



Why is autism relevant to Disability Studies?



Bill McMahon, M.D.
Director, Autism
Community Outreach
Department of Psychiatry



Introduction

- What is Autism Spectrum Disorder (ASD) and what is prevalence in Utah?
- Relevance of ASD for Disability Studies
- Vision for Utah



ASD Diagnostic Criteria

American Psychiatric Association DSM-5, 2013

- A. Persistent deficits in social communication and social interactions across multiple contexts.
- B. Restrictive, repetitive patterns of behavior, interests or activities.
- C. Onset in the developmental period.
- D. Clinically significant impairment in social, occupational or other important areas of current functioning.



Autism in APA Diagnostic & Statistical Manual (DSM)

- 1952 DSM-I: 106 disorders but not autism
- 1968 DSM-II: childhood schizophrenia but not autism
- 1980 DSM-III: autism first listed
- 1987 DSM-III-R: Asperger's listed
- 1994 DSM-IV: Rett's listed
- 2013 DSM-V: Autism Spectrum

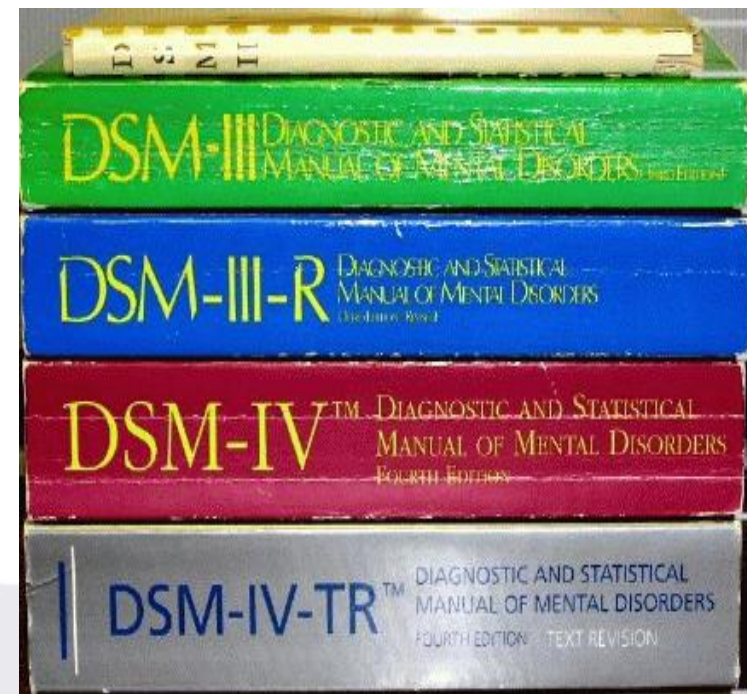
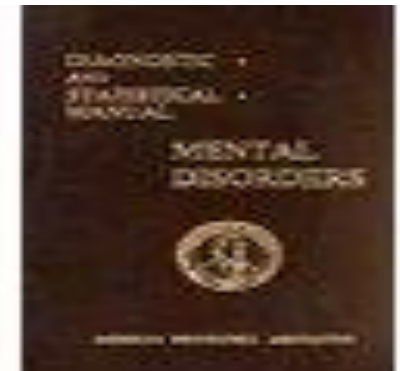
Disorder

– Social-Communication

Categories combined

– Asperger's & PDDNOS

Categories eliminated



How many children were identified with ASD?

