

Assessing CYSHCN Programs Across the Nation: A Visual Profile of State CYSHCN (308050)

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Children with Special Health Care Needs:
Treatment Models and Service Systems (4053)



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Presenter Disclosures

Meredith Pyle

- (1) The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:**

No relationships to disclose

What is AMCHP?

The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

AMCHP Programs: CYSHCN

- National Consensus Framework for Improving Quality Systems of Care for CYSHCN – [Standards Development](#) and [Implementation](#)
- Leadership Institute for State Title V CYSHCN Directors (LICD)
- [State Public Health Autism Resource Center](#)
- Learn the Signs Act Early State Systems Grants

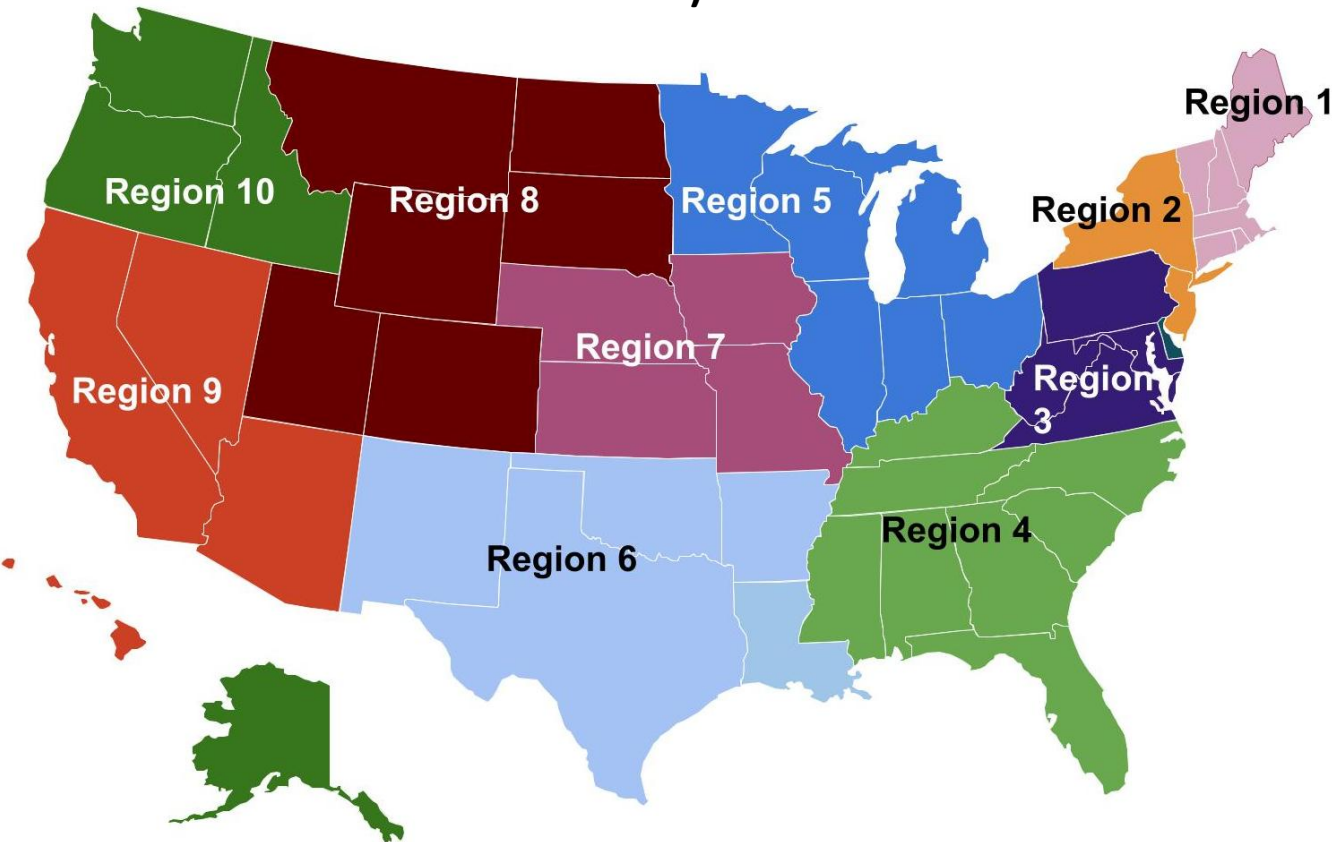
Learning Objectives

- Compare State Title V CYSHCN programs across the nation.
- Identify national trends and emerging issues related to State Title V CYSHCN programs.

Background

HOW MANY CHILDREN IN THE UNITED STATES HAVE SPECIAL HEALTH CARE NEEDS?

