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

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

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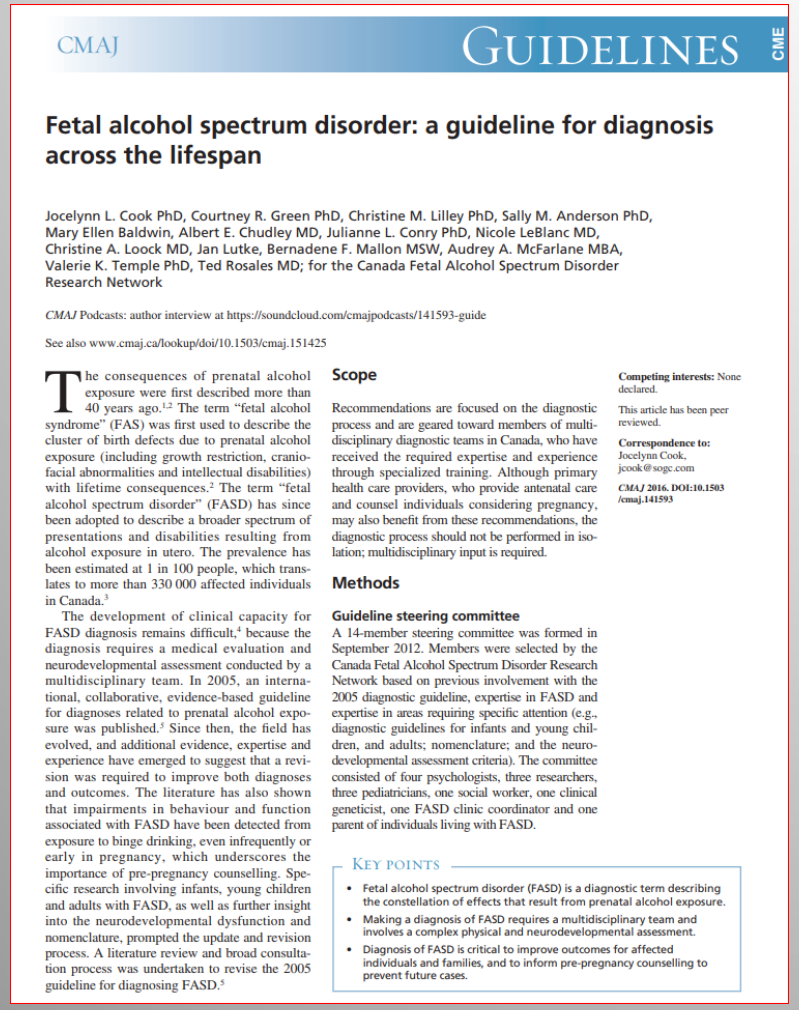
“We need to talk”

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



CMAJ GUIDELINES CME

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

CMAJ Podcasts: author interview at https://soundcloud.com/cmajpodcasts/141593-guide

See also www.cmaj.ca/lookup/doi/10.1503/cmaj.151425

The consequences of prenatal alcohol exposure were first described more than 40 years ago.[1,2] The term "fetal alcohol syndrome" (FAS) was first used to describe the cluster of birth defects due to prenatal alcohol exposure (including growth restriction, craniofacial abnormalities and intellectual disabilities) with lifetime consequences.[2] The term "fetal alcohol spectrum disorder" (FASD) has since been adopted to describe a broader spectrum of presentations and disabilities resulting from alcohol exposure in utero. The prevalence has been estimated at 1 in 100 people, which translates to more than 330 000 affected individuals in Canada.[3]

The development of clinical capacity for FASD diagnosis remains difficult,[4] because the diagnosis requires a medical evaluation and neurodevelopmental assessment conducted by a multidisciplinary team. In 2005, an international, collaborative, evidence-based guideline for diagnoses related to prenatal alcohol exposure was published.[5] Since then, the field has evolved, and additional evidence, expertise and experience have emerged to suggest that a revision was required to improve both diagnoses and outcomes. The literature has also shown that impairments in behaviour and function associated with FASD have been detected from exposure to binge drinking, even infrequently or early in pregnancy, which underscores the importance of pre-pregnancy counselling. Specific research involving infants, young children and adults with FASD, as well as further insight into the neurodevelopmental dysfunction and nomenclature, prompted the update and revision process. A literature review and broad consultation process was undertaken to revise the 2005 guideline for diagnosing FASD.[5]

Scope

Recommendations are focused on the diagnostic process and are geared toward members of multidisciplinary diagnostic teams in Canada, who have received the required expertise and experience through specialized training. Although primary health care providers, who provide antenatal care and counsel individuals considering pregnancy, may also benefit from these recommendations, the diagnostic process should not be performed in isolation; multidisciplinary input is required.

