Birth to One:
Supporting NICU Infants
Hospital to Home

Gabi Chavarria, Nathan Goldbloom
(Paula Holmes, retd)
Shawnda Hicks, Cindy Myers,
Jill McCormick
Kate Orville, Mari Mazon

Birth to One:
Presentation Outline

Birth to One

- **Program description**
- Collaborative
- Measuring impact

Outcomes: Individual/Family and System

- **Lessons learned**
- **Effective Strategies**
- Sustained Impact

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

4-year award from Boston University School of Social Work CMC CoIIN
Funded by Federal Health and Human Services

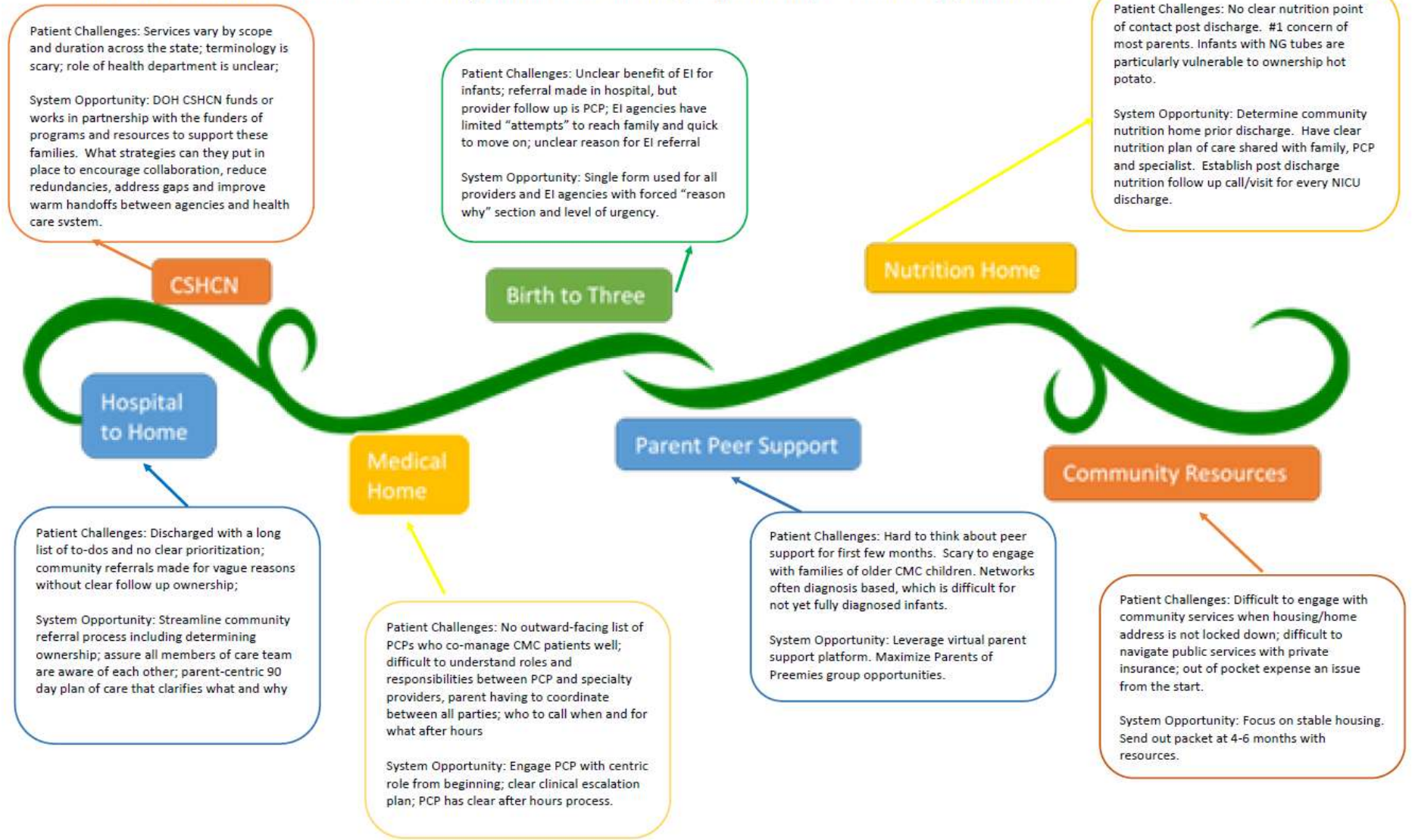
Collaborative

- Seattle Children's Hospital
- PAVE: Partnerships for Action, Voices for Empowerment; Family to Family (F2F)
- WA Title V Children and Youth with Special Health Care Needs (CYSHCN) program
- University of Washington Center on Development and Disability (UW CHDD)
- Washington State Medical Home Partnerships Project for Children and Youth with Special Health Care Needs (MHPP CYSHCN)

