

US Department of Health and Human Services
Health Resources and Services Administration



Addressing Benchmark Two- Child Maltreatment Data

Informed Consent, Data Sharing Agreements, and
Defining Data Elements for Improvement

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Dial-in number: 800-324-5531

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US Department of Health and Human Services,
Health Resources and Services Administration



Maternal & Infant Early Childhood Home Visitation (MIECHV) Technical Assistance Coordinating Center TACC Welcome

- ▶ The Technical Assistance Coordinating Center (TACC) is funded by HRSA
- ▶ ZERO TO THREE and subcontracted partners at Chapin Hall, AMCHP and WRMA
- ▶ TACC provides different levels of support to MIECHV grantees utilizing ZERO TO THREE and partner staff, along with numerous expert consultants, and in cooperation with other TA providers
- ▶ TACC will host webinars regularly and we welcome topic suggestions from you



Holly Wilcher, M.S.
MIECHV TACC Distance Learning Specialist

Welcome!



Jacqueline Counts, MSW, PhD

Housekeeping



Webinar Learning Objectives

- ▶ Develop an understanding of informed consent, data sharing agreements, and Memorandums of Understanding (MOUs), the critical elements that should be included, and how this documentation will assist in the development and strengthening of relationships with Child Welfare.
- ▶ Develop an understanding of NCANDS data, Child File and the variables necessary to collect and report the child maltreatment benchmark constructs.
- ▶ Develop a deeper understanding of the complexity of interpreting child maltreatment data, defining and measuring improvement and selecting an appropriate comparison.



Jill Filene, PhD



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Today's Presenters



Child Welfare Data Sharing Agreements & Participant Informed Consent Forms

Susan Zaid & Jill Filene
DOHVE / James Bell Associates

DOHVE: Design Options for Maternal, Infant, and Early Childhood Home Visiting Evaluation

- ▶ Working with US-DHHS to support the federal Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program
- ▶ DOHVE Technical Assistance (TA):
 - ✓ Evaluations
 - ✓ Continuous quality improvement (CQI)
 - ✓ Management Information Systems (MIS)
 - ✓ Benchmark plans

Goals of Today's Session

To address Child Welfare data collection issues for Benchmark area 2 by:

- ▶ Understanding the importance of developing data sharing agreements
- ▶ Identifying key elements to be included in data sharing agreements
- ▶ Understanding the importance of protection of client rights when developing consent forms
- ▶ Identifying key elements to be included in consent forms as related to collection of child welfare data

Why develop data sharing agreements?

- ▶ Formalizes an agreed upon process
- ▶ Identifies roles and responsibilities
- ▶ Avoids miscommunication between parties
- ▶ Avoids breakdown in process due to factors such as turnover

Key Elements to be Included in Data Sharing Agreements

1. Identify why you need the data
 - ▶ Clearly state reason for data request
 - ▶ “As part of the measurement of benchmark constructs related to percent of children...”

Key Elements to be Included in Data Sharing Agreements

2. Be clear about the parameters for the data collection
 - ▶ Specify start and end of data collection
 - ▶ collection of home visiting intervention families from time X to time Y
 - ▶ Avoid open-ended agreements for an indefinite period of time

