Putting the Person at the Center: Integrating Plans for Long-Term Services and Supports and Health Care Delivery through Health Information Technology

David O'Hara, Ph.D

Joint meeting sponsored by the Office of the National Coordinator for Health Information Technology and the Administration for Community Living

October 16, 2014

Westchester Institute for Human Development
University Center for Excellence in Developmental Disabilities

Westchester Institute for Human Development
Creating Better Futures

Emerging Cognitive Support Technologies:

A Key to Promoting Community Participation and Health for Individuals with Intellectual and Developmental Disabilities

ABLELINK TECHNOLOGIES

Daniel K. Davies
AbleLink Founder and President
2006 Tech Museum Laureate

Tele-Health: Existing and Emerging Technology Platforms

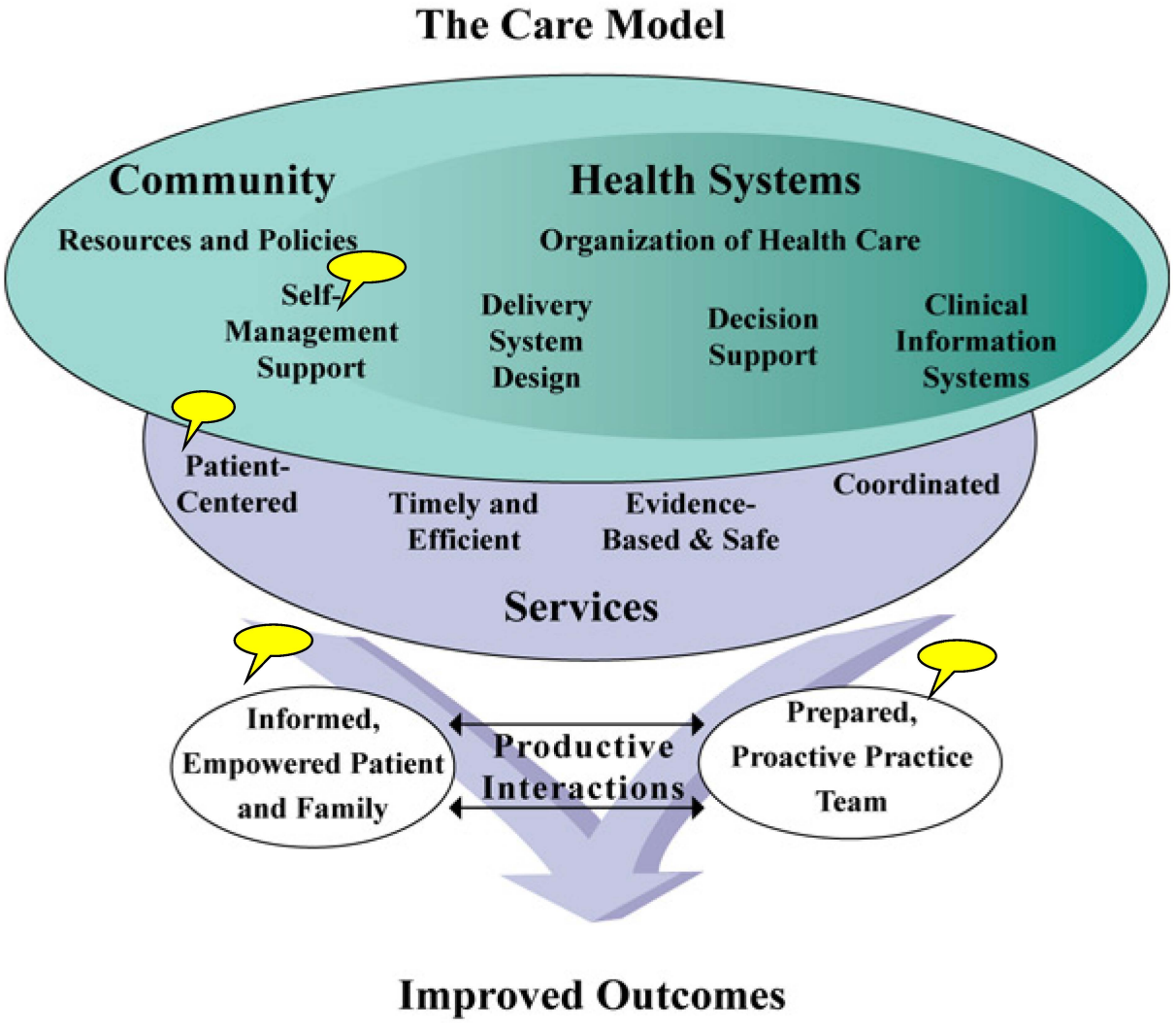
The User Interface is the Key (Software)

Type 2 Diabetes and People with I/DD

- Data from 2006 Medical Expenditures Panel Survey
  - Health status of working age adults with cognitive limitations compared with adults with no disability
    Adults with I/DD significantly higher prevalence
    19.4% vs 3.8%
  - Also significantly higher prevalence 6 other chronic health conditions
  - Adults with I/DD and diabetes significantly more likely to have 4 or more chronic illnesses

Reichard & Stolzle (June, 2011). Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. Intellectual and Developmental Disabilities 49 (3), p 141-154.

The Wagner Chronic Care Model



Health Literacy

- Institute of Medicine workshop reports:
  - Promoting health literacy to encourage prevention and wellness (November 1, 2011)
    - Research to find better pathways to improved health literacy and better health
  - Innovations in health literacy (March 10, 2011)
    - Health literacy and health disparities, better use of IT improve health literacy
  - Overall nearly nine out of 10 adults have difficulty using health information to make proper health decisions

Premature Deaths of People with Learning Disabilities

- **Data from a study between 2010 and 2012 in the UK**
  - Looked at the causes of death among all known deaths among people with learning disabilities in the Bristol area of south-west England
  - Men with learning disabilities died, on average, 13 years sooner than the general population
  - Women with learning disabilities died, on average 20 years sooner than the general population
  - Overall, 22% of the people with learning disabilities were under 50 at the time of death compared with just 9% of the general population
  - "The cause of their premature deaths appears to be because the NHS is not being provided equitably to everyone based on need. People with learning disabilities are struggling to have their illnesses investigated, diagnosed and treated to the same extent as other people."

