

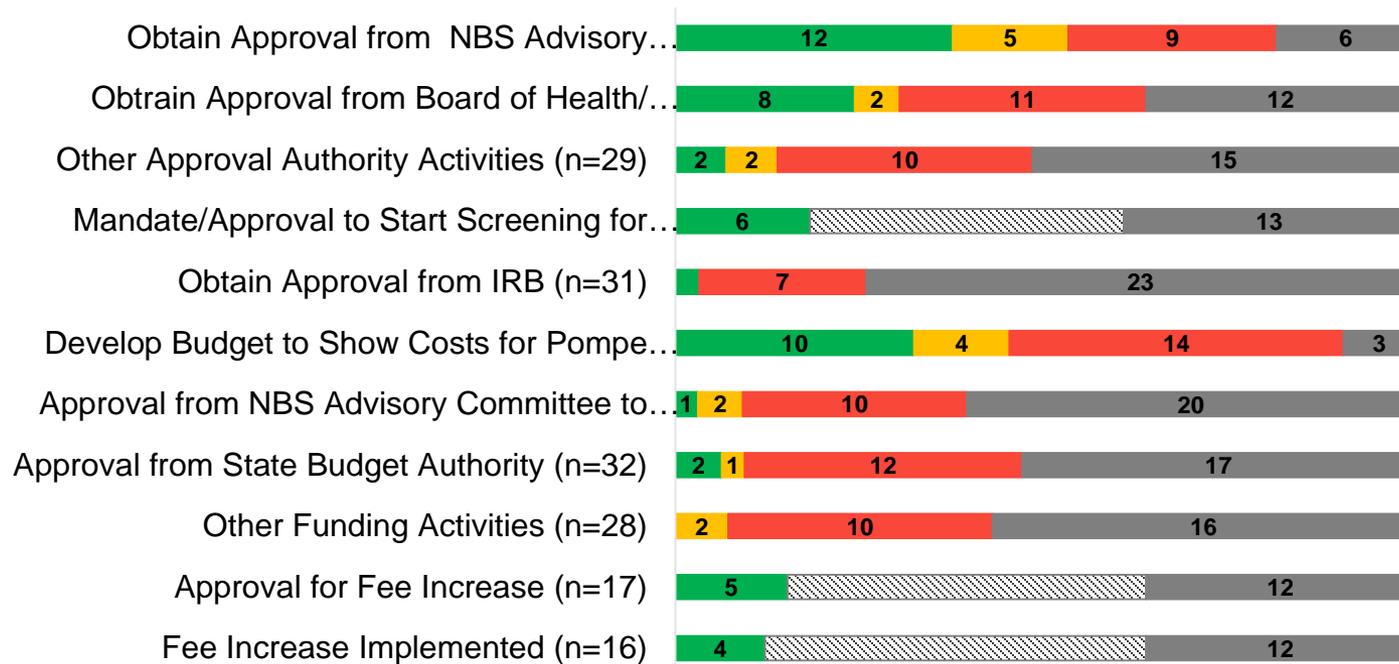
Overview of Phase 1 - Legislation/Mandate Stage

Where States Are at Based on Readiness Tool Data

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Status of Phase 1 Activities for Pompe (n=33)

