

## MANIFESTO OF INCLUSIVE RESEARCH (UPDATE 2)

Clare Inclusive Research Group - Discussion Document

### MAIN IDEAS

“Let’s talk about doing good research”

INCLUSIVE RESEARCH SHOULD...

#### 1/ AIM TO MAKE OUR LIVES BETTER

Research which aims to change our lives, our communities and our society for the better

#### 2/ BE ABOUT OUR ISSUES & MAKE SENSE TO US

Research about our issues which makes sense to us and where our experience helps shape the form the research takes

#### 3/ REFLECT OUR EXPERIENCE

Research which records, values and talks about the experience of people with a learning disability

#### 4/ SUPPORT OUR CAMPAIGNS

Research where its information can be used by people with disability to campaign for change

#### 5/ HAVE ADVOCATES & ACADEMIC RESEARCHERS STANDING TOGETHER

Academic researchers should co-work with researchers with learning disabilities on their issues respecting the essential partnership. Academic Inclusive Researchers (A.I.R.) & Advocate Inclusive Researchers (A.I.R.)

*Without the A.I.R. there's nothing there*

#### 6/ MAKE THE RESEARCH PROCESSES AND FINDINGS ACCESSIBLE

All inclusive research should aim to make the materials of the research, proposals, questionnaires, surveys and especially the findings and recommendations of the research accessible to as wide an audience as possible

#### 7/ BE CLEAR ABOUT ETHICS

Where will the research take place?

How will the research be carried out? (in focus groups, 1:1 interviews etc., that individuals will be fully supported, that you can stop at any time)

Who will be involved in creating the research? Why is the research being done?

This must be made clear to all the researchers and to the responders before the research starts

#### 8/ GIVE ALL THE RESEARCHERS THE CHANCE TO SHARE IN ALL THE TASKS

Advocate Inclusive Researchers and Academic Inclusive Researchers should work together on ethical approval, training, separating out the data, thinking through research methods, ways of recording and communicating/promoting findings.

#### 9/ VALUE EXPERTISE AND EXPERIENCE

If inclusive researchers are asked to do a piece of research or asked to present their own research, a reasonable charge should be made and shared in a way that is agreed between the research team.

#### 10/ SAY "NO" TO TOKENISM

"It's a lonely road when you're on your own in a group." Advocates and all people relevant to the research should be well represented on the Research Team and Advisory Groups.

#### 11/ RESPECT, ENCOURAGE AND CELEBRATE ALL THE WORK OF THE TEAM

Each part of the work is important:

Whatever roles you play, thinking of questions, asking questions, recording answers, looking at what the research might mean, telling people about the findings, should be valued and appreciated.

#### 12/ THINK OUTSIDE THE BOX.

AIM TO EXPLORE DIFFERENT VIEWS AND DIFFERENT IDEAS.

Work with advocates from different worlds like people on personal budgets, in congregated settings, group homes, shared and individual homes, family situations. We should look at a broad range of topics raised by individuals and groups

#### 13/ BE FLEXIBLE

...be prepared to challenge and change your ideas and opinions

...be prepared to challenge and change your research structure

#### 14/ BE EYE CATCHING, FUN & FUNKY

Harness the creative skills of the research team (such as dance, poetry, drama, artwork, photos, music, film) to carry out and promote the research

#### 15/ DO RESEARCH IN NEW, EXCITING WAYS

Different places, different ways, different subjects, environment, climate change, new technology, zoom etc...

Points 1-5 are our easy read versions of 5 principles outlined in Walmsley J, Strnadova I and Johnson K. (2017) The added value of inclusive research p 759: JARID

MANIFESTO OF INCLUSIVE RESEARCH

## THE PROCESS

### THE INCLUSIVE RESEARCH SHOULD...

#### 1/ CHALLENGE THE GATEKEEPERS

Assume the competence of all potential responders. Seek the will and preference of the individual, respecting the role of service managers but looking to reach and uphold the rights of individuals.

#### 2/ REDUCE PEER PRESSURE

Setup research situations which reduce the peer pressure on individuals to agree or conform. Create small groups and one to one situations rather than large groups where people say yes without thinking.

#### 3/ PROMOTE A QUESTIONING APPROACH

Are we putting words in people's mouths? Are people only saying what they want us to hear? We should use open ended questions "Tell us about..."

"How would you describe...?"

#### 4/ TRACK THE CHANGES...

After we've worked on a research project, see what the follow up is. Who needs to hear about our findings? What changes are people asking for? A study can be a powerful tool for change...