

# Supporting adults with learning difficulties in online participation

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Stand for ambition.  
**kent.ac.uk**



# The literature

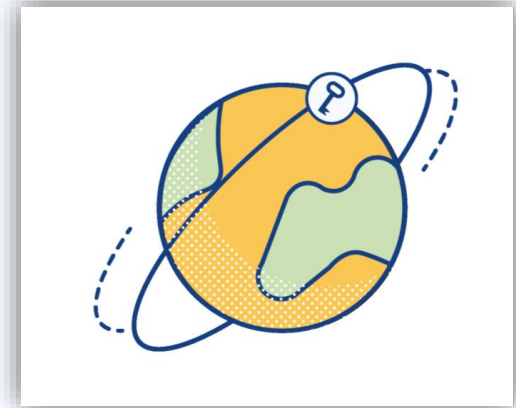
- More than 3 billion people worldwide use the internet (Meeker & Wu, 2018)

Are people with Learning Disabilities different?

- Are less likely to use the internet compared to the general population (Chadwick et al., 2013)
- But increasingly gaining access (Chiner et al., 2017); reaching similar levels with the general population during COVID-19 (Caton et al., 2022)
- They face societal disadvantages and inequalities:
  - Greater digital exclusion (Alfredsson et al 2020)
  - Greater health need and lower levels of health literacy (Latteck & Bruland, 2020)



# The literature



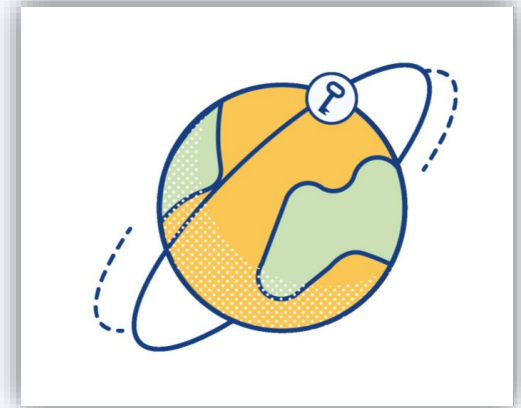
## Barriers:

- Use of ICT – support (Holmes & O’Loughlin, 2014) *gatekeepers* or *enablers*?
- Financial barriers; accessibility (technology, websites etc); literacy (Alfredsson Ågren et al., 2020; Shpigelman and Gill, 2014; Caton & Chapman, 2016; Chadwick et al., 2013)

## Risks:

- Often negative experiences (Jenaro et al., 2018; Chiner et al., 2017) – but no police involvement.
- Can people with learning disabilities be perpetrators of online harm? (Chiner et al., 2017)
- Main strategy to protect adults with LD: gatekeepers , monitor and block access. (Gutiérrez-Recacha & Martorell-Cafranga, 2011)

# The literature

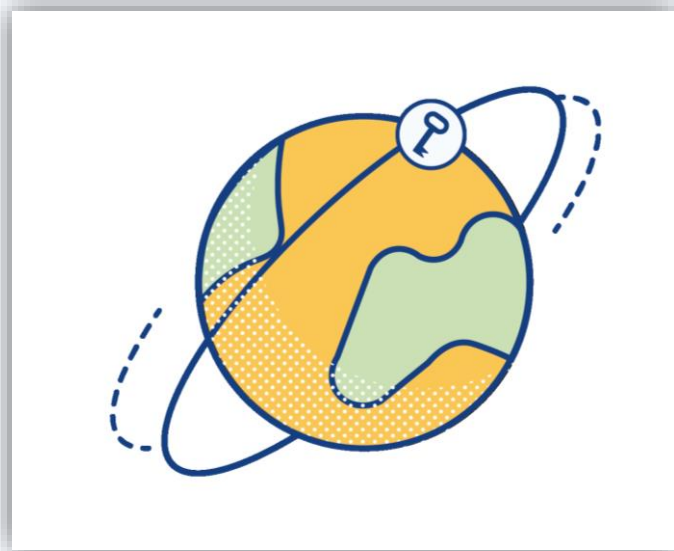


## Benefits & opportunities:

- Improve social capital (Verdonschot et al., 2009)
- Increase and maintain social networks and friendships (Barlott et al., 2019)
- Feel connected during COVID-19; reduce loneliness (Caton et al., 2022)

# How can we help?

Understand the challenges



Safer Online Lives



Our Digital Health

# 'Our Digital Health' Study



## Part 1: Development of Digital Health Participation Measure

- Literature Review (Concepts & Measures)
- Co-creation (Focus groups and Workshops)

## Questions



1. What do you think about it?

- ☐ Good
- ☐ Bad
- ☒ Not sure

## Part 2: Digital Health Participation Survey

- Longitudinal (6 months apart) and
- Comparative (with referent group people without disabilities)



## Part 3: Digital Diary Study

- Qualitative diary data over 5 months
- Qualitative interviews (weekly)



## Part 4: Dissemination & Output Co-creation

- Co-creation workshops
- Suit of guidance
- Valid measure for use

FUNDED BY

**NIHR** | National Institute for Health and Care Research



# Safer Online Lives Timeline

Start of  
study



Interviews

Who would you like to help today?



Akin



Vicky



Lin

Interactive  
App

February 2021

May 2021

November 2021

November 2022

May 2023

January 2024



Online  
Survey



Focus  
Groups



Social Media  
Observations

End of  
study

# Who has been involved in Safer Online Lives?

Over **70** services have been promoting and supporting us with the study, including:

- **31 NHS Trusts**
- **8 Local Authorities**
- **33 service providers**

Services have been stretched, understaffed and burned out following Covid-19, but still recognised the importance of the research, and found ways to support us.



# Central idea: Co-production



Safer Online Lives:  
Advisory group  
members

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# Survey

## ✓ Internet & Social Media use in general

## ✓ Barriers to internet access

- Including: Internet restriction (Molin, Sorbring, & Löfgren-Mårtenson, 2015; Seale 2014), accessibility - items inspired from Caton and Chapman(2016) Systematic Review.

## ✓ Risks










- Including: European Cyberbullying Intervention Project Questionnaire (Brighi et al., 2012; LD survey) and items informed by Chadwick, Quinn and Fullwood (2017).

## ✓ Benefits and opportunities

- Including: friendship, communication, employment etc. (items inspired by and adapted from Chadwick, Quinn and Fullwood (2017).

Please look at these sentences and tell me how much you agree with them.

Put a tick or X in just one of the boxes beside each sentence.

	Agree 	I'm not sure 	Disagree 
1. Social media is part of my everyday activity. 			
2. I am proud to tell people I am on social media. 			
3. Social media has become part of my daily routine. 			
4. I feel out of contact with people when I have not logged into social media. 			
5. I feel that I am part of a social media community. 			
6. I would be sorry if social media shut down. 			

# Who took part?

## Survey – people with LD

- **115** adults with LD
- Aged **18 to 77yrs** (M=37)
- 56 males, 57 females, 2 N/A
- use the internet every day (72.2%)
- 79.1% use social media (Facebook)

## Interviews

- **20** adults with LD
- 11 males, 9 females



# What do people do when online?

Online activity	N(%)
Social media	91(79.1%)
Online shopping	66 (57.4%)
Online Banking	51(44.3%)
Online courses/ training	28(24.3%)
Call friends or family	63(54.8%)
Call paid carers (e.g., support worker)	24(20.9%)
Online dating	10(8.7%)
Look up information (hobbies)	58(50.4%)
Look up information (health or social care)	41(35.7%)
Play online games	45(39.1%)
Chat with other gamers	18(15.7%)
Listen to music	72(62.6%)
Watch movies/ TV shows	64(55.7%)
Watch YouTube videos	68 (59.1%)
Read/ watch the news	53(46.1%)
Watch pornography	11(9.6%)

