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Who's Challenging Who?: A co-produced approach for training staff

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Abstract

Purpose: This paper outlines the development, piloting, and evaluation of the Who's Challenging Who? (WCW) training intervention for social care staff to improve their empathy and attitudes towards people with learning disabilities (LD) and challenging behaviour (CB).

Design/Methodology/Approach: A phased approach was taken to the development and testing of the intervention. Initially, the existing literature was reviewed, the theoretical background of the intervention was developed, and then the intervention was designed. A pilot study was undertaken, followed by further development, and a large-scale Randomised Controlled Trial (RCT).

Findings: WCW had a small positive effect on staff empathy 20 weeks after the intervention, and small to moderate effects for other staff reported outcomes (e.g., positive empowerment attitudes, positive work motivation). Being trained by people with LD and CB encouraged staff to reflect on the impact they have on the people they support. The trainers with LD valued their role, and saw benefits beyond this (e.g., friendships).

Research limitations/implications: It is possible to carry out high-quality RCT evaluations of social care practice, and research should continue to generate evidence in this way, as in healthcare settings. However, there were difficulties in retaining participants.

Practical implications: People with LD can be actively involved in the co-production and delivery of social care training.

Social implications: Employment and a fair wage can increase the confidence and empowerment of people with LD.

Originality/value: This is the first large-scale RCT of an intervention that aimed to improve empathy/change attitudes in social care staff who work with people with LD and CB.

Background and rationale for developing Who's Challenging Who?

Approximately one third (36%) of people with a learning disability (LD) known to primary care services have been found to engage in challenging behaviours (CB) (Sheehan et al., 2015). CBs include self-injurious behaviours and aggression towards others/property. CBs are defined socially in terms of their negative impact on the person themselves (e.g., injury, exclusion) and others (e.g., physical harm, stress) (Emerson, 2001). Hastings et al. (2013) suggested that staff members' actions, particularly related to negative attitudes or lack of understanding about CB, can inadvertently contribute to making CBs more likely to occur, or can exacerbate existing behaviours. Interventions to improve the wellbeing of staff working with people with LD and CB have been explored (e.g., Noone and Hastings, 2009; Noone and Hastings, 2010; McConachie et al., 2014; Smith and Gore, 2012). However, interventions to change staff attitudes towards CB have not been developed and robustly tested.

Several steps must be undertaken before an intervention can be developed and tested. The Medical Research Council (MRC) provide clear guidance for the development and evaluation of complex interventions (MRC, 2000; 2008). The framework recommends a phased approach to intervention development, whereby each phase contributes to developing an intervention to ensure effectiveness and increased likelihood of implementation. According to the MRC (2008) framework, the Development phase should ensure that appropriate groundwork has been undertaken to support the development of novel interventions, and this should provide a clear evidence-based rationale for the intervention aims and content. This should consist of reviewing the existing evidence and theoretical underpinnings of the intervention, and testing how individual components of the intervention work (MRC, 2000; 2008). Once the development work has been undertaken, a feasibility or pilot study can be planned to test the intervention procedures and elements of the potential research design. Finally, a definitive RCT (i.e., an effectiveness trial) can be undertaken, prior to implementation at scale.

Development work for Who's Challenging Who?

The idea for the Who's Challenging intervention for staff empathy and attitudes first emerged during a committee meeting for a third sector organisation in which a woman with LD described her experiences of being labelled as having CB, and the treatment that she had received from professionals and services over many years. This was a powerful story that affected all present. A research partnership was then formed between the third sector organisation and researchers to begin to explore how such personal experiences and stories might be used by people with LD and CB to effect change.

Preparation work for the intervention began with the completion of two thematic syntheses of the literature pertaining to the experiences of people with LD and CB and their family carers. The first of these thematic syntheses (Griffith et al., 2013) included 17 qualitative studies and reported that people with LD and CB feel that they have no control over their lives or where they live. Furthermore, participants in the reviewed research felt that they were often living in a setting that was a cause of their CB: they were reacting to frustrations in their environment, which then led to restrictive interventions that added to their frustrations about where they lived. People with LD and CB in studies included in this synthesis reported that constructive aspects of residential services were having positive, and respectful, relationships with staff members, and where fewer restrictive interventions were being used as a response to incidents of CB.

