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Keep Safe: collaborative practice development and research with people with learning disabilities

Wake, A.¹, Davies, J.², Drake, C.¹, Rowbotham, M. ¹, Smith, N.¹, & Rossiter, R.³ (2020) *Keep Safe: collaborative practice development and research with people with learning disabilities*. Tizard Learning Disability Review, 25, (4) pp 173-180. ISSN: 1359-5474. DOI 10.1108/TLDR-12-2019-0040

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¹ = Aldingbourne Trust, Sussex, UK ; ² = formerly Foundation for People with Learning Disabilities, now Oxleas NHS Trust, UK; ³ = Tizard Centre, University of Kent, UK

Contact: r.rossiter@kent.ac.uk

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Abstract – This collaborative paper (working together) describes collaborative practice development and research by and with people from the learning disabilities community.



Figure 1 Keep Safe Advisory Group

The aim is to show some of the activities which supported the collaborative practice development and research to show and encourage others to do more collaboration. The paper format is based on a previous collaborative paper published in the Tizard Learning Disability Review (Chapman et al., 2013).

The collaborative practice development and feasibility study * focuses on an intervention with a manual called Keep Safe. Keep Safe is an intervention for young people with learning disabilities who are 12 years and older, and have shown “out-of-control” or harmful sexual behaviour.

The paper gives examples of activities of the Keep Safe Advisory Group in planning, doing and thinking about Keep Safe development and its feasibility study. It lists some good things and some difficulties in collaborating.

It looks at which parts of Frankena et al.’s, 2018 Consensus Statement on how to do inclusive research were done, which ones were not, and why.

* = a feasibility study finds out how practical and acceptable an intervention and the method to evaluate its effectiveness are.

The paper ends with some thoughts about collaborating with people from the learning disabilities community: for people with learning disabilities, practitioners and researchers.

Introduction:

Involving service users, Experts by Experience, public and patients in practice and service development and research is recommended (DoH, 1999, 2000, 2006; INVOLVE, 2004; 2009) as it leads to more practical and useful practice and research. People from the learning disabilities communities should and can collaborate (Walmsley, 2001; 2004; 2005).

The people who wrote this paper, some from, and some not from, the learning disabilities community, combined their experience of planning and developing practice and services, training, self-advocacy and research to collaborate on the development and feasibility study of Keep Safe.



Figure 2 Keep Safe Advisory Group – second meeting

They also drew on learning from others' collaborations and inclusive or participatory research (Walmsley and Johnson, 2003; Learning Difficulties Research Team et al, 2006; Lewis et al., 2008; Byers et al. 2008; Nind, 2008). The format of this paper is based on a collaborative paper published in Tizard Learning Disability Review (Chapman et al. 2013).

Keep Safe is a group intervention for children and young people with learning disabilities who are 12 years and older and have shown "out-of-control" or harmful sexual behaviour. A collaborative of practitioners and advisers from the learning disabilities community developed and feasibility* trialled Keep Safe between 2012 and 2017.

Keep Safe was developed because there are more children and young people with learning disabilities who experience harmful sexual behaviour/sexual abuse being done to them, or doing it, (also called "victims" and "perpetrators") than children and young people without learning disabilities (Malovic, Rossiter and Murphy, 2018).

The focus of this paper is the collaboration for Keep Safe practice development and research with people from the learning disabilities community, not the Keep Safe development and feasibility study itself, which is described in Malovic et al. (2018).

How did the collaborative Keep Safe Advisory Group work?

The collaborators used their combined experience of contributing to planning and developing practice and services, training, self-advocacy and research to collaborate on the development and feasibility study of Keep Safe.

Before the start, the collaborators:

- Talked about why developing and evaluating Keep Safe was important at the Learning Disability Research group.
- Got funding – from the Paul Hamlyn Foundation Social Justice stream, plus some university and practice collaborative funds, including funds for participation.
- Recruited advisers from the learning disabilities community through Aldingbourne Trust (<https://www.aldingbournetrust.org/>). Aldingbourne Trust have experience of employing and supporting people from the learning disabilities community as trainers, through their Powerful Trainers and advisers on services and research.
- Held a larger group event with easy-to-understand information of the overall plan, with some possible types of resources. Methods such as use of Talking Mats®, talking through pictures of parts of the plan and the timescale all helped engagement, communication and participation.
- Recruited experienced and inexperienced advisers from the learning disabilities community with a range of ages, gender and sexuality. The advisers needed to be able to think and talk about sensitive, complex things and ethical issues in the project advisory group.

Working together:

- The Keep Safe Advisory Group met where they could get to with support and were familiar
- Time was taken to find out how to work together well. The process included getting to know each other, having the same people and structure/format, taking time, making ground rules and finding out what kind of support suited the members.
- Meetings were two hours – including a refreshment break. 16 meetings were held from January 2014 – April 2015; and two further reflection and celebration meetings were held in 2017 and 2018.



