

Understanding/ameliorating depression risk in neurodivergent youth

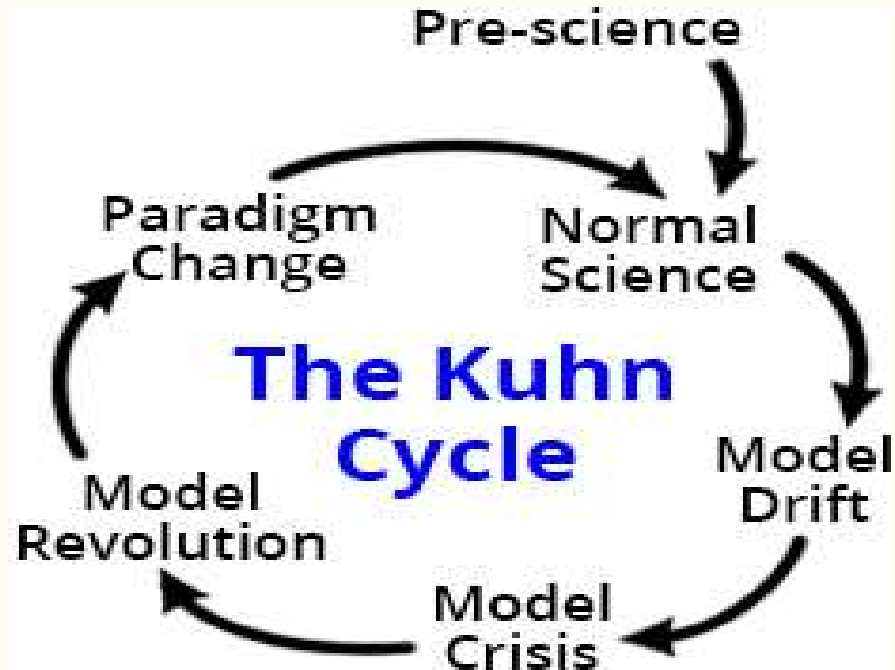


# Regulating Emotion – Strengthening Adolescent Resilience

Part of UKRI's *Adolescent Mental Health & the Developing Mind* initiative.

A research adventure in paradigm flipping.

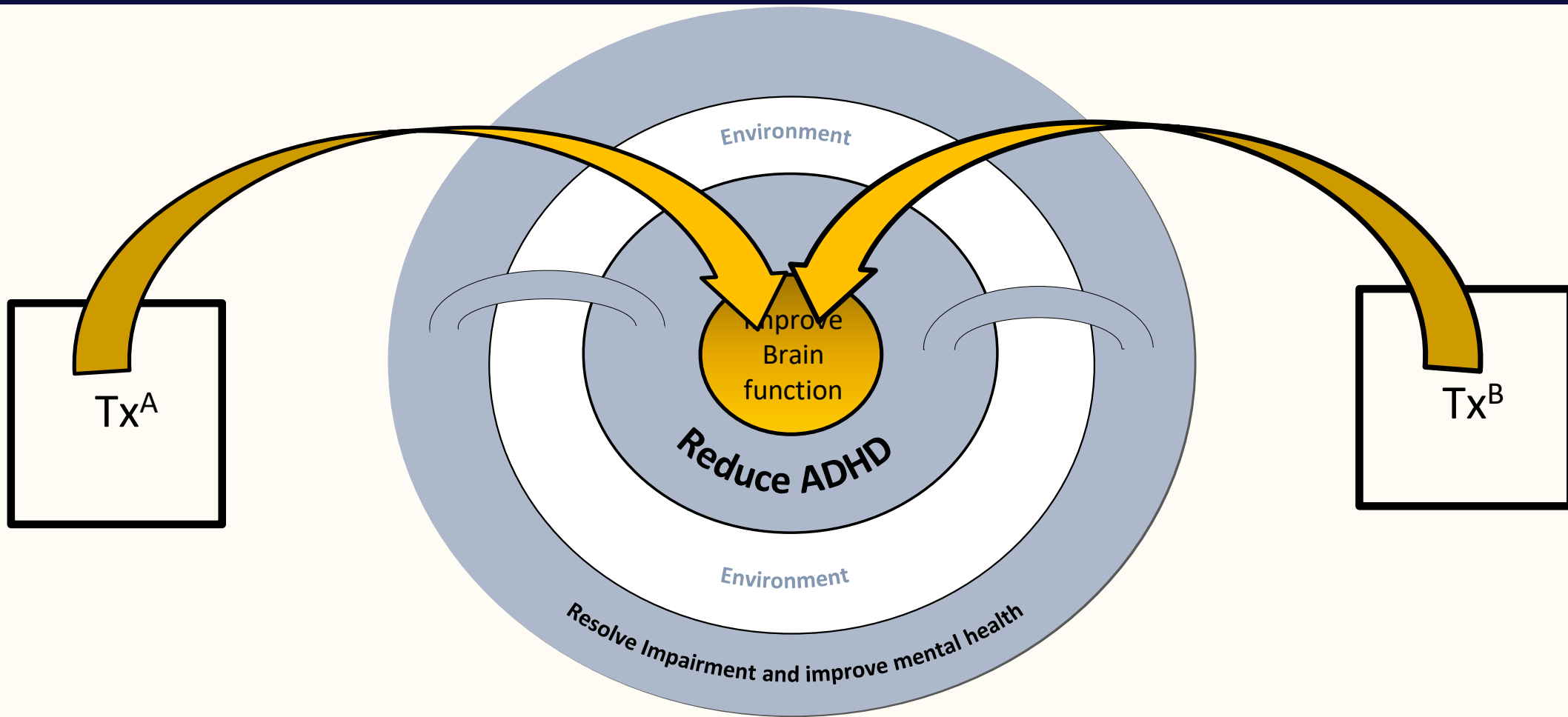
# Science is paradigmatic



Thomas Kuhn  
The paradigm shift guy

Incremental normal science punctuated by periods of crisis.

# Medical model – paradigmatic assumptions



Translational goal – 'fix' dysfunction, reduce disorder, alleviate impact.

# Disorder paradigm coming under pressure from three directions

**...translational value questioned.**

**...scientific credibility challenged.**

**...cultural change.**

# Actively 'flipping' the paradigm?

*Journal of Child Psychology and Psychiatry* 64:10 (2023), pp 1405–1408



The Association  
for Child and Adolescent  
Mental Health

## Editorial: Paradigm 'flipping' to reinvigorate translational science: Outlining a neurodevelopmental science framework from a 'neurodiversity' perspective



Young lady or old?



Disorder or Diversity

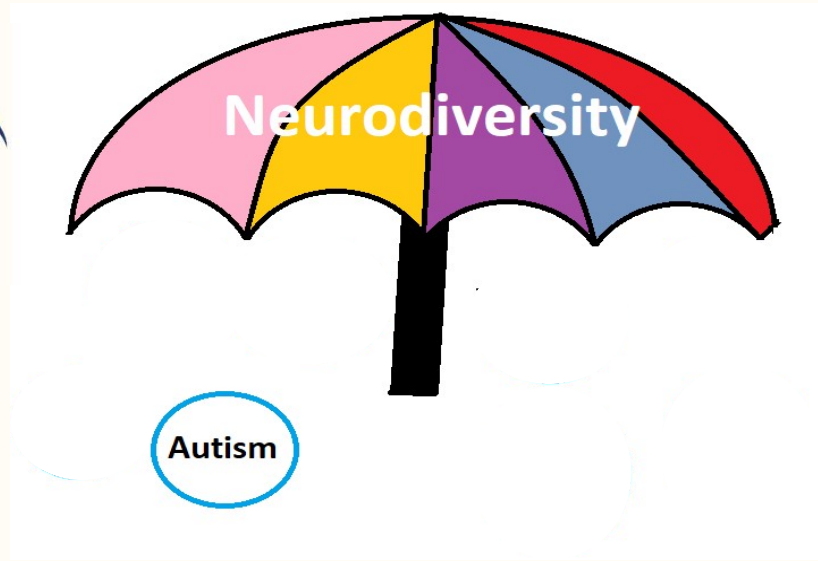
An intellectual tool/a scientific tactic, not a marker of scientific progress.

