What Do NCI Data Show About Adults Who Need Support for Self-Injurious Behavior?

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NATIONAL CORE INDICATORS™
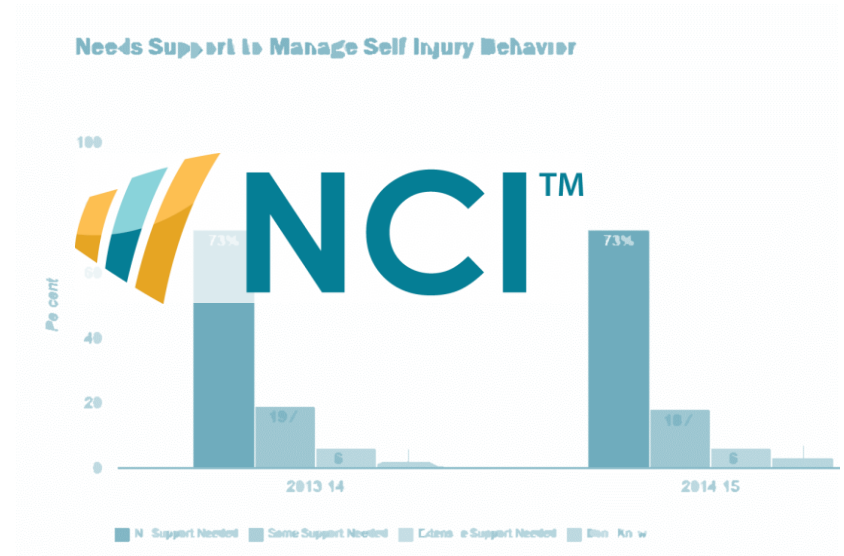NASDDDS & HSRI

HSRI — Human Services Research Institute

NASDDDS

Agenda

- Background
- What is NCI?
- What do the data show?
- Research/policy considerations

Background

- Self-injurious behavior (SIB)
  - Self-inflicted harmful behavior that can result in injury and cumulative physical damage

- For people with ID/DD
  - Affect health, QoL
  - May make it difficult to be in inclusive settings
    - Can lead to social isolation and anxiety
    - Poses caretaking challenges on families

Background (cont.)

- Approaches to supporting people with SIB
  - Aversive and painful interventions
  - Restraints
- Functional Analysis
  - Determining cause of behavior
    - Pain, communication barriers, etc.
- Positive Behavior Supports (PBS)

The National Core Indicators:
A quality and outcomes survey

- NASDDDS, HSRI & State DD Directors
  - Multi-state collaboration, launched in 1997 in 6 participating states – now in 46 states (including DC) and 22 sub-state areas

- GOAL: Measure performance of public systems for people with ID/DD by examining outcomes

- Domains:
  - Employment
  - Community inclusion
  - Choice
  - Rights
  - Health
  - Safety
  - Relationships
  - Service satisfaction etc.

NCI Adult Consumer Survey (ACS)

Random sample of adults who receive services regardless of setting

- Background Information Section
  - Data from agency records or information systems
  - Includes info on need for behavior support for SIB
- Section I
  - Individual satisfaction; no proxy allowed
- Section II
  - Fact-based objective questions; proxy allowed

Adult Consumer Survey
2015-16 Final Report
(revised June 2017)

NATIONAL CORE INDICATORS™

A Collaboration of
The National Association of State Directors of Developmental Disabilities Services
and
Human Services Research Institute

2015-16 ACS Sample

Please identify the level of support the person needs to manage any of the types of behavior listed below.

BI-55   **Self-injurious behavior**

Refers to attempts to cause harm to one's own body; for example, by hitting or biting self, banging head, scratching or puncturing skin, ingesting inedible substances, or attempting suicide.

- ☐ 1   No support needed
- ☐ 2   Some support needed; requires only occasional assistance or monitoring
- ☐ 3   Extensive support needed; frequent or severe enough to require regular assistance
- ☐ 99   Don't know

Valid responses to this Q for
15,581 individuals
in non-institutional settings

# What do the 2015-16 NCI Adult Consumer Survey data tell us about people who need support for SIB?

Analysis Notes
- Does not include respondents living in institutional settings
- Averages are not "average of state averages" (as in NCI reporting) but averages of all respondents
- Differences shown are significant at the p<=.001 level

Demographics and Personal Characteristics

Need some or extensive support for SIB (N=15,581)

Needs some or extensive support for SIB, 23.2%

Does not need support for SIB, 76.8%
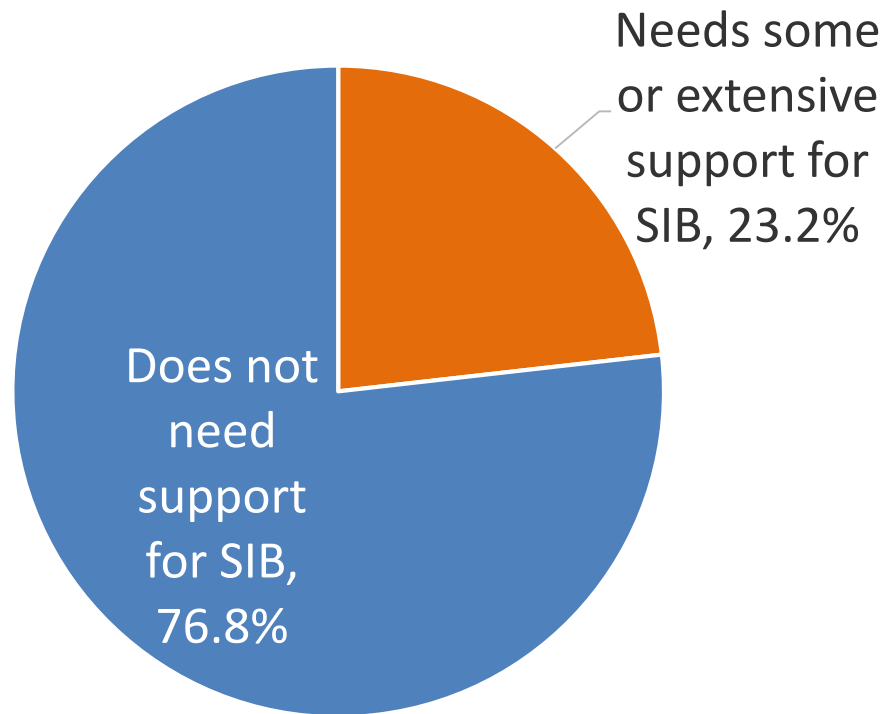
State Variation in Rate of Individuals Needing Support for SIB

