

Barriers and facilitators to neurodevelopmental follow-up among at-risk newborns across Washington State

Sara Neches

skneches@uw.edu

University of Washington <https://orcid.org/0000-0003-3238-4486>

Megan Woods

University of Washington

Krystle Perez

Kendell German

University of Washington <https://orcid.org/0000-0002-0046-621X>

Ulrike Mietzsch

University of Washington, Seattle Children's Hospital <https://orcid.org/0000-0003-4629-2881>

John Feltner

University of Washington

Niranjana Natarajan

Seattle Children's Hospital

Cindy Trevino

Seattle Children's Hospital

Rebecca Penders

Washington Department of Health

Sharilyn Emhoff

MultiCare Yakima Memorial Hospital

Bat-Sheva Stein

Washington State Department of Health

Sandra Juul

University of Washington

Brent Collett

University of Washington

Gregory Valentine

University of Washington <https://orcid.org/0000-0002-3055-2987>

Article

Keywords:

Posted Date: May 20th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-9475637/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: There is **NO** conflict of interest to disclose.

1 Barriers and facilitators to neurodevelopmental follow-up among
2 at-risk newborns across Washington State

3

4 Running title: Disparities in Neurodevelopmental Care for At-Risk
5 Newborns

6 Sara K. Neches MD^{1*}, Megan Woods MD^{1*}, Krystle Perez MD,
7 MPH¹, Kendell German MD¹, Ulrike Mietzsch MD¹, John Feltner
8 BS, MS¹, Niranjana Natarajan MD¹, Cindy Trevino PhD², Rebecca
9 Penders PhD, BSN^{3,4}, Sharilyn Emhoff BSNS³, Bat-Sheva Stein,
10 DNO, RN, MSN, MScE³, Sandra Juul MD, PhD¹, Brent R. Collett
11 PhD^{1,2}, Gregory C. Valentine MD, MEd^{1, 5}

12 Affiliations:

- 13 1. University of Washington School of Medicine, Seattle,
14 Washington
15 2. Seattle Children's Research Institute (SCRI), Seattle,
16 Washington
17 3. Washington State Perinatal Collaborative, Washington
18 Department of Health
19 4. Providence Inland Northwest Washington (INWA),
20 Spokane, Washington
21 5. Baylor College of Medicine, Department of Obstetrics &
22 Gynecology, Houston, Texas

23 *These authors contributed equally to this work

24

25

26

27 Corresponding Author:
28 Sara K Neches, MD
29 Assistant Professor of Pediatrics, Division of
30 Neonatology
31 1959 NE Pacific St, RR539
32 Seattle WA, 98195
33 Tel. 206-884-8517
34 Email: skneches@uw.edu
35

36 **Abstract**

37
38 **Objective:** Identify barriers and facilitators to neurodevelopmental
39 follow-up (NDFU) for high-risk neonates in Washington (WA).

40 **Study Design:** Cross-sectional, mixed-methods study of NDFU
41 centers and neonatal intensive care units (NICUs) across WA to
42 characterize NDFU referral and scheduling practices and identify
43 barriers and facilitators to NDFU attendance.

44 **Results:** Response rates were 84% for NDFU centers and 94%
45 for NICUs. Barriers to NDFU attendance included logistical
46 limitations (n=10, 63%) and scheduling processes (n=10, 63%),
47 while facilitators included provider relationships and
48 communication (n=8, 50%) and community-based access (n=8,
49 50%). No NICU respondent reported receiving any post-discharge
50 communication from NDFU centers regarding patient
51 developmental outcomes.

52 **Conclusion:** Integrating anticipatory guidance and family
53 education before NICU discharge with home-based services and
54 telehealth may improve access to essential developmental follow-
55 up care in this high-risk population. Interventions to increase
56 NDFU attendance should prioritize family-centered
57 communication, reduced logistical burdens, and flexible models of
58 care delivery.

59

60 **Introduction**

61 Although advances in neonatal care have significantly increased
62 survival (1–3), the risk of long-term neurodevelopmental
63 impairment (NDI) remains high for preterm infants and those
64 affected by conditions such as neonatal encephalopathy,
65 congenital anomalies, infections, and *in utero* illicit drug exposure
66 (4,5) (6–8). The American Academy of Pediatrics (AAP)
67 recommends neurodevelopmental follow-up (NDFU) for all high-
68 risk infants to optimize early detection of delays (9–12).

69 In the United States, two complementary systems offer
70 access to NDFU services (13,14). NDFU clinics are typically tertiary
71 hospital-based, staffed by multidisciplinary teams, and focus on
72 longitudinal surveillance and identification of NDI through
73 standardized assessments and interdisciplinary evaluation. These
74 clinics may also provide medical follow-up, nutrition and feeding
75 support, mental health services, and physical or occupational

76 therapy(13,15,16). Early Intervention (EI) programs, mandated
77 under Part C of the Individuals with Disabilities Education Act (17),
78 offer family-centered therapeutic services in the home or
79 community for children under three years of age who have or are at
80 risk for developmental delays, at no or limited cost to families (18).
81 EI programs are typically staffed by physical, occupational, and
82 speech therapists who assess infants and deliver early intervention
83 services as needed (18). Together, NDFU clinics and EI programs
84 form complementary systems of NDFU that support early detection
85 of developmental delays and facilitate timely, individualized
86 interventions to improve outcomes for high-risk infants (13,14,19).

87 EI services facilitated by NDFU centers have positive effects
88 on motor and cognitive development in infancy with cognitive gains
89 lasting into preschool (20,21). Despite these benefits, participation
90 in NDFU remains challenging, with up to two-thirds of high-risk
91 infants lost to follow-up by two years of age (22,23). Attrition is
92 complex and multifaceted, influenced by interconnected medical,
93 family, sociodemographic, and systemic, and sociopolitical
94 factors(23–27). Additionally, differences in institutional practices
95 and community resources lead to variations in follow-up rates,
96 family counseling, and access to care, highlighting an important
97 need to elucidate and overcome barriers to care. However, to
98 determine best practices to promote higher NDFU rates by families
99 of high-risk children, identification of the barriers and facilitators to
100 NDFU care is a critical first step.

101 In partnership with the Washington State Department of
102 Health and the Washington State Perinatal Collaborative, we
103 sought to address this critical gap by identifying barriers that
104 prevent and facilitators that enhance families' attendance at NDFU
105 care by conducting a statewide assessment of neurodevelopmental
106 follow-up services throughout Washington state. Specifically, we
107 examined referral, scheduling, and developmental screening
108 practices across Level III and IV NICUs and NDFU centers, as well
109 as the level of communication and collaboration between referring
110 NICUs and neurodevelopmental programs, with the overall aim of
111 informing strategies to promote equitable access to comprehensive
112 neurodevelopmental care.

113 **Materials, Subjects and Methods**

114 *Study design*

115 Mixed-methods surveys, including both quantitative and qualitative
116 questions, were distributed to providers at 19 NDFU centers (e.g.,
117 EI programs and ND clinics) and 16 regional NICUs across
118 Washington State between September and November 2024. The
119 surveys and study protocol were explicitly designed for providers of
120 neonatal and NDFU care; no patients or direct patient data were
121 obtained for this study. The study protocol was reviewed by the
122 University of Washington Institutional Review Board and was
123 determined to be exempt from review.

124 *Survey Development*

125 Two online surveys were developed and reviewed by the study
126 investigators using Research Electronic Data Capture (REDCap), a
127 secure electronic data capture tool (28). A 27-item survey
128 (Supplemental File A) was distributed to clinical directors at regional
129 Level III and Level IV NICUs to capture information about NDFU
130 referral and scheduling practices, how information on infant
131 neurodevelopment is shared with both families and the NDFU
132 programs to which they are referred, and to assess the
133 developmental screening tools utilized in participating NICUs. A 43-
134 item survey (Supplemental File B) was distributed to program
135 directors of NDFU centers across Washington State, exploring the
136 demographics of patients seen in different types of NDFU centers,
137 funding sources, staffing models, scheduling practices, no-show
138 rates, visit cadence, use of telehealth, types of assessments
139 administered, methods of communication with referring providers,
140 and perceived barriers and facilitators to NDFU attendance.

