

# The Overlooked Connection

Innovative Approaches to Mental Health and Autism

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health | YORK U



# Outline (and main messages)



## What really is mental health?

Mental health involves experiences of mental health problems and flourishing

- We need to support youth to reduce mental health problems AND to live their best life if we want them to experience good mental health



## What goes into achieving good mental health?

Experiencing good mental health is best achieved when a youth's individual needs and their social resources align

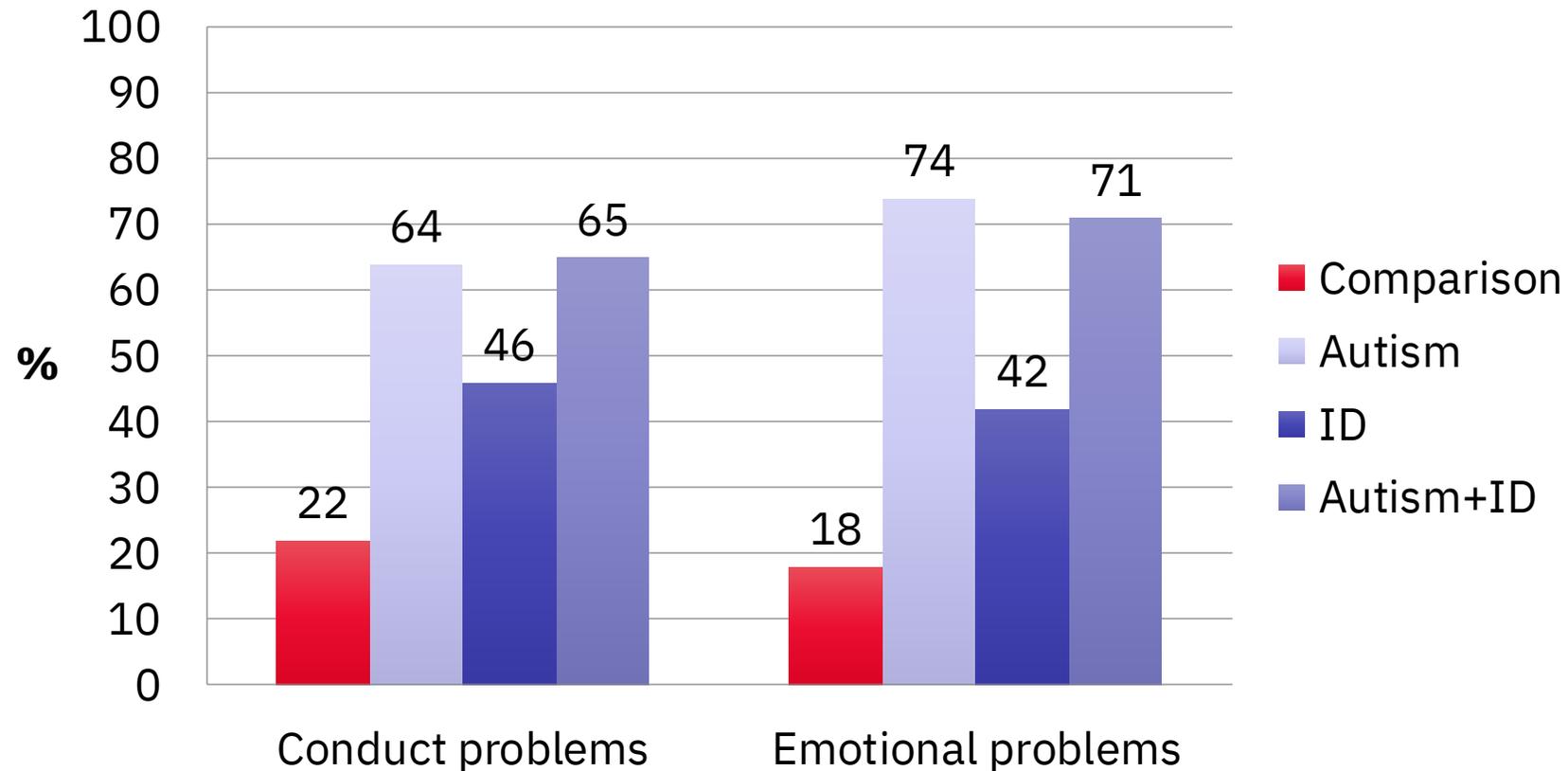


## How can we support in a developmental-contextual way?

It is especially important to address the contexts for youth with developmental challenges

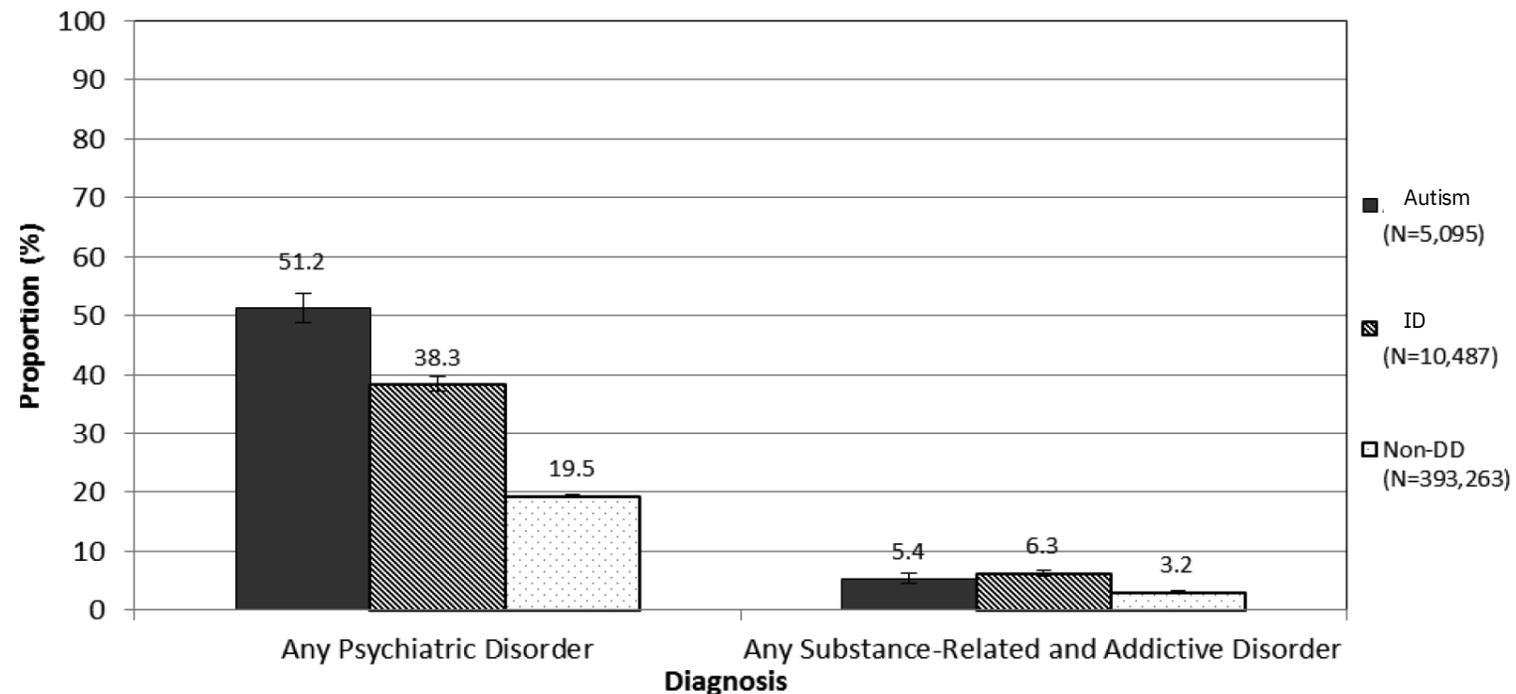
# Not unique to autism

- Large scale community study of 5 to 16 year olds; M age = 10 years (SD = 3.0) (Totsika et al., 2011)



# Mental health difficulties

- Typically, 50-60% of autistic youth and 40% of youth with intellectual disability are experiencing mental health problems (pre-COVID stats; Totsika et al., 2011)
- Many experience ‘subclinical’ challenges too, and deserve to experience supports when they do
- There is a lot of research documenting this struggle

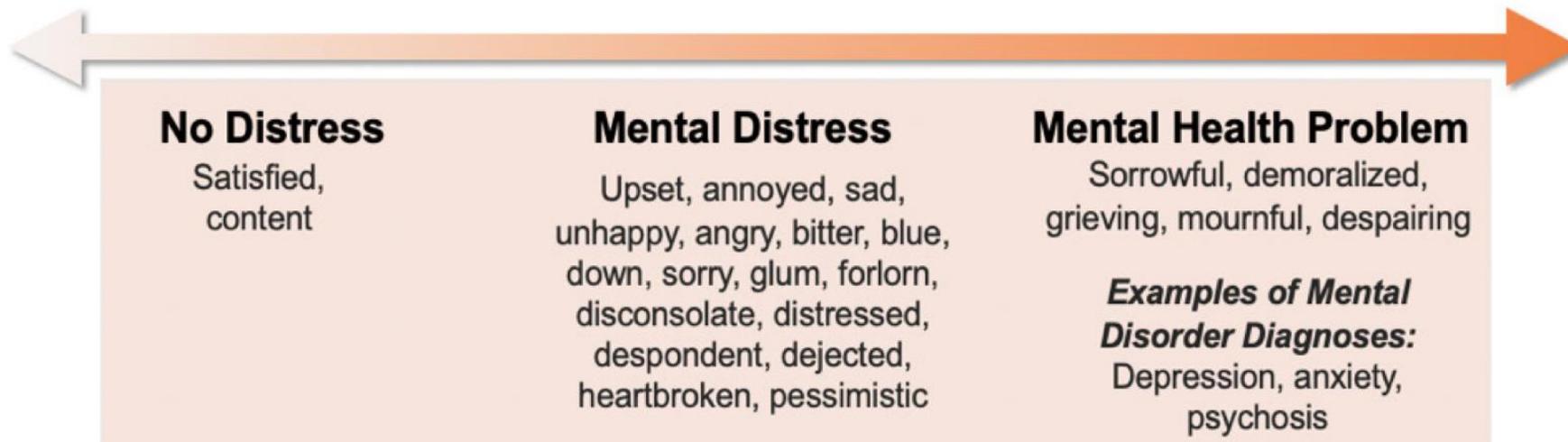


(Weiss et al. 2018)

**Children and adults with ID often experience mental health problems**

# What are 'mental health problems' in the context of developmental disability?

- › Emotional and behavioural problems that lead to significant difficulties beyond challenges from the disability
- › Mental health problems happen when the causes of distress outweigh a person's resources



