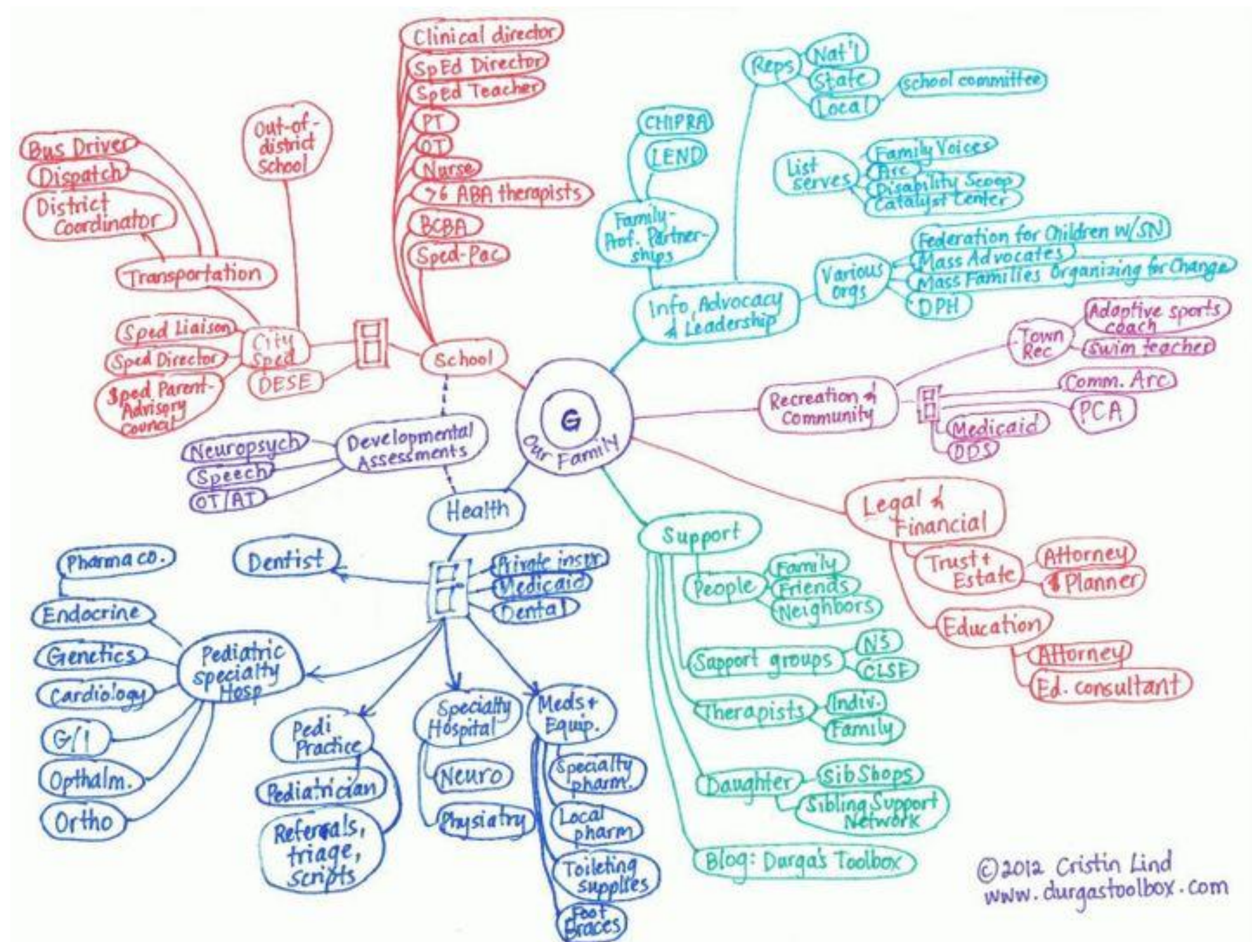
Coordinated Care

ORGANIZING AND LINKING CHILDREN AND FAMILIES WITH NEEDED SERVICES AND SUPPORTS

Why It's Important

Children and youth with special health needs (CYSHN) and their families often need a wide variety of medical, psychosocial, educational, and support services. Figure 1 below is of a care map that a mother of a child with complex health needs developed for her child. The map provides a visual depiction of the number of services and supports that may need to be coordinated.

