Glossary of "Common Language"
for TBI State Partnership Program Grantees
Assigned to ACL's "Using Data to Connect People to Services" Workgroup
(May, 2019)

This product was developed by states assigned to the "Using Data to Connect People to Services" Workgroup in order to ensure that we are all using terminology in the same way. Initially, we learned that the term "TBI Registry" meant different things to different states, not all states had the same understanding of the term P & A, and the abbreviation "Dx" was not understood by all, for example. In response to this, we developed this document to pro-actively address potential communication challenges. Participating States include:

Mentor States: Nebraska, Virginia
Partner States: Alaska, Georgia, Idaho, Kansas, Minnesota, Missouri, Rhode Island, Utah, Vermont, California
Other Contributing States/Organizations: North Carolina, Iowa Brain Injury Alliance

ACRONYM	DEFINITION/DESCRIPTION	USE/RELEVANCE
ABI	Acquired Brain Injury	An insult that occurs after birth and causes damage to brain tissue. Causes may include trauma, stroke, infection, tumor, hypoxia, exposure to toxins.[1]
ACL	Administration for Community Living	Federal agency created around the fundamental principle that older adults and people of all ages with disabilities, including persons with traumatic brain injury, should be able to live where they choose, with the people they choose, and have the ability to participate fully in their communities.[2]
APCD	All Payer Claims Database	Database used to collect insurance billing claims data. Potentially rich source of TBI-related data a number of states may have access to.[3]

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Association vs Alliance States	Refers to state based organizations like the Brain Injury Association of America affiliates and U.S. Brain Injury Alliance member states.	Most states have a non-profit organization that provides some degree of service, support and advocacy with and for individuals with brain injury and their families. These organizations also have a focus on state policy issues around prevention of brain injury and access to medical and long-term services and supports.
BIAA	Brain Injury Association of America	A national organization whose mission is to advance awareness, research, treatment, and education and to improve the quality of life for all people affected by brain injury.[4]
BRFSS	Behavioral Risk Factor Surveillance System	The nation's premier system of health-related telephone surveys that collect data from states about U.S residents regarding their health related risk behaviors, chronic health conditions, and use of preventive services. BRFSS is both national-level and state-level data collection.[5]
CDC	Centers for Disease Control	The nation's health protection agency, working 24/7 to protect America from health and safety threats, both foreign and domestic. [6]
Dx	Common abbreviation/shorthand for the word "Diagnosis."	"Dx" is commonly used to replace the word diagnosis in medical and healthcare settings.
FOA	Funding Opportunity Announcement	The publicly available document that contains all the official guidance on submitting grant proposals to the Federal Government.[7]
Grant Thornton	The current TBI coordinating center under contract with ACL to collaborate with grant funded states and other stakeholders to help	Collaborates with the TBI state partnership program state grantees and other TBI stakeholders to assist all people in the TBI community find and access the information they need.[8]

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HIPAA	Health Insurance Portability and Accountability Act of 1996	United States legislation that provides data privacy and security provisions safeguarding medical information.[9]
ICD 10	International Classification of Disease: Version 10	The World Health Organization's (WHO) "standard diagnostic tool for epidemiology, health management and clinical purposes." Its full official name is International Statistical Classification of Diseases and Related Health Problems. ICD 10 is specific to death data. It is used by Viral Records and the National Center for Health Statistics (NCHS) to code and classify Cause Of Death on death certificates. It is reviewed and updated approximately every 10 years. Since ICD 10's replacement of the ICD 9 codes in 1999, public health agencies also use ICD 10 codes to track public health statistics.[10]
ICD 10-CM	International Classification of Diseases: Version 10 - Clinical Modification.	ICD 10-CM is specific to the system used to classify and code all diagnoses, symptoms and procedures recorded in conjunction with hospital and emergency department care in the United States. To add to the confusion, it is common to say "ICD 10" codes when we are actually referring to ICD 10-CM codes.[11]
ICD 9 & ICD 10 – the issue	Since October 1, 2015, all U.S. hospitals and health care providers covered by HIPPA were required to move from using ICD 9-CM to using ICD 10-CM coding when reporting	Since moving from ICD 9-CM to ICD 10-CM, many states have seen lower numbers of TBI-related injuries being reported to trauma registries. The cause of this change is unknown but it is being

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	medical diagnosis information from hospitals and emergency departments.	discussed at both national and local levels. Are the codes not pulling the right data?
MMWR	Mortality and Morbidity Weekly Report	This is a weekly CDC publication of health-related issues.[12]
Mortality and Morbidity	Morbidity – is the condition of being ill, having a disease or being unhealthy. Mortality - is the condition of being dead.	These are common terms in healthcare and they are often used incorrectly. They are not interchangeable.[13]
MOU/A	Memorandum of Understanding/Agreement	Formal agreement often executed between two governmental agencies that serves as a binding contract.[14]
NCI-AD	National Core Indicators, Aging & Disabilities	NCI-AD™ is a voluntary effort by State Medicaid, aging, and disability agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including service planning, rights, community inclusion, choice, health and care coordination, safety and relationships.[15]
N&R data	Needs and Resource Assessment Data	This typically refers to an electronic or written survey aimed at capturing barriers and gaps in services for persons with a brain injury, their families, caregivers, agency personnel and private providers. Other examples include policy analysis, telephone polling, public forums, focus groups, etc.
NASHIA	National Association of State Head Injury Administrators	National non-profit membership organization that establishes sound national brain injury policy and assists state government administered TBI programs in the development and implementation

