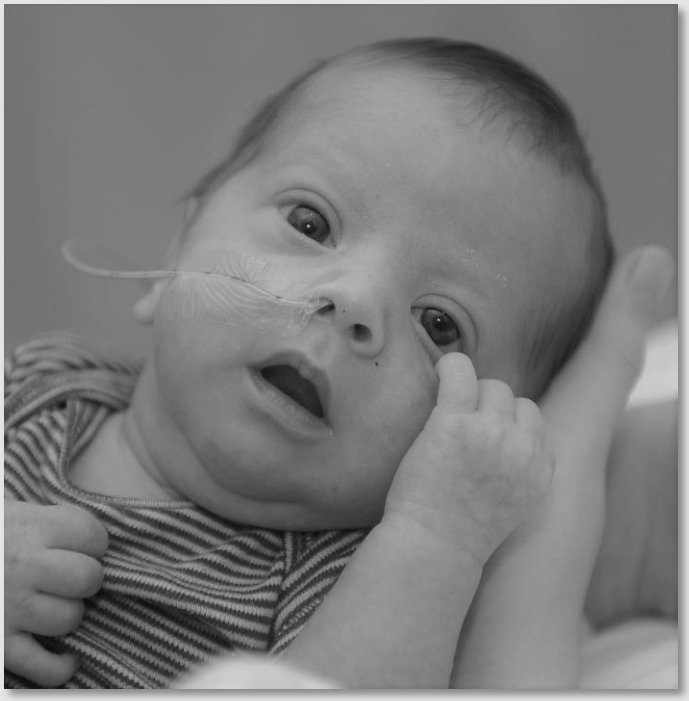
Assessment of Nutrition Services for Children and Youth with Special Health Care Needs



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FINAL REPORT

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Contents

Executive Summary

Children and youth with special health care needs (CYSHCN) are a diverse group with a variety of health needs and trajectories. Up to 40% of CYSHCN also have nutrition risk factors indicating the need for a referral to a registered dietitian nutritionist (RDN). This need is even higher among children in certain subgroups, such as children with autism or those under 3 years of age with developmental delays in early intervention programs.[4-7] For the remainder of the Executive Summary registered dietitian nutritionists (RDNs) will be referred to as dietitians.

About the Assessment of Nutrition Services for CYSHCN Report

The Washington CYSHCN Nutrition Network has 207 dietitian members and 30 interdisciplinary feeding teams. Between 2017 and 2018 the Washington State Department of Health CYSHCN Program conducted a needs assessment among four key groups, to evaluate CYSHCN access to dietitian nutrition services. The goals of this assessment are to create a common understanding of the role and job responsibilities of pediatric dietitians for CYSHCN and provide information to partners on their contribution to health outcomes of the CYSHCN population.

Key Findings

Interviews with Health Care Providers and Parents

Health care providers and parents most frequently reported these nutritional concerns: oral feeding difficulties, growth (underweight/overweight), food insecurity, optimal nutrition, and diet-specific information. Four themes emerged - the need for interdisciplinary care and communication, specialized training, local services, and readily availability resources.

Nutrition Network Dietitian Survey Findings

The majority of Nutrition Network dietitians in the study work at WIC, and on average see up to 10 CYSHCN per month. Community dietitians most frequently provide nutrition education, while clinical dietitians working in hospital or neurodevelopmental settings most frequently provide medical nutrition therapy. Hospital-based dietitians most often receive referrals from hospital-based providers and primary care providers, whereas non-hospital-based dietitians are more likely to receive referrals from primary care providers, WIC, other dietitians, and parents. All dietitians reported not receiving referrals from any source. Forty-five percent of Nutrition Network dietitians surveyed indicate they have capacity in their workload to see more CYSHCN, but do not receive the referrals required to get them scheduled.

CYSHCN Population Estimates within the WIC Program

Twenty-six percent of the infants and children in the Washington State WIC Program may have special health care needs requiring additional nutritional or feeding assistance, particularly among preterm birth and low/very low birth weight children. CYSHCN training for WIC

dietitians on the nutrition needs and common feeding difficulties of these particular CYSHCN populations is beneficial.

WIC Dietitian Survey Findings

Slightly more than half of the WIC Dietitian survey respondents report seeing fewer than 100 WIC clients per month, with the remaining serving more than 100. The majority of WIC dietitians surveyed see up to 20 CYSHCN each month. Almost two-thirds of WIC dietitians in the study refer CYSHCN for nutrition follow up to a dietitian outside of WIC, most often those that work in a hospital-based outpatient setting. The remaining WIC dietitians provide all the nutrition follow up themselves and/or provide detailed nutrition instructions to the primary care provider.

Summary

Four gap areas emerged as a result of the needs assessment: expand nutrition coordination systems and referral processes, address nutrition workforce shortages and development needs, create methods for quantifying and tracking the statewide population of CYSHCN with nutritional needs, and facilitate innovative solutions for nutrition access (telehealth and medical home models). If these gaps are addressed this could have a positive impact on the nutrition system of care in Washington for CYSHCN and their families.

The voices of parents of CYSHCN and health care providers surveyed as part of this needs assessment clearly captured the role and work of pediatric dietitians for CYSHCN. It was clear that pediatric dietitians are valued by families and other health care disciplines as an important part of the interdisciplinary care of CYSHCN. Washington's well established CYSHCN Nutrition Network is an advantage as we work to improve nutrition services for this population within the state.

