

# MA Integrated Systems for Children with Special Health Care Needs Project

~ MA Department of Public Health ~  
Bureau of Family & Community Health  
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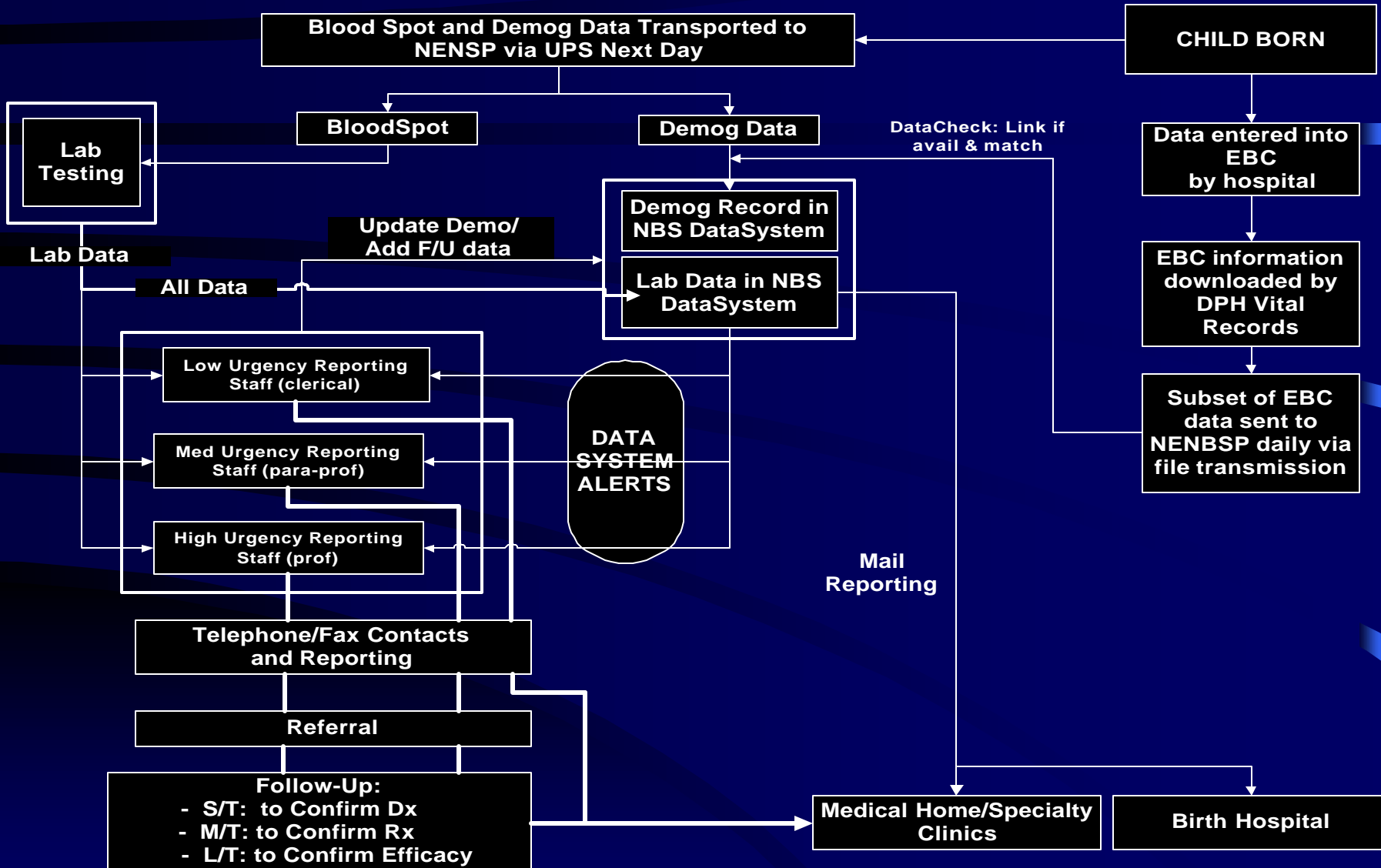
# Overview

- Integrate data and service systems
- Focus on 3 newborn screening programs
- Brings everyone to the table
  - blood screening, hearing screening, FIRSTLink
  - Early Intervention, Care Coordination (Title V CSHCN program), MA Genetics Program, specialty services, medical homes
- Have begun to lay out process: how data are collected and feed into service systems

# Goals of Project

- Assure access to care coordination & timely referral to services for CSHCN, particularly children identified through newborn screening programs & genetics diagnostic centers
- Establish integrated child health data system across DPH programs with links to medical homes
- Increase community & program staff genetics knowledge & capacity