Gaps from families post discharge

- Who and where do I go with my questions?
  - E.G. Families emailed us 10 Qs asking which specialty provider can answer this
- Reason for referral unknown; resource unfamiliar (internal and local)
- Families are overwhelmed with phone calls from different agencies
  - E.G. Within Reach
- Limited coordination/warm-handoff of care for parents of newborns
- Assumptions are made on behalf of families

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



Birth to One: **Intervention**

Program Description

WA State Birth to One CMC CoIIN improved the hospital to home experience including:

Navigation

- Roadmap containing care team In **family's primary language**
- **Guide to resources, care team contacts, and organized**
- Triaging family needs (RN CM)
- Coordinating the coordinators
- Point of contact for ALL referrals

Advocacy

- Inform families of choices
- Bridge communication across providers

Building Skills

- **Encouraging** parents to seek out **peer** support
- Building self-efficacy **and** empowerment
- **Direct to services and resources available**

Education

- Reason and value of referrals and services made
- **Improving the cohesiveness** of the system of care supporting infants with complex needs and their parents.

"I don't know what I don't know- so it's great to have one person I can contact that can see the whole picture to help me and my family navigate multiple systems of care for my newborn. I'm so appreciative of this one-way in."

Birth to One Enrollees

Enrollment (Ever Enrolled)

	FY 2019							FY 2020												FY 2021					
	Q2	Q3			Q4			Q1			Q2			Q3			Q4			Q1			Q2		Q3
	January ...	Februar...	March 2...	April 2019	May 2019	June 2019	July 2019	August 2...	Septem...	October ...	Novemb...	Decemb...	January ...	Februar...	March 2...	April 2020	May 2020	June 2020	July 2020	August 2...	Septem...	October ...	Novemb...	Decemb...	Februar...
New Enrollees	3	5	5	6	6	7	5	4	2	5	6	4	16	5	9	5	6	7	7	5	6	2	7	6	3
Running Total	3	8	13	19	25	32	37	41	43	48	54	58	74	79	88	93	99	106	113	118	124	126	133	139	142

Payor Mix

Commercial	AETNA	4%
	CIGNA	1%
	HEALTHNET	1%
	KAISER GROUP HEALTH	4%
	PREMERA	8%
	REGENCE	6%
	TRICARE	1%
	UNIFORM SVCS FAMILY HE...	1%
	UNITED HEALTHCARE	2%
	UNITED HEALTHCARE COM...	1%
	Total	29%
Commercial w/Medicaid	AETNA	1%
	CIGNA	1%
	FIRST CHOICE	1%
	KAISER GROUP HEALTH	1%
	PREMERA	3%
	REGENCE	2%
	TRICARE	1%
	UNITED HEALTHCARE	1%
	Total	11%
Medicaid MCO	AMERIGROUP	7%
	CHPW HO	10%
	COORDINATED CARE	11%
	MEDICAID	1%
	MOLINA HO	23%
	UNITED	3%
	UNITED HEALTHCARE COM...	5%
	Total	60%
Grand Total		100%

County

Urban/Rural	County	
Grand Total		142
RURAL	**Total**	37
	BENTON	3
	CHELAN	4
	CLALLAM	2
	FRANKLIN	1
	GRAYS HARBOR	4
	ISLAND	2
	KITTITAS	1
	MASON	1
	SKAGIT	5
	WALLA WALLA	1
	YAKIMA	13
URBAN	**Total**	105
	CLARK	3
	KING	54
	KITSAP	2
	PIERCE	15
	SNOHOMISH	23
	THURSTON	2
	WHATCOM	6

Language

Language	
Arabic	1
English	118
Mam	1
Mandarin	1
Marshallese	1
Oromo	2
Somali	1
Spanish	16
Vietnamese	1

Age of Enrollees

Age (Months)	
2 mo	3
3 mo	3
4 mo	4
5 mo	8
6 mo	4
7 mo	6
8 mo	7
9 mo	7
10 mo	7
12 mo	4
13 mo	11
14 mo	3
15 mo	9
16 mo	4
17 mo	2
18 mo	3
19	5
20 Mo	1
21 mo	1
22 mo	1
24	1

Length of Time in Intervention

< 1 month	0
1 month	5
2 months	4
3 months	4
4 months	5
5 months	5
6 months	5
7 months	7
8 months	9
9 months	5
10 months	5
11 months	3
12 months	11
13 months	6
14	4
15	2
16	2

Enrollment Status

Active	95
Graduated	47

WA State Birth To One Roadmap

Patient DOB

Personal Overview: D is a 2-month old infant living in Yakima, Yakima County, with his parents. D is a term infant with hypoplastic left heart syndrome (HLHS). D utilizes a NG-tube for feeding.

