

# Pre-emptive therapy for autism

A new and effective way of supporting early development

Andrew Whitehouse



THE UNIVERSITY OF  
**WESTERN  
AUSTRALIA**

**CliniKiDS**  
Research into Practice

TELETHON  
**KIDS**  
INSTITUTE

Telethon Kids Institute acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of the land and waters of Australia. We also acknowledge the Nyoongar Wadjuk, Yawuru, Kariyarra and Kurna Elders, their people and their land upon which the Institute is located and seek their wisdom in our work to improve the health and development of all children.



# CliniKids



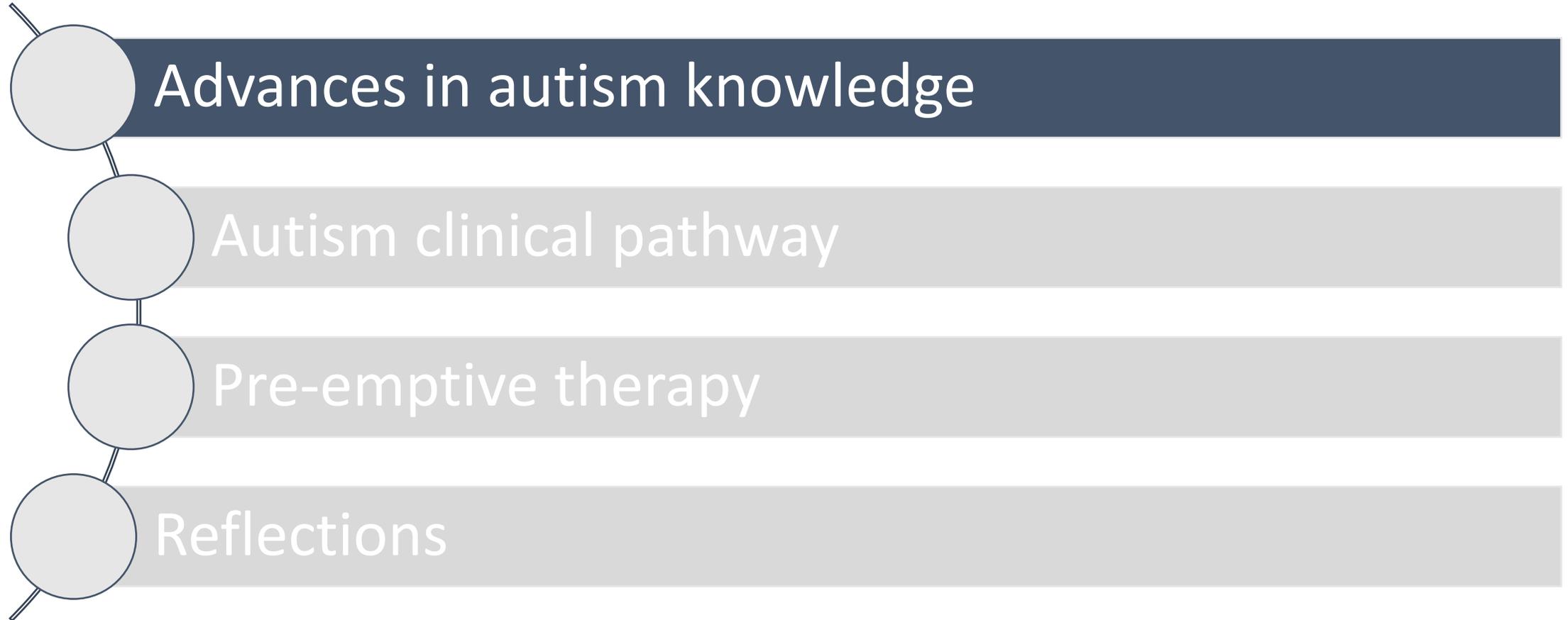
# Acknowledgments

- Families and kids
- Colleagues
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  - Australian Research Council
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  - WA Child Research Fund
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# Overview

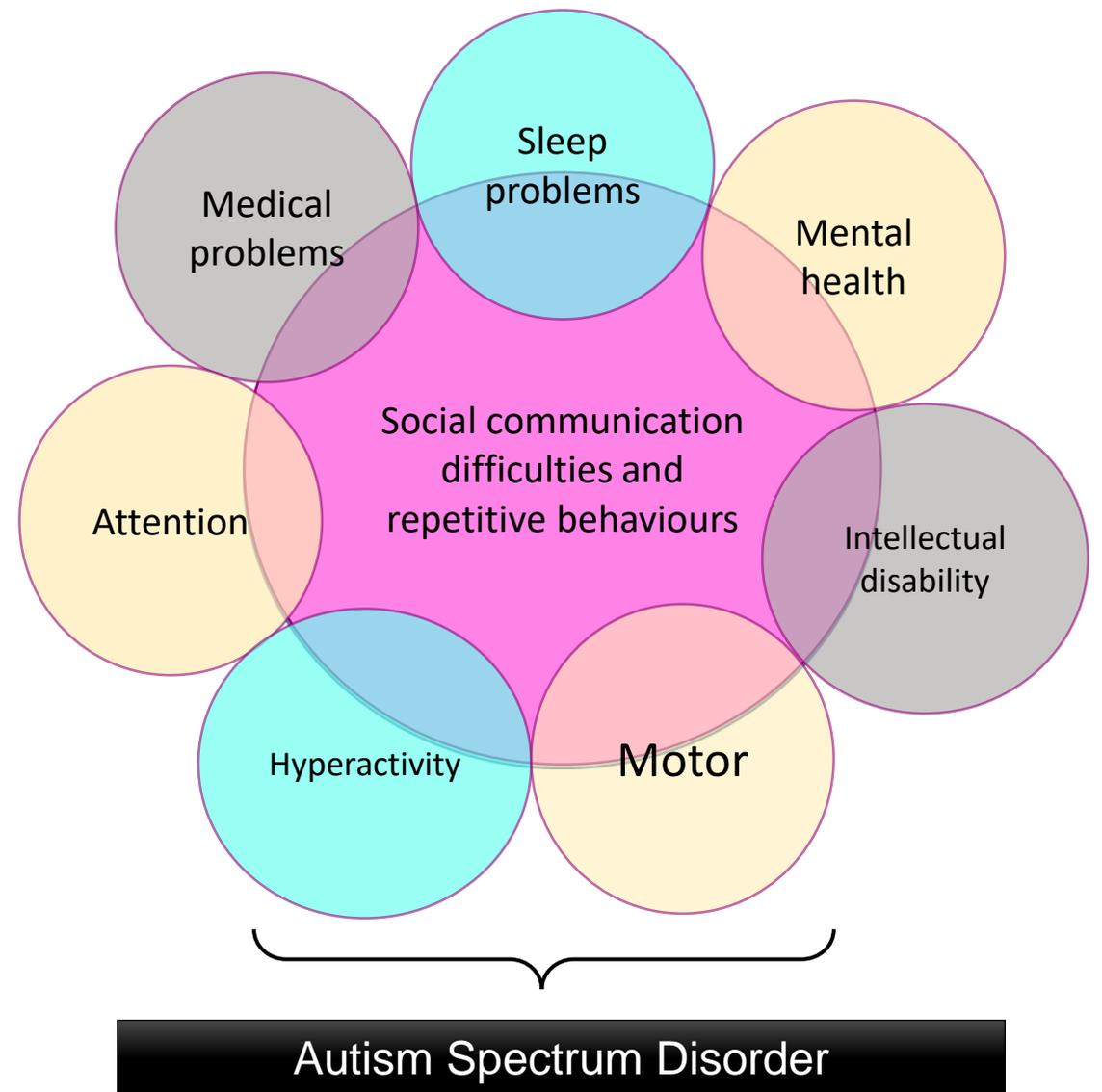


# Overview



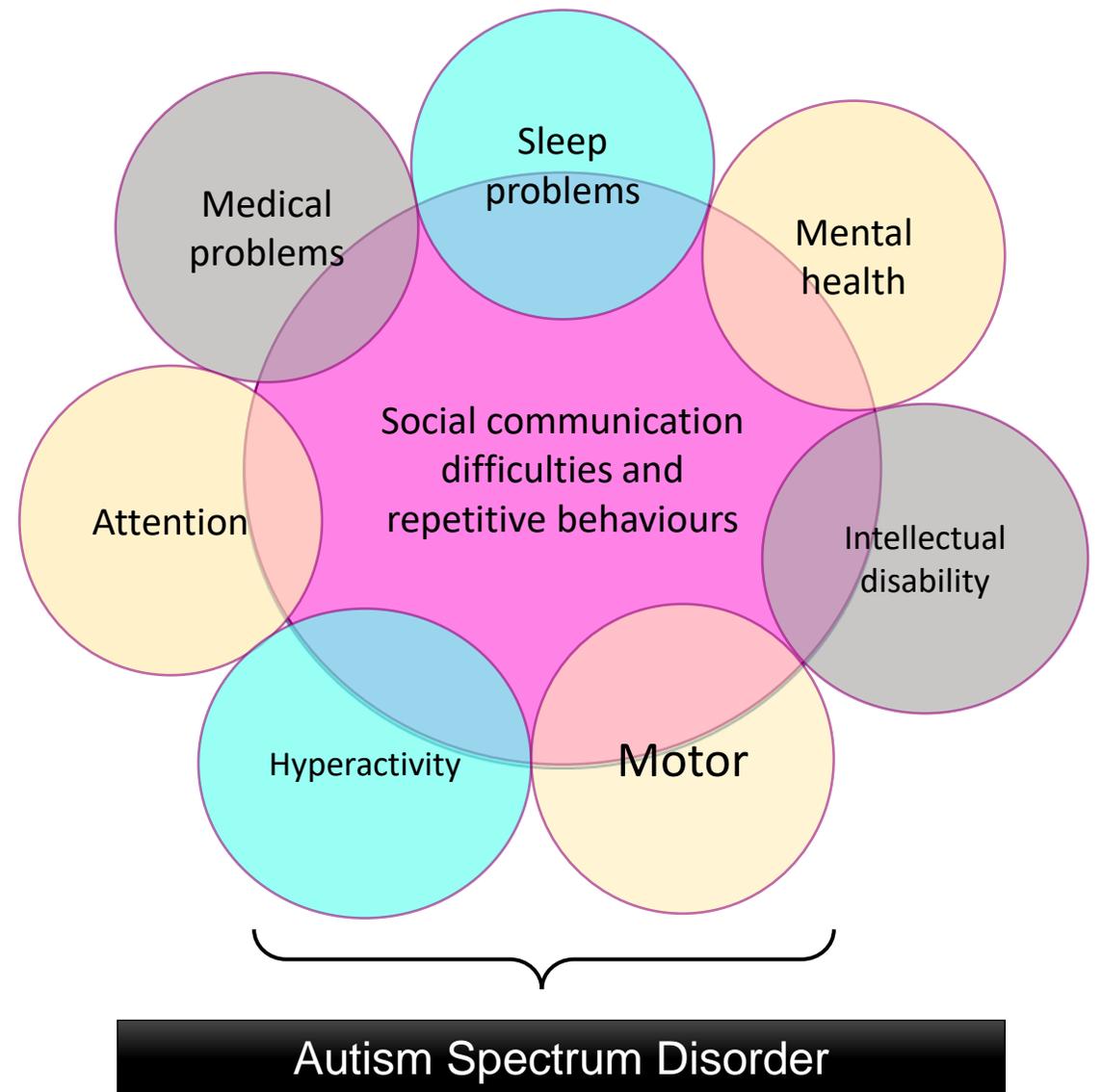
# What is autism?

