

# Child Health & Development Survey Reporting Regulation

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# To Improve Health of Children (& Adults) We Need Better Data on Children

- *A Running Start – Health* is an initiative to improve the health of children 0-5
- Development in early childhood:
  - Is a marker for important psychosocial problems in childhood
  - Is a predictor for health in adult years
    - E.g. adverse childhood experiences → delayed development → mental illness in adults
- We have very little population-based health data on children in the first few years of life
  - Mostly mortality & hospitalization
  - No risk factor data equivalent to BRFSS



# Population-Based Data on Child Development Would Be Invaluable

- Use of child development data:
  - Understanding distribution of developmental delays by demographic subgroups
  - Directing existing resources to subpopulations at greatest need
  - Evaluating programs to improve children's development
  - Tracking progress over time, city-wide and in key subpopulations
  - Advocating for resources



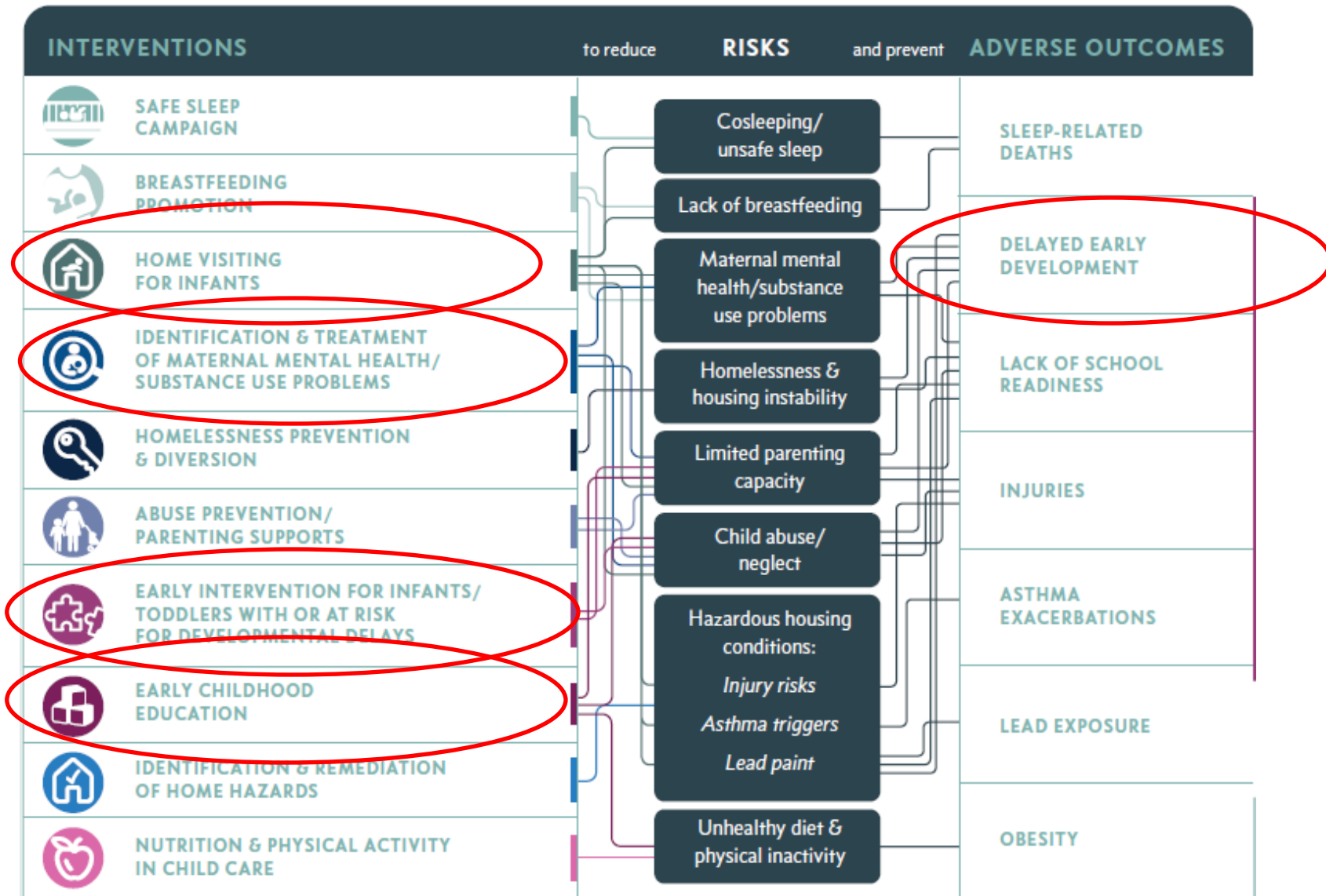
a running  
**START**  
**HEALTH**



# A Running Start – Health Principles

- 1 Lifelong health begins with healthy early childhood
- 2 Today, not all children get an equal start
- 3 A small number of avoidable risks contribute to most health problems
- 4 A sharp, coordinated focus on these risks will protect more of Philadelphia's children

