





Confidentiality and Information Sharing: / Can't Tell You That!...Or Can I?

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A Program of the


**Substance Abuse and Mental Health Services Administration
Center for Substance Abuse Treatment**


and the

**Administration on Children, Youth and Families
Children's Bureau
Office on Child Abuse and Neglect**




U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Administration for Children and Families
www.samhsa.gov






Purpose

- Challenges and real and perceived barriers with sharing administrative and client level data
- Desire to Know vs. Need to Know
- Site Examples







The Importance of Confidentiality

- Confidentiality is an ethical concern reflecting the right to privacy. It differs from privileged communication which is a legal concept.
- As part of informed consent for an intervention, professionals must provide information about exceptions to the promise of privacy.
- In addition to limits on confidentiality, there are times when keeping info confidential can seriously hamper helping an individual.



"Reframing the confidentiality dilemma to work in children's best interests" by L. Taylor & H. Adelman. Published in Professional Psychology: Research and Practice, v. 20, pp. 79-83, 1999.

Privacy and Confidentiality Regulations



The sharing of health information is complicated and subject to state and federal laws, including:

- Federal medical privacy rules issued under the federal Health Insurance Portability and Accountability Act (HIPAA): Passed in 1996 to establish national standards to protect the privacy of health care data, and to promote standardization and efficiency in the health care industry. The HIPAA Privacy Rules took effect in 2003 and:
 - _ Govern disclosure of patient protected health information while protecting patient rights
 - _ Permit health care providers to disclose protected health information between health care providers, without patient authorization, for the purpose of treatment.


Privacy and Confidentiality Regulations


- State privacy laws: Vary across states, may be more restrictive than HIPAA.
- State minor consent laws: Unique considerations for minors, under the age of 18, who may consent to certain health care services without parental consent.
- Family Educational Rights and Privacy Act (FERPA): Passed in 1974 to protect the confidentiality of student education records for those schools receiving US Department of Education Funding.

Privacy and Confidentiality Regulations



- **SAMHSA's 42 C.F.R. Part 2: The Federal Confidentiality of Alcohol and Drug Abuse Patient Records law**
 - Protects "records of the identity, diagnosis, or treatment of any patient which are maintained in connection with the performance of any drug abuse prevention function."
 - Patients must consent in writing in order for programs to disclose any patient information, unless an exception specified in the regulation applies.







How Do Problems Arise?

- When child welfare clients are referred/ mandated to treatment as part of a case plan and CW workers ask for a status report
- When family drug courts seek to monitor a case in the drug court caseload
- When substance exposed newborns are reported to child protective services and parents are referred/mandated to treatment
- When recovery coaches in child welfare or treatment agencies are asked for updates on their clients
- When drug testing results are mandated by courts as a condition of diversion or custody




Often there really isn't a legal issue...

- **But a failure to clarify the purpose of sharing the information**
 - “What do you want to do with this information?”
- **And a failure to build a trained team with adequate trust in procedures that have been carefully negotiated and formally adopted**



Barriers to Sharing Information

- Sharing information across systems can be difficult and complex
- Confidentiality can be a barrier, but it is also a barometer of how much trust partners have about how one another will use the information
- There are points in the family assessment process at which information needs to be shared



Who Needs to Know What, When and Why?

Individual Client Level Data



National Center on Substance Abuse and Child Welfare
Bringing Services Together for Family Recovery, Safety, and Stability