# 'Neurodiversity' is a multi-faceted concept



Dignity and value

Empowerment & self-esteem



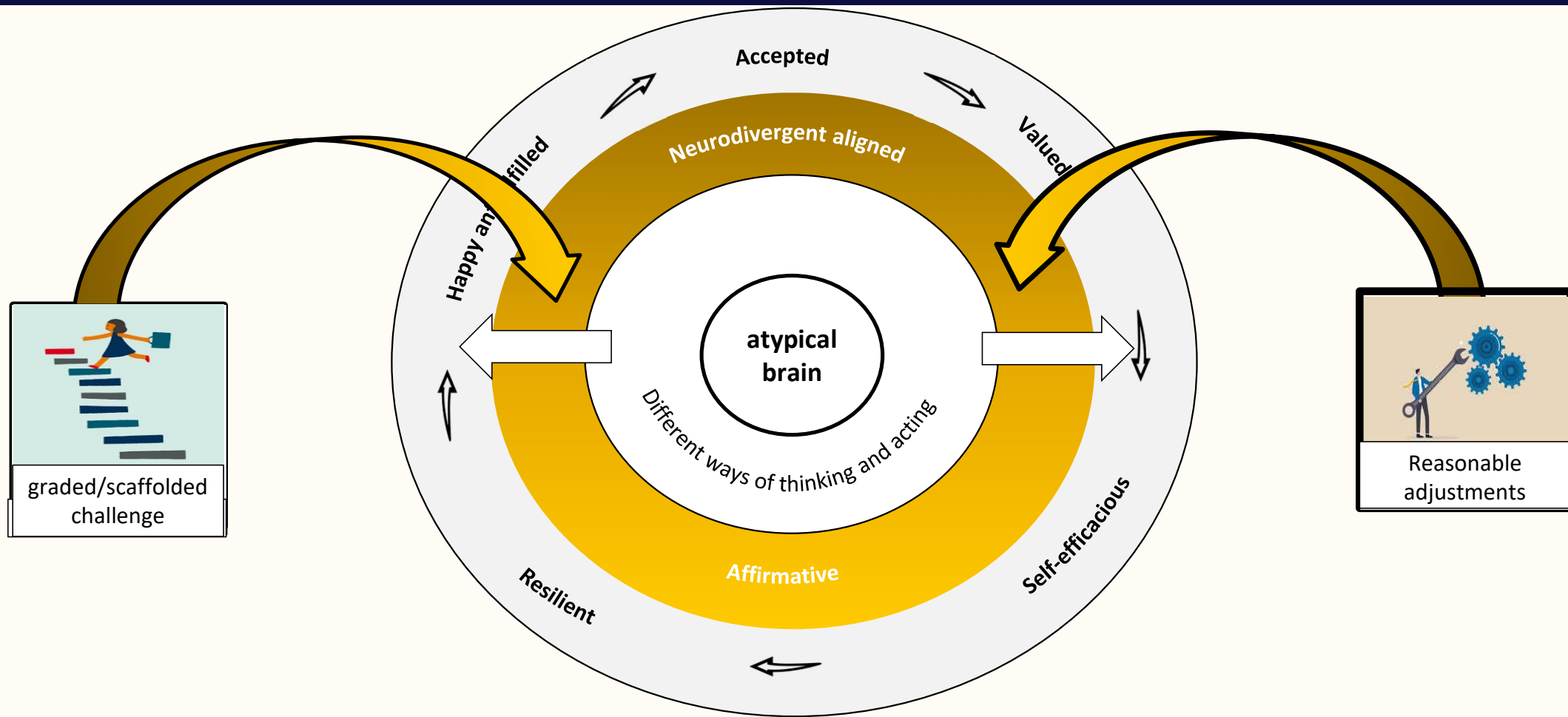
The removal of stigma

Inclusive language

positive perspectives on attributes and contributions

From one perspective, it's a rights-based, self-advocacy movement.

From another perspective it offers a *paradigm flip*



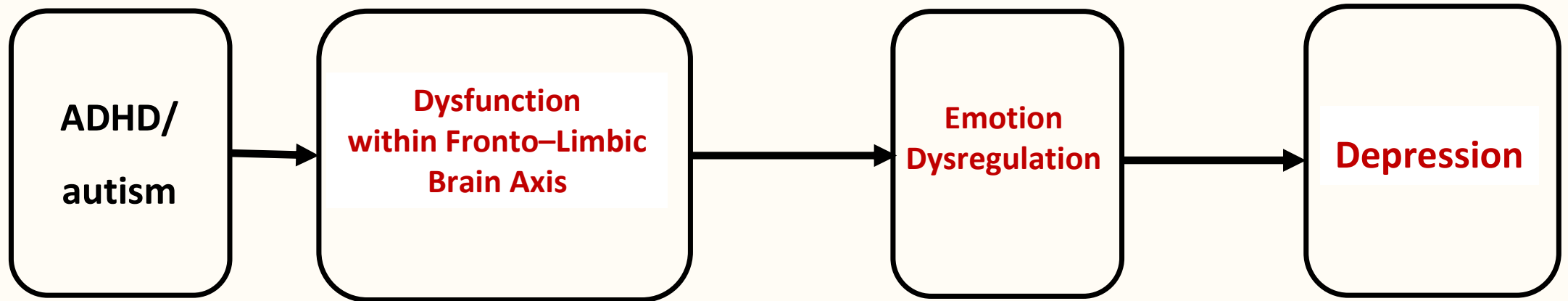
Shift from fixing deficits to promoting thriving.

# Neurodiversity 'flip' changes what's studied

From characterising **deficits in individuals** to understanding how/why **outcomes vary as a function of environment-person fit.**

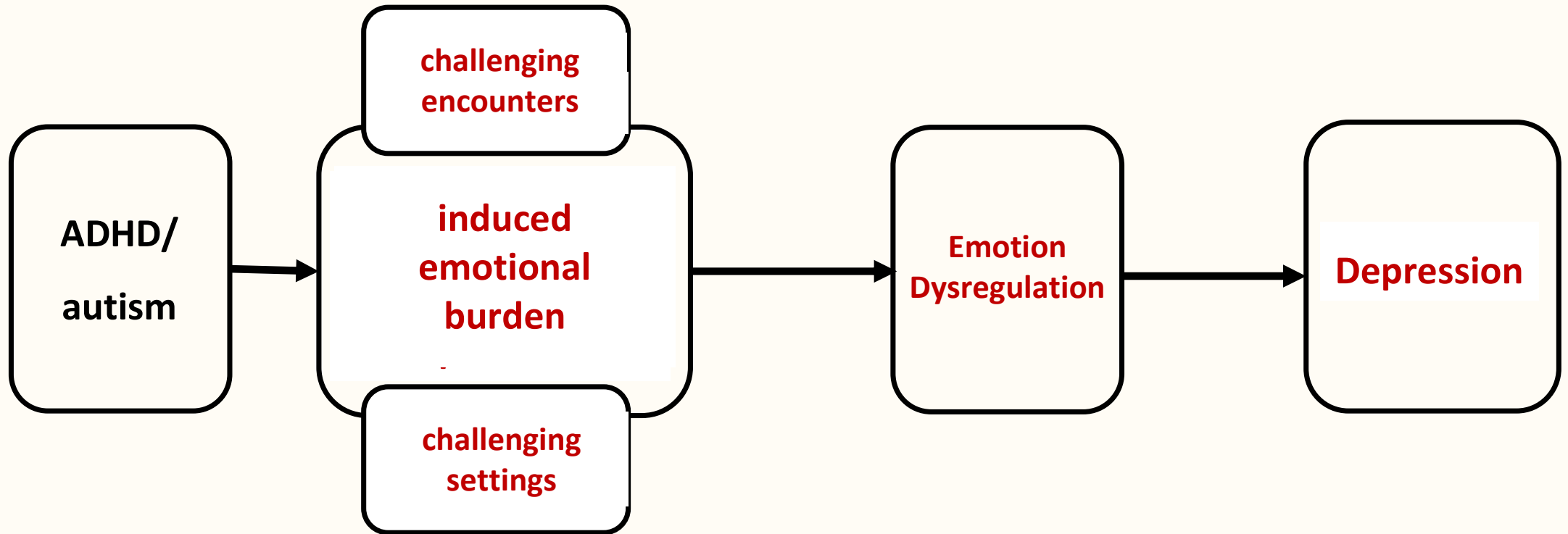


## Disorder Paradigm - Model



We flip focus to neurodivergent emotional encounters & experiences.

## Divergence Paradigm – Core Model



# Neurodiversity 'flip' changes what's studied

From characterising **deficits in individuals** to understanding how/why **outcomes vary as a function of environment-person fit.**

Promotes a participatory model where the experiences of neurodivergent individuals are central.



## Original Article

## Participatory translational science of neurodivergence: model for attention-deficit/hyperactivity disorder and autism research

Edmund J.S. Sonuga-Barke, Susie Chandler, Steve Lukito, Myrofora Kakoulidou, Graham Moore, Niki Cooper, Maciej Matejko, Isabel Jackson, Beta Balwani, Tiegan Boyens, Dorian Poulton, Luke Harvey-Nguyen, Sylvan Baker and Georgia Pavlopoulou on behalf of the RE-STAR team\*

### Background

There are increasing calls for neurodivergent peoples' involvement in research into neurodevelopmental conditions. So far, however, this has tended to be achieved only through membership of external patient and public involvement (PPI) panels. The Regulating Emotions – Strengthening Adolescent Resilience (RE-STAR) programme is building a new participatory model of translational research that places young people with diagnoses of attention-deficit hyperactivity disorder (ADHD) and autism at the heart of the research team so that they can contribute to shaping and delivering its research plan.

### Aims

To outline the principles on which the RE-STAR participatory model is based and describe its practical implementation and benefits, especially concerning the central role of members of the Youth Researcher Panel (Y-RPers).

### Method

The model presented is a culmination of a 24-month process during which Y-RPers moved from advisors to co-researchers integrated within RE-STAR. It is shaped by the principles of co-intentionality. The account here was agreed following multiple iterative cycles of collaborative discussion between academic researchers, Y-RPers and other stakeholders.

### Results

Based on our collective reflections we offer general guidance on how to effectively integrate young people with diagnoses of ADHD and/or autism into the core of the translational research process. We also describe the specific theoretical, methodological and analytical benefits of Y-RPer involvement in RE-STAR.

### Conclusions

Although in its infancy, RE-STAR has demonstrated the model's potential to enrich translational science in a way that can change our understanding of the relationship between autism, ADHD and mental health. When appropriately adapted we believe the model can be applied to other types of neurodivergence and/or mental health conditions.

