### PERSON-CENTRED CARE IN CHILDREN AND YOUNG PEOPLE'S MENTAL HEALTH SERVICES

# Shared decision making: An introduction to what we know

Guidance for practitioners working with children and young people around their emotional health and mental wellbeing











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## What do we mean by person-centred care?

Person-centred care places the individual receiving the service or support at the heart of their care.

The Health Foundation identifies four principles of person-centred care:

- 1. affording people dignity, respect and compassion
- 2. offering coordinated care, support or treatment
- 3. offering personalised care, support or treatment
- 4. being enabling

# What is shared decision making?

Shared decision making is a key component of person-centred care. There are several definitions of shared decision making. We find this definition the most helpful:

**Shared decision making** is an approach that involves a practitioner and a service user collaborating to make decisions about the goals they are working towards and the treatments that will be used.

Together the practitioner, the child or young person, and sometimes their parent/ carer, review all the available treatment options. The pros and cons of each are considered and the young person, along with their practitioners and parents/carers, is an active participant in decision making about care.

For this to be effective, the practitioner needs to share with the child or young person and their parents/ carers up-to-date clinical information about their condition and the options available. The practitioner also needs to discuss progress with the child or young person and their parents/ carers on an ongoing basis.

Shared decision making is based on a number of **key principles**:

- Recognition that young people and their parents/ carers, as well as professionals, have valuable expertise that can be drawn on when making decisions about treatment.
- Genuine collaboration between children and young people, their parents/carers and practitioners.
- A relationship of equal partnership between children and young people, their parents/carers and professionals.



# Should young people be involved in decisions about their mental health care?

## The policy context:

*Future in Mind,* the report of the Children and Young People's Mental Health Taskforce, states that

'the best mental health care and support must involve children, young people and those who care for them in making choices about what they regard as key priorities, so that evidence-based treatments are provided that meet their goals and address their priorities.'

These treatments should, the report suggests, be offered in ways that young people and their families find acceptable, accessible and useful.



## The research evidence:

There is little evidence about the implementation of shared decision making in children and young people's mental health services specifically, but research in hospitals found that children receiving treatment for their physical health wanted to be involved and consulted in decisions about their care. Their inclusion helped them feel in control, treated as a person with rights, and better prepared for treatment.

Many children and young people accessing mental health services say they feel excluded from the decisions made about their care. There is growing evidence that shared decision making enhances patients' motivation, self-esteem, self-management and outcomes.

Much of the evidence about the impact of shared decision making in children and young people's mental health services considers the views of parents. The evidence suggests that in certain settings, shared decision making techniques reduce conflict and make children and young people more likely to continue to engage with treatment.

## The evidence from practice:

The *Closing the Gap* project<sup>1</sup> worked with four children and young people's mental health services to explore how children and young people can be involved in decisions about their mental health care. It found that there is potential for shared decision making to:

- Support young people to feel more involved, engaged and empowered.
- Support practitioners to be more open and transparent with young people about what they were agreeing to work on.
- Facilitate open, honest conversations, even in stressful contexts.
- Improve relationships between practitioners and parents, enhancing collaborative working.



# Facilitators and barriers to shared decision making

We know that certain **attitudes and behaviours** among practitioners support effective shared decision making:

- A trusting, open and honest relationship with service users.
- Supporting service users to participate in and understand decisions about their care, working at the child or young person's pace.
- Balancing the needs of the child or young person with those of their parent/ carer.
- A flexible approach to choosing treatment options (within the bounds of appropriate safeguarding), managing timings and adapting to the individual needs of the child or young person.

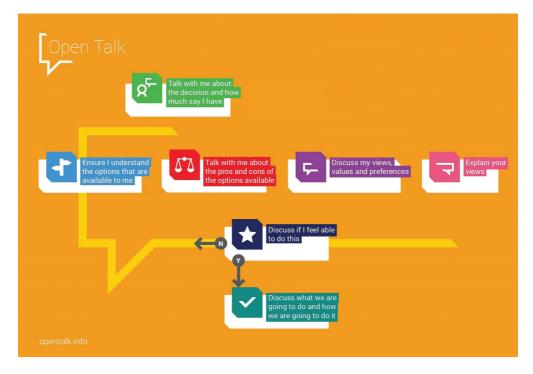
We know there are particular **challenges** for practitioners in working collaboratively to make decisions with children and young people experiencing mental health problems:

- It may involve complex conversations which certain children (for example younger children) might struggle with, or which adults do not know how to have.
- It is likely the child/young person and practitioner will need to make a series of decisions through the course of the treatment (not just one!). This can, however, support trust to grow over time.
- There may be multiple perspectives to balance including those of the child, family and other professionals like social workers, GPs or school staff.
- In some cases practitioners are also taking risk management into account, and giving consideration to wider responsibilities around safeguarding and duty of care. These may have an impact on a practitioner's ability to be open to shared decision making.



