Developing an accessible and useful wellbeing measurement tool for adults with learning disabilities

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The team…

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Key points

- Aim – to make a pre-existing wellbeing measurement tool more accessible for adults with learning disabilities

- The accessible version was as reliable as two preexisting measures. The accessible version was more engaging, collaborative, and inclusive.

- However, it was still extremely resource intensive to use. Most respondents required support to complete.

- The accessible version is a potentially complementary data source in monitoring and evaluation, not a replacement for personalised approaches to understanding services users' wellbeing.

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Background…

- Increasing role of VCSOs
- Performance management of contracts, evaluation

Intellectual disability – a reduced intellectual ability and difficulty with everyday tasks that affects someone for their whole life
Voluntary and community sector (VCS) – non-profit groups focused on social impact, independent of government and the private sector
Wellbeing – how well we are doing as individuals

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AIM

to develop a standardised tool for measuring mental wellbeing that was accessible to adults with learning disabilities (and the people that support them) and that could be used in services for adults with learning disabilities as part of monitoring and evaluation

1. Scope existing measures and identify most suitable for adaption	→	2. Validate identified measure	→	3. Design & validate an accessible version	→	4. Test the 'real world' usefulness
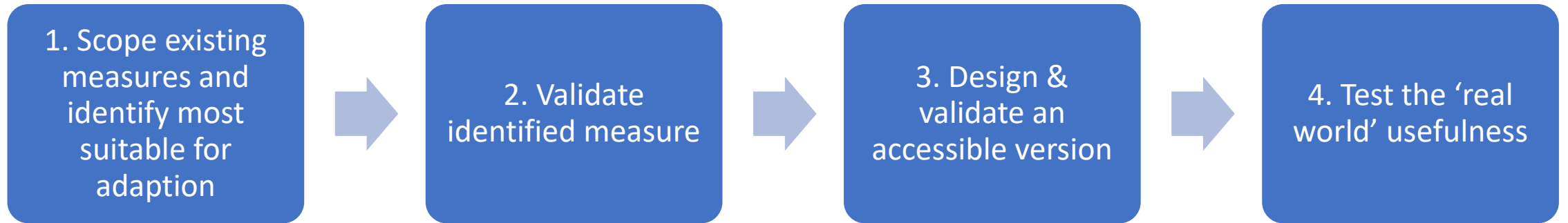
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1. Scope existing measures and identify most suitable for adaption

- Feb 2018 – eight databases searched for existing measures
(*PsycArticles*, *PsycInfo*, *PsycTESTS*, *MEDLINE*, *CINAHL*, *Academic Search Complete*, *ETS Test Collection*, and *Social Policy and Practice*)

- 8,493 publications, 168 unique measure. 34 had ≤10 items (questions).

- Assessment:
  - *Does the measure provide a general measure of wellbeing, or focused on a sub-domain(s) of wellbeing?*
  - *Has the measure been designed and/or validated with adults with intellectual disabilities?*
  - *How practical would it be to use the measure in a service delivery setting?*

- ***Personal Wellbeing Index – Intellectual Disabilities* (PWI-ID)**

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PWI-ID (Cummins & Lau, 2005)

Respondent's Rating
11-pt
(0-10)

Part I: Happy with Life as a Whole [optional]

"How happy do you feel about your life as a whole ?"

Part II: Personal Wellbeing Index – Intellectual Disability

"How happy do you feel about…?"

1. the things you have? Like the money you have and the things you own?

2. how healthy you are?

3. the things you make or the things you learn?

4. getting on with the people you know?

5. how safe you feel?

6. doing things outside your home?

7. how things will be later on in your life?
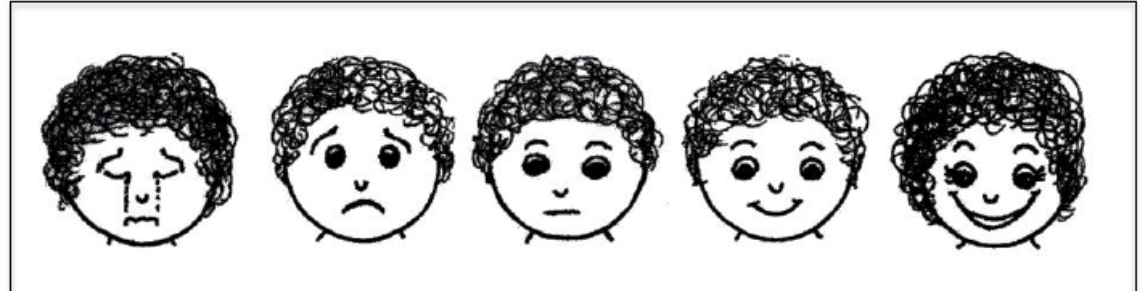
2. Validate the identified measure

No action needed

3. Design and validate an accessible version

Man sat down with his hands on his head looking sad and regretful

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Data collection

- Purple Patch recruited (purposively) participants services users
  - Level of impairment
  - current mental health status (not in crisis)

- 19 participants -
  - Each completed 3 measures (accessible PWI-ID, original PWI-ID, and SWEMWBS)
  - (Supported by Purple Patch staff)

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Results

	Accessible PWI-ID[1]	Original PWI-ID[1]	SWEMWBS[2]
Range	65-100	65-100	19-35
Mean	88.8	89	28.9

1 – 100 being high wellbeing possible, 0 being low wellbeing; 2 – 35 being high wellbeing, 0 being low wellbeing

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4. Test the 'real world' usefulness

- Asked participants about each measure, their preferences
- Interviewed the Purple Patch staff

➢ Preference for accessible version

	Accessible PWI	Original PWI-ID	SWEMWBS	Unclear/don't know
Frequency of participants	12	1	5	1

- Easier to use
- Engaging, interactive – tablet becomes a focus for collaboration
- Enjoyable – using a tablet, gamification
- Empowering – participants more in control (e.g. moving slider)
- More accessible – more likely to complete independently(??)
- Immediate feedback (e.g. star diagram)

- However…preference was for using face images on tablet, not 'personalised' images

➤ Challenges with accessible version
- Technical glitches
- Fine motor skills
- Confusion with 'personalised' images
- Distractions

"Whenever someone didn't chose the smiley face, it got to the point where my heart would sink a little bit because I knew that I was going to have to explain to them that five dogs or five pieces of pizza isn't happy or sad and that is a very hard concept to explain to anyone…how do you show negative dogs?"

➤ Terminology
- Issues with terminology in all measures (especially SWEMWBS) – extra explanation needed

➤ Use for monitoring & evaluation
- Standardised measures (even the accessible PWI) probably not quicker
- No substitute for personal relationships between staff and service users

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Conclusions

- We adapted the PWI-ID to be more accessible – a touchscreen slider that changed an image on the tablet screen

- New version 'worked' (statistically)

- Participants and staff preferred the new version – engaging, interactive, collaborative, empowering.

- However…the new version did not solve all challenges to measuring wellbeing and service evaluation.
  - Whilst more accessible, still resource intensive.

Conclusion…
A tablet-based tool is potentially more useful in a service setting than written questionnaires…but not a substitute for personalised approaches and relationship building to understanding individuals' wellbeing.

More research needed!!

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