The evidence base for interventions for children with autism spectrum disorders

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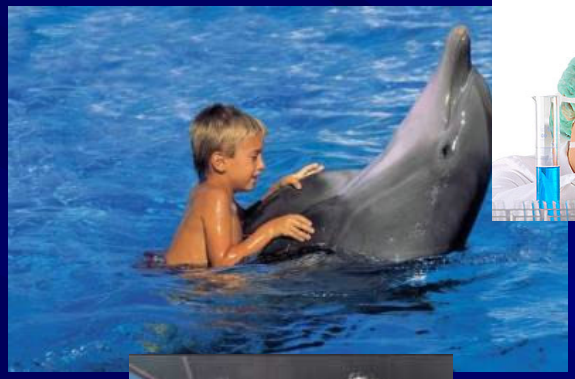
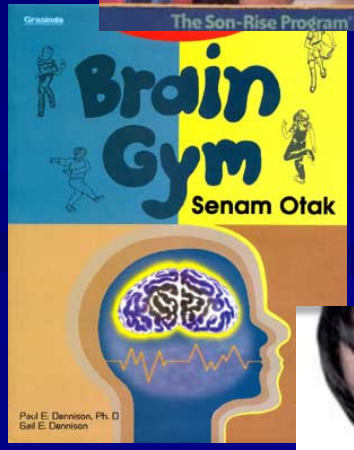
Negotiating the maze!





Web-based survey of ~500 parents (Goin-Kochel, 2007)

- ABA 47%
- AIT 18%
- Early intervention 69%
- Floor time 27%
- Music therapy 27%
- Neurofeedback 3%
- Occupational Th. 75%
- Options 4%
- PECS 48%
- Physical therapy 31%
- Positive behav. 49%
- Sensory integration 53%
- Social skills 51%
- Social stories 41%
- Speech therapy 84%
- TEACCH 18%

% reporting significant improvements

- ABA 37%
- AIT 16%
- Early inter. 24%
- Floor time 23%
- Music therapy 22%
- Neurofeedbk 13%
- Occup. Th. 24%
- Options 14%
- PECS 28%
- Physical ther. 25%
- Posit. behav. 27%
- Sens. Integ.29%
- Social skills 28%
- Social stories 25%
- Speech ther. 32%
- TEACCH 25%

% reporting no change/worsening

- ABA 20%
- AIT 37%
- Early inter. 28%
- Floor time 30%
- Music therapy 35%
- Neurofeedbk 34%
- Occup. Th. 25%
- Options 24%
- PECS 25%
- Physical ther. 26%
- Posit. behav. 26%
- Sens. Integ.25%
- Social skills 24%
- Social stories 28%
- Speech ther. 28%
- TEACCH 36%

Survey of 185 teachers in Georgia (Hess et al., 2008) most used- least evidence!

- Sensory integration (93%)
- Gentle teaching (49%)
- Music therapy (45%)
- Cognitive behav. mod. (33%)
- Art therapy (29%)
- Floor Time (29%)
- Social stories (29%)
- Social decision making (24%)
- Assistive technology (22%)
- Integrated movement therapy (19%)
- Visual schedules (15%)
- Structured teaching (14%)
- PECS (12%)
- Discrete trial (10%)
- Verbal behaviour (10%)
- RDI (10%)
- Holding (8%)
- “LEAP” (8%)
- *Facilitated communication (7%)*
- AAC (5%)
- AIT (4%)
- Power cards (4%)
- Pivotal response training (3%)
- Pet therapy(3%)

RESEARCH AUTISM

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www.researchautism.net

>100 common interventions (Acupuncture to Yoga).

Data evaluated by international panel of experts

Many interventions in common use have no evidence (for or against) or evidence is mixed

"*The Son-Rise Program®* , a powerful, effective and totally unique treatment for children and adults challenged by Autism, Autism Spectrum Disorders, Pervasive Developmental Disorder Asperger's Syndrome & other developmental difficulties"

Some evidence on what ***NOT*** to use

- Auditory integration therapy (listening to tapes of filtered sound)
- Chelation
- Cell therapy
- Dolphin therapy
- Facilitated Communication
- Immune globulin
- Patterning
- Secretin
- Testosterone regulation

Much less information on what does work

Among most widely evaluated:

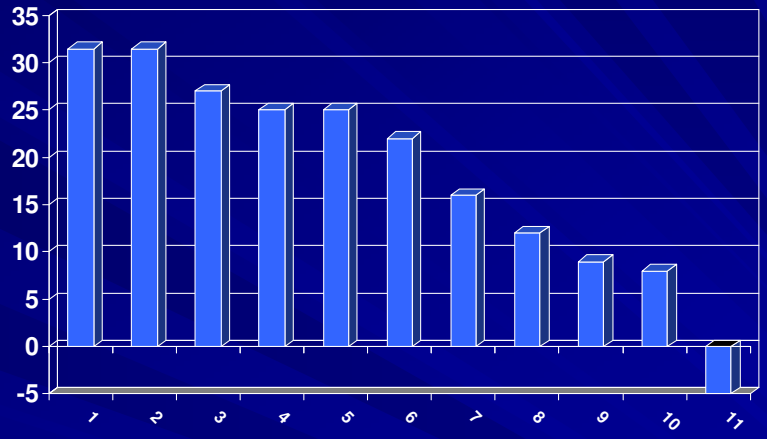
- Early Intensive Behavioral Intervention (EIBI)
- *(Duration 2+ years, from 2-4 years of age; 40+ hours per week)*
- Significant increases in IQ (up to 30 points)
- Around 40% of cases: “indistinguishable from normal peers”
- Replication studies also positive though less change in ritualistic and other behaviours