Key Elements to be Included in Data Sharing Agreements

3. Identify points of contact within child welfare agency
4. Identify points of contact within MIECHV program

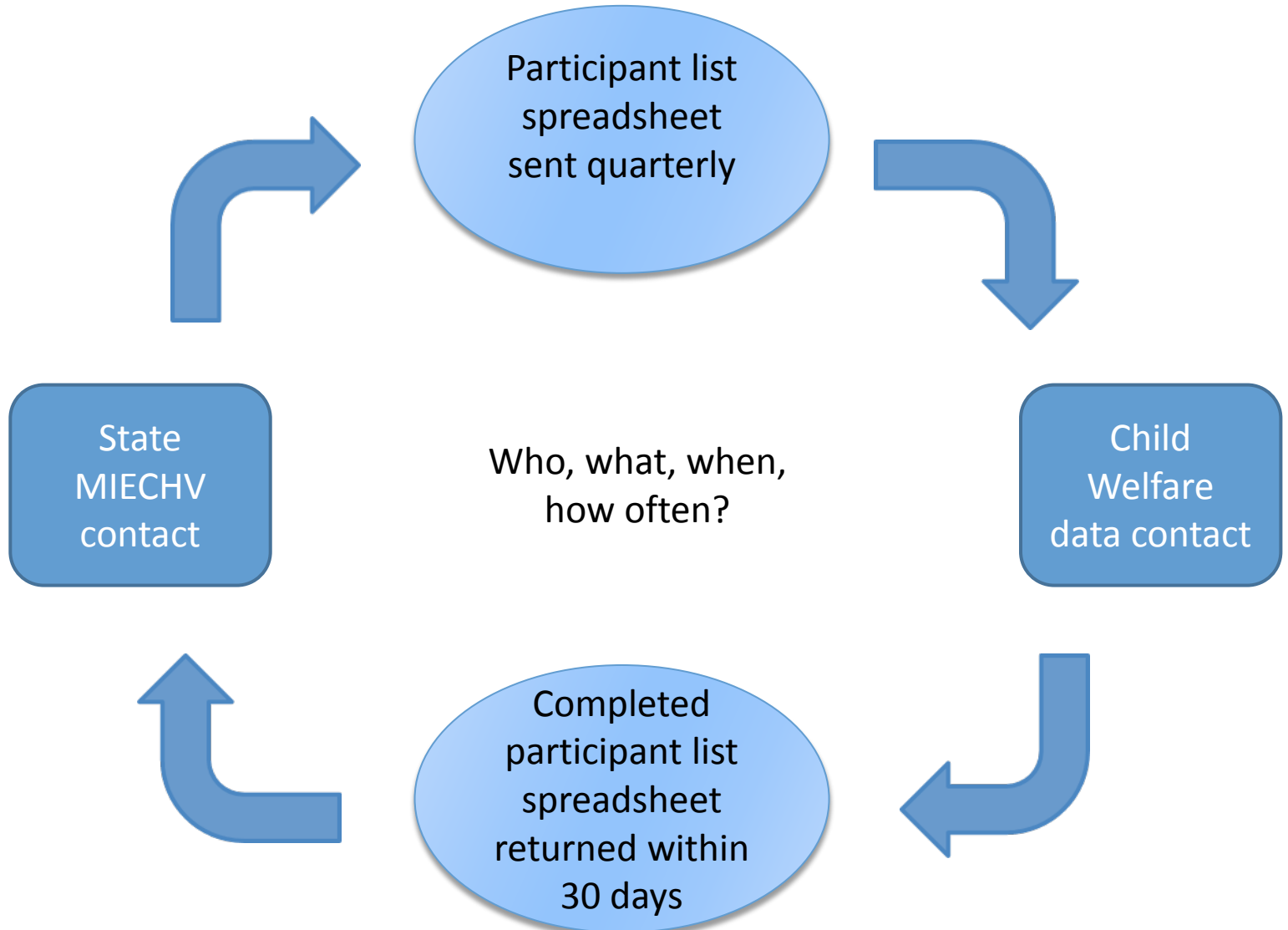
Key Elements to be Included in Data Sharing Agreements

5. Clearly articulate the process
 - ▶ What data is being requested (i.e., variables)
 - ▶ What format will it come in
 - ▶ Data requested will be case-specific (not aggregate)
 - ▶ Who will it be shared with
 - ▶ And if shared with others, whether it will be aggregate or case-specific

Key Elements to be Included in Data Sharing Agreements

6. Clearly articulate the process (cont.)
 - ▶ Process of who will do what, when, how often
 - ▶ Suggested language may include:
 - ▶ “Complete list of program participants are submitted to the research specialist at the Child Protective Services (CPS) office on September 30, December 30, March 30, and June 30 of each year. Requests will be submitted in the format of an Excel spreadsheet identifying client name and DOB. Research specialist will return the list with the information in an Excel spreadsheet within 30 days. Data to be inputted by CPS for each client will include the # of allegations within the reporting period, the # substantiations within the reporting period, and if the identified child was a first-time victim.”

