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Working in partnership: A project example focused on autistic parenting

Kabie Brook & Sue Fletcher-Watson

*Scottish Autism
Glasgow, November 2018*



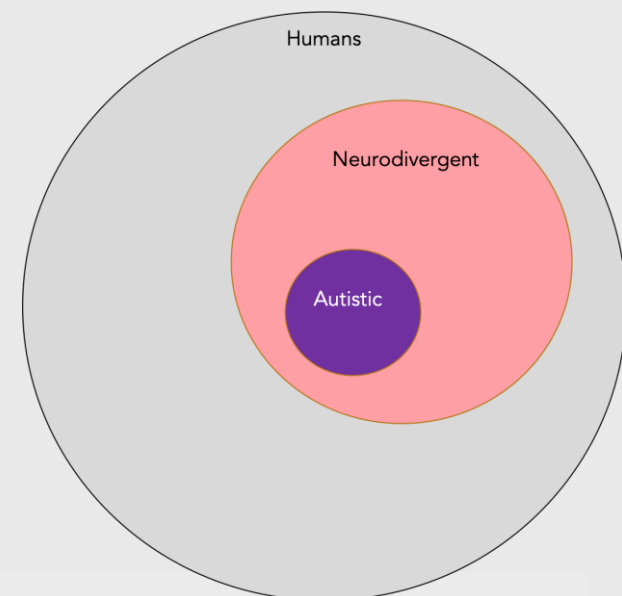
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What Neurodiversity Means...

- ◆ Neurological = brain based
- ◆ Diversity = differences / variation (within & between groups)
- ◆ Naturally occurring
- ◆ Associated with
 - ◆ Disability rights
 - ◆ Social / post-social model of disability
 - ◆ Autism, but other neurodivergencies too





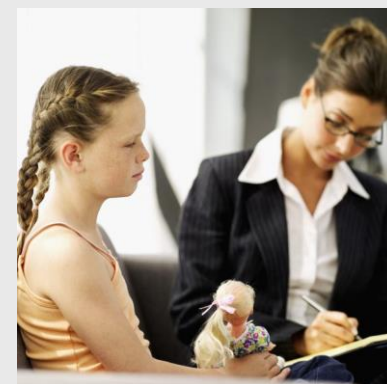
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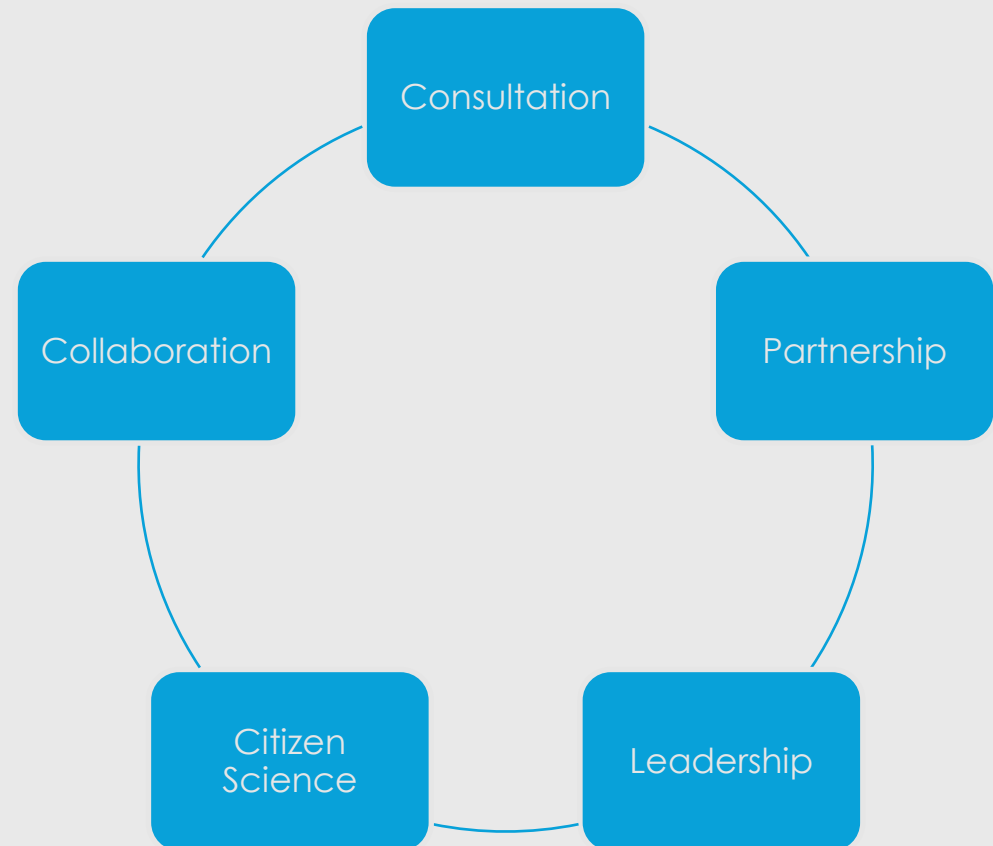
What it *doesn't* mean

