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# Primary Care Transition Planning for Young Adults with Special Needs in Maine: A Preliminary Survey of Pediatric Providers

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## Introduction

It is anecdotally evident, from working within the disability services field in the state of Maine, that care coordination for young adults with special health care needs is often a confusing and disjointed process for the individual, the family, and the medical providers. The present study, consisting of an internet survey with 13 qualified respondents, looked to examine the extent to which Maine primary care providers serving children with special needs use care coordinators and have formalized transition plans in place, as well as what provider-identified training or resource needs might exist. Although limited on several fronts, the preliminary data gathered suggests that Maine providers who serve pediatric patients with special needs often do have care coordinator roles, but do not have formalized transition plans in place. Providers responded with a variety of suggestions regarding their training/resource needs, including online and onsite training, specific contacts in the adult practice, multidisciplinary meetings, and templates/customizable resources. This study was done as part of my NH-ME LEND Leadership activities.

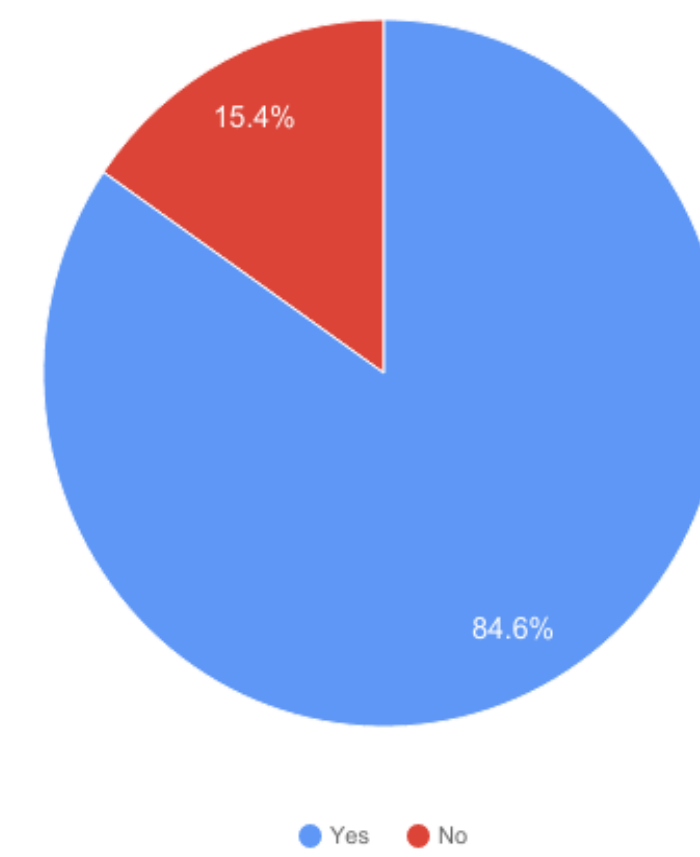
## Background

Research suggests that less than half of young adults with special health care needs are prepared for the transition to an adult primary care provider at the age-appropriate time (McManus et al., 2013). Prior research also indicates that having a “usual source of care” and routinized medical services creates a higher likelihood of adult patients receiving preventative and screening health services (Blewett et al., 2008).