# A Running Start – Health Final Framework



# A Running Start – Health will monitor all adverse outcomes

- Sleep-related deaths
- Delayed early development (under development)
- Lack of school readiness (under development)
- Injuries
- Asthma exacerbations
- Lead poisoning
- Obesity

# Data on Child Development is Now Available

- Pediatricians routinely screen children for developmental status at well-child visits
- Increasingly, developmental screening results are:
  - Recorded in standardized, structured form
  - Maintained in electronic health records
- Survey of Well-Being of Young Children (SWYC)
  - 10 questions asked of parents, age group-specific
  - Used by CHOP, St. Chris., PDPH well-child clinics
    - ~50% of children in Philadelphia?







# SWYC™: 18 months

18 months, 0 days to 22 months, 31 days  
V1.06, 9-1-16

Child's Name: \_\_\_\_\_

Birth Date: \_\_\_\_\_

Today's Date: \_\_\_\_\_

**DEVELOPMENTAL MILESTONES**

These questions are about your child's development. Please tell us how much your child is doing each of these things. If your child doesn't do something any more, choose the answer that describes how much he or she used to do it. Please be sure to answer ALL the questions.

|   | Not Yet | Somewhat | Very Much |
|---|---------|----------|-----------|
| Runs . . . . .  | 0       | 1        | 2         |
| Walks up stairs with help . . . . .   | 0       | 1        | 2         |
| Kicks a ball . . . . .  | 0       | 1        | 2         |
| Names at least 5 familiar objects - like ball or milk . . . . .             | 0       | 1        | 2         |
| Names at least 5 body parts - like nose, hand, or tummy . . . . .           | 0       | 1        | 2         |
| Climbs up a ladder at a playground . . . . .                                | 0       | 1        | 2         |
| Uses words like "me" or "mine" . . . . .                                    | 0       | 1        | 2         |
| Jumps off the ground with two feet . . . . .                                | 0       | 1        | 2         |
| Puts 2 or more words together - like "more water" or "go outside" . . . . . | 0       | 1        | 2         |
| Uses words to ask for help . . . . .  | 0       | 1        | 2         |



# SWYC™ :

## 24 months

23 months, 0 days to 28 months, 31 days  
 V1.06, 9-1-16

Child's Name: \_\_\_\_\_

Birth Date: \_\_\_\_\_

Today's Date: \_\_\_\_\_

### **DEVELOPMENTAL MILESTONES**

These questions are about your child's development. Please tell us how much your child is doing each of these things. If your child doesn't do something any more, choose the answer that describes how much he or she used to do it. Please be sure to answer ALL the questions.

|   | Not Yet | Somewhat | Very Much |
|---|---------|----------|-----------|
| Names at least 5 body parts - like nose, hand, or tummy . . . . .       | 0       | 1        | 2         |
| Climbs up a ladder at a playground . . . . .                            | 0       | 1        | 2         |
| Uses words like "me" or "mine" . . . . .                                | 0       | 1        | 2         |
| Jumps off the ground with two feet . . . . .                            | 0       | 1        | 2         |
| Puts 2 or more words together - like "more water" or "go outside" . . . | 0       | 1        | 2         |
| Uses words to ask for help . . . . .                                    | 0       | 1        | 2         |
| Names at least one color . . . . .                                      | 0       | 1        | 2         |
| Tries to get you to watch by saying "Look at me" . . . . .              | 0       | 1        | 2         |
| Says his or her first name when asked . . . . .                         | 0       | 1        | 2         |
| Draws lines . . . . .   | 0       | 1        | 2         |

# Child Health & Development Survey

- Aggregate data across multiple pediatric providers
- Link to birth certificates to:
  - Statistically adjust for biases caused by providers contributing data
  - Control for prenatal & birth factors influencing development (e.g. prematurity)
- Combine with list of other health problems to adjust for other influencing factors
- Analysis to identify epidemiologic patterns and trends in child development
- Use by wide variety of policy-makers and programs



# Legal Issues

- Board of Health authorized to adopt regulations to promote health of public
  - Including mandatory reporting of health-related data
- HIPAA otherwise puts restrictions on data transfer from medical providers
- Proposed regulation:
  - *Requires* reporting of developmental data *if* maintained in structured, standardized, digital form
  - *Permits* reporting of health data associated with this