

Great LINCS Needs Assessment

Overview

The Washington State Department of Health (DOH) was awarded a three year grant to improve systems of services for children and youth with special healthcare needs (CYSHCN). The grant, Great LINCS (Links to Integrated and Coordinated Services) includes a needs assessment activity to gather parent and caregiver input. The purpose of the needs assessment is to identify gaps and challenges that currently exist for parents, caregivers, and families who use systems or programs funded or supported by the state of Washington. There were five data collection activities conducted for the needs assessment: a parent survey (199 responses), parent focus groups (7 groups in the following languages – Somali, Korean, Spanish, Mandarin/Cantonese, and Vietnamese), a pediatric provider survey (51 responses), and a survey of Local Health Jurisdiction CYSHCN Coordinators (28 responses) and key informant interviews with all 6 of the Medicaid Managed Care plans.

Key Findings

- **More marketing of WithinReach is essential**

WithinReach (WR) is a nonprofit in WA whose mission is to build healthy families and communities. As a statewide organization, they connect vulnerable populations to resources through technology-based and in-person outreach that include toll-free hotlines, community outreach activities, and websites. WR works with Great LINCS to expand their capacity to provide resources for CYSHCN across the state. Of the seven focus groups, a small proportion (3 participants) reported they had heard of WithinReach or the Family Health Hotline (a program administered by WithinReach). All three reported positive experiences. The online parent survey yielded similar results: 5.5% of respondents had heard of the Family Health Hotline. Of the practitioners surveyed, 7.4% said they used the Family Health Hotline as a resource. Similar results were seen among coordinators.

- **Availability of parents and toll-free lines need to match**

Parents participating in the online survey sought information at hours that are not covered by traditional toll-free lines. The majority (53.8%) said they searched for resources in the evening between 6-10 PM. Participants could select multiple time categories, and the second highest category was between 10 PM and 12 AM, with 31.2% of respondents having selected that category.

- **Care coordination is done primarily by parents/Care Coordination that works is very needed**

The parent survey asked if anyone helped arrange or coordinate care among different doctors and services for their child. The majority (87.8%) responded that no one helps arrange care. Parents were also asked if they could use extra help arranging care for their child and 54.6% responded they could, while 7.7% said they did not know. Just over one third (37.8%) responded they could not use extra help.

Parents were also asked what would improve the way their child's care is coordinated or managed in an open-ended question. Many broad themes emerged, with coordination of care being among the top of them. Some parents conveyed they did not just want coordinated care, but coordinated care that was effective.

- **Practices are still not able to share electronic health records (EHRs) containing care plans with other providers**

Parents were able to openly write what would improve the way their child's care is coordinated or managed. The top theme was care coordination and the second highest theme was electronic health records. Parents expressed the need for providers to use one electronic health record system to communicate with all providers regarding their child's treatments. Parents voiced concerns around not only repeating information regarding their child's history, but around conveying information correctly from provider to provider. In the pediatric provider survey, only 29.6% of providers responded they have electronic medical records that allow the sharing of care plans to other providers.

- **Parents and partners experience challenges accessing government services**

Parents, county coordinators, and providers were asked what resources they were aware of, utilized, and found most helpful. Consistently, all groups reported non-profit organizations as being the most helpful in comparison to government agencies. Parents reported having the most barriers and challenges with government agency services compared to non-profit organizations.

- **Issues with wait times and access to needed providers**

Among the focus groups and qualitative portions of the parent survey, an overarching theme was wait times for needed health services which included access to providers as a major barrier. Parents consistently expressed their frustration with, and saw this as possibly the biggest barrier in obtaining the needed care and services for their child.

- **Interpreter issues- different dialects and medical terminology are challenging**

Among focus group participants who used interpreter services, many stated they had encountered issues. Interpreter challenges were raised as an issue in nearly all of the 7 focus groups, conducted in 5 different languages. Some concerns rose to the level of becoming detrimental to their child. More extreme examples included Child Protective Services involvement due to misinterpretation and a child almost having unnecessary heart surgery. Parents also raised the concern around the interpreters' lack of understanding relating to medical terms and the proper translation of health information between the parent and the provider. They also raised the issue of dialects. For example, there are different dialects of languages depending on the region and many times, it is extremely difficult to communicate between them. Some in the Spanish-speaking focus groups expressed they wanted to learn and/or improve their English. Most focus groups wanted to get materials in their native language.