Full Report

Background

According to 2018 national survey data, an estimated 19% of children (311,138 children) in Washington State have special health care needs.[1] Children and youth with special health care needs (CYSHCN) are defined as children ages 0-21 years "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[2] CYSHCN are a diverse group with a variety of health needs and trajectories. Families of these children are managing complex health conditions and treatments that impact growth, affect appetite, coincide with feeding difficulties, can result in drug-nutrient interactions, and disrupt digestion and absorption of essential nutrients. In many situations, these children can require partial or total dependence on enteral (either oral or "feeding tube") or parenteral (intravenous) nutrition support to meet their nutritional needs.[3]

It is estimated that up to 40% of CYSHCN have nutrition risk factors necessitating a referral to a registered dietitian nutritionist for a nutrition assessment and intervention. These risk factors may be even higher in certain subgroups.[4,5] For example, a survey of children birth to age 3 years with developmental delays in an early intervention program found that 70-90% had one or more nutrition risk factors.[6] Another example is from a recent study which found that 70.4% of children with autism have atypical eating behaviors compared to 4.8% of typically developing children.[7]

In general, CYSHCN are at increased risk for the following nutrition related problems:

- Dental caries (tooth decay)
- Delayed growth
- Poor or excessive appetite
- Underweight or overweight
- Altered energy or nutrient needs
- Drug-nutrient interactions
- Inadequate or excessive nutrient intake
- Elimination problems (constipation/diarrhea)
- Delays in feeding progression, oral/motor problems, and altered feeding interactions[3]

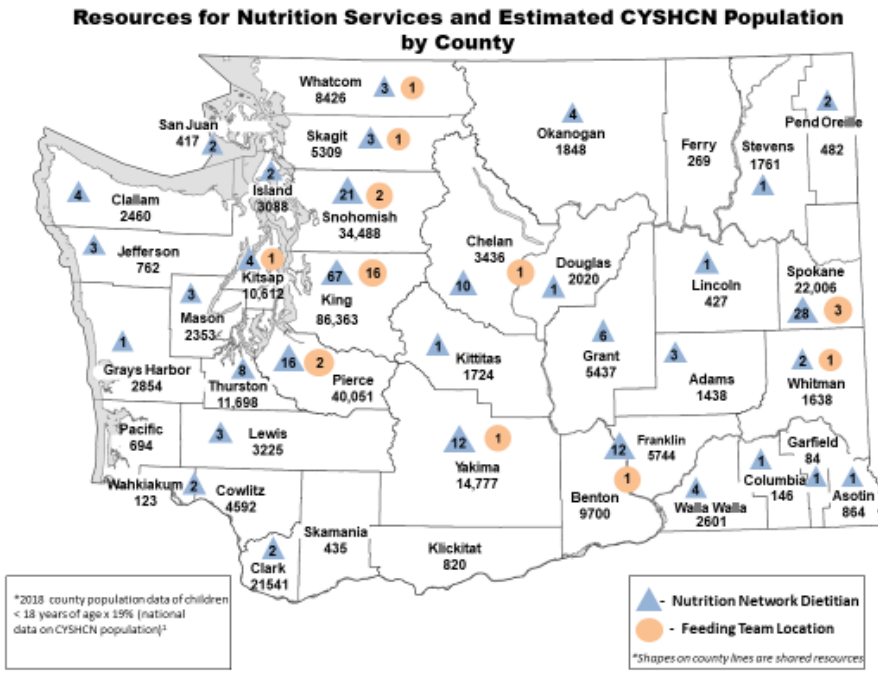
According to the Academy of Nutrition and Dietetics, nutrition services provided by registered dietitian nutritionists (RDNs) are an essential component of comprehensive care for CYSHCN. "Timely and cost-effective nutrition interventions can promote health maintenance and reduce risk and cost of comorbidities and complications. Registered dietitian nutritionists with expertise and training in this area are the best prepared to provide appropriate nutrition

information to promote wellness and improve quality of life."[3] For the remainder of this report, registered dietitian nutritionists (RDN) will be referred to as dietitians.

Washington State began to address CYSHCN access to nutrition services in 1982 through a contract with the University of Washington Clinical Training Unit. In 1987 a three-day training session focused on the unique nutrition needs of the CYSHCN population was developed for dietitians. The eight participating dietitians became the first members of the Washington Nutrition Network for CYSHCN. Today the Network has grown to 207 dietitian members and 30 interdisciplinary feeding teams. The group receives state and federal maternal and child health funding for member training, continuing education opportunities, networking, a member list-serve, and technical assistance. Interdisciplinary feeding teams can include dietitians and feeding therapists (typically speech language pathologists or occupational therapists) and often additional health providers such as physicians, registered nurses, lactation consultants, nurse practitioners, social workers, and/or licensed mental health professionals.

County population estimates for CYSHCN indicate that 19% of children <18 years of age in Washington State have special health care needs.[1] In Figure 1, preliminary estimates of the number of CYSHCN per county are overlaid with available Nutrition Network dietitian and feeding team resources to visually demonstrate gaps in access. Four counties, Pacific, Skamania, Klickitat, and Ferry, have no Nutrition Network dietitian members. This means an estimated 2,219 CYSHCN in these counties are without access to nutrition services in their local area. CYSHCN living in counties on the Olympic Peninsula and in the southwestern and northeastern corners of the state have to travel the furthest distances for access to a feeding team.

