



# Interventions, Supports, and Autistic People's Experiences

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# What is Autism?

- **Deficit**, biomedical perspective
  - Autism is a “disorder”, “disease”, or “condition”
  - Person *with* autism: autism is separable from the person; can and should be ‘cured’
- **Neurodiversity**, social perspective
  - Autism and other neurological differences are part of human variation (Silberman, 2015)
  - Both strengths and weaknesses (not a disorder or superpower)
  - Autistic: autism is a core part of the person’s identity; cannot and should not be ‘cured’
- Differing perspectives of autism and challenges faced by autistic people may relate to the **double empathy problem**: “mutual incomprehension” (Milton, 2014, p. 800)
  - Autistic people are the experts in their own experiences

# Strengths of Autistic People (Grant & Kara, 2021)

- Hyperfocus/monotropism
- Excellent attention to detail
- Direct communication/honesty
- Loyalty
- Different ways of thinking, perceiving the world
- Empathy
- Hyper-plasticity of the brain - affects learning, creativity, and memory (Wilson et al., 2017)

# Challenges Faced by Autistic People

## Traditional Autism Professionals' Perspective

- Social communication and interaction impairments, e.g.,
  - Lack of theory of mind
  - Non-speaking or minimally speaking
  - Difficulties reading and following instructions
- Restrictive and repetitive behaviours
  - Echolalia
  - Stimming
  - Intense interests
  - Rigid routines
- Co-occurring conditions (e.g., epilepsy, intellectual disability)

## Autistic People's Perspective

- Loneliness
- Ostracism, "othering", and bullying (school, work, home)
- Unemployment or underemployment
- Sense of identity (defective versus different)
- Anxiety and depression; suicide (66% to 17% suicidal ideation, Cassidy et al., 2018)
- Physical health challenges (secondary to mental health; reduced access to appropriate care)
- Shorter lifespan

# Improving Autistic People's Lives: Two Approaches

- 1) Intervention:** strategy or treatment aimed to bring about change (in the individual/environment)
- 2) Support:** strategy to maximize access and accessibility

Intervention

# Intervention

- Aim to remediate or “cure” autism (make autistic people appear to be non-autistic/ conform to norms)
- Most closely aligns with deficit, biomedical perspective of autism
- Historically, developed and implemented by non-autistic professionals, without consulting with autistic people; power
- Endorsed by many/most parents of autistic children
- Dominant approach

# Interventions: Learning Theories

- Behaviourism (Skinner, 1957; Lovaas) – Applied behavioural analysis (ABA or IBI)
- Cognitivist theory (Piaget, Greenspan) – looking within the individual; focuses on the attributes of the learner rather than the environment (similar to biomedical models of disability)
- Humanist/social constructivism (Rogers, Berger and Luckman, Campbell) – looking at multiple perspectives and life experiences; building on strengths and interests



# Key Considerations about Interventions

- Milton (2017, p. 89)
  - What is it all for?
  - What is one trying to achieve and why?
  - Are there ethical issues regarding these purposes, or the means by which one tries to achieve them?

# Do Current Interventions Meet the Goals of Autistic People?

- Behavioural

- <https://www.youtube.com/watch?v=MuwYUYHwrJc&t=264s>
- Trauma
- Conflicts of interest in ABA research - Professional industry
- Autistic community fighting against ABA

- Cognitive

- Individualized
- Normative/developmental

- Humanist/ Relationship-based/Social Constructivist

- <http://thecaldwellautismfoundation.org.uk/index.php/gabriel/>
- <..\OneDrive\OneDrive Documents\Carleton Course\Speech and Language Problems 2009\Autism\Videos\Alex and Playdoh.mpg>

- Eclectic approaches/individual clinicians

Support

# Support

- Change the environment to minimize/eliminate barriers to participation
- Advocated for by autistic adults
- Most closely aligned with neurodiversity perspective
- Aim to increase the well-being of autistic people, as defined by them

# Autistic Well-being and Belonging (Milton & Sims, 2016)

- Meeting personal needs
- Living with the consequences of an 'othered' identity
- Connection and recognition
- Relationships and advocacy

# Examples of Supports

- Intercultural exchanges
- Education to promote intercultural communication
- Multi-modal information/ communication (e.g., written, audio, images; asynchronous)
- Sensory-friendly spaces
- Changes in funding priorities
- Unconditional accommodations

# Approaches to (Re-)Designing Systems

Approach	Universal Design	Inclusive Design	** Design Justice **
Description	Design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.	Design that considers the full range of human diversity with respect to ability, language, gender, age and other forms of human difference.	Design that is led by marginalized communities and uses collaborative, creative practices to explicitly challenge, rather than reproduce, structural inequalities.
Pros	<ul style="list-style-type: none"> <li>• Consideration towards the needs of diverse users</li> <li>• Marketable: standardized, can help 'everyone'</li> </ul>	<ul style="list-style-type: none"> <li>• Respects the uniqueness of each individual</li> <li>• Acknowledges that users are experts in their own experiences</li> <li>• Users are active participants in the design process</li> </ul>	<ul style="list-style-type: none"> <li>• Intentional recognition of diversity/ intersectionality and power imbalances</li> <li>• Equity is prioritized</li> <li>• User-led</li> </ul>
Cons	<ul style="list-style-type: none"> <li>• Unrealistic</li> <li>• Does not explicitly acknowledge who will benefit, be excluded, be harmed</li> <li>• Erases certain groups of people</li> <li>• Majority is still prioritized</li> <li>• Designer is the 'expert'</li> </ul>	<ul style="list-style-type: none"> <li>• Not necessarily user-led</li> </ul>	<ul style="list-style-type: none"> <li>• Relatively new; under-utilized</li> </ul>

# The Way Forward

- Must prioritize autistic people's lived experiences and perspectives
- Autistic people with diverse backgrounds should be partners and leaders in research and design processes
- Shift focus to creating supports and eliminating barriers to access them
- Interventions must be neurodivergent-affirming and consensual
- Commitment towards disability/social justice and transforming society