USING DATA FOR RE-ENGAGING PEOPLE WHO HAVE DROPPED OUT OF CARE

ENDING THE HIV EPIDEMIC TASK FORCE, JULY 16, 2020

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- AGENCY/CLINIC LEVEL

- CAREWare MCPHD Administered
 - RW Parts A & C
- Case Manager/HIVe ISDH Administered
 - RW Part B
- Internal Database(s)
 - EMRs
 - Other Internal Tracking
 - Social Media, etc.

LOCAL/COUNTY LEVEL

- Local Disease Intervention Specialists (DIS)
 - Found By In-Person Clinic/Testing Visit
 - Leads Generated From ISDH
 - Eskenazi EMRs
 - Care Web Health Information Exchange Hospital Admissions Data Base (Indiana)
 - Phone Records Apps Spy Dialer, U.S. Phonebook.com (Reverse Look-Up)
 - Social Media
 - Public Records Searches Jail/IDOC/Voter Rolls/BMV
 - Other Methods Learned During Time On The Job

STATE LEVEL

- Accurint/Lexus Nexus Search Engines Used To Locate People
 - Used By Gov't, Collections Agencies, Law Enforcement, etc.
 - No HIPAA-Related Data (No Medical Info)
 - Can Give Current Contact Information
 - Generally Expensive To Use
- eHARS = Enhanced HIV/AIDS Reporting System
 - CDC Developed Collection & Reporting Tool Data Management, Analysis, Transfer Patient Info to CDC, etc.
 - Clinics, Labs Report Patient Medical Activity Labs, Demographics, Other Surveillance Info

STATE LEVEL (CONT'D)

- eHARS (Cont'd)
- National Database
 - Patient Given Unique Identifiers Protect Medical Info; HIPAA Compliant
 - Information Closely Guarded
 - Aggregate Reporting
 - Only Authorized Users Can Access (Small Group)
 - Can Be Cross-Referenced To Determine Individual Patients
 - Information Up-To-Date From Last Medical Visit
 - Information Not Allowed To Be Shared HIPAA, Federal Laws, CDC Rules, State Law

PROBLEM: VERY LITTLE INFORMATION CAN BE SHARED AMONG EACH OTHER

State Can't Share With County Without Specific Arrangement

Can't Share With Agencies (Aggregate Form Only)

County Can't Share With Agencies Without Signed Release Of Information - If Patient Had Previous Care – New Diagnoses' Info Can Be Shared

All Information Goes "Upwards"

GOOD NEWS: WE HAVE ALL THE TOOLS TO FIND OUT-OF-CARE CLIENTS

- Legal Barriers To Share Information
 - HIPAA
 - CDC/Federal Guidelines
 - State Laws
- Restrictive And Time Consuming
 - Constantly Re-Inventing The Wheel

HOW DO WE WORK AROUND OR PUSH THROUGH BARRIERS TO DO OUR JOB?

- Change All The Laws And Regulations To Allow Information To Be Shared Freely
 - Not Likely To Happen Any Changes Or Relaxing Of Policies Would Take Time
 - Indiana Code 16-19-3 Gives ISDH Authority To Adopt Reasonable Rules "To Protect Or Improve Public Health"
- Expand Current Agents And Their Abilities
 - MCPHD EHE Engagement Liaisons (3) Work Directly With ISDH In Same Capacity as MCPHD DIS
 - Embed Additional Liaisons Directly Within Agencies And Clinics
 - ISDH "Deputize" L2C Currently Working In The Field
 - Damien Center Only L2C Program With Client Transportation

GET THE WORD OUT

- Keep It Front And Center In Public Conscience Don't Simply Create Awareness,
 Create Common Knowledge
 - Be Upfront About Searching For Those Out Of Care
 - Attracts Those Out Of Care To Get Back Into Care Saves Time And Effort
- Reflect Absence of Stigma
 - Drop "AIDS" No Word Since "Leper" Has Carried As Much Stigma
- Be Strategic With Marketing
 - Don't Spend Money Where It May Not Be Effective

INVEST IN THE PEOPLE DOING THE WORK DATA MINING IS ONLY THE FIRST STEP

- Use EHE Money To Pay Frontline Workers Higher Wages
 - Create Stability Reduce Turnover
 - Helps Build Better Ongoing Connections With Target Populations/Cultures
- Don't Simply "Throw Money" At The Issue
 - Invest In The People Training, Support, Accountability
 - Let The Workers Be The Experts
 - If The Work Is Being Done, Continue To Support The Effort
- Create City-Wide Team Atmosphere
 - Collaboration With All Partners Across The Board Transparency And Communication

QUESTIONS AND DISCUSSION