

Interviews with service users

Version 1 (28/03/2014)

INFORMATION

You helped us with some research this year. Do you remember speaking to [name and picture of researcher(s)] about the PBS study? [Explain study again using service user information sheet].

You were in the group that got the extra help. The Positive Behaviour Support (PBS) group. Do you remember meeting these people [show pictures of member(s) of staff and say their names and what they do]? They came to see you and your carers to find out what behaviours were a bit difficult [give example, e.g. hitting or shouting when you got upset].

[Name and picture of researcher(s) met with you and your carer find out how things were going with your behaviour. They came before [name and picture of member of staff] came to do the Positive Behaviour Support/PBS work with you and again after six months and 12 months.

Now we want to find out what you think about taking part in our study and the Positive Behaviour Support/PBS.

QUESTIONS AND PROMPTS

[Ask questions using easy-read version to read along with participant]

What do you think?



We would like to find out what you think



We are meeting with you because you took part in the PBS (Positive Behaviour Support) study



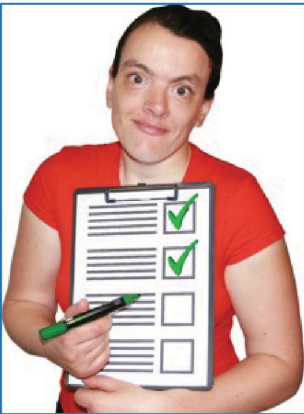
We are asking questions to find out what you think about the therapy



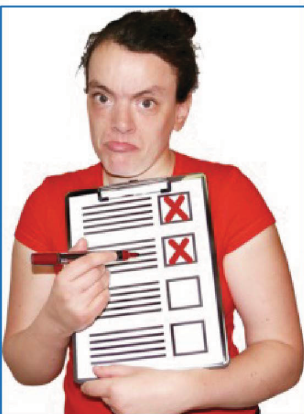
Do you know what challenging behaviour is?



Have you ever had problems with your behaviour like that?



What helps you with this?



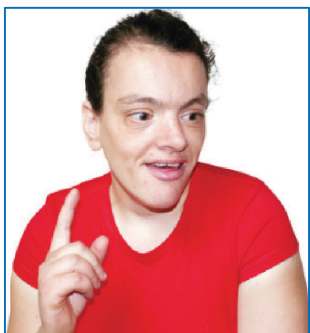
What makes it worse?



Have you ever had any help with your behaviour?



Can you tell us what kind of help you were given?



Have you learned what helps you feel better when you are upset?



Did they change things around in your room or flat to make it better for you?



Did they change what you do during the day?



Did they show your carers
new ways of helping you
with challenging behaviours?



Do you know who this is?



What did you do with them?



Did you like getting this extra
help?

Interviews with paid and family carers

Version 1 (28/03/2014)

INFORMATION

As you know the [Name of service user] recently took part in a study evaluating the effectiveness of Positive Behaviour Support (PBS) for challenging behaviour in people with learning disabilities.

The study was a randomised controlled trial, which means that each LD team taking part, e.g. [name of service user's LD team] was allocated by chance to either the 'Treatment as usual' or the 'PBS' arm. [Name of service user]' LD team was allocated to the PBS arm, which meant that one/two member(s) of staff, [name of member(s) of staff – show picture(s)] who volunteered to take part received additional training in Positive Behaviour Support in three two-day workshops over the course of fifteen weeks. [Name of member(s) of staff] was/were then asked to use the intervention (PBS) with those patients receiving care from their team who took part in the PBS trial, e.g. [name of service user].

We met with you during the study to record levels of challenging behaviour (amongst other questionnaires) before PBS was provided, at six months and again at 12 months.

We would now like to meet with carers like you to ask them about their experiences of taking part in the PBS study, and how useful the intervention was for [Name of service user].

QUESTIONS AND PROMPTS

1. What was your experience of taking part in the PBS study? (*Prompt: below questions as appropriate*).
2. Do you remember the [name of member of staff] who came to work talk with you and observed the person you care for? (*Prompt: show pictures of researchers and therapists*). Do you remember this happening? How often did you see them? (*Prompt: clarify whether carer means researcher or therapists*).
3. What did the service provider/therapist do when they came?
4. Is there anything you would like to change about receiving the intervention? (*Prompt: number of contacts with therapist; communication with LD team; quality of the help received*).
5. Do you feel that receiving PBS has made a difference for the person you support? (*Prompt: What have been good/challenging things about receiving PBS?; can you tell us one or two things that changes because of this?; are there things that changed that you would like to see continue?, would you recommend it to someone else*).
6. Do you think that taking part in this research will help other people with LD? (*Prompt: would you take part in a similar study in the future?; what sort of interventions/treatments do you think are most helpful or should be researched for people with learning disabilities?*)
7. Is there anything else you would like to say?

Interviews with therapists

Version 1 (28/03/2014)

INFORMATION

As you know the [Name of service] LD team recently took part in a study evaluating the effectiveness of Positive Behaviour Support (PBS) for challenging behaviour in people with learning disabilities.

