Including Parent Voices in Prematurity Outcome Research

Rebecca Peace, B.Ed., M.Sc.

CHEER Webinar

Tuesday, April 15, 2025

CHU Sainte-Justine
Le centre hospitalier
universitaire mère-enfant

Université de Montréal

CHILD-BRIGHT Network

Réseau BRILLEnfant

CNFUN
Canadian Neonatal Follow-Up Network
Réseau Canadien de Suivi Néonatal
RCSN

Today’s Objectives

1. Discuss NDI in the follow-up of extremely preterm babies.

2. Present the Parents’ Voice Project and its findings.

Standardized follow-up at 18-24 months
Categorization of children

Neurodevelopmental impairment (NDI)

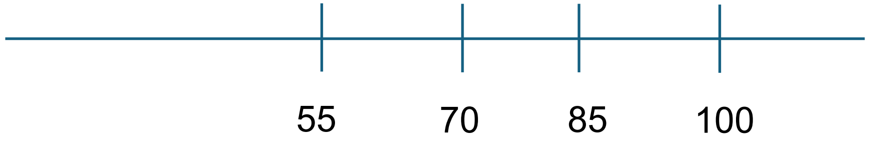
No

Cerebral palsy

Gross Motor Function Classification System 3-4-5

Developmental delay

Bayley Scales



Hearing impairment

Visual impairment

Synnes et al. *ADC Fetal Neonatal ed* 2016
Haslam et al. *J Pediatr* 2017
Adams-Chapman et al. *Pediatrics* 2018

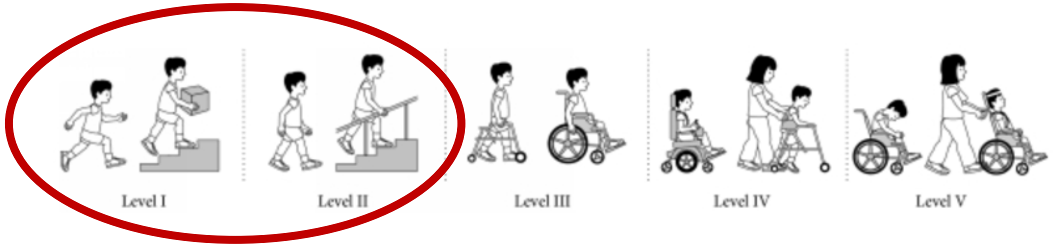
Neurodevelopmental impairment (NDI)

No

Mild-moderate

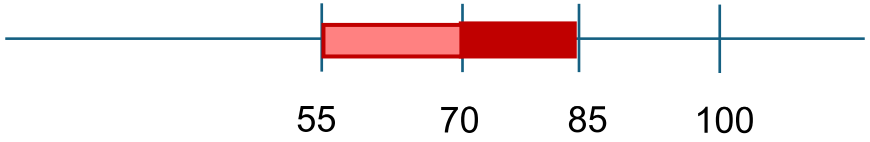
Cerebral palsy

Gross Motor Function Classification System 1-2



Developmental delay

Bayley Scales



Hearing impairment

Visual impairment

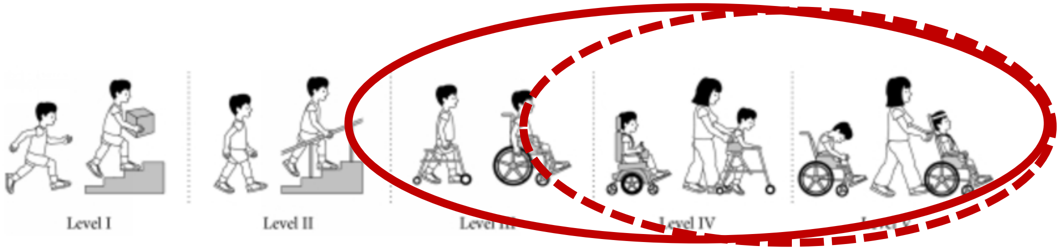
Synnes et al. *ADC Fetal Neonatal ed* 2016
Haslam et al. *J Pediatr* 2017
Adams-Chapman et al. *Pediatrics* 2018