Methods

Guideline steering committee

A 14-member steering committee was formed in September 2012. Members were selected by the Canada Fetal Alcohol Spectrum Disorder Research Network based on previous involvement with the 2005 diagnostic guideline, expertise in FASD and expertise in areas requiring specific attention (e.g., diagnostic guidelines for infants and young children, and adults; nomenclature; and the neurodevelopmental assessment criteria). The committee consisted of four psychologists, three researchers, three pediatricians, one social worker, one clinical geneticist, one FASD clinic coordinator and one parent of individuals living with FASD.

Competing interests: None declared.

This article has been peer reviewed.

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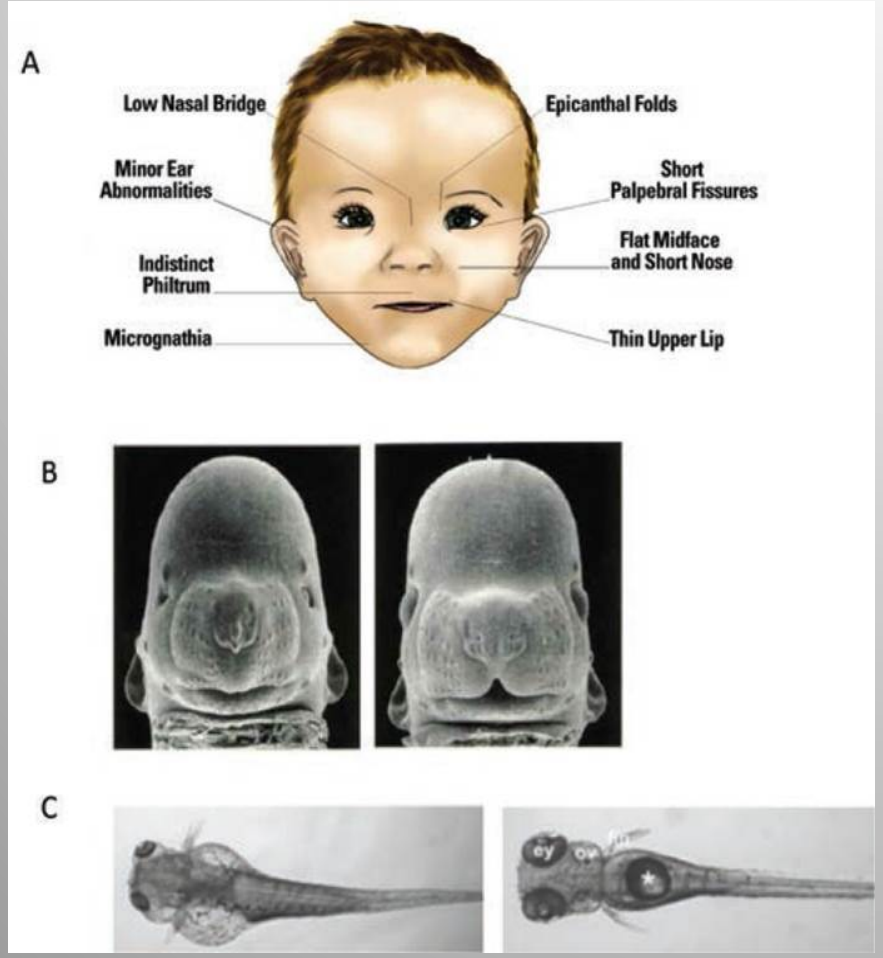
KEY POINTS

- Fetal alcohol spectrum disorder (FASD) is a diagnostic term describing the constellation of effects that result from prenatal alcohol exposure.
- Making a diagnosis of FASD requires a multidisciplinary team and involves a complex physical and neurodevelopmental assessment.
- Diagnosis of FASD is critical to improve outcomes for affected individuals and families, and to inform pre-pregnancy counselling to prevent future cases.