National Percent: 19.8% (14.6 million children)



Region	Percent (%)
Region 1	21.7
Region 2	20.1
Region 3	21.4
Region 4	21.1
Region 5	21.2
Region 6	20.7
Region 7	20.5
Region 8	16.4
Region 9	15.6
Region 10	17.9

2011-2012 National Survey of Children's Health

Children with qualifying responses on one or more of the five CSHCN Screener criteria

Background

- Title V of the Social Security Act is a federal MCH block grant program that requires states to facilitate a system of services for CYSHCN
- Creating quality systems of care for CYSHCN is one of the most challenging and pressing priorities for CYSHCN leaders.
- State Title V CYSHCN programs have widely varying approaches to systems of care (i.e. direct services vs. population health)
- There is a need to understand the shared national vision for State Title V CYSHCN programs

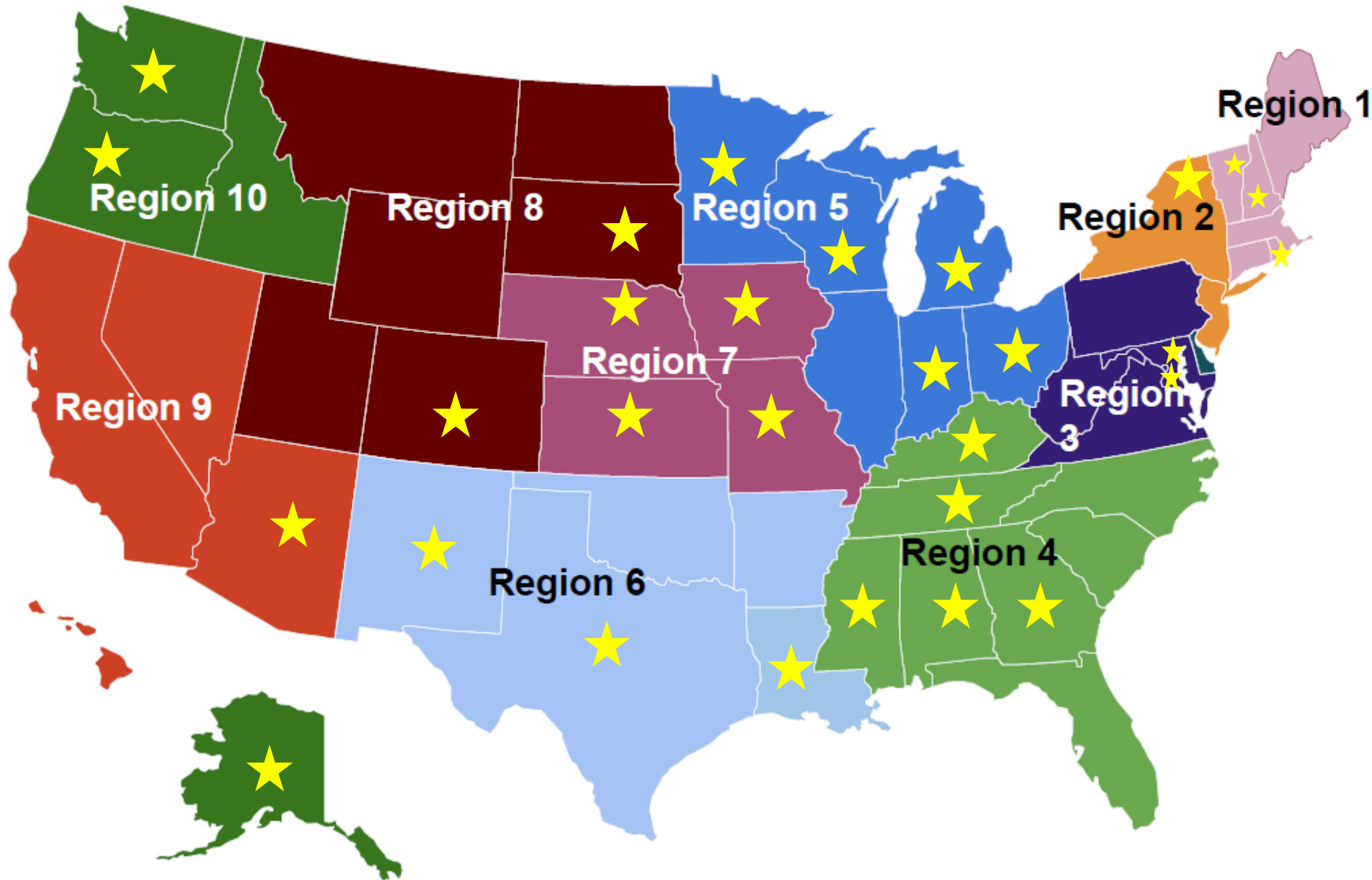
Background

- Survey was conducted as part of the Leadership Institute for Title V CYSHCN Directors project
- Funded through the Lucile Packard Foundation for Children's Health