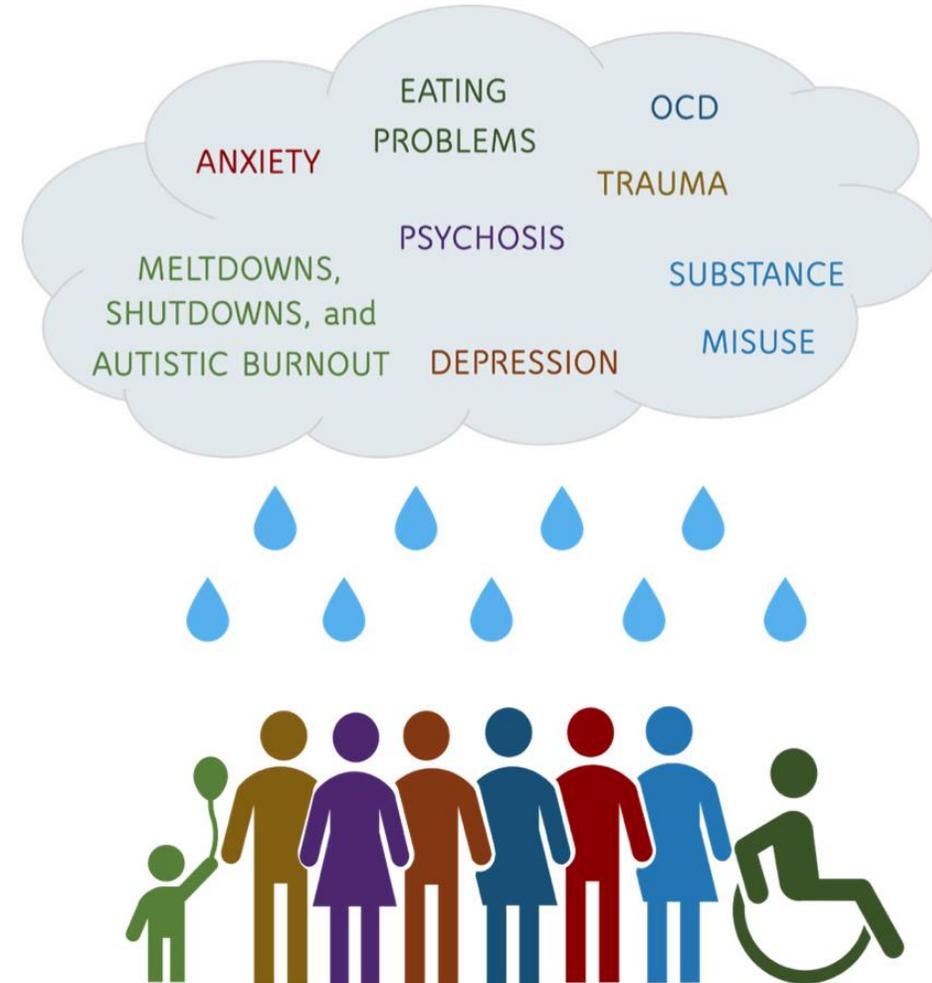
# Identifying mental health problems by knowing the person's usual

## Know 'usual' on a regular day

Changes from that usual

Recognizes uniqueness of each person

Pay attention to thinking, feeling, and body changes



# EXAMPLE ANSWERS

## What's **YOUR** 'NORMAL'?

### What is this toolkit?

If you are an autistic person, or know an autistic person who wants to help people around them understand what their normal is, this tool can help.

The 'know your normal' tool allows you to describe what your normal looks like, things such as how much sleep you get, how much time you spend on your interests and hobbies and how this makes you feel, so that if this changes, it's easier to explain to people who may not understand your autism that something feels different.



When do I normally go to sleep and wake up?

Sleep: 22:45      Wake up: 8:15      Total hours: 7½

Do I find it easy to fall asleep when I go to bed?

Wide awake: [ ]      Sound asleep: [Zzz]

How happy about getting out of bed am I?

Not happy: [ ]      Very happy: [ ]

What's my normal sleep routine?  
(Do I wake up in the night? Or do I have a pre-bed routine?)

I occasionally wake up in the night then go back to sleep again.

How much energy do I have during the day?

No energy: [ ]      Full of energy: [ ]

Do I like to spend time with my family?  Yes  No

The people in my family I'm closest to are:

My sister supports me through the hard times.

Do I like to spend time with friends or other people or do I prefer to spend time alone?

On own: [ ]      With others: [ ]

What do I like doing with friends?

Going to the cinema + getting pizza.

How does spending time with friends make me feel?

Not happy: [ ]      Very happy: [ ]

Do I have any imaginary friends? Yes  No

Do I talk to myself?  Yes  No

# At the individual level

## > Biological determinants

- Genetics: Many of the genetic causes of intellectual disability are also associated with mental health problems (Owen, 2012)
- Brain mechanisms: Shared brain structures and neurotransmitters (Bertolo et al. 2025)
- Physical health: More physical health problems = more mental health problems (Doan et al., 2023)

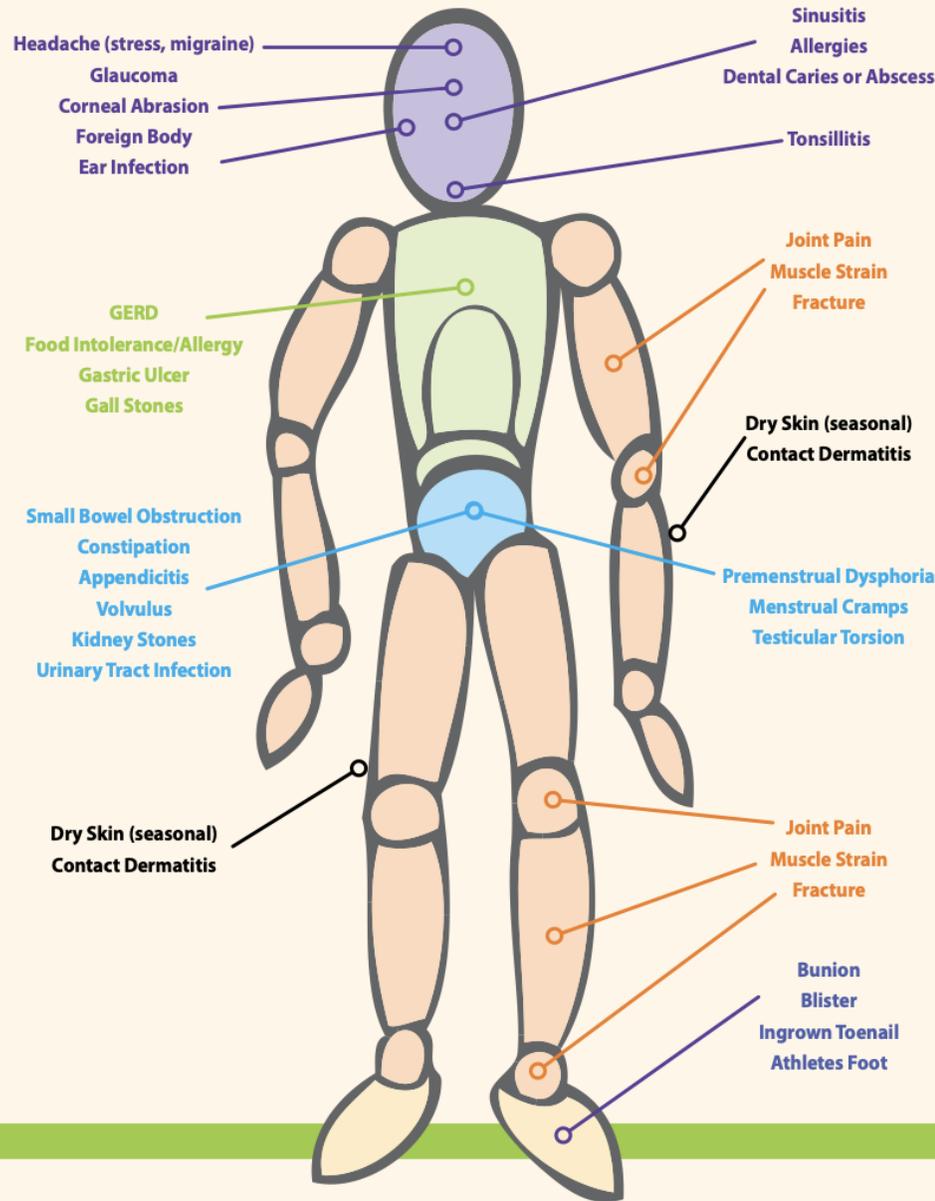
Condition	Intellectual disability (N = 8,021)	No intellectual disability (N = 1,359,500)	Risk*
Epilepsy	18.8%	0.8%	31x
Constipation	14%	2.5%	11x
Visual impairment	3.2%	0.6%	8x
Hearing loss	8.2%	3.8%	3x
Indigestion	10.3%	5.5%	2.5x
Psoriasis or eczema	1.7%	0.7%	2.4x
Thyroid issues	7.9%	5%	2.4x

(Cooper et al. 2015) \*Correcting for age, sex and deprivation

Condition	Autism (N = 5,095)	Neurotypical (N = 393,263)	Risk*
Diabetes	1.67	0.65	2.8x
Hypertension	1.67	0.83	2x
Asthma	24.42	20.59	1.1x
GP visit	68.36	68.62	1.3x
Pediatrician visit	7.91	2.15	4.0x
Neurologist visit	5.77	1.01	6.9x
Gastroenterologist visit	1.14	0.77	1.7x
Respirologist visit	0.29	0.21	1.5x

(Weiss et al. 2018) \*age, sex, rurality, and neighbourhood income

## Body Map of Common Pain Syndromes



- Biological vulnerabilities lead to psychological distress

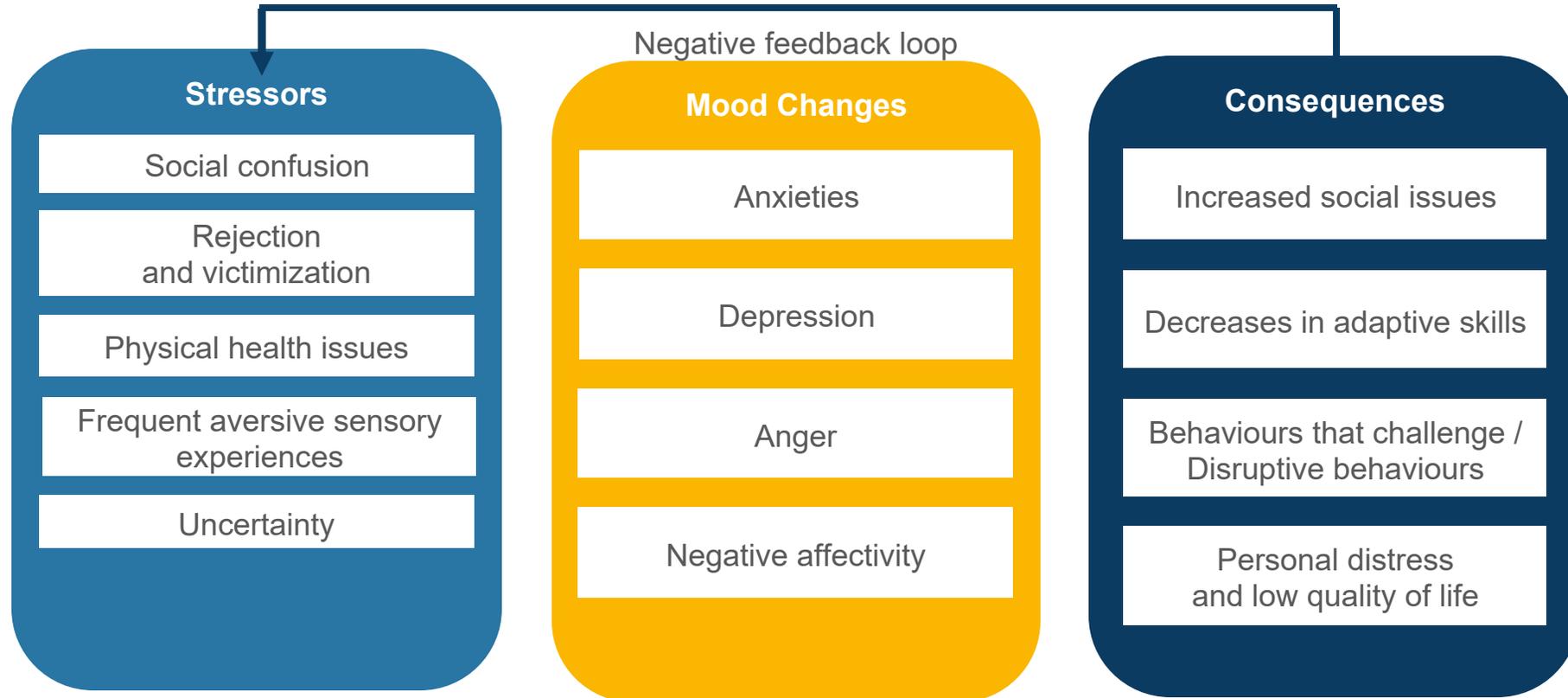
- From: <https://healthytransitionsny.org/wp-content/uploads/2014/01/dualdiagnosisiscaregiverguidefinal2011.pdf>