Recent reviews of EIBI:

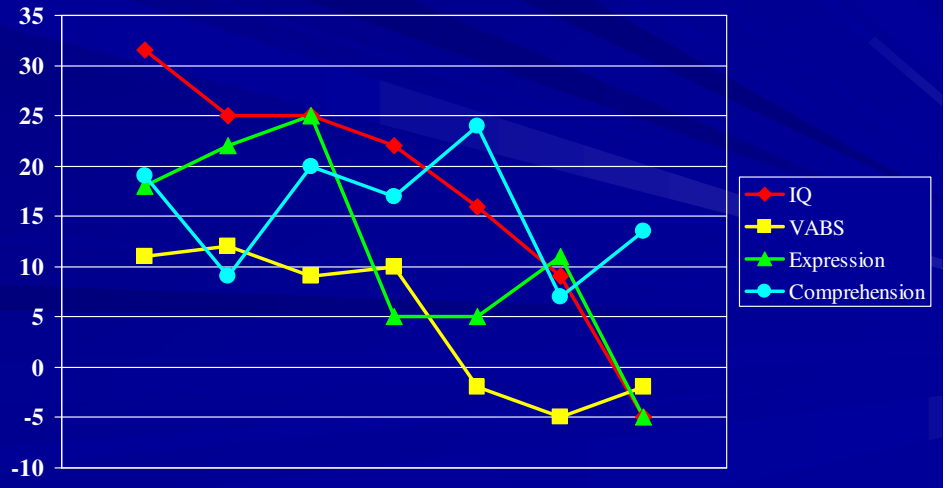
- EIBI groups *mostly* superior outcome to non-EIBI
- Effect sizes moderate to large in most (though range from .3 to >.80)
- *Generally* significant change in IQ but range from no increase to >30 points)
- Impact on specific areas of functioning inconsistent : some reviews = effect size> for language and daily living skills (effect sizes 1.5)
- Others= main effect on IQ

Outcome in 11 intensive ABA programmes 1987-2007: Howlin et al, 2009 (AJMR)

- Variability in IQ changes



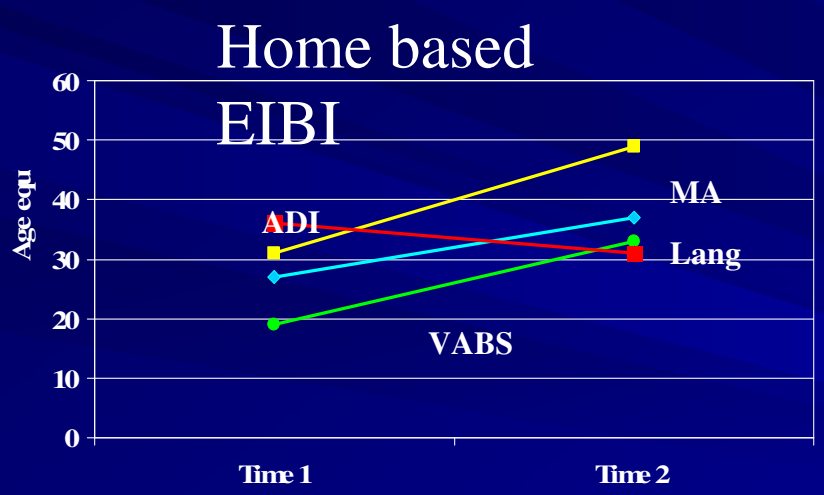
- Variability in Vineland & language scores

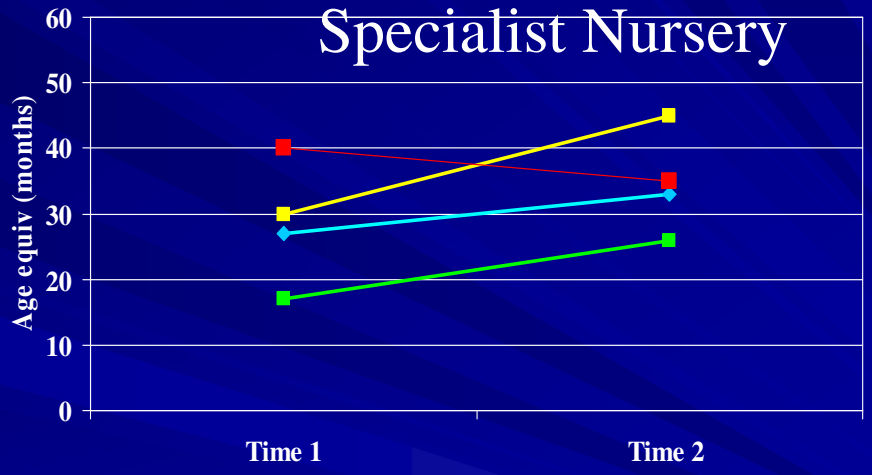


Also:

