NCI

NASDDDS & HSRI

# What Do NCI Data Reveal About Individuals With Intellectual and Developmental Disabilities Who Need Behavior Support?

**September 11, 2014**

# Agenda

- Importance
- Methods, Measures and Sample
- Findings
- Emerging Practices

# Importance

- Individuals with ID/DD are 3-5x more likely to demonstrate challenging behaviors
- Challenging behaviors can lead to
  - Self harm
  - Physical injury to others
  - Destruction of property
  - Limited community involvement
  - Disadvantages

# Methods: WHAT IS NATIONAL CORE INDICATORS (NCI)?

- Multi-state collaboration of state DD agencies
- Measures performance of public systems for people with intellectual and developmental disabilities
- Assesses performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 13 participating states
- Supported by participating states
- NASDDDS – HSRI Collaboration

# WHAT IS NCI?

- Adult Consumer Survey
  - ✓ In-person conversation with a sample of adults receiving services to gather information about their experiences
  - ✓ Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.
- Adult Family, Child Family, and Family/Guardian Surveys Mail surveys – separate sample from Adult Consumer Survey
- Other NCI state level data: Staff Stability

# Methods, Measures and Sample:

- 2012-13 data collection cycle: 25 states and one regional council
- Background Information Section
  - Does person need support to manage:
    - Self injurious behavior?
    - Disruptive behavior
    - Destructive behavior?
- Included in sample for analysis: 12,718

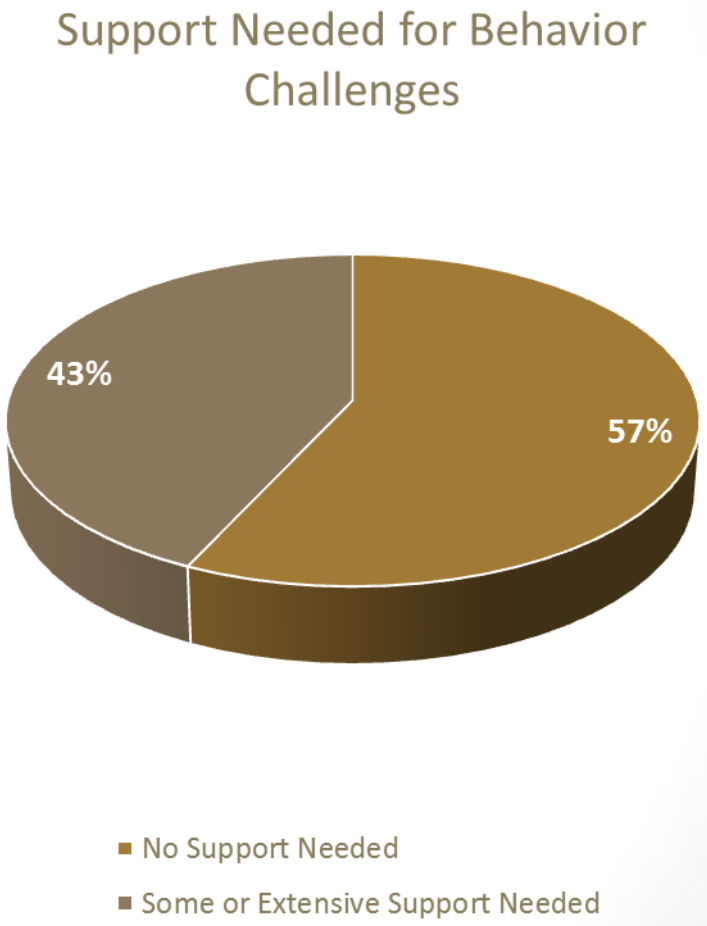
# Finding

- Respondents who needed behavior supports differed significantly from those who did not need such supports in various **demographic characteristics.**

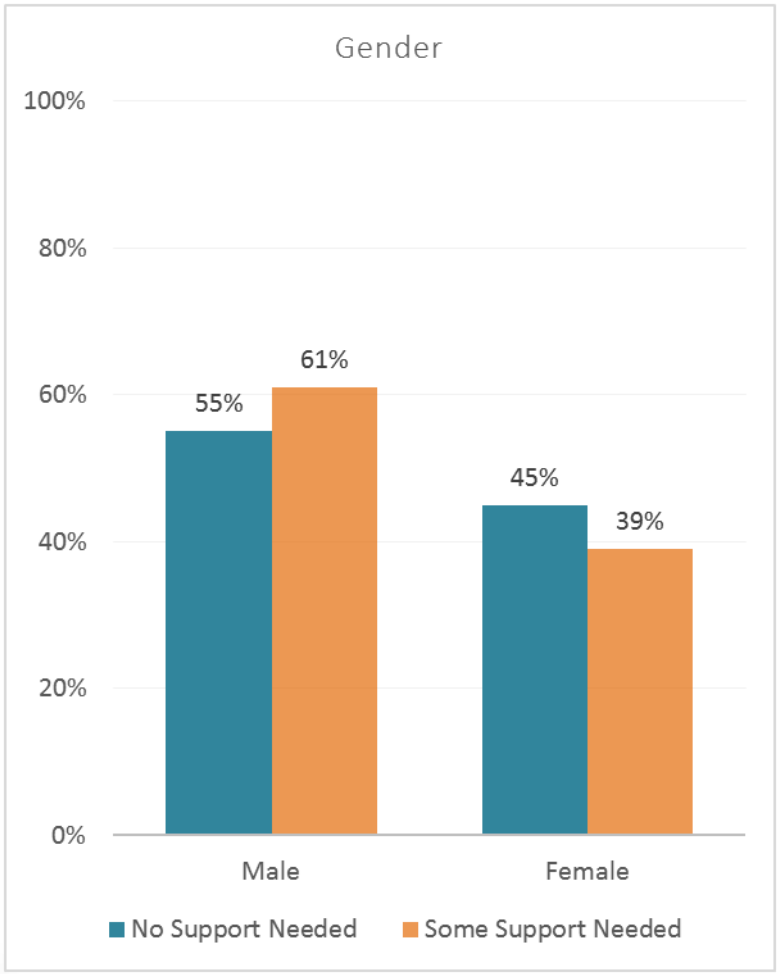
# Demographics

- 43% needed some or extensive support
- Of the respondents who needed at least some behavior support*:
  - 51% needed support for self-injurious behavior
  - 87% needed support for disruptive behavior
  - 55% needed support for destructive behavior

*Note that these categories are not mutually exclusive and therefore exceed 100% when combined.