■ Completed ■ Started ■ Not Started ■ NA



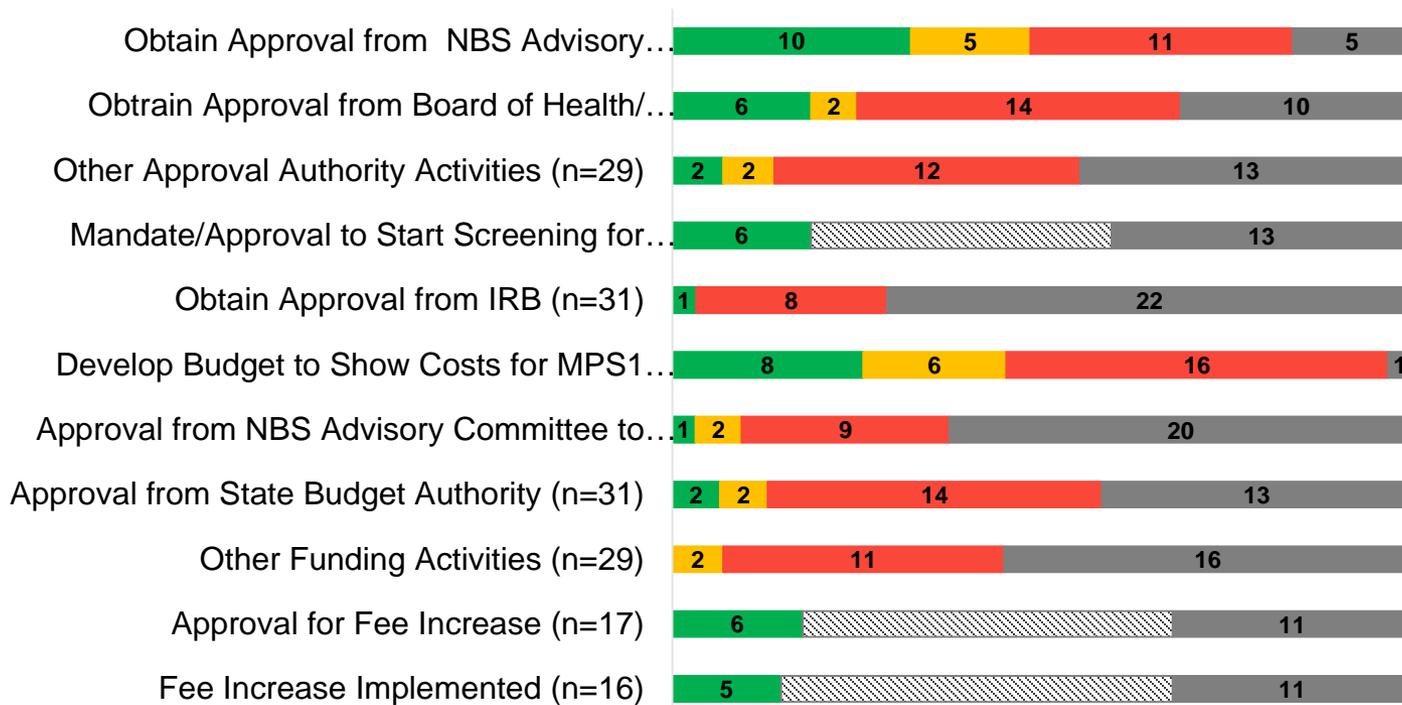
Analysis.
Answers.
Action.



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Status of Phase 1 Activities for MPS1 (n=32)

