



# THE FOUNDATIONS OF AUTISTIC FLOURISHING

# The Foundations of Autistic Flourishing

**01 WHERE WE ARE:  
PANDEMIC LESSONS**

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**02 WHERE WE WANT TO GET TO:  
TOWARDS A THEORY OF AUTISTIC FLOURISHING**

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**03 HOW WE MIGHT GET THERE:  
CHANGING OUR APPROACH TO RESEARCH**





# PANDEMIC LESSONS

# Triple Jeopardy

“

People with disabilities have been differentially affected by COVID-19 because of three factors: the increased risk of poor outcomes from the disease itself, reduced access to routine health care ... and the adverse social impacts of efforts to mitigate the pandemic ... Risk of death from COVID-19 between Jan 24 and Nov 30, 2020, in England was 3·1 times greater for men with disabilities and 3·5 times greater for women with disabilities than for men and women without disabilities

”

TOM SHAKESPEARE ET AL.



# **EVERYDAY LIFE DURING COVID-19: WHAT'S IT BEEN LIKE FOR YOU?**





# THE SOCIAL IMPACT OF THE PANDEMIC

“

I didn't realise how important that incidental human contact was to me. It was so incidental that it never really registered on my radar until it was gone ... The paying for the petrol at the service station, as much as it shits me ... because I work with an assistance dog right, so everywhere I go, I've got this giant, white, majestic beast next to me. So, the soundtrack of my life is, 'oh my god, it's a dog. It's a beautiful dog. What kind is he? How old is he? What does he do?' And like, that drives me bananas most of the time, and I've actually found myself even missing that

[Autistic adult]

”



“

I've always looked at those sort of islands you see for sale going, I could totally be a hermit and just like live somewhere in the middle of nowhere and never see another person, happy days. Because people are really exhausting. But this has taught me that actually I do need people. I think the first, probably six weeks I didn't have enough contact with people and that made my mental health worse

[Autistic parent]

”



# Overarching pandemic lesson

The pandemic reminded us that *human flourishing* should be our fundamental goal as a society and that such flourishing extends beyond basic material and physical security



**DANIELLE ALLEN**

Edmond J. Safra Center for Ethics's  
COVID-19 Rapid Response Initiative



TOWARDS A THEORY OF AUTISTIC FLOURISHING

# Sources



Creating Capabilities  
THE HUMAN DEVELOPMENT APPROACH

MARTHA C. NUSSBAUM

## DON'T MOURN FOR US

Jim Sinclair  
NO. 2 IN THE AUTISTIC UK "KEY TEXTS" SERIES

Parents often report that learning their child is autistic was the most traumatic thing that ever happened to them. Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle. But this grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have. Parents' attitudes and expectations, and the discrepancies between what parents expect of children at a particular age and their own child's actual development, cause more stress and anguish than the practical complexities of life with an autistic person. Some amount of grief is natural as parents adjust to the fact that an event and a relationship they've been looking forward to isn't going to materialize. But this grief over a fantasized normal child needs to be separated from the parents' perceptions of the child they do have: the autistic child who needs the support of adult caretakers and who can form very meaningful relationships with those caretakers if given the opportunity. Continuing focus on the child's autism as a source of grief is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them. For their own sake and for the sake of their children, I urge parents to make radical changes in their perceptions of what autism means.

I invite you to look at our autism, and look at your grief, from our perspective.

