

**Young People's Experiences of Social Recovery Cognitive Behavioural Therapy and
Treatment as Usual in the PRODIGY Trial**

Brioney Gee*¹, Caitlin Notley¹, Rory Byrne², Tim Clarke³, Jo Hodgekins¹, Paul French^{2,4},
David Fowler⁵

¹Norwich Medical School, University of East Anglia, Norwich, UK

²Psychosis Research Unit, Greater Manchester West Mental Health NHS Foundation Trust,
Manchester, UK

³Child, Family and Young People Research and Development, Norfolk and Suffolk NHS
Foundation Trust, Norwich, UK

⁴Department of Psychological Sciences, University of Liverpool, Liverpool, UK

⁵Department of Psychology, University of Sussex, Brighton, UK

***Address for correspondence:**

Brioney Gee

Norwich Medical School, University of East Anglia, Norwich, UK. NR4 7TJ

Email: brioney.gee@uea.ac.uk

Tel: +441603 207206

Word Count: Abstract = 240, Text Body = 2998

Abstract

Aim: The PRODIGY trial is an ongoing randomised controlled trial of Social Recovery Cognitive Behavioural Therapy (SRCBT), a new intervention designed to improve social functioning in young people at risk of long-term social disability due to severe and complex mental health problems. The aim of this qualitative sub-study was to understand trial participants' experiences of SRCBT and the control condition, treatment as usual (TAU).

Method: Trial participants were aged 16 – 25 with socially disabling severe and complex mental health problems. A purposive sample of trial participants took part in in-depth qualitative interviews which were transcribed verbatim and analysed thematically.

Results: Participants from the SRCBT arm valued the relationship with their therapist, the flexibility of intervention delivery and the cognitive and behavioural techniques taught. They viewed SRCBT as challenging but worthwhile. Participants from the TAU arm reported receiving little support, both prior to and during their participation in the trial. Participants from both arms valued opportunities to talk about their difficulties during trial participation. Increased activity was an important goal of participants from both arms and most expressed high motivation and little hopelessness.

Conclusions: Currently available services do not meet the needs of some young people with socially disabling mental health problems. Motivation to change appears high at this early stage of disorder, supporting the potential value of intervening early to prevent longer-term social disability. SRCBT was well accepted by participants and so is a promising intervention to meet this objective.

Key words: Cognitive Behavioural Therapy; Rehabilitation; Youth; Qualitative Research

INTRODUCTION

Three quarters of severe mental health problems are evident before 25 years of age^{1,2}. Such disorder comes at high personal, social and economic cost, much of which is attributable to associated social disability³. However, the needs of young people with severe and complex mental health problems remain largely unmet^{4,5}.

This paper presents a qualitative sub-study of the PRODIGY trial (Prevention of long term social disability amongst young people with emerging psychological difficulties, ISRCTN47998710, UKCRN registration number: 13341). PRODIGY is a multi-site randomised controlled trial (RCT) testing the clinical and cost-effectiveness of Social Recovery Cognitive Behavioural Therapy (SRCBT) in young people with severe and complex non-psychotic mental health problems accompanied by social disability.

SRCBT is designed to improve social functioning in young people at risk of long-term social disability⁶. Barriers to engagement in activity are formulated using a cognitive behavioural therapy approach. The intervention has a strong behavioural focus: individuals are encouraged to test their beliefs about increasing activity in behavioural experiments and therapists liaise with external agencies to support clients to find opportunities to engage in

valued activities. Emphasis is given to understanding individuals' values and goals, and instilling hope.

The use of qualitative methods alongside the PRODIGY trial is an important element of our approach to evaluation. Whilst RCTs are the most rigorous way to evaluate intervention effectiveness, qualitative methods can provide insights crucial to the successful implementation of complex interventions⁷. The current study focused particularly on experiences of SRCBT, aiming to assess acceptability and implementation from participants' perspectives, but also explored experiences of the control condition, treatment as usual (TAU). This was deemed important since little is currently known about what support is accessed, and how this support is experienced, by socially disabled young people, and thus what constitutes TAU for this population.

