



Who are adults with IDD requiring behavioral supports?

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NADD, 10/24/2013

WHAT IS NATIONAL CORE INDICATORS (NCI)?

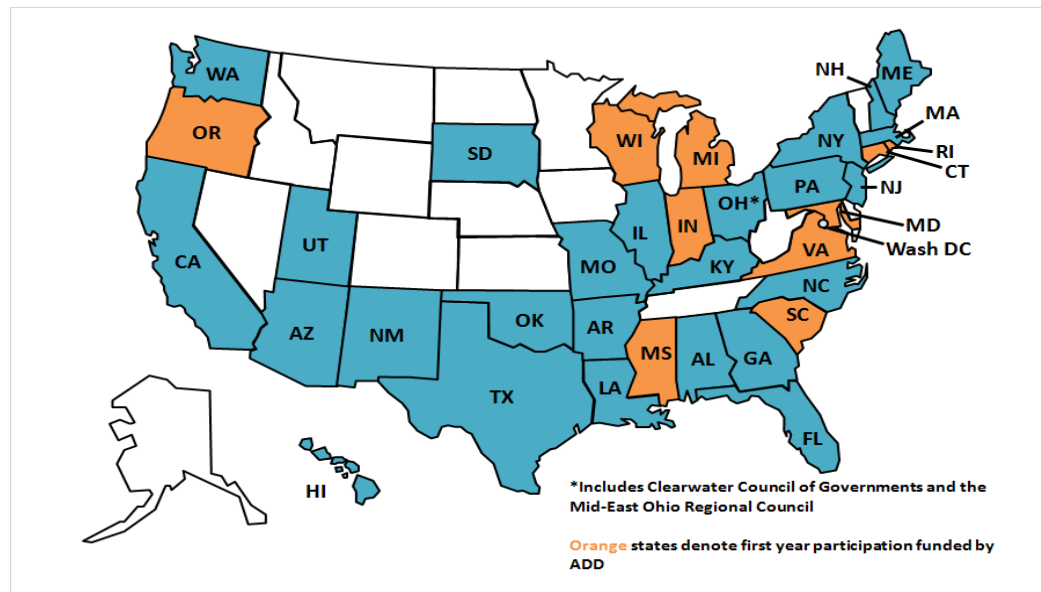
- Multi-state collaboration of state DD agencies
- Measures performance of public systems for people with intellectual and developmental disabilities
- Assesses performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 13 participating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



WHAT IS NATIONAL CORE INDICATORS (NCI)?

- Currently 35 states, the District of Columbia and 25 sub-state regions (including all CA Regional Centers)

NCI State Participation 2012-13



WHAT IS NCI?

- Adult Consumer Survey
- Family Survey
 - Adult Family Survey (person lives at home; 18 and older)
 - Family Guardian Survey (person lives out-of-home; 18 and older)
 - Children Family Survey (child lives at home; under 18 years old)
- Provider Survey
 - Staff Stability
- System Data
 - Mortality
 - Incidents



WHAT IS NCI?

Adult Consumer Survey

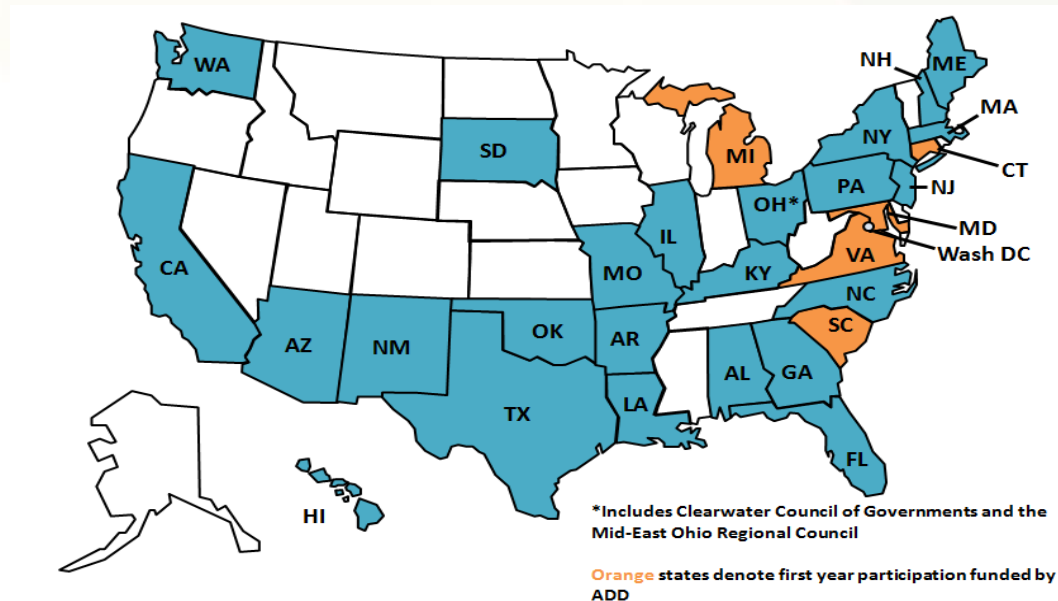
- Standardized, face-to-face interview with a sample of individuals receiving services
 - Background Information
 - Section I (no proxies allowed)
 - Section II (proxies allowed)
- No pre-screening procedures
- Conducted with adults only (18 and over) receiving at least one service in addition to case management
- Section I and Section II together take 50 minutes (on average)



Methods, Measures and Sample:

Data Source

- Adult Consumer Survey (ACS), 2011-2012 data collection cycle
- 19 states, one regional council
- Total N: 11,224 individuals



Methods, Measures and Sample:

Behavioral supports

- Source: three items from Background Section
 - Does the person need support to manage:
 - **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*)
 - **Disruptive behavior** (*Refers to behavior that interferes with the activities of others, for example, by laughing or crying without apparent reason, yelling or screaming, cursing, or threatening violence*)
 - **Destructive behavior** (*Refers broadly to externally-directed, defiant behavior, for example, taking other people's property, property destruction, stealing, or assaults and injuries to others*)



Methods, Measures and Sample:

Behavioral supports

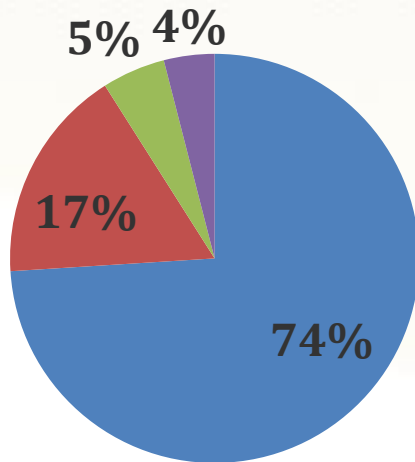
- Response categories:
 - No support needed
 - Some support needed; requires only occasional assistance or monitoring
 - Extensive support needed; frequent or severe enough to require regular assistance
 - Don't know

