WA CMC CoIIN: Birth to One Program

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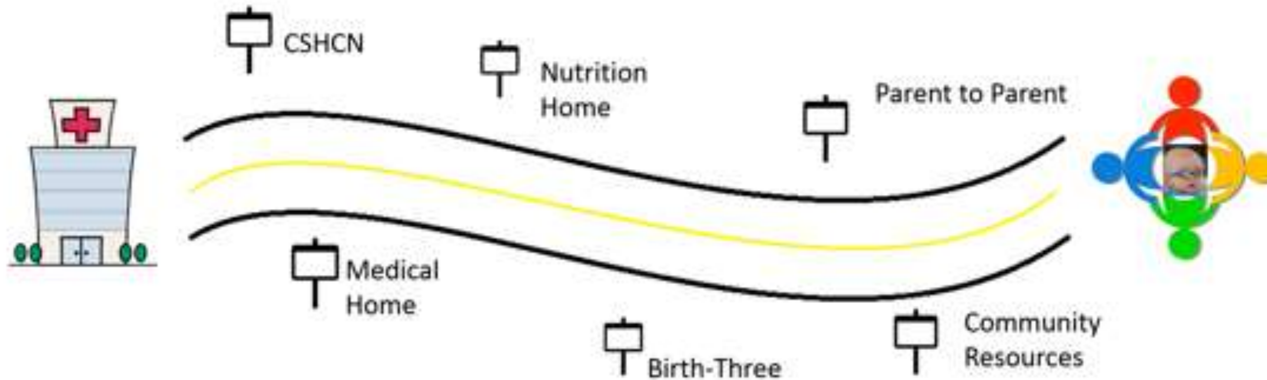
Washington State Birth to One Roadmap
Building a Strong Foundation for Children with Special Health Care Needs



CSHCN. ESIT. SSI. P2P. PCP. DME. FRC. Alphabet soup, for the parent of an infant with complex needs. Everyone wants to help, but the system is fragmented, leaving parents with the burden of connecting the dots, remembering next steps, and communicating between multiple agencies. WA State Birth to One CMC CoIIN will improve quality and cost outcomes for infants with complex needs by:

- Engaging with parents prior to discharge and assisting them in navigating community resources once they are home
- Assuring infants are supported by a medical home, and their developmental and nutritional needs are met
- Encouraging parents to seek out peer support
- Facilitating communication between providers and community agencies
- Improving the cohesiveness of the system of care supporting infants with complex needs and their parents.

WA CMC CoIIN ("Birth to One") is a collaboration of:

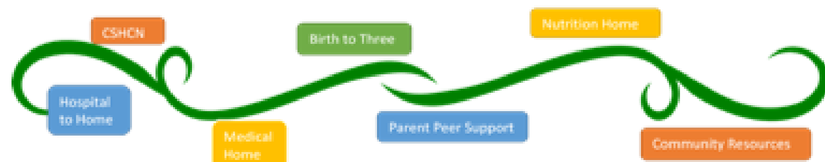
- Seattle Children's (Lead)
- PAVE- Partnerships for Action Voices for Empowerment (PAVE) Family to Family
- WA Title V Children and Youth with Special Health Care Needs (CYSHCN) program
- UW Center on Development and Disability
- WA State Medical Home Partnerships Project for CYSHCN

Intervention:

- Single point of contact community care coordinator for up to one year, partnered with a parent peer support specialist, for infants discharged from the NICU.
- Personalized roadmap with family description, all care and service provider contacts and follow up
- Activation of all referrals (specialty clinic, PHN, PCP, Early intervention, nutrition)
- Virtual parent peer learning community

Birth to One

Washington State Children with Medical Complexity Collaborative Innovation and Improvement Network (CMC CoIIN)



What is Birth to One?

