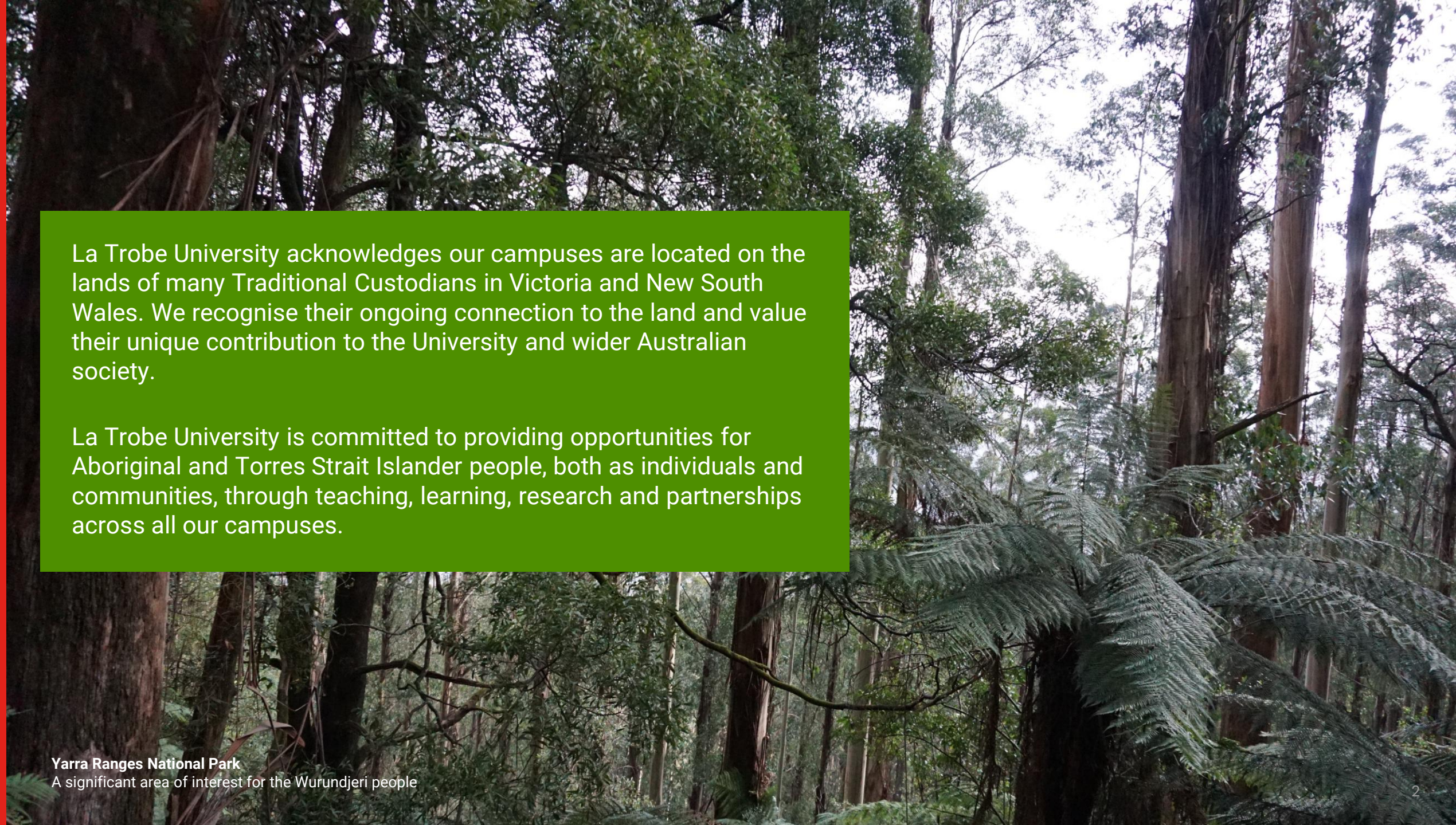
Beyond Assumptions

Building Clinical Evidence that Reflects Autistic Experiences

Dr Lauren Lawson



La Trobe University acknowledges our campuses are located on the lands of many Traditional Custodians in Victoria and New South Wales. We recognise their ongoing connection to the land and value their unique contribution to the University and wider Australian society.

La Trobe University is committed to providing opportunities for Aboriginal and Torres Strait Islander people, both as individuals and communities, through teaching, learning, research and partnerships across all our campuses.

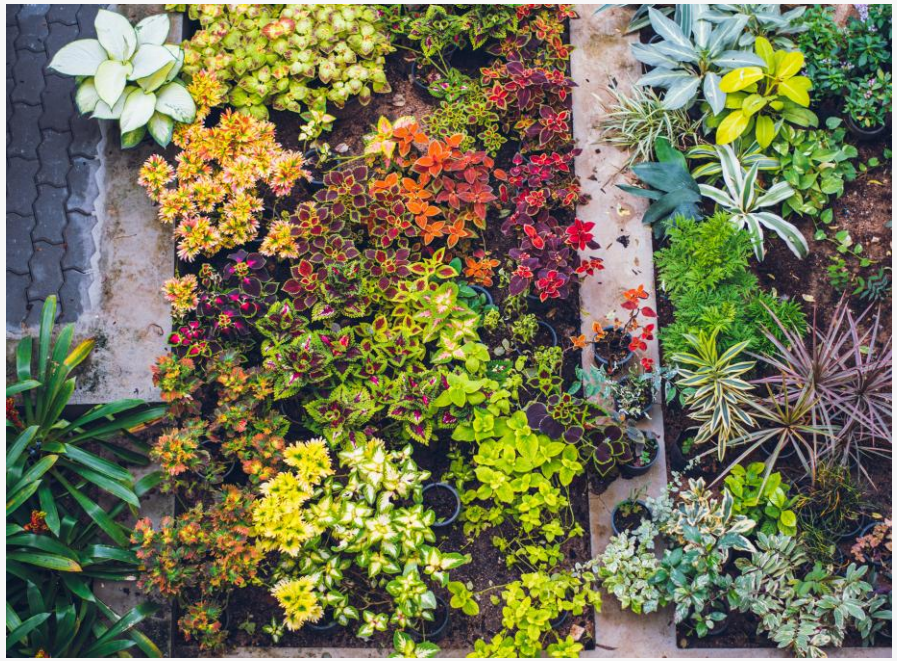
Yarra Ranges National Park
A significant area of interest for the Wurundjeri people

From Labels to Processes



Practice and Research have Grown Apart

Clinical Practice



Clinical Trials







The “Challenge” of Heterogeneity









Asking not assuming

ACTUALISELab

Olga Tennison Autism Research Centre

yellow LADYBUGS

EMORY UNIVERSITY

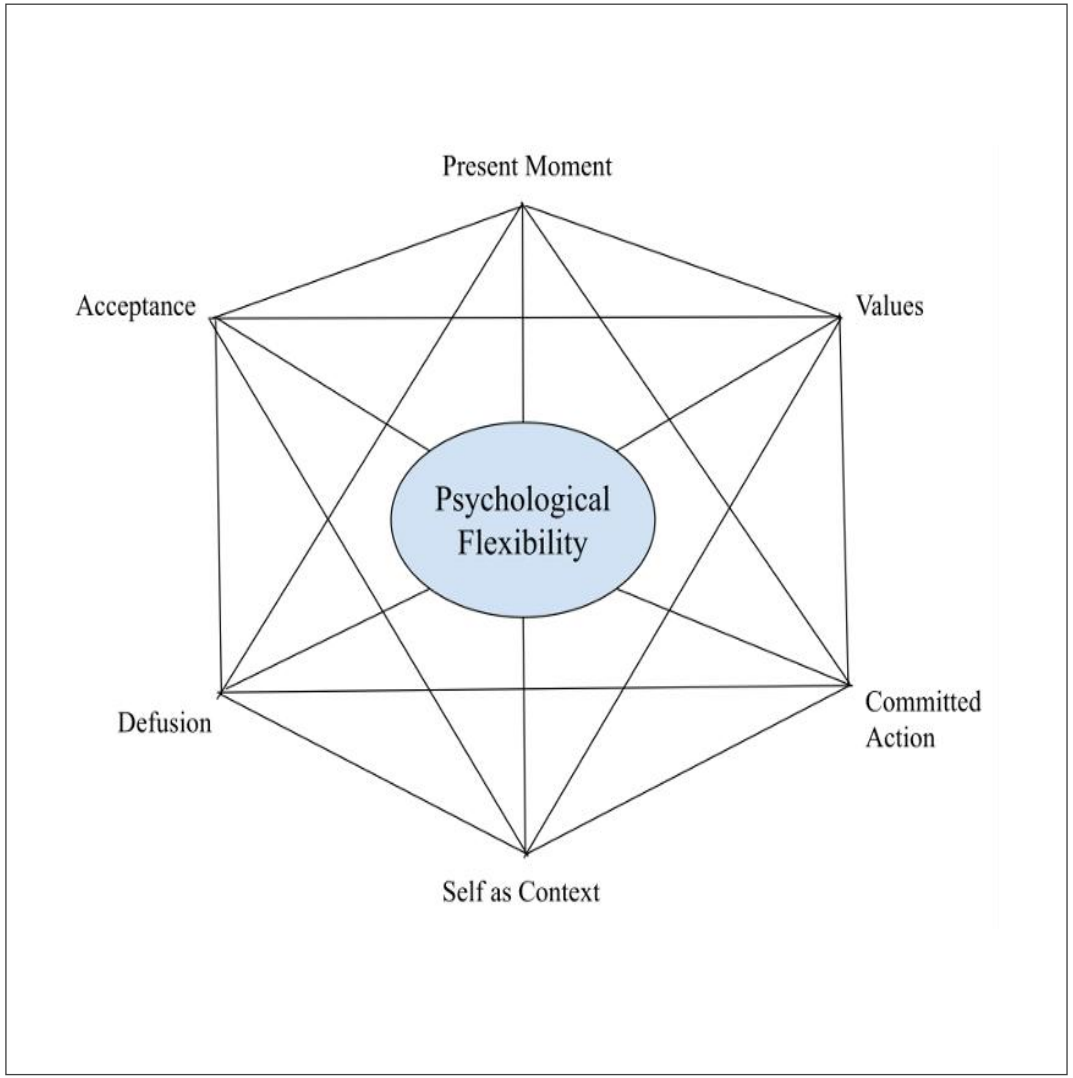
aspect Autism Spectrum Australia



Where we are going

Are we asking the right questions?