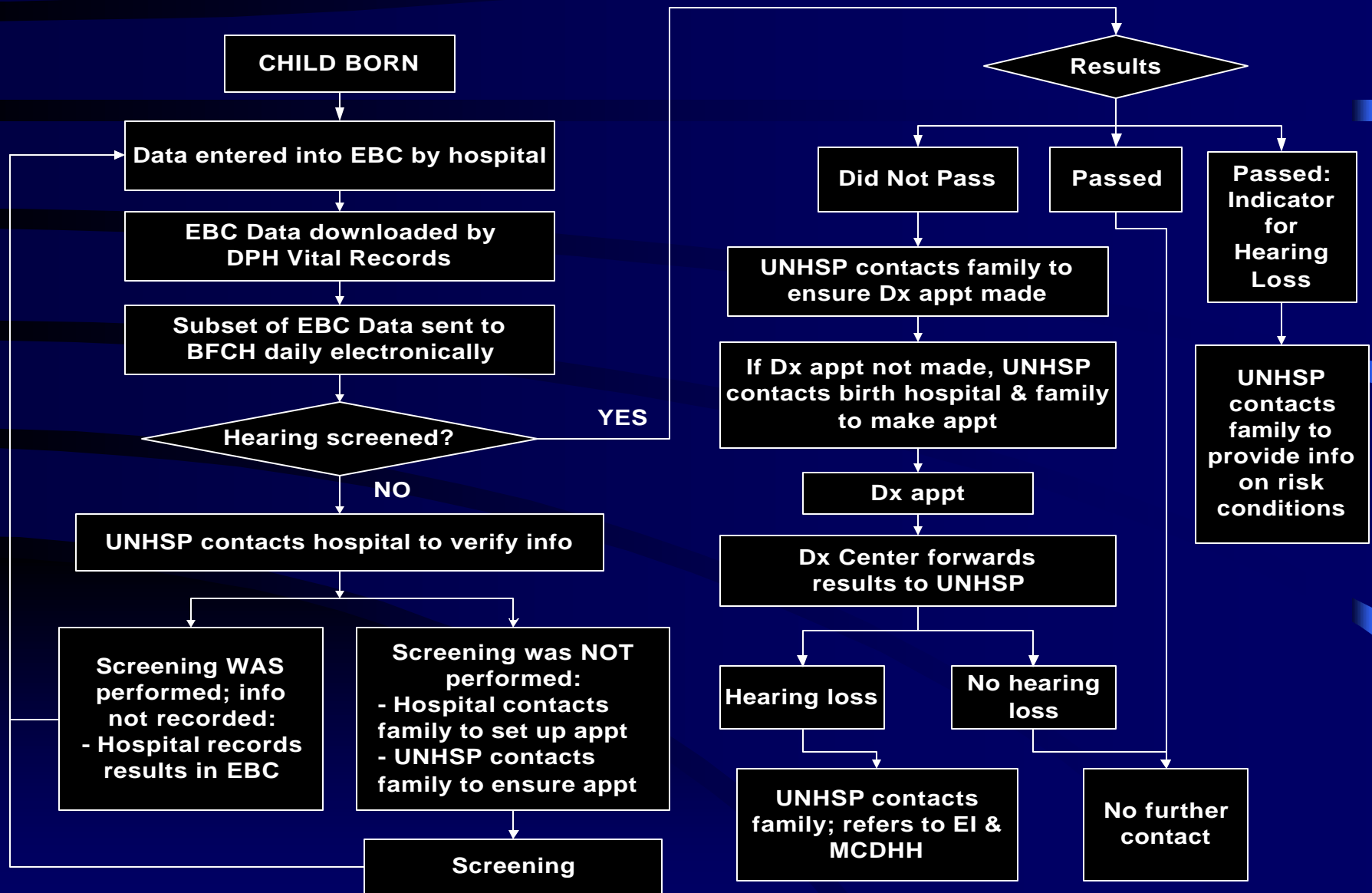
# Newborn blood screening



# Blood screening: Service flow

- NENBSP contacts MD or hospital to inform of out of range values, interpret results, recommend next steps including referral, if necessary
- MD or hospital contacts family & refers child for repeat test, diagnostic & specialty services; may refer to EI, other services
- NENBSP follows up with MD or hospital at various intervals to confirm Dx and Rx (enters data)
- Project objective: Ensure link to EI, Title V CSHCN Care Coordination, family support, other services
- Project objective: Link data (which?, security issues, etc)

# Newborn hearing screening





# Linking data & services - 1

- STEPS:
  - Provide framework (“common architecture”) for developing applications to support DPH services
  - Integrate systems when allowed by law and policy
  - Begin with early childhood programs
- Move NENSP to web-based system
- Determine optimal unique identifiers
  - Work collaboratively to overcome obstacles to effective implementation of unique identifiers

# Linking data & services - 2

- Expand FIRSTLink to all hospitals
- Develop mechanisms for referral to EI and Care Care Coordination
- Strengthen links between screening systems & medical homes
- Increase genetics awareness among DPH staff, community providers, medical homes

# Future considerations

- Add linkages to birth defects registry
- Growing importance of genetics
  - across the lifespan
  - increased number of conditions
- STEPS allows for potential of linkages within families -- track genetic, heritable conditions