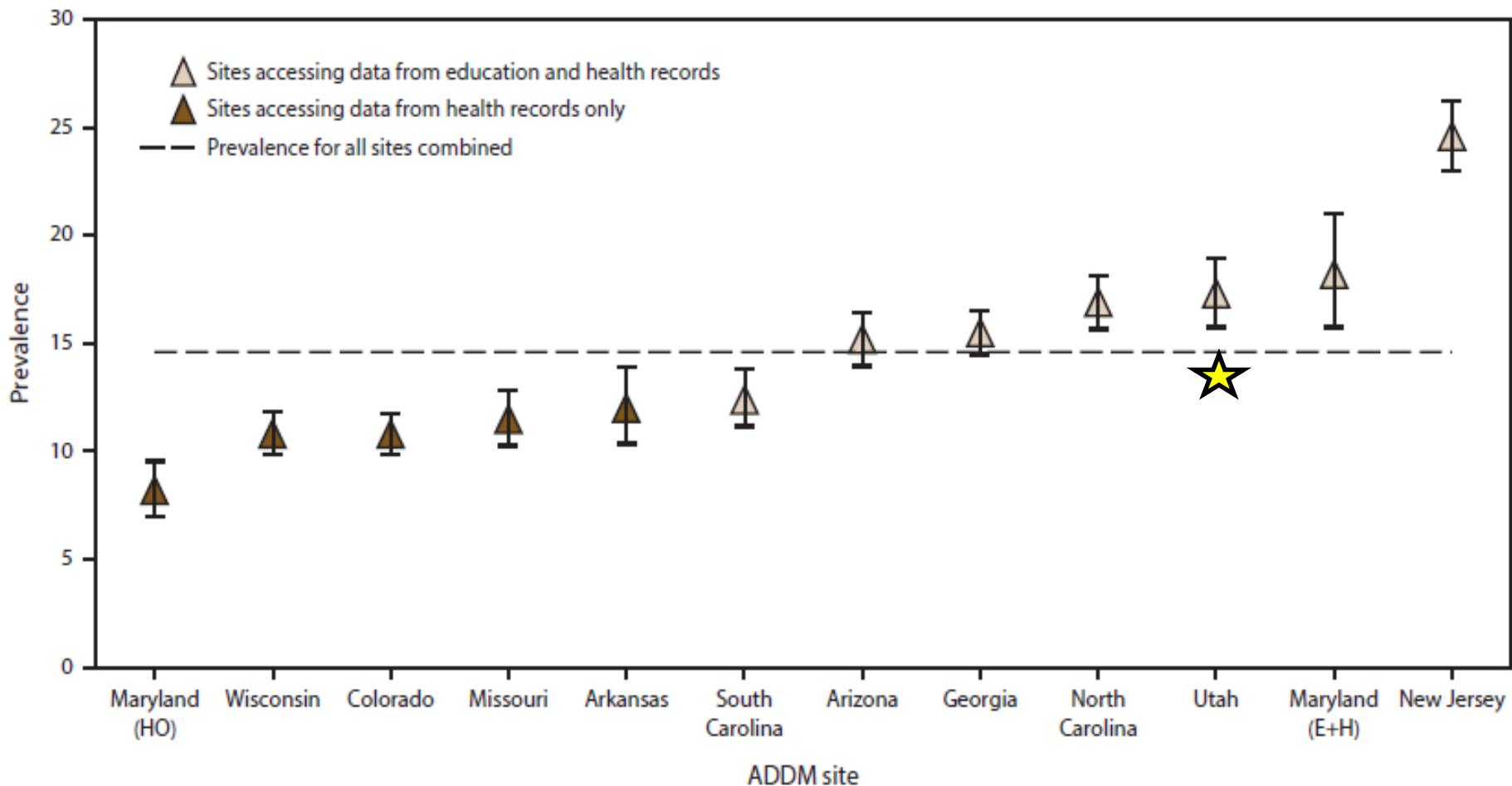
About 1 in 68 or 1.5% of 8-year-olds were identified with ASD by the ADDM Network.



About 1 in 58 or 1.7% of 8-year-old children were identified with ASD by UT-ADDM in 2012. This percentage is higher than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.



FIGURE 1. Estimated prevalence* of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012



Abbreviations: ADDM = Autism and Developmental Disabilities Monitoring Network; E+H = education and health records; HO = health records only.

* Cases per 1,000 children aged 8 years. Bars represent 95% confidence intervals.

Source: Christensen et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. MMWR. 2016; 65(3): 1-23.



Relevance: 10 medical, social, legal, political & economic features of ASD

1. High prevalence
2. Life-long duration
3. Range and variability of impairments
4. Complex causes: hundreds of genes and environmental factors
5. \$1.4M lifetime cost to families and society
6. Association with genius, hyperfocus & special skills
7. Association with sensory hyper- or hypo-reactivity, intellectual disability, seizures & syndromes
8. Opportunity for workforce development
9. Civil rights: housing, employment, education
10. Advocacy for inclusion, autonomy, acceptance

