

Long-Term Follow-up of Newborn Screening: Definitions and Models

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And many others...

Outline

- Definition of long-term follow-up
- Examples of current programs
- “High-level” conceptual models
- Next Steps

Defining Long-Term Follow-Up

- Overarching goal: Achieve the best possible outcome for children and their families

Defining Long-Term Follow-Up

- Chronic disease management / provision of treatment
- Age-appropriate preventive care and health promotion
- Activities to expand the evidence base
- Quality Improvement
- Throughout the lifespan from the time of diagnosis

The Medical Home



- Not necessarily a “physical location”
- Not “Provider” specific
- Changes over time (e.g., transition to adult care)

Examples of Long-Term Follow-Up

- Children's Oncology Group
 - Provides recommendations on how to monitor for the late effects of cancer treatment
 - Includes some active surveillance
 - However
 - Aimed at individuals who have already completed treatment
 - Does not specify how follow-up care should be coordinated

Examples of Long-Term Follow-Up

- Comprehensive Sickle Cell Centers
 - 11 funded by the NHLBI
 - Care coordination
 - Conduct basic and translational research
- With the limited number of sites, many individuals with sickle cell disease do not receive care through these centers

Examples of Long-Term Follow-Up

- Cystic Fibrosis Foundation accredits more than 100 care centers
 - Provide comprehensive care
 - Actively involved in QI and research