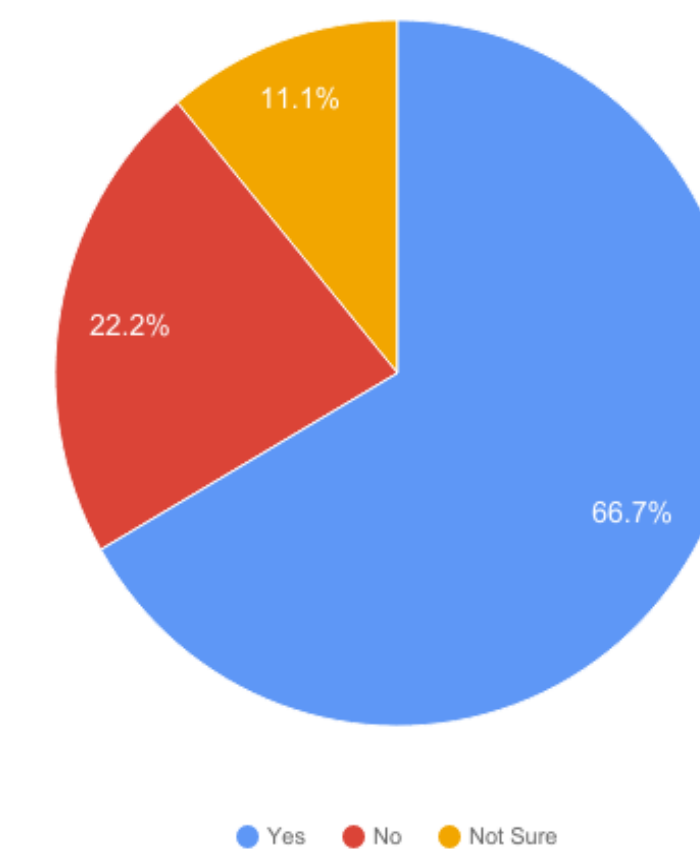
## Materials and Methods

An online survey was used to gather results from pediatric primary care providers in the state of Maine. A link to the survey was initially sent to over 100 pediatric providers using the author’s university email address, as well as the name of the MDDC. The results, after two weeks and one electronic reminder, yielded less than ten responses. The author then reached out to the Board of Directors of the American Academy of Pediatrics (AAP), Maine chapter, and was able to have the link to the survey sent to the AAP’s members via the organization’s official list serve. It was hypothesized that the identity of the sender would validate the authenticity of the request. An additional eleven responses were gathered after the survey was sent out by the AAP. Due to time constraints, the research was halted before more results could be obtained.

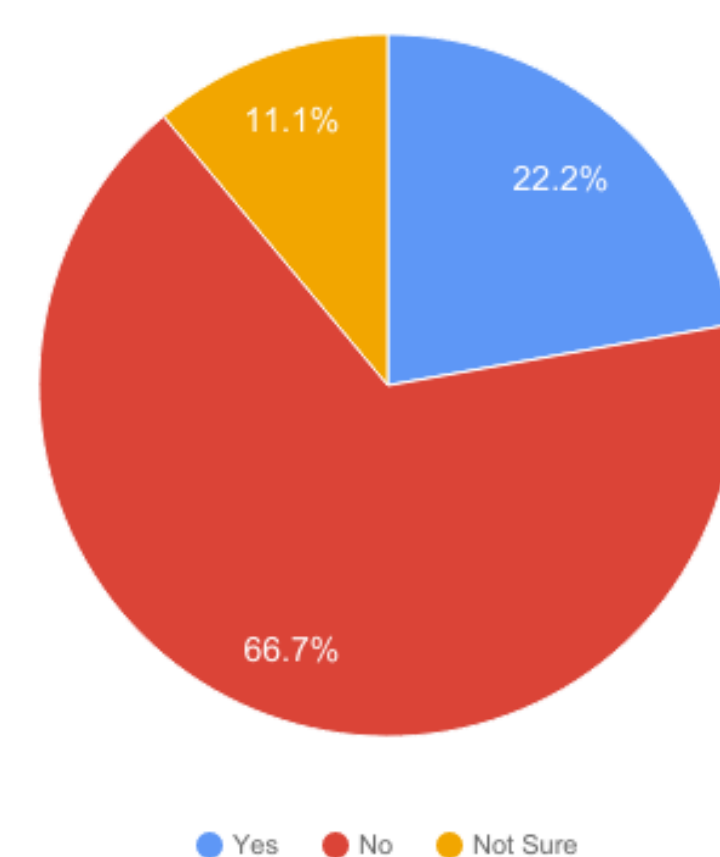
Question 1: Does your practice provide primary care to children with special healthcare needs? Special healthcare needs are chronic physical, developmental, behavioral, or emotional conditions. Examples include ADHD, Autism, Cerebral Palsy, Down Syndrome, and behavior disorders