### Keywords

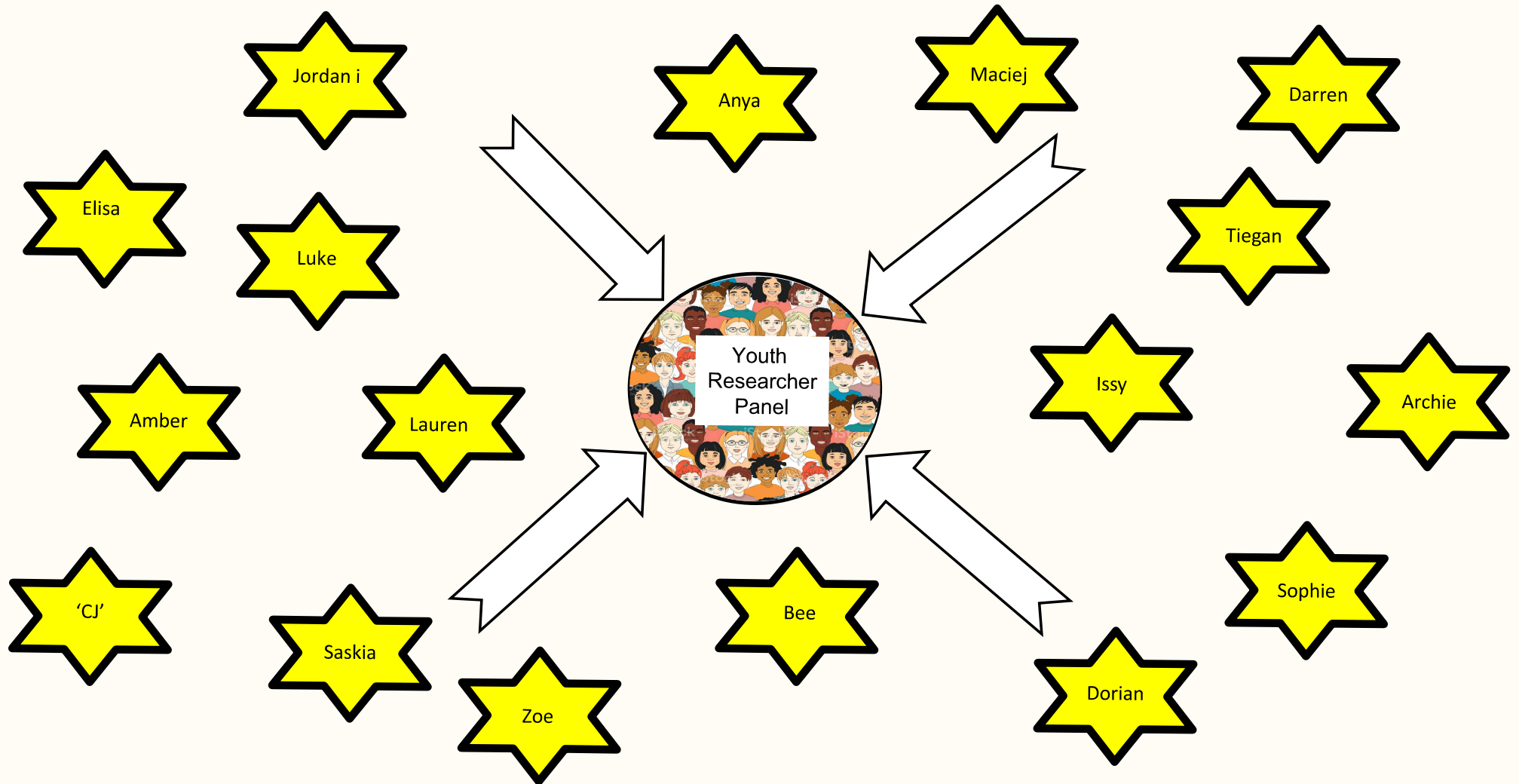
Autism; ADHD; adolescence; neurodiversity; patient and public involvement.

### Copyright and usage

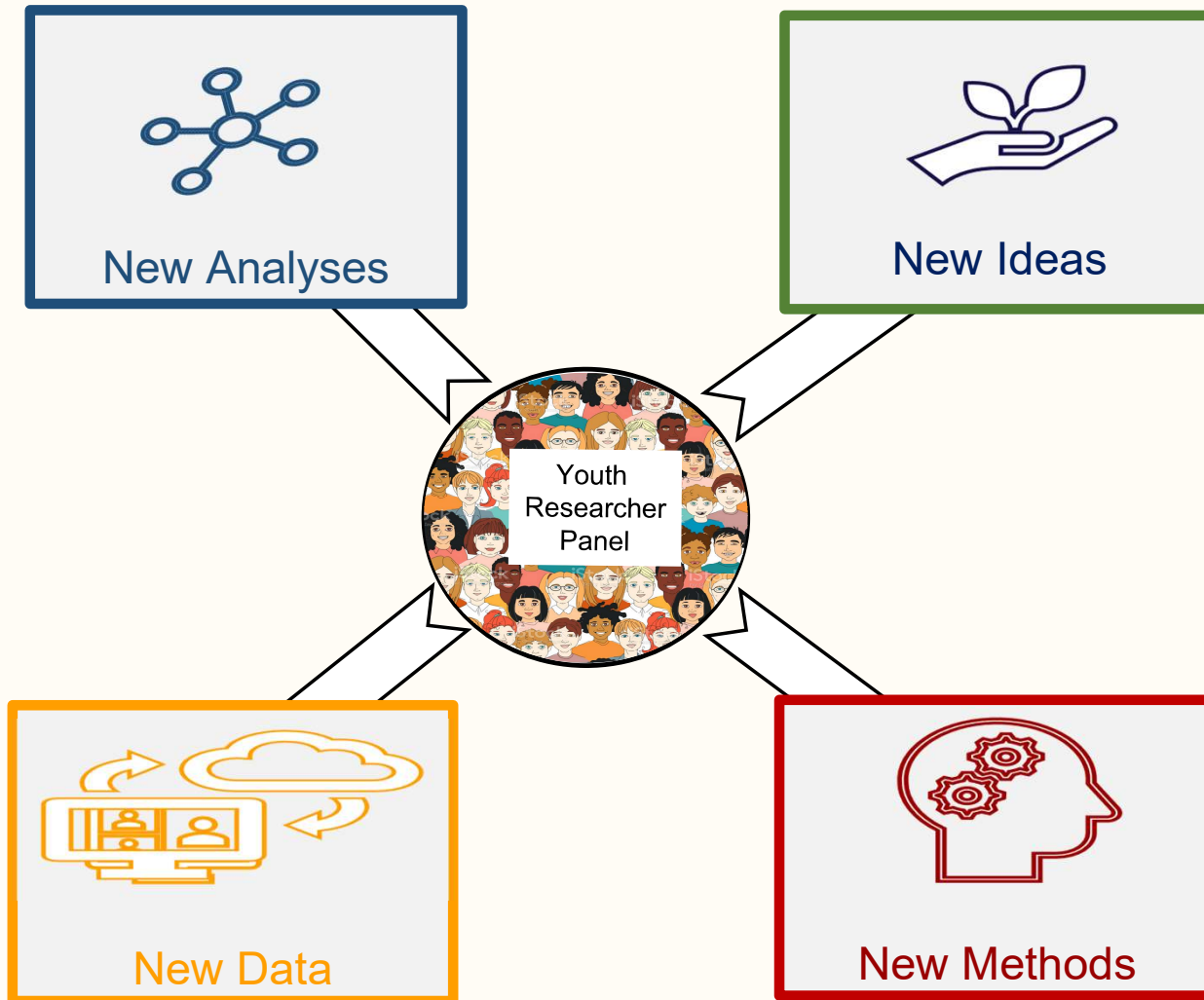
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Making progress towards a new way of doing translational science.

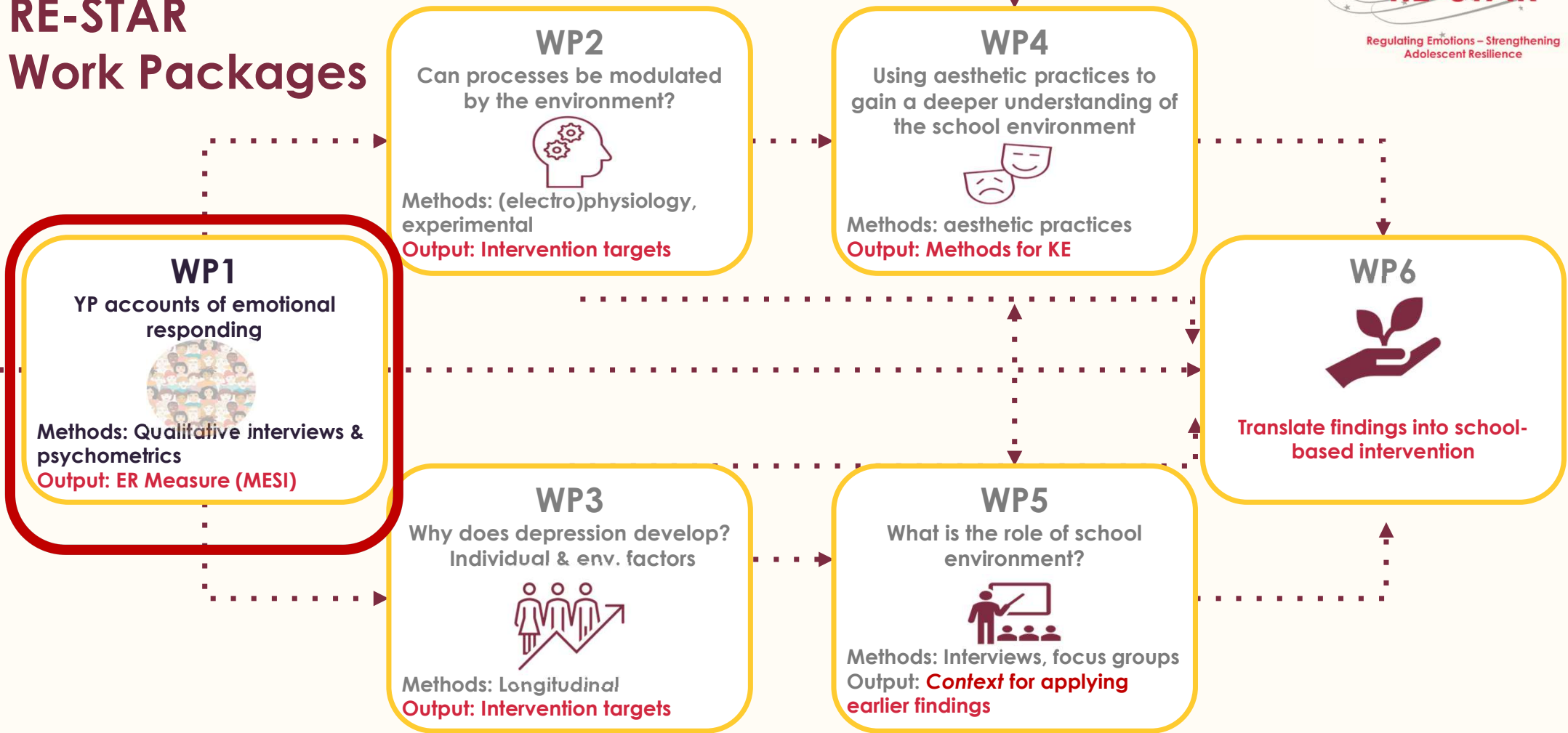
# The Youth Researcher Panel - Y-RPers



# Invigorating research



# RE-STAR Work Packages




## **RE-STAR Work Package 1:**

**Qualitative analysis of personal accounts**



# My Emotions and Me Research Aims & Questions

- 
- **Aim 1:** *To understand* how adolescents with diagnoses of ADHD or autism think and talk about their emotions at school, home and other places.

