Life online for children with SEND
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Foreword

Technology is often a lifeline for parents, particularly those with vulnerable children. Safety and wellbeing are really important to us at Facebook, and that’s why we have plenty of tools on our platform that are designed to keep families happy and safe online.

We know that vulnerable young people and their families are at more risk online and that there is a greater requirement to help children with additional needs to use the internet more safely, alongside supporting parents of children with Special Educational Needs (SEND).

Technology for children with SEND is a huge part of their lives, and they are likely to spend more time online than their peers. It’s a report about how children with additional needs use social media in the same way as their non-vulnerable friends, with potentially different and unconsidered consequences.

About how parents and teachers of these children, who they describe as “innocents online” are profoundly concerned about their online lives. About the gap between what young people are doing online and what parents think they are doing.

It’s a paper on how parents, who are already struggling to support their children with additional needs, believe that it is impossible to keep them safe online.

Parents and teachers have a desire that children with additional needs should be served a different experience – designed to keep them safer. When questioned on how the social media companies would be able to identify such users, parents seemed comfortable in providing that information to companies. This suggests parents prioritise protection over privacy - but it needs significant thought about the ethics and the processes in which this would occur.

Executive Summary

This is a report about differences, and commonalities. About how children with additional needs use social media in the same way as their non-vulnerable friends, with potentially different and unconsidered consequences.

About how parents and teachers of these children, who they describe as “innocents online” are profoundly concerned about their online lives. About the gap between what young people are doing online and what parents think they are doing.

It’s a paper on how parents, who are already struggling to support their children with additional needs, believe that it is impossible to keep them safe online. Equally, they are the same parents who see the immense positives for their children, perhaps their non-communicative autistic son ‘comes alive’ when gaming – because he’s not known in that community as ‘different’ or ‘special’ he’s just a gamer, accepted for his interests and applauded for his skills.

It’s a report about how young people use social media to make connections that would be too hard to sustain offline due to mobility and geography – especially for children who are schooled in specialist provisions often at some distance from home. And like many young people it’s about how they gain affirmation and status from likes, and how they use social media to stay in touch with friends and family.

Juxtaposed with this theme of difference, is the commonality of asks and expectations from parents, carers and young people of what social media companies can and should be doing. The reporting process was criticised – both because of the perception that nothing changes and conversely (on gaming platforms) if something does happen, the reporter may be bullied as a consequence.

Parents and teachers have a desire that children with additional needs should be served a different experience – designed to keep them safer. When questioned on how the social media companies would be able to identify such users, parents seemed comfortable in providing that information to companies. This suggests parents prioritise protection over privacy - but it needs significant thought about the ethics and the processes in which this would occur.

As ever, social media triggers strong feelings amongst these young people and the adults that care for them. They do have demonstrably different needs especially in how advice and education is delivered to them. Their enjoyment of social media and their eagerness to be a part of the social world online was illustrated by their enthusiasm and contributions in the workshops.

We were privileged to draw on the wishes, instructions, wisdom and insights of these young people. Having reflected on what they said they wanted and needed and having compared that to the wishes of their parents and carers we created a microsite especially for them. The site is written and presented in a way they wanted – and indeed have inputted in both the content and design throughout the process. The microsite addresses the young people’s wish for independence – so it has a section for them – which is interactive and populated with animations and videos. The pages are clean and simple and it has been AA accredited by the World Wide Web Consortium to ensure it is widely accessible.

Parents and carers were clear in their requirements too, so we have created a section for them, which mirrors the information given to the young people. We were respectful of their wishes for clear insight and precise instructions. Finally, we created a section of microsite for parents and young people to look at together. We know that the most important thing parents and carers can do to keep their loved ones safe online is to talk to them about what they are doing. This section provides insights, resources and activities to normalise and simplify that communication – so parents are empowered and young people are engaged and listened to.

