:* Great. And if you could tell me what you're doing before you do it, I'd appreciate it.

*Video Speaker B:* You got it, sweets. I'm going to slide this onto your bicep to take your blood pressure. May I take your arm?

*Video Speaker A:* Yes. Thanks.

Lane Edwards: So we can advance on to the next slide. So yeah, that's just an example of one of our videos. There's a pretty wide variety of them. We worked to engage the autistic community at every step, of course as advisors and focus group participants. Also as script writers. We hired five autistic young adults who worked on the scripts of

the videos, which actually is just kind of coming up in the chat over there. We had five autistic script writers from across the US. They had different life experiences, different support needs. We worked with them to help accommodate those support needs. Some folks we worked with in one-on-one meetings writing together. Other folks found that they wanted to accommodate their own schedules and write asynchronously. Some just liked having coworking time where we kind of body doubled to create a productive space. But we had a really interesting time working with a very diverse group of script writers. And then we also, when we went on to film the videos, we also hired a majority of autistic actors to portray our autistic characters in the videos. And that meant we were able, oh, and then also of course, autistic staff on the project such as myself. And that meant we were able to get community input at every stage, from the development of the curriculum to the ideas for the scenarios depicted in the videos and the creation of the videos themselves, and the functionality of the platform. So we can move on to the next slide.

Yeah. So we learned way more amazing things than I can account here from all of those different ways of working with folks. But some of the highlights that shaped things significantly were the accessibility input, making sure the symbols and images we used for the platform made sense to our audience. So at one point replaced a smiley face with a plus sign because people were like, well, it doesn't make me happy, but I do want to add it to my saved list for example. And then also that the site was accessible, had features like a dark mode for folks with sensory sensitivities. We also of course got our priority skill areas from the community, particularly things around support with employment and self-advocacy skills related to intimacy and relationships as well as skills dealing with impacts of things like masking, meltdown and burnouts. One of the biggest things that came from our formative work was the emergence of a subsection of videos called Meet in the Middle Videos.

These are videos that skill fix users can share with friends, family, and other neurotypical folks in their lives that share skills for better understanding and communicating with autistic people. These videos seek to address double empathy theory and recognize that our viewers were saying, we're doing all this work to communicate with neurotypical people. We're watching these videos, we're learning these skills. We also want those people in our lives to be doing work to understand and communicate with us better. Just recognizing that communication is this two-way street. So all of that kind of coming together to be a neurodiversity affirming approach that avoids framing culturally neurotypical communication norms as the right way, and make sure it's to be based in users' strengths. So we can move on to the next slide.

Here's just a fun photo from set. Two of our autistic actors, we filmed for three weeks. We had a really amazing time working with actors to help shape their characters and how their characters portrayed themselves and figure out how we could accommodate everyone's needs from while filming, because sets can sometimes be a challenging space to be accommodated in. As you can see, we've been working on this project for a long time. We had our phase one pilot way back

in 2020 where we did all our usability testing, and it's been a long journey since then. We only very, very recently, like Regina mentioned, concluded our final evaluation, our RCT evaluating the full curriculum, which I will tell you about on our next slide.

So here you can see a little bit about our study design. The study aimed to establish the efficacy of the skill flex training library for autistic young adults to support their skills in communication and healthy relationships. We had an intervention group and a control group. The control group got access to the resource once the study concluded, that control group received access to a flyer site with written content related to skills that weren't included in the evaluation, but were part of that kind of broader skill flex curriculum around things like burnout and self-advocacy. And yes, sorry, that's a randomized control trial. So here you can just kind of see the progression through the study. It happened over the course of four months. We had a baseline, a one month data collection with a survey, and an observational roleplay video call. And then we had another four months, or another three months, of access to the resource and then a final data collection time with the same survey and role plays.