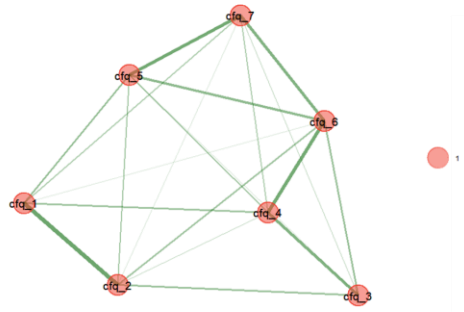


Measurement of Psychological Flexibility

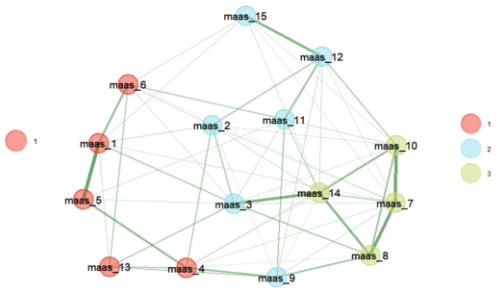
To examine a range of (in)flexibility measures and compare structure between autistic and non-autistic adults.

- **Participants**:
  - 195 autistic adults and 115 non-autistic adults
  - Formal reported diagnosis
- Online survey
  - CompACT, CFQ, BEAQ, MAAS, and VQ
- **Analysis**
  - Bootstrapped Exploratory Graph Analysis (EGA)

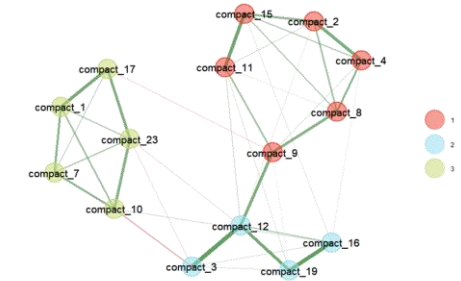
Measurement of Psychological Flexibility



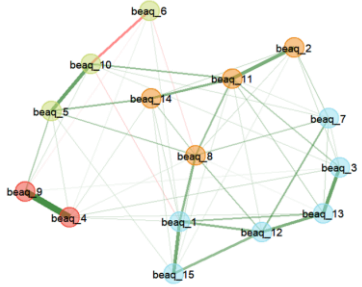
(b) Autism Sample CFQ Median Network



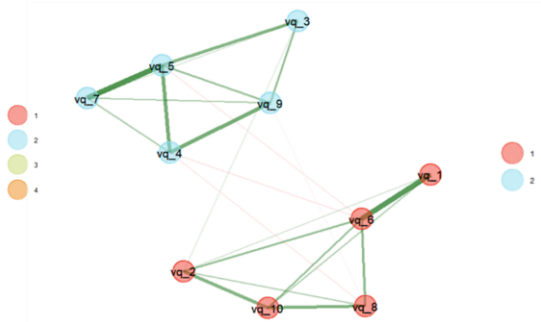
(b) Autism Sample MAAS Median Network



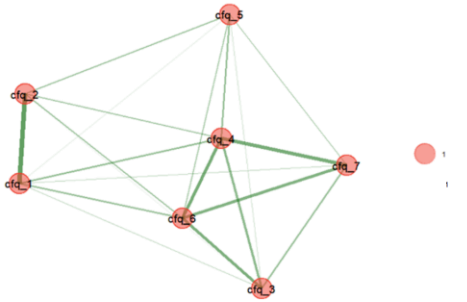
(f) Autism Sample CompACT-15 Median Network



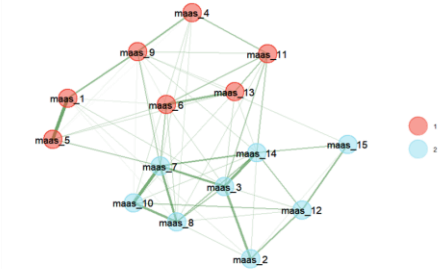
(b) Autism Sample BEAQ Median Network



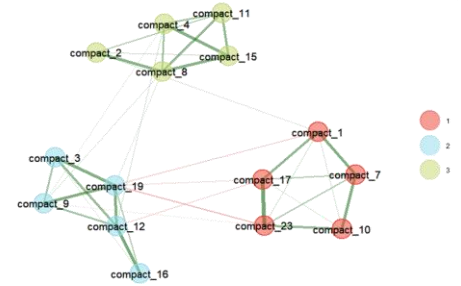
(b) Autism Sample VQ Median Network



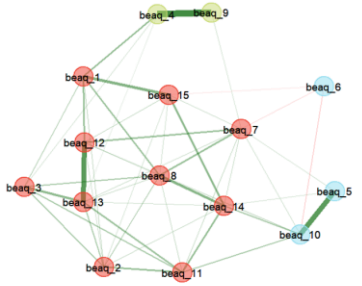
(d) Non-Autism Sample CFQ Median Network



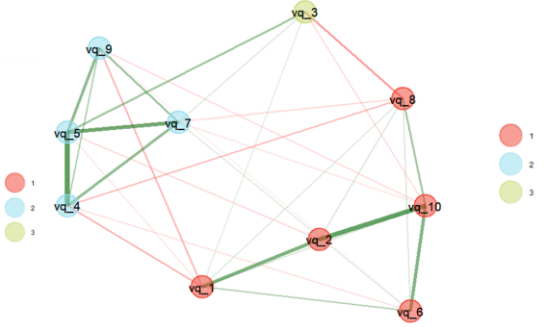
(d) Non-Autism Sample MAAS Median Network



(h) Non-Autism Sample CompACT-15 Network



(d) Non-Autism Sample BEAQ Median Network



(d) Non-Autism Sample VQ Median Network

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Psychological Flexibility and Mental Health

12 months

T1

Baseline survey

MPFI, mental health and wellbeing measures

T2

Follow-up survey

MPFI, mental health and wellbeing measures

154 participants completed both waves of data collection

63 women • 60 men • 11 non-binary/gender diverse

Mean age = 36.9 years [19 – 65 years]