The insight and suggestions the young people, parents and carers gave were invaluable in creating the resource hub www.internetmatters.org/connecting-safely-online/

This report is dedicated to them, with our sincere thanks for their honesty and candour.
Methodology

Two workshops were held with 29 young people, aged 13-16 who have a range of different additional needs. They came from the following schools and settings:

- Beacon Academy – additional support needs (mild/moderate learning difficulty)
- Besthill Academy – autism spectrum condition (ASC)
- The Vine Residential Services – residential care and short break provision for 8-18 year olds with additional needs
- East Sussex Children in Care Council – care and special needs
- Achieving for Children – additional support needs (mild/moderate learning difficulties/EBS/motlal health difficulties) all children with care experience
- Cuckmere House School – emotional behavioral social difficulty/mental health
- Trinity School – dyslexia/dyspraxia/ASC
- Westminster Youth Parliament – additional support needs (mild learning difficulties/mental health difficulties) and living in areas of high deprivation

Methodology for Young People’s Workshops

Two half day workshops were delivered. Large and small group discussions, writing on boards and on the graffiti banner with markers, all offered different opportunities to engage. These were broken into 15–20 minute segments to allow the young people a variety of media to express themselves.

Workshops were delivered by Adrienne Katz, director of Youthworks and facilitated by John Khan to hear direct input from young people. The Youthworks team included graffiti art by Tom Goulden and Ed Shearan, with filming by Caroline Jones and data collection by Marcus Bell.

Parents and Carers Focus Groups

Internet Matters ran simultaneous workshops with parents, carers and teachers. The format of these focus groups was much more traditional, with adults debating and discussing several themes and ideas. As stand-alone pieces of research, the insights from the children and young people and those of the adults who care for them are both very interesting. Synoptically they are fascinating as they tell separate, perhaps parallel stories.

What did we learn?

Young People

- These young people use social media in the same way as everyone else – they enjoy the social validation it brings them, worry about being sufficiently popular online and get frustrated when they report things and seemingly nothing happens. They want to be connected with friends, family and celebrities, to be entertained and to check sites for updates – either news updates or friend’s status updates.
  - Generally they were not satisfied with the outcome of their reports and describe what they would like to see changed such as a kinder message suggesting other ways of getting help, or better reporting ‘categories’ through which they could describe what happened or attach evidence.
  - As part of their additional needs, some of these young people are rule-bound. Therefore, they do not understand why there are not always consequences for wrongdoing online. This also makes them more likely to accept what people say online and trust them.
- They are aware that risks and harms exist, but less able to take steps to avoid them, either because they simply did not recognise them as such in context of their own social feed or did not feel able to act. This lack of critical thinking was a key issue that will impact their online experience and, as we explore later drives a significant amount of parental concern.
  - These young people are more likely than most to accept what people say online and to trust what strangers or friends say, without considering the consequences. However, these young people are also sophisticated enough to recognise that they had received messages that avoided using certain words to evade being picked up by algorithms for contravening standards.
  - Terms and Conditions and Community Standards documents are clearly not written for this community, and they find them impenetrable. This is disempowering and compound the experience of helplessness if reported issues are not addressed by the platform.
  - These young people are more accepting of parental involvement in their online lives than young people without additional needs. Most stated that their Mum checked their phone every night and some were pleased that their Mums were able to sort out issues for them.

- Whilst sharing with Mum is one thing, the lack of concern about privacy and personal data with this group was quite telling. While everyone had heard of privacy settings and some knew a lot about them, there was confusion about what these settings were intended to protect, with some people saying they do not use them because they have nothing private on their profiles.
  - It is clear that some young people had public profiles and followed remarkably high numbers of people in an attempt to increase the number of followers they had, thereby proving they were popular. Private setting means were not deemed desirable by the young people as it would make it impossible to get followers and therefore impossible to demonstrate popularity.
  - Many of the young people also couldn’t see a need for privacy, with one commenting: “I got no personal info so no need”
- These young people wanted online safety resources created specifically for them. This would mean really easy navigation, content provided by experts who were young and relatable, with lots of videos and small chunks of text. These guidelines should be simple, straightforward, and direct.
Life online for children with SEND

- Social media is a benefit for these young people. It allows them to make connections with family and friends that would be much harder to sustain without it. This is particularly important for children whose school location was determined by their needs, rather than location. Their friendship group is drawn from a much wider geography, making it harder to arrange to see friends outside of school.

- It’s clear that these parents, teachers and carers believe their child cannot understand the rules of engagement on social media. Their young people believe that things are as people tell them they are, so asking them to demonstrate critical thinking and judicious judgement is much harder. Likewise that innocence or naivety suggests that these young people are more likely to make errors which may be costly to their emotional well-being.