141 *Survey Distribution*

142 A list of email contacts for medical and/or program directors for
143 Level III and Level IV NICUs (11) and NDFU centers across
144 Washington was made available through the Washington State
145 Department of Health. Public survey links were distributed by email
146 in September 2024. When needed, the surveys were redistributed
147 up to three times through November 2024. An introduction to the
148 surveys explained the rationale for data collection and estimated
149 completion time. Consent was implied if the individual chose to

150 complete the survey. While names were not requested, the surveys
151 assessed respondents' roles and organization names to assist with
152 the categorization of responses.

153 *Statistical Analysis*

154 Survey data were collected and stored in the University of
155 Washington REDCap database and analyzed to explore referral
156 and scheduling practices, as well as barriers and facilitators to
157 NDFU care from providers' perspectives. We used descriptive
158 statistics, including frequencies, means, medians, standard
159 deviations, and interquartile ranges. All data analyses were
160 conducted using SAS Studio OnDemand for Academics (Cary, NC:
161 SAS Institute Inc).

162 Free-text responses from providers at NDFU centers
163 describing perceived barriers and facilitators were analyzed using
164 inductive qualitative content analysis. Responses were imported
165 into NVivo (QSR International) to facilitate data organization and
166 coding. MW performed line-by-line coding using an inductive
167 approach to generate initial codes directly from the data. Codes
168 were iteratively refined and organized into higher-order themes
169 based on the mechanism by which each barrier or facilitator related
170 to NDFU attendance. When codes overlapped conceptually, they
171 were categorized based on their predominant mechanism of
172 influence on attendance. No prespecified frequency threshold was
173 used to create a separate theme; instead, themes were defined
174 based on distinct differences in how barriers or facilitators

175 influenced attendance. SN reviewed the coding framework and
176 thematic organization to ensure consistency, refine code
177 definitions, and resolve discrepancies through discussion.
178 Thematic frequencies were calculated at the respondent level to
179 describe the relative prominence of each category across NDFU
180 centers.

181

182 **Results**

183 *Provider characteristics*

184 A total of 15 providers representing eligible NICUs responded to the
185 survey (94% response rate), including respondents from 10 of 11
186 Level III NICUs and all 5 Level IV NICUs across Washington State.
187 Most NICU survey respondents held medical director roles, though
188 staff knowledgeable in nursing, developmental care, and discharge
189 coordination also had the opportunity to complete the survey. A total
190 of 16 providers representing eligible NDFU centers completed the
191 survey (84% response rate), including all 4 NDFU clinics in
192 Washington State and 12 of 15 EI programs (Figure 1). Most
193 respondents to the NDFU center survey held clinic director or
194 program management roles (Table 1).

195 *NICU Survey*

196 Only 4 NICU respondents (n=4/15, 26.7%) reported that their
197 centers perform standardized neurodevelopmental assessments
198 during the inpatient period; among those performing standardized

199 neurodevelopmental assessments, only n=2 (50%) use the
200 Hammersmith Neonatal Neurological Exam, n=3 (75%) use the
201 General Movements Assessment, and n=1 (25%) use the Neonatal
202 Neurobehavioral Scale. Over half of NICUs (n=8/15, 53.3%) utilize
203 clinical feeding evaluations. Results of neurodevelopmental testing
204 are primarily shared directly with the family by the therapist
205 performing the exam (n=12, 80%), though this information may be
206 shared by another NICU provider (n=4, 27%) or in a
207 multidisciplinary care conference (n=4, 27%). The eligibility criteria
208 for NDFU referral from the respondent NICUs included birth weight
209 (defined as patient <1500 grams at birth, intrauterine growth
210 restriction, or small for gestational age), gestational age (e.g.,
211 prematurity), hypoxic ischemic encephalopathy, seizures, history of
212 surgery, and history of extracorporeal membrane oxygenation
213 (ECMO) (Table 1). Most referrals for neonatal follow-up and early
214 intervention are placed by the medical team (n=9, 60% and n=7,
215 47% respectively), though other providers play a significant role in
216 referral placement, including discharge coordinators, social
217 workers, and inpatient infant therapy team members. NDFU
218 appointment scheduling was completed by a range of individuals,
219 including discharge coordinators, medical providers,
220 neurodevelopmental clinic coordinators, and therapy team
221 members, while parents mostly complete EI scheduling.

222 *Neurodevelopmental Follow-Up and Early Intervention Survey*

223 Of the 16 NDFU center survey respondents, n=7 (44%) reported
224 seeing fewer than 10 infants for developmental follow-up per month,
225 while only one clinic reported seeing more than 40 NICU graduates
226 per month. Among the four responding NDFU clinics, assessments
227 performed included medical (n=2, 50%) and developmental
228 assessments [(motor (n=4, 100%), cognitive (n=3, 75%), speech
229 and language (n=4, 100%)], along with occupational therapy (n=3,
230 75%), physical therapy (n=3, 75%), audiology (n=1, 25%), nutrition
231 (n=2, 50%), and feeding/swallow evaluations (n=2, 50%). Of the 12
232 responding EI programs, none of the respondents reported
233 conducting medical assessments; however, EI program
234 respondents did perform motor (n=11, 92%), cognitive (n=11, 92%),
235 and speech a language (n=10, 83%) assessments, as well as
236 occupational therapy (n=10, 83%), physical therapy (n=9, 75%),
237 and clinical feeding evaluations (n=6, 50%). They also reported
238 completing audiology (n=2, 17%) and vision (n=5, 42%)
239 assessments. Social work support was available in most ND clinics
240 (n=3, 75%) and in half of EI programs (n=6, 50%). None (0%) of the
241 NDFU programs responding reported performing or documenting
242 specific screening for social determinants of health (SDOH).

243 We explored the methods NDFU centers used to share the
244 results of post-discharge developmental testing and infant
245 outcomes with referring NICUs (Figure 2). While three (25%) EI
246 programs and two (50%) NDFU clinics reported using the electronic
247 health record to share results, one (8%) EI program used clinic-to-

248 clinic messaging, and one NDFU clinic (25%) used email or phone
249 to communicate with referring NICUs. Notably, 100% of the
250 surveyed NICU providers reported not receiving communication
251 from NDFU clinics or EI programs with results of post-discharge
252 neurodevelopmental testing or infant outcomes. (Figure 2)

253 Three-quarters of responding centers reported having a
254 method to track no-show appointments. Of those tracking no-
255 shows, nine programs (75%) had a no-show rate below 25%, while
256 two (17%) had a no-show rate between 26% and 50%. Notably,
257 some EI programs track no-show rates based on program-wide
258 data rather than specifically to patients following up post-NICU
259 discharge affecting the accuracy of reported attrition. For instance,
260 one EI program respondent mentions, “This percentage rate...is
261 our total no-show cancel rate of all of our ESIT services and not
262 specific to NICU follow-up services.” Among all NDFU center survey
263 respondents, most (n=12, 75%) offered some form of telehealth.

264 *Barriers and Facilitators for Neurodevelopmental Follow-up*

265 Among NDFU center survey respondents who provided free-text
266 comments, six barrier themes and six facilitator themes were
267 identified through inductive content analysis (Figure 3, Table 2).
268 Although several reported barriers were interrelated, they were
269 grouped into themes based on the predominant way in which they
270 interfered with attendance. The most frequently cited barrier
271 themes to NDFU attendance were *logistical limitations* (n=10, 63%)
272 and *scheduling processes* (n=10, 63%). Logistical limitations

273 included competing caregiver responsibilities (n=6, 38%),
274 transportation challenges (n=5, 31%), and housing instability or
275 relocation (n=2, 13%). Scheduling processes included scheduling
276 conflicts (n=4, 25%), forgotten appointments (n=3, 19%), long
277 waitlists (n=1, 6%), or lack of patient information (n=1, 6%). Half of
278 respondents (n=8, 50%) reported limited family understanding or
279 engagement as a barrier to NDFU attendance, reflecting concerns
280 about caregiver readiness (n=2, 13%), language barriers (n=1, 6%),
281 or uncertainty about the purpose or importance of NDFU (n=7,
282 44%). Less commonly identified barriers included patient-related
283 clinical factors (e.g., patient or caregiver illness, or re-
284 hospitalization) (n=4, 25%), psychosocial and socioeconomic
285 stressors (n=3, 19%), and care coordination and system navigation
286 challenges (n=2, 13%).

