Measuring Marginalization & Equity

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Presentation objective

- To introduce a discussion on measurement of marginalization & equity

Presentation outline

- What is marginalization?
- What is equity?
- Why measure them?
- What should be measured?
- Challenges in measurement
- Conclusions

What is marginalization?

- I’m defining it here as:
- **Children and their families who are actively excluded by economic disadvantage &/or various forms of discrimination from full participation in the society in which they live**

Children in poverty

Every second child in the world lives in poverty (1 billion)

Not just in low income countries

Minority ethnic groups/migrants & asylum seekers

Children from minority groups such as the Roma are actively discriminated against as are many migrant and asylum seeking children

Globalization & war have hugely increased numbers of migrants & asylum seekers arriving in rich countries

Children with disabilities

World Report on Disability estimates that 93 million (5.1%) children suffer moderate to severe disability, 13 million of whom have severe disabilities

Looked after children

Children taken into social care are disadvantaged and often discriminated against

Children in hazardous work & street children

Millions of children are marginalized by having to work in hazardous conditions and living on the streets

Other marginalized groups

- Girls in some societies
- Gay & transgender adolescents in many societies
- Elspeth Webb makes a convincing argument for discrimination against children generally – 'childism' (Webb EVJ. Discrimination against children: developing a conceptual framework *Archives of Disease in Childhood* 2004; **89**: 804-808*)*

What is meant by equity?

- Equity of outcome
- Equity of health care delivery
- Usually measured as a negative – inequity defined as ‘health inequality that is avoidable and unjust’

Why measure them?

- Children's rights & social justice
- Marginalization has a profound impact of child health and well-being
- Major determinants of health and well-being in child populations
- Failure to measure is itself a form of marginalization (see next slide)

Child rights approach to marginalization & equity

- Marginalization of children & resulting inequities are in breach of the UNCRC
- Measurement should enable identification of violations of the CRC & use of a child rights perspective in addressing them

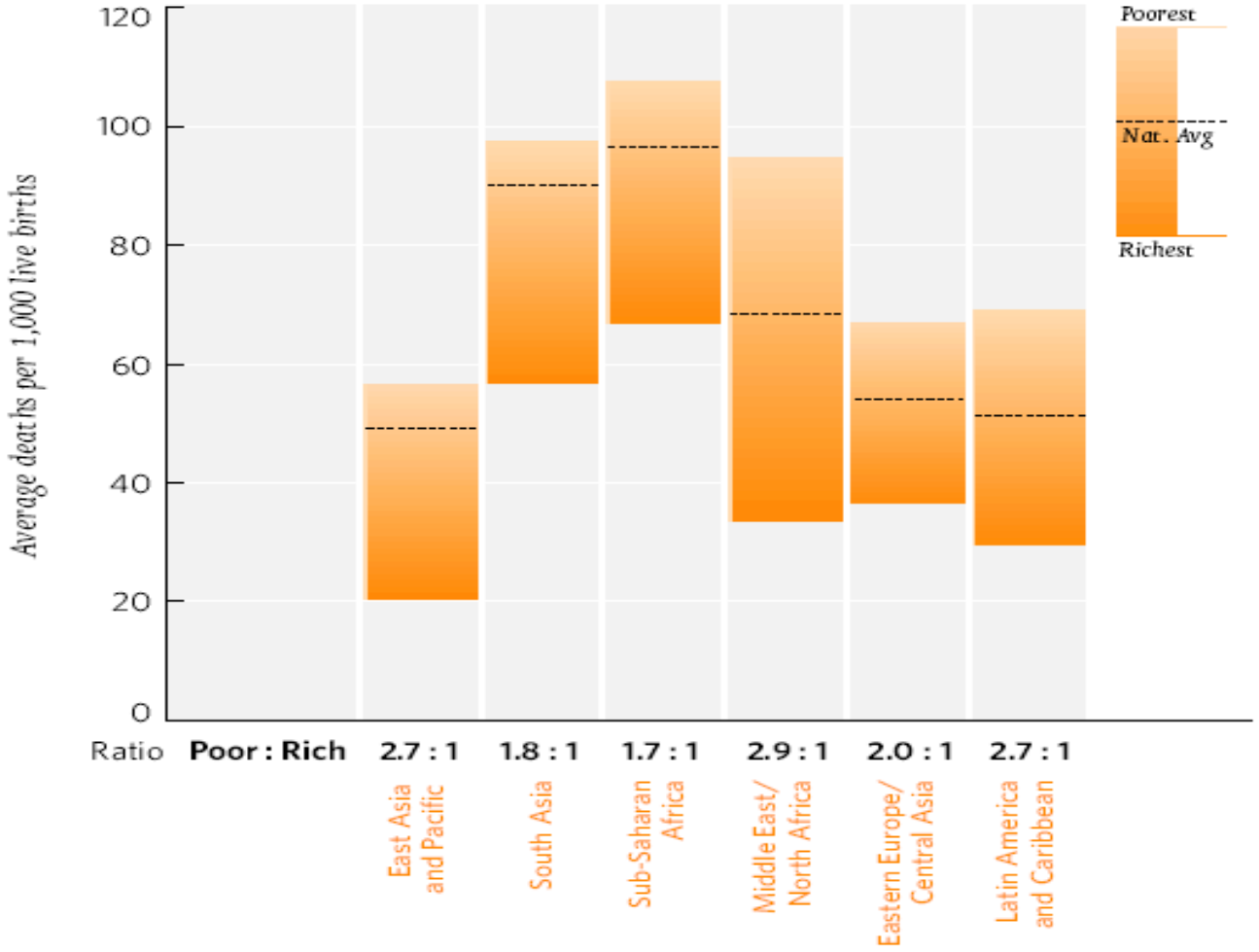
Rendering children with disabilities visible

