Supplementary Materials 2: Phase 2 Screening Protocol

Screening Protocol Helping Families: Evaluation of a new parenting programme

Purpose of this protocol

- This protocol is intended for research therapists in the above-named study. It has been developed by a service user expert and other core members of the research team who are clinical specialists in personality disorder and child mental health, in consultation with collaborating clinical teams.
- The protocol outlines (1) screening process, (2) screening measures and (3) the structure and content of a standard debriefing session.
- The feasibility and acceptability of this protocol has been formally assessed during the initial stages of the research and includes modifications made during this process.

1. SCREENING PROCESS: INTRODUCING THE SCREENING APPOINTMENTS

- All research therapists should explain the screening process, making it clear that this is for research purposes to ensure parents meet the inclusion criteria (parents have a personality disorder and their children are experiencing emotional and or behavioural difficulties).
- All research therapists should make it clear that the screening process is not a reflection on how the intervention would be; this might feel more question and answer and less exploratory. The intervention will give ample time for parents to explore their strengths and difficulties.
- All research therapists should let the parents know in advance that the screening process will take approximately 2 sessions but if more time is needed to complete the screening measures then this will happen. The research worker will also be present at the screening sessions to help if necessary and the research worker will be the person who will be supporting parents to complete the pre and post questionnaires throughout the study.
- All research therapists should make it clear to parents that the screening will take place in the family home as it is a community based intervention, however if for any reason they would prefer the screening to happen in a clinic then this can be arranged. Reasons for this might be the need to access a computer or wanting a quiet environment to have a conversation.
- All research therapists should let parents know that there would be two screening measures used, the first is the DAWBA, then the SCID –II interview, the first is online and the second is a paper version.

- All research therapists should check with the parent that the date, time and location of the screening appointment is suitable, for example is the morning the best time for a parent to concentrate on these questions.
- If the screening measures have to be done over a few appointments it is important that research therapists try to ensure these appointments are as close together as possible so the momentum around the screening is not lost.
- Allow the parent to ask any other questions that they may have about the screening process.

2. SCREENING MEASURES

DAWBA

- The **DAWBA** will be the first screening tool to be introduced and it is important to tell parents that this measure will focus on their child's emotional and or behavioural difficulties. The DAWBA should take approximately 50 minutes to complete.

- All research therapists should introduce the DAWBA by letting parents know that many of the questions they will be asked will focus on what is "usual" for their child and will not focus on "one-off" examples. There are also questions that ask parents to think back over particular timescales e.g. 4 weeks, 6 months and 12 months. Encourage the parent to consider what was happening at these times; e.g. school, summer holidays etc. Other questions focus on how developmentally appropriate their child's behaviour is, for example, is this behaviour different to what you see in children of a similar age. Encourage parents to develop a reference point with other children and their children's friends.

- It is important to check in on how the parent is doing throughout the interview to see whether they would need a break at any point. It might be good to take a break after the PTSD questions.

- Let the parent know that this measure might feel a bit strange as many of the questions require a rating or yes and no, or a number 1, 2, 3, 4. This is just the way the screening measure is set up, and there would be opportunities during the intervention to talk through things in more depth.

- The DAWBA will be completed online so the research therapist would need to discuss this with the parent beforehand to ask if there is internet access and if not the parent will have to complete the DAWBA in a clinic space which has internet access. Ideally we would like the parent to complete this measure in their home, but if this cannot be achieved then a warm and inviting space can be booked. It might be helpful to check with the parent whether they can read and if they can

use a computer so that any barriers to the screening are discussed and managed beforehand.

- All research therapists are encouraged to familiarise themselves with the DAWBA to get used to the questions and language so they are ready to answer any questions the parents may have.