# What do people do when online?

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# Barriers to access

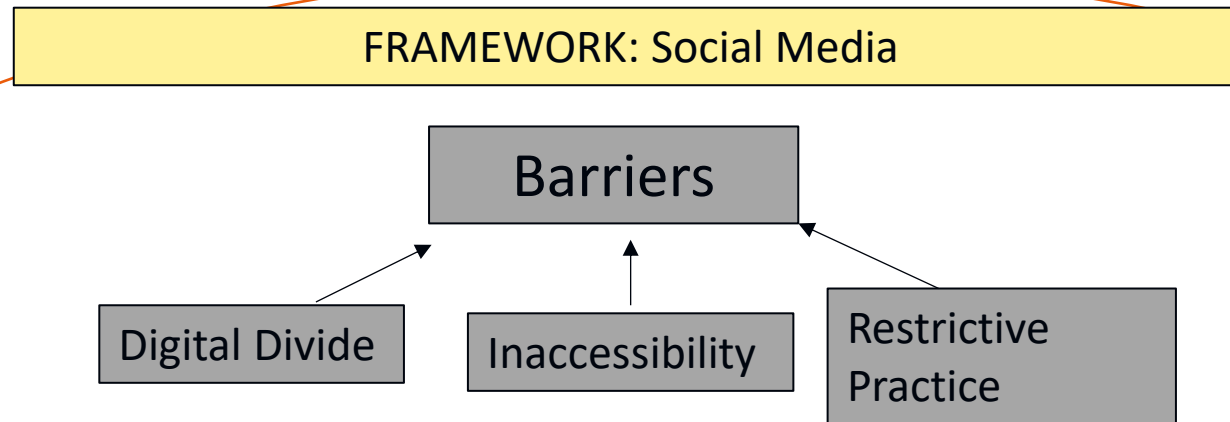
Reported Barriers	N(%)
There are limits to when I can use the internet, or what I can look at	31(28.4%)
I don't always have someone to help me with the internet when I need it.	32(27.8%)
Someone who supports me doesn't know much about using the internet	9(7.8%)
I find it harder to read on the internet without help	21(18.3%)
I find it hard to spell what I want to say or search on the internet without help	28(24.3%)
I find it hard to use the internet because of physical problems (e.g., use my hands to type)	8(7%)
Websites on the internet can be confusing or unclear	36(31.3%)
Websites and social media that I use sometimes change, and I find it hard to learn the new versions	25(21.7)
I find it hard to know what to say, or how to express myself when talking online	22(19.1)
Paying for internet is too expensive	15(13%)



# Barriers to access

Reported Barriers	N(%)
<b>There are limits to when I can use the internet, or what I can look at</b>	<b>31(28.4%)</b>
<b>I don't always have someone to help me with the internet when I need it.</b>	<b>32(27.8%)</b>
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# Thematic analysis -Interviews



“and layouts of stuff as well. It's like instructions. I can't really read instructions, so I don't know, making a bed, if you showed me how to make it I could do it, but I can't read the instructions 'cos they're not in Easy Read.”

“I didn't actually get any equipment myself until I was quite late really. Like, probably not until I was maybe, like, twenty. ‘Cos we couldn't afford stuff basically”

“...mostly at night there are restrictions...like sometimes they switch off the Wi-Fi or change the password...I think they want us to sleep and not to stay on the internet for long.”

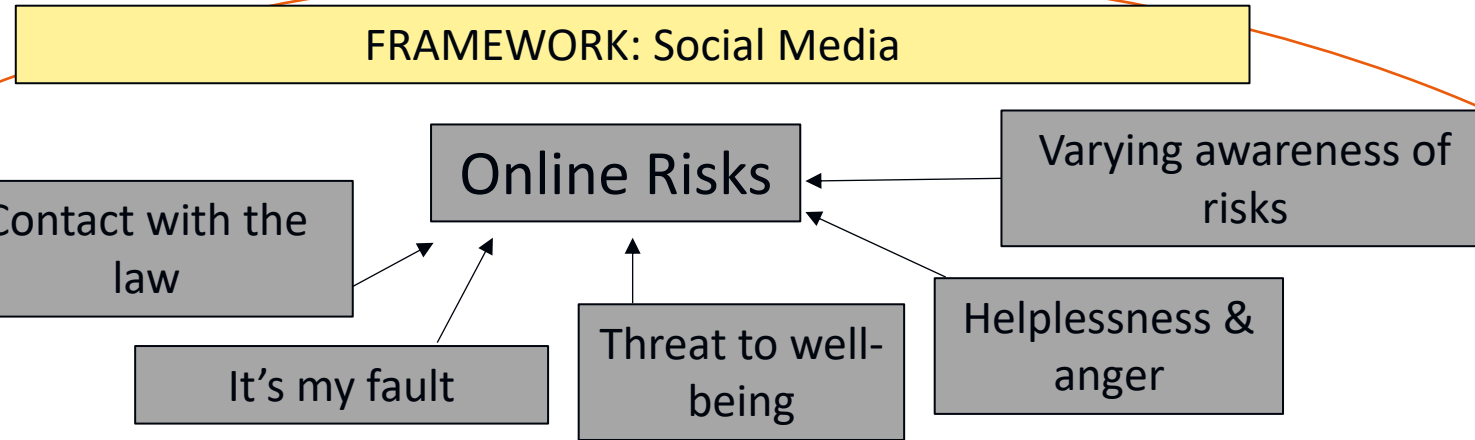
# Online Risks

Online Risks	N(%)
I bought something by mistake online	36(31.3%)
Someone sent me images or videos that I did not want to see or that made me feel uncomfortable	39(34%)
Someone who I have never met face-to-face asked me to meet them in person	34(29.6%)
Someone asked me to send them intimate/private pictures or videos of myself	26(22.6%)
Someone I did not know asked me to give them my bank details	36(31.3%)
I gave my bank details to someone I don't know	15(13.1%)
Someone asked me for my personal details, like my home address	35(30.4%)
Someone who I met online tried to hurt me in real life	15(13.1%)
I accidentally downloaded a virus onto my computer/tablet/phone	35(30.4%)
I gambled online	20(17.4%)
Because I was using the internet, I spent less time with friend and family, doing activities I normally enjoy	36(31.3%)

# Further analysis of Risks

- 58.9% reported to have been victims of cyber-bullying and 29.5% had displayed cyber-aggressive behaviours with 28.4% having experienced both – being victims and aggressors.
- participants who had experienced certain risks, such as harm from someone they met online ( $\chi^2=18.12$ ;  $p<0.001$ ), and participants who engaged in risky behaviours, such as gambling ( $\chi^2=28.10$ ;  $p<0.001$ ), scored significantly higher in cyber-aggression scores.
- participants experienced significantly higher cyber-bullying victimisation than engaging in cyber-aggressive behaviours ( $z=-5.57$ ,  $p<0.001$ )
- For people that social media use was part of their everyday routine also scored significantly higher (mean rank=52.97, median= 13,5) on cyber-bullying victimisation when compared to peers that did not (mean rank=31.91, median=11) use social media everyday [ $\chi^2(df=2, N=95, \eta^2=0.06)=8.26$ ],  $p<0.05$ .
- strong positive correlation between cyber-aggression and cyber-bullying victimisation total scores  $r(1)=0.75$ ,  $p<0.001$

