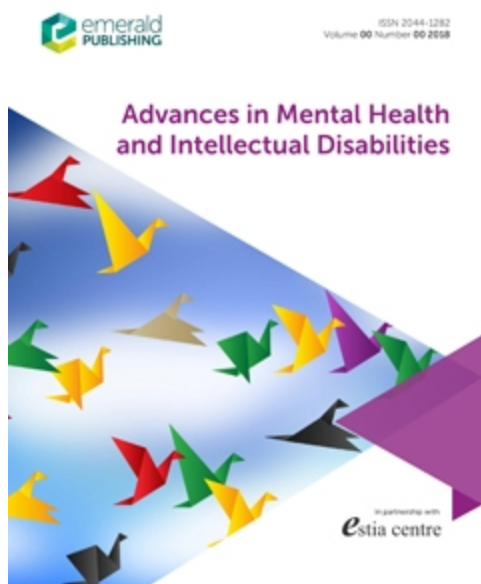


Co-design and development of a multi-component anxiety management programme for people with an intellectual disability

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Co-design and development of a multi-component anxiety management programme for people with an intellectual disability.

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4 It is estimated that there are ~~There is an estimated~~ 1.2 million people with an intellectual
5 disability in England with approximately 30-50% ~~of these people~~ suffering with mental
6 health problems. Among this cohort, a ~~Anxiety~~ related difficulties ranging from ~~between~~ 7%
7
8
9
10
11 to 40% (Reid, Smiley, & Cooper, 2011; Smiley, 2005). However, this figure is thought to be
12
13 higher with underreporting and lack of effective diagnosis impacting on prevalence rates
14
15 (Cooray & Bakala, 2005). A comparative study identified higher rates of mental illness in
16
17 people with intellectual disability than the general population (Cooper, Smiley, Morrison,
18
19 Williamson, & Allan, 2007) with (Deb, Thomas, & Bright, 2001) identifying higher rates of
20
21 anxiety in older adults. Experience of anxiety related difficulties are

22
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25
26
27 ~~Anxiety disorders have been~~ found to have increased over the a person with intellectual
28
29 disability life course of person with intellectual disability, with exposure to negative life events
30
31 being a predictive factor for psychological trauma and resultant anxiety disorders
32
33 (Tsakanikos, Bouras, Costello, & Holt, 2007; Wigham, Taylor, & Hatton, 2014).
34
35
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38

39
40 Anxiety related conditions are increasingly prevalent within people with Intellectual disability
41
42 (Bowring, Painter, & Hastings, 2019; Cooper et al., 2015). However, there is evidence to
43
44 suggest a greater prevalence of anxiety in people with autism and intellectual disability
45
46 (Bakken et al., 2010). Furthermore, the co-morbid association between autism and
47
48 intellectual disability results in a greater propensity for psychiatric disorders (Hill & Furniss,
49
50 2006). The presence of anxiety in people with intellectual disability and autism has been
51
52 found to have a greater association with specific phobias, social anxiety and obsessive
53
54 compulsive disorder (Helverschou & Martinsen, 2011).
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4 Despite this high prevalence, there is limited evidence ~~foref~~ effectiveness and sustainability
5
6 of any current treatment interventions (Bailey & Andrews, 2003; Dagnan, Jackson, &
7
8 Eastlake, 2018; National Institute for Health and Care Excellence, 2016). A meta-analysis
9
10 examining the effectiveness of psychological therapies for people with mild to moderate
11
12 intellectual disabilities found limited evidence of efficacy within studies (Koslowski et al.,
13
14 2016). ~~Research on m~~Modified cognitive behaviour therapy (CBT) for anxiety related
15
16 problems in people with intellectual disability~~ies~~ has~~ve~~ demonstrated limitations of
17
18 ~~effectiveness~~ and ~~sustainability of any sustained~~ therapeutic impact (Hassiotis et al., 2013;
19
20 Unwin, Tsimopoulou, Kroese, & Azmi, 2016). ~~Although,~~ CBT has ~~been found demonstrated~~
21
22 to have some ~~beneficial~~ effect, ~~in a review by (Dagnan et al., 2018)~~ but small samples sizes
23
24 and lack of scientific rigor ~~limited were found to be significant in~~ study outcomes ~~(Dagnan et~~
25
26 ~~al., 2018)~~. ~~Moreover~~ ~~Furthermore, it was the study~~ noted ~~that~~ alternate approaches to
27
28 psychological interventions are needed to improve clinical practices.
29
30
31
32
33
34