Anxiety
GAD-7

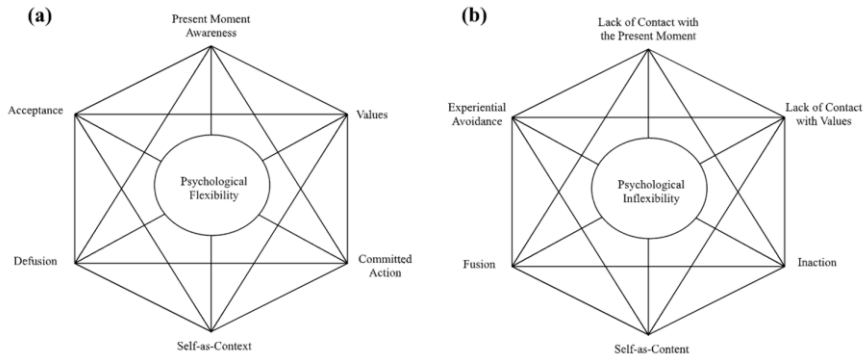
Depression
PHQ-9

Mental wellbeing
SWEMWBS

Insomnia
ISI

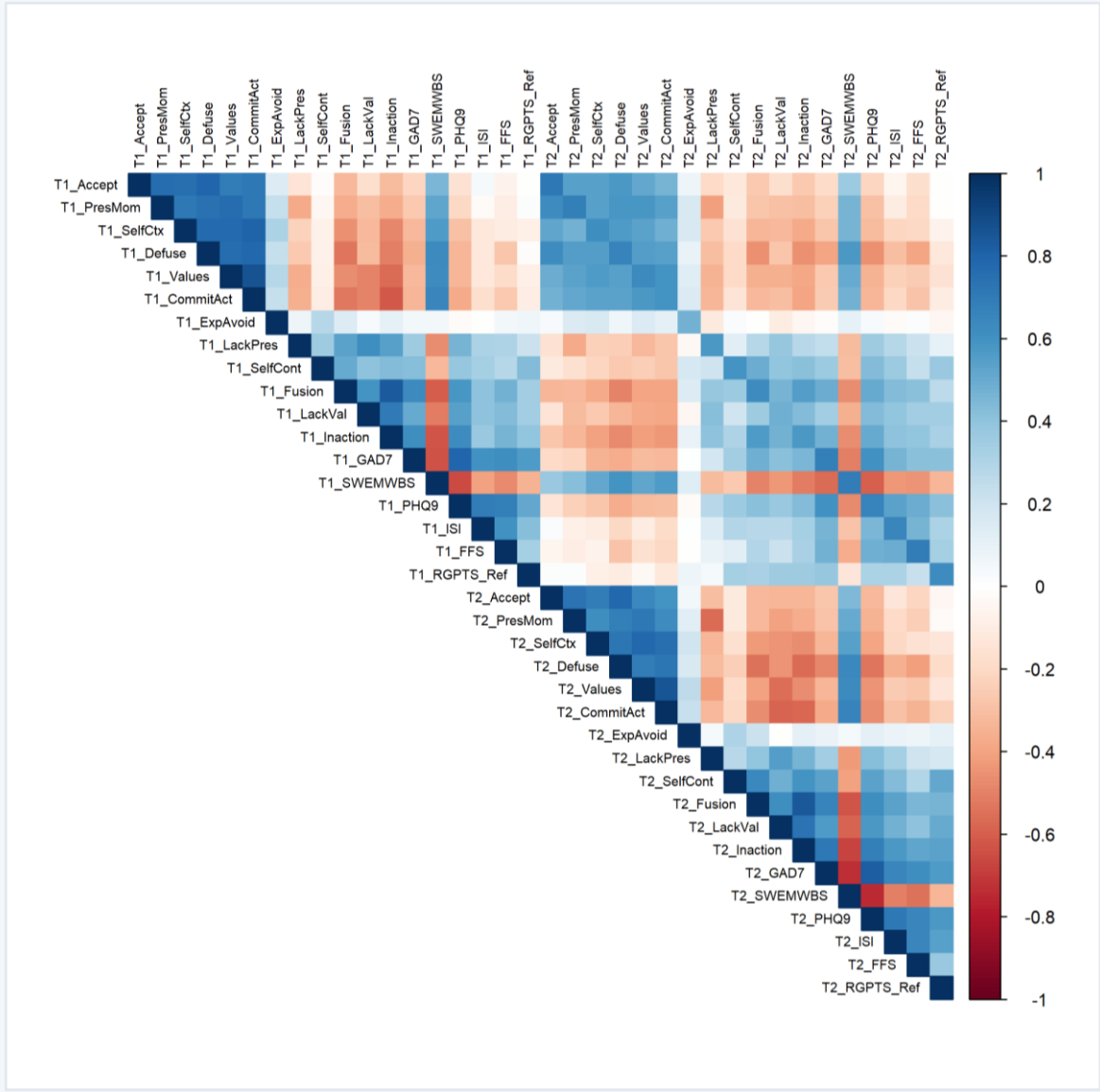
Paranoid thinking
R-GPTS

Fatigue
FFS



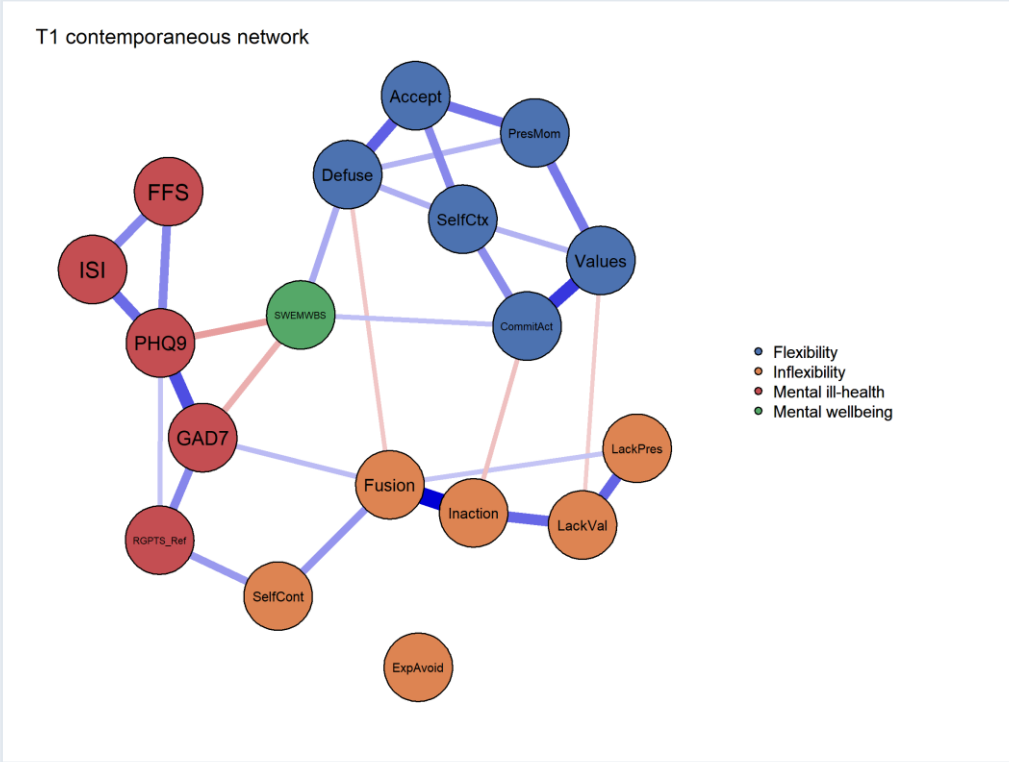
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Partial Correlations