A second thematic synthesis of 17 studies (Griffith and Hastings, 2014) explored the experiences of family carers of people with LD and CB. The review findings showed that family carers felt it was important to get good quality support for their family member with LD and CB, but they were frustrated at poor or inappropriate care being provided. From the research data in this synthesis, there was little evidence of collaborative or partnership working with family carers, and a lack of experience or training for CB in residential services that could lead to exclusion for people with LD and CB. Family carers valued proactive and consistent support more highly than reactive crisis management when CB occurred, and they believed that early intervention would reduce the number of severe CB incidents.

In addition to identifying the evidence base through the two thematic syntheses, it was also imperative that relevant theory was identified to ensure that the theoretical background of the intervention was sound. The theoretical and co-production basis of the intervention was informed by research into mental health stigma. Contact Theory (Allport, 1954) and the results of a meta-analytic research synthesis (Mehta et al., 2015) were used in the intervention development, particularly the idea that stigma reduction and attitude change interventions are more effective when they involve social contact with people from the stigmatised group. To improve the effectiveness of this contact, Contact Theory (Allport, 1954) suggested that contact should be in intimate settings (e.g., small groups), involve a valued role for the stigmatised individuals, involve co-operative activities, and be community-sanctioned (i.e., have the support of someone who is important to those whose attitudes are to be targeted for change).

Initial Development of Who's Challenging Who?

Following the initial review and theory work, the Who's Challenging Who? (WCW) training course was developed. WCW was designed to fill the gap in the literature for an empathy/attitude change intervention for support staff. The first version of WCW training was a four-hour manualised course involving a co-trainer with LD and CB working with another co-trainer without LD to deliver small group sessions for support staff and managers. Whilst support staff and managers would have been in regular contact with people with LD and CB, this would not have been with the people with LD in a position of authority or respect as the trainers were in the WCW training. This was a key part of Contact Theory (Allport, 1954). WCW content was focussed on the direct experiences of people with LD and CB, incorporating the data from the two thematic syntheses with additional direct involvement of people with LD and CB in developing the content (through an initial development workshop). There are six sections in the training course:

- Communication, and how staff listening can prevent escalation of CB
- How the living environment contributes to frustration and CB
- The experience of being physically restrained

- What it is like to be on medication 'for' CB

- Experiences of feeling excluded because of CB

- Unhelpful attitudes and behaviour of support staff, and a discussion of positive qualities that contribute to good support/care

In addition to the first-hand experiences of the trainers with LD and CB being shared in the training course, there were several practical perspective-taking exercises designed to facilitate direct contact with the co-trainer with LD and CB, and to increase support staff empathy for people with LD and CB. WCW trainees were not asked to share the stories of people they worked with, and were instead focused on the first-hand experiences of the trainers with LD. The final exercise in the training involved the development of an action plan about what staff would change in their service following the training.

Piloting Who's Challenging Who?

The intervention was then piloted by Hutchinson et al. (2014), who trained two adults with LD and CB to deliver WCW alongside a co-trainer without LD. The trainers delivered a total of 10 WCW training sessions to 76 staff members. Hutchinson et al. found positive pre-post training changes in empathy towards people with LD and CB, confidence in dealing with CB, and more positive attitudes towards people with LD. Importantly, the pilot study demonstrated that it was feasible to recruit staff to attend the training, and that it was possible to train and support people with LD to successfully deliver training to support staff, with some indication of positive change in outcomes. The results of the pilot study suggested that it would be worthwhile to evaluate the effectiveness of WCW in a large-scale RCT.

Further development of Who's Challenging Who?

Ahead of a large-scale RCT, further development work was undertaken to improve the accessibility of the training for people with LD to be trainers. Changes included improving the flow of the training, as well as simplifying long or difficult words, and using a larger font. Three trainers with LD were

recruited for the RCT. They all underwent a three-day train-the-trainer programme to learn what training is, how people learn, presentation skills, and communication skills. Further revision of the training package was undertaken with the three trainers with LD during the train-the-trainer programme, with changes reflecting the trainers' experiences and needs. For example, personal videos about the trainers' experiences of CB in each of the six WCW course sections were recorded for inclusion in the training materials to ensure that all stories from all trainers were shared during the training, even if anxiety led to stories being forgotten on the day. However, the main change from the pilot work was that there was a clear shift from co-training with people with LD to the person with LD <u>leading</u> the training with a second trainer (without LD) supporting them to do this. For this shift to occur, the trainers with LD were supported to independently deliver as much of the training as they were able to, including information about their own experiences of being labelled as having CB. They were supported to do this through facilitation by the second trainer (without LD), easier to read PowerPoint presentations, practice with the facilitating trainer, and support from Job Coaches (where required and possible).

Evaluation of Who's Challenging Who?

