Lessons Learned in Massachusetts Using NCI Data

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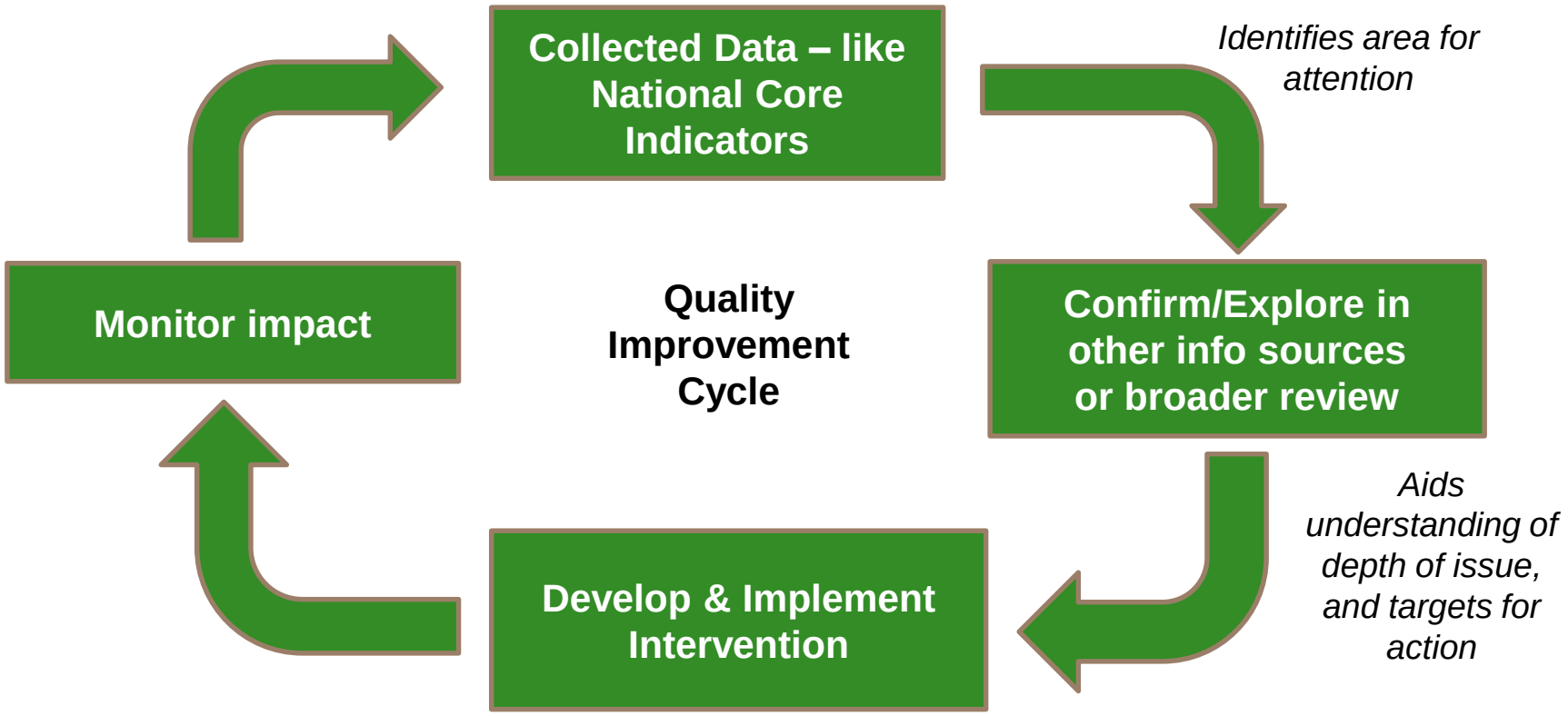
Use of Info in the Quality Improvement Cycle



Tips – using data for systemic improvement

- Triangulate when possible
- Use benchmarks, select carefully
- When is a difference really a difference?
- Consider a range of audiences in how “data” is presented to ensure it’s understood and useful
- Be sure to engage discussion, don’t just show/tell

Reporting & Dissemination Products

- MA has been using NCI data to report to stakeholders starting with data from 2001-2002.
- Early stage: Prepared an annual Quality Assurance Report
  - Aggregated and analyzed multiple sources of data to offer different perspective of several outcomes and indicators of quality
- Enabled open conversations about strengths and weaknesses of the service system involving a range of stakeholders, state staff and other voices.
- Data used: NCI data, survey and certification of provider agencies, medication administration records, investigations, critical incidents, restraints and others!