- A life-long neurodevelopmental condition



# What is autism?

- A life-long neurodevelopmental condition
- 1-2% prevalence
- Male predominance (3M:1F)
- Hugely variable behavioural profile
- Large genetic component
- Clinical pathway



# Research

- What is autism research?
  - 1. Understanding**
    - Who is this wonderful human, and what are his/her strengths and challenges?
  - 2. Explaining**
    - Why do these behaviours develop in some children and not others?
  - 3. Discovering**
    - What can we do to help every child reach their potential?

# Why research?

- Well.....it genuinely improves lives!
- **Childhood (acute lymphoblastic) leukaemia**
  - Incurable in the 1960s, now 90% of children survive
- **Polio**
  - 1985: 350,000 new cases
  - 2017: 22 new cases
- **IVF and ART**
  - 1 in 25 births are from IVF

# How has autism research advanced?

1. Understanding autism
2. Causal pathways
3. Clinical pathway
4. Societal change

# Advances in autism research

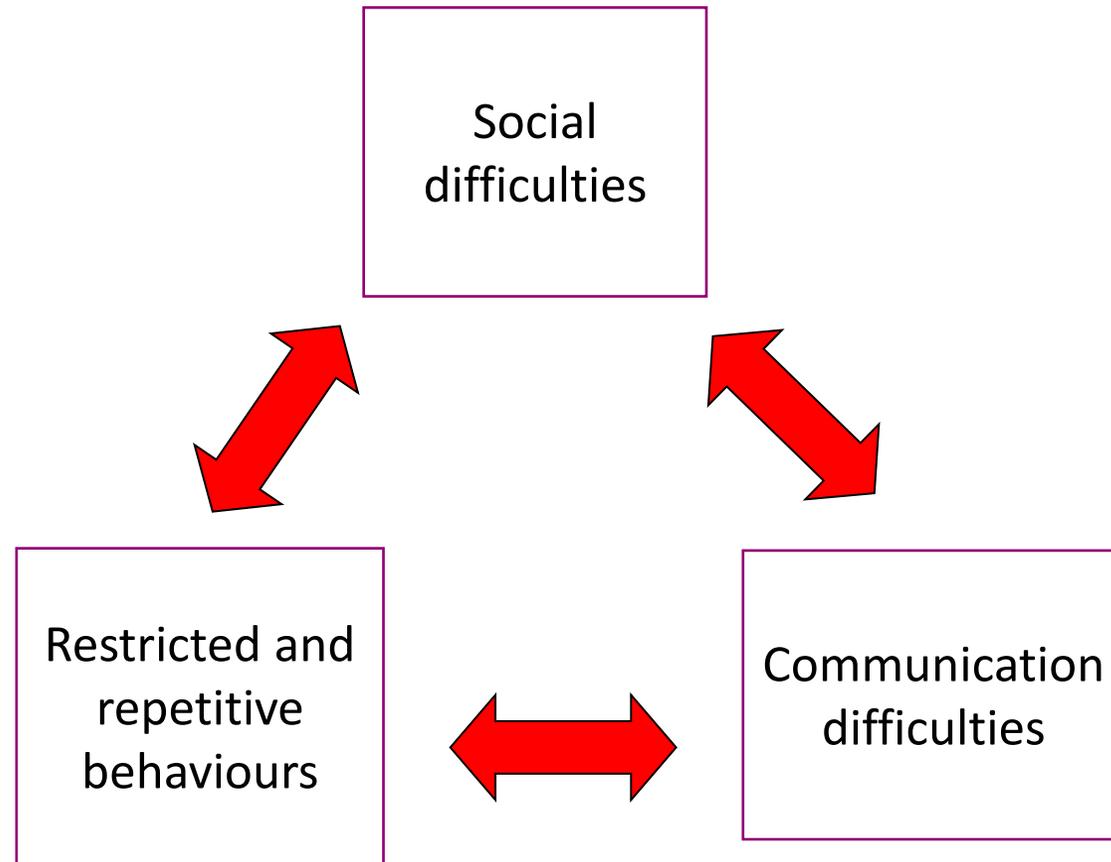
## 1. Understanding autism diagnosis

### 1980s

- One condition with very simple symptom profile.
- Must be diagnosed during early childhood
- Must have significant disability

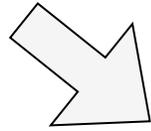
### Now

- Many conditions, often associated with other challenges
- Can be diagnosed at any time in life
- Symptoms vary in their severity, both between individual, and also in the same individual over time.

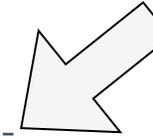


Then...

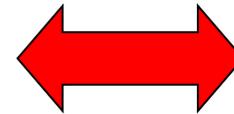
**Physical health conditions**



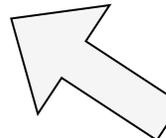
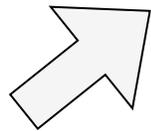
**Movement difficulties**



Social communication and interaction difficulties



Restricted and repetitive behaviours



**Mental health conditions**

**Intellectual disability**

Now...

# Advances in autism research

- Once you understand something, you can finally start to fully appreciate it.
  - We are now focussed on individuals, not a 'disorder'

# Advances in autism research

## 2. Causal pathways to autism

### 1980s

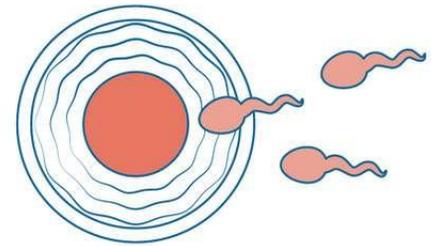
- Unknown origins
- One genetic loci ('THE gene')
- One neuro-difference
- One gene → one neuro-difference

### Now

- Genetic origins (twin studies)
- Dozens (perhaps hundreds) of different causal pathways
- No one neuro-difference

# Causal pathways

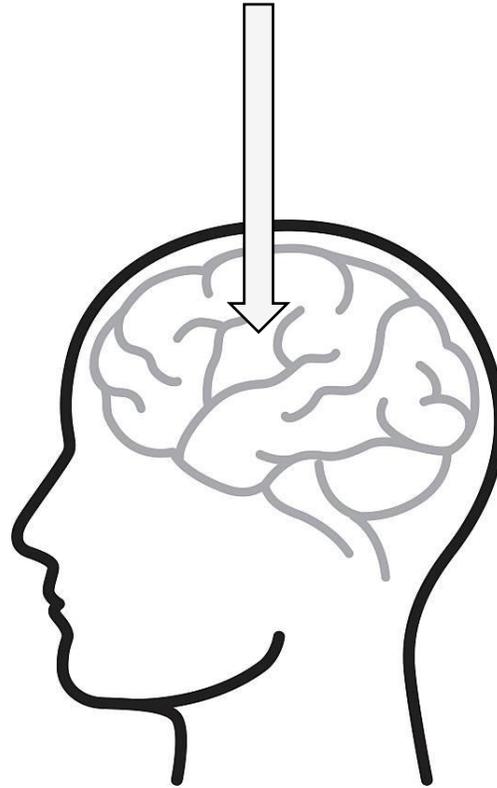
- Genetic differences
  - Rare variants (often 'de novo')
  - Common variation
- Brain differences
  - Unlikely a difference in the structure or function one particular region
  - More evidence for differences in the way brain regions 'talk' with each other.