Heslop, et al, (March 19, 2013). Confidential inquiry into the premature deaths of people with learning disabilities. Norah Fry Research Center, Bristol University, England. http://www.bris.ac.uk/cipold/fullfinalreport.pdf

Living Well With a Disability: a Person-Centered Planning Tool for Integrating Personal Life Goals with a Health and Wellness Plan

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My Health,
My Choice,
My Responsibility

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WHD

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Session 7: Feel Good about Yourself and Others

Listen and Learn

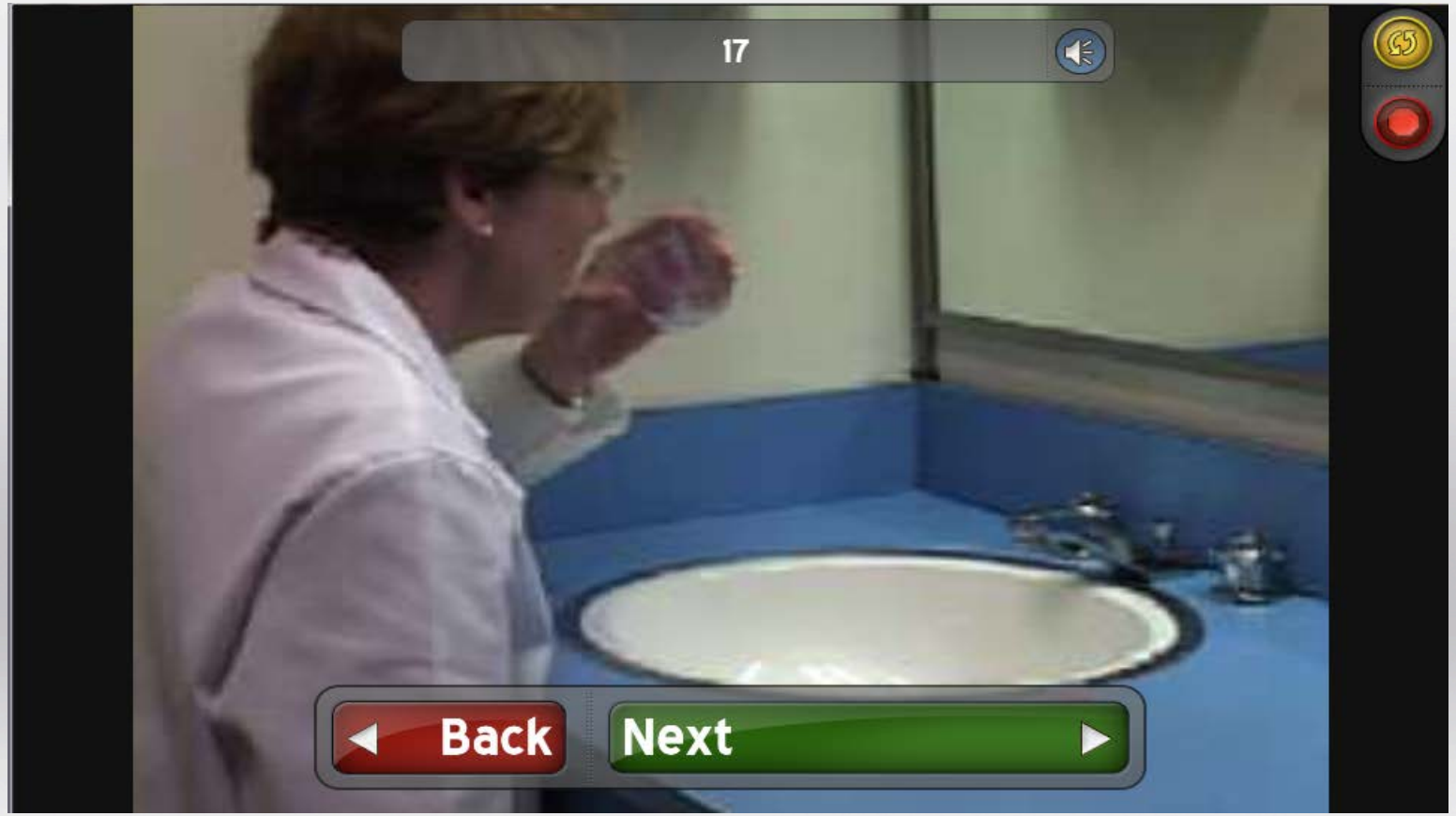
Test What You Learned

Things to Remember

Feelings

Beating the Blues

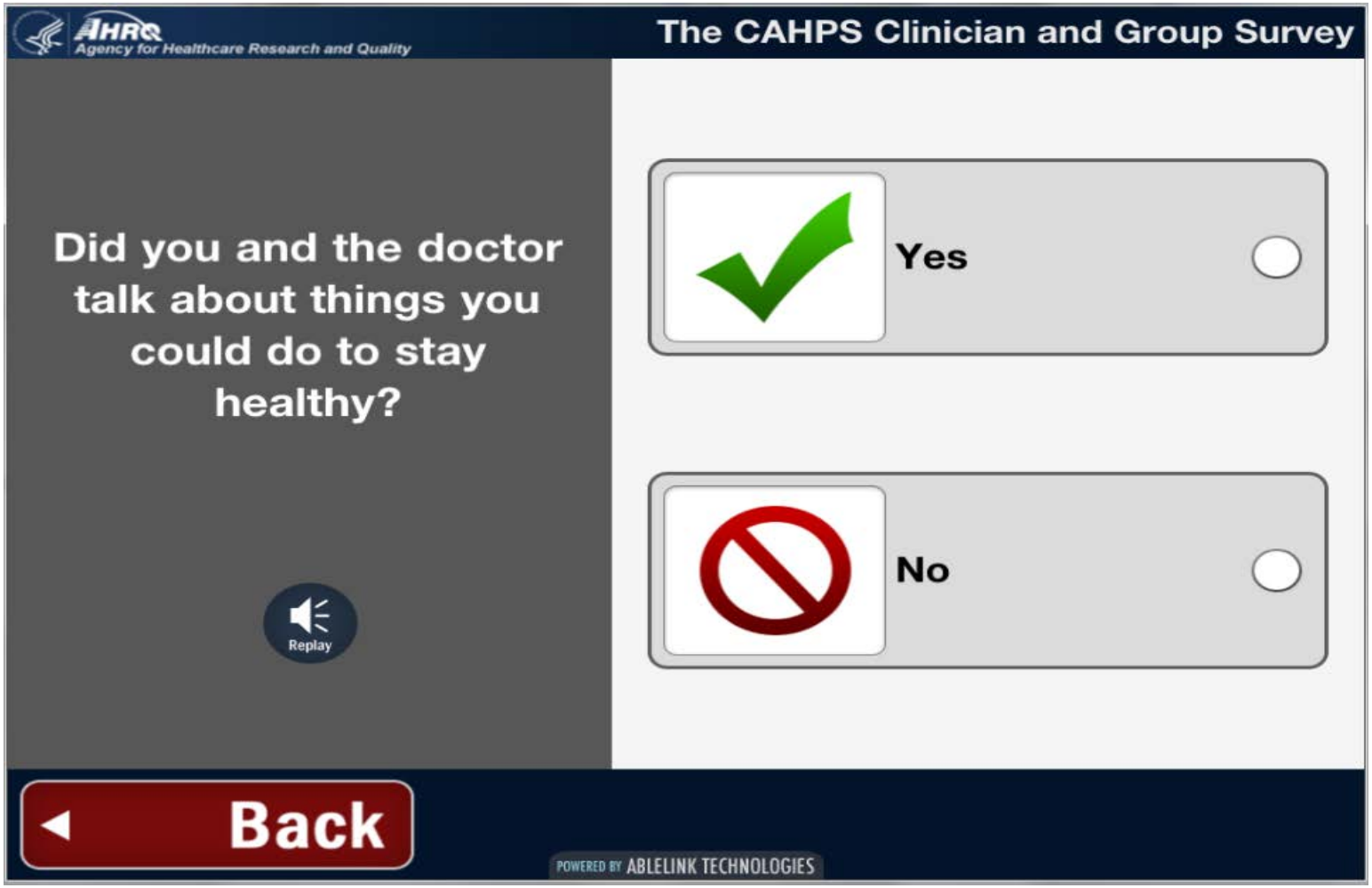
Improving Oral Health



Janice after you eat every meal you need to go brush your teeth and you need to get your brush and your toothpaste and go to the bathroom

Self-Directed Consumer Surveys

Self-directed, survey tools , such as consumer satisfaction surveys, using multi-modal presentation and accessible design can increase independence and reduce staff time interviewing and entering/ aggregating data.