- *"A society cannot be equitable unless all children are included, and children with disabilities cannot be included unless sound data collection and analysis render them visible."* (UNICEF, *State of the World's Children*, 2013 p.63)

Health impact of marginalization I

Figure 4: Infant mortality differentials

Average deaths per 1,000 live births, richest fifth to poorest fifth of population, by region



WAR

Health impact of marginalization II – poverty & selected health outcomes in UK 10 yr olds

Health outcomes:	Unadjusted Odds Ratio (95%CI)	Adjusted Odds Ratio (95%CI) [adjusted for: lone parent; low education; multiple birth]
Severe limiting long-term condition	2.04(1.41,2.92)	1.45(1.02,2.07)
ADHD (ever had)	3.00(1.96,4.46)	2.26(1.42,3.61)
SDQ=>95cle	2.13(1.74,2.61)	1.69(1.36,2.12)
Autism/Asperger's	1.06(0.67,1.67)	1.13(0.70,1.83)
Any accident	0.88(0.77,1.00)	-
Multiple accidents	1.25(0.88,1.82)	1.03(0.61,1.74)
Any hospital admission	1.26(1.05,1.52)	1.12(0.93,1.36)

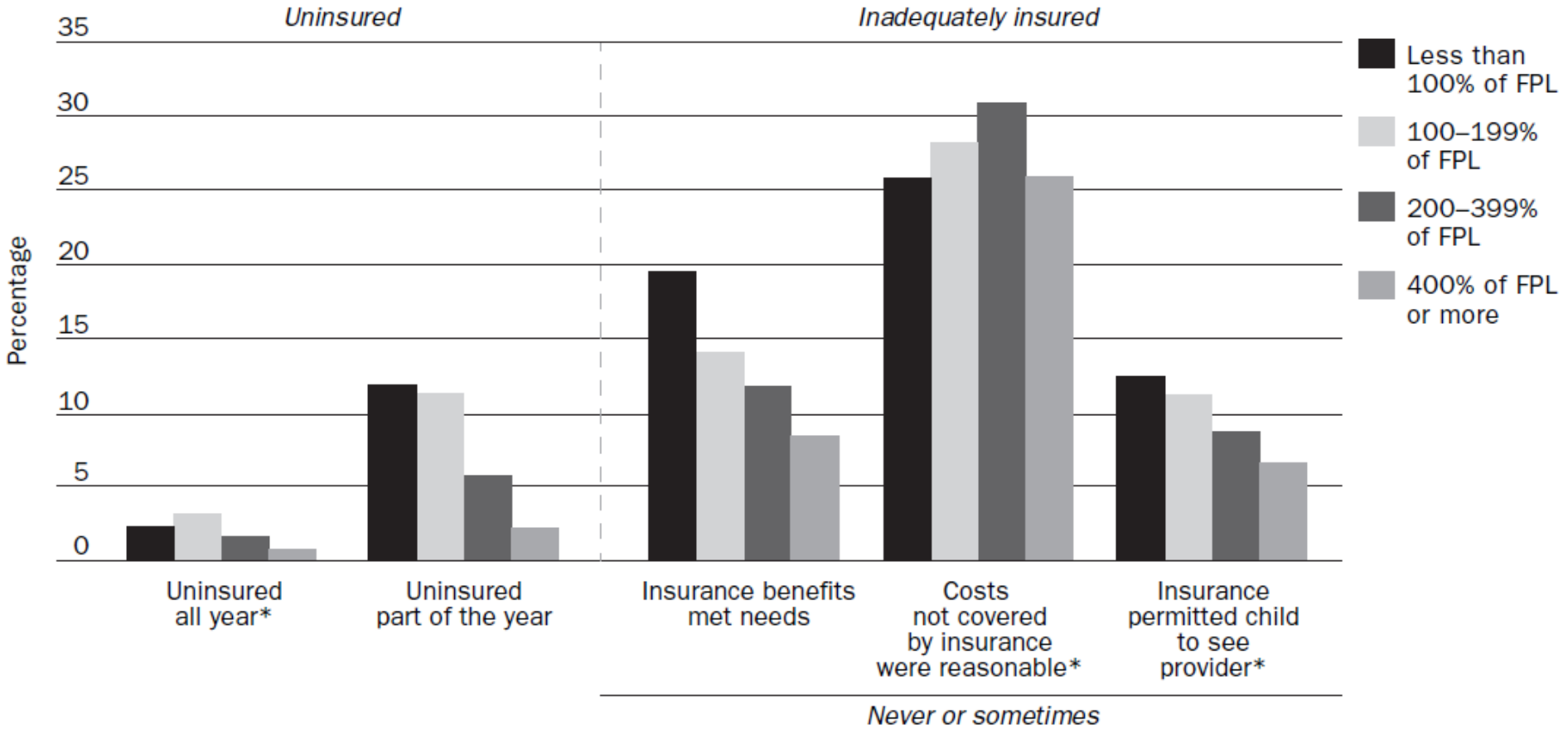
Health impact of marginalization III – ethnic minority children

