Parent-mediated social communication intervention for early neurodiversity and autism (PACT and iBASIS); long-term outcome, mechanism and integrated care

Jonathan Green

University of Manchester, Royal Manchester Childrens Hospital
and Manchester Academic Health Sciences Centre

‘Proven and sustained support from day one’

Principles of an Evidence-led Developmental Approach

- Autism is ***developmental and enduring***
  - *Support needs to reflect this*

‘Proven and sustained support from day one’

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- **Social valency and autonomy** are key to autistic flourishing in communities
  - Focus on the early social environment to promote development - and social outcomes

‘Proven and sustained support from day one’

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- **Current clinical response**
  - Generally reactive, poorly evidenced, episodic and late in development…..

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- **Current clinical response**
  - Generally reactive, poorly evidenced, episodic and late in development…..

- **Need for efficient, evidenced, and developmentally pulsed interventions**

  demonstrating downstream developmental effects

Primary family support for resilience through parent-mediated intervention

Intervention delivered with parents to enhance social development in the neurologically-vulnerable child

iBASIS – from infancy pre-diagnosis

PACT – after diagnosis early years

Caregiver-infant transaction in early development

Caregiver dyadic response

The social environment around the child

Dyadic transaction

'Attunement'
'Goodness of fit'

Early infant development and social communication

Positive outcomes in social communication development, psychological development *(relatedness, trust, social motivation, mental health, well being)*

Caregiver-infant transaction in early development

Caregiver dyadic response

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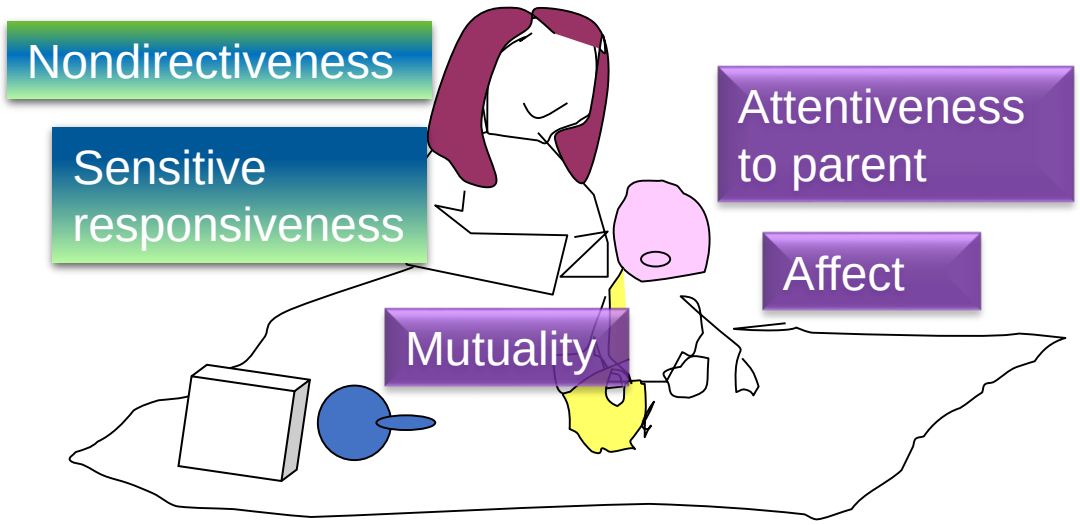
Dyadic transaction altered…..Wan et al 2013/19

Neurodivergent Development and early communication differences

Parent-infant interaction in HL and NL of autism samples

- 6-min parent-infant free floor play videotaped in lab
- *Manchester Assessment of Caregiver-Infant Interaction* (MACI; Wan et al., 2012, 2013, 2019)
- Global rating (1-7) scales, blind-rated, independently validated on HL and NL samples

5 MACI scales of interest



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Distinguishes HL from NL at 7 & 14 mos

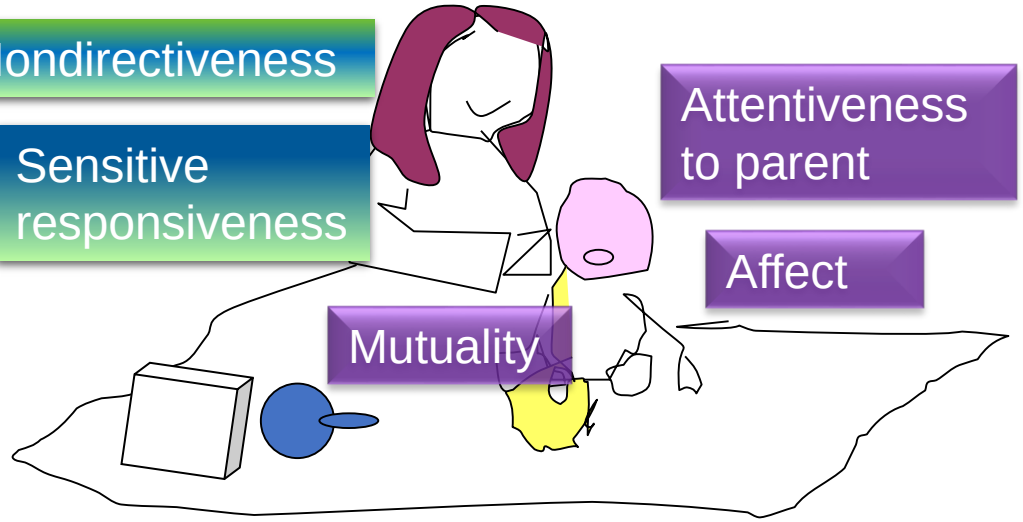
Nondirectiveness

Sensitive responsiveness

Attentiveness to parent

Affect

Mutuality



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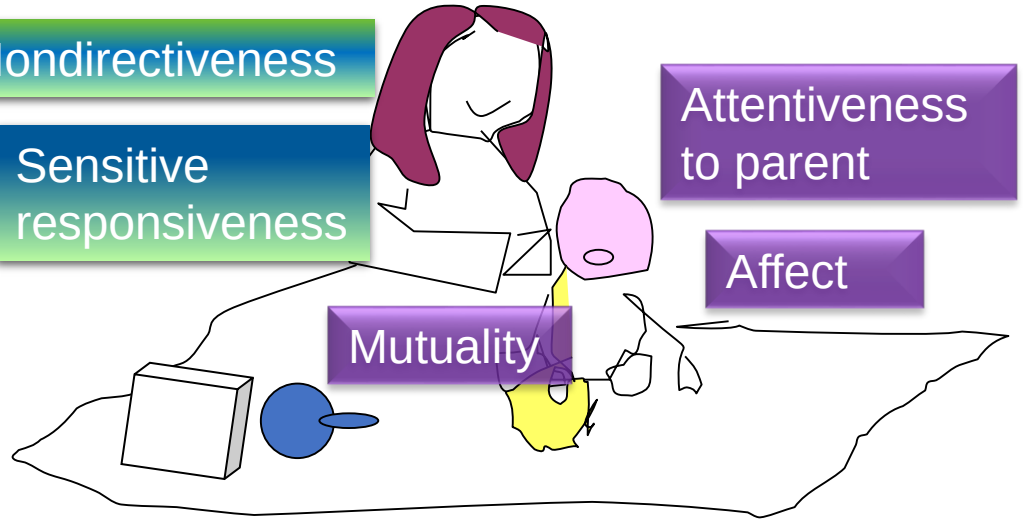
Associated with infant visual ERP atypicality



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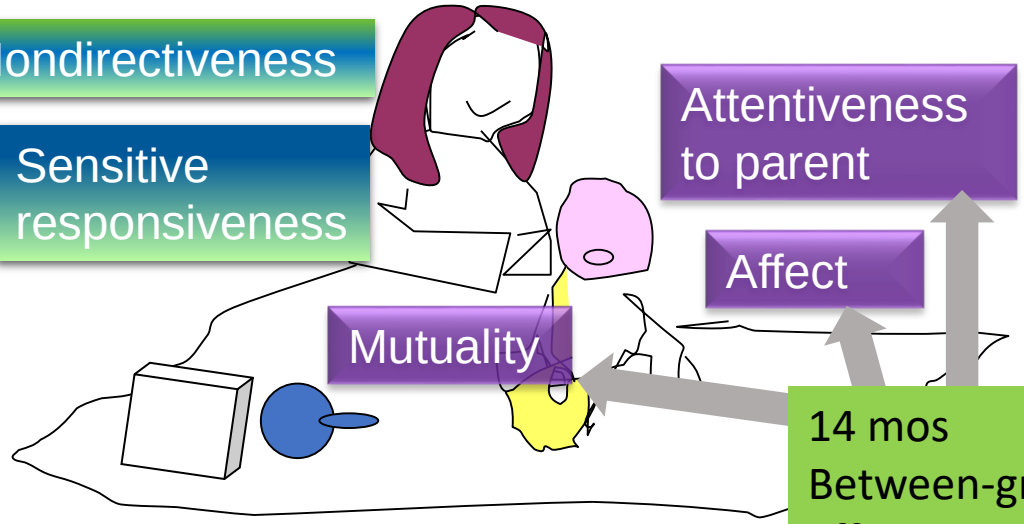