Genetic factors

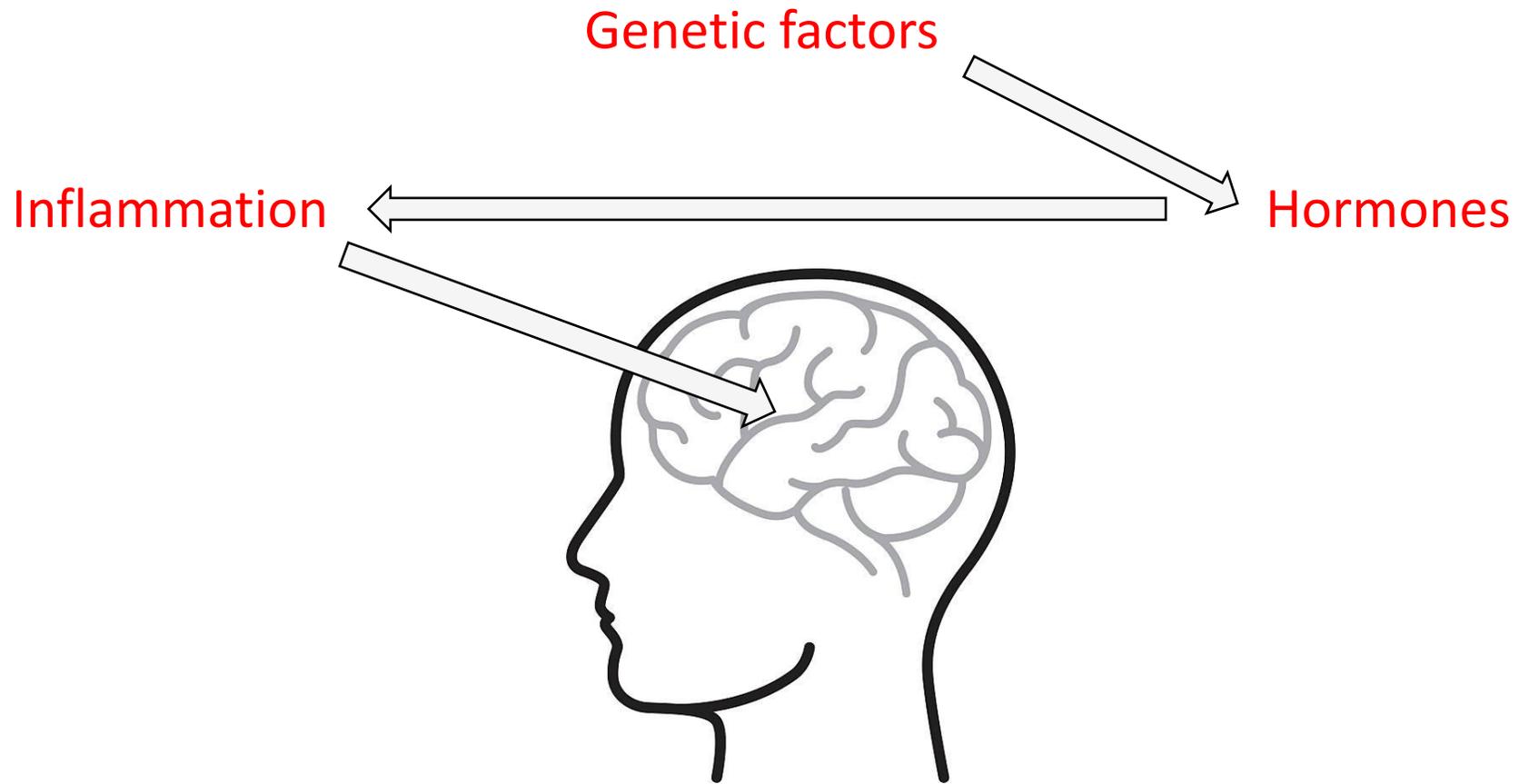
Inflammation

Hormones



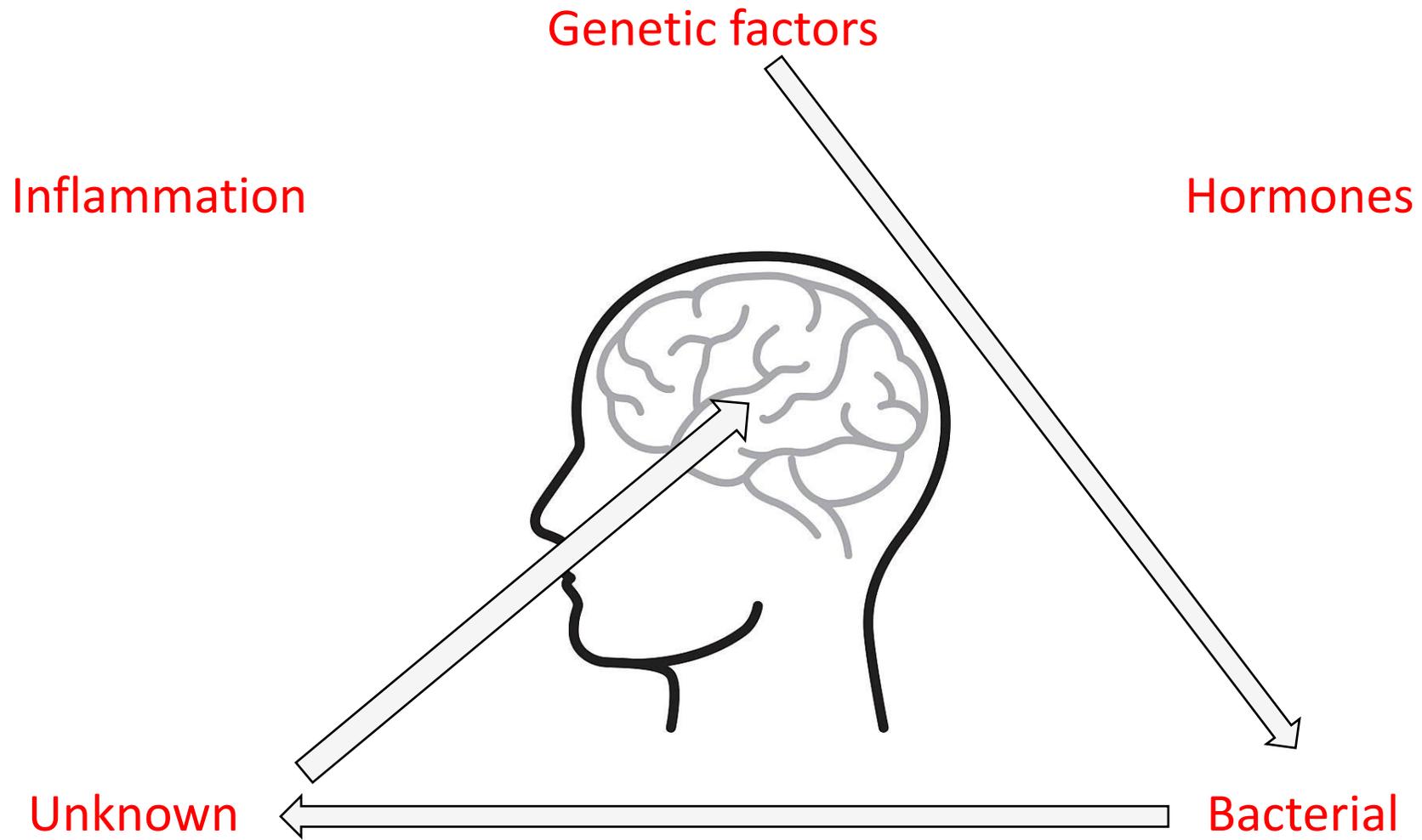
Unknown

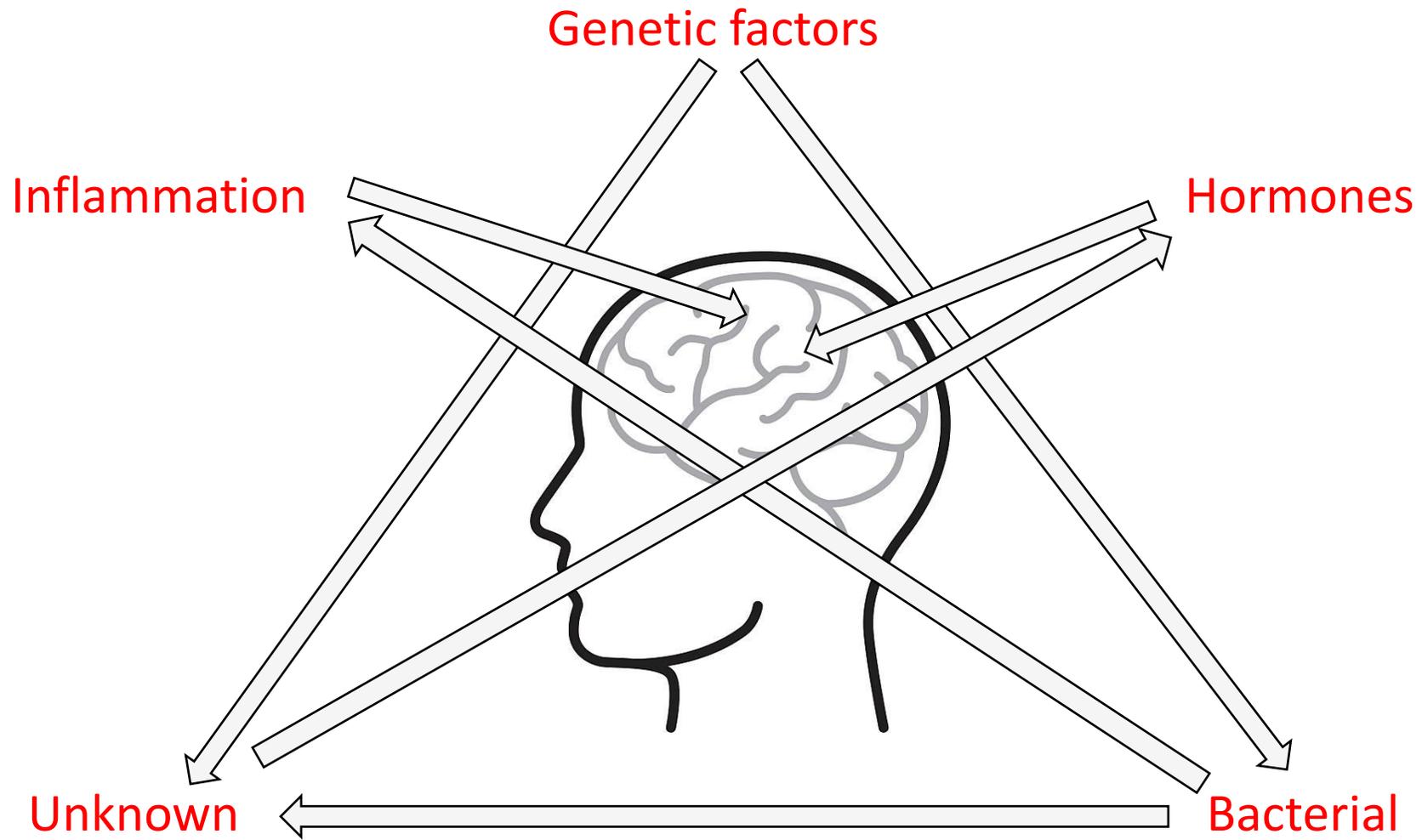
Bacterial



Unknown

Bacterial





# Causal pathways

- Complex causal pathways
  - This is not disheartening, this is liberating!
  - We can focus our minds on the human rather than the molecules that make up that human

# Advances in autism research

## 3. The clinical pathway

### 1980s

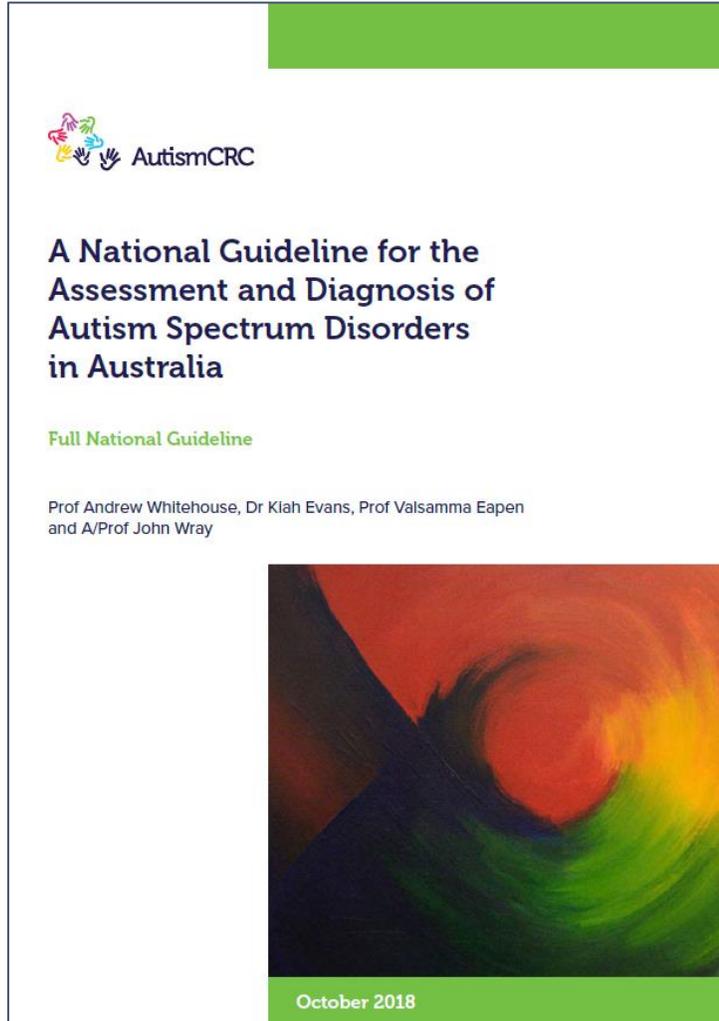
- Autism a mysterious condition
- 'Wait and see' approach
- Inconsistent diagnostic methods
- Little clinical and personal support (4 services only!)

### Now

- Early signs of autism are known
- Consistent diagnostic practices
- Swift pathway to intervention
- A range of high quality service providers

# Guidelines

- Assessment and diagnosis
- Supporting children



The cover features the AutismCRC logo at the top left. The title is centered in a dark blue font. Below the title, the authors' names are listed. At the bottom right, there is a large, abstract painting with a central red and orange sun-like shape surrounded by green and blue brushstrokes.

