

**University of  
South Wales**  
Prifysgol  
De Cymru

# **People with learning disabilities, inclusion and research**

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## Areas to be explored:

- How are people with learning disabilities excluded from research?
- How can inclusion be promoted?
- What are some of the challenges and opportunities?

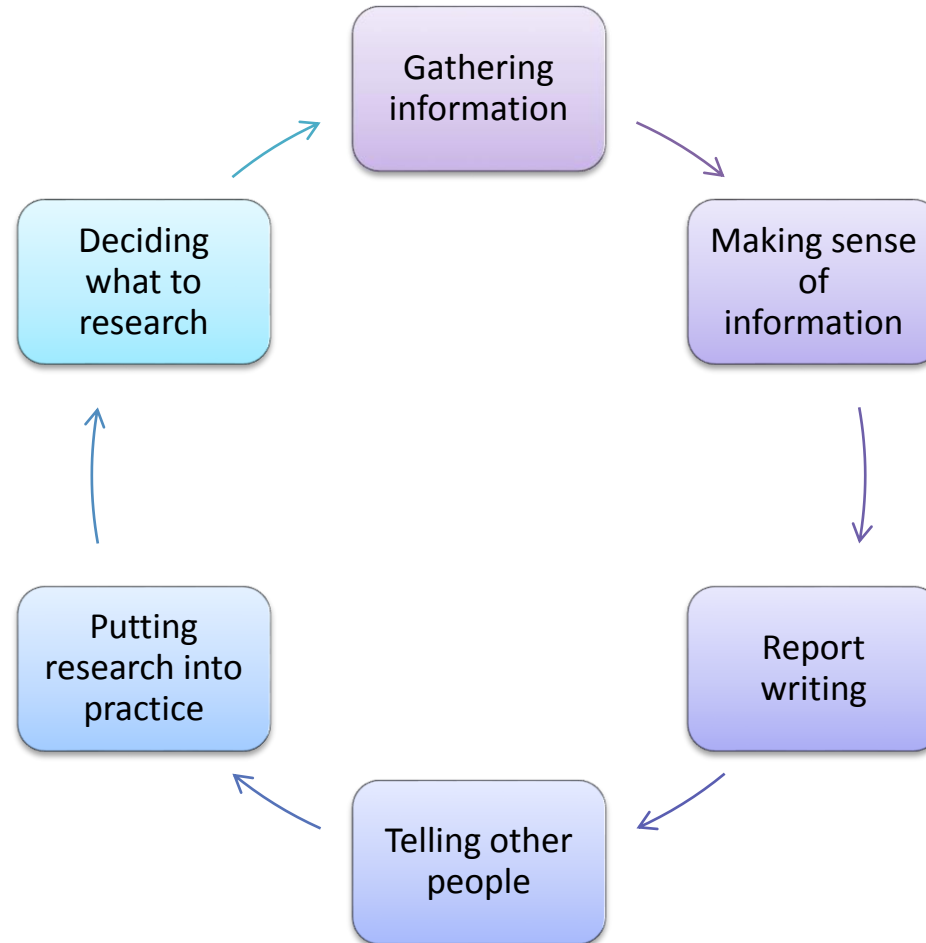
# Inclusion

Starting point =

The right to belong and  
to be included

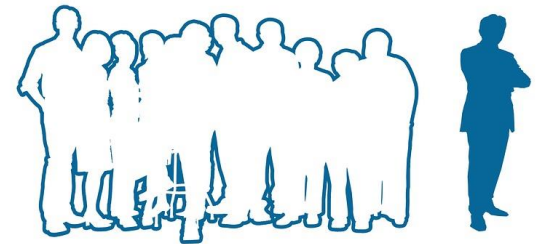


# Exclusion from Research

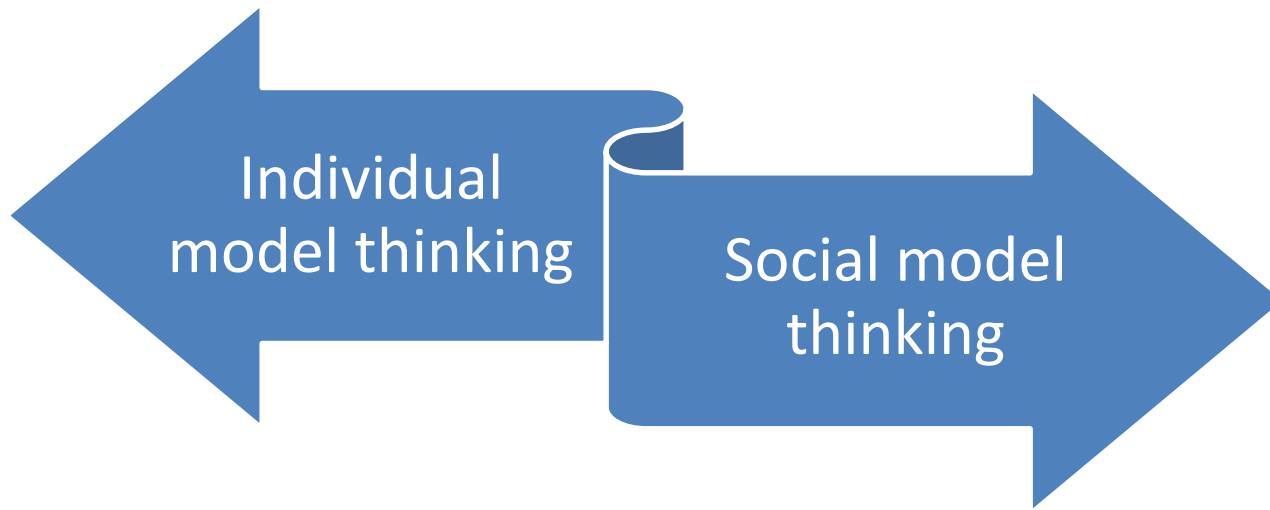


# Effects of Exclusion from Research

- Views and experiences not reflected in research
- Lack of access to innovative interventions
- Relevance?
- Further reinforces marginalisation and powerlessness



# Rethinking Inclusion in Research



# Barriers to Inclusion

- Prejudice and stereotypes
- Traditional ways of thinking about research
- Traditional ways of doing research
- Use of language