35
36 Studies have shown ~~that~~ anxiety has a significant negative impact on the daily lives of
37
38 people with ~~i~~Intellectual disability (Ali, King, Strydom, & Hassiotis, 2015; Cooper et al., 2007).
39
40 The impact on those people with more significant levels of ~~i~~Intellectual disability with limited
41
42 verbal communication , can ~~often~~ manifest in behaviours that challenge ~~as a mode to~~
43
44 ~~communicate distress~~ (Bowring et al., 2019; Challenging Behaviour Foundation, 2021). The
45
46 health impact is often compounded with people requiring high doses of medications to
47
48 manage ~~their symptoms of~~ anxiety (Axmon, El Mrayyan, Eberhard, & Ahlström, 2019; Deb,
49
50 Unwin, & Deb, 2015). This is in contrast with national campaigns to 'stop over medicating
51
52 people with a learning disability and/or autism' and NICE recommended guidance (National
53
54 Institute for Health and Care Excellence, 2016; NHS England, 2016).
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3
4 NICE clinical guidelines suggest psychological therapies be adapted for people with
5
6 intellectual disability and identifies CBT, relaxation and graded exposure as
7
8 recommended treatment for anxiety (National Institute for Health and Care Excellence,
9
10 2016). Additional psychological therapies such as mindfulness, mindfulness has
11
12 demonstrated efficacy are an effective approaches provided therapy that providing when
13
14 people with intellectual disability were given provided with adequate support and
15
16 guidance to practice requisite skills (Idusohan-Moizer, Sawicka, Dendle, & Albany, 2015;
17
18 Robertson, 2011). More recently, a systematic review examined acceptance and
19
20 commitment therapy for the treatment of anxiety in people with intellectual disability. This
21
22 review study noted concluding the potential for adapted acceptance and commitment therapy
23
24 of this intervention with further adaptations and studies incorporating this therapy within being
25
26 incorporated into psychological treatment programmes interventions (Byrne & O'Mahony,
27
28
29
30
31
32 2020).

33
34
35
36 Most therapies for the treatment of anxiety have used a single based therapeutic model, with
37
38 variable effectiveness (Koslowski et al., 2016; Unwin et al., 2016). The limited evidence of
39
40 effective long term sustainability of psychological approaches underlines the need for
41
42 alternate methods for the treatment of anxiety related issues. Non-pharmacological
43
44 approaches are needed to deliver a range of effective therapies to support people in
45
46 improving their self-management skills of anxiety and provide effective psychological
47
48 interventions. It is considered, further exploration of a combination of these psychological
49
50 approaches should be developed to understand what works (or not) for the effectiveness for
51
52 use within clinical practice (National Institute for Health and Care Excellence, 2016).
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57

58 *Aims and objectives*
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4 The aim of this study aim was to make improvements to the treatment of anxiety in people
5 with intellectual disability. Co-producing a treatment programme with people by those who
6 have understanding the with a lived experience was essential in and using this information to
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The aim of this study aim was to make improvements to the treatment of anxiety in people with intellectual disability. Co-producing a treatment programme with people by those who have understanding the with a lived experience was essential in and using this information to the development of a multi-component anxiety management programme. Key project The key objectives of the project were:

- To work with an engagement group, refining and adapting psychological therapies to an anxiety management programme manual for people with ID.
- To understand the lived experience of anxiety from people with intellectual disability
- To work alongside an engagement group, refining and adapting psychological therapies to develop an anxiety management programme manual
- To co-design an accessible user guide to allow engagement from people with more severe intellectual disability.
- To explore the thoughts and experiences of participants in co-producing the manual

Method

The study was conducted in a NHS provider of community intellectual disability services. The service provides specialist care and treatment to people with intellectual disability, their families and carers. The multi-disciplinary services offers a range of multi-disciplinary specialist interventions and support to meet their health care needs of people with intellectual disability. The study was conducted in one of the four community intellectual disability services.

