Purpose

The main purpose of community data sharing is to create a community-wide information system that support interactions with many service providers to deliver a comprehensive, longitudinal perspective on each child, leveraging data and technology to provide better, faster and continuously improved services.

Key Concepts

In Community Data Sharing Initiatives, participants share information regarding children they serve. It is essential to consider how the sharing is managed and authorized and which information is shared.

Data Owners

Data Owners are partner organizations that directly interact with children and record child-driven information in COMET. These organizations "own" the data they record in an explicit or implicit agreement of confidentiality with each child parent *[e.g.: Family Educational Rights and Privacy Act (FERPA) for schools].*

Data Seekers

Data Seekers are partner organizations that are interested in accessing Data Owner's child-related information either in aggregated, de-identified or identifiable format. Commonly, Data Seekers are also Data Owners, but not necessarily *(e.g.: funding organizations like United Way, County or City services).*

Information Sharing

Aggregated reports: Typically, such reports may pull data from multiple Data Owners and consolidate / aggregate the counts accordingly. For example, a report may provide the count of unique children that are actively engaged and are receiving services from all Data Owner partners during a given period. These reports are usually authorized through the data sharing agreement between the service provider partners.

De-identified child-level reports or data extraction: Typically, such reports are used for research purposes. Records are de-identified meaning that they do not contain any data element that would allow to identify a child *(e.g.: name, ID, phone #, email address, etc.)* and in some cases there is a need to mask some demographics *(there may be only 1 Pacific Islander leaving in Zip code 12345).* These reports need to be authorized through the data sharing agreement between the service providers.

Identifiable child level records: Typically this data sharing is provided between service providers to inform their practice. For example, an after-school program may access the school district academic records to address individual child needs. Such data sharing commonly requires valid parent consent and a clear authorization from the Data Owner. Valid parent consent often requires:

- *proper disclosure to the parent,*
- *the ability for the parent to revoke consent and*
- *an expiration date.*

Types of COMET Data Elements

Note: COMET is fundamentally "child centric", meaning that the system is designed to record child "entities" that serve or relate to the child. *(e.g.: Mother of Birth, Father of Birth, Household Environment, Primary Care Provider)*

✓ *Only One Value per Child; No Change Tracking:* These are data elements - *such as Last Name, First Name or Date of Birth* - that are unique for the child and for which change-tracking is not required. COMET manages about a dozen of these fields. *(e.g. First Name may have been entered with a spelling mistake an then fixed; do not track the incorrect First Name)*.

✓ *Only One Value per Child; Track Changes:* These are data elements - *such as Address* or *Temporary Assistance for Needy Families (TANF) eligibility* - that are still unique for a given child at a given date, but we may want to observe the history of change of that field, as well as the current value of the field. Still, the current value is the one that matters most. COMET offers over 150 of these fields.

✓ *Multiple Values per Child:* These are data objects or entities that have multiple instances for each child - *such as Family Relationships, Contacts, Consents, Vaccination Records*. Depending upon each client configuration, COMET manages multiple active/deactivated and current/history records associated with each child.

✓ *Multiple Values per Child with History of Changes / Instruments:* These represent entities that have multiple occurrences for a given child for which we are interested in the history of changes *(e.g.: Pre/Post Analysis, Longitudinal View)*. In addition to the data elements directly collected when completing an response, these instruments are often associated with an assessment. Some assessments are "normalized" (they follow a norm, often authoritative) or standardized (statistically position the child against their peers). Assessments are key for individual progress (to inform the practice, measure individual impact) in a continuous improvement model, but they are also the base for program evaluations *(e.g.: assessing a group of children that has received a service in comparison to a group that has not)*.

✓ *"Operational" Data Elements:* These elements help conduct and control the overall operation *(e.g.: when an email was sent to a parent, when is the date of the next visit, membership or service dues)*. They are often "short lived" and not of value for data sharing.

Program Outcomes

Ideally, programs or interventions are associated with a set of measurable objectives, along with reasonable measurement instruments. Often, such instruments are used for screening purposes to make a determination if a given child will benefit from the program, and also may be conducted at the beginning of the program as a "pre" measurement - when screening provides more simple "pass / not pass" outcomes. There are also instruments for "post" program outcome measurements.

Instead of "dimension-specific" metrics (e.g.: the BMI or the IQ), COMET recommends using percentiles based on children with similar demographics.

Program Start
Either at registration time, acceptance into the program, or after the first session:
- Program / intervention start date,
- Screening results (Instrument, Assessment Variables),
- Pre measurement(s), baseline,
- Case Manager / Child Professionals delivering services,
- Optionally, some administrative information.

Program End
- Program End date / dismissal date,
- Post measurement(s),
- Case Manager / Child Professionals delivering services,
- Dosage of services: number of sessions, hours, $ spent, contacts, visits, etc.,
- From the case / program manager:
  - Assessment of fidelity / compliance to the program specifications: *100% means the protocol / requirements were met; could be > 100% if additional services were provided*,
  - Assessment of fitness of the child into the program: *100% means that the program was well adapted to the child's needs*.