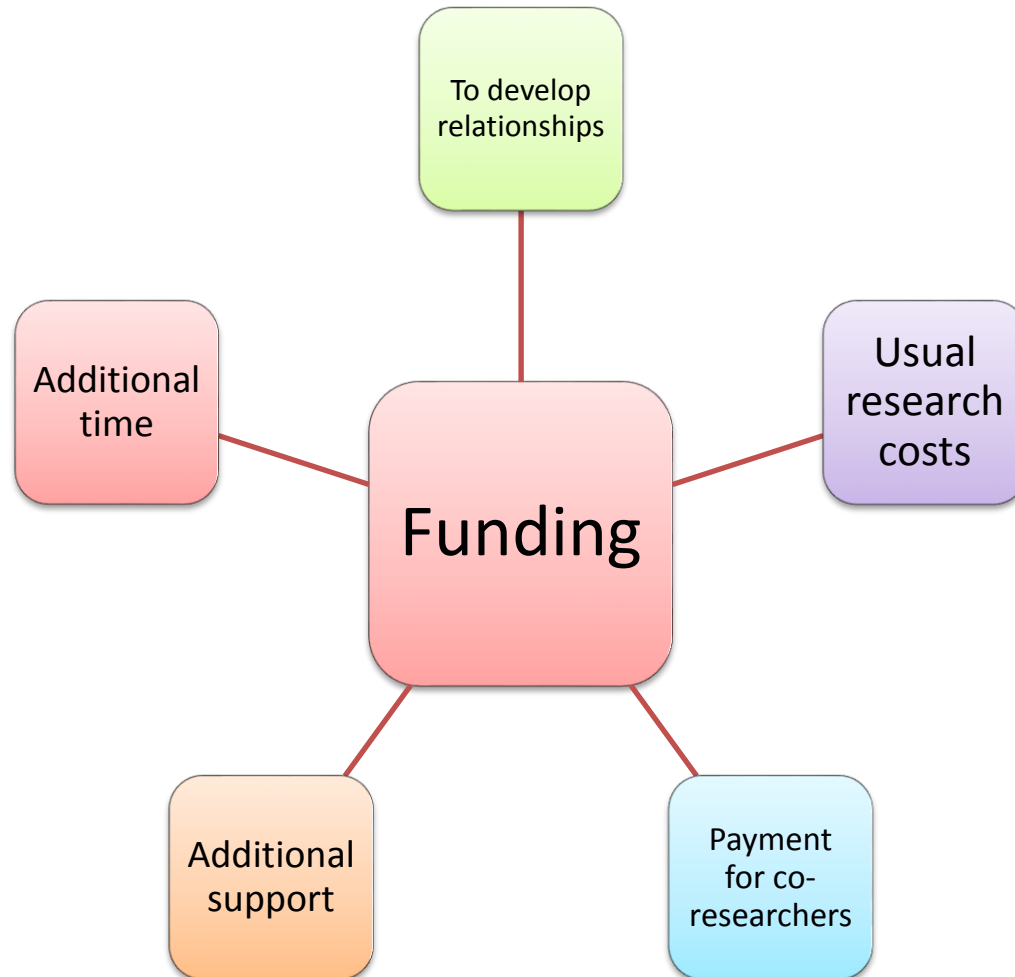
# Challenges

- Knowledge and skills
- Building partnerships and trust
- Ethical concerns
- Time
- Funding
- Organisational constraints

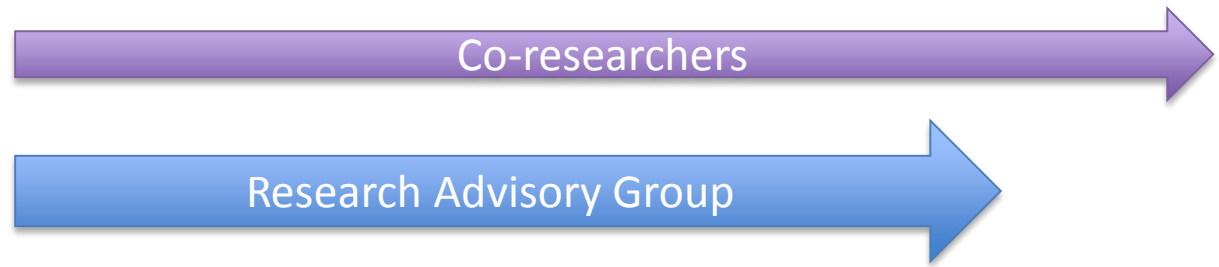




