

First Things First Tribal Data Policy

Introduction and Background

Arizonans created First Things First via a citizens' ballot initiative to give more Arizona children the opportunity to start school healthy and ready to succeed. The very structure of First Things First reflects the organization's respect for and commitment to tribal sovereignty. Arizona's tribes can participate in First Things First in one of two ways: tribes may elect to have their tribal lands treated as a separate region by the statewide First Things First Board or tribes may participate in the designated geographical region or regions in which their tribal lands are located. To date, a total of 19 of Arizona's 22 tribes participate in First Things First.

These partnerships have led to the implementation of dozens of strategies that are expanding early education opportunities for children in tribal communities, supporting parents in their role as their child's first teachers and expanding the use of preventive health in areas statewide.

Comprehensive, accurate data is crucial to the success of Arizona's partnerships with tribes and ultimately to the creation of an effective early childhood system. Data is used to ensure informed decision-making and to measure the progress made in increasing school readiness for all children.

First Things First recognizes Arizona tribes as sovereign nations that have the right to regulate research and data collection on their tribal lands. To this end, First Things First is committed to obtaining all appropriate tribal approvals for data collection, analysis and reporting. This Tribal Data Policy was created to set forth the principles and basic process by which agreements and other approvals will be sought with sovereign tribes for the collection and use of data related to children 5 and younger and their families who are living on tribal lands. This Policy was informed by insight shared by and feedback obtained through formal government-to-government consultation between First Things First and tribes (annually 2010-2017), as well as First Things First's experience in securing tribal data collection agreements as part of its process to develop regional needs and assets reports (2008, 2010, 2012, 2014, 2016, 2018) and statewide School Readiness Indicators (2014-2016).

Related Policies

This Tribal Data Policy serves as one aspect of First Things First's overall effort to appropriately collect and use data. First Things First also has a Tribal Consultation Policy (Addendum A) and specific policies to ensure the security of the data and the privacy of individuals. This includes First Things First's *Data Security Policy & Procedures* (Addendum B). Additionally, First Things First requires its contracted program and service providers to follow First Things First's *Data Security, Submission and Suppression Guidelines and Requirements for Collaborators* (Addendum C), including to follow any requirements set by the tribe, to obtain appropriate consents and to complete, if applicable, Institutional Review Board (IRB) requirements.

Data Purposes

First Things First collects data and other information from tribal governments, early childhood professionals and families living on tribal lands for three purposes, which are all related to the provision of programs and services for young children and families living on tribal lands and early childhood professionals working on tribal lands: (i) needs and assets reports, (ii) program and service administration and implementation and (iii) research and evaluation studies. First Things First often collects this data through contracted program or service providers, who are frequently referred to as grant partners. Sometimes a contracted provider is a tribal entity. First Things First publishes some of the collected data and information, such as in data reports and other hard copy and online documents, to guide decision-making, measure the progress made in increasing school readiness for children and increase public awareness of the needs of young children.

Needs and Assets Reports

First Things First collects data in order to conduct a statutorily required assessment of each of First Things First region's needs and assets every two years. See A.R.S. § 8-1161.C. This type of data helps the First Things First Regional Councils make decisions about what programs and services to fund in their regions, including programs and services that directly benefit young children and families living on tribal lands and early childhood professionals working on tribal lands. See A.R.S. § 8-1161.D.

Programs and Services

Administration

First Things First sometimes conducts a program or service directly. More often, First Things First contracts with another entity, including tribal entities, to provide the program or service. The program or service provider collects information from individuals who are directly benefitting from a program or service for the purpose of administering that program or service. For example, this data might include the recipient's name, birthdate (to verify age eligibility) and address (to provide home visiting services). The collection of this type of information benefits young children and families living on tribal lands and early childhood professionals working on tribal lands because the programs and services could not be provided without this information.