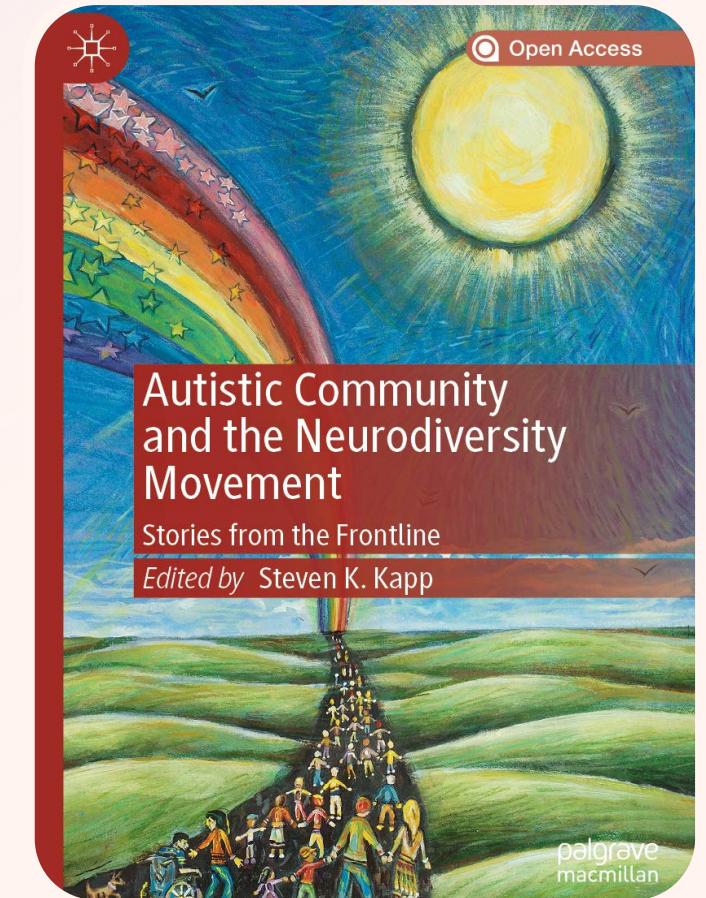
**Autism is not an appendage**  
Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism.

Autism is a way of being.  
It is pervasive.  
It colours every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence.  
It is not possible to separate the autism from the person.  
And if it were possible, the person you'd have left would not be the same person you started with.

This is important, so take a moment to consider it.  
Autism is a way of being.  
It is not possible to separate the person from the autism.  
Therefore, when parents say, "I wish my child did not have autism", what they're really saying is, "I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead".

Read that again.

This is what we hear when you mourn over our existence.  
This is what we hear when you pray for a cure.



# Sources

Jon Adams  
Monique Botha  
Virginia Bovell  
Hayley Clapham  
James Cusack  
Michelle Dawson  
Jac den Houting  
Emma Gallagher  
Katie Gaudion  
Tori Haar  
Gabrielle Hall  
Melanie Heyworth

Julianne Higgins  
Steven Kapp  
Wenn Lawson  
Joanne Mahony  
Damian Milton  
Ari Ne'eman  
Bec Poulsen  
Melissa Richings  
Marion Rabuka  
Abby Sesterka  
Allison Shefcyk  
Robyn Steward



# 1. From Health to Wellbeing

The orthodox approach taken in autism research remains firmly embedded within a conventional medical paradigm

- It prioritises 'bodily health' over 'wellbeing'
- It conceptualises autism as an undesirable deviation from some 'normal' state of health

# 1. From Health to Wellbeing

“

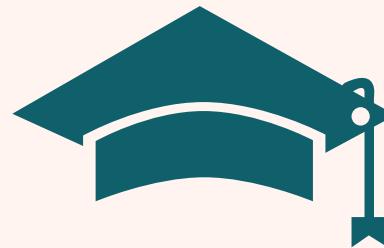
Autistics, like non-autistics, have genuine difficulties in many areas, and like non-autistics, require assistance in areas where their performance is weak. . . But autistics uniquely are seen as pathological when displaying significant or dramatic strengths, creating for Autistics a nearly insurmountable disadvantage or disability not faced by non-autistics

”

MICHELLE DAWSON & LAURENT MOTTRON

## 2. From Other-Defined to Self-Defined

Adult outcome and quality of life studies have also tended to follow the normative tendencies of the conventional approach



## 2. From Other-Defined to Self-Defined

“

Human beings ... are creatures that need to chart their own courses in life. They thrive on autonomy, the opportunity for self-creation and self-governance

”