Average, 23.2% of respondents need some/extensive support for SIB

11.5%

45.1%
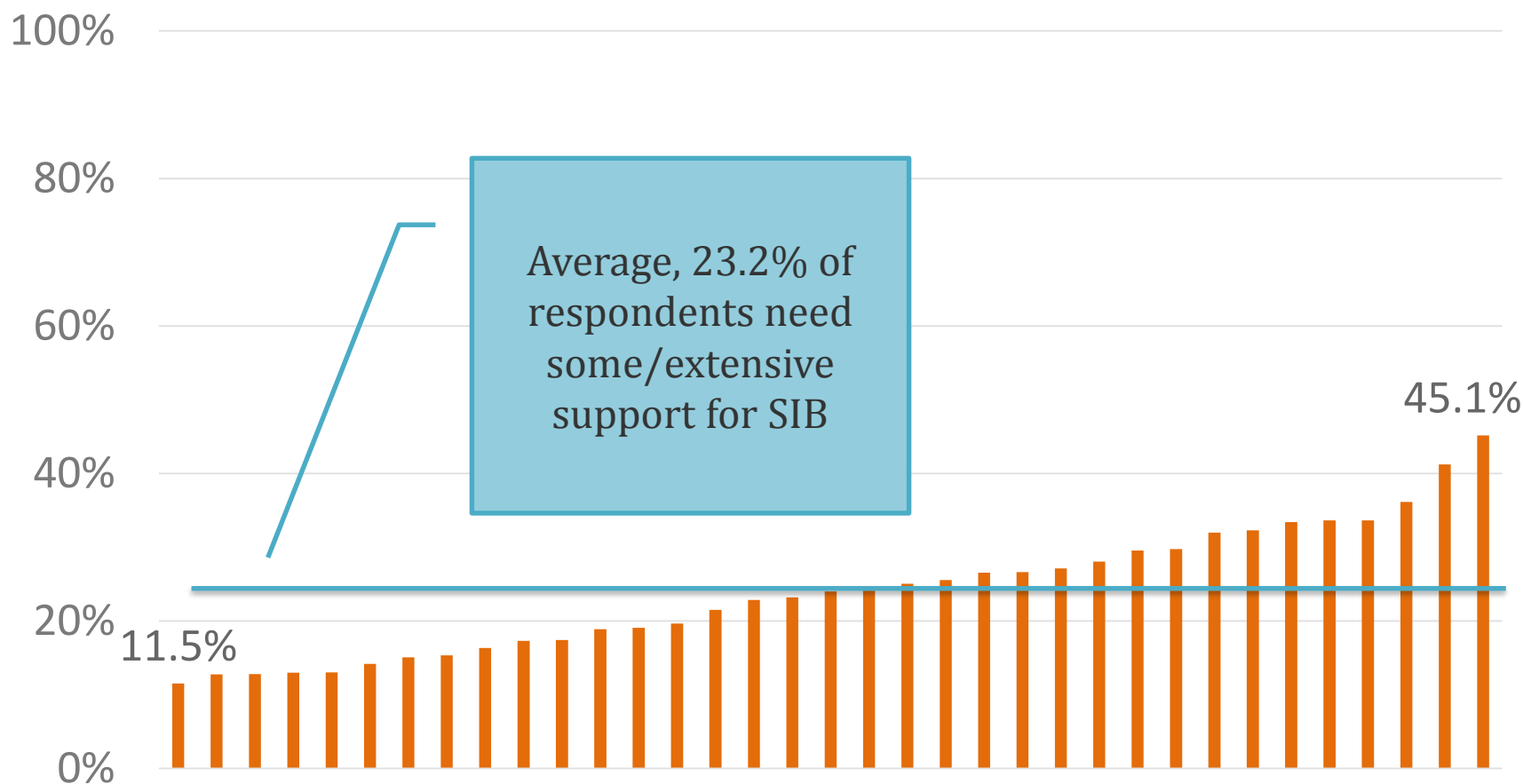
Those with SIB support needs... more likely to have severe or profound ID (N=15,301)

ID Level	No need for support	Need for some or extensive support
N/A- no ID label	6.1%	4.3%
Mild ID	40.3%	27.0%
Moderate ID	29.8%	29.7%
Severe ID	10.5%	18.9%
Profound ID	6.4%	13.0%
Unspecified level	6.1%	6.3%
ID level unknown	0.9%	0.6%
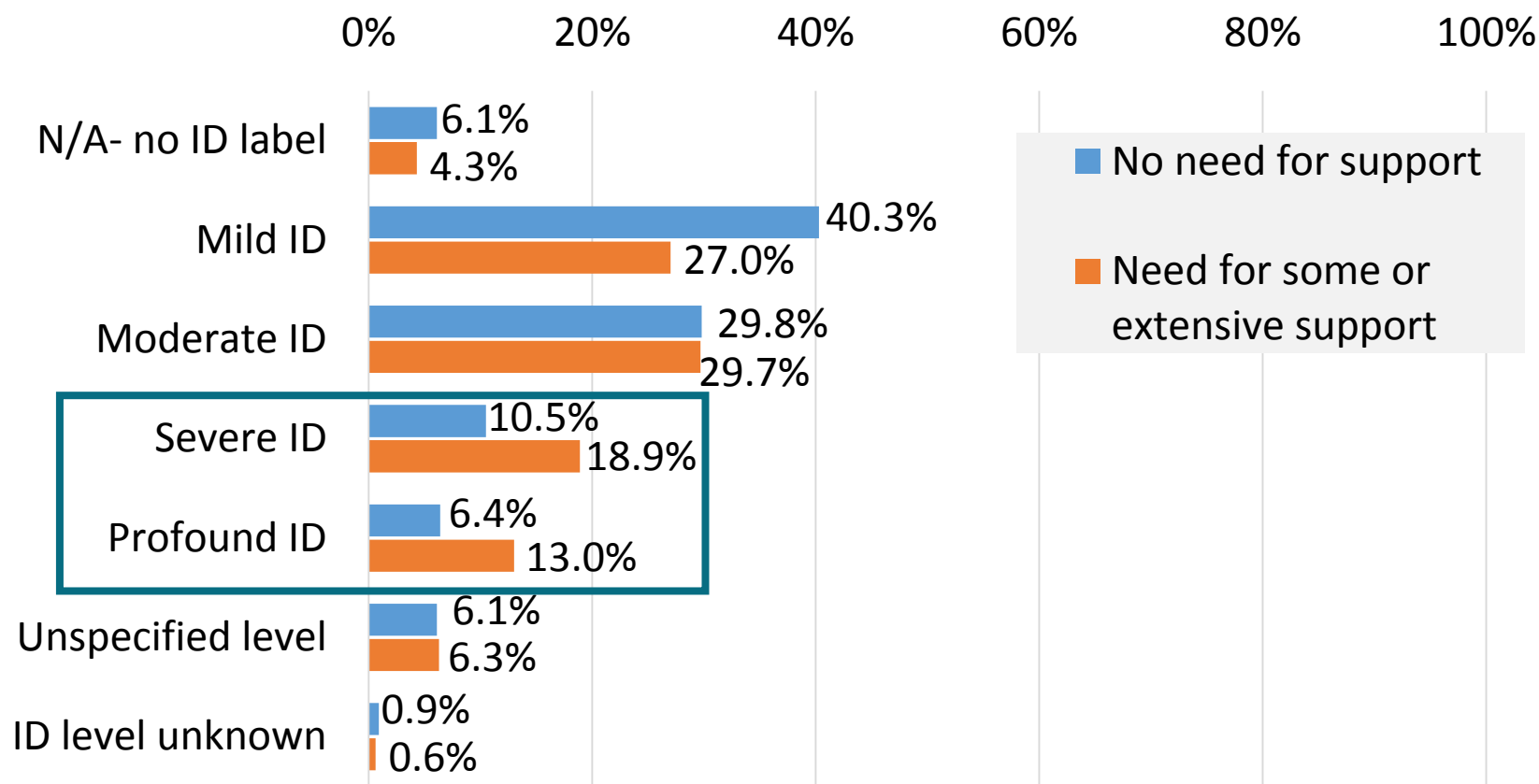
More likely to be diagnosed with mental health diagnoses
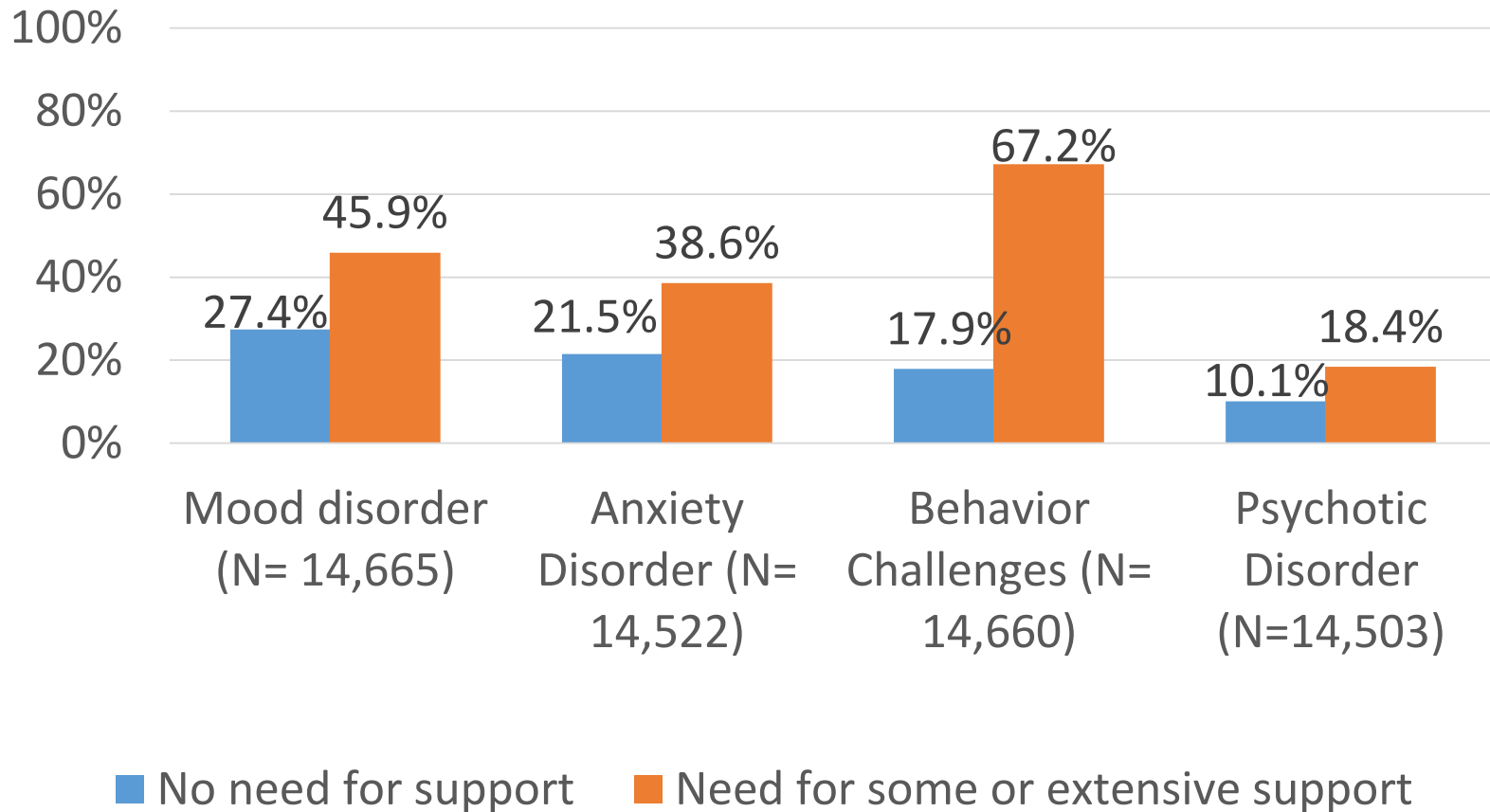
More likely to be diagnosed with ASD, seizure disorder/neuro problem; less likely to have diagnosis of Down syndrome