Assessment Information Must be Communicated

Information needs to be shared throughout the assessment process

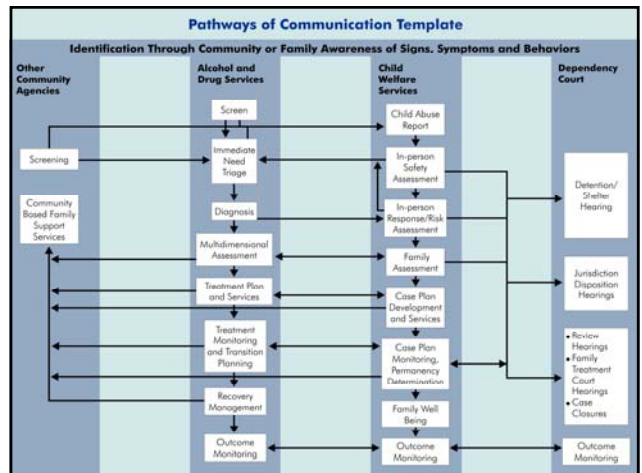
- **Presence and Immediacy**
 - Is there an issue present?
 - What is the immediacy of the issue?
- **Nature and Extent**
 - What is the nature of the issue?
 - What is the extent of the issue?
 - Are there mitigating circumstances (protective factors) or institutionalized cultural biases (stereotyping) that might influence judgment?
- **Developing & Monitoring Change, Transitions & Outcomes of Treatment and Case Plans**
 - What is the response to the issue?
 - Are there demonstrable changes in the issue?
 - Is the family ready for transition?
 - Did the Interventions Work?


Definitions of Terms and Processes

	AOD Services	CWS Services	Court Services
Is there an issue?	▪ Screen	▪ Child Abuse Report	
What is the immediacy of the issue?	▪ Immediate Need Triage	▪ In-Person Safety Assessment	▪ Preliminary Protective Hearing
What is the nature of the issue?	▪ Diagnosis	▪ In-Person Response/ Risk Assessment	▪ Court Findings
What is the extent of the issue?	▪ Multi-Dimensional Assessment	▪ Family assessment	▪ Petition Filed; Preliminary Protective Hearing

Definitions of Terms and Processes


	AOD Services	CWS Services	Court Services
What is the Response?	▪ Treatment Plan	▪ Case Plan	▪ Adjudication/ Dispositional Hearing; Court-ordered Case Plan
Is there demonstrable change?	▪ Treatment Monitoring	▪ Case Plan Monitoring	▪ Court Review Hearings
Is family ready for transition?	▪ Transition Planning	▪ Permanency Determination	▪ Permanency Hearing
What is to happen after discharge?	▪ Recovery Management	▪ Family Well Being	▪ Case Closed
Did the intervention work?	▪ Outcome Monitoring	▪ Outcome Monitoring	▪ Outcome Monitoring



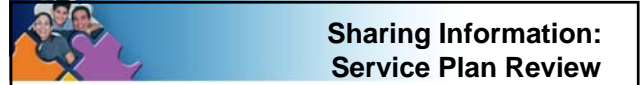


Sharing Information: Parent Information

- Child welfare worker shares:
 - Child abuse and neglect investigation
 - Screening for substance abuse
 - Results of initial interviews with parents
 - Information about service needs of parents
 - Initial case plan




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Sharing Information: Service Plan Review

- Child welfare worker shares:
 - The schedule service plan reviews
 - The content of the service plan and what is expected of parents
 - How the treatment provider can assist the parent to participate in the review
 - How the treatment provider can participate directly in the review




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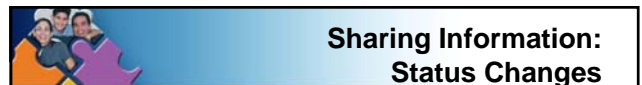


Sharing Information: Dependency Court Hearings

- Child welfare worker shares:
 - The schedule for the court hearings
 - What the court will expect from the client at each hearing
 - Opportunities for the treatment provider to participate
 - Social worker's reports to the court
 - Attorney's reports to the court
 - Court orders issued




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Sharing Information: Status Changes

- Child welfare worker shares:
 - Moving to a new foster home
 - Moving from foster home to residential care
 - Need for special services
 - Serious or life-threatening illnesses or injuries
 - Evidence of use or abuse of substances
 - Serious illnesses or deaths in their care-taking families




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Sharing Information: Visitation Rights

- Child welfare worker shares:
 - Conditions in which these visits can occur
 - Any physical and psychological safety needs of children that may come into play and limit visitation possibilities




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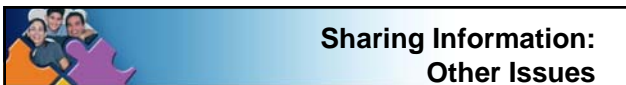