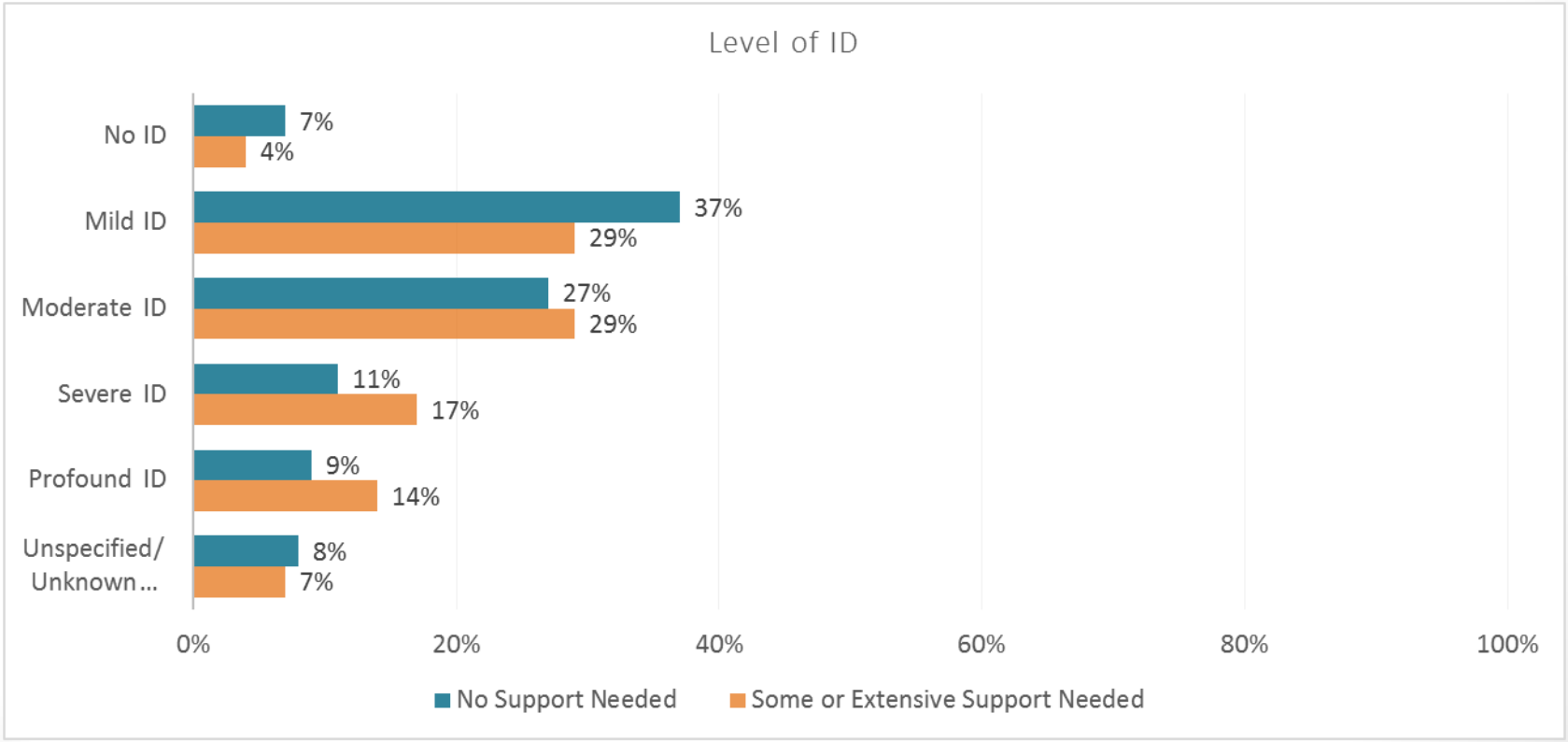
# Demographics



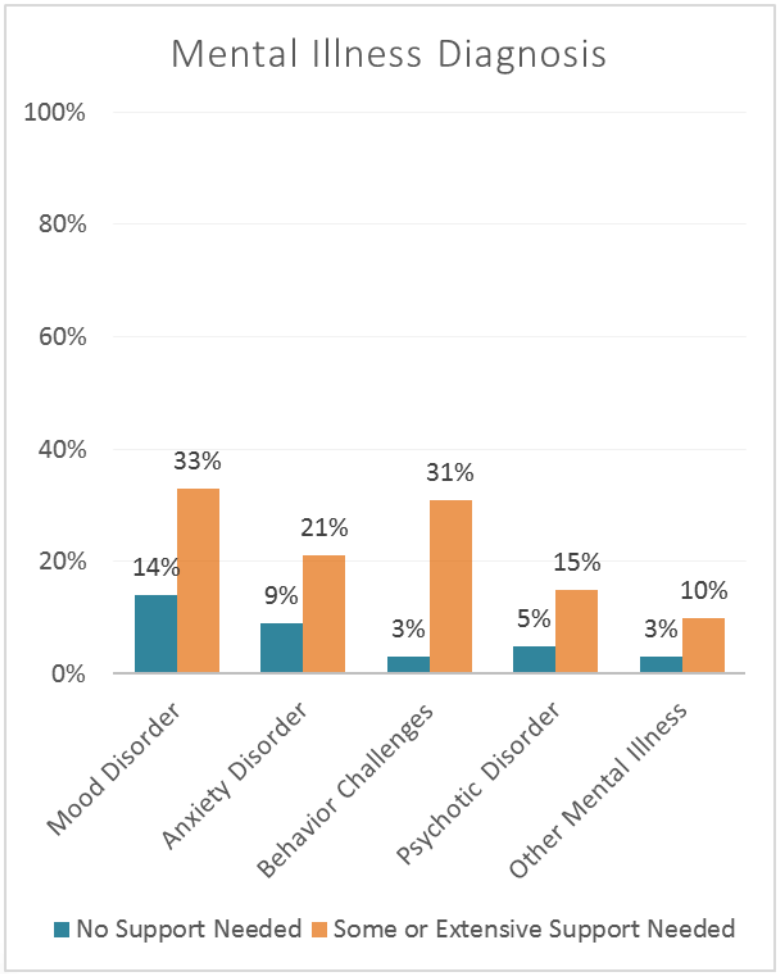

- Respondents who needed behavior supports compared to those who did not were:
  - Slightly younger - 42 v. 43
  - More likely to be male - 61% v. 55%

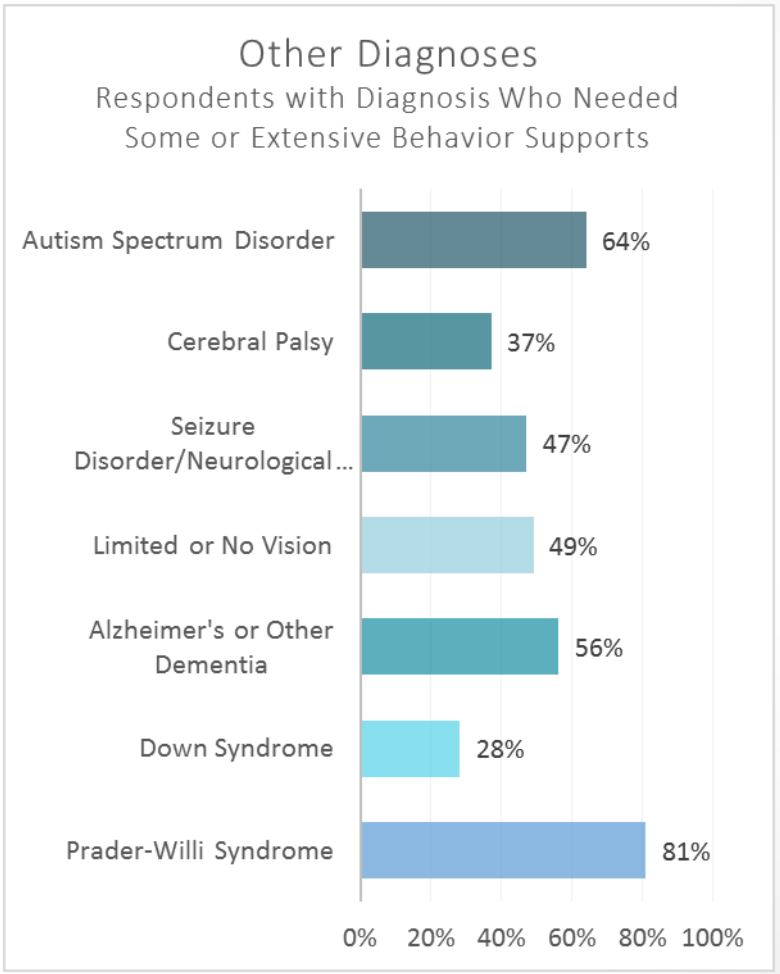
# Demographics

- Significant differences were also found by level of disability



# Diagnoses

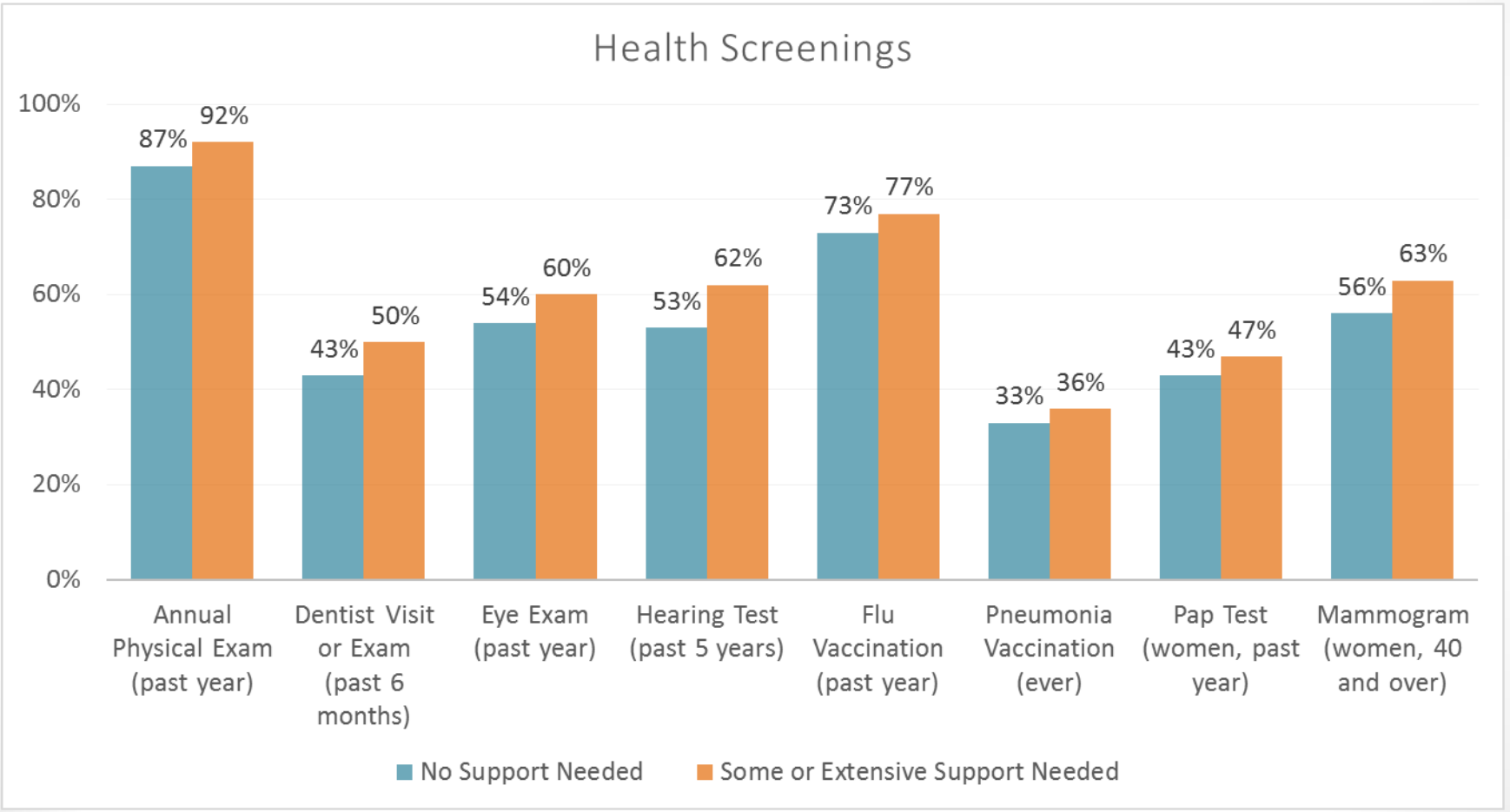

Mental Illness Diagnosis
100%
80%
60%
40%
20%
0%
14%
33%
9%
21%
3%
31%
5%
15%
3%
10%
Mood Disorder
Anxiety Disorder
Behavior Challenges
Psychotic Disorder
Other Mental Illness
No Support Needed
Some or Extensive Support Needed