Chart showing percentages by diagnosis category:

	No need for support	Need for some or extensive support
ASD Diagnosis (N=14,673)	13.4%	29.8%
Seizure Disorder/Neurological Problem (14,781)	27.2%	34.2%
Down Syndrome (N=14,750)	11.0%	5.4%
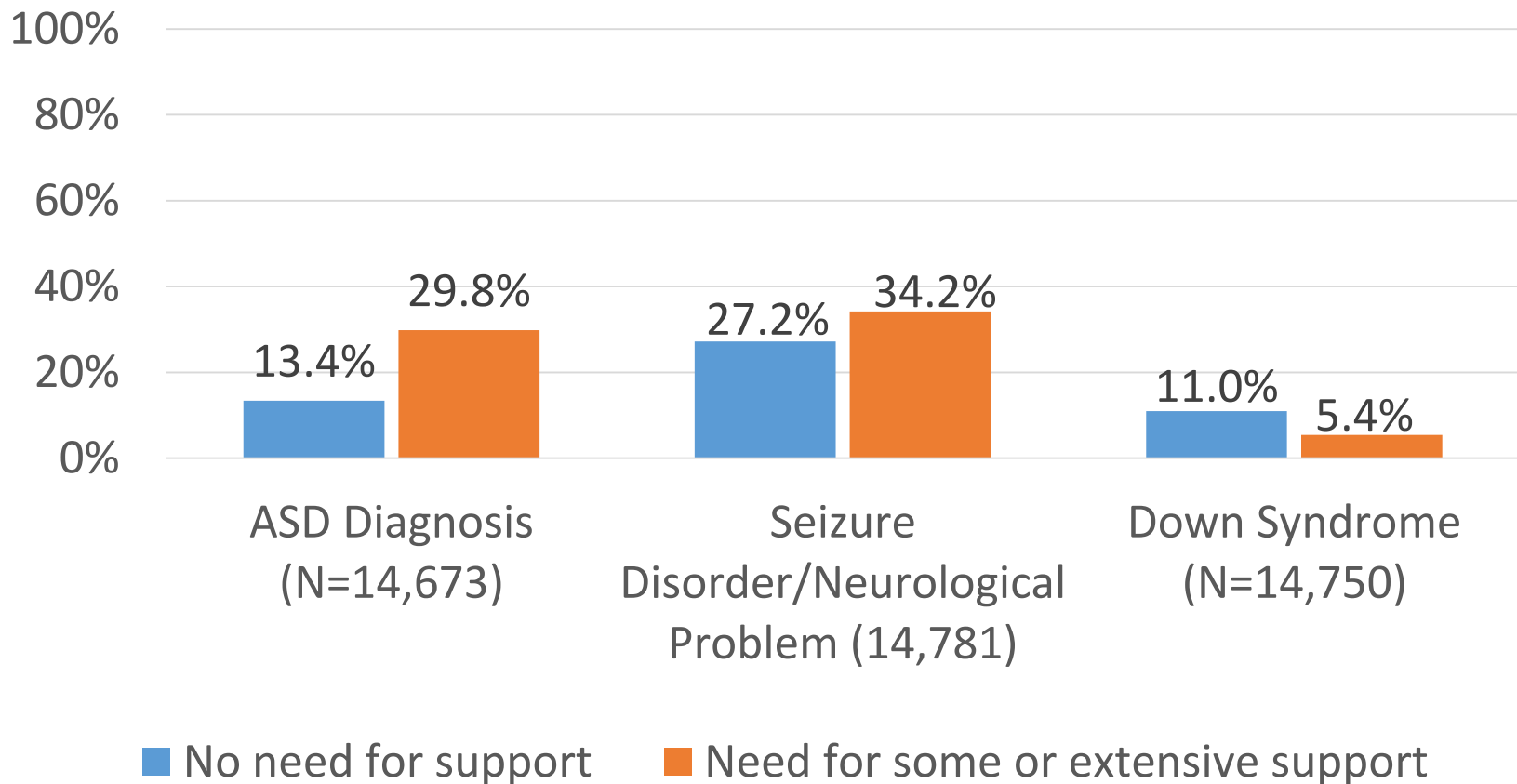
Less likely to prefer to communicate through spoken word; more likely to use gestures/body language (N=15,457)