Methods

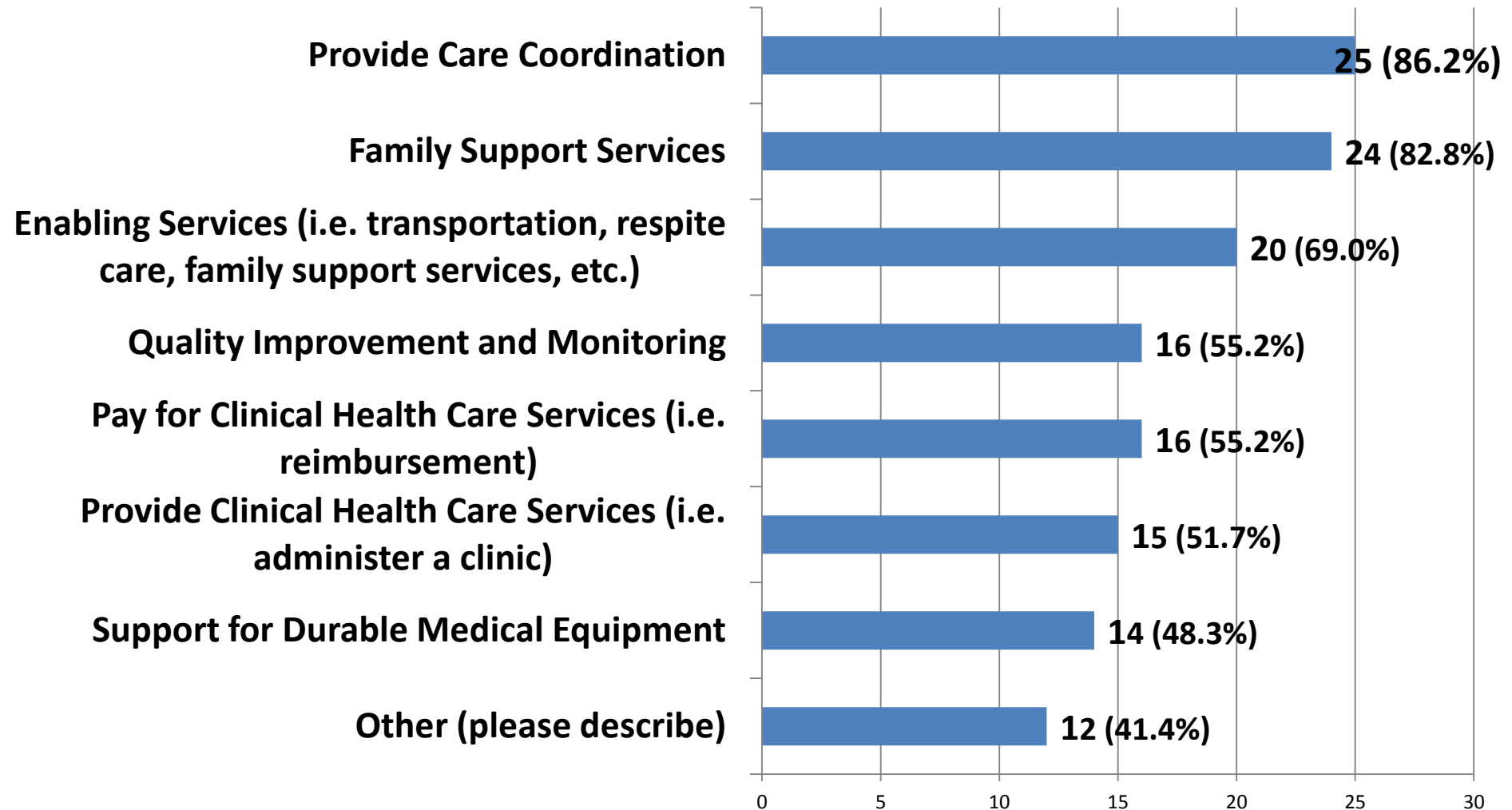
- Online questionnaire: primarily multiple choice questions; some open-ended; 16 items
 - the role of State Title V CYSHCN programs
 - program eligibility
 - significant policy changes
 - health reform
 - system strengths and challenges
- Conducted in late 2013
- Respondents: State Title V CYSHCN Program Directors (29)

