



**Festival
of debate**

Young People's experience of Mental Health:

**Written by Sian Beynon, Chilypep Participation
Project Worker, based on work carried out with
members of STAMP group (Support, Think, Act,
Motivate, Participate)**



#SpeakUp

July 2019

1. Introduction

Chilypep is an empowerment and participation charity for young people. By putting young people at the heart of all the work we do, we support them to influence positive change in their community, city and even across the country.

STAMP is one of the projects at Chilypep and is a Sheffield based group of young people aged 14—25, the majority of whom have accessed mental health services before. They are passionate about making a positive change to mental health services in Sheffield, and further afield. They do this through awareness raising, influencing decisions taken by people higher up in the NHS, mental health service design and delivery, training staff. We do this always with the hope that we can things better for other young people in the city.

Every year, STAMP aims to host a fun, consultation event called 'YOUth MATTER'. In March 2019, we received a Healthwatch Sheffield #SpeakUp grant of £500 to help us do this, and this report is a summary of what we did and what we found out.

2. When the project took place

The project took place over the course of April – June 2019, with our YOUth Matter event taking place on 4th May 2019.

3. Aims of the project

The aim of the event was to give young people the opportunity to #SpeakUp about their life experiences and provide an opportunity for them to influence change, particularly about things that can affect their mental health. We wanted young people to feel comfortable, not under pressure and welcome to discuss their experiences of using mental health services in Sheffield. With the information gathered, we wanted to share the feedback and inform people and services, so things can be improved to better meet young people's needs.

4. What did you do?

Over March and April in 2019, STAMP group met 9 times to plan and organise the event. There were a lot of decisions to make, including venue, activities, publicity, games, questions, refreshments, goody bag items, time and day.

We wanted to make sure we were asking the right questions, so we had lots of discussion about what we wanted to know based on STAMP group's own experience of using mental health services. We also wanted to make sure it was fun for other young people, so the group used their imagination to develop creative consultation activities. We also wanted to make sure it felt safe to share, so people with less confidence to speak about personal experiences and hardship were given the opportunity to take part in ways they felt comfortable, and we had break out spaces if people needed them.

We organised three workshops to run throughout the afternoon. We wanted to keep the workshop sizes small, so the participants were invited to choose two workshops that interested them over the course of the event.

- **Help me to Help you:**
A chance to look at the barriers that need to be overcome when young people seek help. During this workshop, we offered a space for reflection on what support has been helpful and what has been unhelpful from professionals, friends and family. We also then used this to make a 'top tips' for helping someone struggling (*See appendix 1*).
- **Social media: What's on your Mind?**
During this workshop, we discussed helpful and harmful social media posts and shared ideas about how the government could keep young people safe on the internet. This formed the basis of a report that was submitted as evidence to the Government's consultation on social media regulation (*See appendix 2*).
- **Past, Present and Future of Mental Health:**
In 2013, STAMP group wrote a manifesto for mental health in order to find out the priorities for young people: we are working towards redesigning this and launching it in time for 2020. This workshop was planned to generate ideas about ways to improve mental health support in Sheffield by looking at what could have helped in the past; what could be better in the present; and what could be improved in the future? (We are in the process of writing these findings in a separate report which will be released later in 2019/2020).
- **Silverdale extra workshop: Tops and Pants:** This is a straightforward reflection activity where we invited students to write what helped them to maintain wellbeing and good mental health on paper tops and what caused them to struggle with mental health on paper pants (*See appendix 3*).

Alongside the workshops, we set up a selection of activities for people to explore during breaks. We wanted to make sure there were lots of alternative activities for people who needed a break or weren't comfortable taking part in the groups.

- SAYiT, a local LGBTQ+ youth charity, had a stall to promote their service.
- University of Sheffield exhibited images produced as part of a research project called: 'Improving Wellbeing Through Urban Nature'.
- Chilypep's Barnsley group, Oasis, ran a de-stress zone with glitter jars, stress balls and a wall of positivity.
- Chill out zone: A breakout space with sofas and colouring.
- Speeches and poems from STAMP members.
- Make your own goody bag.

