# Three Novel Approaches to Using Data to Inform State-Level Policymaking

Innovative use of NCI Data in State LTSS Systems

Mary Lou Bourne
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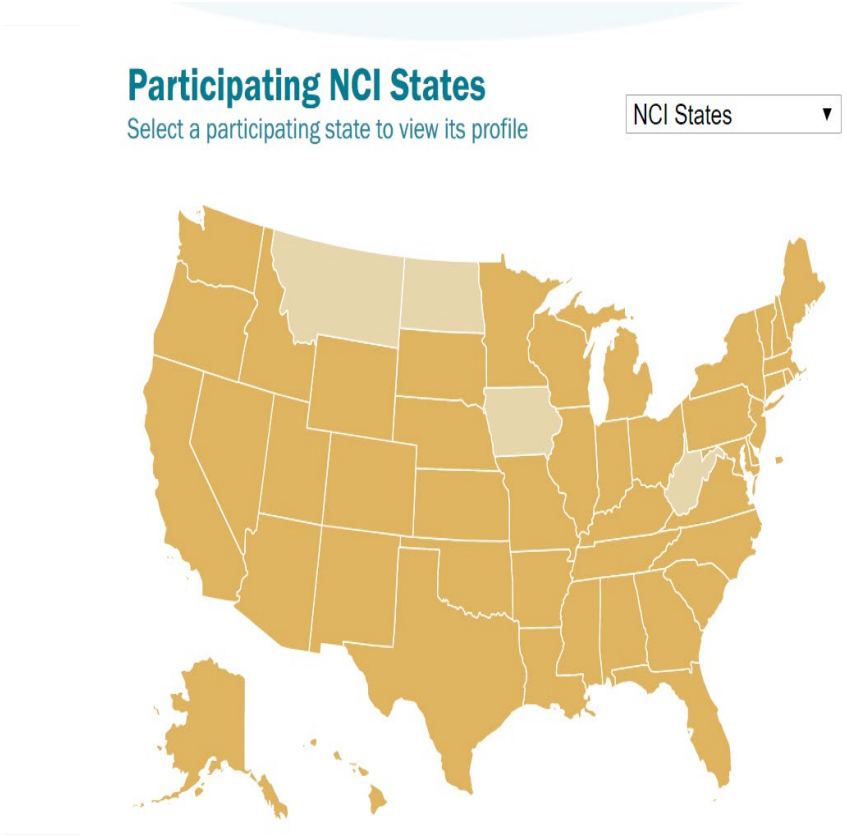
NASDDDS

# National Data

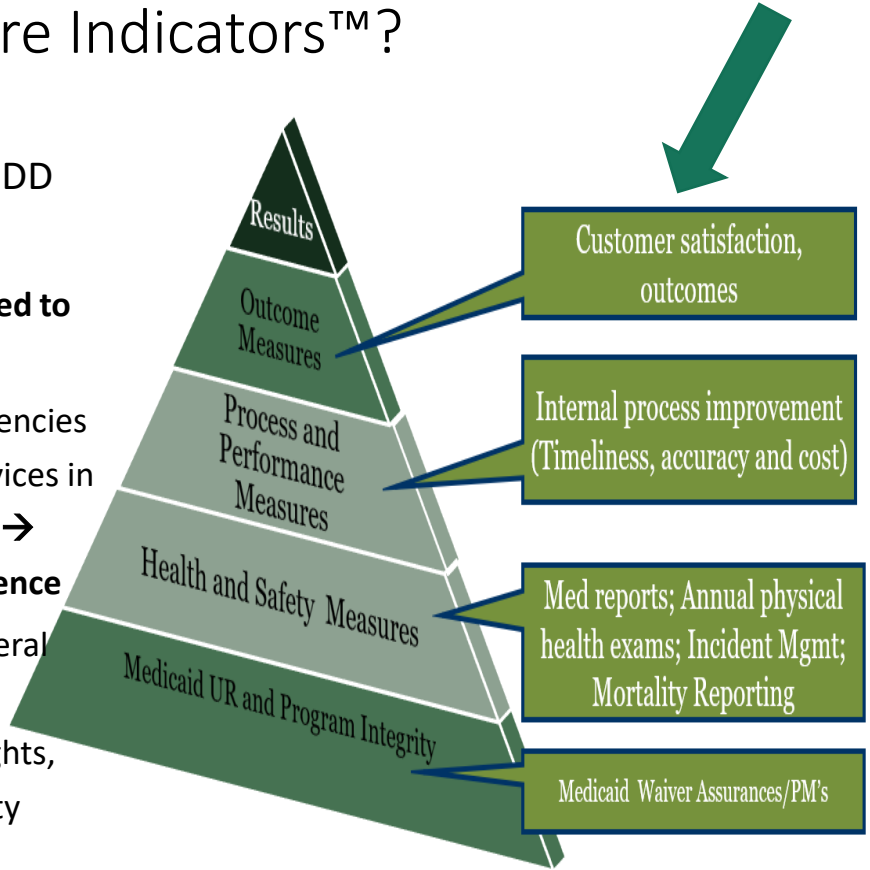



# National Core Indicators

# What is National Core Indicators™?

1997: NASDDDS, HSRI and State DD Agencies shared a common goal

- **View system performance related to outcomes**
- Beyond counting units, State Agencies want to know the impact of services in **people's lives and quality of life→ customer outcomes and experience**
- NCI looks at performance in several areas, including: employment, community inclusion, choice, rights, satisfaction and health and safety




NATIONAL CORE INDICATORS™

# How Does NCI Collect Data? 3 Types of Data Collection

## In-Person Survey

- Background Information Section
  - Data collected from existing systems data.
    - Age, gender, employment, preventive care



- Section I: Subjective, **perception** based questions answered by person receiving services in face-to-face conversation
- Section II: **Fact-based** questions. How many times…? Proxy can participate.

**Adult Family, Child Family, and Family/Guardian Surveys >>** mail surveys – separate sample In Person Survey

**Staff Stability Survey >>** sent directly to providers; information about turnover rates, wages, benefits.

NATIONAL CORE INDICATORS™

# By the Numbers:  2018-19 Data Cycle

- 44 states collected data
- 37 States Collected in-person data
- 14 states collected Adult – Family Survey data
- 14 states collected Child – Family Survey data
- 10 states collected Guardian- Family Survey data
- 27 states collected Staff Stability Workforce data

NATIONAL CORE INDICATORS™

# National Core Indicators offers a unique view


- Individual characteristics of people receiving services
- Outcomes sorted by where people live (residence type)
- Activities people engage in during the day including work outcomes
- The nature of their experiences with the supports received (with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare

NATIONAL CORE INDICATORS™

# NCI – Implications for States

# Two Key Components of All Quality Systems:

- Quality by Perception
- Quality by Fact

# Quality by Fact / Quality by Perception

- Quality by Fact--- evidentiary, indisputable, tend to be binary, can be "proven"
- Quality by Perception--- opinion, impression, influenced by senses or emotions, but nonetheless present


- Effective Quality Management Systems take a Both/And approach, rather than either/or approach to these measure types

# And the Voice of the Workforce

- 27 States
- Residential, In Home, and Non Residential Agencies
- Size of Agency reporting
- Tenure
- Turnover  and Vacancy Rates
- Voluntary and Involuntary Turnover
- Wages – Starting and Overall
- Benefits
- Comparison to Minimum Wage

# How States Use NCI Data

States Identify Initiatives, Transformation, New Program Design

- Initiatives and transitioning programs
- Demonstrate areas for improvement
- Identify progress across years
- Compare segments of data for policy development and program design
- Inform legislators and stakeholders of the need and the purpose

