

# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

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# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- Goal of this Presentation
  - Assess the MCH EPI field for its analytic readiness for the life-course approach
  - Present several key barriers that must be addressed to better implement the life-course approach in MCH EPI (plus also note some opportunities to exploit as well)
  - Stimulate a discussion about future opportunities to advance the life course approach in MCH EPI

# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- The current MCH EPI field is not yet well equipped to support a life course approach
  - Limited longitudinal analytic capacity
  - Scattered longitudinal data bases
  - Virtually no measures of life-course trajectories, cumulative risks, cumulative experiences
  - Confidentiality legal infrastructure not in place
  - Few longitudinal data/life course training opportunities
- Many challenges and opportunities exist which would substantially enhance the evolution of life course approaches in MCH

# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- Domains needing to be addressed
  - Life course data bases
  - Life course variables development
  - Longitudinal analytic needs and applications
  - Contextual analytic needs and applications
  - Confidentiality concerns in a life-course context
  - New research opportunities
- New training needs
- Generating the political will and needed resources

# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- Life course data bases exist, but are underutilized (I)
  - European longitudinal health data bases exist
  - Occasional U.S. intergenerational research studies (of successive birth outcomes)
  - Widespread longitudinal approaches in child development – but not for parents

## A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- Life course data bases exist, but are underutilized (II)
  - School health data is longitudinal, but rarely exploited by MCH EPI community (FERPA)
  - Health Plan (HMO, Medicaid) data could be examined longitudinally more extensively
  - Growth in research-oriented longitudinal data bases (ECLS-B, NLSY, National Children's Study), not utilized by public sector agencies for policy

## A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- New emphasis on data linkages supports a longitudinal/life course approaches
  - Data linkages are inherently longitudinal (PELL)
  - But most data linkages emphasizes short-term temporal associations ( e.g., birth certificate risk factor linked to subsequent program participation)
  - Maternally-linked birth files cover only a limited period of life

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- Our current MCH data systems could be enhanced to include more longitudinal information
  - Capture more maternal history information in PRAMS, YRBS, birth certificates (eg, immigration history, perceived changed social class, early childhood experiences,....
  - If we want to know about prior experiences and history, we have to ask about it

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- There are no or limited data bases for certain life course stages or developmental periods
  - Limited or no systematic/ongoing pre-school (3-5 year old) data bases exist
  - Listening to Mothers is an example of a new maternal experience of birthing data base
  - Early motherhood/fatherhood data bases missing
  - Internatal care/post-partum maternal health status data bases missing

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- Life course variables development (I)
  - Very few and simplistic life course variables exist (years of education, birth place, age, parity..)
  - We need to think about and create more meaningful longitudinal measures

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- Life course variables development (II)
  - We do not know how to measure cumulative risk (allostatic load)
    - Age is our current best measure of the weathering hypothesis
    - Need to create cumulative measures, like person years in poverty, ...
  - We do not know how to measure cumulative health service experience variables
    - Medical home, immunization status are examples of longitudinal services measures
    - Need cumulative program impacts and measures, not simply participation or not

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- Life course variables development (III)
  - We need to enhance how we think about cumulative longitudinal outcomes
    - The geriatric community has thought more about a wider range of life course outcomes than the MCH community. The WHO functional status measures not widely adopted in the MCH community
    - Too often we utilize more simplistic outcome measures; illness (yes/no or severity categories). We need to move from algebraic to calculus thinking. Measurement of trajectories, not simply fixed points.

# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- We need to strengthen or modify our longitudinal analytic methods and applications
  - Compare and improve methods for longitudinal data linkages
  - Establish normative expectation rates for linkages, common approaches to reporting non-linkage biases
  - Utilize more biostatistical modeling to addressing missing data
  - Develop more normative growth curves and standards (e.g. WHO Growth and Motor Development Standards), and deviation pattern functions

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- We need to strengthen or modify our contextual analytic methods and applications
  - Life course is not just about longitudinality, but also about the breadth of factors which influence development
  - Multi-level modeling has begun to address some contextual factors which influence development
  - We need to begin to think about multi-level historical modeling that influences life course development
  - Geographic Information Systems could further add breadth to longitudinal models, but are too often ahistoric

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- Addressing confidentiality issues in a life course context
  - Confidentiality issues are even more complex in a longitudinal context
  - There are conflicts and barriers among current confidentiality laws at different stages of a life course (HIPAA, FERPA)
  - Does a child who becomes an adult (18 years of age) have to re-consent to data collected about him/her as a minor?
  - Does the U.S. want to follow the European lead and have a permanent health identification number?
  - Who will have access to and control complex longitudinal data systems? (MA RADAR Committee)

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- New research opportunities
  - Testing cumulative versus episodic experience causation for a poor health or development outcome
  - Intergenerational SES change/drift theories (e.g., the distinction between wealth and income)
  - WHO growth norms versus growth standards

# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- New longitudinal training needs
  - Life course skills can and need to be taught
  - More longitudinal and multi-level analytic methodologies and theory in MCH EPI
  - Encourage more developmental epidemiology
  - Need for CE and workshops for practicing MCH epidemiologists, and new fellows
  - Better and more life course theory and methods for MPH and doctoral students

# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- Creating the Political Will and needed resources to further life course development in MCH EPI
  - Good things don't just happen because of good ideas, resources are needed to facilitate new approaches
  - The first steps are sessions like this to educate (and get buy-in) of our MCH EPI field's current and future leaders
  - Innovative life course research will create demand
  - Encourage pressure from MCH agencies, which are rapidly embracing life course programs and policies
  - Advocate internally for life course approaches
  - The National Children's Study has moved MCH longitudinal life course models to the forefront

# MCH Epidemiology Life-course Context (changes since 2007)

- MCH life course now more widely embraced
- Changing political environment - National Health Care Legislation
- Electronic Medical Records
- Quality Improvement – New practice measures
- Growth in private Sector health data linkage, data mining
- Growing concerns about confidentiality
- Emerging MCH concerns - Childhood obesity, medical home - are MCH Epi life-course themes

# A Life-course Approach to MCH Epidemiology: MCH Data Needs and Applications

- Concluding thoughts
  - MCH life course models offer new opportunities for theory, practice, education and research
  - Life course models, we believe, can help us better understand and improve the health of women, children and families –*but they remain to be tested; this is the challenge for our MCH EPI field*
  - We need to create a future oriented strategic agenda to implement the life course paradigm shift in MCH EPI
  - Hopefully this session stimulates your imagination to enhance a life course approach to MCH Epidemiology