METHOD

Eligible trial participants were: (a) aged 16–25 years, (b) had severe and complex mental health problems, defined as either meeting 'At Risk Mental State' criteria according to the CAARMS⁸ or scoring ≤ 50 on the Global Assessment of Function Scale⁹, and (c) spending less than 30 hours per week in structured activity (assessed by the Time Use Survey^{10,11}).

Exclusion criteria were psychosis, severe learning disability, organic disorder, and insufficient English language proficiency.

Following ethical approval from the Norfolk Research Ethics Committee, a purposive sample of participants from the RCT's internal pilot who gave consent to be contacted regarding the qualitative sub-study was selected. The aim was to ensure approximately equal representation in terms of gender, study site, randomisation arm, and baseline 'At Risk Mental State'. Further, we sought to recruit participants of a range of ages, with varied previous service-use, and to include looked-after children and the most socially disabled.

After obtaining written informed consent, face-to-face in-depth semi-structured interviews were conducted (by BG in Norfolk and RB in Manchester) either in participants' own homes or a community venue, according to participant preference. Flexible interview schedules focused on history of psychological difficulties, previous experiences of accessing services, experience of trial participation, views on the intervention received, perceived outcomes, and future psychological wellbeing. Interviewers attempted to elicit detailed accounts of treatment experiences and probed for negative as well as positive views. Interviews were audio recorded and transcribed verbatim.

An inductive thematic analysis was undertaken^{12,13}. Data analysis proceeded alongside data collection so that the developing analysis could inform subsequent interviews. We took a critical realist epistemological stance, seeking to understand participants' realities through engagement with their individual perspectives. Analysis involved repeated reading of all transcripts and line-by-line thematic coding, drawing on participants' own words rather than an a priori analytic framework. Each transcript was independently coded by at least two

analysis team members (BG, CN, RB and TC). Where there were discrepancies these were discussed and further analysis undertaken to achieve consensus.

RESULTS

Nineteen young people consented to participate. Of those invited to take part, none declined participation. Unfortunately, one of the nineteen participants did not engage with the interview and a second participant withdrew consent for audio-recording: as such, the final sample comprised seventeen participants (see Table 1 for demographic and clinical characteristics). Three participants had taken part in an earlier qualitative sub-study focusing on experiences of recruitment and randomisation¹⁴. Interviews typically lasted around 60 minutes.

[Insert Table 1]

Thematic analysis revealed four themes specific to the SRCBT arm, three specific to TAU, and three themes spanning the experiences of both arms (Table 2).

[Insert Table 2]

Experiences of SRCBT

'She understood me on a personal level': the therapeutic relationship

The therapeutic relationship was central to participants' experiences of the intervention. Participants consistently commented on the positive personal qualities of trial therapists, and described the relationship that developed as friendly, informal and genuine, whilst remaining professional and boundaried.

I believe she understood me on a personal level as well obviously we didn't go it wasn't any it wasn't unprofessional at all but we spoke about sort of things in general rather than just straight to the therapy it wasn't as clinical as I can imagine some of these services can be with certain people (Liam)

A good rapport appeared to have developed between participants and therapists: participants reported feeling able to talk openly and feeling understood. The way participants spoke about their relationship with their therapist suggested a dynamic of teamwork: participant and therapist working together towards a shared goal, sometimes in partnership with others.

it wasn't like I was being talked at, all my problems were being dissected in front of me without my sort of input, it was a conversation ... it wasn't sort of like someone was talking about the problems they thought I had, it was we were finding out what problems I had and then sorting them out together (Matthew)

Several participants articulated that this strong therapeutic relationship facilitated their continued engagement when the intervention was experienced as challenging. However, for a minority, the closeness of the relationship contributed to difficulties ending therapy.

he was really dedicated to helping me I think he liked me you know and I really liked him so I really found a friend in him um which was really nice really, which has made it even more difficult that you know we had to finish (Harry)

Flexibility

Participants appreciated the flexible way in which the intervention was delivered. They described being offered a choice of locations for sessions and expressed that this helped them to feel comfortable attending and engaging with the intervention.

