Supplementary material 3: Topic guides for service user and family member
topic guide.

## Service user topic guide

### 1) I'd like to check which services you used:

- Confirm details of services received are correct/add in missing ones
- Did you have a key worker? [i.e: who monitored how you were getting on or supported you?] [add to list]
- Were you offered any services or support that you chose to decline?
- Were there any services that you started but didn't complete?
- Were you waiting for any service you did not receive? [add]
- Are you still using any of these services? (e.g. social inclusion hub can be ongoing even after discharge)

### 2) I'd like to ask you about when you first went to the service

- How did you find out about it?
- Was it your idea to go?
  - o [If relevant] What was your reason for doing so?
  - o E.g. was there any particular kind of help you wanted?
  - E.g. was there anything in your life you hoped it would help with?
- Did you know what to expect when you first went?

### 3) I'd like to ask you about the assessment process

- Were you told in advance what would happen in the assessment?
  - o If yes: Is that what did happen?
- What was the experience of the assessment process like for you?
  - o Was anything about it difficult?
  - o Was anything done to put you at ease?
  - o Were the questions asked relevant?
  - o Were you treated with respect?
  - o Was the time and location of the assessment acceptable?
- Is there anything you would have preferred to be done differently?

### 4) I'd like to ask you about whether and how the assessment has helped you

- Has the assessment helped you in any way?
  - o In what ways?
- [If relevant] What were your feelings about the diagnosis?
  - o E.g. did you feel happy? Relieved? Upset?
  - o Has it had any other effects on you?
  - o Has this this changed over time?
- Do you have a care plan?
  - o Did it focus on things that are relevant to you?

- o Did it cover everything you wanted it to?
- o Was there anything it didn't cover?
- Anything you weren't surprised by?
- Have you made changes in your life since the assessment?

### 5) I'd like to ask you about using each of the different services

- Go through each of the <u>list of services used</u> (including key worker)
- Were you told what [x] would involve?
- How have you used [x]? (especially social inclusion hub)
- Was there anything you hoped [x] would help with?
  - o Did it meet these expectations?
- Have you found [x] helpful in any other ways?
  - E.g. Did it give you a better understanding of autism?
  - o Did it change how you felt about autism?
  - o Did you learn any new skills or strategies?
- What aspects of [x] were most helpful?
- Was there anything you would have preferred to be done differently?
  - E.g. Did you have any difficulty participating in [x]?
- Out of all the forms of support on the list, which has made the most difference to your life?
- If there was anything offered but declined: What were the reasons you chose not to take up [x]?

# 6) I'd like to ask you about whether the service has helped you in particular areas of your life (card sorting exercise)

- Based on completed questionnaire: These are the areas of your life you said you had worked on with the service (pile of cards)
  - o What did you do to work on [x]?
  - o Did it help in this area? How?
  - o Is there anything else the service could have done to help in this area?
- For the remaining cards (i.e. things not worked on with the service), make a pile of those you would have liked to work on with the service
  - O What sort of support could the service provide in this area?
  - Was any help offered? [i.e. did they choose not to take it up]
- Remaining cards. So these are the areas you haven't worked on and don't want to work on.
  - o Are these areas that you're generally happy with?
  - If no: Is there a reason you wouldn't want to work on these areas with the service?

### 7) I'd like to ask you about being discharged from the service

- How did you feel about discharge from the service?
  - o Did you feel ready to move on?
  - Do you have any concerns about moving on? (e.g. unresolved problems, loss of support network, losing touch with members of staff, things you want more time to work on, new areas to work on)
- Are you able to return to the service or contact them after discharge?
  - Do you think you will/are you ok with not being able to?
  - o Have they told you where else you can go for support?

# 8) I'd like to ask you about other positive or negative effects of using the service

On your questionnaire, you said the service had had a positive impact overall, and 'just knowing for certain that I am on the autism spectrum has enabled me to give a name to my differences and understand how they affect me.'

- Do you want to say any more about that?
- Have you had any (other) positive experiences as a result of using the service?
  - o E.g. acquiring skills, strategies, social networks, information?
- Have you had any (other) negative/disappointing experiences?
  - E.g. Is there anything you wanted support with that the service couldn't help with?
- The service staff are trained to understand autism. Do you think this made a difference to your experience of using the service?
  - o [Prompt: e.g. in comparison to other health services you've used]
- Would you suggest using this service to someone else living in your area?
  - o Why/why not?
- Is there anything else about your experience with the service that you'd like to talk about?

# 9) Thanks and, if appropriate, ask about passing on a Friends and Family information pack.

## Family member topic guide

### 1) Your involvement with the service

- Were you involved in [service user] approaching [service]?
  - o If so, how?
- Were you involved in [service user]'s use of [service] in any other way?
  - o E.g. accompanying them to appointments, calling the service on their behalf.
- Do you know what forms of support [service user] got from [service]?
- Did you get any forms of support? [make a note for later in interview]

### 2) Your expectations of the service for the service user

- Did you have specific expectations/hopes about the ways that [service] would help [service user]?
  - E.g. getting a specific form of support, helping them in a particular area of their life, improving their wellbeing in some way
  - Particular expectations relating to getting the diagnosis?
  - Particular expectations relating to other forms of support?

### 3) Your views on service user's experience

- What are your views on [service user's] experiences with the service?
- Were they satisfied with the amount of involvement/services on offer?
- Were there any barriers to them participating?
- Was anything done to facilitate their use of the service?
- Did [service user] find the service helpful? In what ways?
  - If participant is familiar with specific forms of support, ask about these individually
  - Ask about domains of life
- Did the service help [service user] to meet any specific goals they had?
- Was there anything they hoped for that they weren't able to achieve through the service?
  - o If so, what do you think prevented that?
- Did they have any (other) specific positive experiences with the service?
- Did they have any (other) specific negative experiences with the service?
- Do they intend to stay/get back in contact with the service?

#### 4) Your experience with the service

- Did you have specific expectations for how the service might help you?
  - Specific interventions but also by proxy the service user getting help might help them by, e.g., reducing their caring responsibilities.

- Did service user have expectations of this?
- If the participant received specific support from the service:
  - o Were these interventions helpful? In what ways?
- Was there anything (else) you hoped the service would help you with?
- Do you have any (other) concerns about your own unmet needs? Plans to address them?
- Did you have any (other) specific positive experiences with the service?
- Did you have any (other) specific negative experiences with the service?
- Do you plan to stay in touch/get back in touch?

### 5) Your overall impression of the service

- What was your overall impression of the service?
  - o Positive, negative? Well-run?
- Is there anything that you think the service should do differently?
- 6) Is there anything we haven't talked about that you'd like to add?

Thanks and close.