Caregiver Contact:

Caregiver Name: K
Phone:
Email:
Language/contact preference/other: Prefers text or phone call.

Primary Care Provider/Medical Home:

Provider: TBD- Central Washington Family Medical - Yakima
Address: 1806 W. Lincoln Ave., Yakima, Washington 98902
Phone: 509-452-4520

Specialty Providers

Seattle Children's Hospital |Main: 206-987-2000

Information About COVID-19| Infoseattlechildrens.org/patients-families/covid-19-novel-coronavirus/				
Clinic Name/ Location	**Provider**	**Telephone**	**Last Appt**	**Future Appointments/ Recommended Follow Up**
Cardiology Clinic	Matthew Files MD Paula Woo RD	206-987-2015	8/28/2020 (Completed)	9/18/2020 at 9am
Otolaryngology Clinic	John Dahl MD	206-987-2105	8/26/2020 (Completed)	
Physical Therapy Clinic	Jennifer Eidgen	206-987-2015		9/18/2020 at 1pm

Nutritionist/Dietician: Paula Woo RD, Seattle Children's Hospital.

WA State Birth To One Roadmap

D's Roadmap

Resource Area	Agency	Contact Info	Updates/Notes
Medical Home	Central Washington Family Medical	See Above	Temporary Medical Home: UW Pediatric Care Center Pediatrician: Henry Evans Phone: 206-598-3000
Specialty	Seattle Children's Hospital	See Above	
Birth to Three Services (Also known as Early Intervention or ESIT: Early Support for Infants and Toddlers)	Yakima Children's Village	Address: 3801 Kern Road, Yakima, WA 98902 Phone: 509-574-3200	Family Resource Coordinator (FRC): TBD To activate referral, call: 509-574-6727.
Nutrition Home	Seattle Children's Hospital	Paula Woo RD See Above	
Home Care	Seattle Children's Home Care	Phone: 425-482-4000	
Parent Support	PAVE + Birth to One partner, Family Support Specialist	Shawnda: shicks@wapave.org Phone: 360-999-6633 (call/text)	*Join our private Birth to One facebook page by searching "Family to Family Health and Information Center Group" or facebook.com/groups/1439338032916517/* **We host virtual ZOOM support groups every 2nd Friday of the month @ 12:30pm! https://uw-phi.zoom.us/j/9255288254 (reoccurring link)*
	Seattle Parents of Preemies (for any child with an extended hospital stay)	facebook.com/SeattleParentsOfPreemies	Arlene Smith, Founder Email: arlene@SeattlePreemies.com
University of Washington's Infant Development Follow Up Clinic (IDFUC)	Center on Human Development and Disability (CHDD) at UW Medical Center (UWMC)	Phone: 206-598-9348 depts.washington.edu/chdd	You were referred to IDFUC. Expect a call when your child is about 4 months if not call to schedule. Let us know if you need more info about this appt.
Insurance Case Manager	Coordinated Care	Coordinated Care: Kathleen Donlin: Kathleen.J.Donlin@coordinatedcarehealth.com	

Resource	Contact	Notes
WIC (Women, Infant's and Children) Nutrition Program	NeighborCare Health at Meridian 10521 Meridian Avenue North, Seattle, WA 98133	Phone: 206-296-4990
Transportation	People for People	Phone: 509-248-6793 Website: Pfp.org
Seattle Children's Hospital Urgent Care	To schedule appt:	

Birth to One: **Family to Family's (F2F) Role**

Family to Family Health Information Center at PAVE

- Parent Support Specialists
- Virtual Parent Support- Zoom meeting
- Multiple programs to support families needs
- Connections to community resources

Partnerships For Action, Voices For Empowerment

"I appreciate the connection with you and your son, having the same diagnosis as PB. It is nice to talk to someone that has done this before".

Shawnda Hicks

PAVE Parent Support Specialist

Monthly check in with Parents: Calls, text, and emails

Birth To One Virtual Peer/Learning Group

Facebook Page "Family to Family Health and Information Center Group." Posted articles, resources, relevant events, postive quotes/inspiration

Virtual Parent Support Group Topics:

Resiliency: Finding strength and celebrating your caregiving journey.

Expanding Social Supports. Sharing ideas and resources around building your village of social support; especially during this time of COVID-19.

Getting the most out of Telehealth. Discussing the pro's, barriers, and experiences on accessing telehealth for your child's Early Intervention therapy, and other medical appointments.