A total of four people consented to participate in the project. All participants had a mild intellectual disability with an equal number of male and female participants. Two participants

1
2
3
4 had a diagnosis of autism. EachAll participants experienced difficulty with anxiety related
5
6 issues on a daily basis.
7

8
9 To understand the lived experience of anxiety, ~~participants~~ participant's focus groups were
10
11 used to collect information about how anxiety impacted upon their lives. ~~The information was~~
12
13 analysed ~~Content analysis was used to evaluate the feedback from participants to~~
14
15 understand areas of the manual which required further modification. The suggested changes
16
17 included the structure of sessions, changes to graded exposure approach, using alternative
18
19 images and terminology. The initial feedback formed ~~then used to form~~ the basis of
20
21 development ~~of a~~ ~~for the~~ ~~co-produced~~ multi-component anxiety management programme (M
22
23 CAMP-ID). By using an iterative approach within the analysis, ~~Additional~~ the feedback was
24
25 obtained was used to identify areas ~~for~~ ~~of~~ further refinement ~~and allowed adaptations be~~
26
27 made ~~to~~ of the programme content and accessible user guide. Feedback from participants
28
29 was continually analysed throughout the development process using the information
30
31 provided to make modification to the manual and user guide.
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38 Figure 1 provides details of feedback questions.
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Figure 1.

Are the sessions easy to follow?

Are the words used in the manual and user guide easy to follow and understand?

What do you think of the Images and pictures in the user manual?

Can you think of any changes we could make to help people better understand the information?

Do any of the sessions need changing or is there any information you don't like?

Do both the user and clinician guide work together?

Can you think of any other changes which are needed?

Discussion groups

Two separate discussion groups were completed ~~involving all participants~~ using open ended questions. ~~This approach was used~~ to gain ~~an insight~~ ~~awareness of~~ the individual challenges ~~participants experienced in their everyday on daily lives~~fe. We explored how anxiety impacted individuals ~~in order to and gain a better~~ ~~understanding of the effectiveness of people's~~ self-management strategies. Insight into the participants lived experience ~~provided additional insight into was used to examine~~ the effectiveness of current clinical interventions.

Additional, feedback on the initial ~~draft~~ M CAMP-ID programme was obtained with prior agreement from all participants ~~by two clinicians~~. The discussion group sessions ~~was~~ ~~were~~ used to capture ~~participants~~ ~~participant's~~ thoughts of the proposed session structure, content and accompanying user workbook and programme manual.

Developing the multi component anxiety management programme

Adaptation of several psychological therapies for the development of the anxiety management manual project used a systematic approach by (Hwang, 2009). The adaptation follows a five [stage process](#) (Box 1.).

Box 1.

Phase 1: Generating Knowledge and Collaborating with Stakeholders

Phase 2: Integrating Generated Information with Theory and Empirical and Clinical Knowledge

Phase 3: Review of Culturally Adapted Clinical Intervention by Stakeholders and Further Revision

Phase 4: Testing the Culturally Adapted Intervention

Phase 5: Synthesizing Stakeholder Feedback and Finalizing the Culturally Adapted Intervention

[A co-production approach](#) ~~was chosen for this project.~~ ~~Co-production is a method of~~ [involving people who use healthcare services to design and support developments to treatment interventions](#) (NHS England, 2017) ~~was used.~~ [Pivotal to improving healthcare services and treatment interventions is involvement from people with a lived experience](#) (Health Quality Improvement Partnership, 2017). ~~There is clear evidence~~ [Ppeople with lived experience are ideally placed to advise on the type of support and interventions which are required to make improvements in people's lives](#) (INVOLVE, 2018). [An essential element to](#)