14 mos Between-group effects

Parent-infant interaction

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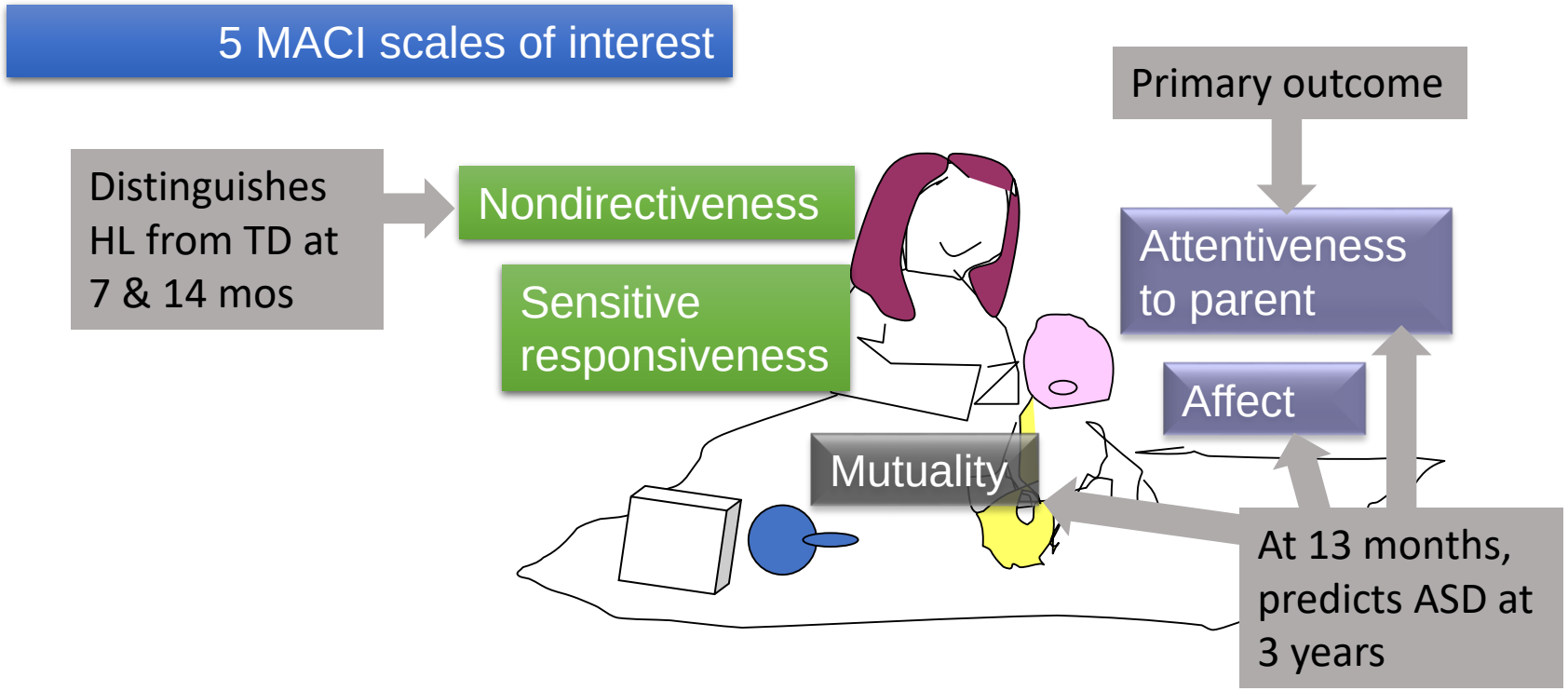

Caregiver-infant transaction in early development

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Dyadic transaction altered…..Wan et al 2013/19

Less ‘Attunement’
‘Goodness of fit’

Less positive outcomes in social communication development, psychological development *(relatedness, trust, social motivation, mental health, well being)*

Neurodivergent Development and early communication differences

What is specific about parent-mediated intervention?

- A paradigm shift from earlier 'behavioural' interventions
  - eg ABA/ESDM/behavioural language training
- Natural environment of family
  - Context for social development
  - Transactional account of known developmental processes
  - Does not imply primary parenting problems
- Parental empowerment, confidence, family function
- Efficient of professional time
- Potential 24/7 therapeutic effect extending beyond treatment end

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- To do this the intervention aims to make focused, reproducible impacts on targeted parental interactions using video feedback
  - More than education or coaching
  - Known to be very effective for observation, reflection and adult learning

Example process – early session 3

Logic model of dyadic interaction therapies

Therapy with caregivers to increase awareness and responsiveness

Child responses in the dyad

Improved functioning in other contexts outside the dyad

follow up

Improved functioning over time in development.

PACT/iBASIS logic model - evidence

Therapy increases parent synchronous response

Increased child communication initiations in dyad

Replicated in 7 RCTs to date

Improved autistic behaviours with researcher in ADOS

Endpoint

3/6 yr follow up

Improved autistic behaviours with researcher in ADOS

Follow up

Replicated in 4 RCTs (-ve in one with less dosage, one equivocal)

3 RCT with preserved ITT

Pre-emptive intervention from infancy

iBASIS

Infancy intervention – 'iBASIS'

- Home based, manualised
- 12 sessions over 5 months (9-14 months)
- Daily practice plans for parents

Sequential themes

- 'Infant watching'
- 'Speaking for the baby' – *inferring intentionality*
- Generalising to mealtime and other activities
- Sharing feelings – *affect matching*
- 'Sharing talk' – *promoting communication*

Adapting to 'atypicality':

- Inflexible attentional style, face preference and visual face processing, affect matching and reciprocity, reactivity, atypical sensory behaviours, social babble/early communication

Chain of effect:
Parent change

Parent and therapist interaction changes parent behaviour

leads to

Child interaction change with parent

Changing parental synchrony impacts child initiations in dyad

leads to

Improved child interaction with others – symptom reduction

Changing initiations by child affects interaction with researcher in ADOS

Baseline

Position
Object focus
Parent initiation
Rhythm and pace
Child not v engaged
Little social learning

Endpoint

More face to face
Child led
Mirroring
Mutuality
Social focus
Affect meshing
Mutual enjoyment
Social learning

Green et al 2017 - iBASIS Intervention RCT N=54, 9-14 months

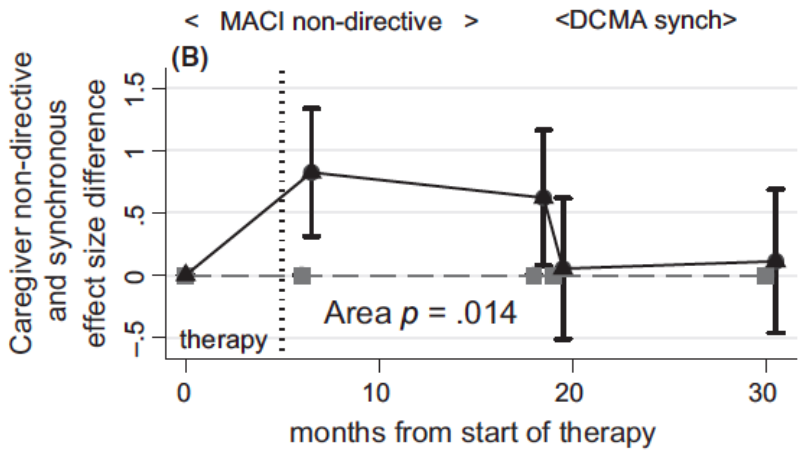
Infants from 9 months at familial autism likelihood within BASIS
iBASIS-VIPP vs TAU

THE JOURNAL OF CHILD PSYCHOLOGY AND PSYCHIATRY
ACAMH THE ASSOCIATION FOR CHILD AND ADOLESCENT MENTAL HEALTH
Journal of Child Psychology and Psychiatry **:* (2017), pp **–** doi:10.1111/jcpp.12728

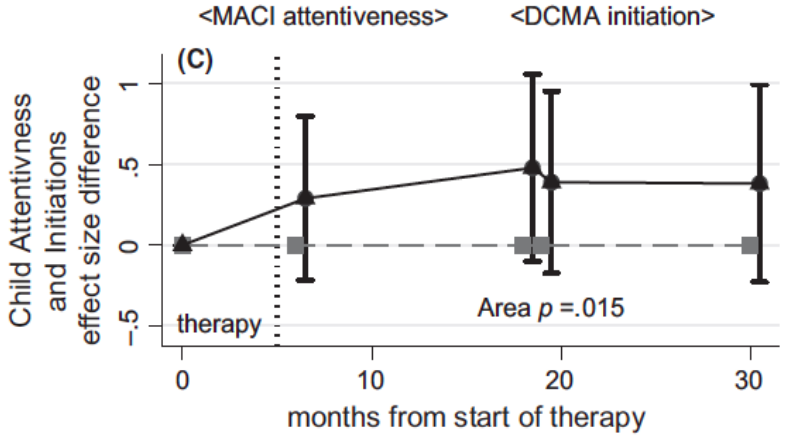
Randomised trial of a parent-mediated intervention for infants at high risk for autism: longitudinal outcomes to age 3 years

J. Green,[1,2] A. Pickles,[3,4] G. Pasco,[3,5] R. Bedford,[3] M.W. Wan,[6] M. Elsabbagh,[5,7] V. Slonims,[8] T. Gliga,[5] E.J.H. Jones,[5] C.H.M. Cheung,[5] T. Charman,[3] M.H. Johnson,[5] and The British Autism Study of Infant Siblings (BASIS) Team*