Birth to One is a collaborative of organizations that provide parent support, primary care medical home and nutrition consultation, and local/state level support for children with special health care needs (CSHCN). This program was carefully designed for families of newborns settling in at home after being discharged from the hospital. We acknowledge navigating multiple resources and services for your child may be a complicated process. We are here to help.

Who qualifies?

Infants 0-4 months with special health care needs.

To Learn More:

- 206-987-2754 office
- 206-473-8680 cell
- Gabriela.Chavarria@seattlechildrens.org

What we will do for you

Families will receive a written "roadmap" with the current and future services their child is receiving including their contact information and explanations of what each service provides, based on the child's geographic area. Here is how it works:

- When you enroll, you will be contacted by a Community Resources Care Coordinator who will get to know your child and family
- You will be provided with a personalized "roadmap" based on the services your child is receiving
- We will connect you to other resources based on any needs you identify
- We plan to check in with you periodically to revisit and update your personalized roadmap

What we are asking of you

- Permit us to talk with members of your child's care team to assure that everyone is communicating effectively and your role as a parent or caregiver is being valued. As we document your child's roadmap journey, we will review with you what is working and what can be improved.
- Respond to specific questions about your child's current services as well as any additional resources you identify throughout the process. This is to assure your child's care team is meeting your needs.
- Participate in a national survey that will measure gaps and improvements with a goal to help children and families like yours in the future.
- Accept our 25$ per survey as a thank you for your time and participation.

What is a Medical Home?

The doctors and nurses who get to know your child and family at well child checkups and who help you figure out what to do when your child is sick. They will work with you to plan your child's care, tell you about helpful programs, and help you find the right specialists and equipment for your child. A medical home is not a building or place; it extends beyond the walls of your doctor's office. A medical home builds partnerships with clinical specialists, your family, and community resources.

What is Children with Special Health Care Needs/Public Health Nursing?

All children (0-18yo) who are at risk for or have a health/ developmental condition, and the family needs help with accessing local resources, are eligible for coordination of care, regardless of income. Services are usually provided by your local health department, and may be offered via telephone or through limited home/community visits. Varies by county.

What is Birth to Three?

Sometimes known as B-3, EI, DDA, or ESIT. Some children, due to conditions noticed at birth, special needs, or developmental delays, may risk missing important learning and developmental milestones. Early Intervention helps keep these children on a path to making the most of abilities and skills developed during the early years. Families also play a critical role in their child's development. EI services support families to help their child's healthy development and are designed to enable young children to be active, independent and successful members in a variety of settings—home, childcare, preschool, and their communities. An EI agency will usually call you, get to know your child, and then set up an evaluation that determines what therapy services your child qualifies for: speech and language pathology (SLP), occupational therapy (OT), physical therapy (PT) and/or feeding therapy. You may also be assigned to a Family Resources Coordinator (FRC) in this agency that can help you access local resources.

What is Feeding/Nutrition Support?

Sometimes called Nutrition Home. Children with special health care needs (CSHCN) are at increased risk for nutrition-related problems. About 40% of CSHCN have nutrition risk factors that could be helped by referral to a registered dietitian (RD). Preventive nutrition services, as well as intervention for identified problems, can help assure a well-nourished child who is healthy, can participate in education and therapy programs, and is better able to function in all activities of daily life.

What is Parent Support?

Personal support from another parent, who has a child with similarly challenging or fragile needs, can be helpful in coping with challenging experiences. Parent to Parent (P2P) can connect you with another parent of a child with the same or similar diagnosis (volunteer peer mentors).

What are Community Resources?

Agencies that provides wrap around services to CSHCN and their families, helping to meet a certain need whether it be a referral for application assistance, housing support, health education, cultural advocacy, transportation, financial and/or food insecurity or any other basic needs.

Initial Family Assessment

Initial Family Contact

Assessment:

- ☑ How was your experience from hospital to home?
- ☑ Who supports you with taking care of your child?
- ☑ What are your goals, next steps, need help with?