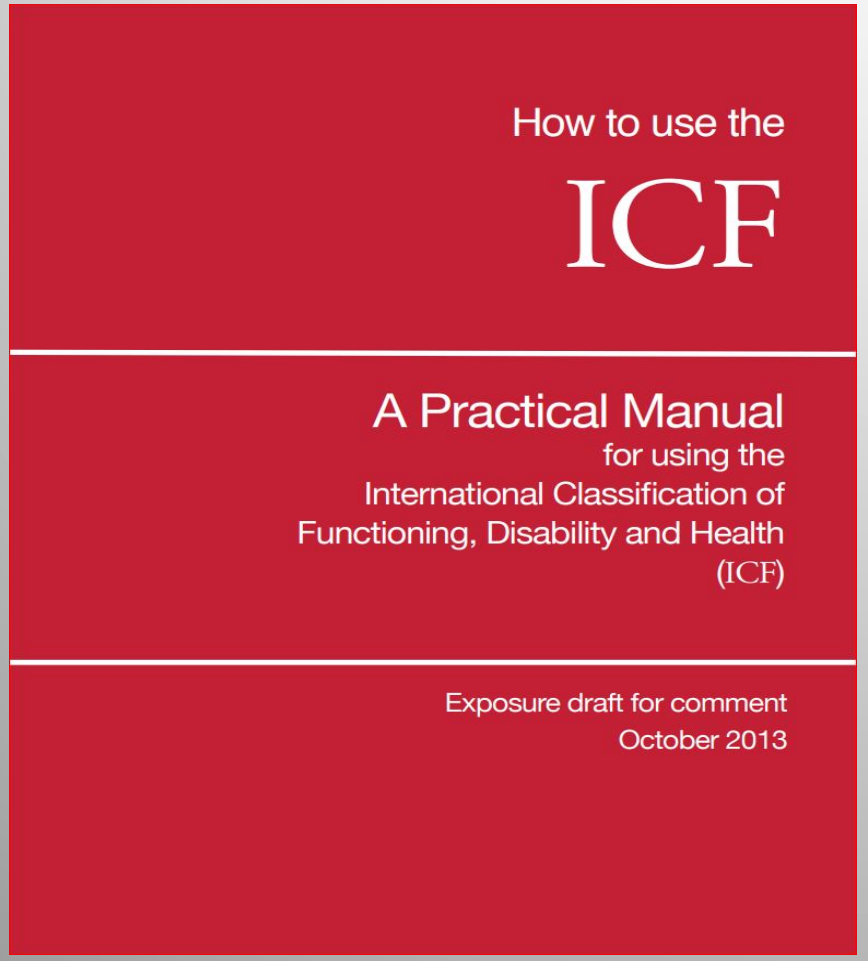
- Diagnosis
- Disorder
- Disability
- Dysfunction
- Disease
- Deficit
- Deficiency
- Deviation
- Defective
- Designation (not a diagnosis)

Diagnostic System : medical



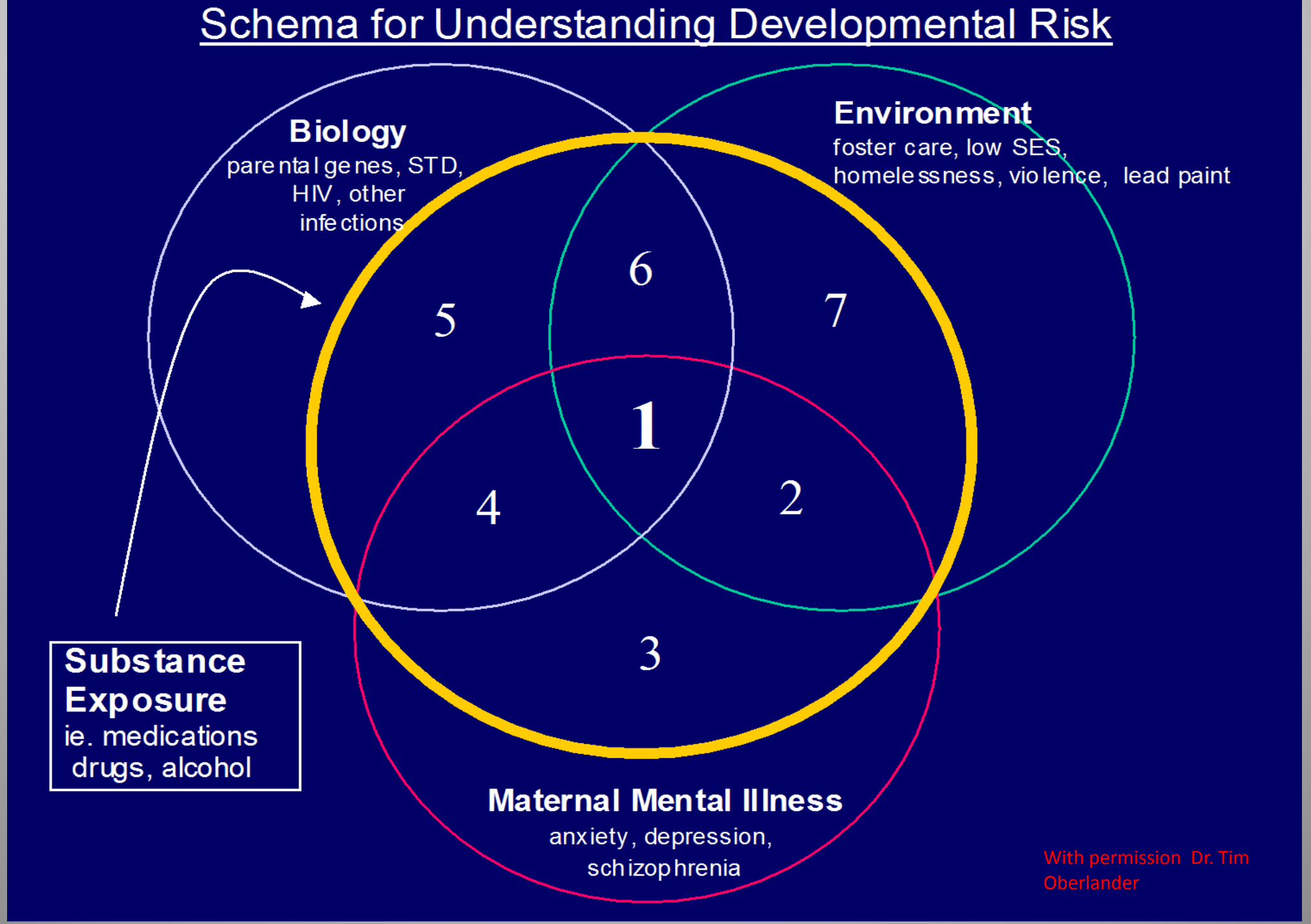
- Animal models
- Teratogenic effects
- Increased awareness
- Educational tool
- No human equivalent
- Multiple risk factors in real life
- Measurement is core feature- quantitative