FINDINGS

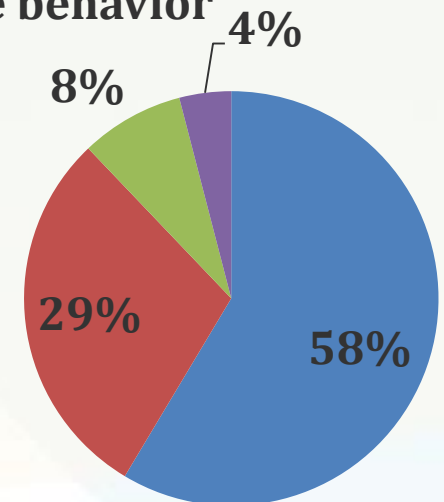


Behavioral supports

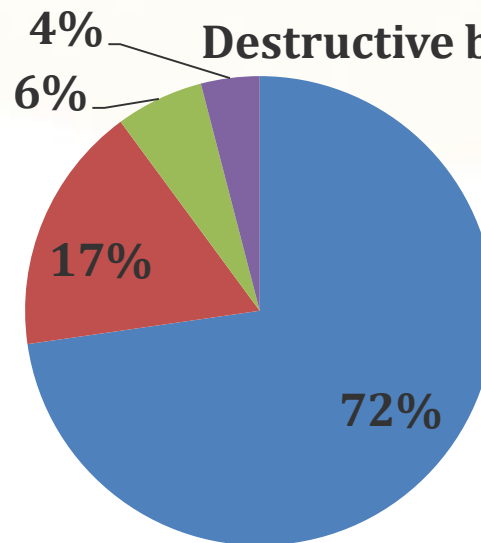
Self-injury behavior



Disruptive behavior



Destructive behavior



- No support needed
- Some support needed
- Extensive support needed
- Don't know/Missing

Behavioral supports

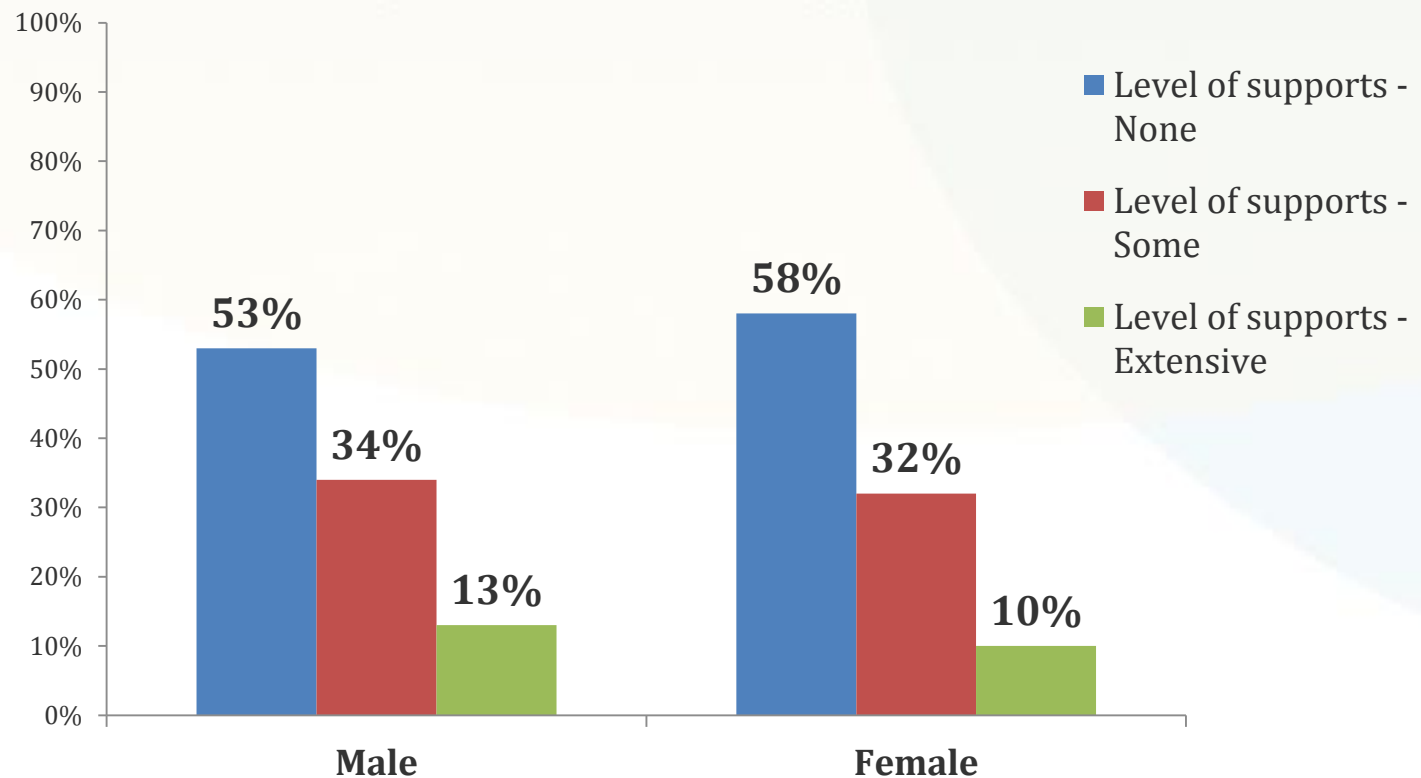
- Overlap:
 - 63% of people who need supports for self-injurious behavior also need them for destructive behavior; 47% of them also need supports for disruptive behavior
 - 91% of people who need supports for destructive behavior also need them for disruptive behavior

Behavioral supports

- Any support needed: 45%
- Level of behavioral support needed:
 - Some: 73%
 - Extensive: 27%