Implementation

First Things First also regularly collects data to assess the effectiveness of its funded programs and services in obtaining outcomes for young children and families. This type of data (also known as implementation data or program outcome data) benefits young children and families living on tribal lands and early childhood professionals working on tribal lands by helping to ensure that financial resources are focused on programs and services that have a positive effect on those served.

Implementation data addresses how a contracted provider is meeting contractual target service units (e.g., number of families served) and performance measures (e.g., percentage of families completing a parenting education series compared to total number of families enrolled). Implementation data begins with the collection of data by the program or service provider. This data might include, for example, the number of people served and sociodemographic information (e.g., age, income level, race and ethnicity) about those served. Implementation data may also occasionally come from program satisfaction surveys or pre and post tests used to gauge how effectively a program or service increased knowledge or skills.

First Things First primarily receives implementation data from quarterly and annual reports submitted by the contracted program or service providers, including contracted tribal providers.

Research and Evaluation Studies

Finally, First Things First may conduct independent research studies to better understand the needs of young children, families of young children, or early childhood professionals (e.g., family and community survey) or conduct formal evaluation studies to better understand the effectiveness and benefits of certain programs and services (e.g., Quality First validation study) state-wide or in specific regions. Someone other than the program or service provider generally conducts these research and formal evaluation studies. These types of studies benefit young children and families living on tribal lands and early childhood professionals working on tribal lands by helping First Things First better identify what programs and services are needed and ensure that those programs and services are having the desired effect on those served.

The information gathering for these studies does not always require collecting data on individuals using an assessment tool. Rather, it may involve gathering summary information from various stakeholders, including partners, early childhood professionals, parents and other caregivers, via surveys or focus groups without collecting personally identifiable information.

Definitions

For the purposes of this Policy, the following definitions apply:

- **Data Collection Agreement** refers to formal approval of any kind (e.g., Tribal Resolution, MOU) by a tribe for First Things First and/or its contractor to collect, utilize, analyze, share and/or publish data.
- **Primary data collection** refers to data obtained first-hand from individuals living on tribal lands by First Things First and/or its contractors (e.g., implementation data and study data).
- **Secondary data collection** refers to data obtained by First Things First and/or its contractors from another organization that collected the data (e.g., tribal departments or agencies and federal, state or municipal agencies), as well as data collected by First Things First from tribes under prior agreements. Secondary data may be received in individual or aggregate form; however, secondary data is only *published* in aggregate form or with anonymity in the case of an individual's story or quote.
- **Tertiary data collection** refers to data already obtained from the tribe and which has previously been published (e.g., reports and policy briefs). All data obtained through tertiary collection will be used in its published format, unless tribal approval is given for a different format.
- **Publication** refers to materials in a printed and/or electronic format released for public distribution (e.g., needs and assets reports, fact sheets, annual reports, etc.). Publication does not include distribution to those responsible for collecting, storing, analyzing, preparing or approving the data or data-based materials for publication. First Things First regional council members may participate in the review, discussion and presentation of data and data-based

information/materials, including data and information publicly displayed on a screen, at their regional council meetings prior to publication.

Authorization to Collect Data

First Things First recognizes that a tribe's approval process to collect data may vary depending on the purpose of the data (e.g., needs and assets report), the source of the data (e.g., primary or secondary) and the sensitivity of the type of data (e.g., number of screenings versus the results of the screenings). If First Things First staff is going to perform the data collection, First Things First will first ascertain the tribe's process for requesting and accessing the desired data and follow the tribe's specified approval process. First Things First will not assume that the approval process completed for one set of data is the same for a different set of data.

If a First Things First contractor is going to perform the data collection for a program or service, then First Things First will require the contractor to obtain all appropriate tribal approvals to collect the data unless First Things First notifies the contractor in writing that First Things First has already obtained the approvals. If a contractor is going to collect data to assist with a needs and assets report or to perform research and evaluation services on behalf of First Things First, then First Things First will take the lead in securing appropriate tribal approvals for the data collection.

