


Interagency data sharing in the age of HIPAA: University - State Partnerships in Evaluation

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Coordinated Family Focused Care (CFFC)

What is CFFC?

It's a five site wraparound services program for children with Severe Emotional Disturbance (SED) at risk for out-of-home placement in Massachusetts.

How are children eligible for CFFC?

- Ages 3-18
- Reside in one of the 5 cities where it is offered
- Child and Adolescent Functional Assessment Score (CAFAS) of 100 or greater
- Presence of Severe Emotional Disturbance (SED)
- Caregiver willing to participate in team process
- Child and family have tried other, less intensive, services



CFFC Services and Outcomes

Blended Funding	Program Goals	Outcome Measures
<ul style="list-style-type: none"> DMH Dept. of Mental Health DYS Dept. of Youth Services (Juvenile Justice) DOE Dept. of Education DSS Dept. of Social Services Medicaid 	<p style="text-align: center;">Increase ↑</p> <ul style="list-style-type: none"> • Family Involvement • Parent Empowerment & Competency • Child Functioning • Child Strengths <p style="text-align: center;">Reduce ↓</p> <ul style="list-style-type: none"> • Out of Home Placement • Cost • Clinical Symptoms • Parental Stress 	<ul style="list-style-type: none"> Child's Mental Health Child's Strengths Child's Functioning Parental Involvement Parental Stress \$\$\$\$ Costs Treatment Fidelity

Key Evaluation Questions

1. **Services:**
What services does the child receive before & during CFFC?
2. **Costs:**
 - What are the costs of providing CFFC?
 - What are the costs of the other services the child receives while in CFFC?
 - What are the costs of services while in CFFC compared with the cost of services 12 months pre-enrollment?
3. **Clinical Improvement:**
Has the child improved in school, home and the community while in CFFC?
4. **Fidelity:**
Does CFFC fit the model of "Wraparound" services?

CFFC Evaluation

The evaluation of the CFFC program is being headed up by the Center for Mental Health Services Research at UMass Medical School (CMHSR). The CFFC Evaluation is being funded by the Center for Health Care Strategies.

UMASS:

- Coordinating Overall evaluation
- Conducting phone interviews with caregivers

Mass Behavioral Health Partnership (MBHP)

- Managing the CFFC program and services
- Oversees collection of program level data
- Cleans, manages and enters data
- Provides data 4x/year on clinical measures and claims

State agencies (DSS, DYS, DMH, Medicaid, DOE)

- Provide data 1x/year on costs and services for children in CFFC

State Agencies: Services Received and Costs

12 months Pre-enrollment

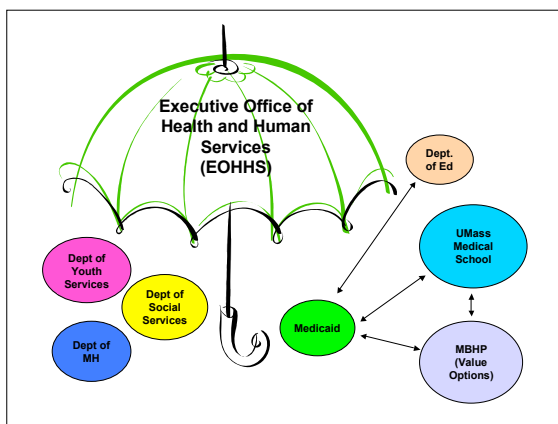
While enrolled in CFFC

Additional services received and paid for by state agencies, such as:

- ER visits & other health care
- Pharmacy costs
- Therapeutic after school program
- Residential placement

Know your context

- EOHHS restructuring
- Many stakeholders = many opinions
- New governor = new appointees
- Pending legal issues
- Budget cuts and constraints
- Competing interests of other programs and other priorities



Data Status

Did we get the data we planned to get?

As we began CFFC, all six involved State Agencies were committed to providing data on **services**.

While our evaluation plan called for **cost** data, this was more difficult to obtain

Currently, we have received:

- Useable Services data from 4 state agencies
- Useable Cost data from 3 state agencies

Primary Reasons for Not Receiving Data are:


- Medical model not applicable when a whole program is funded (vs. when services are paid on an individual basis)
- The data are difficult to get due to different data systems used by different agencies or lack of computerized files

Length of Time to Receive Data from State Agencies (months)

MBHP (Behavioral Health)	5
Dept of Mental Health	13
Dept of Youth Services	14
Medicaid Services (Pharm. & Health)	18
Dept of Social Services	20
Dept of Education	38

What Went Wrong: Reasons for delay in receiving data

- Legalities of data sharing agreements not worked out (EOHHS restructuring contributed to delays)
- Agencies with non-computerized data
- Challenges in flagging the right individuals using available identifiers
- Other agency projects had higher priority at various times
- Lack of clarity about the appropriate agency contact person
- Overworked agency data staff




What Went Right:

Reasons for success in receiving data


- Agency dedicated staff time to the project
- Assigned staff were system savvy and knowledgeable
- Assigned staff were tireless
- Legal data sharing agreements were arranged expediently
- Data were computerized with appropriate identifiers for matching individuals
- HIPAA issues and secure data transfer were adequately addressed

Methods of HIPAA Compliant Data Exchange



- Hand carried data on CD
- Secure Messaging (Encrypted Emails)
- Faxed Data (with confirmed person to receive)
- FedEx data on CD
- Hand delivered or securely mailed paper forms
- Security Portal

Data Challenges




- Project began just as new HIPAA regulations in effect
- Problem-solving difficulties with unique identifiers
- Identifying variables needed from each agency
- Management of large data sets
- Developing protocols for secure means of data exchange
- Working with unfamiliar data systems (Absolute)
- Complex SAS coding on UMass end (upon receipt of raw data), requiring unanticipated resources

Recommendations for Rapport Building with Agency Data Contacts

- Have initial face-to-face meeting
- Don't just rely solely on email...
Make phone calls!
- Respect agency contact's level of busyness; Strive for balance between "giving space" and being persistent.




Facilitation of data exchange: Lessons Learned



- Develop rapport with agency contacts
- Obtain full support of individuals at top of agency hierarchy
- Access to legal consultant to facilitate data sharing agreements
- Obtain a Federal Certificate of Confidentiality at start of project
- Get any available information about agency data sharing protocols when the project is still in development

Facilitation of data exchange: Lessons Learned



- Establish "bi-lingual" agency contacts
- Pilot forms and procedures to avoid database changes later on
- Get a data dictionary prior to the discussion with the data person to best understand what data elements you are asking for
- Concretely explain direct benefits of the research to partnering agencies
- Obtain more resources than you think you'll need