AHRQ
Agency for Healthcare Research and Quality
The CAHPS Clinician and Group Survey
Did you and the doctor talk about things you could do to stay healthy?
Replay
Yes
No
Back
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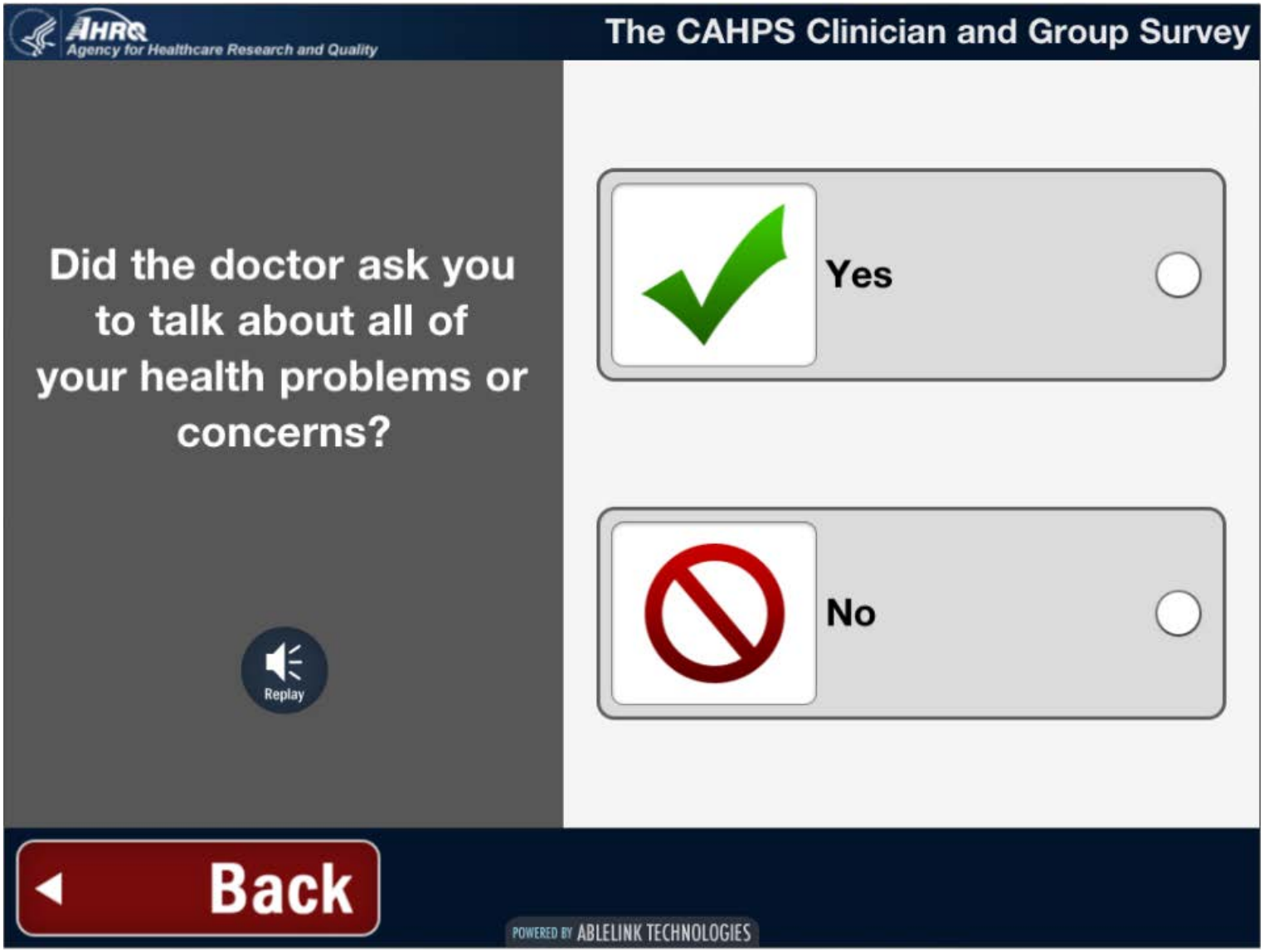
AHRQ
Agency for Healthcare Research and Quality
The CAHPS Clinician and Group Survey
Did the doctor ask you to talk about all of your health problems or concerns?
Replay
Yes
No
Back
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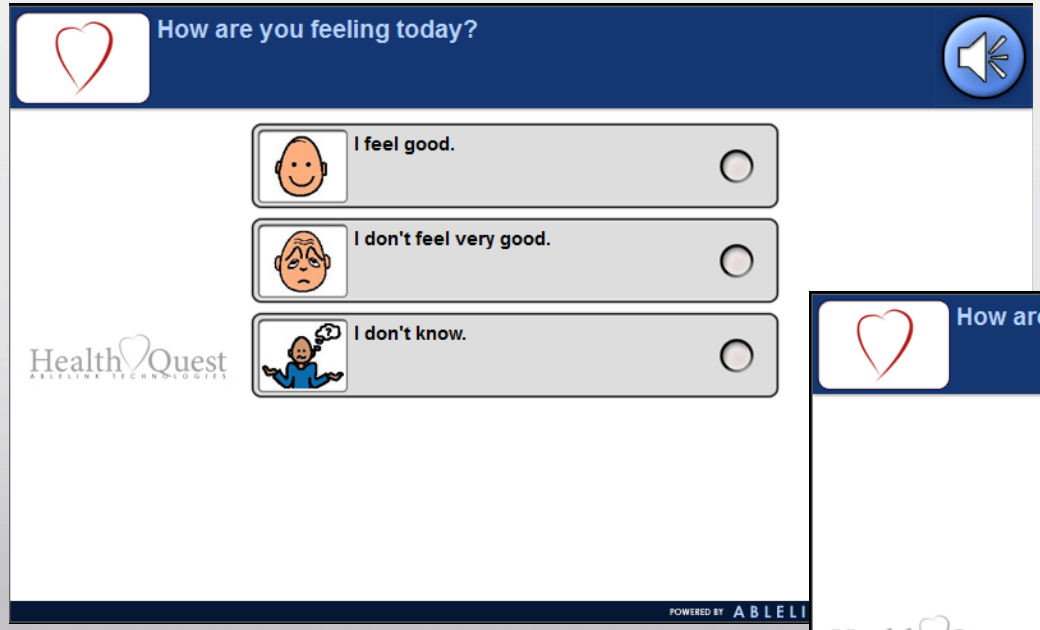
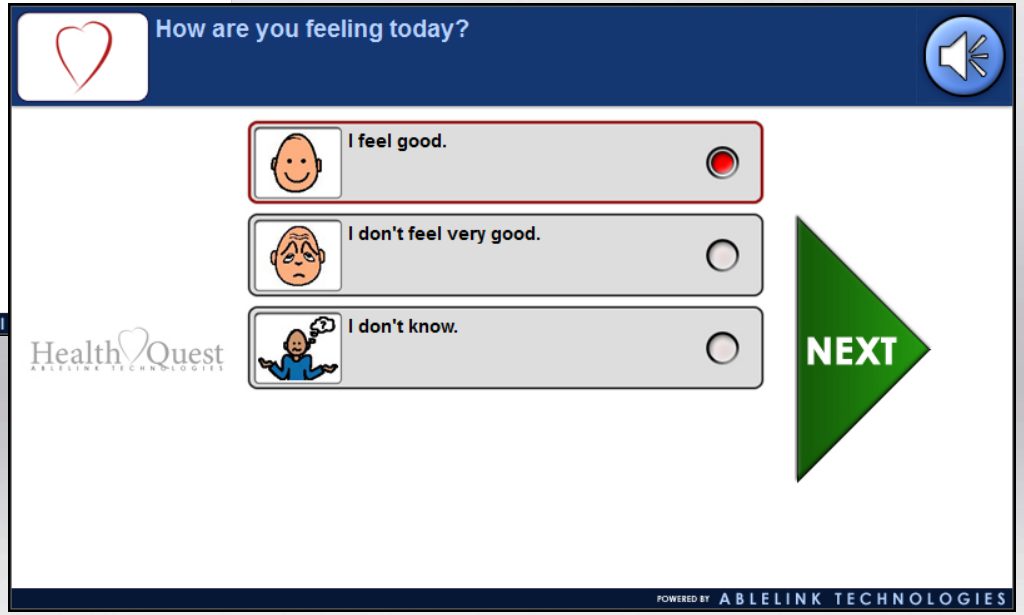
Health Quest

An accessible survey tools to enable individuals with cognitive disabilities to become active participants in their own health and wellness.





