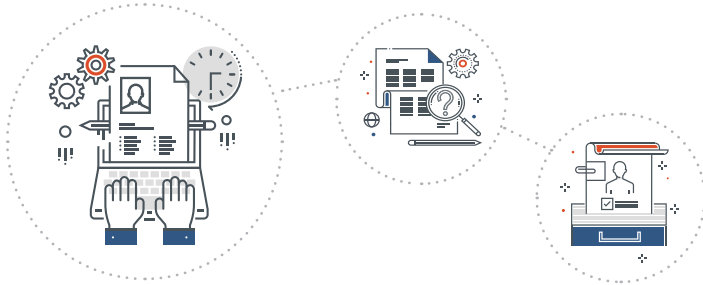# DATA SHARING
IN CHILD WELFARE

QIC•AG

INTRODUCTION

The National Quality Improvement Center for Adoption and Guardianship Support and Preservation (QIC-AG) is a 5-year project working with eight sites to either implement evidence-based and evidence-supported interventions or to develop and test promising practices, which, if proven effective, can be replicated or adapted in other child welfare jurisdictions. Funded through a cooperative agreement with the U.S. Children's Bureau, this brief provides information about data sharing with other Children's Bureau-supported projects, child welfare agency professionals, university researchers, and other entities that might be working on national child welfare initiatives that require data collection.

WHAT IS DATA SHARING?

Data sharing is an exchange of information from one entity to another that share common interests. Data sharing can involve a range of entities such as universities, federal or state governments, and non-profit or for-profit agencies or organizations. The Children's Bureau emphasizes important aspects of data management inherent in data sharing, noting, "efforts to share data among organizations serving children, youth, and families must take several issues into consideration, including confidentiality, policies and procedures, the establishment of common data elements, the integration of different information systems, and more."[1]

WHAT IS A DATA USE AGREEMENT?

Data Use Agreements (DUAs) are legal, contractual documents that govern the use of non-public data subject to restricted use. DUAs outline the terms and conditions of how the data can be used, obligations to safeguard the data, liability for harm arising from the improper use of the data, publication rights and responsibilities, and privacy rights associated with the transfer of confidential or protected data.

IS A DATA USE AGREEMENT ALWAYS NECESSARY?

The need for a DUA should be determined on a case-by-case basis for each project and partner. By clearly setting forth the expectations of both parties (provider and recipient), the understanding established by a DUA can help avoid problems or issues that might emerge over time. In some cases, a DUA might be a prerequisite for the transfer or sharing of certain data, whereas in other cases, a DUA might "simply be a good idea" because it protects both parties: "Determining whether a DUA is required is necessarily context dependent."[2]

WHO IS INVOLVED IN A DATA USE AGREEMENT?

DUAs are typically created by legal staff at the agency that "owns" or is providing the data. The DUA is signed by people with legal authority at the provider and recipient agencies. For example, a DUA signatory could be a general counsel at a state agency or the Vice Chancellor for Research at a university.

1 https://www.childwelfare.gov/topics/management/info-systems/info-sharing/
2 https://research.unc.edu/files/2013/04/CCM3_039360.pdf

WHAT KINDS OF CHILD WELFARE DATA ARE SHARED?

Child welfare organizations typically share two common sources of information: (1) administrative data, such as existing child welfare data, and (2) project data that are collected for a specific project through surveys, focus groups, or other sources that are not routinely collected by the agency.

1. ADMINISTRATIVE DATA.

As part of their daily work, agency staff record information about the people they serve. Although these data can be used for intervention research, these data are not collected specifically for research purposes but rather are recorded to document the day-to-day activities of the agency. These data are interchangeably referred to as *administrative data* (indicating the information is routinely collected as required by agency administration) or *existing data* (indicating the data are collected by an agency without regard to a research project). Given the personal information collected, these data are extremely sensitive and could cause harm or discomfort to an individual if the data were released publicly. For example, administrative data might include an allegation of maltreatment against a specific individual that was unsubstantiated but could still cause harm to the person if the data were made public. These kinds of private data are considered *restricted data*, which means an agency has limitations on sharing sensitive information. To reduce restrictions on use, administrative data can be de-identified, which means the data are stripped of sensitive information. When data are de-identified, information is removed that would allow an outsider to identify individuals or personal information. In addition to supporting intervention research, administrative data can be used by agencies to justify requests for additional staff; to move staff to sites with higher service demands; and to report to state and federal government about child safety, permanence, and well-being outcomes.