5. Who did you speak to?

We invited young people aged 14-25 year old by promoting the event on social media, through Sheffield Live FM, BBC Radio Sheffield, leaflets and posters and through local charities. We had the event registered as part of the 'Festival of Debate' so it was listed in the brochure.

In the run up to the event, we ran four workshops to a total of 120, year 10 pupils at Silverdale school. This gave us a chance to test out simplified versions of the activities, allowed young people to practice facilitating workshops, and start generating feedback, which we have included in this report.

On the day, we had 21 young people attending and the turnout included wide representation of young people of different LGBT+ identities (over half were LGBT+), religious beliefs, ethnicities, genders, housing and care situations.

6. Key findings

Barriers to accessing mental health services:

Arbitrary Thresholds: Eating Disorders Services

This was related to receiving support for Binge Eating Disorder (B.E.D) and Bulimia in particular. The discussion saw that the way people are treated perpetuates the stigma that all people with Eating Disorders (ED's) fit a certain box and they need to fit certain very specific criteria to access help. The culmination of this is that it encourages people to 'get worse' before they can get better and ultimately stops people from asking for help.

Language and Culture: Perpetuating Stigma and Stereotypes

There is a general lack of awareness which was perpetuated by a lack of language, insensitivity around the language we use and inadequate euphemisms when discussing mental health. It was also seen that there was a lack of transparency around mental health and discussions about mental health. Some of this is inherited from traditional views and culture linked to speaking honestly about mental health, and a 'grape vine' effect of discussing mental health with patronising/damaging outcomes. It was also raised that schools were unable to provide appropriate levels of assistance, which may be due to financial restrictions. At worst, young people felt they were stigmatised, targeted and bullied for struggling with mental health problems.

Depression: Mindsets

Living with depression is a barrier to seeking and seeing people; this can impact on people's ability to communicate, the way they view progress and connections, the way they view themselves and receive help they need. Respondents said they were worried about people judging them on one hand and that they would worry people on the other hand. There was a general sense of services being out of touch with what people with depression were experiencing which limited access to professional advice, normalising difficult experiences and a general sense of being uncomfortable to access support.

Managing expectations: Peers, Friends, Family Members

The challenge of asking for help from friends and family members was a barrier to receiving help. The idea that no one understands how you feel, coupled with not wanting to disappoint loved ones can push young people to try and fix symptoms without any help. Speaking with neurotypical people who haven't had the same experiences can make young people minimise their experiences and blame themselves, identifying with feelings of being a failure. If young people are struggling to open up to those closest to them, the effort of taking the first steps to receive treatment is ever greater.

Social Media: Fashionable, Competition, Misinformation

A recent uptake of mental health coverage in mainstream and social media has seen an increase in the number of opinions about mental health. This is potentially a positive move towards destigmatising the broader subject of mental health, allowing more people to develop appropriate language and identify support networks.

However, the young people discussed how the expansion of this debate can lead to further challenges. Firstly, an increase in self-diagnosis (possibly based on misinformation) was recognised as damaging because young people felt they weren't receiving the support they needed, or they weren't provided with the diagnosis that they felt best described their experience. Secondly, a difficulty with knowing when accounts or relationships are toxic, and are in fact damaging to the individual, preventing recovery or reducing the chances that a young person will access the correct, professional help. Thirdly, a competitiveness was recognised between social media accounts, as young people felt they weren't unwell enough to seek support in comparison to others. This tendency towards labelling people as 'better' or 'worse' can interfere with individual recovery and the way in which professional support is perceived.

Self-Harm: Fear of Judgement

There was a discussion around the particular challenges facing young people who self-harm. They felt there was an impenetrable, archaic way of viewing deliberate self-harm. Young people were up against older, prejudiced views from people with limited knowledge about the subject and how to speak with young people who self-harmed. They felt their experiences were minimised in a move towards normalising mental illness which discouraged them from speaking about it or masking the seriousness of it due to fear of judgement from those who don't have the understanding, or time, to understand. There was a more general mistrust in the way that services risk assessed young people who self-harmed including a lack of testing and feeling like they had to jump through hoops to get help.