# At the individual level

- Cognitive / learning profile
  - May lack protective factors against stressors
    - Memory, Problem solving, Communication, Understanding
    - Self-advocacy and self-determination
  
- Risk of poor self-concept
  - Learned helplessness
  - Externally driven
  - Hypersensitivity
  
- Adaptive behaviour
  - Anxiety is positively correlated with deficits in communication, social, and activities of daily living



# At an individual level





**So much has to do with  
context**

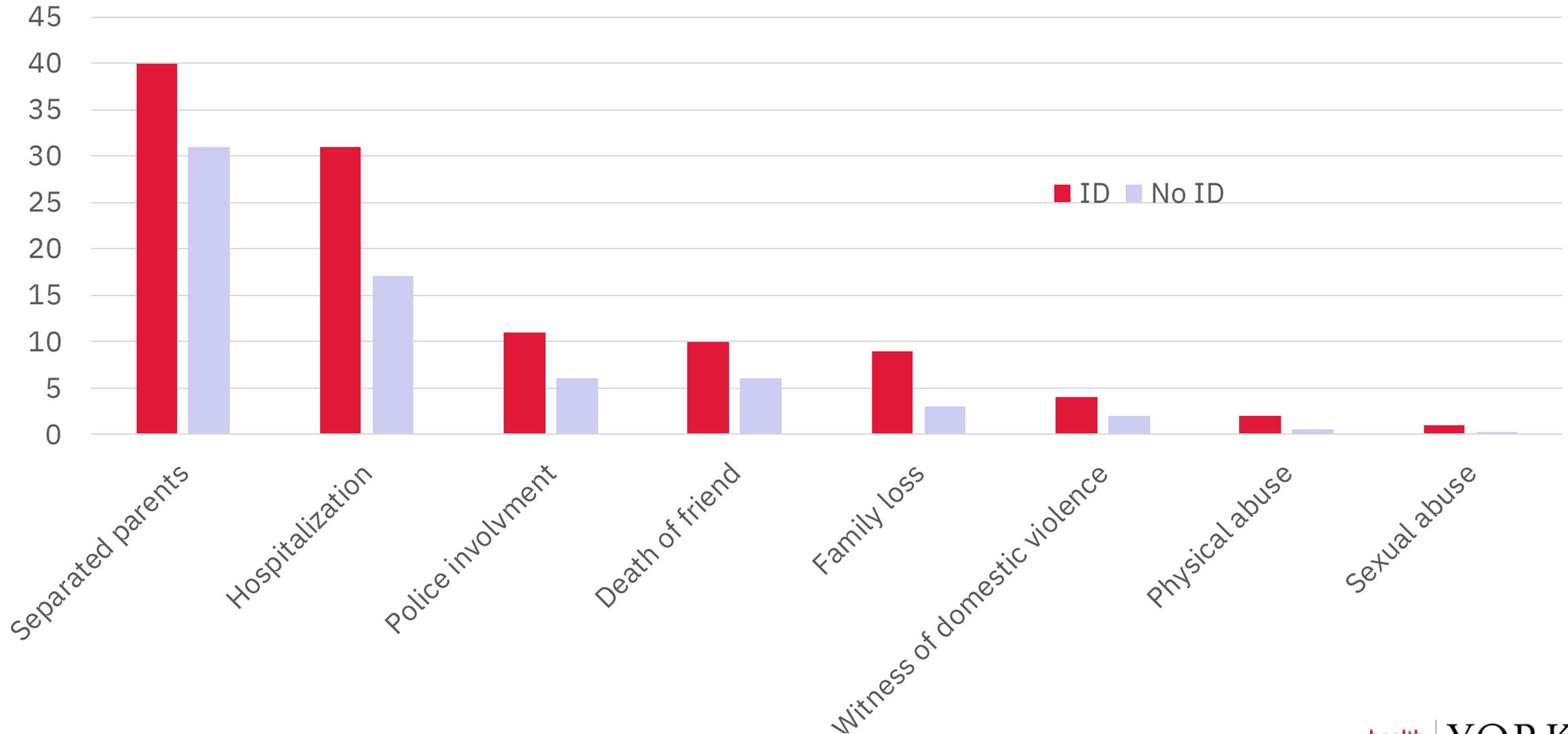


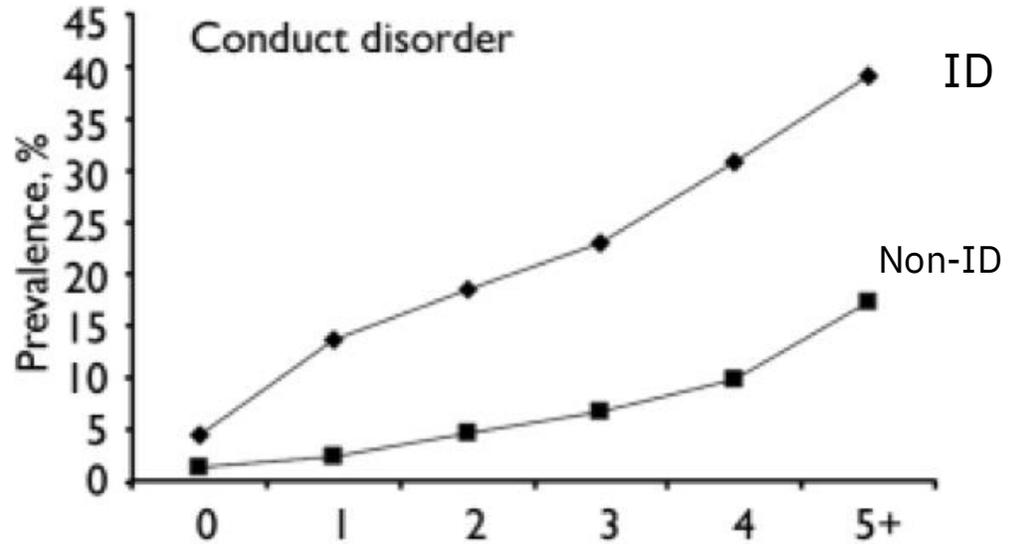
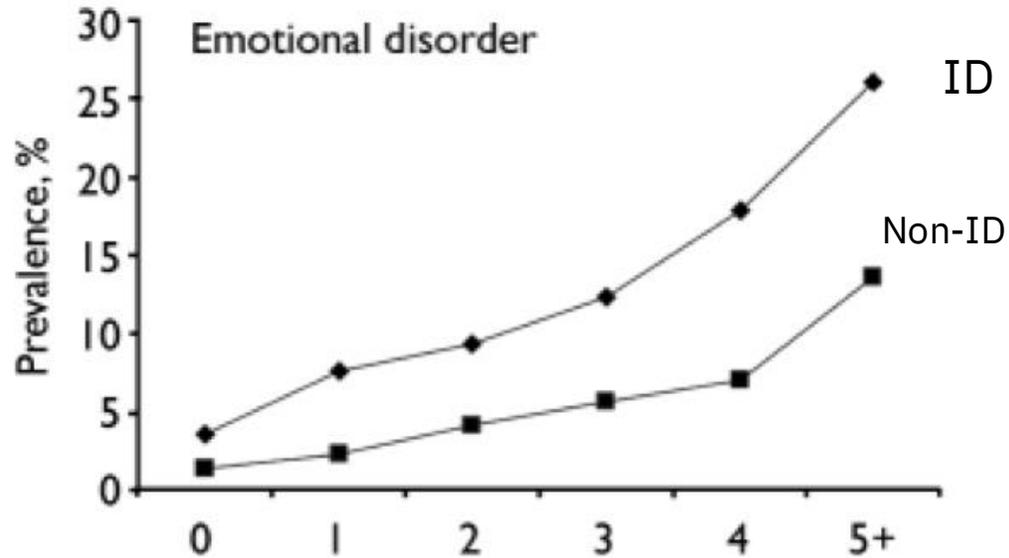
# The contribution of social vulnerabilities

In 18,415 UK children and teens	With DD n = 641	Without DD n = 17774	Odds ratio
Lone parent family	30%	23%	1.4
Income poverty	47%	30%	2.1
Exposure to > 2 negative life events	37%	24%	1.9
Poor family functioning	27%	18%	1.7
Primary caregiver with little education	38%	20%	2.5
Unemployed household	30%	14%	2.5
Mother with mental health problem	33%	24%	1.6
Mother with poor physical health	20%	6%	3.8
Exposure to => 3 risk factors	46%	24%	2.6

Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, 191(6), 493-499.