Referrals:

- ☑ What services have reached out to you?
  - ☑ Early Intervention
  - ☑ Children with Special Health Care Needs (CSHCN) Public Health Nurse
- ☑ Who is your child's home care company?
- ☑ What other referrals were made while you were inpatient?

Medical Home:

- ☑ Who is your child's Pediatrician/clinic?
- ☑ Is there someone who is helping you coordinate appointments?
- ☑ Do you know how to access their after hours, my chart, etc.?

Specialty:

- ☑ What specialty outpatient appointments are scheduled or still need to be scheduled?

Nutrition/Feeding Home:

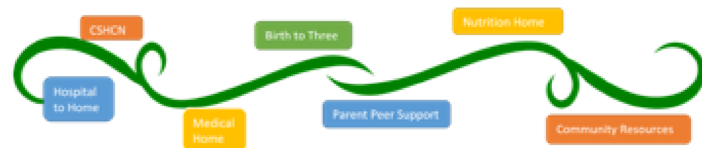
- ☑ Who do you call when you have questions about your child's nutrition, feeding, or diet?

Other Resources:

- ☑ WIC, Transportation brokers, Medicaid Care Management, other basic needs?

Parent Support:

- ☑ Have you been referred to/are you receiving support from any family support organization including Facebook groups, Parents of Preemies, Father's Network, Family Voices, etc.?



DOB

Personal Overview (Resumen del Paciente):
R. es un bebé prematuro de 36 semanas con disfunción alimentaria, hemorragia intraventricular bilateral (Hiv), encefalopatía por hipoxia-isquemia (EHI) y convulsiones. R is an infant boy living in Everett, Snohomish County. Rosendo is a former 36-week preemie with feeding dysfunction, bilateral intraventricular hemorrhage (IVH), hypoxia-ischemia encephalopathy (HIE), and seizures.

Caregiver Contact (Contacto de Padres):

Lenguaje: Triqui Baja (primary), Spanish (secondary)
Madre
Teléfono:
Email

Primary Care Provider/Medical Home (Hogar Medico/Pediatra)

Clínica: Community Health Center (CHC) of Snohomish County- Everett-South Clinic
Dirección: 1019 112th St. SW, Everett, WA 98204
Teléfono: (425) 551-6200
Pediatra: Dr. Yvonne Ma

Specialty Providers (Especialistas Medicas)

Seattle Children’s Hospital: 206-987-2000, Interpreter: 866-583-1527
Patient Navigator: Mica Murray 206-987-8131

Clinic Name (Clínica Especialista)	**Provider (Proveedor)**	**Telephone (Numero de Contacto)**	**Future Appts** (Citas Programados)
Ophthalmology NORTH (oftalmología)	Dr. Carmel Mercado	425-783-6200	2/11/20 2:45pm
Neurodevelopment (Neurodesarrollo)	Dr. William Walker Jenna Szoka, LSW (Trabajadora social); Jennifer Stallings, RD nutricionista)	206-987-2210	2/18/20 10:45am

WA State Birth To One “Roadmap”
Estado de Washington Programa de Nacimiento Hasta Un Año

Neurology (Neurologia)	Dr. Benedetti	206-987-2016	3/13/20 9:30a
Occupational Therapy (terapia ocupacional)	J. Stevenot	206-987-2113	3/20/20 10:00a
Neurosurgery (Neurocirugia)	Dr. Lee	206-987-2016	5/12/20 2:30pm