- This inevitably leads to a different perspective on privacy. Parents prioritise protection above privacy. We saw from the young people a surprising level of acceptance that their Mum (it was always Mums) would check their phones and be actively involved in their online lives. This is mirrored in the thoughts of the parents, who absolutely value safety over privacy, without exception. Recognising that privacy is not a primary concern for these parents helps to explain why their solution to these challenges was a willingness to share personal data with the tech companies so that their child would be served a different version of the platform.

What did we learn?
Parents, carers and teachers

- These parents have no time for nuance. Resources for them must be crisp, clean and stark. There’s no room here for an engagement approach suggesting a variety of options. These families wanted clear, fact based, no nonsense resources, which recognised their children faced additional challenges in staying safe online.

Young People with SEND and Social Media

Young people’s perspective

Social validation
Wanting to fit in is an instinctive human drive, that becomes more acute in our teenage years. Unsurprisingly, therefore this was a key theme for the young people when discussing social media. Using social media as a form of social validation and popularity ran deep throughout many discussions. This desire manifested itself in a number of ways throughout our conversations:

- It was common to use the number of Instagram followers (quantity) to determine popularity.
- Filming and posting school fights to ensure they were “part of the drama” and “part of the in-the-know group”.
- Engaging with “drill music” as part of gang culture to feel part of localised gangs.
- Feeling “depressed” when a picture does not get enough likes.

Using social media to fit in is an issue of particular relevance to these young people who are already singled out due to their additional needs.

Self Esteem
The young people felt that social media was an amazing outlet for them to make friends and to be accepted. However, they did not feel safe from bullying and they argued that the lack of accountability and increased anonymity was a catalyst for negative social interactions. For this reason, they felt more vulnerable to being bullied/rejected socially. They reported the bullying, and it seemed to have a serious impact upon their psychological wellbeing.

However, the young people did have a number of suggestions of how to address this problem:

- More qualitative reporting, where you can insert the quote of what has been said, so the complaint can be analysed in more depth, or more categories beyond bullying or harassment were suggested - for example ‘impersonation’.
- A ‘second chance’ message where the platform has a pop-up box which asks the user if they are sure about the comment/content they want to post, informing them of the negative consequences their actions may have (similar to Instagram).
- To make reporting more personal, instead of robots (AI) coded to look for swear words or racism/sexism/homophobia. Bullingy goes beyond swearing; human beings are needed to be able to spot more discreet bullying.
- Threats, coercion, disability and dangerous content such as urging people to be too thin or to self-harm should be removed.
- Facebook could have ‘friend layers’, so each user can choose who can comment on your posts.
- More information on how to seek external support when bullying is experienced, but deemed not to contravene community guidelines.
Parents’ Role – from the perspective of the young person

We then turned to the role of parents – both in monitoring their child’s activity and the child’s concerns about threats to take away the tech. Young people told us of a balanced approach between conversation and monitoring, with most young people experiencing both. Many young people told us they spoke honestly to their parents and that they were related about their Mum looking at their phones. A few told us that their Mum sorted things out for them if something bad had happened. The knowledge that their Mum was looking at their phone did seem to impact their behaviour – some young people deleted social accounts once their Mum followed them as there was ‘no point’ in having it.

Others are resigned to parents finding things out because they look or get a report every month. Some are positive about this level of parental engagement as they have faced issues in the past, which their Mum had resolved for them.

Resources required by young people

The last area we explored was how platforms should deliver online safety advice. Advice should be created for these young people as a specific audience, which meets their needs.

This means advice needs to be simple, short and easy to understand, so a variety of media – video, written, and audio was important. Functionally the advice should help you find what you want, when you want it, and you should always be able to find the help section. That might mean it should live on the home or welcome page. Interactivity was also important.

The young people also discussed the idea that they did not want to be told what they can and cannot do. They don’t want resources to feel like rule books which they must follow. It was suggested that they could be given more of a guideline of suggestions which gives them the responsibility to decide whether they follow them or not.

Their views about social media companies

The young people had some sage advice for social media companies, which ranged from how safety content should be delivered, to the messages it should deliver.