- **Connections to other parents are vitally important**
Parents in the focus groups repeatedly expressed the value of other parents as a resource. Even when analyzing the focus groups, there was an overall tone of comradery, shared experiences, and ultimately increases in knowledge as the parents shared what has been helpful to them. The online survey asked an open-ended question regarding which services have been most helpful. The combined category of parents/Parent2Parent tied with school as the second highest answer.
- **Internet is major source of getting information for families**
Parents in both the focus groups and the survey responded they get their information from the internet above all other sources. When asked via the online survey where they would like to go when they have a question about services available, 51.3% of parents taking the survey said they used the internet to find detailed information and 43.2% said they used the internet first and then wanted to call for more details (parents could select more than one response, and these two responses were the most selected).
- **Language barriers are common**
Language barriers occurred at a couple levels. Parents of the focus groups expressed frustration around the technical language used among providers. They also expressed a wish to be educated in medical vocabulary around their child's conditions, for themselves and for the interpreters.
- **Inclusivity barriers such as recreational activities and opportunities to interact with and in community – supports for this are needed**
While parents in the focus groups agreed there are services and benefits on one hand, on the other hand, their children are not able to go where those services are offered. A parent gave the example of a swimming class either not being available for her child, or too expensive, if it is a modified class. Parents taking the online survey reported community activities as the number one choice (51.3%) when asked what would be helpful to better care for their child.
- **Need for respite slides**
The availability of respite care was repeatedly cited by parents of both groups as a needed service. If they were currently receiving respite care, they wanted more of it. A large percentage of parents participating in the online survey (41.7%) selected respite care as a service that would be helpful in better caring for their child.
- **Interruptions/breaks in service from school – summer break, holiday breaks – these are disruptive and can result in regression**
Parents in the focus group repeatedly expressed the need for services to continue during times when school does not convene. Parents voiced concern for their child regressing during these gaps in services. A few parents in the focus groups mentioned the summer break being the most challenging, as their child gets the majority of their services from the school system.

- **Confusion among providers related to medical home vs. health home**

The majority of providers considered their practice a medical home, 85.2%. When asked if someone in their office creates plans for children with special health care needs, 74.1% responded no. When asked if they were a Medicaid certified health home, 55.6% responded no and 14.8% said they were not familiar with the term health home.

- **Need for care coordination and medical home**

The majority of responders that accepted Medicaid reported they did not coordinate with Care Coordinators for CYSHCN patients (61.3%). Less than half of the LHJ CSHCN Coordinators surveyed reported developing a care plan with families. When the coordinators were asked about their experience coordinating with primary care, specialists, schools, mental health, substance abuse, early intervention, neurodevelopmental, and other systems, the majority responded either coordinating for a few or none of their clients. This may be due to time and resource limitations among coordinators; the majority of coordinators reported they worked on multiple programs other than CYSHCN. Only 6.9% reported CYSHCN programs were the only ones they coordinate. The largest percentage of participants (37.9%) worked on 5 or more programs.

LIMITATIONS

Participants in the surveys were not selected from a random sample, but instead by convenience. Participants for the parent survey were recruited through parent organizations, parent group Facebook posts, CYSHCN coordinators, and partner websites. Due to this, parents with a higher socioeconomic status may be over-represented. This limits the results to only those participating and extrapolation to any population cannot be done. Although the themes of the parent survey and the parent focus groups were similar, the focus group asked fewer questions, which were all open-ended; whereas the parent survey was longer and had fewer open-ended options. Focus group participants were recruited exclusively by parent organizations, representing parents already connected to some type of service. Participation among parents was incentivized. The participants in the focus groups were paid \$50 for their participation and the online participants had the option to enter a drawing for a \$50 Walmart gift card. There is the possibility that parents less motivated by cash or a gift card option might not participate and they might have offered different responses than those participating. The provider survey was incentivized by a free cup of coffee. While the Spanish-speaking focus groups were translated verbatim, the remaining focus groups were either entirely summarized, or partially summarized by the interpreter before being analyzed and may have compromised specific language. For the purpose of this report, abridged methodology and limitations are described.