Calling all Mothers, Father's, and Caregivers of Birth to One. Welcome guest speakers Arlene Smith, founder of Seattle Parents of Preemies, and Louis Mendoza, director of Father's Network.

Nutrition and Feeding with guest speaker Mari Mazon, MS, RDN, CD Nutritionist, Center for Development and Disability (CHDD), University of Washington. Bring to the table any questions or concerns you may have about your baby's feeding

Holiday's, Traditions, and Support

Returning to Work After Having a Baby

Self-Care (is Self-Preservation!)

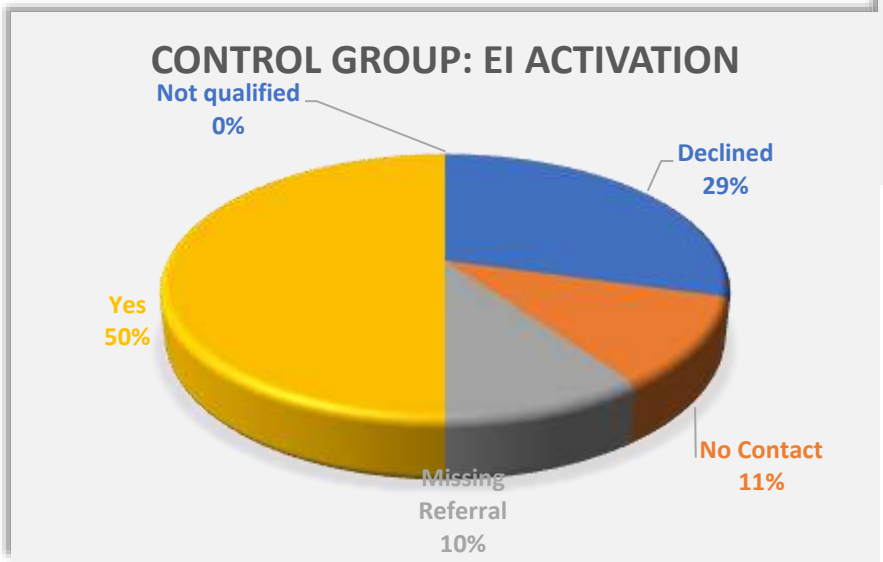
Sibling Support

Birth to One: **Outcomes**

Birth to One: **Measuring Our Impact and Success**

Process Measures: 100% of Birth to One Families:

- Received a comprehensive roadmap
- Parent support referral- PAVE
- Activated medical home- PCP



Program: System Level

Intervention that B 2 one participated/led in the system level

Birth to One:
Lessons Learned- Effective Strategies

Lessons Learned-Effective Strategies: **Individual & Family**

Our keys to success!

- **Flexibility** & adaptation
- **Efficiency** & equity
- **Parent** lens- non-clinical **approach**
- Cultural and resource broker
- Warm-handoff to parent support
- = higher resiliency for families