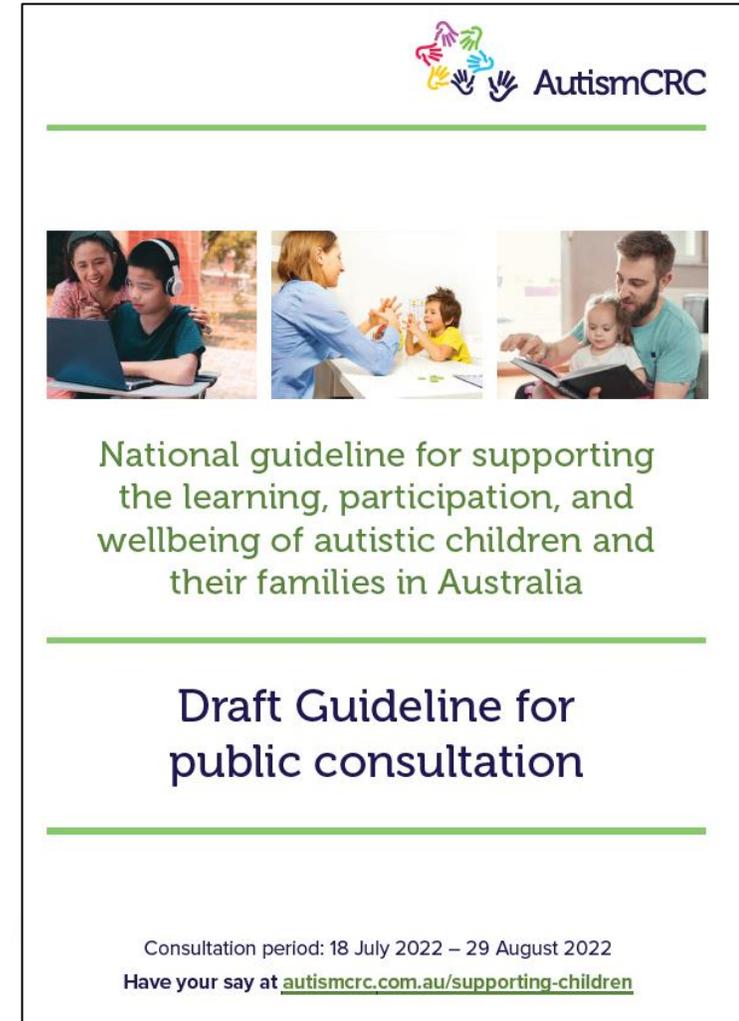
 AutismCRC

**A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia**

Full National Guideline

Prof Andrew Whitehouse, Dr Klah Evans, Prof Valsamma Eapen and A/Prof John Wray

October 2018



The cover features the AutismCRC logo at the top right. Below the logo are three small photographs: a woman and a young man with headphones, a woman interacting with a child, and a man reading to a child. The title is centered in a dark blue font. At the bottom, the consultation period and website are listed.

 AutismCRC

**National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia**

**Draft Guideline for public consultation**

Consultation period: 18 July 2022 – 29 August 2022  
Have your say at [autismcrc.com.au/supporting-children](https://autismcrc.com.au/supporting-children)

# Advances in autism research

## 4. Societal change

### 1980s

- Autism very much unknown until Raine Man.
- A focus on 'cure'
- Little focus beyond childhood

### Now

- Autism widely known (one in four Australians has an autistic relative)
- Focus on the human, and how to remove barriers so they can be themselves
- Greater understanding beyond childhood

# Does this mean the world is sunshine and lollipops?

- Alas, no –
  - It only means that we have know that we can make things better.



**Clir**  
Resear

# What don't we know?

Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?

How can autism diagnostic criteria be made more relevant for the adult population?

How should service delivery for autistic people be improved and adapted in order to meet their needs?

Which interventions improve mental health or reduce mental health problems in people with autism?

Which interventions reduce anxiety in autistic people?

How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?

What are the most effective ways to support/provide social care for autistic adults?

And how do we ensure that autistic adults are appropriately diagnosed?

How should mental health interventions be adapted for the needs of people with autism?

How can sensory processing in autism be better understood?

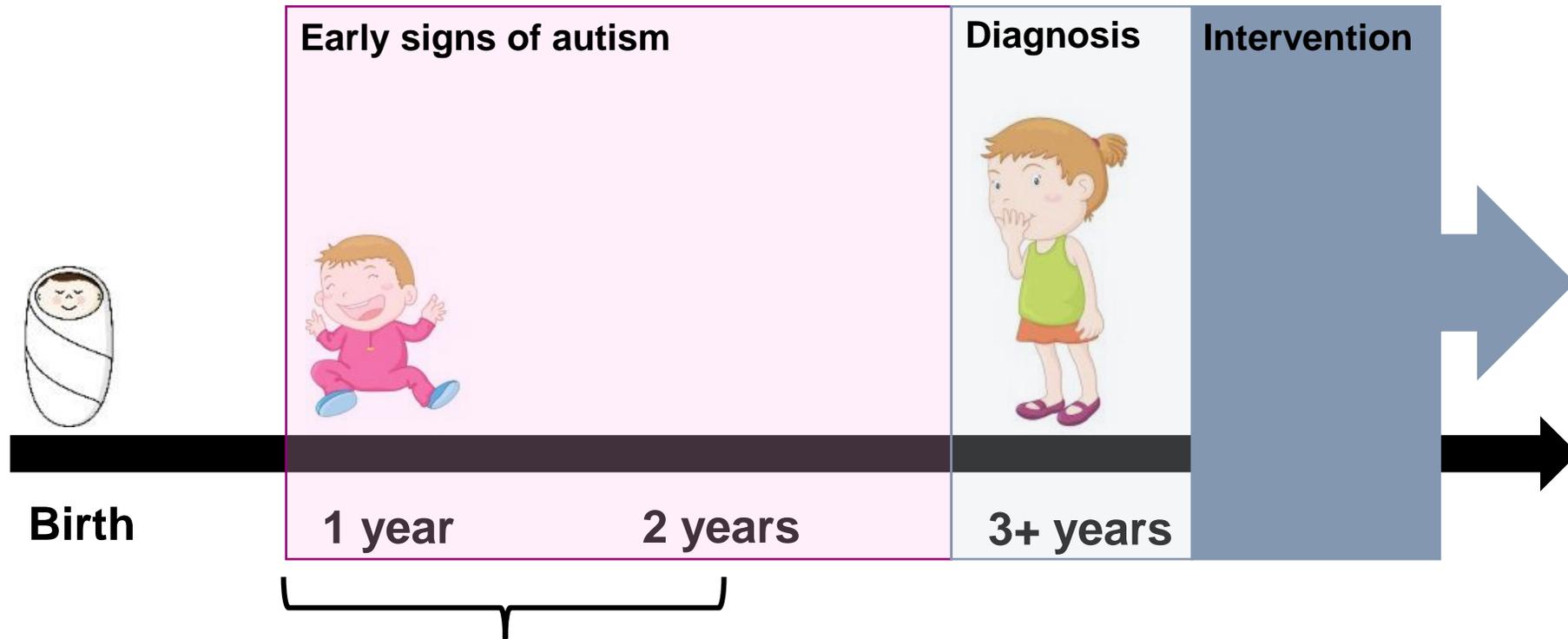
How can parents and family members be supported/educated to care for and better understand an autistic relative?

Which interventions are effective in the development of communication/language skills in autism?

# Overview



# Autism clinical pathway



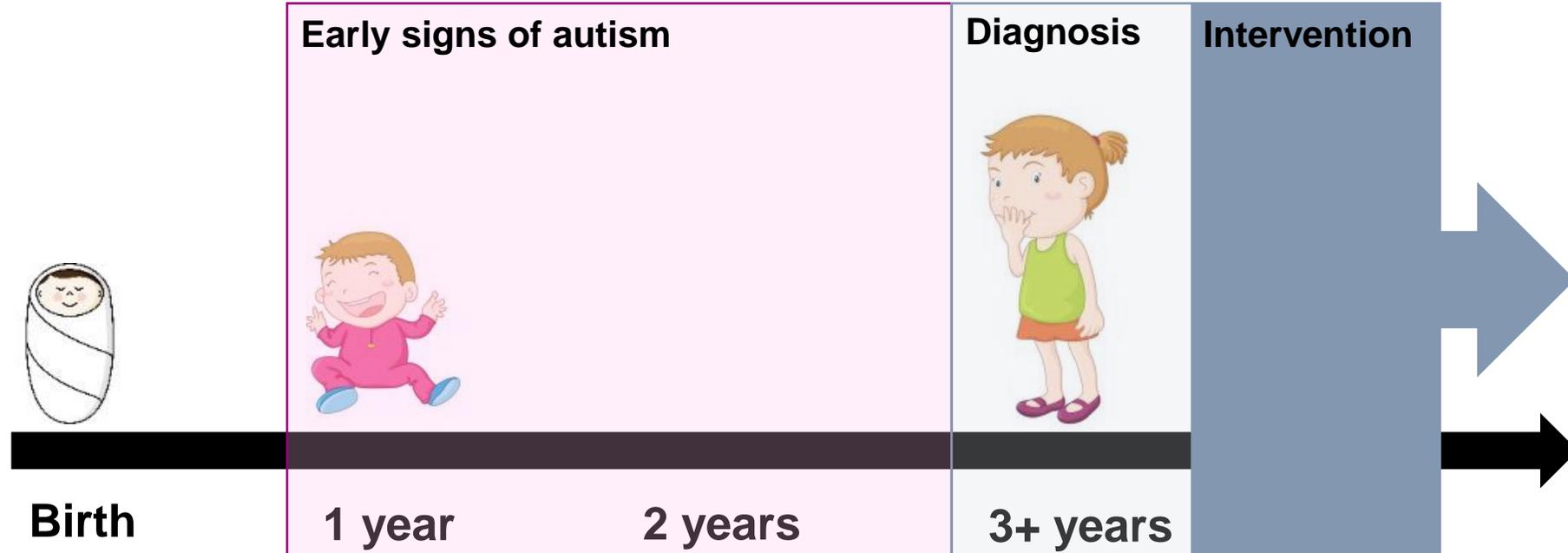
Behavioural signs of ASD typically emerge

# How is the status quo faring?

- Only a minority of individuals have significant reductions in disability
- Current interventions are:
  - Not as impactful
  - Too labour intensive
  - Too expensive
  - Based on outdated principles and evidence

# Is this the best we can do?

- More saliently, is this the best we can do according to evidence?



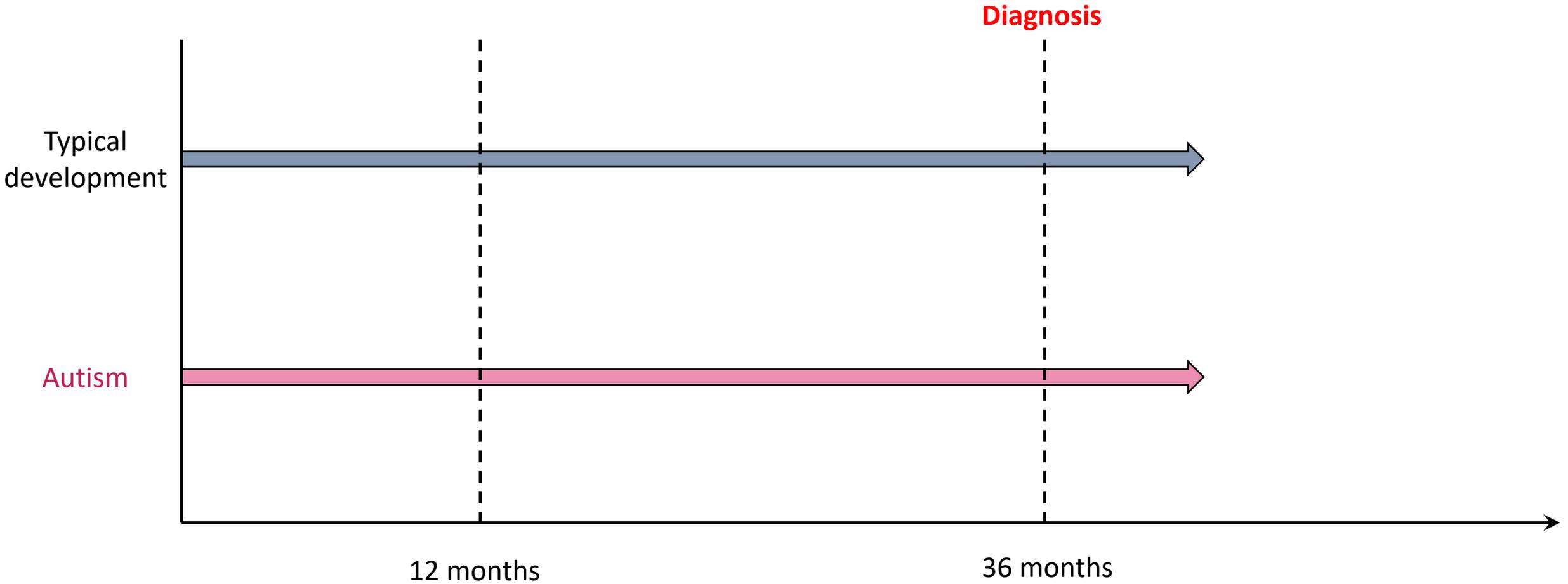
# Is this the best we can do?