Other Diagnoses
Respondents with Diagnosis Who Needed Some or Extensive Behavior Supports
Autism Spectrum Disorder
64%
Cerebral Palsy
37%
Seizure Disorder/Neurological ...
47%
Limited or No Vision
49%
Alzheimer's or Other Dementia
56%
Down Syndrome
28%
Prader-Willi Syndrome
81%
0%
20%
40%
60%
80%
100%

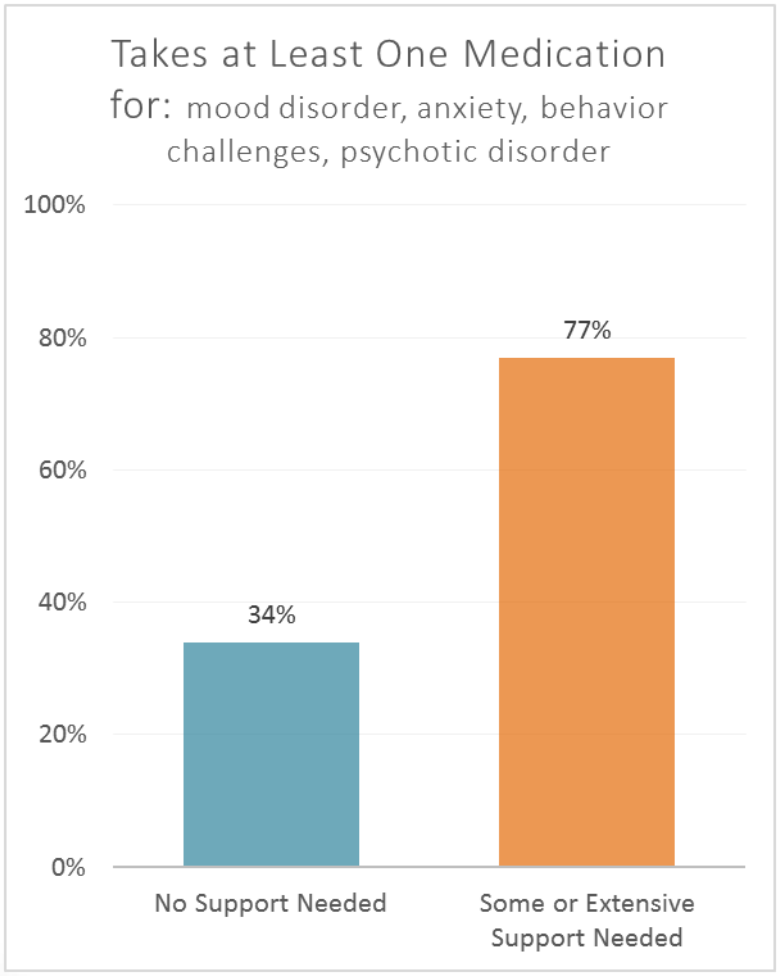
# Finding

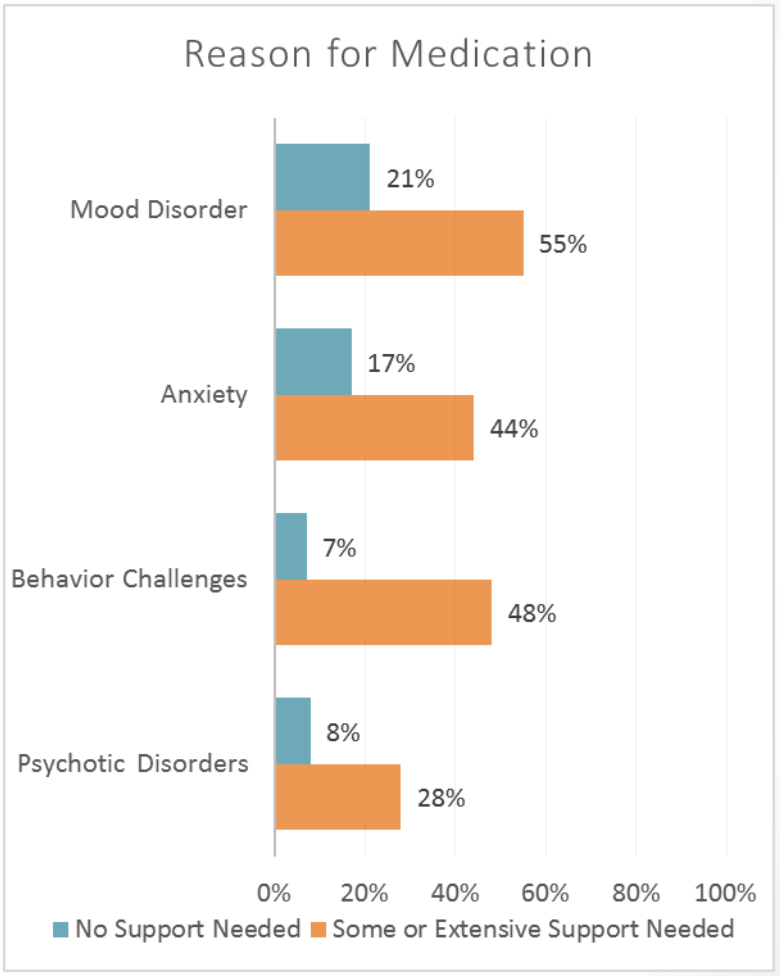
- Respondents who need behavior supports differ significantly from those who do not need such supports in various **health, medication, and wellness outcomes**.

# Health


Health Screenings
100%
80%
60%
40%
20%
0%
87%
92%
43%
50%
54%
60%
53%
62%
73%
77%
33%
36%
43%
47%
56%
63%
Annual Physical Exam (past year)
Dentist Visit or Exam (past 6 months)
Eye Exam (past year)
Hearing Test (past 5 years)
Flu Vaccination (past year)
Pneumonia Vaccination (ever)
Pap Test (women, past year)
Mammogram (women, 40 and over)
No Support Needed
Some or Extensive Support Needed

# Medication



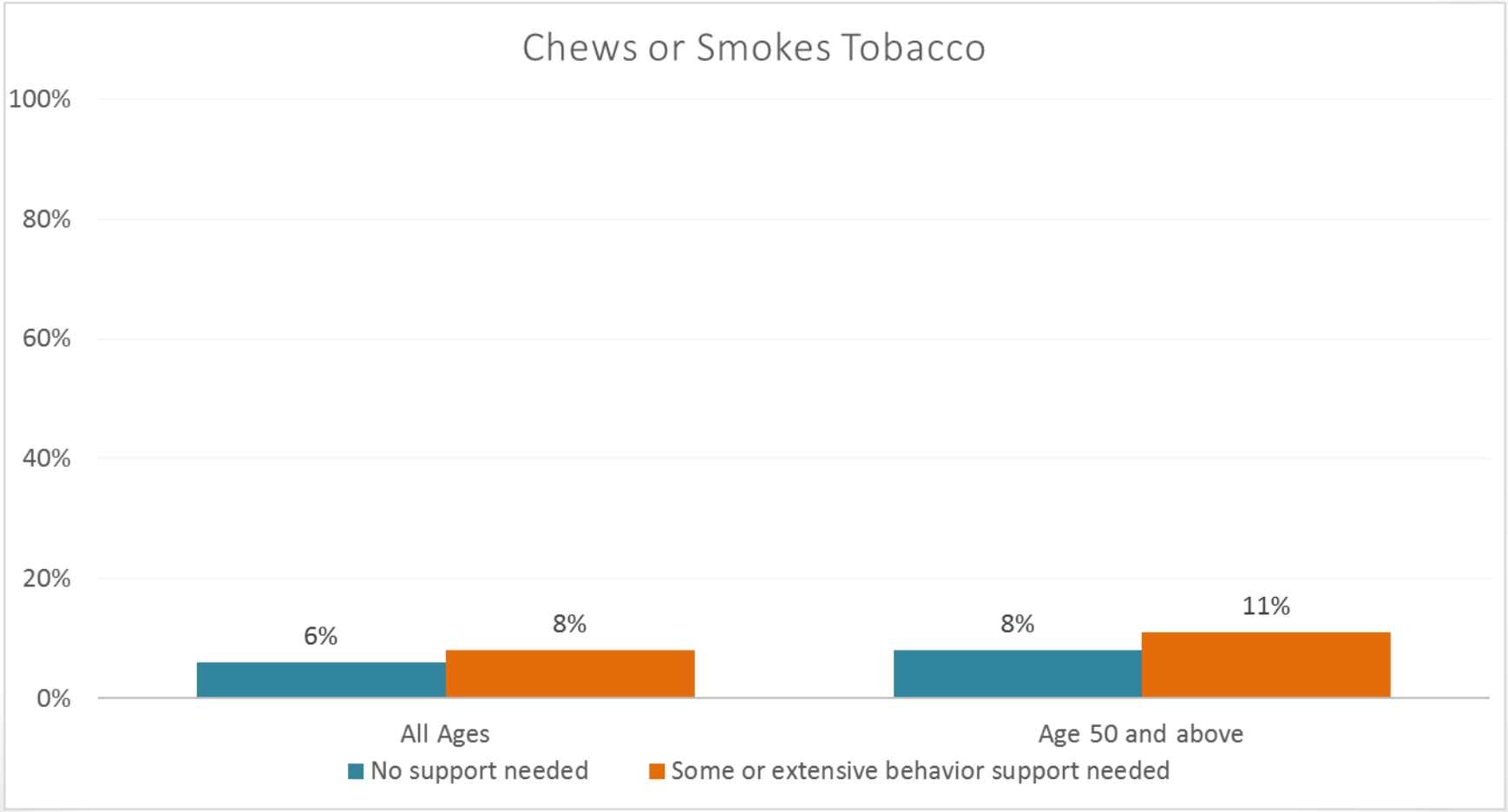




National Core Indicators (NCI)

# Finding

- Respondents who needed behavior support **smoked** at a significantly higher rate than individuals who did not require such supports.