# Family socioeconomic position and household wellbeing matters



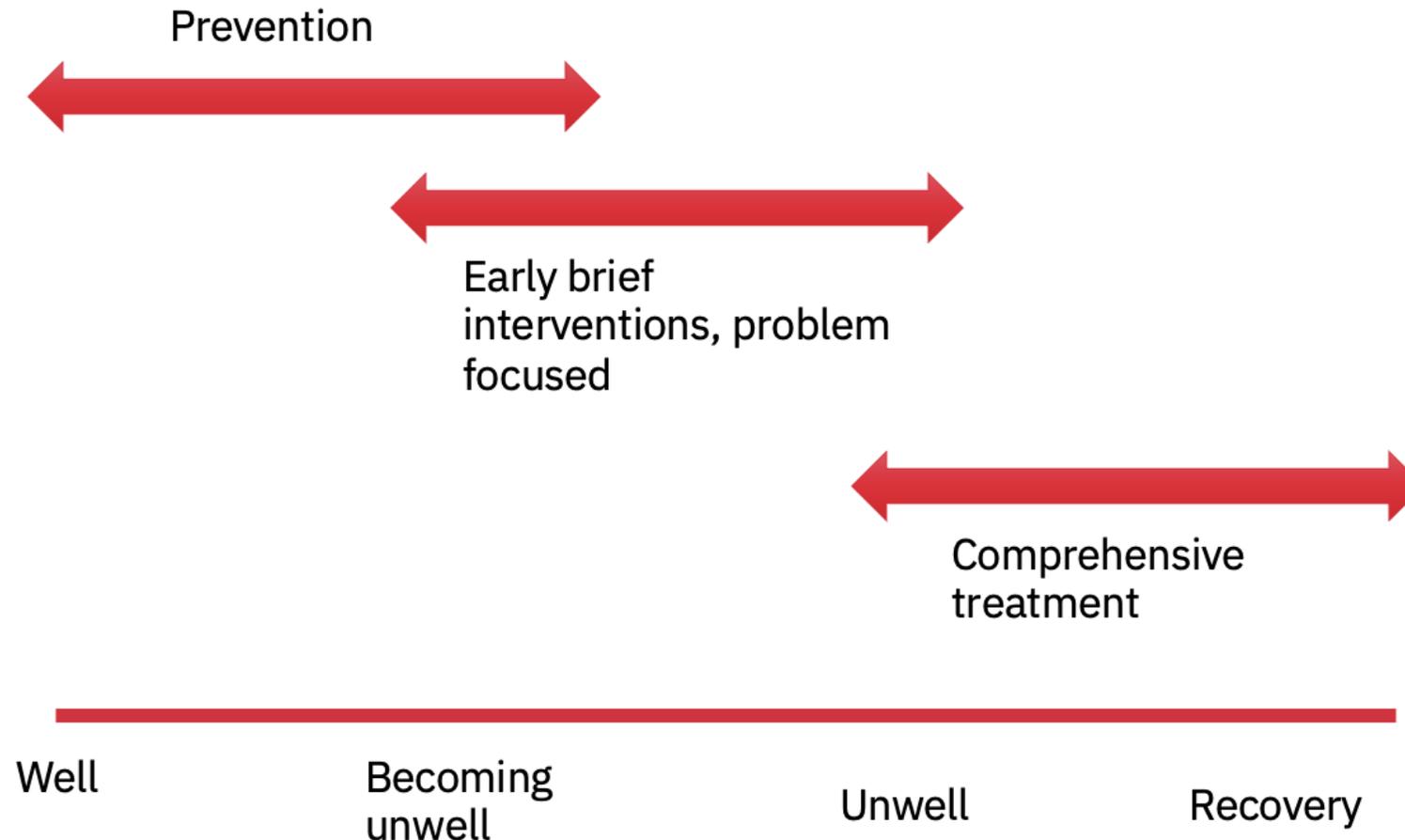


**More social risk factors dramatically increases the rate of mental health problems**

**Youth with DD experience MORE risk factors**

**The impact of these risk factors is greater for youth with DD**

# What do guidelines say about evidence-based interventions for mental health problems?



Kitchener, B., Jorm, A., Kelly, C., Pappas, R., & Frize, M. (2010). *Intellectual Disability Mental Health First Aid Manual*.

Siegel, M., McGuire, K., Veenstra-VanderWeele, J., Stratigos, K., & King, B. (2020). Practice Parameter for the Assessment and Treatment of Psychiatric Disorders in Children and Adolescents With Intellectual Disability (Intellectual Developmental Disorder) Committee on Quality Issues (CQI). In *J Am Acad Child Adolesc Psychiatry* (Vol. 59, Issue 4). [www.jaacap.org](http://www.jaacap.org)

# Deciding on what is ‘effective’ in terms of mental health problem treatment

- Just because it has not yet been researched with an autistic person specifically, or at a specific age, does not mean it will not be helpful

“Important to note, there is not research to suggest that DBT is ineffective for [autistic] clients and, unfortunately, such treatments are often not available for [autistic] clients. For example, one parent who was trying to secure [emotion regulation] treatment for her bright teenage son reached out to us with this story: “I heard back from the medical director at the DBT center I called, and he said DBT isn’t very effective for clients on the spectrum. This isn’t the first time that I’ve heard that traditional DBT does not work for autistic patients.”

White, Conner, Beck & Mazefsky (2021, p. 2)

White, S. W., Conner, C. M., Beck, K. B., & Mazefsky, C. A. (2021). Clinical Update: The Implementation of Evidence-Based Emotion Regulation Treatment for Clients with Autism. In *Evidence-Based Practice in Child and Adolescent Mental Health* (Vol. 6, Issue 1, pp. 1–10). Routledge.

<https://doi.org/10.1080/23794925.2020.1796551>

## Interventions must improve social context

“ Approaches to reducing the personal, social and economic costs associated with psychiatric disorders ...should focus on: (a) reducing their exposure to adverse social conditions; (b) building the resilience of children with intellectual disabilities (and their families) when prevention of exposure to adversity cannot be guaranteed

Emerson & Hatton, 2007, p. 497

” Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, 191(6), 493-499.

If we only focus on the negative



The absence of mental health problems is not the same thing as good mental health

- *If I were to ask you to describe how mentally healthy you are, what words would you use?*

Positive outcomes need to be defined by positive constructs

- *If I were to ask you to describe what successful living means to you, what words would you use?*



# Positive Dimensions: Thriving & Flourishing

## THE JOURNEY: THRIVING

- Actively growing, overcoming adversity, and making progress
- You can thrive in a challenging environment, but you may not fully flourish because the context is difficult
- Thriving involves **resilience**

## THE END POINT: FLOURISHING

- Comprehensive, harmonious, and sustainable life
- Living well in all domains, including contributing to the common good
- From the latin: *florere* ("to bloom, blossom, flower")

Dr. VanderWeele; Human Flourishing Program

# Thriving

## Competence

- *They have the skills to succeed in school, in social situations with friends and adults, in play, and at home. They know how to behave and does what is needed to do well.*

## Contribution

- *They try to do things to help the family, neighbours, and community. They also try to help themselves by staying healthy.*

## Character

- *They know what is right and wrong; and does the right thing; They are honest.*

## Caring

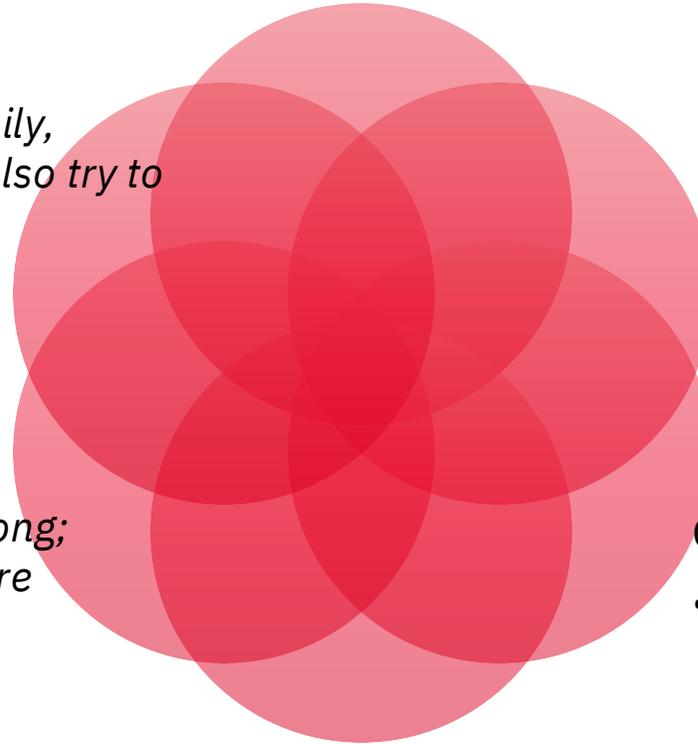
- *Cares about other people. They are concerned about whether others have what they need (shows sympathy) and shows a sense of compassion (empathy). They are sympathetic and empathetic to others.*

## Confidence

- *Can succeed and do what is needed to do well in the family, in school, in social situations with friends and adults, in play and in other areas that are important to them.*

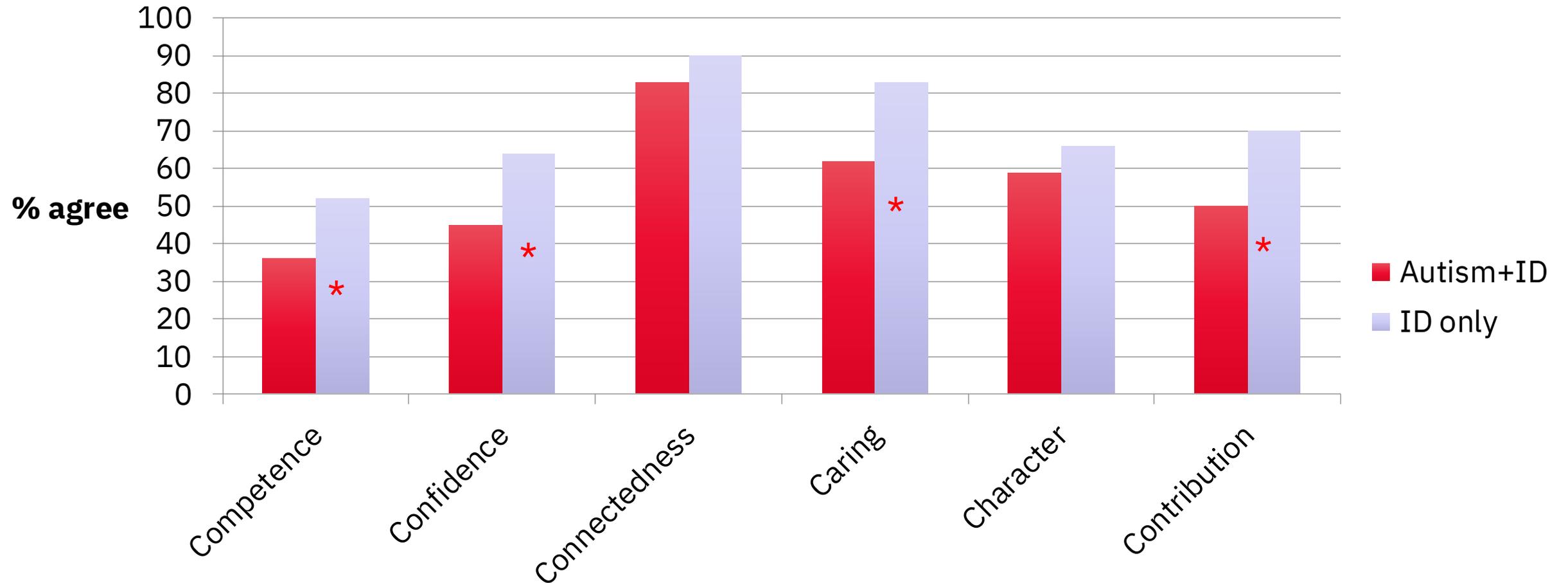
## Connectedness

- *Positive relationships with their parents, siblings, and other family members, and with friends, teachers, coaches, or mentors*



# Less thriving

➤ Autistic youth with ID are reported to achieve less thriving than their peers with ID overall ( $p < .001$ )



# Why were autistic youth with ID thriving less than their peers?

- Similar adaptive skills and intellectual ability
- Similar level of community involvement (which was low)
  