Sustained Impact: System-wide

1. ESIT
   * IDFUC
2. Nutrition
3. Parent Support

* Cloud Care

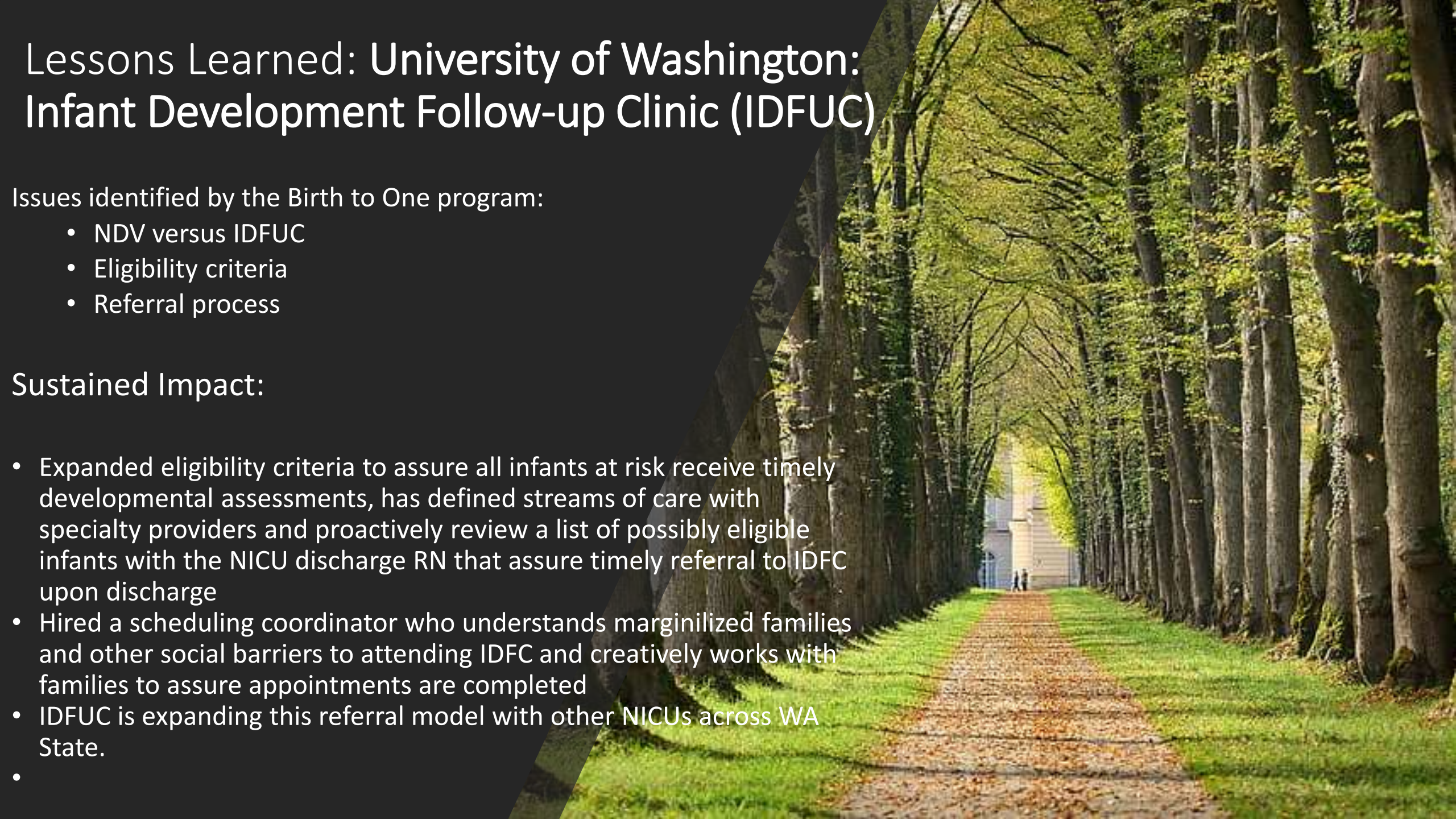
Lessons Learned: University of Washington: Infant Development Follow-up Clinic (IDFUC)

Issues identified by the Birth to One program:

- NDV versus IDFUC
- Eligibility criteria
- Referral process

Sustained Impact:

- Expanded eligibility criteria to assure all infants at risk receive timely developmental assessments, has defined streams of care with specialty providers and proactively review a list of possibly eligible infants with the NICU discharge RN that assure timely referral to IDFC upon discharge
- Hired a scheduling coordinator who understands marginilized families and other social barriers to attending IDFC and creatively works with families to assure appointments are completed
- IDFUC is expanding this referral model with other NICUs across WA State.
-



Mari Mazon- Nutrition

- Highlighted need to "market" Nutrition Network & Feeding Teams
- Identification of partnership opportunities with Medical Homes and Family to Family
- Stronger partnership with Seattle Children's Nutrition Department and NICU discharge team
- Connection to other NICU to home care coordination projects
- Informed development of Hospital to Home Nutrition, Feeding, and Caregiver Mental Health Supports Training

NUTRITION

Children with Special Health Care Needs
Washington State

Sustained Impact: **Seattle Children's Hospital's new "Lay Lactation Consultants" for BIPOC mother's**

Issues identified by the Birth to One program:

- Limited culturally informed lactation support
- NICU mothers of infants with feeding tubes/fragile infants struggling to manage breastfeeding upon discharge; particularly BIPOC mothers

Sustained Impact:

- Lactation Peer Counselor pilot
  - Leverage the unique skills and experience of ICU mothers who have personally overcome lactation barriers to create an evidenced-based Lactation Peer Counselor (LPC) program
  - Increase the duration of provision of breastmilk in BIPOC mothers who have unique barriers

Washington State Medical Home Partnerships Project

Impact on Medical Home Partnerships Project

- Medical Home – family-centered, coordinated primary care – is developed from trusted relationships. Medical Home can be based in Primary care, specialty care or both but needs **clear communication and roles** about who is doing what.
- Challenge for medically fragile infants in the NICU and their families to go from **hospital "bubble" to home community**. Who is in charge of what and do they know my baby?
- Importance of clarifying roles and communication with warm handoffs for medical home, nutrition home, Early Supports (0-3), Parent support before leaving NICU

Washington State Medical Home Partnerships Project

Sharing Products and Strategies

- Sharing products and strategies from Birth to One project on Medicalhome.org – WA Activities Tab
- https://medicalhome.org/stateinitiatives/birth-to-one/
- Birth to One Project sample care plans and road maps and templates for others to use
- Information about similar projects as they happen