# Thematic analysis -Interviews

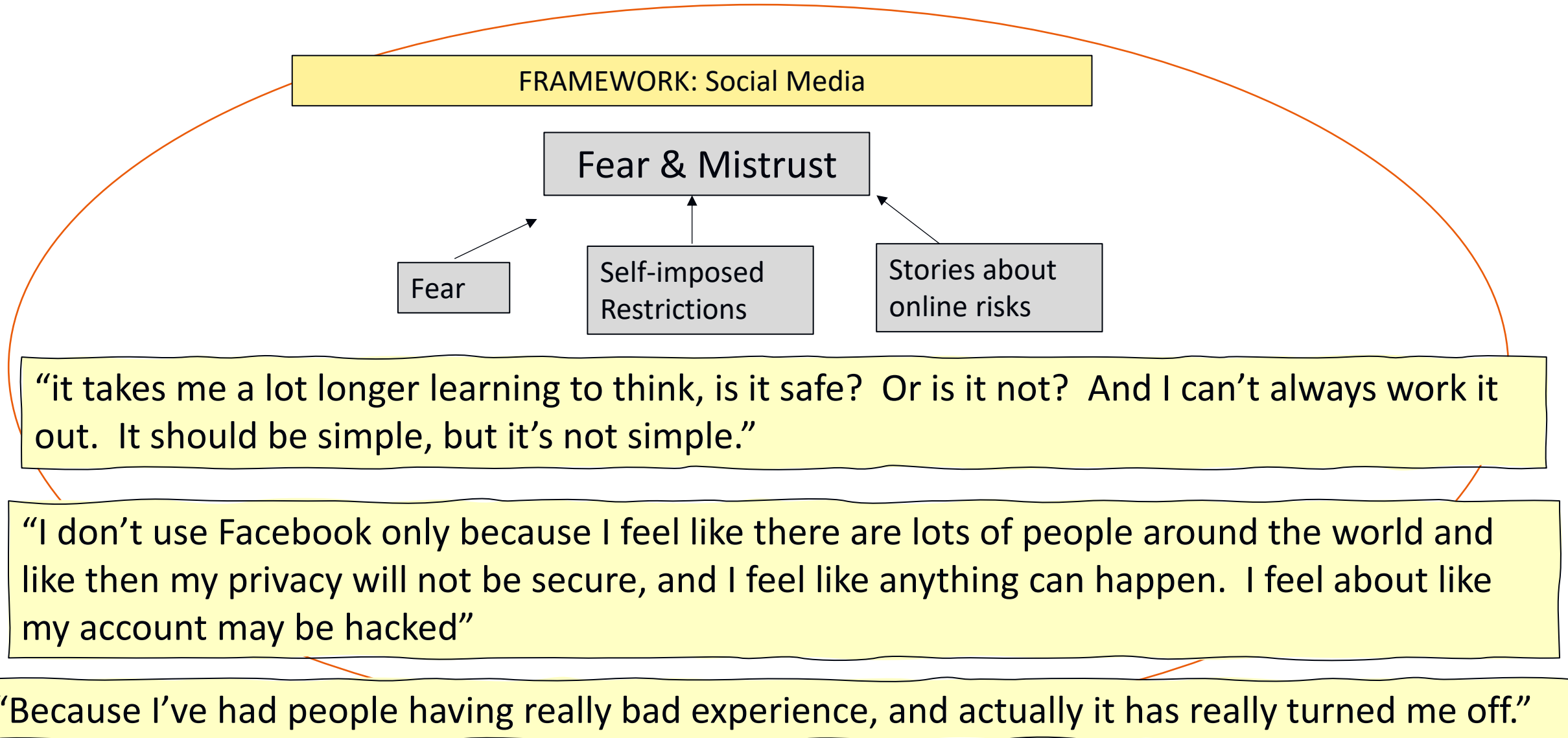


"He just found that he needed to be connected all the time, and he had the fear of missing out ...just found it difficult to switch off."

"I had actually had someone who tried to say that they were like an eighteen-year-old-girl and then they said they weren't. And then they said they were going to contact paedophile hunters. "

"I ordered myself a mobility scooter. Will it come? I don't know. But I paid £43 for it... if it don't come through, then I've lost £43. That's my fault again.."

# Interviews – Thematic analysis



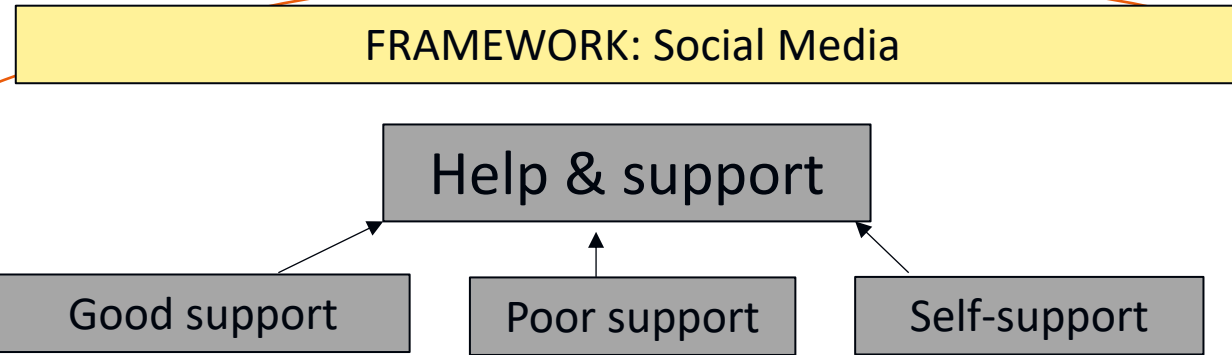
# Online Benefits

\*65% stating that this is not somethings that they have tried when using the internet

Benefits and opportunities statements*	Low Benefit* [N(%)]	Medium Benefit* [N(%)]	High Benefit* [N(%)]
Helps me keep in touch with my friends & family	10 (10.5%)	27 (28.4%)	49 (51.6%)
I was able to make more friends	20 (21.1%)	24 (25.3%)	27 (28.4%)
Helps me get better using the PC	15 (15.8%)	24 (25.3%)	49 (51.6%)
I was able to get better at communicating by using the internet	25 (26.3%)	20 (21.1%)	38(40%)
I learned about other cultures and people	13 (13.7%)	23 (24.2%)	34 (35.8%)
I was able to find about work opportunities through the internet	17 (17.9%)	21 (22.1%)	27 (28.4%)
I was able to find out more about education or courses that I can do	20 (21.1%)	27 (28.4%)	21 (22.1%)
I was able to be part of an online support group	18 (18.9%)	20 (21.1%)	24 (25.3%)
Helped me find out information about my rights	20 (17.4%)	19 (20%)	29 (30.5%)
I was able to use the internet to arrange to see a friend in real-life	14 (14.7%)	23 (24.2%)	29 (30.5%)
I found out information on COVID-19 through the internet	12 (12.6%)	25 (26.3%)	42 (44.2%)
I met my boyfriend/girlfriend through the internet*	5 (5.3%)	6 (6.3%)	9 (9.5%)
I was able to share my opinions on important things through the internet	12 (12.6%)	22 (23.2%)	21 (22.1%)



# Thematic analysis -Interviews



"I've been taught how to do it by [carer]. But if I had to do it on my own, I don't think I'd be talking to you now like this [using zoom]. So its really good to have someone help me do this, to learn on my own."

"I had a support worker... yes I did tell her, but she just basically said "you have to be..." you know ".. be careful on who you are talking to on FB."

"It's like Microsoft Office, I don't know how to use a certain program, then I look on the internet"

# Thematic analysis -Interviews

FRAMEWORK: Social Media

Empowerment

Independence and  
increasing accessibility

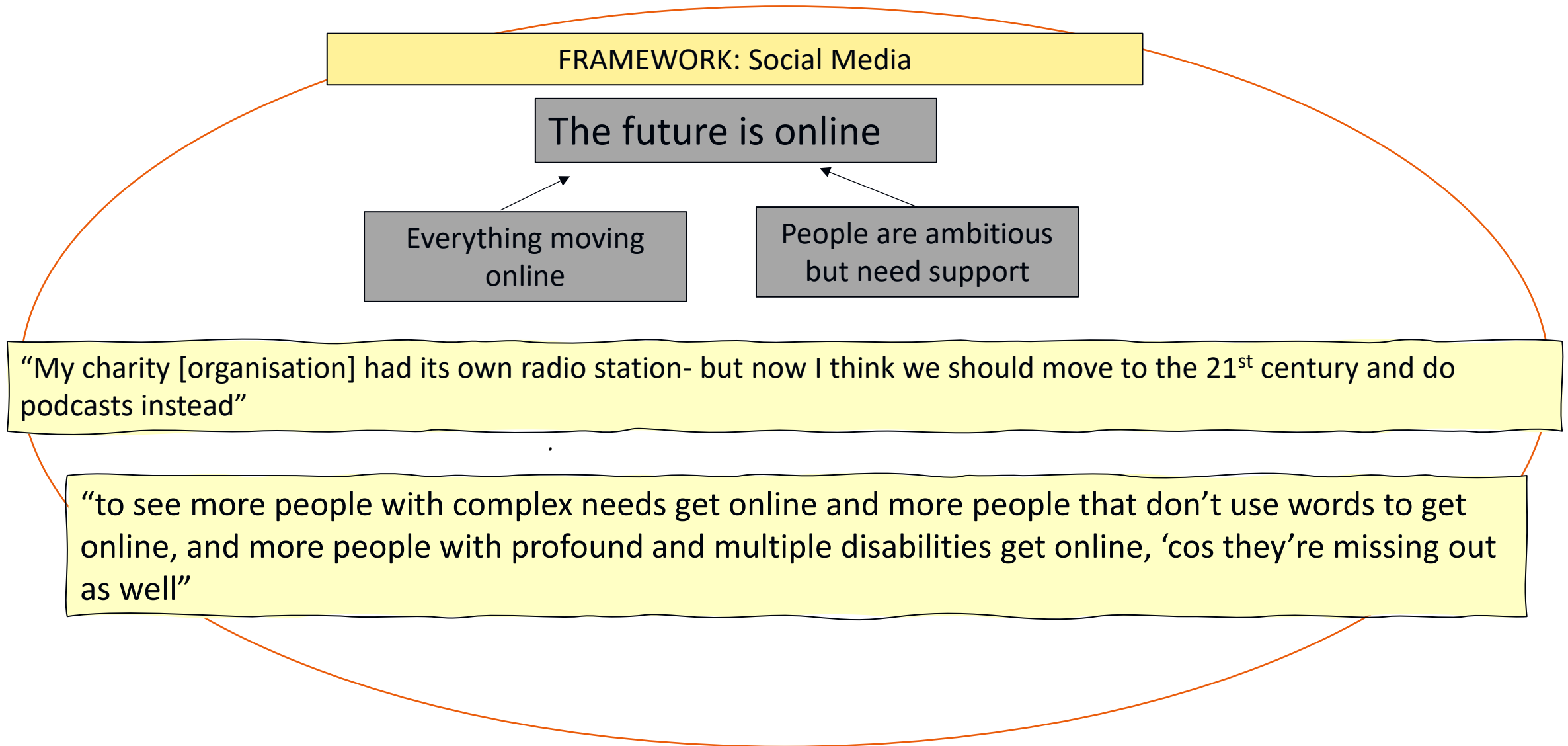
A wider picture  
of the world

Exploring your  
identity

"I love the freedom it gives me. And the stuff I can do on the internet and don't have to rely on anything else. I can even the simple things, I can order my medication through an app and it gets delivered."