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2
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4 this approach are the voices of people with a disability in the creation and delivery of
5 healthcare services (Fenney, Wellings, Lennon, & Hadi, 2022). ~~This approach was adopted~~
6 ~~for the project and included people with intellectual disability with lived experience of anxiety~~
7 ~~related disorders as co-production partners.~~

8
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10
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12
13
14 To support involvement and co-production processes, ~~h~~information on the key underlying
15 psychological principles for the sessions was provided to participants. The information
16 enabled discussion and a clear explanation provided to participants of on the key
17 psychological principles. to allow people to understand the information.

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23
24 A project task and finish group ~~was established~~ ~~was created~~ consisting of the four
25 participants who provided ~~valuable~~ feedback from focus groups session to support the initial
26 development of the programme manual. The draft manual was provided ~~to and~~ participants
27 who were subsequently asked to consider: ~~the~~ treatment principles, optimum session
28 arrangement, presentation of ~~the~~ sessions format, accompanying materials, and length of
29 each the sessions. ~~The group where provided with f~~Feedback questionnaires were provided
30 in advance ~~in advance of each~~ of the development sessions to enable facilitators to support
31 participants to be provided to ~~help process information and~~ prepare feedback.

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44 The anxiety management programme consists of eight therapy sessions, which utilise
45 utilising a range of psychological approaches to achieve ~~an~~ individuals ~~individual's~~ therapy
46 goal. The therapy sessions apply a key focus on the identified area of need which with each
47 session revisiting repeatedly refer to pre-agreed goals. ~~Sessions include multiple adapted~~
48 ~~therapies consisting of cognitive behaviour therapy, mindfulness, relaxation, graded~~
49 ~~exposure and elements of acceptance and commitment therapy.~~ The addition of promoting
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3 meaningful occupation and lifestyle changes provide support to develop self-management
4 skills. This includes a formulation of an individualised person centred anxiety support plan.
5
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8
9 The multi-component anxiety management programme (M CAMP-ID) uses a goal-based
10 approach to therapy. The goals are used to focus on what the patients wants to achieve
11 themselves, surrounding their anxiety. Training for clinicians using this approach allows
12 adaptations to be made to make the treatment more accessible for people with both mild and
13 moderate intellectual disability. The M CAMP-ID programme is integrative in terms of
14 psychological models and /therapeutic modalities and uses a holistic approach to the
15 promotion of wellbeing.
16
17
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20
21 The programme uses graded exposure to systematically desensitise participants to
22 increasing aspects of anthe anxiety causing situation or problem. This process is completed
23 in parallel with multiple psychological therapy sessions to support the exposure exercises by
24 developing self-management skills during each of the sessions. A range of strategies
25 including mindfulness exercises, and acceptance and commitment therapy are used to bring
26 about change to thinking processes. Dialectical Behaviour Therapy (DBT) sessions focus on
27 teaching people to live in the moment and develop real life coping strategies to deal with
28 stress and anxiety. Relaxation, wellbeing and lifestyle sessions provide a framework for
29 patients to work towards supporting the self-management of individual's anxiety and stress.
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49 The inclusion of an accessible user guide connects with the clinician guide to support
50 facilitation of the programme. All session begin with a recap of previous session to maintain
51 continuity and identify further learning prior to progressing onto the next session. Movement
52 through the anxiety management programme aims to maintains clinical focus and to achieve
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4 [the patients](#) identified goal. All sessions begin and end with an exercise to develop breathing
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6 techniques.

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8
9 Table 1 provides an overview of the session format with a brief description of the programme
10
11 content.

12
13
14 Table 1.

17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43	Session 1: About this workbook	Overview of programme and support individual to identify therapy goal. Person centred planning and commitment to programme.
44 45 46 47 48	Session 2: Healthy mind and body.	Activity based session using multimedia aimed at promoting healthy lifestyle changes to promote well-being.
49 50 51 52 53 54 55 56 57 58 59 60	Session 3: What is Anxiety?	Interactive activities to support understanding and recognition of anxiety. Focus on feelings and behaviours, using body mapping exercise.
	Session 4: Graded Exposure	Systematic desensitisation planning and development of individual plan.
	Session 5: Talking about anxiety	Developing understanding of expressing anxious self to others using key words, pictures and body language exercise.

