Ameliorating biopsychosocial risk
mothers with intellectual disability and their children

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April 9, 2014
I. Early observations…
   - A look back at two ‘game changing’ natural experiments

II. Intelligence and socioeconomic disadvantage...
   - Prevention of mild intellectual disability

III. Intelligence, social relationships and parenting capacity...
   - How can we account for the observed heterogeneity?

IV. Strengthening social relationships…
   - A promising start…
I. The early observations of Howard Skeels

“Diagnosis of mental ability: Mental deficiency of imbecile level, which will probably continue with an increase in age. Prognosis: Poor. With the deficiency in mental development [this child] will be unable to make her way outside the care and protection offered by an institution for feebleminded children”.
I. The early observations of Howard Skeels

A “rather fantastic” proposal

“transfer mentally retarded children from the orphanage nursery, one to two years of age, to an institution for the feebleminded in order to make them normal.”
I. The early observations of Howard Skeels

<table>
<thead>
<tr>
<th></th>
<th>Baseline Mean IQ</th>
<th>Post-test Mean IQ</th>
<th>Change in IQ +/-</th>
<th>Follow-up Mean IQ</th>
<th>Adopted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experimental group</td>
<td>64.3</td>
<td>91.8</td>
<td>+ 27.5</td>
<td>95.9</td>
<td>11/13</td>
</tr>
<tr>
<td>(n=13)</td>
<td></td>
<td></td>
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<tr>
<td>Contrast group</td>
<td>86.7</td>
<td>60.5</td>
<td>- 26.2</td>
<td>66.1</td>
<td>0/12</td>
</tr>
<tr>
<td>(n=12)</td>
<td></td>
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</table>

the 1922 Kuhlmann Revision of the Binet was used to obtain standard measures of intelligence.
A brief aside...

- On any given night, around one in five children residing in out-of-home care were taken from mothers with (mostly mild) intellectual disability.

- Contributing factors ...
  - A clustering of ‘risk’ factors
    - Mother maltreated as child, social isolation, mental health issues, etc
  - Systemic discrimination...
    - A lack of suitable support services (unequal opportunity)
    - The fundamental attribution error (and confirmation bias)
    - A generalised (false) assumption of irremediable deficiency
‘Risk’ factors for out-of-home placement

Figure 1. Risk and vulnerability factors in cases featuring mothers with and without intellectual disability

Figure 2. Relative odds of out-of-home placement for children of mothers with intellectual disability

† OR Adjusted for history of maltreatment in the mother’s own upbringing, maternal mental health issues, the use of drugs and/or alcohol, exposure to domestic violence and limited social support. * p < 0.05
I. The early observations of Howard Skeels

“… some one adult [one of the older girls] would become particularly attached to a given child and would figuratively adopt him. As a consequence there would develop an intense adult-child relationship [with the other girls on the ward acting as adoring aunties]. This meant that each child had some one person with whom he was identified and who was particularly interested in him and his achievements.”
I. The early observations of Howard Skeels

Twenty years on...

- The 13 now adult children from the experimental group had completed, on average, 12 years of formal education.
- Most were working in occupations such as nursing or teaching, or were operating small businesses.
- 11 of the 13 had married. Nine had children of their own. They had 28 children combined. *These 28 children had a mean IQ of 104. All had IQs in the normal range.*
I. The early observations of Rene Spitz

Four “conditions”

3. Nursery (institution for delinquent/feebleminded girls)
   “the mothers are mostly delinquent minors as a result of social maladjustment and feeblemindedness...”

4. Foundling home
   “[most of the children] come from socially well-adjusted, normal mothers whose only handicap is inability to support themselves and their children”
I. The early observations of Rene Spitz

The Nursery

“... is run by a head nurse and her three assistants – whose duties consist mainly in teaching the children’s mothers in child care, and in supervising them. The children are fed, nursed and cared for by their own mothers or, in those cases where a mother is separated from her child for any reason, by the mother of another child, or by a pregnant girl who in this way acquires the necessary experience for the care of her own future baby.”
I. The early observations of Rene Spitz