Example: Process Delineating Action Steps



Key Elements to be Included in Data Sharing Agreements

7. Identify data security procedures and how client rights will be protected
 - ▶ who will have access to the data
 - ▶ for what purpose
 - ▶ how the data will be used
 - ▶ how the data will be secured

Data Sharing Agreements

Summary:

- ▶ Data sharing agreements help ensure a stable data collection process; articulates expectations of both parties; avoids surprises in what you get
- ▶ Including identified elements in the agreement helps ensure you will have the data you need to address child maltreatment benchmark constructs

Consent Forms

- ▶ Does your current consent form incorporate the protection of client rights as related to the collection of child maltreatment data?
 - ▶ HIPAA Privacy Rule:
<http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/index.html>
 - ▶ COA Standards:
http://www.coastandards.org/standards.php?navView=private&core_id=545

Consent Forms

- ▶ Does your current consent form incorporate the protection of client rights as related to the collection of child maltreatment data?
 - ▶ Received written summary of rights and responsibilities
 - ▶ Consent to communicate confidential information
 - ▶ Client informed of circumstances the agency may be required to release confidential information

Consent Forms

The Privacy Rule protects all "individually identifiable health information," including demographic data, that relates to:

1. Names
2. Postal address information
3. Telephone numbers
4. Fax numbers
5. Electronic mail addresses
6. Social security numbers
7. Medical record numbers
8. Health plan beneficiary numbers
9. Account numbers
10. Certificate/license numbers
11. Vehicle identifiers and serial numbers, including license plate numbers
12. Device identifiers and serial numbers
13. Web universal resource locators (URLs)
14. Internet protocol (IP) address numbers
15. Biometric identifiers, including fingerprints and voiceprints
16. Full-face photographic images and any comparable images

<http://www.hhs.gov/ocr/hipaa>



Key Elements to be Included in Consent Forms

1. Include a section in the client consent form that identify the type of data to be collected, from whom, the purpose, and how the data will/will not be used
 - ▶ Suggested language may include:
 - ▶ “As part of the federal reporting requirements, we will track the services that you and your child(ren) receive and the outcome of those service. This information may come from the Department of Health and Human Services, Child Protective Services, and other health or mental health service records related to your child’s care.”

Key Elements to be Included in Consent Forms

2. Include a section in the client consent form about confidentiality and how program staff will ensure protection of client privacy
 - ▶ Suggested language may include:
 - ▶ “All information collected for federal reporting will be kept strictly confidential. Steps have been taken to protect your privacy. Only staff associated with the project will have access to your answers. Papers with your names on them will be kept separate from your answers in a secure location. When the program data is reported, answers will be grouped so that neither you nor your child will be identified in any way. Information will only be released when required by law, such as reporting child abuse or your stated intention to harm yourself or others. Your privacy will be maintained, as no identifying information will be shared for federal reporting.”

Key Elements to be Included in Consent Forms

3. Include a section in the client consent form explaining the voluntary nature of participation in the data collection
 - ▶ Client participation in the data collection is voluntary and they may choose to opt out of participation in the data collection at any time
 - ▶ Choosing not to be a part of the data collection will not affect their participation in home visiting services
 - ▶ If they want to discuss their rights with someone or if they have further questions, contact information is provided on the consent form
4. All risks/benefits to participation should be clearly noted on the consent form

Other Considerations When Drafting Consent Forms

- ▶ Is the consent form at a reading level that is understandable to all participants?
- ▶ Is the document formatted well?
 - ▶ Use headings to break the document up into smaller sections
- ▶ A consent form is not a stand-alone document
 - ▶ The consent form should be accompanied by a verbal explanation by trained staff who are knowledgeable on the consent form and how to present the information

Consent Forms

Summary:

- ▶ Consent Forms help ensure the protection of client rights
- ▶ Include necessary elements in the consent form to inform clients of the collection, use, and protection of individual-level data (whether from Child Protective Services or other third party)

Recent DOHVE Webinars

- ✓ Building a Culture of Quality in Home Visiting – January 13, 2011
- ✓ Designing and Using an Effective Data Management System: Components and Considerations – February 24, 2011
- ✓ Measuring Benchmarks: Indicators and Tools – March 3, 2011
- ✓ Evaluations of Promising Programs – April 14, 2011
- ✓ Developing your Evaluation Plan – July 12, 2011
- ✓ Developing Feasible, Measurable, and Reliable Benchmarks & Continuous Quality Improvement for Tribal Grantees – July 21, 2011

All webinar slides and recorded sessions are available at:
<http://eccs.hrsa.gov/Resources/home-visiting.htm>



Other Resources

- ✓ DOHVE Compendium of Measurement Tools for MIECHV Grantees
- ✓ Benchmark Constructs Crosswalk to the Compendium of Measures
- ✓ Model Developer Crosswalk to Benchmarks
- ✓ DOHVE Measurement Brief: Selecting Data Collection Measures for MIECHV Benchmarks
- ✓ DOHVE CQI Brief
- ✓ CQI Checklist: Next Steps for Action Brief
- ✓ Benchmark Technical Assistance Brief
- ✓ Single Case Design Brief (soon to be released)
- ✓ Home Visit Observation Tool
- ✓ Referral and Coordination Tracking Tool

All technical assistance tools and resources are available at:
http://www.mdrc.org/project_12_104.html



For More Information...



