



ON THE PROMOTION OF AUTISTIC FLOURISHING



Understanding Autistic adulthood



REVIEWS

Check for updates

A capabilities approach to understanding and supporting autistic adulthood

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Abstract | There is little comprehensive research into autistic adulthood, and even less into the services and supports that are most likely to foster flourishing adult autistic lives. This limited research is partly because autism is largely conceived as a condition of childhood, but this focus of research has also resulted from the orthodox scientific approach to autism, which conceptualizes autistic experience almost entirely as a series of biologically derived functional deficits. Approaching autism in this way severely limits what is known about this neurodevelopmental difference, how research is conducted and the services and supports available. In this Review,

PELLICANO ET AL., 2022, NATURE REVIEWS PSYCHOLOGY

The core of my argument

- Autistic people should be able to live full and flourishing lives, regardless of their background or characteristics
- And it is our job, as autism researchers and practitioners, to make our own contribution to making that flourishing possible

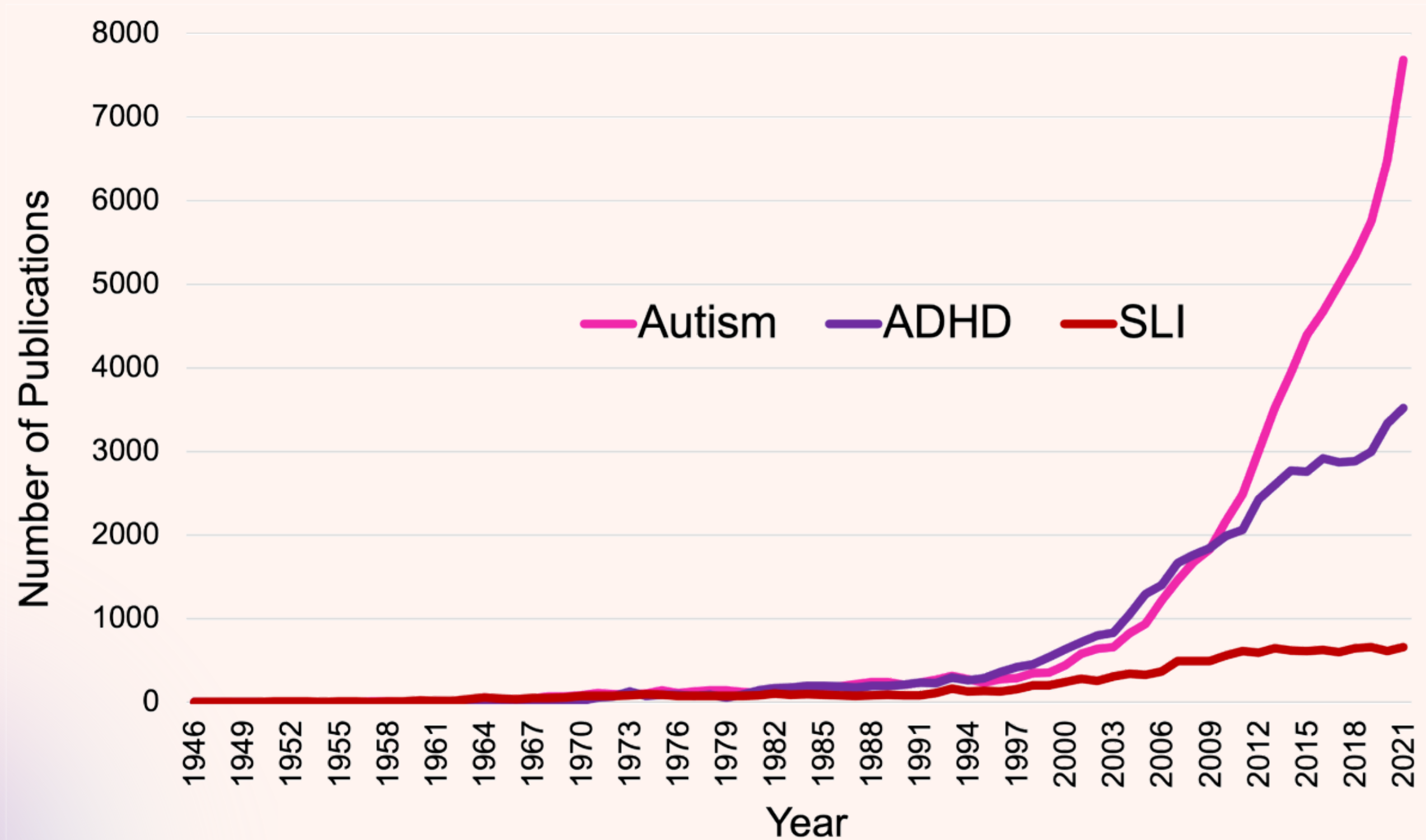
**Billions of
dollars
worldwide for
autism research**



2016 ASD Research Total Funding and Project Counts by Country

Country	Funding Amount in U.S. Dollars (Percentage of total funding)	Project Count (Percentage of total project count)
United States	\$364,435,254 (92%)	1,360 (88%)
United Kingdom	\$14,848,929 (4%)	59 (4%)
Canada	\$10,719,396 (3%)	74 (5%)
Australia	\$5,854,451 (1%)	59 (4%)
Grand Total	\$395,858,120	1,552

Explosion in autism science



Autistic people and economic inequality

Only a minority of Autistic people enjoy full-time, paid employment. Unemployment rates in the UK are higher for Autistic people than other disability groups (Office for National Statistics, 2021). This is despite many Autistic people being willing and able to engage in employment.