DANIELLE ALLEN

### 3. From the Big to the Small

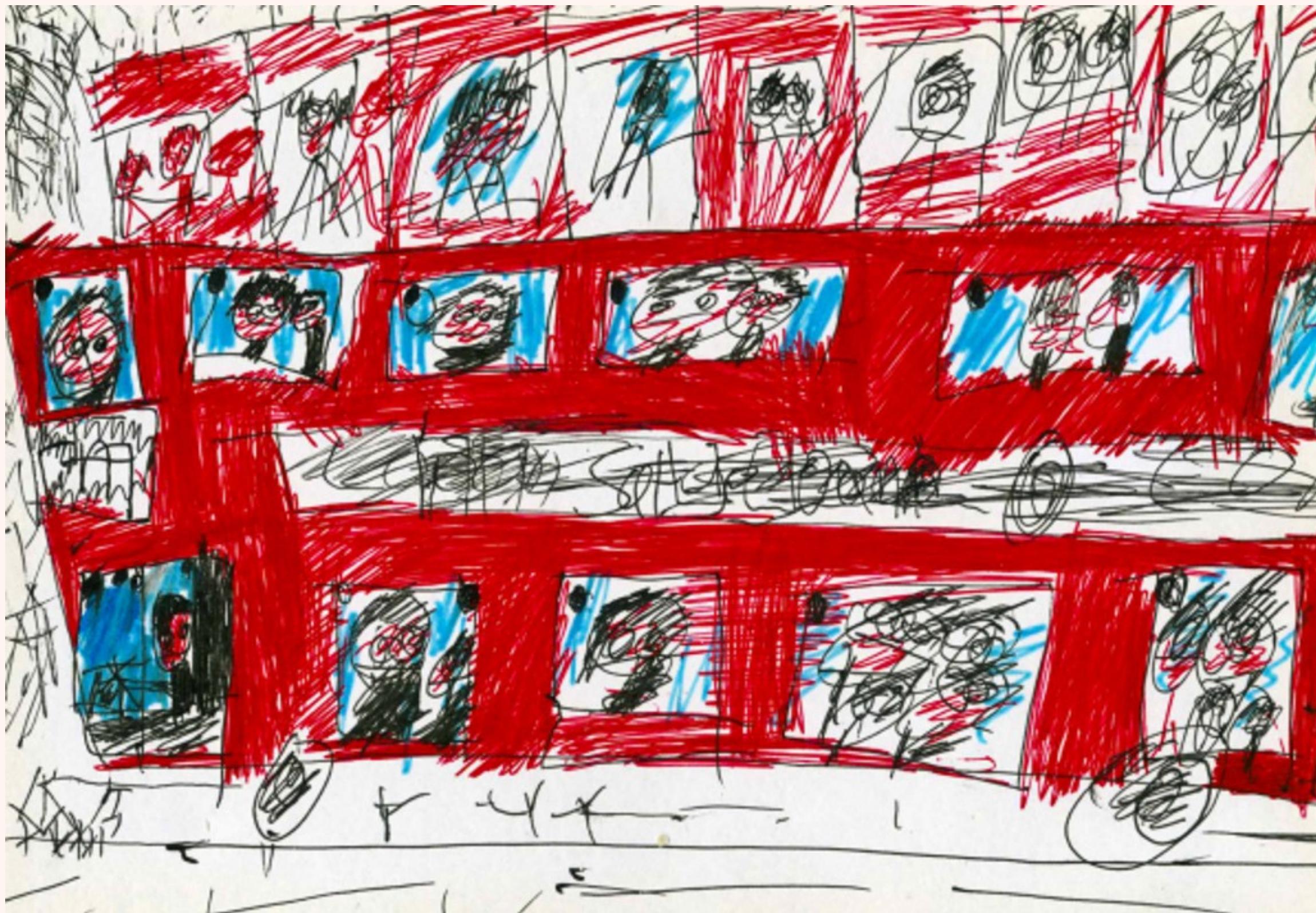


“

I fill in all these questionnaires  
and do everything I can to help  
... but when it comes down to it,  
it's not real life. It's always  
missing the next step. It's great  
you've done this research,  
you've listened to my views ...  
but now do something with it

[parent]

”



#JUSTICEFORLB

### 3. From the Big to the Small

“

Pretty much everything  
in my life that I loved  
doing was taken and  
was just gone...

[Autistic adult]

”

“

The meaningless stuff  
had become meaningful  
and needed...