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Data Elements for Child Maltreatment Constructs

NCANDS TECHNICAL TEAM

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Walter R. McDonald & Associates, Inc.

January, 24, 2012

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Purpose:

- ▶ Provide brief overview of NCANDS
- ▶ Present basic technical background on the data elements for the child maltreatment benchmark constructs
- ▶ Discuss key issues and general steps to developing and measuring these constructs

Child Abuse as Measured by NCANDS

▶ What is NCANDS?

- ▶ National Child Abuse and Neglect Data System: a voluntary data reporting system
 - ▶ 50 States, District of Columbia, and Puerto Rico send data annually to the Children's Bureau, Administration on Children, Youth and Families, Administration for Children and Families, DHHS
 - ▶ Most of the data are case-level data on all children reported to child protective services; in addition some aggregated data are collected
 - ▶ Annual findings are reported in Child Maltreatment
 - ▶ <http://www.acf.hhs.gov/programs/cb/pubs/cm10/index.htm>

▶ What is the NCANDS Technical Team?

- ▶ Under contract to the Children's Bureau, Walter R. McDonald & Associates, Inc. the team collects, validates, and analyzes the annual data

referrals

3.3 million* referrals alleging maltreatment to CPS
(average 1.81 children per referral)
5.9 million children*

61% referrals screened in

39% referrals screened out

reports

2.0 million reports received a CPS response^

Substantiated 22.0%
Indicated 1.3%
Alternative response victims 0.4%

Unsubstantiated 63.5%
Alternative response nonvictim 9.3%
"Other" 1.8%
Closed with no finding 1.6%
Intentionally False 0.1%
Unknown 0.1%

children

3.0 million unique children^
3.6 million duplicate children^
received a CPS response in the form of an investigation
or alternative response

includes 1,560 fatalities*

695,000 unique victims*
754,000 duplicate victims*

2,850,000 million duplicate nonvictims*

services

370,000 duplicate victims^
received postresponse services

641,000 duplicate nonvictims^
received postresponse services

131,000^
removed from home

239,000^
received in-home services

86,000^
removed from home

555,000^
received in-home services

* Indicates an estimated number
^ Indicates a rounded number.

Please refer to *Child Maltreatment 2010* at :

www.acf.hhs.gov/programs/cb/stats_research/index.htm#can

for further information and instructions about how the estimates were calculated.

State Roles in NCANDS

- ▶ All States (and DC and Puerto Rico) have named liaisons in the State child welfare department who is knowledgeable about understanding the NCANDS reporting specifications and providing data to the Federal government.
- ▶ These persons, State Liaisons, are listed in the annual Child Maltreatment report.
- ▶ They are key resources for any State or local initiative intending on using child abuse and neglect administrative data.

Use of NCANDS Data

- ▶ The data from NCANDS (and measures constructed from NCANDS data) are used for multiple reports, and performance reviews including:
 - ▶ The Child Welfare Annual Outcomes Report to Congress
<http://www.acf.hhs.gov/programs/cb/pubs/cwo04-07/index.htm>
 - ▶ The Child and Family Services Reviews
<http://www.acf.hhs.gov/programs/cb/cwmonitoring/recruit/cfsrfactsheet.htm>
http://library.childwelfare.gov/cwig/ws/cwmd/docs/cb_web/SearchForm
- ▶ Data are archived at Cornell University, National Data Archive on Child Abuse and Neglect (NDACAN)
 - ▶ www.ndacan.cornell.edu