Figure 1. Care Map



Source: Cristin Lind. https://cristinlind.com/care-mapping/

Many times systems and services are difficult or confusing to access because they are unorganized or are not available in a consistent manner across locations. When care is not coordinated, children and families can receive fragmented or duplicative services – or may not end up receiving needed services at all. According to the 2016-2017 National Survey of Children's Health (NSCH), CYSHN typically have more

unmet needs related to services than children without special health needs (i.e., 8.1% of CYSHN did not receive needed health care services compared to just 1.8% of those without special health needs). As a result, many times CYSHN receive less than optimal care.

The lack of coordination often contributes to unnecessary stress and frustration for families because they end up with the bulk of the responsibility in coordinating their child's care. This results in parents spending hours arranging or coordinating their child's care – nationally, around 7.2 percent of parents of CYSHN reported spending five or more hours coordinating their child's care. Additionally, 15 percent of parents reported spending 11 or more hours per week providing health care at home for their child. According to a parent of a child with special health needs:

> *"Ultimately, I am in charge of coordinating EVERYTHING… and I face many challenges in doing so. It all takes so much time…making calls, attending appointments, gathering necessary paperwork...it's a full-time job with no paycheck. It's also time taken away from my other children and my family. Sometimes it's even difficult to know 'who' can help with 'what.'" – Parent of a Child with Special Health Needs*

When parents are then required to spend this amount of time coordinating care for their child, other aspects of life may be impacted, such as their health and employment. Parents of children with special health needs often report having poorer mental and physical health than those without special health needs. They also report having to cut back hours or quitting their jobs at higher rates – nationwide, 15.1 percent of parents of CYSHN vs. 2.8 percent of parents of non-CYSHN.

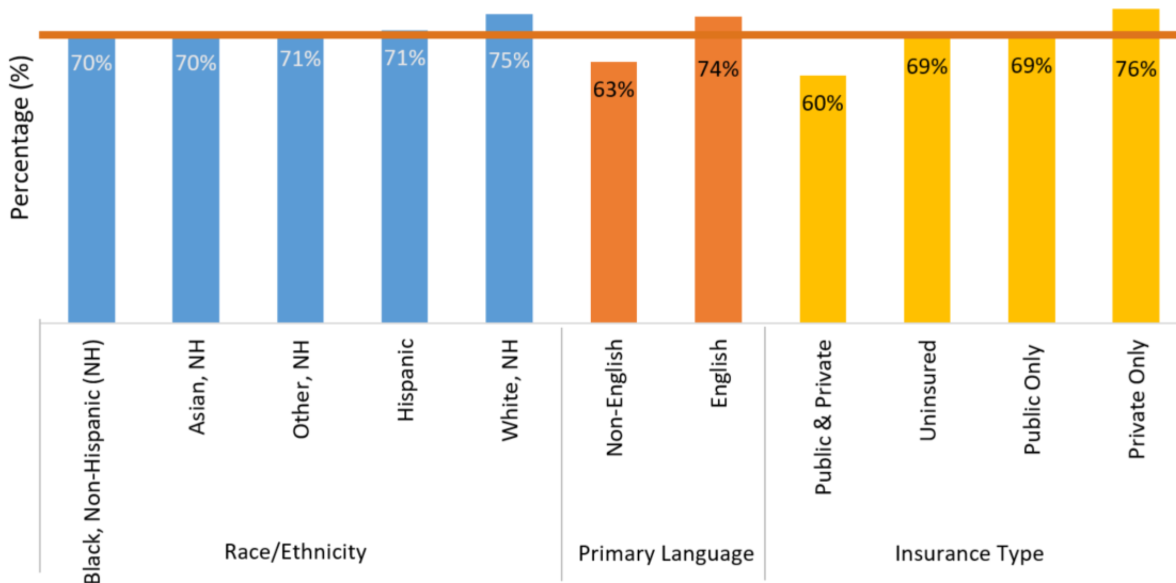
The coordination of care is a core component of a patient- and family-centered medical home. The medical home is an approach to providing comprehensive primary care. According to the 2016-2017 NSCH, only 52 percent of Minnesotan CYSHN received care in a medical home. Furthermore, around 33 percent of Minnesota CYSHN who needed care coordination did not receive it.

Focus on Health Equity

There are certain populations in Minnesota that face more barriers to receiving coordinated care. We know that linking families to needed supports can be difficult in rural areas, where services and supports are limited and often not easily accessible. On the flip side of that there can also be better coordination in Greater Minnesota where one individual may be serving in several roles and knows the needs of families better because they are involved with the family through multiple programs.