Session 6: Working on my anxiety skills	Practical based mindfulness <u>based mindfulness</u> session exploring ways to implement this throughout the day as part of a routine.
Session 7: learning new skills	Scenario based session - exercises using anxiety provoking scenarios of a range of commonly presented environments / situations that can cause anxiety.
Session 8: Review of my anxiety management plan.	<u>Session Programme overview</u> /-recap and review of <u>previously identified intervention</u> goals. Plan to repeat sessions as required.

Analysis

~~Feedback from participants was continually analysed throughout the development process using the information provided to make modification to the manual and user guide.~~

~~The~~ focus group interviews notes were transcribed and coded into themes using six phase thematic analysis (Braun & Clarke, 2006). ~~Emergent~~ The emerging themes where identified following DA, SJ and SLJ reading and re-reading the transcript several times to familiarise themselves with the content and meaning. The second phase generated initial coding during which DA, SJ & SLJ independently identified codes from within the data from participants words and descriptions. The third phase involved searching for themes through analysis by combining related codes to identify overarching themes. Comparisons and differences in proposed codes where frequently discussed between DA, SJ and SLJ until final agreement was reached. In the fourth phase DA and SLJ examined specific quotations which were subsequently grouped into themes. through discussion between project members. The fifth

phased involved naming themes and providing a narrative. In addition, DA, SJ and SLJ determined if any of the themes required a sub-theme. In the final phase, DA and SLJ gathered selected themes and quotes to illustrate participant's feelings and experiences.

Results

Co-design of the multi-component anxiety management programme

The project allowed collaboration as an iterative process throughout the process with feedback used to make adaptations and modifications to the structure and length of sessions.

All participants provided feedback with general and consensus agreement on the content of the manual and user guide. The adaptation of different psychology therapies provided an opportunity for participants' to use their lived experience to be captured and incorporated into to enable each of the therapy sessions, be designed to allow engagement.

By the dovetailing of the user guide and clinician manual it was felt the was deemed essential by participants for this to programme would be more inclusive available to for people with a more severe intellectual disability. However, all group members considered the adaptation process created challenges in making the programme user guide accessible.

The challenges were experienced in aligning the clinician manual with the user guide and maintain uniformity within sessions. The co-design partners provided feedback to allow for several modifications be made to the user guide. A practical solution was to use provided by using different coloured shapes to code each exercise to maintain unity. It was felt this approach provided an additional opportunity within the programme sessions to maintain engagement in each session and limit disruption to therapeutic delivery.

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4 There was agreement from participants on the structure and content of the anxiety
5
6 management manual and programme resources. Co-production partners underlined the
7
8 need for continual self-management strategies to run throughout the programme to allow for
9
10 clinician led instruction to integrate into the manual. Additionally, ~~It was considered~~ setting a
11
12 ~~key~~ therapy goal and formulating a graded exposure plan should run concurrently through
13
14 sessions. The ~~overall~~ aim of this approach is to help people ~~achieve their goal by proving~~
15
16 ~~people with~~ develop the self-management skills to overcome anxiety provoking situations
17
18 which may impact on their lives. ~~Participants underlined the importance of~~ Encouraging the
19
20 practice of anxiety management strategies between session was a key feature from
21
22 participant feedback. ~~by suggesting practice exercises are incorporated in the programme.~~
23
24 ~~These would~~ Furthermore, it was felt different levels of help support will be required for the
25
26 person to achieve their goal and promote graded exposure activities. Therefore, involvement
27
28 from families and carers will be important particularly in the early stages of the treatment
29
30 programme.