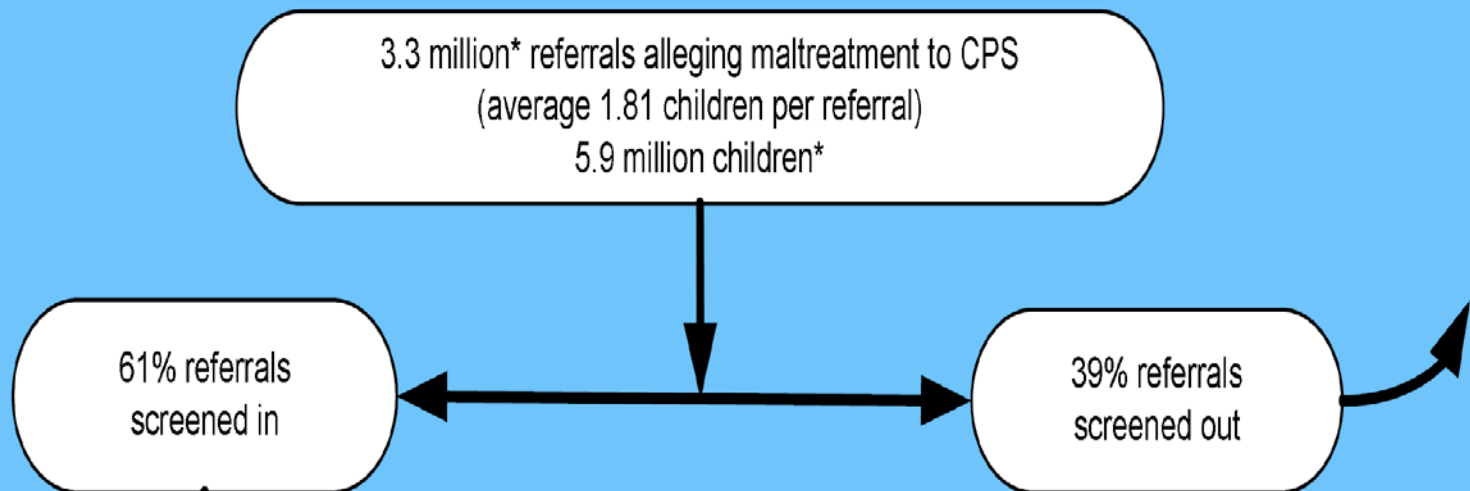
Child Maltreatment Constructs

- ▶ Reported **suspected maltreatment** for children in the program
- ▶ Reported **substantiated maltreatment** (substantiated/indicated/alternative response victims) for children in the program
- ▶ **First time victims** of maltreatment for children in the program

Reported suspected maltreatment

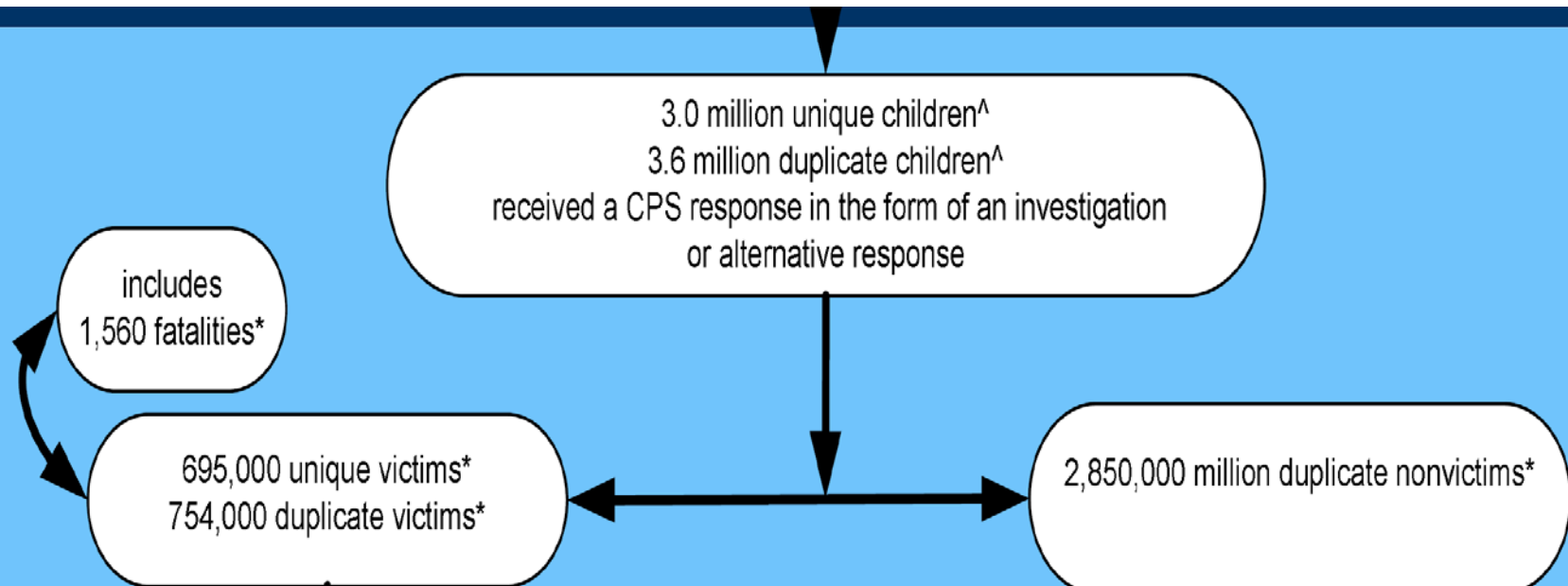
- ▶ In NCANDS, these are called referrals.
- ▶ NCANDS counts actual referrals and estimates the number of children.
- ▶ Referrals may be screened in or screened out.
- ▶ States may have very limited information on the children who were screened out.