"I express myself online because of my own opinion.. Like because I want to have my say of what I think about what's going on in the world [laughs]"

# Thematic analysis -Interviews



# Safer Online Lives Timeline

Start of  
study



Interviews

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Interactive  
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Focus  
Groups



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End of  
study

# Who took part?



## **Survey – Carers & professionals (n=255)**

- 46 family carers, aged 22 to 83yrs (M=52)

20% male, 80% female

- 46 paid carers, aged 19 to 69yrs (M=41)

31% male, 69% female, average 12.6yrs of experience

- 133 safeguarding professionals, aged 23 to 70yrs (M=43)

18% male, 82% female, average 11.8yrs of experience

## **4 Focus Groups (n=19)**

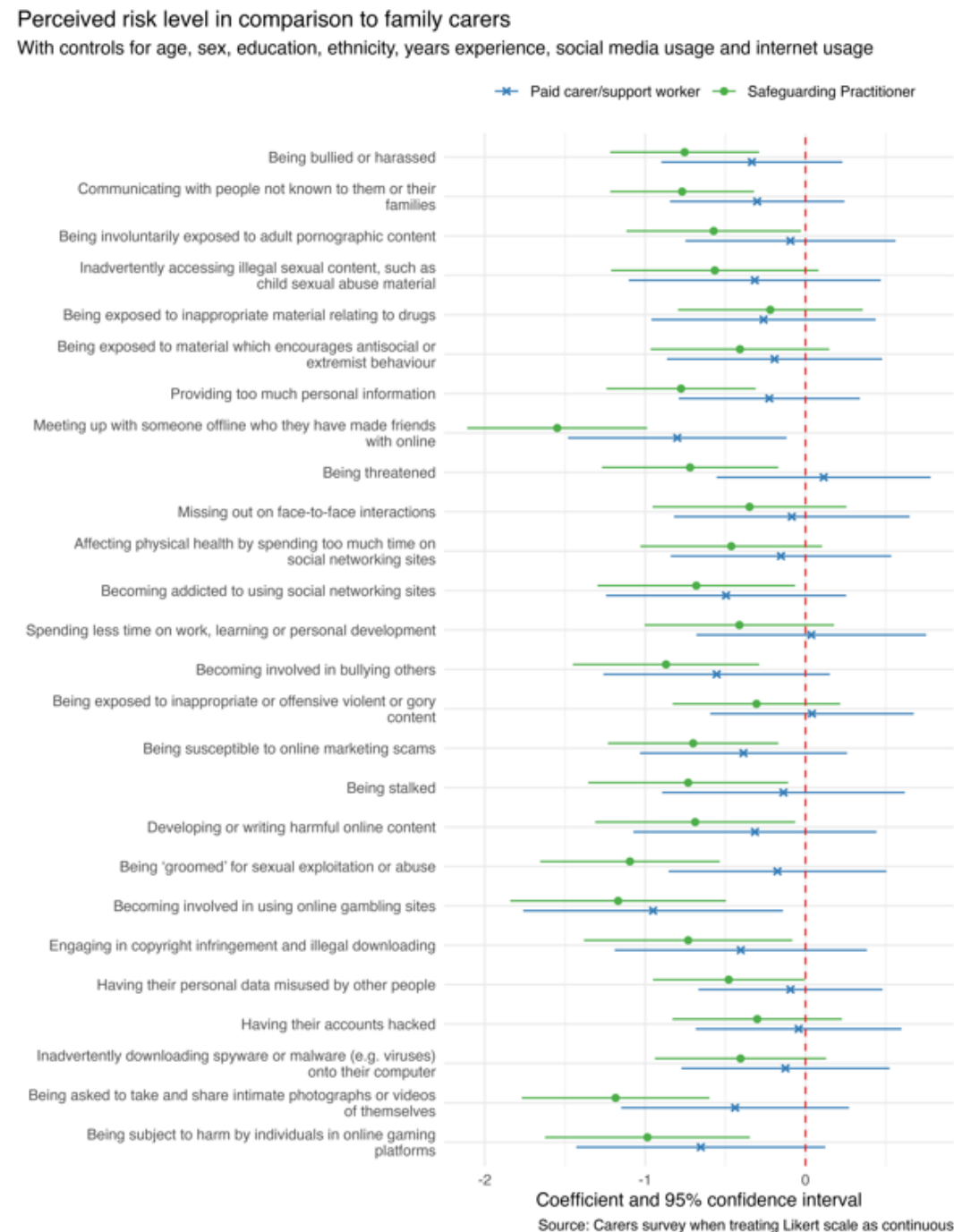
# Survey – what did we learn?

## Restrictions:

- ✓ 72% of family carers agreed that if they felt the individual they support will be at risk while using the internet, they will monitor or restrict their access.
- ✓ 37% of paid carers, and 27% of safeguarding professionals agreed that they would do this.

## Risks:

- ✓ Linear regression: 17 out of 26 items showing a significant difference in relation to family carers



# Survey – what did we learn

## Opportunities:

- ✓ Paid carers and safeguarding professionals -more likely to feel that the opportunities to participate in social groups and online communities that the internet offers, was of high or very high benefit to adults with ID. Only 34% of family carers shared this perspective.
- ✓ Linear regression: 26 out of 32 items showing a significant difference in relation to family carers

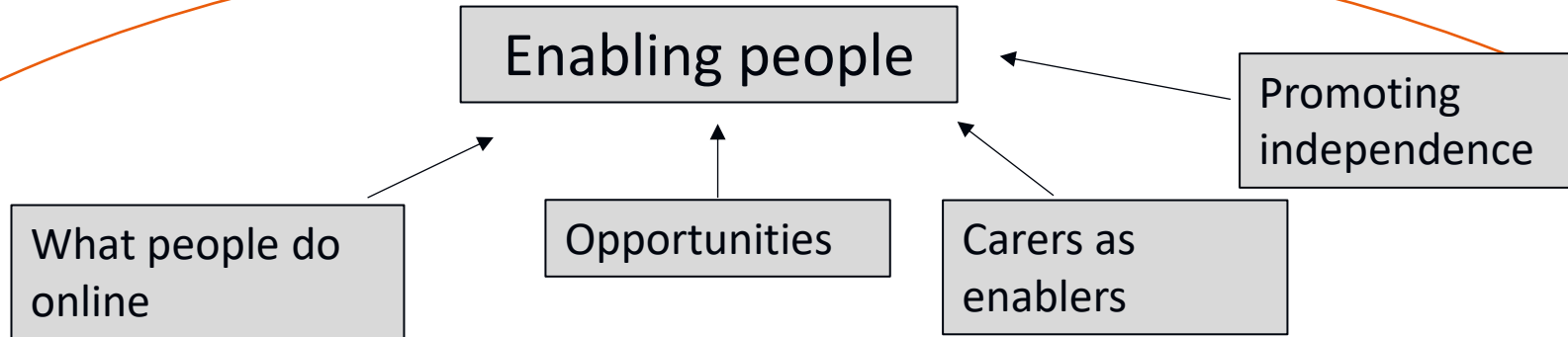
## Perceived opportunity level in comparison to family carers

With controls for age, sex, education, ethnicity, years experience, social media usage and internet usage