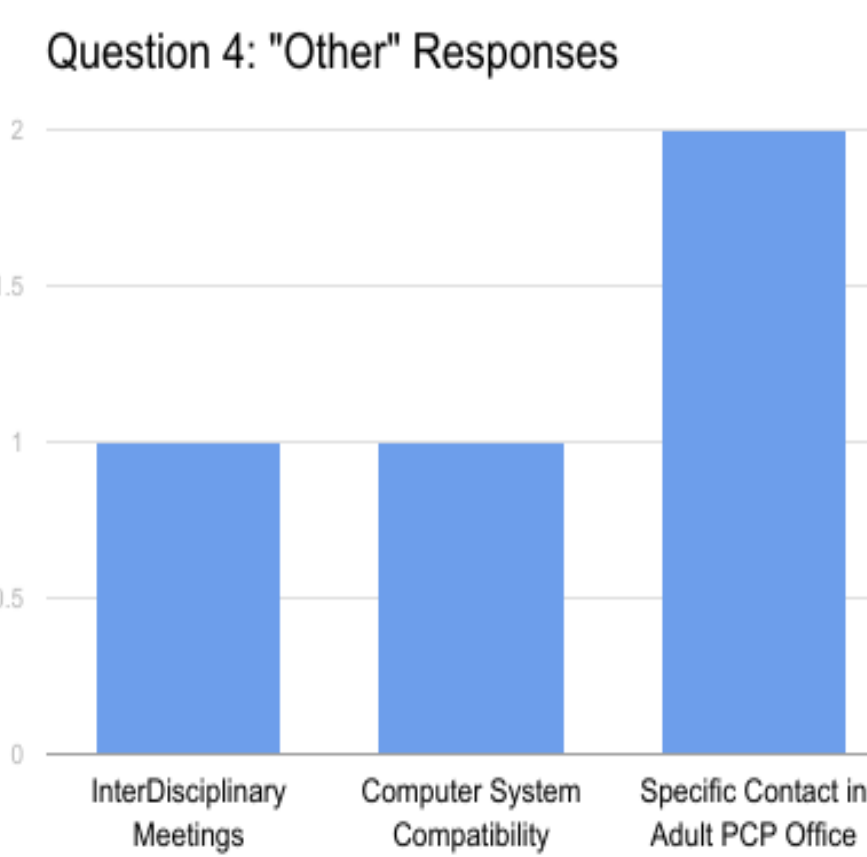
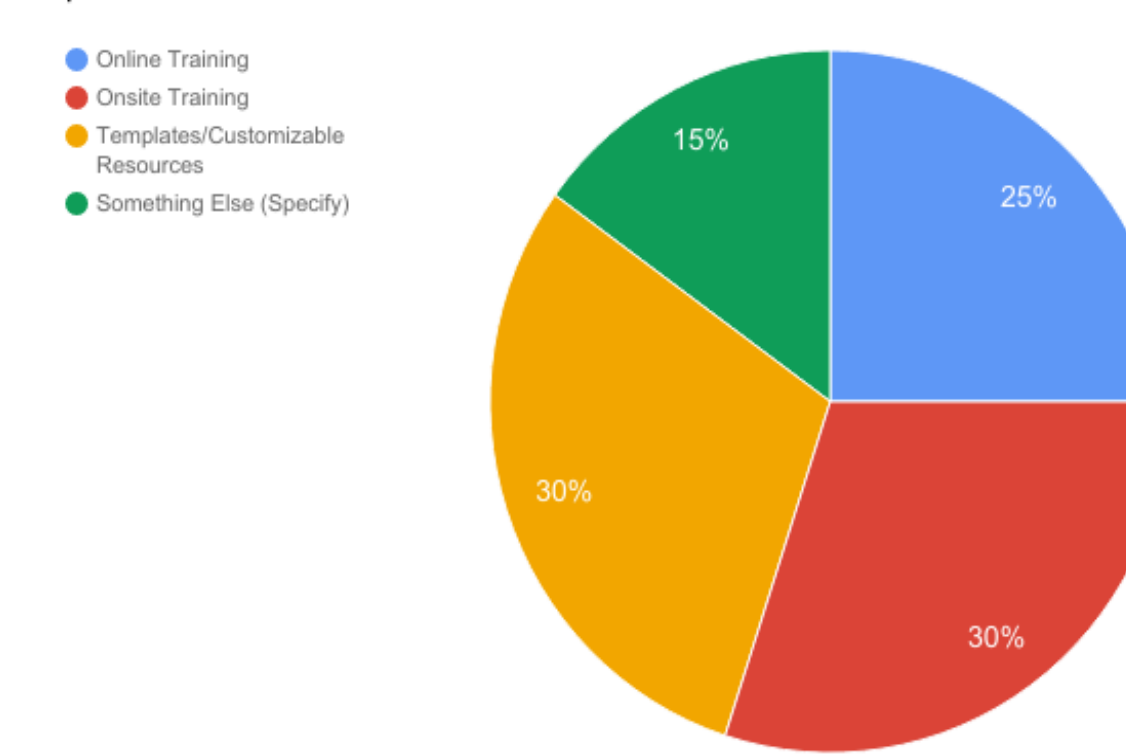
Question 2: Does your practice utilize a care coordinator (sometimes called a “nurse navigator”) to help patients with special healthcare needs transition to adult primary care? Answer “yes” if someone in your practice has this role, even if this is not his/her job title or primary responsibility.