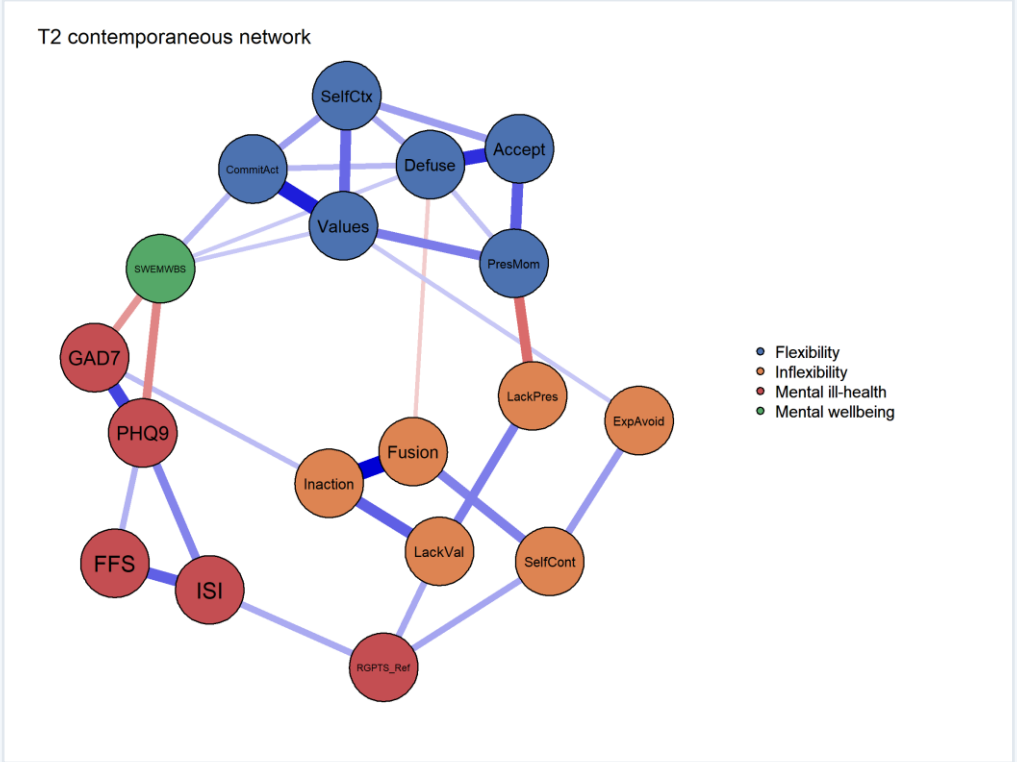


The Cross-Sectional Networks

T1

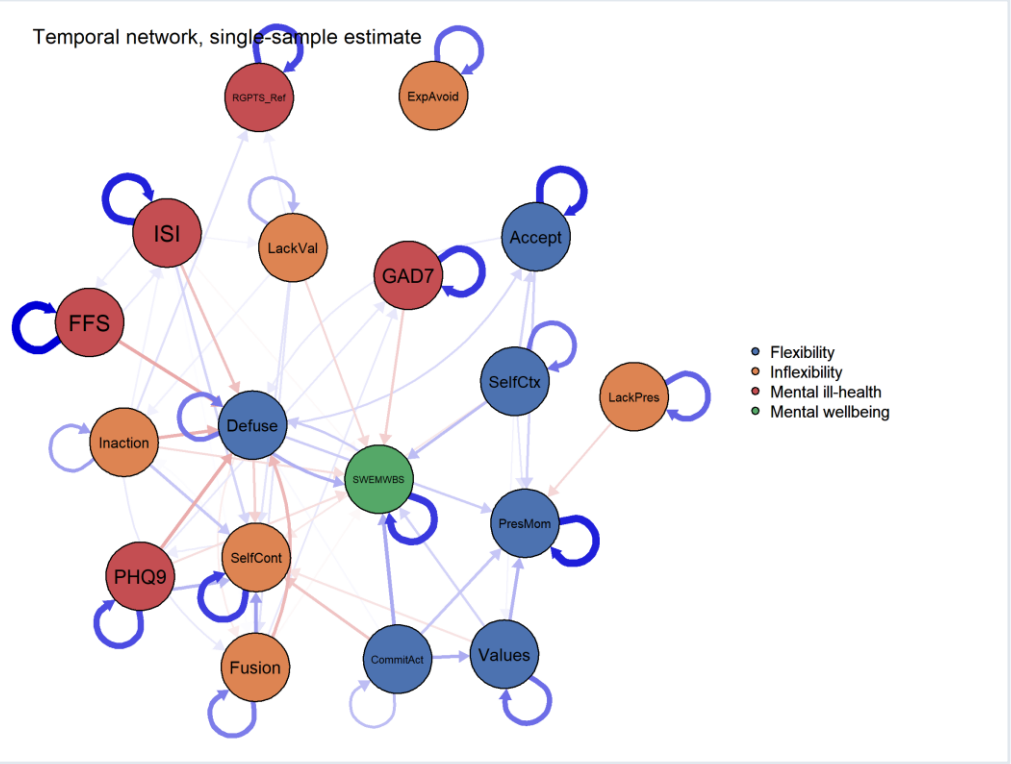


T2

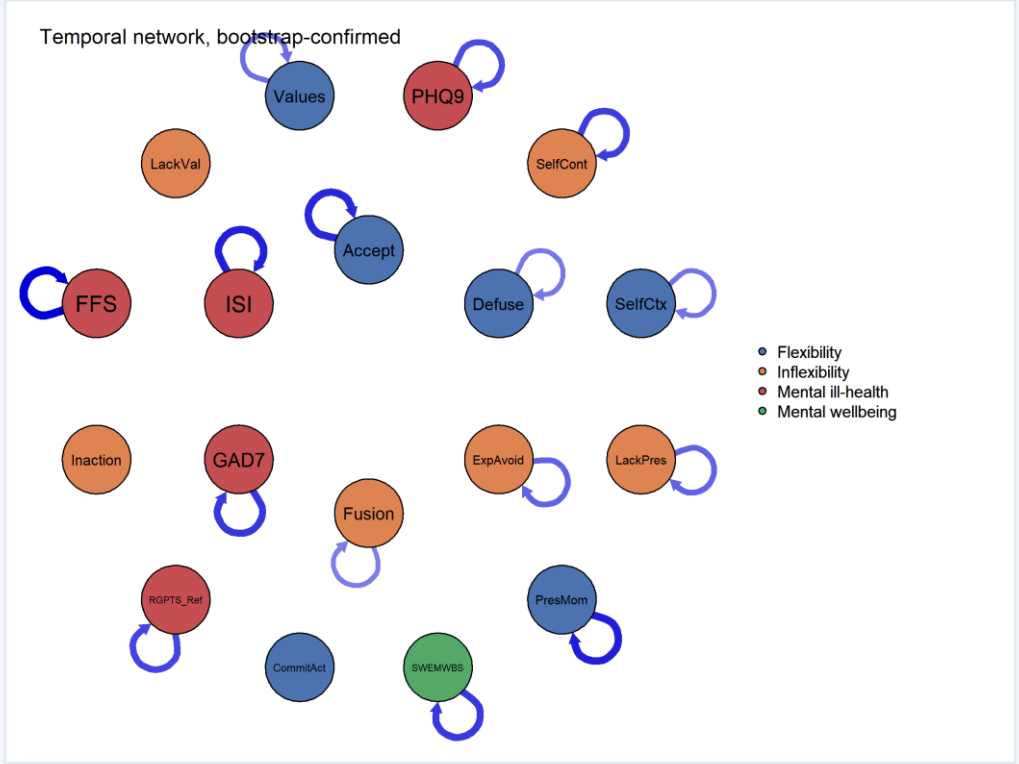


The Longitudinal Network

All edges



Bootstrapped



Implications and Limitations

What this points toward

- Defusion and self-as-content are promising targets, converging across the contemporaneous and temporal analyses
- The contemporaneous networks reproduced many of the relationships ACT theory would predict, replicated independently at both waves

Why to hold this loosely

- Sample size limited power to detect temporal relationships, only self-predictions survived bootstrapping
- Can't separate within-person change from between-person difference, which may wash out meaningful variation
- Next step, more intensive longitudinal designs



A closer look at experiential avoidance

No connection to any outcome at either wave or temporally.

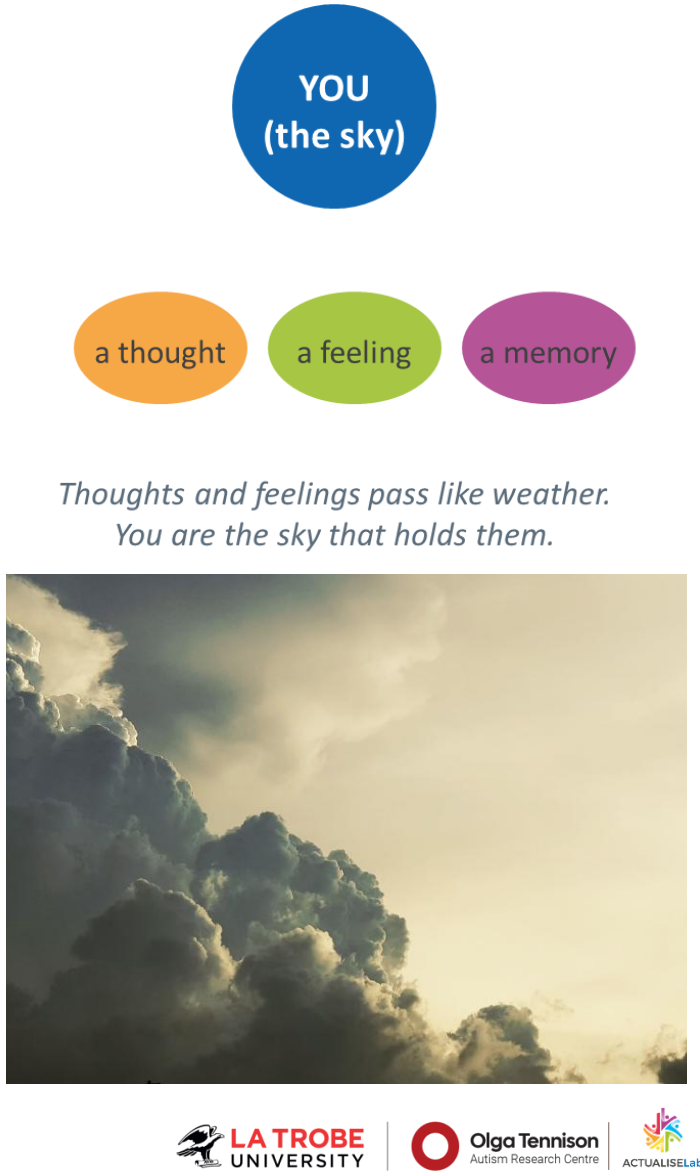
- The process may matter less for autistic adults, or
- The MPFI is not capturing it well for autistic respondents

Self-as-Context

- One of six core processes in the psychological flexibility model underlying ACT
- The part of you that notices thoughts, feelings, memories and sensations, without being defined by them
- Often called the observer self, or the sky above ever-changing weather
- For autistic adults, this may offer a way to hold painful identity experiences with more distance and less shame

AIM: To assess whether teaching Self-As-Context (SAC) improves self-compassion and decreases shame in autistic adults during the recount of a personally emotional event

1. Higher state self-compassion than control after re-reading their experience
2. Lower state shame than control after re-reading their experience



A five-phase online experiment

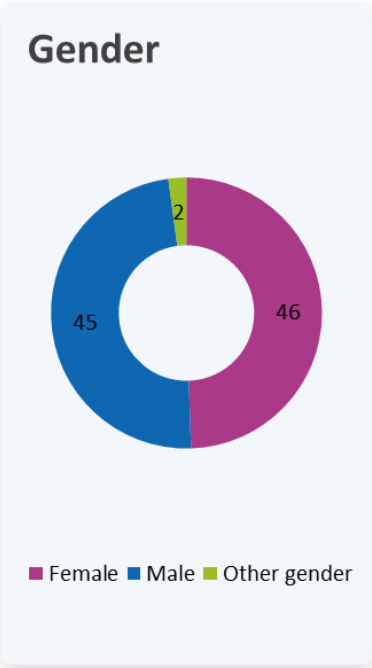
1. **Baseline** — Demographics and baseline measures
2. **Recall** — Write about a time feeling excluded
3. **Intervention** — SAC video or neutral documentary
4. **Re-exposure** — Re-read their written account
5. **Return to baseline** — Calming sensory video

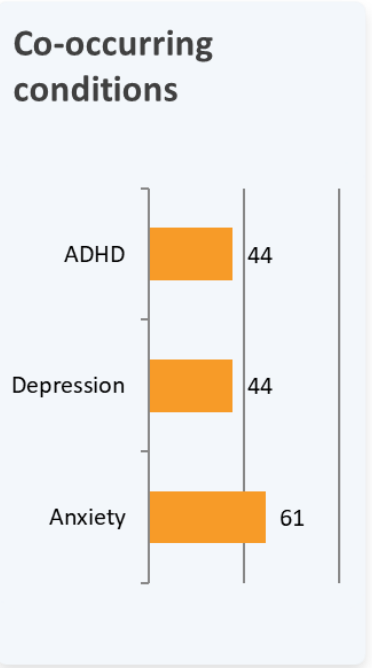
93 autistic adults analysed (101 recruited)