# Tobacco

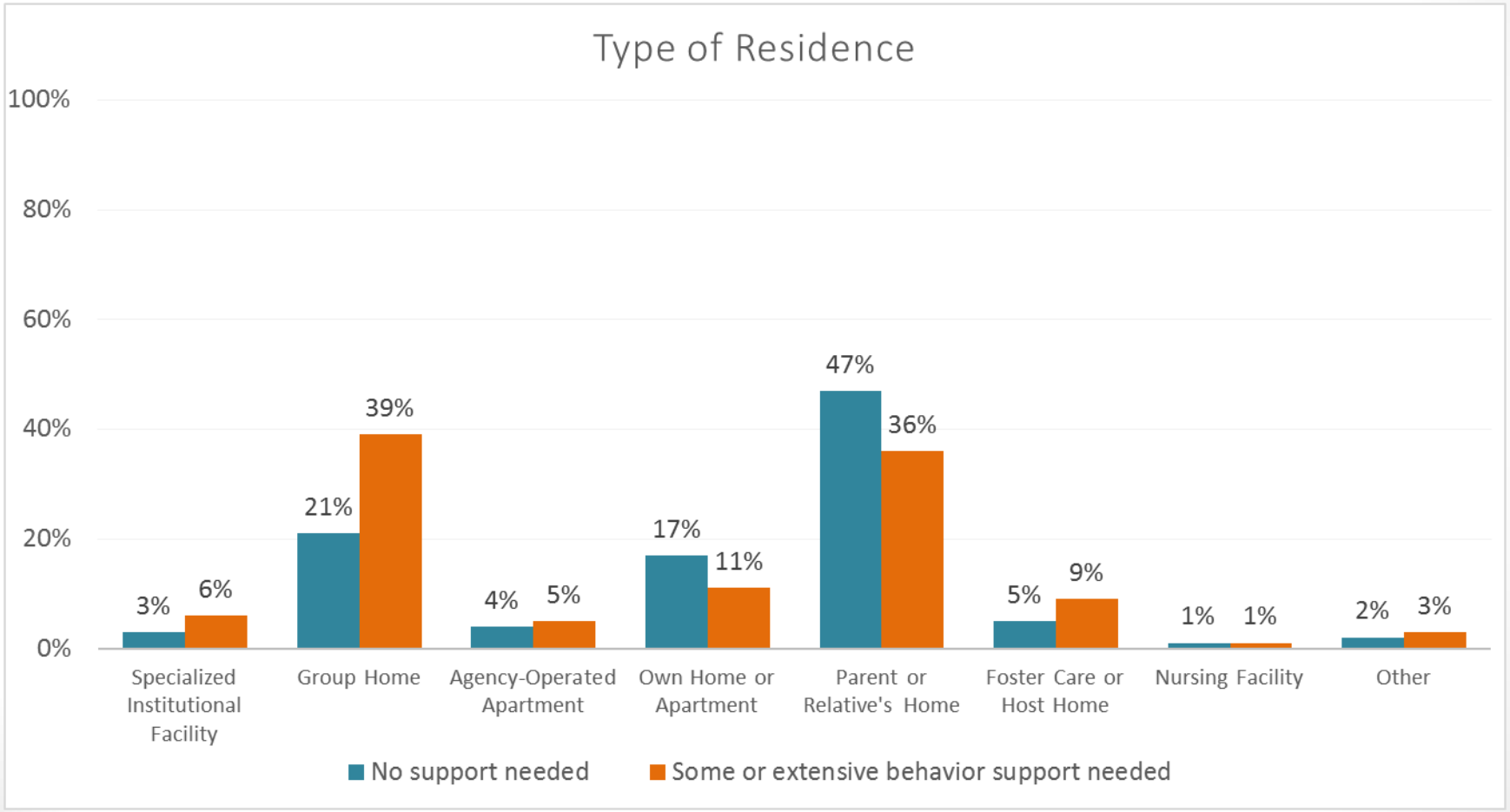



National Core Indicators (NCI)

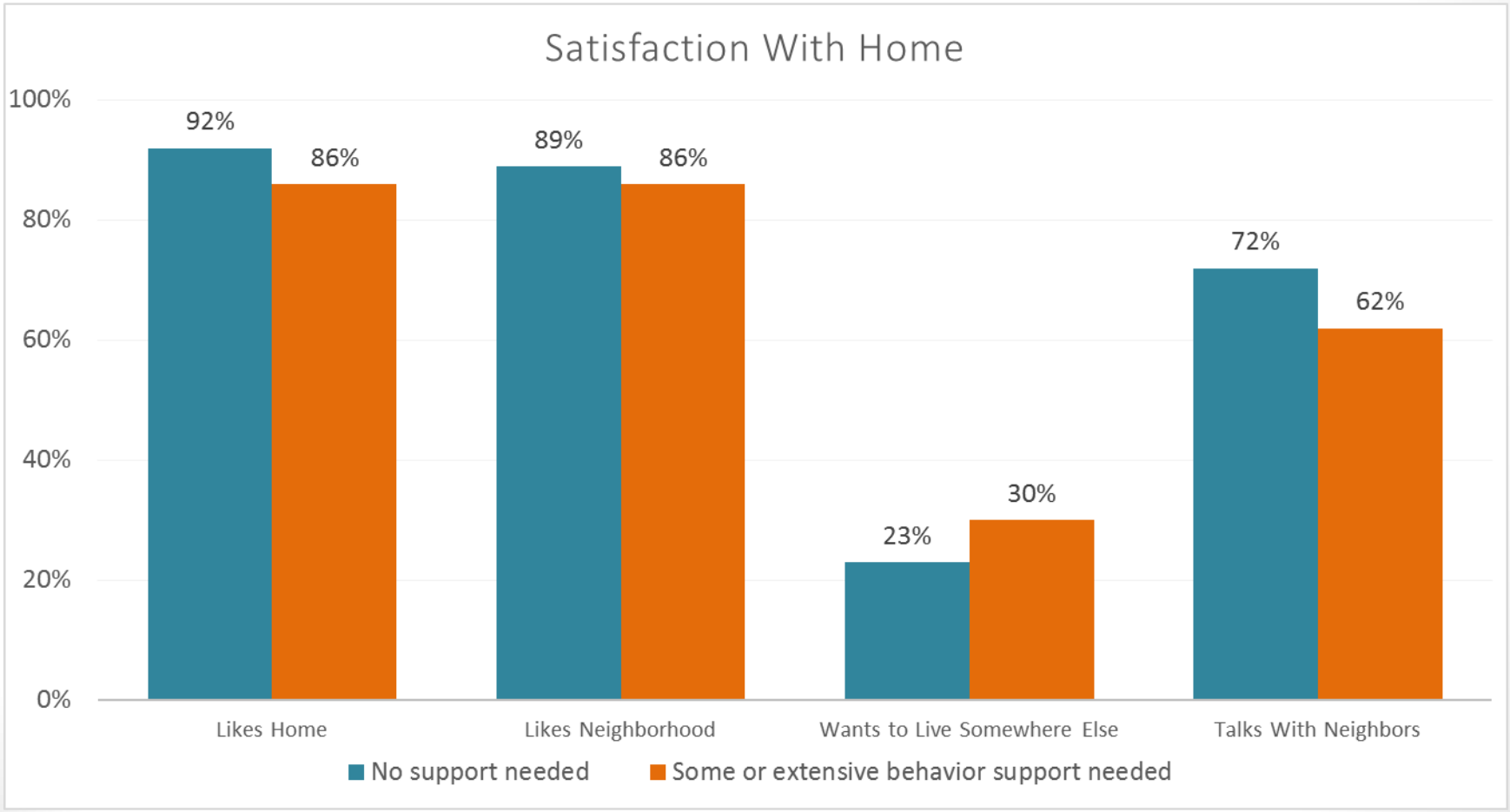
# Finding

- Respondents who needed behavior supports differed significantly from those who did not need such supports in **where they lived and their satisfaction with their living situation as well as what they did during the day**.