Transition
to
Adulthood
is a Cliff
like
Angel's
Landing

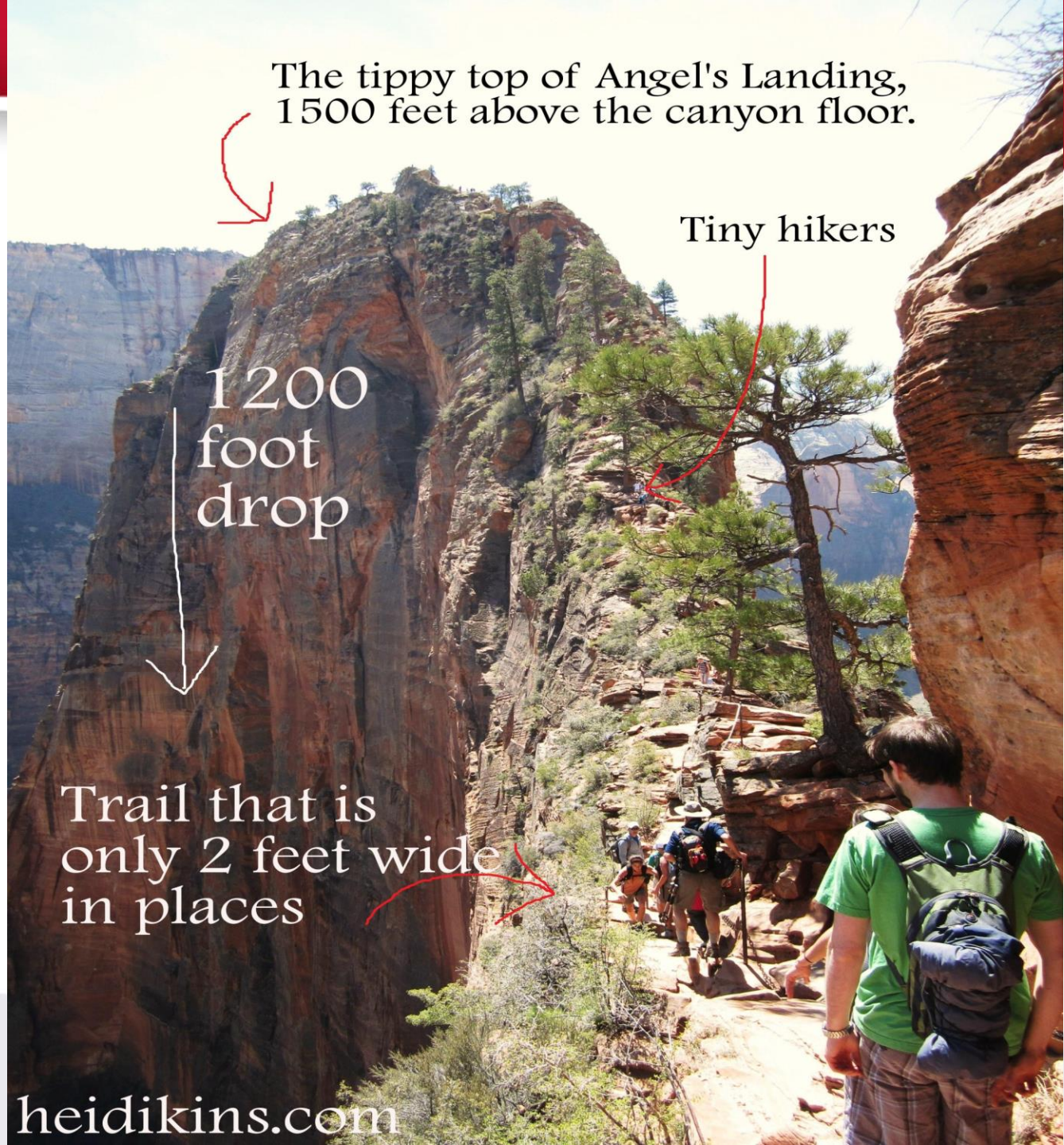
The tippy top of Angel's Landing,
1500 feet above the canyon floor.

Tiny hikers

1200
foot
drop

Trail that is
only 2 feet wide
in places

heidikins.com





Self-Optimization Workshops



Elliot Francis
Co-Founder

- Model for interactive sharing of stories of success that we call *Self-Optimization on The Spectrum*
- Interactive, informative workshops presented by and for adults on the autism spectrum and their adult family members
- Enhances autonomy and self-advocacy by supporting adults who identify as on the autism spectrum
- Model has been piloted through three workshops involving 100 participants



A Challenging Vision

Can we build on our Utah culture of collaboration to develop opportunities to nurture the work skills and interests of individual youth with ASD along a trajectory of lifelong career development?