# Example from a state-report: Initiatives and transitioning programs

## Case Management- Conflict Free Transition

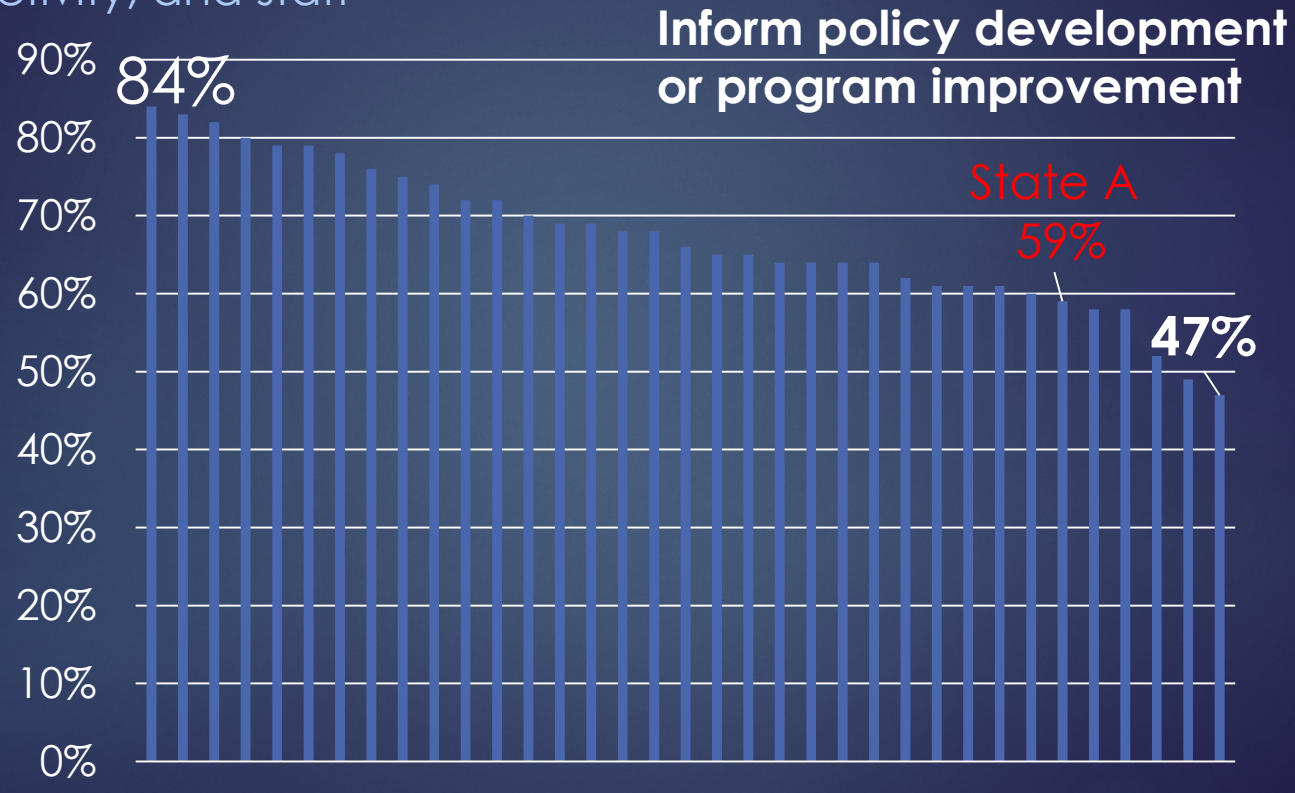
National Core Indicators™

**Table 44. Service Coordination**

| | | Yes | N |
|---|---|---|---|
| Has met case manager/service coordinator | [redacted] | 90% | 214 |
| | NCI | 95% | 13,985 |
| Case manager/service coordinator asks person what s/he wants | [redacted] | 76% | 187 |
| | NCI | 88% | 13,210 |
| Able to contact case manager/service coordinator when wants | [redacted] | 67% | 165 |
| | NCI | 87% | 12,593 |
| Took part in last service planning meeting, or had the opportunity but chose not to | [redacted] | 95% | 128 |
| | NCI | 98% | 11,911 |
| Understood what was talked about at last service planning meeting | [redacted] | 86% | 104 |
| | NCI | 83% | 11,188 |
| Last service planning meeting included people respondent wanted to be there | [redacted] | 75% | 110 |
| | NCI | 94% | 11,151 |
| Person was able to choose services they get as part of service plan | [redacted] | 77% | 115 |
| | NCI | 76% | 11,445 |
| Staff come and leave when they are supposed to | [redacted] | 89% | 204 |
| | NCI | 93% | 12,186 |

# Life decisions scale

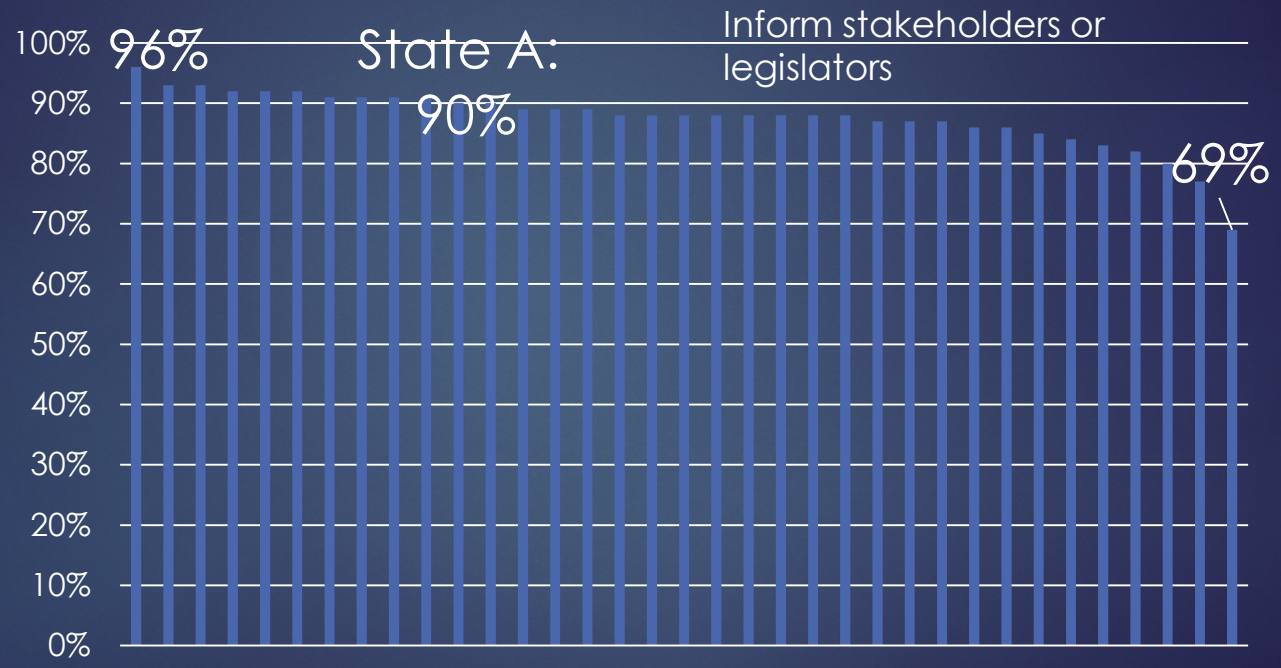
## Includes choice of: residence, roommates, work, day activity, and staff




Results of this scale are risk adjusted. Variables used as risk adjusters are: level of mobility, support needed for behavior problems, level of ID, and age.

# Everyday Choices Scale

## Includes choice of: daily schedule, how to spend money, and free time activities




Results of this scale are risk adjusted. Variables used as risk adjusters are: level of mobility, support needed for behavior problems, level of ID, and age.

