“Will Diagnostic Systems for FASD in Children Work in Adults?”

8th International Research Conference on Adolescents and Adults with FASD April 19th 2018

Dr. Jonathan Down
Developmental Paediatrician
Victoria, BC.
“We need to talk”
Objectives

• To identify the limitations of any diagnostic system for FASD
• To identify some of the challenges of a diagnostic assessment for FASD in adults
• To describe the medical and social components of a diagnostic assessment for FASD in adults
Diagnostic system: medical

- Diagnosis
- Disorder
- Disability
- Dysfunction
- Disease
- Deficit
- Deficiency
- Deviation
- Defective
- Designation (not a diagnosis)
Diagnostic System: medical

- Animal models
- Teratogenic effects
- Increased awareness
- Educational tool
- No human equivalent
- Multiple risk factors in real life
- Measurement is core feature-quantitative
Diagnostic System: social

- Function
- Resiliency
- Talents
- Assets
- Ability
- Strengths
- Protective
ADVERSE CHILDHOOD EXPERIENCES
Adverse Childhood Experiences (ACEs) have harmful impacts on health and well-being across the life course. The Welsh ACE Study measured exposure to nine ACEs in the Welsh population and their association with chronic disease development and health service use in adulthood.

47% of adults in Wales suffered at least one ACE as a child and 14% suffered four or more.

Proportion of Welsh adults suffering each ACE:
- Verbal abuse: 23%
- Physical abuse: 17%
- Sexual abuse: 10%
- Parental separation: 20%
- Household domestic violence: 16%
- Household mental illness: 14%
- Household alcohol abuse: 14%
- Household drug use: 5%
- Household member incarcerated: 5%
Review article

Prenatal alcohol exposure and traumatic childhood experiences: A systematic review

Alan Price\textsuperscript{a,*}, Penny A. Cook\textsuperscript{a}, Sarah Norgate\textsuperscript{a}, Raja Mukherjee\textsuperscript{a,b}

\textsuperscript{a} School of Health Sciences, University of Salford, Manchester, UK
\textsuperscript{b} Surrey and Borders Partnership NHS Foundation Trust, UK
Sources of resilience and their moderating relationships with harms from adverse childhood experiences

Report 1: Mental illness
Welsh Adverse Childhood Experience (ACE) and Resilience Study
Karen Hughes, Kat Ford, Alisha R. Davies, Lucia Morohova, Mark A. Bello
www.publichealthwales.org
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<th>Non–medical determinants of health</th>
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<td>Health behaviours</td>
<td>Smoking</td>
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<td>Heavy drinking</td>
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<td>Physical activity during leisure time</td>
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<td>Breastfeeding practices</td>
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<td>Fruit and vegetable consumption</td>
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<td>Bicycle helmet use</td>
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<td>Living and working conditions</td>
<td>High school graduates</td>
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<td>Post–secondary graduates</td>
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<td>Unemployment rate</td>
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<td>Long–term unemployment rate</td>
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<td>Low income rate</td>
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<td>Children in low income families</td>
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<td>Average personal income</td>
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<td>Median share of income</td>
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<td>Housing affordability</td>
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<td>Crime incidents</td>
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<td>Adults and youths charged</td>
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<td>Household food insecurity</td>
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<td>Personal resources</td>
<td>Sense of community belonging</td>
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<td>Life satisfaction</td>
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<td>Environmental factors</td>
<td>Exposure to second–hand smoke at home</td>
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<td>Exposure to second–hand smoke in vehicles and public places</td>
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<td>Lead concentration</td>
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<td>Bisphenol A concentration</td>
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<td>Mercury concentration</td>
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Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan

Jocelynn L. Cook PhD, Courtney R. Green PhD, Christine M. Lilley PhD, Sally M. Anderson PhD, Mary Ellen Baldwin, Albert E. Chudley MD, Julianne L. Conry PhD, Nicole LeBlanc MD, Christine A. Loock MD, Jan Lutke, Bernadene F. Mallon MSW, Audrey A. McFarlane MBA, Valerie K. Temple PhD, Ted Rosales MD; for the Canada Fetal Alcohol Spectrum Disorder Research Network


Specific problems with adult diagnosis

• Confirmation of PAE
• Sentinel facial features
• Informed Consent-ethics
Specific problems with adult diagnosis

- Adaptive measures-do they capture the real problems?
- How do we address discrepancy between the individual and third party?
Rating Example – Adaptive

- Lower part of chart is area of difficulty
- Red and green lines by independent raters show many difficulties
- Blue line is client self-report – does not indicate much difficulty
Specific problems with adult diagnosis

• Are we doing good?
• Medical and psychiatric conditions e.g. hypertension and substance abuse-access to service?
• Logistical support for assessment-$$?
Specific problems with adult diagnosis

• Personal support initiative (PSI)-how low is low?
• Patient and client (medical and social)
NESSA CAREY

THE EPIGENETICS REVOLUTION

How Modern Biology Is Rewriting Our Understanding of Genetics, Disease, and Inheritance
My momma always said, "Life was like a box of chocolates. You never know what you're gonna get."

Forrest Gump