## Research Questions

1. What specific events and encounters trigger emotional reactions in young people with a diagnosis of ADHD or autism?
2. How are these experienced?
3. What helps reduce chances of negative emotions & what helps recovery from negative emotions?
4. What do autistic and ADHD young people share in common and what is specific to ADHD or autism?

- **Aim 2:** *To develop a new self-report of emotion responses in school* by and for neurodivergent young people (YP) to predict depression – **My Emotions in School Index (MESI)**



# Methods

## Participants (N= 45)



- Adolescents with diagnoses of ADHD (N=24) or autism (N=21)
- 11 to 15 years (ADHD = 13, Autism = 12.9)
- Attend a UK mainstream secondary school
- 29 males and 16 females
- 35 White
- 7 received free school meals

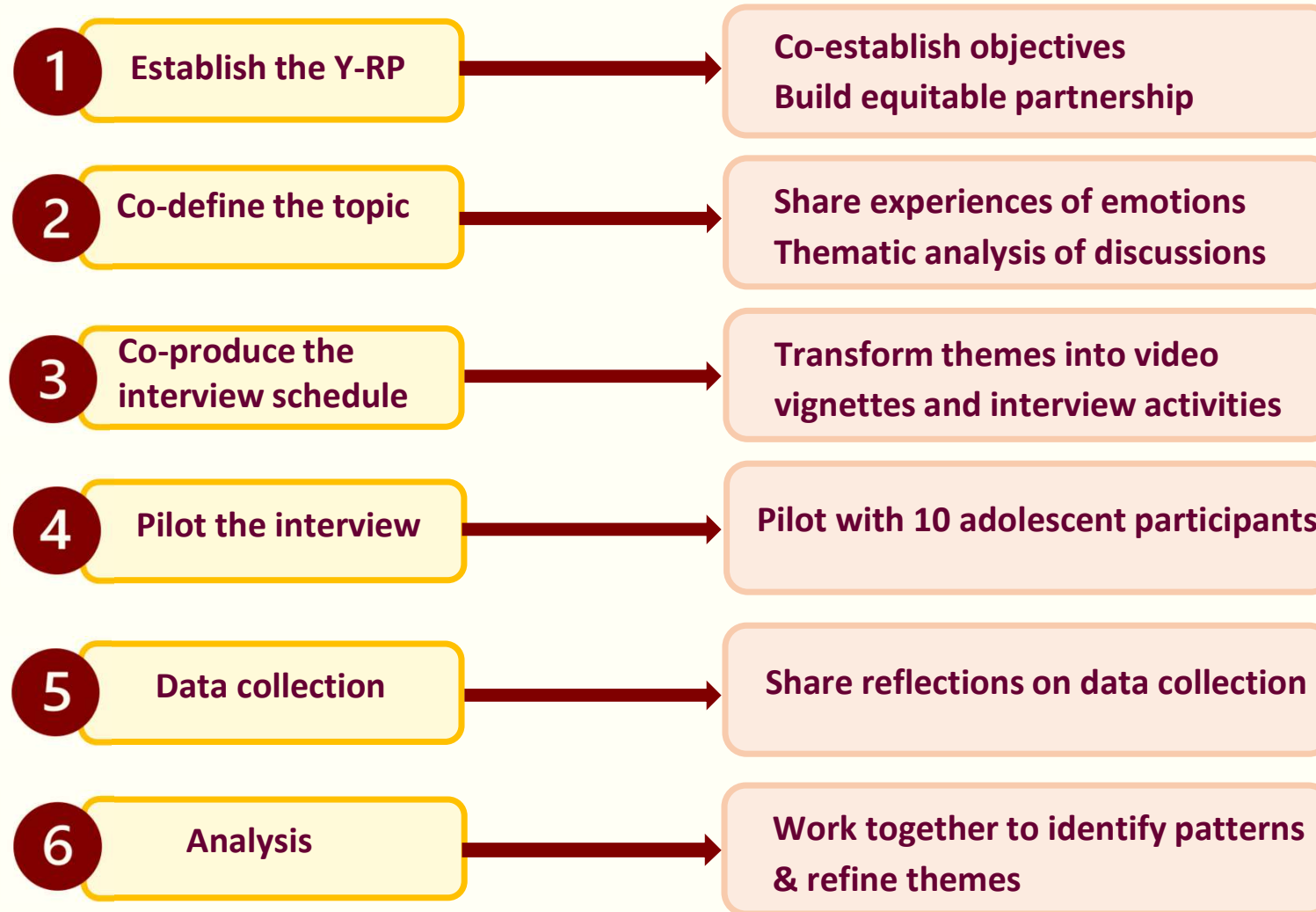
## Procedures



- Online introduction and interview with a researcher
- Complete multimedia creative tasks to respond to prompts about emotional life, triggers and what helps before the interview



# Role of Youth Researcher Panel (Y-RP)



# Fully Co-produced Interview Schedule

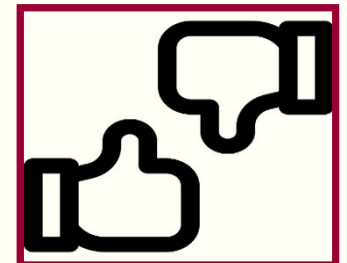
**A. Ice-breakers (e.g., young person's interests/hobbies)**

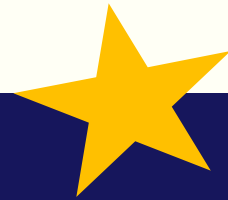
**B. Discussion of the creative task completed at home/Reflection on young person's emotion reactions during calming and/or upsetting situations**

**C. Responding to scenarios (vignettes) described by other young people**

**D. Thinking about different emotions, using an on-screen emotions chart**

**E. Thinking about how to manage emotions, and what helps with this**





# Qualitative analysis of personal accounts

*Emotional triggers*

# Findings - Theme 1: Social Dislocation, Alienation and Conflict

**Theme**

**Social dislocation,  
alienation and  
conflict**

**Sub-themes**

**Lack of sense of  
belonging: not  
fitting in**

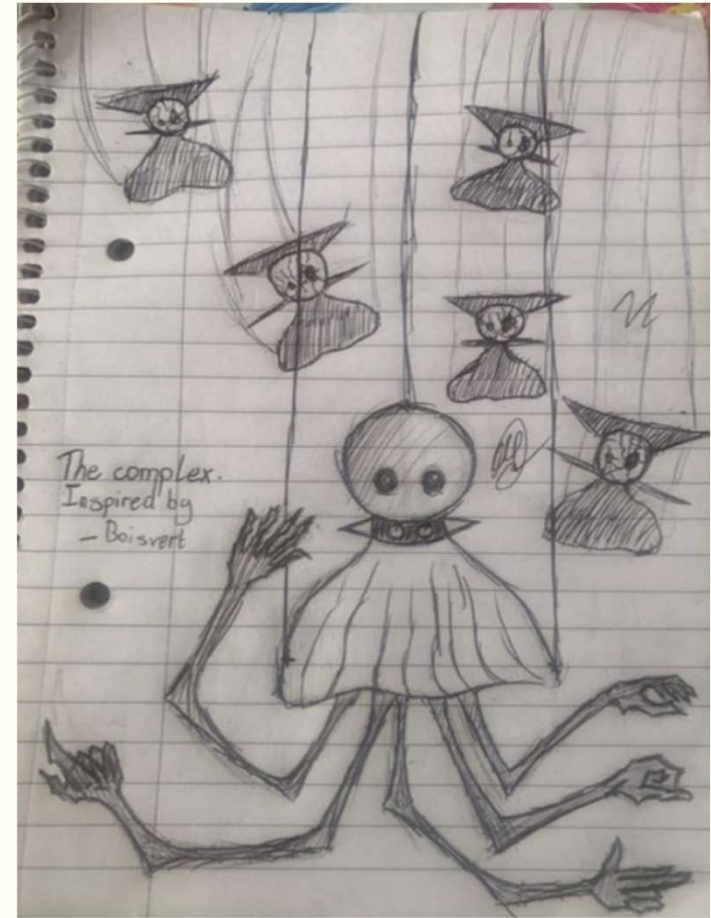
**Victimised/  
Unsafe and  
provoking  
interactions**

 = Autism specific

 = ADHD specific

## Findings - Theme 1: Social Dislocation, Alienation and Conflict

*"... I didn't know why these people didn't like me...I feel like I don't have a concrete friend group, at all. It really does hurt sometimes...That I'm gonna die alone, or without any friends, or I'm gonna die single...I feel like the extra friend a lot ... It feels horrible..."* (Male, 15, Autistic)



# Findings -Theme 2: The Experience of Hiding One's True Self

**Theme**

The experience of  
hiding one's true self

**Sub-themes**

Protecting  
others from my  
feelings

Protecting self  
from  
consequences

 = Autism specific

 = ADHD specific



## Findings -Theme 2: The Experience of Hiding One's True Self

*"I don't feel good masking them [the emotions], but it's better than actually showing my feelings and getting made fun of, me getting angry and maybe get a detention or ....to be seen as a wimp."* (Male, 13, ADHD)

*"If I express stress...., people around me might get stressed...So I think it's just better if I don't tell people and then they don't have to worry about me...I don't want to make it an issue for someone else..."* (Male, 13, Autistic)



# Findings - Theme 3: Internalised Self-Doubt, -Loathing and Embarrassment

Theme

Internalised self-doubt, -loathing and embarrassment

Sub-themes

Struggling putting up with neurotypical standards/low self-esteem

Trapped in repeated negative experiences

 = Autism specific

 = ADHD specific

## Findings - Theme 3: Internalised Self-Doubt, -Loathing and Embarrassment

*"I'm just scared that I'm going to say the wrong thing. In the sense of that, I'll pick up the wrong piece of information (...) I'm scared that they are going to be like 'You lied to me', or something like that." (Male, 15, ADHD)*

*"I'll feel like I've disappointed myself, I'll feel like I've done bad for myself, like I've caused a problem or I've disappointed other people than myself." (Male, 13, Autistic)*

