

#### Introduction

PhD research: Lived experiences of people with complex communication needs in developing romantic and sexual relationships

#### Today's focus is on:

- flirting, dating and sexual experiences
- how AAC influenced these experiences



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Today, I will present and discuss findings from my Doctoral research. I completed a PhD at Flinders University in South Australia in 2019. My research investigated the lived experiences of people with complex communication needs in developing romantic and sexual relationships. In this session I will be focusing on findings relating to flirting, dating and sexual experiences that participants in the research reported, and in particular how AAC influenced these experiences.

### One evening in San Francisco





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Let's start with a story.

On the way to the 2016 ISAAC conference in Toronto, Canada, I decided to stop over in San Francisco. I took a support worker with me. Let's call him Anton.

One evening in San Francisco, after a full day, Anton and I, planned to have a meal before heading back to the hotel. People who have communication and physical disabilities can rarely be spontaneous. Frequently, we must plan, even to do routine tasks. Going back to our hotel I heard a song from my childhood, {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Living next door to Alice.mp3}}, being sung in a bar. I had

paper\Presentation\mp3s\Living next door to Alice.mp3}}, being sung in a bar. I hat to go in. I decided to join a couple of women dancing near me. Starting a conversation with them, I used a mixture of communication techniques, which included using my communication device. After dancing for a while, one of the women offered to buy me a drink. Let's call her Joanne.

Relaxing on a stool with her shoes off from dancing and helping me take a sip of my drink, Joanne put one of her legs across my lap and rested her foot on a stool which was close to my wheelchair.





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I started massaging her bare foot, which she seemed to enjoy. My thoughts went to Shuttleworth's (2000) research project about men with cerebral palsy seeking intimacy.



Foot rubs as dating recommendations (Shuttleworth, 2000)



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One of his dating recommendations was to offer foot rubs to potential partners. As a doctoral candidate with a disability, it was not my intention to turn this moment into research, yet I remember thinking, I now had evidence that supported Shuttleworth's findings.



Foot rubs as dating recommendations (Shuttleworth, 2000)

Decisions to be made



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Enjoying the moment, I realised I had decisions to make. Some of these decisions any man would have to make, such as whether or not to continue flirting which could lead to something more. But I had additional decisions to contend with because of my disability. Would her hotel room be accessible? If we went to the room Anton and I shared, what would Anton do for the night? How would I transfer from my wheelchair onto the bed? Would Joanne understand my speech if we went to bed together? What would happen if I needed assistance that Joanne did not feel comfortable with?



Foot rubs as dating recommendations (Shuttleworth, 2000)

Decisions to be made

Just Facebook friends



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I decided to retire as gracefully as I could and, after exchanging Facebook details and numbers we said our goodbyes.

I used this true story in the prologue of my thesis to set the scene. It highlights some of the issues people with complex communication needs experience in daily life. I also think it is a useful introduction to today's session.

## Sex, dating and flirting





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In preparing this presentation, I realised that we had the title of the paper in the wrong order. Rather than, sex, dating and flirting, it probably makes more sense to talk about flirting, dating and sex.





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That seems to be more the common pathway. Although, it isn't always the case!

- Strong need for romantic relationships
- Reality of human courtship different to the movies (Horgan et al., 2022)
- Online dating sites are often text-based
- Allow delayed disclosure about disability (Miron et al., 2023)



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Humans usually have a strong need to develop romantic relationships. However, while we arguably don't really understand human courtship, the reality is probably different to what we are used to seeing in the movies. More people with disabilities are exploring the use of online dating to find potential romantic and sexual partners. One of the advantages of online dating sites, is that they are often text-based, which allows people to communicate at their own rate and choose when and how to disclose their disability.

- People use text messages for flirting and romance (Wagner et al., 2022)
- Young people are reluctant to consider dating people with disabilities (Ip et al., 2022)



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The use of text messages for flirting and in romantic relationships is also very common in the broader community. The normalisation of this type of communication could be seen as positive for people with communication disabilities. However, recent sobering research into the attitudes of young people in Australia and Hong Kong shows a clear reluctance towards dating people with disabilities.

- UN Convention asserts equal rights to social relationships
- Experiences of people with congenital disabilities rarely explored



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There is little research investigating the lived experiences of people with complex communication needs in developing romantic and sexual relationships. The UN Convention on the Rights of Persons with Disabilities (2006) asserts people with disabilities have equal rights as others to participate in social relationships and acknowledges the additional barriers they face. The lived experiences of people with congenital disabilities in developing intimate relationships have rarely been included in disability and sexuality literature.

