

Disparities in Service Access and Waitlists for People with Intellectual and Developmental Disabilities

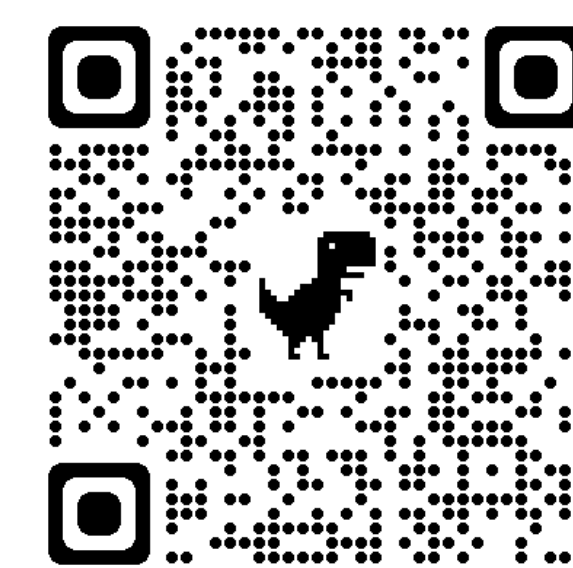
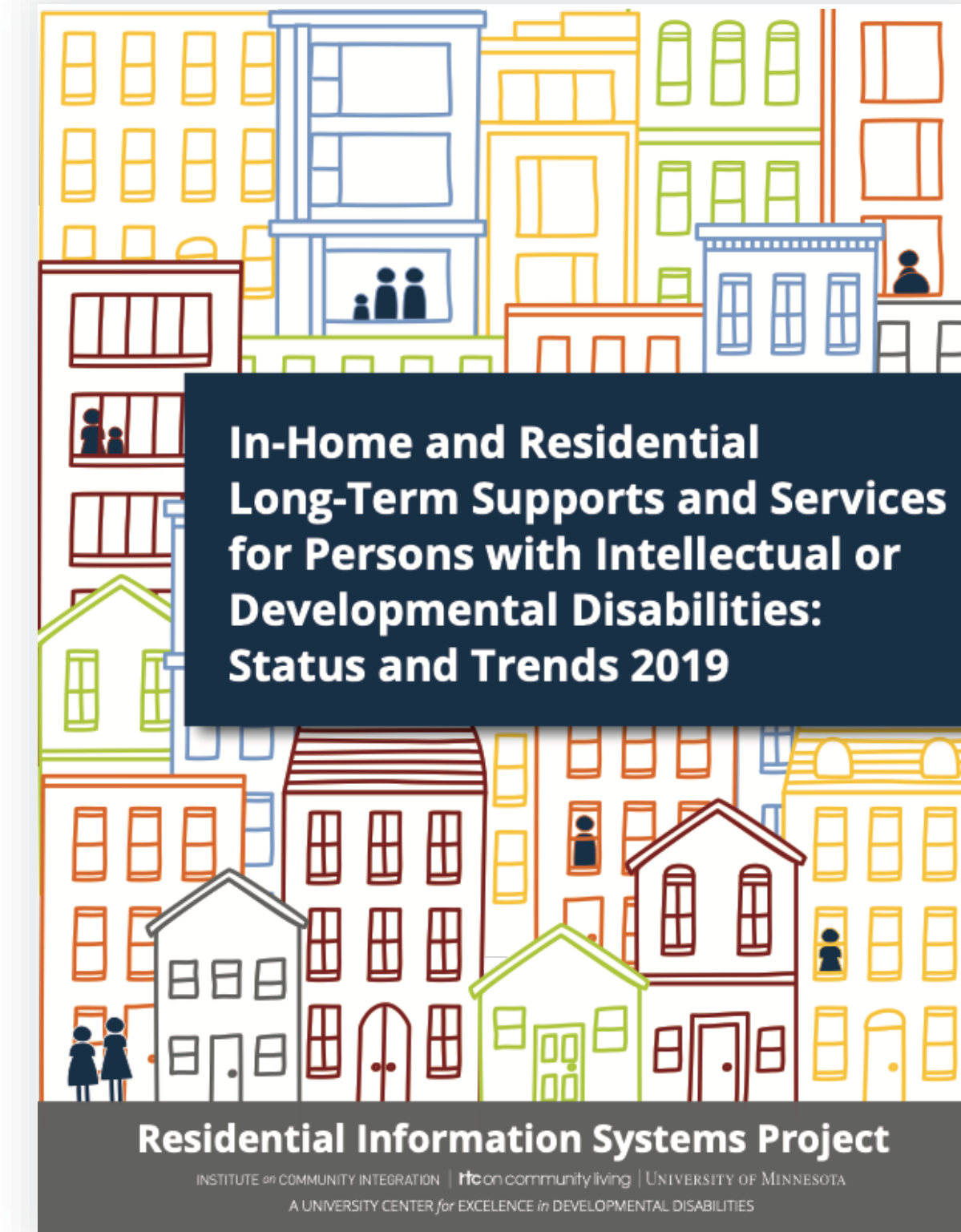
Jon Neidorf and Brian Begin