Figure 1



Objectives and Methods

The goals of this assessment are to create a common understanding of the role and job responsibilities of pediatric dietitians for CYSHCN and provide information to partners on their contribution to health outcomes of the CYSHCN population. The gaps in services and needs identified by this assessment will inform the future work of the CYSHCN Program and Clinical Nutrition Consultant.

In 2017, the Clinical Nutrition Consultant within the Washington State Title V CYSHCN Program reached out to health care providers, dietitians, and families of children with special healthcare needs across the state for their input on nutrition services for CYSHCN. Both qualitative and quantitative information was collected and analyzed. Table 1 shows the mixed method, multi-source data collection and sample.

- Health care providers were recruited by flyer and 11 completed key informant phone or email interviews.
- Parents were also recruited by flyer and 19 participated. Nine completed individual phone interviews and 10 participated in a focus group.
- Two separate distinct surveys were sent via email to dietitian groups in Washington State. 70 dietitian members of the Nutrition Network completed the first survey, and 60 dietitians working at WIC clinics completed the second survey.
- Existing data on nutrition risk criteria from WIC was used to estimate the number of CYSHCN seen at Washington State WIC clinics.

Table 1: Data collection

Source	Recruitment Method	Responses	Counties/Regions represented*	Description
Nutrition Network Dietitian Survey	Email to 207 members	70	29 (75% of WA counties)	Survey of dietitians treating CYSHCN in WA state
WIC Dietitian Survey	Email to ~120 dietitians	60	26 (67% of WA counties)	Survey of WA state WIC dietitians
Health Care Provider Interviews	Recruitment flyer sent via email to partners**	13 completed interviews, 11 included in the analysis	All 4 regions represented	2 hospital-based pediatric physicians, 3 public health nurses, 2 speech language pathologists (1 hospital-based and 1 community), and 4 community setting occupational therapists
Parent Individual Interviews	Recruitment flyer sent via email to partners***	22 responses with 9 completed interviews	NW, SW, and Central Regions	Represented a variety of conditions: cardiac, autism spectrum disorder, cancer, neuromuscular conditions (e.g. cerebral palsy), syndromes (e.g. Praeder Willi, Down Syndrome, fetal alcohol syndrome, other) allergy, failure to grow, feeding difficulties, prematurity, inborn errors of metabolism
Parent Focus Group	Recruitment flyer sent via email to partners***	10 participants	East Region	Survey of dietitians treating CYSHCN in WA state

* all survey groups (dietitians, health care provider, and parent) had respondents from the following regions: NW, SW, East, and Central

** Medical Home Partnerships, Local Health Jurisdiction (LHJ) CYSHCN Coordinators, WA Chapter of the American Academy of Pediatrics, Nutrition Network, Neurodevelopmental Centers, University of Washington and Overlake Neonatologists

*** Parent 2 Parent (P2P), LHJ CYSCHN Coordinators, Medical Home, Various Parent Groups, Nutrition Network, Seattle Children's CYSCHN program

Note: From Dietitian surveys (Nutrition Network and WIC) 5 counties (13%) were not represented: Cowlitz, Columbia, Lewis, Skamania, and Wahkiakum.

Results

Interviews with Health Care Providers and Parents

Among those health care providers interviewed, the most frequently described nutrition concerns encountered in their practice were oral feeding difficulties, growth alterations, and food insecurity. Parents most frequently reported concerns about their child's growth, what to feed their child for optimal growth, and diet information specific to their child's medical condition. Table 2 shows that oral feeding difficulties and growth alterations were the most common nutrition concerns prompting a health care provider to refer a child to a dietitian.

Table 2: Top nutrition concerns for CYSHCN

Health Care Providers	Parents
Oral Feeding Difficulties*	Growth (specifically underweight or overweight)
Growth (specifically underweight or overweight)*	What to feed child to optimize growth
Food Insecurity	Diet information specific to child's medical condition

* the top two nutrition concerns to prompt a referral to a dietitian, as reported by health care providers during interviews

Health care provider and family feedback

Throughout interviews with both health care providers and parents there were four distinct themes that resonated with the groups: interdisciplinary care and communication, specialized training, local services, and readily availability resources.

1. **Interdisciplinary care and communication:** The medical system works well for patients and children when there is interdisciplinary care and good communication between health care disciplines. Dietitians are an important part of interdisciplinary care for CYSHCN. Nutrition referrals are timelier when newborn screening identifies an issue, or when a dietitian is available on site and known by the referring physician.

I have many, many stories of how I would never have been able to successfully get that child off of a tube into oral feeding if I didn't have a dietitian standing arm and arm with me.
--Pediatric Speech Language Pathologist

Ongoing treatment, having an interdisciplinary team working together worked well.
--Parent of a child with a metabolic disorder

2. **Dietitians with specialized training:** There is a difference in care that a child receives from a dietitian versus a dietitian with specialized training in CYSHCN. Both health care providers and

parents described positive experiences and effective care when working with dietitians with specialized CYSHCN training.

