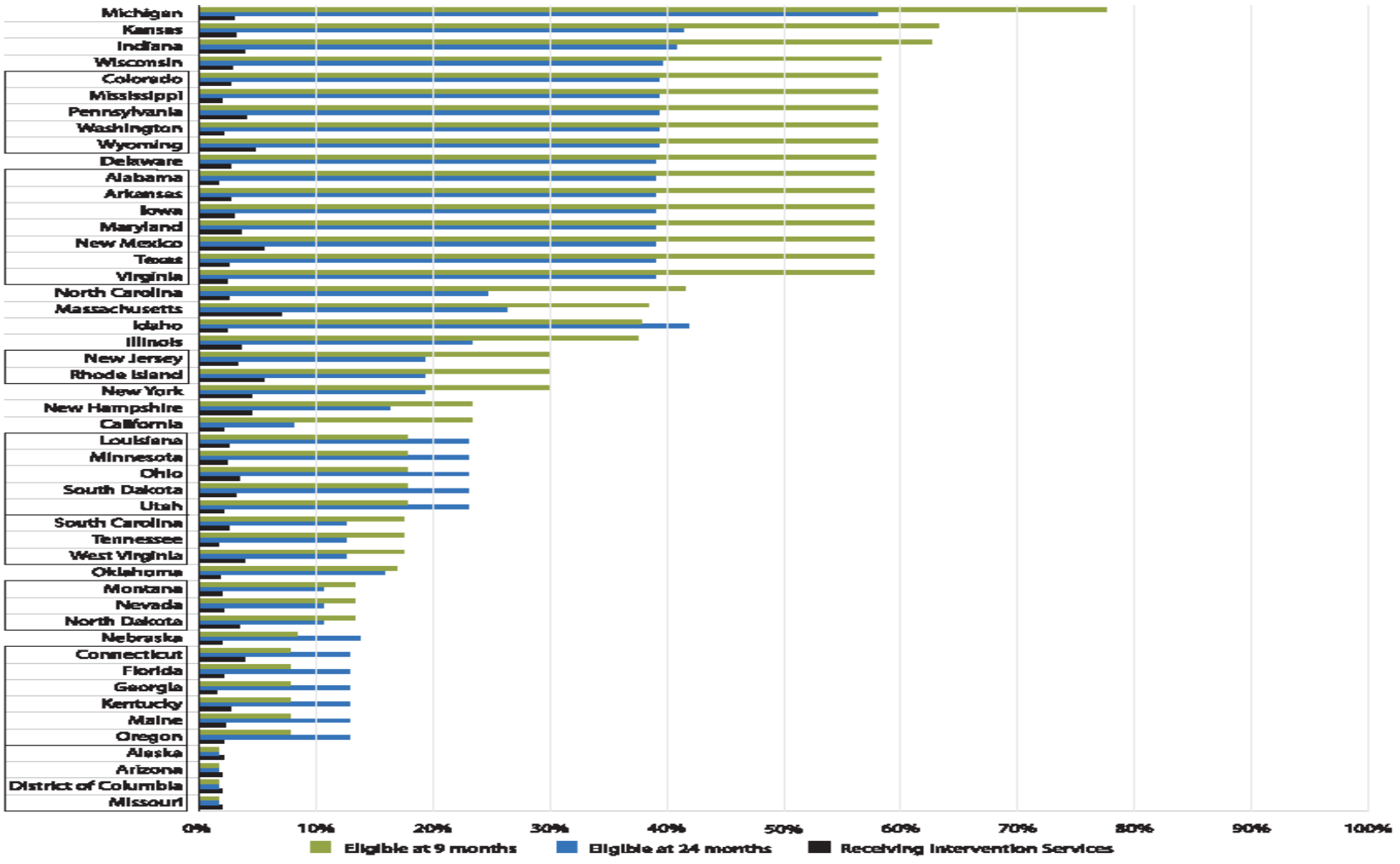
Critical Issues in Early Childhood The UCEDDs' Role

UCEDD Resource Center
2013 TA Institute
Corry Robinson

1. Who is Served?

- No consistency in state specific definitions.
- Many more eligible than served
- CAPTA- we need to advocate for adequate monitoring of this effort
- Autism- we need to advocate that all individuals with neurodevelopmental disabilities deserve attention to their ability to communicate, their social skills and any non-adaptive behaviors

Estimated Rates- Part C Eligibility



Are Too Few Infants and Toddlers Receiving Part C Services?

