Digital adaptation of the Standing up for Myself intervention in young people and adults with intellectual disabilities: the STORM feasibility study

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Plain language summary

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Plain language summary

People with intellectual disabilities (or 'learning disabilities' in United Kingdom language) are more likely to experience poor physical and mental health than the general population. Stigma (negative stereotypes, prejudice and discrimination) has been linked to lower self-esteem, quality of life, and mental and physical ill health. Efforts to empower people with intellectual disabilities themselves to challenge stigma with a view to improving well-being, health and self-esteem are lacking.

In 2017, we developed Standing Up for Myself, a brief group-based programme for people with mild-to-moderate intellectual disabilities aged 16+ to address this gap. As this study got underway, face-to-face meetings were suspended due to the coronavirus disease 2019 pandemic. We used the opportunity to assess whether Standing Up for Myself could be delivered through web-based meetings. We adapted Standing Up for Myself for digital delivery, with close input from advisors with intellectual disabilities and experienced group facilitators. We then tested the digital version in charity and education settings to evaluate if Digital Standing Up for Myself could be delivered as planned and how acceptable it was to group facilitators and participants.

Four groups, with a total of 22 members, signed up to try Digital Standing Up for Myself. One participant dropped out before starting Standing Up for Myself, and the other 21 continued until the end of the programme. Retention and attendance were good; participants on average attended four of the five sessions. Ninety per cent of the core programme requirements were fully delivered as detailed in the Digital Standing Up for Myself manual. Problems with technology were manageable, although facilitators found using the Standing Up for Myself Wiki platform (an online platform for storage and sharing of resources) difficult, particularly when sharing video content. Facilitators felt acceptable levels of privacy were achieved and there were no reports of undue distress. All facilitators and many group members said they would recommend Digital Standing Up for Myself to others. Group members shared how the programme benefitted them, noting increased awareness about disabilities, and for some increased confidence, pride and independence. Some had learnt how to stand up for themselves and manage difficult situations and took pride in this.

Completing outcome and health cost measures via web-based meetings was acceptable and data were largely fully complete and useable.

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