# Innovation and Approaches to Using Data

3 STATE INITIATIVES

# Indiana Experiences: National Core Indicators and Employment

Derek Nord, PhD

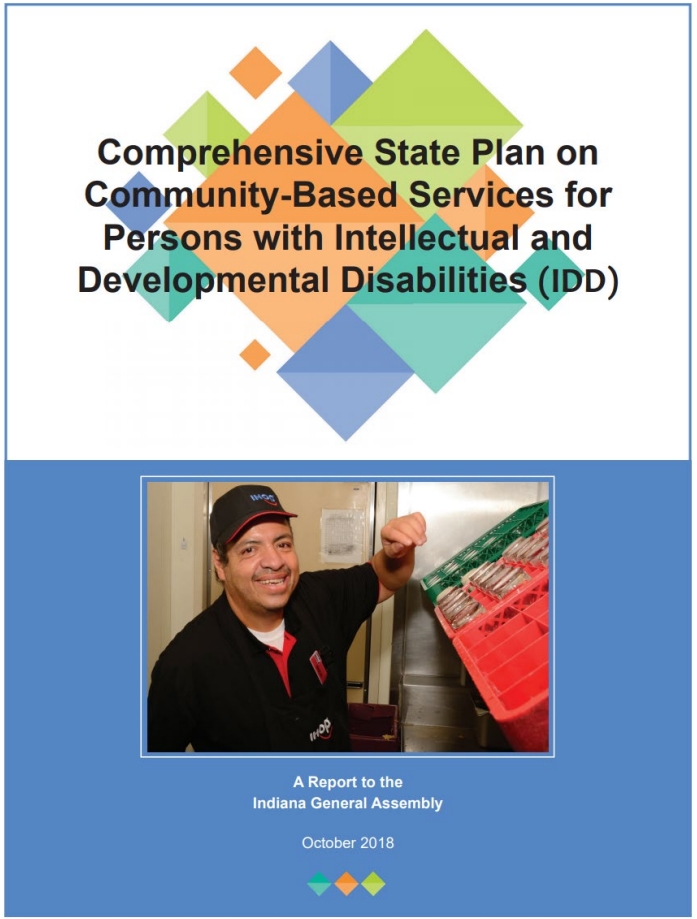
INDIANA INSTITUTE ON DISABILITY AND COMMUNITY & IU SCHOOL OF SOCIAL WORK

# Indiana Context

# State Direction Setting

**Four overarching goals:**

1. Prioritize community settings and individualized approaches.
2. Advance and maximize community/state resources.
3. Respond to individual and family needs.
4. Include a wide array of supports…



# Systems Changes

1. Waiver redesign
2. Quality assurance
3. LifeCourse integration
4. Living Well grantee state

# Policy and Other Initiatives

1. Supported decision making policy
2. Employment First policy and work group
3. Gov Council funded employment town halls
4. Expansion of pre-ets.

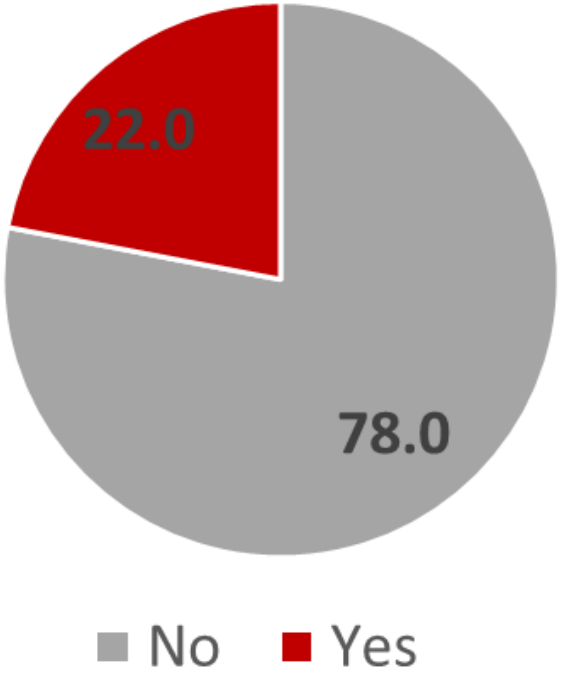
# NCI in Indiana

# Guiding our uses of NCI

1. Evaluate how we're doing.
2. Test new ideas and answer new questions.
3. Compare to other states.

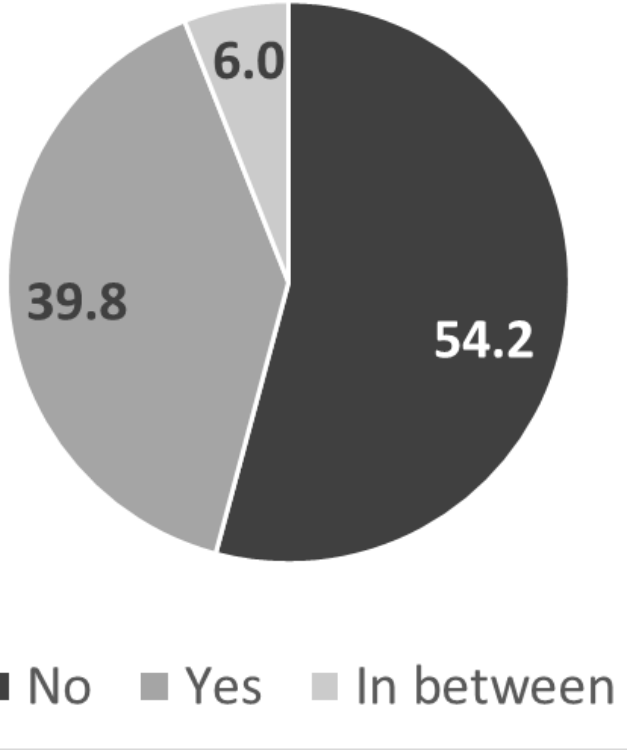
# Indiana data

## Job in the Community
N = 614



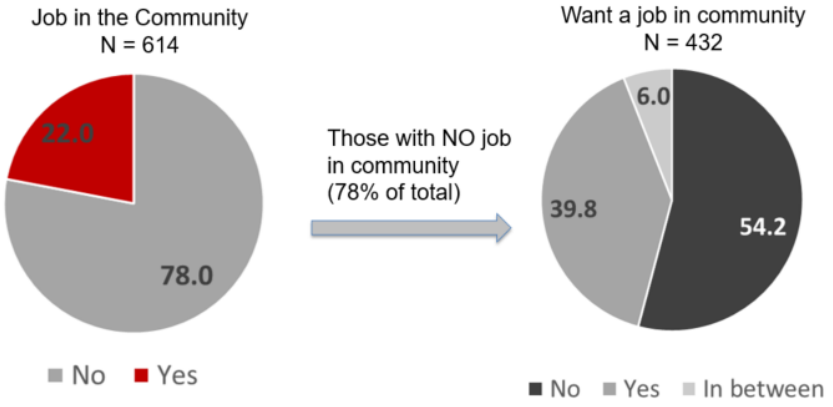

Those with NO job in community (78% of total)

## Want a job in community
N = 432



# What does this mean for systems?

1. **Demand is high**: Approximately 50% of total have or want a job.
2. **Outcomes are low**: Community employment is LOW!
3. **Limited Access:** About 46% of those with no community job would like one or are uncertain.