19–62 years, M = 38.56

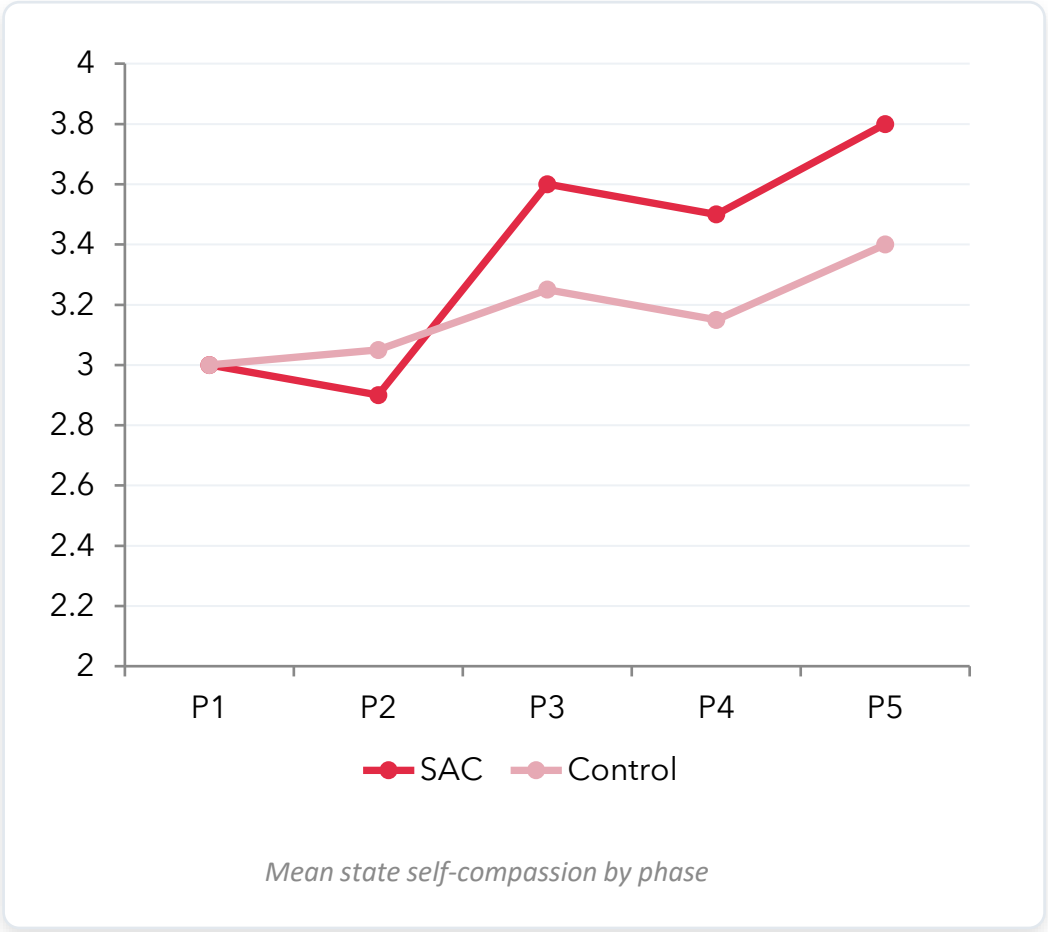
UK recruited via Prolific, self-reported diagnosis

State self-compassion, shame, experiential avoidance and self-as-context were measured after every phase. Ninety-three autistic adults were randomised online via Prolific and QuestionPro; group allocation was allocate at Phase 3.

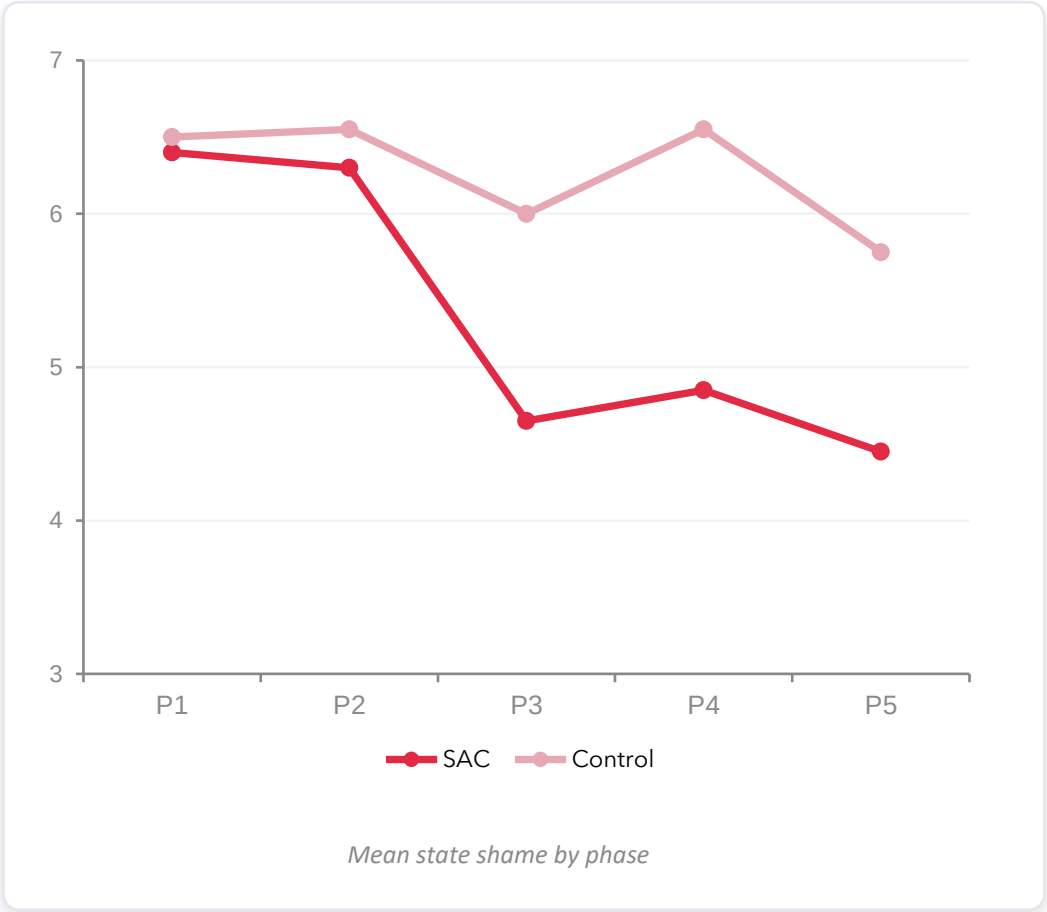




Self-as-Context



Mean state self-compassion by phase



Mean state shame by phase

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Self-as-Context Feedback

I am very comfortable with who I am … I can't change the past, but I can learn from it. I now might think about therapy to help me come to terms with things

I've taken several studies focused on my autistic experience and none have felt as caring and supportive as this one. The Self as Context ACT exercise video really helped me, … and has given me a great new way of thinking that really suits my brain - I love the weather metaphor.

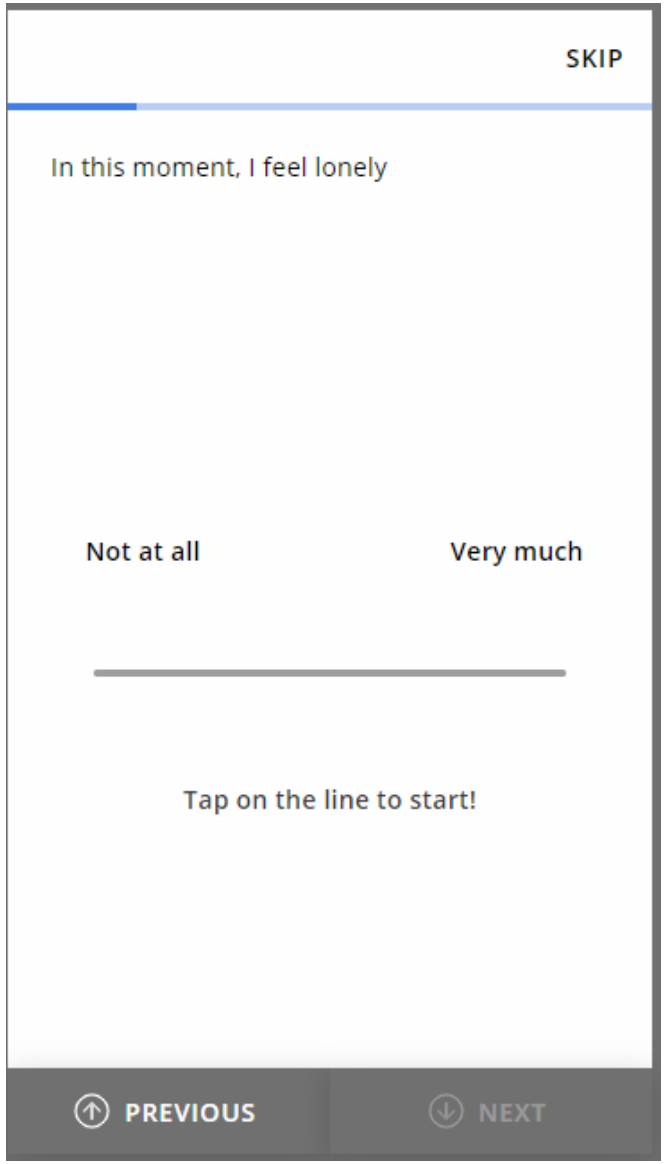
It was challenging to confront those feelings, and I found myself needing to pause and take deep breaths to manage the discomfort …While the process was emotionally taxing, I believe it contributed to a deeper understanding of myself.