In the Foundling home

“...there was a head nurse and five assistants for a total of 45 babies. The nurses have the entire care of the children on their hands. ...These nurses are unusually motherly, baby-loving women; but of course the babies in the Foundling home nevertheless lack all human contact for most of the day... they were condemned to solitary confinement in their cots.”
I. The early observations of Rene Spitz

<table>
<thead>
<tr>
<th>Environment</th>
<th>Condition</th>
<th>Developmental quotients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>baseline</td>
</tr>
<tr>
<td>Parental home</td>
<td>Professional (n=23)</td>
<td>133</td>
</tr>
<tr>
<td></td>
<td>Peasant (n= 11)</td>
<td>107</td>
</tr>
<tr>
<td>Institution</td>
<td>“Nursery” (n=69)</td>
<td>101.5</td>
</tr>
<tr>
<td></td>
<td>Foundling home (n=61)</td>
<td>124</td>
</tr>
</tbody>
</table>

The Hetzer-Wolf baby tests were administered to obtain standard measures of infant development.
I. The early observations of Rene Spitz

In the Foundling home...

“Apart from the severe developmental retardation, the most striking single factor in Foundling home was the change in the pattern of the reaction to strangers in the last third of the first year. The usual behavior was replaced by something that could vary from extreme friendliness to any human partner combined with anxious avoidance of inanimate objects, to a generalised anxiety expressed in blood curdling screams which could go on indefinitely”.
I. The early observations of Rene Spitz

The problem in the Nursery...

“...was how to tame the healthy toddlers curiosity and enterprise. They climb up the bars of the cots after the manner of South Sea Islanders climbing palms... They vocalise freely and some of them actually speak a word or two. All of them understand the significance of simple social gestures. When released from their cots, all walk with support and a number walk without it.”
I. The early observations of Rene Spitz

The difference-maker...

“Nursery provides each child with a mother to the nth degree, a mother who gives the child everything a good mother does and, beyond that, everything else she has. Foundling home does not give the child a mother, nor even a substitute-mother, but only an eight of a nurse”.

See footnote...
I. The early observations of Rene Spitz

footnote…

“For the non–psychoanalytically oriented reader we note that this intense mother–child relationship is not equivalent to a relationship based on love of the child. ... The psychoanalytically oriented reader of course realises that for these girls in prison the child has become a hardly disguised phallic substitute…” [my bold].
I. Early observations suggest...

1. The inter-dependence of ‘the biological’ and ‘the social’
   “The individual neuron or single human brain does not exist in nature. Without mutually stimulating interactions, people and neurons wither and die” (Cozolini, 2006)

2. Children can thrive in the care of women/ mothers with ID: Mothers with ID are quite capable of being the warm and responsive ‘attachment figures’ that all children need.

3. With appropriate instruction and support, mothers with intellectual disability are capable of learning the skills they need to care for and supervise their children.
The evidence has accumulated...

- Over 400 empirical studies, visit www.healthystart.net.au
- “Healthy Start” is a national strategy to build capacity across human service sectors to support parents with intellectual disability and promote a healthy start to life for their children.
- For an overview of “Healthy Start”, see McConnell, Matthews, Llewellyn, Mildon & Hindmarsh (2008) and visit the website
- For a review of literature in the field, see IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008)
- For a review of parent training interventions for parents with intellectual disability, see Wade, Llewellyn & Matthews (2008)
II. Intelligence and socioeconomic disadvantage

“Intelligence is a very general mental capability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly and learn from experience... It is not merely book learning, a narrow academic skill, or test-taking smarts. Rather, it reflects a broader and deeper capability for comprehending our surroundings—“catching on”, “making sense” of things, or “figuring out” what to do.” (Gottfredson, 1997)
II. Heritability and socioeconomic status...

- The heritability of intelligence varies as a function of socioeconomic group.
- In socioeconomically advantaged families, most of the variation in child “IQ” is explained by biological inheritance.
- One interpretation:
  - *Children living in poverty are less likely to develop their full genetic potential.*
  - *There is a threshold (as opposed to a gradient) effect for environment on developing intelligence...*
II. The effect of adoption on Intelligence...

