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## INTRODUCTION

- Current data indicates that 1 in 88 children are on the autism spectrum
- The projected national cost of lifetime care for persons with Autism Spectrum Disorders (ASD) has risen to \$137 billion
- Lack of transitional care planning often results in limited life opportunities and reduced access to healthcare, and wellness, social, and economic outcomes
- Many families of children with special healthcare needs face financial challenges, often aggravated by reduced parental employment, which impedes their ability to seek legal assistance in addressing immediate and long-term, transition, and other needs
- Unmet legal needs can have a negative impact on the overall health of a patient and the delivery of healthcare
- Research supports the benefit of community programs to assist families in long-term planning, education, and access to legal rights for people with disabilities
- A Medical-Legal Partnership is a national healthcare delivery model that integrates a legal presence into the medical home to improve the health of low-income and vulnerable populations, while bridging patient to population-level interventions
- South Carolina is one of 16 states without a Medical-Legal Partnership

## OBJECTIVE

- This project sought to determine the interest in and perceived need for a medical-legal partnership in Upstate/Greenville, South Carolina initially benefiting persons with autism spectrum disorders and related neurodevelopmental disabilities as prepare for transition planning

## PARTICIPANTS AND METHODS

- A needs assessment was completed pursuant to waiver by the Institutional Review Board at Greenville Health System
- Anonymous online surveys were distributed to Three target groups: attorneys, pediatricians, and parents of children with special healthcare needs
- The surveys employed 5-point Likert-type scaled answers
- Population-specific questions examined respondents' knowledge and opinions of the legal needs of children with special healthcare needs, of their considerations of the challenges faced by individuals with special healthcare needs, of their understanding of transitional care planning, of their perception of the need for and interest in integrative medical and legal services specifically for transitioning youth with special healthcare needs, and of the need for affordable legal assistance to families of children with special healthcare needs (See Table 1 for specific wording examples of attorney and pediatrician questions)

## RESULTS

### ATTORNEY OPINIONS

- **45.9%** are willing, highly willing, or extremely willing to provide legal services to families for *pro bono* or appointed work (if approved by the Bar) for children with special healthcare needs (CSHCN)
- **50%** believe that there is a need, a high need, or an extreme need for an integrated legal presence in pediatric healthcare in Greenville
- **75.1%** agree on some level that individuals with developmental differences are challenged by the legal system
- **62.6%** believe that there is a need, a high need, or an extreme need for affordable legal assistance to families of CSHCN as the plan for transitions into adulthood
- **72.9%** are not familiar with the legal needs of CSHCN
- **66.7%** have some level of interest in continuing education on this topic

### PEDIATRICIAN OPINIONS

- **85.8%** would be likely, highly likely, or extremely likely to refer to an onsite attorney to assist in long-term and transitional planning
- **75%** believe that there is a need, a high need, or an extreme need for an integrated legal presence in pediatric healthcare in Greenville
- **85%** believe there is a likely, highly likely, or extremely likely chance that individuals with developmental differences are challenged by the legal system
- **83.3%** believe that there is a need, a high need, or an extreme need for affordable legal assistance to families of CSHCN as the plan for transitions into adulthood
- **56.8%** are interested, highly interested, or extremely interested in continuing education in this area

### FAMILY OPINIONS

- **100%** believe that there is a need or an extreme need for an integrated legal presence in pediatric healthcare in Greenville
- **66.7%** are in extreme agreement that individuals with developmental differences are challenged by the legal system
- **75%**, believe that there is a high or extreme need for affordable legal assistance to families of CSHCN as the plan for transitions into adulthood

## DISCUSSION

- Results suggest that a need exists in Upstate/Greenville, South Carolina for affordable legal assistance to families with children with special healthcare needs, and that there is interest from the necessary parties to create an integrated approach to transitional care planning for individuals with special healthcare needs, ASD, and related neurodevelopmental disabilities..

- This provides initial support for implementation of a formal Medical-Legal Partnership in Upstate/Greenville, South Carolina.

- Respondents also indicated support for interdisciplinary education regarding the law, ASD, related neurodevelopmental disabilities, and special healthcare needs

- Further research is needed to examine the effectiveness of a Medical-Legal Partnership in planning for youth transitions and mitigating negative health, wellness, social, and economic outcomes.

## Table 1. Example Questions/Likert-Type Scale

On a scale of 1-5, how willing would you be to provide legal services that assist financially vulnerable families with children with ASD or CSHCN to meet your 608 appointments (if approved) for your pro bono requirements? (Attorney Question)

- 1: Not Willing
  - 2: Somewhat Willing
  - 3: Willing
  - 4: Highly Willing
  - 5: Extremely Willing
- No response

On a scale of 1-5, how likely would you be to refer families to an on-site attorney to assist in long-term and transitional planning, and to help resolve non-biological determinants of child health, such as poor housing conditions, combativeness with the school system over special services, etc.? (Pediatrician Question)

- 1: Not Likely
  - 2: Somewhat Likely
  - 3: Likely
  - 4: Highly Likely
  - 5: Extremely Likely
- No response