- **UNICEF MICS study in Serbia**:
- U5MR for Roma children 3x average
- Low birth weight x2 average
- Stunting x4 average

- NB: double jeopardy!

Health impact of marginalization IV – special health care needs & insurance, USA (Szilagyi '12)

B. By Income



Source: Author's calculations based on data from the 2005–06 National Survey of Children with Special Health Care Needs.
FPL = federal poverty level.
*Differences are statistically significant (p<.01).

Double jeopardy – chronic disabling conditions & low SES (Blackburn et al '14)

Disabling chronic condition	Studies	Odds ratio (95%CI)	Heterogeneity (I^2 statistic)
All-cause disabling chronic conditions	20	1.72(1.48,2.01)	95.0% (93.7,95.7)
Psychological disorders	55	1.88(1.68,2.10)	93.6%(92.6,94.3)
Intellectual disability	21	2.41(2.03,2.86)	98.1%(97.9,98.3)
Activity-limitation or hospital admission for asthma	13	2.20(1.87,2.85)	96.9%(96.2,97.4)
Cerebral Palsy	6	1.42(1.26,1.61)	64.0%(0,83.1)
Congenital abnormalities	13	1.41(1.24,1.61)	91.2%(87.6,93.4)
Epilepsy	6	1.38(1.20,1.59)	23.4%(0,67.5)
Sensory impairment	9	1.70(1.39,2.07)	57.3%(0,77.2)

What should we measure?

- Whole population level data where possible – representative where not
- Use nationally (& internationally) recognised definitions of marginalized groups
- Broadest possible measures of health & well-being of children
- Qualitative in addition to quantitative
- Monitor over time

Examples of measurement systems

- Wales Electronic Cohort for Children
- Swedish & Danish Medical Birth Records & Data Linkage
- Derby Community Paediatric Data collection
- National child cohort studies (e.g. Millennium Cohort Study; Longitudinal Study of Australian Children)
- Serial cross-sectional surveys (e.g. US annual National Health Interview Surveys)
- Mixed methods

Wales Electronic Cohort for Children (WECC)

- Platform for translating routinely collected data into an anonymised population based e-cohort of children to
  - Investigate the widest possible range of social and environmental determinants of child health and social outcomes
  - Inform the development of interventions to reduce health inequalities of children in Wales

WECC development

- Inclusion criteria
  - Children born or resident in Wales
  - Phase 1: Date of birth between 1st Jan 1990 – 31st Dec 2008
  - Phase 2: extended to include births until 1st October 2012
- Core databases
  - Welsh Demographic Service (WDS)
  - National Community Child Health Database (NCCHD)
- Linking field
  - NHS number --- encrypted anonymised linking field (ALF_E)