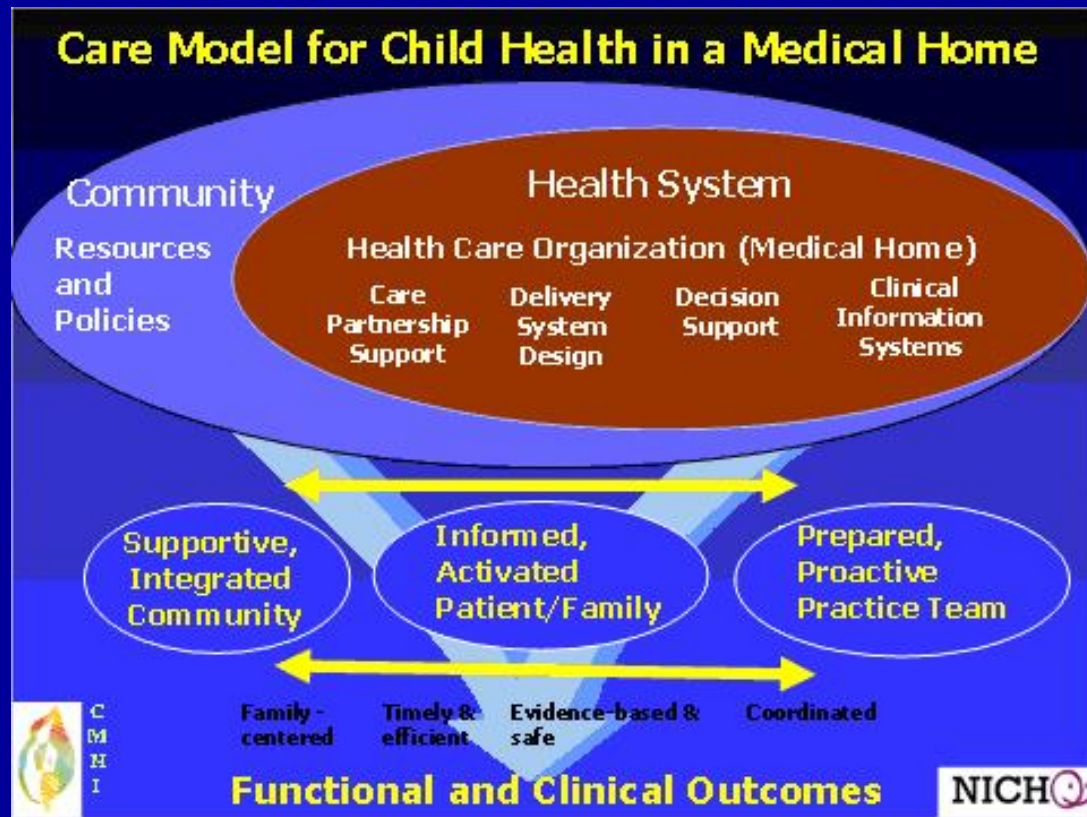
The Medical Home



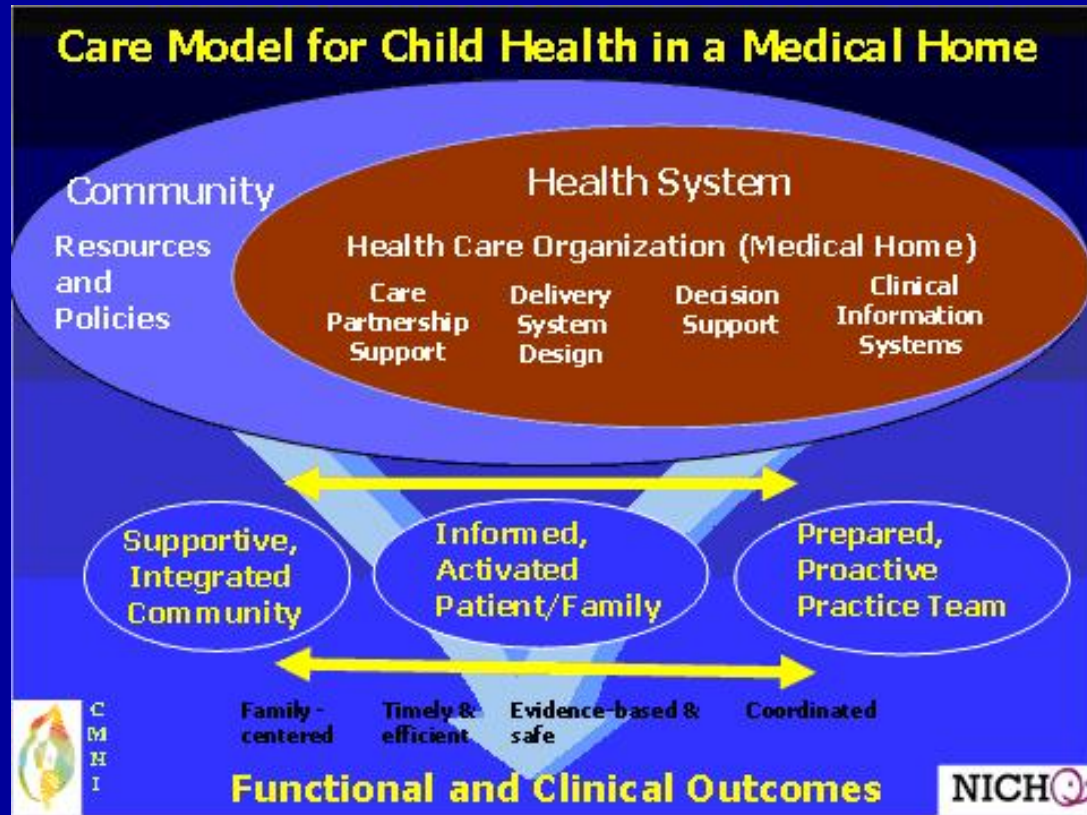
- What is the role of specialized single-gene disorder clinics?