- Simple answer is no

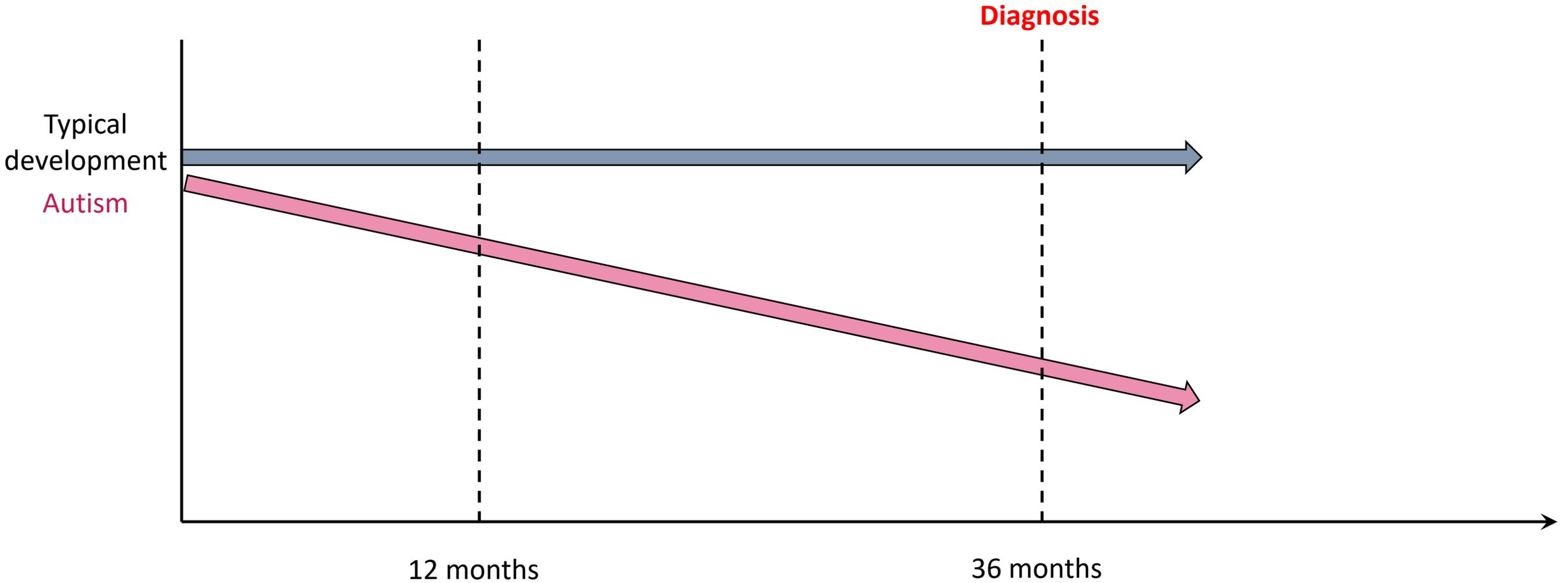
# Why do I say this?

- Adults on the spectrum
  - Broader options
- Parents of children on the spectrum
  - Early worries often ignored
- Clinicians
  - Working with outdated systems that rely too heavily on diagnosis
- Scientists
  - Developmental understanding of pathways to autism diagnostic behaviours

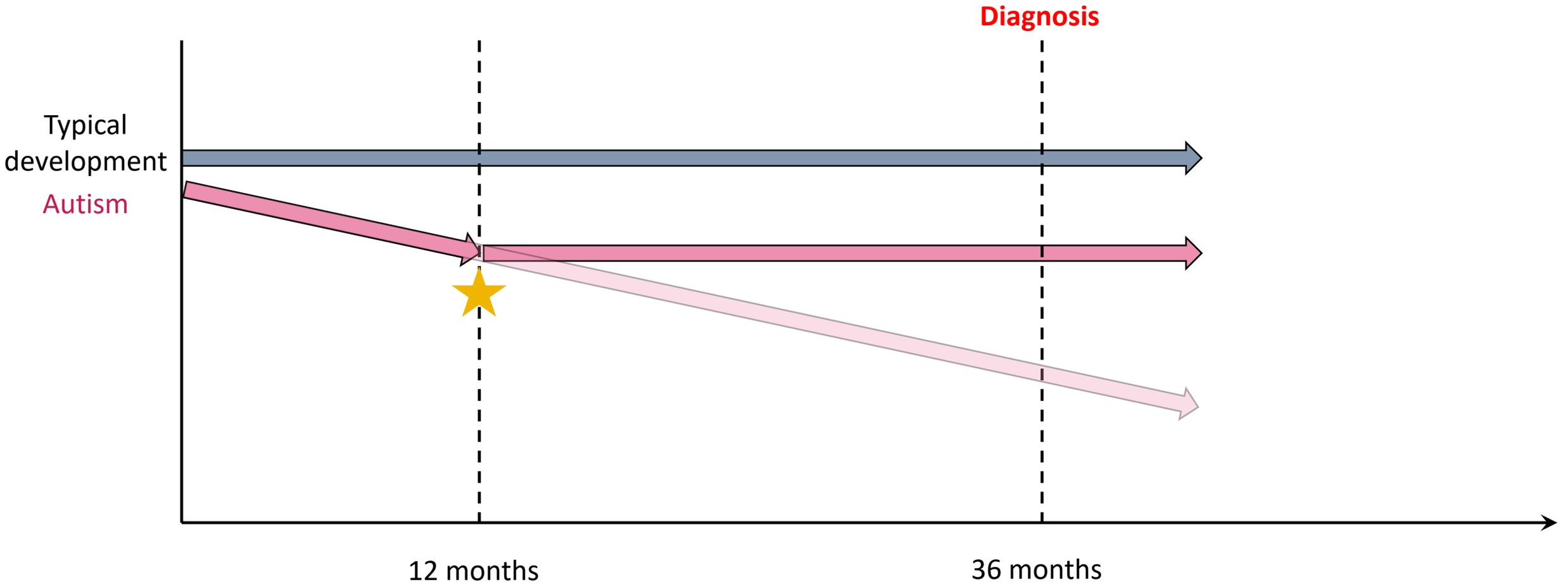
# Previous view



# Emerging view



# Hypothesis – shifting the cascade



# Vision for pre-emptive supports

- What is the vision for pre-emptive supports?
  - Families and children receive affirming supports when they need them
  - That families are embraced by systems rather than received by them
  - That by the time 'downstream' systems first interact with children, that:
    - Families are empowered with knowledge
    - Feel supported by systems
    - Can hit the ground running with supporting their child in a new system

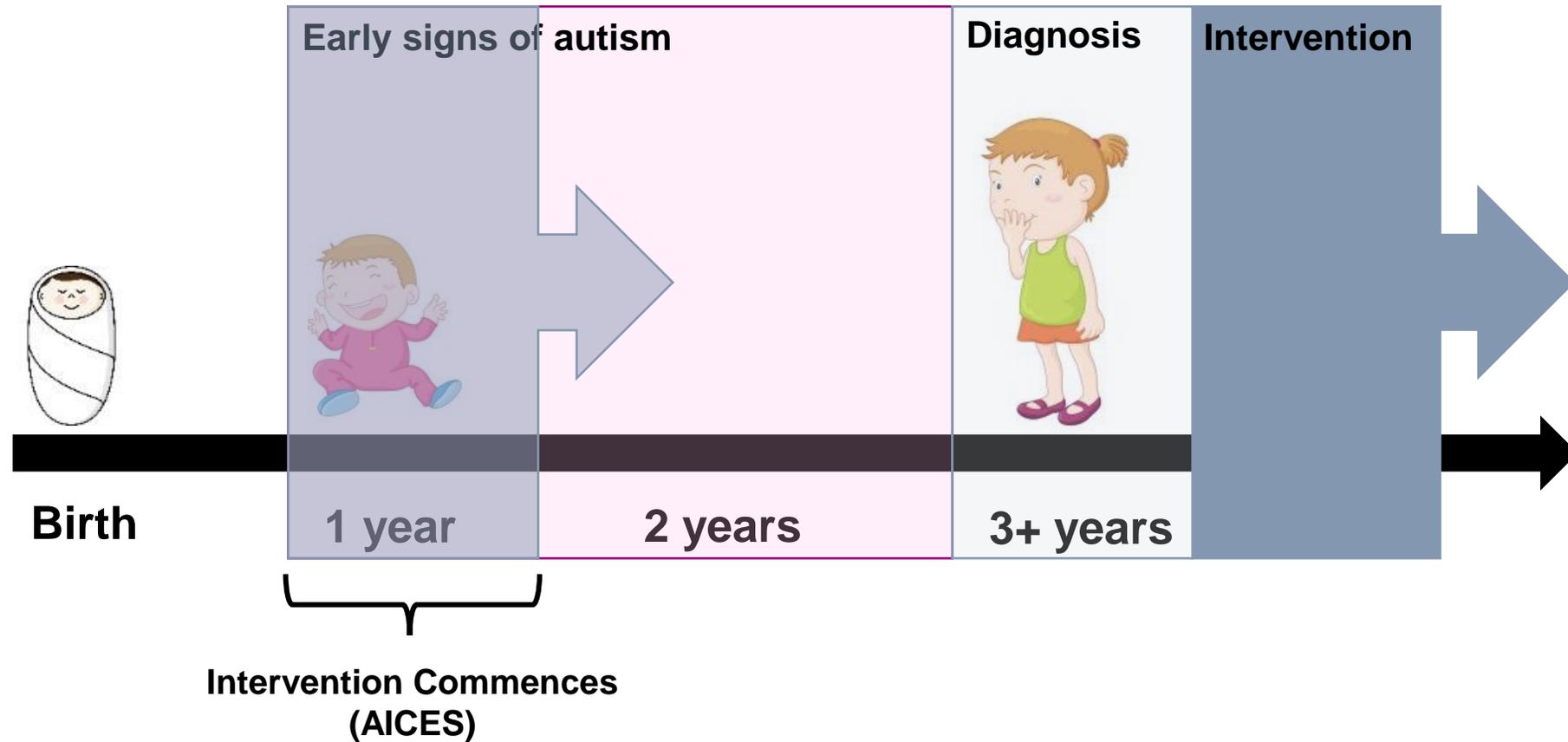
# Why don't we conduct pre-emptive intervention?