• AAC literature rarely explores romance and sexuality (Sellwood et al., 2017)

PhD research investigated the lived experiences of people with complex communication needs in developing romantic and sexual relationships



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The Augmentative and Alternative Communication literature generally focuses on building communicative competency, education, living skills, social networks and employment. A systematic review of the literature was undertaken into the perceived barriers and facilitators experienced to socializing, sharing intimacy and expressing sexuality of people with communication and physical disabilities. Findings of the review revealed that people with communication and physical disabilities do develop romantic and sexual relationships, but little is known of their lived experiences and the barriers and facilitators they encounter. For my PhD, I researched the lived experiences of people with complex communication needs in developing romantic or sexual relationships. A paper about this research was published in the AAC journal last year (see Sellwood et al., 2022). Today, I am presenting on the findings which relate to whether flirting, dating and sex can be supported by AAC devices and strategies.

#### **Method**

Darryl Sellwood, Parimala Raghavendra & Ruth Walker (2022) Facilitators and barriers to developing romantic and sexual relationships: lived experiences of people with complex communication needs, *Augmentative and Alternative Communication*, 38:1, 1-14, DOI: 10.1080/07434618.2022.2046852

Interviewed nine adults with physical and communication disabilities



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The methods used in the research have been described in the paper published in the AAC journal, the reference is on the screen. Briefly, I conducted interviews face-to-face, either in person or over Skype, with nine adults who had communication and physical disabilities. A theoretical framework was developed, to explore the lived experiences, drawing on the concept of ableism, critical hermeneutics, Feminist Standpoint Theory and the International Classification of Functioning, Disability and Health (ICF) model.

#### **Results**

- Six participants experiences discussed today
- · Focus on flirting, dating and sex
- Participants had physical and communication disabilities
- All used multiple AAC strategies and devices
- Ages between 21-60
- Four female, two male



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The findings presented today relate to experiences of flirting, dating and sex reported by six of the participants. We have used pseudonyms to protect their privacy. All the participants had physical and communication disabilities and used multiple AAC strategies and devices. For more detailed information, refer to my PhD thesis which is available online.

The ages of these participants discussed in this presentation ranged from 21 to 60, with four females and two males. All had high school education or higher. The findings revealed that most had enjoyable sex lifes. Two of these participants were in ongoing relationships and the majority identified as heterosexual.

In this session I will discuss the results as I present them but first I will introduce the experiences we will discuss.

The direct quotes have not been edited and they have been re-voiced by actors.

Katie



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Katie met an able-bodied male at a restaurant, and they had several dates before becoming "friends with benefits."

- Katie
- Jasmine



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Jasmine was at a concert when an able-bodied male started to dance with her. They were getting on very well, when other people guided him away from her and made him leave the premises. She did not see him again.

Jasmine also reported connecting with a different able-bodied male through a dating website and communicating online before they eventually met and started a sexual relationship.

- Katie
- Jasmine
- Oscar



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Oscar used LBGTIQ+ dating websites to connect with able-bodied males for sex and used to enjoy seeing their reaction when they realised he had a disability. Now he is more careful, being upfront about his disability before meeting in person.

- Katie
- Jasmine
- Oscar
- Samuel



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Samuel reported experiences with a male friend, who also had complex communication needs, who was a nudist. They would go on the roof of a public building where his friend asked him to undress. They also went to bed together.

- Katie
- Jasmine
- Oscar
- Samuel
- Emma



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Emma met an able-bodied man at a hotel. At the time, her AAC device was a Canon Communicator that printed on strips of paper. Other people collected the printouts, red them and teased her but the man ended up living with her for several years.

- Katie
- Jasmine
- Oscar
- Samuel
- Emma
- Sophie



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Sophie was teaching her able-bodied male friend sign language and they ended up in bed together.

{{Split}}

Horgan et al. (2022) argue that flirting can have multiple objectives beyond looking to develop relationships, including having fun and building self-confidence.

Jasmine explained that she enjoyed the rare occurrence of being pursued and flirted with by a stranger. {{//We danced for ages. He thought I was stunning and wanted to date me. He wanted to know if I found him hot. He was tickling and kissing me, even on the lips. I didn't feel anything when he kissed me but I didn't pull away, either. I was totally engrossed by him. I wasn't able to talk to him and I didn't know how to kiss him back. His touch wasn't perverted, everything he did was about impressing me. He wanted me to hug him and I felt frustrated that I couldn't. He got excited when my friend went away and we were "alone". [...] He was such a sweet man and he cared about impressing me and what I thought of him. I ran over his foot and he didn't seem to notice. He tried so hard to dance with me./}} {{Audio=D:\OneDrive -Flinders\Documents\ISAAC Local\Dating}

paper\Presentation\mp3s\Actors\Jasmine 1.mp3}} {{Pause=1}}

Just when the chance of romance with a potential partner was blooming, Jasmine

reported that her friends and security staff were concerned for her safety and took it upon themselves to usher him out of the door without first checking with her.