- ? “Exhaustion of treatment effect over time” ? - Greatest degree of change in first 12 months
- No evidence of long-term impact
- Few studies used specialist, high quality comparison treatment.
- No studies demonstrating that EIBI superior to other specific intervention
  - Or that one type of EIBI (duration/intensity/style) superior to another

Group changes following 2 year EIBI or nursery programme





No significant group differences controlling for IQ at intake; No children unsupported in mainstream school

At later follow-up (8-9 yrs) no advantages for EIBI group

Recent reviews conclude:

- "EIBI can be an effective intervention for some children… however the intervention has not worked for all
- In all studies some participants made no progress or regressed.
- EIBI is not an intervention that fits the needs of all children with autism"
  - Reichow & Wolery, 2009
  - (cf also, Virués Ortega, 2010; Eikeseth et al., 2009; Howlin et al., 2009; Ospina et al., 2008; Ma, 2009; Rogers & Vismara, 2007; Spreckley & Boyd, 2008; Smith et al., 2008).

Predictors of EIBI success (none very reliable Perry et al., 2011)

IQ	Initial IQ most powerful predictor
Age	Some indication that younger =more progress, but most studies < 6yrs
Adaptive behaviour	> Vineland composite scores
Language	> Receptive language
Autism severity	Some studies= better progress in less severe; others =>severe
Length/ intensity	Data inconsistent (though most response in first year)
Family stress	Low
Social & other skills	???

Note:

- EIBI is NOT the same as ABA
- Applied behaviour analysis is a general approach to behaviour assessment and intervention that can be applied at all ages and for almost all behaviours.
- All EIBI involves ABA
- All ABA does not necessarily involve EIBI

Growing number of other programmes with a strong evidence base

(Randomised control trials)

Parent training in behavioural management
(Jocelyn et al.1998; Tonge et al. 2006)

- Participants :Pre school children & adolescents

- Outcomes:
  - Parents: Significant improvements in mental health; knowledge of autism; perception of control
  - Children: gains in language; some behavioural improvement

Early Start Denver model:
(Dawson, Rogers et al., 2010)

- Home based, comprehensive, developmental/ behavioural/ relationship focussed intervention
- Participants 48 2-3 yr olds over 2 years
- IQ: ↑ 17 points; controls 7 points
- Language: ↑ 19 points; controls 12 points

  VABS: Standard scores stable; controls ↓ 11 points

  Most change in first year.

  No significant change in ADOS or Repetitive behaviour scores

Parent-child interaction

- Programmes:
  - Joint attention and symbolic play (pre-schoolers already in EIBI; Kasari et al., 2005; 2008)
  - Responsive Education & Prelinguistic Milieu Training (RMPT) (focus on turn taking and joint attention. Yoder & Stone; 2006)
  - Pre School Autism Communication Trial (Green et al, 2010)

- Improvements in:
  - parent child interaction
  - language
  - turn taking; joint attention & initiation

  - No significant improvement in adaptive behaviours (Vineland); ritualistic behaviours or autism severity (ADOS); variable change in IQ

Picture Exchange Communication System (PECS)

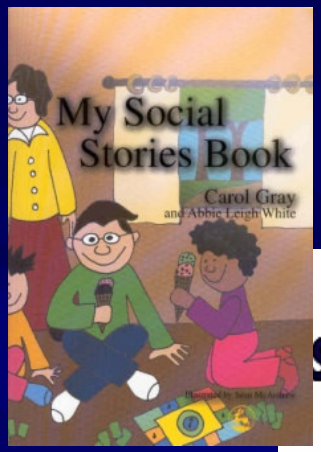
- Participants: pre-schoolers & junior school children (Yoder & Stone, 20006; Howlin et al., 2007

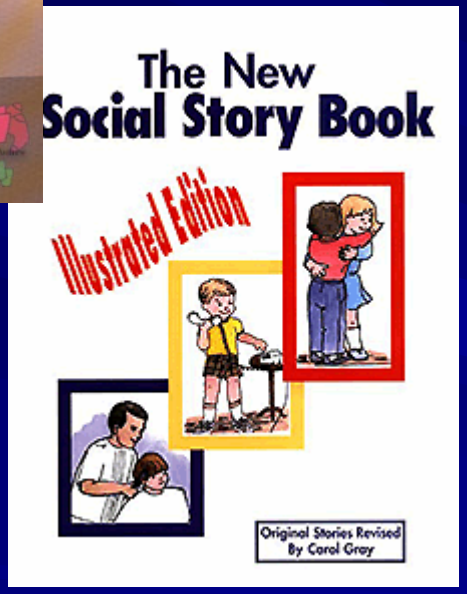
- Improvements in :
  - Requesting & initiations;
  - use of PECS & speech in classroom