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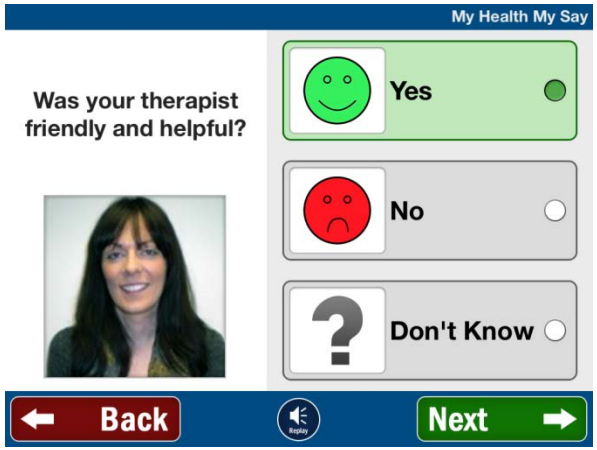
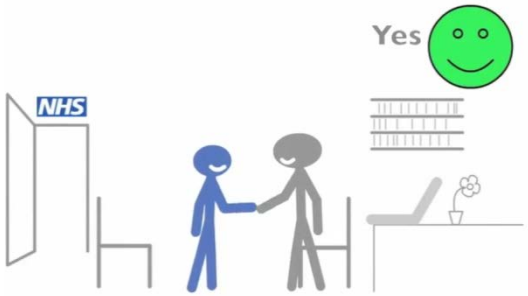
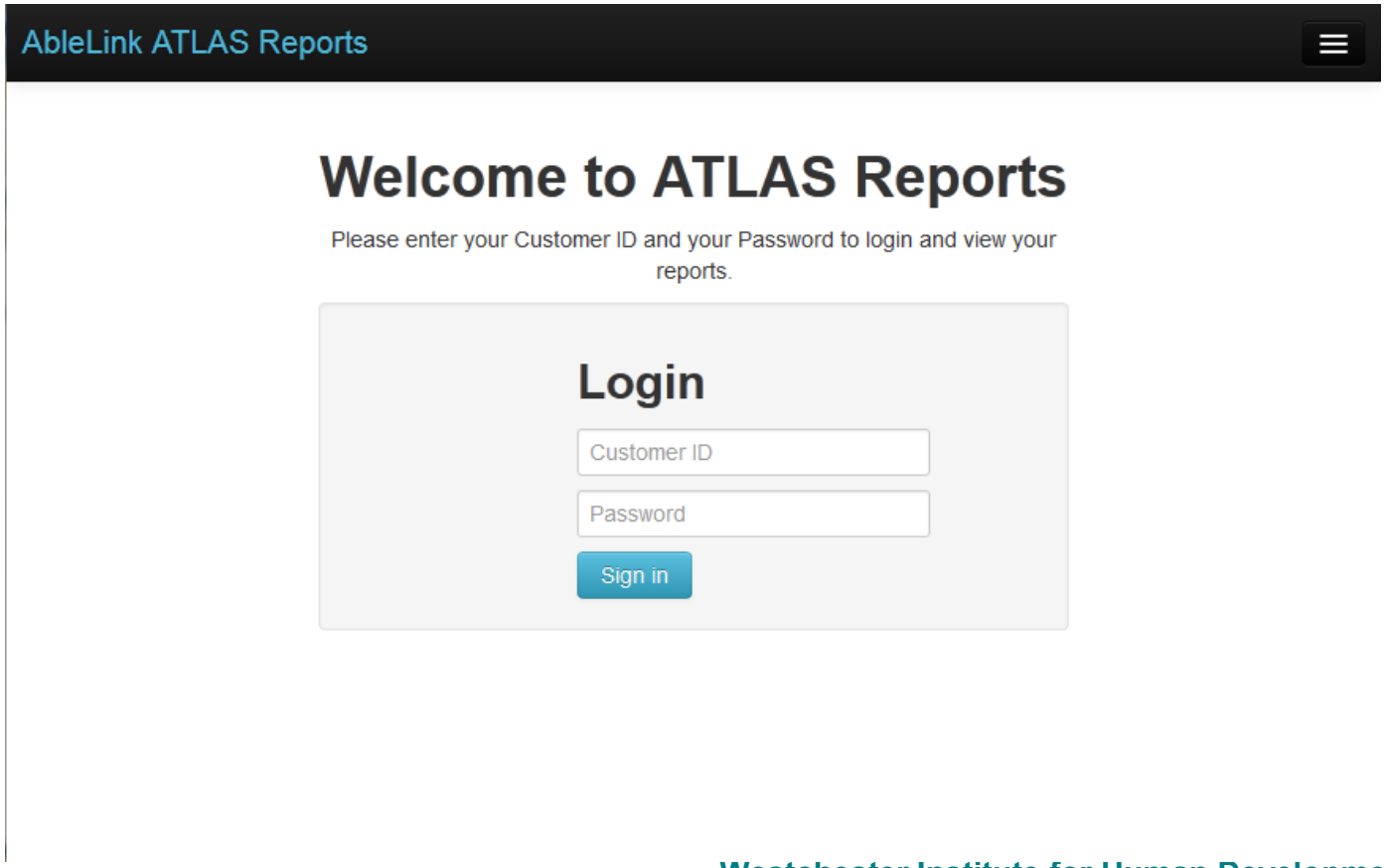
NHS Patient Experience Survey – My Health, My Say