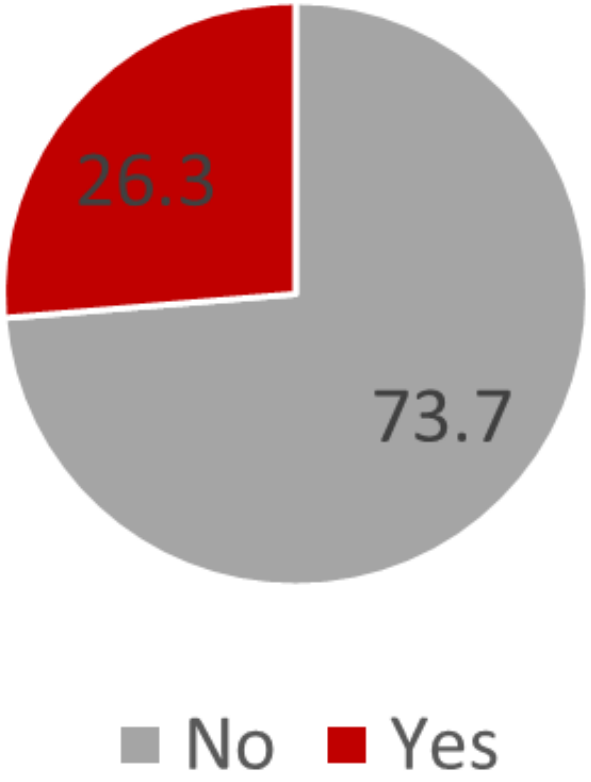


# Pushing data further… Service Planning

Of those with:

- No employment; but,
- Wanting employment

- **The vast majority do not have employment as a goal.**

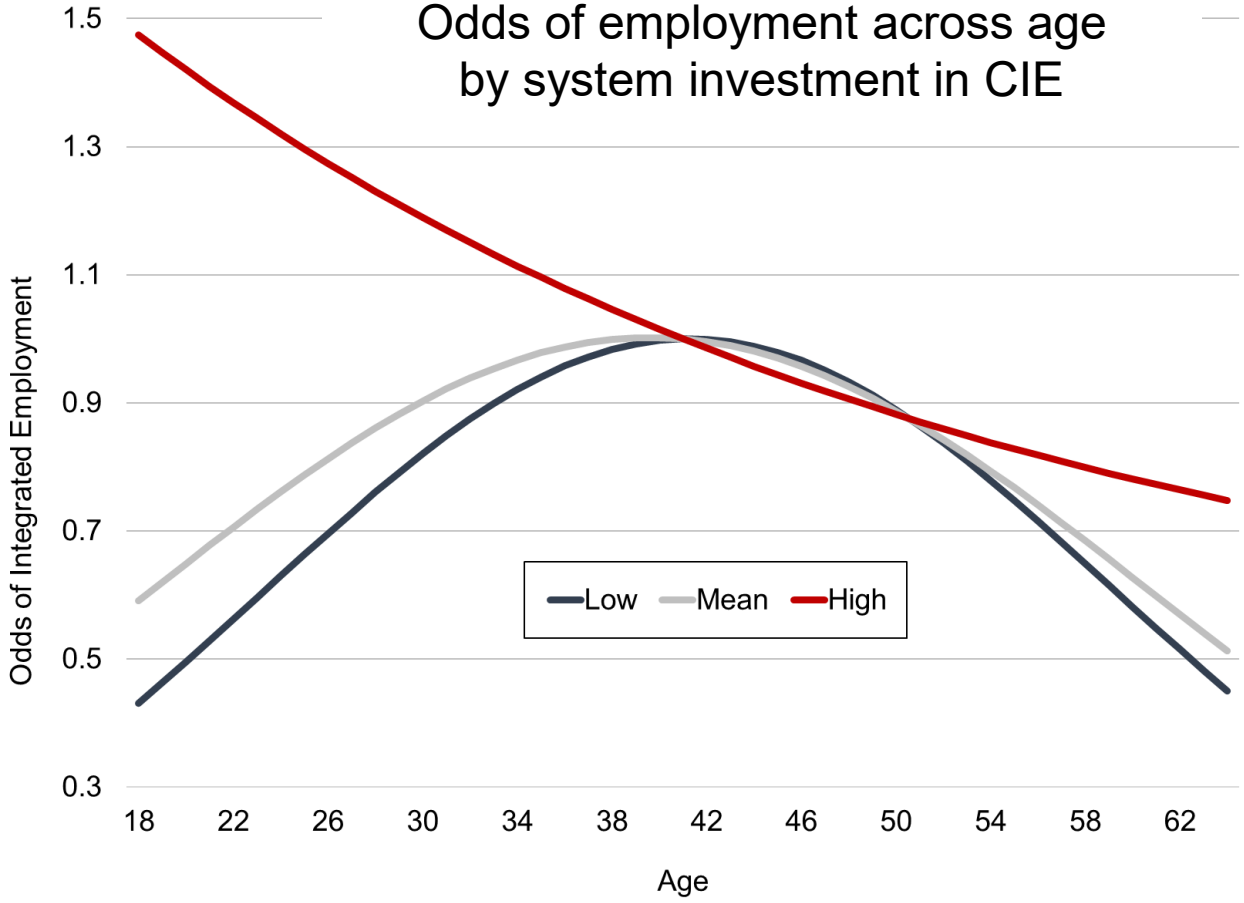


# As we navigate systems changes

1. We might prioritize a sub-population (no employed, want a job, no goal);
2. We might investigate case manager practices and policies related to goal setting, person-centered practices, and choice making;
3. We might consider exploration/education opportunities for the 54% that state they have no job and don't want one;
4. Guardians matter too.  We must look to improving in the new policy context.

# National data

- Indiana HCBS investment is low, as a pct.
- System investment matters;
- Younger people have different experiences;



# Where we’re headed

# Integrating data into decisions

1. Analyzing and presenting internally and to advisors.
2. Informing the public.
3. Supporting rationale for system changes.
4. Future linking to ask new questions.

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INDIANA INSTITUTE ON DISABILITY AND COMMUNITY

# Integrating Complex Datasets to Provide Outcome Insights for HCBS Users with IDD

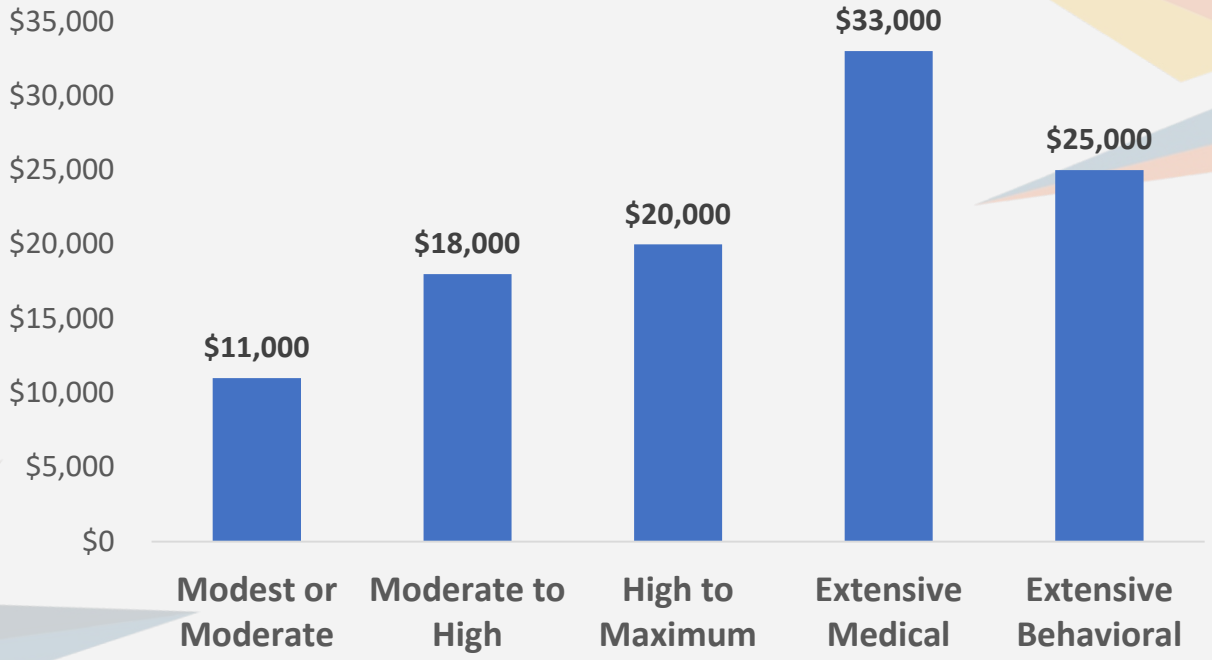
Parthy Dinora & Seb Prohn
Partnership for People with Disabilities