■ Completed ■ Started ■ Not Started ■ NA

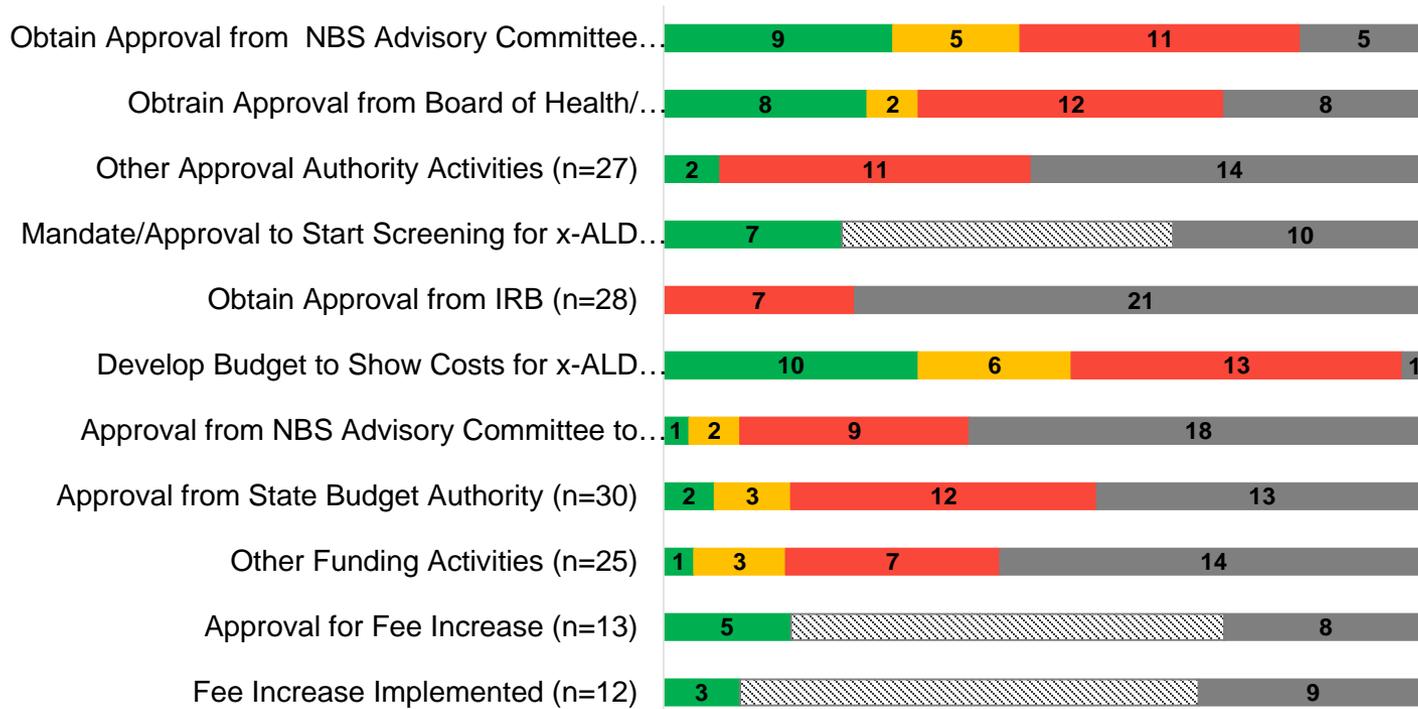


Analysis.
Answers.
Action.



Status of Phase 1 Activities for x-ALD (n=30)

Completed Started Not Started NA



Analysis.
Answers.
Action.





Welcome to “The Chat” – a newborn screening talk show featuring a panel of well-known newborn screening and entertainment personalities having The Chat about current events, pop culture, contemporary issues, family, celebrity and the trending topics of the day. The hosts swap stories, challenge each other on issues, and engage the audience about events in the headlines and their own programs.



The rarely seen world of a polygamist family is documented in "Sister Wives," which follows Kody Brown, his four wives and their combined 17 children trying to live as a "normal" family in a society that shuns their lifestyle. Three of the wives -- Meri, Janelle and Christine -- have worked for years with Kody to develop a cohesive, loving unit, and their marriages produced 13 kids. Then wife No. 4, Robyn, and her three children were added to the family much later, a development that produced mixed feelings, insecurities and uncertainties.

**Analysis.
Answers.
Action.**



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Have you ever had to take on additional work while still trying to keep up with the current workload? Has any of your current work suffered as a result of the additional work you've had to take on?

Analysis.
Answers.
Action.



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Fidget spinners are a popular toy for kids (and some adults). But some say the fidget spinners are a craze that has gotten out-of-control. Some schools have banned them, and health care providers warn about the risk of choking hazard from spinner parts.

Analysis.
Answers.
Action.



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Do you sometimes feel like things are getting out-of-control? What do you do to get back some sense of direction and influence?

Analysis.
Answers.
Action.



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During the last Stanley Cup Hockey finals, the Pittsburgh Penguins beat the Nashville Predators best out of six games by relying on help from their high scorers and improving their offensive strategy. The Penguins won back-to-back NHL championships by relying on their go-to players.



Analysis.
Answers.
Action.



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Where would you go to for help with public policy regarding the adding of new conditions? Who is your “go-to?”

When is the best defense a good offense?

Analysis.
Answers.
Action.



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APHL Public Policy Technical Assistance

- Engage us early and often
- Offense v. defense
- NBS partners
 - ASTHO
 - AMCHP
 - March of Dimes
 - AAP
 - Parent advocacy groups
- Education to legislators upon request
- Resources
 - Legal and Legislative Issues in Newborn Screening
 - StateTrack

Analysis.
Answers.
Action.



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Analysis.
Answers.
Action.



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Prince William met Kate Middleton while both attended the same university. After dating and a brief break up with a subsequent reconciliation, Prince William made big news when he got engaged to Kate. Also attention-grabbing was the fact that William proposed with his mother's iconic sapphire engagement ring.



Analysis.
Answers.
Action.



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Speaking of engagements, do you currently engage your state legislators to provide education on NBS and adding new disorders?

Analysis.
Answers.
Action.



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