Sustained Impact: **Packet of B-1 Resources upon discharge**

packet

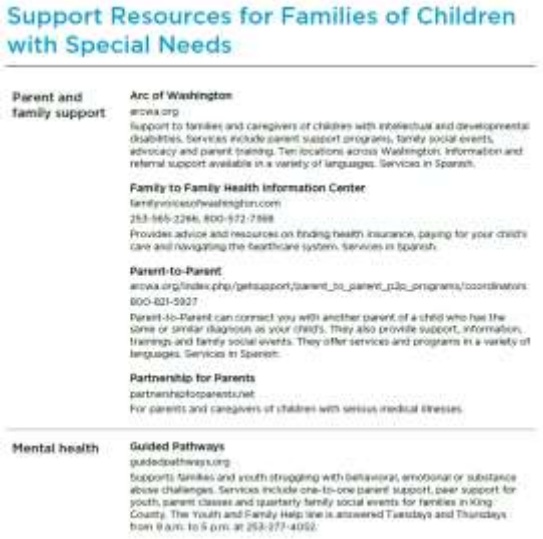
Discharge Packets:

- Review resources with patient families prior to discharge
  - Guide to Early Intervention, Nutrition questions overview, and parent support resources.
- Roll out in NICU, Surgical and Medical to follow.

What to Do When I Have Questions About My Infant's Feeding

If you have questions or concerns around your infant's diet, nutrition, or feeding, it may help to:

Talk to Your Child's PCP (Primary Care Provider) About Your Child	• Tell your child's doctor about your questions or concerns and ask for a consult with an infant feeding specialist or for other nutrition resources in your area. • A feeding specialist can also be called a Registered Dietitian (RD), Nutritionist (NUT), Feeding Therapist, or another therapist such as Occupational or Physical Therapist (OT/PT).
Ask a question in MyChart	• MyChart is a way to access your medical information online. You can message your Seattle Children's provider and feeding specialist. • To signup, go to our website seattlechildrens.org, and click on MyChart.
Meet with an Infant Feeding Specialist at Seattle Children's Hospital	• If you have any upcoming Seattle Children's appointment, request a follow up with an infant feeding specialist. • If you already have a Seattle Children's Nutrition or OT/PT appointment scheduled, call and request to speak with them sooner. •Call Nutrition at: 206-987-4758 •Call OT/PT at: 206-987-2618 • Your local birthing hospital may also have infant feeding specialists. My feeding specialist is: _____
Ask your WIC or Early Intervention Office for more information	• If your child meets with an Early Intervention (also known as ESIT/EI/Birth to Three) program, ask • Contact your local Woman Infant and Children's (WIC) office: https://resources.parenthelp123.org/
Take the Feeding Matters Infant and Child Feeding Questionnaire	• Feeding Matters has a free online questionnaire that can help you decide whether or not it would help to get more feeding evaluation for your infant. The questionnaire asks yes or no questions based on your child's



Support Resources for Families of Children with Special Needs

Parent and family support

Arc of Washington
arcwa.org
Support to families and caregivers of children with intellectual and developmental disabilities. Services include parent support programs, family social events, advocacy and parent training. Ten locations across Washington. Information and referral support available in a variety of languages. Services in Spanish.

Family to Family Health Information Center
familyvoicesofwashington.com
253-565-2266, 800-572-7368
Provides advice and resources on finding health insurance, paying for your child's care and navigating the healthcare system. Services in Spanish.

Parent-to-Parent
arcwa.org/index.php/getsupport/parent_to_parent_p2p_programs/coordinators
800-821-5927
Parent-to-Parent can connect you with another parent of a child who has the same or similar diagnosis as your child's. They also provide support, information, trainings and family social events. They offer services and programs in a variety of languages. Services in Spanish.

Partnership for Parents
partnershipforparents.net
For parents and caregivers of children with serious medical illnesses.