I just feel comfortable in college and it's good that they can do it here cos if I couldn't do it here I wouldn't do it...I wouldn't have done it otherwise (Abigail)

Some participants also commented that the frequency of sessions was tailored to their individual needs and circumstances.

we continued meeting weekly cos I think in the end ... we both agreed that it was a better idea cos obviously things were so manic and obviously in a hostel things would go from really really good to boff really really bad, so it was, yes, we both agreed that it was a really good idea to do it every week because then we could keep it up
(Katie)

'It's given me tools': the CBT toolkit

Participants spoke about the intervention having equipped them with cognitive and behavioural strategies for managing distress and increasing activity. The most commonly described behavioural strategies were behavioural experiments and activity scheduling. The most commonly described cognitive strategies involved identifying and challenging negative thoughts. A range of other techniques specific to participants' personal difficulties were also mentioned. Participants described practicing these strategies with their therapists during sessions and most reported that they continued using these strategies independently after the intervention. Several participants believed that continued use of the strategies learnt during SRCBT contributed to continuing improvement after the intervention's conclusion.

I've improved so much and it's given me a lot of things that I can continue to improve on ... there's always going to be things that make me nervous so there's always going to be things that I'm going to want to push myself to do if that makes sense so I wouldn't say I'm over it but I've improved so much and it's given me the building blocks to continue to improve (Matthew)

However, one participant felt strongly that he was not ready to employ the strategies he had learnt independently and that gains from the intervention were not fully maintained as a result. He felt the intervention would need to have been longer for him to have felt confident using the techniques independently.

I was worried that things would go sour after [the intervention ended] and it turns out that they didn't stay quite as good after he left ... I didn't haven't take quite long enough to really absorb [the techniques] (Harry)

No pain, no gain: SRCBT as difficult

Whilst participants generally expressed positive views of SRCBT, they were clear that engaging with the intervention was not easy: several said that the intervention was difficult, painful or overwhelming at times.

it was very difficult because it was dabbling into things that I think I'd just really, didn't really even realise were there because ... they were so painful to look at that I didn't really want to so yes it was really tough at the beginning (Katie)

However, the participants commonly felt that this pain was worthwhile. Several participants spoke about pushing themselves to complete exercises they knew they would find uncomfortable for the sake of their recovery.

I was nervous I and I was shaking but I thought I need to start somewhere, I could always say no but that's not going to do any good that's not going to help me (Matthew)

Experiences of TAU

Allocation ambivalence

While two TAU participants expressed unambiguous disappointment about their treatment allocation, the majority expressed ambivalent views. Some participants spoke about being relieved to be randomised to TAU since they would not have to go through the anxiety

provoking experience of meeting a therapist and disclosing their problems. Others expressed that their disappointment was countered by altruism.

I'll admit to thinking oh maybe that was a bit of a waste of time but ... as a scientist this research may help other people so at the same time as much as I might not have received direct treatment ... you need a control group (Ewan)

No treatment, as usual

The majority of TAU participants described having received little or no professional support since randomisation. In most cases, this continued a narrative of limited or inadequate support prior to their involvement in PRODIGY. Only two participants described receiving specialist mental health support since trial entry, and one of these reported that he was unable to sustain his engagement with this support as low mood and lack of motivation led him to not attend appointments. Several participants reported having received support from their GP but satisfaction with this was generally low. A number of participants expressed frustration that the only treatment option they had been offered by their GP was medication, illustrated by one participant's comment that GPs '*just give you tablets and guide you on your way*' (Max).

'I was the one who had to do everything to help overcome it'

As most TAU participants received limited professional support, they had to manage their mental health independently. Participants who felt that their mental health had not improved or had deteriorated since entering the trial expressed frustration at the lack of support and a sense of having been abandoned (*'I didn't even get a phone call ... I've got no-one'* (Joshua)). However, some participants had achieved considerable improvement in their mental health despite the lack of support and conveyed a sense of pride and achievement at having done this on their own. Asked what was responsible for her improvement, one participant said:

I don't want to sound big headed but I think myself ... I was the one that had to do everything like to help sort of overcome it like sort of thing so and I have done it
(Amelia)