Diagnostic System : social



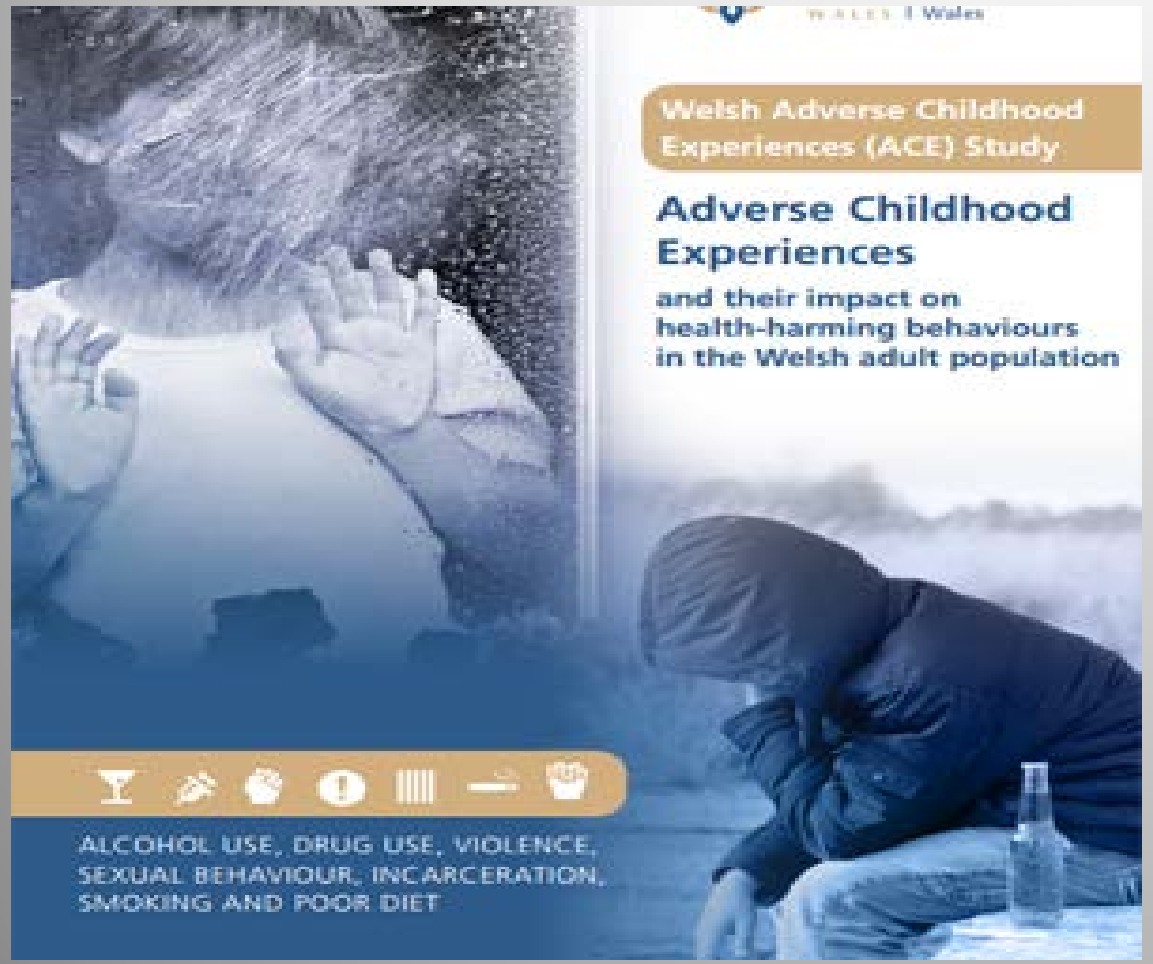
- Function
- Resiliency
- Talents
- Assets
- Ability
- Strengths
- Protective