# Thematic analysis – Focus Groups

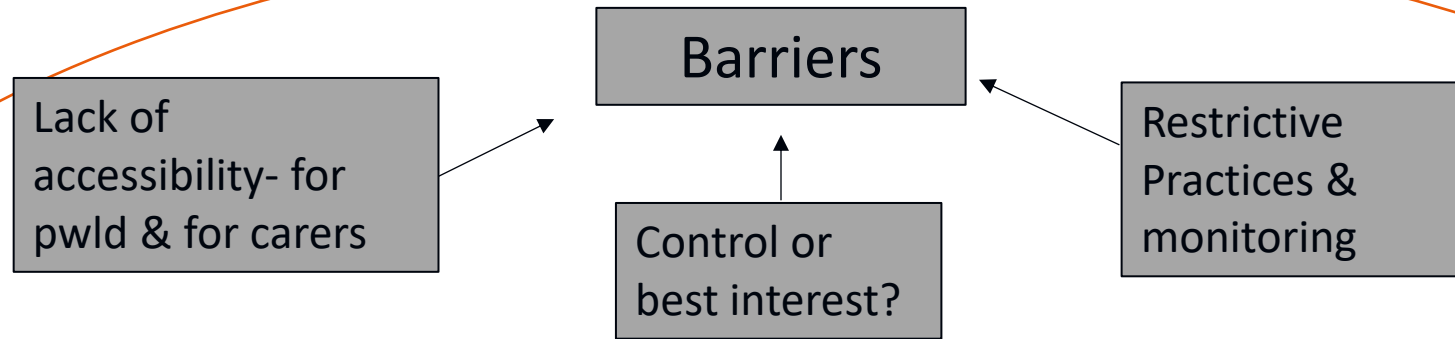


“He enjoys looking up sports and scheduling, buying tickets to go and see his sports teams” (paid carer)

“it’s a massive benefit for my son overall, ‘cos he really struggles to interact with people face to face, you know. But the internet gives him the opportunity to research, explore, entertain himself” (family carer)

“He loves cooking, he learnt how to make many, many new meals because of YouTube” (paid carer)

# Thematic analysis – Focus Groups

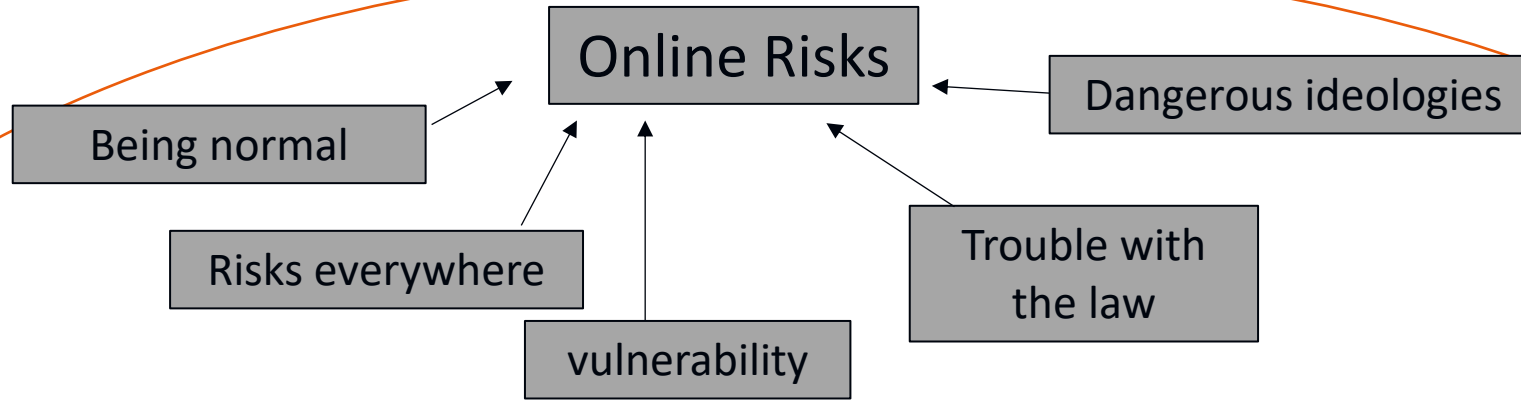


“I managed to get funding for thirteen tablets in total... those people had no knowledge, had never ever worked on a tablet or computer, or used the internet, so we had to really start from scratch. I think- so, that was a bit of the negative side of having those tablets, because they still didn’t use them, ‘cos they didn’t have the support and they’re not confident”

“So, we’re being pushed online, but I don’t feel there’s enough resources...’cos if I go to someone and give them advice, that’s my opinion, but they could quite easily come back at me, “Well, [name] said..” And then, how am I covered?

“I’ve worked with... who’s had a lot of difficulties with pornography online and contacting people.. And its not that it’s all wrong. It’s just that it is a very complicated muddle sometimes and can take a lot of support to disentangle even little parts of it.

# Thematic analysis -Interviews

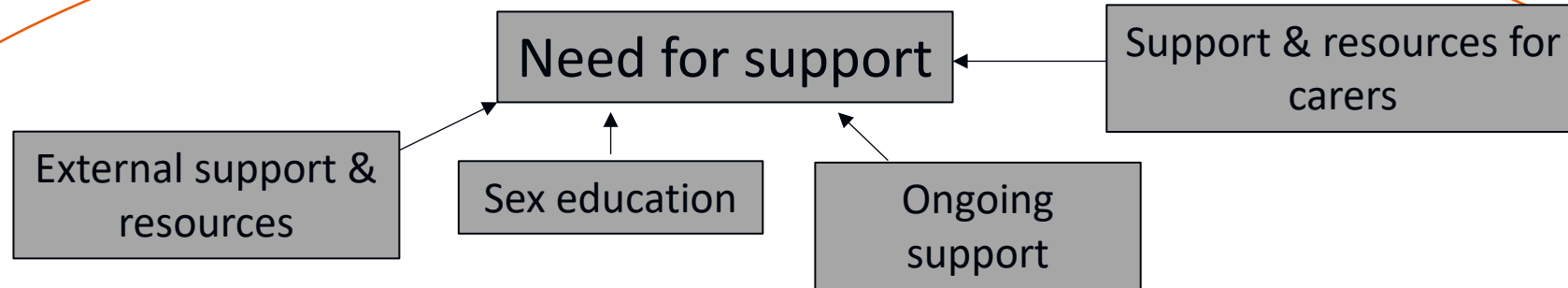


“There’s a conspiracy theory, you know, especially about COVID at the time...obviously, then you have to check and explain to her that just because it’s on Facebook doesn’t mean that it’s true”

“He was the victim of a romance scam, who was buying gift vouchers, iTunes cards and then sending the code to people, which is a way that criminals use for money laundering...it took us a long time to help this guy to realise what he was actually doing was potentially – he was at risk of criminalising himself”

“replicating things that he’s seen online, especially dangerous behaviours...like trying to set a can on fire”

# Thematic analysis -Interviews



“it’s about how we move to a point ... of positive risk taking and supported decision making”

“..is a free link for these courses...but again,it’s child geared, so I need to keep reminding [name] that this is for everybody...he’s not a child you know, and I kind of feel bad hearing them keep saying “child, children, children, child. That’s offensive to him ‘cos he’s an adult taking a children’s course”

“We know we have to do a lot on our own, but we’re not experts, you know. We need help to understand how to prevent these things form coming onto our kids...that’s where we need help”

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# Social media observations

- 20 adults with LD
- Shared newsfeed of their preferred social media platform (Instagram, Facebook and Twitter)
- “Think aloud” observations - interactions of adults with ID on social media platforms.
- Semi- structured interviews, guided by the participants’ social media newsfeed