# **Models for practice**

Several models and approaches to shared decision making in children and young people's mental health services have been developed. Here are some examples that you may find useful:



**The Open Talk** model was developed by Common Room and the Evidence Based Practice Unit with young people and practitioners to support open decision making in a child and young person mental health context. Further information on the model and implementation of it in child and young person mental health services can be found at <u>www.opentalk.info.</u>

**5** key stages to shared decision making in children and young people's mental health services were identified by services as part of the *Closing the Gap* project.<sup>2</sup> Young people and those working with them should:



## Shared decision making tools and resources

A range of **tools** to support shared decision making have been developed. These include discussion prompts, goal setting tools, information resources and decision aids in the form of decision tables and interactive online tools or apps.

The tools offer different benefits to shared decision making:

- Providing something tangible for children and young people to help them engage and participate.
  - Helping to balance the power by facilitating discussions that may otherwise be challenging to have.
  - Supporting children and young people to understand the risks and benefits of treatment options and make an informed choice.
  - Increasing the likelihood of children and young people attending appointments, asking questions and sharing their views.

## **Tools and resources**

#### IncludeMe

An online, interactive platform designed to support collaborative practice and shared decision making with young people and their families. IncludeMe contains a variety of tools that can be used to set and review goals, explore progress, review outcome measures, and facilitate communication.

For more information contact info@silvercloudhealth.com



### My CAMHS Choices – mycamhschoices.org

An online resource developed for young people, which provides information about children and young people's mental health services that aims to equip them to make meaningful choices about their care. The website includes video interviews with young people who have experience of mental health services and practitioners who work in children and young people's mental health services.

#### Choosing what's best for you – www.annafreud.org

A decision aid that sets out an accessible evidence base to help children and families make choices about treatment. This resource is being further developed and will provide a new take on how children and young people choose help for themselves and what parents, carers and professionals can do to support this. The new resource will be available on the EBPU website in 2017.

#### Next Step Resource - cwpcamhscentre.mymind.org.uk

Developed by young people and practitioners at Cheshire and Wirral Partnership Trust, Next Step is a Goal Based Outcomes resource. It takes the form of a set of cards that can be used to engage children and young people in setting and achieving their own mental wellbeing goals. The resource aims to empower service users to determine their own direction, inform the interventions they are offered and take ownership of achieving successful outcomes.

#### Ottawa Personal Decision Guide – decisionaid.ohri.ca/decguide.html

Designed to support any health or social care decision, the Ottawa Personal Decision Guides help people identify decision making needs, plan the next steps, track progress, and share views about a decision. The decision guides are freely available online.

#### Outcomes measures - www.corc.uk.net

These can be used to help children, young people, their parents/ carers and practitioners to review progress during treatment and help inform future decisions about care. A range of measures are available on the Child Outcomes Research Consortium (CORC) website.

#### Shared decision making

Findings from the **Closing the Gap through Changing Relationships** project, which was run by the Evidence Based Practice Unit, the Child Outcomes Research Consortium and Young Minds can be found on the **Health Foundation** website:

www.health.org.uk/programmes/closing-gap-through-changing-relationships/ projects/shared-decision-making-child-and

NHS Right Care provides information on shared decision making and decision aids: www.england.nhs.uk/rightcare/innovation/sdm

**National Voices** has compiled evidence on shared decision making from a broad range of health contexts, highlighting effective approaches. The summary can be found at:

www.nationalvoices.org.uk/publications/our-publications/supporting-shareddecision-making



**The Health Foundation Person-centred care resource centre** Information about person-centred care together with resources from The Health Foundation and recommendations from around the web.

personcentredcare.health.org.uk



The Child Outcomes Research Consortium (CORC) is the UK's leading membership organisation that collects and uses evidence to improve children and young people's mental health and wellbeing.

www.corc.uk.net



Founded in 2006 as a collaboration between UCL Faculty of Brain Sciences and the Anna Freud National Centre for Children and Families, the **Evidence Based Practice Unit (EBPU)** bridges cutting-edge research and innovative practice in children's mental health. We conduct research, develop tools, provide training, evaluate interventions and disseminate evidence across four themes: risk, resilience, change and choice. Our vision is for all children and young people's wellbeing support to be informed by real-world evidence so that every child thrives.

www.ucl.ac.uk/ebpu