Lawson, et al., Making Room for Autistic Identity: An Experimental Investigation of Self-as-Context with Autistic Adults, https://doi.org/10.31234/osf.io/23cuq_v1

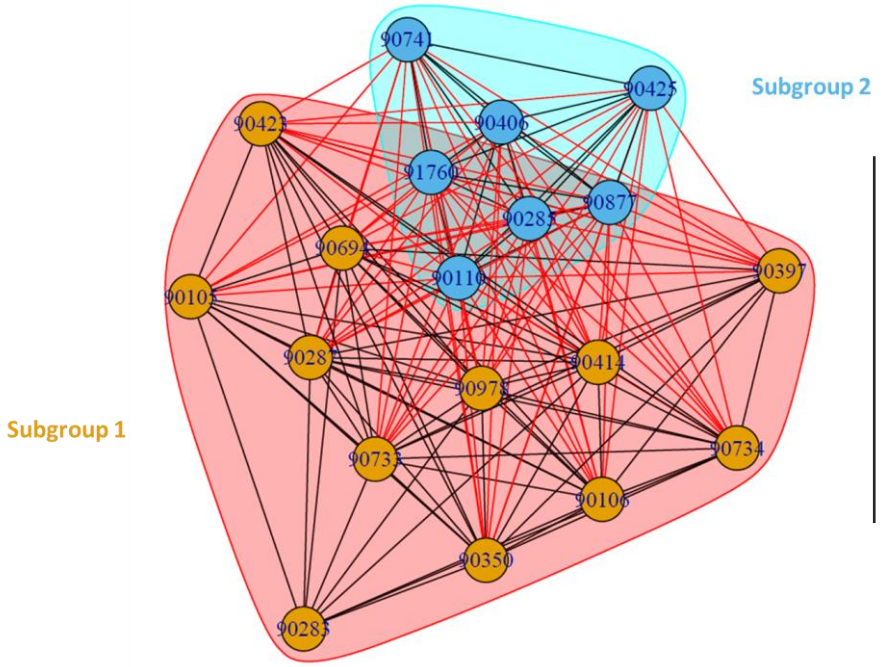
Stigma & Wellbeing

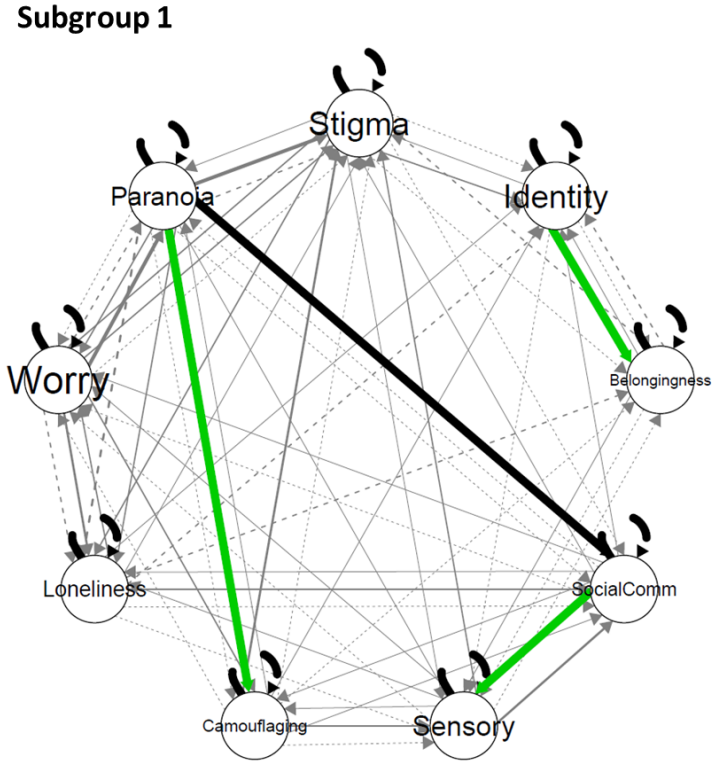
To explore relationships between internalised stigma, autistic identity, camouflaging, paranoid thinking, loneliness, worry and belonginess among Australian autistic adults

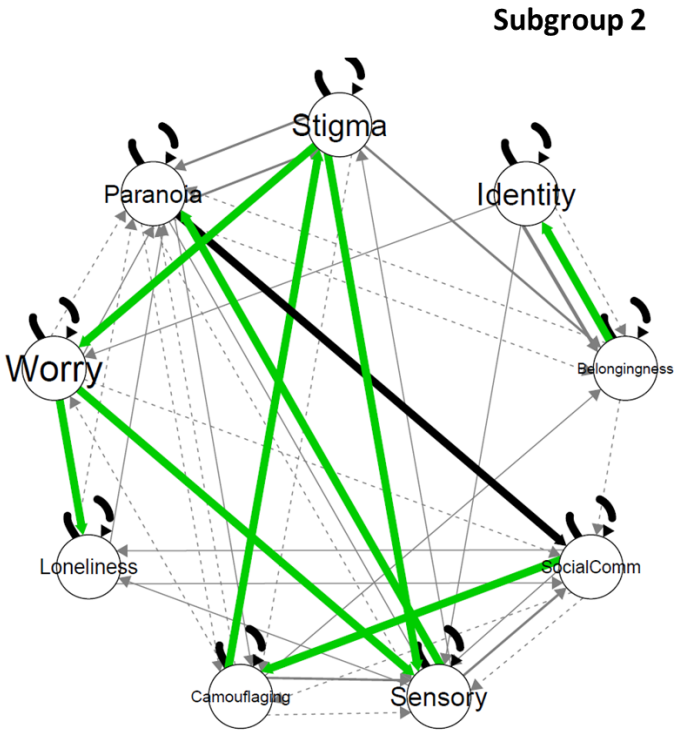
- **Participants**:
  - 30 autistic adults (50% female, 43% non-binary/other, 7% male; M_{age} = 30.23yrs)
  - Diagnosed and self-identified
- Experience Sampling Methodology
  - Four prompts a day for 3-weeks [morning, midday, afternoon, evening]
- **Analysis**
  - Group Iterative Multiple Model Estimation (GIMME)



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Subgroup 2
Subgroup 1
90741
90425
90423
90406
91760
90877
90284
90694
90110
90397
90105
90285
90414
90978
90734
90733
90106
90350
90283


Subgroup 1
Stigma
Paranoia
Identity
Worry
Belongingness
Loneliness
SocialComm
Camouflaging
Sensory


Subgroup 2
Stigma
Paranoia
Identity
Worry
Belongingness
Loneliness
SocialComm
Camouflaging
Sensory

RESULTS



Looking Beneath the Labels

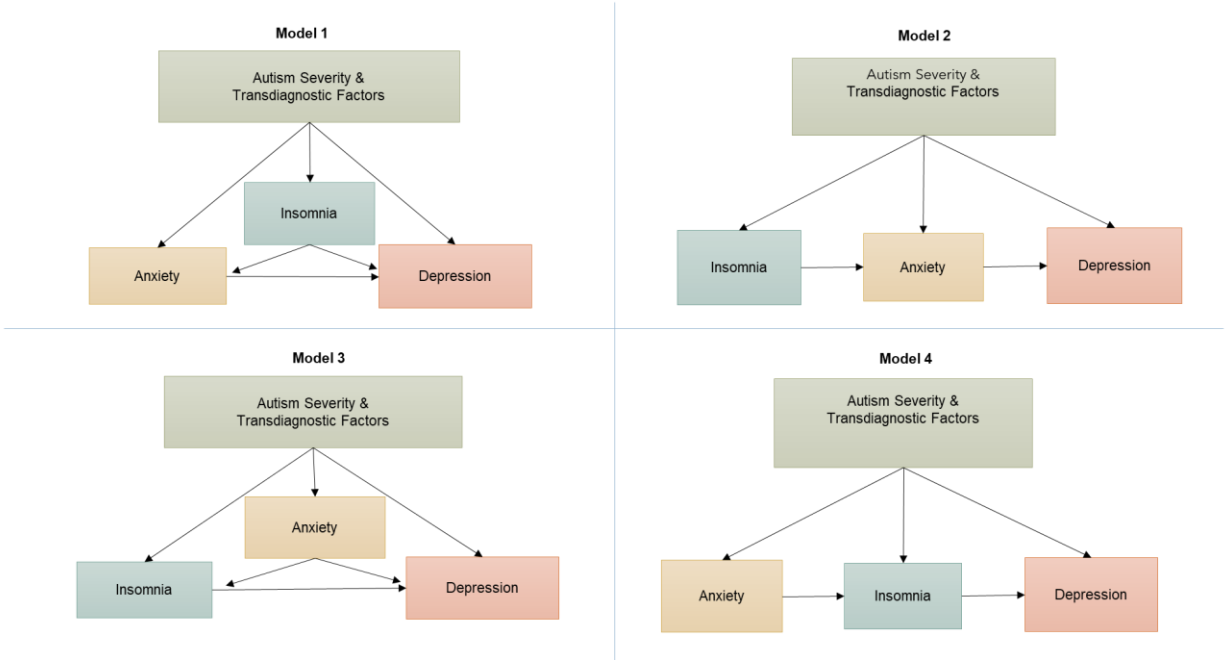
Pathways to Understanding Anxiety & Depression

Aim:

- Explore four hypothesis driven models examining relationships between transdiagnostic factors, autistic traits, insomnia, anxiety and depression

Method

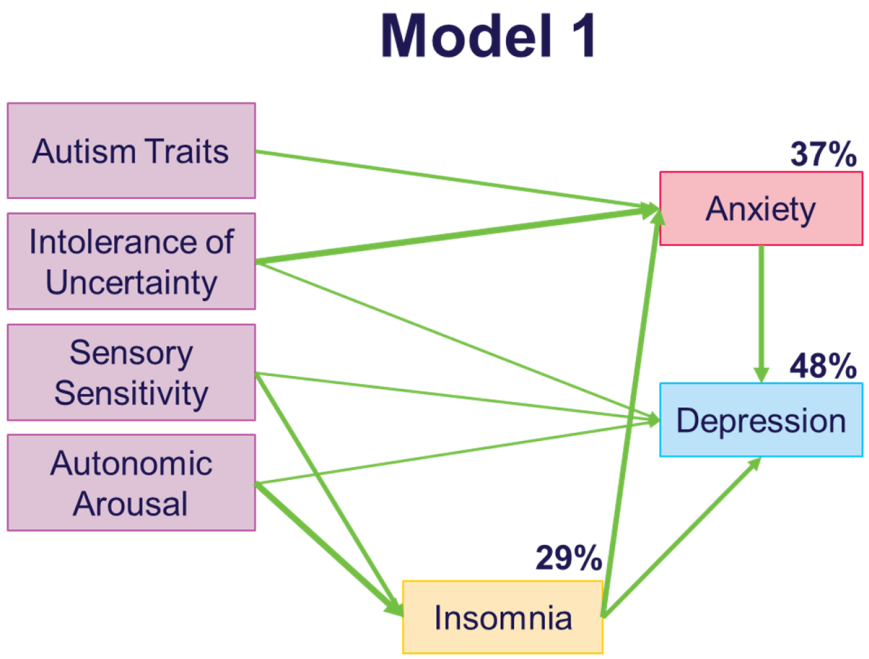
- 183 autistic adults, 15-80 years from SASLA & ALSAA
- Measures:
  - AQ-28, IU, GSQ, COMPASS-31, PSQI, DSM-V GAD, PHQ-9