SCID-II

- For the purposes of this research study the SCID-II parent questionnaire will not be completed. It has been decided that in order to get a clear picture of the parent's personality difficulties we complete the SCID-II clinical interview in its entirety with the parent.
- When introducing the SCID-II, it might be helpful to explain that the interview will be focussed on diagnosing a personality disorder. Within this discussion it might be helpful to share the points highlighted below. We all have personalities and they develop as a result of our experiences. Personality is a learnt way of coping with past experiences and is helpful at certain times but may not be helpful long term or all of the time. The screening identifies clusters of personality traits which can be helpful in making sense of parent responses. For this research the personality cluster will be identified so that we can describe the group of people the intervention is being offered to, and who it could work for in the future. Our personalities influence our thoughts, feelings and behaviour and how we behave can impact on our children. The intervention will focus on parents' thoughts, feelings and behaviours, and therefore the impact on their children but no one's personality will be changed.
- Research therapists should ask all of the SCID-II questions in the interview. We are trying to get a clear picture of the parent and a better understanding of their strengths and difficulties. This information will be useful for the intervention and in developing the relationship between the research therapist and the parent.
- The questions at the beginning of the SCID-II interview are useful for getting people to reflect on themselves which can prepare them for the questions later on in the interview. They also help parents to become familiar with the style of questioning and what is expected from them in their answers.
- It might be helpful to prepare parents for the length of the interview and remind them that they can take a break at any point. Parents will be asked to give specific examples of what they are describing and one or two examples might be needed at certain times. When asking for examples it might be helpful to prompt for an example that was not most recent and was not a big event.

- It might be helpful to let the parents know that the results of the screening will be discussed at a debriefing session and this will be an opportunity to explore the aspects of the parent's personality that causes most difficulty. Research therapists can highlight that a research diagnosis of personality disorder would be given, which can be difficult for some but helpful for others.
- When scoring the parent interview it is important to think about what distinguishes a 1 from a 3 and it is helpful to hold in mind that if the characteristic is present and there are examples of this being pervasive, persistent that they would score a 3. It might help research therapists to think about the overall definition of each disorder and keep this in mind when scoring – is there a pattern here? And to be blunt is this characteristic present or absent? It is important to consider whether the characteristic depicted an unreasonable response that is a feature in other situations or in the past.

3. DEBRIEF

The objectives of the debrief are: (1) to discuss the findings and implications of the study's diagnostic screening assessment; and (2) prepare eligible participants for the next steps of the research. The sessions should be scheduled within one week of a diagnostic screening assessment.

A. Reflection by the research therapist

- How someone receives and understands a mental health diagnosis influences their aspirations and expectations of recovery. However, it can often feel difficult to explain a diagnosis and talk about what it means for an individual and their family, especially where a diagnosis has not been given before. Even if someone has been given a diagnosis already, they may not have had the chance to talk this through. Their feelings and questions about the diagnosis might have changed since the diagnosis was first made, and they may welcome a chance to talk it through with you.
- Before supporting someone to make sense of any research diagnosis, it can be helpful to take time to reflect on your own views of child mental disorder and adult personality disorder. Consider how your views may influence the way you describe or talk about a diagnosis with parents; those who have not been diagnosed before may well take their cue from you about what this all means: what will you communicate verbally and non-verbally?

B. Explaining the differences between research and clinical diagnosis

- After setting an initial agenda for the debriefing session, the research therapist should provide information about the difference between a research and clinical diagnosis. The following can be adapted as necessary.
- A diagnosis is a name for a particular pattern of symptoms that commonly occur together. A diagnosis can help with understanding the nature and development of symptoms over time, as well as identifying the right treatment.
- In some areas of health, it is quite straightforward to make a diagnosis. For example, an x-ray can be used to diagnose a broken arm, or a blood test can help to diagnose infections.
- In mental health, diagnosis is complicated by the fact that there aren't clear biological signs. Instead, we need to rely on observations and interviews about thoughts, feelings and behaviours. This leaves diagnosis more open to interpretation.
- There are two main ways that diagnosis is assessed in mental health.
- A clinical diagnosis is what usually happens in everyday practice in the NHS. It is done by qualified NHS staff and involves information collected from patients, family members and sometimes other professionals. Ideally, it involves an open and honest communication about mental health symptoms and difficulties in living. A flexible, therapeutic approach is often used, focusing on the symptoms that are causing most concern to the patient and their family, and are most relevant to future treatment.
- A research diagnosis works a bit differently. It is used in research studies that require diagnosis to be assessed in a more neutral, scientific way. It involves asking questions in a consistent order, using a fact-based approach that is less flexible than a clinical diagnosis. On the plus side, a research diagnosis can ensure that information is assessed consistently across a large group of people. On the down side, a research diagnosis doesn't always fit with the main concerns of an individual participant.
- Given the different methods and purposes, it is perhaps not surprising that clinical and research diagnoses do not always agree 100%. If there is a disagreement, it is important to keep in mind that the "official" diagnosis used in the NHS will be the clinical diagnosis.
- The point of this session is to be as clear as possible about the research diagnosis and what it means – both in terms of the research study itself, and other services that you're using. As we go along, please ask as many questions as you need and say if anything is unclear or confusing.