Sharing Information: Type of Treatment

- Treatment counselor shares:
 - The treatment process, setting and frequency
 - Particular demands the treatment program may make on the client
 - Whether it includes any resources for the client as a parent
 - Whether children can accompany the parent into residential programs




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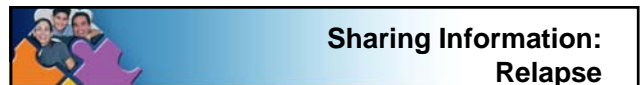


Sharing Information: Other Issues

- Treatment counselor and child welfare worker share:
 - If the child was prenatally exposed to substances
 - Other special issues or needs of the children
 - Whether there are criminal charges
 - The status of the father in the life of the family
 - The status of the parent's health and whether she has health care




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Sharing Information: Relapse

- Treatment counselor and child welfare worker share:
 - Endangerment of a child
 - Interference with a parent's visitations
 - Interference with a client's participation in ongoing treatment
 - Interference with child welfare requirements
 - Results of relapse/positive urine toxicology




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Sharing Information: Case Conferences

- Treatment counselor and child welfare worker share:
 - Scheduling of strategies and support for each other's approaches
 - Additional services parents receive
 - Services that are needed but are not being provided, and developing joint strategies to access them
 - Progress with treatment and case plans




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Sharing Information: Personnel Changes

- Treatment counselor and child welfare worker share:
 - Changes in child welfare workers or treatment counselors
 - Changes in other key personnel involved in the clients' lives, such as TANF workers, physicians, or mental health counselors




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Sharing Information: Requirements Met

- Treatment counselor and child welfare worker share:
 - Client discharged from treatment
 - Follow-up plans
 - When parents have achieved critical steps in the child welfare requirements
 - Increased visitation with children
 - Return of children
 - Case closure




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Engaging Dependency Court Professionals

- Familiarize yourself with the dependency court and child welfare systems in your county
- Ask your clients for their legal representatives' and social workers' contact information
 - Have them sign releases of confidentiality for both.
- Review case plan and timelines with the client
- Stay informed of the client's court dates
- Mail progress letters to their attorney and social worker




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Concerns of the Dependency Court

- What drug treatment services are actually available and are they suitable for the parent? Are they culturally appropriate?
- How many days after removal of a child or a court order for treatment was referral to treatment made?
- Have psychological evaluations and parenting assessments been completed in a timely manner?
- If the treatment is residential, does it include children? If not, what contact does the parent have with the child?




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Concerns of the Dependency Court

- Are transportation and other services being provided, if needed?
- If the parent fails to appear for treatment or misses appointments, what is being done to respond to this problem?
- Has the child been placed near enough to the parent to allow visitation? How is contact and visitation with the child being supported, and how often is it occurring?
- If the parent is incarcerated, are contact and visitation with the child being facilitated? Are treatment services being provided? What other services are available to the parent?




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The special case of child welfare

- Duress exists to the extent that a parent may lose custody or not regain it if consent is refused
- The 1986 child welfare exceptions to 42CFR: restrictions on disclosure “do not apply to the reporting under state law of incidents of suspected child abuse and neglect ...”
- Clarifying language: *substance abuse in itself is not child abuse*




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Key Confidentiality Issues

- If a parent is not participating in or progressing in treatment, the parent may want to hide this information
- Sometimes a parent's attorney will advise against any disclosures between systems
- Often the child's attorney for will want full disclosure of information




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Identify Information to be Shared

- Share information on issues that:
 - Affect child safety and maltreatment
 - Affect the removal of children from the home
 - Affect the ability to meet child welfare or dependency court requirements
 - Are likely to cause treatment relapse
 - Are likely to cause a client to leave treatment





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Solutions

- Informed consent forms
- Court orders
- Negotiated interagency protocols
- Family drug court data sharing for a unified caseload
- QSOAs: Qualified Service Organization Agreements
- Appropriate software barriers to EHR misuse [LAC 2010 statement]
- Prohibitions do not apply to no-shows, only to patients





Sharing Information Across Systems

- Name of the program permitted to make the disclosure
- Name of the individual or organization that will receive the disclosure
- Name of the patient
- Purpose or need for the disclosure
- How much and what kind of information will be disclosed
- A statement that the patient may revoke the consent at any time
- Date, event, or condition upon which consent expires if not revoked
- Signature of the client
- Date on which the consent is signed




<http://ecfr.gpoaccess.gov> e-CFR, Title 42, Part 2



Solutions

- Clarify values, goals and expected outcomes across systems and with regards to shared clients
- Work to establish and maintain trust!