Doctors aren't always familiar with the elemental formula the child needs. And so having someone who is trained in nutrition has been really helpful for us… Someone who is well versed in elemental formula and… different avenues when insurance won't cover your product.

--Parent of a child with eosinophilic food allergy

Without the partnership with our dietitian, I would be lost with what to feed her and how to ensure she was getting the things she needs that were safe for her body.

--Parent of a child with a metabolic disorder

3. **Local services:** More dietitians working in local communities need specialized training to see CYSHCN. This reduces travel for families, and decreases the burden on hospital-based pediatric dietitians within our state. As the data suggest, when parents and health care providers are able to get specialized nutrition services locally they are more likely to have positive experiences and improved health outcomes.

Further from metropolitan areas, it's real hard to find a person that…knows how to manage these complex kids that are living and going into a community so much sooner than what they used to on a combination of enteral and oral feedings. A dietitian is really critical in the management of these kids.

--Pediatric Speech Language Pathologist

My local experience here was amazing. She got diagnosed in the NICU, we had an NG tube for about a month. When we left… we had a lady [dietitian] coming out every couple days weighing her and adjusting her calorie count and letting us know what volume to put in here. And all of that stuff in the beginning was amazing.

--Parent of a preterm baby with medical complexity

4. **Resource availability:** Our medical system is complex and can be a burden for families navigating it. Resources on nutrition services for CYSHCN need to be readily available to health care providers and parents across Washington State.

The frustrating part was that our local pediatrician wasn't aware of where to start when there was a nutrition concern. And we had to go all the way to Seattle and there weren't any options that were given to us that were going to be any closer.

--Parent of a child with autism

I wish more [physician] offices had a relationship with dietitians so if you do need a referral it can happen a bit faster.

--Parent of a child with eosinophilic food allergy

I am not sure where to refer for nutrition services.

--Private Practice Speech Language Pathologist

Throughout the interviews and focus group discussion participants described how pediatric dietitians help children with special needs achieve their health goals, including weaning from a feeding tube, coordinating insurance coverage, facilitating prescriptions and delivery of specialty formulas needed for treatment of uncommon health conditions, and nutrition education. These data indicate that pediatric dietitians are valued by families and other health care disciplines as an important part of the interdisciplinary care of CYSHCN.

Nutrition Network Dietitian Survey Findings

As of April 2019 there are 207 dietitian members of the WA Nutrition Network. These dietitians have all participated in an introductory training on the unique nutrition needs of CYSHCN. As part of the Network they also have access to annual continuing education and technical assistance from experienced dietitians in the specialty of CYSHCN. For this needs assessment, Nutrition Network dietitians were surveyed about where they work, how many CYSHCN they see, what type of nutrition services they provide, and their billing and referral processes. Nutrition Network representatives from 29 of the 39 counties responded to the survey. There were no responses from Nutrition Network members in the following 10 counties: Columbia, Cowlitz, Grays Harbor, Kittitas, Lewis, Mason, Pacific, Skagit, Skamania, and Wahkiakum.

Where Nutrition Network dietitians see CYSHCN

The majority of Nutrition Network dietitians that completed our survey work at WIC (48%), followed by outpatient hospital based clinics (21%), and inpatient hospitals (19%) (Table 3).

Table 3: Work setting of Nutrition Network dietitians

Setting	Percentage
WIC	48
Hospital based clinic-outpatient	21
Hospital based-inpatient	19
Early intervention	19
Public health department	18
Other Outpatient Setting	18
Home infusion	13
Neurodevelopmental centers	8
Other	6
Early Childhood Education and Assistance Program	3
Head Start	3

Note: Total exceeds 100% due to some individuals working in multiple settings

The Nutrition Network dietitian population is relatively balanced. Of those who responded to the survey, 40% of members work in a hospital-based setting compared with the majority who work in community nutrition settings, most commonly WIC. This is representative of the proportion of pediatric dietitian job opportunities.

Number of CYSHCN seen by Nutrition Network dietitians

Table 4 describes the number of CYSHCN seen by Nutrition Network dietitians (n=106*) per setting (n=10) and percentage seen per month. The majority of Nutrition Network dietitians see up to ten CYSHCN per month (Table 4). Dietitians working in an inpatient hospital, outpatient hospital-based clinic, or home infusion company were the most likely to report seeing greater than 10 CYSHCN per month. Many settings have high percentages of dietitians reporting they see no CYSHCN. This could be due to small sample size in several of the settings as well as variability in the positions that dietitians hold within these settings, such as leadership or administrative roles.

Table 4: Number of CYSHCN seen by Nutrition Network dietitians by work setting

Setting	1-10 per month	10-50 per month	>50 per month	None
Inpatient Hospital Setting (n=12)	63%	15%	1%	21%
Outpatient Hospital-Based Clinic (n=13)	75%	13%	0%	12%
Early Intervention (n=12)	40%	6%	0%	54%
Head Start (n=2)	100%	0%	0%	0%
Early Childhood Education and Assistance Program (n=2)	75%	0%	0%	25%
Neurodevelopmental Center (other than Birth to 3) (n=5)	55%	5%	0%	40%
WIC (n=30)	85%	7%	5%	3%
Public Health Department (n=11)	75%	2%	0%	23%
Home Infusion (n=8)	69%	19%	12%	0%
Other Outpatient Setting (n=11)	64%	2%	0%	34%

*Note: n=106 which exceeds total number of 70 dietitians that completed the survey due to some individuals working in multiple settings

Many dietitians seeing CYSHCN work in multiple settings either as part of their single position or by holding multiple part-time positions. The large number of work settings demonstrates that CYSHCN utilize a variety of health services and programs which employ dietitians. This highlights the need for nutrition care coordination and communication between hospital and community dietitians.