B. Discussing child diagnosis

Exploration

- Explore the parent's expectations for the research diagnosis. Reflect upon the main concerns that were raised in the previous screening session.
- If the child has been seen in CAMHS before, explore the parent's previous experience of receiving a diagnosis for their child. Acknowledge the difficulties that some parents have around 'labelling' their child. Explore how they feel about their child potentially receiving a diagnostic label.

Explanation

- Share the findings from the DAWBA assessment in a clear and sympathetic way. Encourage the parent to ask questions about the meaning and implications of the assessment. If necessary, reiterate the different purposes/meanings of research and clinical diagnoses.

C. Discussing adult personality disorder diagnosis

Exploration

1. Meaning

- Was the parent familiar with the term 'personality disorder' before their participation in the research? If not, have they looked up any information about it? What does it mean to them?

2. Controversies

- Acknowledge the controversy surrounding the diagnosis and the discomfort many people feel using it.
- Many service users, carers and mental health professionals strongly dislike the term 'personality disorder' because it is seen as invalidating to their whole identity and sense of self. It implies a criticism or judgment, rather than a description.
- The diagnosis on its own does not provide an explanation of the difficulties that people experience. Explaining that it is actually shorthand for 'complex and long term emotional and psychological difficulties' and does not imply any judgment or blame, is likely to be reassuring, especially if accompanied by a reminder that they can find out more and get parenting support by taking part in the research.
- Acknowledge that not everyone agrees with the diagnosis and it is just one way to understand their experience, based on a medical framework for understanding human difficulties and emotions.

- If someone has experience of accessing mental health services themselves it can be helpful to acknowledge that mental health services do have a history of marginalizing and excluding such people because they were not seen to have a treatable 'illness'. However, we now know that personality disorder is treatable; the vast majority of people can benefit from the right support at the right time.

3. Potentially helpful aspects of diagnosis

- Discuss why a diagnosis of personality disorder can be helpful, despite the label still having stigmatizing connotations attached to it.
- The diagnosis can help some people to make sense of their experience and enables them to put a name to things they grapple with but are difficult to explain.
- It also enables people to become more informed about the different treatment options available to them. Many specialist therapy services use a diagnosis as entrance criteria.
- For some people it can enable them to seek out peer support and connect with others who have a shared experience, which can be extremely powerful.

Explanation

- Explain 'personality disorder' as a term that is used within mental health services to describe longstanding difficulties in how an individual thinks and feels about themselves and others, and consequently how they behave in relation to other people.
- We all have personalities, and we all have aspects of our personalities that are troublesome at times. People with personality disorder are not fundamentally different from anyone else, but might, at times, need extra help.
- Many people understand personality disorder as an adaptation to difficult life experience, which can at times, be necessary, helpful or protective, but over time can lead to further difficulties.
- Discuss the SCID-II outcome and parts of their personality which they feel cause them particular difficulties
- It is also important to help parents to think about the impact their personality traits have on how they think, feel or behave with others; specifically their child. This would be a good opportunity to reiterate that the intervention will not focus on changing personality, but will focus on the way in which our personality affects interactions with others and what is helpful or less helpful for parents and their children. The intervention will also focus on offering techniques that will help parents whose personality can get in the way of being the parent they want to be.
- Remind parents that if they choose to take part in the next stage of the research, the parenting programme, they will have the chance to find out more about personality disorder and explore this in detail.

D. Reassurance

- Give specific reassurance, as appropriate.
- By identifying a research diagnosis (or ruling out a diagnosis) for the child and/or parent, this doesn't change who they are or affect services currently available to them.
- Child emotional/behavioural disorders and adult personality disorder are treatable; the vast majority of people can benefit from the right support at the right time.
- However, parents from CAMHS pathway (not in contact with adult mental health services) should not feel compelled to seek extra support for their own mental health, if they feel they are coping well enough at the moment.
- Likewise, parents from adult mental health service pathway (not in contact with CAMHS) should not feel pressured to seek extra support for their child, if they feel that the family is coping well enough at the moment.
- Remind parents they have been given this diagnosis for the purposes of research - if it feels like it fits, they can use it as a tool to get help and support; if they don't like it, or don't agree with it, they do not have to share the research diagnosis with anyone.