Clinical Culture: Professionalism, Communication, Accessibility

Within this theme, a number of topics were identified within a general idea of the challenge of clinical culture and the officiality of the process of receiving help. We have combined them into staffing, systems and structure of mental health services.

Staffing: The key relationships which work towards improving young people's chances of recovery can often be undermined by overly formal, unprofessional and often stressed staff.

- Staff attitudes can be condescending, and the participants highlighted there was often a tendency for staff to take on a role of 'expert', assuming they know more about you than yourself. This places an excessive distance between the patient and professional. In a number of cases, young people spoke of a difficulty in building rapport with staff, feeling that they were not open to fully understanding what was going on for an individual, which led to disengagement with the treatment and underrepresenting symptoms.
- Staffing levels were perceived to be too low. Staff weren't available when they were needed and those who were available were thought to be under a lot of pressure. A feeling of being a burden to a busy person meant that young people were more likely to mask what they were really feeling as they were protecting that member of staff and were discharged before receiving the treatment they required.
- Conversely, it was also noted that, despite settings having adequate staff numbers, they were observed sitting in office, focusing on paperwork or socialising, rather than engaging with service users and encouraging them to feel welcomed, accepted, safe and secure.

- An extra distance between staff and service user was noted due to a perceived lack of understanding from staff as to how 'broken' their own system appears. It was acknowledged that staff see their small part of the story, rather than the whole picture. This meant young people's experiences and attitudes, including feelings of disillusionment and often being reticent to engage, are seen as being the fault of the individual, not a product of their journey towards seeking help.

Structure: There is general disillusionment in the way mental health services, in particular CAMHS is perceived due to long waiting times and unsuitable treatment.

- A persistent and significant barrier that is regularly raised around accessing mental health services is excessively long waiting times, both for the initial meeting and internal waiting times. One young person had to wait for over a year for her therapy to begin, only to find that she was too old to receive it when she was at the top of the list.
- At the point where an intervention occurs, often a long wait sets a high expectation for the effectiveness of treatment. Young people often said they felt they were lacking the level of treatment they thought they needed; a case of too little too late.
- Once in treatment, young people spoke of being rushed through a 'check list' style treatment within a limited number of weeks. There was an implicit (sometimes explicit) expectation that they would be able to manage their own mental health at the end of the treatment. Young people felt they had been let down and worried they were more unwell, as they were 'unfixable' by professionals.

Systems: The current approach to managing data across health and social care services is designed for administration, management and is not young person centred.

- 'E-systems' appear abstract and removed from 'patient experience', but the way in which services communicate on behalf of young people is detrimental to their experiences of accessing mental health support. When service E-Systems don't communicate between each other, staff have missed vital information about a young person which can undermine a sense of trust with the treatment.
- Communication around the young person was discussed as often being inadequate. Particularly when communicating across services, receiving referrals or keeping in contact with parents and carers.

Transitions support: More investment needed

Young people saw a number of issues around transitions that prevent them from accessing the mental health support they thought they required. They saw a general lack of funding being a major factor affecting transition provisions leaving gaps within the wider system. In particular there are not enough trained professionals and no alternative service provision to catch young people between services. From their experience of transition, young people felt a lack of communication left them with a sense of being excluded from the conversation about their care pathway. They were confused as to what transition would involve, when it happens and what their future support would look like.

Accessibility: Signposting fatigue

Participants of the workshop recognised wider barriers to accessing mental health services, particularly around signposting. There was a fatigue recognised around tedious signposting. Young people felt they were bounced around services, offered generic solutions which weren't appropriate for their needs. There was also a lack of acknowledgement of the effort or offer of support needed to access a new service.

Accessibility: Services designed for people with disabilities

Young people spoke about the challenges of feeling able to physically access a service without judgement or adding to the other stresses of accessing a mental health service. There was discussion about the fair inclusion of young people living with physical disabilities and those with invisible illnesses. When a service feels like it is not designed for people like you, there is lower chances of young people responding to the treatment and therapies on offer.