- If all states set their eligibility criteria to 2 standard deviations below the mean on all 5 developmental domains about 9% of children would be candidates for Part C.
- About 2.8 percent of children received Part C services based on the 2010 Child Count.
- This suggests that many children who are likely to need EI aren't receiving Part C services.

Rosenberg and Robinson, AUCD Webinar 2013

Are Too Few Infants and Toddlers Receiving Part C Services?

- The answer depends on the State. In some states as few as 2% of children under 3 are likely to be eligible, while in 17 states more than half of the children could qualify at 9 months and over a third at 24 months.
- How useful is it to have definitions of eligibility that make far more children candidates for Part C than can be served?

Rosenberg and Robinson, AUCD Webinar 2013

2. How are Young Children and Their Families Served?

- We need to be more specific and refined in our metrics for intervention.
- ABA is important but not sufficiently specific; Autism insurance legislation is a mixed blessing; Availably of insurance drives diagnosis; Crowds out other disabilities;
- We need to come to terms with the current status of evidence and work for improving adequacy of evidence base.

Some Questions

- Does current evidence guide us?
- Population-based approach (high-quality universal early care/education)
- Identify children with delays (and/or at risk) to provide individual services?
- What is the role of response to intervention (RTI) in early childhood

Jeffery P Brosco, MD, PhD, Mailman Center for Child Development, University of Miami

What can be learned by focusing on treatment intensity?

1. A given treatment that is moderately effective at one intensity level may be more/less effective at another level.
2. Changes in intensity may have different effects on individuals with different developmental profiles.
3. Some intensity levels may generate unforeseen side effects (e.g. stress, problems behaviors, etc).