[Autistic parent]

”

## **4. From the Individual to the Contextual**

Within the conventional model, autism and its associated disabilities are seen as something inherent to the individual

This individualistic starting point suggests that the ‘fault’ for difficulties in life resides with the individuals themselves - and the burden of ‘correcting’ perceived difficulties lies there, too

## 4. From the Individual to the Contextual



“

It sort of metronomes everything in your body to sort of go at that speed... so it just sort of helps quell everything

[Autistic adult]

”

STEVEN KAPP ET AL.



## 4. From the Individual to the Contextual

“

Taking into account the reality of context necessitates that we wrestle with the systematic power asymmetries that structure the world we share, which then requires us to account, and seek to mitigate the effects of oppression and domination

”

DEVA WOODLY

## 5. From Researcher-led to Autistic-led

“

Right from the start, from the time someone came up with the word “autism”, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced

”

DONNA WILLIAMS

## 5. From Researcher-led to Autistic-led

Autism science has typically been designed and conducted without any significant input from Autistic people and their families - which results in feelings of disenfranchisement



LIVED  
EXPERIENCE

RESEARCH  
EXPERIENCE





CHANGING OUR APPROACH TO RESEARCH

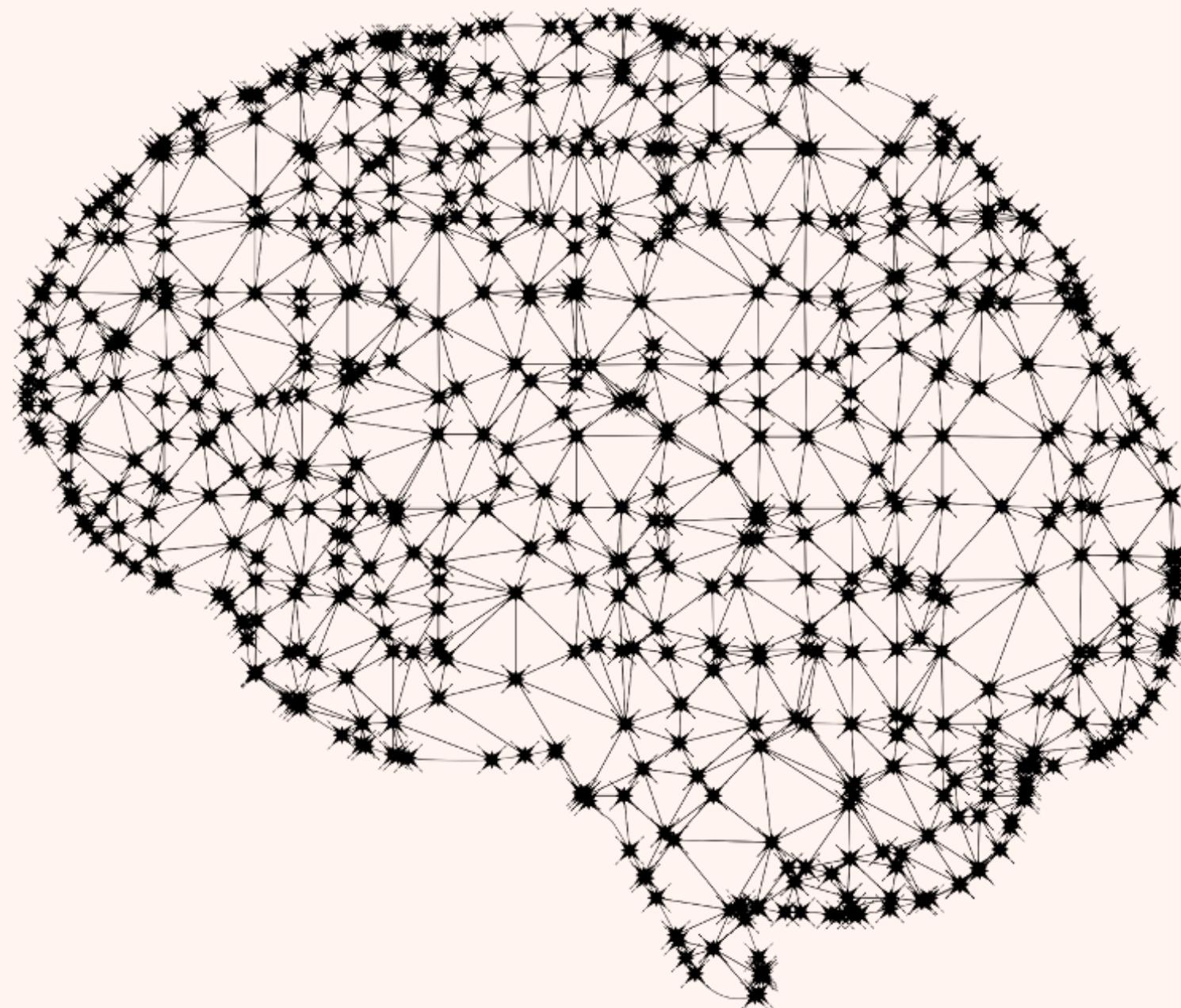
# A New Approach to Practice

Research that accepts the importance of Autistic flourishing will:

- 01 GIVE WELLBEING PROMINENCE**
- 02 AMPLIFY AUTISTIC AUTONOMY**
- 03 ATTEND TO THE EVERYDAY**
- 04 ACKNOWLEDGE CONTEXT**
- 05 CO-DESIGN AND CO-PRODUCE**

# Executive Function (EF)

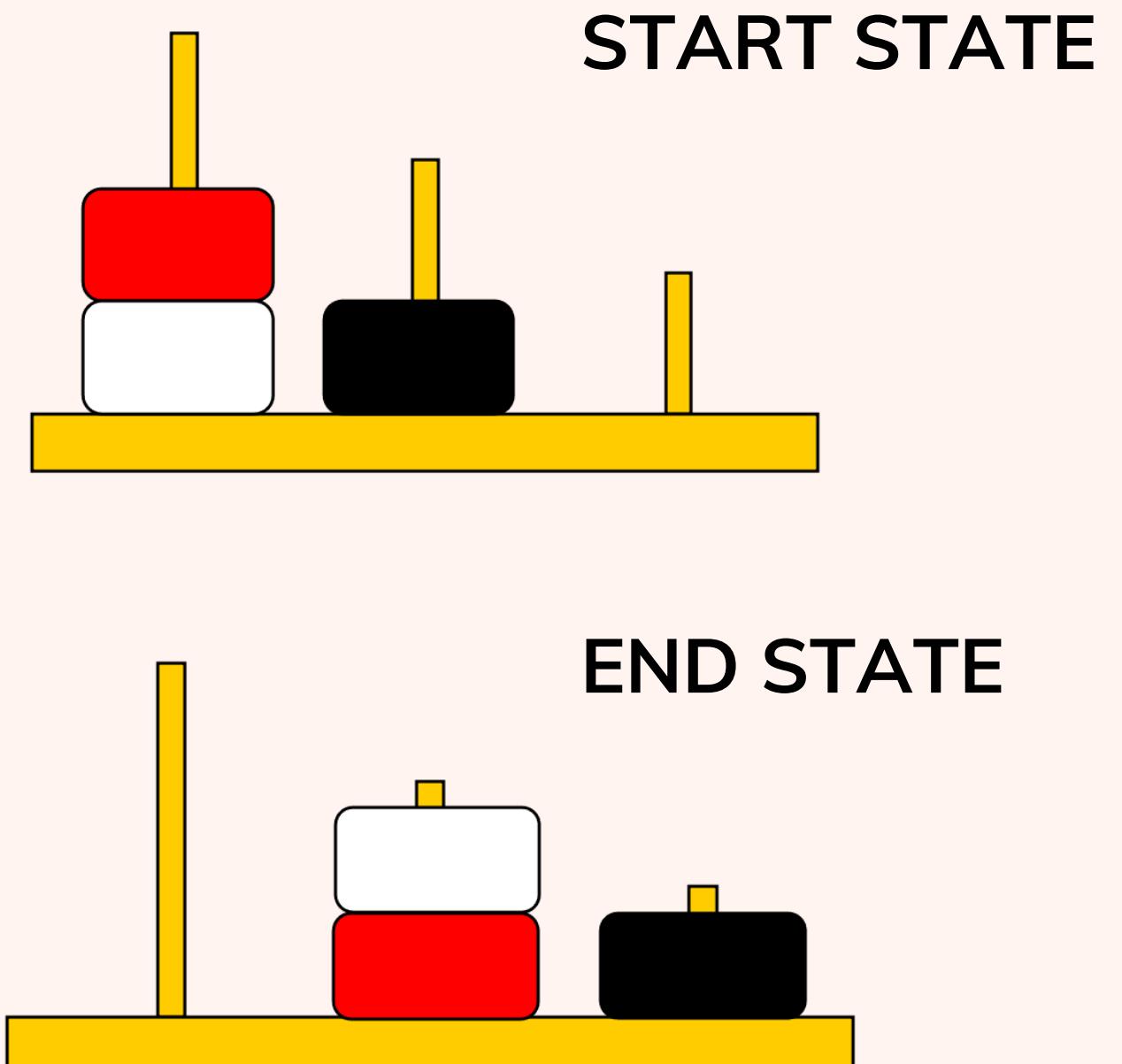
Researchers have long held that Autistic people have EF problems – but the literature remains contradictory and “confusing” (Kenworthy et al., 2008) and doesn’t map on to anecdotal reports of real-world executive issues



