Let’s Talk about Foster Care and HIEs

Sharing Data on Children in Foster Care:
Building a Culture of Trust, Providing Tools

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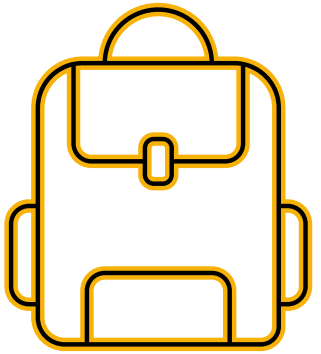
A Vexing Reality on the Ground

- Regulations restrict demographic data that can be shared about children/youth in care – for their safety.
- Regulations don’t apply to ALL agencies that interact with these children/youth.
- Restrictions make it nearly impossible to share their data through HIEs.

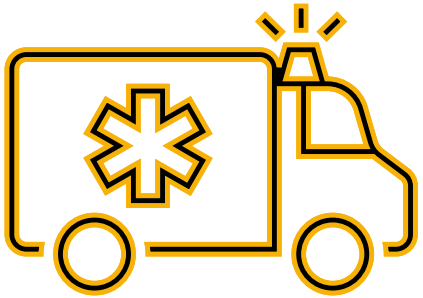
400,00 + Children and Youth in Foster Care

Foster Family Time Constraints



Due to Being Transient, No Existing Longitudinal Medical Records Follow the Child

Lack of Consistent Care



Emergency Placement into Foster Care at all Hours 24/7

High Rates of Trauma and Mental Health

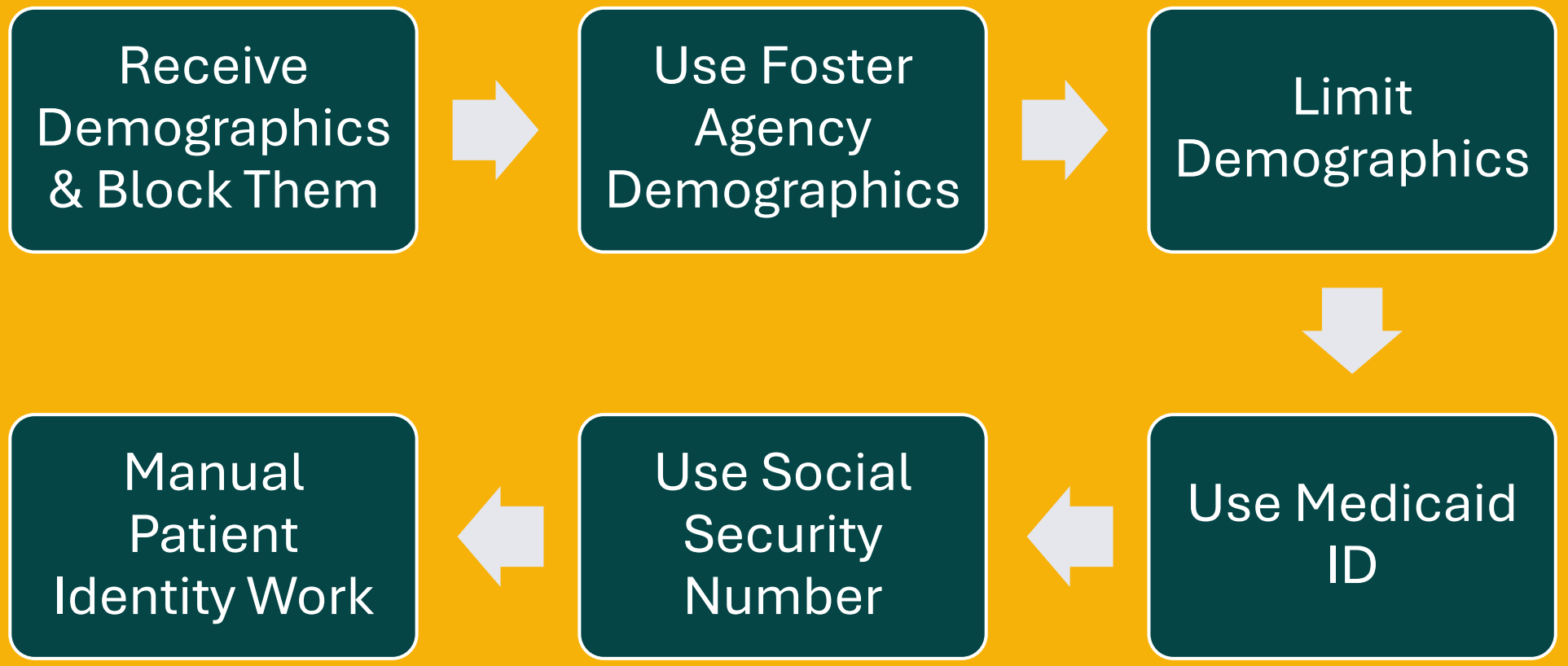
Disparate Health Information from Multiple Sources Throughout the Family Due to Often Being on Separate Insurance Plans