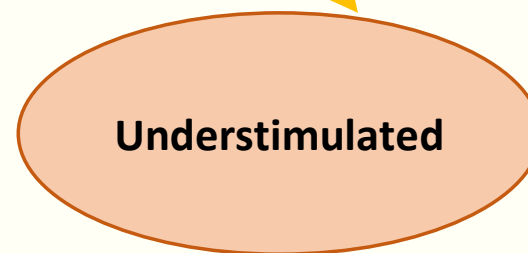
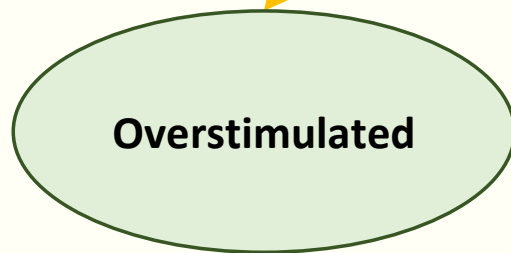


# Findings - Theme 4: Under/Overstimulation and Sensory Mismatch

**Theme**

Stimulation levels  
and sensory  
mismatch

**Sub-themes**



 = Autism specific

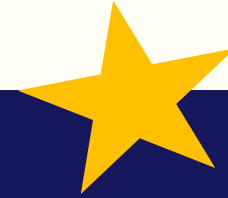
 = ADHD specific

## Findings - Theme 4: Under/Overstimulation and Sensory Mismatch

*"(...) if I'm trying to focus on something and then there's kind of noises in the background, they will really irritate me. Or if I'm really anxious by something, and then there's that extra noise and things like, I can be very irritable with, like, all my senses really."* (Female, 12, Autistic)

*"During school [I experience big emotions], mostly, because what we do now is just going over the stuff we've already learned which is just a bit boring, the repetition. And then I guess **when a lesson or doing something is boring and I just switch off.**"* (Male, 15, ADHD)