- ◆ Denying disability, denying intervention or support
- ◆ Focusing only on adults who can advocate for themselves
- ◆ Excluding parents
- ◆ Introducing bias
- ◆ Forgetting about autistic researchers
- ◆ Abandoning good science



Applied neurodiversity

- ◆ Working with neurodivergent people
- ◆ Understanding their needs and priorities
- ◆ Delivering meaningful research
 - ◆ Useful
 - ◆ Respectful
 - ◆ Kind





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Outline

- ◆ Working in partnership: why?
- ◆ Working in partnership: how?
- ◆ A case example: autistic parenting project
- ◆ Issues for the future



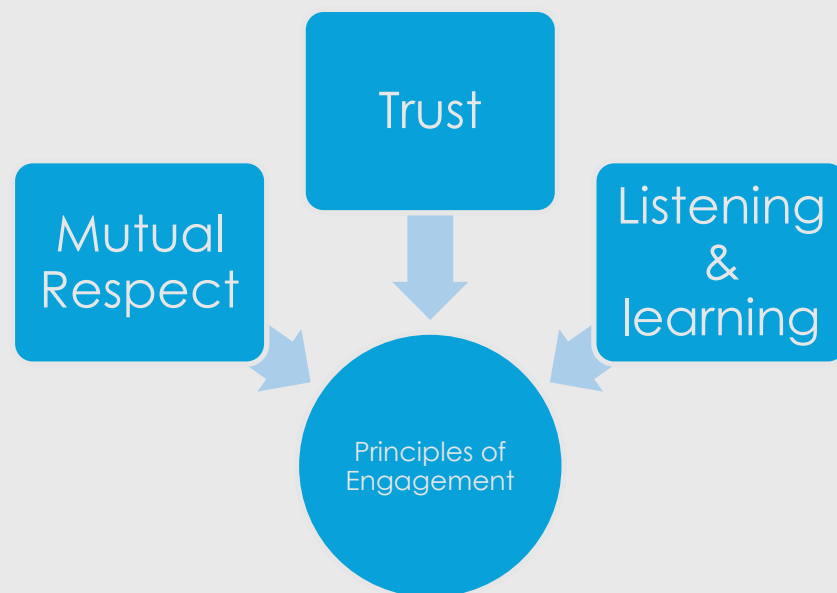
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The basics

- ◆ Building personal relationships
- ◆ Planning & preparation
- ◆ Fair payment
- ◆ Transparency, honesty
- ◆ Willingness to change



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The advanced model





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Autistic parenting & play

- ◆ Play is important in family life
- ◆ It also plays a key role in clinical and social care practice
- ◆ The odds are stacked against autistic parents
 - ◆ Unfamiliar setting
 - ◆ Not their preferred toys
 - ◆ Normative frameworks
 - ◆ Lack of knowledge among practitioners
- ◆ Outcomes can be severe



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A new project

- ◆ Review existing practices
 - ◆ What's reported in the literature? (systematic review)
 - ◆ What are researchers doing? (online survey)
 - ◆ What are practitioners doing? (survey & interviews)
- ◆ Detailed examination of one measure
- ◆ Contrast with autistic parents' experiences
 - ◆ Ethnographic explorations in the home
 - ◆ Interviews
 - ◆ Autobiographical notes



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Working together

Kabie

- ◆ Lived experience
- ◆ Focus on autistic parents
- ◆ Community connections
- ◆ Capacity to do an ethnographic study which a non-autistic person just couldn't do

Sue

- ◆ Research methods training
- ◆ Link to researchers and practitioners
- ◆ Proposal writing and project management
- ◆ Resources
- ◆ Prestige

Collaborative practices

- ◆ Working in partnership isn't easy
- ◆ Developing trust and mutual respect
- ◆ Establishing effective working practices
- ◆ Building a robust methodology
- ◆ Combating inertia while allowing for flexibility
- ◆ Agreeing to disagree



Thank you



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