Challenges to Changing the Status Quo

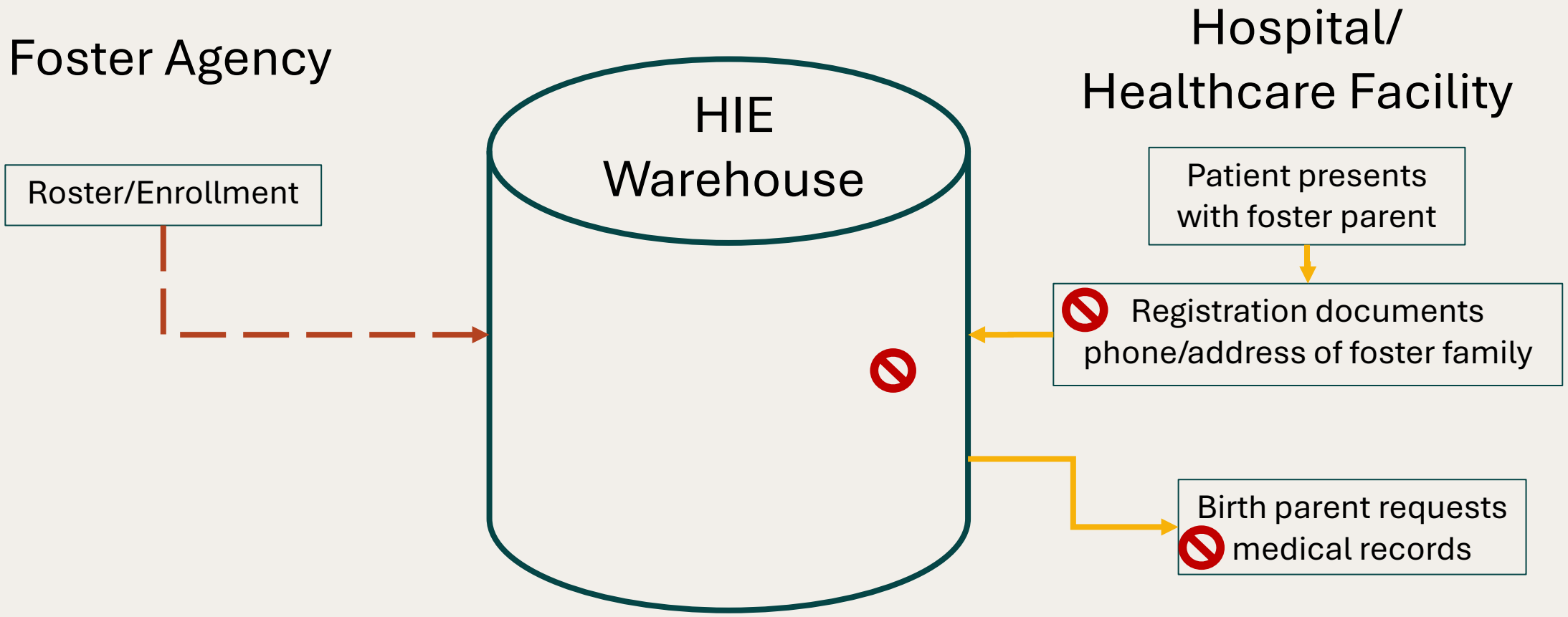
- Child welfare must navigate a complex landscape -- HIPAA, FERPA, 42 CFR Part 2, Office of Children and Family Services, and many more.
- Focus is on safety, permanency, reunification, etc. (i.e., not necessarily healthcare providers' priorities).
- Culture is insular and protective, shaped by privacy/confidentiality; a two-way street of trust is essential for data sharing.
- All of the above, plus stressful and heavy workloads, can be overwhelming – and they aren't allowed to exchange data even when they want to.