31 32 33 34 35 36 37 *Discussion group sessions*

38
39
40 ~~The~~ discussion group sessions provided an opportunity to understand the ~~enable~~
41
42 exploration into the lived experience of the effect anxiety has on participants lives from a
43
44 lived experience ~~prospective~~ perspective. ~~In addition, the group sessions~~ provided insight
45
46 into areas of clinical focus ~~Areas of improvement in clinical delivery were~~ valuable in
47
48 understanding the needs and using a multi-method approach for the treatment of ~~to~~
49
50 development of the anxiety management programme. ~~There were~~ Three key themes ~~were~~
51
52 identified.

53 54 55 56 57 58 *Physical and psychological impact of anxiety*

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4 Three of the participants explained thinking about situations which have triggered anxiety
5
6 and recognising how this is often not helpful. One participant elaborated by explaining ~~they~~
7
8 ~~often feeling~~ overwhelmed when using public transport. ~~The leading to~~ experiencing of
9
10 physical ~~symptoms~~ ~~symptoms caused the person to~~ ~~which have resulted in being sick vomit~~
11
12 due to ~~high levels of~~ anxiety ~~levels~~. This ~~had~~ led to ~~the~~ participant ~~to~~ worrying they would
13
14 always be sick when faced with the same situation. ~~resulting in participating avoiding going~~
15
16 ~~out as they had no other form of transportation~~. Another participant identified ~~with~~ feeling
17
18 faint when in ~~a the~~ similar situations, ~~and emphasised how they with equal avoidance~~
19
20 ~~avoided using of~~ public transport. ~~Both participants highlighted how a lack of alternate~~
21
22 ~~transportation significantly affected their social networks and leisure activities.~~
23
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26
27

28 All participants reported ~~the physical impact~~ anxiety ~~having some on their body~~. ~~These~~
29
30 ~~feelings physical impact on them which created particular problems and exasperated often~~
31
32 ~~resulting in the~~ panic and fear. ~~often experienced~~. ~~A repeated theme was the~~ Fear of feeling
33
34 ~~of being~~ trapped and unable to escape ~~a situation~~. ~~were a repeated theme~~. One participant
35
36 ~~explained~~ feeling ~~suffocated when travelling by train and experiencing difficulty breathing~~
37
38 ~~due to a heightened state of anxiety~~. ~~like the walls are closing in on them and feeling~~
39
40 ~~suffocated~~. There was recognition ~~from participants~~ the physical impact of anxiety created a
41
42 ~~clear barrier to~~ ~~towards~~ accessing social and recreational activities. ~~Consequently~~, often
43
44 leading to ~~increased~~ isolation ~~with contributed to feelings of and~~ loneliness within
45
46 ~~participants~~.
47
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52 *Management of anxiety in social situations*

53
54
55 All participants ~~identified expressed~~ close family members ~~as to be~~ supportive and ~~being as~~
56
57 ~~an essential-necessary~~ part of their ~~every~~ daily lives. ~~Participants emphasised their reliance~~
58
59
60

1
2
3 on family members to feel confident ~~to interact and~~ to engage in social situations settings.

4
5
6 There was a general feeling that members of the public were not always sympathetic to their
7
8 difficulties. One participant reported that people and would usually often ~~stared~~ and made
9 derogatory comments or ~~offer~~ ed limited ~~support~~ support. ~~when~~.

10
11
12
13 Three ~~of the~~ participants identified crowded areas being a specific problem and created
14
15 difficulties for themselves with in a variety of activities such as shopping, or attending the
16
17 gym. A participant detailed a situation when of attending a ~~football stadium to watch their~~
18
19 ~~team play sporting event~~ and experienced ing an episode of heightened anxiety due to crowd
20
21 noises. This resulted in the participant triggering an ~~having an~~ 'extreme panic attack' and
22
23 requiring support from a family member. ~~to calm~~. This situation ~~had~~ resulted in the
24
25 participant feeling increasingly reliant on family members to provide support to attend
26
27 subsequent sporting events, thus football matches impacting on their level of independence.
28
29
30
31
32

33
34 All participants considered their social anxiety weighed heavily on ~~their~~ on their families and
35
36 carers. They described feeling the 'eyes of others' watching them in social situations.

