MICE Protocol

**Stigma** 

#### **Use This:**

For young people/parents for whom stigma is a relevant issue leaving them feeling isolated and unable to access the support they need so that the stigma is contributing to the maintenance of the difficulties.



If stigma has been identified as an issue in session 1, then this module should be used. However, it is unlikely that issues about stigma will be the main focus of many sessions of treatment. Rather, it will be an agenda item added to other MATCH modules throughout treatment. The amount of time allocated to this module will vary according to need but the therapist should ensure it is not taking up so much time that it is interfering with implementing the other modules. Only do one strategy at a time.

#### Goals

- To help the young person/parents understand the different forms of stigma relating to epilepsy, mental health and related issues (such as intellectual disabilities)
- To identify stigma issues that may be impacting on the mental health of the young person
- To use strategies to reduce stigma

### **Materials**

- The Child Stigma Scale (p. 420), The Parent Stigma Scale (p. 421)
- Sheet with video links p. 422)
- Weekly questionnaires and Monitoring Sheet (see pages 268 285)
- Therapist Note Taking Sheet (p. 267)

**If time is tight:** Identify any stigma that may be affecting progress with mental health treatment and consider at least one strategy to support the family in managing this.

Main Steps	
☐ Set an Agenda	Remember to start by setting an agenda together and by
	reviewing any practice assignments.
☐ Obtain Weekly	Review the Weekly questionnaires and Monitoring sheet.
Ratings	Complete the <i>Child Stigma Scale</i> , and <i>Parent Stigma Scale</i> (if
	applicable). Complete the questionnaire together over the
	phone or else send it prior to beginning this session.

# ☐ The different forms of Stigma

Different types of stigma:

- (i) Experiences of discrimination i.e. others' behaviour towards them because of having a mental health problem or epilepsy. These experiences vary for young people a major problem is the response of peers, which may include social distancing and bullying. Young people and their families may also experience enacted stigma from family members, peers, teachers and health professionals.
- (ii) Anticipated discrimination: this is very common even in the absence of experiences of discrimination. Due to worry about being treated differently/negatively by others, people may avoid other people or avoid telling other people. While this allows people to reduce the risk of bullying, this may result in failure to access mental health or epilepsy treatment and loss of social support.
- (iii) Self-stigma: awareness of mental illness or epilepsy stereotypes may lead people to think negatively about themselves e.g. 'I am weak'; this may compound feelings about the self due to the epilepsy and feelings of incompetence, defectiveness.

Stigma can be described as:

- Stereotypes = <u>ideas</u>
- That can lead to prejudice = beliefs
- That can play out in discrimination = <u>behaviours</u>

#### **Example script**

There are different forms of stigma with different meanings. One is where you/your child have actually experienced discrimination because of the epilepsy emotional/behavioural or related problems. For example, not being invited to parties when the rest of the class has been invited. Another is where you are worried that you/your child might experience discrimination if you told people about the epilepsy, so you keep it a secret. A third is where you/your child thinks negatively about themselves because of their difficulties e.g., they might think 'I won't ever achieve anything as an epileptic person'. Can you tell me about your/your child's experiences with any of these types of stigma?

☐ The Impact of Stigma	Discuss the impact of stigma on how the epilepsy is managed and/or on emotional/behavioural problems. For example, the child/parent may not access support that they need, may not go on sleepovers or to nightclubs etc.
	Example script
	Can you tell me about how these issues affect how you/your child manage the epilepsy or emotional/behavioural aspect of epilepsy?
☐ Choosing a strategy	Based on the experience of stigma so far and the family's circumstances, choose a strategy.
☐ Strategy 1: Social Contact	A recent review found that social contact is an effective type of intervention to improve stigma-related knowledge and attitudes in the short term. Therefore discuss with the young person/parent their current social contact and consider together ways in which it might be increased/changed to help reduce the stigma. Refer back to the 'Roadmap of resources' for practical suggestions of local groups/networks. If the family want education about epilepsy in schools, refer them to Young Epilepsy's information about what they can offer.
	Example script
	It sounds as though you are incredibly busy managing things but that you are also quite isolated. I was wondering if there might be some ways to increase your contact with other people, perhaps starting with those that are in the same situation as you? Are there things that stop you from having that contact? Might an internet based group be an easier starting point?
☐ Strategy 2: Videos	Some education can help reduce stigma and change attitudes. Discuss this with the young person/parent and ask them to watch the videos below as an assignment. You will talk about them next week. Discuss with the young person/parent if they think sharing the videos with other people might help them better understand epilepsy/mental health issues.
	Example script
	There are a couple of videos that might be interesting to you and you might be able to use to help other people understand what it is like to have epilepsy and/or mental health problems. Would you watch them between now and next session and we can discuss what you think and if they might be helpful?
	Tell the parent you will send the <b>Sheet with video links</b> after the session.