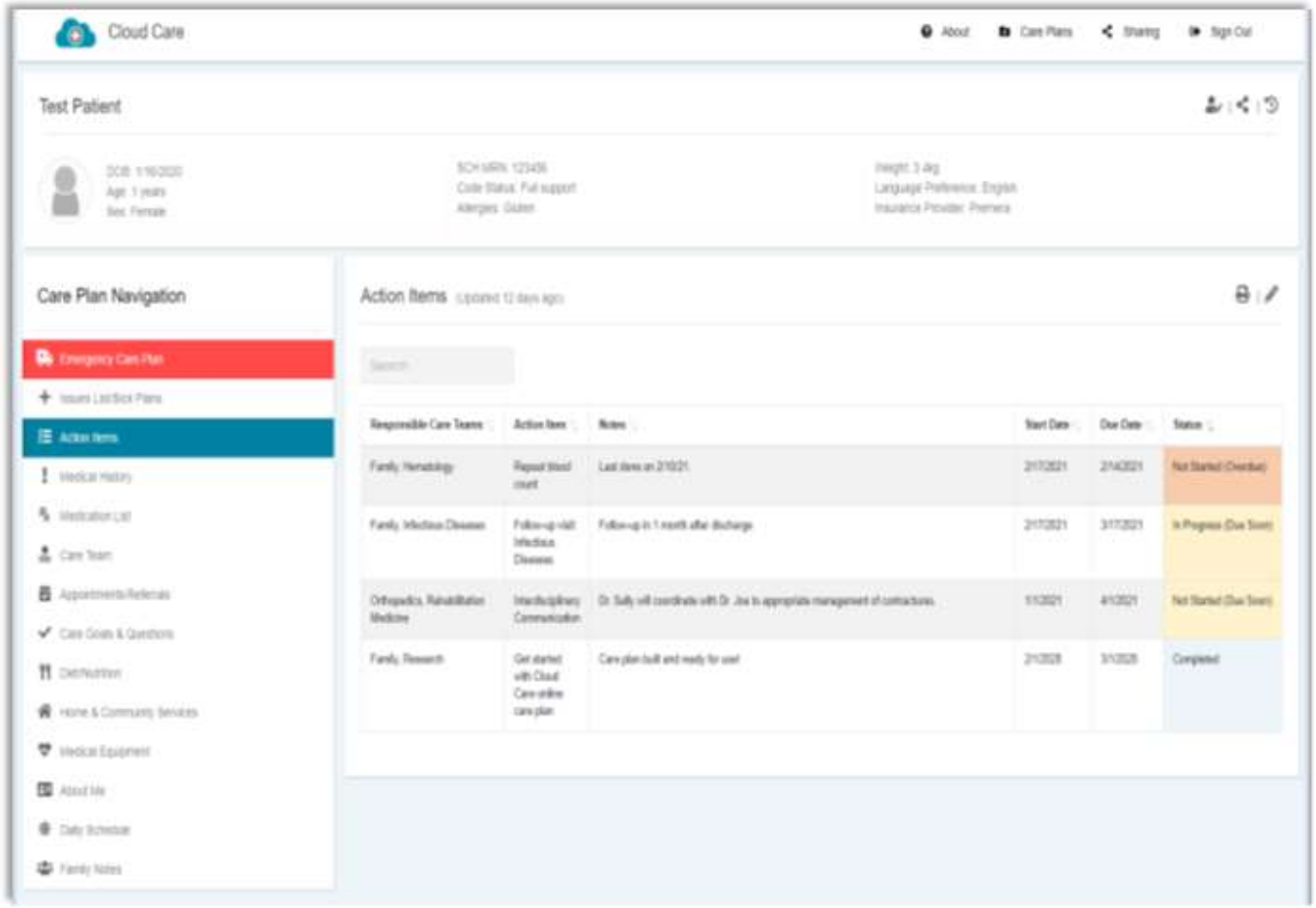
Mental health

Guided Pathways
guidedpathways.org
Supports families and youth struggling with behavioral, emotional or substance abuse challenges. Services include one-to-one parent support, peer support for youth, parent classes and quarterly family social events for families in King County. The Youth and Family Help line is answered Tuesdays and Thursdays from 9 a.m. to 5 p.m. at 253-277-4052.