Overarching Themes

'It's just the speaking to someone': the value of talking

Participants from both trial arms emphasised the value of speaking to someone about their problems, many having been reluctant to talk about their problems prior to participating in the trial (*'[I realised] talking to people about things isn't a bad thing to do, it actually really*

helps' (Katie)). The noted benefits of talking formed two sub-themes: *'it's not boiled up in me no more'* and *'it helped me recognise the things that I wanted to change'*. The first sub-theme included descriptions of the way in which talking about problems can provide a sense of release. The second sub-theme encompassed expressions that talking had facilitated greater self-understanding.

it helped to identify little problems that I was having or little symptoms um and I feel like once they'd been identified to you then you can deal with them a lot better
(Ewan)

'Just do it': the importance of activity

Meaningful activity was seen as important by participants from both trial arms. For participants who received SRCBT, 'doing things' was an important element of the intervention. Increasing occupation also appears to have been important for the TAU group with several describing making a concerted effort to increase their activity levels.

doing things that like I wouldn't normally you know stuff that would make me feel really anxious just like I know I have to just do it like regardless of the feelings I've got or thoughts or anything I know I have to just do it (Amelia)

Amongst TAU participants who did not achieve such positive outcomes, continuing inactivity served as a marker of limited progress. Asked to elaborate on his statement that things had got worse for him, one participant responded: *'[I'm] stuck in the house all day doing nothing, just eating and that, just doing nothing'* (Max).

Motivation to change

A determination to make changes was evident in nearly all participants' interviews. This determination was evidenced in participant's willingness to engage with challenging aspects of SRCBT, and in the resolve of members of the TAU group to move forward despite limited support. For a number of participants, high motivation appeared to be related to age: both impending adulthood and relative youth were cited as impetuses for change. The lack of hopelessness in participants' accounts was notable.

I've always had a little bit of fight left inside me no matter what I'm going through, always wanted to be a better person and you know live a normal life, so no matter how depressed or sort of ill so to speak in those terms I can become there's still something inside me that says you will, you need to beat this, you need to carry on
(Liam)

DISCUSSION

The themes identified suggest that participants in the PRODIGY trial found SRCBT acceptable and perceived it to be beneficial. The strength of the therapeutic relationships that developed between therapists and participants, and the flexible way in which the intervention was delivered, appear to have been key to successful engagement of a potentially hard to engage population. Although several participants described the intervention as sometimes difficult, this temporary discomfort was seen as necessary for achieving longer term gains. Participants expressed that the intervention had equipped them with a 'toolkit' of cognitive and behavioural strategies which most, but not all, felt able to use independently after the intervention's conclusion.

TAU participants expressed more mixed opinions of the support received. Most TAU participants reported having received limited professional support and were often dissatisfied with this support. Nonetheless some participants had made considerable gains since entering the trial and conveyed a sense of pride at having made these positive changes independently.

The study's findings indicate that it is possible to successfully engage young people with socially disabling mental health problems in treatment. The surprisingly high motivation to change and low hopelessness expressed by participants suggests that investing in

interventions for young people at this relatively early stage of disorder might pay dividends. The aspects of SRCBT participants valued mirror priorities for mental health services consistently identified in previous research: for instance the importance of service flexibility and accessibility, and practitioners able to establish supportive relationships with young people¹⁵. However, these consistent messages about what young people want have often failed to translate into service provision¹⁶. Given this, it is perhaps unsurprising that specialist mental health services are accessed by only a small proportion of young people in need¹⁷, reflected in the low mental health service utilisation of the TAU group.

There is an increasing focus in psychotherapy research on acknowledging possible adverse effects of therapy^{18,19}. Qualitative studies of CBT have identified a range of possible negative effects, usually described by study participants as short-term, acceptable consequences of addressing difficult issues²⁰⁻²². Similarly, a number of participants in the present study identified some negative effects of SRCBT. Importantly, these were viewed as short-term and necessary; no participant described sustained negative effects of SRCBT.

Limitations

Since the study was qualitative, the findings cannot be assumed to generalise beyond the setting in which it was conducted. For instance, whilst we found participants were motivated and hopeful, this finding may be specific to those young people willing to engage in a RCT. In addition, although purposive sampling was intended to maximise the likelihood of capturing a wide range of views, it was only possible to select from the subset of

consented trial participants. Those with less positive experiences of trial participation may have been less likely to consent to being approached, resulting in failure to capture certain experiences.