7. Recommendations

Throughout all the recommendations the top three, recurrent themes were:

- 1) Appropriate education and learning opportunities about mental health should start from an earlier age, focusing on areas to prevent mental health problems from developing in the first place.
- 2) Training for all frontline staff on mental health first aid and mental health conditions should be in place.
- 3) Provide information and support for parents, carers and friends.

Other recommendations for improving mental health services relating to the key findings:

Eating Disorders Treatment

- Treating them as a mental health illness first and not through an overly clinical or physical health model.
- Including options for self-referral.
- Investing in charities like SYEDA (South Yorkshire Eating Disorders Association).

Language and Culture

- Educate children from an early age on the use of language and self-awareness when speaking about mental health.
- Access to training for young people to identify, verbalise and realise their own mental health needs.
- Assertiveness training around complaining and making needs known.
- Reducing use of the word 'emerging' when describing personality disorder.
- Advertising campaigns should focus on prevention, not reaction.
- Supporting people who have had experience of mental health problems - or can relate to, advocate for and champion mental health - to speak up.

Depression

- Educate children from an earlier age about neurodiversity and stigma.
- Introducing distractions for people worrying about appointments in the waiting rooms: sensory toys, mindful colouring, music, books and magazines.
- Don't isolate people in separate rooms: 'If I'm waiting for an appointment, don't make me sit by myself in a room'.
- Engage with people who are waiting for appointments, helping them to feel at ease.

Managing Expectations

- Workshops for parents, carers, peers and friends to help them understand/spot the symptoms.
- Offer supportive 'middle ground' spaces and time for peers, friends, parents, carers to have appropriate, informed, non-judgmental discussions.
- Support friendship groups, with opportunities to make, and develop trust, with friends.

Social Media

- More training on what is a 'toxic' account and how to deal with this.
- More informed representation of symptoms and treatment in youth focused media (e.g. Snapchat).

Self Harm

- Educating the general public, parents and carers with identifying indicators of different illnesses.
- Don't write people off for opportunities because of mental health barriers.
- Befriending service in GP waiting rooms.
- More capacity within Crisis Services - referral times need to be improved, helplines and safe spaces to be commissioned (especially for 18-25).

Clinical Culture

- Promote opportunities for participation by young people to Engage, Hear, Act, Re-engage again and listen.
- Rehumanise clinical relationships; treat those with mental health issues like people, not statistics, items or things.
- Engage with people on waiting lists: via young person friendly communications, postcards, accessible website, social media, support groups, peer mentors. Don't forget about them!
- Building in reflection time to allow staff time to notice and respond to mental health issues.
- Provide opportunities for staff to understand the mental health problem from the perspective of the young person.

Transitions

- Commissioning youth provision up to 25 (as a minimum age) so transition occurs when young people have fewer life upheavals are feeling more settled.
- In-patient units working specifically with 18-25s; staff to have particular experience in working with young adults with Personality Disorders.
- More professionals to be trained and specialise in working with 18-25s. It is a unique time for personal growth and development.

Signposting Fatigue

- Particularly within education, stop signposting students to oversubscribed services like CAHMS. Instead, those within education should consider how they can make lessons, or their own provision of services, more comfortable and safe.
- Educate young people on mental health issues and what they can do to help themselves.
- Provide Mental Health First Aid training to organisations that provide a first point of call to young people who may not need/want a signposting process

Disability access

- Make bathrooms/calm spaces accessible (e.g. Disabled toilets/gender neutral loos)



About Healthwatch Sheffield

Healthwatch Sheffield is the city's local consumer watchdog for health and social care services. The organisation exists to help adults, children and young people to influence and improve the way health and social care services are designed and run in the city. Healthwatch Sheffield is completely independent from the NHS and Sheffield City Council.

About the #SpeakUp grants

In 2018/19 Healthwatch Sheffield ran a small grants programme called 'Speak Up'. Sheffield-based voluntary and community sector organisations were invited to apply for a small grant of up to £1,000 to run consultation and engagement activities. Organisations were asked to relate their projects to one of the aims and priorities in the 2018 – 2020 Healthwatch Sheffield ['Together for Good' Strategy](#).