# Financial Considerations



# Looking Into Abuse (Research Project)



## Becoming a Researcher (Flood et al 2012)

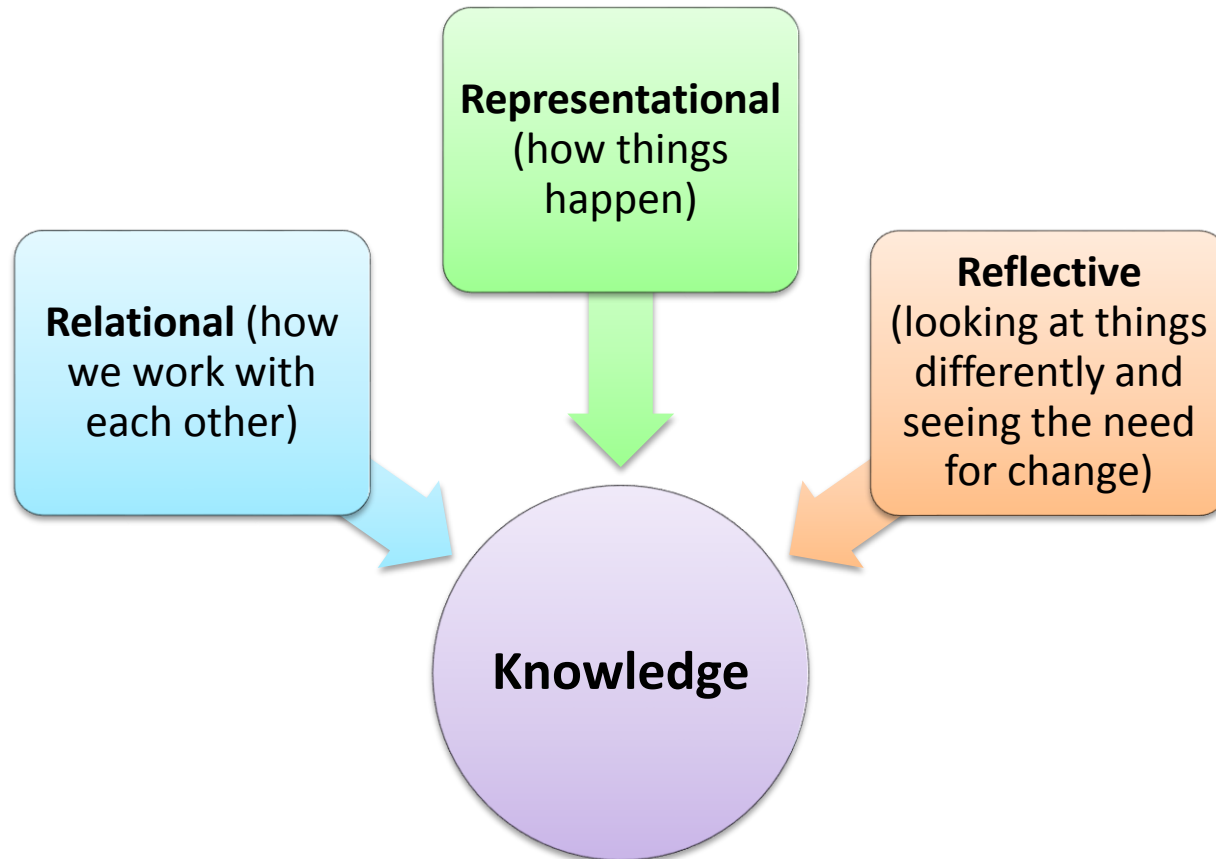
*'At the beginning, we found it difficult to speak up especially in big meetings. As we have got more confident, this has become easier.'*