- Adopted children typically score 12-18 points higher than comparison children (e.g., siblings/peers who ‘stayed behind’ with their low SEP family) on measures of intelligence.
  - Selection effect? It is possible that (some) adopted children are selected for adoption because they are brighter or have better social skills than children not selected for adoption.
- Little or no difference is found between adopted children and their new ‘environmental siblings and peers’ on measures of intelligence, but differences are observed in language and school achievement.

  (Meta-analysis, Ijzendoorn, Juffer, Klein Poelhuis, 2005)
II. The Flynn effect

- Since the *industrial revolution*, large and persistent gains in ‘IQ’ have been observed from one generation to another.
  - If children in 1932 took the 1997 test, the mean IQ would be about 80. One-quarter would be ‘deficient’ – (Neisser)
  - When scored against 1982 norms, Dutch men in 1952 would have had a mean IQ of 79 – (Vroon)
  - In 1918, the mean IQ in the USA would have been 75 if scored against today’s norms – (Flynn)
- Many parents with intellectual disability today would demonstrate ‘normal’ intelligence if their performance was indexed to the norms of yesteryear.
II. Relationship between ID and socioeconomic status

- Children in families of lower socioeconomic position face increased risk of all forms of intellectual and developmental disability
  - However, low family SEP is more strongly associated with mild-moderate ID than it is with more severe forms of ID and PDD.
  - By comparison with high family SEP, low family SEP increases the odds of mild-moderate ID by a factor greater than four.
- Area-level (community) deprivation is associated with mild-moderate intellectual disability (but not more severe ID), even after controlling for household SEP (see Emerson, 2012)
II. Two discernible populations of persons with ID

- Population A: theoretical distribution of IQ among adults with genetic/neurological disorders
- Population B: theoretical distribution of IQ among adults with no apparent ‘disorders’
II. Prevention of mild-moderate intellectual disability

The “Swedish program for mental retardation” (1930-1980)

<table>
<thead>
<tr>
<th></th>
<th>Prevalence 1930</th>
<th>Prevalence 1980</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>1.88%</td>
<td>0.10%</td>
<td>-95%</td>
</tr>
<tr>
<td>Moderate</td>
<td>0.50%</td>
<td>0.14%</td>
<td>-72%</td>
</tr>
<tr>
<td>Severe</td>
<td>0.13%</td>
<td>0.17%</td>
<td>+28%</td>
</tr>
<tr>
<td>Total</td>
<td>2.5%</td>
<td>0.42%</td>
<td>-83%</td>
</tr>
</tbody>
</table>

- Dramatic decrease in the prevalence of mild-moderate ID, but not severe ID. Change associated with:
  - an equally dramatic decrease in the number of children living in poverty
  - improved maternal-infant health care
  - community-based ‘rehab’ programs for at-risk children (i.e., prevention/early intervention)
  - Note that the prevalence of ID among children in high income countries is approximately 3%. 

III. Parental intellectual disability & parenting role performance

- In high income countries parents with intellectual disability comprise a fairly homogenous group with respect to (1) “IQ”; (2) socioeconomic position; and, (3) culture (e.g., cultural models).
- Yet, with respect to parenting performance/competence, parents with intellectual disability comprise a heterogeneous group. The question is how can we account for this?
- Perhaps, if we can account for this heterogeneity – if we can understand why some struggle and others succeed – we can use this knowledge to design better systems of support.
III. A (somewhat simplistic) interactional model
III. cognitive-affective aspects of ‘parenting capacity’?

- Parenting IQ
  - Acquired parenting-related knowledge, skills
  - Reasoning, problem-solving, learning, planning

- Self-regulation
  - Modulating affect
  - ‘Noise’ filtering, focused attention

- ‘Mindsight’ (attunement)
  - Impulse control
  - Anticipation
  - Empathy

- Parenting capacity

Empathy
“Given our dependence on groups for our survival, primates have evolved elaborate neural networks for interacting with others as well as reading their minds and predicting their intentions” (Cozolino, 2006)
III. Limited social support and child functioning

- Feldman, McConnell & Aunos (2012)
- A sample of 1,170 children of parents with ID subject to child maltreatment investigations in Canada
- Selected findings...
  - Approximately one-half of the sample had no suspected or confirmed functioning issues (learning, developmental, behavioural).
  - Evidence consistent with a causal chain running from low maternal social support [social relationships], through maternal mental health issues [related to parenting capacity?], and in turn, alleged emotional maltreatment [parenting behaviours], to child emotional/behavioural issues [child functioning].
III. Happiness is a property of groups of people