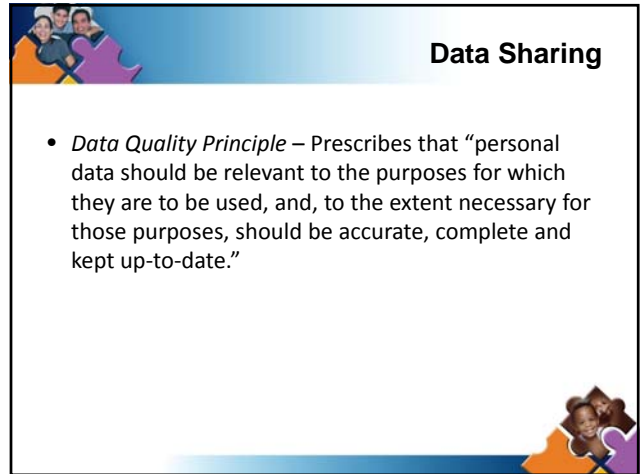




Who Needs to Know What, When and Why?

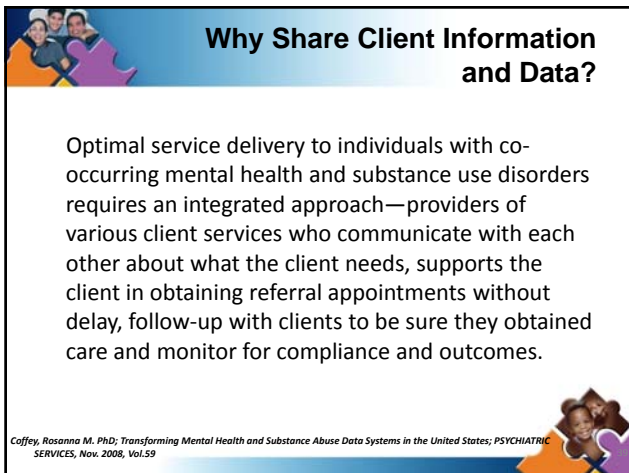
Administrative Level Data

National Center on Substance Abuse and Child Welfare
A Strategic Response Initiative for Family Resilience, Safety, and Stability



Data Sharing

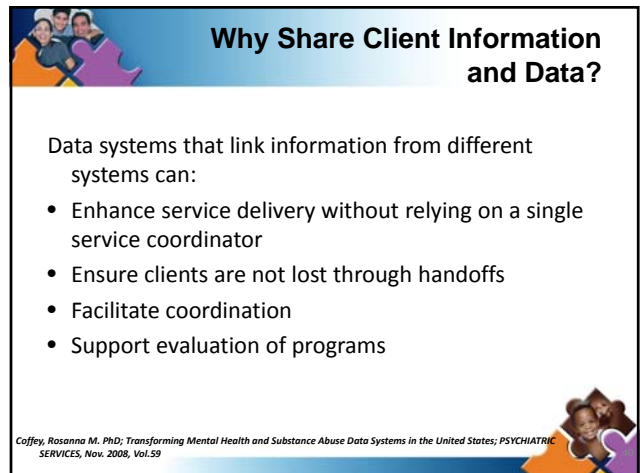
- *Data Quality Principle* – Prescribes that “personal data should be relevant to the purposes for which they are to be used, and, to the extent necessary for those purposes, should be accurate, complete and kept up-to-date.”



Why Share Client Information and Data?

Optimal service delivery to individuals with co-occurring mental health and substance use disorders requires an integrated approach—providers of various client services who communicate with each other about what the client needs, supports the client in obtaining referral appointments without delay, follow-up with clients to be sure they obtained care and monitor for compliance and outcomes.

Coffey, Rosanna M. PhD; Transforming Mental Health and Substance Abuse Data Systems in the United States; PSYCHIATRIC SERVICES, Nov. 2008, Vol.59



Why Share Client Information and Data?

