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Analysis of Care Coordination for Children with Special Health Care Needs: a Parent’s Perspective

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Background
Care coordination involves organizing patient care activities and sharing information among all of the participants concerned with a patient’s care to achieve improved outcomes. In recent years there has been a focus to improve care coordination nationally. Compared to the national average, a higher percentage of Vermont children are cared for in an office that meets medical home criteria. However, there is limited research on medical home and care coordination for children with special health care needs (CSHCN) in the state of Vermont.

Objectives
The goal of this study was to assess family perceptions, knowledge, and attitudes about how well care coordination is working for Vermont families with CSHCN.

Methods
A paper and an electronic anonymous survey was developed for Vermont families with CSHCN. The surveys were then distributed by Vermont Family Network and the UVMCC Department of Pediatrics. 30 surveys were initiated by participants. Focus group interviews were also conducted at Vermont Family Network to provide family insight to explain the quantitative data.

Survey Response Rate
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<th>Eligible to complete survey</th>
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<td>30%</td>
</tr>
<tr>
<td>Did not complete survey</td>
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<td>3%</td>
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</table>

Results

Fast Facts
100% of respondents were parents
95% of respondents were female
79% of respondents were over 40 years of age
69% of respondents were the primary caregivers for 2 or more children
58% of respondents were residents of Chittenden County

Care Coordination Survey Results

Quotes from Parents Regarding Barriers to Care Coordination
• “We had to educate our coordinator on what should be covered [by insurance]. It took us a good three weeks of constant phone calls to get what we were legally qualified for.”
• “…the communication [is] huge…the care and relationship are so important.”

Care Conferences
• “Care conferences are a huge asset…the parent is a part of the team, not the one responsible for coordinating your child’s care keep in contact with you, even when your child received health care by others.”

References

Discussion
Overall, the findings indicate that families are not satisfied with the level of care coordination currently provided.
• Composite Satisfaction Score*: 54%
• Barriers to adequate care coordination include but are not limited to: lack of access to care coordination services during transitional periods, lack of communication between health care providers, insurance formalities, and outsourcing of medical services outside of hospital network (i.e. Care in Boston although primary care is provided in Vermont)
• Sample size (n=20) limited the ability to conduct specific statistical analysis to prove significance. Therefore, future directions include recruiting the involvement of more families receiving care coordination services.

Recommendations
• Care Conferences
• Individualization of services
• Family Centered Care
• Provision of educational materials for families within the clinic setting
• Provider education on complex health care needs
• Pre/post appointment phone calls

Quotes from Parents

Q17: Overall, how well have the care coordination services offered by my child’s primary care office met your needs?
Q12: In the past 12 months, how often did your child’s primary healthcare provider seem informed and up-to-date about the care received from specialist providers?
Q10: In the past 12 months, how often did you receive enough support from your child’s care coordinator in getting necessary medical equipment and/or services for your child?
Q6: In the past 12 months, how well did the person responsible for coordinating your child’s care keep in contact with you, even when your child received health care by others?

* Composite Satisfaction Score = \( \sum (\text{average of questions #6, 10, 12, 17}) \)