- Less social and communication skills
- **Less meaningful participation at home and at school\***
  
- **We can program for the positive**
  - **Improve social and communication skills**
  - **Improve meaningful participation**





The ability to **bounce back after difficulty** or adversity



The capacity to **adapt positively to stress** and recover from emotional setbacks



A **protective factor** for mental health and wellbeing



The ability to prevail over negative, or even tragic, life circumstances



The ability to **adapt to difficult situations** that cannot be changed

## What is Resilience?



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# Resilience Beyond Rugged Individualism

## Role of Supportive Environment

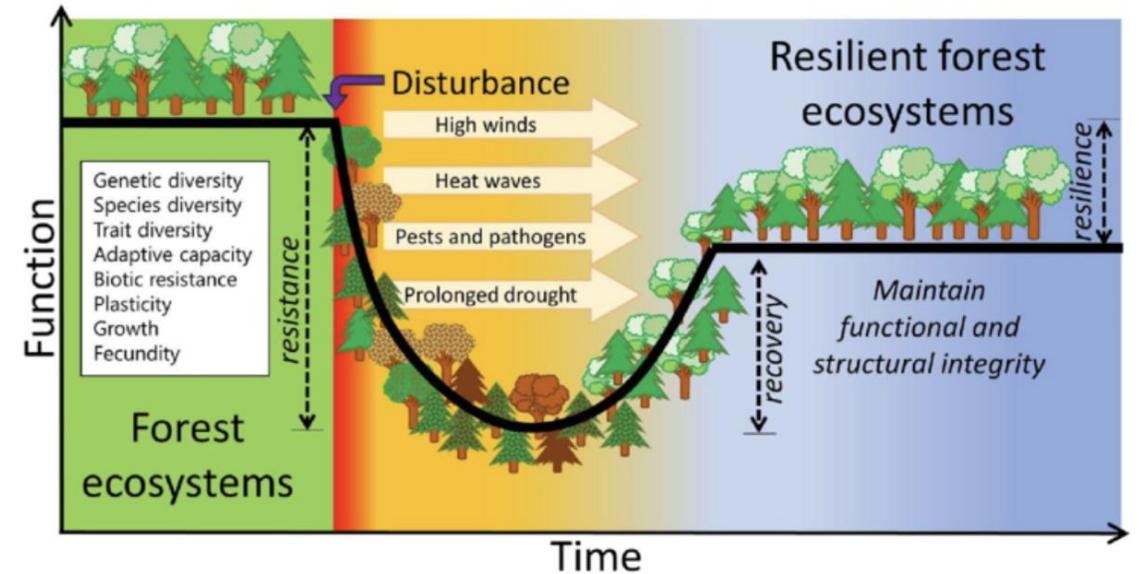
Success depends on more than individual traits; a nurturing environment is important

## Navigation for Resources

Resilience involves finding and accessing resources in one's surroundings through purposeful exploration

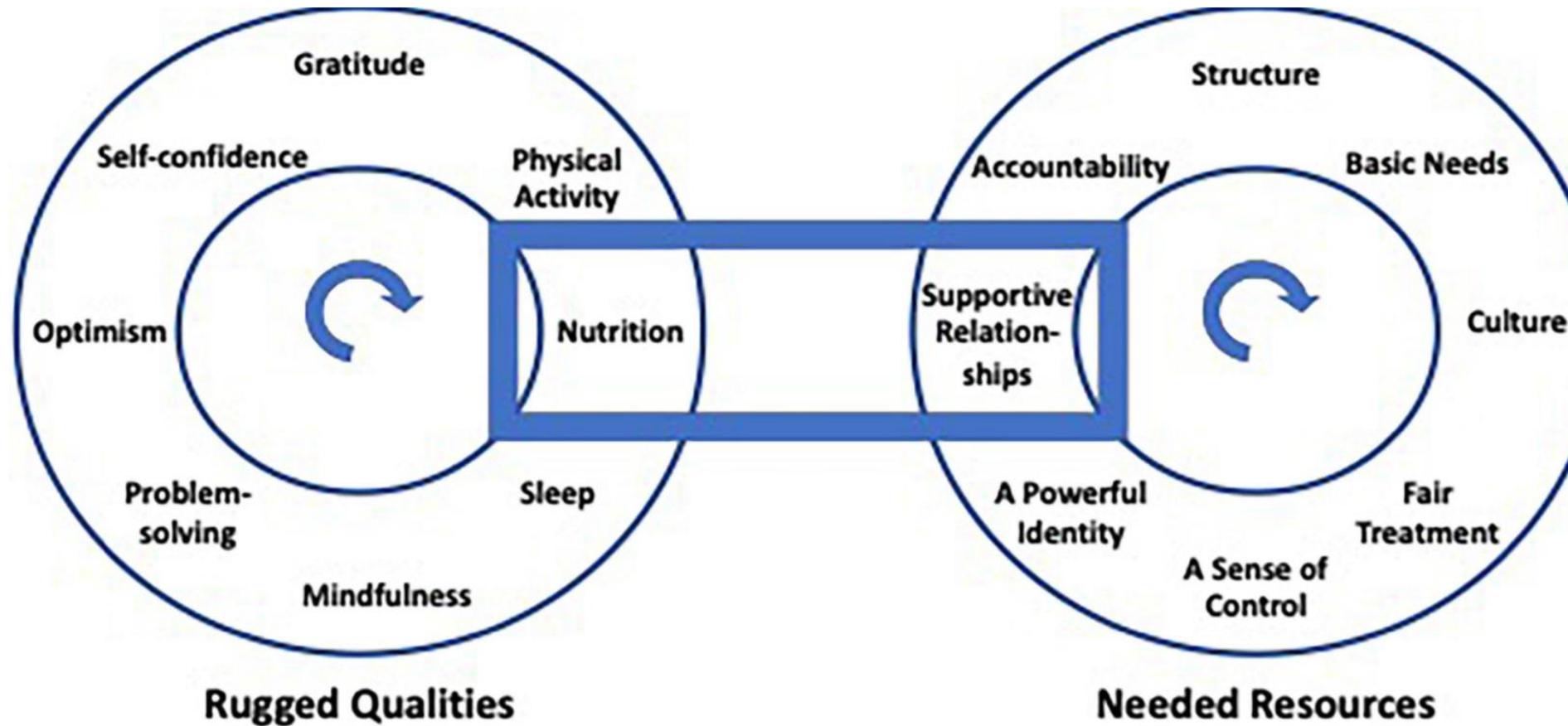
## Negotiation for Meaningful Support

Individuals must advocate for resources to be provided in ways that hold cultural significance for them



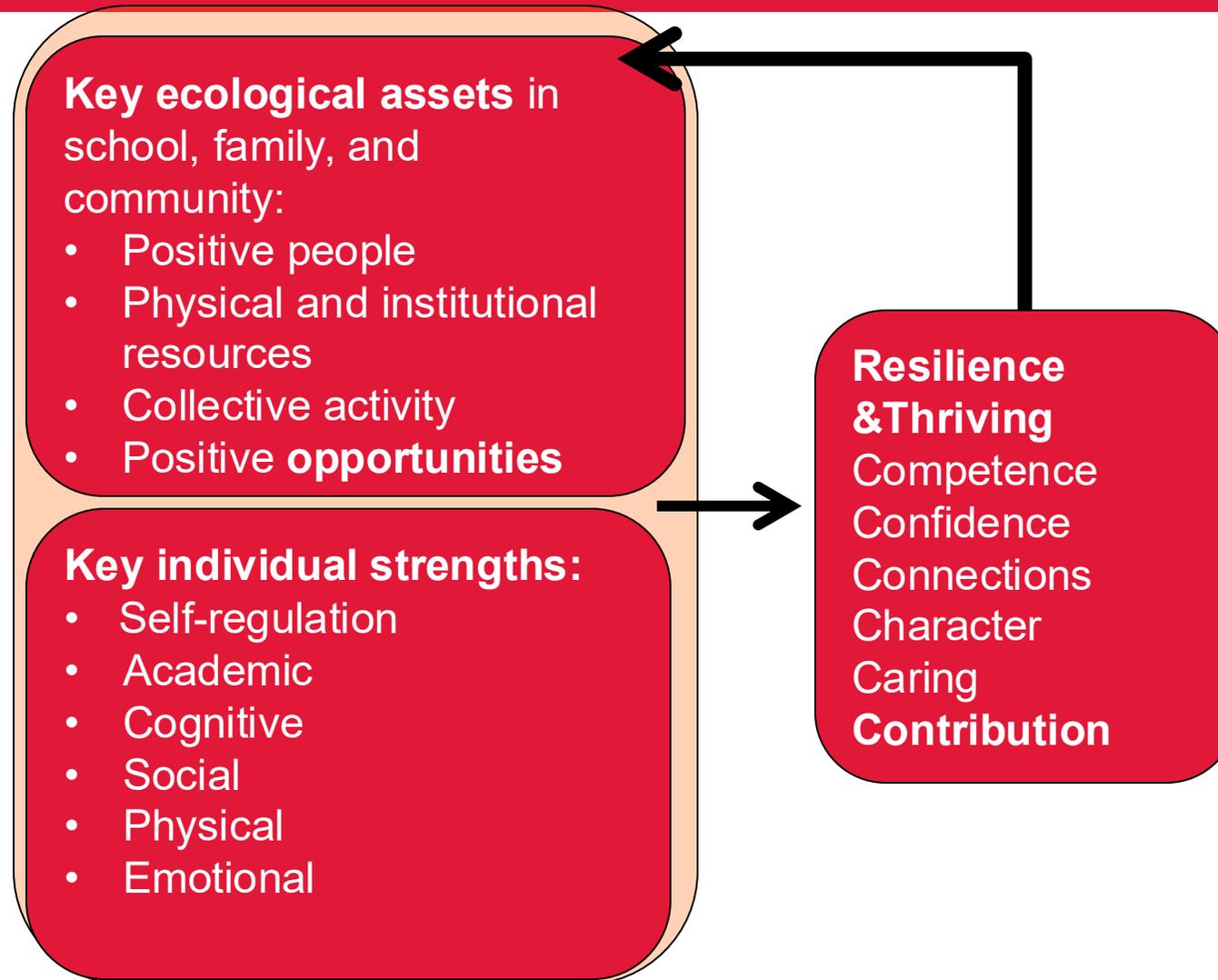
Conceptualisation of resilience in forest ecosystems over time following a disturbance event, adapted from Llorech et al. (2011). The black line represents variation in a function relating to forest eco-