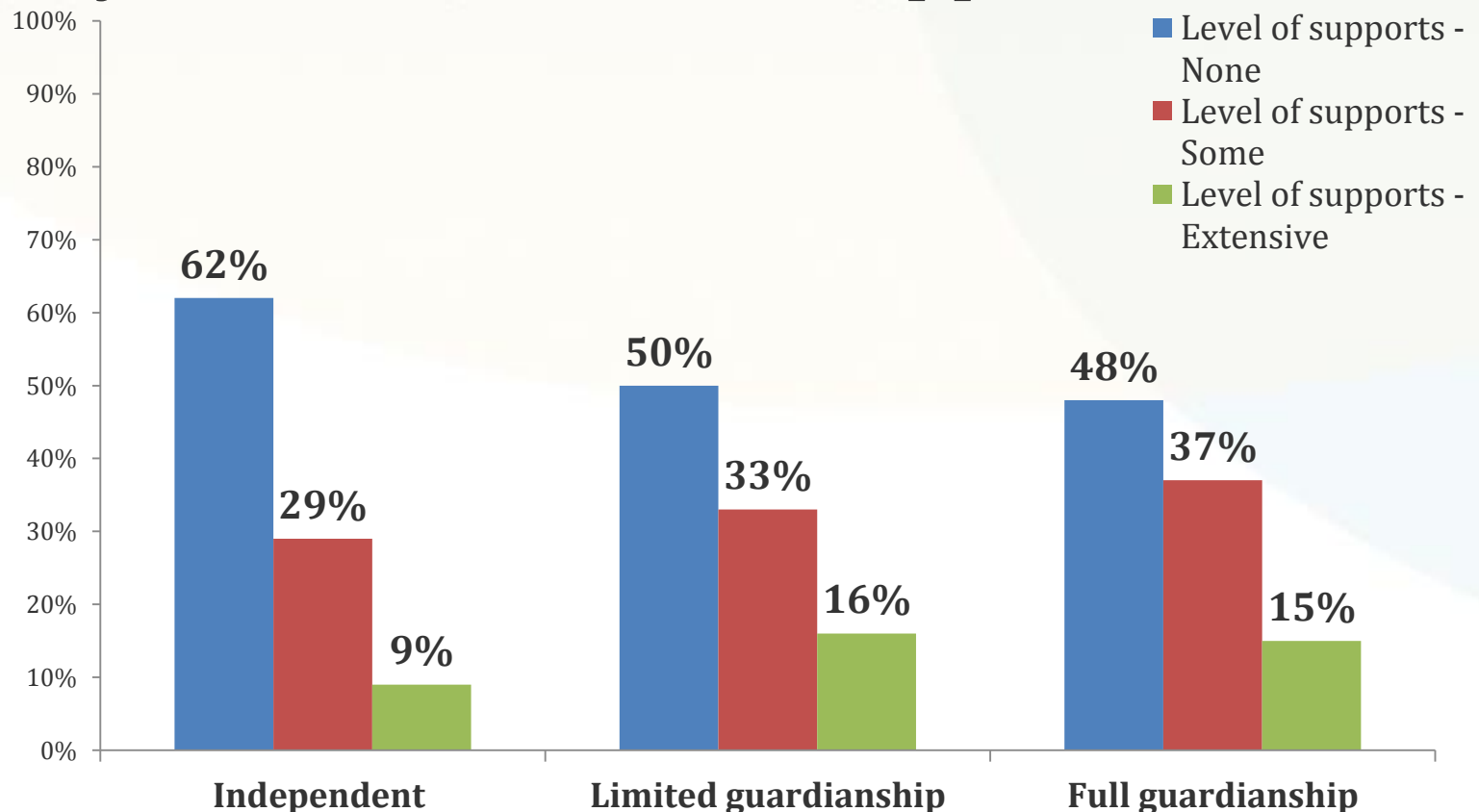
Characteristics: Gender

- Females slightly less likely to require supports



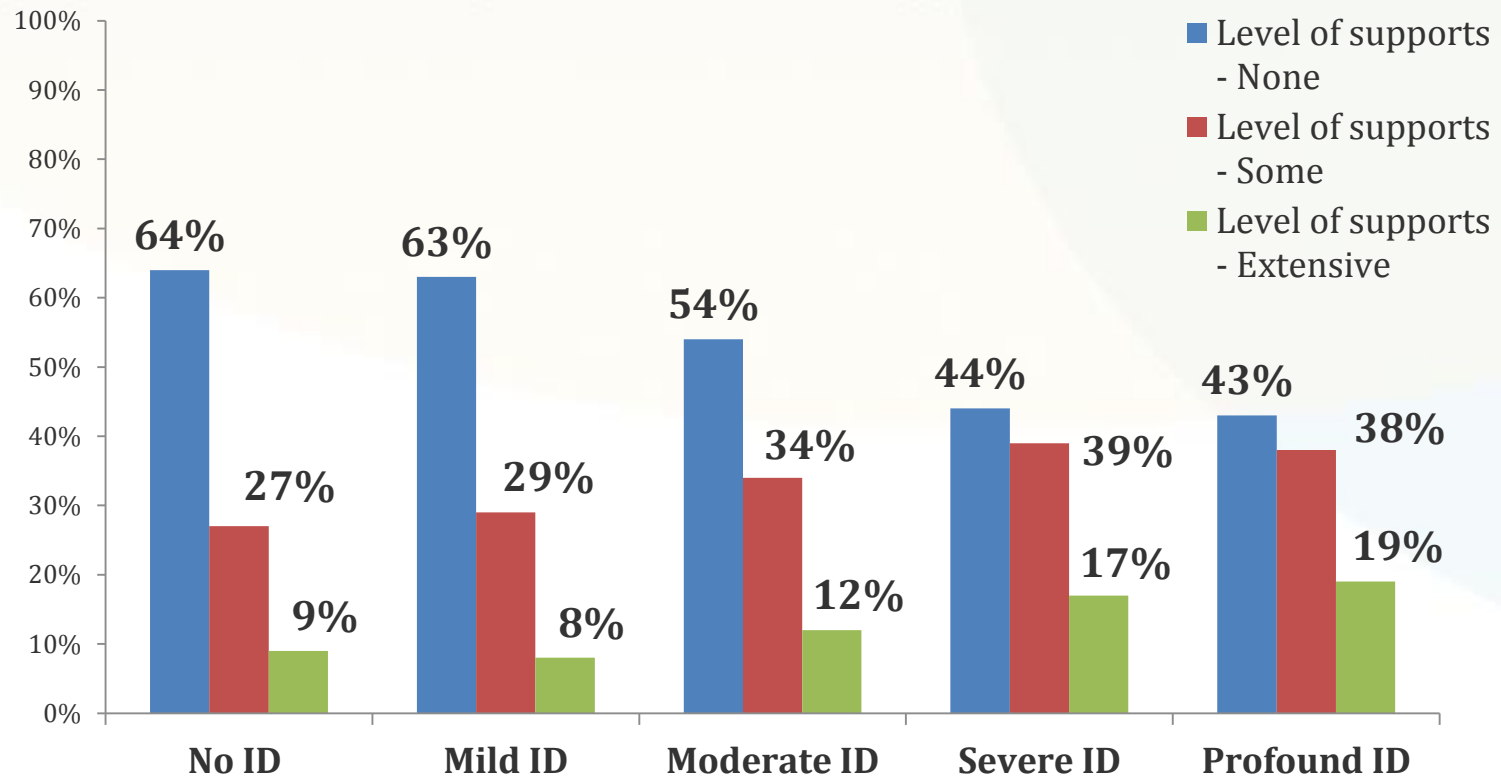
Characteristics : Guardianship

- Those independent of guardianship less likely to need behavioral supports

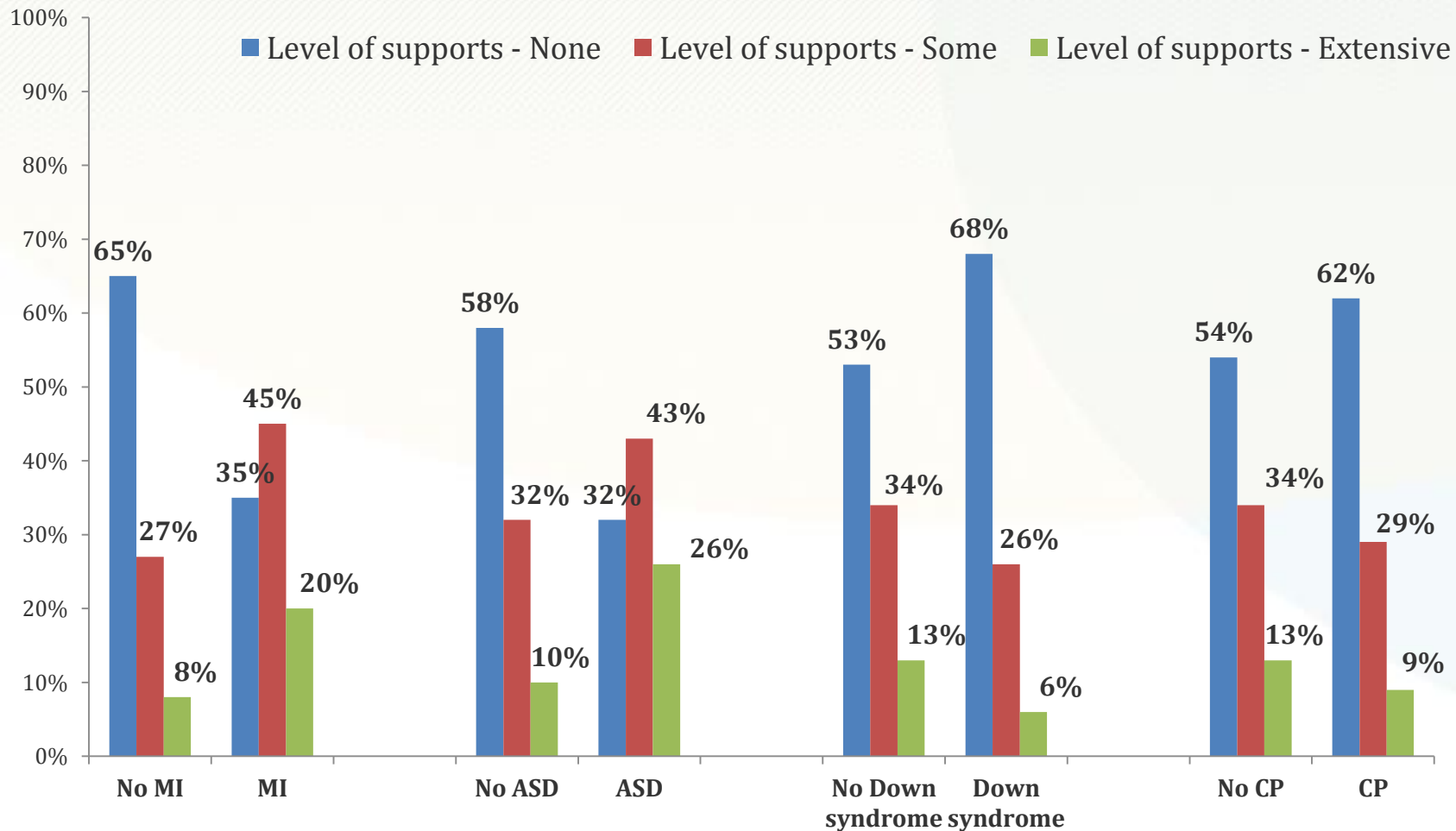


Characteristics : Level of ID

- Those with no ID or milder ID label less likely to require supports

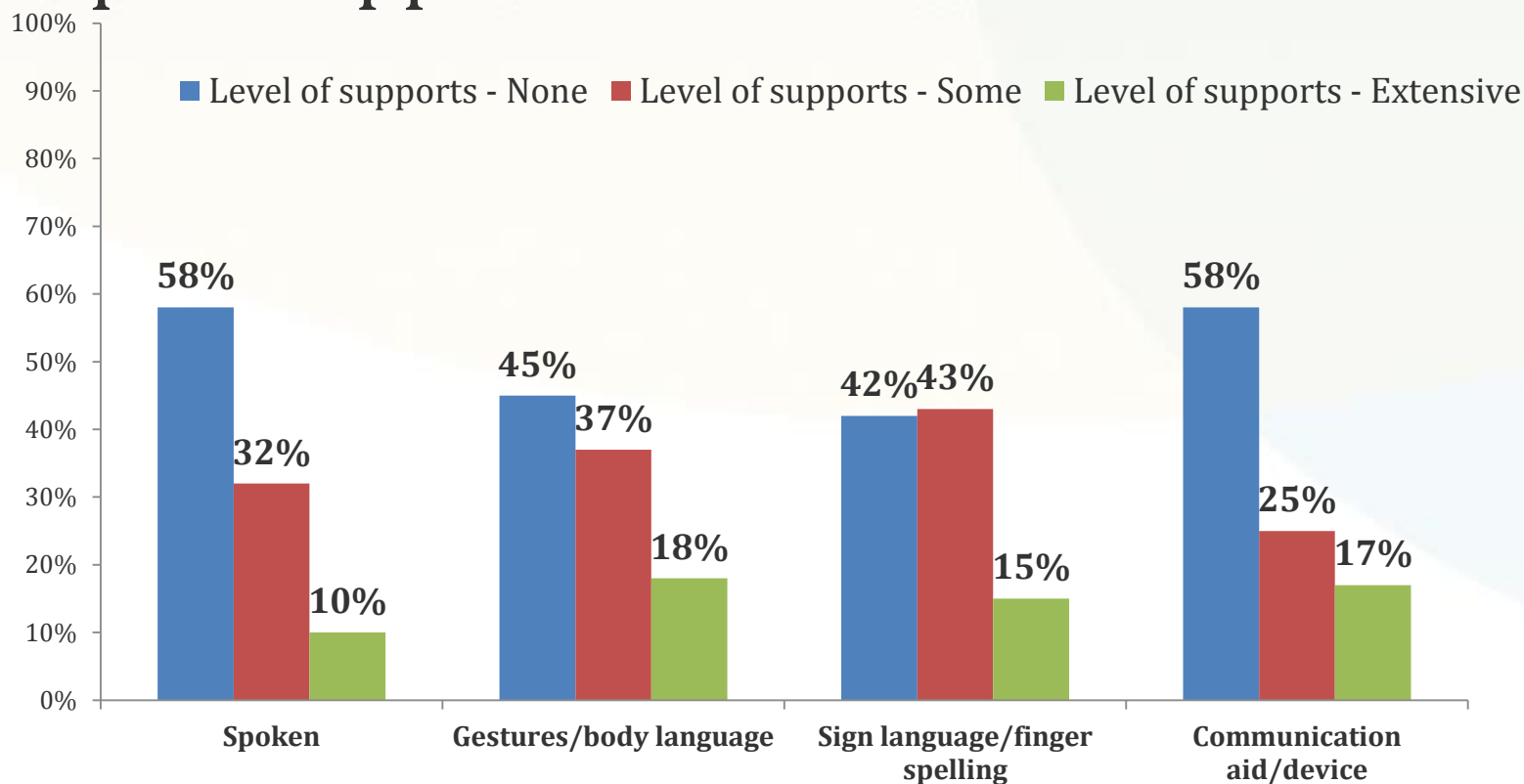


Characteristics : Diagnoses



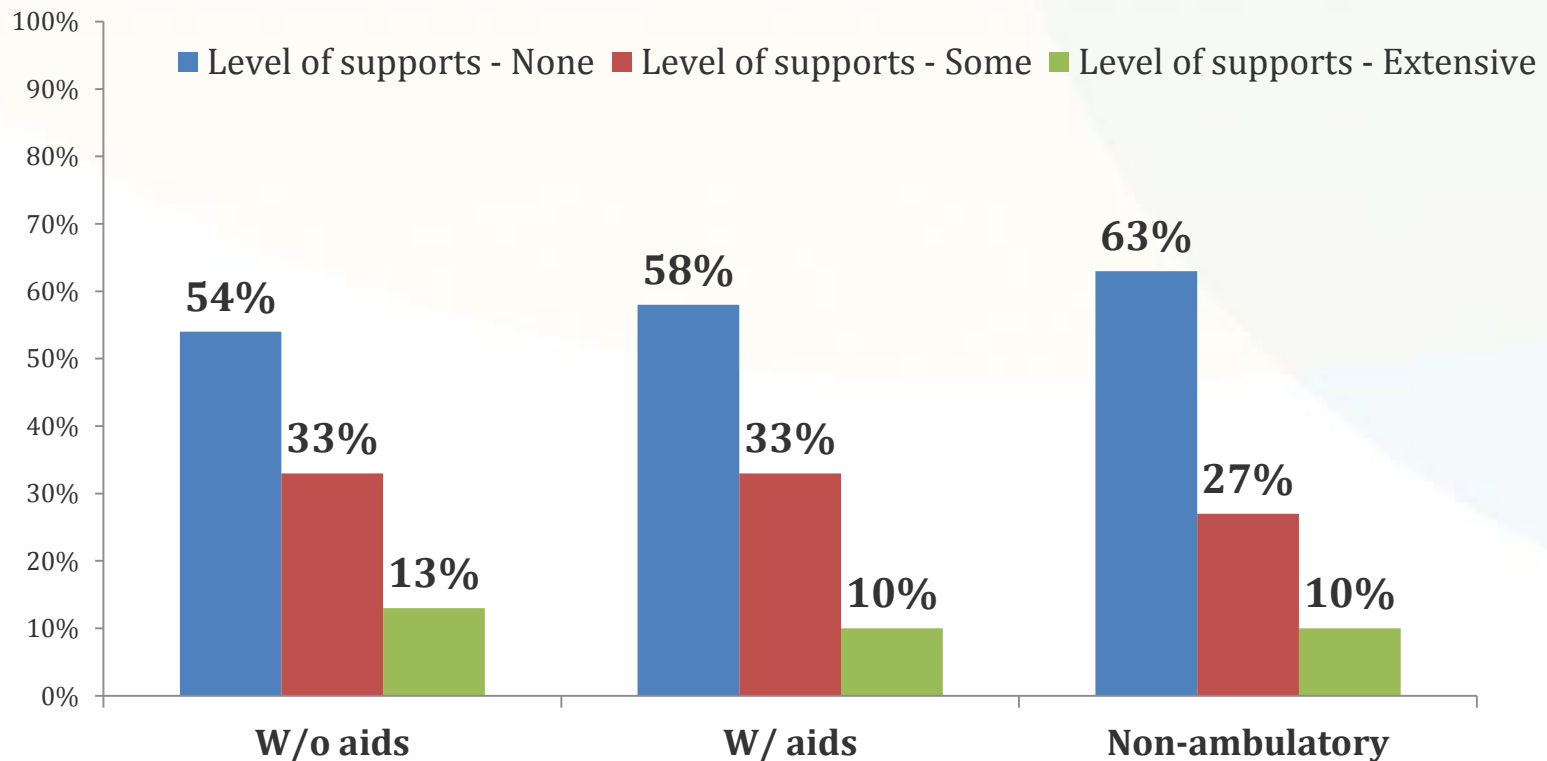
Characteristics : Expression

- Those with spoken expression less likely to require supports