Type of nutrition services provided by Nutrition Network dietitians

On average, Nutrition Network dietitians primarily provide nutrition education (88%) and medical nutrition therapy (72%) services to the children and families they see (Table 5). All of the Head Start, ECEAP, and WIC dietitians surveyed provide nutrition education, followed closely by >90% of dietitians working in an outpatient hospital-based clinic, early intervention, public health department, or non-hospital-based outpatient setting. Greater than 90% of surveyed dietitians working in an inpatient hospital setting and at neurodevelopmental centers provide medical nutrition therapy, followed closely by 80-90% of dietitians working at a home infusion company, outpatient hospital-based clinic, and early intervention.

Table 5: Most common services provided by Nutrition Network dietitians

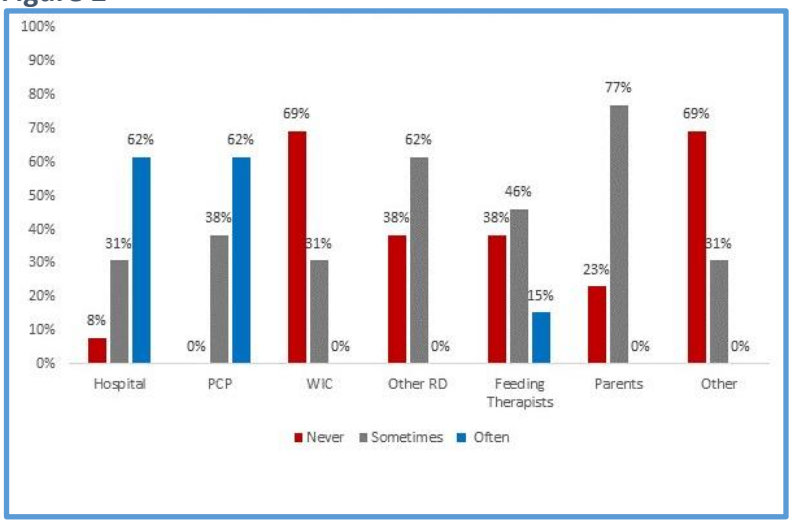
Service	Percentage
Nutrition Education	88
Medical Nutrition Therapy	72
Screening and Referrals	30
Provision of enteral supplies/products	17
Program Administration	8

Provision of disease specific nutrition education and medical nutrition therapy is what distinguishes the Registered Dietitian Nutritionist from other nutritionist professions. These data suggest that Nutrition Network dietitians are practicing dietetics within their professional scope and at the height of their abilities.

Who refers to Nutrition Network dietitians?

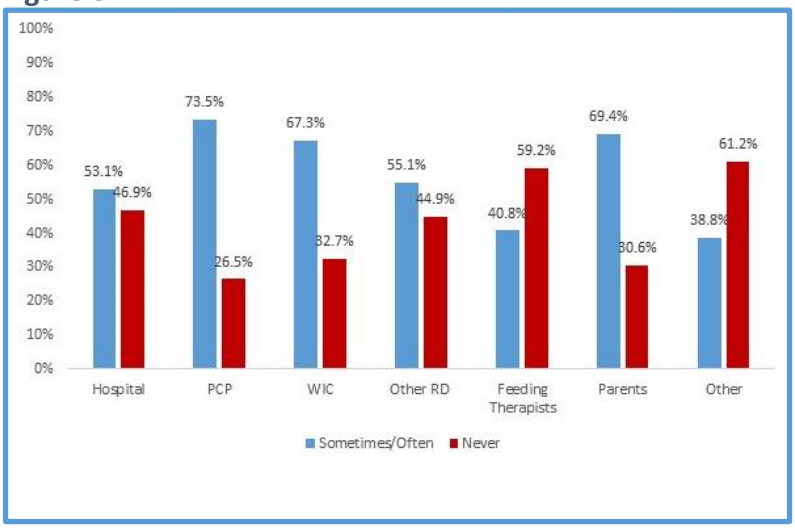
Referrals for Nutrition Network dietitians come from a variety of sources, depending on the location of the dietitian (in-hospital vs. non-hospital-based). Figure 2 shows that hospital-based dietitians most often received referrals from hospital-based providers and primary care providers. They were less likely to receive referrals from WIC, other dietitians, feeding therapists, and parents. In contrast, Figure 3 shows non-hospital-based dietitians were more likely to receive referrals from primary care providers, WIC, other dietitians, and parents. They were less likely to receive referrals from hospital providers and feeding therapists.

Figure 2



Source of referrals to hospital-based dietitians

Figure 3



Source of referrals to non-hospital-based dietitians

These data echo the interdisciplinary care and communication theme heard during health care provider and parent interviews - health care providers are more likely to refer to a dietitian available on site and known by them.