Data Restrictions on Foster Agencies

Data Integration Approaches



Foster Data Conundrum



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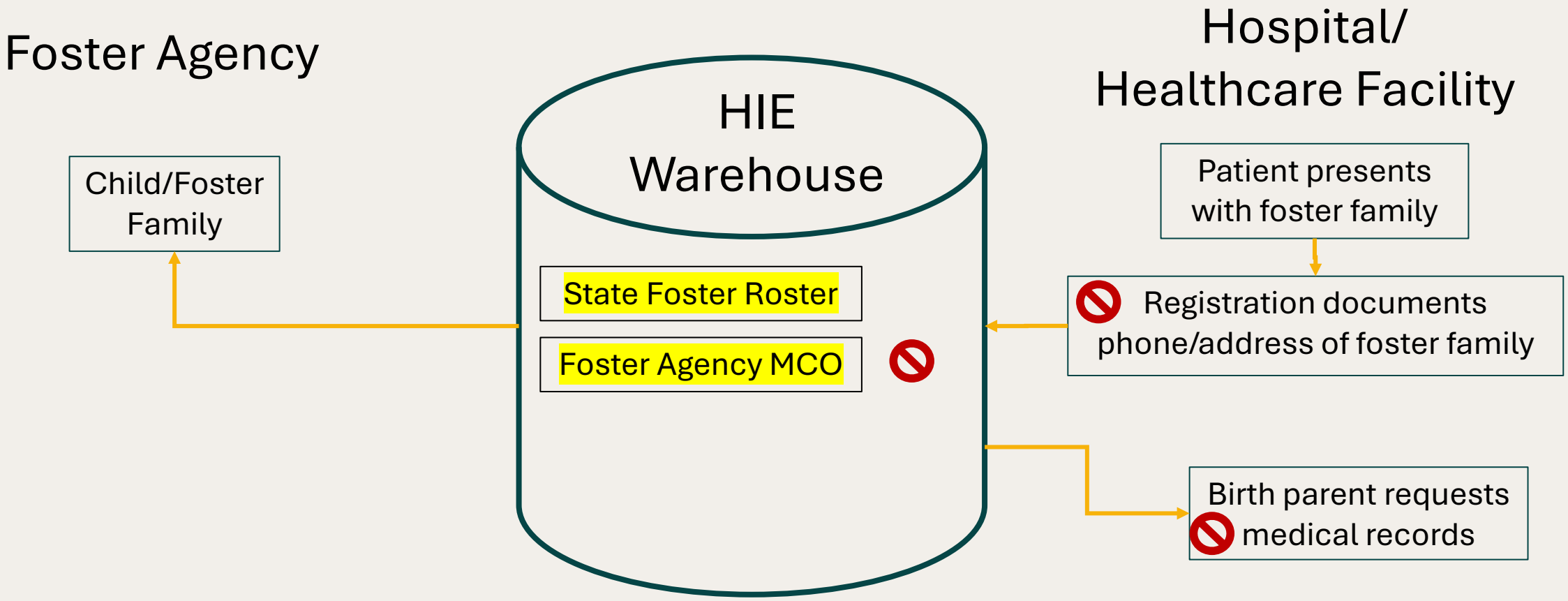
Foster data inconsistency