Themes emerged about simplicity – of terms and conditions and of how information is displayed. Terms and conditions must be simpler, shorter and written to be read. The second area was one of privacy – there was a desire for accounts to be private by default. Thirdly there was a desire for unpleasant comments to be challenged before they were sent – with the platform providing a prompt to think before pressing send. Finally, there was real desire for reporting to be more effective. This had three parts to it – firstly that reporting should be more effective and differentiated, so you could report impersonation as well as bullying. Secondly that if the post met community guidelines and so the report would not be acted on, other suggestions were made about what to do (perhaps being referred to a national helpline). Finally, that the speed of response really matters, and currently it is nowhere near fast enough.

Benefits of Social Media

All of the parents, teachers and carers told us that connectivity and social media brought good things to their children’s lives. Themes emerged around the benefits of connections with others – either friends from school who live too far away for real world contact to the freedom of being online without being known as someone with ‘additional needs’. Parents also saw being online as a place where young people could develop skills and find supportive and nurturing environments.

Also, there’s no doubt that both parents and carers and the young people accept and engage in some conversation about, and monitoring of, online activities. The parents echoed the young people’s messages of checking phones, daily, and of taking phones away at certain times. That said, parents had no idea how many followers their children had on social media accounts.

Benefits of Social Media

- It can be a place where parents and their children can connect with other families to seek support.
- A welcome distraction for young people needing downtime.
- A way to learn and supplement their child’s education.
- At times it can be seen as a safer option to interact with others (depending on what children are doing) than allowing children to go outside (avoids risks of face-to-face bullying / increased fears around knife crime etc).
- Some children find socialising behind a screen easier than face to face which makes them feel included and able to make friends and build connections.
- The viral nature of the online world means children and young people can put a spotlight on issues and concerns to affect change in the real world.

Levels of Concern

The level of concern and the intensity of feeling expressed in both groups was salutary. These are families for whom many things are already harder than perhaps they should be. They are already struggling with the education system, with being accepted in society, with funding cuts, and for many of them, social media has layered on another strata of issues to deal with, which can become a daily battle ground.

We heard from two mothers with older children with SEND, stories of aggression and physical violence from their sons when games were turned off, or when they were required to take a break. They told of rooms being physically destroyed, or homes ‘trashed’ in reaction to young people being told to come off a game. These aren’t toddler tantrums. These are reactions of teenagers, albeit with a younger developmental age than their physical size would suggest.

Whilst these experiences were related by only two respondents, no-one else in the group challenged them or said anything to suggest that this experience was unusual or not something they thought could or would happen when their child gets older.

It’s unsurprising therefore that parents and carers have a significant number of concerns about online safety and their SEND children. Whilst it’s true that parents of children without additional needs could also read that list and agree with all of it, the parents and carers of these SEND children spoke of the additional challenges they loved ones faced.
Developing extreme views based on a lack of critical thinking and digital literacy to discern between what is fact and fiction online.

Fear that children be easily manipulated into changing views, even political views by repeatedly being served information that may reinforce a particular ideology.

Context is often missed as these young people do not understand nuance and consequently can be exposed to real world consequences.

Strong emotional desire to be accepted online in a way that many are not accepted offline which can often drive behaviour.

Lack of cognitive ability means it is easier to make a mistake.

Parents say they have low visibility of what their children are actually doing online. Once they have approved an app or a platform for their child to use, they are reluctant to share what they are actually doing on the platform.

Although parents can approve/block apps children use, there is a concern that there are a lack of monitoring tools that will allow parents to have a full view of what their child is doing while in the app which might put them at more risk as parents are unable to intervene early enough to stop issues from escalating.

There was a strong consensus among parents that in order to fully protect their vulnerable children, they had to disregard their child’s right to privacy. Unlike other children, vulnerable children require more supervision and more guidance to keep them safe from potential risks that could lead to harm.

A parent also brought up the need to consider cultural differences alongside vulnerabilities as it relates to a child’s privacy online. They expressed the need to factor in that in some cultures children’s right to privacy was not considered as essential so to battle against this power struggle with parents, children often saw the internet as a place where they could lead a separate life free from parental oversight.

Children tend to spend a longer period online and this can interrupt eating, going to the toilet and some can turn violent if the Wi-Fi is turned off.

What should social media companies do?