37
38 Participants ~~discussed~~ ~~creating~~ discussed creating solutions which could be personalised.

39
40 These included methods of alerting members of the public to increasing levels of anxiety by
41
42 creating a simple step by step instruction card which could guide people in providing
43
44 support.

45
46
47
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49
50
51 Participants described ~~detailed situations of panic and fear with discussion relating to~~
52
53 hospital environments and described as being 'scary places' and with ~~reflected~~ on
54
55 healthcare situations within healthcare that were anxiety provoking. There was consensus
56
57
58
59
60

1
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3
4 between participants the most provoking situations surrounded medical interventions or
5
6 attending GP surgery. a routine health check.
7

8
9 In contrast, participants highlighted the level of anxiety and stress experienced when
10
11 Additionally, anxieties often involved visiting loved ones in hHospital. finding these equally
12
13 stressful experiences. Participants talked about their families and medical professionals not
14
15 always a lack of information providing to them with information about a family members
16
17 condition. Participants considered that often feeling people this paternalistic outlook focused
18
19 on try to provide reassurance, rather than consider providing information about the family
20
21 members persons medical condition. There was a general consensus between participants
22
23 that being provided with was information would be beneficial useful in alleviating their worry
24
25 and better understanding a prognosis.
26
27
28
29

30 31 *Coping strategies*

32
33
34 In discussing individual coping strategies used to manage anxiety symptoms Pparticipants
35
36 highlighted a range of reflected on self-management strategies. skills adopted having
37
38 varying effect on their anxiety. Key Sstrategies included using digital media to access
39
40 resources to practice anxiety management techniques. However, some participants reported
41
42 they often needed direction to access and effectively use relaxation resources. effectively.
43
44 All participants described Pphysical exercise as an effective method was used by all
45
46 participants and walking was of particular benefit in for relieving stress and which all
47
48 considered provide a small amount of some level of independence.
49
50
51
52

53
54 Distraction techniques were frequently used by all participants. a repeated topic discussed
55
56 throughout the sessions with informers viewing several strategies as being effective.
57

58
59 Participants reported listening to music effective in a successful strategy when starting to
60

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2
3
4 feel anxious allow some self-control of symptoms and. This was particularly helpful when
5
6 approaching crowded areas or traveling on public transport. Furthermore, participants
7
8 considered tasks and hobbies that reduced anxiety were viewed as beneficial in reducing
9
10 anxiety on a general level.

11
12
13 The participants detailed the preserved benefits underlined the need for of continued
14
15 development of their individual self-management skills. were important. All participant
16
17 reported the co-production group had provided the opportunity to examine and gain a
18
19 enabled a greater insight into their own specific needs. and recognised the barriers to
20
21 participation that were equally felt from group members.

22 23 24 25 26 Discussion

27
28
29 To our knowledge, tThis is the first UK study in the UK which has used a qualitative
30
31 approach to understand the lived experience of people with intellectual disability and
32
33 involved these people in developing an intervention for the treatment of anxiety in clinical
34
35 practice. There are several findings identified through this study.

36
37
38
39 Firstly, co-production partners identified through their personal experiences the challenges
40
41 anxiety places on them on a daily basis.

42
43
44
45 The themes which emerged from the discussion groups provided a greater understanding of
46
47 how anxiety impacted eds people's lives. This understanding illustrated the daily challenges
48
49 faced by people with intellectual disability and some strategies used by them to overcome
50
51 anxiety provoking situations. The participants detailed their daily struggles in managing their
52
53 psychological distress and the interconnected relationship with physical symptoms of
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55 anxiety.
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4 Social peer support between participant members within the group allowed for the exchange
5 and sharing of experiences. The emotional support participants demonstrated towards each
6 other during the group session enabled identification with others. In addition, it provided
7 opportunities for peer support when participants were self-critical in reporting a difficult
8 anxiety provoking experience. The shared learning from the discussion groups was
9 incorporated into recommended strategies to promote and develop self-management skills.
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11 A key strategy identified in the discussion groups was the value of physical activity and
12 digital resources to enhance the development of self-management skills.