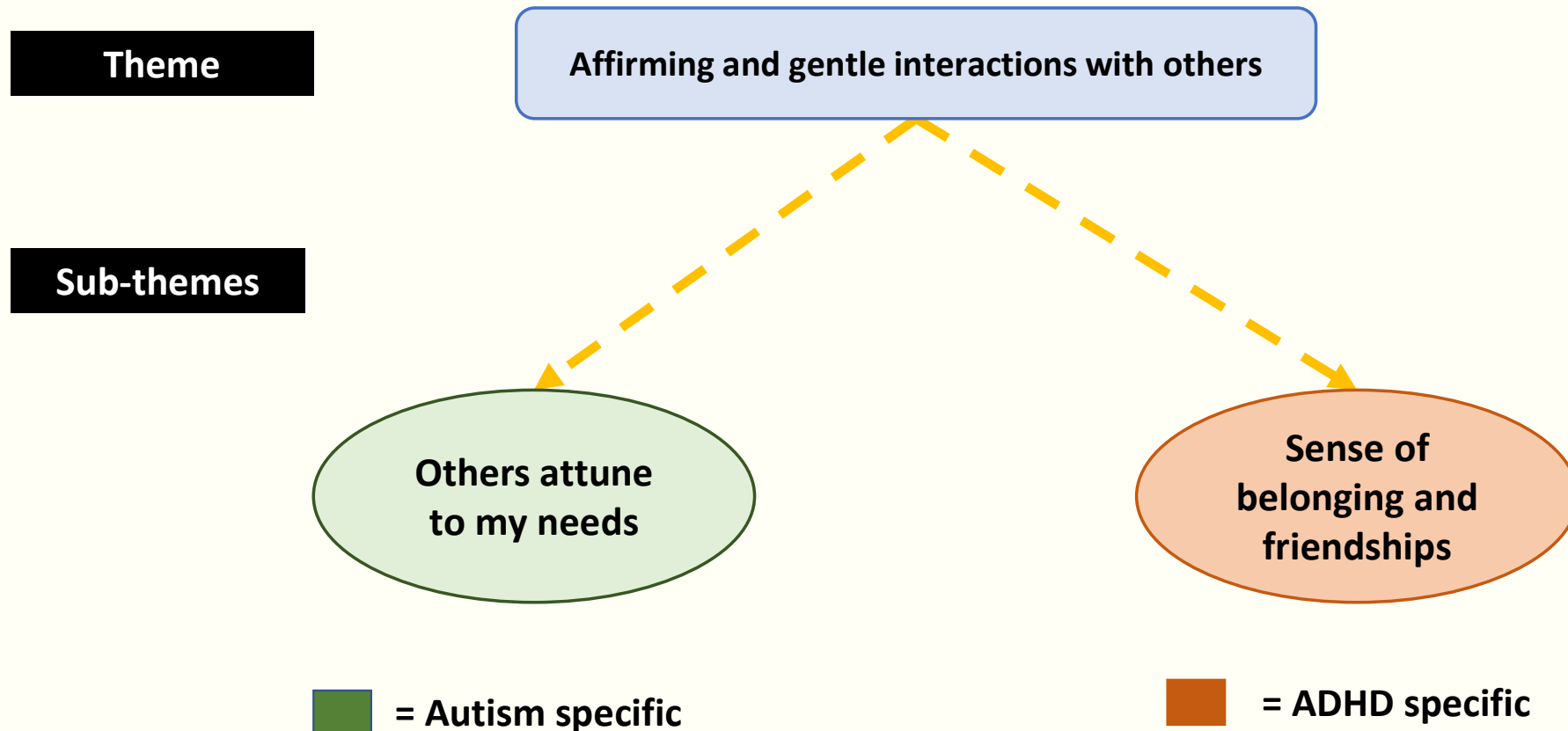


# Qualitative analysis of personal accounts

*What helps*

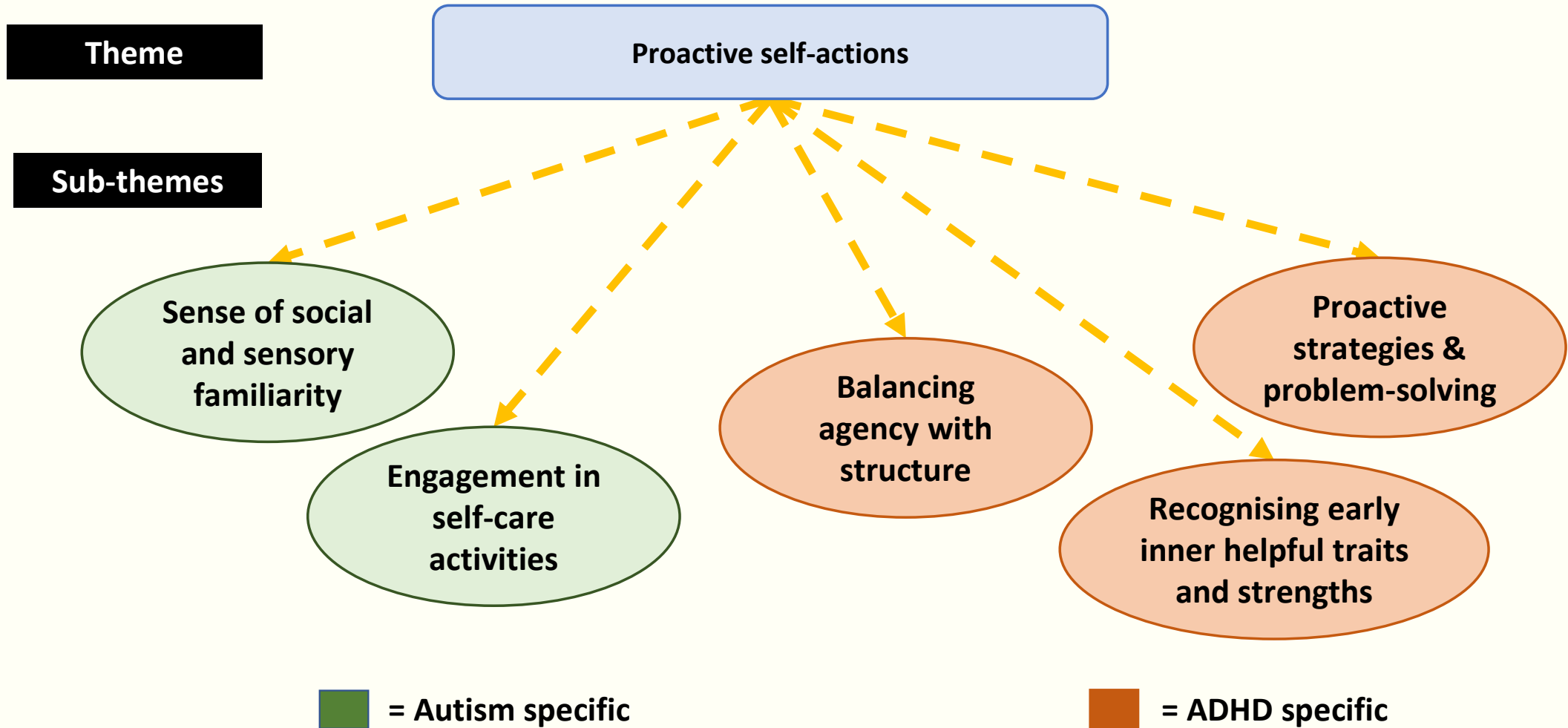
# What reduces negative emotions

## Theme 1: Affirming and gentle interactions with authority figures and peers



# What reduces negative emotions

## Theme 2: Proactive self-actions





# What helps when experiencing negative emotions

Theme: Achieving a compassionate resolution & feeling supported by others

Theme

Achieving a compassionate resolution & feeling supported by others

Sub-themes

Others acting as allies

Just the right amount of stimulation

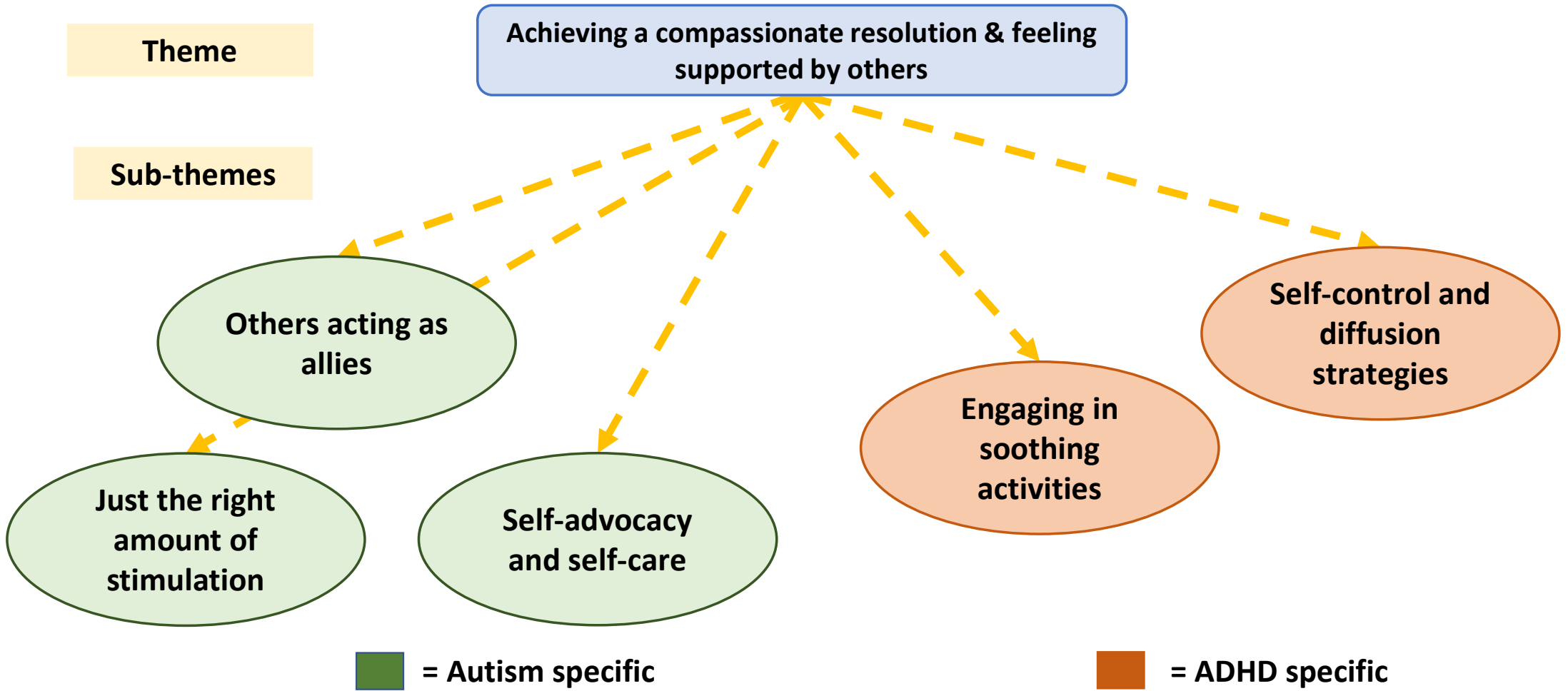
Self-advocacy and self-care

Engaging in soothing activities

Self-control and diffusion strategies

■ = Autism specific

■ = ADHD specific



# What helps with negative emotions

*"In the situation when I came off the ride, I said to my dad, **I was just so happy at myself because I did it, because I was a bit nervous to do it at first. Then I just pushed myself to do it.** So that's probably why I was so happy."* (Female, 12, ADHD)

*"When others can't understand things...you've got to be there to support them. No matter if they are struggling, no matter if they don't, if it's the easiest question in the world. **No matter, you always try to help them, if they're sad or if they're angry.**"* (Aaron, 11, Autistic)

**School-based triggers in neurodivergent young people:  
Findings from the  
*My Emotions in School Inventory (MESI)***

# The Structure of the MESI

## A. Triggers (25 items)

- 5-point scales measuring:
  - Frequency - how often?
  - Impact - how upsetting?
  - **Emotional burden = freq\*impact**

## B. Responses (24 items)

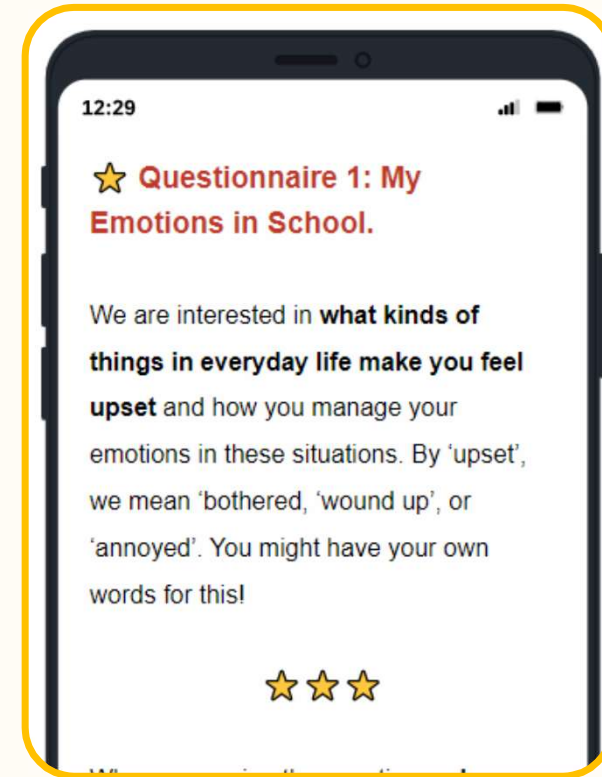
- What would you do if...
- 5-point likelihood rating

## C. Self-concept (7 items)

- How would it make you feel about yourself

## D. Recovery (7 items)

- What do you do when you get home, after a stressful day?



# Trigger items

“Finding out your peers have been **talking** about you **behind your back**”

“Unexpectedly having to **wait for ages** in a queue”

“Being told off by your teacher **in front of your classmates**”

“School **staff don't listen** to you or challenge what you say”

“Being in a **chaotic classroom and/or playground** (e.g., too noisy, too many people around you, too many visuals)”

“When you're asked to do **something really boring**”

“School staff **don't understand** your feelings and reactions”

“The **sights, smells, or sounds in the classroom** make you feel uncomfortable”

“Being made to stop doing something you really enjoy by school staff”

“The person in charge makes a **last-minute change** of plan”

“**Losing or forgetting something important** for your lessons (e.g., your school bag or Physical Education (PE) kit)”



Social and sensory aspects of the environment.

# Our Research Questions



- How does emotional burden relate to the concepts of emotional regulation and mental health?
- Does the emotional burden of these provocations differ:
  - between **neurodivergent** vs. **neurotypical** adolescents?
  - between the **clinical groups**? (especially **autistic** vs. **ADHD**)

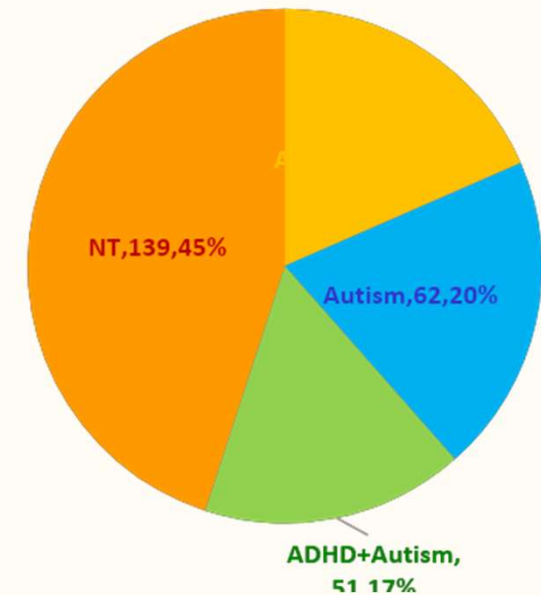
# MESI Psychometric Study

- **Participants**

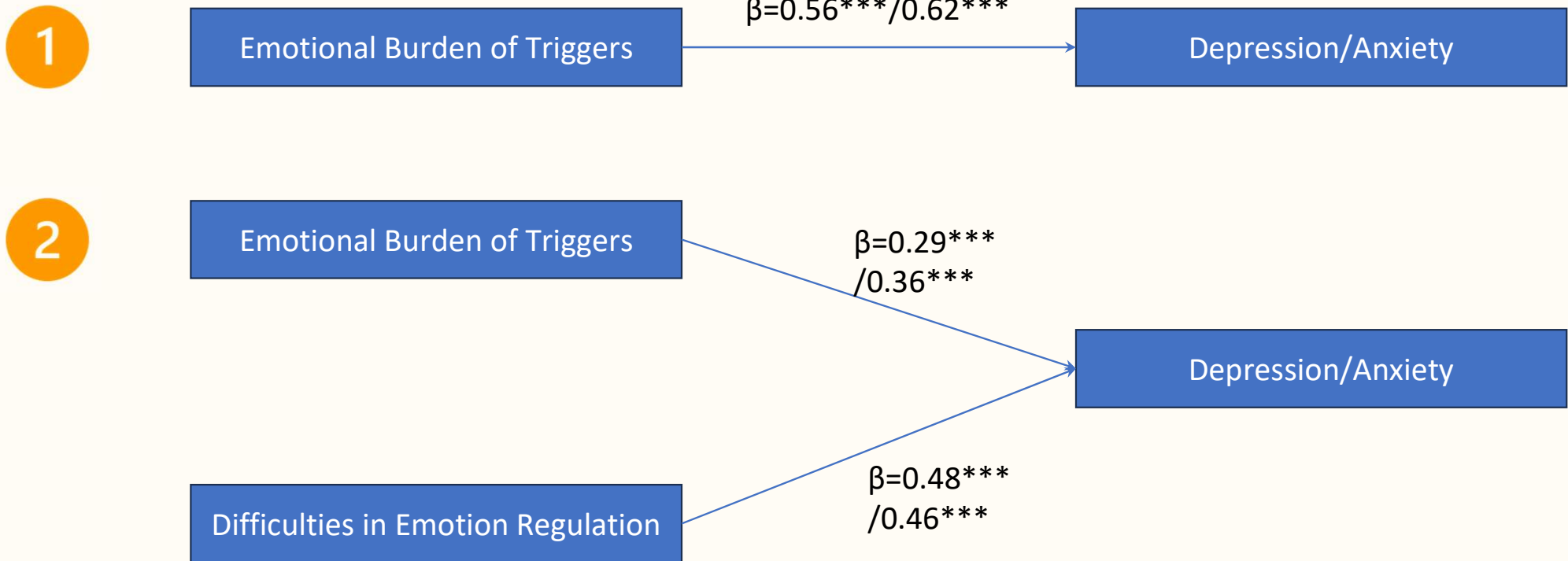
- 309 11–16-year-olds attending mainstream school (58% male).
- Clinical cases (**ADHD**, **Autism**, **ADHD+Autism**)
- **Neurotypical** individuals.