rtc on community living | INSTITUTE on COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA

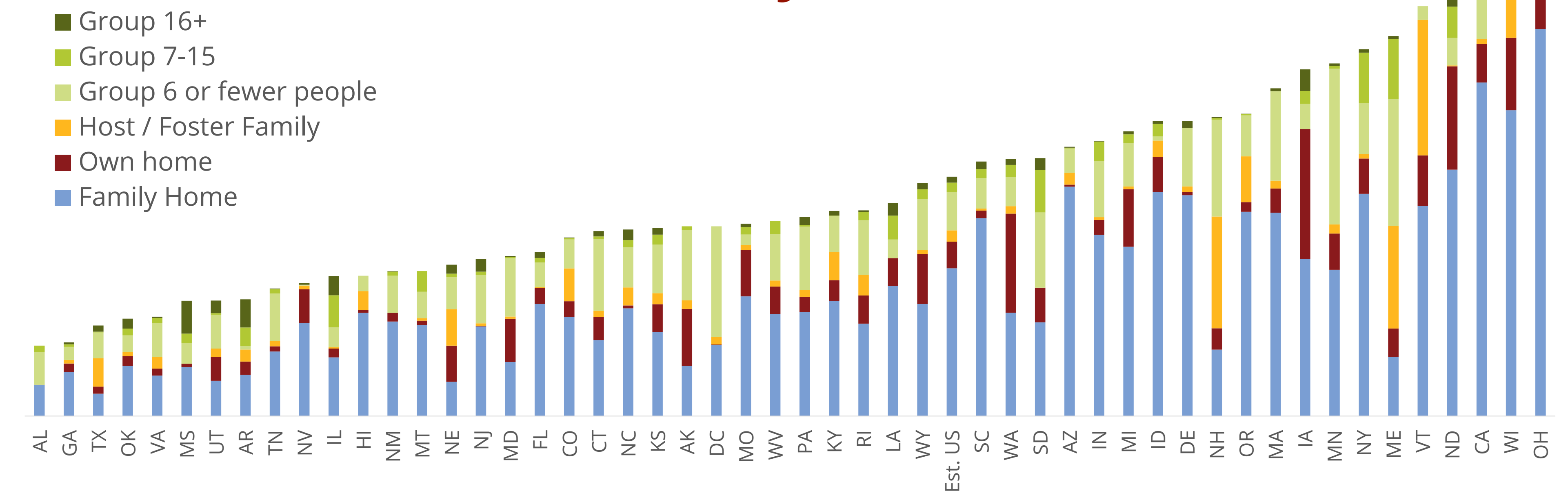


Residential Information Systems Project (RISP)

RISP is a 40-year longitudinal study of Medicaid long-term supports and services (LTSS) for people with intellectual and developmental disabilities (IDD). An annual survey of state IDD agencies is used to gather information about the settings in which LTSS recipients live, federal and state funding mechanisms used, residential setting type and size, age of recipients, and expenditures.