# Home


Type of Residence
100%
80%
60%
40%
20%
0%
3%
6%
21%
39%
4%
5%
17%
11%
47%
36%
5%
9%
1%
1%
2%
3%
Specialized Institutional Facility
Group Home
Agency-Operated Apartment
Own Home or Apartment
Parent or Relative's Home
Foster Care or Host Home
Nursing Facility
Other
No support needed
Some or extensive behavior support needed

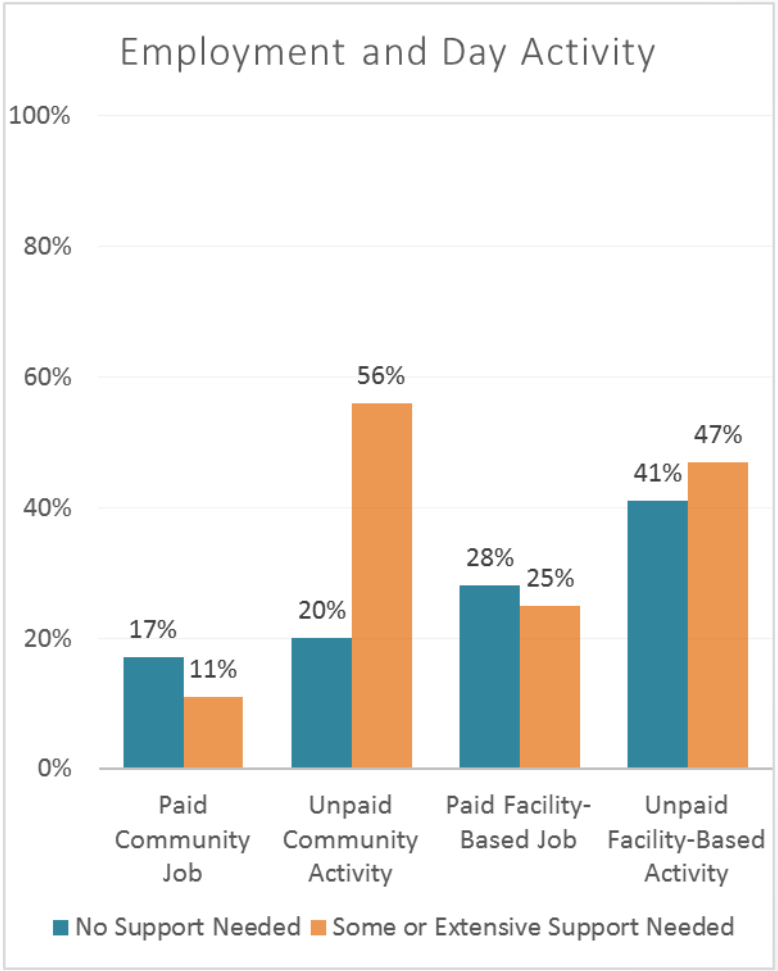
# Home




National Core Indicators (NCI)

# Work and Day Activity

- Respondents who do needed behavior support were:
  - less likely to have a paid community or facility-based job
  - more likely to participate in unpaid community or facility-based activities



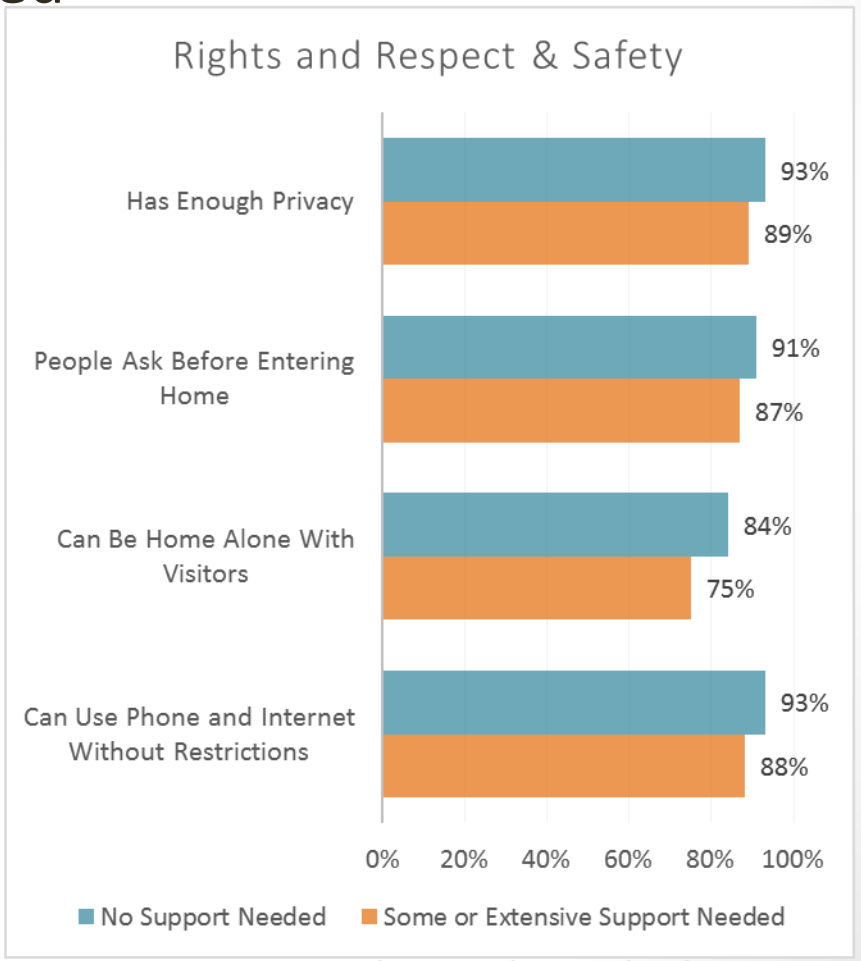

National Core Indicators (NCI)

# Finding

- Respondents who needed behavior supports differed significantly from those who did not need such supports with regard to **rights, respect, and safety.**

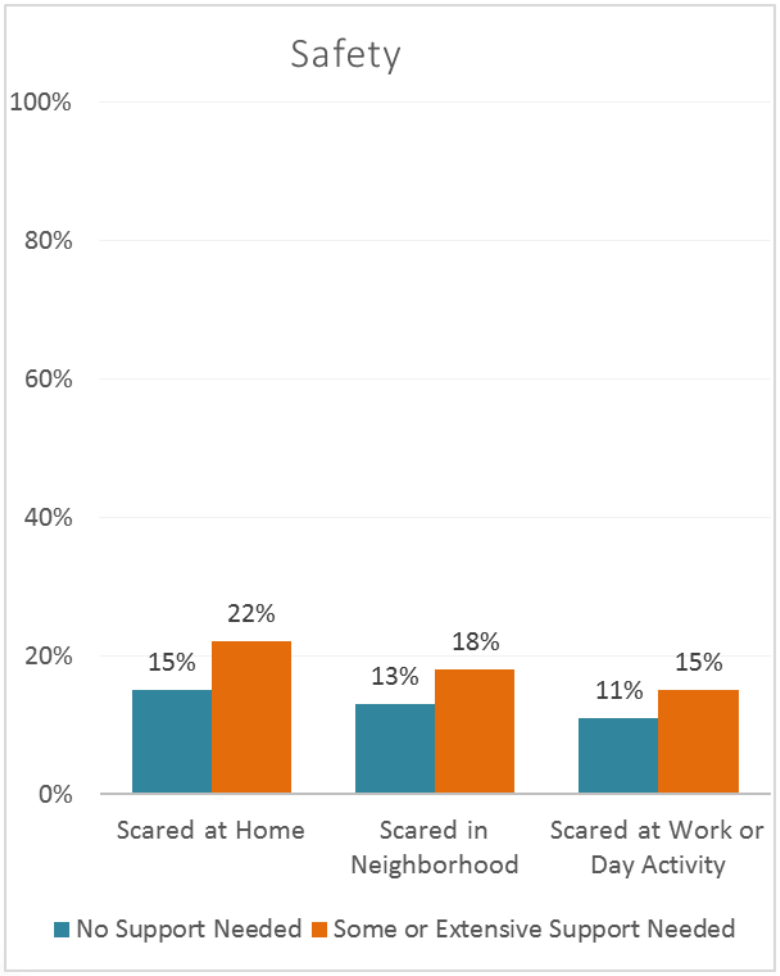
# Rights and Respect

- Respondents who needed behavior support reported lower rates of:
  - Having enough privacy
  - People asking before entering their home
  - Being able to be home alone with visitors
  - Being able to use phone and internet without restrictions




National Core Indicators (NCI)

# Safety



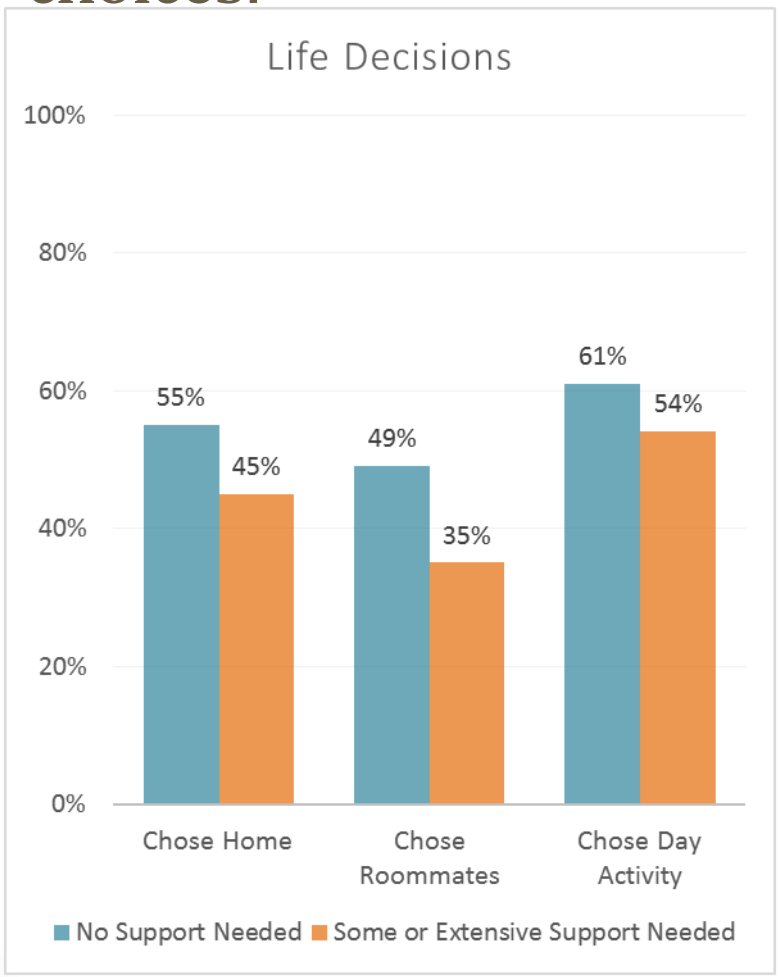

- Respondents who needed behavior support were significantly more likely to feel scared in their home, neighborhood, and/or work/day activity than those who did not require support.