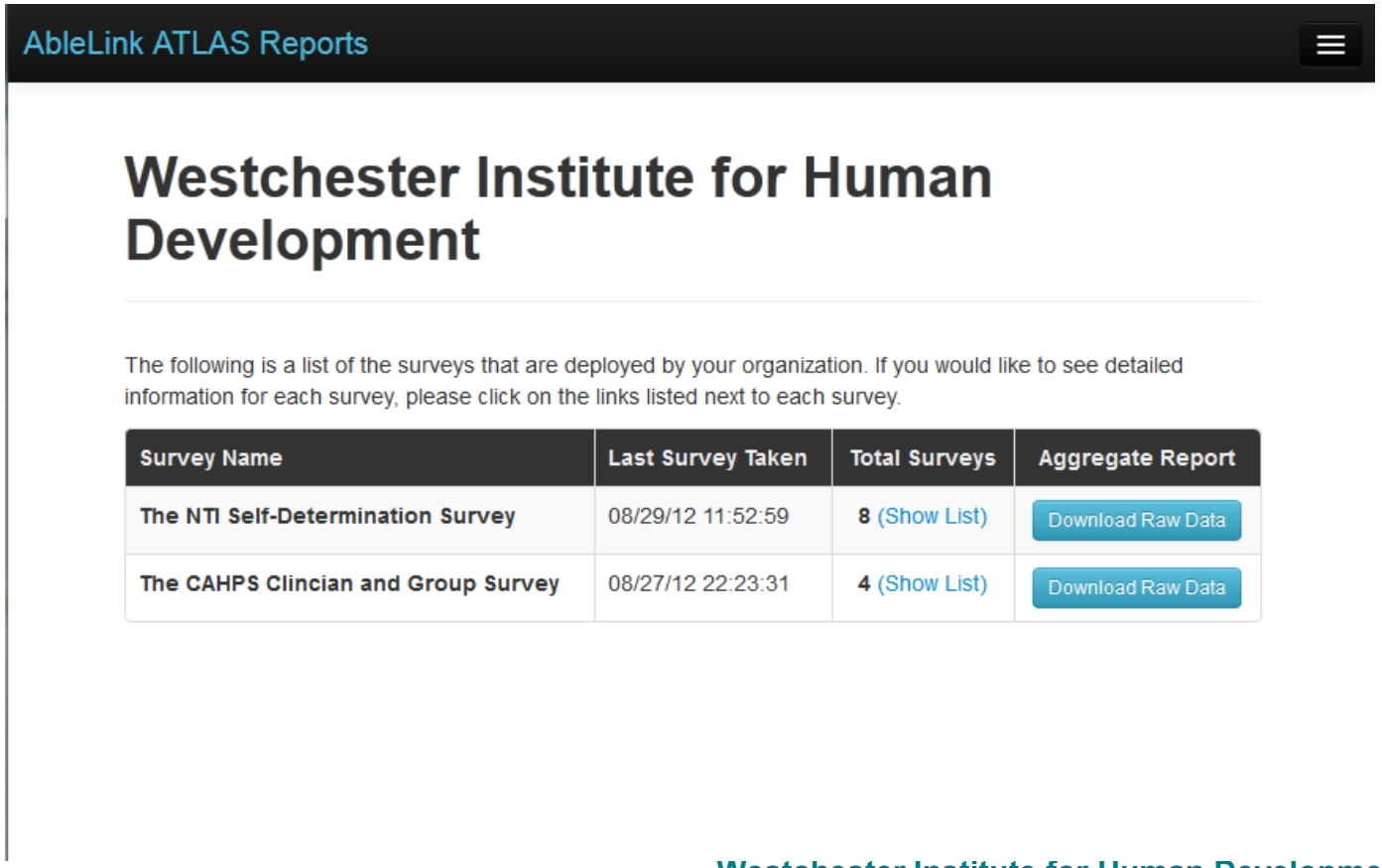




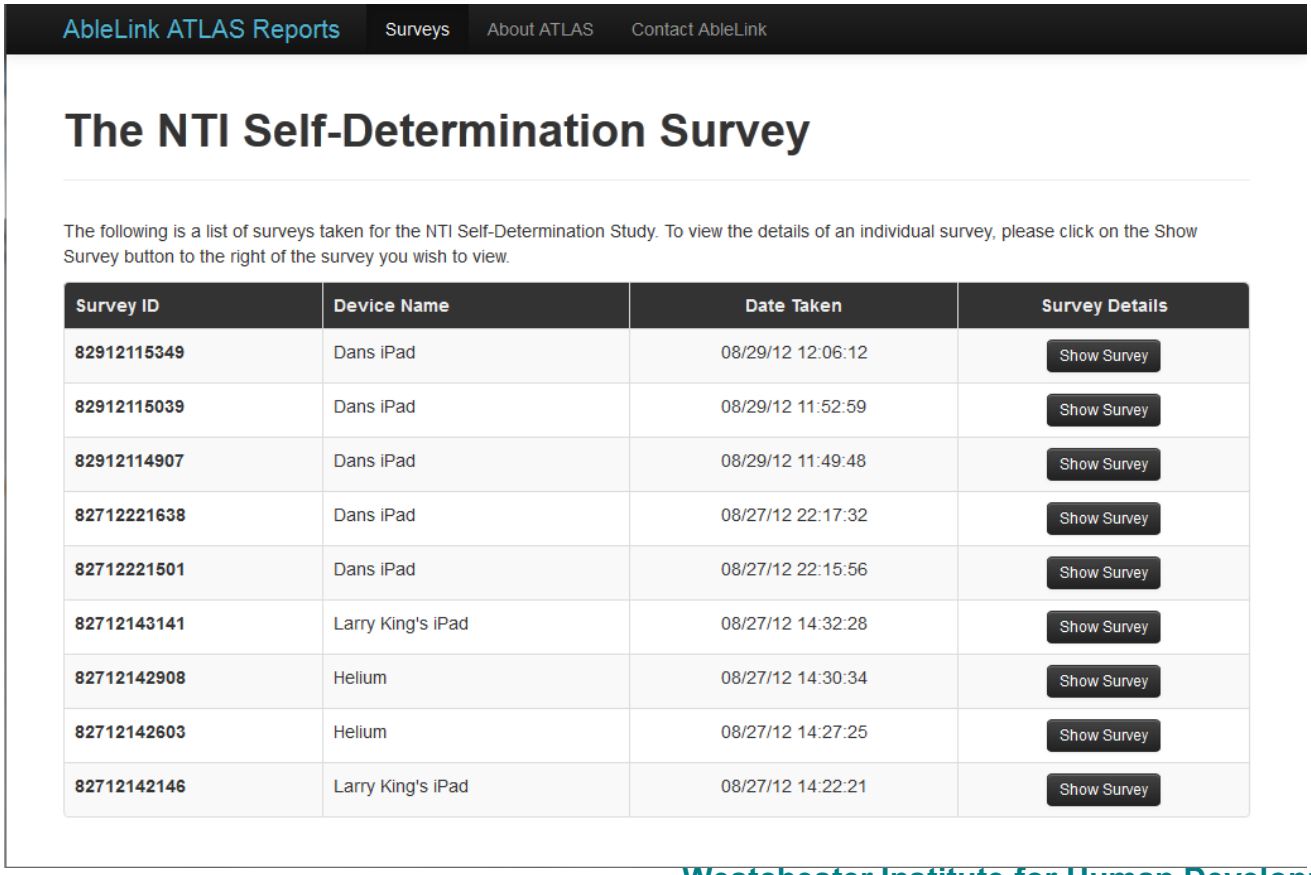
Access to Cloud-Based Data



Survey Response Summary



Survey Response Detail



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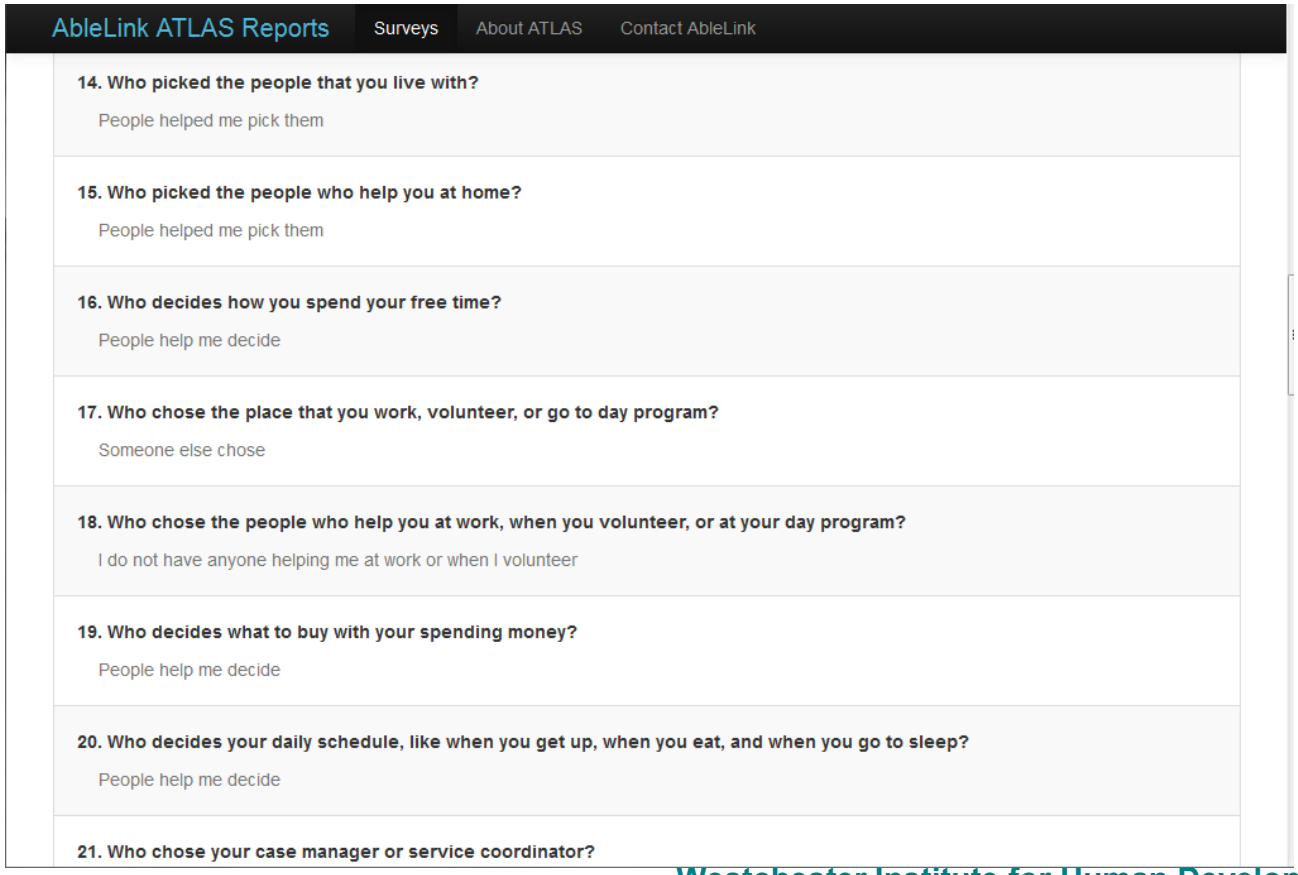
The NTI Self-Determination Survey

The following is a list of surveys taken for the NTI Self-Determination Study. To view the details of an individual survey, please click on the Show Survey button to the right of the survey you wish to view.

Survey ID	Device Name	Date Taken	Survey Details
82912115349	Dans iPad	08/29/12 12:06:12	Show Survey
82912115039	Dans iPad	08/29/12 11:52:59	Show Survey
82912114907	Dans iPad	08/29/12 11:49:48	Show Survey
82712221638	Dans iPad	08/27/12 22:17:32	Show Survey
82712221501	Dans iPad	08/27/12 22:15:56	Show Survey
82712143141	Larry King's iPad	08/27/12 14:32:28	Show Survey
82712142908	Helium	08/27/12 14:30:34	Show Survey
82712142603	Helium	08/27/12 14:27:25	Show Survey
82712142146	Larry King's iPad	08/27/12 14:22:21	Show Survey

Individual Responses



The Future

2014-2015 - Health Information Technology Fellow

- one of 12 selected by the Office of the National Coordinator for Health Information Technology

Projects:

- Foundation grant submitted to evaluate the effectiveness of using smart technology to improve the oral health of people with I/DD.
- Joint planning grant: WIHD, University of Ulster and Trinity College, Dublin to modify the UK Type 2 Diabetes standard of care for use with smart technologies and people with IDD
- Proposal accepted by Special Olympics International to ensure full accessibility of their new EHR:

