UNIVERSITY OF SUSSEX

Informed Consent: In the Context of 'Sharenting' of Severely* Autistic Children

Education & Social Work

My research is about **children and young people's agency**; exploring the concept of **informed consent** in the **context of 'sharenting'**. Responding to the current **increase in sharenting of autistic children**, I seek to **understand different viewpoints** surrounding this, alongside **ethical questions and concerns**, and **explore possibilities for informed consent**.

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Summary of Research Progression

- Obtaining ethical clearance
- Finalising interview questions & activities
- Finding participants & gaining consent
- Carrying out interviews & focus groups
- Developing transcripts
- Conducting thematic analysis

What is 'Sharenting'?

Sharenting is the practice of parents/carers sharing content of their children online, commonly via social media sites, which may be with or without the child's knowledge or agency to consent (Kopecky et al, 2020).

Study participants took part in co-creating a shared meaning of sharenting. Participants articulated that **sharenting includes photos, videos and anything that can be uploaded online**. Participants also expressed that **sharenting is dependent on the situation, and specifically the level of risk** (to the child) associated with the parent's online activity.

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> "I think some subjects... they need to be more private, and so I think depending on what it is, it could be considered sharenting."

What is Informed Consent?

Informed consent refers to consent which is granted by an individual who is in full knowledge of what's involved, including potential risks and consequences.

Academics such as Livingstone (2014) recognise that children's digital agency (capacity to have control and make decisions within a digital world) must be held at paramount importance. Therefore **informed consent is crucial in upholding both the digital safety and agency** of children and young people.

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During a focus group, participants used mind-mapping to explore the concept of informed consent. ②

Interview Methods

- 1-1 conversation & group discussion
- Mind-mapping (writing & drawing)
- Watching videos (3-6)
- Creating with Lego ⑦

Interviews conducted with **young people aged 15-19**

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Research Questions:

- Is it ok to post autistic children with high support needs on social media?
- How could this put them at risk of harm?
- How could 'sharenting' support autistic children, their parents/carers and community?
- How can autistic children with high support needs provide informed consent?
- Is this possible or appropriate?

My findings (so far!): Participant responses

Informed consent for autistic children with high support needs

Consent is informed when:

- Question and answer is **clear and direct**.
- An individual is of **age to make choices for themselves**, and **understand potential consequences**.
- It is adapted to allow autistic children **agency and control**.
- It is facilitated to **utilise familiar communication methods.**

It is important:

- That children are **aware of content of them** shared online.
- **Not to ask too much,** if the child is unable or uncomfortable with giving consent.
- **Not to post online without the child's consent.**

> "if they can't comprehend it then they will not be able to give true informed consent which makes then any video posted exploitative."

> "I think that people should not post their [autistic] children under the age of 13... because that's the age for children to be posting themselves."

Reasons and motivations behind 'sharenting'

- For views, likes, shares and to gain **social status & online popularity**.
- Seeking **sympathy**.
- For home videos.
- To build **support and advice** amongst a **community**.
- To **spread awareness** about caring for an autistic child.

> "Parents will kind of excuse themselves by saying they're spreading awareness when that's obviously not all it is."

> "They [parents] should do what they can to care and protect you from everything... I don't think that [being posted online] is putting you in the best position."

Possible harms and risks of 'sharenting'

- It could be **insensitive and disrespectful** towards the individual and they may feel uncomfortable.
- Parent's focus can be **drawn away from meeting their child's needs**.
- Content could be used with **malicious intent**, e.g. bullying, or **receive harmful responses**.
- Sharenting of autistic children could contribute to **negative stigma**.

My Motivation...

Being autistic myself, I am **passionate about advocating for autistic children** and young people and **challenging stigma surrounding autism**. I aim to further **pursue this area of research** going into the final year of my degree as I feel there is much **more to be explored**.

Possibilities for informed consent, and positive 'sharenting' of autistic children

Participants expressed that it is **important to spread awareness** about autism in ways that allowed **digital agency, safety and informed consent...**

- Sharenting **without identifiable factors**, e.g not showing a child's face.
- Sharenting to have a **focus on the parents' behaviour**.
- To share on a **less public scale**, e.g within an autism family support group.

In response to a **video by ACoRNS** (an Autism Research Network, who use creative participatory research methods that value individuals' voice), participants noted that it was:

- In **first person**, coming from the child themselves
- Sharing **autistic joy!**
- Not showing the child upset, but still **acknowledging their challenges respectfully**.

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* I acknowledge there are differing views on descriptive terms used associated with autism. I have chosen to use the term 'severely autistic' for the title of my research project, for the purpose of this being better recognised and therefore more understandable. Throughout the rest of the poster, I use the up-to-date language of 'high support needs'.