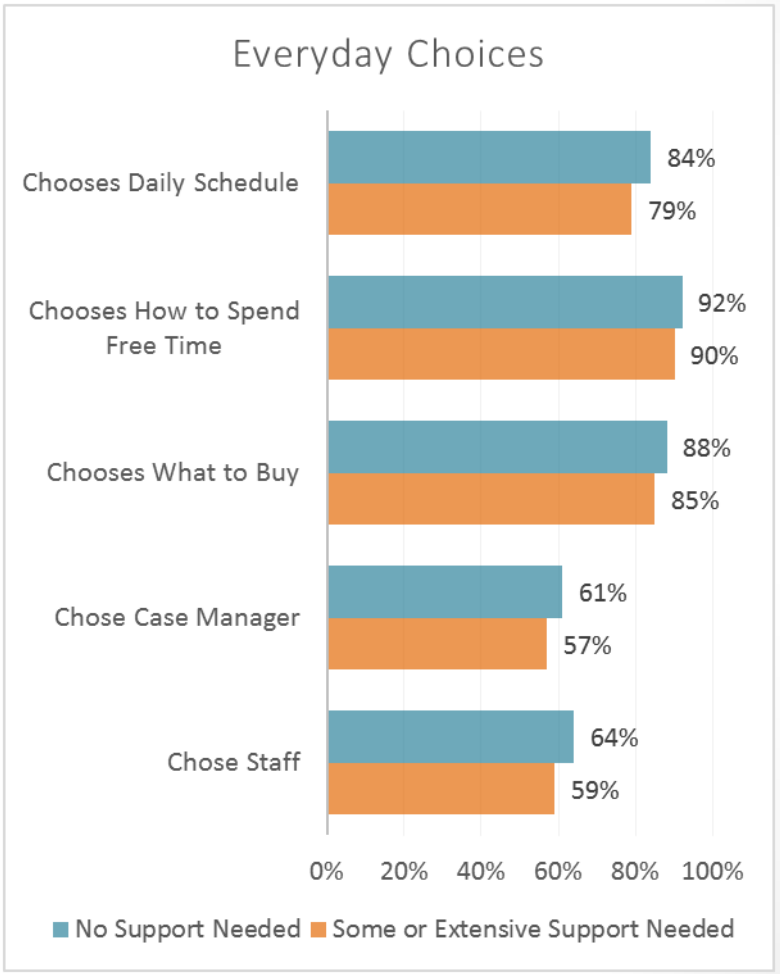
# Finding

- Respondents who need behavior supports showed significantly less autonomy in **everyday choices and life decisions and reported fewer close relationships**.

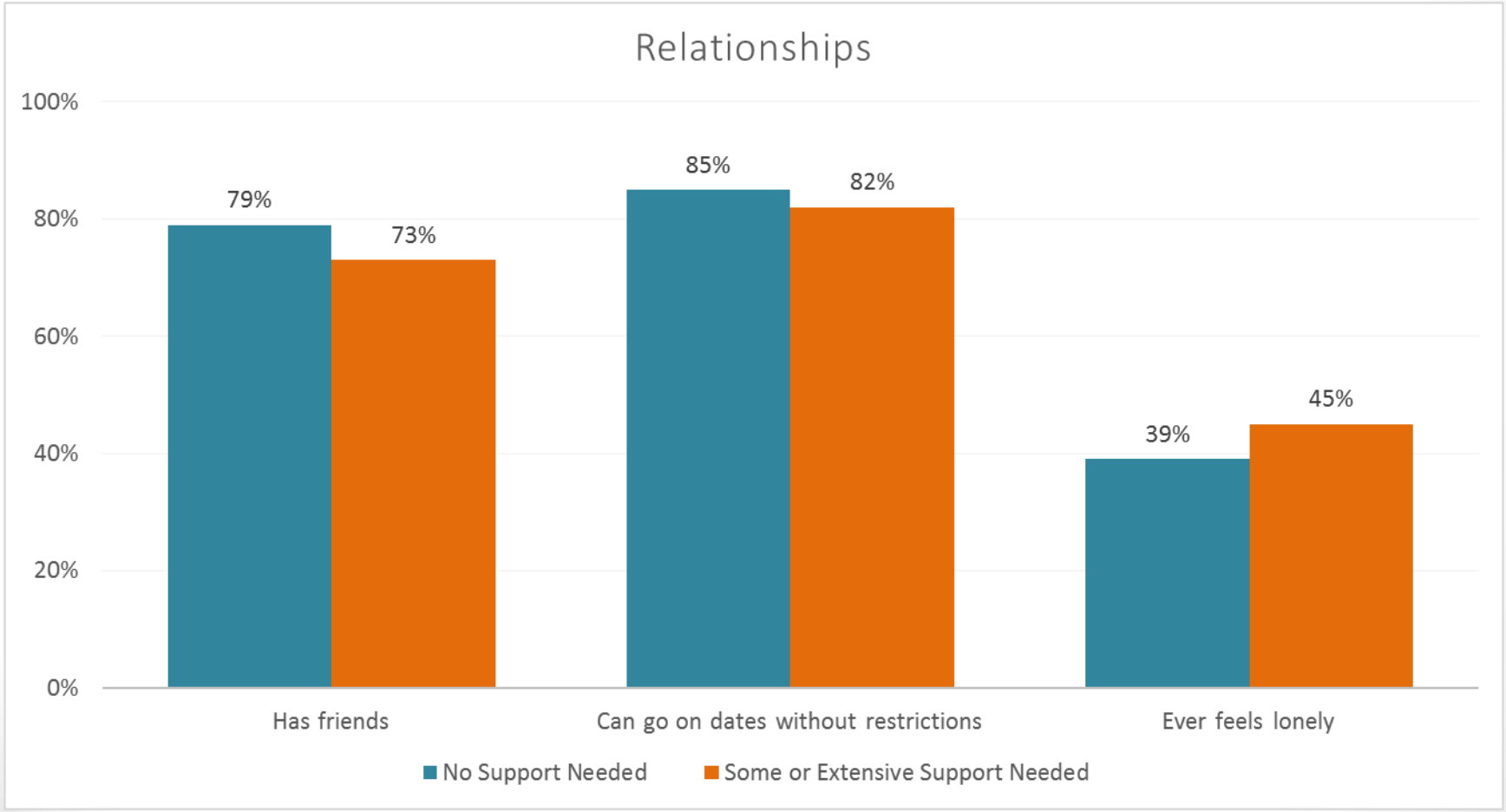
# Choice

## Respondent had at least some input in the following choices:



# Relationships




National Core Indicators (NCI)

# Emerging Practices: New Mexico

- DD Supports Division made agency-wide commitment to Positive Behavior Supports
- Established Bureau of Behavior Support
  - Consultations
  - Socialization and Sexuality Ed
  - Preliminary risk screenings
  - Crisis supports

# Emerging Practices New Mexico

- Bureau of Behavior Supports collaboration with the Trans-Disciplinary Evaluation and Support Clinic (TEASC) UNM School of Medicine
  - Comprehensive consultations
    - connection between the behavioral issues and any underlying medical, psychiatric, environmental and/or adaptive skill/cognitive factors
  - Adult Special Needs Clinic
    - Transdisciplinary approach to address co-occurring factors affecting behavior
  - Continuum of Care Project
    - Training to medical practitioners and non-medical professionals
  - The Developmental Disability/Mental Illness Initiative
    - Works to support mental health practitioners to better serve ID/DD population

# Emerging Practices New Mexico

- Annual review of behavior support effectiveness.
- Establish benchmarks of individual experience
- Assess support effectiveness rather than provider performance criteria

# Emerging Practices: OHIO

- DODD's MIDD Coordinating Center for Excellence (CCOE)
  - Appropriate treatment for individuals with co-occurring MI and DD.