Evolution of Reporting

- Early Reporting
  - Highly informative
  - Format was dense, had a LOT of info *(80 pgs!)*
  - Challenge to get to the main takeaways
- Stage 2 of Reporting: Briefs
  - 1 topic per brief, issued throughout the year
  - More emphasis on simple, understandable presentation

Evolution of Reporting

- Stage 3 – Infographics
  - Format used to focus on the main findings
  - Didn't require the reading of as much text
  - "At-a-glance" reading style
  - Tested with a variety of stakeholders
- Allowed for a more focused, engaged conversation across stakeholders

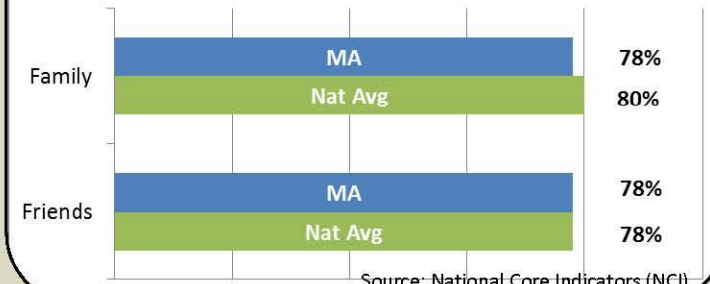
→ Let's look at some examples…

Massachusetts DDS Quality Assurance Brief

People with intellectual and developmental disabilities are supported to:

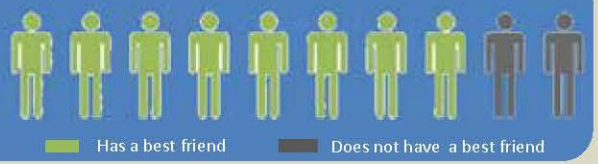
Develop and Maintain Relationships with Family and Friends

People receive the support they need to visit family and friends FY14



8 out of 10 people have a best friend

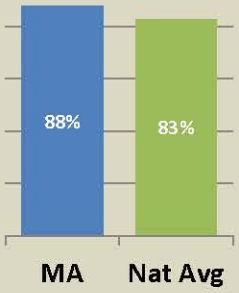
(Source: NCI FY14)



4 out of 10 people feel lonely at least half of the time

(Source: NCI FY14)

People can go on a date, or can date with some restrictions, if they want (NCI, FY14)



Providers support people to explore, define, and express their need for intimacy (L&C data)

Most Recent Licensure and Certification Data FY15

Providers support people to:

No significant changes FY12 – FY15

Licensure and certification (L&C) data include community-based homes with staff support, individualized home supports, placement services and day programs. **NCI data** include these populations, as well as people living independently or with their parents. The NCI survey asks about **people's satisfaction** with specific outcomes. Licensure and certification assesses whether **people are supported** by staff to achieve personal outcomes.