VCU Sc

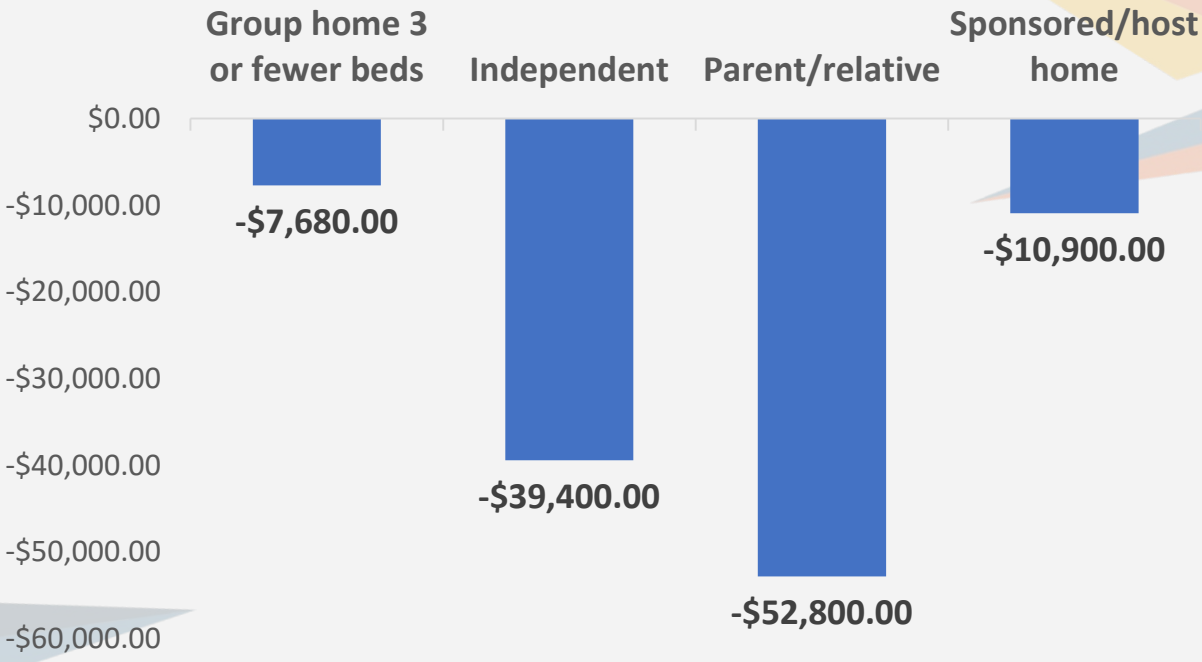
# Contexts for the Study in Virginia

# Initial Findings

# Predicted Medicaid Expenditures Compared to Least Support Needs Group ($;fy2014)



# Predicted Medicaid Expenditures Compared to Congregate settings with 4 or more beds ($;fy2014)



# Personal Outcomes

- Support needs (SIS) predicted
  - Social participation and relationships
  - Everyday choices
  - Social determination
  - Rights
- Living arrangements
  - Social participation
  - Everyday choices

# Revisiting Personal Outcome Measures (Virginia NCI, fy2018)

## Personal Opportunity

- Social participation
- Choice
- Rights

## Wellness

- Heart health
- Mental health
- Behavioral health

# Measuring Progress

- 2014 compared with 2018 & 2019
- The possibilities!

# Using NCI Data to Inform Priority Areas of Quality Improvement

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Assistant Commissioner of Quality Management
MA Department of Developmental Services

**Courtney Dutra, MPA**
Project Manager
Center for Developmental Disabilities Evaluation and Research (CDDER)
University of Massachusetts Medical School

# Context from Massachusetts

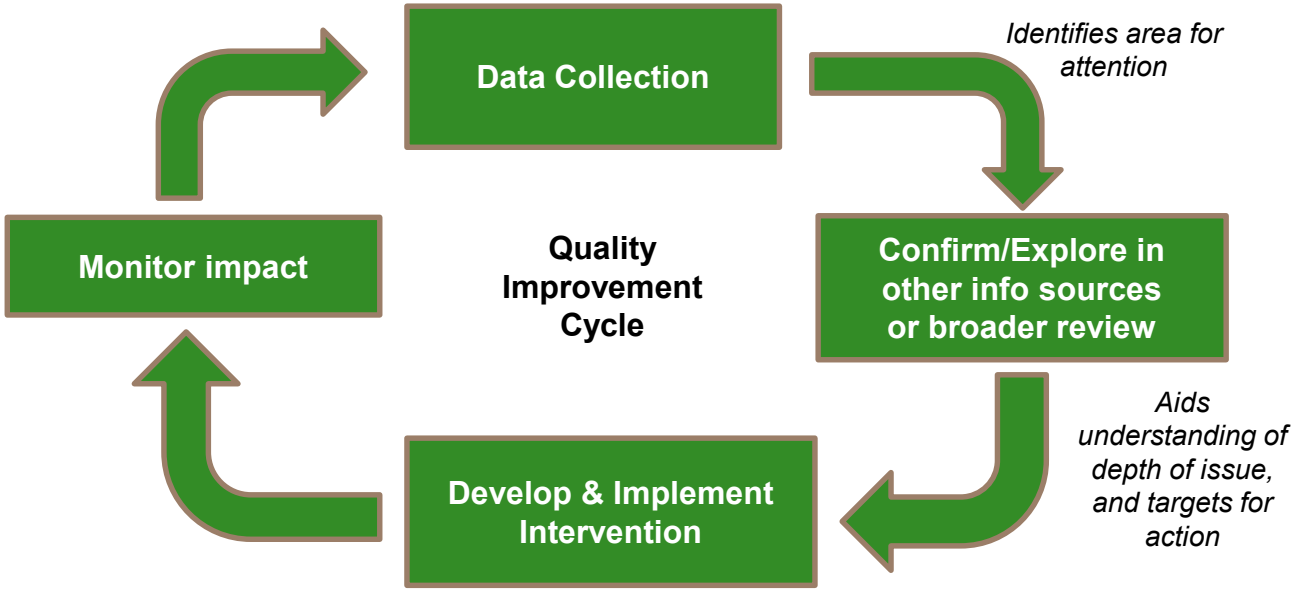
- DDS has built a sophisticated community-based service system.
  - From serving >10,000 individuals in nine large institutional settings
  - To serving >35,000 individuals supported in a variety of community settings.

- **Mission:** The Department is dedicated to creating, in partnership with others, innovative and genuine opportunities for individuals with intellectual disabilities to participate fully and meaningfully in, and contribute to, their communities as valued members.

# Quality Council

- Began in 2007
- DDS recognized the need to establish one group that could advise the Department about how to measure quality and where to improve services and supports.
- Membership is comprised of self-advocates, family members, providers and DDS staff.