Data Collection Agreements

If a tribe requires a data collection agreement, then First Things First or its contractor should provide the tribe with the following, as applicable:

- Information on how the data collected will benefit the tribe, Arizona's early childhood system and First Things First.
- The specific data to be collected, including the context for and background on the data.
- The sources of the data, including when possible, the organizations providing the data, the data fields to be collected from each organization and whether the data includes information on tribal membership.
- Identification of the type of data to be collected (including target populations).
- The method of data collection.
- The use(s) for the data, including descriptions of the final products the data is to be used/published in.
- The specific measures in place to ensure data security and the confidentiality of individuals whose data is collected.

- The desired term of the agreement (for recurring projects, such as regional needs and assets reports and School Readiness Indicators, a timeframe covering at least three cycles of data collection is recommended).
- Identification (if known) of any contractors that will be collecting data.

In addition, as applicable, the agreement should include:

- For regional needs and assets reports and formal research and evaluation studies specific to a region, a provision allowing the tribe to receive information on data collected and conclusions drawn in draft format – and to provide feedback, context, etc. to the data – prior to any data-based materials being published to ensure compliance with the data collection agreement. The tribe has the discretion to identify the preferred format in which the draft information should be presented to the tribe (e.g., in-person presentation or written report). The data collection agreement must stipulate the date by which the tribe must complete its review. In situations where there are persistent questions or concerns regarding data presented, First Things First will enter into a consultative process with the tribe with the goal of resolving issues to ensure that the information can be made suitable for public use.
- A stipulation that affirms the tribe’s right to request a copy of the data from First Things First, and a description of the process the tribe will follow to request the data.
- Explicit language that First Things First does not need to seek tribal approval to use data collected under valid agreements in future publications (i.e., publications not specifically listed in the agreement) UNLESS additional data analysis is completed or additional conclusions are drawn.

Addenda to data collection agreements should only be required if collection of additional data elements (not previously identified) is desired OR if First Things First is completing additional analysis on existing data for other publications/products. Tribes will be notified if any changes occur in the contractors collecting data on behalf of First Things First during the course of the agreement.

Once a data collection agreement is in place, First Things First will provide the tribe with a principal point of contact for all communications and requests associated with the data collection covered by the agreement. Additionally, First Things First will request the tribe to provide a principal point of contact for all communications and requests associated with the data collection covered by the agreement.

First Things First will keep data collection agreements as long as First Things First continues to house data collected under the agreement. If First Things First plans to destroy/delete any primary data collected under a data collection agreement, First Things First will reach out to tribes to ensure the safe and efficient transfer of any data to the tribe prior to completing the destruction. First Things First will not, however, transfer data in violation of the law or transfer confidential personally identifiable information except when required by an IRB or a data collection agreement or allowed for research purposes under First Things First’s *Data Security Policy & Procedures* (Addendum B).

Data Collection

In cases of **Primary Data Collection** for needs and assets reports and formal research and evaluation studies, First Things First will provide to the tribe the name of the contractor completing the data collection and associated timeframes. If any questions or concerns with the identified data collection contractor arise, First Things First will work with the tribe in a consultative process.

For needs and assets reports and formal research and evaluation studies, participants in primary data collection activities will be advised that personally identifiable information they provide is confidential, that they may withdraw from participation at any time prior to the completion of data collection activities and that if they withdraw the information obtained from them will not be used in the report or study. Cultural considerations around language of data collection tools either selected or created, as well as the utilization of a variety of data collection modalities to help ensure a diverse sample, will be considered. In addition, for needs and assets reports and research and evaluation projects specific to a region, First Things First staff and the Regional Council may be involved in the selection or creation of tools utilized for primary data collection and the selection of the contractor.

In cases of **Secondary Data Collection**, for each organization/agency that houses desired data, First Things First will determine the source's process/protocol for data requests and will follow that process/protocol. In some cases, First Things First may need to request assistance from the tribe in securing the data if this is required by the source's process/protocol.

Information obtained through **Tertiary Data Collection** (previously published) will be used in its published format, unless tribal approval is given for a different format.