Richdale, Lawson, et al., Pathways to Anxiety and Depression in Autistic Adolescents and Adults, https://doi.org/10.1155/2023/5575932

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Pathways to Understanding Anxiety & Depression



Trimmed Model 1: Path analysis controlling for sex. Width of line denotes relationship strength

Significant Indirect Pathways

Autism traits → Anxiety → Depression

IU → Anxiety → Depression

Sensory Sensitivity → Insomnia → Depression

Sensory Sensitivity → Insomnia → Anxiety → Depression

Autonomic symptoms → Insomnia → Depression

Autonomic symptoms → Insomnia → Anxiety → Depression

Insomnia → Anxiety → Depression

Mapping Heterogeneity

To identify subgroups of autistic individuals' profiles

- **Participants**:
  - 799 autistic adults (393 women, 306 men, 99 gender diverse)
  - Diagnosed and self-identified
- Online Survey
  - Autistic traits – e.g., sensory sensitivity
  - Transdiagnostic factors – e.g., emotion regulation
  - Mental health – e.g., anxiety
- **Analysis**
  - Growing Self-Organising Maps (GSOM)



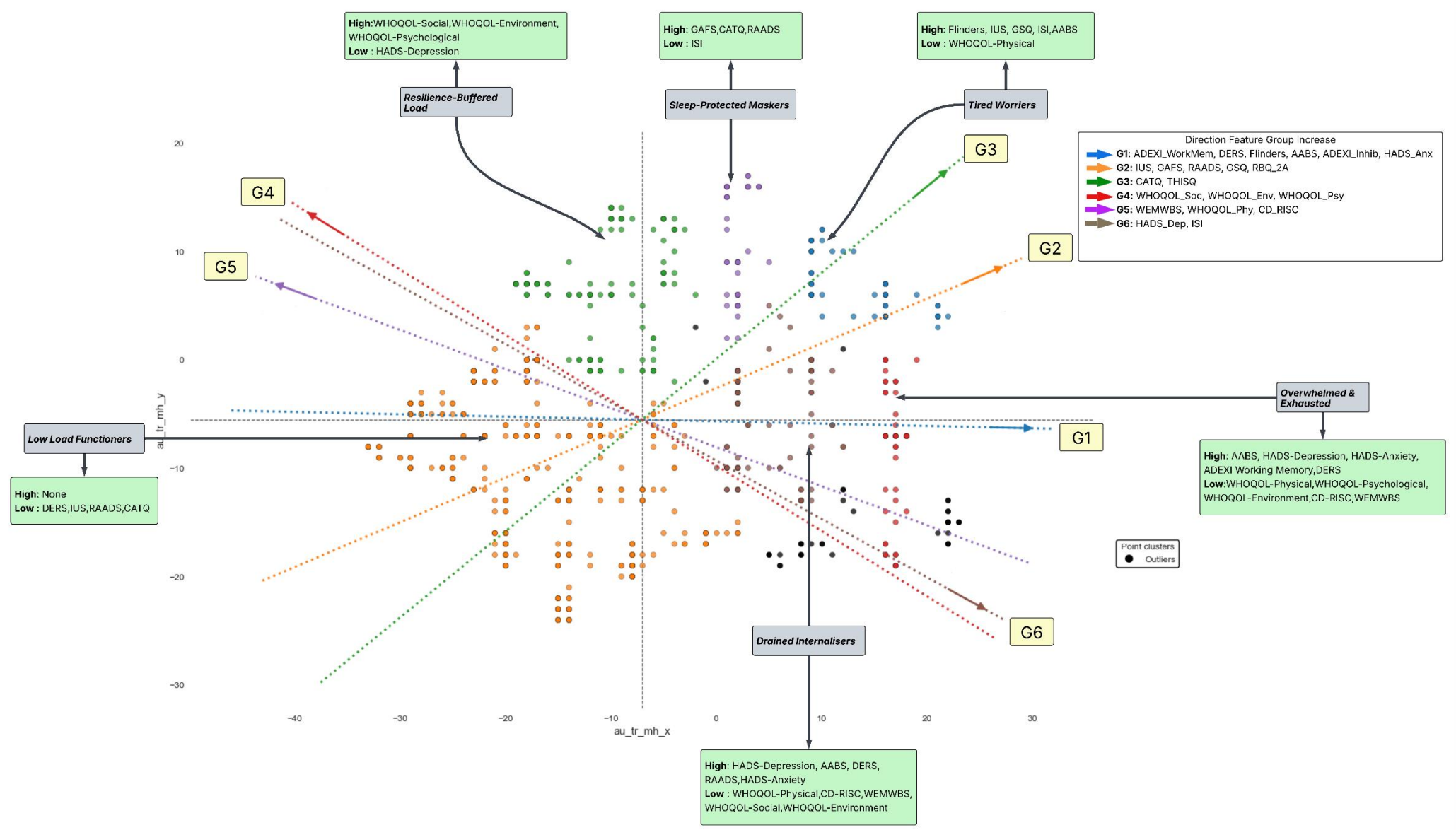
What is GSOM?

- Unsupervised machine learning
- Learns the underlying structure of the data
- Models graded transitions between profiles – continuous nature
- Once built, the map exists independent of original data
- New individuals can be positioned within the map
- Can continue to learn with new input
- Living framework, not a fixed analytical endpoint








High:WHOQOL-Social,WHOQOL-Environment, WHOQOL-Psychological
Low : HADS-Depression
High: GAFS,CATQ,RAADS
Low : ISI
High: Flinders, IUS, GSQ, ISI,AABS
Low : WHOQOL-Physical
Resilience-Buffered Load
Sleep-Protected Maskers
Tired Worriers
Direction Feature Group Increase
G1: ADEXI_WorkMem, DERS, Flinders, AABS, ADEXI_Inhib, HADS_Anx
G2: IUS, GAFS, RAADS, GSQ, RBQ_2A
G3: CATQ, THISQ
G4: WHOQOL_Soc, WHOQOL_Env, WHOQOL_Psy
G5: WEMWBS, WHOQOL_Phy, CD_RISC
G6: HADS_Dep, ISI
G4
G3
G5
G2
G1
G6
Low Load Functioners
Overwhelmed & Exhausted
High: None
Low : DERS,IUS,RAADS,CATQ
High: AABS, HADS-Depression, HADS-Anxiety, ADEXI Working Memory,DERS
Low:WHOQOL-Physical,WHOQOL-Psychological, WHOQOL-Environment,CD-RISC,WEMWBS
Point clusters
Outliers
Drained Internalisers
High: HADS-Depression, AABS, DERS, RAADS,HADS-Anxiety
Low : WHOQOL-Physical,CD-RISC,WEMWBS, WHOQOL-Social,WHOQOL-Environment
au_tr_mh_y
au_tr_mh_x
20
10
0
−10
−20
−30
−40
−30
−20
−10
0
10
20
30