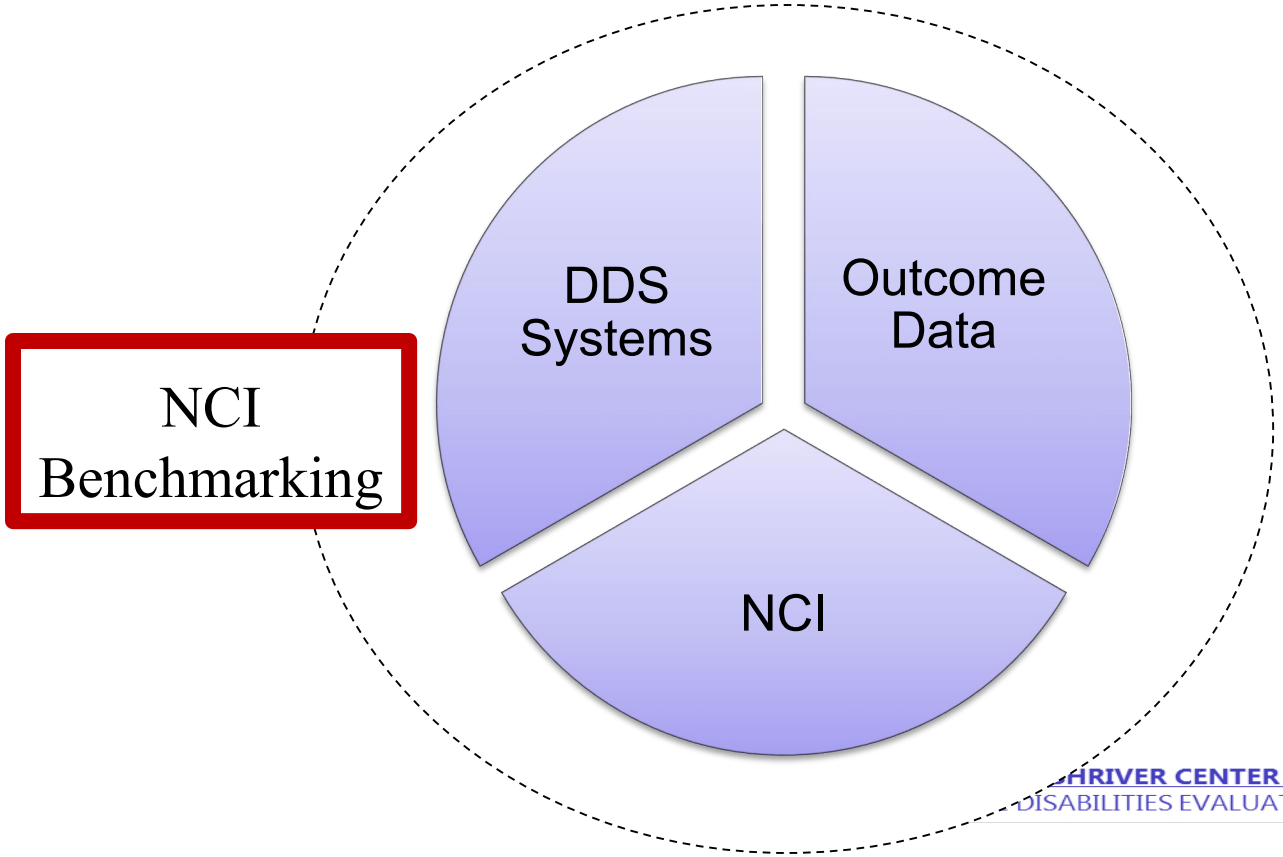
# Use of Data in the Quality Improvement Cycle



# How is NCI data used?

- Compliments DDS system indicators
  - To describe the experience of individuals in service settings
- To benchmark performance against other states and the national averages.

# Informing the QC Perspective



# EXAMPLES

# Health

Data are from licensing and certification processes, heath care record analysis and NCI.

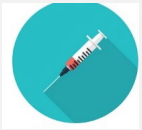
Percentages of people receiving annual physical and dental exams has always been an important indicator.

Generally these percentages are fairly consistent across the data sources

# Healthy Lifestyle 2010-2011[1]

85% received an annual physical.

83% received an annual dental exam.



67% received flu vaccine

Below NCI state and national averages

[1]Analysis of DDS Health Care Records for adults aged 18+ eligible for DDS community-based residential services.

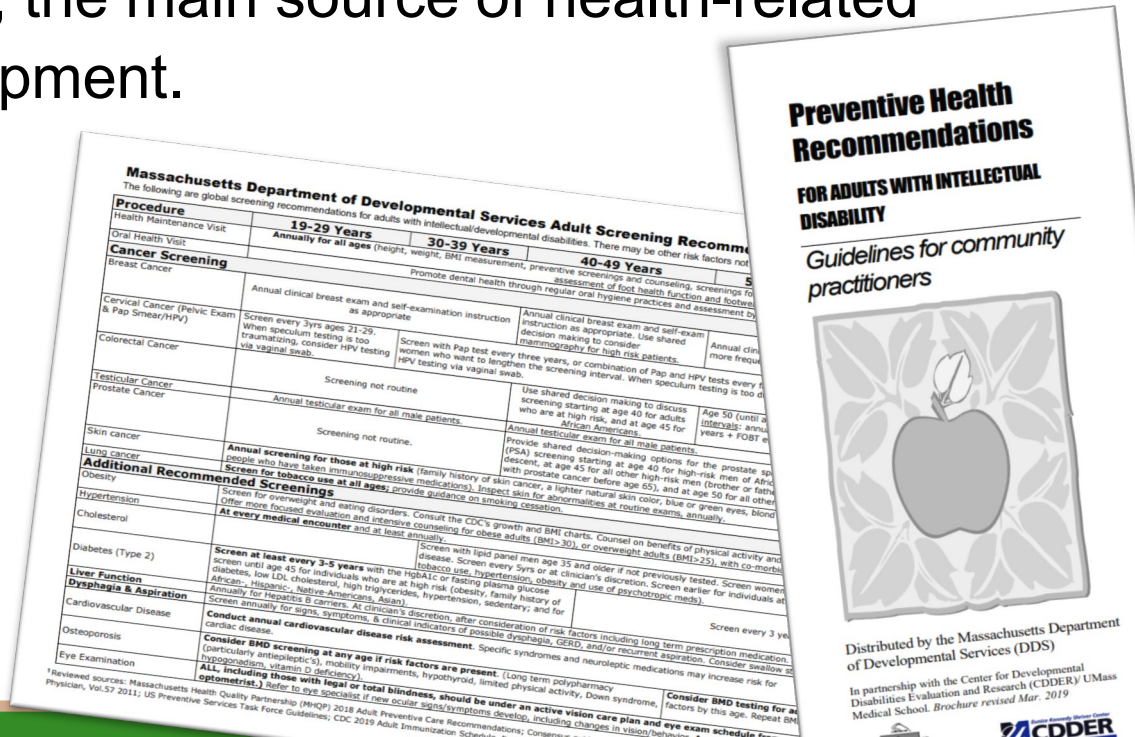
# Health Promotion and Coordination Initiative

Goal: enhance the quality of health care by focusing on the important role that direct support professionals play in health care advocacy, including:

- The preventive health screening recommendations
- A health review checklist which is completed by direct support professionals and taken to every primary care appointment to aid in communication and follow up.
- Easy to use informational sheets for observing and reporting signs and symptoms of illness.
- Training for direct support professionals

# Preventive Screening Guidelines for Adults with Intellectual Disability

- **Target:** Improve emphasis on & decrease variation of preventive health at annual physical, the main source of health-related information in ISP development.