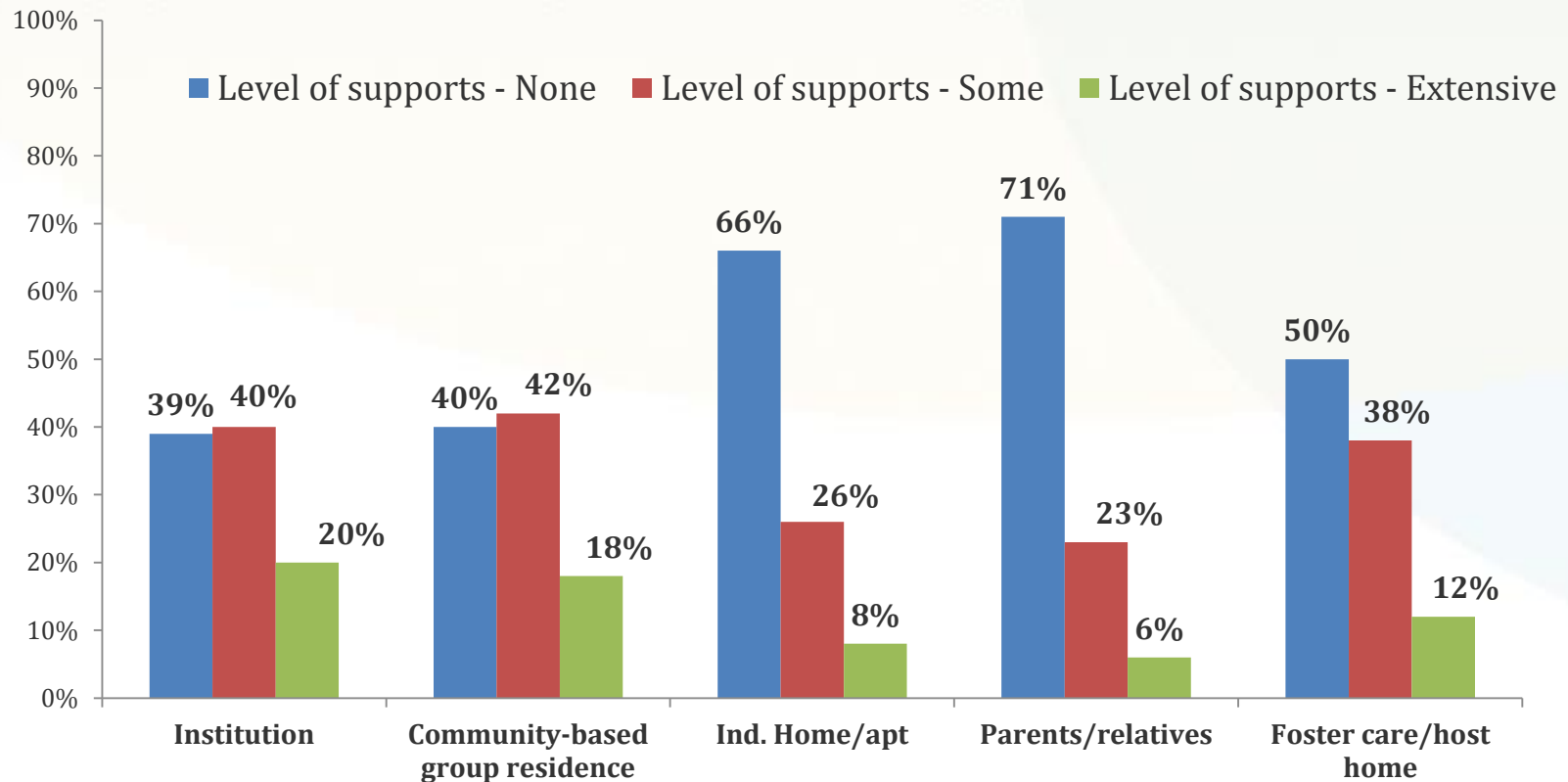
Characteristics : Mobility

- Those who are self-mobile more likely to require supports



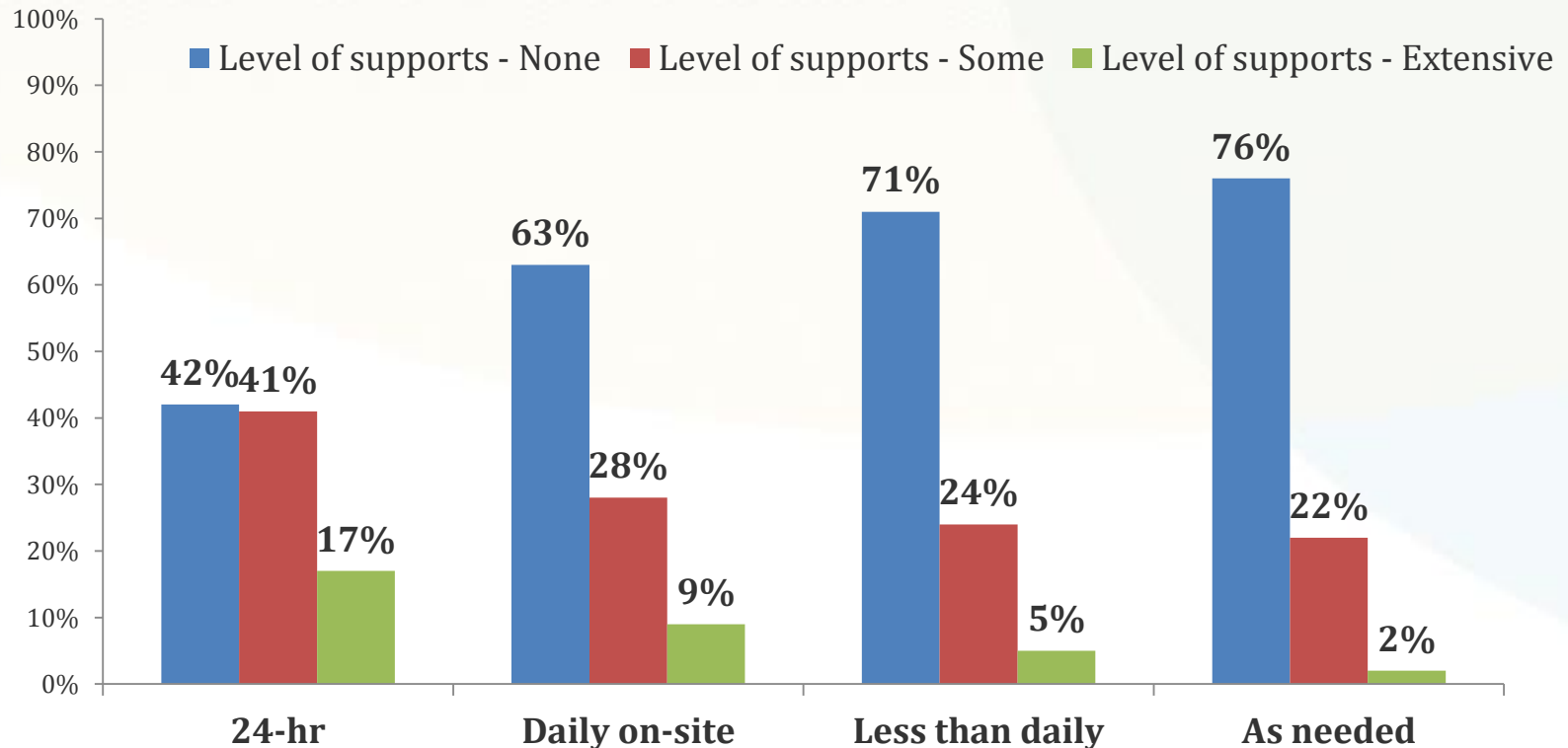
Characteristics : Residence

- Those living independently or with family less likely to require supports



Characteristics : Staffing

- Those with 24-hr staffing more likely to require supports



Differences between those requiring supports and not

- Those requiring extensive supports are younger:
 - None – avg. 43.8 yrs, Some – 44.2 yrs, Extensive – 41.0 yrs
- Less likely to use spoken communication:
 - None – 80%, Some – 73%, Extensive – 65%
- More likely to use gestures/body language:
