

Anna Freud Learning Network B R I E F I N G

Towards a better knowledge of self and community approaches for children and young people with mental health difficulties

'Self or community approaches?'

Any approach to managing mental health which does not involve a mental health professional. These include approaches children and young people may take up alone, with peers, family members, or in the community.

1. Context and overview

In early 2018 the Anna Freud National Centre for Children and Families (AFNCCF) and UCL Centre for Behaviour Change held a couple of knowledge exchange events to engage professionals in our work to improve our knowledge of self or community approaches for children and young people with mental health difficulties.

Progressing knowledge in this area seems to us particularly pressing, given our understanding from recent research that

- Most people will have mental health problems at stages over their life time (Schaefer et al 2017)
- Many still have problems at the end of treatment (Wolpert et al 2016)
- Many have ongoing problems but manage in life (Rutter 2016)
- The number of people experiencing problems is greater than the number who can be supported directly by specialist professionals

We know self and community approaches are already part of the mix for many in addressing mental health difficulties, with growing interest from commissioners, policy makers, schools and public health – among others - in widening our knowledge about what supports children and young people.

Despite this, our early scoping review suggested that while a wide range of these approaches are in use, **we lack a comprehensive list, and we lack a synthesis of the current evidence base.**

In this briefing we summarise our work in this area to-date, in which we have sought to

- more comprehensively understand the range of self and community approaches available to children and young people with mental health difficulties, and to review the available evidence base for these
- engage young people and professionals in debate about what is in use, what helps, and what is currently informing that
- begin a dialogue about ways to structure our knowledge of self and community approaches – to help us think about what works for whom, and to identify and address evidence gaps

From here, our intention is to

- share more widely with children, young people, and the adults who support them, the 100-odd self or community approaches cited in literature and advice for addressing mental health difficulties
- bring together and share feedback data from young people about the approaches they are using, and how and why they find they help
 - to help others seeking support
 - to inform the direction of more formal research
- understand the factors influencing young people's choices of self or community approaches
 - to inform the design and delivery of support
 - to inform the development of a taxonomy

2. Identifying a comprehensive list of self or community approaches

To inform and open up dialogue in this area we wanted to identify a comprehensive list of the self or community approaches available to or suggested for children and young people as part of managing their mental health difficulties, and to understand what evidence was available about their relative effectiveness.

As a first step in this we commissioned Dr Roz Ullman of LLP Partners to do a scoping and systematic review of the literature (2000–2018).

The scoping review sought to identify the full range of interventions referenced in the literature as being used, or suggested for use by children, young people and working-age adults as a way of improving symptoms of anxiety and depression, without input from a professional.

The scoping review identified 133 self or community approaches. These varied widely across approaches involving social relationships, technology (and the absence of), thinking and attitudes, relaxation, healthy living, talking and learning and hobbies and activities. The wordle below offers a taster

The systematic review sought to identify how many of these approaches have been researched and evaluated for children and young people with anxiety and/ or depression. Of the 133 approaches identified, 104 were referenced in relation to children and young people. However the systematic review identified that only 20 of these have ever been researched. Of these, the vast majority were studies where the evidence arising is graded as of low or very low quality.

Given the large number of approaches identified in the scoping review, we feel this suggests a large knowledge gap.

- In the absence of a formal research base, we hypothesise that children and young people, and those supporting them, are currently drawing on combinations of informal or indirect evidence, and personal experiences of trial and error to guide them in identifying self or community approaches to help manage mental health difficulties
- We also hypothesised that situational, contextual and other preference factors also have a role in determining the approaches they adopt
- We wanted to understand more about both of these areas, and to build on the lived experience of children and young people managing mental health difficulties, to help others

3. Reflections from young people

Over autumn/ winter of 2017/18, Common Room undertook some exploratory consultation with young people. The sessions were not very structured, with the aim of starting with a fairly blank page in exploring young people's views and experiences of self or community approaches to managing their mental health

Common Room facilitated three workshops, in Leeds, Bristol, Liverpool which involved 24 young people aged 14 – 25.

In their discussions young people identified a wide range of strategies they used to support their mental health. These also exposed that what helps is different for everyone, and the strategies that some young people found most useful, were also ones that other young people felt had not worked for them. Some key points were highlighted:

- The critical underlying factor for most young people was that they had been involved in choosing, trying and out and deciding for themselves which strategies worked best for them. Many young people described being told or advised which strategies work best. However, they felt that it techniques are very personal to the individual and they needed to be supported to find the ones that worked best for them.
- The most important criteria which determined which techniques people use were
 - being able to do it alone (this is a big factor important to nearly everyone)
 - financial considerations (i.e. it 'would have to be at a low cost')
- The young people said it was important to know that self-care approaches they find useful may change over time. Self-care techniques can stop being helpful and young people may need to find other techniques to replace them.

- Young people also highlighted some areas to remain conscious of when thinking about self-care:
 - There were concerns that self-care could be commodified and over individualised and seen as cheap replacement for therapy or support from a professional.
 - Young people felt this could then be seen as their fault they were struggling – as they weren't looking after themselves and "everything would be ok if only you looked after yourself better" as if mental health issues are individual choice and responsibility.
 - Participants felt the benefit of self-care is that young people can do it themselves – but this could be a challenge if they feel low, overwhelmed or found it hard to do nice things for themselves
 - They also stressed that there was potential for these strategies to be actively unhelpful – e.g. too much sleep, comfort eating, too much time alone, getting bad advice from the internet
- All of the young people said they had not received any advice on what types of techniques may work better for different feelings. They all felt a framework of some kind that gave trusted information on self-care techniques would be helpful

4. Towards a taxonomy?

Anna Freud National Centre for Children and Families (AFNCCF) and UCL Centre for Behaviour Change have been particularly interested in the idea of developing a taxonomy for self or community approaches.