- Framingham Heart Study
  - Fowler & Christakos, 2009
- Longitudinal social network analysis
- 4739 individuals followed from 1983 to 2003
  - People who are at the center of social networks tend to be happier
  - People who socially interact with happy people are more likely to become happy in the future
  - The spread of happiness seems to reach up to $3^0$ of separation. [Our happiness is connected to the happiness of our friend’s friend’s friends].
- Our emotional/affective states are regulated by our social interactions.
III. Social relationships and risk of mortality

- A meta-analytic review
  - 148 prospective studies (308,849 subjects)

- Aspects of social relationships
  - Structural aspects: number of social ties, membership in groups
  - Functional aspects: perceived availability, and received instrumental, emotional and informational support

- Main finding
  - Social integration exerts an independent influence on risk of mortality comparable with smoking cessation.

**Effect sizes: % reduction in mortality risk**
III. Disability, social integration and suicidal ideation

- McConnell, Hahn, Savage, Dube & Hyun (2014)
- Secondary analysis, Canadian Community Health Survey
- 19,740 adult respondents (Alberta & BC only)

**Table 3. Disability and Suicidal Ideation: Adjusted odds ratios**

<table>
<thead>
<tr>
<th>Dependent</th>
<th>Adjusted for age, sex, ethnicity</th>
<th>OR</th>
<th>95% CI</th>
<th>Adjusted for age, sex, ethnicity &amp; psych. morbidity&lt;sup&gt;*&lt;/sup&gt;</th>
<th>OR</th>
<th>95% CI</th>
<th>Adjusted for age, sex, ethnicity, psych. morbidity, marital status and social conditions&lt;sup&gt;†&lt;/sup&gt;</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifetime suicidal ideation</td>
<td></td>
<td>3.3</td>
<td>3.0 – 3.6</td>
<td>2.4</td>
<td>2.2</td>
<td>2.2 – 2.7</td>
<td>2.1</td>
<td>1.9</td>
<td>2.3</td>
</tr>
<tr>
<td>12-month suicidal ideation</td>
<td></td>
<td>6.2</td>
<td>5.0 – 7.7</td>
<td>3.5</td>
<td>2.8</td>
<td>2.2 – 4.4</td>
<td>2.8</td>
<td>2.2</td>
<td>3.5</td>
</tr>
</tbody>
</table>

<sup>*</sup> = diagnosed mood and/or anxiety disorder; <sup>†</sup> = food insecurity and community belonging
III. Potential mechanisms linking social relationships to parenting capacity

- The ‘stress-buffering’ hypothesis
- The ‘social exclusion (literally) hurts’ hypothesis
- The ‘psychological rewards’ hypothesis
- The ‘social regulation’ hypothesis
III. The stress-buffering hypothesis

*Put simply,*

1. Life events are stressful to the extent that people appraise the events as threats (primary appraisal), and perceive themselves as lacking adequate coping resources (secondary appraisal).

2. Social support is a ‘coping resource’, and when people have it they are less likely to perceive life events as threats, and they are more likely to have confidence in their ability to cope.
Human beings **physiologically** respond to social exclusion in much the same way as they respond to physical pain or danger.

When our physiological ‘threat-defense’ system is activated (and the limbic system is flooding the prefrontal cortex with “Danger Will Robertson, Danger”), our ability to modulate our emotions and control our impulses may be overwhelmed.

Chronic activation of the ‘threat-defence’ system (i.e., high levels of stress hormones) can have a long-term detrimental effect on immune system functioning, neural connectivity and behavior.
III. The ‘social regulation’ hypothesis

- Cultural transmission:
  - *via* social interactions we learn what is ‘normal’ or ‘respectable’ behavior (e.g., for a mother) *within our cultural community*, and this knowledge guides our (inter)actions.
  - “To the extent that individuals accept their social roles as self-defining (i.e., as identities), they obtain behavioural guidance from [sociocultural] role expectations” (Thoits, 2011)

- Social regulation:
  - The mere presence of others may ‘cue’ conformity with social norms. However social network members may directly intervene (monitoring, encouraging, persuading, reminding, or pressuring) to foster conformity (or non-conformity as the case may be).
III. The ‘psychological rewards’ hypothesis

- Sense of belonging and security
  - Belonging implies acceptance and inclusion by members of one’s social group, and with this comes the security that one’s needs will be met by the group.