Foster Care Health Solution (FCHS)

Empowering Children Who Have Experienced Foster Care & Their Families

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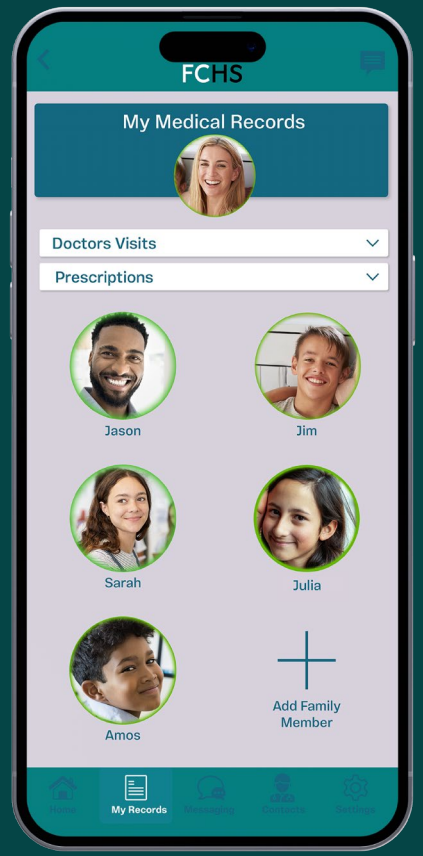
Solution

Deliver actionable insights via a secure application directly to foster children and their families



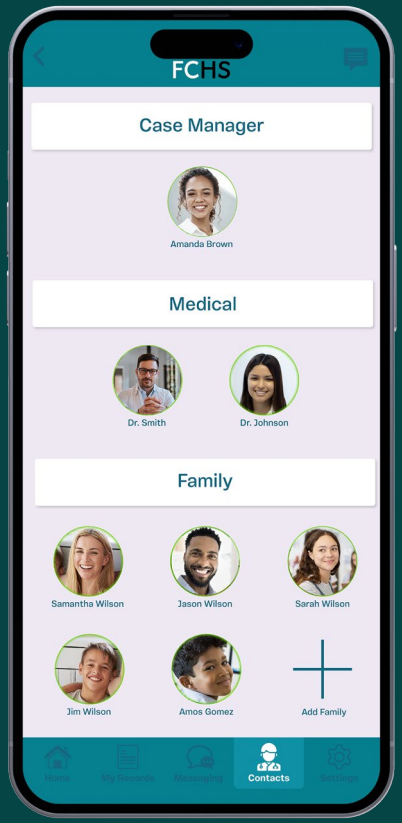
Not Child Welfare Information nor Medicaid Claims System dependent

Provides automated push notifications (e.g., reminders for prescription refills and upcoming annual visits)

Saves time and creates efficiencies for the foster parent, child, and caseworker

Streamlines and improves communication with relevant, timely information and resources

- Transportation
- Maps
- Revise contact information
- Scheduling



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Foster Care Health Outcome Improvement Program

Seeking Interest in Pilot Participation

The barriers are always formidable when we try to improve health outcomes, and even more so for children/youth in foster care.

Our organization is prepared to work closely with state agencies to address these landscapes:

- Technical
- Legislative
- Operational
- Political

We can begin with a pilot project that limits the initial effort to a subset of the total population and/or to specific diagnoses.

Potential Steps to Fuel Progress

- Educate on the benefits of receiving (not necessarily “sharing”) data, including better outcomes for children/youth.
- Stress that confidentiality, security and person-centered services are paramount in healthcare, too.
- Education healthcare on realities of foster care (racial/economic inequities, trauma, stigmas, etc.
- Offer tools and solutions in a broader effort to build trust and institutionalize collaboration over time.

Broad Recommendations

- Update the foster data restrictions to align with data exchange in 2024 and beyond (starting @ State level)

- Develop (sensitive) data sharing/access rules that apply universally
  - like Minor Protected Services, Mental Health, Part-2

- Empower foster agencies to improve care by encouraging data access, exchange & transparency