We have now confirmed that a vast number of self or community approaches for managing child and young person mental health difficulties are used and talked about, but there is no common, accepted approach to grouping, categorising or describing these approaches.

We feel a taxonomy for self or community approaches would bring great value, bringing some structure to this wide-ranging field in a way that could:

- Standardise and improve our descriptions/ definition of approaches and what they involve, to avoid confusion or clashes in meaning

This can help us avoid **Jingle-jangle fallacies**: the erroneous assumptions that two different things are the same because they bear the same name (**jingle fallacy**) or that two identical or almost identical things are different because they have different labels (**jangle fallacy**). Think - crisps, or chips?

- Help us communicate about the different types of approaches in existence, and how and when each is effective (or not)
- Enable precision in evaluating different approaches
- Help in identifying gaps, replicating approaches, or developing future approaches

5. Stakeholder engagement

We are grateful to the UCL Knowledge Exchange and Innovation Fund for grant funding enabling us to take forward two knowledge exchange activities:

- An expert advisory group meeting in February 2018
- An stakeholder workshop, bringing together a cross-sector group of 33 participants, in May 2018

These events engaged a broad range of stakeholders and provided an opportunity to

- Disseminate, test and explore our work to-date with a cross-sector audience of interested peers
- Engage a network of stakeholders with an interest in contributing to the future direction of the work
- Begin to consult on categorising the many self-care strategies available in a way that is accessible, both to CYP experiencing mental health problems and to all those who support them - to maximise the impact of an emerging taxonomy

Categorising self or community approaches: the 'basket' exercise

Workshop participants worked in small groups to list all of the self or community approaches that, based on their real-world experience, they believed to be relevant to CYP with mental health difficulties.

Participants were then asked to group these strategies into logical 'baskets', and to give each basket a name.

The exercise has been valuable in generating a list of categories which can be carried forward for further consideration and investigation during the next stages of this work. Combined, the categories resulting from the basket exercise are:

- communication and social
- environment and nature
- distraction and relaxation
- sensory and cognitive
- body and physical activity
- hobbies and enjoyment
- self-expression/exploration
- changing perceptions
- technology

The group's discussion also surfaced some challenges, in particular that many approaches could reasonably be categorised in multiple ways, and many do not sit neatly under a single heading. Two possible approaches were discussed:

- One possible logic for categorising approaches would be to focus on the change mechanism – *how* the strategy has a positive effect on the mental health of a young person. However it was acknowledged that this may also vary by individual, and that an approach might involve more than one change mechanism
- This could alternatively be approached by taking our lead from young people – what are the categories that make most sense to them?

Shaping the future direction of the work

Participants made practical contributions, identifying certain missing approaches from the scoping review ('digital detox', physical touch) and expressed surprise at the paucity of research evidence for the majority of approaches. Moving forward they identified several key points to consider in supporting children, young people, families and practitioners in this area:

- That more/better evidence would be of value – particularly in education contexts, for instance, where staff who are not trained mental health professionals may be working with CYP who have high levels of difficulties
- That until research evidence catches up, they were likely to continue to recommend self-care strategies based on what *seems* to work for young people, and what they know of the individual in question
- That, while acknowledging existing hierarchies of evidence, there is potential in this area to consider a range of evidence types e.g. experience of peers, realist synthesis approaches – as well as more formal quantitative or qualitative research
- That what will be helpful will vary according to age and stage of CYP. Participants reflected that the approaches identified seem focussed more on older CYP groups, and that it would be beneficial to know what would be good for parents to use with younger children
- That a focus on the individual is important – a young person might be exploring their personal 'ultimate combination' of self-care strategies - it is likely that more than one thing might help.

Participants felt that given the number of self-care strategies for CYP mental health emerging from the literature review, a classification system (taxonomy or similar alternative output) is needed to make the list useable for CYP and those working with them. Important audiences were considered to be

- Primarily: direct use to support schools; parents; children and young people; and voluntary and community based services.
- Secondly: to support CYP/families on a waiting list for specialist professional support, and mental health professionals needing to signpost CYP to strategies beyond those used as part of formal treatment
- Public sector funders and policy

6. Next steps

We are currently working to

- share more widely with children, young people, and the adults who support them, the 100-odd self or community approaches cited in literature and advice for addressing mental health difficulties
- bring together and share feedback data from young people about the approaches they are using, and how and why they find they help
- understand the factors influencing young people's choices of self or community approaches

In autumn 2018 the Anna Freud National Centre for Children and Families launched a new set of online youth pages, including a self-care page. This allows young people to explore the comprehensive list of self or community approaches we have identified, and asks them to share feedback about approaches they have tried, including:

Did this activity help your mental wellbeing

If so, why do you think it helped?

What would you say to other young people who are thinking of trying this?

Over time we aim to collate feedback from young people about what they find helpful and why, and present it back to them using the same site.

We have also launched an online survey to ask young people which self or community approaches they have used to help manage their mental health, which they would use again, and why. A parallel survey is running for parents and carers.

We have also put out a call to youth groups/services to ask them to contribute to our research by hosting a session with the young people they work with. These focus on these groups is similarly to understand which self or community approaches to managing mental health are most commonly used by participants, why they choose the approaches they use, and why they feel these are effective for them.

7. Acknowledgements

We are grateful to participants who joined our workshops and have contributed to the content and development of this work. We hope they will contribute to future phases in the development of this work.

We are grateful to the UCL Knowledge Exchange and Innovation Fund for grant funding enabling us to take forward two knowledge exchange activities.

Please continue to look out for opportunities to participate in the development and dissemination of our knowledge in this area.