E. Next steps

Care co-ordination and information-sharing

- As per Joint-Working Protocol (see separate document), discuss the options for sharing the assessment information with clinical keyworkers in adult mental health services and/or CAMHS.
- If the child and/or parent does not meet research criteria, explore whether the family would still benefit from support related to parenting and/or child mental health. Explain that not meeting research criteria does not prohibit a referral to CAMHS (or any other service), if this is something the parent wants. Note that a referral to another service will not automatically guarantee further input, as each service will conduct its own assessment before deciding whether input can be offered.
- If the child and parent both meet research criteria, explore whether the parent is still interested in continuing with the research intervention. If the child is already in contact with CAMHS, explain how the research intervention would fit with CAMHS involvement. If the child is not currently in contact with CAMHS, explore whether the parent is interested in a CAMHS referral alongside (or instead of) participation in the research intervention. The parent may wish to begin the research intervention before making a decision about this.

- Likewise, if the parent is already in contact with adult mental health services, explain how the research intervention would fit with usual care. If adult mental health services are not involved, explore whether or not they would like a referral to be made.
- Significant issues of risk or safeguarding that might emerge in the course of the debriefing session should be managed according to the Joint-Working Protocol.

Further research activities

- For eligible families, go on to review the aims and structure of the research intervention.
- Emphasise that "Helping Families" is not a treatment for personality disorder; it is a 16-week programme that focuses on parenting skills. It is designed to help with (1) setting individual parenting goals; (2) learning about personality traits and what they mean for bringing up children; and (3) developing positive parenting skills. Specific strategies for managing parental mental health difficulties may be introduced, but only if this fits with their parenting goals.
- If an eligible parent would like to proceed with the research intervention: (1) get permission to pass on contact details to a research worker, who will arrange a time for baseline data collection; (2) schedule a time (ideally within one week) for the first intervention session.

Further resources

- A parent might not be able to take in information if they are upset about the diagnosis for their child or themselves, so provide resources that they can take away. Also remind the parent that they can find out more about the diagnosed disorder(s) by taking part in the parenting programme.
- Suggest reading materials for the parent to learn more about difficulties that they or their child may be experiencing.
- Give caution that there is as much misinformation and unhelpful material on the Internet as there is accurate information, so be sure to read information from trustworthy sources.
- Links for further info:

  www.emergenceplus.org.uk

  www.mind.org.uk

  http://www.rcpsych.ac.uk/healthadvice/problemsdisorders.aspx

  http://www.youngminds.org.uk/for_parents/parents_guide

- Consider information about service user groups, organizations and Recovery Colleges where they can meet other people with the same diagnosis if they want to:

Emergence Arts and Social Network; admin@emergenceplus.org.uk

SUN Project (service user network): sun.project@swlstg-tr.nhs.uk

ADDITIONAL GUIDANCE TOOLS FOR DABWA AND SCID FEEDBACK

A. Development and Well-being Assessment (DAWBA)

Below is a list of the different categories for which children may meet criteria for on the DAWBA. The list gives examples of how you could describe the extent to which the child may have those particular difficulties, e.g. probable difficulties, possible difficulties and like most children. It also reframes the DABWA diagnostic categories (see in brackets) to provide a brief description which might be more helpful when discussing this with the parent.

Possible difficulties for problems with language, routines, play and social skills (Autism)

Probable difficulties with leaving their Parent/Carer (Separation Anxiety)

Possible difficulties for fears of specific things (Phobia)