RESULTS

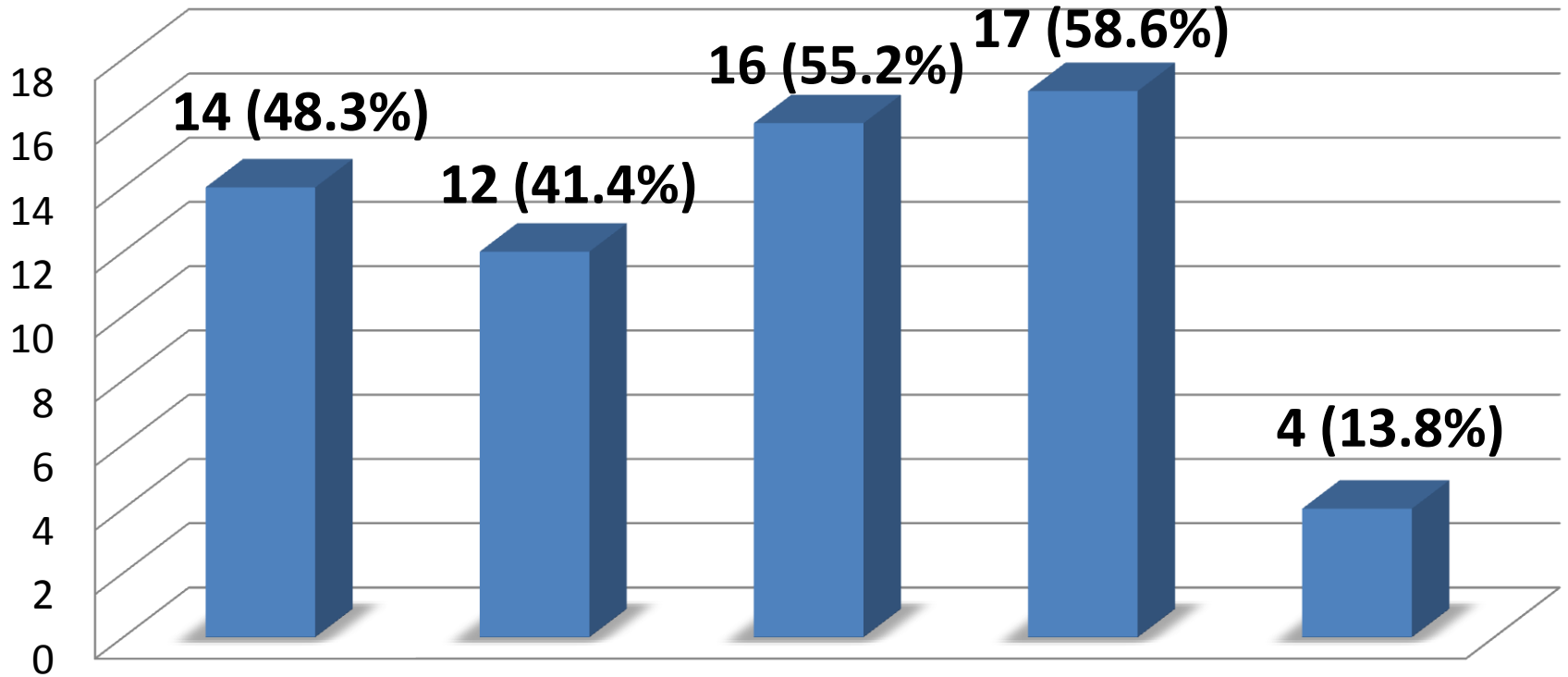


State Title V CYSHCN Respondents

The Role of State Title V Program in CYSHCN System (Check all that apply) (N=29):