Following the further development work on WCW, a large-scale RCT (Hastings et al., 2018) was undertaken. The primary aim was to assess the effectiveness of WCW to increase the empathy of staff working in residential homes for people with LD compared with a waiting list control group, using a cluster randomised controlled trial design. This was the first large-scale RCT of a co-produced training course delivered by people with LD. Two staff from each of 118 residential settings for adults with LD in which at least one person displayed aggressive CB were randomised to either receive WCW (59 settings) or to receive WCW after a delay (59 settings). Staff participants completed questionnaires at baseline, and then six and 20 weeks post-randomisation.

The primary analysis included data from 121 staff in 76 settings (51% of staff, 64% of settings). Findings indicated a small positive (but statistically non-significant) effect on increased staff empathy at 20 weeks, and small to moderate effects for staff reported secondary outcomes (e.g., positive empowerment attitudes towards people with LD and CB, increased personal accomplishment

at work, and positive work motivation), in favour of the intervention group. Referring to the small change in empathy following the WCW training course, Hastings et al. (2018) noted that the study "was not powered to detect such small effect sizes." (p. 807). It is also worth considering whether training only two staff members is sufficient to engender attitude and culture change within the setting, and this may have had some impact on the findings of this study. Although it is practically difficult to train whole services in a new approach (e.g., WCW), we may need to explore strategies to change the wider culture within services, in order to detect changes at the staff level. The intervention was consistently delivered with high fidelity to the training manual for all three trainers with LD. Further to these findings, trainees on the WCW courses indicated, in the post-training evaluations, that WCW was a good use of their time, that being trained by a person with LD was an effective way to deliver training about CB, and that they would be able to apply the learning from the training to their job. They also indicated that they enjoyed the training, that the training activities and materials were appropriate, they had the opportunity to participate, and did not feel uncomfortable during the training.

In addition to the quantitative study outcomes, a series of semi-structured interviews were conducted with managers (n=7), support staff (n=6), and the WCW trainers (n=4; three had LD). Verbatim interview transcripts were analysed using Thematic Analysis (Braun and Clarke, 2006). The results from this study (Flynn et al., 2019) suggested that being trained by people with LD and CB encouraged support staff to reflect on their own practice, and the impact that they have on the behaviours of the people they support. Although trainees often indicated that they had been engaging in increased reflection on their practice, they did not see this as a tangible outcome of the training. The trainers with LD saw both material and personal benefits from working as expert trainers, both of which were of great value to them. There were some discrepancies between how the trainers and trainees perceived the role of the trainers as experts, and this incongruence may undermine the impact of having valued contact with people with LD to engender attitude change, a core principle of Contact Theory (Allport, 1954) and an important aspect of the WCW training. In future, efforts may need to be made to counteract this perception, and to place greater value on the expertise of people with LD

about their care and support provision, in line with current policy recommendations (Association of Directors of Adult Social Services et al., 2015).

The impact of the WCW training

There were positive impacts for both the trainees (support staff and managers) and the trainers, and some of these are represented here:

"I found it interesting, and for somebody with learning disabilities to be there and put their point of view across was interesting. It makes you see things from their point of view and not your own." (Lauren*, Support staff)

"Yes definitely – I think it definitely helped [the support staff] understand a little bit more about how they were impacting on the service users." (Alice, Service manager)

"Psychologically it got a lot off my chest because […] I've had to boil a lot of the stuff up." (Jonathan, trainer with LD)

"I didn't think on the money side it was going to be that much. I thought it was going to be little but it was a shock." (Michael, trainer with LD)

"I feel a lot more confident in myself [since starting to do the training]." (Luke, trainer with LD)

"I can work with people with a learning disability in a different way. So I can work with them as equal partners." (Trainer without LD)

*All names are pseudonyms

Trainers' experiences of working on Who's Challenging Who?

As part of the evaluation of WCW, the trainers with LD and research team members directly collaborated to write an article about their views and reflections on the intervention and the research study (Richards et al., 2018). The trainers reported that they enjoyed the power they felt of being able to share their personal experiences of living in residential services and their experiences of CB support (or lack thereof) within these services. Being able to self-advocate was important and powerful, especially considering the obvious reversal of traditional power dynamics that had often been experienced by the trainers with LD. Being trainers on WCW led to the trainers feeling more confident about their abilities to train support staff, and opened up opportunities for new experiences and professional development that would not have been experienced without their role on WCW. Being paid a fair wage was a significant benefit highlighted by the trainers who were keen to spend their additional income on small luxuries (e.g., day trips, gaming equipment, home furnishings) that it would not have been possible to pay for without their role. As well as this additional income, the trainers were aware that they were being treated equally by the project team and this was important to

them. An unexpected outcome for the trainers was that they developed friendships with the other trainers, and that these lasted beyond the duration of WCW.