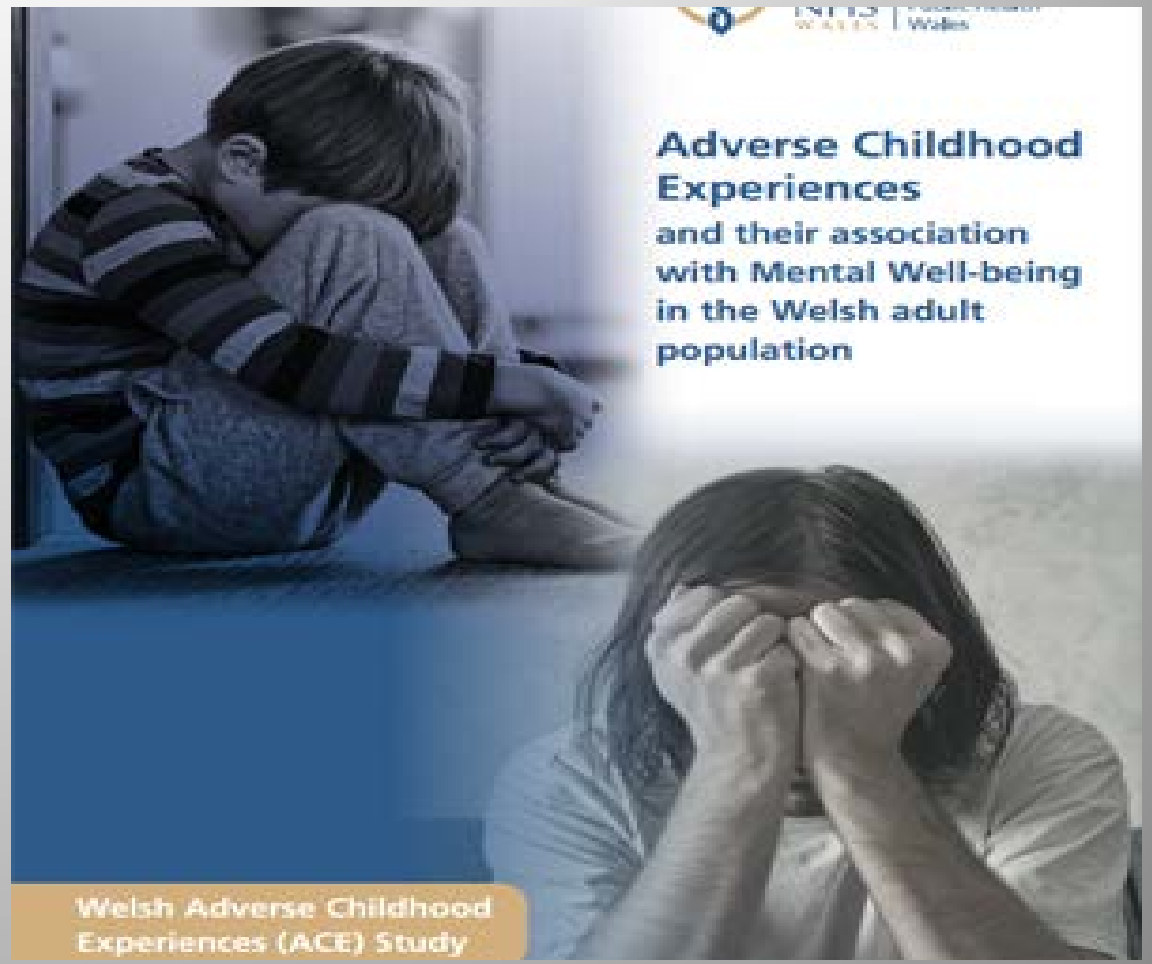
Schema for Understanding Developmental Risk