 - None – 16%, Some – 22%, Extensive – 30%
- More likely to be self-mobile:
 - None – 74%, Some – 78%, Extensive – 81%

Differences between those requiring supports and not

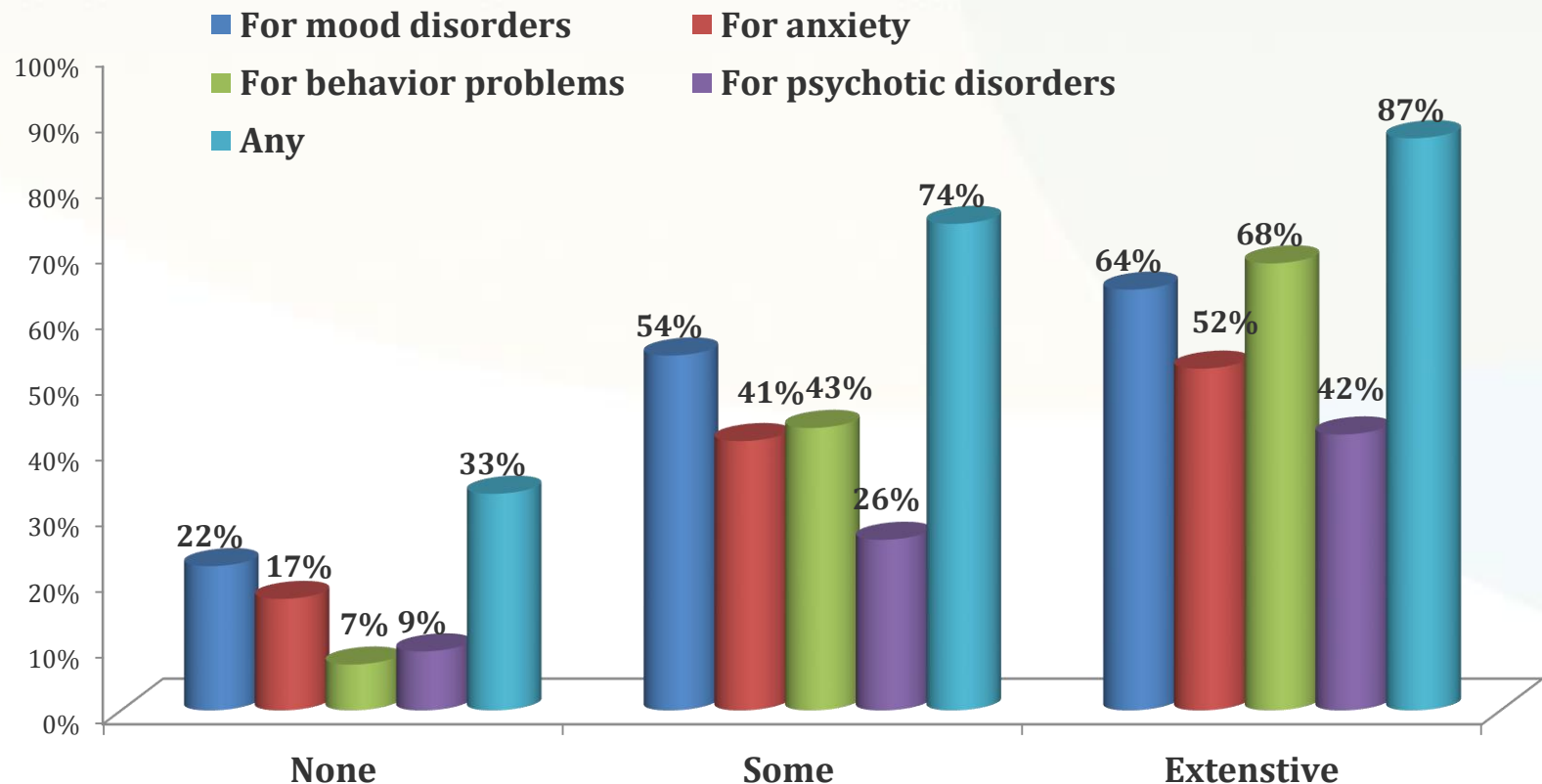
- More likely to live in group residence:
 - None – 28%, Some – 49%, Extensive – 58%
- Less likely to live independently:
 - None – 15%, Some – 10%, Extensive – 8%
- Less likely to live with relatives/parents:
 - None – 44%, Some – 24%, Extensive – 58%
- More likely to have 24-hr staffing:
 - None – 41%, Some – 68%, Extensive – 80%

Differences between those requiring supports and not: Selected outcomes

- Those requiring extensive supports less likely to have friends:
 - None – 72%, Some – 69%, Extensive – 63%
- Less likely to be able to see friends:
 - None – 80%, Some – 78%, Extensive – 73%
- Less likely to be able to see family:
 - None – 82%, Some – 77%, Extensive – 73%
- More likely to be lonely:
 - None – 38%, Some – 41%, Extensive – 47%
- Less likely to participate in self-advocacy meetings:
 - None – 32%, Some – 31%, Extensive – 25%

Differences between those requiring supports and not: Medications

- 68% of those requiring extensive supports take meds for behavior problems and 64% for mood disorders



Speaking of medications.....