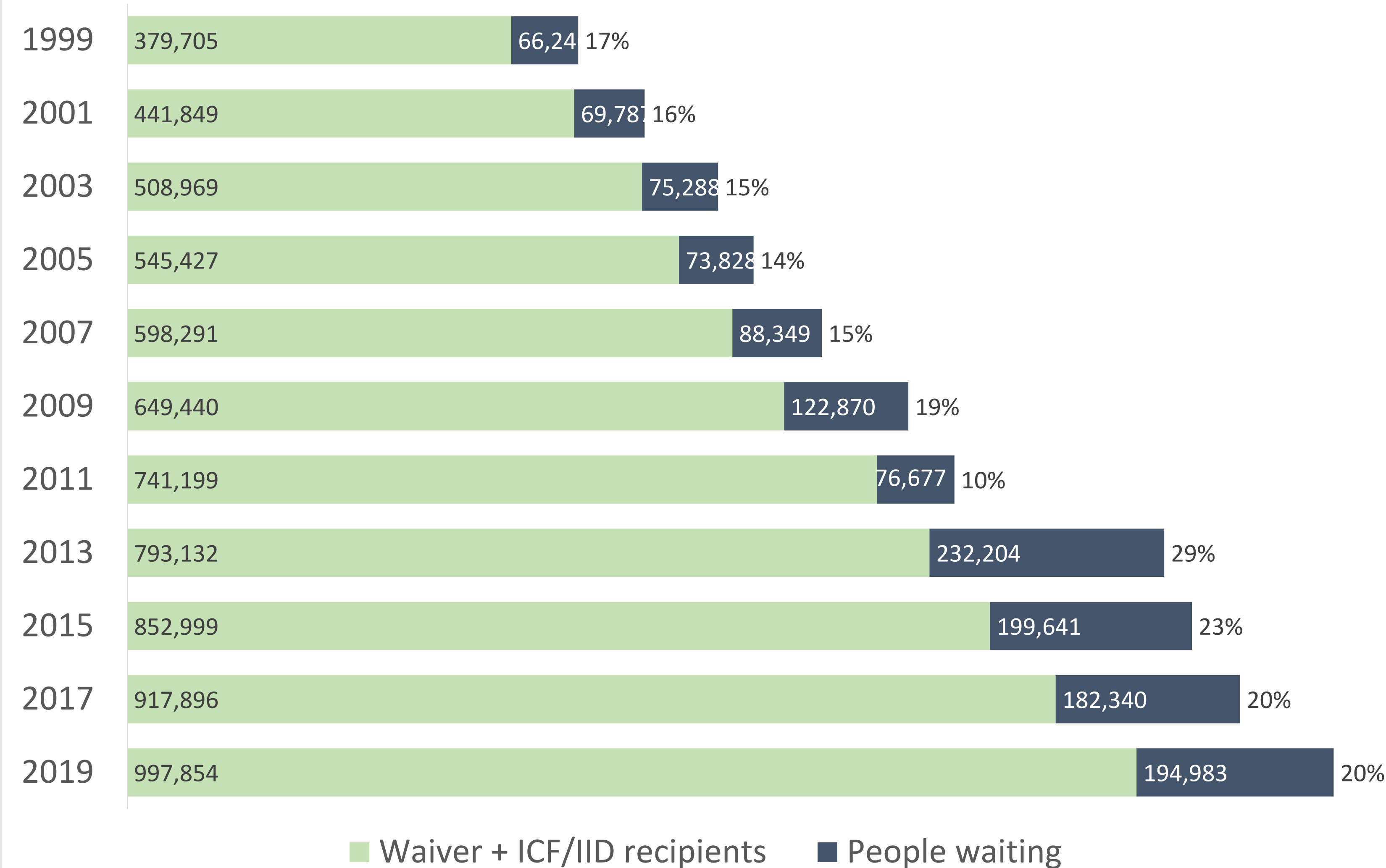
Access to services—and individualized housing—varies by state.



Waiver Service Recipients with IDD per 100,000 of the Population by Funding Authority, June 30, 2019

As the service system grows, state waitlists grow.