**Massachusetts Department of Developmental Services Adult Screening Recomm**

The following are global screening recommendations for adults with intellectual/developmental disabilities. There may be other risk factors not

| Procedure | 19-29 Years | 30-39 Years | 40-49 Years | 5 |
|---|---|---|---|---|
| Health Maintenance Visit | **Annually for all ages** (height, weight, BMI measurement, preventive screenings and counseling, screenings fo | | | |
| Oral Health Visit | Promote dental health through regular oral hygiene practices and assessment D | | | |
| **Cancer Screening** | | | assessment of foot health function and footwe | |
| Breast Cancer | Annual clinical breast exam and self-examination instruction as appropriate | Annual clinical breast exam and self-exam instruction as appropriate. Use shared decision making to consider mammography for high risk patients. | Annual clin more freque | |
| Cervical Cancer (Pelvic Exam & Pap Smear/HPV) | Screen every 3yrs ages 21-29. When speculum testing is too traumatizing, consider HPV testing via vaginal swab. | Screen with Pap test every three years, or combination of Pap and HPV tests every f women who want to lengthen the screening interval. When speculum testing is too d HPV testing via vaginal swab. | | |
| Colorectal Cancer | Screening not routine | Use shared decision making to discuss screening starting at age 40 for adults who are at high risk, and at age 45 for African Americans. | Age 50 (until a intervals; annu years + FOBT e | |
| Testicular Cancer | Annual testicular exam for all male patients. | Annual testicular exam for all male patients. | | |
| Prostate Cancer | Screening not routine. | Provide shared decision-making options for the prostate sp (PSA) screening starting at age 40 for high-risk men of Afric descent, at age 45 for all other high-risk men (brother or fath with prostate cancer before age 65), and at age 50 for all other | | |
| Skin cancer | **Annual screening for those at high risk** (family history of skin cancer, a lighter natural skin color, blue or green eyes, blond | | | |
| Lung cancer | people who have taken immunosuppressive medications). Inspect skin for abnormalities at routine exams, annually. | | | |
| **Additional Recommended Screenings** | **Screen for tobacco use at all ages;** provide guidance on smoking cessation. | | | |
| Obesity | Screen for overweight and eating disorders. Consult the CDC's growth and BMI charts. Counsel on benefits of physical activity and | | | |
| Hypertension | Offer more focused evaluation and intensive counseling for obese adults (BMI>30), or overweight adults (BMI>25), with co-morbi | | | |
| Cholesterol | **At every medical encounter** and at least annually. | | | |
| Diabetes (Type 2) | **Screen at least every 3-5 years** with the HgbA1c or fasting plasma glucose | Screen with lipid panel men age 35 and older if not previously tested. Screen women disease. Screen every 5yrs or at clinician's discretion. Screen earlier for individuals at tobacco use, hypertension, obesity and use of psychotropic meds). | | |
| **Liver Function** | screen until age 45 for individuals who are at high risk (obesity, family history of diabetes, low LDL cholesterol, high triglycerides, hypertension, sedentary; and for African-, Hispanic-, Native-Americans, Asian). | | | |
| **Dysphagia & Aspiration** | Annually for Hepatitis B carriers. At clinician's discretion, after consideration of risk factors including long term prescription medication. | | | |
| Cardiovascular Disease | Screen annually for signs, symptoms, & clinical indicators of possible dysphagia, GERD, and/or recurrent aspiration. Consider swallow st | | | |
| Osteoporosis | **Conduct annual cardiovascular disease risk assessment**. Specific syndromes and neuroleptic medications may increase risk for cardiac disease. | | Screen every 3 ye | |
| Eye Examination | **Consider BMD screening at any age if risk factors are present**. (Long term polypharmacy (particularly antiepileptic's), mobility impairments, hypothyroid, limited physical activity, Down syndrome, hypogonadism, vitamin D deficiency). | | | |
| | **ALL, including those with legal or total blindness, should be under an active vision care plan and eye exam schedule fr optometrist.)** Refer to eye specialist if new ocular signs/symptoms develop, including changes in vision/behavior | | **Consider BMD testing for a** factors by this age. Repeat BM | |

[1] Reviewed sources: Massachusetts Health Quality Partnership (MHQP) 2018 Adult Preventive Care Recommendations; Consensus
Physician, Vol.57 2011; US Preventive Services Task Force Guidelines; CDC 2019 Adult Immunization Schedule

**Preventive Health Recommendations**

**FOR ADULTS WITH INTELLECTUAL DISABILITY**

*Guidelines for community practitioners*

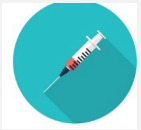
Distributed by the Massachusetts Department of Developmental Services (DDS)

In partnership with the Center for Developmental Disabilities Evaluation and Research (CDDER)/ UMass Medical School. *Brochure revised Mar. 2019*

CDDER

93% received an annual physical exam.

88% received an annual dental exam.



69% received flu vaccine

[NCI: 77%; MA BRFSS 91%]

# Healthy Lifestyle 2018[1]

Above NCI state and national averages

[1]Analysis of DDS Health Care Records for adults aged 18+ eligible for DDS community-based residential services.

# Preventive Screenings 2018

| Screenings | Adults with I/DD[1] | MA General Population[2] |
|---|---|---|
| Eye exam or vision screening in the past year | 70% | N/A |
| Hearing test in the past 5 years | 35% | N/A |
| Women: Pap test in the past 3 years:, ages 21-65 | 38% | 84% |
| Women: Mammogram in the past 2 years, ages 50-74 | 56% | 86% |
| Colorectal cancer screening in the past 10 years , ages 50-74 | 56% | 76% |

NCI data are consistent.

Some differences in screening time frames.

[1] Analysis of DDS Health Care Records updated 1/1/18 or later for adults aged 18+ who area currently eligible for DDS community-based residential services.

[2] Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) 2016 survey.

# Preventive Health Screenings: Cancer-related deaths in adults served by DDS

**Comparison of Adult Cause-specific Mortality Rates Between MA DDS and MA General Population**

*(rates per thousand people)*

| Cause of Death | State of MA | MA DDS |
|---|---|---|
| All Cancers | 2.3 | 2.3 |

*Adults served by DDS have a similar rate of death from cancers overall as other adults living in MA*

*However, adults served by DDS are much more likely to die from female breast and colorectal cancers – both of which have early detection screenings.*

**Cancer deaths compared with Healthy People 2020 Mortality Objectives**

*Rates per 100,000 population*

| Objective Number | Healthy People 2020 Objective | Target 2020 | MA DDS | | General Population |
|---|---|---|---|---|---|
| | | | Avg. Crude Adult Rate | Target Status | MA |
| C-2 | Lung Cancer | 45.5 | 27.9 | ✓ | 41.4 |
| C-3 | Female Breast Cancer (per 100,000 females) | 20.7 | 42.5 | ● | 18.4 |
| C-4 | Uterine cervix (per 100,000 females) | 2.2 | 2.0 | ✓ | 1.0 |
| C-5 | Colorectal Cancer | 14.5 | 35.5 | ● | 13.0 |
| C-6 | Oropharyngeal Cancer | 2.3 | 1.7 | ✓ | 2.4 |
| C-7 | Prostate Cancer (per 100,000 males) | 21.8 | 13.7 | ✓ | 18.5 |
| C-8 | Malignant Melanoma | 2.4 | 3.4 | ● | 3.2 |

# Given the cancer mortality rates, are adults served by DDS getting screenings?

- **Adults served by DDS in residential supports obtain annual physicals at a higher rate than other adults living in MA.**
- **However, adults served by DDS in residential supports have lower rates of receiving cancer screenings than other adults living in MA.**

| | Adults with I/DD in DDS residential supports | MA General population |
|---|---|---|
| Annual Physical Exams | 93% | 79% |
| Pap test in past 3 years (ages 21-65) | 38% | 84% |
| Mammogram in the past 2 years (ages 50-74) | 56% | 86% |
| Colorectal cancer screening in past 10 years (ages 50-74) | 56% | 76% |

Notes/Source: Analysis of DDS Health Care Records for adults 18+ years eligible for DDS community-based residential services. General population data from MA BRFSS 2016 survey data. Analysis completed with the assistance of CDDER/UMass Medical School.

