Developmental Surveillance for Autism in Infants and Toddlers within the MCH system: the Social Attention and Communication Study-Revised

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Autism Spectrum Disorder; DSM 5

Social interaction and communication deficits
Repetitive, stereotyped, sensory behaviours or interests

Why early detection/intervention is important

Early intervention
- Maximises developmental outcomes
- Brain plasticity; move towards more typical developmental trajectory

Parental and family stress
- Main factor associated with parental satisfaction is early detection/diagnosis
- Begin seeking services and access professional support earlier
- Better equipped to help their child before symptoms become unmanageable

Current research on early identification for Autism

- Indicates there are key early social-communication markers for Autism in infancy
  - Eye contact
  - Response to name
  - “Joint attention behaviours” (pointing, following gaze and point)
  - Gestures
  - Reciprocal smiling
  - Imitation
  - Pretend play
  - Showing
  - Sharing affect

La Trobe University

Prevalence

La Trobe University
Research on screening for Autism

- There is currently NO instrument sufficiently robust to recommend universal screening
- **Checklist for Autism in Toddlers** (CHAT; Baron-Cohen et al., 1992; 1996)
  - Misses over 60% of 18-month olds who develop Autism
- **M-CHAT** (Robins et al., 2001)
  - Accuracy of 1.5% to 11% in identifying Autism (Kleinman et al., 2008; Stenberg et al., 2014)

Research on screening for Autism cont...

Main issues identified (Barbaro & Dissanayake, 2009, JDBP):
- Measures all used at one time point in development
- Same tool used across ages
- Parental report (Barbaro, Mitchell, & Dissanayake, in preparation)
  1. Lack of parental concern does not imply typical development
  2. Lack of consistency in parental responses
  3. Lack of agreement between parental report and professional observations
The Social Attention and Communication Study (SACS)

Prospective Identification of Autism Spectrum Disorders in Infancy and Toddlerhood

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LGAs in original 2006-2008 SACS

Banyule         Yarra
Bayside         Monash
Boroondara      Moonee Valley
Glen Eira        Nillumbik
Hobsons Bay      Port Phillip
Knox            Stonnington
Maribyrnong      Whitehorse
Maroondah       Whittlesea
Melbourne

SACS 2006-2008 method

• 241 Maternal and Child Health (MCH) Nurses trained; 17 LGAs involved
• 3 hours duration, videos comparing Autism vs typical development
• 20,770 children monitored at 12, 18, 24 month routine consultations
• Children ‘at risk’ assessed by SACS team every 6-months until 24-months; followed up at 48 months
• Gold standard diagnostic and cognitive assessments used

PPV and Prevalence of ASDs in SACS 2006-08 cohort

• PPV = 81%
• Prevalence = .84
• 86% stability of Autism diagnoses from 2- to 4-years

Cognitive improvements of original SACS children

SACS-Revised (SACS-R)

• Revised based on results from original SACS to increase psychometric properties
• Replicated method with 2 major changes:
  1. Use of secure computer database (Salesforce) as a platform for data entry by MCH nurses
  2. Follow-up of ALL children monitored, not just those “at risk”
SACS-R Items at MCH Consultations

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Age at which behaviour monitored</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>12-months</td>
</tr>
<tr>
<td>Pointing</td>
<td>✓</td>
</tr>
<tr>
<td>Eye contact</td>
<td>✓</td>
</tr>
<tr>
<td>Response to name</td>
<td>✓</td>
</tr>
<tr>
<td>Showing</td>
<td>✓</td>
</tr>
<tr>
<td>Imitation</td>
<td>✓</td>
</tr>
<tr>
<td>Gestures (Waving)</td>
<td>✓</td>
</tr>
<tr>
<td>Pretend play</td>
<td>✓</td>
</tr>
<tr>
<td>Social smiling</td>
<td>✓</td>
</tr>
<tr>
<td>Joint attention – following point</td>
<td>✓</td>
</tr>
<tr>
<td>Use/understanding of language</td>
<td>✓</td>
</tr>
<tr>
<td>Loss of skills</td>
<td>✓</td>
</tr>
<tr>
<td>Parallel play</td>
<td>✓</td>
</tr>
<tr>
<td>Interest in peers</td>
<td>✓</td>
</tr>
</tbody>
</table>

RED ticks indicate “KEY” items

SACS-R Preliminary Results: PPV and estimated prevalence

Positive Predictive Value: 80.5%
Estimated Prevalence of Autism: 1.75% (1/57)

16108 monitored between 12-24 months
22 “at risk”
300 assessed
226 Autism (80.5% PPV)
66 Autism estimated
12 Autism “missed” – ID by 3.5 years
200 assessed
77 declined
14109 monitored between 12-24 months
292 “at risk”
147 Autism
1 in 57

SACS-R Method

- 125 MCH nurses trained on SACS-R
- 8 local councils in metropolitan Melbourne
  - Banyule
  - Boroondara
  - Bayside
  - Hume
  - Kingston
  - Knox
  - Moonee Valley
  - Nillumbik

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Discussion

- Developmental surveillance using SACS-R is most effective method for early identification of Autism to date
- SACS-R accuracy on par with original SACS (80.5% vs 81%)
- Very promising results for sensitivity
- Developmental surveillance ✓
  - Professional observations
  - Repeated observations
- Screening ❌
  - Parental questionnaires
  - One time point

Future Directions and Current Implementations

- All children monitored to 3.5 yrs (2017)
- Dissemination and Translations
  - VIC, TAS, QLD, NSW – Autism CRC
  - South Korea – 2011
  - Poland – 2011 ongoing
  - Japan – 2011 ongoing
  - Bangladesh – 2013
  - China – 2013-2020
- SACS items to be incorporated into new Victorian MCH online system (CDIS from DRA computing)
Conclusions

• SACS-R models a new approach for early identification of Autism
• US Preventative taskforce has withdrawn their support for universal screening due to lack of evidence – but this is based on current screening tools – this conclusion is therefore misleading
• The way in which we monitor young children for Autism needs to be changed – developmental surveillance not screening
• SACS-R can be used, modified, and disseminated in various contexts and healthcare systems around the world

Importance of early detection and intervention cannot be underestimated...

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