Psychotropic medication use among adults with IDD

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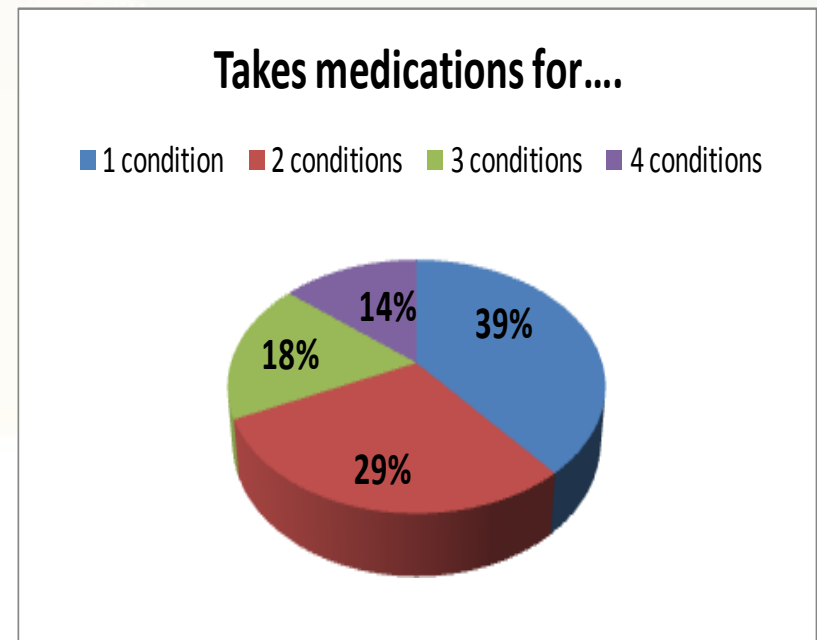
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Measures and Data Source

- Adult Consumer Survey
- Background Section
- “Does the person take medications to address”:
 - Mood disorder
 - Anxiety
 - Psychotic disorder
 - Behavior

Takes medications to address:

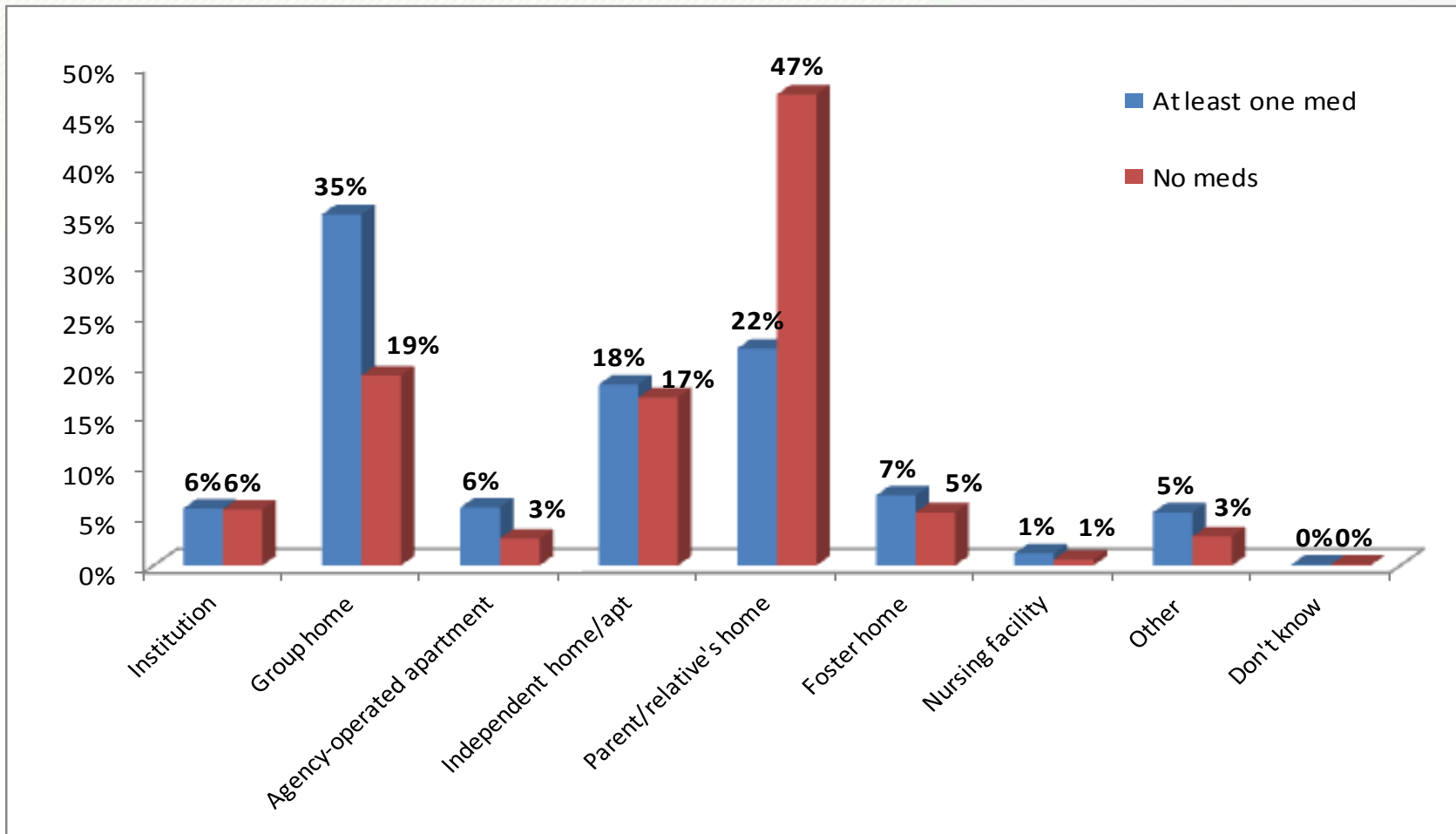
- ❑ 53% of people with IDD receiving services are taking medications for at least 1 of these conditions:
 - mood disorders
 - anxiety
 - behavior challenges
 - psychotic disorders
- ❑ Most common condition medications are taken for is mood disorders (38%).
- ❑ 14% of those taking at least one medication are taking them for all 4 conditions.



