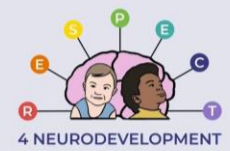




Responsible Neurotechnology

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Next generation neurotechnology: Benefits and risks



- Neurotechnology has the potential to revolutionise early detection, early intervention, targeted support for neurodivergent children, but
- What if neurotechnologies are not aligned with what users - children, families – want or need?
- "New" ethical and legal issues: What are the long-term effects of the technologies on people's lives
 - Potential misuse
 - Who can access them/ will pay for them?

Objectives of the Responsibility Working Group



- Identify main priorities and challenges for the responsible development of neurotechnologies for neurodivergent infants and children
- Outline avenues to address them
- Interface between participatory research, ethics and other working groups
- Help network members to be aware of/ address these considerations

Whose perspectives should be included in the design of neurotechnologies?



- Neurodivergent children
- Neurodivergent parents
- People from diverse cultural and socioeconomic backgrounds
- Funders
- Engineers
- Neuroscientists
- Clinicians
- Psychiatrists
- Psychologists
- Ethicists

Focus groups

Risks and benefits of different types of neurotechnologies for different clinical applications?

Type of application

Type of neurotechnology

		Type of application					
		Early detection	(Pre-emptive) intervention	School support	Other		
Type of neurotechnology	Eye-tracking					Respondent	Neurodivergent respondent
	EEG						Parent of neurodivergent child
	MRI						Parent of typical developing child
	Brain stimulation						

Respondents: Autistic people (who also have an autistic child)

- If I come from a professional view, it will be good to have [a] likelihood marker in the range of 25% . As a mother, without understanding the scientific background, I would never go with a child of a few months or up to 2 years to have an MRI to check that there might be an issue of autism, without having traits in the family.
- False negatives are a problem: they may prevent access to support for many years
- For me I would only want to know if particular interventions are available. it's like predictors of getting a heart attack in 10 years. If it doesn't change anything for me, I wouldn't want to know. if I had a child with autism that cannot speak and something that could be given to my child, then I would do the MRI or EEG.
- It helps parents to prepare

Practical considerations:

- Repeated hospital visits are a burden. Every time stress for families
- Many of our parents [without autism in the family] don't see the need to get a diagnosis at first. They don't like extra medical tests if they are not necessary. If someone says they are having an MRI or EEG, it's a very scary place. ...It's very tiring for families with neurodivergent children, to go there and have a meltdown
- I think for every child it's important not to get tested too often. Because of development concerns. It has an effect on a child if they are singled out for a test.... If [the test] is covert, like eye-tracking in tablets, it's less of an intervention, a disturbance
- Who pays for it?

Example: Early interventions



Early pre-emptive intervention:

- having modifications from the start is probably not a good idea because you don't know what the issues are. If you take away stimuli [sensory input]...for a child that potentially doesn't have the issue it would also mean that the child doesn't learn how to cope with those stimuli. You would make the environment far too protective.
- If it's low risk [executive function training] do it for all.

Early targeted intervention

- ... if you start early on basics, at the roots, there was never a negative experience, because you offer to the child how to developmentally go from the point they are. But if you start from ABA, which is no good for us, I don't do ABA.
- I make the child's surrounding applicable to the child's needs, not my needs.

Scalability group

- How can we ensure that neurotechnologies do not exacerbate existing healthcare and societal inequalities
- We must ensure that scalable neurotechnologies are culturally appropriate
- We must have safe/robust ways to store/transfer potentially sensitive data, particularly if using scalable technology in the community

Personalisation group

- If we move to more personalised measures, is there a risk that this might detract from people's group-based identities (e.g. autistic identities)
- How can we make sure personalisation approaches don't magnify disparities (e.g. through biased algorithms)

I have a great neurotechnology, where do I start?

- Turn to the participatory research committee for help
- Invite a broad and varied base of stakeholders to the conversation to begin with
- Listen to stakeholder needs, set capturing methods accordingly
- Be open to novel methods!



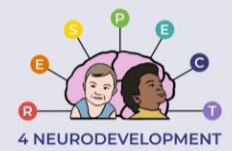
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Consulting those with lived experience



- Consider implications for your project of childrens' parents being neurodivergent themselves: e.g. executive functioning, communication needs, informed consent.
- Consider hospital play specialists or occupational therapists – children with complex needs may perceive some experiences as intrusive.
- 'Apraxia – proofing!' – discuss how to make devices robust to associated wear and tear, and that the process of using them is as safe as possible.
- Discuss the child's role in assent/consent process and consider how you can make this accessible to them.
- Consider the potential harm of too much sensory load associated with neurotechnology and explore how to mitigate this.
- Explore multiple methods of communicating and engaging with with participants so that your project is as accessible as possible – e.g. videos/home visits/phone calls.
- Consult on participant preferences regarding data storage and sharing – a standardised approach to this across the network would be helpful.

How to ensure that different perspectives are integrated in neurotech development?



- Establish timelines for each point raised to be addressed.
- Assign accountability per point raised to help with extrinsic motivation
- Commit to feeding back any actions taken to your PPI group
- Collaborate with your PPI group to determine an appropriate rubric for assessing whether a point has been adequately addressed