Number of People Receiving ICF/IID + Waiver Services, Number on Waitlist, and Percentage Growth Necessary to Eliminate Waitlists

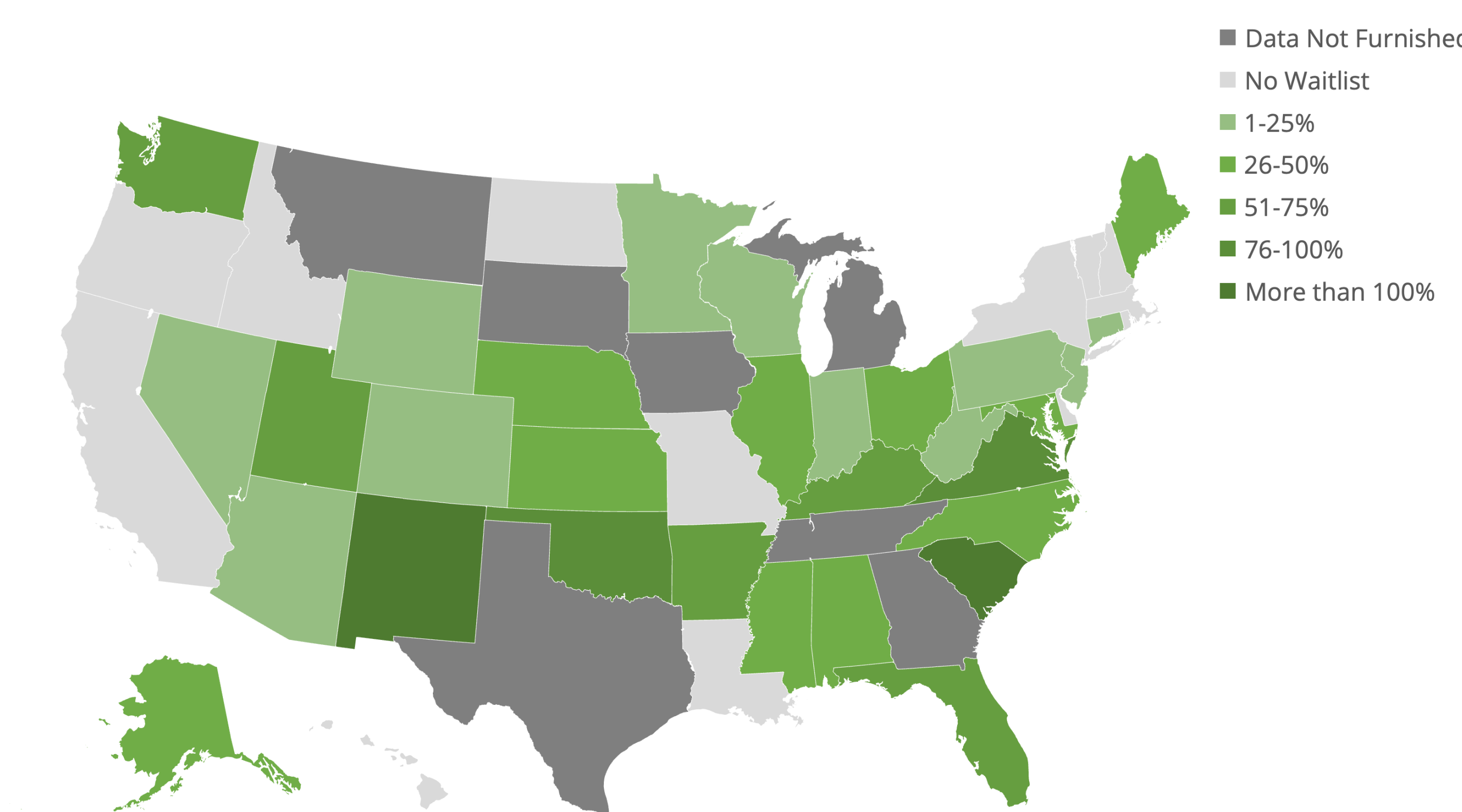


What are waitlists?

- People in a state's IDD service system waiting to receive some type of long-term service.
- Most states have waitlists for waiver services, but states are not allowed to make people wait for institutional services.
- RISP only counts people living on their own or with family who are not waiting for waiver services and who do not already receive some other waiver service.

14 states have eliminated waitlists...

How Many More People Need to be Served to Eliminate Waitlists (Proportionate to Current LTSS Recipients)?



...but that doesn't necessarily mean more people's needs are met.

- States can use specific funding sources to provide everyone in the system minimal support, but only provide sufficient services to a small number of people.
- By re-configuring waitlists as "interest lists," states can boast they have no one waiting while leaving people unscreened for eligibility for months or years (illegal on waitlists).