287 The most frequently identified facilitator themes of NDFU
288 attendance were *provider relationships and communication* (n=8,
289 50%) and *community-based access and reduced travel burden*
290 (n=8, 50%) (Table 2). Responses within the provider relationships
291 and communication theme emphasized supportive provider
292 interactions (n=7, 44%) and accessible communication (n=1, 6%).
293 Community-based access and reduced travel burden included
294 home-based services (n=5, 31%), telehealth availability (n=2,
295 13%), NDFU center location (n=2, 13%), and transportation
296 assistance (n=1, 6%). Additional facilitator themes included flexible
297 and coordinated care delivery (n=6, 38%) and availability of

298 specialized services (n=3, 19%). Less commonly cited facilitator
299 themes were family education and information received at NDFU
300 visits (n=2, 13%) and family-centered and culturally responsive care
301 (n=2, 13%). Together, these findings demonstrate that logistical
302 access and clinic workflow factors were the most prominent
303 barriers, whereas relational aspects of care and proximity of
304 services were the most frequently described facilitators.

305 **Discussion**

306 This survey of regional NICUs and NDFU centers is the first study
307 to examine current practices, potential barriers, and facilitators of
308 neurodevelopmental assessment and follow-up for high-risk infants
309 across Washington state. This study's findings revealed that 73.3%
310 of surveyed Washington state NICUs do *not* perform standardized
311 neurodevelopmental evaluations of neonates during their NICU
312 hospitalization. While the criteria for NDFU referral are similar,
313 referral placement and scheduling practices differ across programs,
314 adding to confusion and fragmentation of care for high-risk infants.
315 NDFU centers (including NDFU clinics and EI programs) report
316 variable patient volumes, developmental assessments performed,
317 and availability of telehealth services. In addition to potentially
318 creating disparities in care, these differences may complicate
319 longitudinal evaluation of high-risk infants who relocate or change
320 developmental care providers.

321 *Neonatal and Neurodevelopmental Follow-up Care in Washington*
322 *State*

323 In 2024, one in eleven, or 9.0% of infants born in Washington, were
324 premature (<37 weeks' gestation), resulting in roughly 7,600 NICU
325 admissions annually (49), not including term infants with both pre-
326 and postnatal diagnoses of complex congenital disorders or birth-
327 related trauma requiring NICU-level care. The regionalization of
328 perinatal and neonatal care in Washington state generally
329 concentrates services in urban economic centers, creating
330 challenges for families who must travel from the state's vast rural
331 regions to large academic centers to access care. This is likely a
332 commonality shared with other states and settings throughout the
333 US and globally.

334 *Inter-program Communication: NICU and Neurodevelopmental*
335 *Follow-up Centers*

336 This analysis highlights opportunities to improve communication
337 between NDFU centers and the NICUs who refer patients to them.
338 We identified significant variation among institutions regarding
339 which NICU provider or staff member places NDFU referrals,
340 including discharge coordinators, care coordinators, medical staff,
341 infant therapy staff, and social workers. Although NICU providers
342 who place referrals may be alerted that a child is seen at an NDFU
343 center, results are not tracked in a central data repository, and while
344 approximately 50% of NDFU center respondents report sharing
345 evaluation data with referring NICUs, *0% of the NICU providers*
346 *stated that they routinely receive data on their referred patients.*
347 These findings highlight a striking disconnect between the NDFU

348 centers and the referring NICUs, elucidating an opportunity for
349 enhancing communication between institutions.

350 The current lack of communication between institutions may
351 limit the ability to conduct clinical audits, quality improvement
352 initiatives, or research. Given the emphasis on regionalizing
353 subspecialty neonatal and perinatal care in Washington state, there
354 is a unique opportunity for broader institutional collaboration to track
355 outcomes in these areas. Establishing a large regional database to
356 which NICUs and NDFU programs submit de-identified data, similar
357 to the California Perinatal Quality Care Collaborative (29) may play
358 a broader role in tracking outcomes as process changes and
359 advances in neonatal research continue to evolve.

360 *Practical and Logistical Considerations for NDFU Attendance*

361 Given resource constraints that limit the expansion of NDFU
362 appointments, strategies must be proposed to ensure that infants
363 at the highest risk of NDI maintain timely access to evaluation and
364 therapeutic services. The use of neurodevelopmental assessments
365 during NICU admission, as part of early detection pathways, has
366 led to earlier diagnosis of cerebral palsy (30) and earlier access to
367 early intervention services, which may improve long-term
368 functioning (31). Early detection and risk identification of NDI during
369 NICU hospitalization using predictive models for risk stratification
370 (32,33), may help shape referral pathways, and determine
371 appropriate appointment timing, frequency, and modality for follow-
372 up and early intervention.

373 While some aspects of follow-up care, such as hearing
374 exams, must be conducted in person, some neurodevelopmental
375 screening assessments can be conducted remotely via telehealth,
376 potentially improving access to neurodevelopmental follow-up care.
377 A large retrospective study of 55 Federally Qualified Health Centers
378 (FQHCs) in Texas found that when appointments were available via
379 telehealth rather than in person, the odds of a missed appointment
380 were reduced by 13% (34). Moreover, a local investigation of
381 pediatric neurology patients in Washington state during and after
382 the conclusion of the COVID-19 pandemic, found that patients from
383 rural areas of the state had far greater odds of utilizing telehealth
384 even after in-person appointments could be rescheduled (35).
385 During telehealth visits, experts may guide families in conducting
386 certain developmental assessments of their child (36,37). This
387 presents a valuable opportunity to engage families in care as
388 parents learn how to observe and interpret their child's movement
389 and behavior(12,36,38). Finally, there is evidence that evaluating
390 an infant in their home environment may be more reliable than an
391 evaluation done in an unfamiliar exam room (39). Given the existing
392 telehealth infrastructure through a majority of regional NDFU
393 centers, and our finding that 75% of NDFU centers surveyed utilize
394 telehealth services, more emphasis on utilizing this technology may
395 improve access to care and directly overcome several key identified
396 barriers to NDFU including concerns about competing caregiver
397 responsibilities, limited means of transportation, and rising costs of
398 childcare for other children in the household.

399 Social disparities have been found to be associated with
400 reduced rates of NDFU. (23) In a large, population-based
401 investigation in California, sociodemographic variables such as
402 lower maternal education and single-parent households with
403 reduced resources were associated with lower rates of neonatal
404 follow-up before 12 months of corrected age (40). Given that no
405 NDFU centers surveyed formally evaluate aspects of SDOH, this
406 also highlights a potential opportunity for a simple screening
407 assessment at intake or during appointment scheduling to help
408 identify families at high risk of becoming lost to follow-up. For
409 example, in response to these survey results, clinics at the Institute
410 for Human Development and Disability (IHDD) at the University of
411 Washington have initiated quality improvement work to improve
412 SDOH screening documentation paired with immediate assistance
413 with resources for needy families. Implementation of these
414 processes on a larger scale would necessitate NDFUs to be
415 resourced to support targeted interventions to improve access to
416 care.

417 *Anticipatory Guidance*

418 Our thematic analysis identified six prominent barriers, including
419 logistical limitations, scheduling processes, and limited family
420 understanding or engagement, which emerged as the most
421 significant factors perceived by NDFU providers to negatively
422 impact attendance. Concerns regarding the caregiver

423 responsibilities, lack of transportation, affordable childcare, missed
424 workdays to attend clinic visits, language barriers, and other family
425 stressors have been described in other investigations, as has the
426 concept that families often do not understand the rationale for
427 NDFU (41,42). A modified Delphi study performed by Miller et al
428 (2025) explored interventions to strengthen the NICU-to-home
429 transition and identified “anticipatory guidance” for families,
430 including discussions of important referrals such as NDFU and EI,
431 as a crucial component of NICU discharge. However, finding an
432 appropriate time to disclose concerns regarding an infant’s
433 development that takes into consideration parental stress and
434 anxiety surrounding uncertain prognoses is challenging (43–47).

435 We explored how families receive information about their
436 infants' developmental progress before NICU discharge, and how
437 that information is typically disclosed. From our surveys of NICU
438 providers, we found that most developmental testing results are
439 shared directly with families by the NICU’s physical, occupational,
440 or speech therapists, while 4 (27%) of the NICUs surveyed hold
441 interdisciplinary meetings between providers and families before
442 discharge to discuss testing, such as imaging or developmental
443 screens. Unsurprisingly, respondents felt that parents’
444 understanding of the importance of NDFU can serve as a key
445 facilitator to attendance. Furthermore, the strong relationships that

446 families build with their therapists and NDFU providers were seen
447 as beneficial.