Spoken: 83.3% (No need for support), 68.4% (Need for some or extensive support)

Gestures/body language: 12.9% (No need for support), 25.1% (Need for some or extensive support)

Sign language/ finger spelling: 1.3% (No need for support), 3.1% (Need for some or extensive support)

Communication aid: 0.9% (No need for support), 0.9% (Need for some or extensive support)

Other: 1.6% (No need for support), 2.5% (Need for some or extensive support)

Legend:
- No need for support
- Need for some or extensive support

Less likely to live in own home or with parent/relatives (N=14,325)

Group residential setting (e.g., group home): No need for support 31.2%, Need for some or extensive support 51.4%

Own home or apartment: No need for support 22.9%, Need for some or extensive support 17.2%

Parents/relatives home: No need for support 45.9%, Need for some or extensive support 31.4%

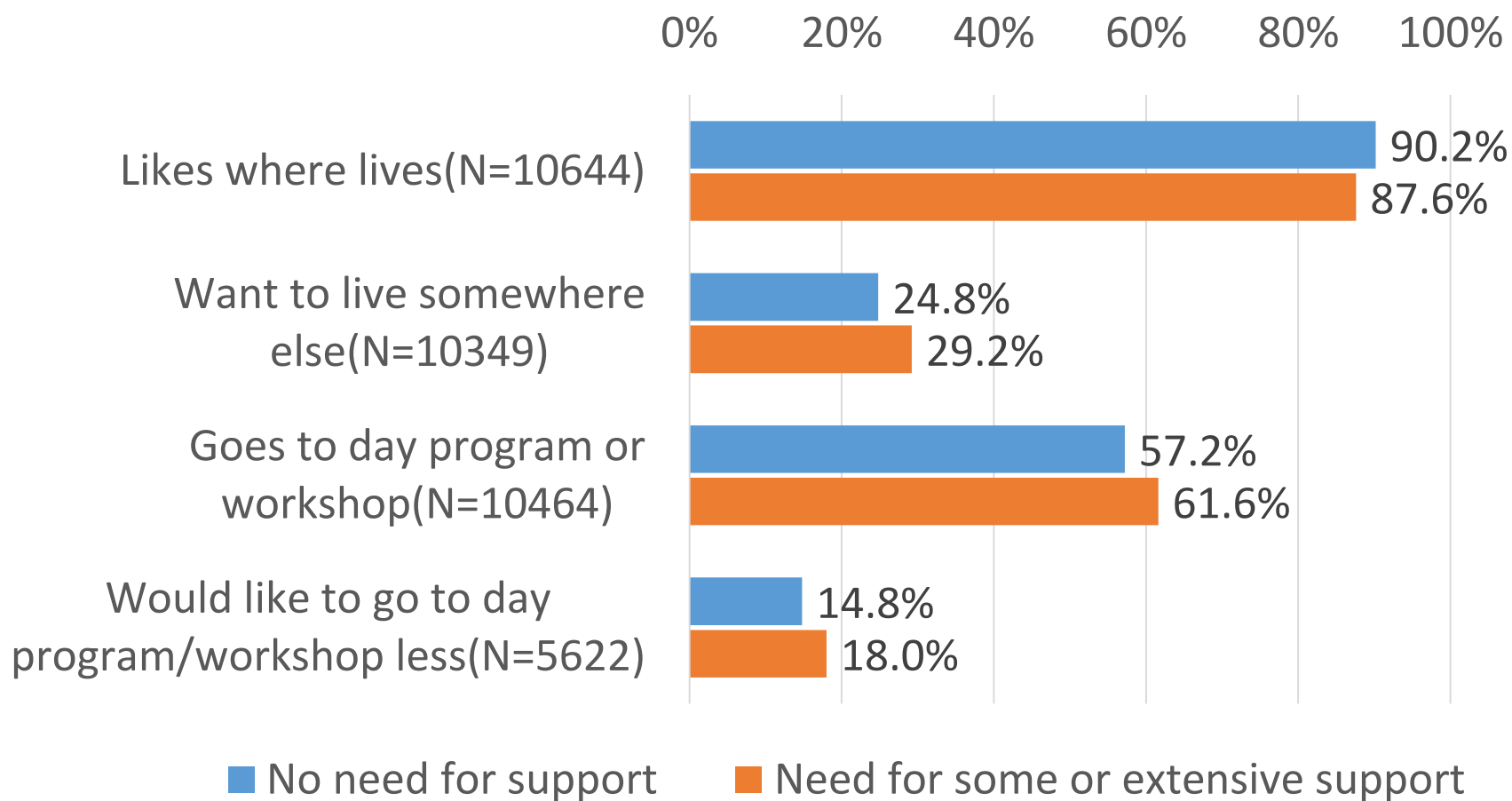- No need for support
- Need for some or extensive support
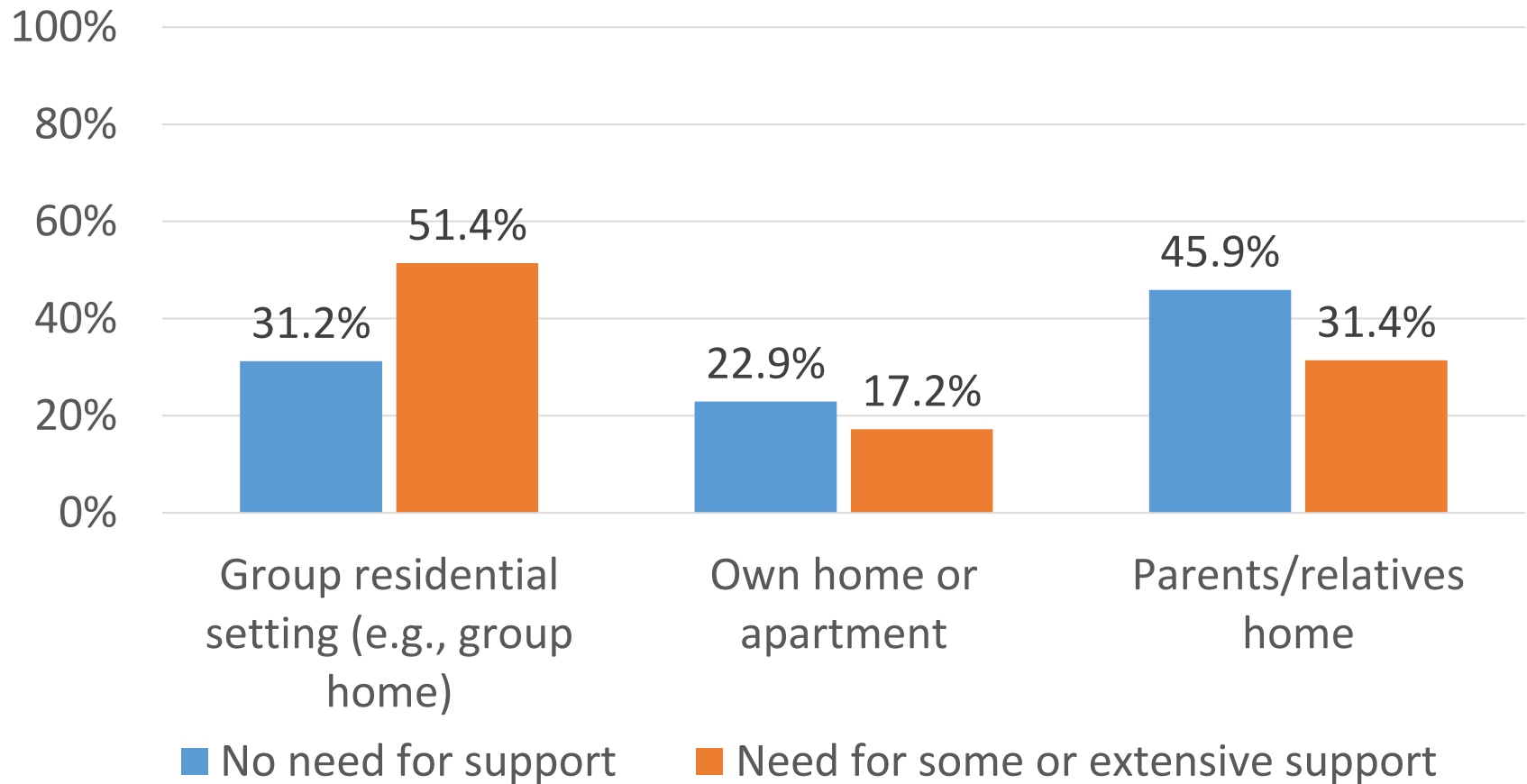
Of note…

