

Appendix E Children and Young People's Expert Reference Group summary report

Background to the Children and Young People's Expert Reference Group

NICE and the NCCSC were committed to involving children and young people (under 18) in the development of the guideline to ensure that the guidance is acceptable and relevant to them. It was acknowledged throughout that their involvement needed to occur within an ethical framework in which young people's voices are valued, and their participation adequately supported (see NICE Patient and Public Involvement Policy).

Discussion during the scoping phase of the guideline and early guideline committee meetings identified that the most appropriate way to engage children and young people under 18 was via a separate 'expert reference group' that would meet at several points during development. This was thought to be the best way to ensure that participation would be meaningful, fully supported, and able to be tailored to young people's needs.

The objectives identified for the expert reference group were to:

- Provide insight about their perspectives on specific questions and issues identified by both the guideline committee and themselves.
- Comment on the recommendations made by the guideline committee
- Contribute ideas to a possible 'Information for young people' version of the final guideline, and, along with the guideline committee, to wider dissemination and implementation of the guideline.

A decision was taken to appoint an external facilitator with specialist experience in working with vulnerable children and young people to facilitate the group sessions.

Facilitator and group recruitment

Against Violence and Abuse (AVA) was commissioned by the NICE Collaborating Centre for Social Care (NCCSC) to recruit and facilitate an Expert Reference Group (ERG) of young people who have been affected by child abuse and neglect. AVA

put out a national call for participants to be recruited via organisations who would be able to support the young people throughout the process.

As a result of this 15 young people were referred, ten from London and five from Sheffield. In London the referring partner was a local Pupil Referral Unit and in Sheffield the partner was a housing project. Both organisations provide support to young people who have experienced abuse and/or neglect and were able to support participants during the process.

All young people were given information about the project and voluntarily chose to take part. Four participants were male and eleven were female with an age range of 14-21. All young people had experienced various forms of abuse and/or neglect and the group included looked after children and teenage mothers.

Methodology

The ERG met four times between November 2015 and November 2016 with meetings taking place in London and Sheffield. The group also had a joint meeting in June 2016 in London with members of the guideline committee.

Given the sensitive nature of the issues under discussion, significant thought was given to how to ensure that the young people were kept safe and supported during the discussions. All discussions were facilitated by a DBS-checked experienced youth worker and facilitator. A process had been agreed for what would happen if what a young person said suggested that they were at risk of harm, or if a young person became distressed. Close working with the referring partners ensured that young people were supported after discussions as necessary.

Prior to each meeting the NCCSC sent a document to AVA outlining the questions that the guideline committee were currently considering, and with outline questions for the children and young people. This formed the basis for the discussion with the ERG. The themes for each ERG meeting were structured to mirror the work of the guideline committee and were as follows:

1. Early help
2. Recognition and assessment
3. Response after identification of abuse/neglect
4. Overview of draft recommendations for comment by the ERG.

AVA planned each session to be inclusive and interactive so that all young people felt safe and confident to take part. The general agenda for each session involved the following:

- Welcome and ice-breaker activity
- A re-cap on the guideline process and any updates/feedback from the guideline development group
- A re-cap on group agreements and support available
- An introduction to the current theme
- Interactive activities and discussions based on the questions and themes identified by the guideline development group (recorded by AVA facilitator)
- Wrap up and debrief, including re-cap on support options.

AVA wrote a report of the ERG's feedback and recommendations after each meeting which the AVA facilitator presented to the guideline committee on a quarterly basis. The young people also requested a meeting with representatives of the guideline committee so that they could gain a better understanding of the process and how their views would be fed into the guidelines, which took place in June 2016. The guideline committee welcomed the meeting and it was hugely beneficial for all involved. This meeting helped the young people to feel empowered and gave them a belief that their experiences and expert views were being taken seriously and would have an impact.

Key themes

The ERG have directly influenced many of the recommendations in these guidelines. Over the year they worked together some key themes emerged in both the London and Sheffield groups. The group were able to eloquently discuss their experiences of the many services they have been in contact with and offer recommendations for improved practice.

The content of their discussions was considered as part of formulating the recommendations. The groups also commented on the draft recommendations, and their feedback taken in to account.

Some key themes and recommendations from the young people's discussions, mapped against the sections of the guideline (see also Section 3.11 of full guideline), included:

Overarching principles

- Practitioners should always explain their role, why they need to speak to a child/young person and what actions they will need to take. They should also specify a timeframe in which things will happen and follow up with the child.
- Involving children and young people in their care and support as much as developmentally appropriate, including sharing and agreeing written records.
- Practitioners checking when and how it is safe to contact a child/young person
- Services must be aware of the role of technology in young people's lives and now much of the abuse they experience also takes place via technology. Do not assume that it will be safe to contact someone via phone/text/email.
- Ensuring that involvement with children and young people happens at a time and in a place that suits them, for example arranging to see children and young people in breaks or after school, rather than taking them out of class which can cause issues related to stigma and bullying.
- Waiting rooms and services to be more welcoming and child friendly with relevant information about abuse/neglect.
- Confidentiality is key, young people understand this sometimes has to be broken but want to know why and when this will happen.

Recognition and assessment

- The need for health practitioners to understand the dynamics of abuse (including emotional abuse and coercive control) rather than just focusing on physical health.
- Mental health services avoid labelling or medicating without explanation and support.
- The crucial need for specific training for all professionals working with children to be better able to identify and respond to abuse and/or neglect and to be able to respond in a non-judgemental and empathic manner.

- The need for an understanding about the causes of behaviour and to see abuse and neglect as a form of trauma that will impact children and young people in various ways. This includes understanding self-harm, substance misuse, running away and so on as forms of coping. Only dealing with surface behaviours will not address the underlying issues.
- The overall importance of a trusting relationship in order to feel safe to tell people about abuse or neglect.

Early help

- The need for services and practitioners to recognise warning signs of abuse and neglect and to provide earlier interventions.

Response and therapeutic support

- A creative approach to support and not just assuming counselling is appropriate or needed. If offered, counselling should be provided by someone with a good understanding of the dynamics of abuse or neglect.
- Some poor experiences of therapeutic interventions such as cognitive behavioural therapy, which were perceived by some young people as re-traumatising.

Service planning

- The importance of having one nominated person to talk to, rather than having to re-tell their story to multiple professionals.

Next steps

The ERG members will be involved in developing a children and young people's version of the guideline after consultation.