Data systems that link information from different systems can:

- Enhance service delivery without relying on a single service coordinator
- Ensure clients are not lost through handoffs
- Facilitate coordination
- Support evaluation of programs

Coffey, Rosanna M. PhD; Transforming Mental Health and Substance Abuse Data Systems in the United States; PSYCHIATRIC SERVICES, Nov. 2008, Vol.59

One State's Rationale and Business Plan for Data Sharing

Across the Department of Children and Families, Substance Abuse and Mental Health, and Family and Community Services to:

- Reduce duplication of effort
- Build upon successful interventions currently underway or those that have worked in the past
- Ensure plans do not conflict or contradict each other, and
- Provide clear guidance to the families they agencies seek to serve—in a timely and accurate fashion

Drop-off Points

50,000 Children with Substantiated Abuse/Neglect
33,000 Parents

60% of Parents Need Assessment
19,800 Parents

15,029 Cases Referred for Assessment

11,469 Received Assessment
(24% Drop Off = 3,560)

Referred to Treatment
7,022

Went to Treatment
2,744=61% Drop-Off

Completed Tx, 844*

PAY-OFF

* Some clients still in treatment & may successfully complete

Reason for Removal: Any Alcohol or Drug Use by the Parents, 2007

2007 Adaption and Foster Care Analysis Reporting System (AFCARS data)


Research and Evaluation Solutions

- Research and evaluation uses of data: data matching by unique identifier; aggregates only
- Aggregates are critical in determining where the “dropoff points” are
- Memorandum of Understanding across departments with Privacy Policies





Research and Evaluation Solutions

- Clarify State Policy on importance of data integration and information sharing
- Create an inventory of information sharing barriers and develop recommendations to overcome the barriers
- Identify common technology standards and strategies to maximize the sharing of information resources
- Coordinate and leverage existing investments in data and information sharing



Continuing Challenges

- **Data sharing at the project level that leaves systems untouched: boutique data sharing**
- **Enforcing CAPTA requirements for reporting prenatal exposure**
- **Florida request for SAMHSA clarification on disclosure to contract agencies**
- **Growing pressures from**
 - Health Information Technology implementation
 - Neurodevelopmental pediatrics and the prenatal exposure issues: early identification for early intervention
- **The potential political collision of women's privacy rights with legislation on prenatal exposure and reporting**

Continuing Challenges


- **Co-occurring substance abuse, mental illness, and domestic violence: three sets of laws on disclosure may apply, with child welfare exceptions as well**





Child Abuse Prevention and Treatment Act (CAPTA) 2003 Amendments

2003 Keeping Families Safe Act Amendments

- Policies and procedures (including appropriate referrals to child protection service systems and for other appropriate services) to address the needs of **infants born and identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure**, including a requirement that health care providers involved in the delivery or care of such infants **notify the child protective services system of the occurrence of such condition in such infants**, except that such notification shall not be construed to (I) establish a definition under Federal law of what constitutes child abuse; or (II) require prosecution for any illegal action (section 106(b)(2)(A)(ii));
- The development of a **plan of safe care** for the infant born and identified as being affected by illegal substance abuse or withdrawal symptoms (section 106(b)(2)(A)(iii))







Effects of Poor Information Quality



- Individuals are harmed
- Agencies are held liable
- Public confidence is injured
- Resources are not used efficiently
- Inaccurate information is disseminated
- Agencies act at cross-purposes

National Resource Center for Child Welfare Data and Technology, 2011



Resources



- Legal Action Center *Confidentiality and Communication*, 2006 edition
- Legal Action Center: *Confidentiality of Alcohol and Drug Records in the 21st Century*, 2010
- California Child Welfare Council statement
- Screening and Assessment for Family Engagement, Retention and Recovery – SAFERR: www.ncsacw.samhsa.gov



National Center on Substance Abuse and Child Welfare

How do I access technical assistance?

- Visit the NCSACW website for resources and products at <http://ncsacw.samhsa.gov>
- Email us at ncsacw@cffutures.org
- Call us: 1-866-493-2758



Contact Information

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