448 Prior studies have similarly shown that family education
449 initiatives are associated with improved follow-up attendance rates
450 (48). Thus, by combining anticipatory guidance and family
451 education prior to NICU discharge with the availability of home-
452 based services and strategic adoption of telehealth after NICU
453 discharge, paired with improved screening for perinatal mood and
454 anxiety disorders and social determinants of health in both the
455 NICU and NDFU periods, we may improve access to follow-up
456 care and overcome systemic barriers to obtaining important
457 screening tests for developmental delay in this vulnerable
458 population. Furthermore, the development of a regional neonatal-
459 perinatal database in WA state may bridge the gap in
460 communication between academic and community NICUs and the
461 outcomes of the infants that they serve.

462 **Strengths and Limitations**

463 A main strength of this study is the high response rate, with
464 correspondence occurring between all identified NICUs and
465 NDFU/EI centers in WA state. Also, the collaboration with the
466 Washington state Department of Health and the Perinatal Regional
467 Nurses enhanced the ability to reach almost all NICUs and
468 NDFU/EI centers in WA state. Additionally, our study is a

469 contemporary cohort, making the findings generalizable to the
470 current time. As a survey-based study, our design is subject to
471 response bias, although our overall response rates were robust
472 (i.e., 94% NICU providers, 84% NDFU center providers), which
473 minimizes this concern.

474 However, our study has several limitations. One limitation
475 includes relying on provider-reported survey data, which may be
476 subject to recall bias and reflect individual respondents'
477 perspectives rather than institutional practice. Consequently,
478 reported practices, particularly regarding referral, scheduling, and
479 follow-up processes, may not fully reflect actual implementation in
480 clinical workflows across institutions. While providers are well-
481 positioned to identify systems-level processes and challenges,
482 engagement in neurodevelopmental follow-up is also shaped by
483 family experiences, preferences, and social determinants, which
484 were not directly captured in this study. As a result, systems-level
485 barriers and facilitators may be overrepresented relative to family-
486 level determinants. While this study is the first assessment of NDFU
487 practices across WA state, its findings may not generalize to other
488 geographic regions with differing healthcare infrastructures, referral
489 pathways, or access to follow-up services.

490 **Conclusion**

491 This state-wide evaluation of NICU and NDFU programs identifies
492 key opportunities to strengthen NDFU systems for high-risk infants.
493 The variation in type and timing of screenings, assessments and
494 support both within NICUs as well as in NDFU/EI centers may
495 contribute to challenges in improving overall childhood health.
496 Standardization of approaches may offer the benefit of statewide
497 quality improvement opportunities. Barriers to returning for NDFU
498 among high-risk families include limited access to clinics, difficulties
499 in scheduling, and limited family understanding or engagement.
500 Prominent facilitators include enhanced provider relationships and
501 communication, as well as the flexibility of community- or home-
502 based services. A lack of communication between NDFU programs
503 on referred children's outcomes and the referring NICUs highlights
504 the need for a state-wide database or other methods to overcome
505 this notable barrier for providers. Future research incorporating
506 family perspectives, including qualitative interviews with families
507 who do and do not attend NDFU, is a critical next step to inform the
508 development of comprehensive, patient- and family-centered
509 strategies to improve engagement in NDFU. These findings are
510 crucial for enacting and implementing meaningful efforts to
511 ultimately improve the care of high-risk newborns to help ensure
512 that all children can live to their fullest potential.

513 **Additional Information**

514 **Conflict of interest**

515 The authors declare no conflicts of interest.

516 **Ethics approval**

517 This study used a general survey link to collect data from
518 providers across institutions in Washington State. We did not
519 collect any patient data in this investigation. The study protocol
520 was reviewed by the University of Washington Institutional Review
521 Board and was determined exempt from review.

522 **Availability of data and materials**

523 The data that support the findings of analysis may be made
524 available at reasonable request.

525 **Funding source**

526 This investigation was made possible through a generous grant
527 from the University of Washington Population Health Initiative.

528 **Author contributions**

529 KP, SJ, BC, and GCV were responsible for the study concept, and
530 SKN & MW designed and distributed surveys, analyzed data,
531 drafted the abstract and manuscript. SKN, KG, UM, JF, NN, CT,
532 KP, SJ, BC, and GCV contributed to grant writing, editing the
533 surveys, abstract, and manuscript. RP, SE, and BSS,
534 representatives from the Washington State Perinatal
535 Collaborative, assisted in reviewing and distributing the surveys,
536 conducted follow-up, and contributed to the editing of the
537 manuscript.

538 **Acknowledgments**

539 We would like to thank the WA State Department of Health and
540 Washington State Perinatal Collaborative (WSPC) for their
541 support for an investigation to improve access to neonatal follow-
542 up. We also thank the many survey respondents from
543 Neurodevelopmental Follow-up Clinics, Early Support for Infants
544 and Toddlers programs, and Neonatal Intensive Care Units across
545 the state of Washington who shared their institutional knowledge
546 with our team. Study data were collected and managed using
547 REDCap electronic data capture tools hosted at the Institute of
548 Translational Health Sciences (ITHS), which is supported by the
549 National Center for Advancing Translational Sciences of the
550 National Institutes of Health, under award number UL1TR002319.

551 **Declaration of AI-assisted technologies in the writing process**

552 During the preparation of this work the authors used Grammarly to
553 improve the readability of this manuscript. After using this
554 tool/service, the authors reviewed and edited the content as
555 needed and take full responsibility for the content of the
556 publication.

557

558

559

560

561

562

References

- 563 1. Backes CH, Rivera BK, Pavlek L, Beer LJ, Ball MK, Zettler ET, et
564 al. Proactive neonatal treatment at 22 weeks of gestation: a
565 systematic review and meta-analysis. *Am J Obstet Gynecol*. 2021
566 Feb;224(2):158–74. doi:10.1016/j.ajog.2020.07.051 PubMed PMID:
567 32745459.
- 568 2. MANUCK TA, RICE MM, BAILIT JL, GROBMAN WA, REDDY
569 UM, WAPNER RJ, et al. Preterm Neonatal Morbidity and Mortality
570 by Gestational Age: A Contemporary Cohort. *Am J Obstet Gynecol*.
571 2016 Jul;215(1):103.e1-103.e14. doi:10.1016/j.ajog.2016.01.004
572 PubMed PMID: 26772790; PubMed Central PMCID: PMC4921282.
- 573 3. Stoll BJ, Hansen NI, Bell EF, Walsh MC, Carlo WA, Shankaran S,
574 et al. Trends in Care Practices, Morbidity, and Mortality of
575 Extremely Preterm Neonates, 1993-2012. *JAMA*. 2015 Sep
576 8;314(10):1039–51. doi:10.1001/jama.2015.10244
- 577 4. Song IG. Neurodevelopmental outcomes of preterm infants. *Clin*
578 *Exp Pediatr*. 2023 Jul;66(7):281–7. doi:10.3345/cep.2022.00822
579 PubMed PMID: 36596743; PubMed Central PMCID:
580 PMC10331553.
- 581 5. Cheong JLY, Olsen JE, Lee KJ, Spittle AJ, Opie GF, Clark M, et al.
582 Temporal Trends in Neurodevelopmental Outcomes to 2 Years After
583 Extremely Preterm Birth. *JAMA Pediatr*. 2021 Oct 1;175(10):1035–
584 42. doi:10.1001/jamapediatrics.2021.2052 PubMed PMID:
585 34279561; PubMed Central PMCID: PMC8290336.
- 586 6. Perez A, Ritter S, Brotschi B, Werner H, Caflisch J, Martin E, et al.
587 Long-term neurodevelopmental outcome with hypoxic-ischemic
588 encephalopathy. *J Pediatr*. 2013 Aug;163(2):454–9.
589 doi:10.1016/j.jpeds.2013.02.003 PubMed PMID: 23498155.
- 590 7. Kuban KCK, Joseph RM, O'Shea TM, Allred EN, Heeren T,
591 Douglass L, et al. Girls and Boys Born before 28 Weeks Gestation:
592 Risks of Cognitive, Behavioral, and Neurologic Outcomes at Age
593 10 Years. *J Pediatr*. 2016 Jun;173:69-75.e1.
594 doi:10.1016/j.jpeds.2016.02.048 PubMed PMID: 27004675;
595 PubMed Central PMCID: PMC4884461.
- 596 8. Hee Chung E, Chou J, Brown KA. Neurodevelopmental outcomes of
597 preterm infants: a recent literature review. *Transl Pediatr*. 2020
598 Feb;9(Suppl 1):S3–8. doi:10.21037/tp.2019.09.10 PubMed PMID:
599 32206579; PubMed Central PMCID: PMC7082240.
- 600 9. Grantham-McGregor S, Cheung YB, Cueto S, Glewwe P, Richter L,
601 Strupp B, et al. Developmental potential in the first 5 years for
602 children in developing countries. *Lancet*. 2007 Jan 6;369(9555):60–