2. PROJECT DATA.

Project data are collected as part of a specific project; when agencies collect project data, those data are in addition to the information routinely collected by staff. Project data can include survey responses, focus group content, and information related to outreach efforts or program participation. These data are often collected through direct contact with participants. Many of the same data safeguards that apply to administrative data also apply to project data, especially safeguards for how personal information is collected, stored, and used. Project data can be used alone or in combination with administrative data to track outcomes; to assess intervention uptake or success; and to better understand the population, child, and family experiences, as well as other aspects of a site or an intervention.

The QIC-AG Evaluation Team needed access to both administrative child welfare data and project data to evaluate the interventions delivered in each site. The QIC-AG Evaluation Team asked each site to share de-identified data, meaning sensitive information (e.g., names, addresses, and other identifying information) was removed before data were shared with the QIC-AG. Further, the QIC-AG Evaluation Team analyzed the data and reported it in aggregate form (e.g., the number of children who entered care during a specific year rather than a list of all children who entered care).

FOUR STEPS TO SUCCESSFUL DATA SHARING

STEP 1: Assess site capacity to share data.

As early as possible in the development of a project, the project team should contact potential sites to notify the site about the project's need to access data. The project team should be prepared to describe the steps in the data sharing process, and seek information about a site's capacity and willingness to share data. Both the project team and potential sites should engage in discussions to determine whether a formal data use agreement is needed to share data. If so, project administrators should seek detailed information about the site's data sharing capacity. The agency that owns the data might have a data sharing template they would like to use to initiate the negotiation process. Similarly, a DUA template might be provided by a university or other research partner who will enter into the formal data sharing agreements with each site. An initial review of the terms of the DUA template by each potential project site can help determine if any system-level barriers (e.g., restrictive state legislation about data storage) might prevent data sharing or negatively impact the project's ability to effectively track outcomes and intervention evaluations. DUAs do not have to be signed before a site is selected, but it is important that the project team has early knowledge of any system-level barriers that might prevent project partners from sharing data.

STEP 2: Discuss data ownership.

A DUA details how data can be used by the project. Project teams should expect to explicitly address site concerns about data use, specifically the content of materials (e.g., reports, manuscripts) that the project will produce. Because sensitivity about data sharing and use is a real and growing concern for most organizations, it is important for project teams to be culturally responsive, to actively explore each site's capacity and inclination to share data, to clearly identify site concerns early in the process, and to address those concerns as sensitively and early as possible. Each site is unique, and each data sharing agreement will likely involve a negotiation among legal teams about specific language that reflects a site's own culture, policies, and practices. The DUA template used by the QIC-AG stated

> *UNC-Chapel Hill and Project Partners may use the Data for educational research purposes, including but not limited to: (a) creating a longitudinal data set; (b) producing aggregate secondary analyses of child welfare outcomes; and (c) evaluation of the QIC-AG.*

Publication rights associated with the project are stipulations all universities require. The University of North Carolina at Chapel Hill (UNC) entered into DUAs with 6 of the 8 QIC-AG sites. The two sites that did not enter into agreements with UNC had cultural or administrative restrictions on how and with whom they could share data. One tribal site wanted to work directly with their data, in close partnership with their evaluator, to understand the effectiveness of the intervention in the context of their culture and traditions. Another site had to include data storage requirements that not all project partners could meet, so the agreement was made between the site and one university partner with the capacity to meet the data storage standard. In both instances, the site entered into data sharing agreements with their QIC-AG evaluator's university, limiting access to the data to just one of the two evaluators.

A third example of data ownership affecting the process occurred in the project's only county-level site. For this site, two DUAs were needed: one DUA with the county for project- and county level data, and another DUA with the state government for state-level data.

STEP 3: Identify key partners to include in the negotiation process.