State Title V CYSHCN Program Eligibility



Diagnosis-Based

Income-Based

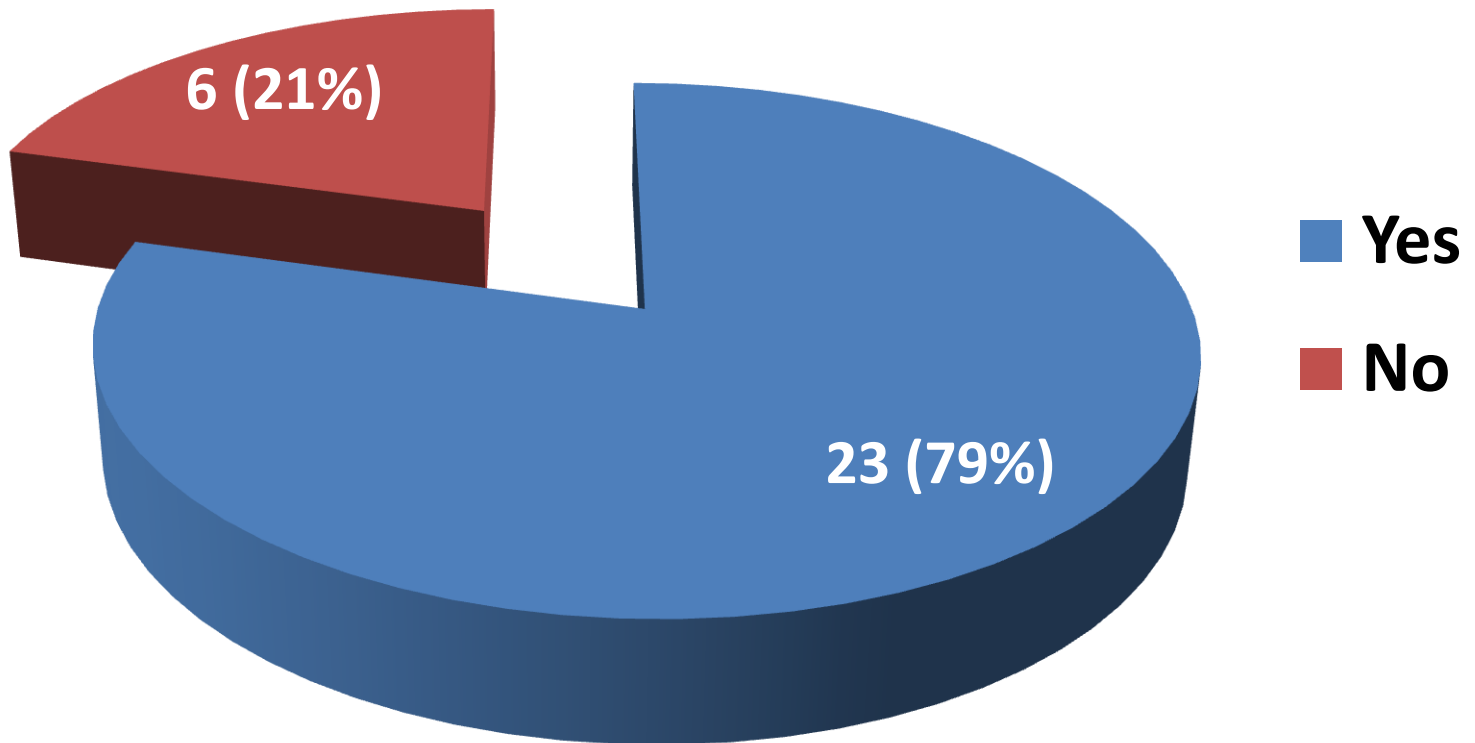
Age Criteria

All CYSHCN Eligible

Other

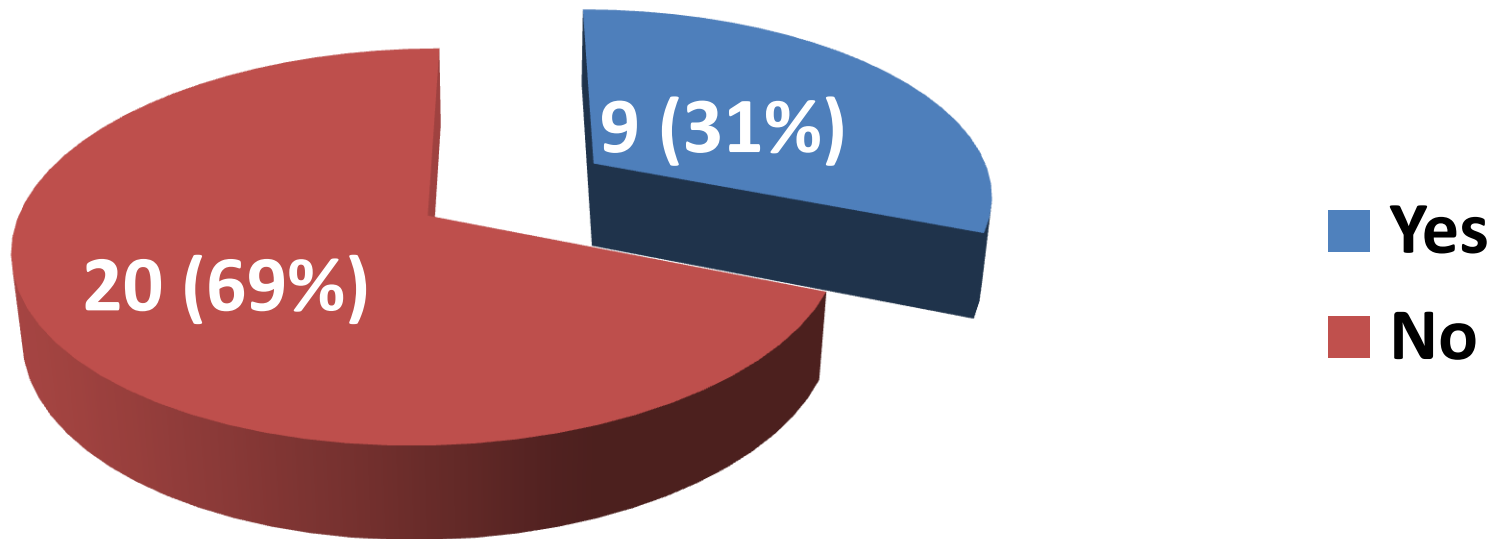
Governing State Laws or Rules

Is the State Title V CYSHCN program governed by a state law or rule that specifies what the program should do and who the program should serve? (N=29)