# Emerging Practices: OHIO

- Telepsychiatry Project
  - Increase access to clinicians for individuals with ID/DD and MI
- Trauma Informed Care Initiative
  - Advance trauma-informed care statewide
- *Strong Families, Safe Communities*
  - establishing treatment models of care that focus on crisis stabilization for children and youth (8-24) with intensive needs

# Emerging Practices: MASSACHUSETTS

- Positive Behavior Supports (PBS) Initiative
  - DDS made commitment to
    - measure socially valued outcomes
    - implement systems to effectively execute empirically validated and practical practices
    - collect and analyze data to aid in decision-making

# Emerging Practices: Contacts

- NM:
  - Jennifer Thorne-Lehman, Deputy Director Office of Behavioral Supports
    New Mexico Developmental Disabilities Supports Division
    Jennifer.Thorne-Lehman@state.nm.us

# Emerging Practices: Contacts

- OH:
  - Teresa Kobelt, Assistant Deputy Director
    Ohio Department of Developmental Disabilities
    Email: Teresa.Kobelt@dodd.ohio.gov
- MA:
  - Janet George, Assistant Commissioner for Policy, Planning, and Children's Services
    Department of Developmental Services
    Email: janet.george@state.ma.us

# Data Brief

"What Do NCI Data Reveal About Individuals With Intellectual and Developmental Disabilities Who Need Behavior Support?"

http://www.nationalcoreindicators.org/upload/core-indicators/NCI_DataBrief_MAY2014_FINAL.pdf

# Contacts

- HSRI
  - Dorothy Hiersteiner: dhiersteiner@hsri.org
- NASDDDS
  - Mary Lee Fay: MLFay@nasddds.org

- NCI website: www.nationalcoreindicators.org


NASDDDS

# *The Universal Precaution of Trauma-Informed Care: Making Sure Each Individual Feels Safe and In Control*

*Julie P. Gentile, M.D.*
*Professor of Psychiatry*
*Wright State University*
*Dayton, Ohio*

# *Objectives*

- Ohio's Coordinating Center of Excellence in Mental Illness/Intellectual Disability
- Ohio's Telepsychiatry Project for Intellectual Disability
- Trauma Informed Care

# Ohio's CCOE in Mental Illness/Intellectual Disability

- Coordinating Center of Excellence in Mental Illness/Intellectual Disability
- Initiated in 2004
- Grant Funded Project:
  - Ohio Dept. of Developmental Disabilities
  - Ohio Dept. of Mental Health and Addiction Services
  - Ohio Developmental Disabilities Council

# Ohio's Coordinating Center of Excellence in Mental Illness/Intellectual Disability

- Assessment Capacity
- Educational Programming
- Dual Diagnosis Intervention Teams

| Community Development | Education | Assessment and Consultation |
|---|---|---|
| → 38 Dual Diagnosis Intervention Teams developed<br><br>→ 60 counties covered by Dual Diagnosis Intervention Teams<br><br>→ >18,000 inquiries on the CCOE website<br><br>→ $382,646 mini grants awarded to local communities | → 19,877 education attendees<br><br>→ 51,624 education contact hours<br><br>→ 354 programs directly sponsored, co-sponsored, and/or with CCOE partners providing educational programming | → 872 provided ongoing psychiatric care<br><br>→ >150 new assessments annually<br><br>→ Regional assessment backup clinics in the CCOE network<br><br>*Access Ohio Mental Health Center of Excellence……..……..*Dayton, Ohio*<br><br>*Nisonger Center (The Ohio State University)……*Columbus, Ohio* |

# Telepsychiatry

- Simms et al 2011
- Research shows alliance is not compromised by use of videoconferencing.
- Medium made some patients feel less embarrassed and more able to express difficult feelings
- Clinicians length of time in the field affected their openness to the new technology

# Telepsychiatry

- Reduction in travel time, costs, ER visits and hospitalizations.
- Not necessary to be ‘tech savvy’
- Established programs use ‘buffet menu’ (phone, Email, MD-MD, MD-patient, etc)
- Cancellation rate/show rate

# Ohio's Telepsychiatry Project for Intellectual Disability

- Prototype from 2005-2011 treating 90 individuals from 23 counties
- Telepsychiatry services initiated in 2012
- Virtual software which abides by patient privacy guidelines
- As of June 2014, 258 individuals from 44 counties engaged in the project
- Prioritize individuals from Developmental Centers and State Psychiatric Hospitals

# Ohio's Telepsychiatry Project for Intellectual Disability

- Required Criteria for Individuals Referred
- Child or adult with co-occurring mental illness/intellectual disability
- Medicaid Enrolled
- Self/Parent/Guardian consents and agrees to participate fully

# Ohio's Telepsychiatry Project

- In rural communities ~50% of mental health care is provided by primary care physicians.
- Patients may have to travel long distances or ***forgo such services altogether.***
- Telemedicine helps disseminate skill set to PCPs.
- Many patients prefer to go to a PCP clinic for appointments as opposed to a MH clinic (decreased stigma).
- Increasing data shows reliability/validity are similar to face to face interaction.

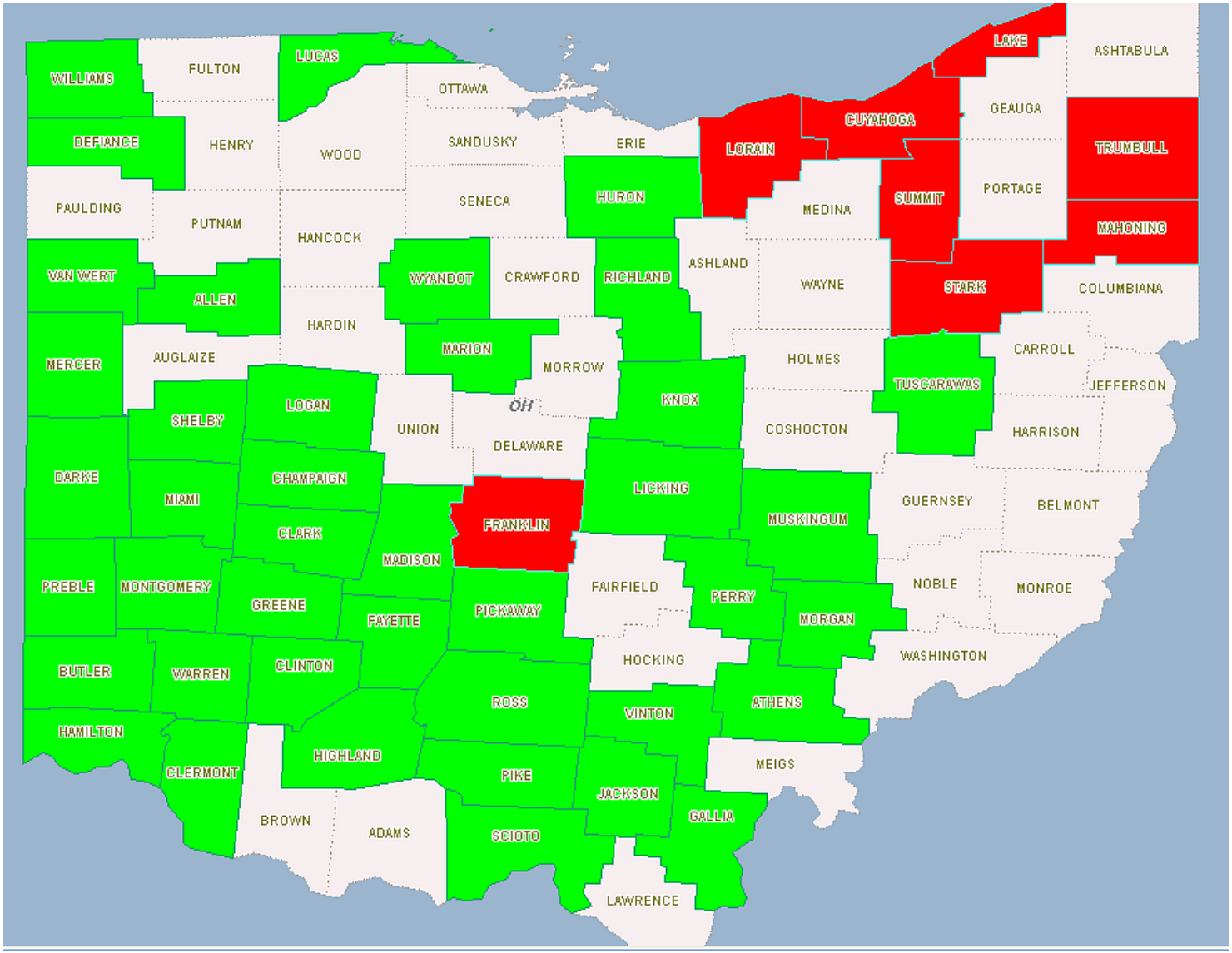
# Ohio's Telepsychiatry Project

- Expectations of County Developmental Disabilities Board
- Arrange staffing/computer equipment
- Accept lead role in coordinating access to emergency services as deemed necessary, to include hospitalization.
- Develop a collaborative relationship with local MH Board in order to best support the person's full range of MH needs.

# Telepsychiatry Project Preliminary Results

- For the first 120 individuals engaged in the program, **emergency room visits** decreased from 195 to 8 and **hospitalizations** decreased from 74 to 10 (comparisons are 12 months prior to telepsychiatry use to 12 months post treatment ).
- A number of the individuals were discharged from state operated institutions and others were in danger of short-term admission, none of the 120 involved in the project were admitted or readmitted to state operated institutions. This saves the state approximately **$80,000 per person per year** in support costs.
- **Travel costs** were reduced in some cases by 68% by not having to travel distances for specialty psychiatric care.