- But:
  - No effect on other areas of communication
  - No changes in autism severity (ADOS) or formal language tests
  - Treatment effects not maintained when intervention ceased

Social strategies

Social stories

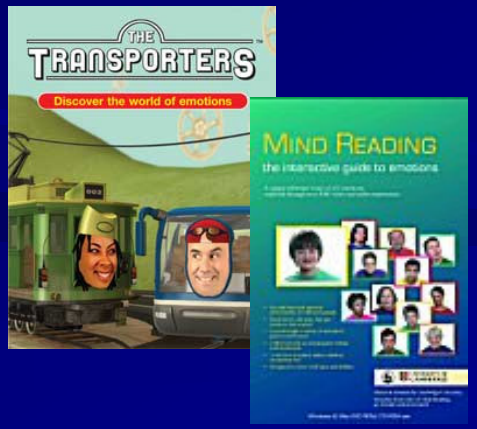


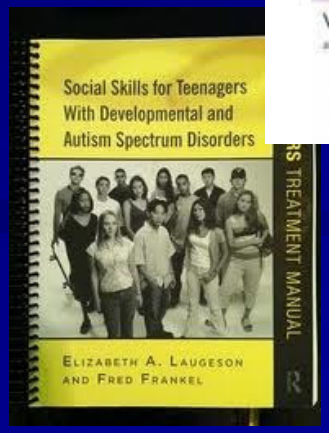


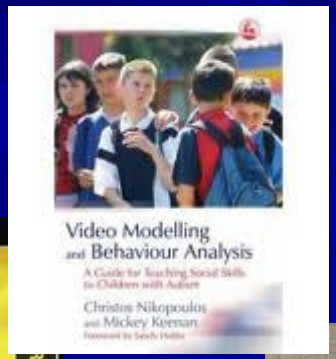
- ? More effective for improving behaviour than social skills; best when incorporated within class room settings (Kokina et al., 2010; Karkhaneh et al., 2010)
- ? More effective for children with at least borderline VIQ and better play skills (Quirmbach et al, 2009)

Other social strategies

- Theory of mind: Golan, Baron Cohen et al)
- Social skills groups (Lopata et al, 2010; Koenig et al.2010; de Rossier et al., 2011)
- UCLA PEERS project (Laugeson et al, 2009; 2010;)
- Video modelling



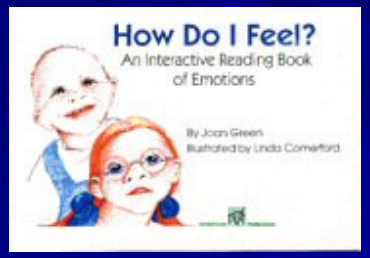


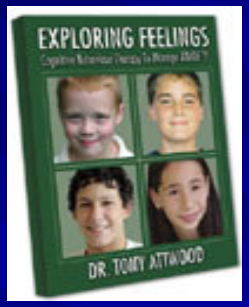


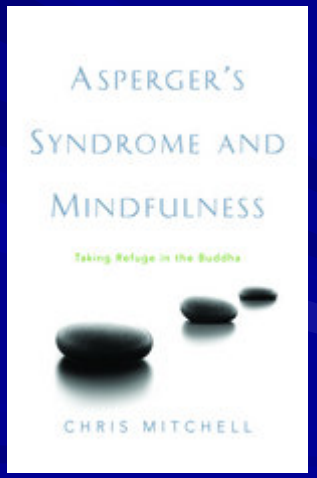
Results often situation specific; little evidence of generalization to other settings; training needs to be conducted in as many settings as possible
And from as early an age as possible.
Also need to teach sexually/culturally appropriate behaviours

Mindfulness :

Improvements tend to be teaching/situation specific; less evidence of wider generalisation or impact on real life (Begeer et al., 2011)
Positive self reports (Mitchell)



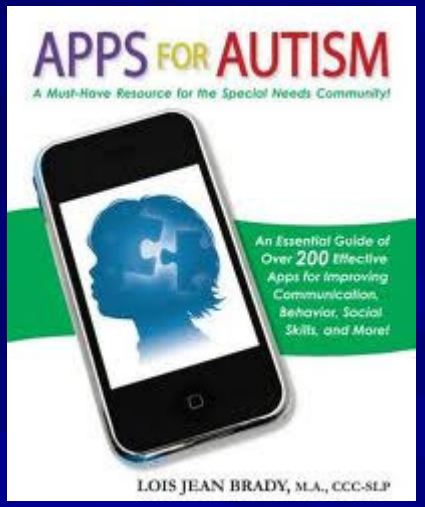




TEACCH

Significant gains reported in child behaviour, cognitive and adaptive skills, parent satisfaction; some generalisation to non-treatment settings (though comparative studies few & samples small) /

New technology …?