# What goes into resilience (and thus to thrive) –Individual and Context

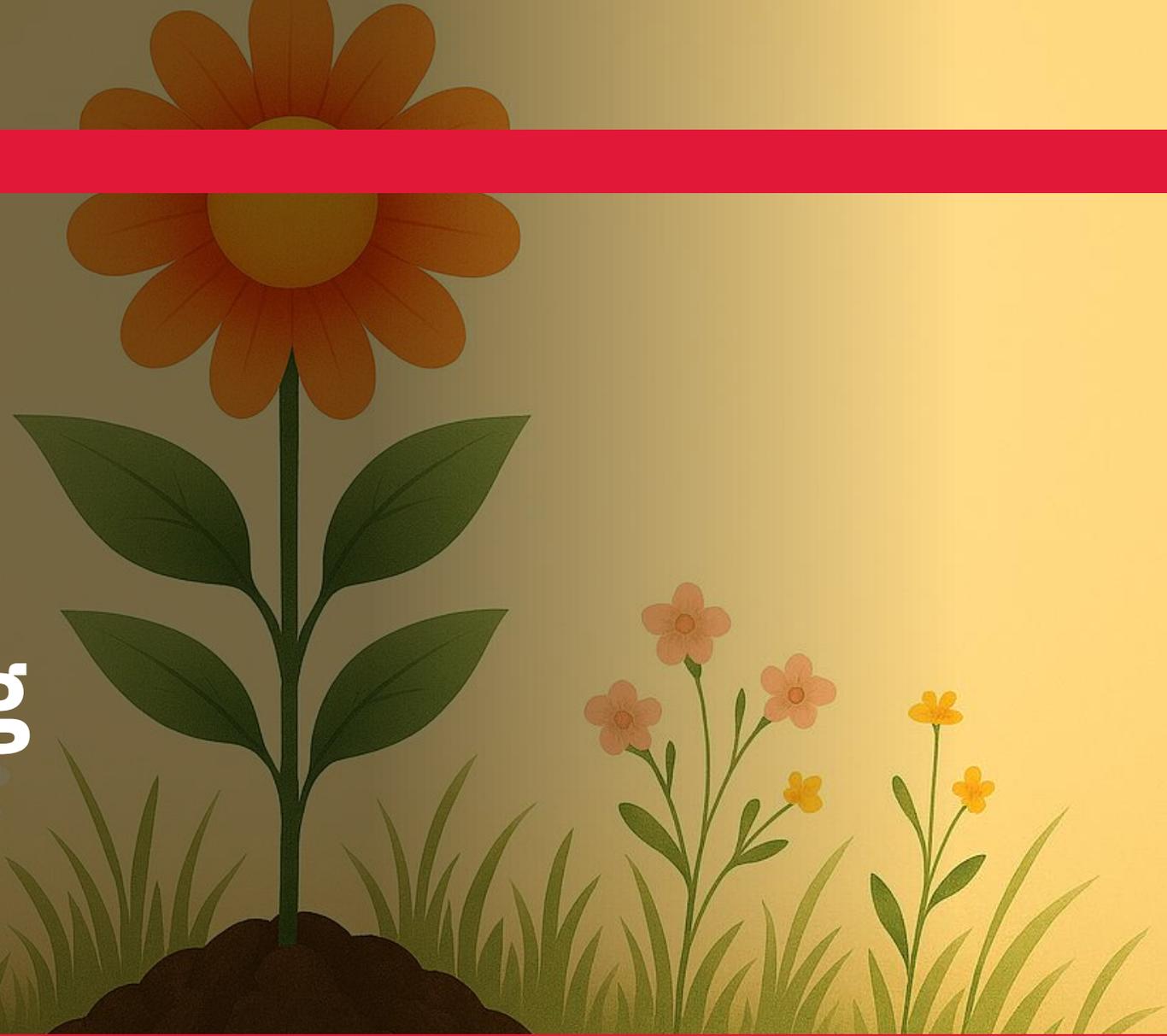


<https://resilienceresearch.org/welcome-r2/>

# Using a mental health framework



# Thriving to Flourishing



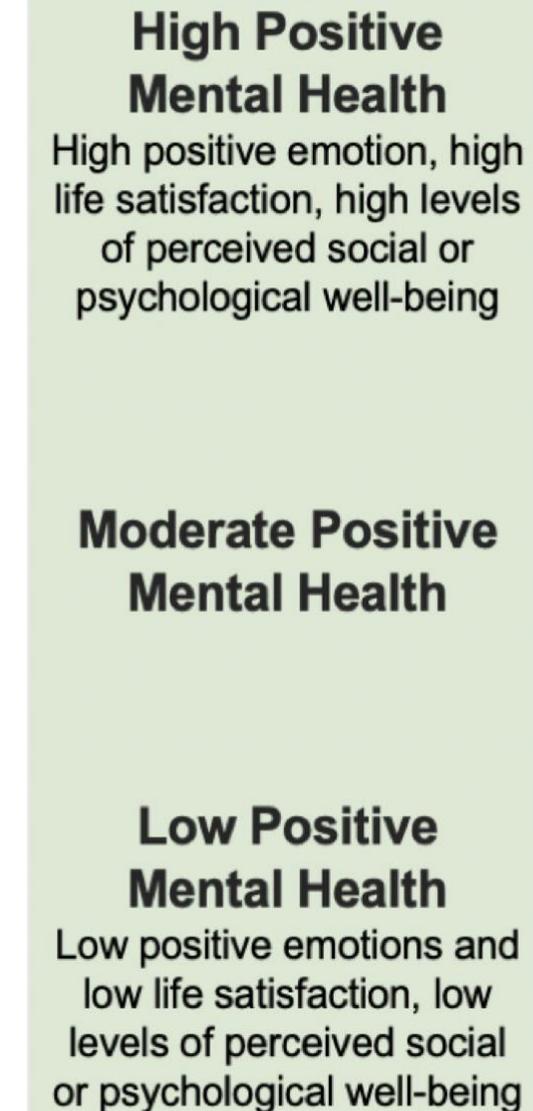
# Flourishing

## •Hedonic well-being

- Pleasure, happiness, and life satisfaction
- Subjective feelings of joy, comfort, and the absence of negative emotions.

## •Eudaimonic well-being

- The sense of meaning, purpose, personal growth, and self-realization
- Living in accordance with one's values, fulfilling one's potential, and contributing to something greater than oneself



# Context: Supporting families

- The health of the family interacts with the health of the individual
- Supporting caregivers is critical
  - Parent psychological resources: Empowerment, psychological acceptance, focused coping at the right time
  - Family respite, timed social support from the right people
  - Positive engagement with systems of care
- Acceptance and Commitment Therapy Workshops (Maughan et al. 2024)
  - Get trained to deliver workshops here:
  - <https://www.actforcaregivers.com>



# Positive peers

- **Better quality of life**
  - Young adults who report affectionate and frequent contact with their social network have higher perceived quality of life (Friedman & Rizzolo, 2017)
  - Positive peer relationships are correlated with positive outcomes across safety, health, autonomy, and community inclusion (National Core Indicators data)
- **Happiness and emotional well-being**
  - Perceived social support from friends and family predicted higher positive mood and life satisfaction over time (Lunsky & Benson, 2001)

## Understanding Special Olympics Experiences from the Athlete Perspectives Using Photo-Elicitation: A Qualitative Study

Jonathan A. Weiss, Priscilla Burnham Riosa<sup>1</sup>, Suzanne Robinson, Stephanie Ryan, Ami Tint, Michelle Vecili, Jennifer A. MacMullin and Rebecca Shine

*Department of Psychology, York University, Toronto, ON, Canada*

### Theme 1: Connectedness

### Theme 2: Training in Sport



•Friedman, C., & Rizzolo, M. C. (2017). Friendship and quality of life: The importance of relationships in the lives of people with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities*, 29(6), 785–798. <https://doi.org/10.1007/s10882-017-9555-1>

•Lunsky, Y., & Benson, B. A. (2001). Association between perceived social support and strain, and positive and negative outcomes for adults with mild intellectual disability. *Journal of Intellectual Disability Research*, 45(2), 106–114. <https://doi.org/10.1046/j.1365-2788.2001.00334.x>

•National Core Indicators. (n.d.). Data brief: Relationships and community inclusion among individuals with intellectual and developmental disabilities. National Association of State Directors of Developmental Disabilities Services & Human Services Research Institute. Retrieved from <https://www.nationalcoreindicators.org/>

# Positive opportunities

## ➤ Recreation participation is linked to higher life satisfaction and emotional well-being

→ Engage in leisure activities report greater happiness and quality of life (Diz et al., 2024)

→ Recreational involvement **buffers** the negative effects of stress and supports better coping and emotional regulation (Bishop-Fitzpatrick et al., 2017)

## ➤ Sports and group activities enhance self-esteem and confidence

→ Participation in programs like Special Olympics is associated with increased self-worth and pride (Crawford, Burns, & Fernie, 2015).

→ Individuals with broader recreational involvement are more likely to feel respected, connected, and included in their communities (Giordano et al., 2016)

### The Right Fit

For the Virginia study, a control group of high-school seniors with autism remained in their regular schools, receiving their usual individualized education programs, while a treatment group spent the year in an intensive, custom-designed study and job-training program at a suburban hospital. The two hospitals participating in the study were Bon Secours St. Mary's Hospital in Henrico County, Va., and Bon Secours St. Francis Hospital in Midlothian, Va.



Damien Jenerette became a pharmacy technician at Bon Secours St. Mary's Hospital. JENNIFER T. MCDONOUGH

Badia, M., Orgaz, M. B., Verdugo, M. Á., & Ullán, A. M. (2013). Relationships between leisure participation and quality of life of people with developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 26(6), 533–545. <https://doi.org/10.1111/jar.12051>

Bishop-Fitzpatrick, L., Smith DaWalt, L., Greenberg, J. S., & Mailick, M. R. (2017). Participation in recreational activities buffers the impact of perceived stress on quality of life in adults with autism spectrum disorder. *Autism Research*, 10(5), 973–982. <https://doi.org/10.1002/aur.1753>

Crawford, C., Burns, J., & Fernie, B. A. (2015). Psychosocial impact of involvement in Special Olympics: A mixed methods study exploring perspectives of athletes with intellectual disabilities. *Research in Developmental Disabilities*, 45–46, 93–102. <https://doi.org/10.1016/j.ridd.2015.07.009>

Giordano, A., & Stancliffe, R. J. (2016). Community participation and quality of life outcomes of adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 60(9), 865–875. <https://doi.org/10.1111/jir.12269>

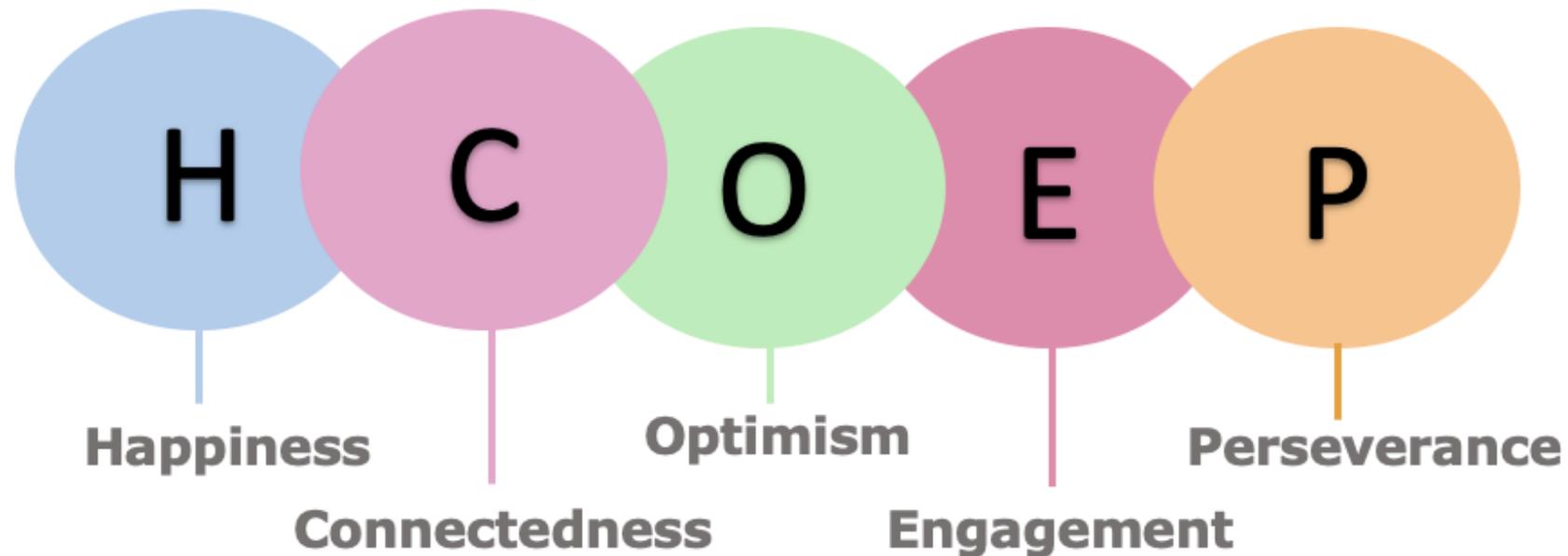
# Can we use photography to improve wellbeing?