# Thematic analysis

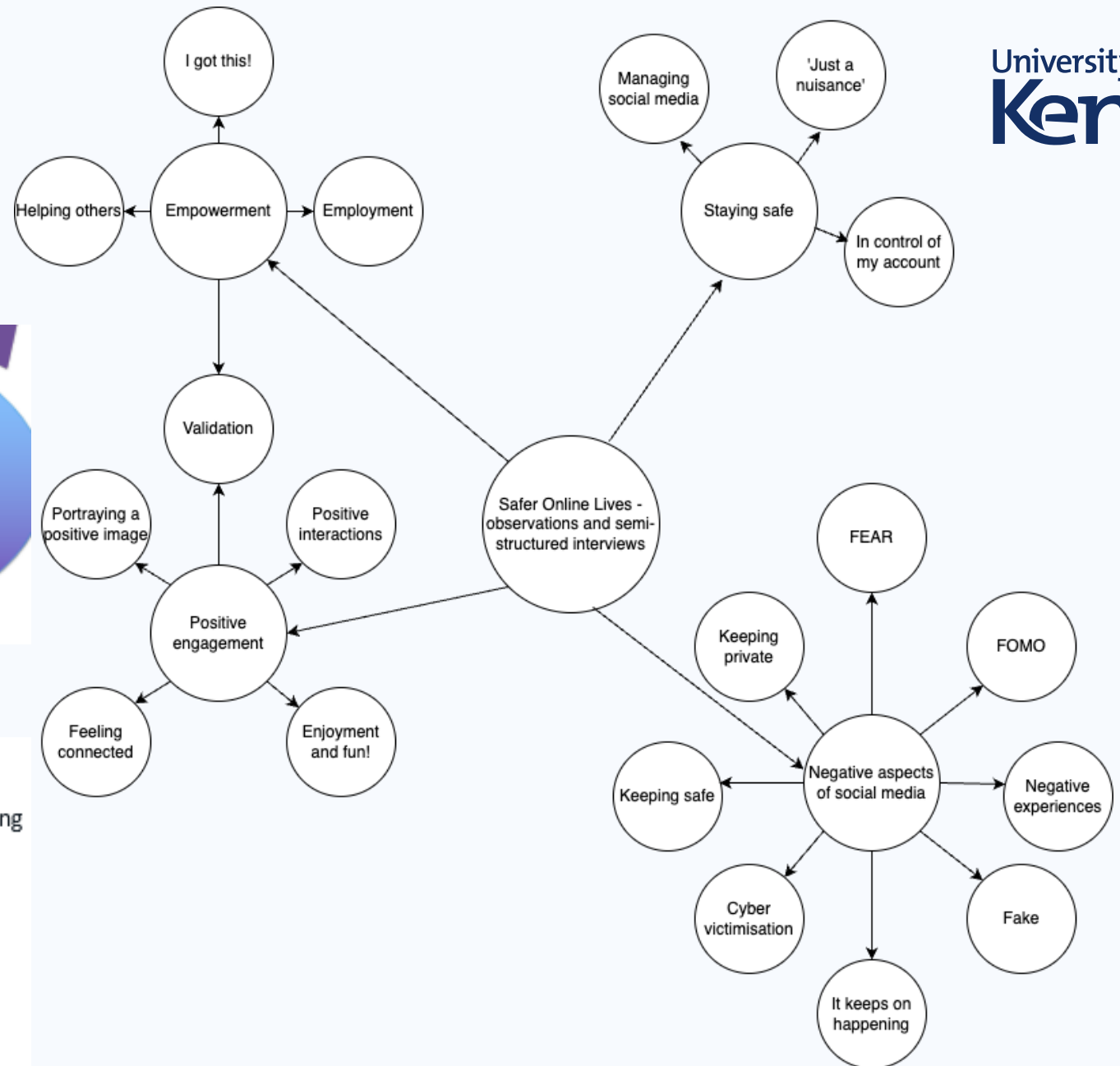
## Findings

**1. Positive engagement**  
with social media such as feeling connected, having positive interactions, experiencing enjoyment and fun.

'They're all positive, yeah. Some of my mates who I don't see very often anymore, because their jobs changed, they're moving away and stuff, they always want to know what I'm up to or something.'

**2. Empowerment**  
through social media use by seeking employment, gaining validation, helping others, and developing a strong sense of achievement at engaging in social media independently.

'I like to give help health wise, a shoulder to cry on, or if they need just – if they want to talk to, I'm there.'





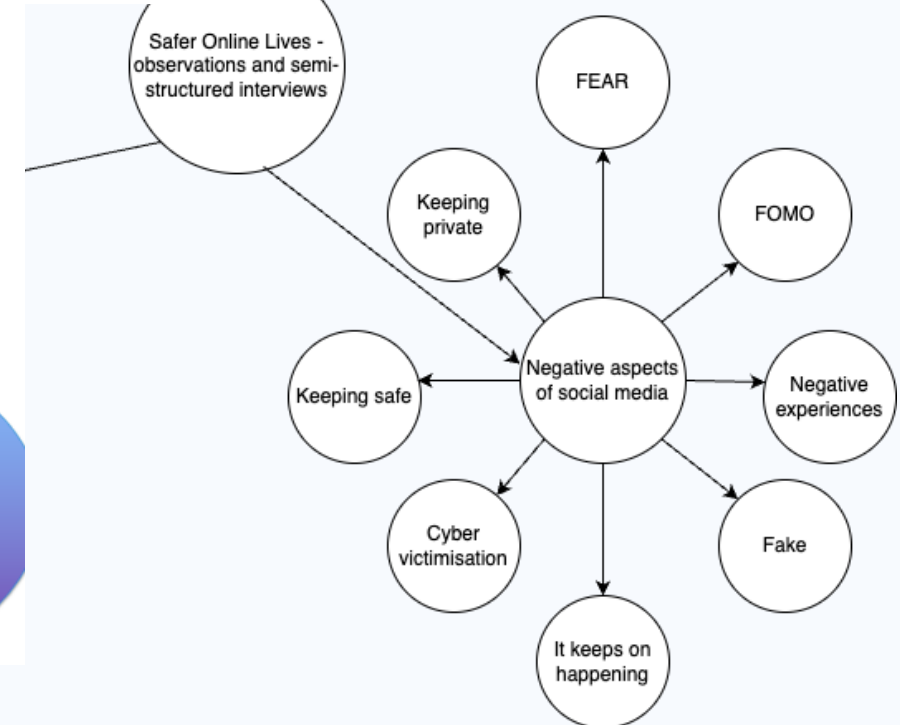
# Thematic analysis

3. **Staying safe** by managing social media and being in control of their social media account. Participants highlighted the lack of accessibility of privacy settings and how they developed strategies to stay safe when using social media.

'There is a few pictures that I have taken, which I don't really share over Facebook. Facebook is a public sort of thing, so you have to be careful what sort of pictures you share and stuff.'

4. All participants reported on the **negative aspects** of social media. They all shared personal negative experiences or experiences of someone they knew directly (friend or family member). Participants reported being often victims of scams and on the receiving end of cyber aggression incidents such as online stalking, hate crime, and trolling. As a result, they were often fearful of sharing information on social media.

'He wanted me to send him £2,000... I was sending him money like £100 here, £100 there and it led up to £300.'



# Safer Online Lives



**Interviews &  
Focus Groups**

November 2021



Who would you like to help today?



Akin



Vicky



Lin

**Interactive  
App**

May 2023

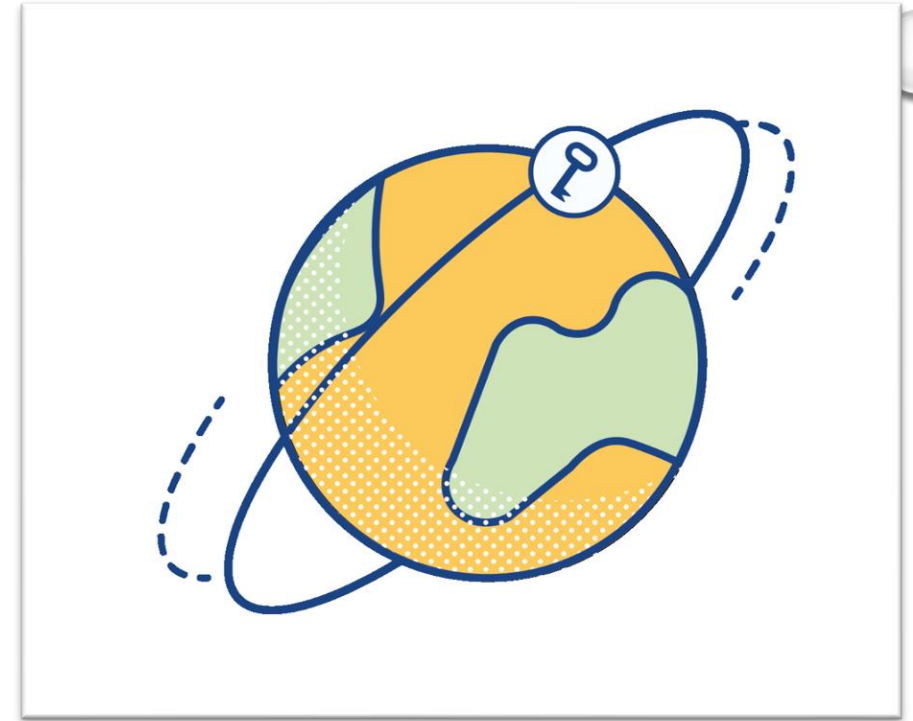
**Aim:**

To explore how adults with Intellectual Disabilities navigate different potential online scenarios, and how they respond to risks, barriers, and opportunities online.

