

PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

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DOI: 10.1542/peds.2020-0360

Journal: *Pediatrics*

Article Type: Pediatrics Perspectives

Citation: Horbar JD, Edwards EM, Ogbolu Y. Our responsibility to follow through for NICU infants and their families. *Pediatrics*. 2020; doi: 10.1542/peds.2020-0360

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Our Responsibility to Follow Through for NICU Infants and Their Families

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Financial Disclosure Statement: Dr. Horbar is Chief Executive Officer, President, Chief Scientific Officer, and an unpaid member of the Board of Directors of Vermont Oxford Network. Dr. Edwards receives salary support from Vermont Oxford Network. Dr. Ogbolu is an unpaid member of the Board of Directors of Vermont Oxford Network.

Funding Source: None

Conflict of Interest Statement: The authors have no conflicts of interest relevant to this article to disclose.

Abbreviations: PBP: potentially better practice

Contributors Statement Page

Dr. Horbar made substantial contributions to the conception and design of the manuscript, drafted the initial manuscript, and critically reviewed and revised it.

Drs. Edwards and Ogbolu made substantial contributions to the design of the manuscript and critically reviewed and revised it.

All authors approved the final manuscript as written and agree to be accountable for all aspects of the work.

In America, health and well-being are, to a large extent, determined by a person's race, ethnicity, income, immigration status, and neighborhood of residence. Racism, segregation, and inequality of income, opportunity, and wealth cause disparities in health outcomes across the life course¹. The effects are particularly pronounced for infants requiring neonatal intensive care and their families because of the already significant risk for neurodevelopmental disabilities and need for specialized services.

As health professionals, pediatricians, and neonatal healthcare providers, we have the responsibility to address these social determinants of health. We must learn to practice social as well as technical medicine² and follow through, accepting that our responsibility to the infants and families we serve extends beyond the hospital or clinic walls. Although in this article we focus on follow through in the neonatal intensive care setting, the ideas for practicing social medicine we present have wider application in pediatrics, obstetrics, and beyond.

We have proposed the term “follow through” to distinguish our proposal from the more typical neonatal practice of “follow up” where the services and staffing of clinics are focused primarily on medical conditions and assessment of neurodevelopment after discharge from the NICU. Only 70% of follow-up clinics provide any social services, for example, and fewer than 10% providing legal services.³ We propose a more comprehensive approach that begins before birth and continues into childhood involving health professionals, families and communities as partners to meet the social as well as medical needs of infants and families.

Responsibility to Follow Through

In proposing follow through to the neonatal community, we have heard two main concerns. First, “this is not my responsibility. I am a physician, nurse, respiratory therapist,

pharmacist, nutritionist or other allied health professional. This is a social problem, something to be addressed and solved by government and society at large, not by me or other health professionals. Let someone else take this on.” Second, “even if I accept that this is my responsibility, there is nothing I can do about it. I already have my hands full providing the technical aspects of bedside care.”

We argue that it is our responsibility to follow through and address the social determinants of health with the same energy and expertise that we devote to the technical aspects of the care we provide. As citizens of a country that has systematically denied rights and opportunities to many of our fellow citizens, we believe that follow through is our ethical responsibility. As a result of longstanding federal, state, and local laws and policies, black and other minority Americans live in poorer neighborhoods, attend lower quality schools, and receive care at lower quality hospitals. Non-traditional and LGBT families and immigrant families face ongoing discrimination. We have the responsibility to do what we can to remedy the impact of past and ongoing injustices on the infants and families we serve.

Potentially Better Practices for Follow Through

Vermont Oxford Network has developed 68 specific Potentially Better Practices, PBPs, to assist NICU teams to follow through that individuals and teams can test and implement in their own units (Supplemental Table). We refer to improvement ideas as Potentially Better Practices rather than “better” or “best” practices to indicate that no practice is better or best until adapted, tested and shown to work in the local context.

The PBPs are divided into four main categories. Each category includes multiple ideas that teams can adapt and test in their own units. Users are free to mix, tweak, and build upon the

PBPs with appropriate attribution under a creative commons license. We provide a few examples.

Promote a culture of equity

Follow through requires establishing culturally sensitivity in staff (PBP 2), acknowledging and managing implicit and explicit personal biases (PBP 3), and promoting a culture of equity (PBP 4) where all individuals work to eliminate health disparities through respect, fairness, and cultural competency. A specific example of action recommended by nurse leaders is nurse-led rounds focused on improving the patient experience and supporting culturally sensitive care for diverse populations. Purposeful nurse rounding requires empathy and deep listening for understanding, skills that must be modelled by leaders and expected of all staff⁴.