Barriers to accessing Nutrition Network dietitians

Lack of referrals from hospital and primary care providers is the most common barrier for CYSHCN who need access to nutrition services (Table 6). While 45% of Nutrition Network dietitians said they have capacity in their workload to see more CYSHCN, they do not receive

the referrals required to get them scheduled. Nutrition Network dietitians reported they also need more time (31%) and funding (29%) to see more CYSHCN.

Table 6: Barriers for Nutrition Network dietitians to see more CYSHCN

Barrier	Percentage
Referrals	45
Time	31
Funding	29
Training	15
Management approval	15
Other	11

During parent interviews it emerged that many community health care providers are not aware of where to refer CYSHCN for nutrition services. Combined with a large percentage of Nutrition Network dietitians who require referrals in order to provide needed services, this points to a gap in the system. To ensure health care providers have the referral network in place, perhaps referrals for nutrition services could be addressed in coverage requirements by insurance companies.

Nutrition Network dietitians and billing for nutrition services

Survey responses indicate a general lack of knowledge regarding billing practices. Table 7 demonstrates that in general, many dietitians working in multiple settings were unfamiliar with reimbursement for their services. Dietitians working in early intervention (25%), WIC (63%), or public health (45%) settings had some knowledge that their services were not reimbursed compared to dietitians working in inpatient (17%) or outpatient hospital (8%) settings and ECEAP (0%). Most dietitians working in an inpatient hospital setting (50%), Head Start (50%), and ECEAP (100%) did not know if they could bill for their services. This may be explained by the fact that many of the survey respondents work for large organizations and are themselves disconnected from billing processes.

Table 7: Reimbursement knowledge of Nutrition Network dietitians

Setting	Not reimbursed	Don't know
Inpatient Hospital	17%	50%
Outpatient Hospital-Based Clinic	8%	15%
Early Intervention	25%	8%
Head Start	50%	50%
ECEAP	0%	100%
Women, Infants, and Children	63%	10%
Public health	45%	9%

This overall lack of knowledge on reimbursement of nutrition services within the nutrition profession demonstrates another gap that needs to be addressed in order to better serve families as they navigate our complex healthcare system. Dietitians who understand service reimbursement in the settings they work can improve the system in a number of ways. First, they may better assist families and health care providers with referral requirements. It could also lead to more dietitians entering private practice or offering telemedicine services in underserved areas of the state. Additionally, this knowledge may encourage dietitians to participate in larger numbers in policy change around health care coverage of nutrition services.

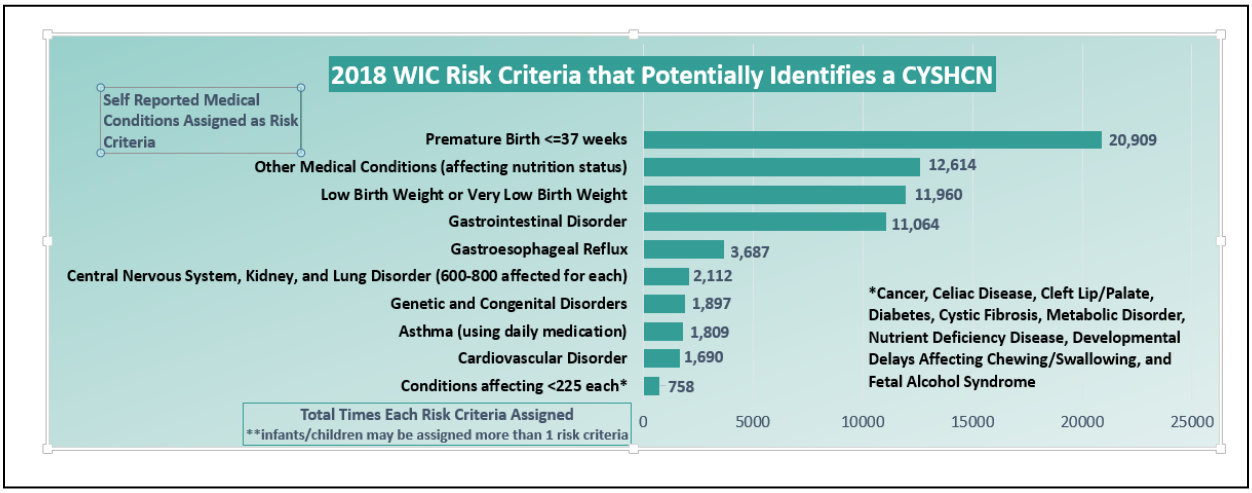
Determining CYSHCN Population Estimates within the WIC Program

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), administered through the U.S. Department of Agriculture, provides federal grants to states. WIC supports low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and their infants and children up to age five who are found to be at nutritional risk. WIC services include health assessment, health and social service referrals, focused nutrition education and breastfeeding support, and specific nutritious foods for those at risk. There are 70 nutrition risk criteria used by WIC to determine eligibility, nutritional risk, and focused education or referral interventions. Information used to assign risk criteria is self-reported. As part of this needs assessment, data on participant risk criteria was analyzed in order to estimate the number of CYSHCN participating in the WIC Program.