With permission Dr. Tim Oberlander

ADVERSE CHILDHOOD EXPERIENCES



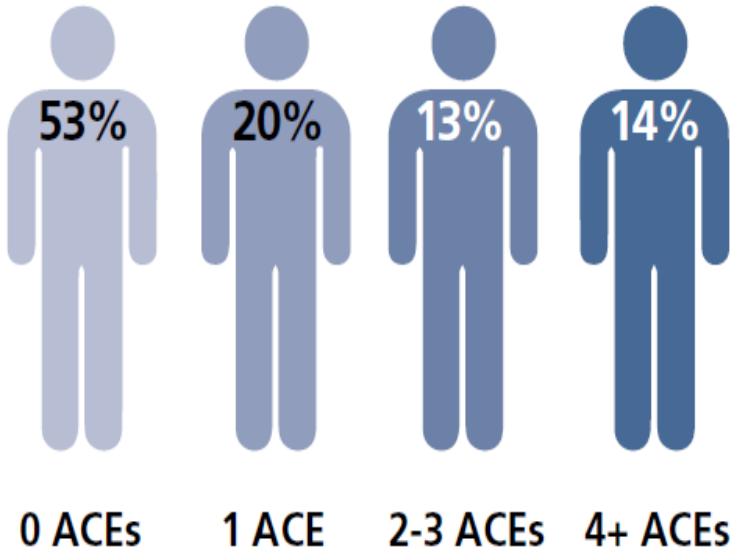


GIG CYMRU NHS WALES | Iechyd Cyhoeddus Cymru Public Health Wales

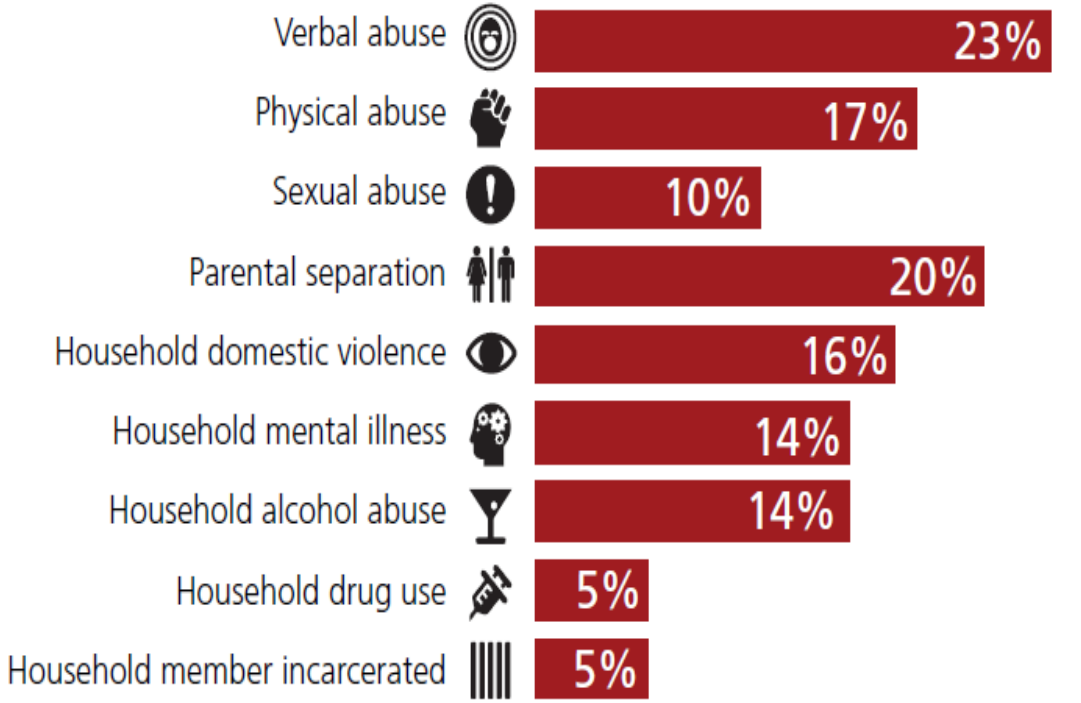
Adverse Childhood Experiences, chronic disease and health service use in Wales

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



PAE and ACE

Neuroscience and Biobehavioral Reviews 80 (2017) 89–98

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Review article

Prenatal alcohol exposure and traumatic childhood experiences: A systematic review