Analysis of Data

For secondary data, First Things First Research and Evaluation staff works with staff from each of the data source organizations/agencies to obtain the calculation/methodology behind the accessed data to ensure First Things First's analysis plan and interpretation of the data is accurate for the selected region, the state and the representative population. Additionally, this will safeguard the integrity of the data presented in its final format, as well as what is shared with tribal leaders, regional councils, the First Things First Board and stakeholders.

When First Things First is the data source, First Things First follows the same protocol for data integrity and quality assurance checks to ensure accurate data is utilized for analyses. In addition, First Things First Tribal Affairs staff and regional staff are consulted to ensure culturally sensitive approaches are taken to handle data elements and are done in accordance with the First Things First Tribal Consultation Policy (Addendum A). Data analysis is done by the First Things First Research and Evaluation staff and/or First Things First contractors (reviewed and approved by First Things First Research and Evaluation). Data held by First Things First will be stored securely in the First Things First data warehouse per the First Things First *Data Security Policy & Procedures* (Addendum B). All data released will be in accordance with the First Things First *Data Security Policy & Procedures* (Addendum B) and *Data Security, Submission and Suppression Guidelines and Requirements for Collaborators* (Addendum C).

First Things First will not share unpublished data collected from tribal land without the appropriate tribal approvals, unless the data is being shared as described in this Tribal Data Policy, with another agency or entity for a purpose described in the “Partner Access to Data” section of First Things First’s *Data Security Policy & Procedures* (Addendum B) or as required by law. In the case of sharing with a partner, the partner will be required to follow the confidentiality and publication provisions of this Tribal Data Policy as well as any applicable requirements in a tribal data agreement.

Communication of Project Status

First Things First will maintain regular communication with tribes regarding the status of needs and assets report data collection efforts in tribal communities. First Things First regional directors are the primary local liaison and work with tribal governments to implement First Things First early childhood initiatives in their area. The regional staff is directly responsible for communicating with tribes about the status of First Things First’s work with the specific tribe, including data collection agreements and contracted provider performance. First Things First will seek guidance from tribes regarding their preferred method of communication. Methods of communication may include letters, electronic correspondence, presentations and status reports to tribal leaders, as needed.

The First Things First Senior Director for Tribal Affairs serves as the organization’s primary statewide liaison with tribal partners and is directly responsible for communicating with tribes on issues that are broadly related to facilitating or improving First Things First’s work with tribes, including Tribal Consultation, biennial regional designations and representing First Things First with major tribal organizations, such as the Inter-Tribal Council of Arizona and the National Indian Education Association.

Protection of Privacy and Confidentiality Assurance

It is the intent of First Things First to avoid any possibility of inadvertently reporting personally identifiable information. While First Things First uses only aggregate data in its reporting, there are some cases where specific populations may include only a few individuals. In such cases, the First Things First Research and Evaluation team will enforce the First Things First Data Suppression guidelines found in the *Data Security Policy & Procedures* (Addendum B) and the *Data Security, Submission and Suppression Guidelines and Requirements for Collaborators* (Addendum C).

In accordance with the First Things First *Data Security Policy & Procedures* (Addendum B), First Things First staff and contractors must ensure that all confidential information in their possession is kept secure at all times against unauthorized or unlawful loss or disclosure.

First Things First will cooperate with tribes to ensure suitable reporting and review opportunities of regional needs and assets reports and formal research and evaluation studies specific to a region are established prior to publication of the final report or study.

Review of Data by Tribes

For regional needs and assets reports and formal research and evaluation studies specific to a region, if required by a data collection agreement, tribes will receive information on data collected and conclusions drawn by First Things First in draft format prior to the data being published to ensure compliance with the agreement. Tribes have the discretion to identify a preferred format in which the draft information should be presented to the tribe (e.g., in-person presentation or written report). The data collection agreement must stipulate the date by which the tribe must complete its review. In situations where there are persistent questions or concerns regarding data presented, First Things First will enter into a consultative process with the tribe with the goal of resolving issues to ensure that the information can be made suitable for public use.

