iBASIS and PACT
Towards an evidenced, integrated early care pathway for autism

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‘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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  - *Support needs to reflect this*

- **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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• **Social valency and autonomy** are key to autistic flourishing in communities
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• **Current clinical response**
  • Generally reactive, poorly evidenced, episodic and late in development.....
‘Proven and sustained support from day one’

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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
Dyadic transaction

‘Attunement’
‘Goodness of fit’

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

The social environment around the child

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

Neurodivergent Development and early communication differences
Parent-infant interaction

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

5 MACI scales of interest

- Nondirectiveness
- Sensitive responsiveness
- Mutuality
- Attentiveness to parent
- Affect

Distinguishes HL from TD at 7 & 14 mos

Primary outcome

At 13 months, predicts ASD at 3 years
Caregiver-infant transaction in early development

Caregiver dyadic response

The social environment around the child

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

Less ‘Attunement’
‘Goodness of fit’

Neurodivergent Development and early communication differences

Less positive outcomes in social communication development, psychological development (relatedness, trust, social motivation, mental health, well being)
What is specific about parent-mediated intervention?

• 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
Therapy increases parent synchronous response

Increased child communication initiations in dyad

Improved autistic behaviours with researcher in ADOS Endpoint

3/6 yr follow up

Improved autistic behaviours with researcher in ADOS Follow up

PACT/iBASIS logic model
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

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

3/6 yr follow up

Improved autistic behaviours with researcher in ADOS Follow up

3 RCT with preserved ITT

PACT/iBASIS logic model - evidence
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
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

Parent dyadic response

Child dyadic response

Child AOSI/ADOS symptom change over time

No difference in clinical best estimate outcomes (small N)
N=103 babies from 12 months identified with community concerns and assessed on SACS
5 month intervention
3 year FU to diagnosis

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

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

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

Replication of AOSI/ADOS symptom change against TAU over time
Communication and dialogue with the autistic community

- Support for early neurodivergence not ‘eradication’
- The ADOS/Phenotype paradox
- The core nature of the neurodivergent phenotype
- Improvements in ADOS after intervention
Preschool Autism Communication Therapy (PACT)

- 6-12 month programme
- Developmentally staged from early communication pre-curators
- Targeting parental awareness and accurate response to child communication signals
- **Video-feedback** to produce the intervention effect
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
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 Leadbetter, Kristelle Hoddy, 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 Leadbetter, Erica Selmanova, Rachel Coli-Fletcher, Hannah Tobin, Isabel Gimenez, Jessica Leary, George Vamvakas, Sarah Byford, Catherine Aldred, Vicky Slonims, Helen McConachie, Patricia Howlin, Jeremy R Pinn, Tony Charman, Jonathan Green

The Lancet (2016); 388: 2501-2509
Effect of Therapy on Targeted Parent Behaviour

Treatment trial period: baseline to endpoint
Followed from endpoint to follow-up

Parent acts: proportion synchronous

Cohen's d effect size

Time since start of therapy (months)

Better

Baseline | Mid-trial | Endpoint | Follow-up

Months from therapy start

PACT group

Treatment as usual group
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, 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)
Therapy increases parent synchronous response

Strong mediation

Increased child communication initiations in dyad

Very strong mediation

Improved autistic behaviours with researcher in ADOS Endpoint

Mediation (unpublished)

3/6 yr follow up

Improved autistic behaviours with researcher in ADOS Follow up

Mechanism of the PACT results
Pickles et al 2016/Carruthers et al
Therapy increases parent synchronous response → Increased child communication initiations in dyad

Very strong mediation

Improved autistic behaviours with researcher in ADOS Endpoint

3/6 yr follow up

Mechanism of the PACT results
Pickles et al 2016/Carruthers et al

Mediation results show the salience of child social initiation/motivation in autistic development argues against primary social impairment
Health system innovation - Integrated care pathway
An integrated early care pathway

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

**PRE-DIAGNOSIS**

- **Stepwise monitoring**
  - To recognise divergent development
- **Pre-diagnosis care**
  - Pre-emptive intervention to support social interaction skill development

**AROUND-DIAGNOSIS**

- **Family support**
  - Intervention to support understanding and adjustment

**POST-DIAGNOSIS**

- **Primary intervention**
  - Family-focused intervention to optimise child development and build caregiver skills

**LONG-TERM SUPPORT**

- **Family/Carer management**
  - Sustained by skills and child progress developed during post-diagnostic care
  - Supported by Case Management and other local services
- **Case management**
  - To ‘step up’ and ‘step down’ care during transition points or to react to co-occurring conditions
- **Step-up care**
  - Specific interventions and support for co-occurring problems

Based on an ideal early identification pre-school
Can be adapted for later emergence and identification
A developmentally-phased pathway young autistic children

A) PRE-DIAGNOSIS

Pre-diagnosis care
- Pre-emptive intervention to support social interaction skill development

Stepwise monitoring
- To recognise divergent development

B) AROUND-DIAGNOSIS

Family support
- Intervention to support understanding and adjustment

C) POST-DIAGNOSIS

Primary intervention
- Family-focused intervention to optimise child development and build caregiver skills

D) LONG-TERM SUPPORT

Family/Carer management
- Sustained by skills and child progress developed during post-diagnostic care. Supported by Case Management and other local services

Case management system
- To ‘step up’ & ‘step down’ care during transition points or to react to co-occurring conditions

Step-up care
- Specific interventions and support for co-occurring problems

Family Resilience

Improving child function

Maximising adaption

Step up care as needed
An integrated early care pathway

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

Pilot implementation in UK 2022

SACS-R

iBASIS therapy

PACT (JASPER)

Based on an ideal early identification pre-school

Can be adapted for later emergence and identification
Mediation results show the salience of child social initiation/motivation in autistic development argues against primary social impairment
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
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
Pathway Implementation in routine care

**NHSE innovation funding** - S Manchester and Cambridgeshire/Peterborough

**Detection**
- Cross agency; health visitors/nursery nurses/paediatric nurses – SACS-R
- Triage to:

**Intervention**
- iBASIS/PACT for autism or HL autism
- Speech and Language Therapy, Portage for other neurodisability conditions

**Evaluation**
- Real-time clinical casenote based

**Policy development** *(CAPE funding with NHSE)*
- Evaluation evidence
- Stakeholder group co-construction
- Evidence policy document
Intervention in the British Autism Study of Infant Siblings (iBASIS)

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

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

Vicky Slonims, Rhonda Booth

Andrew Pickles, Tony Charman, Greg Pasco, Rachael Bedford

Funding:

Background funding…
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Guy’s and St Thomas’ NHS Foundation Trust

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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 autumn
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