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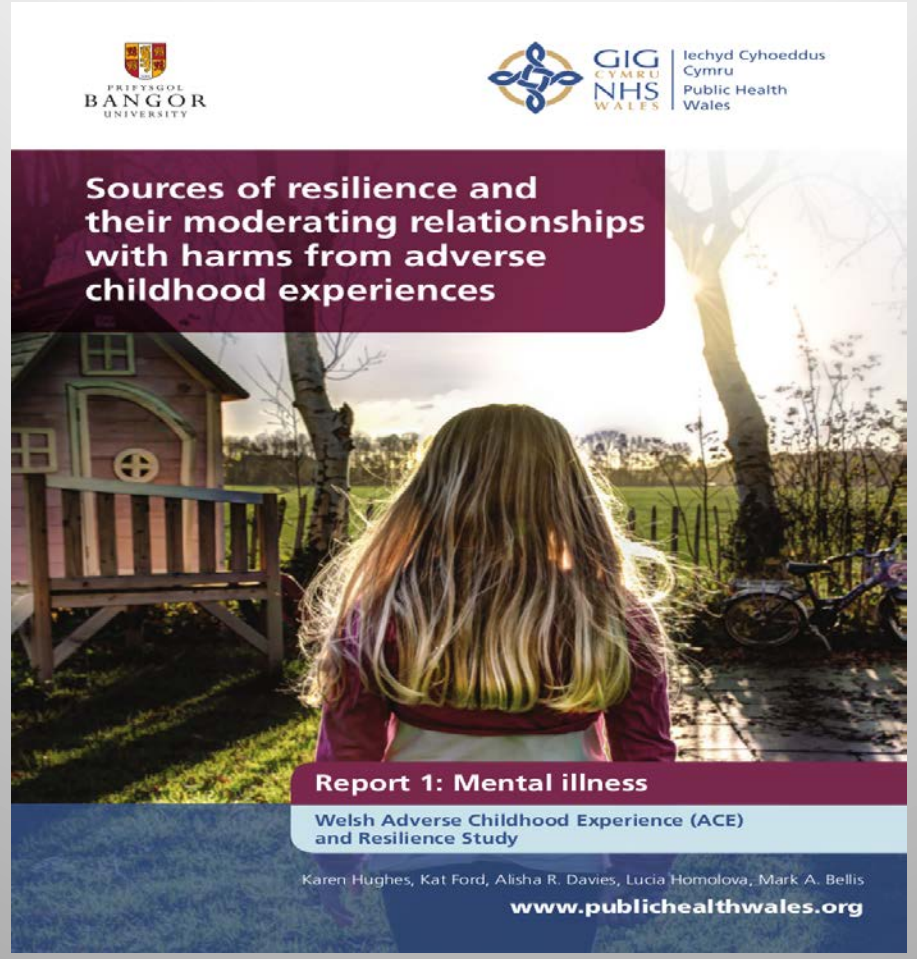
[b] Surrey and Borders Partnership NHS Foundation Trust, UK

RESILIENCE


Prifysgol Bangor University
GIG CYMRU NHS WALES
Iechyd Cyhoeddus Cymru
Public Health Wales
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 Homolova, Mark A. Bellis
www.publichealthwales.org

Non–medical determinants of health	
Health behaviours	• Smoking • Heavy drinking • Physical activity during leisure time • Breastfeeding practices • Fruit and vegetable consumption • Bicycle helmet use
Living and working conditions	• High school graduates • Post–secondary graduates • Unemployment rate [1] • Long–term unemployment rate • Low income rate • Children in low income families • Average personal income • Median share of income • Government transfer income • Housing affordability • Crime incidents [2] • Adults and youths charged [2] • Household food insecurity
Personal resources	• Sense of community belonging • Life satisfaction
Environmental factors	• Exposure to second–hand smoke at home • Exposure to second–hand smoke in vehicles and public places • Lead concentration • Bisphenol A concentration • Mercury concentration

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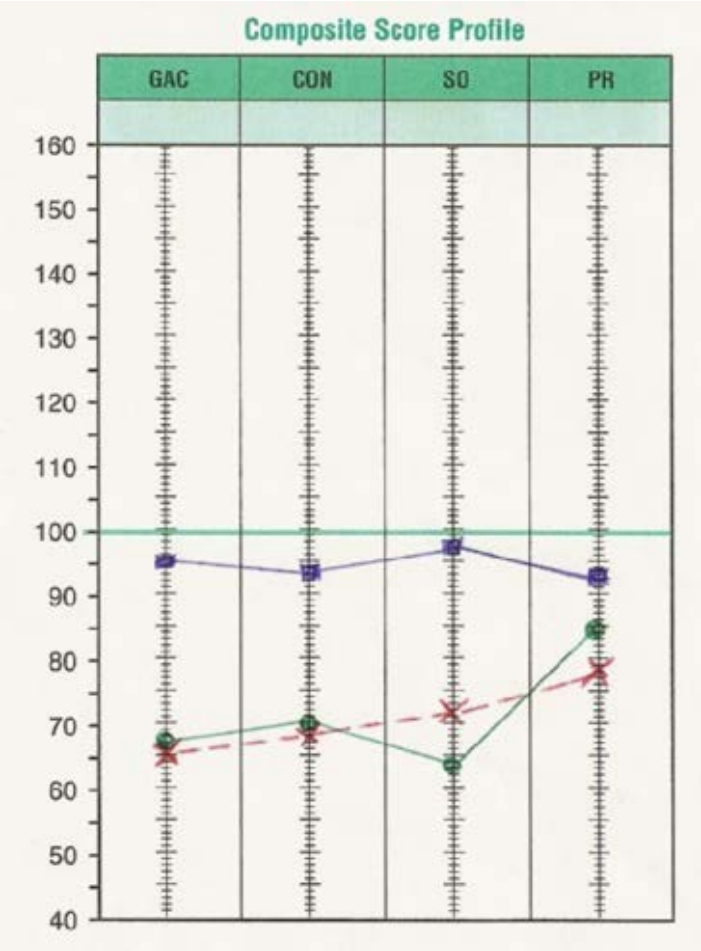
Specific problems with adult diagnosis