Neurodevelopmental impairment (NDI)

No Mild-moderate Severe

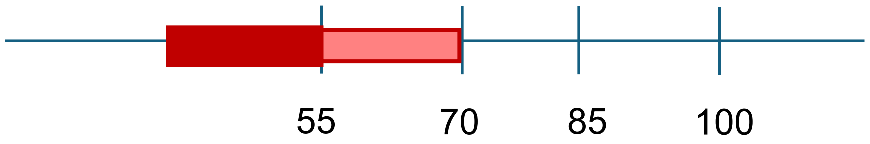
Cerebral palsy

Gross Motor Function Classification System 3-4-5



Developmental delay

Bayley Scales



Hearing impairment: hearing aids, profound HL (>90dB)

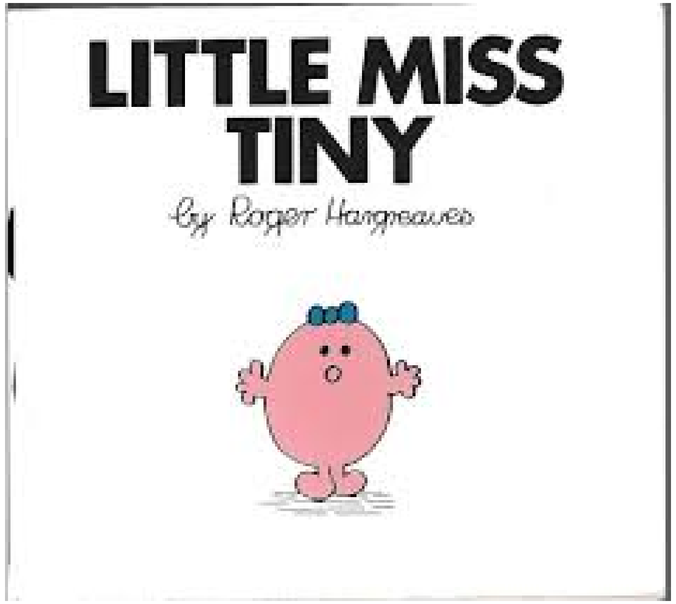
Visual impairment: bilateral blindness

Synnes et al. *ADC Fetal Neonatal ed* 2016
Haslam et al. *J Pediatr* 2017
Adams-Chapman et al. *Pediatrics* 2018

Problems and Questions

- Different definitions of severe NDI (Haslam et al. 2018)
- Severe NDI in infants from 23-28 weeks GA varied from 3.5% to 14.9% depending on the definition used by the neonatal network
- NDI is used to counsel parents
- Should NDI be the only focus?

Where am I and what just happened?



Pearce, R., & Baardsnes, J. (2012). Term MRI for small preterm babies: Do parents really want to know and why has nobody asked them? *Acta Paediatrica*, *101*(10), 1013-1015.

So Much Bad News…

- NDI and deficits – why?
- Dichotomous vs. continuous outcomes
- Composite outcomes – XXX or death?

Janvier, A., Farlow, B., Baardsnes, J., Pearce, R., & Barrington, K. J. (2016). Measuring and communicating meaningful outcomes in neonatology: A family perspective. *Seminars in Perinatology, 40*(8), 571-577.

Why have we chosen NDI as a measure of NICU ‘success’?

- *“Why has it become central to the way patients’ families are counselled and how prognoses are discussed with them?”*
- *“Do the answers address the real concerns and needs of parents of infants born preterm?”*
- *“…to their mind these are not the major issues.”*
- It is imperative to redefine the way outcomes are described after preterm birth

Bell EF, Rysavy MA. *J Pediatr* 2018
Janvier A, Farlow B, Baardsnes J et al. *Sem Perinatol* 2016
Marlow et al. Sem Fetal Neonate M 2020

The Parents' Voice Project: what we have learned

Kate Robson

Rebecca Pearce

Lindsay Richter

Paige T Church

Anne Synnes

CPBF FBPC
Canadian Premature Babies Foundation
Fondation pour Bébés Prématurés Canadiens

CHILD-BRIGHT
Network

CNFUN
Canadian Neonatal Follow-Up Network
Réseau Canadien de Suivi Néonatal
RCSN

CJ Bourque

Thuy Mai Luu

Annie Janvier

Magda Jaworski

To *engage* parents to co-create definitions of neurodevelopmental impairment.