CBT

- Growing number of randomised control trials – mainly for anxiety; also anger management, social skills
- Beaumont & Sofronoff, 2008; Chalfant et al.2006, Reaven et al., 2009; Sofronoff et al. 2005; Sung et al., 2011; Wood et al., 2009
- Huge range of strategies/ group vs. individual interventions/ most involve parents
- (see Moree & Davis, 2010 for useful review; also Research Autism)

Limitations

- Short term follow-ups only
- Analogue, not real life measures
- Not clinically referred cases
- Huge range of intervention strategies in additional to “traditional” CBT
- What are the boundaries of CBT?

Crucial aspects of CBT

- Assessment
- Psycho education
- Cognitive restructuring (identifying & challenging negative thoughts, perceived threats, negative self evaluation)
- Exposure & practice
- How useful are these with ASD?

Successful research trials emphasise following modifications

- Need specifically to address ASD symptoms & the impact of these
  - May need to address social & communication problems, ritualistic & stereotyped behaviours/ thought patterns, additional behavioural problems BEFORE CBT for anxiety etc commences
- Also need to change environment ("bullying groups" not much point if bullying a continuing problem in school)

Also crucial:

- Involvement of families(& schools?)
  - For generalization, maintenance and reliable feedback on progress
  - Otherwise home work unlikely to happen (might try enlisting child to check that *parents* do homework)
  - To ensure attendance

Treatment dilemmas 1.

- Many treatments do work
- But they don’t work for all children
  - And larger trials often fail to replicate initial positive effects

Early mother child communication & synchrony

- Participants 156 2-4 year olds (Green et al., 2010)
- Outcomes:
  - Significant improvements in parent child interaction; parental reports of child language
  - No change in autism severity; adaptive behavior; school functioning or formal language assessments
  - Child effects less than in previous smaller trial (Aldred et al; 2004)

Parent training for toddlers

- Home based parent training programme (behavioural + joint attention+ communication vs TAU
  - (Oosterling et al., 2010)

- Participants 75 2-4 year olds
- Outcomes:
  - No group differences in language (primary outcome measure); GGI or engagement- improvements in both groups.
  - No improvement in parenting skills in either group.

  Lowest DQ associated with least improvement.

  Did not replicate findings of smaller trial by Drew et al., 2002

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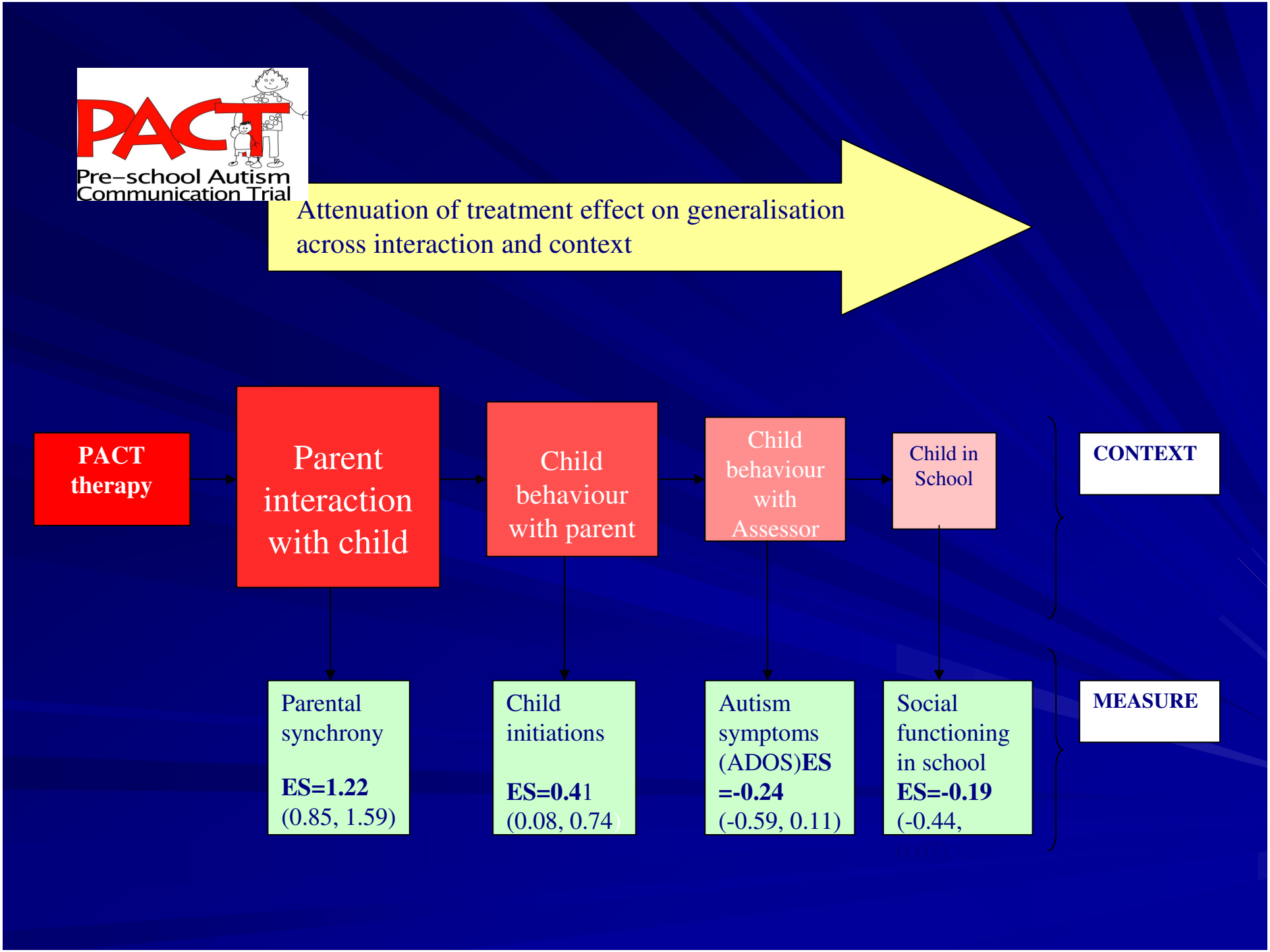
Treatment dilemmas 2.

