



Gathering data on children with disabilities and learning about administrative data.

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Data Webinar: International Disability Alliance

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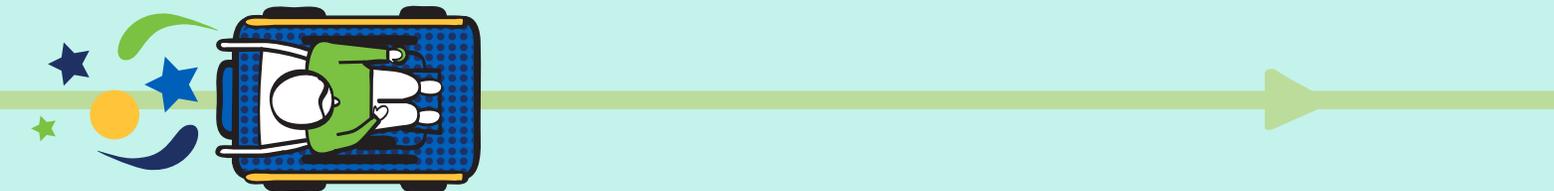
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Give everyone the chance to try.



- The essence of our teaching method is to ensure the right of all children access to the power of safe personal movement and that this should be made available to children with disabilities at the earliest possible age.
- Smile have seen over 30 years of working with children with disabilities, the importance of encouragement from family and carers for children to reach their optimum potential at all ages.
- We focus on what functions a child with disabilities **does** have and work to nurture those skills. This is seen as the most important element in ensuring inclusion to education, the community and employment at a later stage.





Early Intervention

We believe that the notion of non-intervention and delays in access to education for children with disabilities until the age of 7-8 years is an outdated concept.

Where assistive technology devices are available, we believe that children with disabilities should be encouraged and supported to develop their skills, using AT at the same time as children without disabilities.