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Acting on the findings

- Loneliness finding was an important launching ground for a social inclusion initiative
- Findings were presented to MA DDS's Quality Council that includes varied stakeholders
- Impact of efforts in this area are being tracked

Massachusetts DDS Quality Assurance Brief

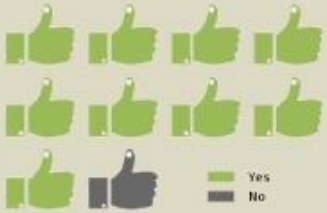
People with intellectual and developmental disabilities are supported to:

OUTCOMES

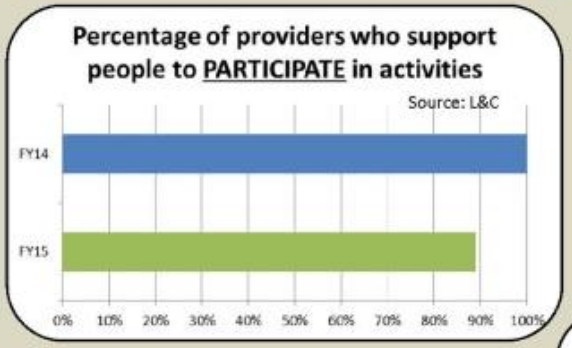
- **Access the community**
- **Regularly participate in community activities**

92% of providers surveyed in FY15 support people to EXPLORE their interests in cultural, social, recreational, and spiritual activities. This has remained above 90% for the past 4 fiscal years. Source: L&C Data

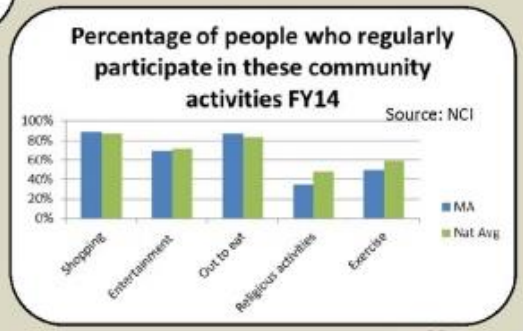
9 out of 10 providers provide community activities



Source: Licensure and Certification Data (L&C). 90% or more of providers surveyed over the past 4 fiscal years met the standard for providing community activities based on people's preferences and interests.



Licensure and certification data (L&C) include community-based homes with staff support, individualized home supports, placement services and day programs. **National Core Indicators (NCI) data** include these populations, as well as people living independently or with their parents. The NCI survey asks about **people's satisfaction** with specific outcomes . Licensure and certification assesses whether **people are supported** by staff to achieve personal outcomes.



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Quality is No Accident Briefs

- Started in 2010
- Audience: House Managers, Service Coordinators, Families
- Briefs of topical focus
  - Identify risks, strategies to manage the risks, and data about the topic
  - Includes “Did you know?” facts to help inform and dispel misconceptions.

Example Brief

Quality Is No Accident

Massachusetts DDS • Quality & Risk Management Brief • Dec 2012 Issue#7

Oral Health

People with ID are more likely to have poor oral health and poor oral hygiene than people in the general population, along with higher rates of caries, gingivitis and other periodontal diseases.

Oral health disease may develop and persist in adults with ID due to: fear of dentists or dental procedures that prevent individuals from receiving needed care; physical or behavioral limitations that make it difficult to maintain oral hygiene or cooperate during dental visits; access barriers to dental clinics or services; and lack of knowledge from caregivers on proper oral hygiene support strategies.

In many cases, associated conditions can place individuals with ID at an even greater risk for oral disease. People with Down syndrome, for example, have jaw structure that can cause mouth breathing, which can result in oral dryness and increased caries. People with ID generally experience greater rates of obesity, and are therefore likely at greater risk for Type II diabetes, which in turn has a greater risk for periodontitis. There may also be a link between poor oral health and other health conditions such as heart disease.

People with ID may require assistance or oversight from staff in maintaining essential good oral hygiene habits like tooth brushing, flossing, and use of oral rinses. Developing strategies for improving routine care may help staff to support good oral hygiene, along with effective use of clinical strategies to enhance dental encounters.

DID YOU KNOW?

Rates of untreated caries are consistently higher in adults with ID than in the general population.

Periodontal disease is present is over 90% of adults with Down syndrome (Pilcher, 1998).

Special Olympics reports that 39% of the athletes screened have visible, untreated dental decay.

DDS recommends that all adults receive dental checkups at least once every 6 months.