- Many treatments do work
- But they don't work across all behaviours:
  - What you teach is what you get!


PACT
Pre-school Autism Communication Trial
Attenuation of treatment effect on generalisation across interaction and context
PACT therapy
Parent interaction with child
Child behaviour with parent
Child behaviour with Assessor
Child in School
CONTEXT
Parental synchrony
ES=1.22
(0.85, 1.59)
Child initiations
ES=0.41
(0.08, 0.74)
Autism symptoms (ADOS)ES =-0.24
(-0.59, 0.11)
Social functioning in school
ES=-0.19
(-0.44,
MEASURE

Treatment dilemmas
3.

- Is it worthwhile in the longer term…..
- How long do the effects last?

How long do the effects last?

- Joint attention/play (Kasari et al., 2008): 6 weeks x 30 mins a day
  - Continued improvements in parent-child interaction &

  and language 6m and 12m later

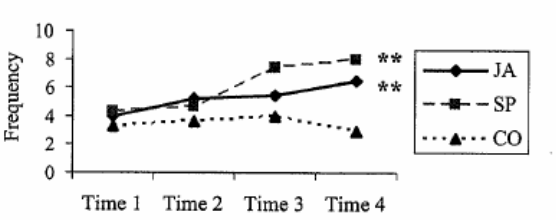


Figure 4. Growth in JA initiation skills in mother–child interaction and Early Social-Communication Scales. JA = joint attention; SP = symbolic play; CO = control group. **JA & SP > CO, $F(2, 164) = 5.35$, $p < .01$.

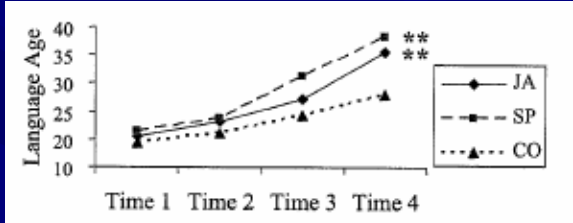


Figure 2. Growth in expressive language, measured in months. JA = joint attention; SP = symbolic play; CO = control group. **JA & SP > CO, $F(2, 164) = 6.84$, $p < .01$.

- PECS/ RPMT (Yoder & Stone, 2006): 6 months of 20 mins 3 times x week
  - PECS training: improvements in speech at 6m; RPMT improvements at 6 & 12 months.
- PECS (Gordon et al., 2011)
  - Improvement in spontaneous initiation persisted after 9 months, no change in requesting
- Later outcomes??????

Treatment dilemmas
4
Avoiding risk of harm

- Financial costs
- Family costs
- Time costs
- Time wasted
- Emotional costs (hopes dashed, expectations unmet)

Treatment dilemmas
5.

- How can we make the right treatment choices?
  - Which child characteristics
  - Interacting with which treatment characteristics
  - Lead to better outcomes
  - On which dimensions
  -
- No treatments work equally well for all children-

Autism: highly heterogeneous

Genetics	Familial inheritance	Spontaneous mutation
Intelligence	Severe impairment	Superior IQ
Language	No speech, severe receptive impariments	Excellent vocab. Abstract difficulties
Motor skills	Extreme clumsiness	Good coordination
Social	Extreme withdrawal	Indiscriminate contacts
Special skills	None	Outstanding
Autism severity	Severe impairment in all domains	Moderate impairment in some/all domains

Problems also change with age

Hanen More than Words
(Carter et al., 2011)

- Home & group based parent training programme
  - 62 toddlers (15-25 months)
- No treatment effect on parental responsivity (primary measures) or child communication
- Children with higher rates of object exploration pre-treatment (ie higher functioning?) - made ***less*** progress than non-treatment group.