And those who are employed, are all too often in posts that are deemed unsuitable: malemployed and/or underemployed

Autistic people and social inequality

Autistic people are far less likely than non-autistic people to live independently when they want to do so, or to report having friends and more intimate relationships

Many Autistic people have co-occurring difficulties with their physical and mental health, which can be debilitating

And most disturbingly, Autistic people die, on average, too many years earlier than non-autistic people – and more likely to die of suicide

PELLICANO ET AL., 2022, NATURE REVIEWS PSYCHOLOGY



Photo features Zoe Gross, then Director of Operations at the Autistic Self Advocacy Network (ASAN)



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:

1. An overfocus on 'deficits' or 'impairments'
2. An overemphasis on specific attributes of individuals as opposed to people's broader contexts

**PELLICANO ET AL., 2022, NATURE REVIEWS PSYCHOLOGY
PELLICANO & HEYWORTH, 2023, CURRENT PSYCHIATRY REPORTS.**

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*'

Academics weren't taking enough notice of real-life issues



“

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]

”

Left out of the decisions around research

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



Unfortunately, community views on autism research haven't changed

“ We're always described by what is 'wrong' with us, as disordered neurotypical people rather than normal, healthy Autistic people

”

“ A lot of autism research is full of blind spots and false assumptions, because it's still failing to fully incorporate Autistic perspectives

”

Amplifying Autistic autonomy

Amplifying Autistic autonomy



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

Harvard University



What do we need to do differently?

We need to identify key dimensions of a flourishing life, but leave the content of each of those dimensions flexible enough to respond to the particular needs and desires of people themselves



FOUR DIMENSIONS OF AUTISTIC FLOURISHING

Four dimensions of Autistic flourishing

1. PEOPLE
2. PLACE
3. PURPOSE
4. POWER

Four dimensions of Autistic flourishing

1. PEOPLE

2. PLACE

3. PURPOSE

4. POWER

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





ILLUSTRATION BY
BRIAN STAUFFER

Far from welcoming the isolation that came from lockdown, Autistic people reported deeply missing the social contact that used to be a key aspect of their world

**PELLICANO ET AL., 2021, AUTISM
SCHEEREN ET AL., 2023, CURR DEV DISORD REP.**

“

All the social aspects of my life have been cut out

”

“

I can't deal with being isolated like this... I just want to hug someone

”

“

I don't need a lot of human contact... but I have been really needing a lot more contact from my friends than I perhaps usually would

”



PEOPLE

How can we support Autistic friendship and family, enable them to be comfortable, confident and authentic in those relationships?

How can we deepen the human relationships Autistic people have with those who care for and support them – like teachers, work colleagues, clinicians?

How can we develop a deeper empathy between non-Autistic people and Autistic people in a host of social interactions?



Four dimensions of Autistic flourishing

1. PEOPLE

2. PLACE

3. PURPOSE

4. POWER

“

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]

”



PLACE

What is required to enable Autistic people to be fully connected to the world around them?

What can enable Autistic people to enjoy a sense of belonging to their communities?

And how can they hope best to relate to nature and the environment and to enjoy the physical and sensory spaces in which we all reside?



Four dimensions of Autistic flourishing

1. PEOPLE

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Autistic Flow

“

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 adult]

”

RAPAPORT ET AL., 2023, *AUTISM IN ADULTHOOD*
POPAZOV ET AL., IN PREP.





“

It's when that internal voice stops. No, stop's not the right word. You're not second-guessing, you're not worrying about what anybody else is thinking. You're not worried about anything. You're just existing. It's purely being who you are, kind of thing. And they're just pure thoughts.

[Autistic adult]

”

PURPOSE

How can we ensure that Autistic people have the best possible opportunity to shape their own lives?

How can Autistic people be supported best to engage in creative recreation?

How can we ensure that they can make their own social, spiritual and other affiliations, rather than have those affiliations determined by others?



Four dimensions of Autistic flourishing

1. PEOPLE

2. PLACE

3. PURPOSE

4. POWER



“




For three months, I've managed to gain experience which is absolutely priceless. I've not only felt like I've further improved on skills I've gained before joining this internship, but I feel like I've gained lots of new and different skills I could've never thought I would have achieved. It's been absolutely great

[Autistic adult]

”

REMINGTON ET AL., 2021, AUTISM

I AM NOT A
PUZZLE

I AM A
PERSON

NOTHING
ABOUT US
WITHOUT
US

AUTISM SPEAKS
DOES NOT
SPEAK
FOR ME

**Extending
Autistic agency
and control**



POWER

How can Autistic people's citizenship be properly recognised and power be more equitably shared in our key institutions?