#### **Flirting**

"We danced for ages. He thought I was stunning and wanted to date me. He wanted to know if I found him hot. He was tickling and kissing me, even on the lips. I didn't feel anything when he kissed me but I didn't pull away, either. I was totally engrossed by him. I wasn't able to talk to him and I didn't know how to kiss him back. His touch wasn't perverted, everything he did was about impressing me. He wanted me to hug him and I felt frustrated that I couldn't. He got excited when my friend went away and we were "alone". [...] He was such a sweet man and he cared about impressing me and what I thought of him. I ran over his foot and he didn't seem to notice. He tried so hard to dance with me."

Jasmine



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She explained how having an able-bodied man show her attention made her feel sexually desirable, although, she added, {{//"The whole time I was a bit suspicious of him, thinking I wasn't the real woman he wanted. [...] This made me, in a way, put up a barrier between us [...] until it was too late."/}} {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating

paper\Presentation\mp3s\Actors\Jasmine\_2.mp3}} Following that night, she tried to re-connect with the man but was unable to locate him.

#### **Flirting**

"The whole time I was a bit suspicious of him, thinking I wasn't the real woman he wanted. [...] This made me, in a way, put up a barrier between us [...] until it was too late."

Jasmine



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Reflecting on the incident later, she said, {{//"Wow, an able-bodied guy made me feel desirable, sexy, and wanted me physically and emotionally,"/}} {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating

paper\Presentation\mp3s\Actors\Jasmine\_3.mp3}} but she perceived that the surrounding people rejected her womanhood by having him removed. However, she said this experience boosted her self-esteem. {{//"He made me believe in myself so I joined an on-line dating site where I met my partner."/}}{{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Actors\Jasmine\_4.mp3}}

#### **Flirting**

"Wow, an able-bodied guy made me feel desirable, sexy, and wanted me physically and emotionally"

"He made me believe in myself so I joined an on-line dating site where I met my partner."

Jasmine



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Three participants discussed using online dating sites to increase their opportunities to meet potential partners. All three successfully met partners, and the two female participants formed long-term relationships.

Jasmine raised an interesting point related to managing the effects of ableism. She highlighted that going online was an environment where she could personally be in control by saying, {{//"I got to know him without anyone else getting involved.

Nobody has [taken] him away from me yet."/}} {{Audio=D:\OneDrive -

Flinders\Documents\ISAAC Local\Dating

paper\Presentation\mp3s\Actors\Jasmine\_5.mp3}} This control also included the power to decide when and how to disclose her disability. Unlike face-to-face interactions, the online environment allowed for a degree of anonymity.

### **Dating**

Using online dating sites

"I got to know him without anyone else getting involved. Nobody has [taken] him away from me yet."

Jasmine





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Oscar, a young gay male, talked about his first face-to-face meetings with men he had met online. {{//"Some [guys] have never met anyone with a disability before, so when I rock up I open the door, it is like people not knowing how to react."/}} {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Actors\Oscar - Camp.mp3}} He went on to say that he enjoyed turning up to people's places and seeing their reactions when he 'came out' as disabled.

However, he changed his approach over time. Whereas in the beginning he would not mention his disability before meeting others face to face, he is now more up front regarding having a disability. It seems that he became more careful as he aged.

#### **Dating**



Disclosing disability

"Some [guys] have never met anyone with a disability before, so when I rock up I open the door, it is like people not knowing how to react."

Oscar



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In her interview Emma said she had recently returned to using online dating sites and made the point that she only disclosed that she had a disability after they had become better acquainted, saying: {{//i'd not say straight up i have a disability, i want them to know me first, then i say i have a disability n can't talk, but that makes me almost perfect, cos i can't whinge or argue - put a positive spin on it./}}{{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Actors\Emma\_6.mp3}}

Emma described using humour to overcome possible discrimination because of her disability. All the participants in this research experienced ableism in the attitudes of others. This is reinforced by research findings that ableist attitudes in the broader community influence people's perceptions about dating people with disabilities.

### **Dating**

Disclosing disability

"I'd not say straight up I have a disability, I want them to know me first, then I say I have a disability n can't talk, but that makes me almost perfect, cos I can't whinge or argue - put a positive spin on it."

Emma

• Ableist attitudes influence people's perceptions about dating people with disabilities (Ip et al., 2022).



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It was commonly reported that the accessibility of AAC devices was a major issue when in bed. While Sophie could use her AAC device in bed, she reported, {{//"I did not like intimate conversations, written or printed.... sign helps,"/}} {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Actors\Sophie\_7.mp3}} suggesting text communication is not conducive to intimacy. She preferred to use sign language with her partner.