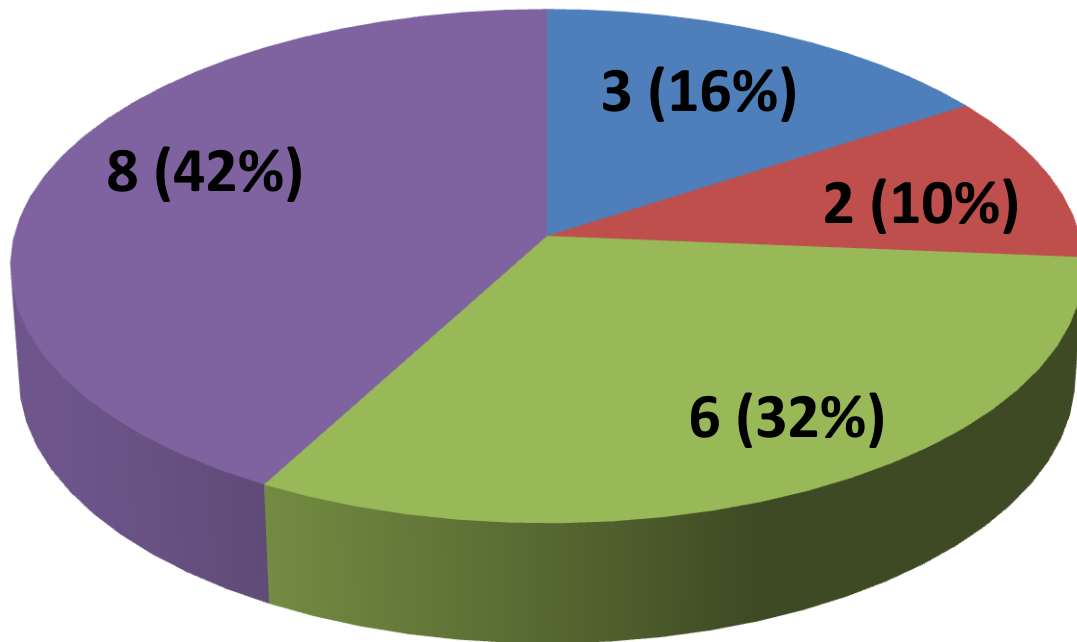


Significant Policy Changes

Within the past year, has your department/agency, executive branch, or legislative branch made significant policy changes that affect your State Title V CYSHCN program's work or everyday functioning? (N=29)



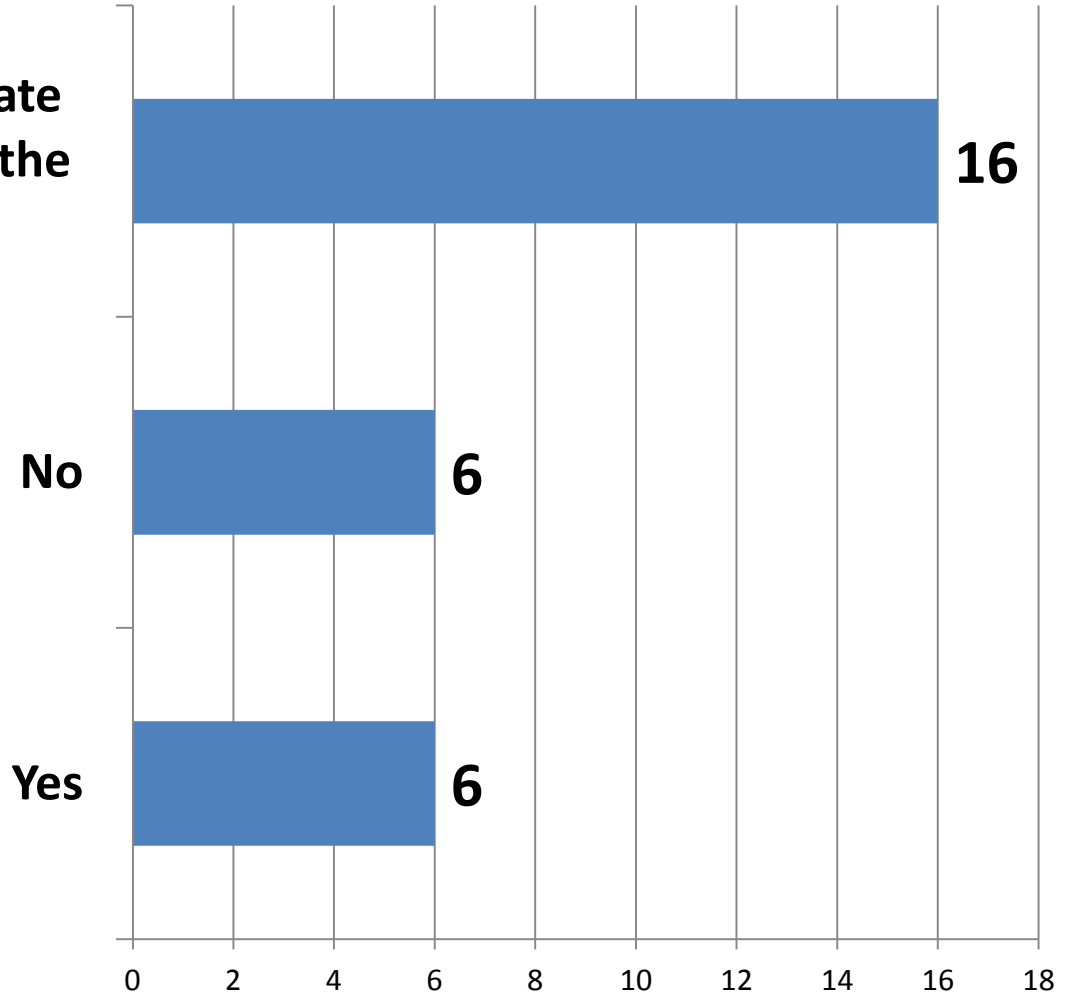
Regarding Medicaid Managed Care arrangements and CYSHCN, where is your state currently? (N=19)