- **Measures**

- My Emotions in School Inventory or MESI
- PHQ-8 (Depression), GAD-7 (Anxiety)
- DERS (Difficulties in Emotion Regulation).



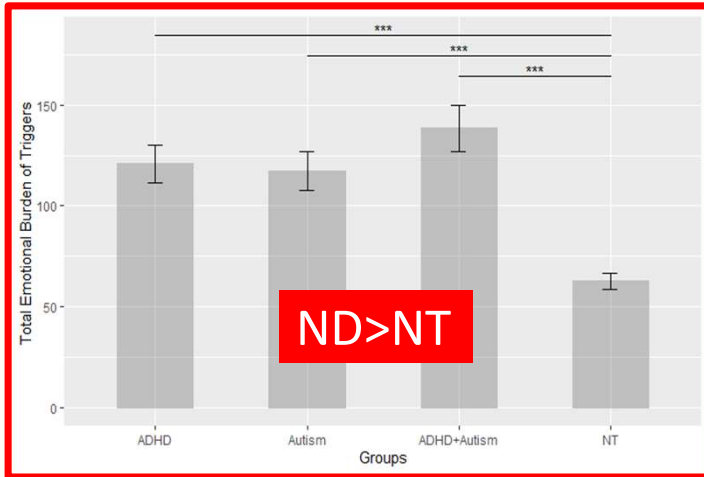
# Emotional Burden, Emotional Regulation and Mental Health



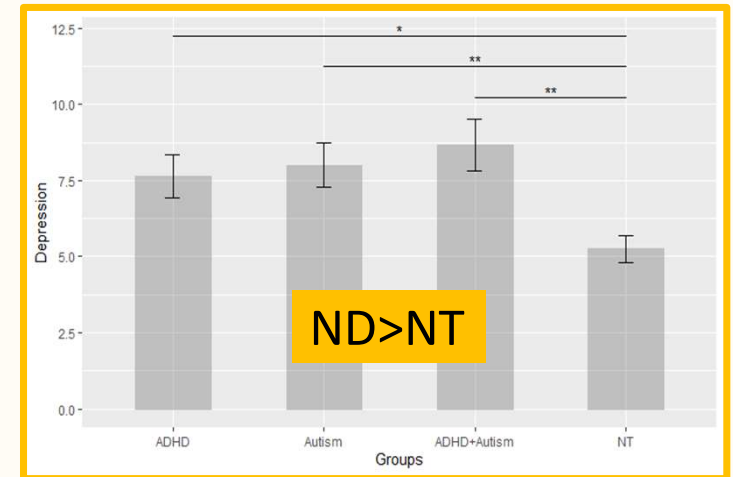
Unique contribution of emotional burden of triggers towards mental health.



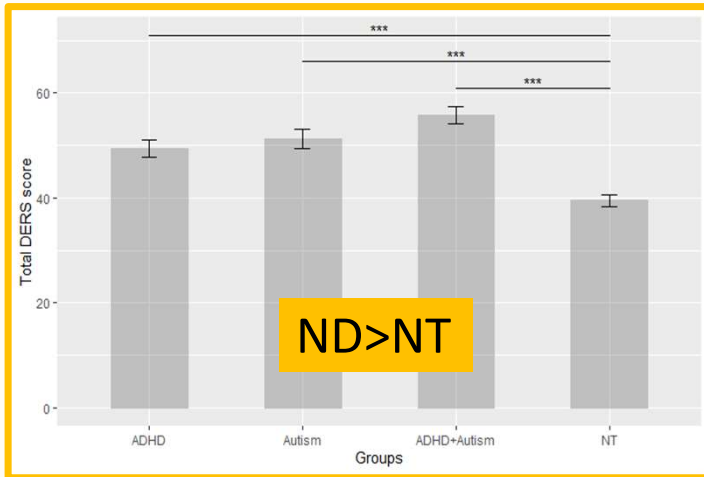
# Emotional Burden, Emotional Regulation and Mental Health



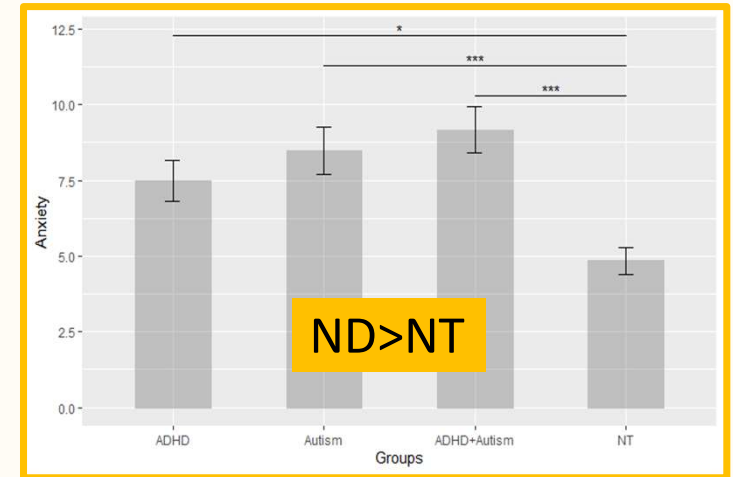
Depression



Emotion Dysregulation



Anxiety



# Emotional Burden, ADHD and Autism: Specificity of Triggers

## Autism

1. Peers talking behind back \*
2. Unexpected wait in a queue \*
3. Teachers tell me off
4. Sensory discomfort \*
5. Not understanding others
6. Peers teasing and bullying \*

Being othered, unmet expectation and sensory overload

## ADHD

1. Teachers don't listen \*
2. Not able to do tasks
3. Boring lessons or tasks \*
4. Stopped from doing something you enjoy
5. Losing, forgetting
6. Told to try harder \*
7. Accused of something I didn't do \*
8. Having too many options \*

Relationship with teachers, understimulation, rewards

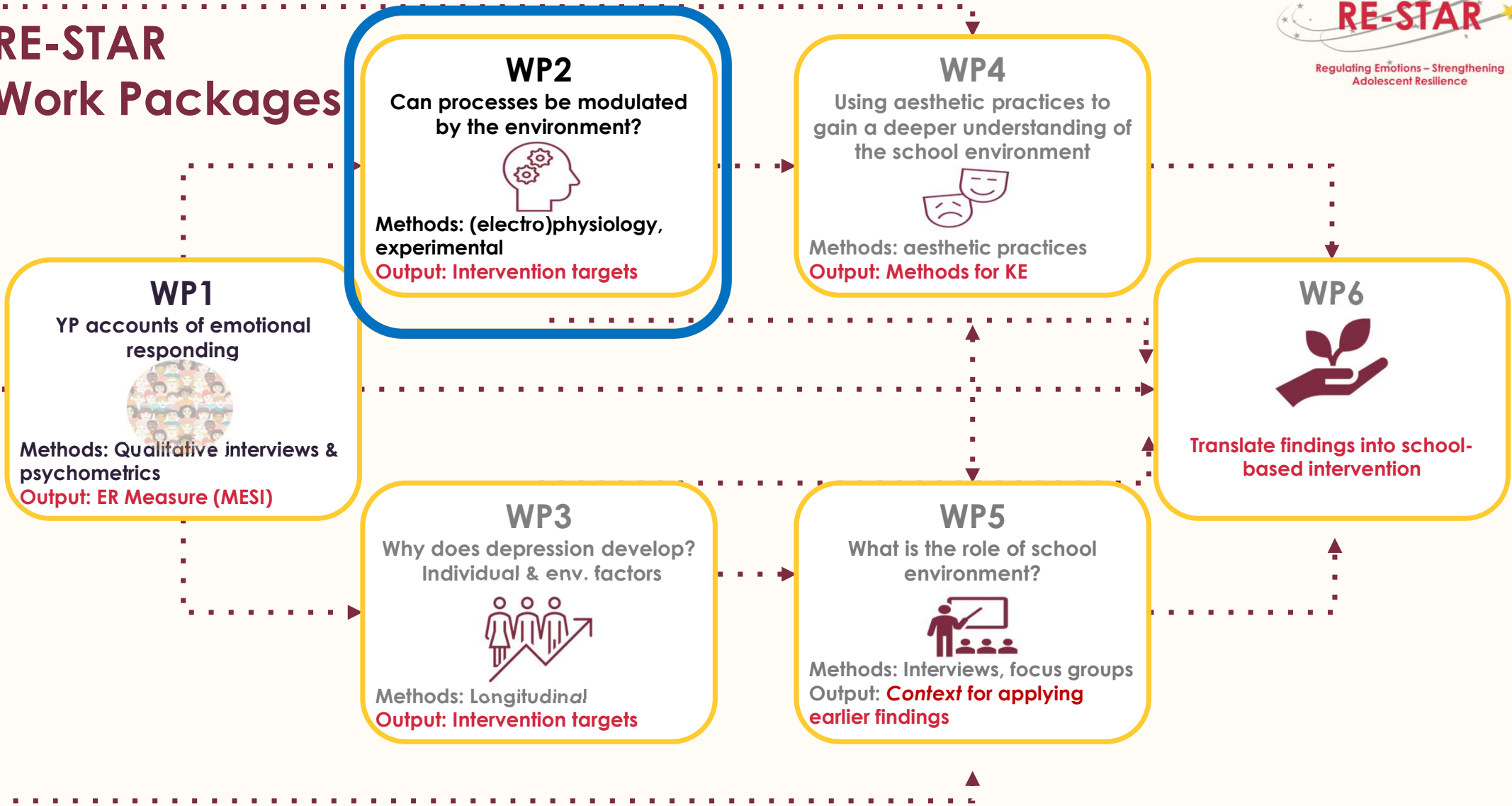
ADHD and autism carry many common emotional burdens of triggers.