About 83% of adults with ID living in DDS-funded residential supports had at least one dental exam in FY 2010-2011.

Glossary of Dental Health Terms

Periodontal Disease: another name for gum disease, like gingivitis or periodontitis.

Caries: tooth decay or "cavities."

Gingivitis: inflammation and infection of the gums. Gum tissue is swollen, reddish, and may bleed easily when touched or brushed.

Periodontitis: infection and inflammation spreads from the gums to the ligaments and bone that support the teeth. The inner layer of the gum and bone pull away from the teeth causing the teeth to become loose and eventually fall out.

Quality Is No Accident was developed by the Center for Developmental Disabilities Evaluation and Research (CDDER) of the E.K. Shriver Center/University of Massachusetts Medical School in collaboration with the Massachusetts DDS.

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Prevention

Promoting good oral care at home

Consider these strategies:

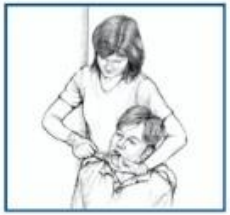
Build Individual and Caregiver Knowledge: Do not assume that people with ID or caregivers have the same understanding of proper brushing and flossing or the same appreciation of good oral hygiene. The American Dental Association is a good resource for increasing knowledge: http://www.mouthhealthy.org

Understand Risk Factors for Oral Disease in adults with ID: This includes tobacco use; dependence on others for care of teeth and gums; mouth breathing, which can result in oral dryness and increased caries; dry mouth, sometimes caused by medications; and age, which helps determine someone's risk for periodontal disease, gingivitis, and caries (more on age correlation with disease on p.4).

Recognize Behavioral Signs of Mouth Pain: Pain from mouth or gum infection or disease may result in ear-rubbing, head banging, or face-striking on one or both sides of the head; disturbed sleep or eating; gum-rubbing, drooling, biting or chewing; and general unhappiness or irritability. These symptoms should be investigated to determine if there is a cause related to oral health. Be aware that some adults with ID have an increased tolerance for pain.

Try creative approaches to enhance oral health habits

- Location – Consider a location other than the bathroom, like a kitchen or living room, would be more comfortable for brushing teeth.
- Encourage people to hold special items or listen to music while brushing.
- Adapt equipment to promote independent function, for example by sliding a bicycle grip onto a toothbrush handle (top figure).
- Caregivers can assist with brushing by using good lighting and assuming a supportive position: stand behind the person, lean against a wall for support, and gently holding the person's head against their body (bottom figure).
- Tell-show-do: Tell the person about each step, show the equipment and process, do the steps. Offer positive reinforcement for each step.



Resources

Preventive Care in Special Care Dentistry open courseware from Tufts: http://ocw.tufts.edu/Course/56/
Content in this course includes:
Brushing techniques: http://ocw.tufts.edu/Content/56/learningunits/675434
Oral desensitization & Task analysis to overcome resistance to tooth brushing and learn step-by-step steps for brushing: http://ocw.tufts.edu/Content/56/learningunits/675434

Dental Care Every Day: **A Caregiver's Guide** to helping someone brush, floss and have a healthy mouth http://www.nidcr.nih.gov/OralHealth/Topics/DevelopmentalDisabilities/DentalCareEveryDay.htm

Oral Motor Products, for example, an 'extra grip' toothbrush handle or a Mouth Rest Prop: http://www.white2th.com/products/oral_motor_products/oral_motor_products/ Northampton, MA

Support for the Oral Health Exam

Many people experience apprehension at visiting the dentist and present differing responses to the oral exam. Individuals with low cooperation levels may not receive all of the oral health treatments that they need. Enhancing the ability to receive good oral health care includes supporting people to move up the Cooperation Level Scale. This increases their likelihood of accepting dental evaluations and treatment procedures.

One way this tool can be used is to assess an individual's baseline cooperation level, implement strategies for improving cooperation (see below), and reassessing at a later time to determine the effectiveness of the strategies.