- No significant differences
  - In level of mobility
  - For those with hearing impairments

- Slightly significant difference in self-perceived health status
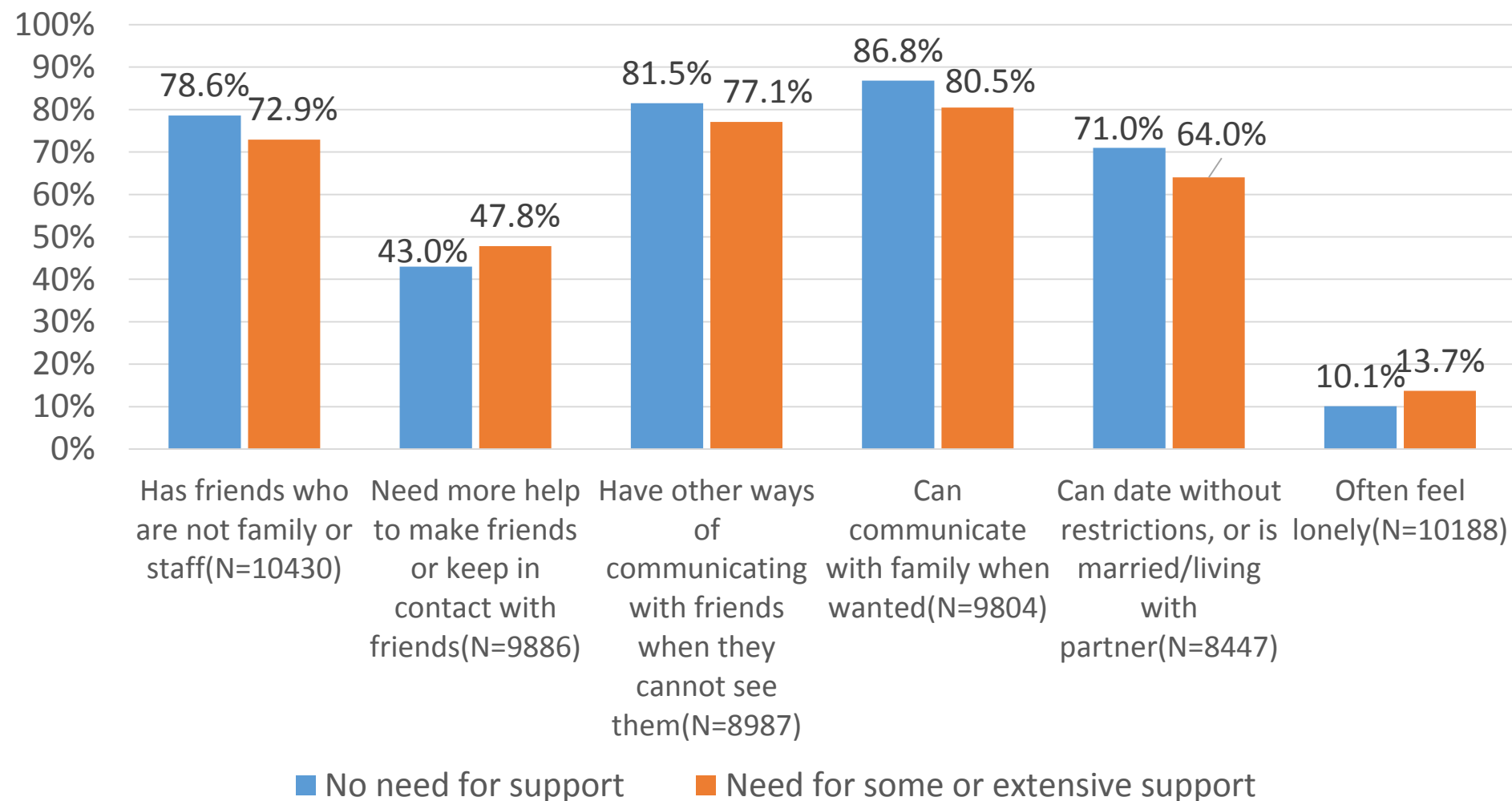 - Those with SIB support needs were slightly more likely to report being in poor health

Outcomes

Those with SIB support needs express lower satisfaction

0%   20%   40%   60%   80%   100%

Likes where lives(N=10644)
- No need for support: 90.2%
- Need for some or extensive support: 87.6%

Want to live somewhere else(N=10349)
- No need for support: 24.8%
- Need for some or extensive support: 29.2%

Goes to day program or workshop(N=10464)
- No need for support: 57.2%
- Need for some or extensive support: 61.6%

Would like to go to day program/workshop less(N=5622)
- No need for support: 14.8%
- Need for some or extensive support: 18.0%

■ No need for support   ■ Need for some or extensive support

National Core Indicators (NCI)

Less positive outcomes in the domain of relationships

National Core Indicators (NCI)

... the domain of community inclusion, participation and leisure

Chart showing percentages for three community inclusion indicators, comparing "No need for support" (blue) and "Need for some or extensive support" (orange):

- Can go out and do the things likes to do (N=10274): No need for support 86.1%, Need for some or extensive support 83.3%
- Has enough things likes to do at home (N=10364): No need for support 83.5%, Need for some or extensive support 81.1%
- Participates in community groups and/or activities (N=14440): No need for support 38.9%, Need for some or extensive support 35.9%

Legend: ■ No need for support ■ Need for some or extensive support

...Choice

Person had at least some input in choosing …

| | 0% | 20% | 40% | 60% | 80% | 100% |

Category	No need for support	Need for some or extensive support
Home(N=8386)	64%	47%
Who lives with (N=8251)	53%	37%
Staff(N=13596)	73%	67%
Daily schedule(N=14739)	87%	80%
What to do in free time(N=14741)	94%	90%
Day activity(N=10655)	70%	57%
What to buy with spending money(N=14633)	90%	83%
Case manager(N=14092)	72%	68%
Job(N=2382)	87%	79%