Figure from Riley Children's Hospital

Chronic Care Model

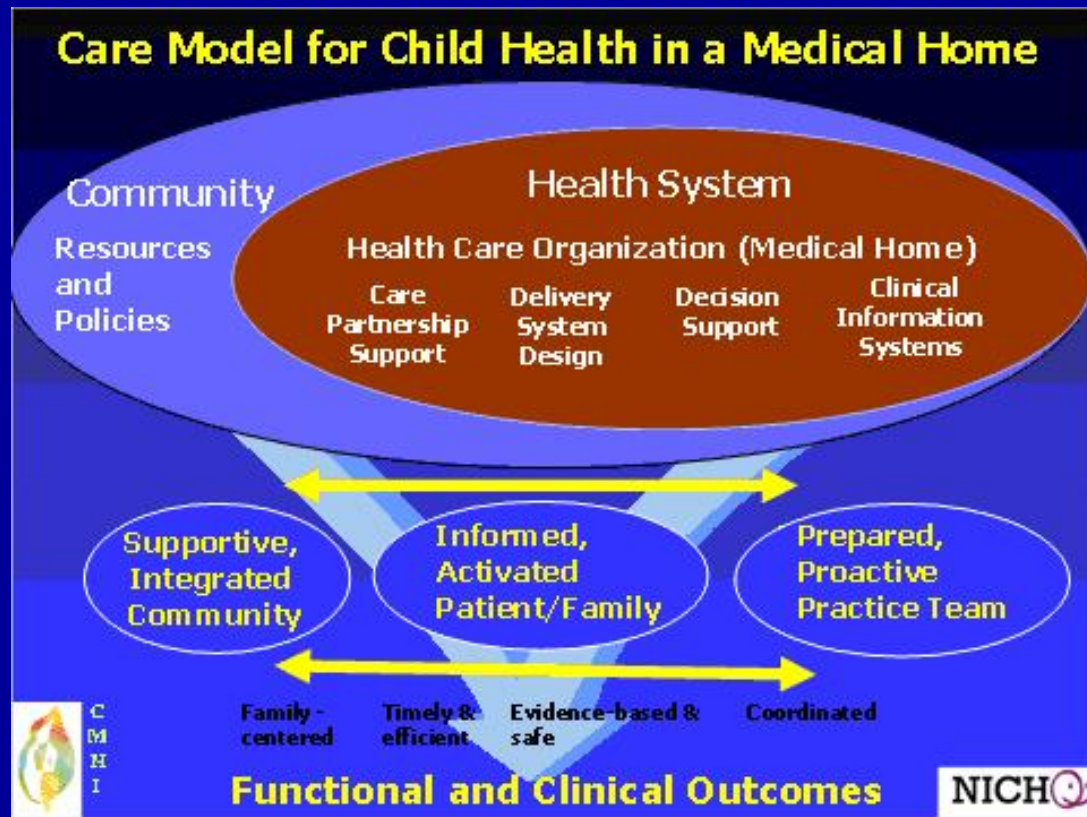


Chronic Care Model



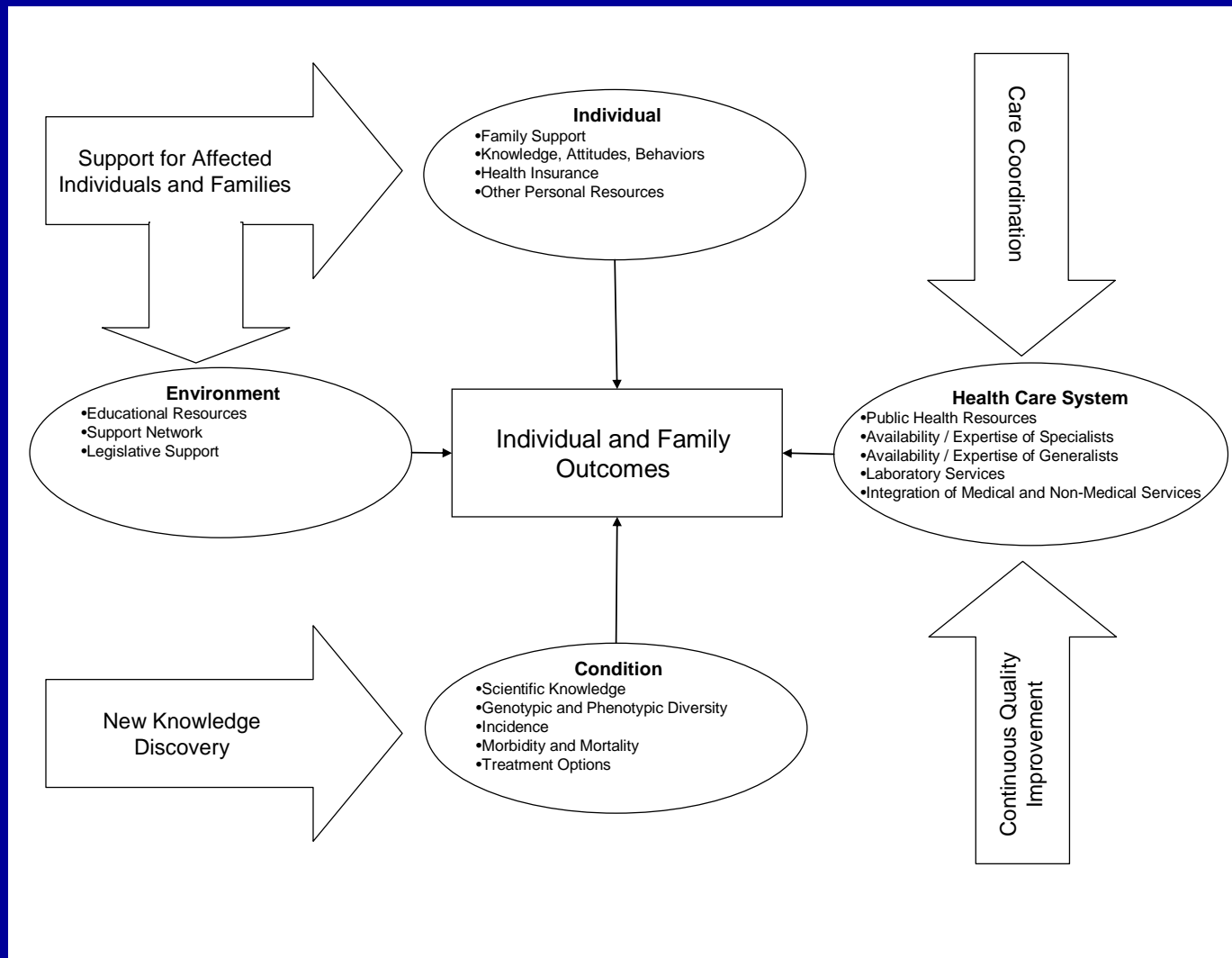
- Asthma
- Well-child care

Chronic Care Model

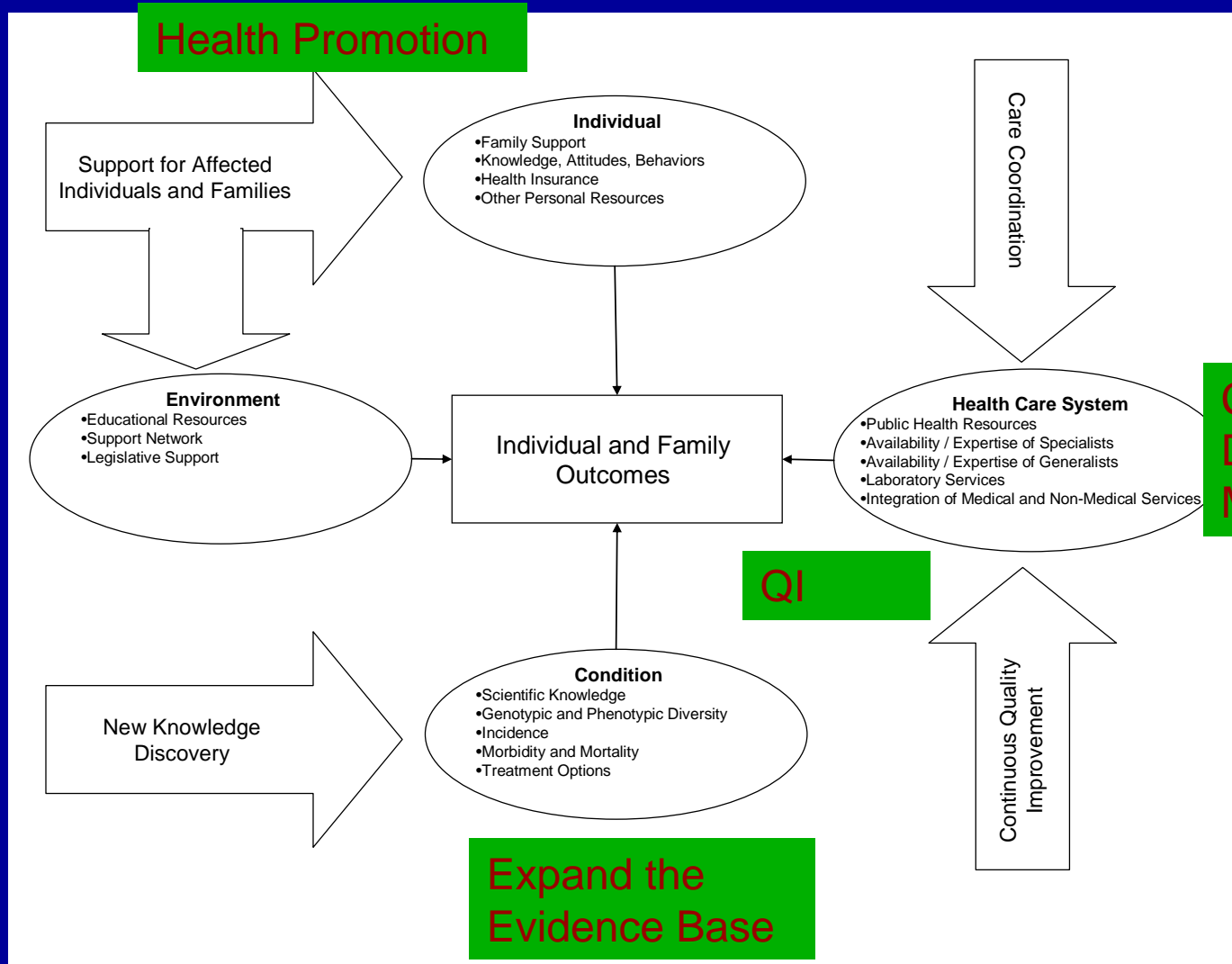


- Lacks specificity for NBS, including the heterogeneity of the conditions
- No clear spot for public health

Newborn Screening Specific Model



Newborn Screening Specific Model



Next Steps

- In the April meeting, we considered
 - Roles and responsibilities for implementing long-term follow-up
 - Barriers – modifiable and non-modifiable
 - The role of health information systems as a tool, not a solution

Next Steps

- Developing a “staged” vision for the future, with explicit and achievable practical goals – perhaps as a logic model
- Defining the relationship between public health, care providers (of all types), and researchers

Questions?