The programme was designed to enable local organisations and community groups to gather views and experiences of health and social care services from Sheffield residents, especially from those who do not traditionally have a voice. The aim is to ensure that health and social care decision makers in the city hear from a diverse range of people about their experiences of services.



Stamp
c/o Chilypep
11 Southey Hill
Sheffield
S5 8BB

Telephone: 0114 234 8846
Email: info@chilypep.org.uk
www.chilypep.org.uk



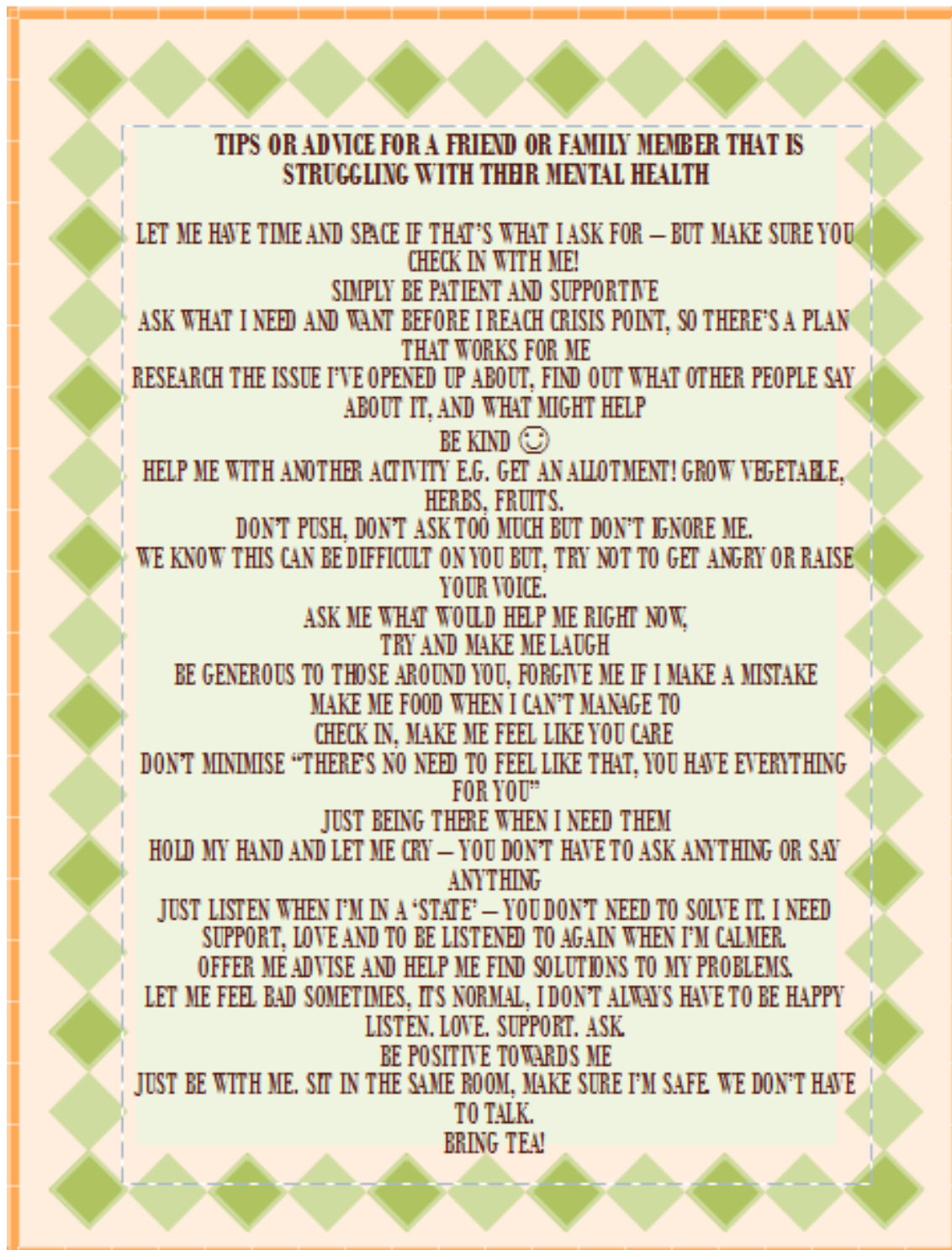
The Circle
33 Rockingham Lane
Sheffield
S1 4FW

Telephone: 0114 253 6688
Email: info@healthwatchsheffield.co.uk
Text: 0741 524 9657
www.healthwatchsheffield.co.uk

8. Appendices

Appendix 1:

Help Me to Help You: Tips and Advice for a Friend or Family Member



Appendix 2:

Online Harms: Report submitted to Government White paper call for evidence

Online Harms White Paper Consultation

The Online Harms White Paper sets out the government's plans for a world-leading package of online safety measures.