- We do.....in a limited way.
- System inertia
  - Diagnosis has been the trigger
  - Systems have developed around that
- Scientific and economic evidence

# Overview



# Autism clinical pathway



# Challenge

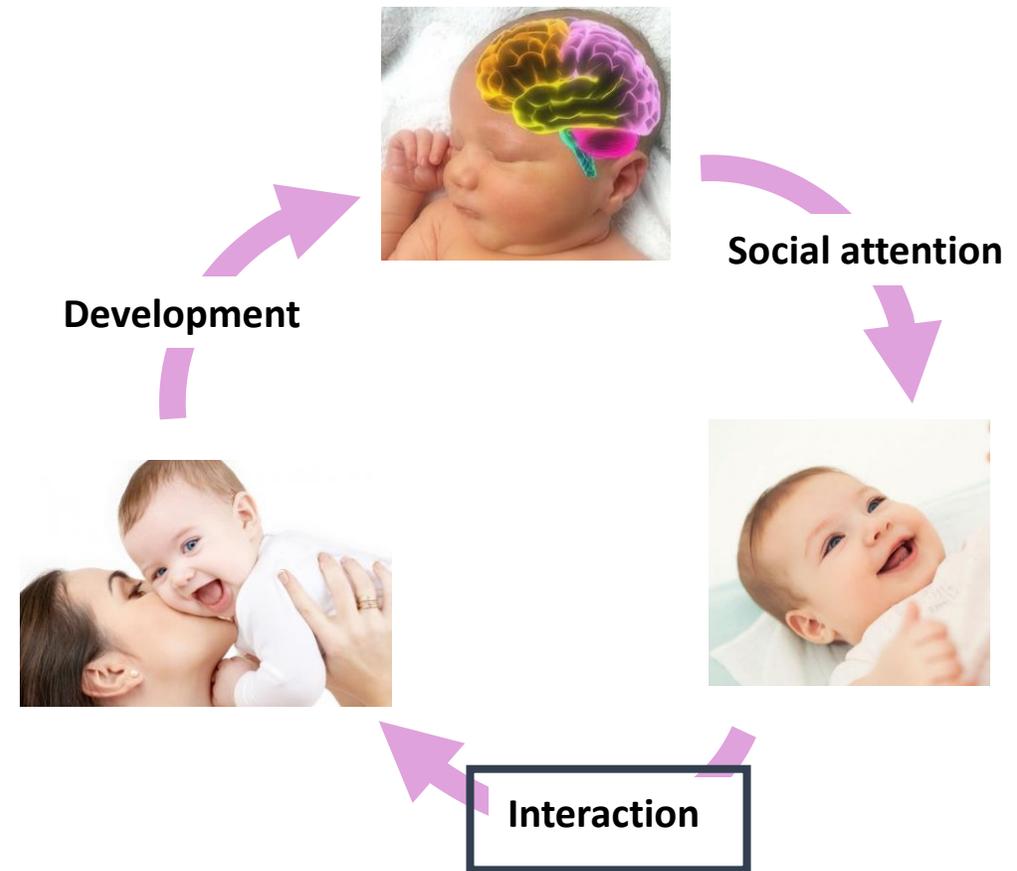
- What supports are most appropriate?

# Therapy development

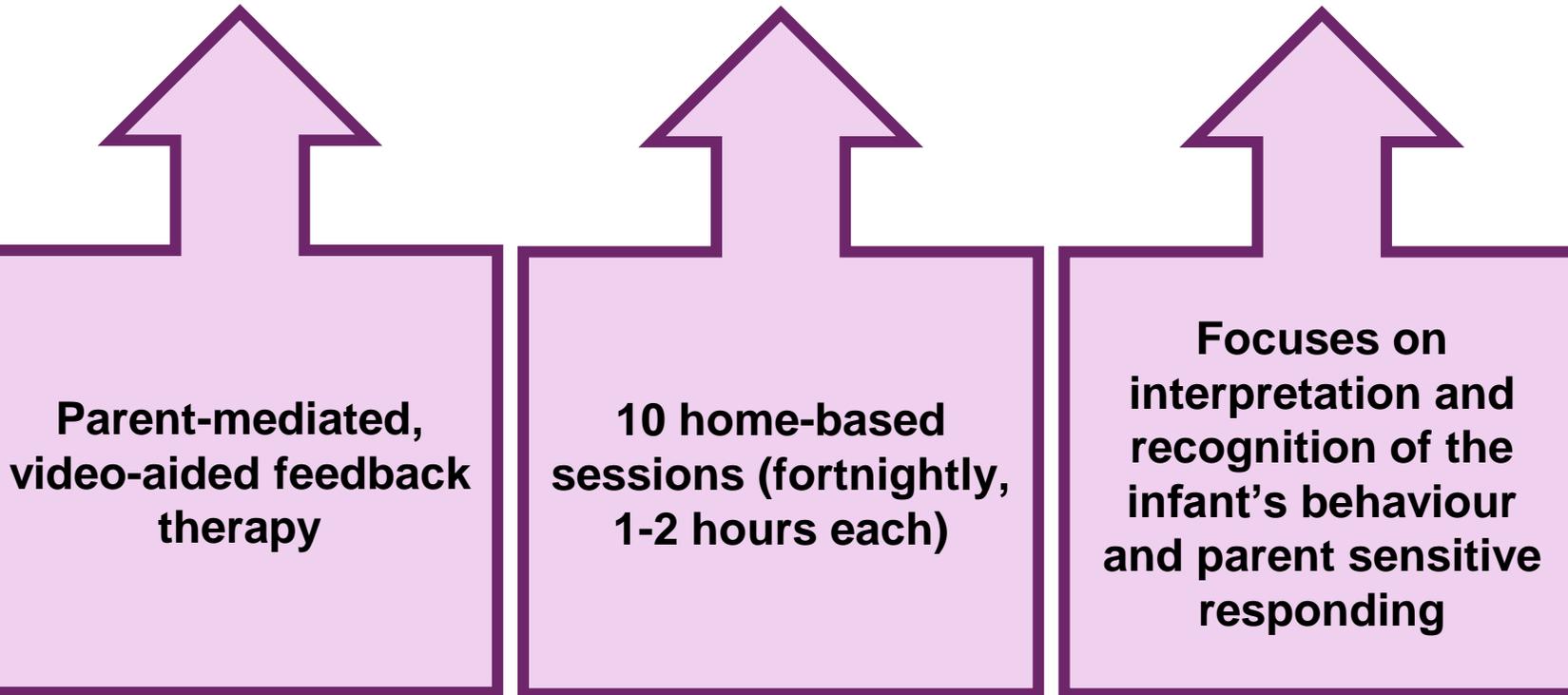
- Developed over 2000s and 2010s
  - Emerged directly out of discussions with the autistic community
  - ‘Double empathy’ – two-way issue
  - Therapy works by helping support parents adapt their communication style
    - Does not work directly with the baby
    - Instead adapts the social environment to help babies learn in a way that is best for them
    - Helps parents understand the unique abilities and skills of their baby and how they can best interact to help their baby feel perceived and understood.
- 10 sessions (fortnightly) over 5 months
  - On NDIS rates, **costs \$3,000 in total (maximum)**

# Therapy mechanism

- Modification of social interaction patterns an intervention target
- Critically, interaction not 'primary cause'
  - amplify initial neural and behavioural differences



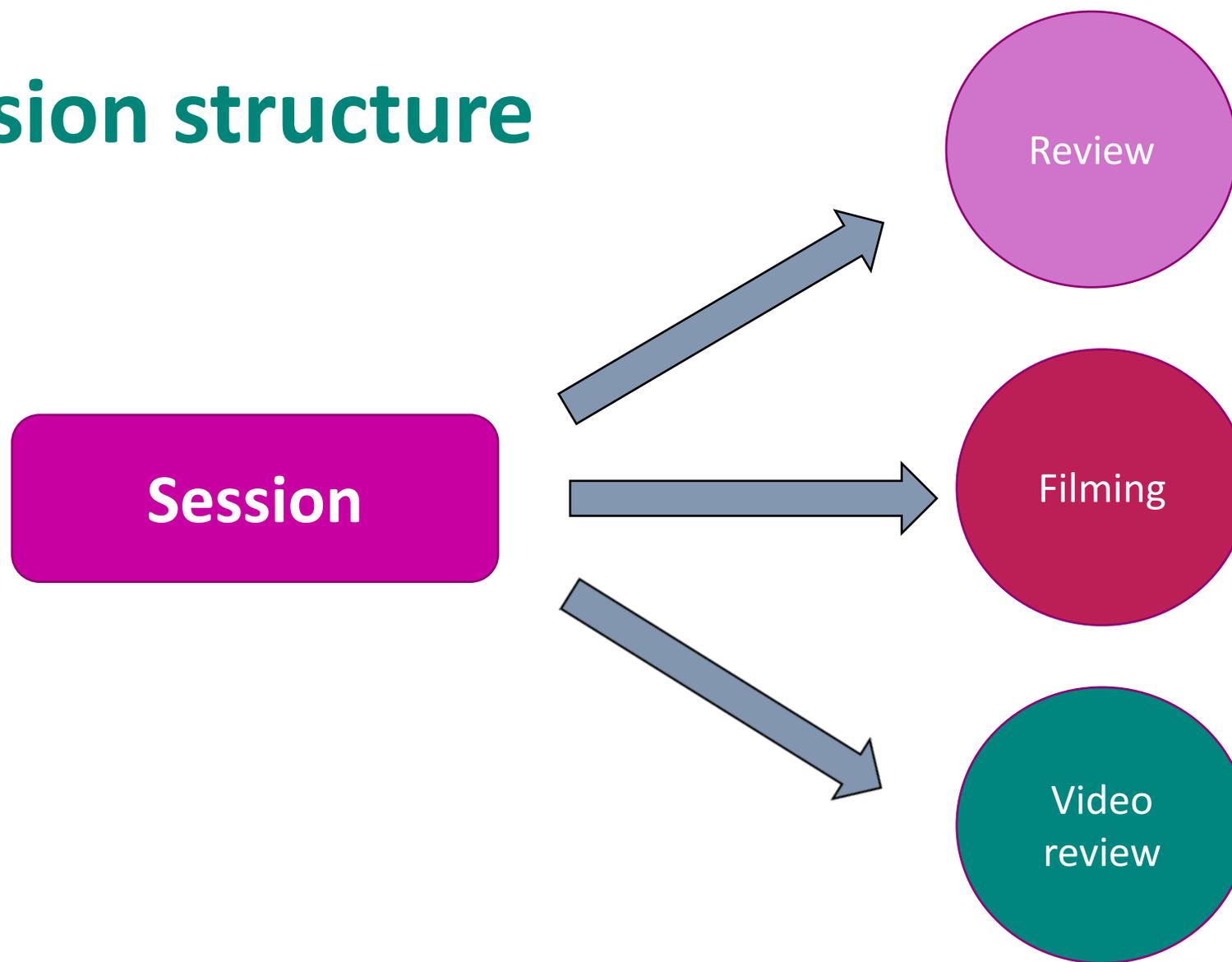
# iBASIS-VIPP



# iBASIS-VIPP sessions

	Session	Session name	Session theme
Core sessions	1	Wait to Understand	Observing, thinking about, and understanding the baby.
	2	Wait for Discovery	Exploring and interacting.
	3	Wait and Respond	Developing back-and-forth communication during play.
	4	Wait and Respond at Mealtimes	Developing back-and-forth communication during daily routines.
	5	Wait and Share Feelings	Recognising, accepting, and responding with empathy to baby's feelings.
	6	Wait and Share Talk	Having 'conversations' with baby and building language abilities.
Focused sessions	7-10	Booster/Reinforcement	The number and content of the focused sessions are based on the individual needs of the parent and baby