■ No need for support   ■ Need for some or extensive support
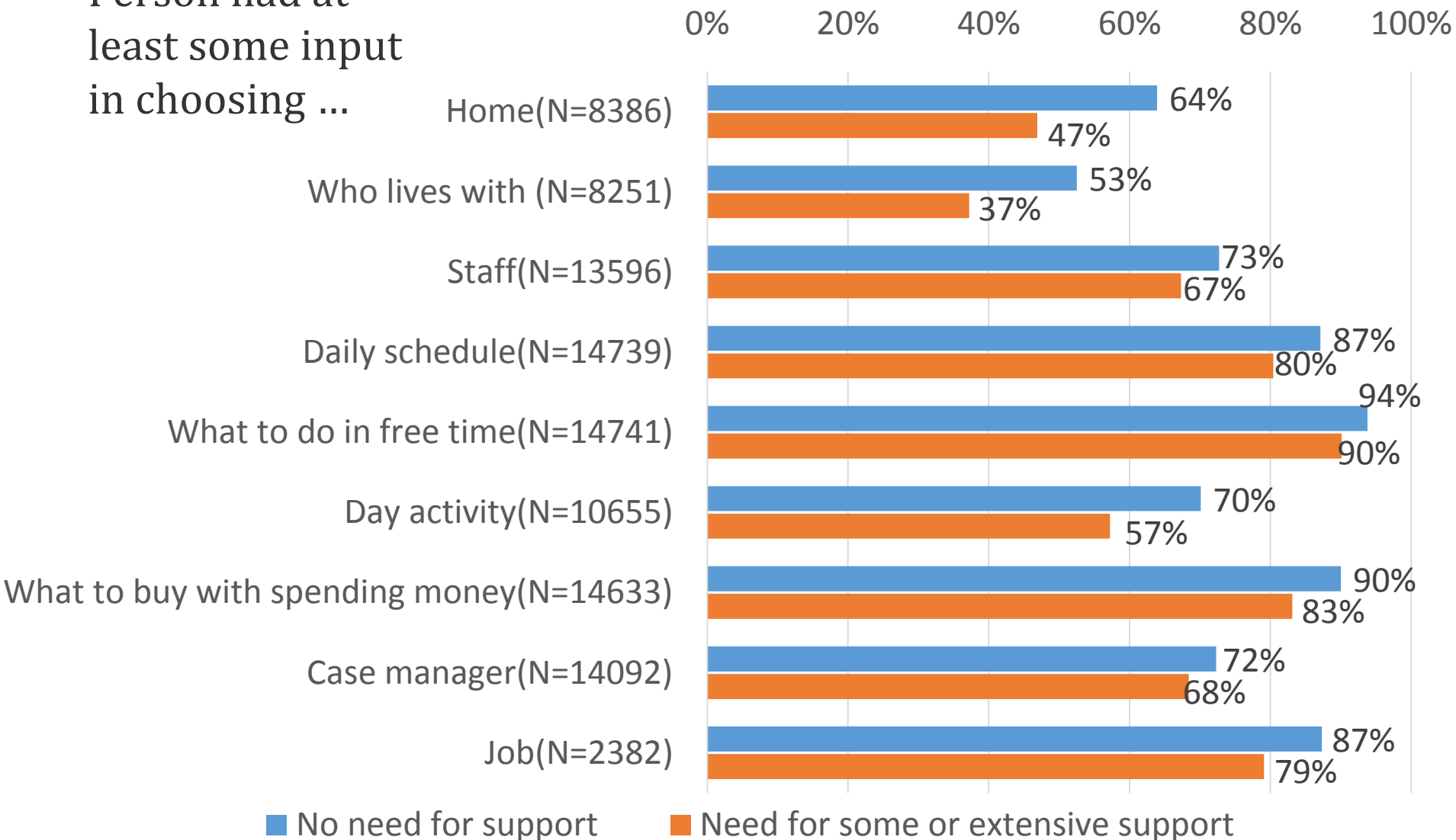
And were less likely to have a paid, community-based job

Chart data:

Category	No need for support	Need for some or extensive support
Had paid, community-based job in the past two weeks(N=14840)	20.7%	11.1%
Had unpaid, facility-based activity in the past two weeks(N=14603)	35.6%	40.9%
Community employment is goal in service plan(N=14891)	31.1%	22.9%

■ No need for support   ■ Need for some or extensive support
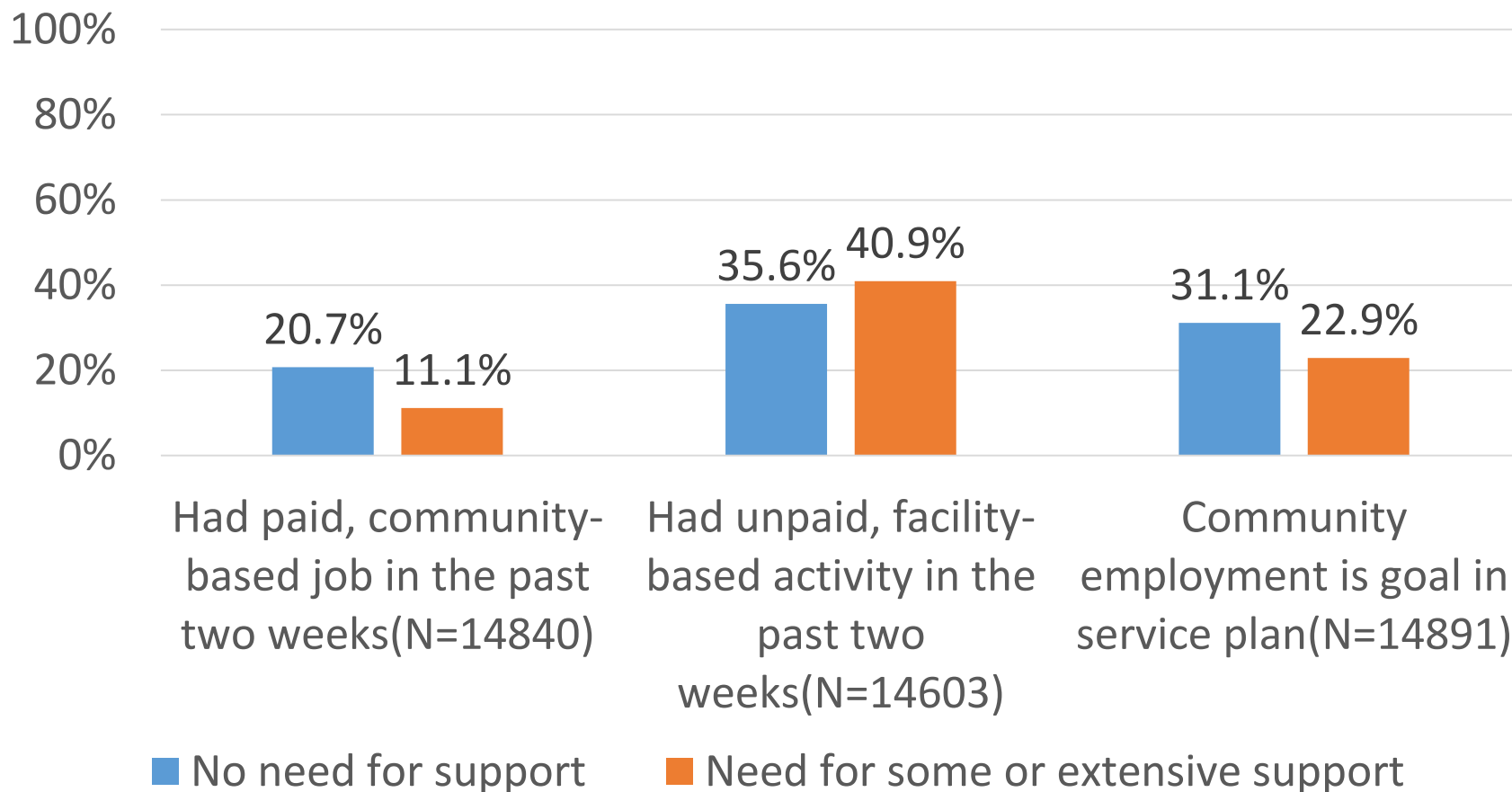
Considerations for future research