Some members of the study team were involved in the implementation of the RCT and may have unwittingly minimised negative views of trial participation and emphasised positives. We attempted to decrease this risk by remaining cognizant of and reflecting on our potential biases throughout and by involving researchers not involved in the RCT. Further, although efforts were made to encourage participants to express negative views, perceived lack of independence may have discouraged this.

Acknowledgments

This study was funded by NIHR Health Technology Assessment grant: 10/104/51 PRODIGY Trial: ISRCTN47998710 (UKCRN trial registration number: 13341). This article presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. We thank the young people who participated in the study.

References

- 1 Kim-Cohen J, Caspi A, Moffitt TE. Prior Juvenile Diagnoses in Adults With Mental Disorder. *Arch Gen Psychiatry* 2003; **60**: 709–17.
- 2 Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE. Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry* 2005; **62**: 593–603.
- 3 Friedli L, Parsonage M. Mental Health Promotion: Building A Case. Belfast: Northern Ireland Association for Mental Health, 2007.
- 4 Children and Young People's Mental Health and Wellbeing Taskforce. Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing. London: Department of Health, 2015.
- 5 Birchwood M, Singh SP. Mental health services for young people: matching the service to the need. *Br J Psychiatry Suppl* 2013; **54**: s1–2.
- 6 Fowler D, French P, Hodgekins J, Lower R, Turner R, Burton S, *et al*. CBT to address and prevent social disability in early and emerging psychosis. In C Steel ed. *CBT for Schizophrenia: Evidence Based Interventions and Future Directions*. Oxford: Wiley-Blackwell, 2013; 143-67.
- 7 Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, *et al*. Process evaluation of complex interventions: Medical Research Council guidance. *Br Med J* 2015; **350**: h1258.
- 8 Yung AR, Yuen HP, McGorry PD, Phillips LJ, Kelly D, Dell'Olio M, *et al*. Mapping the onset of psychosis: the Comprehensive Assessment of At-Risk Mental States. *Aust N Z J Psychiatry* 2005; **39**: 964–71.
- 9 Jones SH, Thornicroft G, Coffey M, Dunn G. A brief mental health outcome scale-reliability and validity of the Global Assessment of Functioning (GAF). *Br J Psychiatry* 1995; **166**: 654–9.
- 10 Short S. The United Kingdom 2000 Time Use Survey. London: Office for National Statistics, 2003.
- 11 Hodgekins J, French P, Birchwood M, Mugford M, Christopher R, Marshall M, *et al*. Comparing time use in individuals at different stages of psychosis and a non-clinical comparison group. *Schizophr Res* 2015; **161**: 188–93.
- 12 Notley C, Green G, Marsland L. Qualitative Analysis. In DM Walker ed. *An Introduction to Health Services Research* London: Sage Publications, 2014: 327-42.

- 13 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; **3**: 77–101.
- 14 Notley C, Christopher R, Hodgekins J, Byrne R, French P, Fowler D. Participant views on involvement in a trial of social recovery cognitive-behavioural therapy. *Br J Psychiatry* 2015; **206**: 122–7.
- 15 Lavis P, Hewson L. How Many Times Do We Have to Tell You? A Briefing from the National Advisory Council About What Young People Think About Mental Health and Mental. National Advisory Council for Children's Mental Health and Psychological Wellbeing, 2010.
- 16 Worrall-Davies A. Barriers and Facilitators to Children's and Young People's Views Affecting CAMHS Planning and Delivery. *Child Adolesc Ment Health* 2008; **13**: 16–8.
- 17 Singh SP, Paul M, Ford T, Kramer T, Weaver T. Transitions of care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK Study): a study of protocols in Greater London. *BMC Health Serv Res* 2008; **8**: 135.
- 18 Dunn G, Fowler D, Rollinson R, Freeman D, Kuipers E, Smith B, *et al*. Effective elements of cognitive behaviour therapy for psychosis: results of a novel type of subgroup analysis based on principal stratification. *Psychol Med* 2012; **42**: 1057–68.
- 19 Goldsmith LP, Lewis S, Dunn G, Bentall RP. Psychological treatments for early psychosis can be beneficial or harmful, depending on the therapeutic alliance: an instrumental variable analysis. *Psychol Med* 2015; **45**: 2365–73.
- 20 Shearing V, Lee D, Clohessy S. How do clients experience reliving as part of trauma-focused cognitive behavioural therapy for posttraumatic stress disorder? *Psychol Psychother* 2011; **84**: 458–75.
- 21 Waller G, Evans J, Pugh M. Food for thought: a pilot study of the pros and cons of changing eating patterns within cognitive-behavioural therapy for the eating disorders. *Behav Res Ther* 2013; **51**: 519–25.
- 22 Goodliffe L, Hayward M, Brown D, Turton W, Dannahy L. Group person-based cognitive therapy for distressing voices: Views from the hearers. *Psychother Res* 2010; **20**: 447–61.