Publication of Data

All data collected by First Things First or its contractors may be used in aggregate form (not personally identifiable) at the regional, county or state level in a variety of public formats, including, but not limited to: reports and policy briefs, web pages and marketing materials. Although data collection agreements stipulate the specific products in which data collected will be used, First Things First reserves the right to use data previously collected/published in future publications, so long as the new publication does not involve additional data collection and/or analysis.

In addition, as a public entity, the work of First Things First is subject to state public records law. All final work products—including any materials published or publicly disseminated by First Things First—are subject to public records law and must be made available for inspection upon request by any member of the public in accordance with that law.

Tribal Access to Data

First Things First has the right to store all data collected and to utilize that data consistent with this Policy and individual data collection agreements or other tribal approvals. Tribes may officially request copies of collected data from First Things First by submitting the First Things First Tribal Data Request Form (sample attached). The form allows tribes to easily request data for specific First Things First activities, according to tribal preference and the needs of their communities. First Things First will work with a tribe to provide the data in a mutually agreeable format (e.g., Word or Excel). First Things First will not, however, provide data in violation of the law or provide confidential personally identifiable information except when required by an IRB or a data collection agreement or allowed for research purposes under First Things First's *Data Security Policy & Procedures* (Addendum B).

First Things First Contractor Use of Data

When a First Things First contractor is collecting data, the contractor needs the appropriate approvals from the tribe to collect and use the data or share the data with third-parties. The requirements for contractors are described in more detail in First Things First's *Data Security, Submission and Suppression Guidelines and Requirements for Collaborators* (Addendum C). This includes when the contractor has an additional funding source (e.g., federal government) to which the contractor has to report data and when the contractor is an affiliate of an evidence-based program/service model (e.g., Parents as Teachers home visitation model) and has to share certain information with the national organization that oversees the model.

SAMPLE

FIRST THINGS FIRST TRIBAL DATA REQUEST FORM*

Depending on the nature and format of the data being requested, formal documentation from the tribe (such as a letter/resolution from the tribal government) may be required before First Things First can release data. Requests will be assessed on a case-by-case basis, and the requestor will be notified of any tribal documentation required prior to release.

Data Requestor:

Name of Person Requesting Data:

Tribal Affiliation:

Contact Address:

Contact Telephone/Email:

Purpose of the data request: _____

Example: To use for a grant proposal, for tribal data updates, for strategic planning

Preferred Data Format: _____

Example: Excel file, data tables of key variables from the report

Timeframe for Receiving Data (at least 15 days required once all documentation is received) _____

Data Requested:*

Data Collected as part of Needs & Asset Reports

- Name of data fields: Health; Family Support, Coordination; Early Learning
- Which agency data—DHS, IHS
- Current vs. historical data—Report Cycle

Example: Oral health data collected from IHS for 2012; WIC data from ITCA for 2014.

Data Collected on School Readiness Indicators

- Name of the school readiness indicator(s)
- Year of data collection

Other Data — please specify

Example: Quality First Rating and Enrollment data; First Things First Quality First Child Care Scholarships data for SFY 2014

The requestor must specify data they are requesting. First Things First Tribal Affairs and/or Research and Evaluation staff may contact the requestor to clarify the request. Any changes to the request based on this contact will be documented in follow-up correspondence with the requestor.

Data Recipient:

The data requested above will be directly submitted to:

- Name of Designated Person:
- Title/Affiliation:
- Address:
- Phone/Email:

First Things First will not provide data while collection, quality assurance and analysis activities are taking place. Only final data that has been reviewed for accuracy and integrity will be shared with the designated person of contact in the agreed upon format.

Please fill out the form and send it to:

First Things First

ATTN: Tribal Affairs

4000 North Central Avenue, Suite 800

Phoenix, AZ 85012

For questions regarding this form (or to submit the request electronically), please contact:
cahunter@firstthingsfirst.org.