#### Sex



 Accessibility of AAC devices in bed is a major issue

> "I did not like intimate conversations, written or printed.... sign helps" Sophie



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Others developed their own non-aided communication strategies. Katie discussed the methods of communication she used in bed with her male friend saying, {{//"We had to use yes or no questions"/}} {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Actors\Katie\_8\_YesOrNo.mp3}} and {{//"Going through the alphabet."/}} {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Actors\Katie\_8\_Alphabet.mp3}} When she was asked if she used any quick gestures she replied, {{//"A smile registering good."/}} {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Actors\Katie\_8 Smile.mp3}}

#### Sex



 Accessibility of AAC devices in bed is a major issue

"We had to use yes or no questions" "Going through the alphabet."

"A smile registering good."

Katie



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While! Samuel used a more sophisticated strategy with his partner who also had complex communication needs. He explained their low tech method that they developed to communicate while they were in bed together.

{{// "When we slept together when if I was unable to see his face, I put my finger in his mouth., start with 'before L' and [he] would bite/suck me to communicate [using the alphabet]."/}} {{Audio=D:\OneDrive - Flinders\Documents\ISAAC Local\Dating paper\Presentation\mp3s\Actors\Samuel.mp3}}. {{Pause=1}} The results suggest that in intimate settings, many AAC devices are not conducive to good sex.

#### Sex

 Accessibility of AAC devices in bed is a major issue

"When we slept together when if I was unable to see [his face], I put my finger in his mouth., start with 'before L' and [he] would bite/suck me to communicate [using the alphabet]."



#### Samuel



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One of the key implications of this research is the need to acknowledge the huge amount of ableism people with complex communication needs face in all parts of our lives. This is especially true when trying to develop romantic and sexual relationships. Parents and teachers of teenagers and young adults with communication disabilities need to acknowledge this with the people they are supporting and work alongside them as they learn and develop strategies to recognize and manage this rife ableism.

#### **Implications**

Understanding and subverting ableism in dating



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This is a growing area but more research is needed that listens to the experiences of people with physical and communication disabilities in participating in flirtatious, romantic and sexual activities. This should help us better understand their success stories and how they have approached the barriers they face. This type of research will assist to inform education for young people with disabilities and their supporters (e.g. friends, family, partners and professionals). As highlighted by Ippe et al (2022), we also need broader education in the wider community to help change attitudes toward people with disabilities being considered as potential lovers.

Research in this area can also inform developments and improvements to AAC systems and tools. How amazing would it be if there were AAC-friendly sex toys which could empower individuals with complex communication needs to fully engage in intimate moments? I can see such things having a much broader mainstream appeal.

## **Implications**

- Understanding and subverting ableism in dating
- More research is needed to inform
  - education for young people with disabilities and their supporters
  - broader education in the community
  - developments and improvements to AAC systems and tools



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I have been encouraged by emerging research in this field, such as Megan Walsh's Australian PhD study looking into the sexuality of young people with communication and physical disabilities.

### **Implications**

- Understanding and subverting ableism in dating
- More research is needed to inform
  - · education for young people with disabilities and their supporters
  - · broader education in the community
  - developments and improvements to AAC systems and tools
- Megan Walsh PhD research



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The noteworthy limitations of this research include:

Although recruitment took place over 13 months and involved numerous approaches, the final participant pool was slightly smaller than we hoped.

Communication difficulties of both the researcher and the participants, meant the three-hour time limit for each interview was only enough to scratch the surface. Gaining a fuller understanding would take more time and effort.

While the project was intended to provide an opportunity for people whose voices are often unheard, the participants may not be a representative sample, and findings may not be transferrable to the general population of people with complex communication needs.

#### **Limitations and Future Directions**

- Small participant pool
- Three-hour time limit only scratched the surface
- May not be a representative sample



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There has been a focus on the social participation of children and adults with communication disabilities over decades, yet, very little on the type of social participation which many of us who are users of AAC possibly have a strong desire and need for. Participation in flirtatious, romantic and sexual activities. This research demonstrated that although AAC devices and strategies can assist people with complex communication needs to participate in these kinds of social participation, they are still inadequate in intimate situations.

I am involved with the panel here talking about the future of AAC. I would like to see a suite of AAC devices, software and strategies which allow everyone involved to freely communicate with ease through the different phrases of their flirtatious, romantic and sexual relationships.

#### Conclusion

- · Little AAC research around flirting, dating and sex
- · AAC can assist people to participate
- Still inadequate in intimate situations
- Looking forward to the future of AAC sex toys!



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On a personal note, before finishing and opening up for questions, I would like to acknowledge the support I have received from Associate Professor Pammi Raghavendra, and Associate Professor Ruth Walker throughout my PhD candidature, and to Dr Paul Jewell for his endless red herrings! We miss you, Paul. Thanks to Pammi and Ruth for their continued support in numerous ways in my post-doctoral career.

## Thank you

- Thanks to
  - Associate Professor Pammi Raghavendra
  - Associate Professor Ruth Walker
  - Dr Paul Jewell



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