- 603 70. doi:10.1016/S0140-6736(07)60032-4 PubMed PMID: 17208643;
604 PubMed Central PMCID: PMC2270351.
- 605 10. Hadders-Algra M. Early Diagnostics and Early Intervention in
606 Neurodevelopmental Disorders-Age-Dependent Challenges and
607 Opportunities. *J Clin Med*. 2021 Feb 19;10(4):861.
608 doi:10.3390/jcm10040861 PubMed PMID: 33669727; PubMed
609 Central PMCID: PMC7922888.
- 610 11. Stark AR, Pursley DM, Papile LA, Eichenwald EC, Hankins CT,
611 Buck RK, et al. Standards for Levels of Neonatal Care: II, III, and
612 IV. *Pediatrics*. 2023 Jun 1;151(6):e2023061957.
613 doi:10.1542/peds.2023-061957
- 614 12. Griffiths N, Spence K, Loughran-Fowlds A, Westrup B.
615 Individualised developmental care for babies and parents in the
616 NICU: Evidence-based best practice guideline recommendations.
617 *Early Hum Dev*. 2019 Dec;139:104840.
618 doi:10.1016/j.earlhumdev.2019.104840 PubMed PMID: 31445697.
- 619 13. Litt JS, Campbell DE. High-Risk Infant Follow-Up After NICU
620 Discharge: Current Care Models and Future Considerations. *Clin*
621 *Perinatol*. 2023 Mar;50(1):225–38. doi:10.1016/j.clp.2022.11.004
622 PubMed PMID: 36868707.
- 623 14. Davis BE, Leppert MO, German K, Lehmann CU, Adams-Chapman
624 I, COUNCIL ON CHILDREN WITH DISABILITIES, et al. Primary
625 Care Framework to Monitor Preterm Infants for
626 Neurodevelopmental Outcomes in Early Childhood. *Pediatrics*. 2023
627 Jul 1;152(1):e2023062511. doi:10.1542/peds.2023-062511 PubMed
628 PMID: 37357736.
- 629 15. Bockli K, Andrews B, Pellerite M, Meadow W. Trends and
630 challenges in United States neonatal intensive care units follow-up
631 clinics. *J Perinatol*. 2014 Jan;34(1):71–4. doi:10.1038/jp.2013.136
632 PubMed PMID: 24177221.
- 633 16. Quiñones Cardona V, Cohen SS, Cook N, Cizmeci MN, Chandel A,
634 DiGeronimo R, et al. The Current State of Neonatal
635 Neurodevelopmental Follow-up Programs in North America: A
636 Children’s Hospitals Neonatal Consortium Report. *Am J Perinatol*.
637 2024 Oct;41(14):1956–64. doi:10.1055/a-2283-8843 PubMed
638 PMID: 38458236.
- 639 17. The Individuals with Disabilities Education Act (IDEA), Part C:
640 Early Intervention for Infants and Toddlers with Disabilities
641 [legislation] [Internet]. [cited 2026 Mar 16]. Available from:
642 <https://www.congress.gov/crs-product/R43631>
- 643 18. ECTA Center [Internet]. [cited 2026 Apr 9]. ECTA Center: Part C of
644 IDEA. Available from: <https://ectacenter.org/partc/partc.asp>

- 645 19. Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early
646 developmental intervention programmes provided post hospital
647 discharge to prevent motor and cognitive impairment in preterm
648 infants. *Cochrane Database Syst Rev*. 2015 Nov
649 24;2015(11):CD005495. doi:10.1002/14651858.CD005495.pub4
650 PubMed PMID: 26597166; PubMed Central PMCID: PMC8612699.
- 651 20. Spittle AJ, Olsen J, Kwong A, Doyle LW, Marschik PB, Einspieler
652 C, et al. The Baby Moves prospective cohort study protocol: using a
653 smartphone application with the General Movements Assessment to
654 predict neurodevelopmental outcomes at age 2 years for extremely
655 preterm or extremely low birthweight infants. *BMJ Open*. 2016 Oct
656 3;6(10):e013446. doi:10.1136/bmjopen-2016-013446 PubMed
657 PMID: 27697883; PubMed Central PMCID: PMC5073614.
- 658 21. Orton J, Doyle LW, Tripathi T, Boyd R, Anderson PJ, Spittle A.
659 Early developmental intervention programmes provided post
660 hospital discharge to prevent motor and cognitive impairment in
661 preterm infants - Orton, J - 2024 | Cochrane Library [Internet]. [cited
662 2026 Mar 11]. Available from:
663 [https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD00](https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD005495.pub5/full)
664 [5495.pub5/full](https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD005495.pub5/full)
- 665 22. Litt JS, Edwards EM, Lainwala S, Mercier C, Montgomery A,
666 O'Reilly D, et al. Optimizing High-risk Infant Follow-up in
667 Nonresearch-based Paradigms: The New England Follow-up
668 Network. *Pediatr Qual Saf*. 2020;5(3):e287.
669 doi:10.1097/pq9.000000000000287 PubMed PMID: 32656462;
670 PubMed Central PMCID: PMC7297406.
- 671 23. Swearingen C, Simpson P, Cabacungan E, Cohen S. Social
672 Disparities Negatively Impact Neonatal Follow-up Clinic
673 Attendance of Premature Infants Discharged from the Neonatal
674 Intensive Care Unit. *Journal of perinatology : official journal of the*
675 *California Perinatal Association*. 2020 Mar 23;40(5):790.
676 doi:10.1038/s41372-020-0659-4 PubMed PMID: 32203182.
- 677 24. Fortune A, Perkins E, Paize F, Palanisami B, Gladstone M.
678 Managing mothers' and fathers' uncertainty during their journey
679 through early neurodevelopmental follow-up for their high-risk
680 infants-A qualitative account. *Child Care Health Dev*. 2024
681 Jan;50(1):e13168. doi:10.1111/cch.13168 PubMed PMID:
682 37737651.
- 683 25. Fraiman YS, Edwards EM, Horbar JD, Mercier CE, Soll RF, Litt JS.
684 Racial Inequity in High-Risk Infant Follow-Up Among Extremely
685 Low Birth Weight Infants. *Pediatrics*. 2023 Feb
686 1;151(2):e2022057865. doi:10.1542/peds.2022-057865 PubMed
687 PMID: 36594226; PubMed Central PMCID: PMC10696436.