We asked parents what specific support they wanted social media companies to provide for their children. This prompted a long debate, with parents almost requesting a walled garden approach. When we probed how the social media company would know that a particular account was set up by a person with SEND - and should therefore be served up a different mix of content - parents were adamant that:

- There should be support if posts are hurtful but compliant.
- Consequences of bad behaviour on the platform is not adequate - they perceive there is often a 24 to 48 hour ban, which doesn’t resolve the issue.
- Parents are not satisfied with the reporting function, it should be clearer and with greater transparency. As a lot of the accounts set up are fake or anonymous, it’s hard to report someone or know who is behind the account.
- Children see reporting as ‘snitching’ so often do not report as they feel it’s not safe if they are found to be the one who has reported. Blocking someone can also cause issues in the real world as it can escalate a bullying situation if one party finds out they have been blocked.

Parents wish list included:

- At the point of set-up, there should be an option to alert the app or platform to set additional safeguards for SEND (you would have to share with the platform only that you were a user with SEND).
- If a parent creates their child’s social media account, there should be an option to receive or navigate to bespoke information and links to relevant resources that will help them support their child (especially if this is their first social media account).
- If a user has SEND between the ages of 13–18, parents should have oversight when opening their social media account.

Parents views on reporting:

- Consequences of bad behaviour on the platform is not adequate - they perceive there is often a 24 to 48 hour ban, which doesn’t resolve the issue.
- Parents are not satisfied with the reporting function, it should be clearer and with greater transparency. As a lot of the accounts set up are fake or anonymous, it’s hard to report someone or know who is behind the account.
- Children see reporting as ‘snitching’ so often do not report as they feel it’s not safe if they are found to be the one who has reported. Blocking someone can also cause issues in the real world as it can escalate a bullying situation if one party finds out they have been blocked.

Resources required by parents, carers and professionals

The last section of our focus groups considered at what point parents and carers would require resources, and what they would need to look like to be helpful. Parents were clear that they would seek out resources at the point of crisis, whilst teachers were driven either by calendars or by events in school that required interventions.

Parents were keen for there to be resources for them, which would provide insight and advice in bite sized chunks, and stark, factual, crisp resources for families to explore together. There was a strong sense that parents and carers don’t have time to wade through long reports, but they do need actionable accessible information.

When thinking about resources for young people with additional needs, parents wanted them to be age specific and very clear on what is and what is not acceptable. Parents identified several differences between examples of general online safety resources and the things they would need for the resources to be effective for their families/schools. Parents were adamant that:

- Resources should be stark, factual and easy to understand.
- Resources should be rules based, there’s no room for maybees.
- Resources should include practical steps on what parents could and should do and other places they could go for support.
- Resources should include things they can do together with their child, rather than just be aimed at parents or young people.

It would also be useful for professionals to understand more about what resources already exist – there is definitely room to make more of existing support structures - like the Professionals Online Safety Helpline (POSH) – for professionals which no-one knew about.
Conclusion

The purpose of this research was to inform the creation of a suite of resources for young people with SEND and their families and teachers. It was fascinating to see the differences and commonalities between young people and the adults that care for them and to tease out how to make the resources genuinely useful. At the heart of that was the understanding that these teenagers use social media in precisely the same way as every other teen – to socialise, to connect, to be entertained and to learn.

Three things are profoundly different for this community. Often, they lack the critical thinking skills, and sometimes the consideration for consequences that typical young people have. Secondly, they are much more accepting of parental mediation, up to and including regular checking of their devices. Thirdly, most existing resources and all community standards and terms & conditions were too densely written to be meaningful for these young people.

The over-riding message of this report is that young people want simplicity and parents want starkness in how online safety is delivered. Merging these two desires together into a cohesive and comprehensive guide to staying safe online when living with SEND has been a significant challenge. Throughout the development of the resources, we’ve kept the voices of the young people who attended these workshops and their parents and carers loud and clear in our minds. We also wanted to offer some experiences and conversation starters that families can do together, to build upon the higher degree of parental involvement and in recognition of the frequent need for conversations about online safety.

The strong parental desire for a different social media experience for their teenager needs significant thought – about ethics, about data, about parental responsibility and the boundaries of parental control – especially around the difference between chronological and developmental age. This is a really sensitive area with long term consequences which will require consideration, consent, and caution. If this is not a viable option for any one of a wealth of ethical, technical or desirable considerations, we should begin to explain this to parents and policymakers.

This insight report and the resources it informed have been created with and for young people with SEND and their families – and is offered to you with our respect and thanks.