Cooperation Level Scale.*

0 Does not enter clinic, dental chair or both
1 Sits in dental chair only
2 Allows brushing of teeth, visual examination or both
3 Allows dental examination and practitioner to place dental instruments intraorally; requires behavioral assistance from caregiver, dental assistant or both
4 Allows dental procedures; requires behavioral assistance from caregiver, dental assistant or both more than 50 percent of time
5 Allows dental procedures; requires behavioral assistance from caregiver, dental assistant or both less than 50 percent of time
6 Allows dental procedures; needs no assistance

* Developed by clinicians at Tufts Dental Facilities Serving Persons with Special Needs, Massachusetts.

In a study of 4,710 adults with ID, more than half were able to have a dental exam with only minor assistance (levels 5 & 6). 40% required behavioral assistance more than 50% of the time (Levels 3 & 4). (Morgan, 2012)

Strategies for enhancing the oral health exam

Before the Exam	During the Exam
Know the person's dental history and past successes or challenges in staff supporting the person.	Encourage the person to bring comfort items from home such as a favorite book or pillow.
Use pictures, videos, or actual dental equipment to familiarize the individual to equipment and procedures they may encounter at the dental visit.	Offer positive reinforcement and highlight achievements as the individual progresses through each step of the procedure.
Schedule appointments early in the day if possible to help ensure that everyone is alert and attentive and that office waiting time is reduced.	Accompany the person into the dental area and offer reassurance by holding their hand, patting their shoulder, or maintaining conversations, if helpful for the person.
Check with office staff to see if the individuals can visit the office once before beginning treatment.	Allow the individual extra time to get comfortable with the office, staff, and with the dental chair.
Keep appointments short and postpone difficult procedures until after the person is familiar with the dental staff.	Help control for unexpected movements due to noise, vibration, or water by clearly explaining each step to the individual.
Control for environmental stimulus that may bother the individual such as bright lights or overhead radio.	If someone is particularly anxious or an invasive screening procedure is necessary, the clinician might consider sedation prior to the appointment.

Information provided from the Tufts Open Courseware course *Special Care in Dentistry,* Spring 2008 and the National Institute of Dental and Craniofacial Research:
http://www.nidcr.nih.gov/OralHealth/Topics/DevelopmentalDisabilities/PracticalOralCarePeopleIntellectualDisability.htm

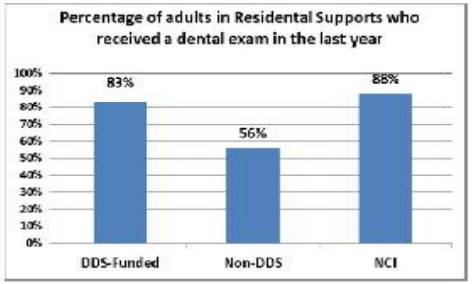
Dental Screening and Disease

Current oral health status of Adults with ID in Massachusetts

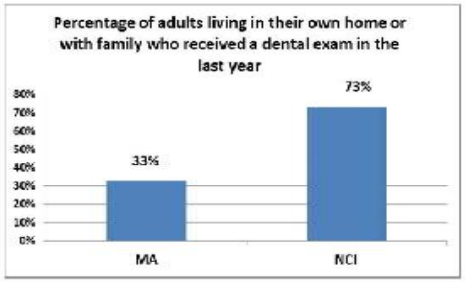
Receipt of Dental Exams

An analysis of electronic DDS Health Care Records in fiscal year 2010-2011 revealed that 83% of adults in DDS-funded residential supports received a dental exam in the last year. A smaller percentage of adults living in Non-DDS residential supports (56%), and adults living in their own home or with their family (33%) reported receiving an exam*.

*Includes adults with DDS electronic healthcare records.



Similarly, face-to-face interviews were conducted in 2008-2009 as part of the National Core Indicators project (www.nationalcoreindicators.org) with Massachusetts adults with ID. Results indicated that 88% of adults in DDS residential supports had received a dental exam in the last year. This is higher than the percentage of people living in their own home or with family who reported having received a dental exam in the last year (73%).