- 688 26. Ponnappakkam A, Carr NR, Comstock BA, Perez K, O'Shea TM,
689 Tolia VN, et al. Factors Associated with Outpatient Therapy
690 Utilization in Extremely Preterm Infants. *Am J Perinatol*. 2024
691 Mar;41(4):458–69. doi:10.1055/a-1692-0544
- 692 27. Guillén U, DeMauro S, Ma L, Zupancic J, Roberts R, Schmidt B, et
693 al. Relationship between attrition and neurodevelopmental
694 impairment rates in extremely preterm infants at 18 to 24 months: a
695 systematic review. *Arch Pediatr Adolesc Med*. 2012
696 Feb;166(2):178–84. doi:10.1001/archpediatrics.2011.616 PubMed
697 PMID: 22312176.
- 698 28. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG.
699 Research electronic data capture (REDCap)--a metadata-driven
700 methodology and workflow process for providing translational
701 research informatics support. *J Biomed Inform*. 2009
702 Apr;42(2):377–81. doi:10.1016/j.jbi.2008.08.010 PubMed PMID:
703 18929686; PubMed Central PMCID: PMC2700030.
- 704 29. Profit J, Lyell DJ, Gould JB. The California Perinatal Quality Care
705 Collaborative: Together We Are Stronger. *Obstet Gynecol Clin*
706 North Am. 2026 Mar;53(1):51–64. doi:10.1016/j.ogc.2025.09.008
707 PubMed PMID: 41692541.
- 708 30. Ryder S, Kerner-Rossi M, Brachio S, Yoon L, Brennan K,
709 Hammond J, et al. Standardizing early cerebral palsy detection in
710 high-risk infants: reducing age at diagnosis through a quality
711 improvement initiative. *J Perinatol*. 2025 Sep 9. doi:10.1038/s41372-
712 025-02412-z PubMed PMID: 40925942.
- 713 31. Damiano DL, Longo E. Early intervention evidence for infants with
714 or at risk for cerebral palsy: an overview of systematic reviews. *Dev*
715 *Med Child Neurol*. 2021 Jul;63(7):771–84. doi:10.1111/dmcn.14855
716 PubMed PMID: 33825199; PubMed Central PMCID: PMC9413025.
- 717 32. He L, Li H, Wang J, Chen M, Gozdas E, Dillman JR, et al. A multi-
718 task, multi-stage deep transfer learning model for early prediction of
719 neurodevelopment in very preterm infants. *Sci Rep*. 2020 Sep
720 15;10(1):15072. doi:10.1038/s41598-020-71914-x PubMed PMID:
721 32934282; PubMed Central PMCID: PMC7492237.
- 722 33. Carlton K, Zhang J, Cabacungan E, Herrera S, Koop J, Yan K, et al.
723 Machine learning risk stratification for high-risk infant follow-up of
724 term and late preterm infants. *Pediatr Res*. 2024 Jun 26.
725 doi:10.1038/s41390-024-03338-6 PubMed PMID: 38926547;
726 PubMed Central PMCID: PMC11669732.
- 727 34. Adepoju OE, Chae M, Liaw W, Angelocci T, Millard P, Matuk-
728 Villazon O. Transition to telemedicine and its impact on missed
729 appointments in community-based clinics. *Ann Med*. 54(1):98–107.

- 730 doi:10.1080/07853890.2021.2019826 PubMed PMID: 34969330;
731 PubMed Central PMCID: PMC8725902.
- 732 35. Ch'en PY, Barry D, Morgan LA, Wainwright MS, Patel PB.
733 Telehealth usage patterns among pediatric neurology patients during
734 and after the COVID-19 pandemic in Washington state. *Equity*
735 *Neuroscience*. 2025 Sep 1;1(2):100011.
736 doi:10.1016/j.neuros.2025.100011
- 737 36. Maitre NL, Benninger KL, Neel ML, Haase JA, Pietruszewski L,
738 Levengood K, et al. Standardized Neurodevelopmental Surveillance
739 of High-risk Infants Using Telehealth: Implementation Study during
740 COVID-19. *Pediatr Qual Saf*. 2021 Jul 28;6(4):e439.
741 doi:10.1097/pq9.0000000000000439 PubMed PMID: 34345752;
742 PubMed Central PMCID: PMC8322542.
- 743 37. Ke JC, Hayati Rezvan P, Vanderbilt D, Mirzaian CB, Deavenport-
744 Saman A, Smith BA. Similar early intervention referral rates
745 following in-person administration of the Bayley Scales of Infant
746 and Toddler Development, 4th Edition versus Telehealth
747 Administration of the Developmental Assessment in Young
748 Children, 2nd Edition in the high-risk infant population. *Early Hum*
749 *Dev*. 2024 Mar;190:105971. doi:10.1016/j.earlhumdev.2024.105971
750 PubMed PMID: 38367589.
- 751 38. Kodjebacheva GD, Culinski T, Kawser B, Amin S. Provision of
752 telehealth services to pediatric clients during the COVID-19
753 pandemic: A scoping review related to health outcomes. *Health*
754 *Sciences Review*. 2024 Jun 1;11:100156.
755 doi:10.1016/j.hsr.2024.100156
- 756 39. Albayrak B, Dathe AK, Cordier L, Felderhoff-Müser U, Hüning B.
757 Clinical experience on video consultation in preterm follow-up care
758 in times of the COVID-19 pandemic. *Pediatr Res*. 2021
759 May;89(7):1610–1. doi:10.1038/s41390-020-01169-9 PubMed
760 PMID: 32961545.
- 761 40. Hintz SR, Gould JB, Bennett MV, Lu T, Gray EE, Jocson MAL, et
762 al. Factors Associated with Successful First High-Risk Infant Clinic
763 Visit for Very Low Birth Weight Infants in California. *The Journal*
764 *of Pediatrics*. 2019 Jul;210:91-98.e1.
765 doi:10.1016/j.jpeds.2019.03.007
- 766 41. Ballantyne M, Stevens B, Guttman A, Willan AR, Rosenbaum P.
767 Maternal and infant predictors of attendance at Neonatal Follow-Up
768 programmes: Predictors of attendance at Neonatal Follow-Up
769 programmes. *Child Care Health Dev*. 2014 Mar;40(2):250–8.
770 doi:10.1111/cch.12015
- 771 42. Brady JM, Pouppirt N, Bernbaum J, D'Agostino JA, Gerdes M,
772 Hoffman C, et al. Why do children with severe bronchopulmonary

- 773 dysplasia not attend neonatal follow-up care? Parental views of
774 barriers. *Acta Paediatr.* 2018 Jun;107(6):996–1002.
775 doi:10.1111/apa.14265 PubMed PMID: 29420848.
- 776 43. Miller K, Willett S, Mccarty D, Dusing SC. Neonatal therapy
777 principles during transition from neonatal intensive care unit to
778 home: A modified Delphi study. *Dev Med Child Neurol.* 2025
779 Mar;67(3):357–64. doi:10.1111/dmcn.16075 PubMed PMID:
780 39187953; PubMed Central PMCID: PMC11794667.
- 781 44. Bry A, Wigert H. Psychosocial support for parents of extremely
782 preterm infants in neonatal intensive care: a qualitative interview
783 study. *BMC Psychol.* 2019 Nov 29;7(1):76. doi:10.1186/s40359-
784 019-0354-4 PubMed PMID: 31783784; PubMed Central PMCID:
785 PMC6883543.
- 786 45. Finlayson F, Olsen JE, Remedios L, Spittle A. Interventions to
787 support parents of infants at risk or with a diagnosis of
788 neurodevelopmental disability. *Acta Paediatr.* 2021
789 Mar;110(3):1068–9. doi:10.1111/apa.15683 PubMed PMID:
790 33314289.
- 791 46. Garfield CF, Simon CD, Rutsohn J, Lee YS. Stress From the
792 Neonatal Intensive Care Unit to Home: Paternal and Maternal
793 Cortisol Rhythms in Parents of Premature Infants. *J Perinat Neonatal*
794 *Nurs.* 2018 Sep;32(3):257–65. doi:10.1097/JPN.000000000000296
795 PubMed PMID: 29194078; PubMed Central PMCID: PMC5976503.
- 796 47. Okito O, Yui Y, Wallace L, Knapp K, Streisand R, Tully C, et al.
797 Parental resilience and psychological distress in the neonatal
798 intensive care unit. *J Perinatol.* 2022 Nov;42(11):1504–11.
799 doi:10.1038/s41372-022-01478-3 PubMed PMID: 35927487.
- 800 48. Brachio SS, Farkouh-Karoleski C, Abreu A, Zygmunt A,
801 Purugganan O, Garey D. Improving Neonatal Follow-up: A Quality
802 Improvement Study Analyzing In-hospital Interventions and Long-
803 term Show Rates. *Pediatr Qual Saf.* 2020;5(6):e363.
804 doi:10.1097/pq9.0000000000000363 PubMed PMID: 33575523;
805 PubMed Central PMCID: PMC7870232.
- 806 49. March of Dimes. (2024). *Preterm birth by state*. PeriStats. Retrieved
807 April 10, 2026, from <https://www.marchofdimes.org/peristats>