Roadmap/ Guía de Servicios de Fernanda

Resource (Recurso)	Agency (Agencia)	Contact Info (Info de contacto)	Notes (Notas)
Insurance Coordinator (Coordinadora de seguranza: CHPW)	CHPW Nurse Case Manager	Marlene Norris, RN Ph: (206) 731-7739	
CSHCN PHN (Niños con Necesidades Especiales Complejos, Enfermera Publica)	Snohomish County Public Health (Salud Publica de el condado Snohomish)	Sue Starr, PHN 425-339-5244 sstarr@snohd.org	
Birth to Three or Early Intervention (Programa de Intervención Temprana)	Child Strive Everett	Main: 425-245-8377	FRC: Family Resources Coordinator (Coordinadora de Recursos Familiares) Joelle Friesen 425-231-3349 joelle.friesen@childstrive.org
Seattle Children’s Home Care (Equipo Médico)	Seattle Children’s Home Care	425-482-4000	
Parent Support (Apoyo a Padres)	Arc of Snohomish County	Mely Cervantes mely@arcsno.org ph: 425-258-2459 x114	Rosmeyri Romero

Community Resources (Recursos Comunitarios)	Agency (Agencia)	Contact Info (Info de Contacto)
Schedule Seattle Children’s Hospital Urgent Care appt	https://mychart.seattlechildrens.org/mychart/OpenScheduling	Pedir cita de Seattle Children’s Urgent Care (Centro de Atención Urgente)
Hopelink	Transporte	855-766-7433
WIC	Silverlake Clinic: 1819 100th Pl SE, Everett, WA , 98208	(425) 316-8929

Documentation Process

Philips Population Health Application

Early Intervention Referral	Yes/No	View	Birth to One Roadmap Activation
Early Intervention	Yes/No	View	Birth to One Roadmap Activation
Early Intervention Intake	Yes/No	View	Birth to One Roadmap Activation
Early Intervention Detail	Free Text		Birth to One Roadmap Activation

Birth to One Updates

03-18-2019 01:19 PM

Outreach performed for Communication Documentation on 03-18-2019 . The Phone Call Contact: PCP
Outreach Comment: CC called PCP backline (425) 251-3224 for Renton Pediatrics Associates and spoke to someone who said that having the fax/address/number for Renton or Kent doesn't matter as any records faxed will end up in the pt's chart. CC will relay this to mom at next POC.

delete

Gabriela Chavarria Public

03-26-2019 11:11 AM

Outreach performed for Communication Documentation on 03-26-2019 . The Phone Call Contact: Community Agency
Outreach Comment: CC called Children's Therapy Center Kent 253.854.5660 and spoke to front desk who confirmed they've outreached to family several times and have been unsuccessful so referral will be closing unless family calls them. CC will let mom know at next POC.

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ALERTS

Birth to One Virtual Parent Support : Yes
Birth to One: Enrolled

INITIATIVES

Birth to One Program

ASSESSMENTS

Birth to One Parent Stipend	2019-03-19
Birth to One Roadmap Activation	2019-03-19
Birth to One WA CoIIN survey	2019-01-28
Virtual Parent Support Interest	2019-04-08

CARE PLAN

Goal: Hospital to Home
Supports Problem: Birth to One Roadmap Progress (CCP: Birth to One Roadmap) 100 % Completed
Goal: CSHCN/PHN
Supports Problem: Birth to One Roadmap Progress (CCP: Birth to One Roadmap) 100 % Completed
Goal: PCP/Medical Home

Birth to One Enrollees

Enrollment (Ever Enrolled)

	FY 2019							FY 2020						
	Q2	Q3			Q4			Q1			Q2			Q3
	January 2019	February 2019	March 2019	April 2019	May 2019	June 2019	July 2019	August 2019	Septembe r 2019	October 2019	November 2019	December 2019	January 2020	February 2020
New Enrollees	3	5	5	6	6	7	5	4	2	5	6	4	21	5
Running Total	3	8	13	19	25	32	37	41	43	48	54	58	79	84