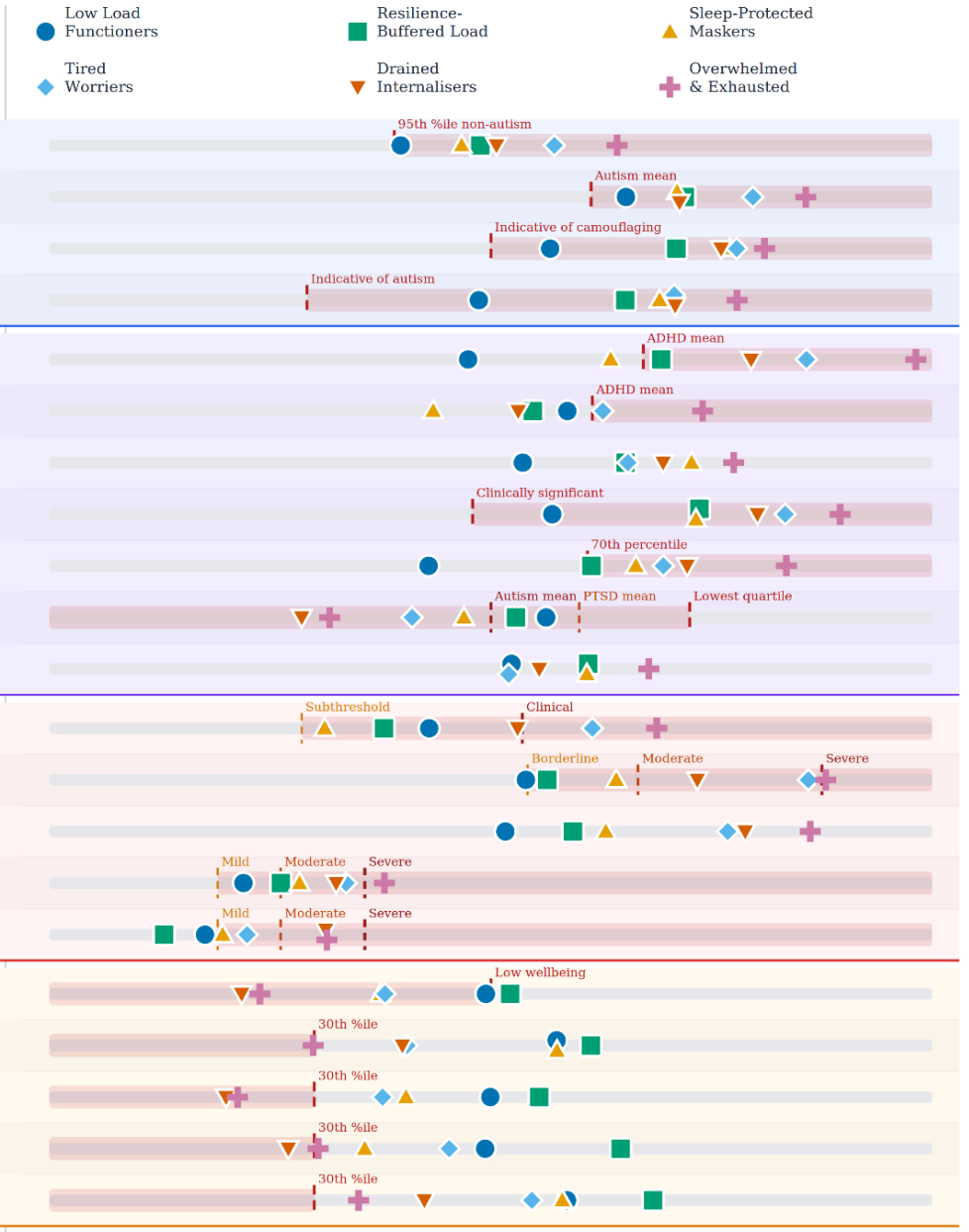
Deviation from Sample Mean

	Measure	Low Load Functioners	Resilience-Buffered Load	Sleep-Protected Maskers	Tired Worriers	Drained Internalisers	Overwhelmed & Exhausted
AUTISTIC LOAD	GSQ	-0.0666	+0.0232	+0.0224	+0.1135	+0.0374	+0.1701
	RBQ-2A	-0.0506	+0.0201	+0.0051	+0.0935	+0.0116	+0.1536
	CAT-Q	-0.0777	+0.0450	+0.0983	+0.1054	+0.0871	+0.1349
	RAADS-14	-0.1159	+0.0702	+0.1194	+0.1332	+0.1343	+0.2163
TRANSDIAGNOSTIC LOAD	Working Memory	-0.0710	+0.0078	-0.0355	+0.1206	+0.0738	+0.2114
	Inhibition	-0.0457	+0.0134	-0.0771	+0.0768	+0.0000	+0.1681
	GAFS-8	-0.0890	+0.0437	+0.1275	+0.0527	+0.0874	+0.1816
	IUS	-0.0883	+0.0433	+0.0421	+0.1223	+0.0965	+0.1720
	DERS	-0.1082	+0.0389	+0.0831	+0.1044	+0.1297	+0.2175
	CD-RISC	-0.0734	-0.0382	+0.0198	+0.0794	+0.2044	+0.1790
	THISQ	+0.0323	-0.0395	-0.0305	+0.0281	+0.0063	-0.0937
MENTAL HEALTH	Insomnia (ISI)	-0.0372	-0.0860	-0.1513	+0.1569	+0.0625	+0.2211
	Fatigue Scale	-0.0493	-0.0347	+0.0001	+0.1335	+0.0642	+0.1457
	AABS	-0.0990	-0.0193	+0.0160	+0.1524	+0.1760	+0.2421
	HADS – Anxiety	-0.0885	-0.0033	+0.0390	+0.1414	+0.1248	+0.2311
	HADS – Depression	-0.0510	-0.1415	-0.0103	+0.0503	+0.2278	+0.2311
WELLBEING	WEMWBS	-0.0492	-0.0697	+0.0466	+0.0424	+0.1731	+0.1526
	QoL Physical	-0.0426	-0.0724	-0.0421	+0.0960	+0.0967	+0.1783
	QoL Psychological	-0.0508	-0.0958	+0.0250	+0.0462	+0.1881	+0.1774
	QoL Social	-0.0204	-0.1451	+0.0885	+0.0100	+0.1577	+0.1289
	QoL Environmental	-0.0230	-0.1009	-0.0162	+0.0071	+0.1076	+0.1669

Better — Mean — Poorer

+0.1500 = significant +0.0500 = non-significant

Raw Score vs Clinical Threshold



Shaded zone = score range indicating clinical concern

ACTUALISELab

Six profiles
six starting points for support

Low Load Functioners (50%)

Lowest burden, high resilience

→ **Maintenance & strengths**

Resilience-Buffered (16%)

Moderate traits, protected by coping

→ **Build on existing strengths**

Sleep-Protected Maskers (5%)

High masking, poor social QoL

→ **Reduce masking demands**

Tired Worriers (7%)

High worry, IU, sleep disruption

→ **Target IU first, then sleep**

Drained Internalisers (11%)

Fatigue, burnout, lowest resilience

→ **Stabilise before adding skills**

Overwhelmed & Exhausted (6%)

Pervasive impairment across all domains

→ **Safety first, stabilise, then plan**

Lawson, et al., From Noise to Signal: Leveraging Heterogeneity to Inform Personalised Mental Health for Autistic Adults.
https://osf.io/preprints/psyarxiv/f4zn2_v1

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Making it Practical

What is their profile?

Thriving → maintenance | At risk → targeted
Exhausted → demand reduction | Overwhelmed → stabilization

Which pathways are active?

High IUS? Alexithymia? Cumulative sleep debt? Low resilience?
Self-blame? These are your treatment targets.

What does their experience tell you?

"Do you feel rested?" "How many bad nights in a row?"
Trust the patient.

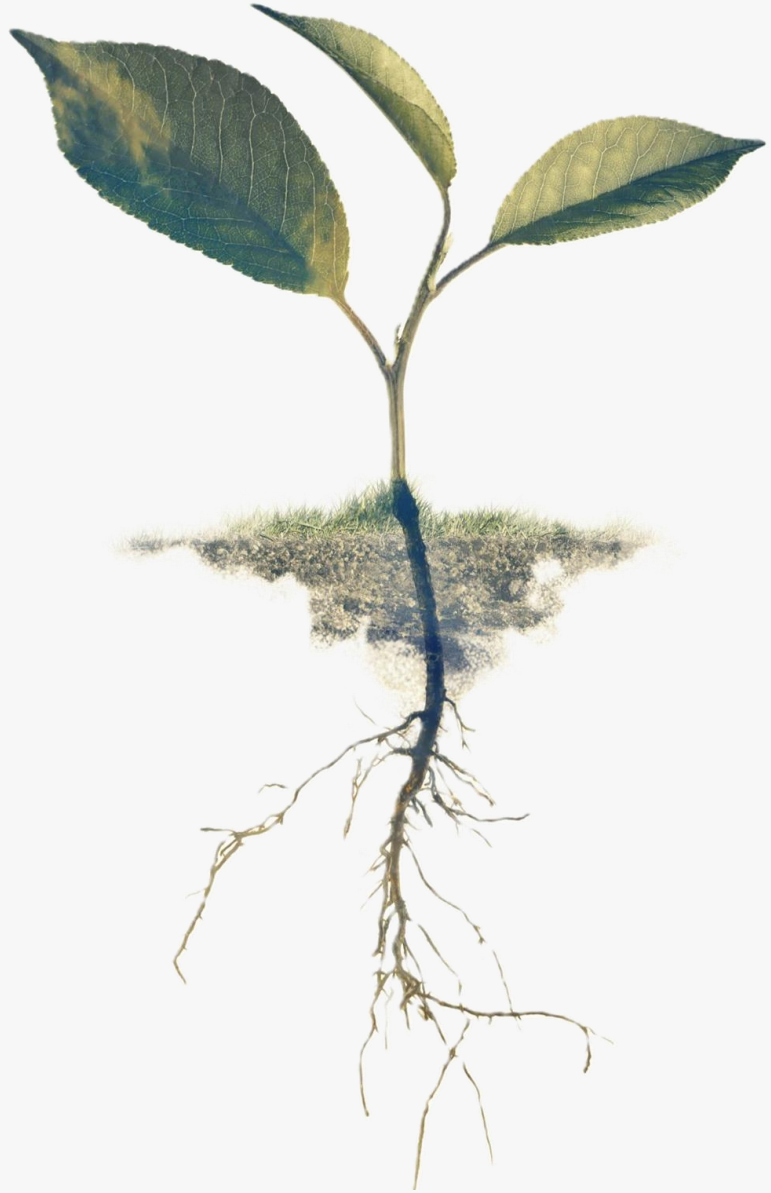
What strategies are they using?

Promote acceptance and reappraisal.
Reduce self-blame and suppression attempts

Transdiagnostic Toolkit

Abbrev.	Measure	Target
PHQ-8	Patient Health Questionnaire-8	Depression
GAD-7	Generalized Anxiety Disorder-7	Anxiety
IUS-12	Intolerance of Uncertainty Scale	Intolerance of Uncertainty
GAFS-8	General Alexithymia Factor Score	Alexithymia
CATQ-SF	Camouflaging AQ – Short Form	Masking
ISI	Insomnia Severity Index	Insomnia
BRS	Brief Resilience Scale	Resilience
DERS-16	Difficulties in Emotion Regulation	Emotion Dysregulation

Coming back to the roots




REIMAGINING RIGOUR



If we want science that services people, we must build it from processes up, not diagnoses down

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THANK YOU


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