



Supporting flourishing Autistic lives

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1. What needs to change in autism research
2. Autistic flourishing and the Capabilities Approach
3. The task ahead



Changing our approach to research

What needs to change

The orthodox approach to autism research remains firmly embedded within a conventional medical paradigm. There is an:

1. overfocus on 'deficits' or 'impairments'
2. overemphasis on specific attributes of individuals as opposed to people's broader contexts
3. over-reliance on Autistic life goals that are defined by others

This narrow focus on deficits results in a radically constrained understanding of the experiences that shape Autistic lives, limiting the range of supports and services to those that seek to 'change the individual' rather than consider how to 'change the world'

A new approach

Research that accepts the importance of Autistic flourishing should:

1. Prioritise Autistic wellbeing
2. Recognize that Autistic people's life chances are shaped by a range of social, economic and other factors
3. Amplify Autistic autonomy
4. Co-design and co-produce for the future





A Capabilities Approach

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1. A capability is an actual opportunity to be or do something in the world.
2. Having (or not having) a capability is very rarely just the product of our own strengths/weaknesses. It is the result of society, politics, economics and the environment too.
3. Capabilities are not specific outcomes, set in advance. Instead, they are what allow a person to make their own choices in the world.

1. Life

Being able to live a life of normal length

Unfortunately, socio-economic and other disadvantages lead Autistic people to die younger than non-autistic people

There is little knowledge of what ageing well means for Autistic people and the most effective ways to support it

“I recognise that I often don’t realise just how bad things have become. In the last year I have started thinking about suicide, even though I don’t want to die, and that has been the thing that’s made me realise how bad things might be”

2. Bodily health

Being able to have good health; adequate nourishment and shelter

Autistic adults' constrained access to healthcare influences their bodily health

Homelessness and other housing concerns are higher among Autistic adults than non-autistic adults

"I had become homeless ... the ground was frozen at that time so it was quite cold ... I had two pancakes a day and I lived off of water during those times ... I went from something like ten stone down to six"

3. Bodily integrity

Being able to move freely from place to place; being free from violent assault; sexual satisfaction & reproductive choice

Bodily integrity is crucial for reducing victimization of Autistic adults, including sexual violence

Safety on, and accessibility to, public transport are a particular concern

“It’s harder for me to rely on instinct because in my childhood I was often told that I don’t have instinct so I was told to always doubt my gut”

4. Senses, imagination & thought

Being able to use the senses; to imagine, think and reason; to have freedom of expression, including pleasurable experiences

Greater recognition of distinctive Autistic imaginative and sensory experiences is needed

“I remember as a child spinning all the time and loving spinning and loving swinging and feeling that movement all the time ... it actually still feels glorious if there’s nobody around and I can skip or I can spin and it’s like I’m breaking the rules”

5. Emotions

Being able to have attachments to things and people and to feel a range of emotions; not being blighted by fear or anxiety

Loneliness and social isolation
are acute for many
Autistic adults

Greater efforts at ensuring
social acceptance could
substantially improve wellbeing

*“I never knew how much I
actually needed human
interaction and how much
humans actually are
somewhat a valuable
component of my life”*

6. Practical reason

Being able to form a conception of the good and reflect about the planning of one's own life

Autistic adults often report challenges in everyday-life and life-course planning

New support programmes offer promise for supporting Autistic people's goal-setting and decision-making skills

“Even if I feel totally relaxed and happy, you know, some days, I can't formulate the plan so I don't go out at all and that happens once or twice a week. So that is very disabling”

7. Affiliation

To live with/show concern for others; to engage in social contact; to be treated with dignity; not being discriminated against

Peer groups and friendship networks are a priority for many autistic adults

Face-to-face services and community building activities are of vital importance

“With my autistic friends ... people are very sensitized to people being or feeling left out ... so many of them seem to make a really big effort to stop that from happening ... I don’t have to make all the effort, which is how I feel with neurotypical people. Autistic people are willing to meet halfway”

8. Other species

Being able to live in relation to the natural world

Autistic adults intensely value their relationship to the natural world

Access and support services are key to supporting this connection

“Blue and blooming every which way, Blown in the breeze each and every day. I walk past you morning and afternoon, You remind me to stay strong and always stay in bloom”

9. Play

Being able to laugh, play and enjoy recreational activities

Greater social acceptance is required of Autistic people's passions and interests

It is also important to ensure recreational activities are accessible to Autistic people

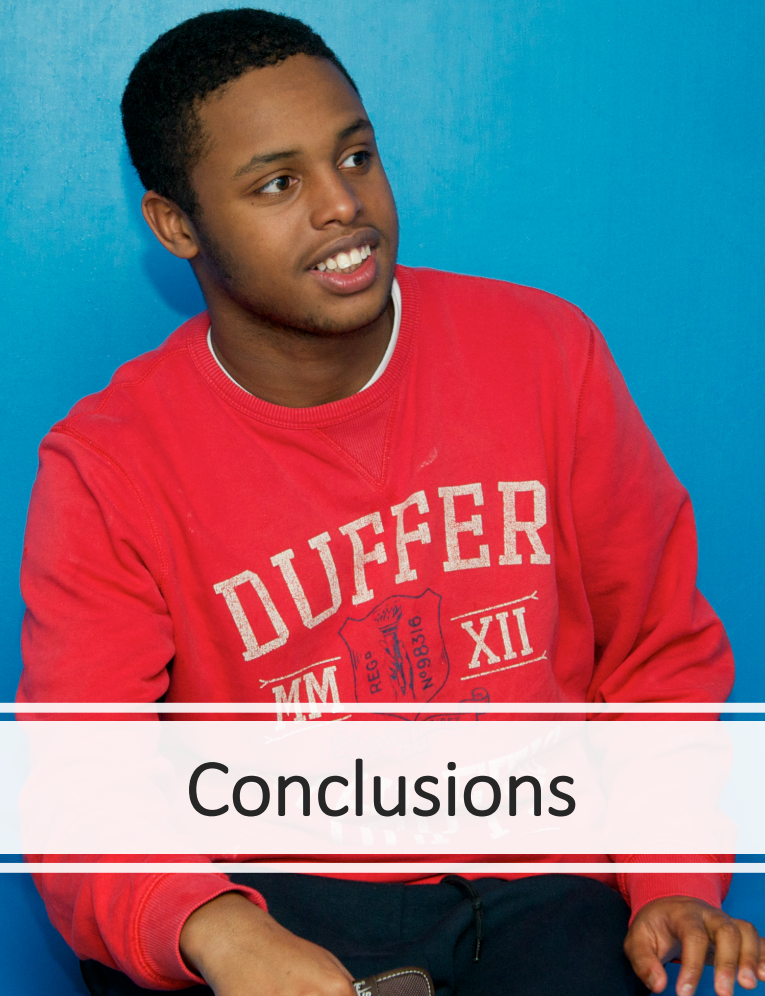
“Why is obsession bad and the ability to focus on something that you like [good]. Why was Sir Isaac Newton bad when he was so obsessed about that apple falling from that tree?”

10. Control over one's environment

To participate in political choices; to hold property and to have access to employment on an equal basis to others

Autistic self- advocacy organizations and workplace reforms have the capacity to extend Autistic agency and control

“For three months, I’ve managed to gain experience which is absolutely priceless. ...It’s been absolutely great”



Conclusions

REVIEWS



A capabilities approach to understanding and supporting autistic adulthood

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Available at:

<https://rdcu.be/cUZkz>

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