- Therapeutic Photography (TP): Self-initiated photo-taking activities + mindful reflections of photos
  - Self-guided; no therapist, accessibility and cost-effectiveness
  - Self-Expression and Communication: Accessible, portable, and flexible tool for self-expression
  - Creative: Represent experiences using metaphor, composition, and staging
  - Reflection and Insight: Encourages reflection
  - Meaning-Making: *Making sense of WHY I feel the way I feel. What do I see?*



# Therapeutic photography to promote positive mental health

Each week, for 4 weeks, use a device (e.g., your phone, tablet, or camera) to take photos that are a part of well-being



# Week 1: Happiness

➤ Feeling generally **happy, cheerful, and content** with life. I feel happy when....



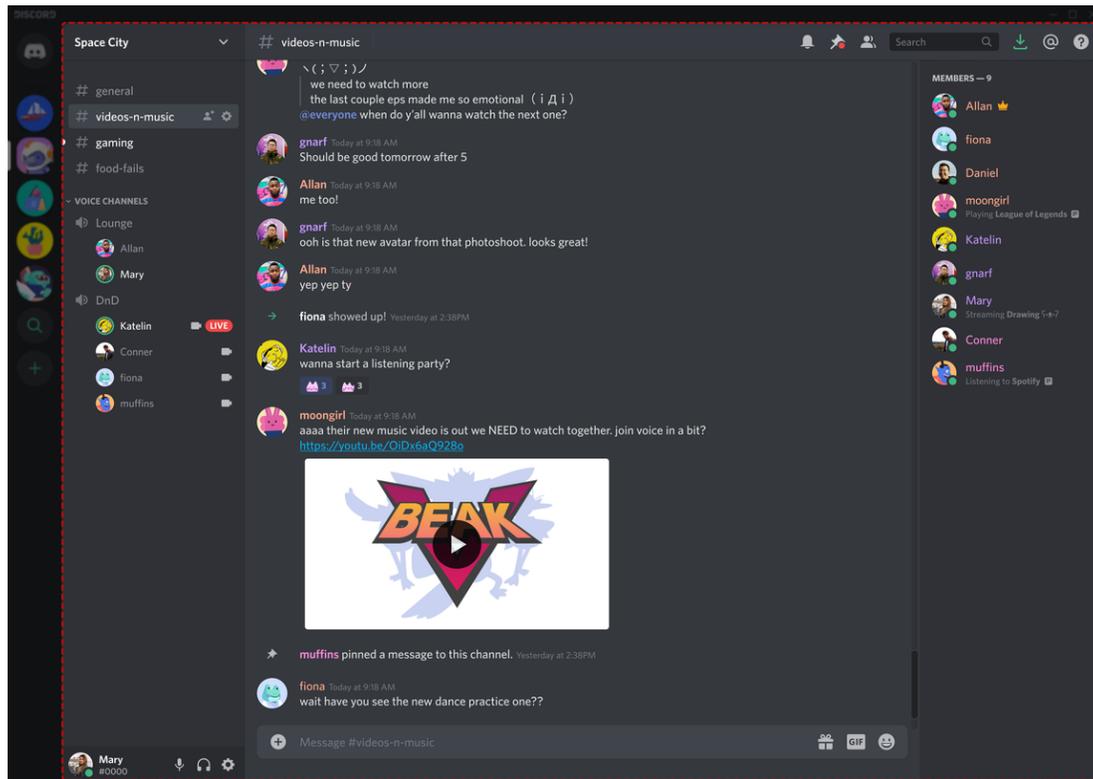
I spend time with my family



I take my dog to the park YORK 

# Week 2: Connectedness

- Feeling **loved, supported, valued, and close** to others. I feel connectedness when...



I participate in chats on  
Discord



I play boardgames with my friends

# Week 3: Optimism

➤ Having **hope and confidence about the future**. Believing things will always work out in a good way. I feel optimism when...



The flowers start to bloom



I'm getting ready for the day

# Week 4: Engagement & Perseverance

- Engagement is being **involved, interested, or absorbed** in an activity or your environment, sometimes even spending a lot of time doing it. I feel engaged when I....



I cook



I play video games



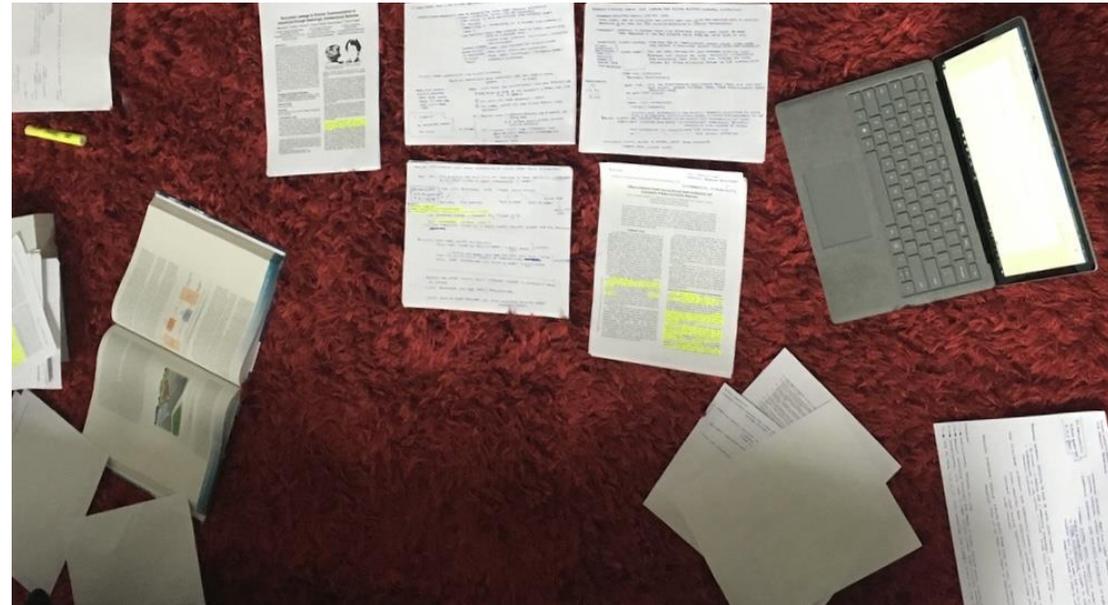
I make a puzzle

# Week 4: Engagement & Perseverance

- Perseverance is **continuing to work towards something** (like a goal), even when its challenging. I feel perseverance when...



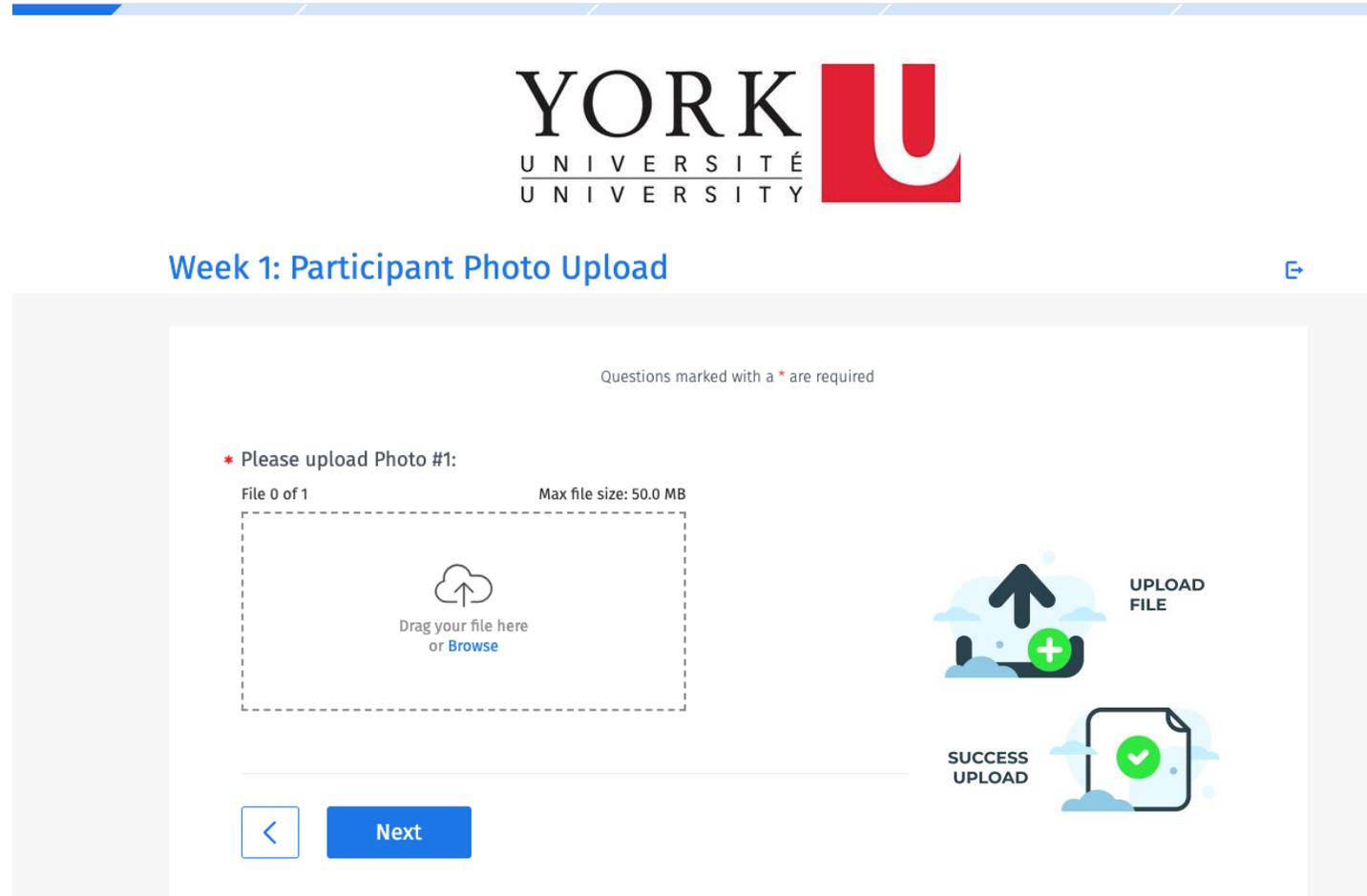
I keep going to the gym



I work on my homework or a tough project

# What happens after I take my photos?

- When you upload your photos, you will answer 4 questions for each photo
- You can write OR record your answers



The screenshot shows the York University logo at the top right. Below it, the page title is "Week 1: Participant Photo Upload". The main content area is a form with a dashed border. At the top of the form, it says "Questions marked with a \* are required". Below that, there is a red asterisk followed by the text "\* Please upload Photo #1:". Underneath, it says "File 0 of 1" and "Max file size: 50.0 MB". In the center of the dashed box is a cloud icon with an upward arrow and the text "Drag your file here or Browse". To the right of the dashed box are two icons: one with an upward arrow and a plus sign labeled "UPLOAD FILE", and another with a checkmark in a green circle labeled "SUCCESS UPLOAD". At the bottom left of the form are two buttons: a back button with a left arrow and a "Next" button.