# Executive Function

Why is there such a disparity?

Structured experimental tasks fail to model abilities in contexts that are typical of everyday life, like shopping in the local grocery store or finding one's way around a new town



# Real-life Executive Function

“

So, if it's something which I really don't like, I find that I'm often a lot slower than if it's something which I really do like... And yeah, sometimes my Mum has said stuff like, 'Once you've finished your college assignment, you can play your clarinet' and I'm just like, 'Well, seeing as I really don't enjoy clarinet playing, I don't think I'll ever get [laughter] this assignment done

[Autistic young person]

”



## Monotropism (Murray et al., 2005)

“

I have a one-track mind. And that's nothing to be particularly ashamed about, it's just the way I work... I just think it's because my mind, like subconsciously or consciously, just prioritises one piece of information over the other, and for that reason I'm not able to remember everything

[Autistic young person]

”

# Autistic Inertia / Flow

“

It's the single most disabling part of being Autistic  
for me. It's a daily struggle

[Autistic adult]

”



“

The flow feels really good while I'm in it. It's fantastic. I'm actually doing something. I'm actually making progress, or I'm actually making a difference. I'm doing something that I like to do for once

[Autistic young person]

”

# Autistic Hidden Histories



## Share Your Story

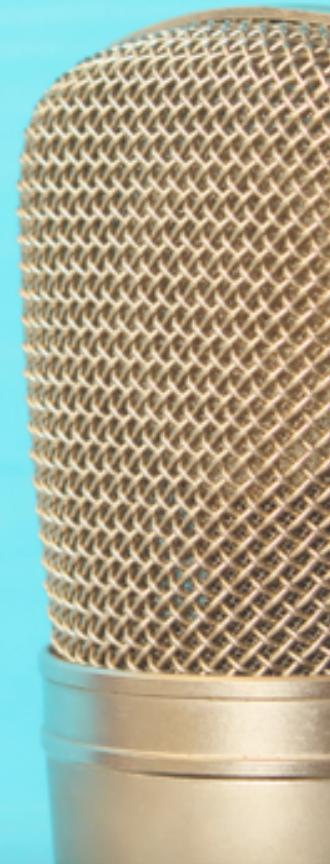
### Autistic Hidden Histories

We'd love to hear from you, if you are:

