

TOMORROW
STARTS
TODAY.

The Link Between Research and Medical Care

Global Down Syndrome Research and Medical Care Roundtable

July 12, 2018 / Brian Chicoine, MD Medical Director Adult Down Syndrome Center

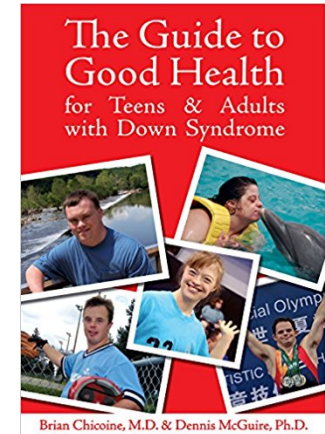
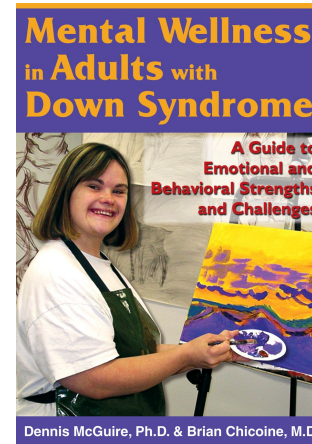


Advocate Medical Group

Tomorrow starts today.

Disclosures

- Author
 - **Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges**
Dennis McGuire, PhD & Brian Chicoine, MD
 - **The Guide to Good Health for Teens & Adults with Down Syndrome**
Brian Chicoine, MD & Dennis McGuire, PhD



Adult Down Syndrome Center



TOMORROW STARTS TODAY.

Leo Foley
1907-1947



Life Expectancy

- Life expectancy:
 - 1907: 9 years
 - 1984: 28 years
 - Today: 60 years
- One of the oldest well-documented individuals with Down syndrome, 83 years old at death
 - Chicoine, B. & McGuire, D. (1997) Longevity of a woman with Down syndrome: a case study. *Mental Retardation* 35(6):477-9.



Three (but not only three) Issues Linking Research and Patient Care

- Do no harm and safety
- Optimal ways to promote health and treat health problems
- Health care WITH people with Down syndrome



Do No Harm and Safety

- Health care guidelines project
 - What screening tests should be included?
 - What screening tests should NOT be included?
 - E.g. mammograms and colonoscopies
- Gaps in knowledge



Optimal ways to promote health and treat health conditions

- Many health issues to consider
- Life expectancy
 - Plateau
 - Age 50-62
 - Why?
- The next big research and patient care hurdle
- Alzheimer's disease
- But all is not Alzheimer's



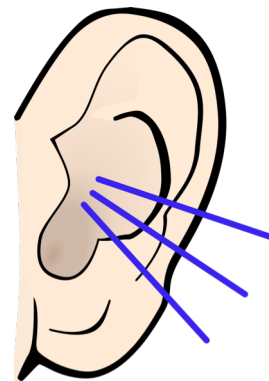
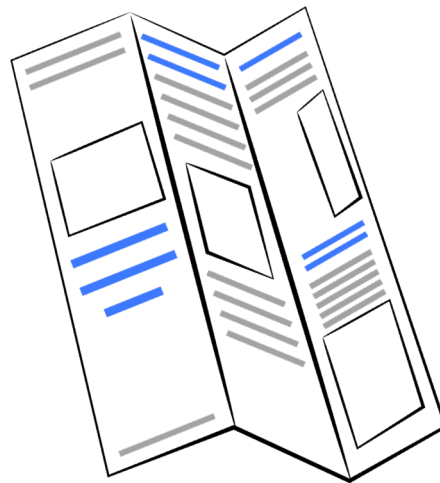
Health Care WITH People with Down syndrome

- How do we include individuals with Down syndrome in their own health promotion?
- The balance between promoting independence and promoting health
- EDUCATION!!!!!!



Health Information Retention

- How much do we retain?
- Why don't we remember?
- What about people with an intellectual disability?



People with Down syndrome as teachers and peer supporters

- Peer support
- Conference
- Visuals:
 - Pictures, videos
 - Video modeling
 - Research



Resources

Web site – <https://www.advocatehealth.com/health-services/adult-down-syndrome-center/> (or search for “Adult Down Syndrome Center)

Facebook – <https://www.facebook.com/adultdownsyndromecenter>

Contact

Laura Chicoine, Project Manager, Research and Education

Laura.Chicoine@advocatehealth.com

847-318-2368

Questions?

Discussion