The evidence base for interventions for children with autism spectrum disorders

BNPS conference, March 2012
Patricia Howlin
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%
- Neurofeedback 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!

<table>
<thead>
<tr>
<th>Method</th>
<th>Frequency</th>
</tr>
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<tbody>
<tr>
<td>Sensory integration</td>
<td>93%</td>
</tr>
<tr>
<td>Gentle teaching</td>
<td>49%</td>
</tr>
<tr>
<td>Music therapy</td>
<td>45%</td>
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<tr>
<td>Cognitive behav. mod.</td>
<td>33%</td>
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<tr>
<td>Art therapy</td>
<td>29%</td>
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<tr>
<td>Floor Time</td>
<td>29%</td>
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<tr>
<td>Social stories</td>
<td>29%</td>
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<tr>
<td>Social decision making</td>
<td>24%</td>
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<tr>
<td>Assistive technology</td>
<td>22%</td>
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<tr>
<td>Integrated movement therapy</td>
<td>19%</td>
</tr>
<tr>
<td>Visual schedules</td>
<td>15%</td>
</tr>
<tr>
<td>Structured teaching</td>
<td>14%</td>
</tr>
<tr>
<td>PECS</td>
<td>12%</td>
</tr>
<tr>
<td>Discrete trial</td>
<td>10%</td>
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<tr>
<td>Verbal behaviour</td>
<td>10%</td>
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<tr>
<td>RDI</td>
<td>10%</td>
</tr>
<tr>
<td>Holding</td>
<td>8%</td>
</tr>
<tr>
<td>“LEAP”</td>
<td>8%</td>
</tr>
<tr>
<td><em>Facilitated communication</em></td>
<td>7%</td>
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<tr>
<td>AAC</td>
<td>5%</td>
</tr>
<tr>
<td>AIT</td>
<td>4%</td>
</tr>
<tr>
<td>Power cards</td>
<td>4%</td>
</tr>
<tr>
<td>Pivotal response training</td>
<td>3%</td>
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<tr>
<td>Pet therapy</td>
<td>3%</td>
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</tbody>
</table>
>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

- 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

(Perry et al., 2011)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>IQ</td>
<td>Initial IQ most powerful predictor</td>
</tr>
<tr>
<td>Age</td>
<td>Some indication that younger = more progress, but most studies &lt; 6yrs</td>
</tr>
<tr>
<td>Adaptive behaviour</td>
<td>&gt; Vineland composite scores</td>
</tr>
<tr>
<td>Language</td>
<td>&gt; Receptive language</td>
</tr>
<tr>
<td>Autism severity</td>
<td>Some studies = better progress in less severe; others =&gt; severe</td>
</tr>
<tr>
<td>Length/ intensity</td>
<td>Data inconsistent (though most response in first year)</td>
</tr>
<tr>
<td>Family stress</td>
<td>Low</td>
</tr>
<tr>
<td>Social &amp; other skills</td>
<td>???</td>
</tr>
</tbody>
</table>
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 focused 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, 2006; Howlin et al., 2007)

- Improvements in:
  - Requesting & initiations;
  - use of PECS & speech in the 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 classroom 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)
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
Many treatments do work
But they don’t work across all behaviours:
– What you teach is what you get!
Attenuation of treatment effect on generalisation across interaction and context

**PACT therapy**

**Parent interaction with child**
- Parental synchrony
  - ES = 1.22 (0.85, 1.59)

**Child behaviour with parent**
- Child initiations
  - ES = 0.41 (0.08, 0.74)

**Child behaviour with Assessor**
- Autism symptoms (ADOS) ES = -0.24 (-0.59, 0.11)

**Child in School**
- Social functioning in school ES = -0.19 (-0.44, 0.07)
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

- 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)
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

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

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 treatment could suit all individuals and across the whole age span
- Need to tailor the technique (s) to suit the child, not fit the child to the techniques! —
  - i.e. need personalized targets for individual children within evidence based psychosocial interventions

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

% Children receiving specialist intervention

% Access to evidence based programmes
% No access
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
References

- Patterson et al. (2012) A systematic review of programs for parents of children with autism spectrum disorders Autism (on line early)