Examples of analyses

- Gestational Age, Birth Weight, and Risk of Respiratory Hospital Admission in Childhood (Paranjothy S. *et al (*2013) *Pediatrics* **132:6** e1562-e1569)

- Association between hospitalisation for childhood head injury and academic performance (Gabbe B.J. *et al (*2014)*Journal of Epidemiology and Community Health, J Epidemiol Community Health.***68:5** 466-470)

- Frequent house moves and educational outcomes (Hutchings H. *et al* (2013) *PLoS One.* **8**(8) e70601)

- Influence of the physical social and environment on childhood obesity

Cerebral palsy & SES – based on Swedish population data (Hjern & Thorngren-Jerneck '08)

Abstract

Background: There is a controversy regarding the existence of a socio-economic gradient for cerebral palsy. Perinatal emergencies and preterm birth increase the risk for the offspring to develop cerebral palsy. The aim of this study was to investigate the association of socio-economic indicators with cerebral palsy (CP) and the role of perinatal health as mediator of this association.

Methods: Register study of a national cohort of 805,543 children born 1987–93, including 1,437 children with cerebral palsy that were identified in hospital discharge data from national registers. Socio-economic indicators of the household were taken from the Census of 1985. Logistic regression and chi-square analyses of linearity were used to test hypotheses.

Results: There was a linear association between the incidence of CP (excluding cases caused by registered injuries or malformations) as well as of major perinatal indicators and the socio-economic status (SES) of the household of the mother ($p < 0.001$). Children in households with low SES had a higher odds ratio of CP (OR 1.49 [95% C.I. 1.16–1.91]) compared with high SES after adjustment for demographic confounders. This OR decreased to 1.36 (1.05–1.71) after adjustment for perinatal indicators with preterm birth as the most important mediating variable.

Conclusion: This study suggests that there is a continuous socio-economic gradient for CP in Sweden. Further studies in more complete populations of children with cerebral palsy are needed to confirm this. Perinatal complications seem to mediate some of this gradient.

Derby Community Paediatric data – promoting equity of access (Maharaj et al, '12)

Background Deprived children constitute a large population with high levels of ill health, and difficulty with access to healthcare contributes to their poor health outcomes. There is debate on how best to engage deprived families and the literature on differential access to paediatric care based on deprivation is limited.

Aims

1 To demonstrate that community paediatrics can contribute to reduction of health inequalities by providing services that are accessible to and preferentially used by children whose health is likely to be affected by deprivation.

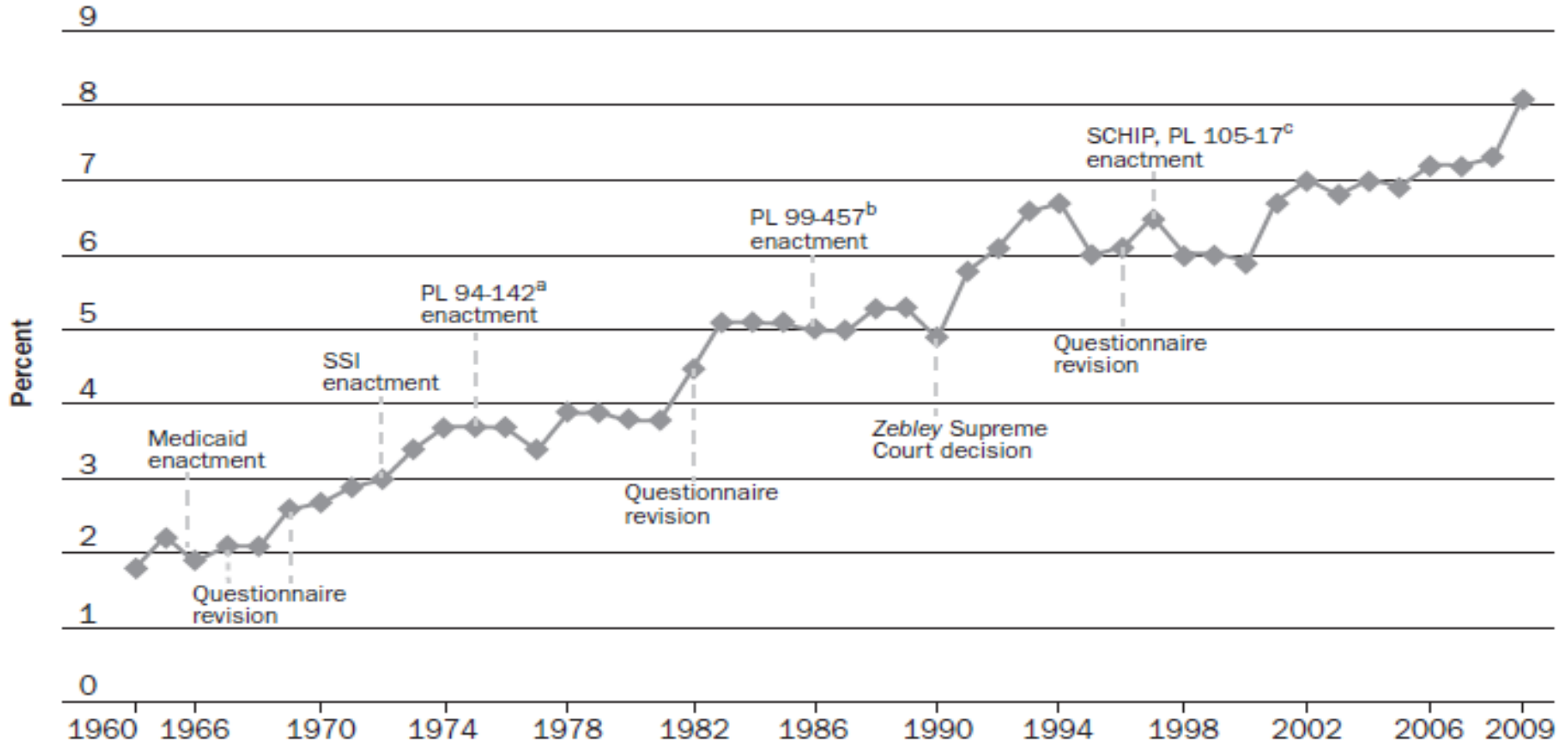
2 To provide a template for others to improve and monitor equity in their services.