Identify social risks of families and provide interventions to prevent and mitigate those risks

Follow through starts when infants are still in the hospital with screening for social determinants of health (PBP 8) and providing social support when necessary, including mental health, drug, alcohol, and smoking cessation counseling (PBPs 13 and 14) and assistance with housing, meals, and transportation (PBP 15). Social workers and legal specialists, disciplines not routinely represented in current follow-up clinics³, can help address families' problems and improve health equity outside of the hospital (PBPs 9 and 11). A successful example of legal participation on pediatric primary care center teams that can serve as a model for NICU teams is the Cincinnati Child Health-Law Partnership (Child HeLP), a medical legal partnership between Cincinnati Children's Hospital Medical Center's primary care centers and the Legal Aid Society of Greater Cincinnati. Child HeLP resolves legal issues common among families living in

poverty such as substandard housing, denial of public benefits, immigration issues, and intimate partner violence⁵. Attorneys with expertise in poverty and immigration law will be valuable members of multidisciplinary teams.

Take action to assist families after discharge (transition to home)

The transition to home is a critical point at which social factors must be addressed. Families leaving the controlled environment of the hospital will need to rely on their own skills, those of family and supportive individuals, and available neighborhood and community resources. Providing carefully tailored discharge teaching (PBP 23), assuring a medical home for families after discharge (PBP 26), utilizing home visiting and social media (PBPs 32, 36), and ensuring links to community services (PBP 29) are a few of the PBPs in this category. In some cases, meaningful clinical-community partnerships (PBP 41) may be necessary to change home environments. Administrators of Nationwide Children's Hospital in Columbus, Ohio, developed the Healthy Neighborhoods, Healthy Families effort in recognition that the hospital's responsibility did not end once people left the campus. The beginning of the program focused on improving housing; now the program also addresses job training and leadership development⁶. Programs like Healthy Neighborhoods, Healthy Families

Maintain support for families through infancy

Our responsibility to follow through extends into infancy and childhood. Use of parent coaches and innovative medical visit structures (PBPs 42, 44) and providing contraception, family planning, and high-quality obstetrical care to improve outcomes for future pregnancies can help improve equity for children and their families (PBP 50). Evidence-based early

intervention programs (PBP 43) are effective and should be routinely available to at risk NICU graduates.

Develop robust quality improvement efforts to ensure equitable, high-quality NICU and follow through care to all newborns by eliminating modifiable disparities

Quality improvement provides the ideal structure within which NICU teams can identify, test, and implement PBPs to address the social determinants of health. By establishing measurable aims (PBP 51), engaging all NICU disciplines, parents, and primary care providers on the teams (PBPs 53, 54), and obtaining support from organizational leaders through a formal charter (PBP 55), teams will create the structure within which improvements can be made and tracked. An innovative quality improvement program that achieved reductions in hospital days for children from two high morbidity, high poverty neighborhoods in Cincinnati, Ohio and which could be adapted for NICU patients and families is an example of how quality improvement methods can be applied successfully to address social determinants of health⁷.

Advocate for social justice at the local, state, and national levels

Finally, and perhaps most importantly, we must advocate for social justice, ensure that social justice is part of every organization's mission, and make sure that our health care organizations accept and act on their responsibility for the populations and neighborhoods that they serve (PBPs 61,62 and 67). A successful example of bringing together multiple stakeholders to address social justice at the community level is the Social Determinants of Health Taskforce of Baltimore, a multi-sector voluntary collaborative action group comprised of community organizations, government representatives, academia, urban planners, entrepreneurs, and

healthcare system leaders working to address social determinants of health (<https://msa.maryland.gov/msa/mdmanual/26excom/html/04bcitysocial.html>). This grassroots taskforce works collectively to address and eliminate the negative social factors that are cyclical in nature, by collaborating with local community based and public agencies to improve health, housing, education, workforce development and issues of social justice.

Time to Get Started

The list of Potentially Better Practices for Follow Through from Vermont Oxford Network is intended as a starting point for individuals and teams. The PBPs vary greatly in ease of implementation and potential cost. Medical-legal partnerships are feasible but may involve additional cost unless attorney resources can be obtained without cost, whereas implementing nurse rounds to address follow through may be inexpensive and feasible, only requiring a dedicated champion. Hospital administrators and champions outside of the hospital may be required for some PBPs, such as clinical-community partnerships.