## Summary

- ND young people experience substantially higher overall emotional burden from everyday provocations compared to NT.
- The emotional burden of everyday provocations is associated with increased mental health difficulties.
- While there is an overlap in the type of emotionally burdensome triggers across the diagnostic groups, some triggers contribute more burden to Autism and others to ADHD.
- We need to test the interplay between emotional burden, emotion dysregulation and depression in WP3 and its impact on school in WP “20”.

## **Next steps in RE-STAR**

# RE-STAR Work Packages



# My Brain, Emotions and Me



## Question

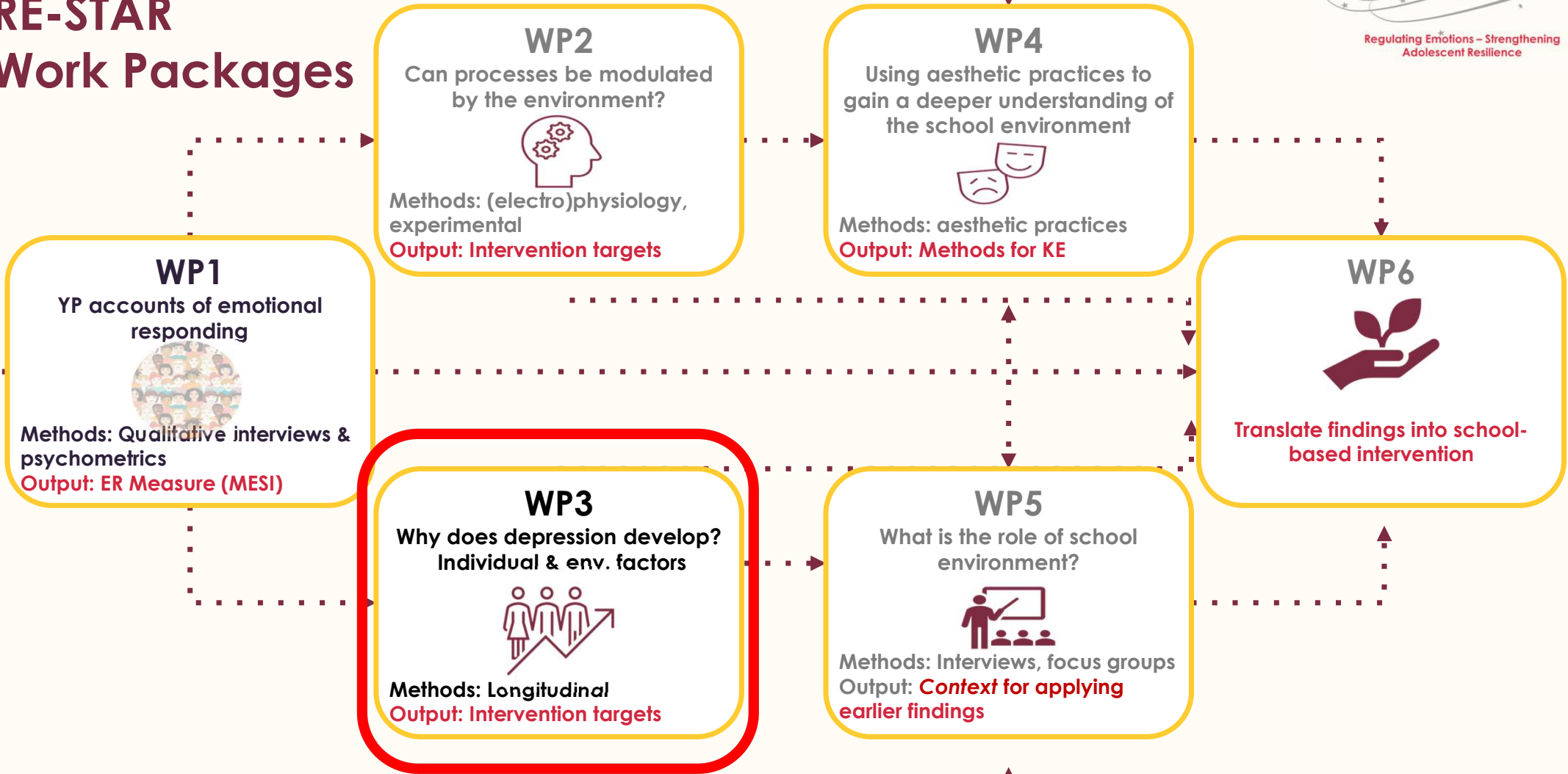
How do different **classroom settings** (ND-affirmative vs ND non-affirmative) impact **brain** responses to everyday **classroom triggers** and provocations?

Does this differ for those with autism traits vs ADHD traits vs neurotypical young people?

Welcome! This is a task about classroom situations and people's responses to them.



# RE-STAR Work Packages



# My Emotions and Me Over Time



## Questions



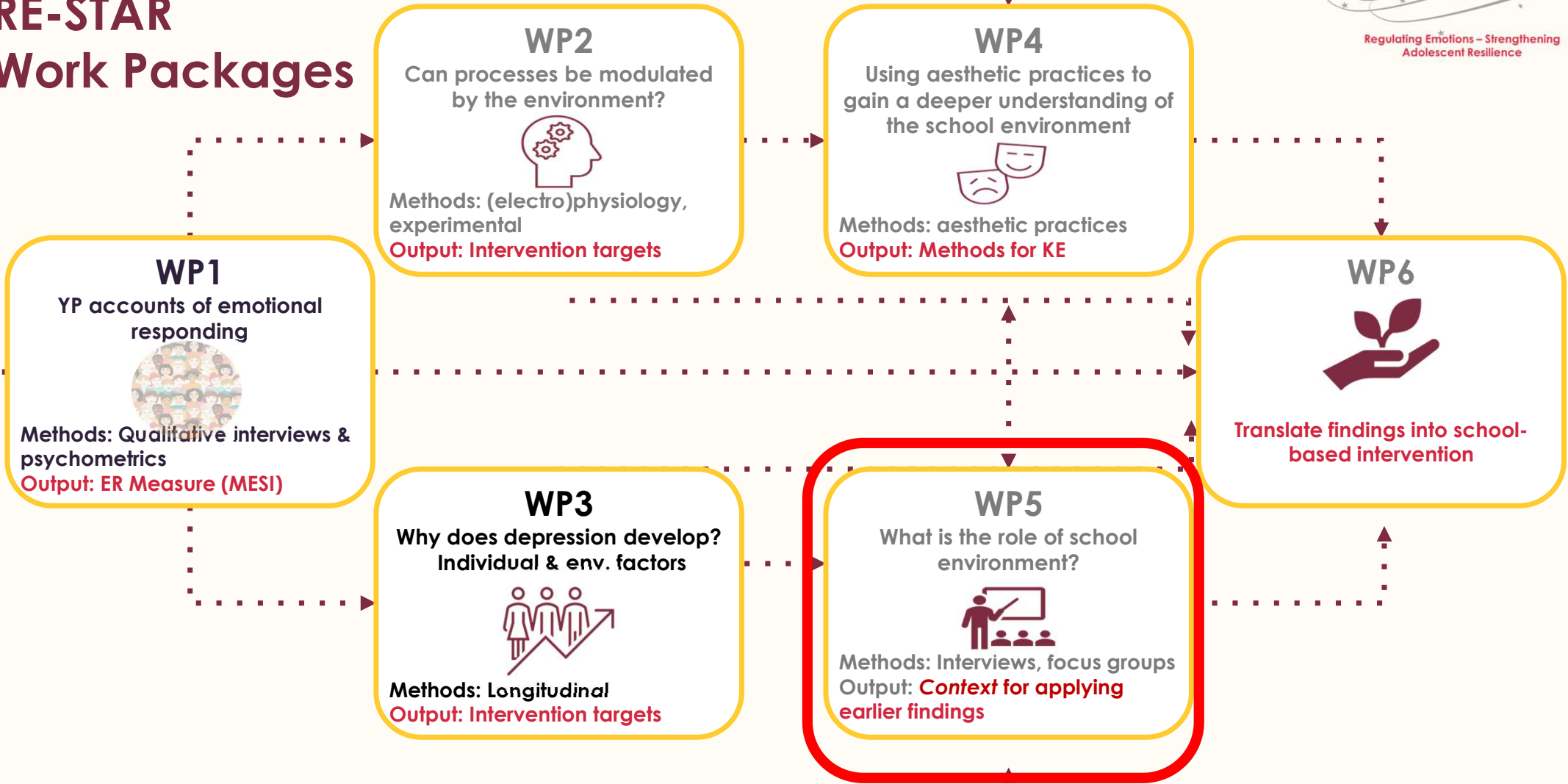
- Do **neurodivergent traits** increase the risk of depression during adolescence?
- Are the trajectories different for ADHD and autism, and during early and later adolescence?
- What role do the following play in the emergence of depression :
  - **school-induced emotional burden?**
  - **emotion dysregulation**
- How do **other background factors** impact this pathway?



# My Emotions and Me Over Time



# RE-STAR Work Packages



# The Emotions Lives of Young People and Staff in School

## Call for school staff

with a pastoral role in  
mainstream secondary schools  
in England!



A national survey of school actions to  
support the mental health of neurodivergent  
students

### What is involved?

- Complete a **30-minute survey** by scanning the QR code or emailing us.
- Survey co-designed with school staff and neurodivergent young people.
- **Earn a £10 e-voucher**, access resources and enter a **prize draw for a £100 e-voucher!**



Take part 📍

[https://qualtrics.kcl.ac.uk/jfe/form/SV\\_a9tWBdrhQGpxxFI](https://qualtrics.kcl.ac.uk/jfe/form/SV_a9tWBdrhQGpxxFI)

# Thank you!

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 [www.kcl.ac.uk/research/re-star](http://www.kcl.ac.uk/research/re-star)



Improving children's  
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