# Ohio's Telepsychiatry Project in ID
# June 2014



# Aggression: A Behavior

- TRAUMA HISTORY
- Means of expressing frustration
- Learned problem behavior
- Expression of physical pain or acute medical condition
- Means of communication
- Signal of acute psychiatric problem
- Regression in situations of stress, pain, change in routine, or novelty

# Aggression: A Behavior

- Dementia
- Loss of independence and/or physical functioning
- Grief and loss issues
- Escape or avoidance of unwanted demands or situations
- Attention seeking
- Self stimulatory behavior

# Bio-Psycho-Social-Developmental Formulation

- *A complete gathering of information through client interview, discussion with family members and/or caretakers, review of clinical records, and contact with collaborating agencies that leads to a formulation, diagnoses and treatment plan. The goal is to address and understand the developmental needs of the individual in a meaningful way utilizing Trauma Informed Care principles as a universal precaution.*

# Biological Aspects

- Demographic data
- Medical illness
- Genetic predisposition
- Medications (past and present)
- Substance use

# Biological Aspects

- 85% have untreated, under-treated or undiagnosed problems
- worsened by restrictions on care (labs, office visit frequency and length)
- medications used in ways they were never intended, in unsafe ways, with abbreviated monitoring protocols

# Communication Issues

- Talk to the patient
- Expressive language vs. receptive language
- Set the stage when appointment begins
- Summarize at the end

# Communication Issues

- Observation
- Relatedness
- Expression of Affect
- Impulse Control
- Attention Span
- Activity Level
- Unusual or Repetitive Behavior

# *Interview Techniques and Considerations*

- Sub-vocalizations
  - reflects a strategy to vocalize the thought processes in the individual's mind ("hearing)" what they are thinking
  - rehearse what is going to be said or to practice something the individual is planning to do
  - These should not be considered stalling tactics or an attempt to lie
  - Not the same as "talking" from person with a psychiatric disturbance (hallucination)

# *Fragile X Syndrome Communication Patterns*

- Indirect style of verbal expression
- Eye contact/Sitting at an angle
- "Cluttering"
  - How do you feel about going for a ride?
  - Cars run on gas, you need oil, too

# *Fragile X Syndrome Communication Patterns*

- Avoidance of eye contact
- Echolalia
- Staccato speech
- Unusual response to sensory stimuli
- Fragile X handshake
- **Mental Status Examination**
- Perseveration (**Automatic Phrases**)

# Crystal

- 15 year old female
- Seen in Emergency Department at Children's Medical Center
- No mental health history
- New onset aggression, refusal to eat
- Appears paranoid
- Rule out Schizophreniform Disorder

# Commonly missed medical conditions

- ***Seizure disorders***
- ***Pain (chronic)***
- ***Pulmonary (Asthma, Dysphagia, Infx)***
- ***Autoimmune disorders***
- ***Reflux (GERD)/Constipation***
- ***Sleep apnea***
- ***Extrapyramidal Side Effects***
- ***Vitamin Deficiencies***

# Most Common Causes of Behavioral Problems

- Pain (physical or emotional)
- Medication side effects
- Sleep disorders
- Psychiatric illnesses

# Usually NOT Psychosis

- Self-injury
- Explosive aggression
- Phenomena the person can stop or start at will
- Self talk

# Interpreting Behavior: Biting side of hand

- Usually Gastro-esophageal Reflux Disease/(GERD)
- Also: eruption of teeth, asthma, sinusitis, otitis, rumination, nausea, anxiety, painful hands/paresthesia, gout

# Interpreting Behavior: Intense rocking

- Not “normal” for the individual with ID
- Visceral pain
- Headache
- Depression
- Anxiety
- Medication side effects

# Interpreting Behavior: Head Banging

- This is not “normal” for anyone
- DEPRESSION/TRAUMA HISTORY
- Headache
- Dental
- Seizure
- Otitis/Mastoiditis
- Sinus problems
- Tinea capitus

# *Trauma Informed Care*

The world breaks everyone, and at the end, some are stronger at the broken places.
--Ernest Hemingway

# Trauma Informed Care

- Research suggests that many people have some form of traumatic event in his or her lives *(SAMSHA, 2010)*. Some experts believe as many as 95% of individuals with ID have some level of traumatic stress. It makes sense to treat EVERYONE as if trauma has possibly occurred. Making sure someone feels **safe** and **in control** of their own lives will help someone with trauma, and will not hurt anyone who does NOT have a history of trauma.

“Sit in the chair”

--Jerald Kay MD

# Grief and Loss Issues:

*Attempt to characterize developmental level and concept of loss/death at that stage*

# Developmental Implications of Loss and Grief/ Piaget

- Sensorimotor stage
  - Profound ID; developmental age 0-2 years
  - Experience of loss may be one of an expectation that lost object will return
  - Constantly unfulfilled expectation

# Developmental Implications of Loss and Grief/ Piaget

- Pre-operational Stage:
  - Developmental age 2-7 years
  - Severe/Moderate ID
  - How will the loss affect me? Who will understand me now? Who will take care of me? Who will be my friend? Who will give me things?
  - Fantasy and magical thinking may be used

# Developmental Implications of Loss and Grief/ Piaget

- Concrete operations
  - Developmental age 7-11 years
  - Moderate/Mild ID
  - Can understand clear and specific explanations of loss and death
  - Tend to take things literally

# TRAUMA

- Normal response: banish it from consciousness
- When the trauma story is told, recovery can begin
- If the story is not told, trauma becomes a symptom

# TRAUMA

- Trauma syndromes have a common pathway

- Recovery syndromes have a common pathway
  - Establish safety
  - Reconstruct story
  - Restore connections

# Trauma Experience: Mild/Moderate ID

- Will take cues from others' non-verbal behavior regarding the seriousness of situations and how to respond
- May discount verbal explanations
- May over-estimate or under-estimate the seriousness of situations (knowledge is power)
- Use imagination to 'fill in the blanks' when limited or no information is given to them ("The staff left because of me")

# Trauma Experience: Mild/Moderate ID

- Can experience significant grief/loss reactions, even if loss expected (complicated grief processes)
- Need routine, predictability, and behavioral limits to re-establish feelings of safety and security (What/who is home base for you?)
- May imagine illness, injury or pain (physical or emotional) are punishments for past wrong doing

# Trauma Interventions: Moderate ID

- Provide concrete explanations for what is happening, what will happen next, and for potentially traumatic sights and sounds in the environment Norwegian ship wreck

- Help identify and label what he/she may be thinking and remind him/her that others feel the same way ("I'm sad")

# Trauma Interventions: Moderate/Mild

- Address distortions and magical thinking and help ‘fill in the blanks’ with realistic information
- Help them create a coherent story to tell others about when happened or what will happen
- Explain and talk about events before they happen; tell them what to expect

# Trauma Informed Care

- Manipulating
- Lying
- Stealing
- We can explore these behaviors, determine the underlying meaning and assist the patient in communicating his or her needs more effectively.

# Recovery

- Allow patients to save themselves
- Remember what your role is
- Not a savior or rescuer
- Facilitator, support
- Help reinstate renewed control
- The more helpless, dependent and incompetent the patient feels, the worse the symptoms become

# The Contract

- Commitment to the future
- Commitment to moving forward
- Commitment to health and well being

- Clarify roles

# Psychotherapy for ID

| | |
|---|---|
| Flexible sessions | Length of therapy sessions should match the individual's attention span. For some patients, this may be no longer than 30 minutes. |
| Simplification of interventions | Break down intervention into smaller segments and reduce the complexity of the techniques being utilized. |
| Adjust language | Reduce level of vocabulary, sentence structure and length of thought to match the cognitive ability of the patient. |
| Augment interventions with activities | Use of activities can help to deepen change and learning and may include the use of drawing, therapeutic games, role play and homework assignments. |
| Involve caregivers | Important source of collateral information necessary to ascertain progress between sessions. |
| Increased length of care | Most research indicates that a longer length of treatment (1 to 2 years) is a best practice with this population. This allows the psychotherapy to move at a slower pace so that the clinician can spend additional time on each intervention utilized, ensuring that the skills being taught are internalized. It also allows for the inclusion of additional treatment stages which may be necessary. |

# Phamacotherapy

- Currently no evidence based medicine in the area of dual diagnosed
- Prevalence studies, clinical cases, and side effect studies available
- Consensus-based and practice-based medicine will suffice

# Evidence Based Medicine

- Four groups excluded from large, double-blind, placebo controlled trials
- Rationale for exclusion of individuals with ID
- Use timelines

# Biological Risk Factors in Patients With DD

- Probable abnormalities in serotonin pathways (varying turnover rate, possibly decreasing circulating serotonin levels)
- Co-occurrence of aggression, depression, and OCD
- High rates of sleep disorders

# Consensus Guidelines

- Rush AJ, Frances A. *The Expert Consensus Guidelines™: Treatment of Psychiatric and Behavioral Problems in Mental Retardation.* **American Journal on Mental Retardation 2000;105:159-228.**

- Aman MG, Crismon ML, Frances A, et al.: Treatment of psychiatric and behavioral problems in individuals with mental retardation: an update of the expert consensus guidelines. **Expert Consensus Guidelines, 2004.**

- International Guide for Using Medication. The **World Psychiatric Association** (WPA): Section on Psychiatry of Intellectual Disability (SPID)**1st September 2008**

- CLINICAL BULLETIN *of the* DEVELOPMENTAL DISABILITIES DIVISION. **International guide** to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities. **World Psychiatry Assn 2010**

# Summary

# Signs the diagnosis is incorrect

- *Using more than one medication in the same class*
- *Residual signs/symptoms*
- *Use of toxic dosages or presence of side effects*

# Medications

- Medications prescribed should improve cognitive function (or at least not cause decline)
- Should treat conditions fully
- Should be similar to medications offered to anyone else with the same disorder

# Summary

- ID do not protect one from developing MI
- ID do not make one resistant to the effects of psychotropic medications
- Danger of over-diagnosis AND under-diagnosis
- Myth that patients with ID can't benefit from mental health services including trauma informed care, psychotherapies and state of the art medication regimens

# Contact Information:


- *julie.gentile@wright.edu*
- www.midd.ohio.gov
- *www.juliegentile.com*
- *Julie P. Gentile, M.D.*
- *Professor, Wright State University Department of Psychiatry*