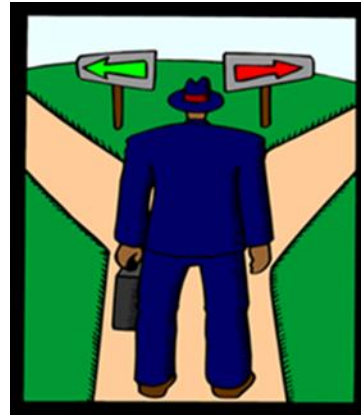
Figures 3 and 4 slides from the Advisory Group’s participation in training the feasibility study staff

- Keep Safe practice models, resources, activities and research materials were developed from looking at other interventions, for example, the Good Lives Model (Ward, 2005) and then Good Way Model (Ayland & West, 2006). Resources and activities were adapted or developed.
- Resources, pictures, words, visuals, types of communication support (for example, Photosymbols, Widget, diversity (for example, Tools for Talking) were all discussed. A range of methods were used including Talking Mats®, putting ideas or pictures in order of preference, voting, improving words and pictures, then looking and thinking again at the next meeting.



Figure 5 Easy-to-understand Keep Safe Good Lives Model developed by Advisory Group

(words, pictures, layout)



Good Way Model
 'Good Side/Bad Side' and 'Man At Crossroads'

Figures 6 and 7 Model and resources (Ayland and West, 2006) liked by the Advisory Group

What went well:

- Making easy-to-understand information and consent materials for the Keep Safe feasibility study and the NHS Research Ethics submissions.
- Developing and choosing easy-to-understand, engaging activities and resources for the Keep Safe intervention. These included simplified, visual Good Lives Model, Good Way Model and other resources.
- The meetings and easy-to-understand notes; listening and learning together

3		Good lives model
		<p>Jill and Ro showed the group the different styles of the Good lives model. The group decided:</p> <ul style="list-style-type: none"> • The portrait version looks better • They liked the photo in the Independence section • They liked the photo in the Feeling good section • The relationship section should include these photos – a family; friends; men kissing • The healthy section should be changed to include – healthy body; healthy mind; health sex

	Notes from Keep Safe Focus Group Meeting	
	9 th February 2015	
<p><u>People who were there:</u> Anthony, Celia, Gillian, Michael, Nicola, Ro, John attended the start and finish of the meeting.</p> <p><u>People who weren't there:</u> Jill</p>		
1		Welcome
2		Minutes from last meeting
		<p>We went through the notes of things that were discussed in the last meeting in January</p>
3		<p>People liked the new Good Lives model and the big rules of sex words and pictures (Thank you Kate).</p> <p>People liked The Good Lives Model with the statue/model better than the one with the condom.</p>

Figures 8 and 9 Examples of easy-to-understand meeting notes

- Collaborating with visuals, words, size and space of visuals, word size and layout.

- Contributing to staff training for Keep Safe delivery for feasibility study*.
- Planning what questions to ask to get feedback from young people, their parents/carers and co-facilitators involved with Keep Safe.
- Contributing to sharing learning -video on website, posters and presentations at national conferences and this paper.
- Celebrating the Keep Safe manual completion and start of public Keep Safe training.

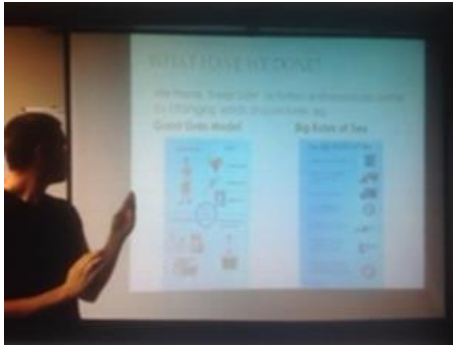


Figure 10 Collaborate with staff training
What was difficult?



Figure 11 Celebrating completion of manual

- Near the beginning, those from the learning disabilities community said “wanting to say the right thing”, understanding hard words and reading were difficult. As meetings went on, this got better and all collaborators became more confident
- Things took longer than planned because ethics and getting the groups going took much longer than expected. This meant that it was not possible to collaborate on getting and analysing feedback.

What was learned from the collaboration?





Mapping this collaboration with Frankena et al.'s 2018 Consensus Statement on how to do inclusive health research:

What was achieved? a collaborative mindset; recruiting researchers; developing a research plan and research materials; collaboration to make things easy-to-understand; dealing with practical issues - working hard together get the funding and systems to make these happen thoughtfully.

What was not achieved? contributing to collecting feedback and analysing the results as planned. Time issues were barriers to the planned collaboration in these phases, as ethical approval was very complex and took a lot of time.

Reflections and implications

As with other papers on collaborative/inclusive practice development and research noted in the introduction, and some published since (Durrell, 2016; Riches and O'Brien, 2017; Strnadova and Walmsley, 2017; Frankena et al., 2019), this collaboration led to an engaging, useable intervention and feasibility study*, collaborators grew in confidence and the experience felt worthwhile.

There was recognition of, and a plea for "people from the learning disabilities community should be more involved as of right, all research should be inclusive from the start".

As Durrell 2016 noted:

"This is vital if inequalities in healthcare are to be addressed by, and with, people with learning disabilities, because when they have a say in the production of knowledge, "this leads to better research, better data and the chance of real change" (Learning Difficulties Research Team, 2006).

The collaborative Keep Safe Advisory Group demonstrates how this can be done.

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