How Small is Too Small? Considerations in Evaluating the Outcome of the Tiny Infant

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From 1990 to 2005 the rate of preterm birth rose from 10.6/100 live births to 12.7/100 live births.
2007 Natl Vital Statistics Rep

In 1980, I got yelled at by the neonatology attending for resuscitating a 1000 gram 28 week gestation premie
Survival of babies 23-25 weeks gestation UCLH 1981-2000 (as percentage of admissions to NICU)

Riley et al. Acta Paediatrica 2008; 97:159-65

NICU Risk Factors for Poor Developmental Outcome

1) Significant congenital anomalies
2) Significant perinatal asphyxia
3) Significant prematurity

Domains of Development

- Gross Motor
- Fine Motor
- Language
- Social-Emotional
- Cognitive

Sequelae

Major sequelae:
1) Cerebral palsy
2) Mental handicap
3) Severe visual handicap
4) Deafness

Minor sequelae:
1) Speech and language delay
2) Learning disability
3) Behavior problems

Percentage of surviving extremely preterm infants with neurodevelopmental impairment at 1 year of age, UCLH 1981-2000

<table>
<thead>
<tr>
<th>Year</th>
<th>Normal (%)</th>
<th>Impairment without disability (%)</th>
<th>Impairment leading to disability (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1986-1990</td>
<td>19 (56)</td>
<td>7 (21)</td>
<td>6 (23)</td>
<td>34</td>
</tr>
<tr>
<td>1991-1995</td>
<td>13 (35)</td>
<td>10 (27)</td>
<td>14 (36)</td>
<td>37</td>
</tr>
<tr>
<td>1996-2000</td>
<td>29 (57)</td>
<td>9 (18)</td>
<td>13 (25)</td>
<td>51</td>
</tr>
</tbody>
</table>

Riley et al. Acta Paediatrica 2008; 97:159-65
EPICURE nationwide study of all babies in UK and Ireland, born 22-25 weeks gestation in 1995. 
Assessment at 6 years of age

Out of 241 survivors:
• 15 were unable to walk due to cerebral palsy
• 27 had severe learning difficulties
• 4 blind and 7 severe hearing loss
• Total of 32 had any severe disability

Marlow et al. NEJM 2005; 325: 9-19

"Preterm birth is a strong predictor of infant mortality and morbidity, and is shown to be significantly associated with a number of poor health outcomes. These outcomes include cerebral palsy, problems with vision and hearing, poor motor skills, asthma, and learning difficulties."
– Acting Surgeon General Steven Galtson, 2008

Factors besides BW/GA which might lead to pessimism regarding developmental outcome

Neurodevelopmental outcome at 8 years of age

<table>
<thead>
<tr>
<th></th>
<th>&lt; 28 weeks (n = 137)</th>
<th>28 – 32 weeks (n = 445)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability</td>
<td>23%</td>
<td>12%</td>
</tr>
<tr>
<td>Brain lesion detected by ultrasound</td>
<td>48%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Vollmer et al, Pediatrics 2003, 112, 1108-1114
It's not all just about the baby!
Factors Influencing Low Risk Infant’s Acceptance into EI Services (more likely if urban with longer LOS)
Josephine Baker helped to establish some of the first programs in preventive medicine and public health. In order to curb the enormous death rates among infants in the city, Dr Baker used school nurses in the summer of 1908 to visit the homes of newborns to teach mothers how to take care of their babies. There were 1200 fewer deaths that summer than the previous one.

2004 IDEA

IDEA (PL 108-446) or Individual with Disabilities Education Improvement Act
- Part A: 3R's + independence
- Part B: Kids 3-21 get FAPE with IEP
- Part C: Kids 0-3 get FAPE with IFSP
- Part D: Authorizes activities to improve special education services
- Part E: Establishes National Center for Special Education Research

The health care provider, in his role in “child find” in Part C of PL 108-446, refers the child of concern for an evaluation for services by a multidisciplinary team (MDT). If the team feels that the child has significant functional delay, with the agreement of the parents, an Individualized Family Service Plan (IFSP) is established.

**BOX 41-1 Factors Affecting Outcome of the Infant with Very Low Birthweight**

- Birthweight < 750 g or < 25 weeks gestation
- Periventricular hemorrage (grades III and IV) or infarction
- Posthemorrhagic hydrocephalus
- Persistent ventricular dilatation
- Neonatal sequelea
- Crowding (disease
- Neonatal meningitis
- Subnormal head circumference at discharge
- Parental drug abuse
- Poverty and parental depression
- Cerebral palsy and malformation
National Center for Medical Rehabilitation Research (NCMRR) Disability Classification Terminology

- Pathophysiology – interruption of normal physiology
- Impairment – loss of normal function
- Functional limitation – restriction of ability to perform functional activities
- Disability – restricted participation in societal roles
- Societal limitations – external barriers to full participation

Example of NCMRR Terminology in Cerebral Palsy

- Pathophysiology – cystic PVL
- Impairment – spasticity, contractures
- Functional limitation – awkward walking, difficulty dressing
- Disability – education in restricted environment, limited sports access
- Societal limitation – exclusion from school, medical treatment, insurance

The Bayley

Probably the “gold standard” used for developmental assessments in the followup literature is the Bayley. Be careful though. The BSID III is much different than the older BSID II and scores are probably 8-10 points higher. It also divides “cognitive” scores into a cognitive composite and language composite as opposed to the BSID II which had a single MDI (and PDI). These tests have a mean of 100 and SD of 15. The BSID III Screener, however, has competent, emerging, and at risk categories.
"The Committee on Understanding Premature Birth and Assuring Healthy Outcomes estimated that the U.S. economic burden is $26.2 billion, or roughly $51,600 per preterm infant." – from Galston in Public Health Reports, 2008

TABLE 2: Chance of Survival Without Any Impairment for Live-Born Infants

<table>
<thead>
<tr>
<th>GA (wks)</th>
<th>Survival Without Any Impairment, % (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>12 (8.4–15.7)</td>
</tr>
<tr>
<td>23</td>
<td>4.5 (3.1–6.3)</td>
</tr>
<tr>
<td>24</td>
<td>0.5 (3.4–22.7)</td>
</tr>
<tr>
<td>25</td>
<td>0.0 (0.1–50.9)</td>
</tr>
<tr>
<td>26</td>
<td>0.0 (0.1–89.8)</td>
</tr>
<tr>
<td>27</td>
<td>0.0 (0.1–93.7)</td>
</tr>
</tbody>
</table>

* Estimates available from 1 study.