Our advice is to find something on the list that makes sense for your unit. Adapt a change idea to work in your local context. Test it. Start small. If others on your team are not ready, find a change you can make as an individual. Over time, we will learn together as a community how to most effectively practice social as well as technical medicine in the NICU. We will learn which interventions are most cost effective and how to successfully implement them. The list of PBPs will be refined. The most important thing is to get started. By following through, we will play our part in addressing the inequities and injustices so deeply ingrained in our society while improving the health and well-being of the infants and families we serve.

Addendum

In the few months since this Pediatric Perspective was submitted, the COVID-19 pandemic has exposed us to extraordinary challenges and disruptions in our personal and professional lives. Millions have been infected; hundreds of thousands have died. Health systems around the world are overwhelmed with uncertain consequences for pregnant women, newborn infants and young families. The social safety net is fraying. Unemployment is soaring. Community resources are stretched beyond the breaking point. Minorities, the poor, and those in living in disadvantaged neighborhoods with already insufficient access to medical and social services are at the greatest danger. Social distancing and staying at home are luxuries for the well-to-do. The racial and economic inequities deeply ingrained in our society will only be magnified.

We realize that as the pandemic unfolds, health professionals will be under extreme stress, heroically caring for infants and families in the face of significant personal risk and severe shortages of beds, equipment, and supplies. Although the comprehensive approach to follow through described in this Pediatric Perspective may be difficult to provide in the near term, we must remain sensitive to the plight of the most disadvantaged among us and do everything we can to address their social as well as medical needs. As a result of the pandemic, following through for patient and families is more important than ever.

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Table. Examples of Potentially Better Practices for Follow Through¹

Promote a Culture of Equity	<ul style="list-style-type: none"> • Establish cultural sensitivity • Acknowledge and manage implicit and explicit personal biases • Facilitate nurse-led rounds
Identify Social Risks of Families and Provide Interventions to Prevent and Mitigate Those Risks	<ul style="list-style-type: none"> • Screen for social determinants of health • Provide support when necessary such as assistance with housing, meals, and transportation and counseling for mental health, drug or alcohol problems, or smoking cessation • Include social workers and legal specialists on teams
Take Action to Assist Families After Discharge	<ul style="list-style-type: none"> • Provide carefully tailored discharge teaching • Utilize home visiting and social media • Establish meaningful clinical-community partnerships
Maintain Support for Families Through Infancy	<ul style="list-style-type: none"> • Use parent coaches and innovative medical visit structures • Provide contraception, family planning, and high-quality obstetric care • Provide evidence-based early intervention programs
Develop Robust Quality Improvement Efforts to Ensure Equitable, High-quality NICU and Follow Through Care to All Newborns by Eliminating Modifiable Disparities	<ul style="list-style-type: none"> • Establish measurable aims • Engage all disciplines, parents, and primary care providers • Obtain support from organizational leaders through a formal charter
Advocate for Social Justice at the Local, State, and National Levels	<ul style="list-style-type: none"> • Ensure that social justice is part of every organization's mission • Advocate that health care organizations accept and act on their responsibility for the populations and neighborhoods that they serve • Speak out!

1. Additional Potentially Better Practices can be found in the Supplemental Table.

Supplemental Table

Vermont Oxford Network Potentially Better Practices for Follow Through

I. Promote a culture of equity

1. Provide training and education in the social determinants of health to staff^{1,2}
2. Provide cultural sensitivity training to staff³⁻⁷
3. Acknowledge and manage implicit and explicit personal bias⁸⁻¹⁵
4. Promote a culture of equity¹⁶⁻¹⁸
5. Create a disparities dashboard¹⁹⁻²¹
6. Create a culture committed to follow through^{19,22}