- Identity, meaning and self-worth
  - Participation in socially valued roles, or simply put, ‘mattering to others’, gives life meaning and significance.

- Sense-of-control and mastery
  - Successful role performances, i.e., fulfilling role obligations, engender a general sense of control or mastery over life.
IV. Approaches to strengthening social relationships:

- Enhance existing social supports
  - e.g., “Circles of Support” (Willer, et al., 1993)
- Provision of compensatory support
  - e.g., support groups, volunteer home visiting,
- An adult-learning approach
  - E.g., Supported Learning Program (SLP)
IV. The supported learning program: (3) components
IV. The SLP: *not* just another parent training program

- A focus on empowerment: building critical awareness and confidence
- A problem-posing approach: reflection, action, and reflection-upon-action
- Person-centered and strengths-based
IV. The Supported Learning Program

- **Cycles of Critical reflection**
  - Increased confidence & awareness
  - Increased social integration

- **Problem-solving action**
  - Increased social support

- **Outcomes**
  - **Short-term**
    - Decreased depression, anxiety & stress
  - **Medium to long-term**
    - Increased positive mother-child interactions
IV. Three main devices for the group-work

The discussion object: the community mural

A three-step questioning strategy

A stepping-stones activity for action planning
IV. The community mural

Learning about opportunities and resources

• Over the course of approximately ten weeks, participants undertake a collaborative project, i.e., to map community assets/resources.
• Participants learn about community resources and gain experience working cooperatively together

A focus for reflection and dialogue

• Re-presents the community (places of interest or challenge) back to participants
• The mural is then used to facilitate personal and group reflection and discussion
IV. SLP pilot study findings

**Main findings**

- The measured effects of the SLP on social support and psychological wellbeing were greater than established benchmarks for parent training and family support programs.

- These findings were reinforced by a high level of personal and program goal-attainment: the participants were ‘getting out and about’, they were volunteering, enrolling in courses, joining other groups, and so on.

### Table 3: Effect of the ASLP on mother’s psychological wellbeing and social relationships

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-ASLP</th>
<th>Post-ASLP</th>
<th>Post-pre,</th>
<th>Cohen’s d</th>
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<tbody>
<tr>
<td>Mastery and constraints</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mastery</td>
<td>5.31 (1.20)</td>
<td>5.62 (1.03)</td>
<td>0.31 (1.22)</td>
<td>0.25</td>
</tr>
<tr>
<td>Constraints</td>
<td>4.64 (1.00)</td>
<td>4.36 (1.30)</td>
<td>-0.29 (1.40)</td>
<td>0.25</td>
</tr>
<tr>
<td>Depression, anxiety and stress</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DASS (total)</td>
<td>47.29 (31.52)</td>
<td>33.87 (21.76)</td>
<td>-12.29 (27.81)</td>
<td>0.50</td>
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<tr>
<td>Depression</td>
<td>16.90 (12.61)</td>
<td>11.38 (7.37)</td>
<td>-5.3 (10.64)</td>
<td>0.54</td>
</tr>
<tr>
<td>Anxiety</td>
<td>11.73 (9.48)</td>
<td>8.32 (7.61)</td>
<td>-3.4 (9.46)</td>
<td>0.40</td>
</tr>
<tr>
<td>Stress</td>
<td>18.13 (11.36)</td>
<td>13.81 (9.05)</td>
<td>-4.13 (10.8)</td>
<td>0.43</td>
</tr>
<tr>
<td>Interpersonal relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>49.22 (9.27)</td>
<td>52.09 (7.07)</td>
<td>2.88 (7.55)</td>
<td>0.35</td>
</tr>
<tr>
<td>Perceived conflict</td>
<td>44.77 (11.42)</td>
<td>43.91 (9.78)</td>
<td>-0.77 (8.91)</td>
<td>0.08</td>
</tr>
</tbody>
</table>
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