A critical step in the data sharing process is determining which partners need to enter into the formal, legally binding DUA. Important considerations at this step include an organization's capacity to securely transfer and store data; this capacity is critical in selecting the project partner who will house the data. Generally, a university partner is a good option because universities are accustomed to sharing data as part of their research activities and universities generally

have up-to-date data storage and security protocols in place. Determining the right partners is a project- and site-specific issue that should be decided as early in the process as possible. Data sharing negotiations might include some or all of the following project partners:

» Legal staff from each organization involved in providing or receiving data, who have the knowledge to negotiate legal terms and the authority to sign an agreement on behalf of their organization.
» Project evaluators who can describe the specific data that will be shared.
» Information technology (IT) staff who can describe the process of transferring data as well as the safeguards in place to protect and store data securely.
» Project staff and administrators who can describe the project and follow up with legal staff as needed to keep the process moving forward.

Although many partners need to be involved in the development of the data sharing terms, based on the QIC-AG's experience, only the agency sending the data and the agency receiving and storing the data need to sign the agreement. Because the UNC School of Social Work had successfully negotiated data sharing agreements with several of the QIC-AG sites and had a protocol in place for data uploading and storage, the project team decided that UNC was the best project partner to securely receive and store project data. As the host of the data sharing portal and provider of secure data storage, UNC entered into agreements with Spaulding for Children (the "prime" organization that entered into the cooperative agreement with the Children's Bureau and was accountable for all project deliverables), the University of Texas at Austin and the University of Wisconsin–Milwaukee (where the principal project evaluators were based).

STEP 4: Negotiate terms.

Negotiating the terms of the DUA is typically the most time-consuming part of the process. Negotiations can be especially lengthy when entities propose changes to reflect their agencies' policies. UNC provided a DUA template to each site. The site's legal team could either accept the template "as-is" (meaning they would go ahead and sign without any chang-

es), or propose edits to the terms using "track changes." The UNC legal team and QIC-AG Evaluation Team reviewed and accepted changes, or countered with different language intended to meet the site's and UNC's requirements. In one instance, a site elected to use their own DUA template and UNC provided the edits. If UNC and the site could not reach agreement by exchanging written documents through e-mail, then a call was arranged between the site's and UNC's legal teams. Generally, one phone call could resolve questions about language, with the two legal teams able to find mutually agreeable terms. Once the teams agreed on the language, both parties' signed the agreement and the DUA was considered fully executed.

QIC-AG'S EXPERIENCE WITH DATA USE AGREEMENTS

HOW LONG DID IT TAKE TO NEGOTIATE?

DUAs can take a long time to negotiate. Although one QIC-AG DUA took 30 months to execute, the average time for QIC-AG sites was about 13 months (see Table 1). For other projects, QIC-AG project staff have experienced shorter negotiation times, with the process taking as little as 1–3 months, especially when a state agency has a well-established data sharing process in place. Delays experienced by the QIC-AG have usually been due to the various reviewers' workloads.

HOW DID THE MECHANICS OF QIC-AG DATA SHARING ACTUALLY WORK?

Once a DUA is finalized, the process by which data are shared must be carried out. To accomplish this, each QIC-AG site was given instructions on how to upload data to UNC's secure server. Managing the technical aspects of the upload required the QIC-AG to hire a data manager who had expertise in a variety of data transfer and storage options and the ability to adapt to the different requirements of specific sites. The data manager worked with each site to securely transfer their data. Some sites installed an open-source secure data transfer system (Globus) whereas others required the data manager to use an existing state system. The data manager worked with each site individually to troubleshoot issues that arose with data transfers. At times, this trouble-

TABLE 1. TIME TO ESTABLISH QIC-AG DATA USE AGREEMENTS

SITES	DATE DUA TEMPLATE SENT TO SITE	DATE DUA EXECUTED	MONTHS TO EXECUTION	NOTES
SITE 1	5/28/2015	3/16/2016	10	
SITE 2A (COUNTY)	5/28/2015	4/6/2016	11	SITE REQUIRED 2 DUAS: ONE WITH THE STATE, ONE WITH THE COUNTY
SITE 2B (STATE)	5/28/2015	11/30/2016	18	SITE REQUIRED 2 DUAS: ONE WITH THE STATE, ANOTHER WITH THE COUNTY
SITE 3	5/28/2015	4/7/2016	11	
SITE 4	5/28/2015	4/4/2016	11	
SITE 5	5/28/2015	12/7/2017	30	SITE DUA IS A CONTRACT THAT REQUIRED APPROVAL FROM TOP STATE ADMINISTRATORS
SITE 6	5/28/2015	8/23/2016	15	
SITE 7	5/28/2015	9/26/2017	28	SITE ENTERED INTO DUA WITH THEIR LOCAL UNIVERSITY ONLY
SITE 8	5/28/2015	8/22/2016	15	SITE ENTERED INTO DUA WITH THEIR LOCAL UNIVERSITY ONLY