While Minnesota-specific subgroup data is not available for children and youth with special health needs in Minnesota due to small sample sizes, we do know that there are important differences in effective care coordination at the national level by race, language, and insurance type (see Figure 2).

Figure 2. Children (0-17 years old) in the United States Receiving Effective Care Coordination, 2016-2017



Source: National Survey of Children's Health, 2016-2017

Additional Considerations

In 2015-2016, MDH conducted an assessment to learn about the strengths, challenges, gaps, and redundancies inherent in providing and receiving care coordination for CYSHN in the state. Strengths were discussed in terms of things that are currently working, and challenges were defined as things that needed improvement.

"Care coordination of CYSHN in Minnesota currently works because…"

- Care coordinators are passionate and dedicated to helping families
- A lot of focus has been placed on early childhood
- There is strong networking and collaboration between care coordinators
- More care coordinators are being employed by primary care and specialty care
- Certified health care homes have care coordinators
- There is a focus on developing relationships and a sense of community
- Care coordinators are knowledgeable of the needs of families
- Care coordinators do a good job linking families with resources
- There are a lot of resources available (*more applicable to Metro*)

"Care coordination of CYSHN in Minnesota would be better if…"

- Parents would not have to coordinate all the care coordinators
- Coordinators would communicate more with each other and not rely on the family to do the back and forth
- There were more sustainable funding for care coordination (and the funding better met the needs of children and families)
- A universal Release of Information was available
- Data sharing laws and practices didn't get in the way

- Electronic health records would communicate between each other
- There was more collaboration between schools and health care
- There were more resources available (more applicable to out-state regions)

It is also important to acknowledge how difficult it can be to be a care coordinator. Key components of effective care coordination include understanding that progress may be made incrementally, supporting families in their choices, and recognizing that families are the experts in the care of the their child. Care coordinators face many challenges in doing their work, including but not limited to: building trust and rapport with families and providers, being knowledgeable about community resources and eligibility criteria, and experiencing vicarious trauma when working with families that have a lot of needs and wishing more could be done.

One last additional consideration is that it is difficult to report on important differences in care coordination due to data limitations. The National Survey of Children's Health is the primary data source for CYSHN, but the Minnesota Department of Health is unable to conduct sub-analyses, even when combining data years, due to small sample sizes.

Important Note on Equity and Intersectionality

The Minnesota Department of Health's Title V Needs Assessment team acknowledges that structural (social, economic, political and environmental) inequities can result in poor health outcomes across generations. They have a greater influence on health outcomes than individual choices or a person's ability to access health care, and not all communities are impacted in the same way.

All people living in Minnesota benefit when we reduce health disparities.

We also acknowledge that the topic addressed in this data story does not exist in isolation– which is important to remember as we do needs assessments and as we start thinking about how we approach solutions. In addition to the needs themselves being intersectional, there are also intersecting processes and systems through which power and inequity are produced, reproduced, and actively resisted.

Citations

1. Why is Medical Home Important? National Resource Center of the American Academy of Pediatrics. Retrieved April 2019. https://medicalhomeinfo.aap.org/overview/Pages/Evidence.aspx.
2. Child and Adolescent Health Measurement Initiative. 2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved [04/30/2019] from www.childhealthdata.org. CAHMI: www.cahmi.org.
3. Child and Adolescent Health Measurement Initiative. 2016-2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved [04/30/2019] from www.childhealthdata.org. CAHMI: www.cahmi.org.
4. Wholey, D.R., Finch, M., Shippee, N.D., et al. (2015). Evaluation of the state of Minnesota's health care homes initiative evaluation report for years 2010-2014. Retrieved from http://www.health.state.mn.us/healthreform/homes/legreport/docs/hch2016report.pdf.
5. American Academy of Pediatrics. (2018). Minnesota state profile. Retrieved from https://medicalhomeinfo.aap.org/national-state-initiatives/State-Profiles/Pages/Minnesota.aspx.

Child and Family Health Division
Title V Maternal and Child Health Needs Assessment
Minnesota Department of Health
PO Box 64975
St. Paul, MN 55164-0975
651-201-3589
health.cfhcommunications@state.mn.us
www.health.state.mn.us

8/1/2019

To obtain this information in a different format, call: 651-201-3589. Printed on recycled paper.