Payor Mix

Commercial	AETNA	5%
	KAISER GROUP HEAL..	2%
	PREMERA	5%
	REGENCE	4%
	TRICARE	2%
	UNIFORM MEDICAL P..	1%
	UNIFORM SVCS FAMI..	1%
	UNITED HEALTHCARE	4%
	Total	24%
Commercial w/Medicaid	AETNA	2%
	CIGNA	1%
	FIRST CHOICE	1%
	KAISER GROUP HEAL..	1%
	PREMERA	5%
	REGENCE	4%
	UNITED HEALTHCARE	2%
	Total	17%
Medicaid MCO	AMERIGROUP	7%
	CHPW HO	13%
	COORDINATED CARE	10%
	MEDICAID	1%
	MOLINA HO	21%
	UNITED HEALTHCAR..	7%
	Total	60%
Grand Total		100%

County

Urban/Rural	County	
Grand Total		84
RURAL	**Total**	21
	BENTON	1
	CHELAN	2
	CLALLUM	1
	FRANKLIN	1
	GRAYS HARBOR	4
	KITTITAS	1
	MASON	1
	SKAGIT	3
	WALLA WALLA	1
	YAKIMA	6
URBAN	**Total**	63
	KING	38
	KITSAP	1
	PIERCE	6
	SNOHOMISH	13
	THURSTON	1
	WHATCOM	4

Language

Language	
Arabic	2
English	67
Oromo	2
Spanish	13

Age of Enrollees

Age (Months)	
2 mo	9
3 mo	4
4 mo	6
5 mo	7
6 mo	4
7 mo	5
8 mo	7
9 mo	4
10 mo	3
11 mo	3
12 mo	1
13 mo	3
14 mo	10
18 mo	1

Length of Time in Intervention

0 months	4
1 month	21
2 months	3
3 months	7
4 months	4
5 months	2
6 months	4
7 months	4
8 months	3
9 months	6
10 months	4
11 months	1
12 months	2
13 months	2

Enrollment Status

Active	67
Graduated	17

WA CMC CoIIN Birth to One: First 90 Days after NICU Discharge System Improvement Opportunities

CSHCN

Patient Challenges: Services vary by scope and duration across the state; terminology is scary; role of health department is unclear;

System Opportunity: DOH CSHCN funds or works in partnership with the funders of programs and resources to support these families. What strategies can they put in place to encourage collaboration, reduce redundancies, address gaps and improve warm handoffs between agencies and health care system.

Birth to Three

Patient Challenges: Unclear benefit of EI for infants; referral made in hospital, but provider follow up is PCP; EI agencies have limited "attempts" to reach family and quick to move on; unclear reason for EI referral

System Opportunity: Single form used for all providers and EI agencies with forced "reason why" section and level of urgency.

Nutrition Home

Patient Challenges: No clear nutrition point of contact post discharge. #1 concern of most parents. Infants with NG tubes are particularly vulnerable to ownership hot potato.

System Opportunity: Determine community nutrition home prior discharge. Have clear nutrition plan of care shared with family, PCP and specialist. Establish post discharge nutrition follow up call/visit for every NICU discharge.

Hospital to Home

Patient Challenges: Discharged with a long list of to-dos and no clear prioritization; community referrals made for vague reasons without clear follow up ownership;

System Opportunity: Streamline community referral process including determining ownership; assure all members of care team are aware of each other; parent-centric 90 day plan of care that clarifies what and why

Medical Home

Patient Challenges: No outward-facing list of PCPs who co-manage CMC patients well; difficult to understand roles and responsibilities between PCP and specialty providers, parent having to coordinate between all parties; who to call when and for what after hours

System Opportunity: Engage PCP with centric role from beginning; clear clinical escalation plan; PCP has clear after hours process.

Parent Peer Support

Patient Challenges: Hard to think about peer support for first few months. Scary to engage with families of older CMC children. Networks often diagnosis based, which is difficult for not yet fully diagnosed infants.

System Opportunity: Leverage virtual parent support platform. Maximize Parents of Preemies group opportunities.

Community Resources

Patient Challenges: Difficult to engage with community services when housing/home address is not locked down; difficult to navigate public services with private insurance; out of pocket expense an issue from the start.

System Opportunity: Focus on stable housing. Send out packet at 4-6 months with resources.