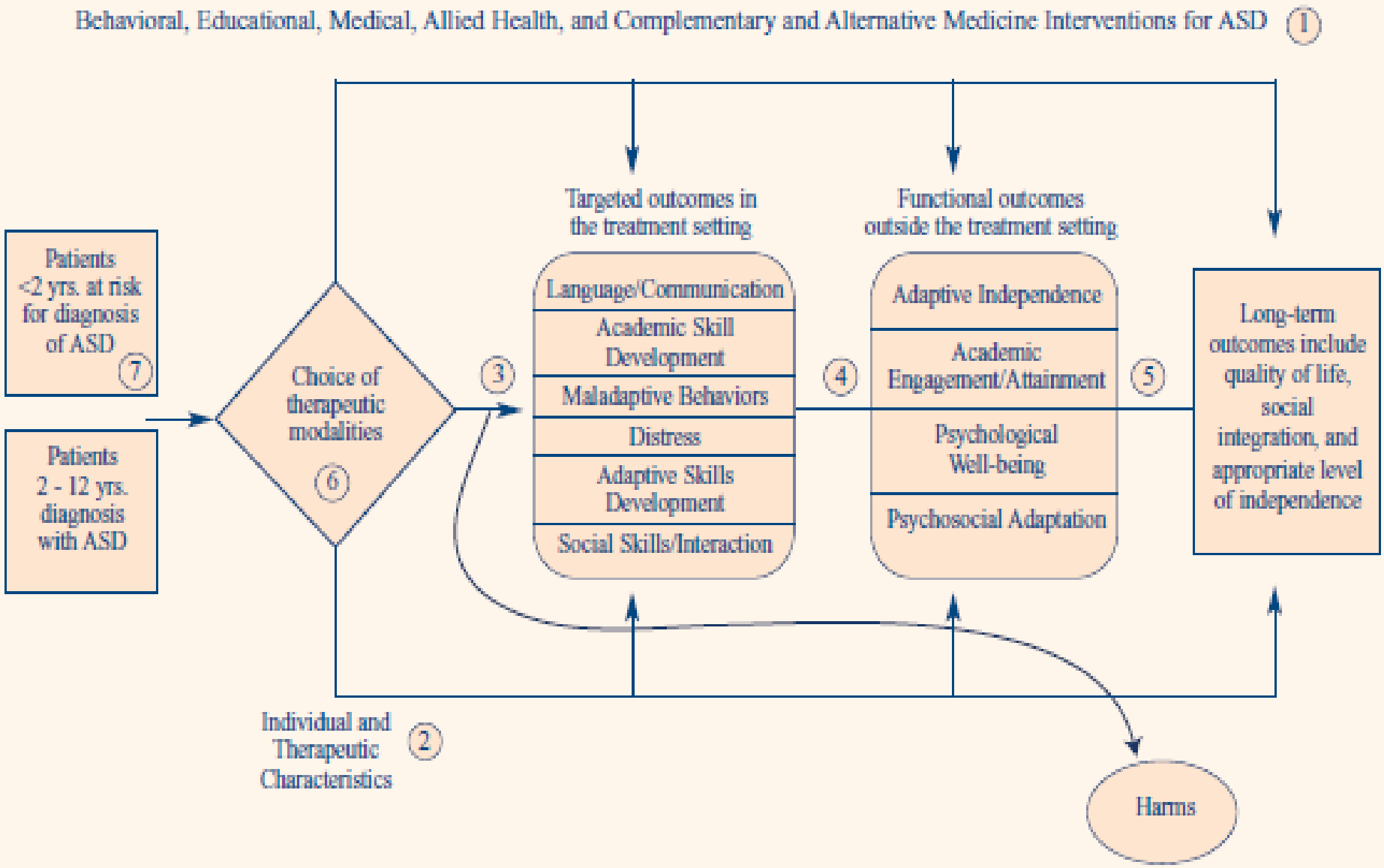
Steve Warren

http://www.aucd.org/resources/webinar_detail.cfm?event=2450&parent=741

An Example: Evidence for Hours of Treatment for Autism

2000 National Research Council Recommendations of 20 hours per week of direct intervention fostered the push for insurance legislation

- Based on consensus of opinion of those who provided comprehensive early intervention against community comparison groups
- Only common metric across the intervention - hours
- Research now calling for more specific documentation of intervention.


Behavioral, Educational, Medical, Allied Health, and Complementary and Alternative Medicine Interventions for ASD
1
Patients <2 yrs. at risk for diagnosis of ASD
7
Patients 2 - 12 yrs. diagnosis with ASD
Choice of therapeutic modalities
6
3
Targeted outcomes in the treatment setting
Language/Communication
Academic Skill Development
Maladaptive Behaviors
Distress
Adaptive Skills Development
Social Skills/Interaction
4
Functional outcomes outside the treatment setting
Adaptive Independence
Academic Engagement/Attainment
Psychological Well-being
Psychosocial Adaptation
5
Long-term outcomes include quality of life, social integration, and appropriate level of independence
Individual and Therapeutic Characteristics
2
Harms

3. How Part C is Evaluated?

- Too much process evaluation;
  - Respond to referrals – 2 days
  - IFSP in place – 45 days
  - Services in place – 30 days
- Outcome evaluation – required under GPRA is a flawed process

Our Role as Professionals

- Provide evidence based (research)
- Help determine appropriate goals (e.g., ready to learn) and how to measure those goals
- Use evidence to help determine best approach to achieving goals
- Advocate for sufficient resources.

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Conclusion

Finally, we have to get past our rigid ideological position that early intervention works;

Families deserve access to high quality information about what we know and what we don't know.

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