It proposes establishing in law a new duty of care towards users, which will be overseen by an independent regulator. Companies will be held to account for tackling a comprehensive set of online harms, ranging from illegal activity and content to behaviours which are harmful but not necessarily illegal.

This consultation aims to gather views on various aspects of the government's plans for regulation and tackling online harms, including:

- the online services in scope of the regulatory framework;
- options for appointing an independent regulatory body to implement, oversee and enforce the new regulatory framework;
- the enforcement powers of an independent regulatory body;
- potential redress mechanisms for online users; and
- measures to ensure regulation is targeted and proportionate for industry.

This is an open public consultation. We particularly encourage responses from organisations, companies and others with relevant views, insights or evidence.

onlineharmsconsultation@culture.gov.uk

Response

Chilypep works with up to 1500 young people a year in a variety of settings. This particular consultation was done four times at local Sheffield school and at an event planned and facilitated by young people for young people, approximately 120 young people, aged 14-24, took part in the consultation.

To make the consultation youth appropriate, the questions we asked were

1. What should Theresa and the government do?
2. What advice would you give to a young person who is new to the internet

The following feedback brings together the views of the young people into the consultation descriptors.

The online services in scope of the regulatory framework

The young people mentioned the following sites in the consultation:

Instagram
Facebook
Twitter
WhatsApp
Snapchat
YouTube
Tinder

The enforcement powers of an independent regulatory body

Social media 'laws'

Young people thought that social media laws should have parity of esteem with those in the real world e.g. stalking online treated the same as in real life.

Regulate harmful content on social media

Some of the points young people were eager to be regulated included:

- **Not body shaming** – This includes not promoting being skinny or the 'perfect body image'. Young people also thought photos should have to say if they are photoshopped (similar to how influencers have to make it clear if it is an advert).
- **Tackling hate** – Young people have noticed the 'internet police' have blocked words they have tried to use in the past. They think this same technique should be used for hate speech, e.g. filtering homophobic, transphobic, racist and sexist slurs on all social media sites.
- **Remove online 'competition'** – Young people are driven by likes and this can affect them negatively. Young people suggested taking likes off social media sites for other people to see (on sites like Instagram and Facebook).
- **Posts provoking or promoting self-harm or suicide** – These can be disturbing and triggering for young people. However, see the next section for a detailed description of how to manage triggers.
- **Investigate large companies for holding monopolies on opinions** – large companies can have an influence over social media, make sure their influence isn't for political or personal gain.

Triggers and mental health support

Trigger and trauma support needs improvement. A scenario was explained where when using the social media site Instagram, there may be a trigger warning on a post where multiple pictures were posted. However, when users refresh the page and scroll down the next image in that post automatically comes up on their 'feed'.

Young people do not think that all triggering images should be banned, for example, young people reported that sharing their own images through recovery of self-harm can be helpful to their recovery. If they must ban these there should be an option for young people who have shared their own self-harm recovery posts to privatise them, so they do not lose track of their progress. Young people do believe there needs to be an improvement in how the trigger warnings work.

There needs to be a way where the trigger warning can cover up a whole post rather than just the one picture.

If someone does decide to/accidentally looks at a triggering post, there should be a help link attached to the post directing them to somewhere they can get help, e.g. an online chat room, Samaritans etc.

There could be measures put in place to prevent people from being triggered in the first place, for example, social media sites could make questionnaires where people can disclose what triggers them so that content can be personally censored to their information. Some young people had the idea that each website should have their own mental health support, e.g. Facebook has a page dedicated to this and they are responsible for hiring the professionals that run this.