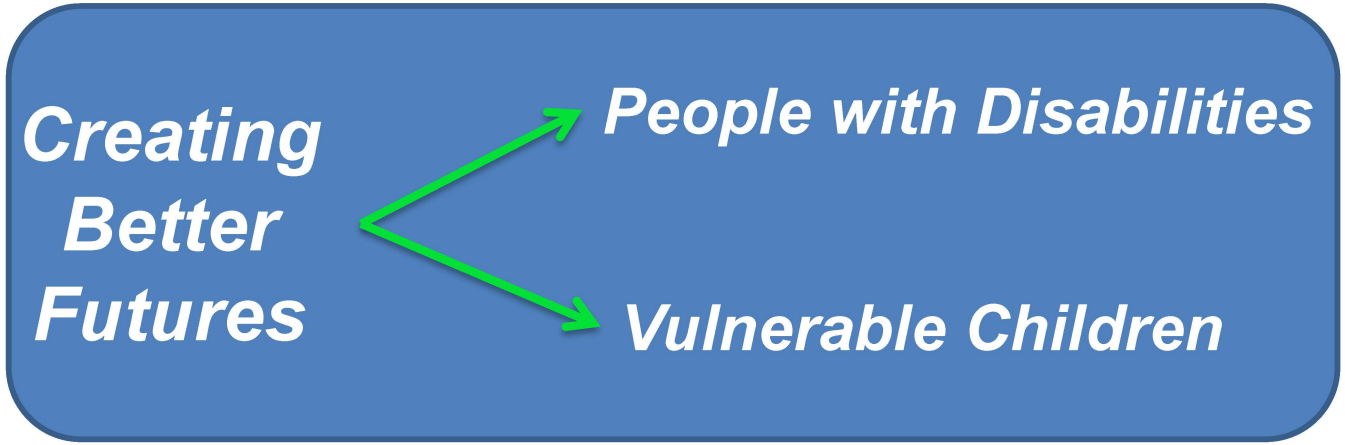
  "Positioning for the Future: Intersecting Global Digital Health, Person-Centered Technology, and Health Promotion"
- Grant proposal with Cleveland Clinic to create a "virtual" consultation team to primary care physicians of adults with Down Syndrome

The Future

Projects:

- Develop and deploy accessible health education, health promotion and wellness resources through currently available EHR's
- Integrate direct response patient satisfaction survey into WIHD Patient-Centered Medical Home model of care
- Create Apps for use smart technologies to support transitions for young adults with I/DD from pediatric to adult health care
- Adapt UK NHS "simple" telehealth strategy so that it is accessible for people with IDD
- "Encourage" EHR vendors to explore integration of health and social care information and goals

WIHD Today

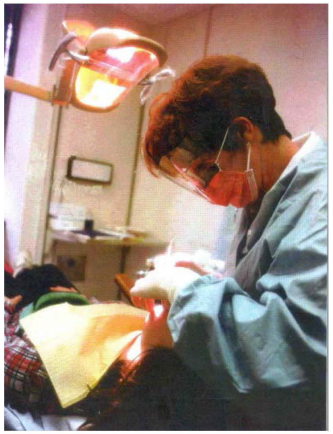


- Education and Training
- Innovative Services and Supports
- Community Training and Technical Assistance
- Research and Dissemination

Programs and Services

For People with I/DD

- Health Center
- Assistive Technology
- Speech and Hearing Center
- Behavioral Psychology
- Early Intervention
- Community Support



For Vulnerable Children

- Children's Advocacy Center (Child Abuse)
- Child Welfare Services

WIHD Health Services

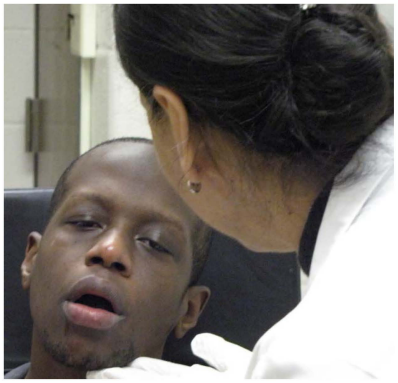
Outpatient Health Center

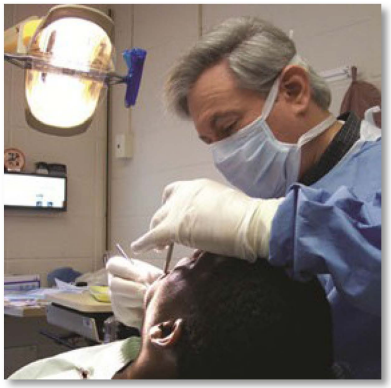
- Primary Care (Internal Medicine and/or Family Practice)
- Specialty Care (Neurology, Endocrinology, Cardiology, ENT, GYN, Physiatry, Podiatry, Ophthalmology, Urology, Gastroenterology, Nutrition, Psychology)
- Psychiatry
- Behavioral Psychology
- Dentistry
- Dental Van
- Speech and Hearing Center
- Assistive Technology

- 7,000 patients with I/DD
- 33,000 visits

Health Service Use:
Profile of one community agency (2012)

- 176 individuals with I/DD
- 2219 visits in total
- 12.6 = Average visits/individual
- 47 different addresses





Same Community Agency: Services Used

- Dental - 148
- Audiology - 113
- Endocrinology - 76
- Primary Care - 71
- Neurology - 62
- Ophthalmology- 52
- Psychiatry - 37
- Podiatry - 36
- ENT - 26
- Physiatry -17
- Urology - 11
- Cardiology - 9
- GYN - 7
- Nutrition - 5
- Speech - 1
- Metabolic Disorders - 1

Health Service Use of Individuals seen by Psychiatry (2012)

- 697 Individuals
- 5342 visits to psychiatry
- 7.7 = Average visits per patient

Other services utilized by these individuals

SERVICE	INDIVIDUALS	VISITS
Primary Care	478	2327
Dental	455	1710
Audiology	359	453
Ophthalmology	321	416
Neurology	266	797
Podiatry	220	680
Endocrinology	174	762
Urology, ENT, Physiatry, Nutrition, Cardiology	51-90	127-183
GYN, Speech, Behavioral Psychology, AT, Dermatology, OT, Metabolic	3-13	2-221