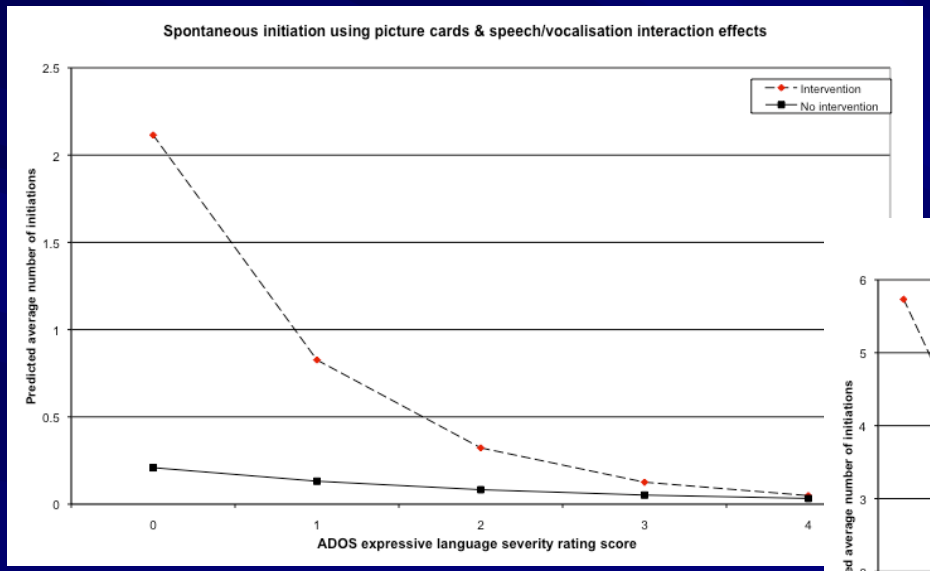
Other examples:

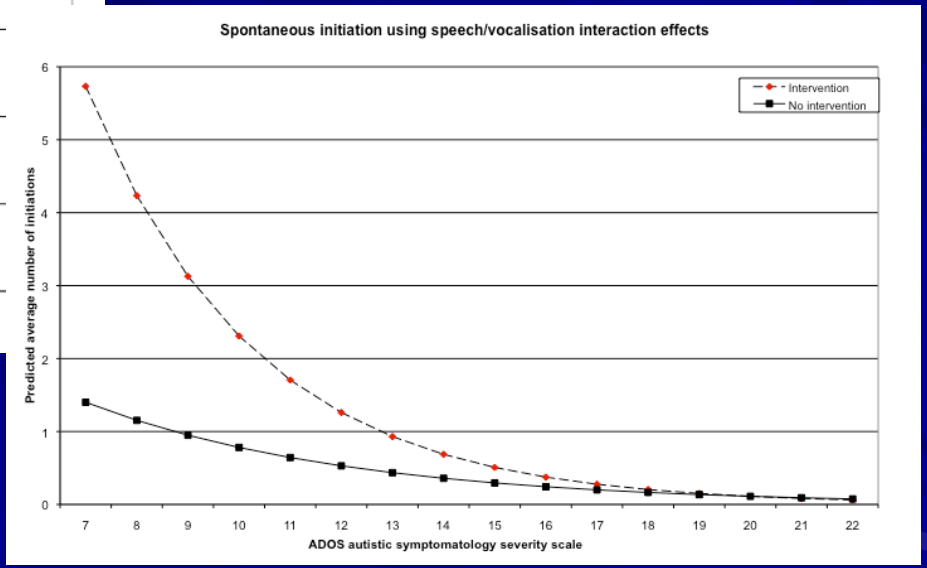
- Early behavioural programmes
  - > gains *for children* **with higher IQ, language and social initiations**
  - < gains if ***parental stress high-***(high intensity programmes no better than low intensity; Osborne et al, 2008)
- Social integration
  - > gains in children with ***low social avoidance*** (Ingersoll et al, 2001)
- Joint attention
  - > language gains *for* **lowest language level children** (Kasari et al., 2008)

Examples:

- Responsive Education & Prelinguistic Milieu Training.
  - > language gains in ***children who initially displayed little object exploration***
  - > turn taking & initiation of joint attention - But only in ***children who began treatment showing some joint attention*** (Yoder et al., 2006/7)
- PECS
  - > generalised requests, but ***only in children with very little initial joint attention*** pre-treatment. (Yoder et al 2006)
  - > improvement ***in children with less severe autism symptoms and > expressive language*** *pre-treatment.* (Gordon et al., 2011)

Effect of PECS X autism severity/initial language on spontaneous communication (Gordon et al., 2011)





> Initial language= greatest improvement

< ADOS severity language= greatest improvement

Other individual factors related to outcome?

- Symptom severity: findings inconsistent
- Age at start of treatment: little controlled research
- Personality?? temperament??.
- Other family characteristics (racial, cultural, intellectual, social, financial, genetic)???

Severity and nature of the condition

- Varies from child to child and over time
- Inconceivable that any single treatm
  individuals and across the whole ag
- Need to tailor the technique (s) to su
  the child to the techniques! –
  - i.e. need personalized targets for indivic
    evidence based psychosocial interventi

One size does not fit all!