# The app

Developed **FOUR** different scenarios

- All scenarios derived from the interviews
- Scenario 1: Risk- Online “Trolling”/ bullying
- Scenario 2: Risk- Online dating money scam
- Scenario 3: Barrier – Online Accessibility
- Scenario 4: Opportunity- Online job seeking



# The avatars

- **Three** avatars developed
- We asked participants to advise/support one of the avatars through the 4 scenarios.
- Avatar characteristics: Williams syndrome, Down Syndrome and wheelchair user.

Who would you like to help today?



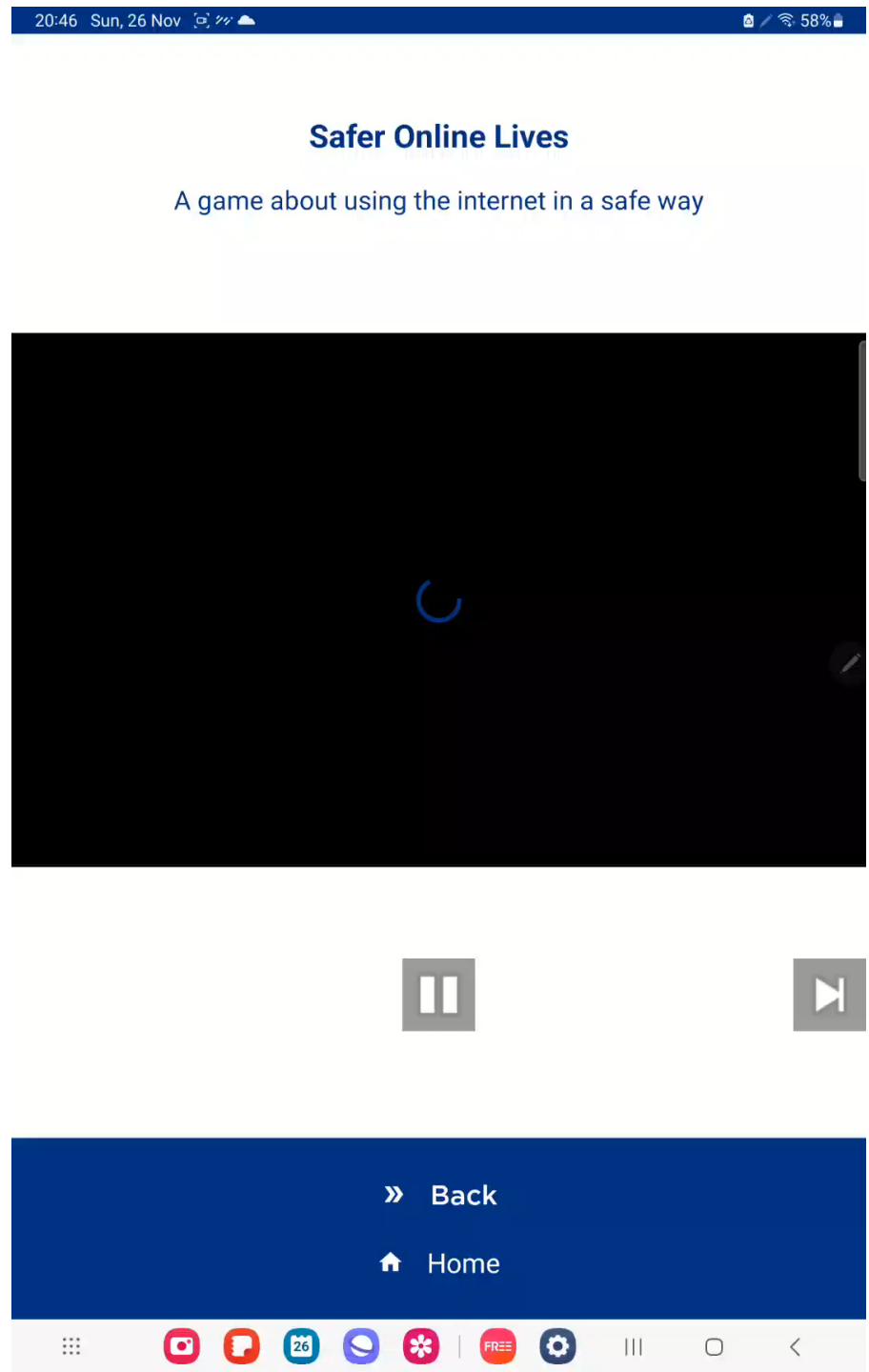
# Participants

- 30 adults with intellectual disabilities
- Age range: 21 to 80 years (59% males and 41% females)
- All using the internet
- All from Kent & London area in England
- All went through all 4 scenarios



Here is how  
the app  
works:

Example of Vicky  
being **'trolled'**  
(bullied) online





# Scenario 1- Online Trolling

## Online 'Trolling'/bullying

### Adult with ID:

I just got a message online from someone that I don't know. They said some bad things, and called me names. I feel really upset, I'm not sure what to do next. What do you think would be best?

### Option 1

Don't do anything, just ignore it. Hopefully, it won't happen

### Adult with ID:

Oh no, they messaged me AGAIN! I thought they would stop if I just ignored it.

### Carer:

### Option 2

Reply, and say something nasty back to them.

### Adult with ID:

I called them a nasty name back, and now we are fighting. They are saying more bad things to me.

### Carer:

When someone says something nasty, we might want to get back at them and say something to hurt them too. We shouldn't do this. This is because it isn't okay to bully people and say nasty things, even if they have hurt you. If

### Option 3

Report the message and block the person who sent it.

### Adult with ID:

Their online profile got taken down because they were bullying. Now they can't message me again!

### Carer:

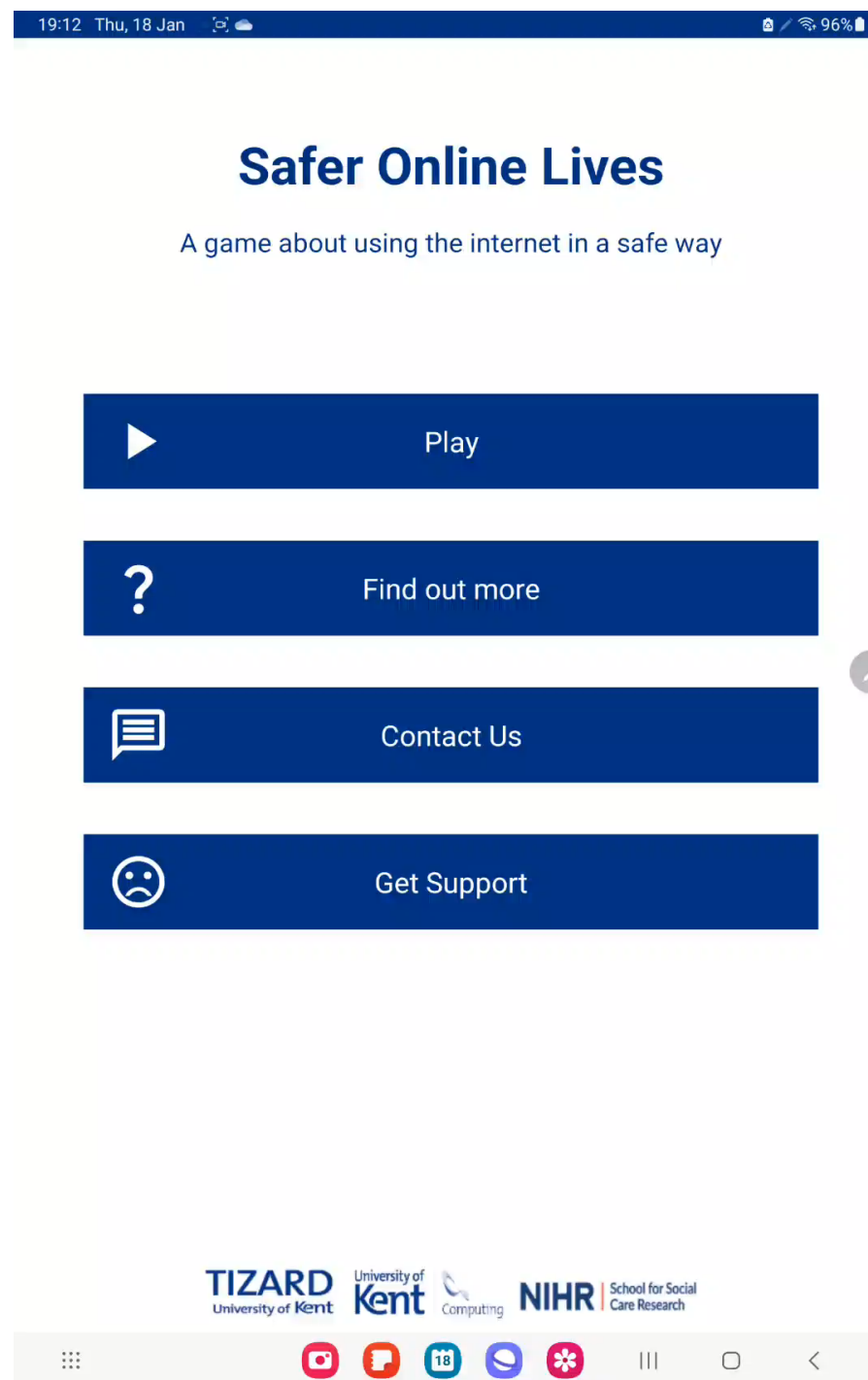
Nice! I am happy they can't message me again and got their profile removed for bullying. We should always report bullying