Stop article 13

Some young people were passionate about putting a stop to article 13. They believe content should not be judged by whether it is copyrighted or not, it should be judged by what is harmful or helpful. Despite this, they are aware that copyright is bad and can be harmful for companies, therefore, have the view that amendments need to be made so that it does not affect memes and youtubers.

From experience, they believe that too many rules mean young people will find alternative ways to access the content. They believe the focus should be on making the internet a safer place rather than reducing copyright.

Fraud/hacking

Young people thought there should be a responsibility to increase regulation by FCA to prevent websites saving credit card details.

Continuous feedback

Internet sites should have the responsibility to respond to feedback. For example, if someone reports a comment there is no feedback from the site as to if this comment has been removed.

Potential redress mechanisms for online users

Tackling hate

As mentioned, tackling hate was important to the young people. As well as blocking clearly offensive words, they believe that the culprits who do not take this rule seriously should receive a “speeding ticket” style fine where people who have posted hate speech get fined to deter them from repeating the offence.

They believed it is important to still be aware of freedom of speech, sometimes it’s hard to differentiate what should be taken down as people may be offended by different things. In those cases, give the users of social media sites some power - social media posts should be taken down if enough “flags”/reports are made.

Monitoring and responsibility of people in the public eye

Social media ‘influencers’ have such a large following, particularly of young people. The young people felt that influencers and famous people should have what they post regulated.

Young people expressed that influencers should be held accountable and take responsibility for their actions. Influencers need harsher punishments for harmful posts e.g. Logan Paul, who has a large young person following, posted a video online of dead body he found hanging from a tree in Japan’s “Suicide Forest”. Young people believed he did not receive enough punishment for this and should have been judged in a court.

Be tighter on age restrictions

Young people highlighted how easy it is lie about their age and how they notice other young people doing this now. They feel there should be a process where to gain access to certain websites, including social media sites, they should have to prove their age and identity.

This could also help when it comes to fake accounts and ‘trolls’, young people discussed how they had observed other young people using fake accounts to lie about their age and raised this as something that needs to be stopped.

Young people thought that there should be more blocks to what young people are able to access on social media, similar to TV companies such as the BBC (but requiring more thorough age checks). For example, some accounts that are open to the public should be age restricted.

Education for young people and those around them

Schools have responsibility to educate young people around social media. The young people believe:

- All schools, academies and colleges should have compulsory lessons around social media.
- All teachers and other professions that work with young people should have training around social media and be up to date with harmful trends that may affect young people.
- Schools should have open conversations with young people; teach children about online safety and health; and support with the self-esteem and confidence.

For young people to engage, it is important to make school sessions interesting and relatable for young people.

As there is a large generational difference between knowledge and use of social media young people also thought that parents/carers should have access to education around social media; this could be online support but also inviting them into schools.

Other thoughts

Look at the bigger picture

Young people thought it was important to address the issues with wider society that make them feel insufficient on social media. They think it is important that there is more effort put into building self-esteem and confidence so young people can understand that they don't need 'likes' or 'followers' to be valued.

Money could be used elsewhere

Some of the young people from the school thought that the idea of an independent regulatory body was a good idea so that the government can concentrate on other matters they believe to be important e.g. convicting paedophiles, knife crime. Whilst the social media sites should take responsibility for online hate crimes etc.

Top tips for young people

Keep private!

Make sure your account is private (as oppose to public or friends of friends)

Only accept friends

Don't talk to people you don't know

Don't share personal information

Think before you act

Stay away from arguments

Keep personal views private

Be careful with your actions

Don't post offensive content



Be nice!

Be aware of other people's feelings

Be responsible

Be aware of creepy people

Don't talk to people you don't know

The internet has some triggering content – don't be afraid to ask for help

Use sensitive content feature

Be wary of negative social media communities

If triggered call mental health safety hotline

The internet can be good... People can support you through tough times

Ask someone for help

Appendix 3

Silverdale School: What is Tops (What helps with my mental health)



Silverdale School: What is Pants (What I struggle with and/or doesn't help with my mental health)

