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

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Joint meeting sponsored by the Office of the National Coordinator for Health Information Technology and the Administration for Community Living
October 16, 2014
Emerging Cognitive Support Technologies:

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

Concern for man himself and his fate must always constitute the chief objective of all technological endeavors...in order that the creations of our minds shall be a blessing and not a curse to mankind.

Albert Einstein
Science & Happiness
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

The Wagner Chronic Care Model

The Care Model

Community
- Resources and Policies
- Self-Management Support

Health Systems
- Organization of Health Care
- Delivery System Design
- Decision Support
- Clinical Information Systems

Services
- Patient-Centered
- Timely and Efficient
- Evidence-Based & Safe
- Coordinated

Improved Outcomes
- Informed, Empowered Patient and Family
- Productive Interactions
- Prepared, Proactive Practice Team
Health Literacy

• Institute of Medicine workshop reports:
  o Promoting health literacy to encourage prevention and wellness (November 1, 2011)
    Research to find better pathways to improved health literacy and better health
  
  o Innovations in health literacy (March 10, 2011)
    Health literacy and health disparities, better use of IT improve health literacy
  
  o 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.”

Living Well With a Disability: a Person-Centered Planning Tool for Integrating Personal Life Goals with a Health and Wellness Plan
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.
Did you and the doctor talk about things you could do to stay healthy?

- Yes
- No
Did the doctor ask you to talk about all of your health problems or concerns?
Health Quest

An accessible survey tools to enable individuals with cognitive disabilities to become active participants in their own health and wellness.
NHS Patient Experience Survey – My Health, My Say
Access to Cloud-Based Data

Welcome to ATLAS Reports
Please enter your Customer ID and your Password to login and view your reports.

Login
Customer ID

Password

Sign in
Survey Response Summary

### Westchester Institute for Human Development

The following is a list of the surveys that are deployed by your organization. If you would like to see detailed information for each survey, please click on the links listed next to each survey.

<table>
<thead>
<tr>
<th>Survey Name</th>
<th>Last Survey Taken</th>
<th>Total Surveys</th>
<th>Aggregate Report</th>
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<td>The NTI Self-Determination Survey</td>
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<td>8 (Show List)</td>
<td>Download Raw Data</td>
</tr>
<tr>
<td>The CAHPS Clinician and Group Survey</td>
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<td>4 (Show List)</td>
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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.

<table>
<thead>
<tr>
<th>Survey ID</th>
<th>Device Name</th>
<th>Date Taken</th>
<th>Survey Details</th>
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<td>Larry King's iPad</td>
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<td>82712142908</td>
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<td>82712142146</td>
<td>Larry King's iPad</td>
<td>08/27/12 14:22:21</td>
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</tbody>
</table>
Individual Responses

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Who picked the people that you live with?</td>
<td>People helped me pick them</td>
</tr>
<tr>
<td>15. Who picked the people who help you at home?</td>
<td>People helped me pick them</td>
</tr>
<tr>
<td>16. Who decides how you spend your free time?</td>
<td>People help me decide</td>
</tr>
<tr>
<td>17. Who chose the place that you work, volunteer, or go to day program?</td>
<td>Someone else chose</td>
</tr>
<tr>
<td>18. Who chose the people who help you at work, when you volunteer, or at your day program?</td>
<td>I do not have anyone helping me at work or when I volunteer</td>
</tr>
<tr>
<td>19. Who decides what to buy with your spending money?</td>
<td>People help me decide</td>
</tr>
<tr>
<td>20. Who decides your daily schedule, like when you get up, when you eat, and when you go to sleep?</td>
<td>People help me decide</td>
</tr>
<tr>
<td>21. Who chose your case manager or service coordinator?</td>
<td></td>
</tr>
</tbody>
</table>
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
Creating Better Futures

People with Disabilities

Vulnerable Children

- 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
Outpatient Health Center

- Primary Care (Internal Medicine and/or Family Practice)
- Specialty Care (Neurology, Endocrinology, Cardiology, ENT, GYN, Psychiatry, 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

<table>
<thead>
<tr>
<th>Service</th>
<th>Count</th>
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</thead>
<tbody>
<tr>
<td>Dental</td>
<td>148</td>
</tr>
<tr>
<td>Audiology</td>
<td>113</td>
</tr>
<tr>
<td>Endocrinology</td>
<td>76</td>
</tr>
<tr>
<td>Primary Care</td>
<td>71</td>
</tr>
<tr>
<td>Neurology</td>
<td>62</td>
</tr>
<tr>
<td>Ophthalmology</td>
<td>52</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>37</td>
</tr>
<tr>
<td>Podiatry</td>
<td>36</td>
</tr>
<tr>
<td>ENT</td>
<td>26</td>
</tr>
<tr>
<td>Physiatry</td>
<td>17</td>
</tr>
<tr>
<td>Urology</td>
<td>11</td>
</tr>
<tr>
<td>Cardiology</td>
<td>9</td>
</tr>
<tr>
<td>GYN</td>
<td>7</td>
</tr>
<tr>
<td>Nutrition</td>
<td>5</td>
</tr>
<tr>
<td>Speech</td>
<td>1</td>
</tr>
<tr>
<td>Metabolic Disorders</td>
<td>1</td>
</tr>
</tbody>
</table>
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

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