II. Identify social risks of families and provide interventions to prevent and mitigate those risks

7. Screen all families for social risks and social support using a standardized tool²³⁻³⁰
8. Use electronic health records to identify patterns and inform clinical decisions^{28,31-33}
9. Include a social worker or other social health professional on the team^{34,35}
10. Create alliances with community organizations (clinical-community partnerships)³⁶⁻⁴⁵
11. Include a paralegal or attorney on the team⁴⁶⁻⁴⁸
12. Provide parenting and family support tailored to individual family strengths and needs⁴⁹⁻⁵¹
13. Provide mental health services for families during the hospital stay⁵²⁻⁵⁷
14. Provide referrals for drugs, alcohol, and smoking cessation counselling and treatment⁵⁸⁻⁶³
15. Provide housing, meals, and transportation vouchers for families⁶⁴⁻⁷⁰
16. Provide back to sleep education⁷¹⁻⁸⁰
17. Provide sibling care for families^{81,82}
18. Practice family integrated care tailored to the capabilities and needs of families⁸³⁻⁸⁵
19. Provide trauma-informed care^{86,87}
20. Provide lactation support using peer counsellors and other approaches⁸⁸⁻⁹⁹
21. Assess eligibility for SSI, WIC, early intervention, and other public benefits¹⁰⁰⁻¹⁰³
22. Provide language support and culturally appropriate translation services for families¹⁰⁴⁻¹⁰⁷

II A. Take action to assist to families after discharge (transition to home)

23. Provide discharge education and planning tailored to each family's needs^{106,108-113}
24. Begin discharge planning and teaching at admission¹¹⁴
25. Estimate discharge date at admission and revise regularly during the stay¹¹⁵⁻¹¹⁷
26. Implement a medical home model for patients and families¹¹⁸⁻¹²²
27. Establish effective communications with the primary care provider¹²²
28. Create a health coach program¹²³
29. Connect families with appropriate community organizations and services^{19,103,124-128}
30. Screen for developmental risk¹²⁹
31. Provide high risk infant follow up¹²⁹⁻¹³⁶

32. Conduct home visit before discharge and at intervals after discharge^{137–143}
33. Facilitate parent support groups and peer counselling that extend beyond the stay^{88,98}
34. Implement strategies to identify and minimize risk for readmission^{144–150}
35. Provide telehealth support after discharge^{151–156}
36. Use technology and social media to support families^{157–166}
37. Facilitate access to all necessary clinical specialists after discharge^{122,135}
38. Provide reminders to facilitate health behaviors and keeping of appointments^{79,167–170}
39. Provide mental health and addiction services for families after the stay^{54,57,171}
40. Provide family planning education and contraception referral^{172–177}
41. Develop meaningful clinical-community partnerships²²

II B. Maintain support for families through infancy

42. Use parent coaches to support families^{98,99}
43. Provide evidence based early intervention programs^{103,178–183}
44. Utilize innovative approaches to medical visits^{99,184–187}
45. Establish a reach out and read program for patients and siblings^{188–193}
46. Provide medical and developmental follow up^{129–136}
47. Provide resources regarding available public benefits at follow-up visits¹⁰⁰
48. Establish partnerships with pre-K programs for patients and siblings^{194,195}
49. Develop and support tools that utilize parent reported outcomes¹⁹⁶
50. Provide access to quality high risk obstetrical care^{197–205}

III. Develop robust quality improvement efforts to ensure equitable, high-quality hospital and follow through care to all newborns by eliminating modifiable disparities

51. Establish measurable improvement aims related to social determinants of health^{206–208}
52. Adopt standardized measures for social determinants of health^{20,21,28,209}
53. Develop strategies to support QI participation by parents including economically challenged, non-traditional and racially and ethnically diverse families^{210,211}
54. Include pediatricians and other primary care providers for children on QI teams²¹²
55. Establish a charter with organizational leaders setting goals and resources for family advisors²¹³
56. Provide salary support for family advisors²¹³

IV. Advocate for social justice at the local, state, and national levels

57. Conduct and disseminate research that identifies disparities in access and outcomes^{22,207}
58. Serve on committees and in leadership roles within the local health system and raise awareness of need for social justice in healthcare^{45,214–216}
59. Actively recruit a diverse workforce with respect to race, ethnicity, gender, age, religion, and sexual orientation²¹⁷
60. Educate organizational leaders about social determinants of health
61. Engage organizational leaders with a social determinants of health charter

62. Advocate, organize, inform and lobby to change policy at the local, state and national levels²¹⁸⁻²²⁰
63. Play a role in addressing global health inequities^{214,221,222}
64. Advocate for environmental health and justice²²³⁻²²⁶
65. Name racism and ask, "How is racism operating here?"^{220,227}
66. Engage local, state, and federal agencies with responsibilities for infants and families
67. Advocate to include population health and social justice in the organizational mission^{228,229}
- 68. Speak out!**

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They also appear as a Supplement in: Horbar JD, Edwards EM, Ogbolu Y. Our responsibility to “follow through” for NICU infants and their families. *Pediatrics*. In press.

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Pediatrics originally published online June 16, 2020;

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Pediatrics originally published online June 16, 2020;

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