## Participants

41 autistic youth, aged 16 – 25 years (M = 21 years)

39% Cisgender women; 22% non-binary

56% White

Many with anxiety disorders (71%) and depression (43%)

Most did not have intellectual disabilities

Charalampopoulou, M., Ibrahim, A., Prime, H., Eddy, N., Panetta, L., Brown, H., ... & Weiss, J. A. (2025). "It fostered a greater appreciation for my little corner of the world": A feasibility study of a therapeutic photography intervention for the well-being of autistic youth. *Autism*, 29(11), 2774-2790.

# Results

## IT WAS FEASIBLE

- › 90% completed the intervention
- › 83% completed all 4 weeks
- › 86% agree that it was a positive experience
- › There was very low negative impact of the intervention, but it did cause some stress and hard feelings at times

## POTENTIALLY BENEFICIAL

- › Improvement in meaning & purpose,  $p = .01$ , with a moderate effect
- › In interviews
  - Benefits experienced in hedonic wellbeing and in feelings of connectedness, optimism and personal growth



**Next steps:** Focus specifically on adapting for youth with intellectual disabilities, with measures that we now know work for youth

# Take home messages

- Positive mental health is not just the absence of the negative
  - It is diverse: Enjoyment of life, growth, connection, mattering and a positive sense of self
  - The presence of meaningful relationships, roles, and enjoyable experiences
- Quality of relationships and meaningful community inclusion is central to flourishing
  - Individual strengths AND context
- Don't leave me out: The Dual Continua Model
  - Program for the positive, not just the negative
- Photo-based projects may be a way in
  - To understand and change





**No one size fits all**

Chel Silverstein

# THE MISSING PIECE

This Photo by Unknown Author is licensed under CC BY-NC



We need to plan for fit: Individual  
AND changes in context

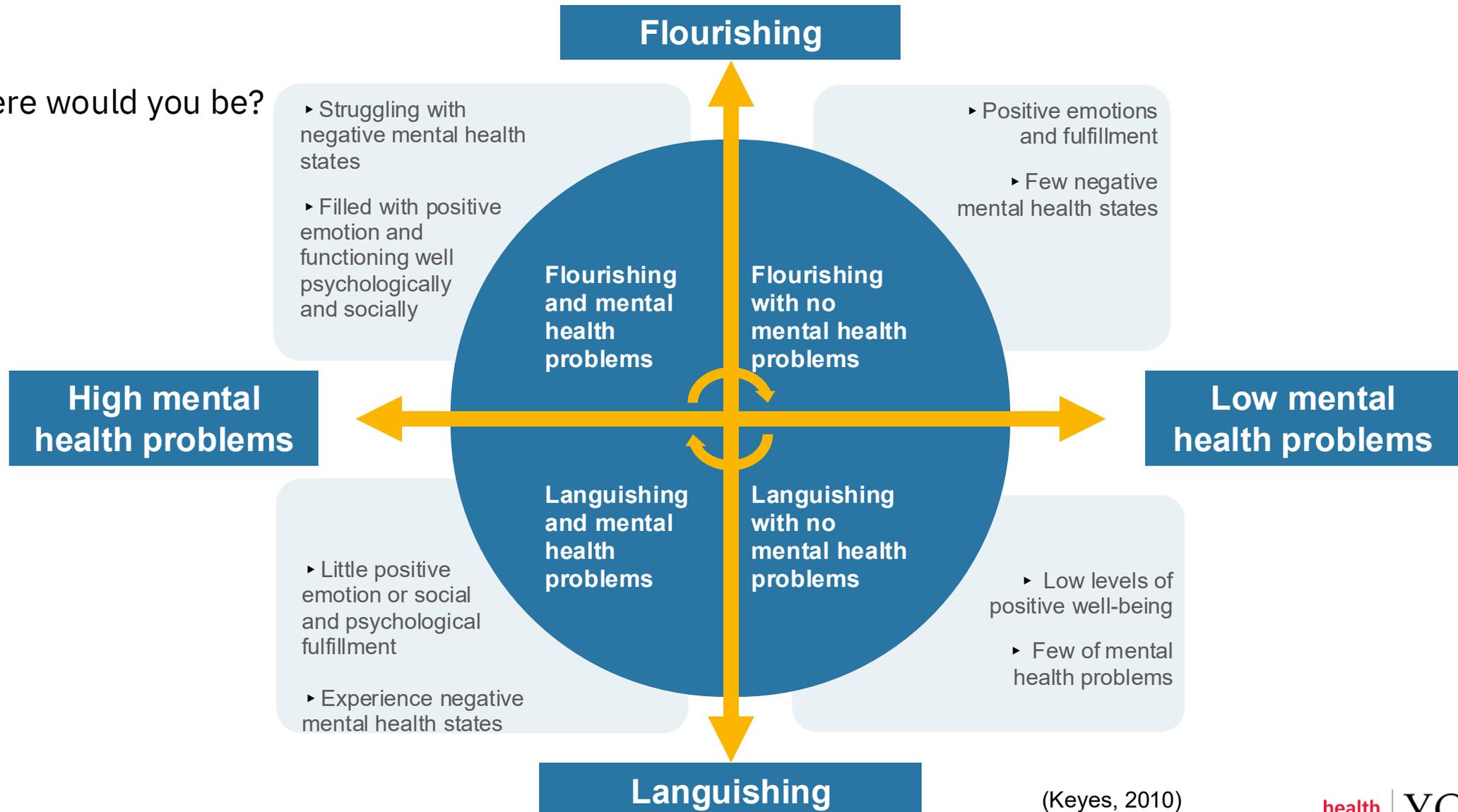
“

*The missing piece sat  
alone... waiting for  
someone to come along  
and take it somewhere*

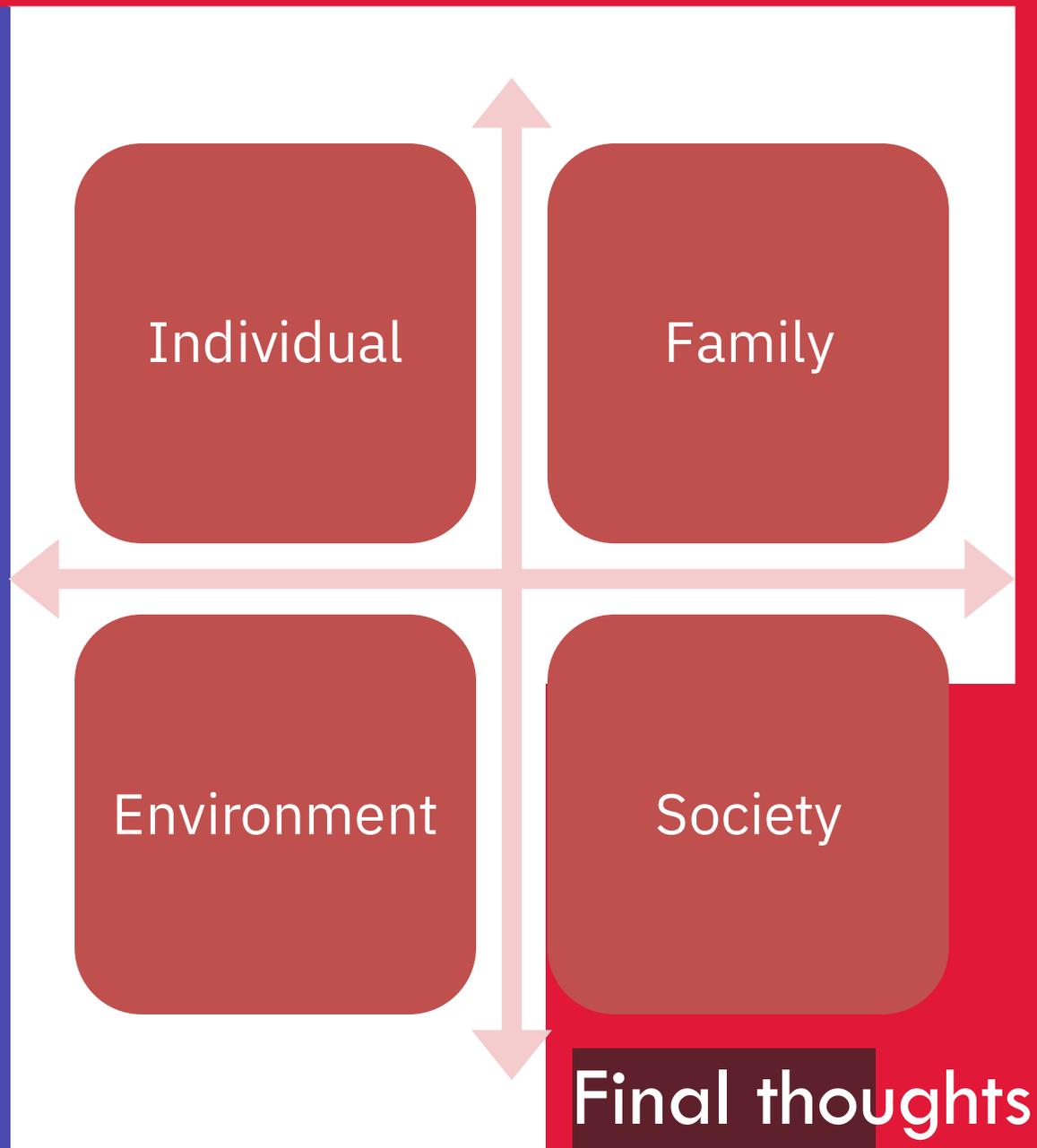
”

# A 'dual continua' model

➤ Where would you be?



(Keyes, 2010)



- Skills to manage stress
- Good physical health and physical activity
- Sense of control over one's life
  
- Reciprocal, non-stressful relationships
- Caregivers who are nurtured and supported to promote mental health in those they care for
  
- A safe place to live and learn
- An environment with limited stresses
- Meaningful activities in community