808

809

810

811

NICU Provider Survey (N=15)	n (%)	Criteria for NDFU Referral	n (%)
Level of NICU		Birth weight ¹	14 (93)
Level III	10 (67)	Gestational Age ²	14 (93)
Level IV	5 (33)	Neonatal Opiate Withdrawal Syndrome	13 (87)
Role of Respondent		Hypoxic Ischemic Encephalopathy	12 (80)
Medical Director	6 (40)	Seizures	10 (67)
Nurse Manager	5 (33)	Cardiac Surgery	6 (40)
Case Manager	1 (7)	Non-Cardiac Surgery	5 (33)
Discharge Coordinator	1 (7)	Extra Corporeal Membrane Oxygenation	5 (33)
Lactation Consultant	1 (7)	Genetic Diagnosis	3 (20)
Therapy Services Manager	1 (7)	Perinatal Brain Injury	1 (7)
		Hyperbilirubinemia at Exchange	1 (7)
		Apgar <5 at 5 min	1 (7)
NDFU Center Provider Survey (N=16)	n (%)	NDFU Center Characteristics	n (%)
Type of NDFU Center		Number of Patients Seen per Month	
Early Intervention Program	12 (75)	Less than 10	7 (44)
Neurodevelopmental Clinic	4 (25)	10-20	5 (31)
Role of Respondent		21-30	2 (13)
Director	8 (50)	31-40	1 (6)
Program Manager	3 (19)	More than 40	1 (6)
Lead Therapist	3 (19)	Clinic Utilizes Telehealth	12 (75)
Care Manager	2 (13)	Clinic Tracks No Shows	12 (75)
		% No Show at First Visit³	
		0-25%	9 (75)
		26-50%	2 (17)
		Unknown	1 (8)
		% No Show at 12-Month Visit³	
		0-25%	6 (50)
		26-50%	1 (8)
		Unknown	5 (42)

812 Table 1

813 Title: Characteristics of Surveyed Neonatal Intensive Care Unit (NICU) and
814 Neurodevelopmental Follow-up (NDFU) Center Providers and Their Practice
815 Settings

816 Caption:

817 ¹NICU providers reported examples of birthweight criteria to include: ≤1500g at
818 birth, Intrauterine Growth Restriction and Small for Gestational Age
819 (<10%³tile).

820 ²Most gestational age criteria included infants <32 weeks' gestation at birth,
821 though the upper gestational age cut-off ranged from 30-37 weeks' gestation.

822 ³Only NDFU center providers indicating their clinic tracked no-shows (N=12)
823 were surveyed about percentages of no-shows at initial and 12-month visits.

Table 2

Barrier Theme	Definition	Facilitator Theme	Definition
Care Coordination and System Navigation	Challenges related to coordinating NDFU care and navigating the healthcare system, including gaps in coordination, unclear processes, and difficulty accessing appropriate resources.	Availability of Specialized Services	Presence and accessibility of specialized clinical or therapeutic services within NDFU, including providers with specific areas of expertise such as infant mental health or specialized therapies.
Limited Family Understanding or Engagement	Family-level factors related to limited understanding of or engagement with NDFU, including unclear concerns, lack of readiness or interest, language barriers, and confusion about the purpose or importance of NDFU.	Community-Based Access & Reduced Travel Burden	Structural and operational features that increase access to care, including community-based NDFU center locations, home-based services, telehealth availability, and transportation assistance that reduce travel burden for follow-up.
Logistical Limitations	Factors that limit families' ability to access or attend NDFU, including transportation, time constraints, caregiver responsibilities, caregiver illness, housing instability, and competing life demands.	Family-Centered and Culturally Responsive Care	Care practices that actively involve families in care and adapt to families' cultural and linguistic contexts.
Patient-Related Clinical Factors	Acute or ongoing illness of the patient, including rehospitalization or post-discharge complications, that interferes with attendance or participation in NDFU services.	Family Education and Information Received at NDFU	Families receiving, understanding, and valuing information about their child's care and services at NDFU, including explanations of why and how they are involved in programs or therapies.
Psychosocial and Socioeconomic Stressors	Social, emotional, and economic stressors that affect families' capacity to engage in NDFU, including family dynamics, financial strain, psychosocial distress, and prior negative healthcare experiences.	Flexible and Coordinated Care Delivery	NDFU center structures and processes that promote coordinated, continuous, and adaptable access to services, including flexible scheduling, streamlined intake, and goal-oriented care-planning.
Scheduling Processes	Clinic- and system-level processes related to appointment scheduling that affect families' ability to attend NDFU visits, including scheduling conflicts, long waitlists, forgotten appointments, and outreach challenges.	Provider Relationships and Communication	Relational and communication aspects of care, including supportive provider interactions, consistent therapeutic relationships, and accessible communication between families and care team members.

Table 2

Title: Defined Themes of Perceived Barriers and Facilitators to Neurodevelopmental Follow-Up

Caption: Barrier and facilitator themes were defined for open-ended survey questions of NDFU center providers.

Figure 1

Title: Geographic Distribution of Survey Respondents and Non-Respondents Across Washington State.

Caption: The locations of all NICU and NDFU centers approached for surveys were identified using the Global Positioning System (GPS) and plotted on a map to indicate the type of center and respondent status.

Figure 2

Title: Methods Used by NDFU Centers to Share Developmental Testing Results with Referring NICUs¹

Caption:

Grey bars indicate methods of communication used by Early Intervention programs and hatched bars indicate methods of communication used by Neurodevelopmental Clinics.

¹Note that 0 (0%) of NICU survey respondents reported receiving information from NDFU programs regarding developmental testing for referred infants.

Figure 3

Title: Thematic Analysis of Barriers and Facilitators to Neurodevelopmental Follow-Up

Caption: Frequency of barrier and facilitator themes (defined in Table 2) were analyzed from open-ended survey questions of NDFU center providers. Gray bars indicate facilitators, and hatched bars indicate barriers to NDFU

Figures

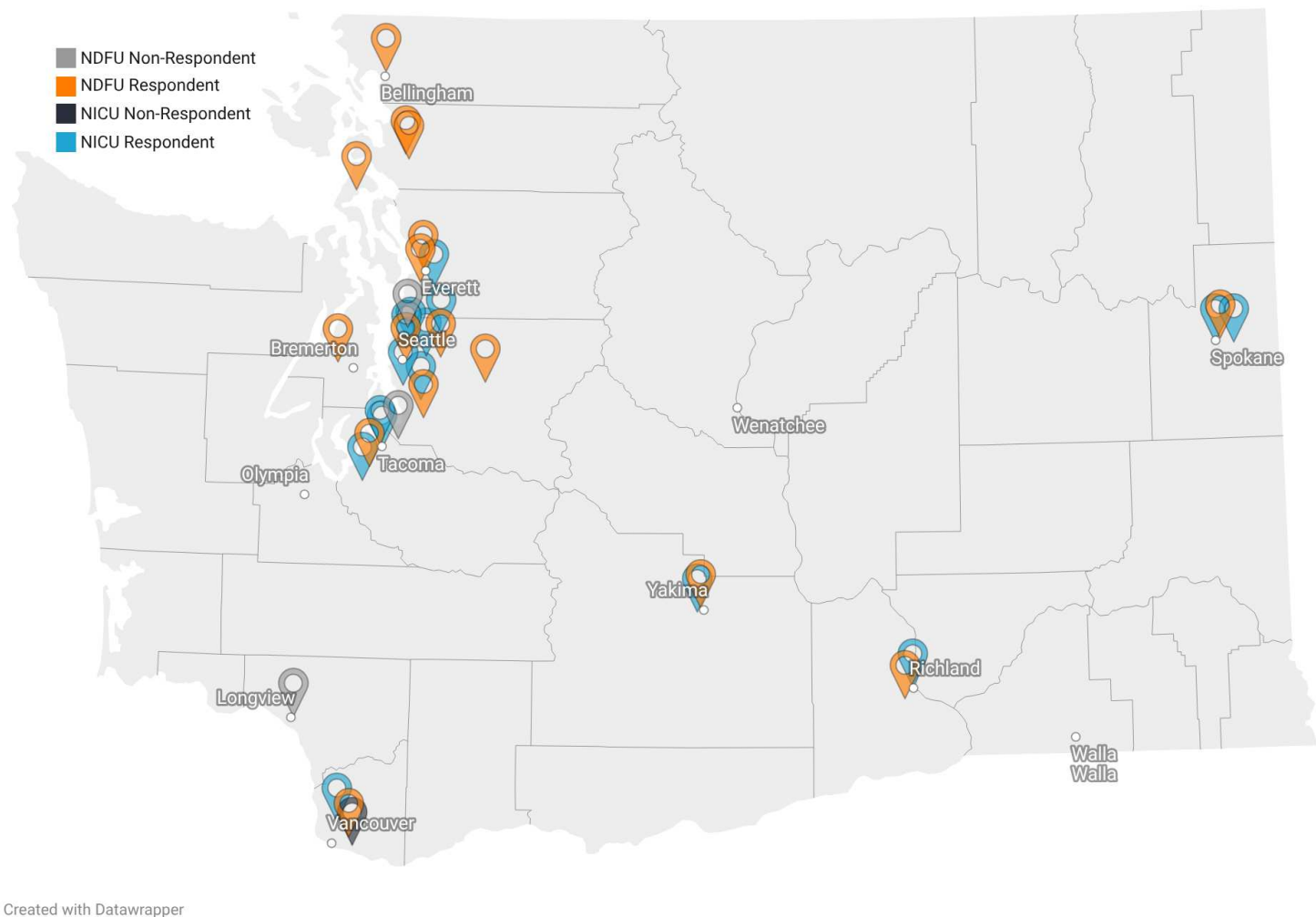


Figure 1

Title: Geographic Distribution of Survey Respondents and Non-Respondents Across Washington State.
Caption: The locations of all NICU and NDFU centers approached for surveys were identified using the Global Positioning System (GPS) and plotted on a map to indicate the type of center and respondent status