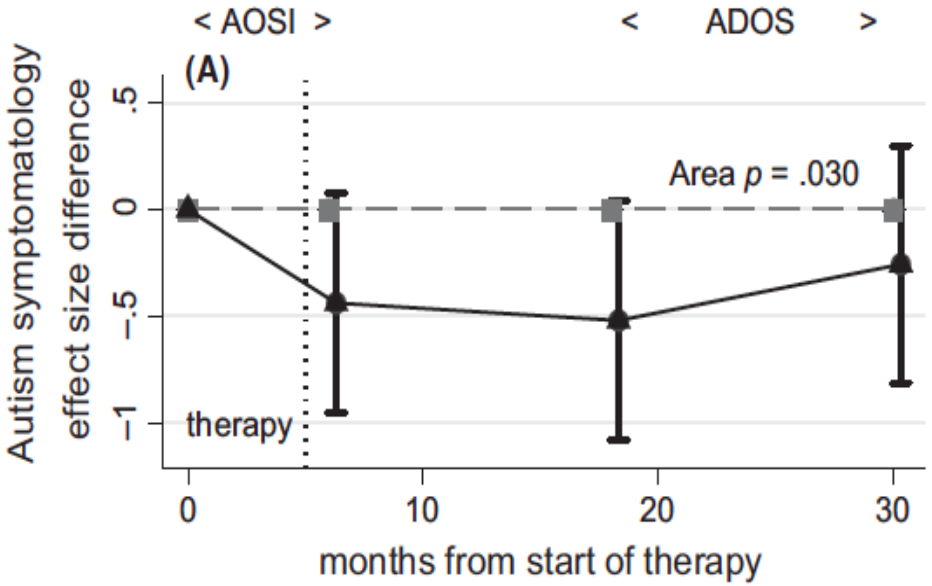
Parent dyadic response



Child dyadic response



Child AOSI/ADOS symptom change over time



No difference in clinical best estimate outcomes (small N)

Whitehouse et al Sept 2021 Australian replication of iBASIS with indicated sampling……

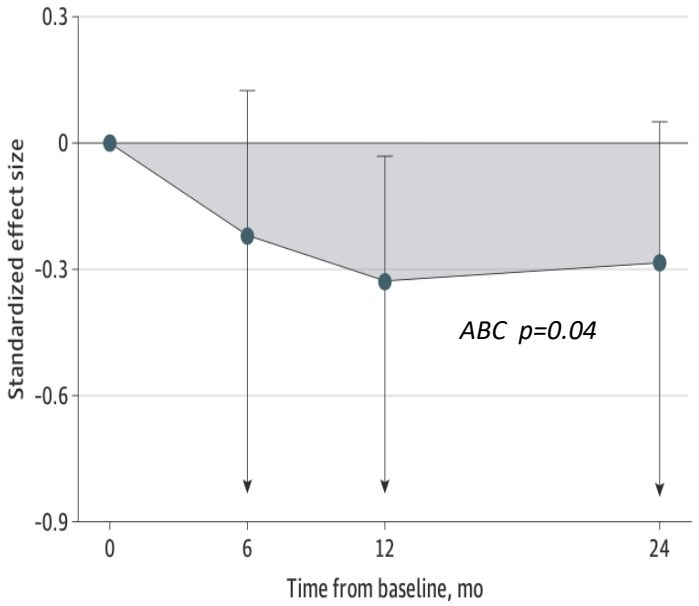
JAMA Pediatrics | Original Investigation

Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism

A Randomized Clinical Trial of Outcomes to Diagnosis

N=103 babies from 12 months
identified with community concerns
and assessed on SACS
5 month intervention
3 year FU to diagnosis

Replication of AOSI/ADOS symptom change against TAU over time



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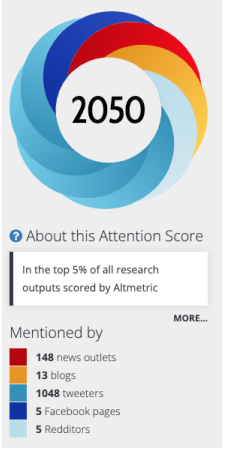

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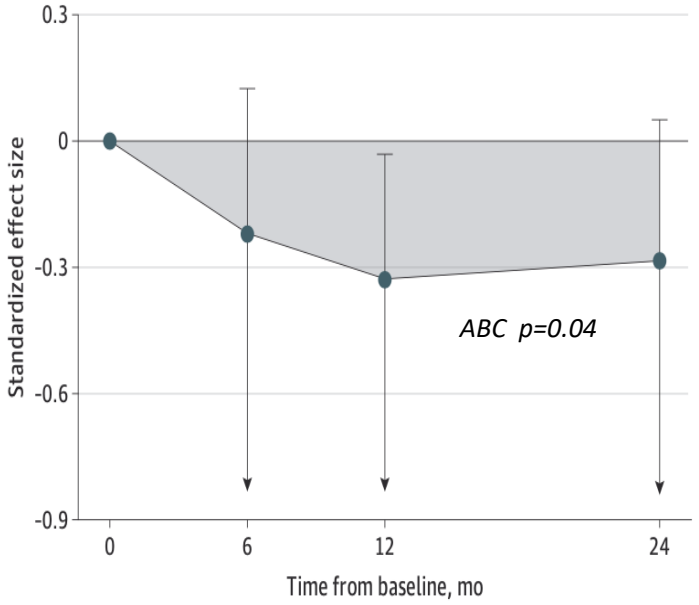


CBE Autism Diagnosis

- Independent blinded clinicians x2
- Access to all data, including ADOS, PCI, other measures
- Against individual DSM criteria
- Overall consensus classification

2/3 reduction in clinical Autism Diagnosis at 3yr (3/45 (6.7%) vs 9/44 (20.5%), OR 0.18 95%CI 0-0.68, p=0.02) **– NNT 7.2**

Parent and therapist interaction changes parent behaviour

Changed parental synchrony impacts child initiations in dyad

Changing initiations by child affects interaction with researcher in ADOS

Preschool Autism Communication Therapy (PACT)

- Manualised 6-12 month programme
- Developmentally staged from early communication pre-cursors to evolved language
- Targeting parental awareness and accurate response to child communication signals
- **Video-feedback** to produce the intervention effect

Stages of the programme

1. Establishing shared attention
2. Synchrony/ Sensitivity
3. Focusing on language input
4. Establishing routines and anticipation
5. Increasing communication functions
6. Expanding language and conversations

First session

J: 2 years 10 months
Very object focused. No initiation of play.
Mum having to work hard to try and engage him, but with little success.
Very little language: observed “ready steady go” some colours and numbers used.

By the end…

Ask questions and give instructions

Negate

Make comments

Take part in social routines

‘Lightbulb moments’ of child recognition and relatedness

‘It was a revelation to me… I thought I was the only person who knew my child… and I didn’t… now I know him best… but I didn’t at the start of PACT.’

The University of Manchester

Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial

Jonathan Green, Tony Charman, Helen McConachie, Catherine Aldred, Vicky Slonims, Pat Howlin, Ann Le Couteur, Kathy Leadbitter, Kristelle Hudry, Sarah Byford, Barbara Barrett, Kathryn Temple, Wendy Macdonald, Andrew Pickles, and the PACT Consortium

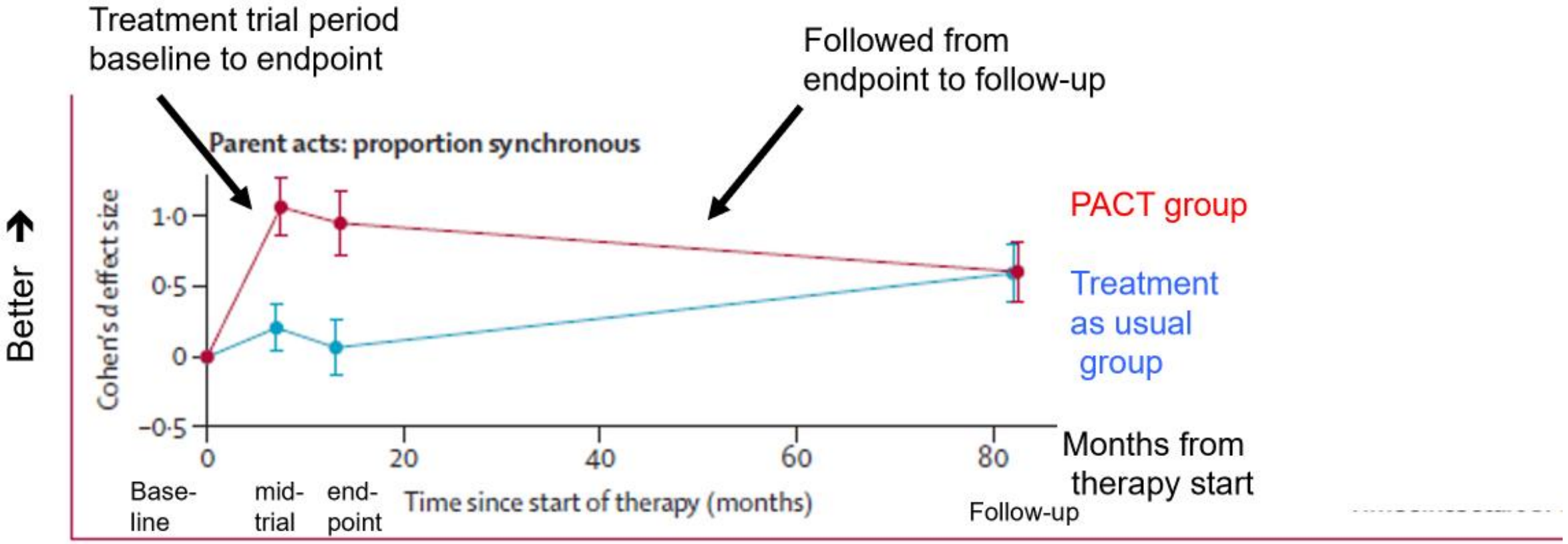
The Lancet (2010), 375, 9732; 2152-2160

Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial

Andrew Pickles, Ann Le Couteur, Kathy Leadbitter, Erica Salomone, Rachel Cole-Fletcher, Hannah Tobin, Isabel Gammer, Jessica Lowry, George Vamvakas, Sarah Byford, Catherine Aldred, Vicky Slonims, Helen McConachie, Patricia Howlin, Jeremy R Parr, Tony Charman, Jonathan Green