# Session structure



# Research questions

- Does 'pre-emptive' intervention:
  1. Mitigate the emergence of autistic symptomatology;
  2. Reduce the likelihood of an ASD diagnosis
  3. Improve a range of developmental outcomes

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**AICES**

The Australian Infant Communication and Engagement Study



**WA Child Development Service**

John Wray  
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**Guys & St Thomas' Hospital, UK**

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**La Trobe University**

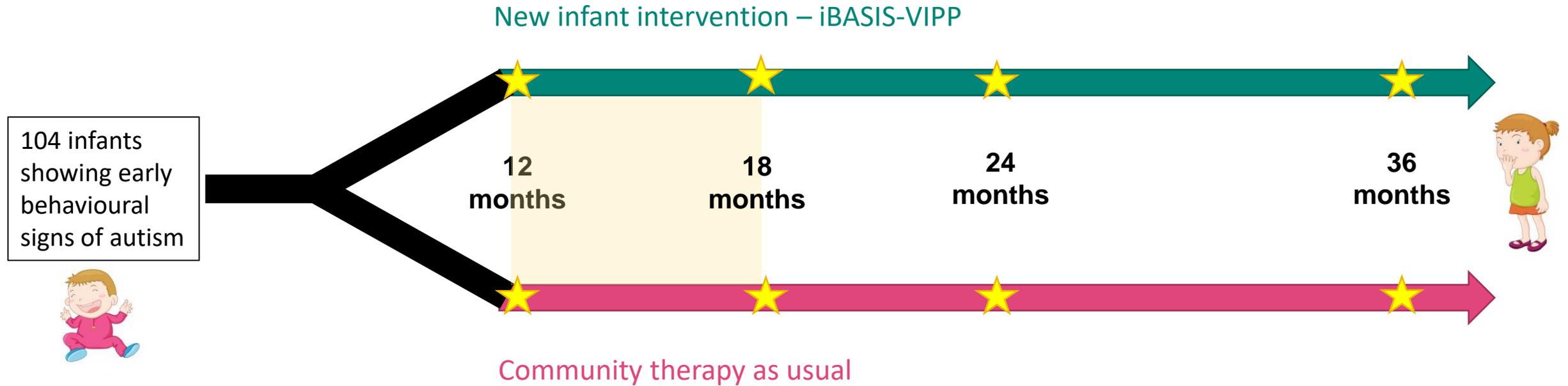
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# Randomised controlled trial

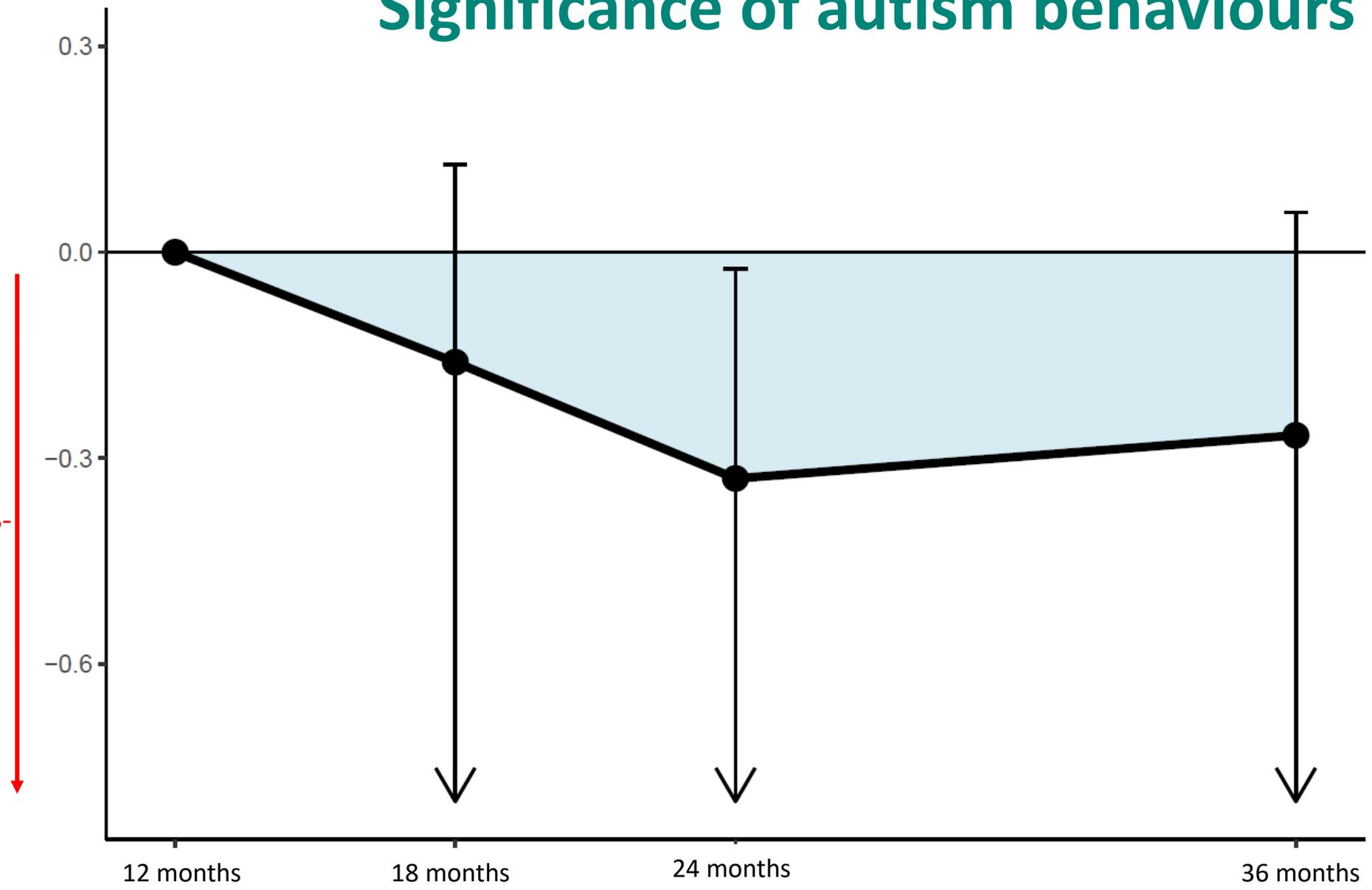


# Strengths of the study design

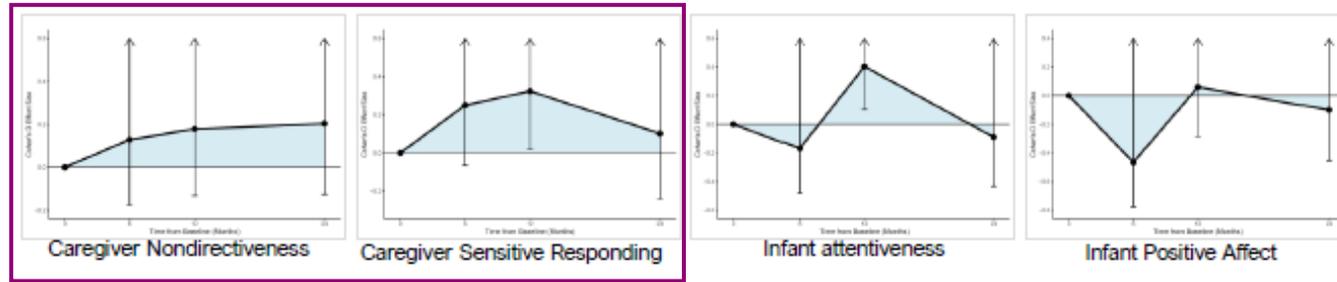
- Moderately large sample size
- High sample retention
- Longitudinal follow-up
- High-level of masking/blinding
- Pre-specified analysis plan

# Significance of autism behaviours

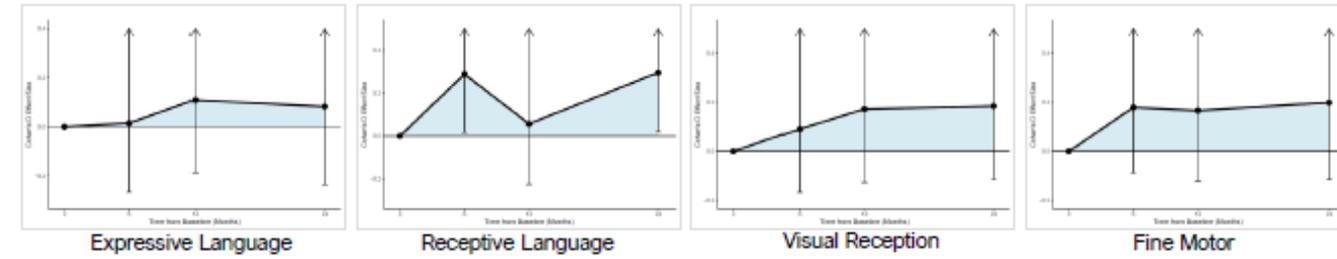
Reduced severity of autism diagnostic behaviours in iBASIS-VIPP group