Oral Health Status

Electronic dental records for 4,732 adults with ID who had at least one dental examination visit at a Tufts Dental Facilities in Massachusetts between April 2009 and March 2010 were analyzed with the following results:

- 87% of participants had caries experience; 32% had untreated dental carries, 80% had periodontitis, and 11% had edentulism (missing teeth).
- Caries experience varied significantly with age and was highest among those aged 40-59 years.
- Untreated caries also varied by age: Those aged 20-39 and 40-59 years had similar rates of untreated caries, but they were higher than those 60 years and older.
- The prevalence of periodontitis was highest in those 60 years and older, whereas gingivitis was more prevalent in the 20-39 age groups.

This analysis suggests that adults with ID remain vulnerable to dental diseases, despite access to comprehensive dental services (Morgan, 2012).

References

Pilches, E.S. (1998). Dental care for the patient with Down Syndrome. *DS Res & Prac*, 5(3), 111-116.
Morgan, J.P. et al (2012). The oral health status of 4,732 adults w/ intellectual & developmental disabilities. *JADA*, 143(8), 838-846.

Analyses conducted by:
Center for Developmental Disabilities Evaluation and Research (CDDER),
E.K. Shriver Center, UMass Medical School

For more information on oral health and DDS efforts, contact:
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VALUATION AND RESEARCH

Topics to date…

- Aging with Intellectual and Developmental Disability (IDD)
- Alzheimer's and Dementia
- Age-related Health Issues
- Friendships in People with Intellectual Disabilities
- Sexuality
- Safe Transportation of People in Wheelchairs
- Emergency Room and Urgent Care Strategies
- Ingestion of Foreign Objects (Pica)
- Dysphagia, Aspiration, and Choking
- Preventable Hospital Use: Dehydration, Constipation, and Urinary Tract Infection
- Constipation and Bowel Obstruction
- Oral Health
- Preventive Health Screenings
- Medication Errors
- Missing Persons
- Falls

https://shriver.umassmed.edu/programs/cdder/dds-quality-assurance-reports

Webinars

- Benefits of format
  - Allows for live participation and interaction
    - Questions, audience polling, knowledge check questions, etc.
    - Recorded and closed captions – creates longer-term, accessible resource
  - Slide-supported narrative presentation allows for more in-depth discussion of certain risks/strategies

Webinars

- Additional Benefits:
  - Can provide different sections of content for different audiences
  - Can be used in train-the-trainer format to ensure consistent messaging.
  - Affordable, efficient, effective.
  - Users can revisit/refresh training as needed.

Tips

- If using slides as a background, keep it interesting for visual users
  - Frequent movement on the screen tied to content, highlighting of concepts on slides
  - Use images – not just text
  - Don’t overdo it - avoid too many distracting slide transitions
- In developing content:
  - Consider your audience in balancing content– ex. make content understandable for non-clinicians, but informative enough for clinicians

Tips (cont.)

- For live webinars being recorded:
  - Test sound/setup before beginning
  - Encourage users to type in questions to assist with smoother Q&A section
    - Some questions are best answered outside of a live webinar format
  - Use caution (and testing!) with videos to assess bandwidth issues, especially with larger webinars
  - Employ sound-managing tools to mute listener phone lines as needed, etc.

Topics to date…

- Human Rights: What Families Need to Know
- Mandated Reporting of Abuse and Mistreatment
- Safe Transportation of People who use Wheelchairs
- Widening the Circle: Expanding Opportunities for Friendship
- Psychotropic Medications and Side Effects
- Hospice/Palliative Care: What are they?
- Best Practices for Supporting People in the ER/Advocacy
- Falls Prevention and Intervention
- Oral Health Practices
- Dysphagia, Aspiration, and Choking
- Constipation and Bowel Obstruction
- Pica and the Ingestion of Non-Food Items

Thank you!

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