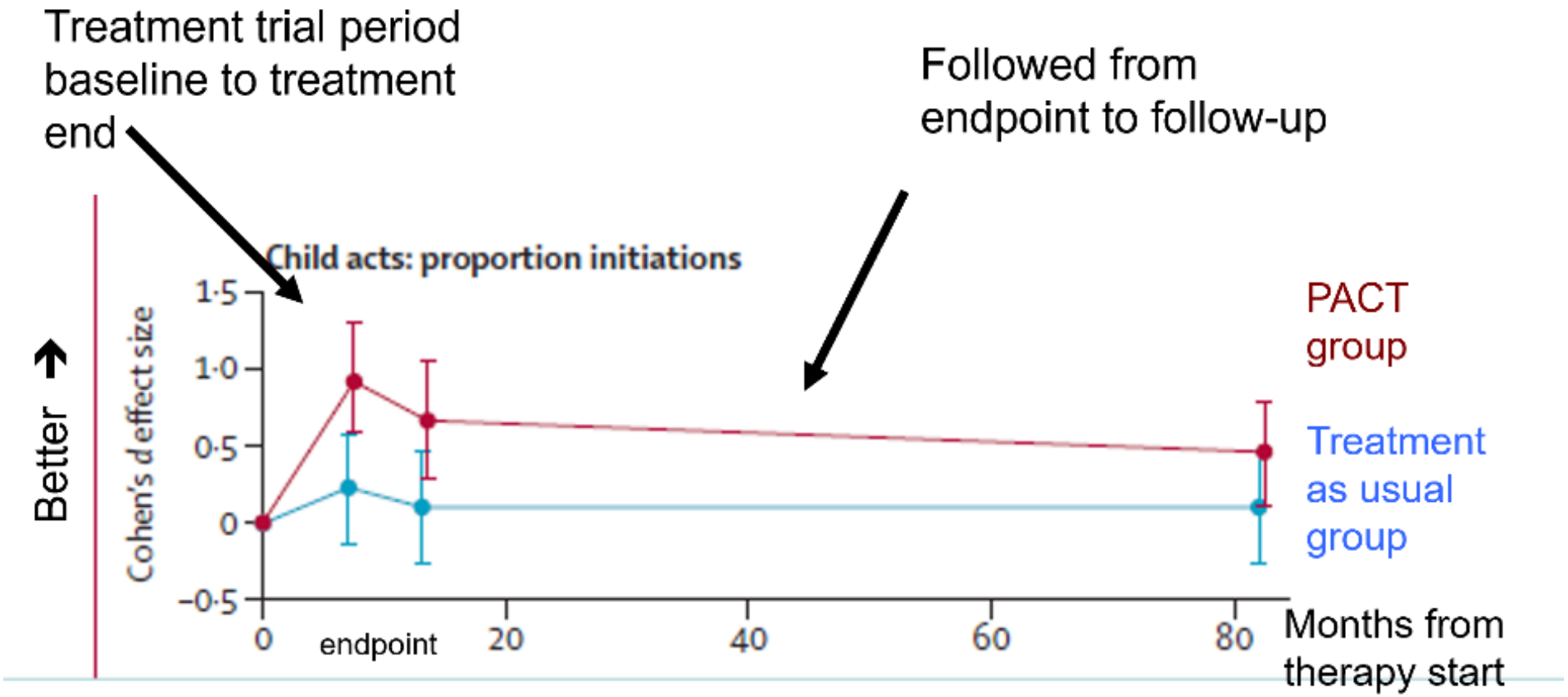
The Lancet (2016); 388: 2501-2509

Effect of Therapy on Targeted Parent Behaviour

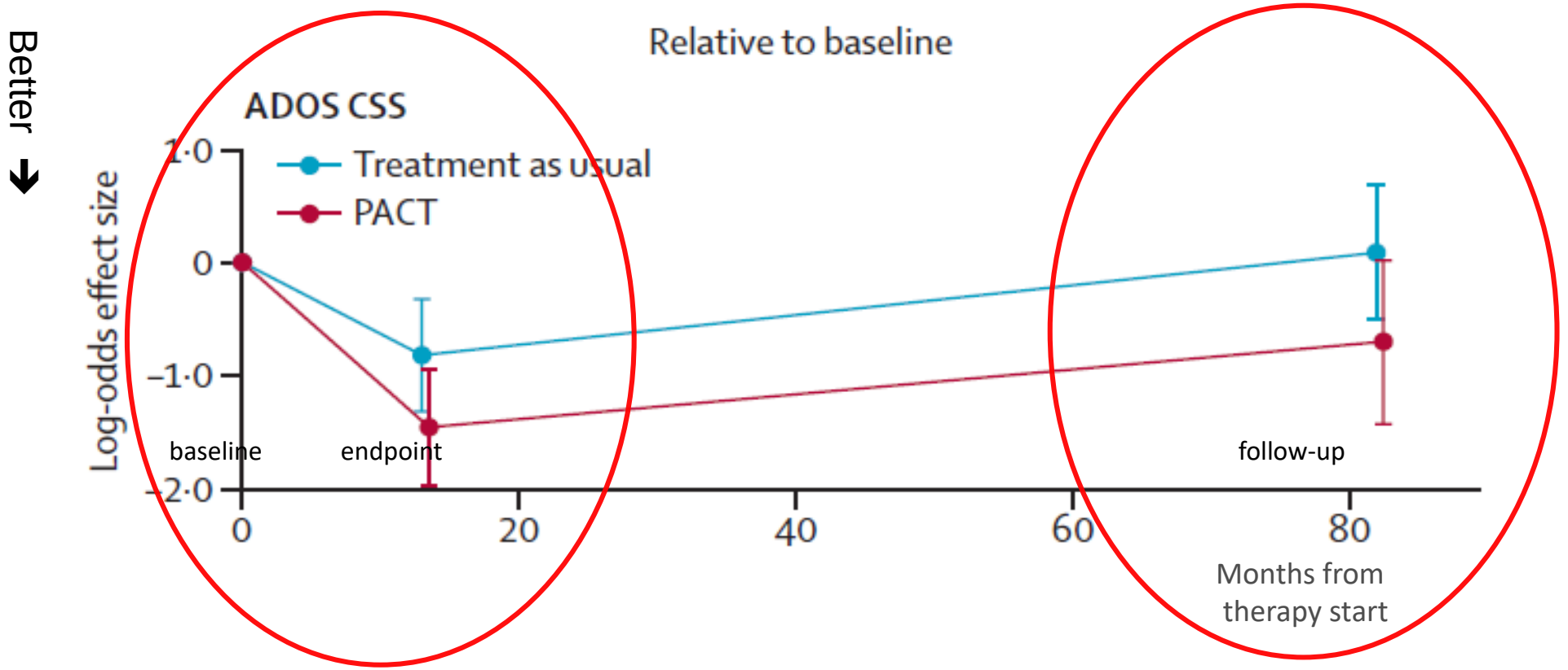


Effect of Therapy on Targeted Child Behaviour with Parent

Increase in social communication with parent persisted

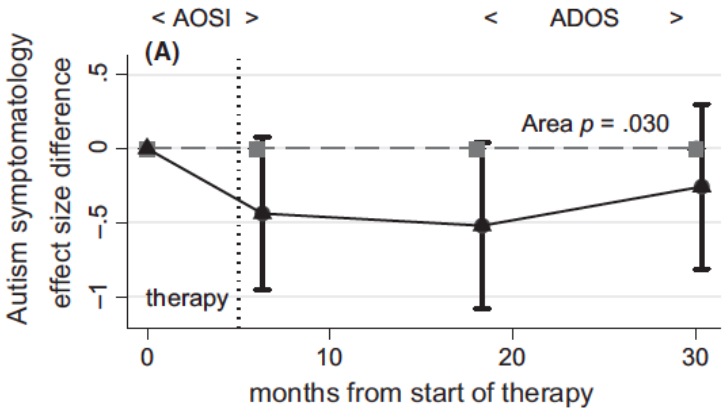


The Time Path of Autism Symptom Severity



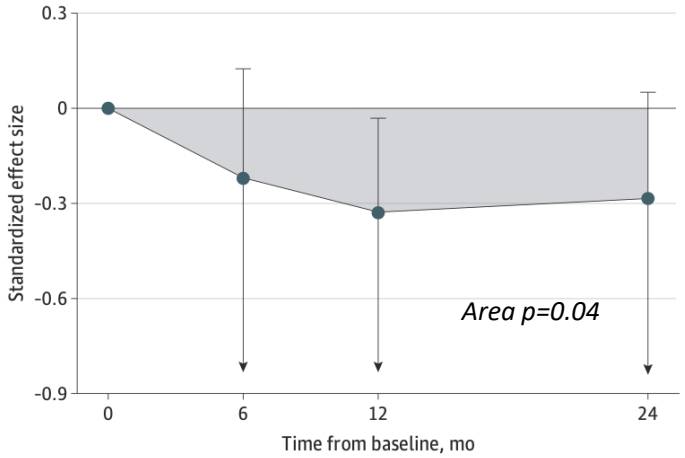
Parent *and teacher* outcome ratings support the blinded findings

Comparative effects on long-term outcome symptom severity across development and samples



Green et al (JCPP 2017). iBASIS N=54 – selective sampling from 9 months, FU to 3 years

(ABC Effect size 0.32, 95% CI 0.04, 0.60)