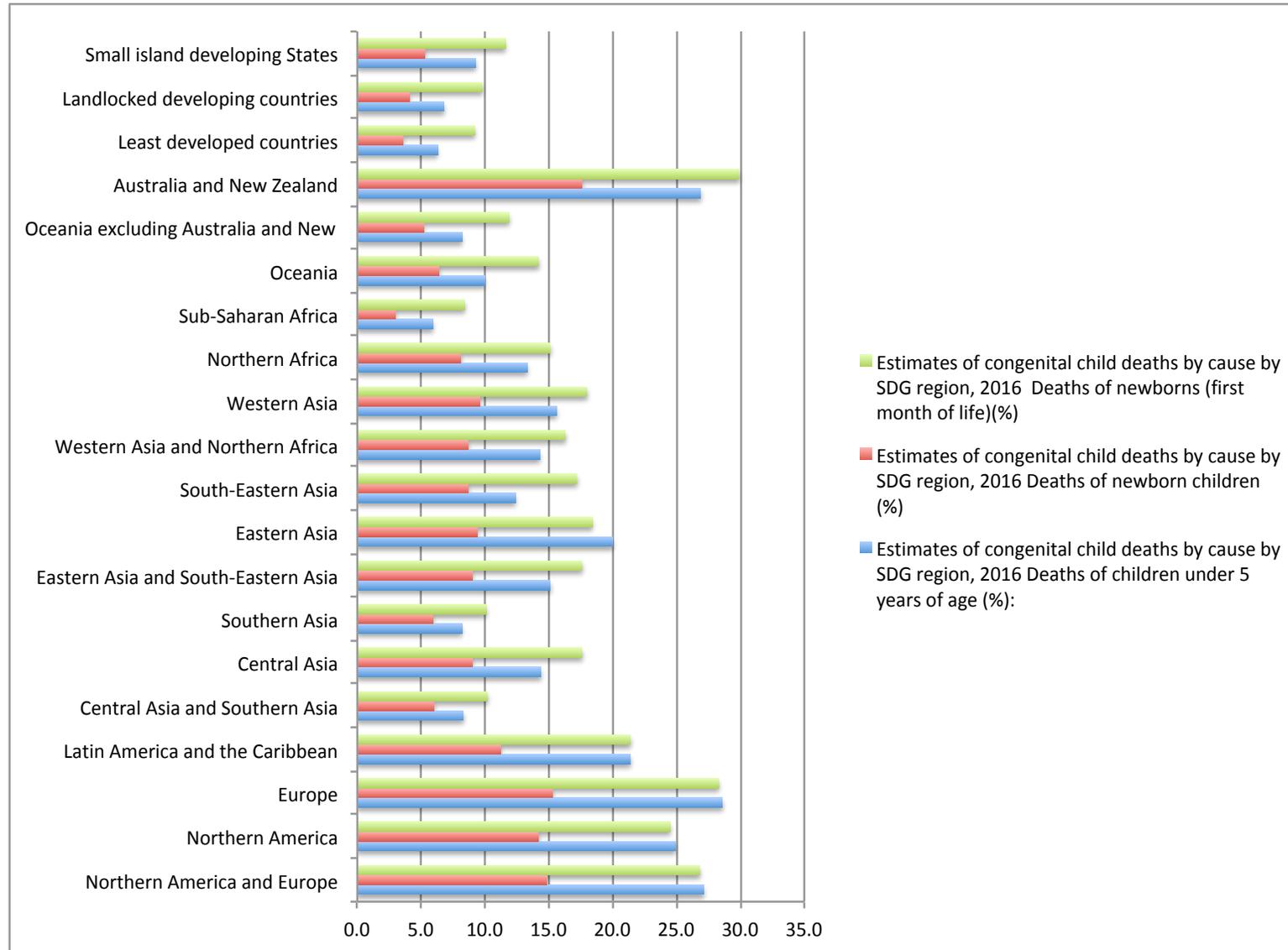


- Holistic early years development of skills and community inclusion through the support of health and education for children with disabilities, has shown that quality of life is improved for children and their families. This is not the historical perception of how children with disabilities should be treated in many societies.
- Inclusion in every facet of society is absolutely possible for children with disabilities if social attitudes, technology and the built environment are better informed on the challenges and also the future potential of children with disabilities.
- At the 69th World Health Assembly launching of the WHO Priority Assistive Products List, improving access to assistive technology (AT) for the estimated 90% of the world population who have some form of disability but no access to quality AT, support for persons with disability was described as an '*investment*' in a nation.

- The idea that the investment of inclusivity in society for persons with disability is a way to raise the productivity and wealth of an entire nation was a powerful message. This is diametrically opposed to historical paradigms which have seen the norms of abandonment, exclusion and institutionalisation of children and adults with disabilities.
- In order for policies to be created to support inclusivity development programming there must be data available to advise policy makers and publics.
- There is increasingly helpful data available from UNICEF's most recent MICS6, which have started arriving now via national censuses. Some national surveys include the Washington Group 2016 ICF-CY Child Functioning from 2 -4 years of age surveys. This will be a positive step in aiding the modelling of future policy interventions.

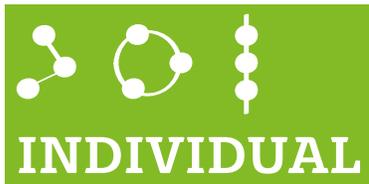
- If indicators were aligned with the functional domains surveyed through EMIS (Data Collection and Education Management Information Systems) via schools, then service providers will be able to trace clear functional development of individuals for correlative study at micro, meso and macro levels.
- Due to the developmental capacity of 0-2 years a medical approach is recommended by UNICEF. This would therefore align with RMNCH (Reproductive, Maternal, Neonatal and Child Health) monitoring programmes.
- Existing data for 0-2 years disability is limited and most clearly disaggregated through WHO and Maternal and Child Epidemiology Estimation Group (MCEE) 2017 estimates.
- Causes of mortality are recorded as, Preterm, Intrapartum, Congenital, Sepsis, Tetanus, Pneumonia, Diarrhoea, Malaria, AIDS, Measles, Injury, Meningitis and Other.

Estimates of congenital child deaths by cause by SDG region, 2016/18 (WHO/UNICEF) (Fig.1)





- Without stronger training of survey personnel to define disaggregated data at birth we lack a true base line in disability data, from which to focus further research and age related development priorities. This is particularly relevant for congenital disability recording.
- This is a challenging indicator to disaggregate due to the broad range of congenital determination available and the lack of specialised disability healthcare training and knowledge available at most primary levels, particularly in LMIC rural locations.
- If more focus is placed upon defining complex disability at birth and early years then thresholds for classifying disability levels and possible interventions would be more effective; particularly where early action can be so critical to amenable mortality as with Spina Bifida.