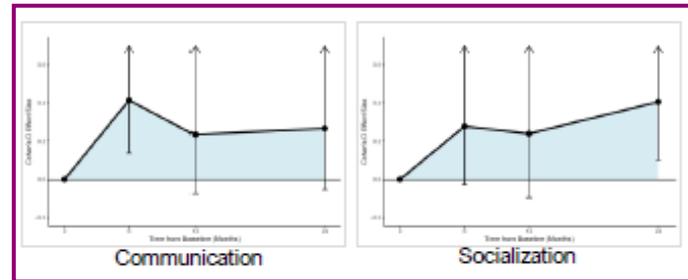
Parent child communication



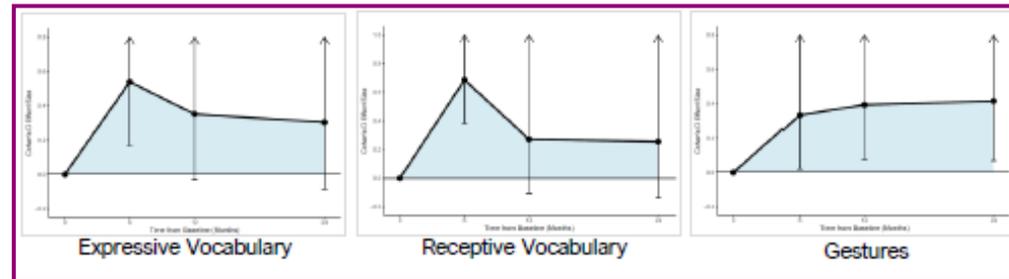
Developmental abilities



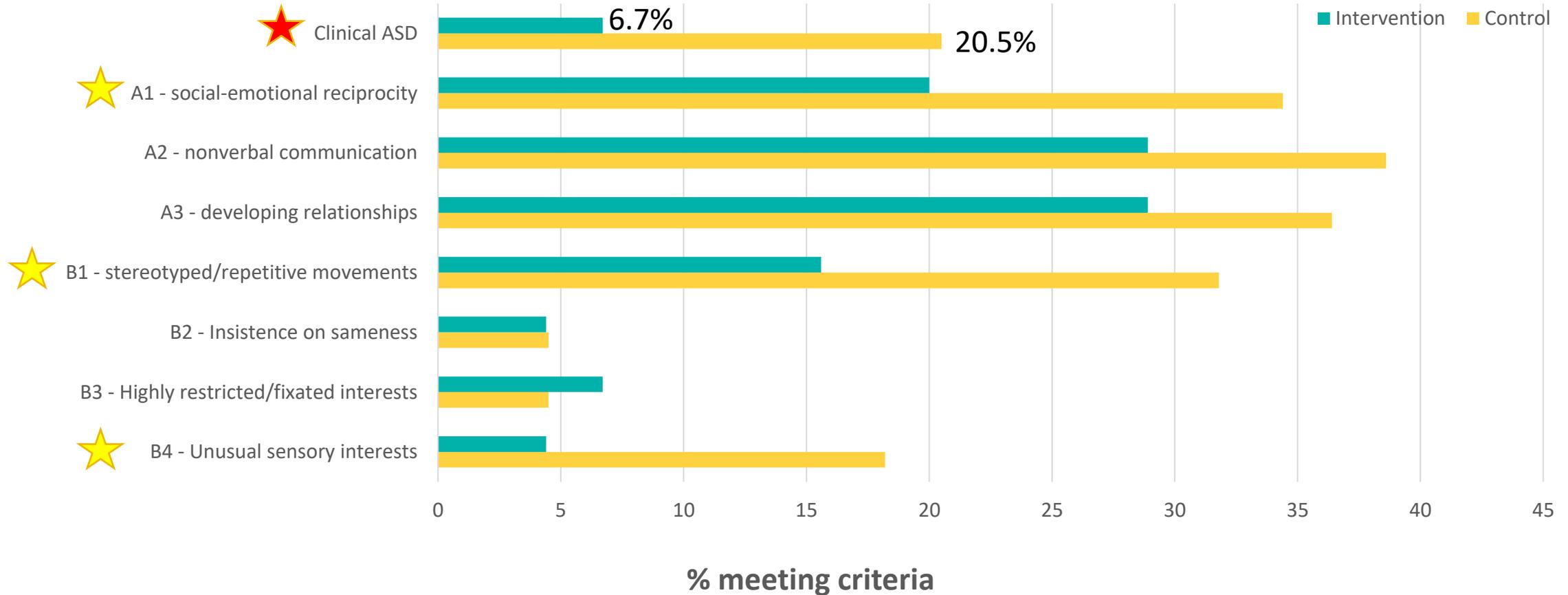
Functional abilities



Language abilities



# ASD diagnosis



# Summary of findings

- Pre-emptive intervention:
  - Reduced autistic symptoms
  - Improved language outcomes
  - Reduced likelihood of an Autism diagnosis at age three years
- Low cost
- No adverse effects
- Provides evidence for a new clinical model that prioritises intervention prior to the emergence of the full ASD syndrome.

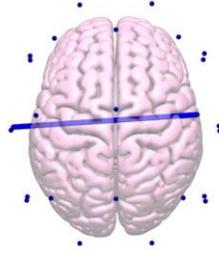
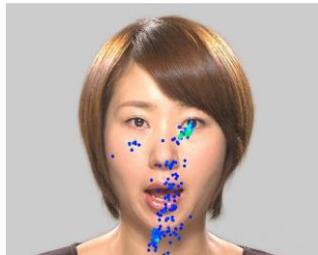
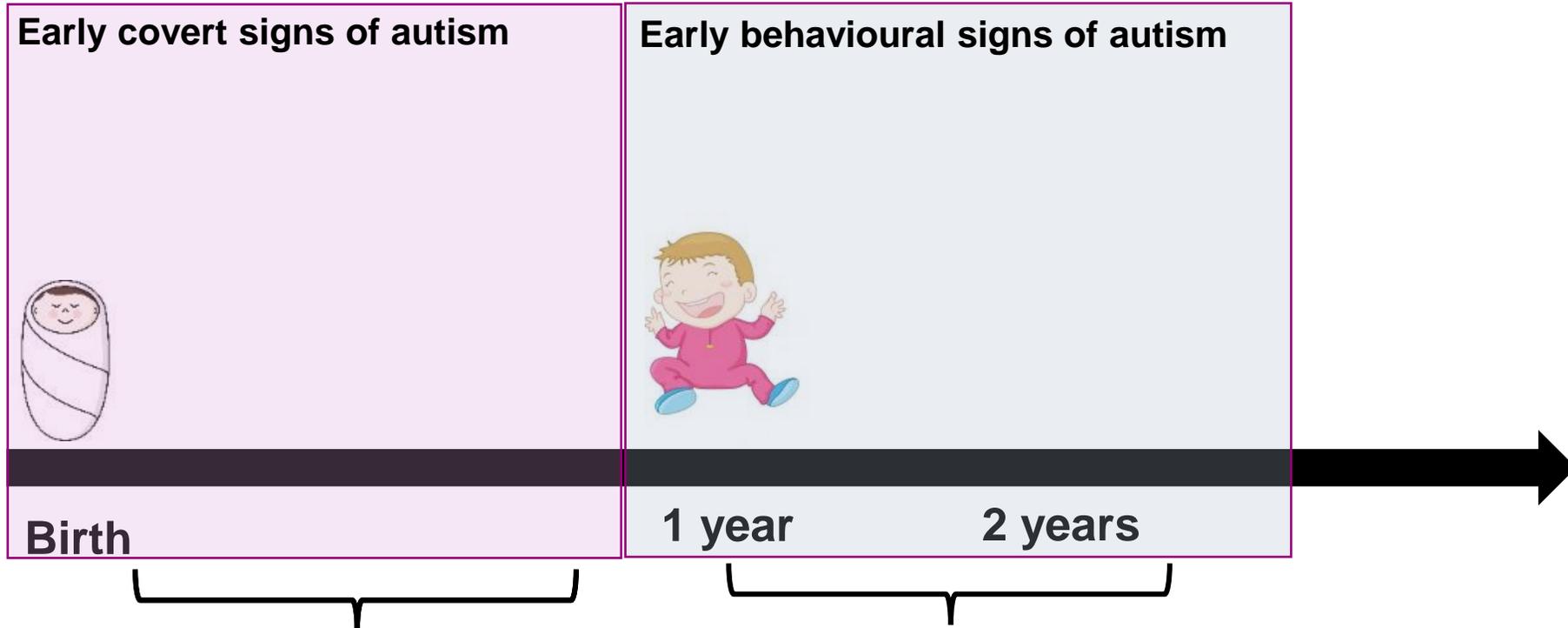
# Key communication points

- Parents are not a cause of autism
  - Babies are born with developmental vulnerabilities (likely genetic in origin)
- This study had no focus on cure or prevention
  - Focused on reducing barriers to participation
- Access to supports
  - Highlights flaws of diagnostic-based systems
  - National Guideline

# Implementation

- State-wide trial of new clinical pathway
- Schools

# Autism and Early Development



Behavioural signs typically emerge

# CUBS

**Authors:** Andrew Whitehouse, Michelle Renton, Jane Doyle, Jonathan Green, Lindy Henry, Angela Bunney

Session	Baby's age	Format/Location	Time	Theme/Focus
A1	3 <sup>rd</sup> trimester	Small group/clinic	3 hours	Introduction to the program & newborn communication
C1	4 weeks	Individual/home	1 hour	Discovering the unique capacity of the infant (NBO)
C2	6 weeks	Individual/home	1 hour	Infant intentionality, cues, and pace
C3	8 weeks	Individual/home	1 hour	Sensitive interaction
C4	10 weeks	Individual/home	1 hour	Shared engagement and sensitive, contingent responding
C5	3 months	Individual/home	1 hour	Empathic responding, organizing emotions, emotional literacy
C6	4 months	Individual/home	1 hour	Two-way interaction and semantically contingent responses
C7	5 months	Individual/home	1 hour	Motor exploration and following a baby's lead
F1-3	6, 7, 8 months	Individual/home	1 hour	Reinforcement in any areas, targeting any concerns

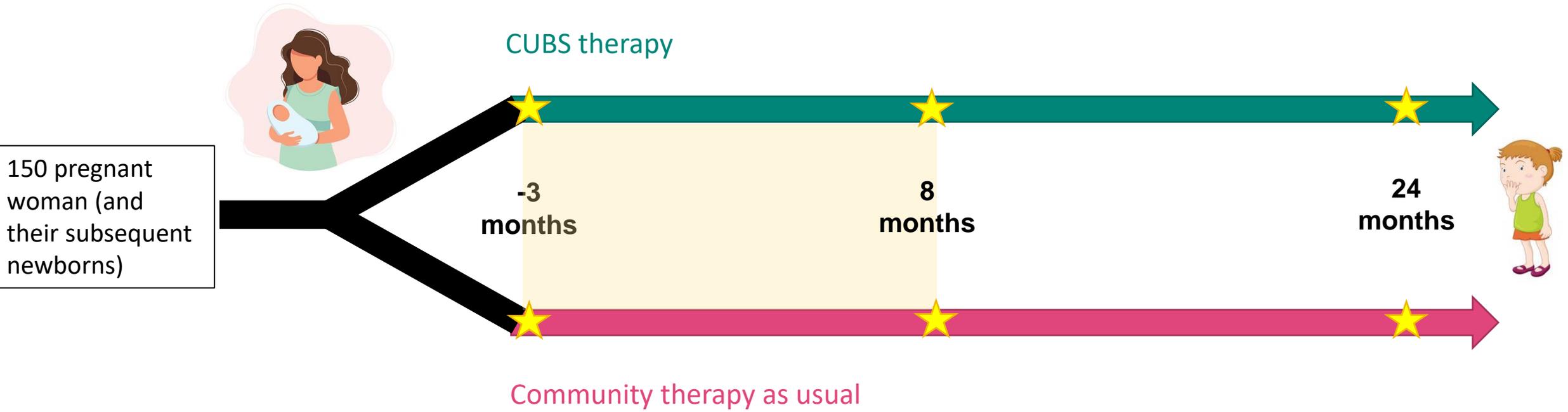
# Video feedback technique

- Clinician films a video of a caregiver and infant interacting

# Video feedback technique

- Clinician then reviews the tape with the caregiver(s) to elicit 1-2 key messages

# Randomised controlled trial



# Vision

- What is the vision for pre-emptive supports?
  - Families and children receive affirming supports when they need them
  - That families are embraced by systems rather than received by them
  - That by the time 'downstream' systems first interact with children, that:
    - Families are empowered with knowledge
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# Overview



# Summary

- Autism
  - So much to be optimistic about!
  - Significant opportunity to tackle some of the most thorny clinical issues with autism
- Built around:
  - Respectful collaboration
  - Being bold, smart and strategic
  - Making the choice
- More to do!
  - ‘Supporting Children’ guideline

# Thank you!



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