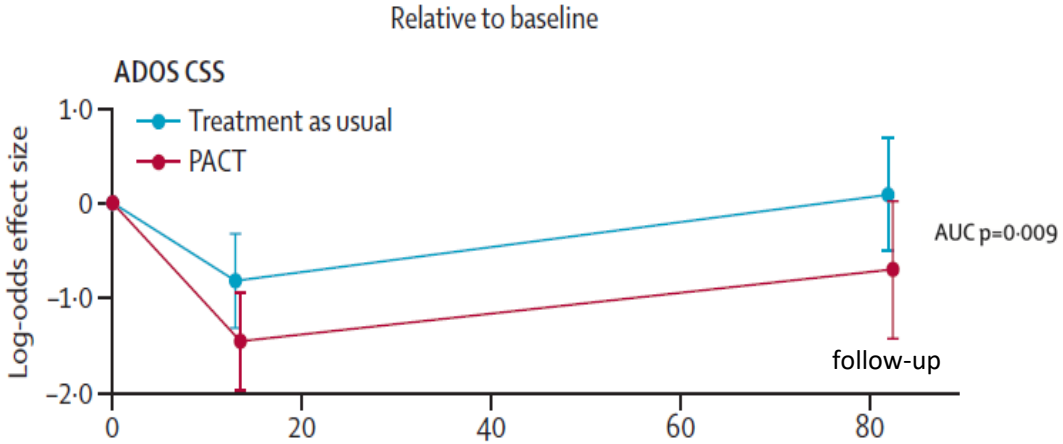


Whitehouse et al (JAMA-P 2021). iBASIS N=103 – indicated sampling from 12 months, FU to 3 years

(ABC Effect size 5.53, 95% CI, −□ , 0.28)

Pickles et al (Lancet 2016). PACT N=152 – post diagnosis pre-school, FU to 10.5 yrs

(ABC Effect size 0.55, 95%CI 0.14, 0.91)



Mechanism in PACT

(Aldred et al 2012/Pickles et al 2016/Carruthers et al 2023)

Therapy increases parent synchronous response

Strong (70%) mediation

Increased child communication initiations in dyad

Very strong (97%) mediation

73% mediation

Reduced autistic behaviours (ADOS) with researcher

Endpoint

3/6 yr follow up

Reduced autistic behaviours (ADOS) with researcher

Follow up

Near significant improvement in T VABS

Follow up

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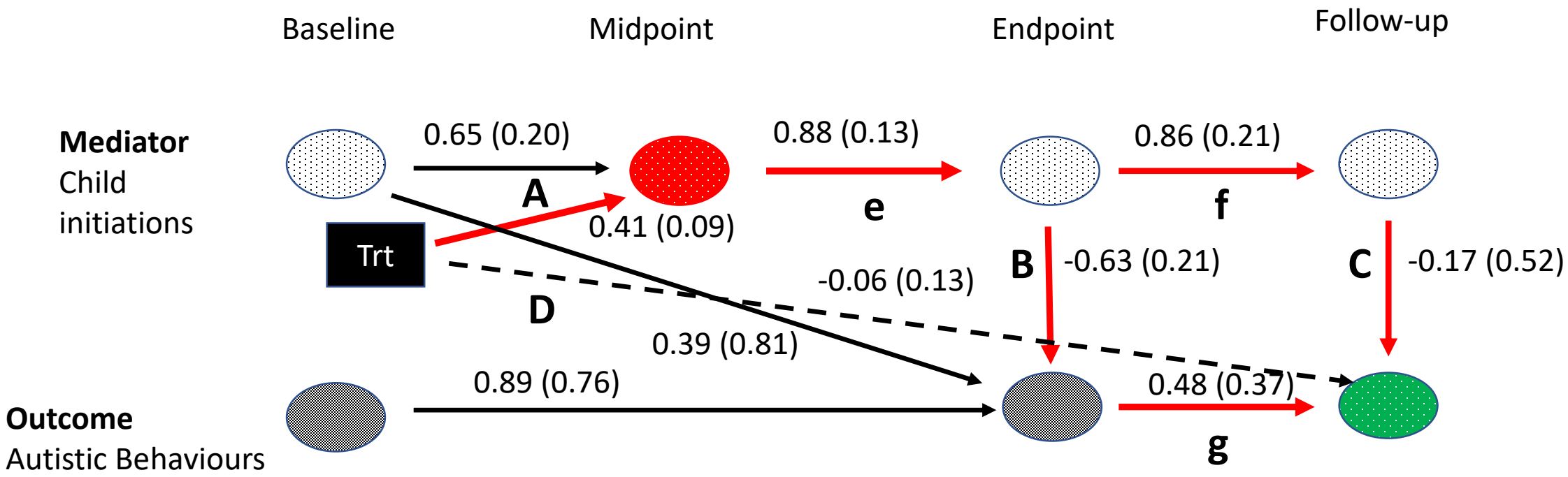
Endpoint and FU CSS outcomes strongly mediated by the therapy change in child dyadic social initiations (DCMA)



Total Mediated Effect via Midpoint Child Initiations: A*e*(B*g+f*C)= -0.16, CI -.42, -0.05

73% Mediation through Midpoint Child Initiations, 27% direct effect via path D

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Mediation results show the salience of child social initiation/motivation in autistic development argues against primary social impairment

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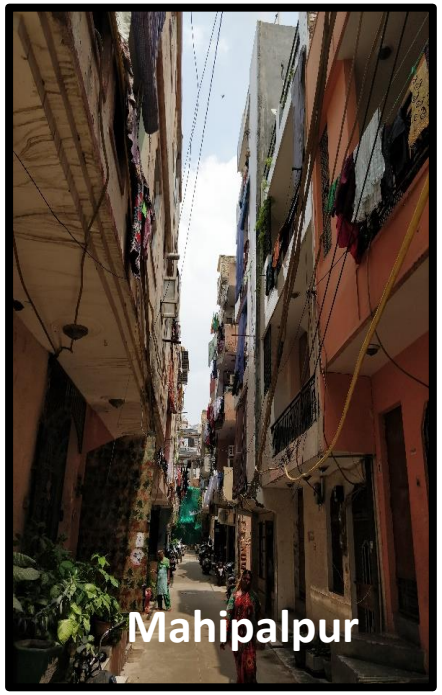
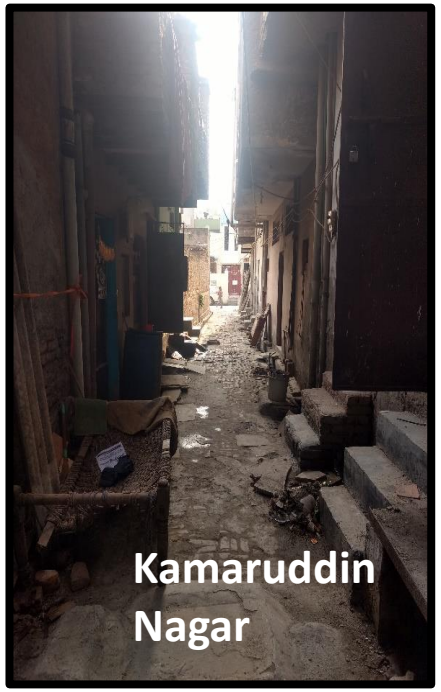
Follow up

Mechanistic understanding allows flexible modular adaptations and innovation

What can produce the same mechanistic change?

Adaptation for non-specialist delivery in South Asia





Parent-mediated intervention for autism spectrum disorders in South Asia (PASS)

Institute of Psychiatry, Rawalpindi, Pakistan
Fareed Minhas
Ayesha Minhas
Zafar Iqbal

Sangath, Goa, India
Vikram Patel
Gauri Divan
Vivek Vajaratkar

University of Manchester
Jonathan Green
Catherine Aldred
Carol Taylor
Kathy Leadbitter

University of Liverpool
Atif Rahman

AUTISM SPEAKS
It's time to listen.

Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial

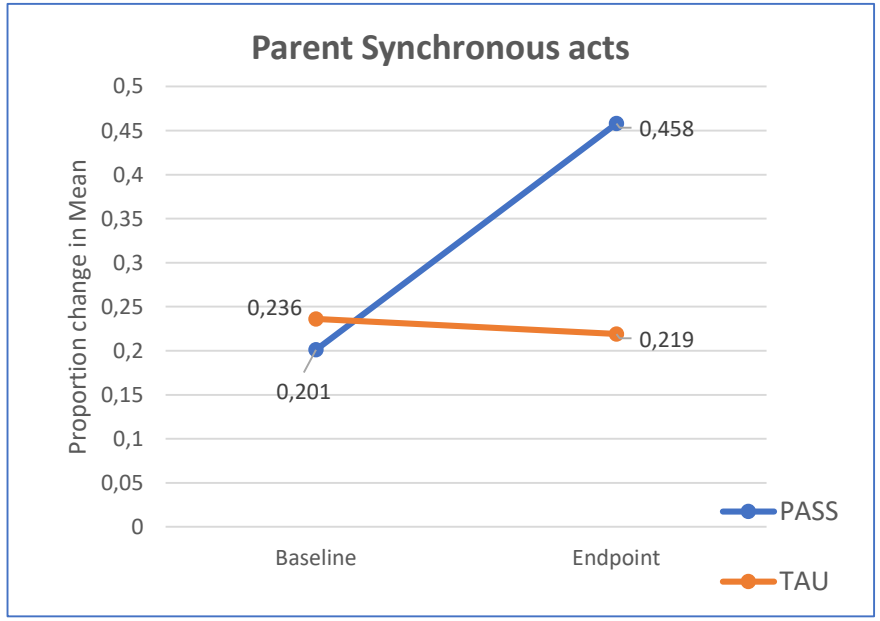
Atif Rahman, Gauri Divan, Syed Usman Hamdani, Vivek Vajaratkar, Carol Taylor, Kathy Leadbitter, Catherine Aldred, Ayesha Minhas, Percy Cardozo, Richard Emsley, Vikram Patel, Jonathan Green**