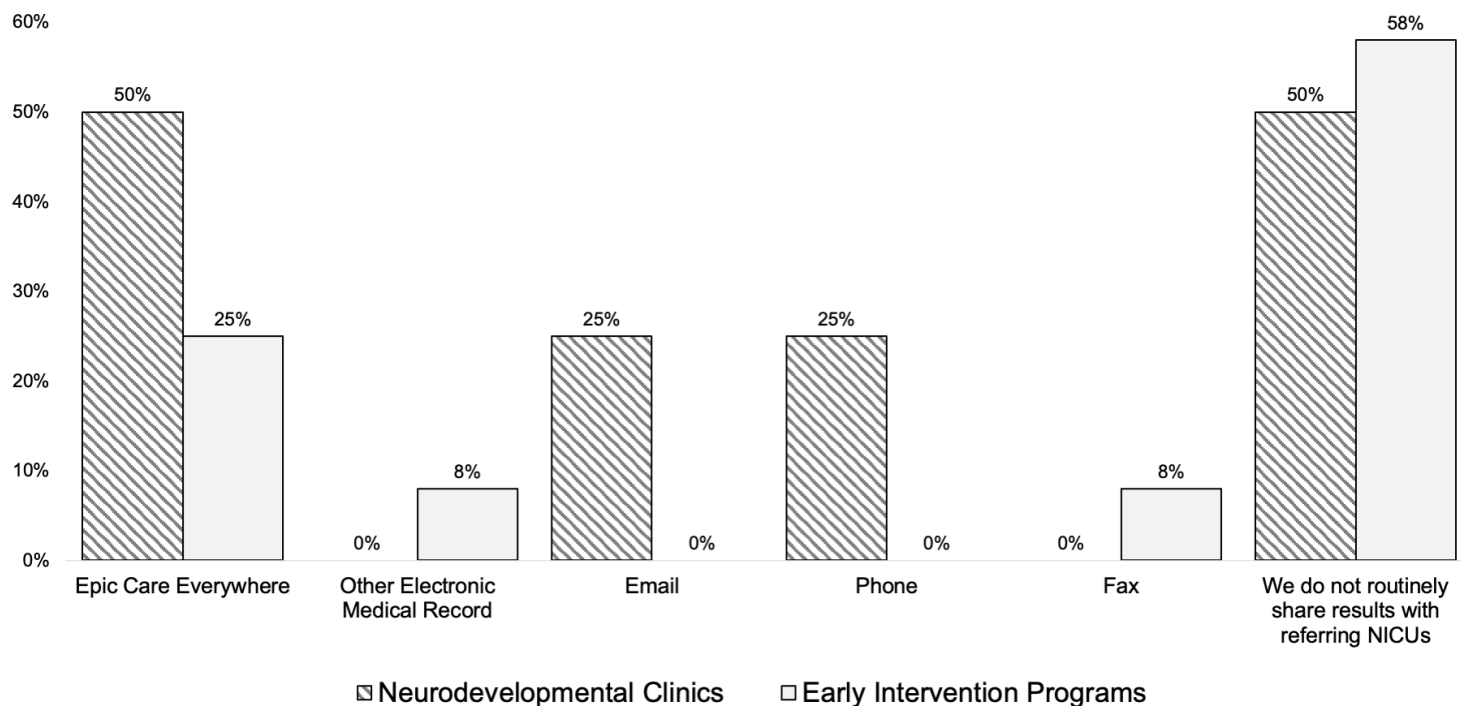


Figure 2

Title: Methods Used by NDFU Centers to Share Developmental Testing Results with Referring NICUs ¹

Caption:

Grey bars indicate methods of communication used by Early Intervention programs and hatched bars indicate methods of communication used by Neurodevelopmental Clinics.

¹ Note that 0 (0%) of NICU survey respondents reported receiving information from NDFU programs regarding developmental testing for referred infants

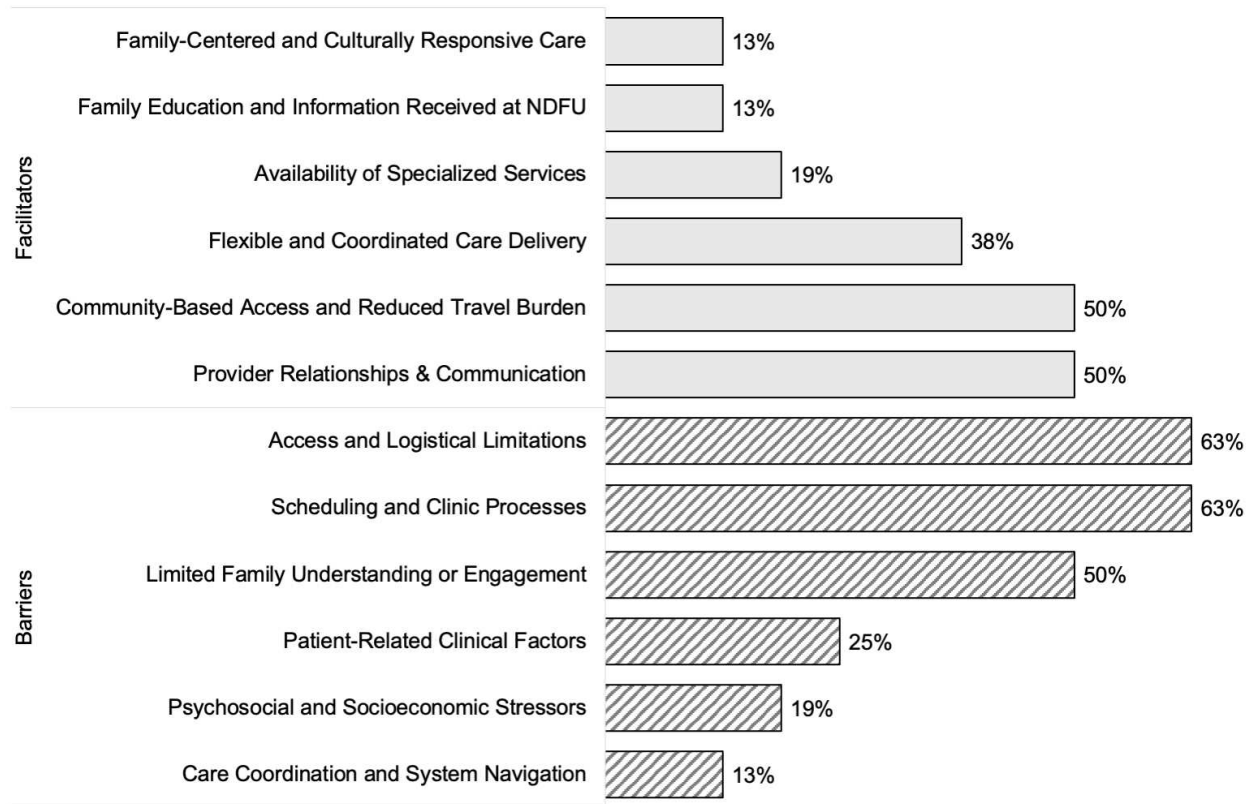


Figure 3

Title: Thematic Analysis of Barriers and Facilitators to Neurodevelopmental Follow-Up

Caption: Frequency of barrier and facilitator themes (defined in Table 2) were analyzed from open-ended survey questions of NDFU

center providers. Gray bars indicate facilitators, and hatched bars indicate barriers to NDFU

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [NDFUcenterprovidersurvey.pdf](#)
- [NICUprovidersurvey.pdf](#)