- 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



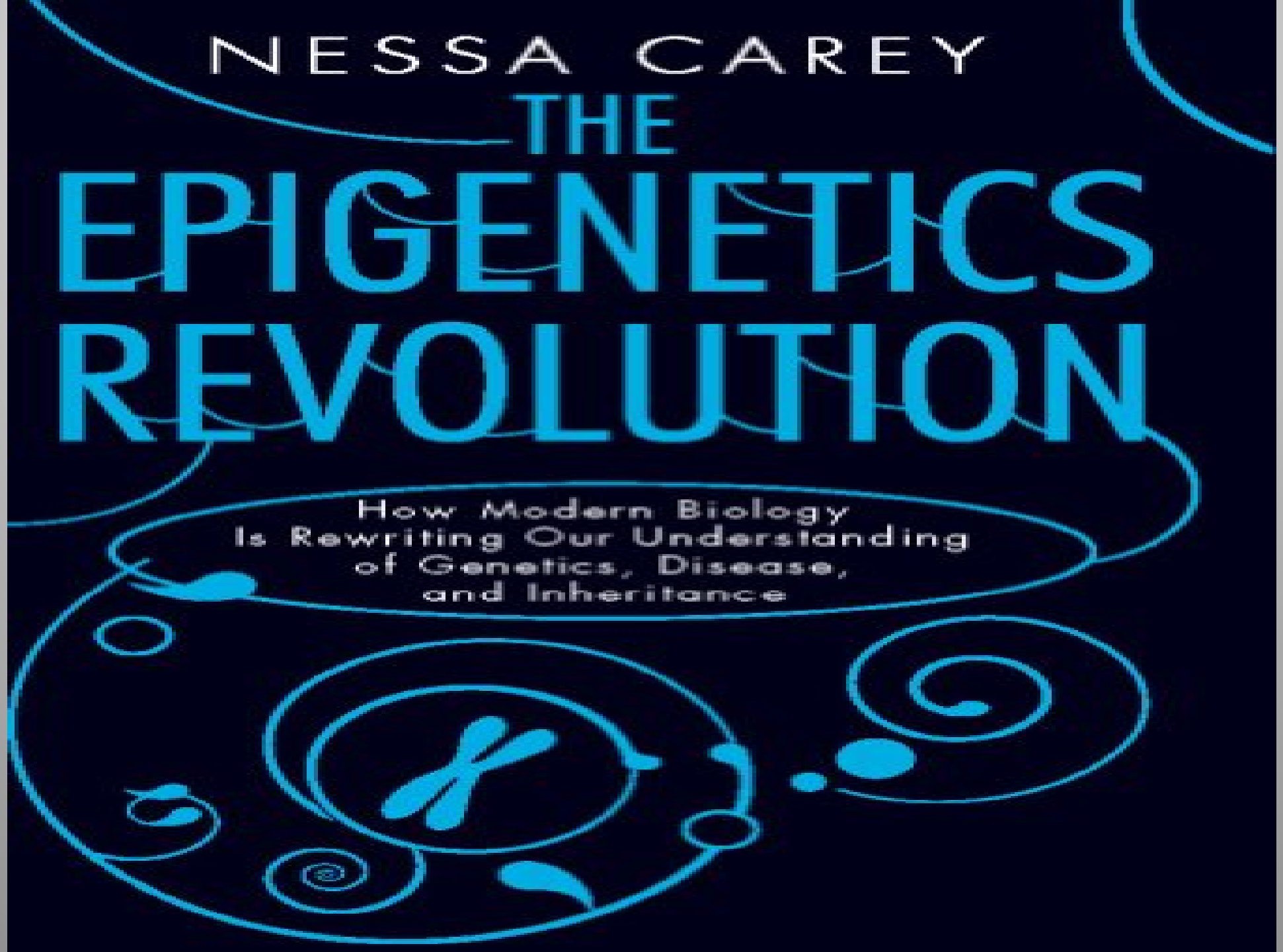
- Lower part of chart is area of difficulty
- Red and green lines by independent raters show many difficulties
- Blue line is client self-report – does not indicate much difficulty

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