The study was a randomised controlled trial, which means that each LD team taking part was allocated by chance to either the 'Treatment as usual' or the 'PBS' arm. Your team was allocated to the PBS arm, which meant that one to two members of staff who volunteered to take part received additional training in Positive Behaviour Support in three two-day workshops over the course of fifteen weeks. Staff receiving training were then asked to use the intervention (PBS) with those patients receiving care from their team who took part in the PBS trial.

We met with carers of participants to record levels of challenging behaviour (amongst other outcome measures) before the intervention was provided, at six months and again at 12 months.

We would now like to meet with staff who volunteered to take part in the trial and received the PBS training to ask them about their experiences of taking part in the PBS study, how useful they found the intervention.

QUESTIONS AND PROMPTS

1. What was your experience of taking part in the PBS study? (*Prompt: below questions as appropriate*).
2. What do you think about the PBS training you received? (*Prompt: has it provided you with necessary knowledge and skills to deliver the intervention?; would you make any changes to the training?*).
3. How do you feel PBS fits in with other interventions?
4. What do you think about the intervention (PBS)? (*Prompt: how well did it fit in with the overall treatment of CB?; did you carry on with other interventions, e.g. family systemic therapy, medication?; how well do you feel you were able to stick to the PBS plan; do you think you will continue to deliver PBS or elements of it within your work?*)
5. Do you think it helped the people you delivered it to? (*Prompt: what do you think is helpful?; what is less helpful?*)
6. What were some of the challenges you faced in delivering the intervention to participants over the past year? (*Prompt: practical issue, e.g. time management, balancing with existing time load; difficulty in identifying appropriate behaviours to replace CB; difficulty arranging appointments; problems with FA; significant events in participant/family's life (e.g. bereavement)*)
7. What helped you to deliver the intervention to participants over the past year? (*Prompt: did you feel that there were any specific participant characteristics or factors which enabled you to deliver the intervention successfully?; carer involvement*).

8. Do you have any recommendations in how to best provide PBS within a community service?
9. What is your experience of taking part in a randomised controlled study? (*check that they knew the study was an RCT; would they take part in another similar study? What have they gained? How could we do the study better?*)
10. Is there anything else you would like to say?

Interviews with service managers

Version 1 (28/03/2014)

INFORMATION

As you know the [Name of service] LD team recently took part in a study evaluating the effectiveness of Positive Behaviour Support (PBS) for challenging behaviour in people with learning disabilities.

The study was a randomised controlled trial, which means that each LD team taking part was allocated by chance to either the 'Treatment as usual' or the 'PBS' arm. Your team was allocated to the PBS arm, which meant that one to two members of staff who volunteered to take part received additional training in Positive Behaviour Support in three two-day workshops over the course of fifteen weeks. Staff receiving training were then asked to use the intervention (PBS) with those patients receiving care from their team who took part in the PBS trial.

We met with carers of participants to record levels of challenging behaviour (amongst other outcome measures) before the intervention was provided, at six months and again at 12 months.

We would now like to meet with service managers to ask them about their experiences of taking part in the PBS study, and how useful they found the intervention.

QUESTIONS AND PROMPTS

1. What was your experience of taking part in the PBS study? (*Prompt: below questions as appropriate*).
2. How do you feel taking part in the PBS study has impacted on the service? (*Prompt: finance; staff availability; staff skills*).
3. Do you feel that PBS has made a difference on patient outcomes, i.e. less CB?
4. What do you think were some of the benefits and challenges in taking part in the study?
5. Do you have any recommendations in how to best provide PBS within a community service?
6. Would you recommend prioritizing this intervention within your organisation?
7. Did you receive any feedback about the PBS study from service users or carers/others, i.e. concerns or compliments?
8. What is your experience of taking part in a randomised controlled study? (*check that they knew the study was an RCT; would they take part in another similar study? What have they gained? How could we do the study better?*)
9. Is there anything else you would like to say?

Interview with trainers

1. What was your experience of training the volunteer staff? (prompts: venue, timing, support from study team, other arrangements, feedback by volunteers)
2. What worked?
3. What were the challenges (Prompts: any after the training?, Did you receive feedback from PBS research team about difficulties raised by Staff members?)
4. How was the mentoring perceived by volunteer staff?
5. Time management was consistently reported as a difficulty for managers and volunteer staff members who trained in PBS, what do you think the issue was related to? (Prompts: uncertainty about time commitment to the intervention, balancing different professionals' workload)
6. Would a meeting session with all professionals involved in the PBS plan be more easy and manageable to do instead of having each professional writing a report for the plan? It has been reported that the writing up process of the plan takes a lot of time to do and clashes with the existing workload of volunteer staff members.
7. The training received was regarded as a positive experience and the information received very comprehensive. What would you think would make a difference to differences in fidelity regarding the intervention?
8. What could be done differently? (prompt: re mentoring, e.g. on site vs via email, other suggestions)
9. Is there anything else you would like to add and we have not asked about?