- Identify system components that are related to better outcomes
  - Person-centered planning, Employment First policies, positive behavior supports
- What is the impact of other demographic/personal characteristics on outcomes for people with SIB support needs?
  - Do the presence of other factors have influence on outcomes for individuals with SIB support needs?

Considerations for public policy

- Standardized construct to facilitate accurate assessment of SIB

- Policy can reinforce the importance of functional assessment of adults with SIB; these assessments are critical to identifying potential causes and consequences of the behavior

- States can look at adoption of evidence-based practices such as positive behavior supports

- Necessitates training and education of those who implement the support

Considerations for public policy (continued)

- States can review state policy regarding behavior plans
- Public managers can look at their policies regarding aversive treatments
- States can also work to develop and maintain high standards regarding qualification, training, and quality assurance of those who provide support for SIB
- States can work to expand family supports (e.g., quality crisis and respite care)

What did she say?

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National Core Indicators (NCI)

Positive Behavior Support: South Carolina Department of Disabilities and Special Needs

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Executive Director

Center for Disability Resources (UCEDD/LEND)

University of South Carolina School of Medicine

Susan Kreh Beck, Ed.S., L.P.E.S., N.C.S.P.

Associate State Director- Policy

SC Department of Disabilities and Special Needs

Why Did South Carolina DDSN Decide to Implement PBS?

- Focus Group Results
  - What training do you need to do your job better?

- Frequent Requests for Assistance

  - Requests for alternative residential placement based on behavioral needs

- Complaints about quality of behavioral services and some behavioral providers

Why Did South Carolina DDSN Decide to Implement PBS Cont'd

- Advancements in Professional Practices (PBS)

- The motivation was "How Can We Improve the Quality of Behavior Supports in the South Carolina DDSN System?"

- There was (and is) no involvement from the Department of Justice and no lawsuit related to behavior supports.

How Was the Plan Developed?

- Collaboration between DDSN and the USC Center for Disability Resources (UCEDD/Rotholz).

- Task Force on How to Improve the Quality of Behavior Supports
  - Behavior Analyst, family member, community behavioral provider, clinical supervisor, community residential coordinator, DDSN training coordinator, pharmacy director (DDSN), psychology director for residential center, program director, direct support professional supervisor.

What Did the Plan Propose?

- Coordinated effort across the areas of:
  - Paradigm Shift to PBS

  - Capacity related to behavioral and psychiatric services

  - Training

  - Provider Qualifications

  - Quality Review specific to behavior supports

Quote from Rotholz & Ford (2003)

- It is a simple task to provide examples of existing literature on behavior support. It is considerably more difficult to point to widespread implementation of these methods at the local level or systems that promote and support them (p. 355).

A Lesson Learned . . .

- "There is a considerable difference between recommendations and the actual implementation of efforts . . . The recommendation that that training be provided differs considerably from the process of securing funding, developing a request for proposals, selecting a contractor, collaboratively developing a curriculum, and implementing competency-based training for hundreds of staff persons throughout South Carolina" (p. 356).

How Was the Plan Operationalized?

- Implementation Workgroup
  - Training

  - Qualifications

  - Provider Applicant Approval/Enrollment

  - Quality Assurance

Training

- For Supervisors of DSPs
    - AAIDD PBS Training Curriculum
        - Editions 1 - 3
    - Follow up course to train local trainers

- For Behavior Support Plan Authors
    - University Based
    - Began as 3-course sequence, evolved into full BACB approved 6-course sequence
        - 2 years before QA process implemented

Qualifications & Approval Process

- Revision of Medicaid Waiver, creation of Behavior Support Service

- Interview and Work Sample required

  - 2 year approval status
  - CEU requirement

Quality Assurance

- Originally based on 13 criteria (from Medicaid Waiver service) and conducted by DDSN and CDR faculty/staff

- Revised to 6 standards with operationalized guidance and weighted scoring
  - Conducted by contracted BCBA-Ds trained to inter-rater reliability on standards and guidance

Challenges and Adaptations

- Legal
  - 2 lawsuits – none lost
  - Medicaid administrative appeals on removal from provider list – none lost

- Political
  - Legislative Audit Council review focused on DDSN included a few items on Behavior Supports approval process

Changes Over Time

- Added skills check for local PBS trainers

- Interviews as part of qualification process

- Screening of applications

- Revision of criteria --> standards (2014)

- Discontinuation of interviews

- New QA process based on 2014 standards

Outcomes

- Process and Provider Outcomes
    - Process (partial examples)

        - QA reviews show that required components are part of the service provided.

        - Functional Assessment (with competing behavior pathways diagram)

        - Replacement Behavior (objective & graph)

        - Observation-based fidelity checks

Other States Models

Minnesota

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       Institute on Community Integration

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Missouri

      Teresa Rogers, Ph.D., BCBA-D
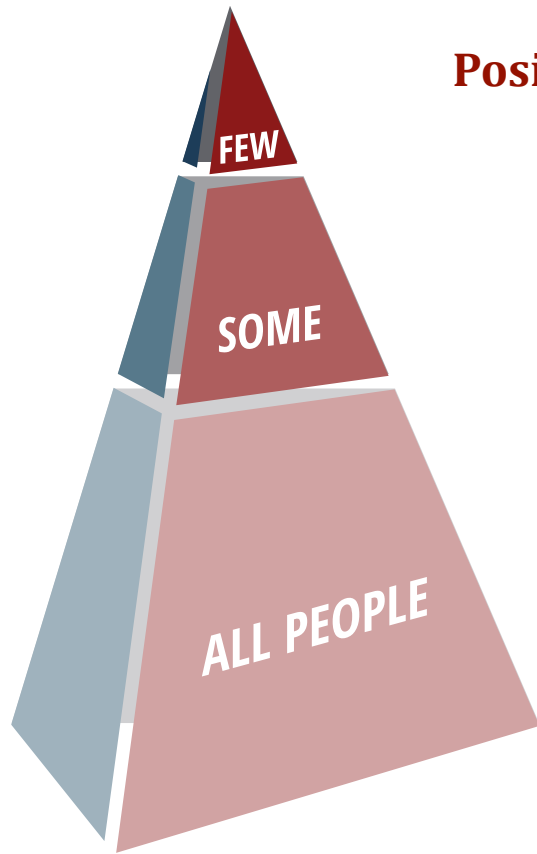
      Division of Developmental Disabilities

      Missouri Department of Mental Health

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Implementing Multi-Tiered Systems of Support - Minnesota