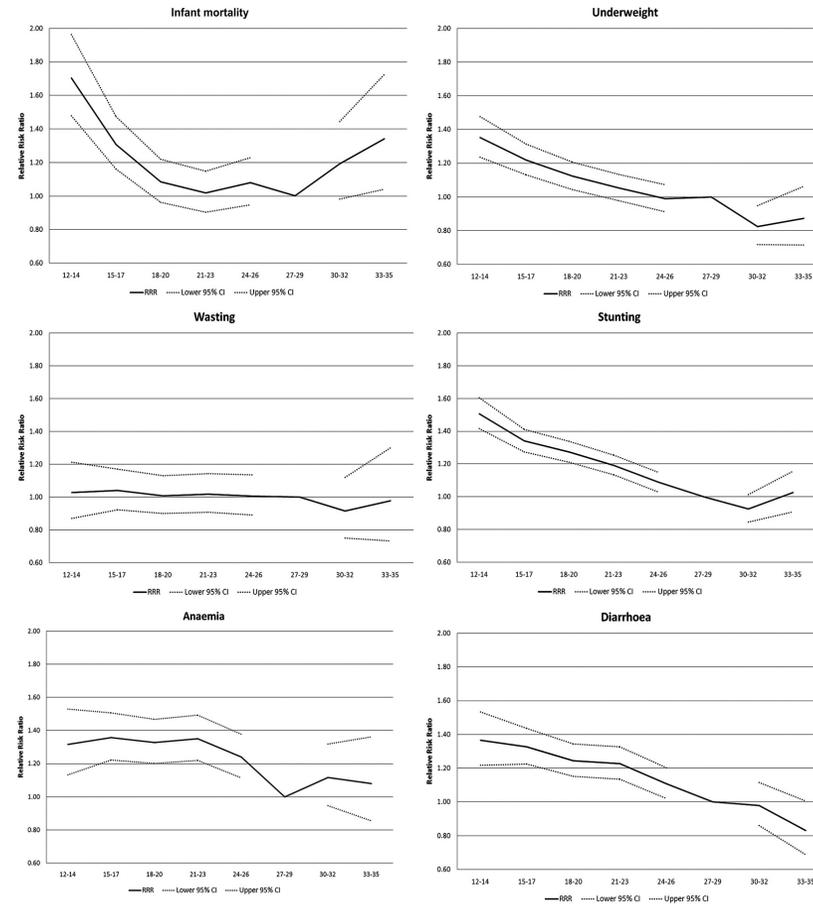
- More accurate survey collection and disaggregation would highlight where improvements in service readiness are necessary to treat and support those individual children and support groups for those with congenital disabilities and also disabilities where nutritional, cultural, environmental, clinical factors have been factors in disability.
- The diagram below indicates a small selection of maternal age-related health outcomes all of which correlate to disability occurrence, particularly in very young and older mothers, where age could be considered a cultural determinant.

*(Finlay JE, Özaltın E, Canning D; The association of maternal age with infant mortality, child anthropometric failure, diarrhoea and anaemia for first births: evidence from 55 low- and middle-income countries; BMJ Open 2011;**1**:e000226. doi: 10.1136/bmjopen-2011-000226)*

Fig.2



Plot of: Adjusted RR (95% CI) of infant mortality and child health outcome by age of the mother at first birth



Jocelyn E Finlay et al. *BMJ Open* 2011;1:e000226





- One of the challenges in data collection for children 0-2 years is the lack of birth registration, particularly in rural areas across many SDG regions. UNICEF estimate that only one quarter of all children under the age of 5 are registered.
- In alignment of Article 12 of the CRPD, the right to registration secures the right to a legal personality and is key to accessing potential governmental support through educational and medical disability intervention programming, particularly in the early years. Stronger support for registration, monitoring of 0-2 years is vital.
- UNICEF are currently piloting a 0-3 years initiative, an ECD (Early Child Development) platform with multiple entry points, particularly around identification and intervention, based on the hypothesis that with intervention children with disabilities are able to reach the same progress goals as other children without disabilities.



EXPLORE



- The geographical disparity between estimates in congenital mortality figures (UNICEF/WHO 2016/18)(Fig. 1) show a wide variance between high income and LMIC SDG regions.
- This should be explored further to understand if there are correlative factors in disability data with for example those shown in Fig. 2.
- A reduction of proxy measures and more accurate disaggregated data on these disability indicators would be helpful in understanding rights to medical treatment, amenability and provide a base line for future stronger developmental function-based survey research.