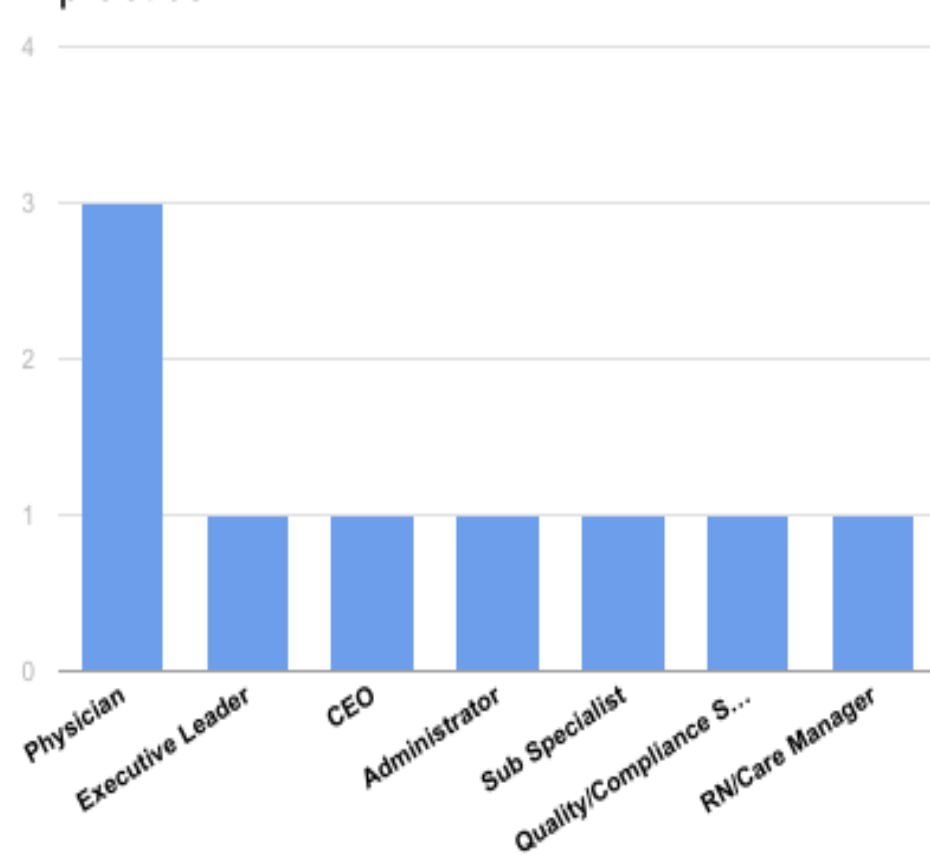
Question 3: Does your practice have a formal transition plan protocol in place to transition children with special health care needs to adult primary care?



Question 4: If your practice does not have a formal transition plan protocol in place at this time, what would help support the development of such a protocol?



Question 5: What is your role within your practice?



## Results

A total of 14 respondents completed the survey, including one who did not identify as a pediatric provider and was therefore not included, for a total of 13 participants in the final results. Of these, 4 did not complete all items. These data represent a preliminary probe into the issue of special needs health care transitions in Maine, and should not be taken as a definitive confirmation of any particular hypothesis. They are, however, sufficient to raise concerns around the difficulty with special needs medical transition planning that is anecdotally evident in many Maine communities. Directions for further research should include the following: (1) the extension of the survey to a broader and more representative sample of pediatric practices in the state of Maine; (2) further investigation into the nature of the nurse navigator/care coordinator role for practices that reported utilizing such a role, particularly whether the individuals in these roles have other primary duties as part of their professional responsibilities; (3) further investigation into the nature of the formal transition protocol system for practices that reported having such protocols currently in use; and (4) further investigation into the nature of training needs for practices that indicated an interest in online or onsite training, and/or materials and templates.

## References

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