Method Long-term service reconfiguration and health equity audit. We used routinely collected activity data and the Indices of Multiple Deprivation to construct equity profiles of the children using our service, and compared these with the profile of the population aged 0–16 years in the geographical area covered by the service.

Results The new patient contact rate for the most deprived children in the population was more than three times that of the least deprived [odds ratio (OR) 3.29, 95% confidence interval (CI) 2.76–3.93]. Deprived children were more than twice as likely to require multi-agency meetings as part of their medical care (OR 2.28, 95% CI 1.94–2.69). Seventy per cent (3693/5312) of our total contacts were with children in the two most deprived quintiles. There was a marked socio-economic gradient in all types of contact.

Conclusions The model of care used by our community paediatric service successfully engages deprived families, thereby reducing health inequalities due to poor access. Key features are multi-agency working, removing barriers to access, raising staff awareness and use of health equity audit. Our findings provide support for tackling health inequalities via health services that are available to all, but capable of responding proportionately according to level of need, a model recently described as proportionate universalism.

Activity-limiting chronic conditions in US – changing prevalence (Halfon et al '12)



Source: National Health Interview Survey.
Note: Under 17 years of age for 1960–81; under 18 years for 1983–2009; no data available for 1982.
a. Education for All Handicapped Children Act of 1975.
b. Education of the Handicapped Act Amendments of 1986.
c. Individuals with Disabilities Education Act Amendment of 1997.

Inequity in activity-limiting conditions in US '08-'09 (Halfon et al '12)

Category	Estimated number of cases	Number of cases per 1,000 children
Overall	5,666,000	76.8
Child age		
Under 6	1,175,000	46.5
6–11	2,260,000	94.7
12–17	2,231,000	90.4
Child gender		
Male	3,711,000	98.4
Female	1,955,000	54.1
Race/ethnicity		
White, non-Hispanic	3,535,000	84.1
Hispanic	934,000	57.8
Black, non-Hispanic	969,000	84.0
Asian, non-Hispanic	116,000	36.5
Other, non-Hispanic	112,000	120.3
Family income, as % of federal poverty level		
Under 100	1,390,000	108.1
100–199	1,296,000	87.9
200–299	768,000	75.7
300–399	616,000	84.3
Over 400	967,000	57.5

Social gradient

Challenges

- Meaningful/standardised definitions
- Data collection in countries with poor infrastructure
- Translating findings into policy & practice based on child rights, equity & social justice

Conclusions

- Marginalization – major impact on child health & well-being globally
- Violates children's rights
- Measurement essential to underpin equity & social justice practice/policy initiatives
- Child rights approach