And so yeah, basically those role plays involved getting on a video call with the project staff and going through these structured, semi-scripted scenarios that demonstrated a variety of communication skills that were part of the curriculum that we asked the users to watch. So we can move on to the next slide now. So I'm sure you all know how human subjects research can be. We had a time we expected to be done with all our study activities, but things ended up taking more time. We only very recently finished the study activities and are just jumping in the data analysis, but we do have some fun things to share. Here's first our participant demographics. Our average age was 22, ranging from 18 to 28. We had two thirds that were professionally diagnosed and a third that were self-diagnosed. Of the professionally diagnosed folks, we saw that the median age of diagnosis was 16 and a half, which is a relatively late diagnosis for a lot of folks.

We also saw that a large portion of our participants were employed either full or part-time, had completed at least a year of college, and were dating or in long-term relationships. And then you can also see the gender and race spread there. You might notice those don't necessarily add up to 115. We let people select everything that applied to them and are going to be recoding to break that down into all the different fun combinations that can happen there. So yeah, I think it's kind of an interesting snapshot. It's a group of folks who described it. They hadn't had a lot of prior access to autism-related resources in the past. This was kind of some of their first introduction to accessing resources related to autism. So we can move on to the next slide. I'll be really quick with this one because we didn't actually get to show the results from either of these, but we had our online survey that had a couple different scales looking at things like interpersonal competence and mental health and wellbeing.

And then we had these observational role plays where the facilitators followed responsive scripts. They had flowcharts directing how to respond based on what

the participants said. The scenarios covered the skills addressing conflict, navigating compromise and giving feedback, which were focused skills in the assigned portion of the skill flex library. And those videos are currently being coded to determine a demonstrated skill score using qualitative coding of the skills demonstrated on a scale of zero to 10. And we have three coders working on it who were trained. They triple coded videos until they reached 85% inter-rater reliability. Now they're working hard on their remaining videos. Can go onto the next one.

Regina Firpo-Triplett: And Lane, it's probably worth mentioning that there are 330 recordings that need to be coded. So it's a big job.

Lane Edwards: Yeah, they're all about 15 minutes long. There's 30 of them. It's quite a task. And here it's just we don't need to get too into it because obviously this is very in the weeds. This is what our coders are working with the rubrics. It has kind of the skills that were demonstrated in the videos related to compromise and then breaks them down into what kind of constitutes ranging from not at all to completely in terms of executing that skill. And that is added as a sum to create a total skill score. But also we'll be looking at the different components and how those change as well. So we can move on to the next one. What I do have to share, while I don't have skill scores, is some of our usability results. When we asked which skills our participants found useful, 18% mentioned emotional awareness skills such as body scans, 20% mentioned skills related to self-advocacy.

And then other skills mentioned include consent and intimacy, navigating burnout and conflict resolution. We also saw some of these usability scores that got very favorable. It's overwhelmingly favorable. Some ones that were significantly favorable include ease of access, use and understanding, likelihood of recommendation, a favorable depiction of autism, as well as the usefulness of the shareables and the satisfaction with the content. So we got very, very favorable feedback from folks, and I can move on to the next one. One part that we were excited to see so much responsiveness to was folks sharing the Meet in the Middle videos and having a lot of success with that. Quite a few people shared the videos and also shared that they found them useful. They helped their people in their lives understand the emotional places they were coming from. They helped them better compromise with each other, understand each other better, had more open communication, more acceptance and more accommodation.

So I think that was really exciting because that's a smaller portion of our videos, but we're really interested in how we can expand that in the future. We can move on to the next one, almost to the end right on time. And as usual, we got some really exciting and amazing suggestions for the future. People were excited by our law enforcement section, our medical care section, wanted to see that expanded into some other professions. See all sorts of different ways of navigating these challenging professional situations. Wanted to see more extreme conflict as well as more materials on self-advocacy and especially in the workplace and social situations with acquaintances. So you can move on to the last one. Clearly, looking forward, our biggest priority for us is going to be diving into all of our data. We've

got a really large and rich, you would not believe my spreadsheet, it's going out to column ZZZ or something. So we're working on our video coding, our qualitative and quantitative analysis. We're really excited to get into it and hopefully to be able to share our results with everyone soon. And so if you're interested, definitely give us a follow on LinkedIn, because we will be sharing more there when the time comes. And I will put that in the chat.