What do we all collectively need to do to enhance the capacity of Autistic self-advocacy?

And how can we ensure that every Autistic person has the best possible chance of influencing the decisions that shape their lives - including in therapeutic contexts?





Autistic Autonomy – what it means to Autistic people and why it matters

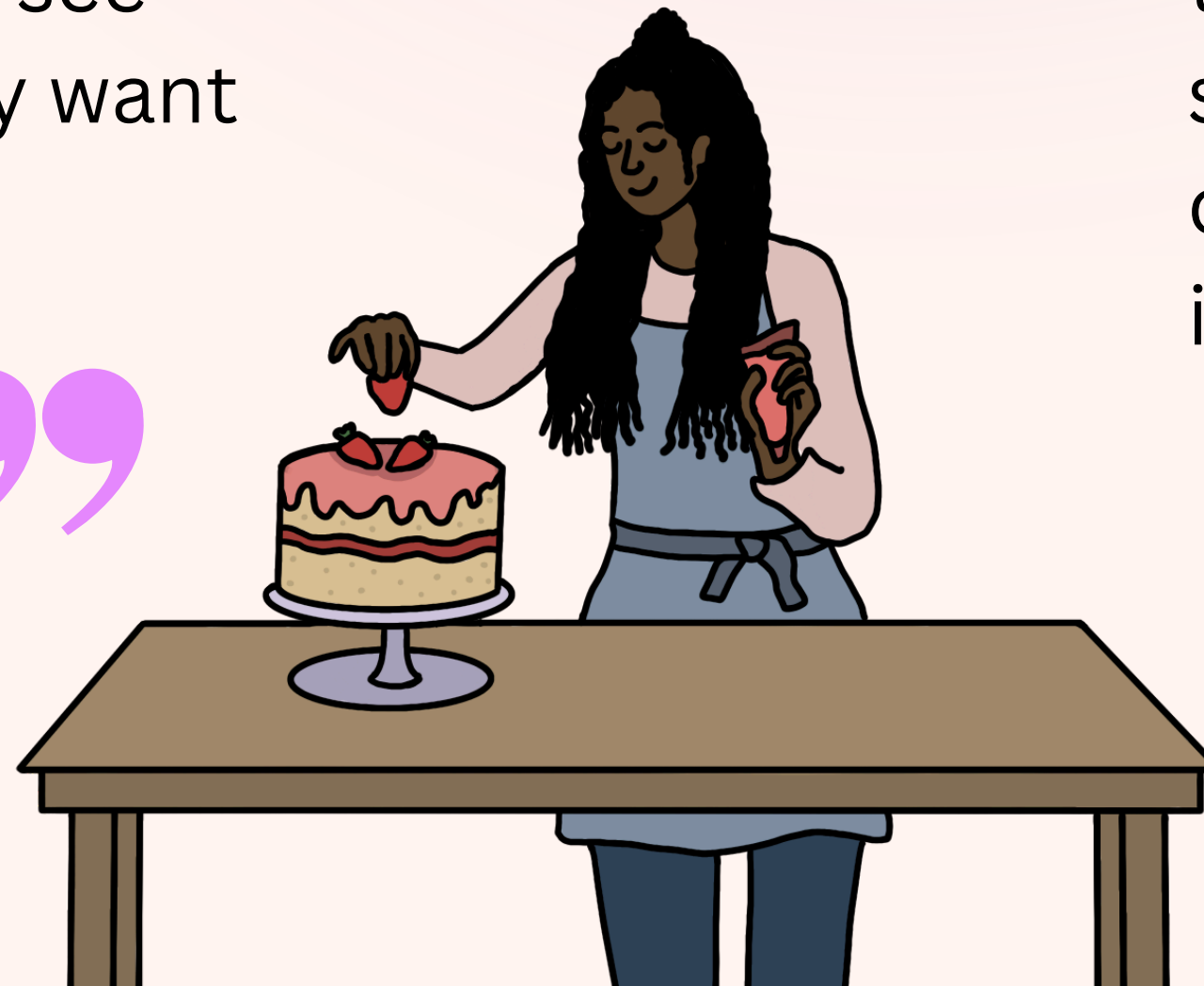
Autistic Autonomy – what it means to Autistic people and why it matters



We wanted to hear about the role that autonomy plays in Autistic people’s everyday lives - the moments when they felt able to make the choices that matter to them, and about the times when things, or other people, have gotten in the way and stop that from happening

Sally's story

“ I'm of Nigerian background, and my family's belief is Christian... And I guess that affects like how they see things, and what they want for my life, too – like marriage and kids, for example ”



“ Some people say that I'm vulnerable... and sometimes I think I'm vulnerable too... but the charity's view is that I should meet people in the church or the library, which is a very backdated view ”

POWER

And how can we ensure that every Autistic person has the best possible chance of influencing the decisions that shape their lives?

How can we support other people – parents, teachers, carers – to promote Autistic people's autonomy, rather than limit it?





CONCLUSIONS

**LIVED
EXPERIENCE**



**RESEARCH
EXPERIENCE**

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 Observatorium for artwork



Australian Government

Australian Research Council