Sustained Impact: cloud care

Cloud Care

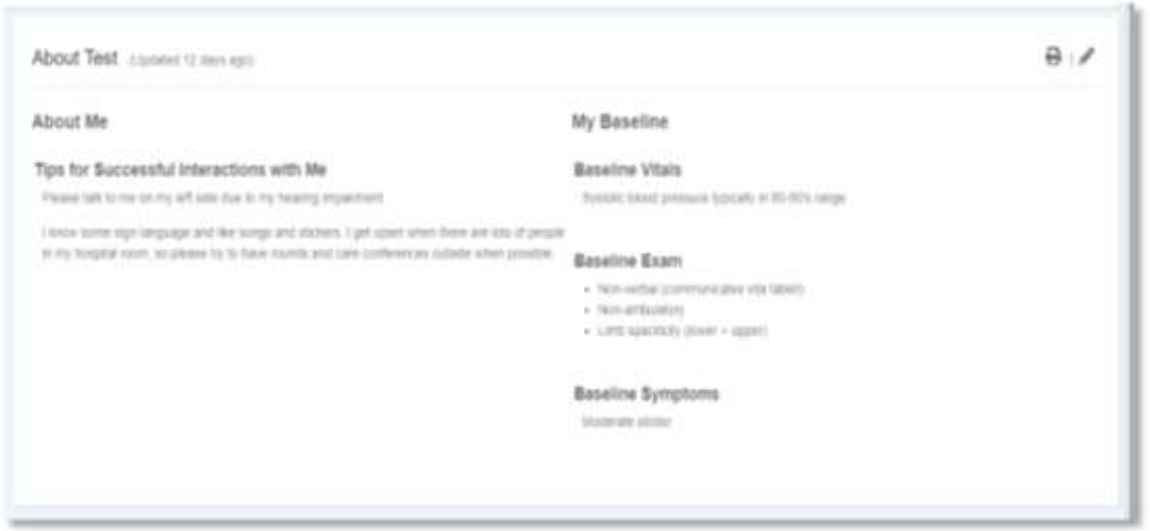
- An online shared care coordination tool for families/guardians and care teams
  - Updated in real time
  - Care team can update regardless of clinic, EHR, or location
- Information included:
  - Patient Overview
  - Emergency Care Plan
  - Action Items
  - Care Plan
  - Appointments
  - Care Team
  - Community Resources
  - About Me



cloud care

"I have incorporated everything that lead to the success of Birth to One. How important it is to catch a family where they are and setting a journey in place. Starting from scratch, when families are first learning how to navigate. As a hospital we should be putting much more attention on and effort into that first transition from hospital to home. "

Arti Desai, MD



Sustained Impact: **Direct Parent Support Referrals**

Hard wired referrals will be made to PAVE for parent support

- Identfied by Care Coordination (SCH discharge planning team)
- Parent support specialists will contact families directly/triage to resources in community
- Specialists loop back to SCH for clinically relevant care coordination
- Launching in July!

TEAM WASHINGTON

BIRTH to ONE

OUR SECRET SAUCE: CONSISTENT, RELATIONSHIPS WITH FAMILIES

0 PROACTIVE → 1 KEY MILESTONES to CHECK IN

HOSPITAL to HOME · MEDICAL HOME · PARENT PEER SUPPORT · COMMUNITY RESOURCES

CSHCN · BIRTH to THREE · NUTRITION HOME

THIS WORKS — IT'S NOT THAT EXPENSIVE — IMPACT is AMPLIFIED

ACCOMPLISHMENTS!

MAINTAINED MOMENTUM EVEN DURING COVID!

CREATING SOMETHING NEW!

LEADERSHIP · COLLABORATION

ADAPTIVE TEAM

HOSPITAL · HOME · COMMUNITY

WHO NEEDS OUR SUPPORT?

NICU FAMILIES!

HELPS FAMILIES MAKE the EASIEST CHOICE

CREATED a ROADMAP for NICU FAMILIES

SO... NOW WHAT?

UM... THIS is SCARY...

WHERE DO WE COME FROM? WHERE ARE WE NOW?

LESSONS LEARNED

IT TAKES A VILLAGE

ADAPTABILITY is KEY

We like Mia's Coordinator

OK!

FAMILY PEER SUPPORT NAVIGATORS = KEY!

COORDINATING the COORDINATORS

COMMUNITY RESOURCE CARE COORDINATORS → BILINGUAL SUPPORT

CONNECTION ↳ for a year

HAND-OFFS were ALWAYS a CHALLENGE

BUILDING FACE-to FACE CONNECTIONS with FAMILIES

WALKING TOGETHER!

WHAT DO WE NEED?

HOW HAVE OUR NEEDS CHANGED?

NEEDED SUPPORT ↳ I'M DROWNING...

NO DIAGNOSIS...

REFERRALS THAT WORK!

WE REALIZED the INTEGRATED SYSTEM WE THOUGHT EXISTED... DIDN'T.

WHERE ARE WE GOING?

THE CASE of WHY CARE COORDINATION is IMPORTANT.

WE HAVE DATA!

ADAPTABLE for YOUR SITUATION!

HOW DO WE COMMUNICATE the VALUE of COLLABORATIONS LIKE THIS?

FUNDING

Hospital Associations?

How to include Programmatic work in the existing model?

HOSPITALS... WHAT do THEY NEED to KNOW?

THIS is a LONG-TERM INVESTMENT

CHALLENGING IN TODAY'S COVID BUDGET CLIMATE

HOW CAN WE REALLY HELP OUR FAMILIES?

Illustrated by CarverSketch.com

How can you use the capacity of your role to more effectivelty stitch the fabric of the safety net for families you serve?

-Paula Holmes


Gabi Chavarria
Nila Williamson (WA DOH CYSHCN...
Mari O Mazon
Paula Holmes
Monica Burke
Cindy Myers

Questions?