

Session 1: Promising practices from your state

OH:

- Use NBS fee to fund network of regional centers (SCD, CF and Genetic Ctrs); families are 2 hours or less away from genetic services
 - Criteria for clinics [**Anna will provide link**]
- Inter operability between or access to data systems -- genetic centers input encounters; BDR is built from vital statistics – start from general profile; part C, CSHCN and NBS data systems --- access and work within all systems
- Collect dx data – confirmed, pending, referred and no evidence
- TitleV/CSHCN program – last resort for children without adequate insurance; CSHCSN pays medical bills; in order to pay, have a network of providers who meet certain credentialing – specifically metabolic and sickle cell providers
- Metabolic formula program – centralized in CSHCN program and coordinates payment – whether its WIC, Medicaid or CSHCN --- allows competitive pricing
- Integrating with other partners is key – big cancer and genetics partnerships; birth defects and gestational diabetes; FASD initiatives with various
- SCD-trait follow-up – disease too; face to face contact with all babies who are presumptive positive and /or confirmed

MN – get more information on Quickr!

- Coordinated communication between systems; ltfu, bdr, nbs, ehdi and large system/staffing
- Starting to utilize the same data system – MEDSS
- Utilize LPH for lost to follow-up and other follow-up; connected to EI
- Web-based secure team collaborative software – “quickr” – IBM program; easy to add people – role-based, etc; it also archives and is searchable; user fee, but it is minimal; it is paperless – no hard files; very secure – sends “f-up on positive screen” link to email, not the information via email.
 - Positive result from lab; GC views, goes in and confirms viewing; realtime system; keeping tabs on follow-up (outside NBS system); like email – attach reports; can use for specialists, following up with no-shows, etc
 - Has reduced time to dx and tx
 - Still call PCP and page Specialist with results
- Healthcare home – proactive to getting ltfu access
 - Priority for state – HCH being certified, and want to make better use of the system
 - Certification is handled by MN Dept of Health – HCH unit and incorporated special needs staff ; doing special needs outreach and doing HCH develop

WI

- Walkthrough – shows they have good data systems; but they don’t talk to each other
- One lab does all screens
- BDR – option to refers to regional centers for CSHCN
 - Less likely to lose someone
- Follows baby from hearing to referral to services; good checks/measures with trigger system to notify admin and birth hosp
- SPHERE system is good

- If approval to link is made; it would be painless
- E-birth cert; agreement to put blood spot number on cert; some birth circumstance on that card and can access that info in that system
- Pilot for bdr – contact family to give contact information
- MH working with PCP – awareness of regional centers; physicians getting NBS results? – good number were not
- Lab and follow-up is in one section – reporting done from bench; additional follow-up to get started on tx and retesting --- no separate follow-up dept – prevents data transfer
 - Communicates directly with PCP/ specialist

MI

- Data integration – NBS MCIR connection; helps with communication to PCP and act with them; EHDI/NBHS results in MCIR too --- no single data system but moving in that direction
- LHD do a lot of follow-up as needed for NBS; read-only access to CSHCS database, CHAMPS-read/access; access to MCIR
 - HGB, EHDI, school vision screening
 - PCP – done components for EPSDT?
 - Missing link to do followup sometimes
 - Stand along silos of information – biggest challenge
 - MCIR may not be funded after 1 year
- Health Information Exchanges – push to develop those; planning stages
- **EI systems – last week, draft of regs published for re-authorization of IDEA**
 - **Regulations are coming out and will be effective soon**
 - **One particular piece: EI is going to be partnering with EHDI and CSHCS to allow more/better data sharing**
 - **Look for more information coming soon!**

IL

- Services in 3 different state agencies; data is separate and doesn't share well
- CSHCS has simplified app for dx services – to be covered by CSHCS when they don't have Medicaid/other ins

KY

- Enrolling NBS cases into BDR; BDR sends to EI to be ready for need of services
- Contract with Univ's as peds specialists; contract of timeframes to report back for dx
 - CH/CAH have 30 day deadline
- Hosp to vital stats; into NBS follow-up and can generate reports
- NBS Fup and Lab don't communicate in data systems
- Food/formulas program; ombudsman helps with appeals

IN

- Integrated data system – ISDH repository; houses all systems and allows role-based/limited views
- INSTEP program for long term follow up