# Barriers to Mammography among women with ID

- Retrospective chart review of 89 women over age 40 in a residential support setting.
- 59.6% of women had a mammogram in previous year (in 2008 MA: 84.9% ; US:76%)
- Women needing special positioning 25 times **less likely** to have screening.
- If able to give consent: 20 times **more likely**

# ADDITIONAL EXAMPLE - FALLS

# Massachusetts DDS Falls

- **Incident Management System**
- 1,500 reported *serious* injuries from falls
- Estimate10,000 falls occur without injury

- **Emergency Room Visits (2011-2012)**
  31% of ER visits were from physical injuries
  49% of physical injuries were from falls

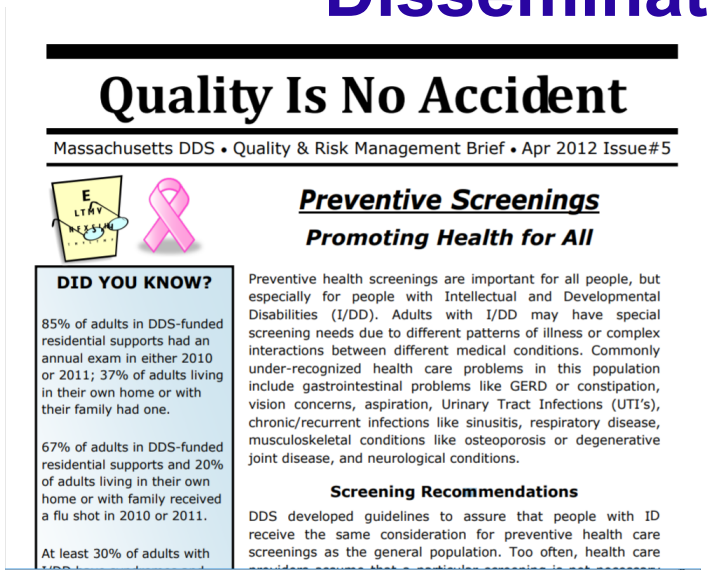
# Falls Prevention Initiative

- Training to all providers
- Developed falls risk screening tools
- Developed post-fall assessments

# STOP Falls Pilot

| STOP Falls Pilot | Results |
| --- | --- |
| 910 Individuals for 6 months | • 33% reduction in monthly rate of falls and reduction in # of people who fell |
| Staff tracked all falls and completed post-fall assessments | • **Factors that increased falls risk:** Recent falls history (5x), unsteady balance (5x),4 or more prescription drugs (2.5x) |
| Piloted tool use | • Loss of Balance and Trip/Slip (53%) were the most common ‘why’ |
| Identify falls patterns to reduce risk | • 46% of falls occur while the person was “walking around” |

# Dissemination - QINA



## Quality Is No Accident

Massachusetts DDS • Quality & Risk Management Brief • Apr 2012 Issue#5

### *Preventive Screenings*

### *Promoting Health for All*

**DID YOU KNOW?**

85% of adults in DDS-funded residential supports had an annual exam in either 2010 or 2011; 37% of adults living in their own home or with their family had one.

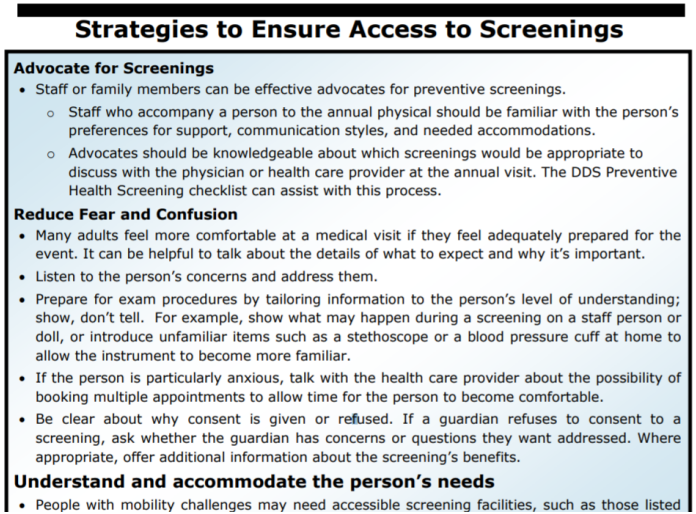
67% of adults in DDS-funded residential supports and 20% of adults living in their own home or with family received a flu shot in 2010 or 2011.

At least 30% of adults with

Preventive health screenings are important for all people, but especially for people with Intellectual and Developmental Disabilities (I/DD). Adults with I/DD may have special screening needs due to different patterns of illness or complex interactions between different medical conditions. Commonly under-recognized health care problems in this population include gastrointestinal problems like GERD or constipation, vision concerns, aspiration, Urinary Tract Infections (UTI's), chronic/recurrent infections like sinusitis, respiratory disease, musculoskeletal conditions like osteoporosis or degenerative joint disease, and neurological conditions.

**Screening Recommendations**

DDS developed guidelines to assure that people with ID receive the same consideration for preventive health care screenings as the general population. Too often, health care



## Strategies to Ensure Access to Screenings

**Advocate for Screenings**

- Staff or family members can be effective advocates for preventive screenings.
  - Staff who accompany a person to the annual physical should be familiar with the person's preferences for support, communication styles, and needed accommodations.
  - Advocates should be knowledgeable about which screenings would be appropriate to discuss with the physician or health care provider at the annual visit. The DDS Preventive Health Screening checklist can assist with this process.

**Reduce Fear and Confusion**

- Many adults feel more comfortable at a medical visit if they feel adequately prepared for the event. It can be helpful to talk about the details of what to expect and why it's important.
- Listen to the person's concerns and address them.
- Prepare for exam procedures by tailoring information to the person's level of understanding; show, don't tell. For example, show what may happen during a screening on a staff person or doll, or introduce unfamiliar items such as a stethoscope or a blood pressure cuff at home to allow the instrument to become more familiar.
- If the person is particularly anxious, talk with the health care provider about the possibility of booking multiple appointments to allow time for the person to become comfortable.
- Be clear about why consent is given or refused. If a guardian refuses to consent to a screening, ask whether the guardian has concerns or questions they want addressed. Where appropriate, offer additional information about the screening's benefits.

**Understand and accommodate the person's needs**

- People with mobility challenges may need accessible screening facilities, such as those listed

# Dissemination – QA Briefs

Massachusetts Department of Developmental Services (DDS)

## Quality Assurance Brief

### Preventive Care

August 2019

**2017-2018 National Core Indicator Data: All adults served by DDS**

- 50% had an eye exam in the past year 
- 63% had a hearing test in the past 5 years 
- 77% had a flu vaccine in the past year 

**Adults in community-based residential supports[1]**

**Physical Exams:**

- 96% of providers adequately supported people to receive annual physical exams.
- 93% of people had a complete physical exam in the past year. This is higher than the Massachusetts general population (79%).[2]

**Dental Exams:**

# Thank you!

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

https://shriver.umassmed.edu/programs/cdder/dds-preventive-health-screenings-adults-intellectual-disabilities