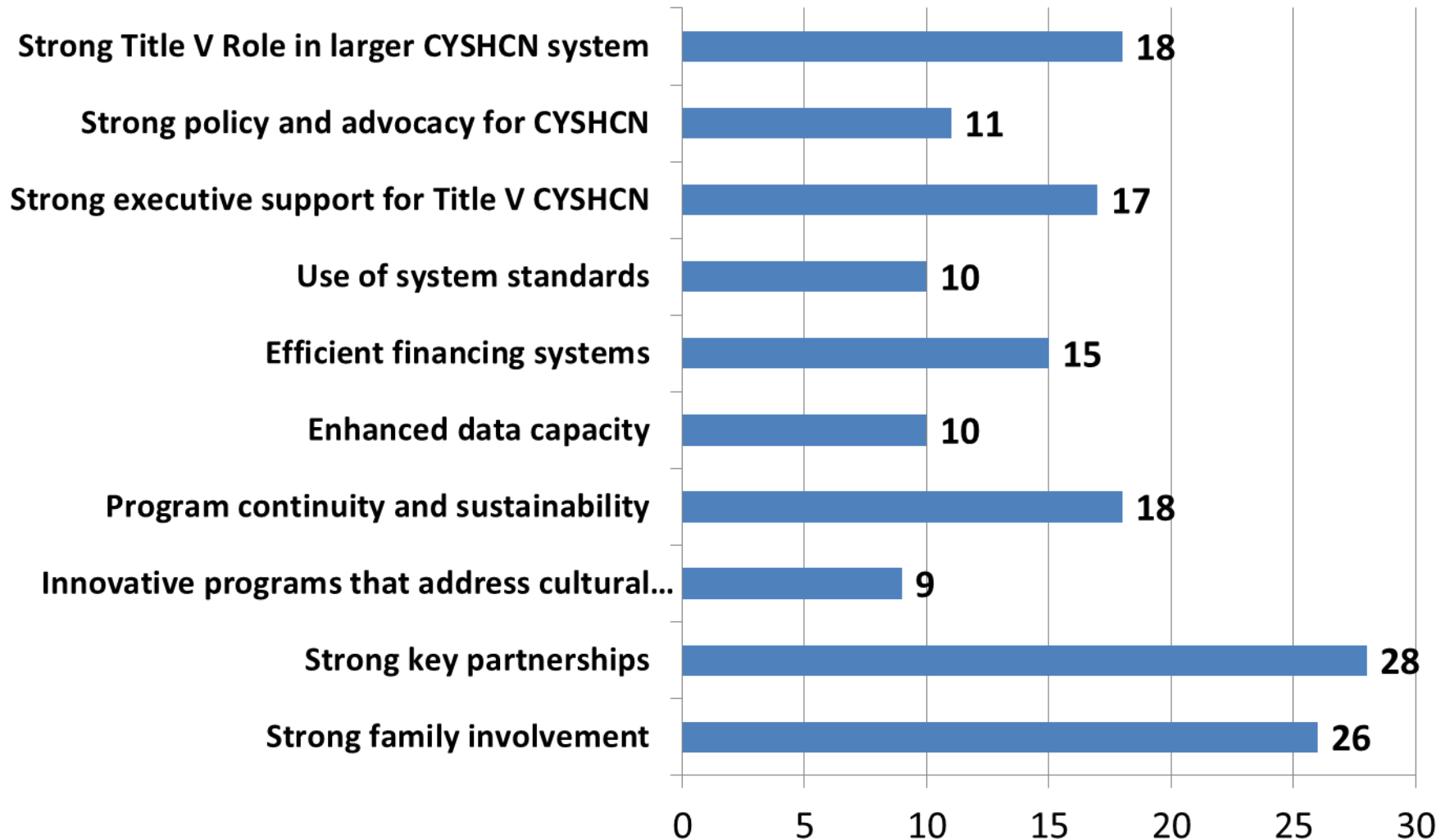
- Considering moving CYSHCN into Medicaid Managed Care arrangements (i.e. early discussions at the state level)
- Planning to move CYSHCN into Medicaid Managed Care arrangements
- Currently moving CYSHCN into Managed Care arrangements
- CYSHCN in my state have already been moved into Medicaid Managed Care arrangements.