The project offered fixed-term employment for the trainers with LD, which led to uncertainty about their employment on the WCW project for some of the trainers as the project drew to a close. The wider project team ensured that appropriate steps were taken to end the working relationship, and to provide support for any uncertainties expressed by the trainers. These steps included:

- Giving them regular reminders about when the project would end from around six months beforehand;

- Changing their role from trainers to consultants (once all training sessions had finished) for as long as possible, within the constraints of a pre-approved research study budget, so that they could continue to be involved with the dissemination of journal articles and other materials;

- Having a series of ending meetings where they gave their feedback about what it was like to deliver the training, including making suggestions about delivering future training, and video recording their experiences of being trainers on the WCW project;

- Holding an end-of-project conference where their achievements and involvement were recognised and celebrated with the research team and conference attendees (including other researchers, LD support workers, and health and social care professionals);

- Keeping in touch with the trainers. Some members of the project team who worked closely with the trainers kept in touch with them, if this was wanted and possible, after the end of the project; and,

- Giving all trainers a certificate and personalised statement of their roles to support future employment prospects at the end of the project.

Implications for future research

It is possible (and desirable) to carry out high quality RCT evaluations of social care learning disability practice, and more evidence of this type needs to be generated and used; as it is in healthcare settings.

The biggest challenge faced in carrying out the research was the retention of social care staff at follow-up points. This may need further thought in future social care RCTs, especially in terms of the infrastructure and culture relating to large scale social care research. We identified retention as a concern during Phase 1 of the RCT (Hastings et al., 2018), and in consultation with the research team, the Project Advisory Group, and the Study Steering Committee, we implemented multiple additional strategies to improve retention. These governance and advisory groups proved to be a rich source of ideas for strategies to improve retention. These included: telephone, email, and text reminders for participants, the provision of a completion certificate upon completion of the questionnaires and training, the offer of a visit from a Research Assistant to collect the questionnaires, email versions of the questionnaires, and prompts from service managers. Newsletters were also sent out to participants to remind them of the format of the study and of any upcoming data collection periods. This message was reiterated via social media in an effort to reach as many participants as possible. Finally, it was decided that should all of these strategies be ineffective, we would aim to collect a minimum dataset (comprising data pertaining to the primary objective). These strategies were used in both phases of the study, but there were still difficulties collecting data from participants.

On reflection, we would have costed into the research proposal small incentives for staff for completion of research measures especially at the main outcome point at 20 weeks post-randomisation.

Conclusions and implications for policy and practice

Given that the Who's Challenging Who training is short, low cost to deliver (we estimated approximately £360 for a group training of 6 staff, excluding trainee travel and staff replacement costs), has some positive outcomes, receives positive evaluations from staff, has no known adverse

effects, and is demonstrably led by people with LD, it has potential to contribute to the range of training staff are offered when working with individuals with CB.

Targeting attitude change in social care and other contexts is best achieved by direct contact with stigmatised individuals. People with LD can be actively involved in the co-production of theoretically strong social care training that incorporates their experience. People with LD can also deliver high quality training to social care staff, with minimal support, and with excellent fidelity to a training manual.

Employment and a fair wage can increase the confidence and empowerment of people with LD. Employment as a part of social care research and/or the delivery or co-delivery of social care training interventions is a positive method to increase the quality of life of people with LD. There were some difficulties in identifying people with LD and CB to be WCW trainers through health and social care services. We cannot be certain about the reasons for this difficulty, as services did not share these with us, but we can speculate that the perceived difficulties of working with people with CB in a role of responsibility may have been the main barrier.

Qualitative data suggested that many service providers may downplay the potential benefits of self-reflection to improve staff well-being and reduce CB in social care practice. A greater value could be placed upon reflection as a learning outcome from staff training in social care services.

One manager from each setting was required to attend a WCW training course with a member of support staff, but we did not explore whether the settings were ready to implement the change from the WCW Action Plan or whether higher level support was in place to facilitate these changes. This is something that would be interesting to consider in future research projects and broader implementation work of WCW. Another consideration for future implementation or research is that the WCW training course is essentially a framework into which individuals or groups can insert their personal stories and experiences. Thus, the WCW training package has significant flexibility to be adapted and delivered in a variety of additional contexts (e.g., schools, inpatient settings, for individuals training their own support staff teams).

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