Students: Thuy-An Mai-Vo, Laurie-Anne Duquette, Aurélie Fortin, E Thivierge.

Publications: Parents' Voice Project

- Richter, L., Janvier, A., Pearce, R., Bourque, C.J., Church, P.T., Luu, T.M., & Synnes, A. (2024) Parental and medical classification of neurodevelopment in children born preterm. *Pediatrics*, in press.
- Pearce, R., Synnes, A., Lam, M. M., Richter, L. L., Bacchini, F., Jones, M., Luu, T.M., Janvier, A,. & PARENTS' VOICE NETWORK. (2024). Partnering With Parents to Change Measurement and Reporting of Preterm Birth Outcomes. *Pediatrics*, e2024067093.
- Milette AA, Richter LL, Bourque CJ, Janvier A, Pearce R Terrien Church P, Synnes A, Luu TH. Parental perspectives of outcomes following very preterm birth: Seeing the good, not just the bad. Acta Paediatr 2023 Mar;112(3):398-408
- Thivierge E, Luu TM, Bourque CJ, Barrington KJ, Pearce R, Jaworski M, Janvier A. Pulmonary important outcomes after extremely preterm birth: Parental perspectives. Acta Paediatr 2023 May;112(5):970-976.
- Janvier A, Bourque CJ, Pearce R, Thivierge E, Duquette LA, Jaworski J, Barrington KJ, Synnes A, Church P, Luu TM. Fragility and resilience: Parental and family perspectives on the impacts of extreme prematurity. Arch Dis Child Fetal Neonatal Ed. 2023 Nov;108(6):575-580.
- Synnes A, Chera A, Richter LL, Bone JN, Bourque CJ, Zhang-Jiang S, Pearce R, Janvier A, Luu TM. Redefining Neurodevelopmental impairment: Perspectives of very preterm birth stakeholders. Children (Basel) 2023 May 14;10(5):880.

Publications: Parents' Voice Project

- Thivierge E, Luu TM, Bourque CJ, Duquette LA, Pearce R, Jaworski M, Barrington KJ, Synnes A, Janvier A. Guilt and regret experienced by parents of children born extremely preterm. J Pediatr 2023 Jun:257:113268. doi: 10.1016/j.jpeds.2022.
- Jaworski M, Janvier A, Bourque CJ, Mai-Vo TA, Pearce R, Synnes AR, Luu TM. Parental perspective on important health outcomes of extremely preterm infants. Arch Dis Child Fetal Neonatal 2022 Sep;107(5):495-500. doi: 10.1136/archdischild-2021-322711.
- Luu, T. M., & Pearce, R. (2022). Parental voice - what outcomes of preterm birth matter most to families? *Seminars in Perinatology*, 6(2), p 151550-151556. https://doi.org/10.1016/j.semperi.2021.151550
- Duquette, L.-A., Luu, T. M., Janvier, A., Mai-Vo, T.-A., Fortin, A., Thivierge, E., Bourque, C. J., Pearce, R., Synnes, A., & Jaworski, M. (2020). More than meets the eye: Parental perspectives on the health of their extremely preterm children when they reach 18 months, 5 and 7 years. *Paediatrics & Child Health, 25*(Supplement 2): e9.
- Thivierge, E., Duquette, L.-A., Mai-Vo, T.-A., Fortin Aurélie, Jaworski, M., Bourque, C. J., Pearce, R., Luu, T. M., & Janvier, A. (2020). Not what clinicians thought: Decisional regret in parents of extremely preterm children. *Paediatrics & Child Health, 25*(Supplement 2): e9-e10

Do parents agree with our classifications?