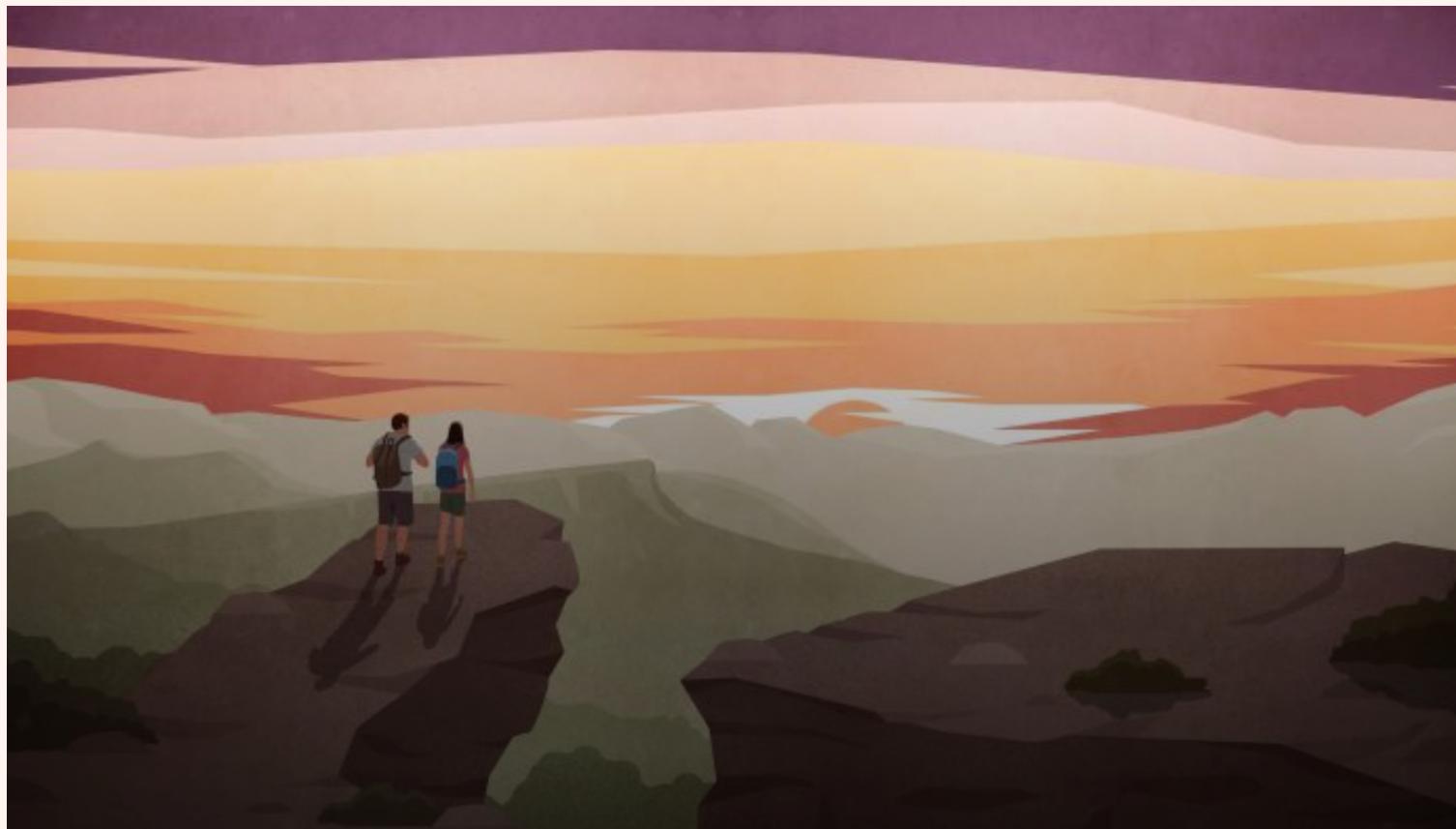
- Aged 45 years and over
- Diagnosed after 35 years of age
- Spent most of your life in Australia
- Willing to have your story recorded and made available to the public

You'll be sharing your story with another late-diagnosed autistic adult. They've helped design this research project.

To register your interest, please email  
[hidden.histories@mq.edu.au](mailto:hidden.histories@mq.edu.au)



# Autistic Hidden Histories



“ And what was my life before diagnosis? It was bits and pieces of disconnected things . . . I was a failure, right? And there was no centre. But there was a centre, me, the centre is I’m Autistic. And that explained all of that

[Veronica]

”

Our study revealed the vital importance of deep and sustained efforts at genuine co-production in all aspects of autism research





## CONCLUSIONS

# Thanks

All of my many brilliant collaborators – Autistic and non-autistic – for their wonderful insights and all of the wonderful Autistic children, young people, adults, their families and those who support them, who have so generously taken part in our research

And to Ben Connors and Jon Adams - Flow Observatory for artwork



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