☐ ACTIVITY
Strategy 3: RolePlay

Sometimes it can be very difficult to raise the issue of epilepsy and related problems with people. Practising with the young person/family may help.

#### **Example script**

Some people find it helpful to practise what they would say to someone. Would it be worth a role-play? Shall we take the situatio where you/your child is having what looks like a tantrum in the middle of a supermarket? A shopper says quite loudly to her friend 'Goodness me, that child isn't TWO! She's at least 10! Dear oh deal what an awful brat'. How about you are that horrible, uneducated shopper and I will be you/your parent?

Role play situation in which you calmly impart information about epilepsy, mental health and behaviour. End with the shopper apologising and saying she didn't realise.

☐ Strategy 4:
Communicating
with people in
authority

It can be difficult to communicate with people in authority about epilepsy and mental health. This may be partly due to felt stigma (shame and expectation of stigma from others) or enacted stigma (the experience of unfair treatment by others). Examples of people in authority include teachers, head teachers, plus a whole range of health professionals. Practising assertive communication can help.

#### Example script

Communicating assertively, which means that you express your own feelings and needs at the same time as respecting the feelings and needs of the person you are communicating with, is a skill that gets better with practice. Have a go at writing down what you might want to say to e.g. a doctor or teacher and practise expressing it clearly, try to start the sentence with 'I' rather than 'You'. We can then practise role-playing it (like strategy 3). If it is hard/ too difficult to communicate with a person in authority then can we talk about who might be able to represent you on your behalf?

☐ Strategy 5: Self- stigma reduction/Disclosu re tips	If the child feels they are unable to talk to a friend or doesn't know who to speak to about their issues, it could be useful to utilise some of the content within the existing MATCH modules.  • If self-stigma is an issue, and in order to reduce hurtful self-talk, a Thought Challenging exercise could be useful. E.g. "No one wants to be friends with me due to my epilepsy/ mental health conditions". Refer to Changing B-L-U-E Thoughts worksheet [Cognitive Blue, Depression module].  • Applied Problem Solving could help the child decide whether now is the right time to disclose to others about their epilepsy/ mental health issues or not. Refer to Five S-T-E-P-S to Problem Solving worksheet [Problem Solving, Depression module].
	Example script
	Some people can find it helpful to talk to others about their epilepsy and mental health issues. Let's try a game where we list the pros and cons of revealing your condition(s).
	<ul> <li>Help the child think of a friend who s/he can talk about issues with. Refer to Coping through TLC worksheet [Cognitive Coping TLC, Depression module].</li> </ul>
☐ ASSIGNMENT	Ask the parent to implement the strategy you have discussed
Practising Strategy	and to send back any notes on how the strategy has gone prior to the next session so you can evaluate its impact.
☐ Send the materials for next session	Tell the parent/s you will send a written summary and the materials for the next session. Remind them that they <u>do not</u> need to be completed for next session as you will go through them together in the session. Tell the parent/s you will also send the <i>Weekly questionnaires, Monitoring sheet</i> and <i>Checklist of Strategies</i> (if necessary) which need to be completed for the next session.
	Confirm date and time of the next call.
☐ Summarising	Ask if they would like you to summarise the session, if they want to summarise or if you should do it together. When you are summarising from the module you are implementing (e.g., One-on-One or 'Special' time) ensure you also add in the summary from this module.

## Leave 'Em Laughing

End the session on a positive note.

## **How's Your Style?**

- Did you praise often?
- Did you review often, by asking questions?
- Did you simplify the steps as needed?
- Did your pace match that of the child or family?
- Did you stay on track?

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