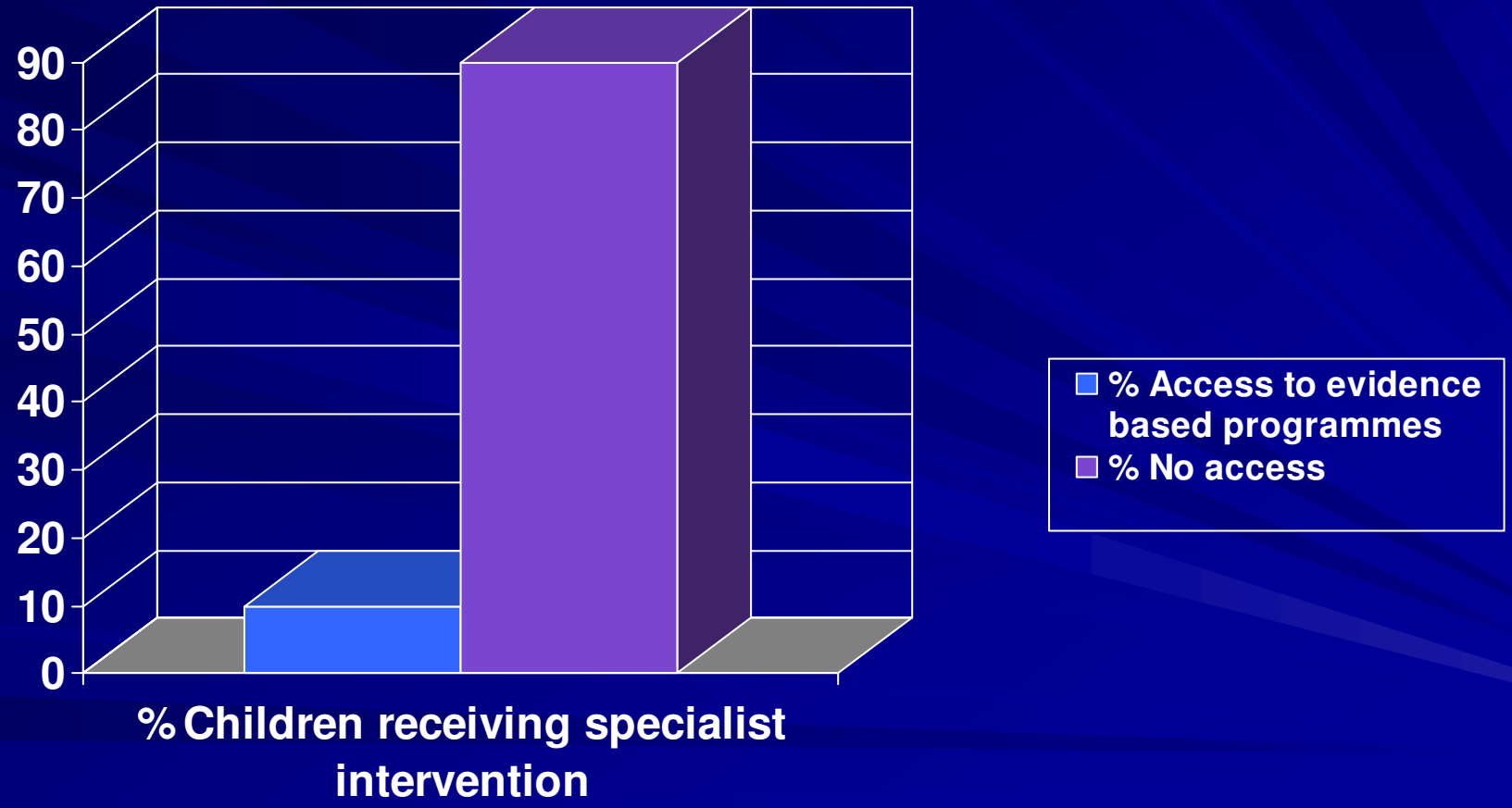
Different approaches helpful at different stages

- Early interventions may do best to focus on:
  - social communication
  - mother child interaction- parent-child synchrony/ joint attention
  - Object exploration; symbolic play
- Later:
  - Parent training in behaviour management
  - Direct behavioural therapy with child (though intensity and duration controversial)
  - Cognitive skills
  - Non-verbal communication (e.g. PECS) for those who have not developed language

Also need :

- More research into effective short term programmes
- Improved access for the many- not intensive interventions for the few

Most children have NO access to highly specialised programmes



Kanner 1973

- Hope that in following decades we would have answers to questions about successful intervention for autism
- But- ever more questions than answers

Conclusions

- Few therapies in common use have a strong evidence base – highest is moderate; most low-very low
- This does not mean they are ineffective- simply that there is insufficient evidence to support their use
- Even in the behavioural field- no one approach clearly superior to others
- Different approaches affect different areas of skill – but no systematic research
- Many more, large, well designed randomised control trials needed
- Also, need systematic comparisons between different treatments
- Individual child differences (including gender, race/ethnicity) largely ignored.

Conclusions: effective intervention necessitates-

- Close liaison between families and professionals
- Emphasis on skills, not weaknesses
- Modifying the environment/people within it often more effective than direct attempts to change the individual with ASD
- Avoid situations that trigger problems
- Improve others' awareness of the needs of someone with autism

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