To estimate the number of CYSHCN seen at the WIC Program, 20 of the 70 risk criteria were selected by the CYSHCN Clinical Nutrition Consultant based on the criterion's ability to potentially identify a child with special health care needs. Data were compiled on the number of infants and children seen in WIC clinics in 2018 using these 20 identified risk criteria. Of the

180,689 infants and children participating in the Washington State WIC Program in 2018, 46,574 were assigned 1 or more of these risk criteria. Only one risk criteria is needed to indicate a special health care need, however many infants/children were assigned more than one when appropriate. These data indicate that up to 26% of infants and children in the Washington State WIC Program have special health care needs. This is 7% greater than national data which shows that 19% of children <18 years of age in Washington State have special health care needs.[1] This suggests that the Washington State WIC Program serves a population of infants/children with a higher concentration of CYSHCN than the state overall.

Figure 4*



*The 20 specially selected risk criteria and the frequency in which they were assigned to WIC participants are shown in Figure 4. For visibility, several of the risk criteria that were infrequently assigned were bundled together.

As demonstrated in Figure 4, the four risk criteria most commonly assigned by WIC that are suggestive of a CYSHCN are:

- Prematurity (<=37 weeks gestation)
- Other medical conditions affecting nutritional status
- Low birth weight or very low birth weight
- Gastrointestinal disorder

Compared to many of the 20 risk criteria indicating a special health care need, these four frequently assigned criteria are very broad. For example, “Other medical conditions that affect nutritional status” does not have a precise definition in the WIC Manual. Therefore, this “catch all” category for a variety of conditions may not be effective in recognizing a special health care need. Compared to the other more specific risk criterion indicating a special health care need, it is more likely that children assigned one of these four frequently assigned but broad criteria, capture children along a spectrum. This spectrum varies from a healthy child, to one at risk for future health care needs, to a child currently experiencing significant special health care needs

and interventions. Therefore it is likely that many children with these four broad risk criteria may not be followed by a dietitian in any other setting. Appointments with WIC dietitians are vital as they may be the only touchpoint these children and their caregivers have with a nutrition professional. These appointments can result in much needed nutrition intervention, or in more severe cases, a referral and connection to other needed health care providers to address concerns. This highlights the benefit of CYSHCN training for WIC dietitians, particularly education focused on the nutrition needs of preterm and low/very low birth weight infants, and the feeding challenges commonly seen in these specific populations.

WIC Dietitian Survey Results

60 dietitians that work in WIC clinics across the state completed a survey for this needs assessment. They were surveyed about how many CYSHCN they see compared to their overall caseload, their documentation of high risk clients, and if/where they refer CYSHCN for nutrition follow up. WIC representatives from 26 of the 39 counties responded to the survey. There were no responses from WIC dietitians in the following 13 counties: Asotin, Clallam, Columbia, Cowlitz, Douglas, Franklin, Jefferson, Lewis, Lincoln, San Juan, Skamania, Spokane, and Wahkiakum.

Of the 60 WIC dietitians participating in the survey, slightly more than half reported seeing fewer than 100 WIC clients per month, with the remaining serving more than 100. The majority of WIC dietitians see up to 20 CYSHCN each month. WIC dietitians document appointments with clients that are assigned a high nutrition risk criteria by preparing a High Risk Care Plan (HRCP). Table 8 demonstrates the frequency with which HRCP are developed each month by the WIC dietitians surveyed. Most WIC dietitians (42%) surveyed reported completing 10-50 HRCP per month. HRCPs are created for any WIC participant (including pregnant women) with high nutrition risk. Therefore, CYSHCN are just a portion of the WIC participants who require preparation of a HRCP.

Table 8: Frequency of High Risk Care Plan Development by WIC Dietitians

1-10 per month	10-50 per month	>50 per month	None
27%	42%	30%	1%

For ongoing nutrition follow up, almost two-thirds of WIC dietitians refer CYSHCN to a dietitian outside of WIC, most often those that work in a hospital-based outpatient setting. The remaining WIC dietitians in the study provide all the nutrition follow up themselves and/or provide detailed nutrition instructions to the primary care provider. This variability is likely related to many factors and client dependent. It speaks to the diversity of the nutrition needs of the CYSHCN population. Another factor may be the type of nutrition intervention a WIC dietitian may feel confident in providing, or not, depending on their experience and training.

Other factors could include time constraints of appointments, children with previously established dietitian care outside of WIC, etc.

Limitations

The limitations of each results section are listed and described in this section.

Map of CYSHCN population and nutrition services resources

Figure 1 visualizes location access for CYSHCN to dietitians and feeding teams but does not assess access in any other way. Whether or not the nutrition resources are adequately meeting the needs of the county population in terms of availability of appointments, insurance acceptance, and skills of the teams and Network dietitians, this information was not gathered as part of this needs assessment. Future work in this area would be beneficial.

Health care provider and parent interviews

No general pediatricians or family practice care providers working in community or rural settings were interviewed for this needs assessment. Additionally no community dietitians participated in interviews. We presume this was due to a lack of response to the recruitment flyers by these stakeholders. Many of the families surveyed reported community primary care providers lacked knowledge about local nutrition resources. However, our needs assessment did not capture the perspectives of these health care providers, so we were unable to follow up on those reports.

Dietitian surveys

There was no representation of dietitians from either the Nutrition Network or WIC in this needs assessment from the following 5 counties: Columbia, Cowlitz, Lewis, Skamania, and Wahkiakum.