## Scenario 1: Cyber-Bullying

	%	n
Report the message and block the person who sent it.	63.3%	19
Don't do anything, just ignore it.	23.3%	7
Reply, and say something nasty back to them.	13.3%	4

Here is how  
the app  
works:

Example of Akin  
– an online  
friend asking for  
money

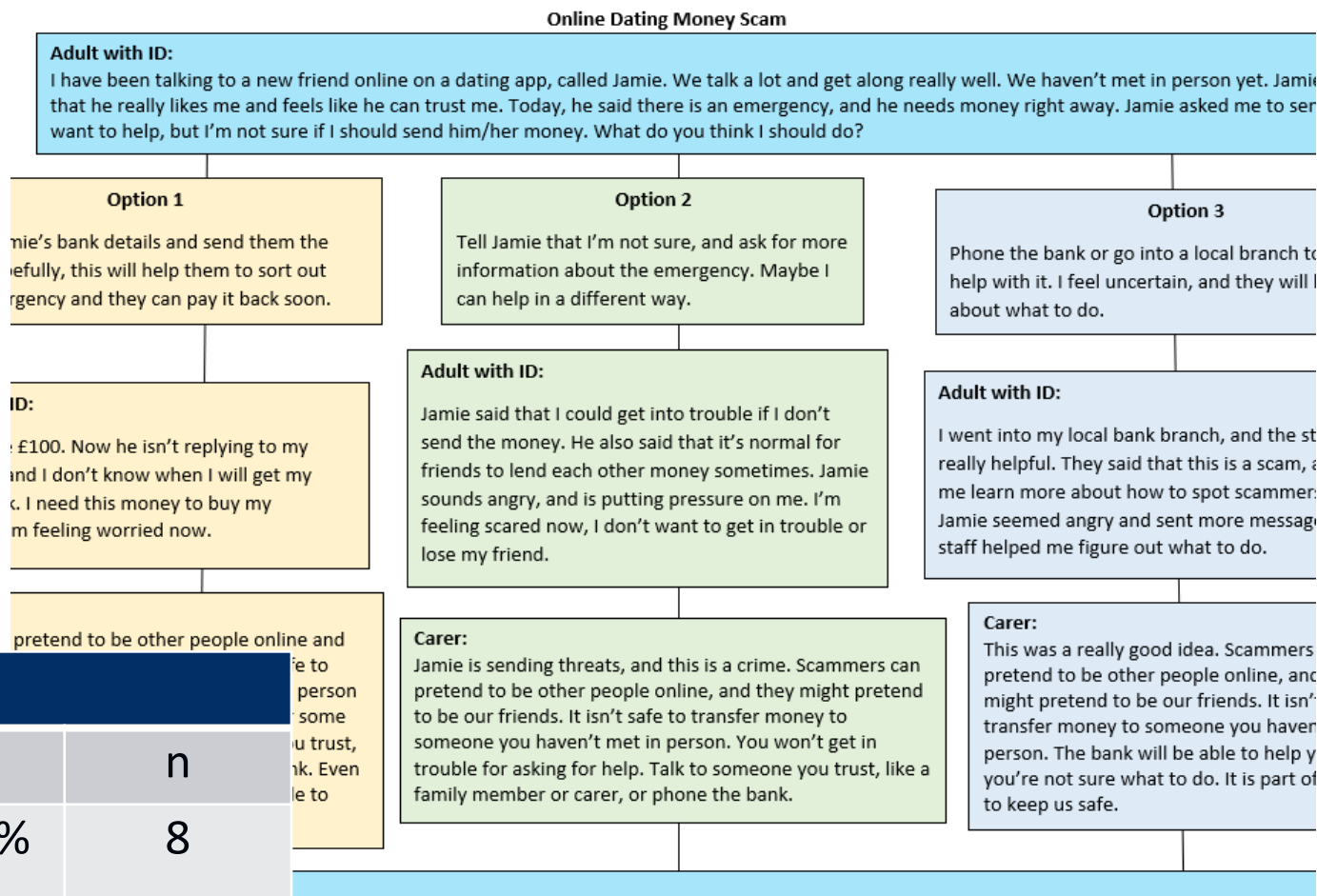




# Scenario 2- ONLINE DATING MONEY SCAM

## Scenario 2: Online Dating Money Scam

	%	n
Phone the bank or go into a local branch to ask for help with it.	26.6%	8
Ask for more information about the emergency.	43.3%	13
Send them the £100.	30%	9



# Interventions

## Scoping review:

- Training young adults with LD to read critically on the internet (Delgado et al 2019)

## Grey literature:

- Mostly for parents or children

Website	URL
Mencap	<a href="https://www.mencap.org.uk/sites/default/files/2016-11/Internet-Safety-web-2016.pdf">https://www.mencap.org.uk/sites/default/files/2016-11/Internet-Safety-web-2016.pdf</a>
NSPCC	<a href="https://www.nspcc.org.uk/keeping-children-safe/online-safety/online-safety-families-children-with-send/supporting-children-with-send-talking-online/">https://www.nspcc.org.uk/keeping-children-safe/online-safety/online-safety-families-children-with-send/supporting-children-with-send-talking-online/</a>
Ann Craft Trust	<a href="https://www.anncrafttrust.org/how-to-stay-safe-online-guidance-for-adults-and-young-people-with-learning-disabilities/">https://www.anncrafttrust.org/how-to-stay-safe-online-guidance-for-adults-and-young-people-with-learning-disabilities/</a>
CHANGE - Learning Disability Rights Charity	<a href="https://www.changepeople.org/Change/media/Change-Media-Library/Blog%20Media/Keeping-Safe-Online-Easy-Read-Guide-Small-File-Size.pdf">https://www.changepeople.org/Change/media/Change-Media-Library/Blog%20Media/Keeping-Safe-Online-Easy-Read-Guide-Small-File-Size.pdf</a>
CEREBRA	<a href="https://cerebra.org.uk/download/learning-disabilities-autism-and-internet-safety/">https://cerebra.org.uk/download/learning-disabilities-autism-and-internet-safety/</a>
Internet Matters	<a href="https://www.internetmatters.org/inclusive-digital-safety/advice-for-parents-and-carers/supporting-children-with-send/">https://www.internetmatters.org/inclusive-digital-safety/advice-for-parents-and-carers/supporting-children-with-send/</a>
Kelsi	<a href="https://www.kelsi.org.uk/__data/assets/pdf_file/0011/74576/Online-Safety-for-SEND.pdf">https://www.kelsi.org.uk/__data/assets/pdf_file/0011/74576/Online-Safety-for-SEND.pdf</a>
LD Online	<a href="https://www.ldonline.org/ld-topics/educational-technology/online-safety-children-ld">https://www.ldonline.org/ld-topics/educational-technology/online-safety-children-ld</a>

# Conclusions & next steps...

- People with learning disabilities are ambitious!
  - But might need support for some online situations.
  - Having support with things is empowering!
  - Not enough studies looking at effective interventions for this population
- 
- App very useful tool for services – looking to make it widely available
  - Let us know if you would like us to notify you when this is available to the public





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**Thank  
you.**