FEW

SOME

ALL PEOPLE

Positive Behavior Support

Tertiary Stage
- Individualized PBS Plans
- Integrated with Other Positive Supports (PCP, Trauma-Informed Care, DBT, Etc.)
- Plans Are Monitored- Data-Based Decision Making
- Teams Monitor Progress of Each Person

Secondary Stage
- Early Intervention and Data Monitoring
- Additional Supports for Key Social Skills
- Function-Based Decisions
- Simple Interventions
- Mental Health and Wellness Interventions

Universal Stage
- Teach and Encourage Communication
- Predictable and Proactive Settings
- Encourage and Reinforce Social Skills
- Consensus-Based Team Focus
- Emphasis on Using Data For Decisions

Positive Behavior Support

Person-Centered Practices & Planning

Organizational Workforce

Implementing Multi-Tiered Systems of Support Minnesota

Person-Centered Practices & Planning

Positive Behavior Support

Person-Centered Practices & Planning

Organizational Workforce

FEW

SOME

ALL PEOPLE

Tertiary Stage
- In Depth Person-Centered Plans
- Integrated Plans (PCP, PBS, Trauma-informed Therapy)
- Teams Monitor Plan Progress

Secondary Stage
- Monitor PCT Action Plans
- Additional Quality of Life Strategies
- Increase Strategies for Supporting Independence and Community Involvement
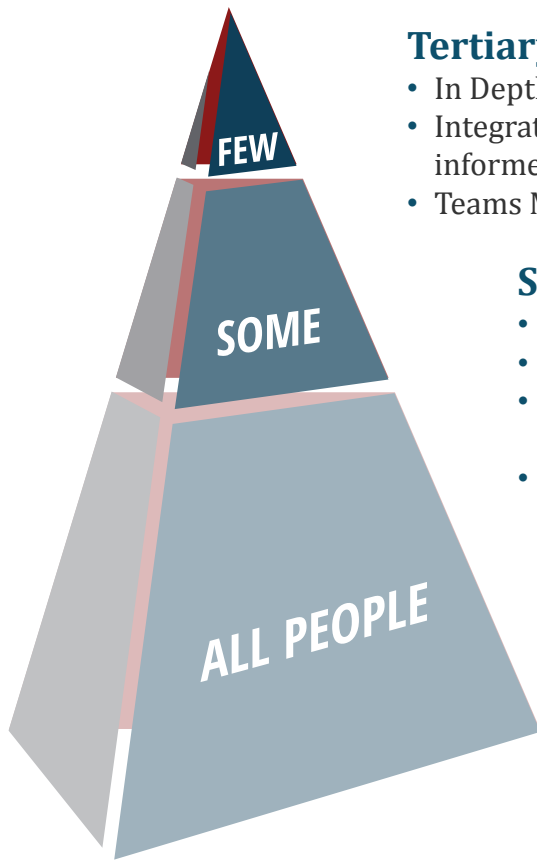- Mental Health and Wellness Interventions

Primary Stage
- Universal Person-Centered Strategies
- Encourage Self Expression
- Self-Determination and Choice Making
- Meaningful Participation in the Community

Implementing Multi-Tiered Systems of Support - Minnesota

Organizational Workforce Development
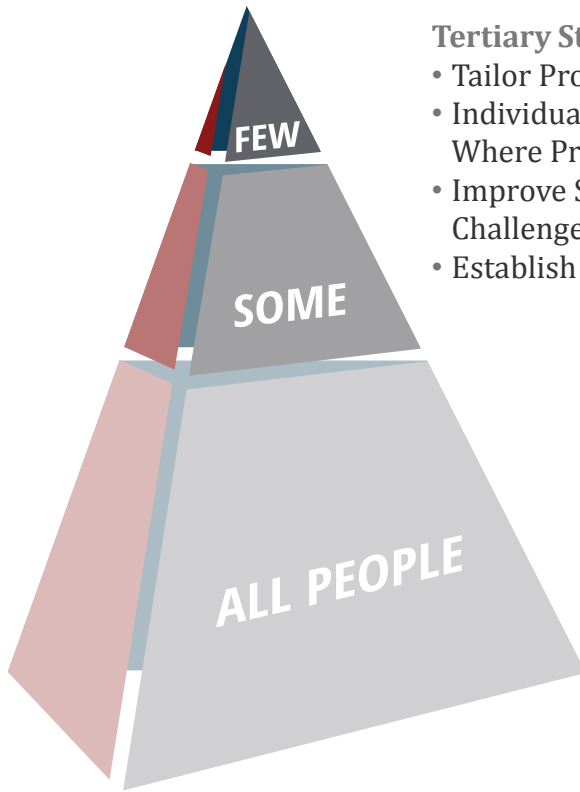
Tertiary Stage
- Tailor Problem Solving for Specific Problematic Situations
- Individualize Training and Mentoring to Address Unique Settings Where Problems Occur
- Improve Supervision and Mentoring for Locations Experiencing Challenges
- Establish Matching/Hiring Tailored to Individualized Plans

Secondary Stage
- Monitoring and Early Intervention
- Training Targeted for Groups
- Targeted Strategies to Improve Specific Settings
- Simple Problem Solving for Challenging Situations That Occur in More Than One Situation

Universal Stage
- Align Policies to Person-Centered Practices
- Revise Job Descriptions, and Performance Evaluations
- Integrate Person-Centered Practices and PBS With New Orientation and Ongoing Instruction
- Use Data for Decision Making

Positive Behavior Support

Person-Centered Practices & Planning

Organizational Workforce

Missouri's Tiered Supports Vision is strategy implementation at the level of the service provider of each of the levels of prevention

Person Centered Strategies

- Integrated Plans
- Trauma informed therapy
- Individuals with positive supports
- Teams monitor progress

Positive Support Strategies

- Behavior Analysis
- Specialized Mental Health Services,
- Intensive Supervision

Intensive Individualized Strategies

1-4% need if levels below present

More intensive supports teaching skills for Independence and community involvement, choice making, self-advocacy

- Problem Solving,
- Coping Skills
- Social skills
- Visual Schedule
- Check in/check out

Focused Strategies

5-10% - group based teaching, reinforcement common problems & situations

Encourage Self Expression & Choices Meaningful participation in community

Use of Tools of Choice, Teach & Recognize Life Values, Reinforcement System, Meaningful Day, Healthy Relationships

Universal Strategies

All Designed to Improve Quality of Life

All Need and 80-90% Successful with this level only

MO-DD Tiered Supports state-level implementation mirrors the PBS School-wide model at Tier 1 Level of Prevention

Mo DDD Tiered Organization- wide Model

State wide Coordinator

Regional Resource Teams

Organization-wide teams (Agency teams)

Mo School-wide Model

State-wide Coordinator

Regional Consultants

School-wide teams

Systems

Unit of implementation = Agency

- System of Recognition of implementation

-Trainings designed for Implementation phases

Unit of Implementation = School Building

- System of Recognition (Bronze, Silver Gold)

- Training designed for implementation phases

Data

-Agency systems and support evaluation tools (ASSET)

- Incident reports

-Organization-wide Improvement data, e.g. Positive-Negative Interaction ratios

- School systems and supports evaluation tool (SET)

-Office referrals

-School-wide Improvement Data

Practices

Agency team – designs and implements Universal Strategies including Staff Interactions skills (Tools of Choice), and teaching and recognizing Life Values

School Team designs implementation of school wide Tier 1 and 2 strategies

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