The WIC dietitian survey asked questions about the frequency in which they develop High Risk Care Plans. High Risk Care Plans are developed by WIC dietitians for infants, children, and also high risk pregnant and post-partum women. They are developed for a WIC participant that is assigned any of the 70 high risk criteria, not just the 20 risk criteria selected for their ability to identify a CYSHCN. Therefore data in this assessment on frequency of HRCP development at WIC should not be used as a proxy to estimate how frequently WIC dietitians are seeing CYSHCN for appointments.

CYSHCN population estimates within the WIC Program

There are limits to using WIC risk criteria to determine the actual number of CYSHCN seen in the WIC program. Risk criteria selection is influenced by staff choice and proficiency, and when used as a proxy has the potential to both over and under capture CYSHCN.

Why WIC risk criteria methods could underestimate CYSHCN seen at WIC:

- Inaccurate risk criteria selection by WIC staff
- Omission of a risk criteria in data selection that may have captured CYSHCN
- Risk criteria selection relies on the accuracy of the child's caregiver self-reporting a diagnosis by a medical professional

Why WIC risk criteria methods could overestimate CYSHCN seen at WIC:

- Inaccurate risk criteria selection by WIC staff
- False positives, particularly within the broad risk criteria such as "gastrointestinal disorder" or "other medical condition" (impacts nutritional status)
- Risk criteria selection relies on the accuracy of the child's caregiver self-reporting a diagnosis by a medical professional

Summary with Recommendations for Future Work

The voices of parents of CYSHCN and health care providers that were surveyed as part of this needs assessment most clearly captured the role and job responsibilities of pediatric dietitians for CYSHCN. Throughout the interviews and focus group discussion participants described how pediatric dietitians have helped a child with special needs achieve their health goals. A wide variety of services were described such as assistance in weaning a child from a feeding tube, coordinating insurance coverage, facilitating prescriptions and delivery of specialty formulas needed for treatment of uncommon health conditions, and nutrition education on topics that range from selective eating habits to metabolic conditions that severely restrict protein intake. It was clear that pediatric dietitians are valued by families and other health care disciplines as an important part of the interdisciplinary care of CYSHCN.

A strength identified as part of this needs assessment is Washington's CYSHCN Nutrition Network. This network is unique to our state and has been in place for over 30 years. Having such a well-organized and funded system for training dietitians specializing in CYSHCN nutrition is critical to improving nutrition services for this population within our state.

Following completion of this needs assessment and analysis of the data, four areas emerged as gaps that, if addressed, could have a positive impact on the nutrition system of care in Washington for CYSHCN and their families. The four areas of need are:

- Expand nutrition coordination systems and referral processes
- Address dietitian workforce shortages
- Create systems for quantifying CYSHCN with nutrition needs
- Facilitate innovative solutions for nutrition access (telehealth and medical home models)

The WA Department of Health CYSHCN Clinical Nutrition Consultants who completed this needs assessment suggest ways to address these four areas of need. These suggestions are designed as a starting point for stakeholders to discuss and prioritize.

1. **Expand coordination, communication, and referral systems between hospital-based and community-based dietitians and other health care providers.**
    a. Educate health care providers on available nutrition and feeding screening tools. These tools can help them determine when to refer to a child to a dietitian, and how to find a local dietitian with CYSHCN expertise.
    b. Improve communication, collaboration, and care coordination between hospital-based pediatric dietitians and community-based pediatric dietitians.
    c. Explore methods of reimbursement for care coordination between hospital-based and community-based dietitians.
    d. Partner with Washington State Academy of Nutrition and Dietetics (WSAND) to improve public understanding of the expertise of the dietitian health care profession and their role in improving health outcomes.

2. **Address dietitian workforce shortages with professional development opportunities and system changes at the state level.**
    a. Survey existing Nutrition Network members on their current practice setting and ability to accept CYSHCN referrals. This will improve identification of underserved areas within the state, not based solely on the location of members, but on CYSHCN's ability to access a dietitian in their local area.
    b. Target invitations for Nutrition Network training to community pediatric dietitians in areas of the state with low access to nutrition services for CYSHCN. Use contract funding to assist financially as needed.
    c. Explore opportunities to partner with WIC on CYSHCN workforce development and innovative solutions for improving access to nutrition services in rural areas of the state.
    d. Work with partners at DOH and HCA to speed the state dietitian credentialing process. Faster credentialing of new hires means hospital and community based dietitians can bring medical nutrition therapy and nutrition education/counseling services to their communities more swiftly.

3. **Create systems for quantifying and tracking Washington's population of CYSHCN with nutritional needs.**
    a. Partner with WIC to explore improved methods of estimating CYSHCN participation in the WIC Program.

b. Explore strategies for quantifying CYSHCN in our state with nutritional needs using diagnosis code data.

4. **Facilitate innovative solutions to improve access to CYSHCN dietitians such as telehealth or inclusion in medical homes.**
    a. Facilitate connections to support and build telehealth nutrition services (financial, infrastructure, policy) to bridge current workforce gaps in nutrition services for CYSHCN.
    b. Develop metrics for measuring costs and outcomes of pediatric dietitian inclusion in pediatric medical homes.

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