

# Co-Production: Nothing About Us Without Us

*Jointly working together: Co-production is not just a word, it's not just a concept, it is a meeting of minds. A coming together to find a shared solution. In practice, it involves people who use services, being consulted, included and working together from the start to the end of any project that affects them.*

# Participatory Methods May Differ From More traditional Methods

- **Traditional Methodology:** One researcher plus multiple subjects. The Researcher instructs subjects. The Researcher collects data from subject performance. The Researcher analyses the data. The researcher informs the discussion from the analysed results.
- **Participatory Methods include:** Focus groups and multi stakeholder meetings, participatory inquiry, action research, oral testimonies and story collection as a foundation for collective analysis, photo- digital stories, photo-voice, drawing and essay writing competitions, participatory video, and immersions.



# Co-Researching together

- In participatory/co-produced research, participants have control over the research agenda, the process and actions.
- The process isn't dominated by any one person, but all are in it together.
- From agreement on the topic to research, to methods for enquiry, to the process of acquisition & analysing the data, to actioning any outcomes: we are in this together so it's ALL a joint affair.
- No one person has power over another.



# **Building capacity in a powerless population?**

- As autistics: used to having others make decisions for us.**
- As autistics: referred to by way of our 'deficits'.**
- As autistics: skills and strengths are undervalued and under employed.**
- Take time, work with us to enable 'healing' from hurt and pain. This foundation begins restorative structures leading to co-produced participatory credible research.**

[https://www.youtube.com/watch?v=iJjmFYSB\\_qo](https://www.youtube.com/watch?v=iJjmFYSB_qo)

# What co-production isn't

- One person's idea that others are invited to share in some aspects of, but the boss delegates.
- Involving another person in the beginning but not fully keeping them in the loop. You conclude they don't need to be involved in every thing!
- Sharing a research project proposal, staying on board together through the project but not sharing in the finished product.

# Partnerships?

**Can a partnership be a partnership if it's not equal?**

**Can we have equality between autistic & non autistic people?**

**We need to think how we can ensure an 'equal' Partnership. Then make it happen!**



# Co-production: Participation?

- **The Autism CRC (Cooperative Research Centre) in Australia held our first Research Academy in 2015... We learnt from this time and ran another one in 2017. We are running further academy days in 2019.**
- **We bring together a number of autistic adults , usually over 21yrs. Of age, and spend 3 days together learning about research (terms, methods, ideas, practice, dissemination etc.). We brought researchers and autistic individuals together, on neutral turf, for one day.**





# Researching Together Project

- **Upon mutual consultation it was decided we would create a visual dictionary of research terms. This was one way of gaining understanding of research terms while building capacity for researching together.**
- **<https://www.autismcrc.com.au/sites/default/files/inline-files/Research%20Academy%20-%20Visual%20dictionary%20of%20research%20terms.pdf>**

# Creating a safe space to share

- **My uneven skills shake confidence.**
- **AS & NT share together those things they find undermine ability**
- **Making time for processing**
- **Creating inclusive opportunities, environments and plans together for how to make it happen**

# Practically: I get lost easily, I might need...

- To work hard to focus upon processing. I might prefer to read ahead of any meeting.
- I might prefer to join with others over Skype or Zoom. I get lost if.
- I might work best when I don't attend with others, therefore we need to think of alternatives.
- We need to facilitate co-production via accommodating individual needs (sensory, processing time etc)
- What are the most comfortable circumstances for the team?



# Autistic Researchers

- **Come in all shapes & sizes**
- **May be verbal and interactive**
- **May be quiet and need time to think and process**
- **Have a wealth of knowledge & experience to share in ways that suit them**
- **Will bring perspectives to enrich the research process in ways that only autistic researchers can**
- **Will give authenticity and credibility to the work in ways not available if they are not included.**



# Communication

- **Sometimes it's hard to 'notice' when others are attempting to tell me something, like 'my time to talk' or 'time for you to stop'.**
- **I use a speaking clock on my laptop monitor because I'm not likely to notice someone putting up a hand or notice for time.**
- **What works for you?**



# My Experience of Co-production

- The first time I was valued for my ‘story’ but not treated as an equal (received flowers) rather than enumeration in dollars like the others .
- Valuing myself?
- Setting pay scale.
- Not over extending.
- Setting limits.
- Knowing my topics & keeping up to date.

# **Actions speak louder than words.**

- **HOW will we engage in research**
- **– inclusive practices – What does this mean?**
- **transforming how researchers do research –**
- **meaningful and inclusive partnership with autistic people will mean what?**
- **How are we planning and allowing for this?**
- **Do we need to challenge our own thinking?**



# What's our role to make sure our research is co-produced?

- **People**
- **Skills**
- **Environment**
- **Communication**
- **Continuity**
- **Community**



# Collaborative Co-production

***Collaborative co-production requires users to be experts in their own circumstances and capable of making decisions, while professionals must move from being fixers to facilitators'***

**(The Health Foundation, 2010. p. 3).**



# Questions?



**What about accountability?**

**Who takes the lead?**

**Who decides which research?**

**Who says what actions to take ?**

**What if the researchers don't agree?**



# Summary

- **Nothing about us without us:**
- **Capacity building to enable the benefits of participatory research means taking time to come together and work on upskilling autistic adults so we can appropriately contribute to: Nothing about Us Without Us.**

# Resources to look at?

- CRC: <https://www.autismcrc.com.au/>
- <https://www.autismcrc.com.au/search?fulltext=Visual+diction+ary>
- <https://www.education.sa.gov.au/supporting-students/children-disability-and-special-needs> (Nothing about us without us)
- <https://www.education.sa.gov.au/supporting-students/health-e-safety-and-wellbeing/health-support-planning/managing-health-education-and-care/neurodiversity/autism-spectrum>