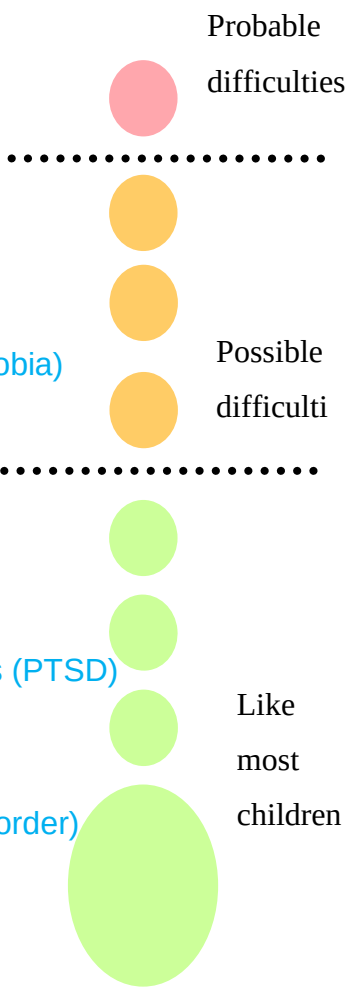
Like most children for fears when being around other people (Social Phobia)

Possible difficulties with feeling panicky (Panic and Agoraphobia)

Possible difficulties from experiencing stressful and traumatic life events (PTSD)

Like most children for repetitive behaviours (Obsessive Compulsive Disorder)

Probable difficulties for fears and worries (Generalised Anxiety)



- Possible difficulties for feeling sad and unhappy (Depression)
- Not reported/reported Deliberate self-harm
- Like most children for over activity and paying attention (ADHD)
- Like most children for being argumentative and ignoring rules (Oppositional Defiant disorder)
- Like most children for troublesome behaviour (Conduct Disorder)
- Like most children for problems around eating (Anorexia/Bulimia)
- Probable difficulties for tics (Tics)

Predictions from the DAWBA

The DAWBA combines information from whoever completes it, and compares what has been said with what was said about a large number of school age children. It tries to predict how likely a child is to have emotional, behavioural or concentration problems severe enough to need a discussion with your family doctor and possibly a specialist. For each kind of problem, there are three possible predictions: ‘like most children’, 'possible difficulties' and 'probable difficulties'. In general, these predictions agree fairly well with what an expert would say after a detailed assessment of the child; approximately 70% of children who are rated as having ‘probable difficulties’ do have significant difficulties according to experts. Between 15-50% of children

'possible difficulties' group and only 0.1-3% of children in the 'like most children' group will have get a diagnosed difficulty.

B. Personality Disorder – the different diagnoses

Below is a list of the different diagnostic categories as identified by the SCID. A short summary is provided which might be helpful when discussing this with the parent. Rather than referring to the specific diagnosis one can describe the characteristics relating to the diagnosis which are relevant for the parent.

Paranoid personality disorder

The main characteristic of this personality disorder is a strong feeling that other people cannot be trusted. This is different from the feeling that you are always being watched or followed and others are constantly persecuting you, which is more often linked to the diagnosis schizophrenia.

Schizoid personality disorder

The main characteristics of schizoid personality disorder are being detached from others, preferring not to have close relationships and finding it very difficult to express feelings to others.

Schizotypal personality disorder

It is described as an ongoing and widespread pattern of difficulties in social and interpersonal relationships, including feeling extremely uncomfortable with close relationships and finding it very difficult to start or maintain them. In addition, people given this diagnosis are likely to be seen by others as eccentric in the way they dress, behave, and think, and may have unusual beliefs and perceptions.

Antisocial personality disorder

The main characteristic of antisocial personality disorder is a disregard for moral and legal standards that exist in the individual's culture. As a result, it is very closely linked to criminal behaviour in adults.

Borderline Personality Disorder

The main characteristics of borderline personality disorder are someone having unstable relationships, self-image and emotions, as well as impulsivity.

Histrionic personality disorder

The main characteristic of histrionic personality disorder is expressing emotions in ways that others see as excessive or exaggerated, which is understood by others to be a means of seeking attention.

Narcissistic personality disorder

The main characteristics of narcissistic personality disorder are an exaggerated sense of your own importance, a lack of empathy, and a strong need to be admired by others.

Avoidant personality disorder

The main characteristics of avoidant personality disorder are overwhelming feelings of inadequacy and anxiety about being negatively evaluated by other people, leading to avoidance of social situations.

Dependent personality disorder

The main characteristic of dependent personality disorder is an extreme need for other people, and in particular for others to make decisions on your behalf, to take care of you, and take responsibility for many aspects of your own life.

Obsessive compulsive personality disorder

The main characteristics of obsessive compulsive personality disorder are a preoccupation with perfectionism, orderliness, and control.