Tables

Table 1. Demographic and clinical information about participants.

Pseudonym ^a	Age Group	Gender	Group	Site	SCID ^b Research Diagnoses	At risk mental state ^c	Social Functioning ^d
Liam	20-25	Male	SRCBT	Manchester	GAD	No	Very low
Abigail	16-19	Female	SRCBT	Manchester	Depression, Panic disorder, PTSD	No	Very low
Ewan	20-25	Male	TAU	Manchester	Dysthymia, OCD	No	Low
Ben	20-25	Male	TAU	Manchester	Social phobia	No	Very low
Kirsty	16-19	Female	TAU	Manchester	Agoraphobia without panic	No	Very low
Sarah	20-25	Female	SRCBT	Manchester	PTSD, Anxiety disorder not otherwise specified	Yes	Very low
Joshua	20-25	Male	TAU	Manchester	Depression, Agoraphobia, GAD	Yes	Low
Maria	16-19	Female	TAU	Manchester	Depression, OCD	Yes	Low
Katie	16-19	Female	SRCBT	Norfolk	Depression, Specific phobia	Yes	Very low
Emma	16-19	Female	SRCBT	Norfolk	Social phobia, Body dysmorphic disorder	Yes	Very low
Harry	20-25	Male	SRCBT	Norfolk	None	No	Low
Sophia	16-19	Female	TAU	Norfolk	Depression	No	Very low
Matthew	16-19	Male	SRCBT	Norfolk	Depression, Social phobia, GAD	Yes	Low
Bethany	16-19	Female	SRCBT*	Norfolk	Depression, Panic disorder, Social phobia	No	Low
Max	16-19	Male	TAU	Norfolk	Agoraphobia without panic, GAD	No	Very low
Luke	16-19	Male	TAU	Norfolk	Social phobia	No	Very low
Amelia	16-19	Female	TAU	Norfolk	Depression, Panic disorder, GAD	No	Very low
SRCBT, Social Recovery Cognitive Behavioural Therapy; TAU, Treatment As Usual; PTSD, Post-Traumatic Stress Disorder; OCD, Obsessive Compulsive Disorder; GAD, Generalised Anxiety Disorder							
^a Pseudonyms are used throughout to protect the anonymity of participants.							
^b Structured Clinical Interview for DSM-IV.							
^c Assessed using the Comprehensive Assessment for At Risk Mental States (CAARMS).							
^d Assessed as hours per week of structured activity as reported in the Time Use Survey (low, 15-30 hours per week structured activity; very low, < 15 hours per week structured activity).							
*Did not receive a 'dose' of SRCBT due to difficulties with engagement.							

Table 2. Themes identified as characteristic of the experience of SRCBT, TAU and both.

SRCBT	TAU
<p>'She understood me on a personal level': the therapeutic relationship</p> <p>Flexibility</p> <p>'It's given me tools': the CBT toolkit</p> <p>No pain, no gain: SRCBT as difficult</p>	<p>Allocation ambivalence</p> <p>No treatment, as usual</p> <p>'I was the one who had to do everything to help overcome it'</p>
Overarching Themes	
<p>'It's just the speaking to someone': the value of talking</p> <ul style="list-style-type: none"> - 'it's not boiled up in me no more' - 'it helped me recognise the things that I wanted to change' <p>'Just do it': the importance of activity</p> <p>Motivation to change</p>	