NO

They tend to be more positive

Categorization of children: poor agreement between parents and physicians

κ = 0.29; 95% CI: 0.25-0.34

		CNFUN Classification			
		No NDI	Mild-Moderate NDI	sNDI	
Parental Classification	No NDI	483	189	60	**732 (68%)**
	Mild-Moderate NDI	100	127	100	**327 (30%)**
	sNDI	1	2	22	**25 (2%)**
		584 (54%)	**318 (29%)**	**182 (17%)**	**N=1084**

83% of parents agreed

40% of parents agreed

12% of parents agreed

Do parents agree that conditions doctors’ call « severe disability » are actually severe?

NO

They tend to be more positive

VIGNETTES TO EVALUATE PARENTAL PERCEPTION OF SEVERITY OF DISABILITY

- Clinical scenarios or vignettes developed based on CNFUN definitions of “severe outcomes”

Survey distributed to:

- Parents of very preterm children
- Parent foundations made the survey available to parents & key stakeholders nationally and internationally using a snowball sampling technique

Example

SCENARIO 4 (Language impairment)

Lina is an 18-month-old child. She says ‘mama’ and ‘dada’ and one other word, which is less than expected for her age. She does not point to her ears and eyes when asked. She does not use words to make her wants known but cries or grabs you instead. She can see and hear normally. She walks, runs, and moves like other children her age. She learns, plays, and explores the environment like other children her age.

- If 0 is the worst possible health and 10 is the best possible health, where do you think Lina fits on the scale? - Scale from 0 to 10
- Does Lina's case describe a severe health condition?

(Yes, No)

Condition « Severe » in the neonatal literature	Health evaluation on 10 (n = 827) (median)	% reporting condition in vignette as « severe » (n = 827)
No impairment	10	4
Cognitive delay	8	10
Motor delay	8	11
Motor and language delay	7	14
Motor and cognitive delay	7	15
Hearing impairment	8	17
Language and cognitive impairment	6	23
Cerebral Palsy	7	43
Visual impairment	6	51
Cerebral palsy and language delay	6	55

We also asked parents about

1) The health of their premature baby.
2) The impact of prematurity on their lives.
3) Their need for information (what clinicians could do better).
4) Their decisional regrets.

Speak to us about positive stories too, not only the negative and all the bad that can happen. It’s impossible to always live in fear.

‘Being scared all the time, more than other parents, as soon as they are sick and the fear of having to go back to the hospital. The fear of losing them every time, the hypervigilance that we have since we left the hospital. Not sleeping, avoiding public places to avoid decompensations. Many appointments, missing work.

He has brought the family together. Has given meaning and brought love and joy to everyone's life. Everyone has a new/better perspective on life.

Do not just speak about cerebral palsy, but about what we will have to do in a practical sense, as a family. How many appointments, where, for what? What does it mean for others, the good and the bad. A diagnosis does not help much, what we can do about it helps.

Perspectives of parents and families: not associated with disability

- The majority of parents (74%) report both positive and negative impacts of prematurity
  - Positive: Gratitude, perspective, stronger family connections, child
  - Negative: Stress, anxiety, loss of family equilibrium, child’s development
- Decisional regrets are similar
  - Self care, regrets for preterm birth, parental role in the NICU

Perspectives of parents and families: not associated with disability

- Parents evaluate the health of their child as being good Median of 9 on 10 at 18 months
    - Important outcomes for families (not systematically measured): breathing, feeding, sleeping, medical fragility, behavior

- Prepare parents for the NICU trajectory, their role, discharge, be more optimistic

Key Messages

- Parents have a generally positive perception of their child.
- Parents describe both positive and negative impacts.
  - Themes of resilience and positive transformations.
- For parents, function is more important than diagnosis
- The « NDI classification » used in Neonatology does not correspond to the lived experience of parents
  - More pessimistic and sometimes missing the point
- Many important outcomes are forgotten - respiratory health, eating, sleeping, etc.

Conclusions

- Redefining outcomes and classification of outcomes in neonatology is essential
- « Severe » categories should no longer exist
  - Describe the outcome: non-ambulant CP, deafness (use of cochlear implant)
- Function should be measured (not only diagnoses)
- Research integrating stakeholder important outcomes is developing quickly

Thank you!