Did State Title V CYSHCN Program participate in the development of insurance exchanges? (N=28)

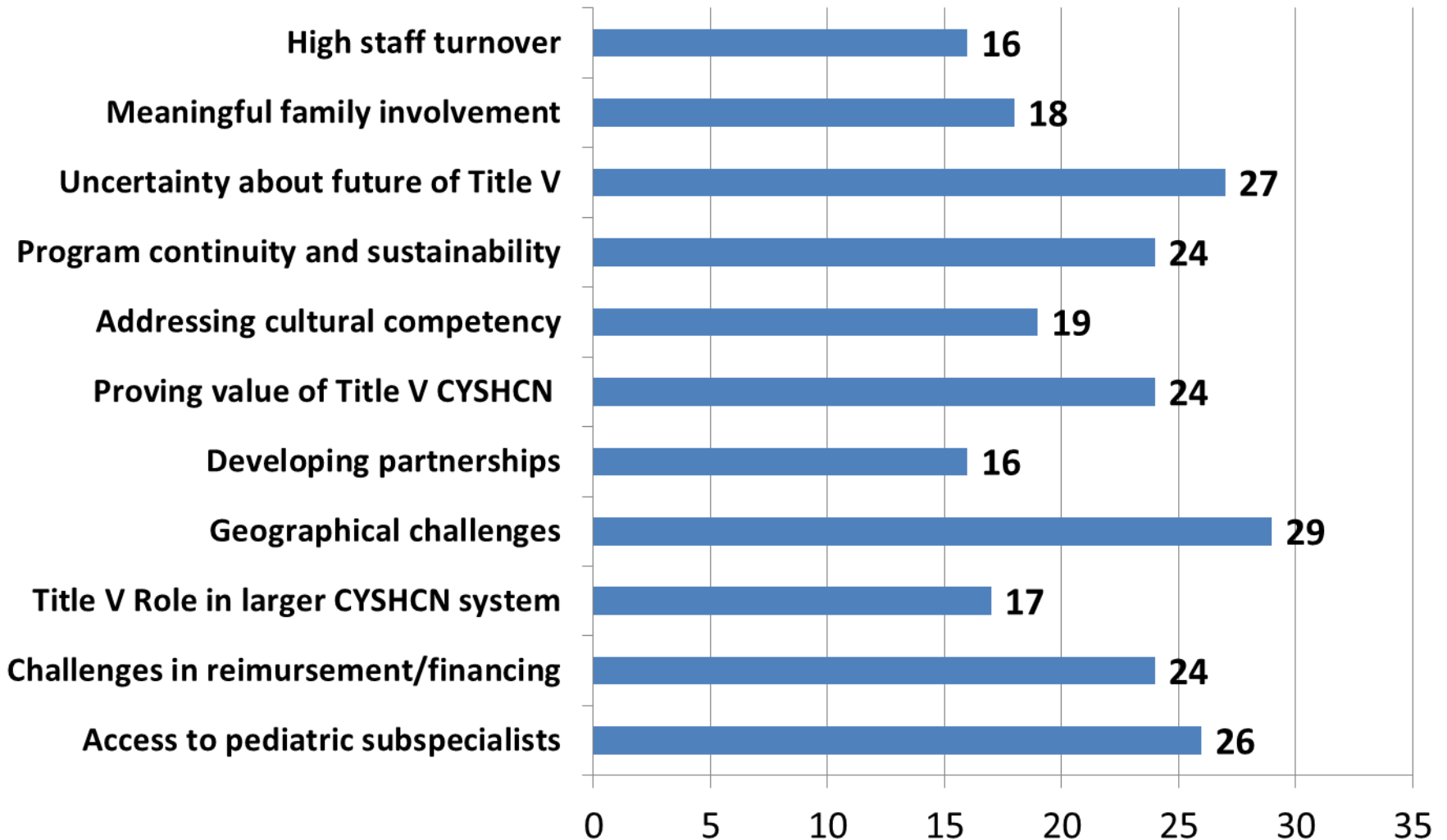
My state did not develop a state exchange system and is using the federal exchange system.



CYSHCN System Strengths (N=29)



CYSHCN System Challenges (N=29)



Conclusions

- Most responding Title V programs provide enabling services (care coordination, family support, etc.)
- In many states, CYSHCN covered by Medicaid are in or moving to managed care arrangements
- Greatest system strengths include family involvement and strong partnerships
- Greatest system challenges include access issues (i.e. pediatric subspecialists) related to geography and uncertainty about the future of Title V

Next Steps

- Additional surveys of State Title V CYSHCN Directors:
 - Family involvement
 - In-depth exploration of system challenges and strengths as Title V Block Grant Transformation occurs
- Promoting and assisting with implementation of [CYSHCN Standards](#) in states

Healthy Children. Healthy Families. Healthy Communities.

Thank You!

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