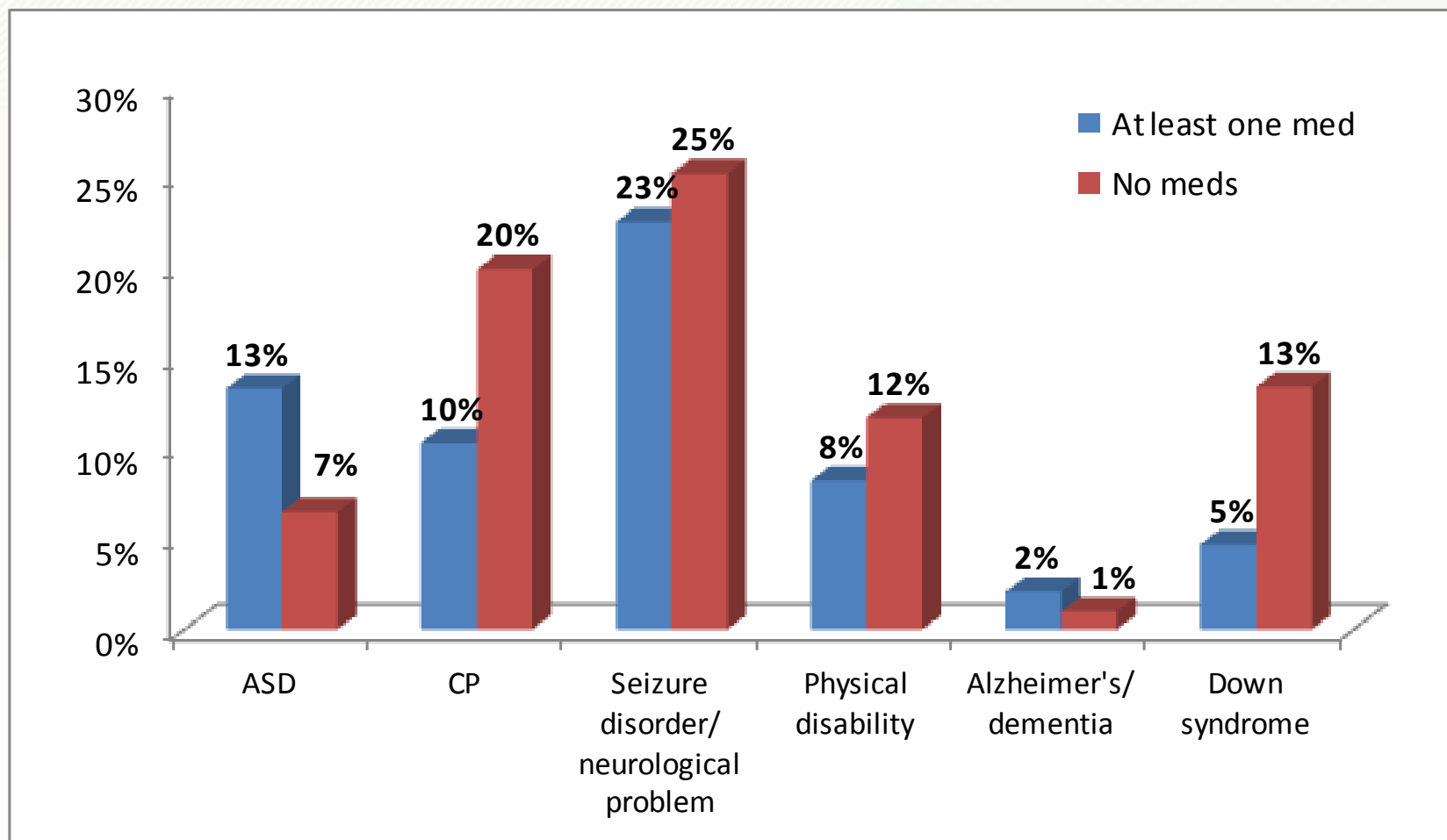
Takes medications to address:

- ❑ 88% of those with a co-occurring psychiatric diagnosis (MI) were taking medications for mood, anxiety or psychotic disorders.
- ❑ However, 30% of people without a psychiatric diagnosis (MI) were also taking medications for mood, anxiety or psychotic disorders.

Residence type and medications



Other disabilities

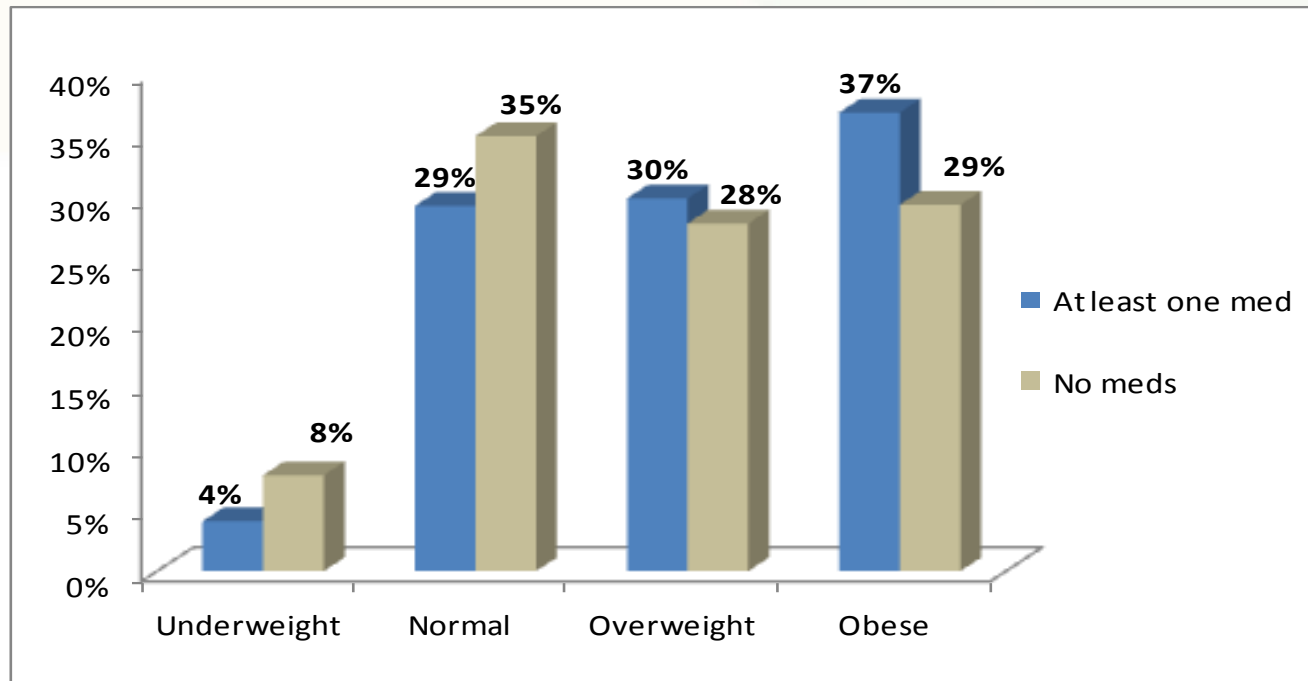


Other differences

- Those who take at least one medication are also:
 - Slightly older
 - Slightly less racially diverse
 - Less likely to be diagnosed with profound level of ID

Health differences

- Those who take at least one medication are:
 - Less likely to be in very good or excellent health
 - More likely to use tobacco products
 - More likely to be obese / less likely to be of normal weight



Health differences

- Higher likelihood of being overweight and obese persists after controlling for other personal characteristics (mobility, residence, ASD, CP, Down syndrome, age)

Contacts

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NASDDDS



Questions