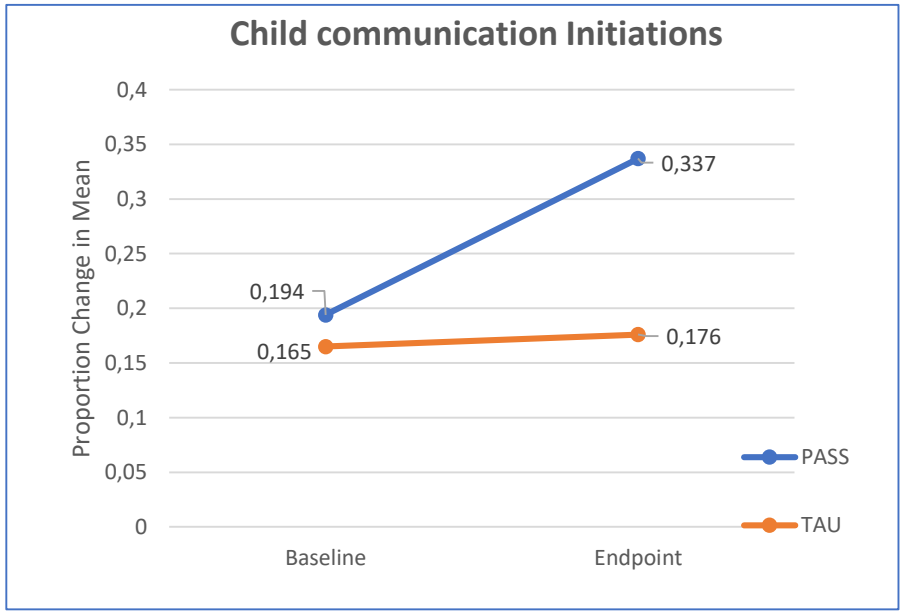
Lancet Psychiatry 2016;
3: 128–36

- n=65; two site two arm RCT
- PASS vs TAU
- Graduate level counsellors with no previous training in child development

First definitive RCT of a systematically adapted evidence-based intervention delivered through the process of task sharing by non-specialists in a LMIC setting

PASS trial primary outcomes





TAU= Treatment as Usual

Rahman A et al, Lancet Psychiatry 2016

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(Aldred et al 2012/Pickles et al 2016/Carruthers et al 2023)

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Follow up

Mechanistic understanding allows flexible modular adaptations and innovation

What can produce the same mechanistic change?

Modular intervention: PASS to PASS+

2 Years Global Mental Health-Seed Grant

Grand Challenges Canada®
Grands Défis Canada
BOLD IDEAS WITH BIG IMPACT®

Low awareness, especially in rural communities leading to delayed recognition and lost opportunities for early interventions

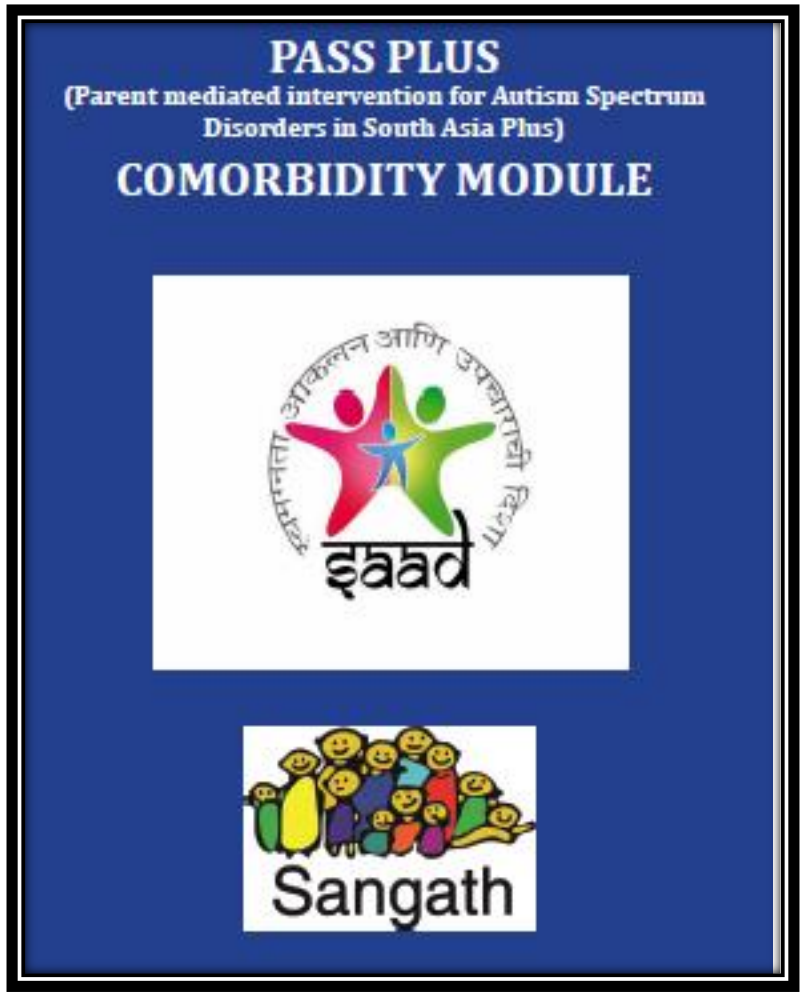
- Detection package

Co-morbidities impede delivery of the communication intervention

- Intervention package

MANCHESTER 1824
The University of Manchester

PLUS Modules



- Administered after Session 4 of the PASS communication intervention
- Each module follows an algorithmic approach to identifying the nature of the problem or difficulty

Co-morbidites addressed

- Module A : Exploring comorbidities- the nature of the problem, the intensity, the frequency and the impact
- Module B: Sensory Module
- Module C: Behavioural Module
- Module D: Feeding Module
- Module E: Toileting Module
- Module F: Sleep Module
- Module G: Parental Wellbeing

Administration of Plus modules

Gives simple psychoeducation on the possible reason for the problem

Gives strategies to address them

Helping parents understand

- The nature of the problem by keeping charts
- Supporting information on
  - Visual schedules
  - Rewards
  - Social stories

COMPASS

Communication-centred Parent-mediated treatment for Autism Spectrum Disorder in South Asia (COMPASS)

Scale-up trial in New Delhi

N=240 children 2 to 9 years with ASD

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The University of Manchester

Sangath

KING'S College LONDON

HARVARD MEDICAL SCHOOL
DEPARTMENT OF Global Health and Social Medicine

UKaid from the British people

MRC Medical Research Council

NHS National Institute for Health Research

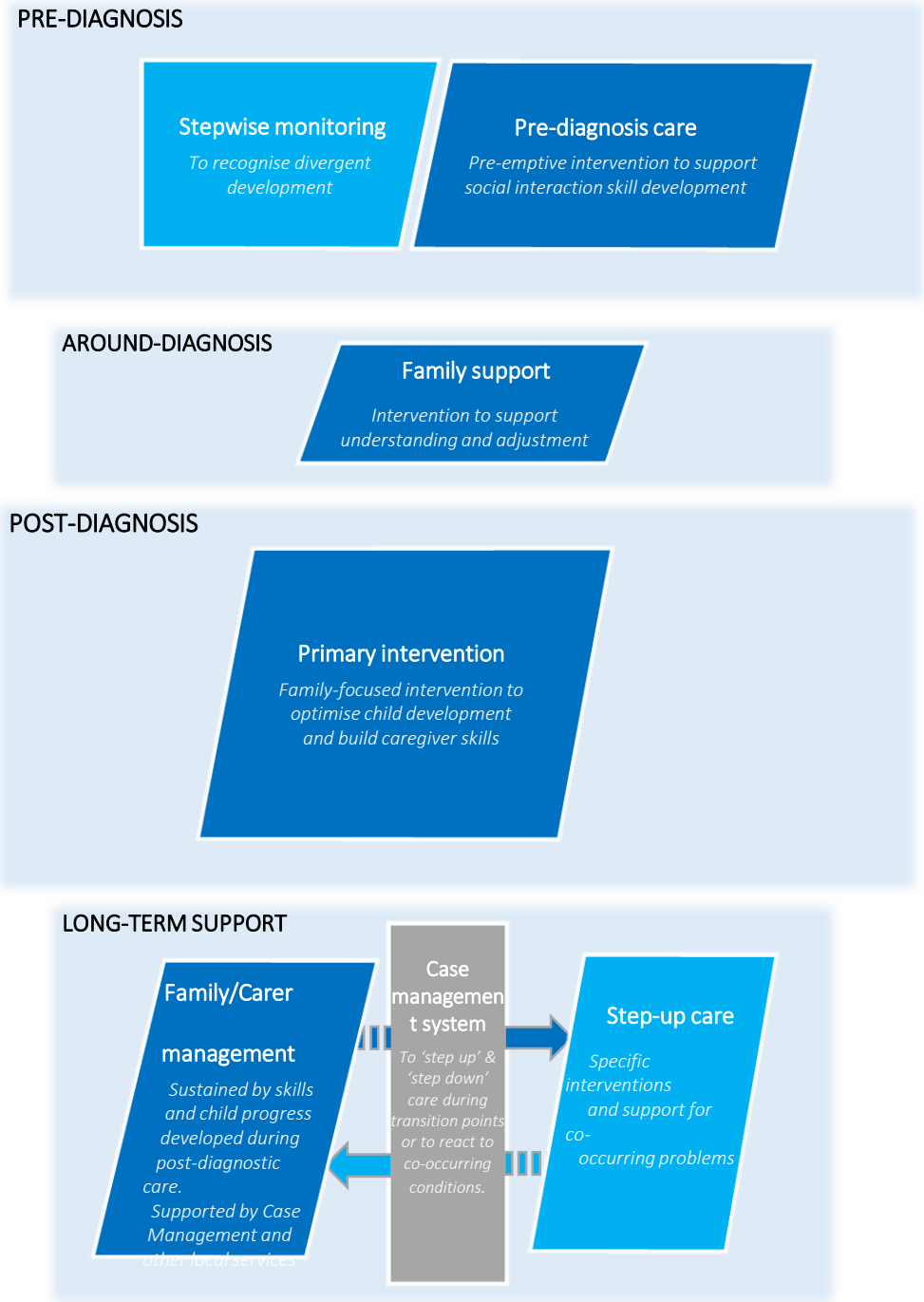
wellcome

Embedding early intervention in a model focused on autism as a developmental enduring condition