shooting meant addressing security issues stemming from older data systems used by sites that did not have the most up-to-date systems.

For project evaluators to access the data stored at UNC, they became formal UNC Affiliates. The Affiliate status involves a vetting process to ensure that only approved project staff can access project data. After project data were uploaded to the secure UNC server, the project evaluators could use their UNC Affiliate credentials to login and securely access the data.

❓ WHAT CHALLENGES WERE ENCOUNTERED IN DATA SHARING?

Although each data sharing process was unique, some common challenges emerged.

o Data security laws. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) includes regulations pro-

tecting the privacy and security of sensitive health information. In a time when data security is increasingly important, some states and organizations have increased their data security requirements to match HIPAA requirements. According to HIPAA standards, site administrative data and QIC-AG project data were not sensitive health information; nevertheless, state law required that HIPPA standards were met.
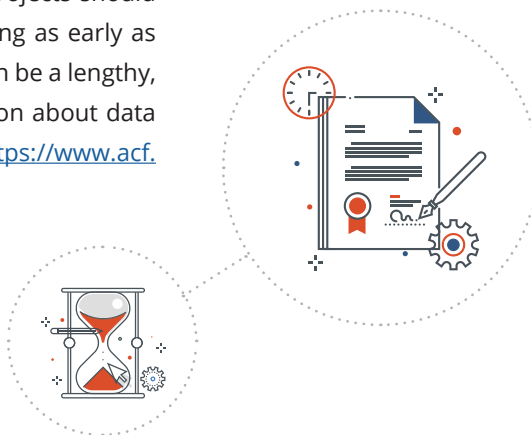
o Multiple data partners. Data sharing is more complex when multiple universities are involved. To avoid negotiating site-specific DUAs between each site and each project partner (each site would have had to negotiate four DUAs), UNC entered into a Collaboration Agreement with each of the three QIC-AG project partners: Spaulding for Children, the University of Texas at Austin, and the University of Wisconsin–Milwaukee. All three partners were able sign UNC's Collaboration Agreement, which legally bound them to comply with the terms of the DUAs negotiated between UNC and each QIC-AG site.

o Data archiving. Projects supported by the Children's Bureau are required to upload their project data to the National Archive for Child Abuse and Neglect (NDACAN). NDACAN promotes scholarly exchange among researchers in the child maltreatment field by serving as a repository and data hub for data acquired from research projects and national data collection efforts. These datasets (https://ndacan.cornell.edu/datasets/datasets-list.cfm) are available to the research community for secondary analysis. However, some sites might have concerns about archiving project data, especially if they are not familiar with NDACAN, so these terms of the agreement may need to be negotiated on a site-by-site basis.

In conclusion, data use and sharing are not only important parts any research-based project but also essential for evidence-building. Through collecting and analyzing both administrative and project data, evaluators determine if interventions are effectively addressing the intended targets and achieving the desired outcomes. Because child welfare data can be sensitive, child welfare project partners should examine whether a formal DUA is needed. Projects should begin considering data needs and data sharing as early as possible because negotiating a formal DUA can be a lengthy, time-consuming process. For more information about data sharing, visit the Children's Bureau website: https://www.acf.hhs.gov/cb/site_search/data%20sharing

DUA NEGOTIATION SUMMARY: KEYS TO SUCCESS

» Determine if a data sharing agreement is necessary.

» Start the Data Use Agreement (DUA) negotiations as early possible.

» Think through all the data partners who need to review the agreement, and include them early on in the process.

» Respect culture, policy, and practice when addressing the terms of "data ownership."

» Be flexible about adapting the data sharing process to meet each site's specific needs.