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23 This information provided a key contribution to making further developments to the
24 anxiety management programme. sessions and involving participants as co-production
25 partners. The feedback provided by co-production partner's generated ideas and allowed
26 changes to be made the session manuals, with several modification and adaptations. In
27 addition † this process enabled improved alignment of the clinical and user manual guides
28 and additional resource development. Feedback group sessions underlined the importance
29 of using a range of interactive strategies to engage people with varying abilities to maintain
30 motivation and interest.

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43 Secondly, † The inclusion of an accessible user guide aims to provide support for participant
44 engagement in the programme and provide clear guidance throughout the sessions. The
45 inclusion of practice exercises and graded exposure withinbetween sessions further
46 promoteds † the development of self-management strategies. Although, involvement from
47 families and carers to support exposure exercises between sessions will be important in the
48 initial stages of the programme.

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4 A potential benefit of the anxiety management programme is an increased exposure to life
5 events and the potential to reduce paternalistic outlook. This could lead to increased
6 autonomy, improved self-esteem and quality of life in people with intellectual disability.
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11 Thirdly, tThese findings highlight the potential clinical implications. Although, caution is
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13 needed as the anxiety management manuals and programme needs to be tested in clinical
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15 practice with people who have an with intellectual disability and anxiety.
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19 There were few strengths to this study. The study used co-production in partnership with
20 people with intellectual disability in the development of a treatment programme.
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24 Furthermore, it took into account insights gained from a lived experience perspective and the
25 effect anxiety has on people's lives. The authors felt that this allowed for the treatment
26
27 programme to be more person centred and relevant for people with intellectual disability. It
28
29 also meant that there was likelihood of greater acceptability of and engagement with such a
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31 treatment programme when used in the management of anxiety in people with intellectual
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33 disability.
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39 However, the study had some limitations. Due to the nature of the co-production work
40 needed, the study could only involve a small number of people with lived experience who
41 had agreed to participate in the discussion groups. In addition, feedback was provided by
42 people with mild intellectual disability and might not represent those people with more severe
43 intellectual disability.
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50 51 **Next Steps**

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54 It is important to test the manual in clinical practice. A future study will provide an opportunity
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56 to examine the multi component programme and manuals in a clinical environment. A key
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58 objective will be obtain further understanding from people with intellectual disabilities and
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4 make recommended changes or adaptations. A clinical trial will aim to evaluate the
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6 comparative differences of a multi model approach as a psychological treatment of anxiety
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8 for people with intellectual disability. Examination of any improvements in mood, behaviour
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10 and quality of life will help evaluate the effectiveness of the programme.
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14 A potential challenge could be the commitment of practicing and completing steps of
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16 exposure between sessions. People with more severe intellectual disability will require
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18 additional support during and between sessions. which the user manual. The manual is
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20 designed to be modified to individual needs assist with this process and form the basis for
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22 become a person's anxiety management plan. Therefore, involvement within the anxiety
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24 management programme from families and carers those who provide care is paramount will
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26 be vital.
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31 Ethical Information

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33 Ethical approval was deemed not to be required for this study and was completed as part of
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35 a service improvement. Data was extracted was anonymised from the standard electronic
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37 patient record system. According to the Health Research Authority algorithm (see
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39 <http://www.hra-decisiontools.org.uk/research/>) this study was not defined as research and
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41 therefore did not require submission to the Integrated Research Application System (a single
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43 system for applying for the permissions and approvals for health and social care / community
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45 care research in the UK).
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51 The study was approved through the Trust's research ethics approval process. Data
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53 was extracted and anonymised from the standard electronic patient record system
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55 used in routine clinical care. According to the Health Research Authority algorithm
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57 (see <http://www.hra-decisiontools.org.uk/research/>) this study was not defined as
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[research and therefore did not require submission to the Integrated Research Application System..](#)

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