referrals



Reported substantiated maltreatment

- ▶ In NCANDS these are called victims
- ▶ Child specific data are collected on all screened in children (victims and nonvictims) by each screened-in referral (report)
- ▶ A child can have more than one substantiated report in one year
- ▶ A child may be the victim of more than one type of maltreatment in one year



First Time Victims

- ▶ The child welfare agency determines who is a first time victim based on the status of data in its information system.
- ▶ According to NCANDS:
 - ▶ In 2010, out of a total 646,996 unique victims, 479,424 did not have a prior report that resulted in a determination that they had been maltreated.
 - ▶ The percent for each State ranged from 53.7 percent of all victims were first time victims to 93.6 percent were first time victims. (Percentages of over 95 percent were excluded for data quality reasons.)

The Good News

- ▶ The good news is that all child welfare departments are familiar with these three constructs.
- ▶ BUT:
 - ▶ There will be several steps to obtaining the data, if a grantee needs to obtain data at a specific client level, a specific group of clients, or for a different time period than is normally analyzed by the child welfare agency.

Key Issues

- ▶ Data Definitions
 - ▶ Determine precise definition of each key term and computation
- ▶ Data Specifications Include
 - ▶ Population to be reported on
 - ▶ Time period
 - ▶ How to count children
- ▶ Data Aggregation and Transformation
 - ▶ Determine how the data will be supplied from the data source to the grantee
 - ▶ And how data will be reported by the grantee to HRSA

General Steps: (Need to tailor for yourself)

- ▶ **Familiarize** yourself with *Child Maltreatment* and terminology
- ▶ **Meet** your NCANDS State Liaison; determine if interagency data sharing agreement will be needed; find out concerns of the child welfare agency
- ▶ **Prepare draft** data definitions and specifications with your own program people
- ▶ **Review** these with the NCANDS State Liaison or their designee; may need several meetings
- ▶ **Refine** data request, addressing the agency's concerns
- ▶ **Find out** if IRB approval will be needed and obtain approval
- ▶ **Pilot data** request and establish quality assurance procedures
- ▶ **Receive data** and report to HRSA

Potential Challenges and Solutions to Obtaining Data

Challenge

- ▶ Lack of common vocabulary
- ▶ Perceived undue burden upon data source
- ▶ Lack of interest of data source

Solutions

- ▶ Do not assume meaning of terms; document definitions
- ▶ Clarify all specifications; provide additional resources to data source
- ▶ Think about potential carrots for the data source

Summary

- ▶ Start early
- ▶ Get general help from someone knowledgeable about child abuse and neglect and the State information system
- ▶ Be prepared for delayed or prolonged discussions
- ▶ Build relationships for ongoing collaboration or cooperation
- ▶ Get technical help from an information system specialist
- ▶ Develop means of reviewing the data and providing feedback to the data source
- ▶ Keep detailed notes of all decisions, discussions, and definitions (the 3 Ds)

Further contacts:

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- ▶ John Gaudiosi John.Gaudiosi@acf.hhs.gov
- ▶ Melissa Brodowski Melissa.Brodowski@acf.hhs.gov
- ▶ Sharon Newburg-Rinn Sharon.Newburg Rinn@acf.hhs.gov

- ▶ Ying-Ying Yuan yyyuan@wrma.com
- ▶ Lana Zikratova lzikratova@wrma.com

Q&A





Thank you!

A copy of this presentation, audio recording and written transcripts will be posted on the MIECHV TACC website (coming soon).