Green Editorial Perspective, Delivering autism intervention through development JCPP Oct 2019

An integrated early care pathway

Green et al. Lancet Child and Adolescent Health, March 2022



Based on an ideal early identification pre-school

Can be adapted for later emergence and identification

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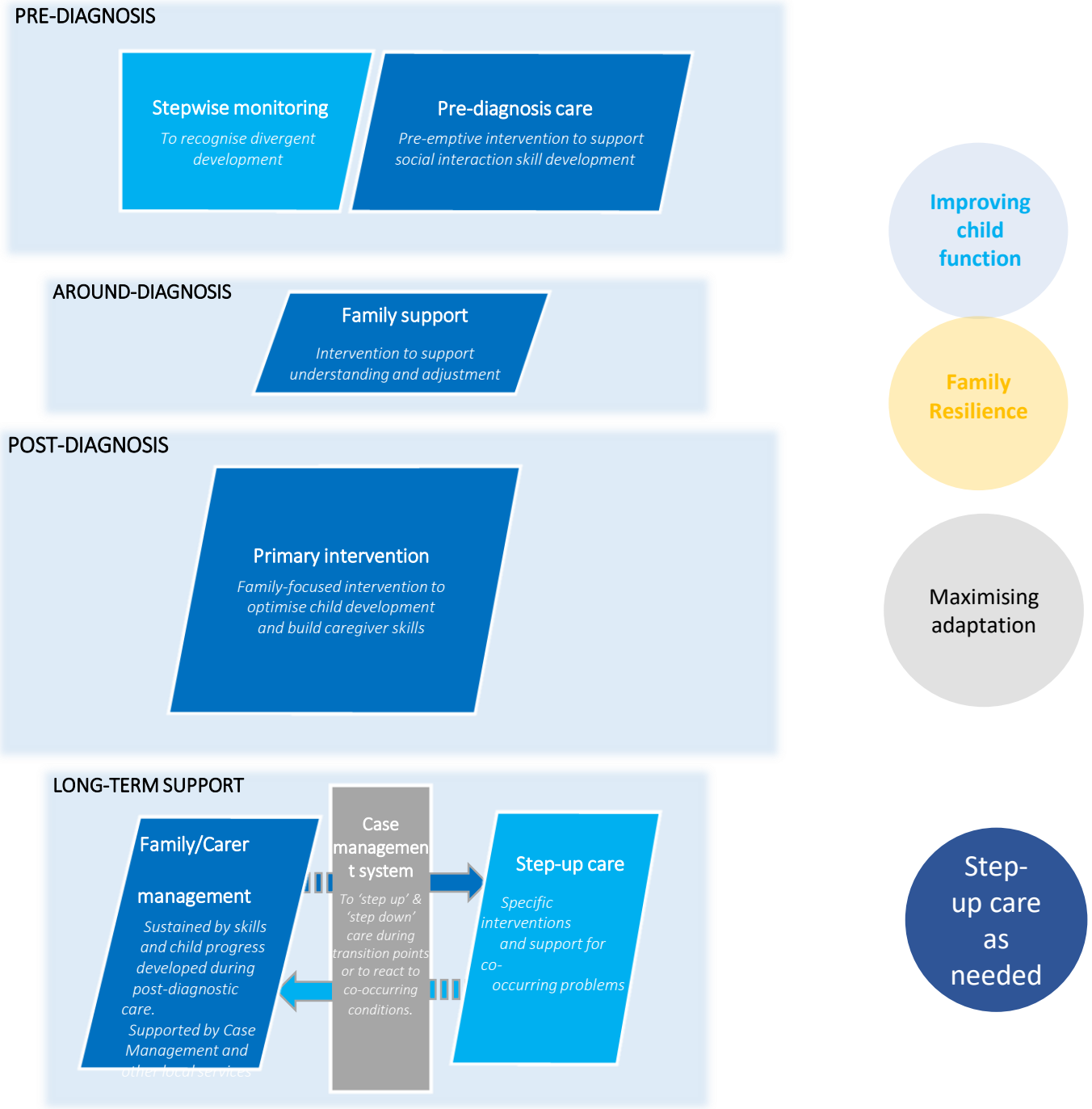
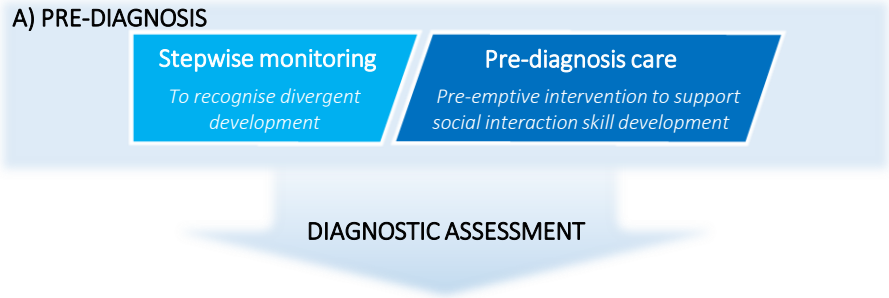


Pre-diagnosis

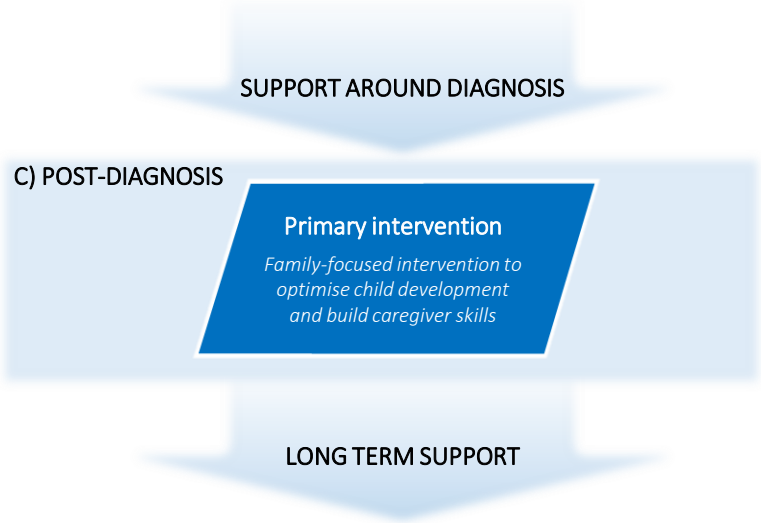


- Tackling the diagnostic bottleneck

- ***Surveillance instruments evidenced to pick up early likelihood or concern***
  - Within the HV/Community Child Health infrastructure
  - ***Social Attention and Communication Surveillance (SACS) – plus ASDetect****….*
    - PPV for autism >80%; remaining are other Developmental Conditions

- ***Triage to personalized evidenced support for early child social development***
  - ***5 month, video-aided intervention with parents (iBASIS-VIPP)*** improves subsequent symptom development, reduces 3 year diagnosis (Green et al 2017, Whitehouse et al 2021)
  - Conversations with stakeholders on implications
  - Other supports for complimentary indications: eg ***More than Words, Language therapy, Portage***

Post-Diagnosis Primary Intervention



- Family-focused developmental interventions to provide….
- ***Strengths-based sustained support*** for child social development and mitigation of negative impacts from sensory issues and repetitive behaviours
- ***Skilling and empowering parents and families*** – enhancing family 'self-care' and resilience long-term
  - Parent-mediated social communication interventions have the best evidence (NICE 2013/21)
  - ***PACT pre-school*** shows sustained effects into middle childhood. ***JASPER.***

- *Training available and pilot schemes active*
- *Issue of workforce skilling and availability*

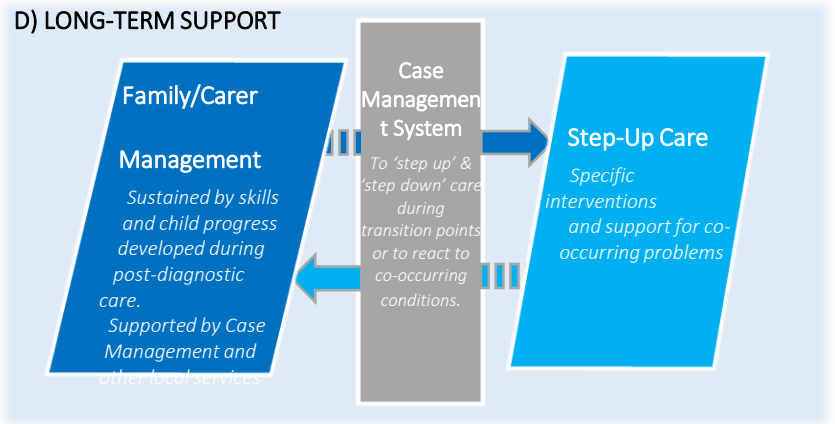
Longer term support

Key working and continuity in the context of family resilience

Co-occurring conditions arise consequent on autistic vulnerability

Step-up, step-down ***specialist care***

- Formulation of difficulties
- *Environmental modification*
  - Social and educational policy
- *Specific treatments for co-occurring conditions*
  - eg Anxiety, Depression, ADHD, OCD, behavioural challenges
  - We need more research on specificity of these for autistic children and YP
- Delivery by autism-specialist teams