*'Even though we have come across some difficulties, we feel it has been good to be challenged to do new things.'*

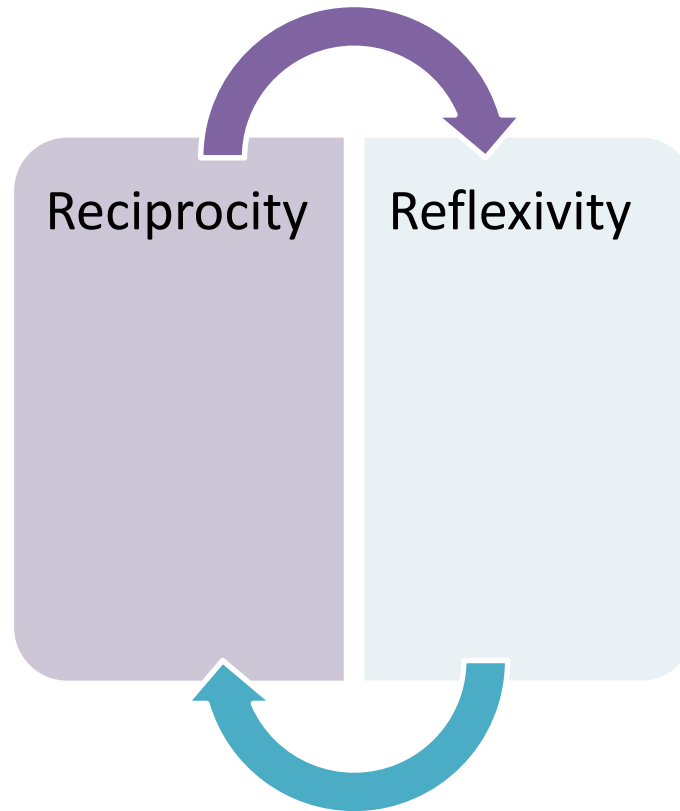
*'Having a job and working as a group are important to all of us. Meeting other people and working with other people have been good. It gives us a sense of satisfaction, and we feel we are helping people. We are more confident.'*



## Forms of knowledge (Park, 2001)



# Personal Considerations



# What is possible?



# Ways Forward

- Challenging our own perceptions
- Enhancing our own knowledge and skills
- Developing effective ways of working in partnership
- Identifying and removing barriers to inclusion
- Challenging accepted wisdom and approaches
- Don't be paralysed by the ideal



## Some Other Points To Consider:

- How do we promote inclusion in wider research?
- Is it just people with learning disabilities who are excluded from research?





## Further Reading

- Frankena, T., Naaldenberg, J., Cardol, M., Garcia-Iriarte, E., Buchner, T., Brooker, K., Embregts, P., Joosa, E., Crowther, F., Fudge Schormans, S., Schippers, A., Walmsley, J., O'Brien, P., Linehan, C., **Northway, R.**, van Schrojenstein Lantman-de Walk, H., Leusink, G. (2019) A consensus statement on how to conduct inclusive health research, *Journal of Intellectual Disability Research*, 63 (1) 1 – 11
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- Northway, R., Melsome, M., Flood, S., Bennett, D., Howarth, J., Thomas, B. (2013) How do people with intellectual disabilities view abuse and abusers? *Journal of Intellectual Disabilities*, 17 (4) 361 – 375
- Flood, S., Bennett, D., Melsome, M., Northway, R. (2012) Becoming a researcher, *British Journal of Learning Disabilities*, 41, 288 – 295

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