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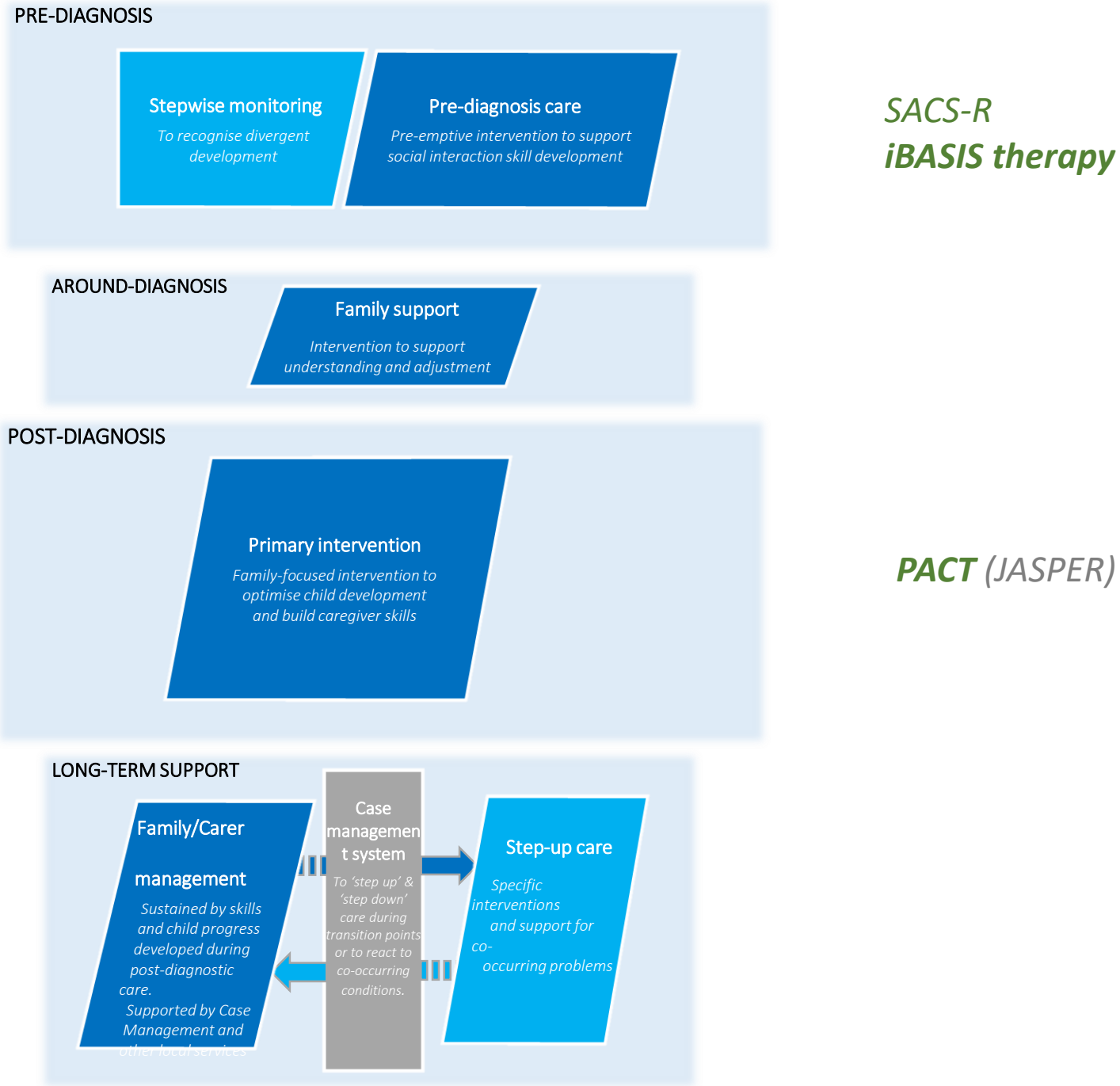

SACS-R

iBASIS therapy

PACT *(JASPER)*

Pilot implementation in UK 2022

Integrating PACT with other treatments

- iBASIS/PACT as a foundational early developmental intervention
  - Increases family understanding and resilience

- Pre-school PACT reduces mid-childhood anxiety (trend) *(Pickles et al Lancet 2016)*
- Combined multimodel home/school PACT (PACT-G) decreases later behavioural difficulties *(Green et al Lancet Psychiatry 2023)*

- In any event it is a foundation for additive medication and behaviour-targeted interventions if needed…
  - Improved alliance and compliance
  - Improved parental wellbeing and confidence *(Leadbitter et al JADD 2017)*

Health system provision to make such a model possible

Integrated detection and response

Online registration, family inclusion, symptom monitoring, case management

Specialist step-up services within integrated autism teams in an area

Intervention in the British Autism Study of Infant Siblings (iBASIS)

The University of Manchester

Jonathan Green, Ming Wai Wan, Samina Holsgrove, Janet McNally, Clare Harrop, Carol Taylor, Hannah Venton-Platz, Ami Brooks

Birkbeck UNIVERSITY OF LONDON

Mark Johnson, Mayada Elsabbagh, Emily Jones, Teea Gliga, Helen Maris, Helen Ribeiro, Kim Davies, Jeanne Guiraud, Janice Fernandes, Leslie Tucker

Guy's and St Thomas' NHS
NHS Foundation Trust

Vicky Slonims, Rhonda Booth

KING'S College LONDON

Andrew Pickles, Tony Charman, Greg Pasco, Rachael Bedford

Funding:

autiɂtica
Science in the Service of Autism

AUTISM SPEAKS
It's time to listen.

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Background funding…

MRC Medical Research Council

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

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MANCHESTER 1824
The University of Manchester

Guy's and St Thomas' NHS
NHS Foundation Trust

KING'S College LONDON

Newcastle University

DH Department of Health

MRC Medical Research Council

department for children, schools and families

Thank you!

More information (papers, videos, blogs, interviews, media):
Search **‘iBASIS’ or ‘PACT 7-11’ Manchester**

Training in PACT: **info@pacttraining.co.uk**

Training in iBASIS - from this spring
jonathan.green@manchester.ac.uk

autistica

AUTISM SPEAKS
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E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

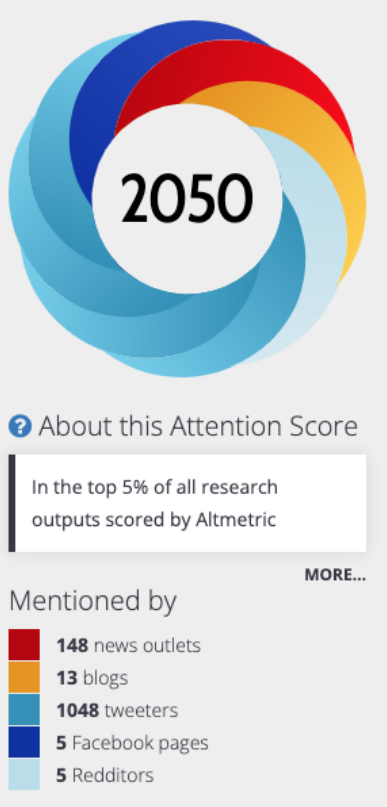
MRC Medical Research Council

NHS National Institute for Health Research

Central Manchester University Hospitals NHS
NHS Foundation Trust

MANCHESTER BIOMEDICAL RESEARCH CENTRE

Communication and dialogue with the autistic community



Support for early neurodivergence not ‘eradication’

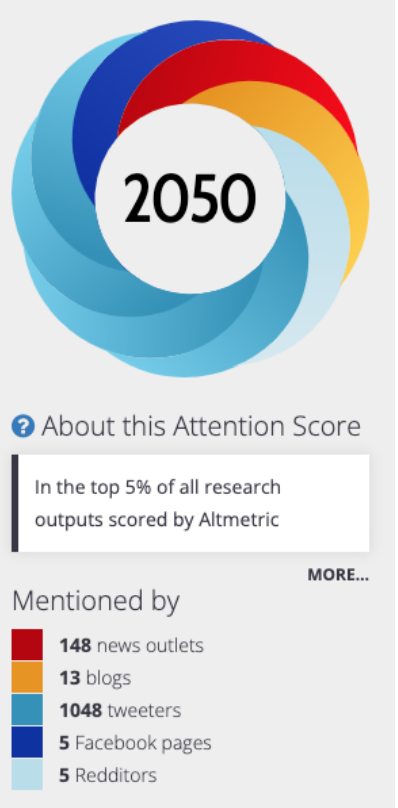
The ADOS/Phenotype paradox
- do improvements in ADOS after intervention challenge the very idea of autism?

Improvements relate to:

- ***improved interaction, social functioning, decreased stress and arousal, improved RRB and sensory sensitivity***

- **What then is the ‘core’ of the phenotype?**

Communication and dialogue with the autistic community



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Green, J 2022, 'Autism as emergent and transactional', *Frontiers in Psychiatry*. https://doi.org/10.3389/fpsyt.2022.988755

The 'Neurodiversity' context

- Neurodiversity as individual difference, not pathology
- The nature of autism and clinical autism
- The nature and ethics of early in intervention in this context….

Theoretical base

- *Atypical communication in autism*
  - Reduced shared attention and mutuality
  - Child communicative signals weak or infrequent
- *Imbalanced Parent-Child interaction*
  - Parent perplexity
  - Reduced 'meshing' - 'asynchrony'
  - 'Fill in the gaps' or withdraw
  - Increase adult initiations/non-reciprocal interactions
  - Reduced child opportunities for communication learning, relating
- *But positively* –
  - Attending to communication acts increases them
  - Expansion from child's base ('semantic contingency') increases communication
  - Children with autism need a high dose of this
- *Developmental hierarchy -* of pre-cursor skills for communication