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		of state and local prevention, rehabilitation and community support services programs and policies for persons with traumatic brain injury and their families.[16]
NCHS	National Center for Health Statistics	The CDC's National Center for Health Statistics (NCHS) provides statistical information that will guide actions and policies to improve the health of the American people.[17]
NHCS	National Hospital Care Survey (accessed via the CDC)	NHCS collects data on patient care in hospital-based settings to describe patterns of health care delivery and utilization in the United States. Settings include inpatient, emergency (EDs), and outpatient departments (OPDs). The survey will provide hospital utilization statistics for the nation. In addition, NHCS will also be able to monitor national trends in substance use-related ED visits including opioid visits.[18]
Ohio Questions	Questions related to TBI via BRFSS	Ohio State University has been successful submitting questions to the state-level BRFSS administrators. The questions have been rigorously vetted and are generally accepted as reliable and valid. Many states choose to forgo their state-level vetting processes by re-using the "Ohio Questions" that have already been successfully vetted and accepted.
P & A	Protection and Advocacy	Every state has a Protection and Advocacy organization that is funded through ACL.[19]
PHI	Protected Health Information	This is personal information related to a person's health that is protected by HIPAA and is commonly

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		found in medical records and databases. Strict "protections" on this data must be observed at all times.[20]
PI	Principal Investigator	The primary individual responsible for the preparation, conduct, and administration of a research grant, cooperative agreement, training, or public service project, contract, or other sponsored project in compliance with applicable laws and regulations and policy governing the conduct of research.[21]
PII	Personally Identifiable Information	This is personal information that can result in a person's privacy being violated. PII is protected under HIPAA and is commonly found in medical records and databases. Strict "protections" on this data must be observed at all times.[22]
Qualtrics,	Subscription software for collecting and analyzing data for market research, customer satisfaction, evaluations and feedback.	Web based software that allows the user to create surveys and generate reports without having any previous programming knowledge.[23]
RedCap	A free, easy to use, secure method of flexible yet robust data collection	Secure web application for building and maintaining online surveys and databases.[24]
SAS/SPSS	Statistical Analysis System/Statistical Package for Social Sciences- statistics software used to perform statistical operations	Software application that can aid in quantitative data handling for advanced statistical analysis.[25]
SCI	Spinal Cord Injury	A spinal cord injury (SCI) is damage to the spinal cord that causes temporary or permanent changes in its function. Symptoms may include loss of muscle function, sensation, or autonomic function in the parts of the body served by the spinal cord below the level of the injury.[26]

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TBI	Traumatic Brain Injury	CDC defines a traumatic brain injury (TBI) as a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head, or penetrating head injury. Everyone is at risk for a TBI, especially children and older adults.[27]
TBIMS	The Traumatic Brain Injury Model Systems (TBIMS) of Care program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) , Administration for Community Living, U.S. Department of Health and Human Services	Supports innovative projects and research in the delivery, demonstration, and evaluation of medical, rehabilitation, vocational, and other services designed to meet the needs of individuals with traumatic brain injury.[28]
TBI Registry	For purposes of this TBI SPP grant cycle, the term "registry" refers to whatever database a state uses to collect TBI-related data.	Can be used to connect people who experience brain injury to appropriate services and supports in or near their communities. For example, per Nebraska Rev. Stat. § 81-662, the Department of Health and Human Services is required to provide a one-time mailing of information and resources to each individual that is reported to the state's TBI Trauma Registry, within 30 days of the report.[29]
TBICC	TBI Coordinating Center	Organization contracted through ACL to provide assistance to TBI State Partnership Program grantees and others.[30]
TBI SPP	Traumatic Brain Injury State Partnership Program	ACL's name for this federal grant program.[31]
Trauma Registry	A system of timely data collection that aids in the evaluation of trauma care for a set of injured patients who meet specific criteria for inclusion.	See example listed under "TBI Registry". It should also be noted that "Trauma Registries" are both national-level and state-level reporting.[32]

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USBIA	United States Brain Injury Alliance	A national organization whose mission is to engage the community in preventing brain injury and improving lives.[33]
Waiver	A provision in Medicaid law which allows the federal government to waive rules that usually apply to the Medicaid program.	Many states have waivers that individuals with TBI are able to access; many do not. The development of such waivers are frequently discussed as priorities for future funding and efforts.[34]
WISQARS	Web-based Injury Statistics Query and Reporting System	An interactive, online database that provides fatal and nonfatal, violent death, and cost injury data from a variety of trusted sources. Data can be used to learn more about the public health and economic burden associated with unintentional and violence-related injury in the United States.[35]
YRBSS	Youth Risk Behavior Surveillance Survey	Monitors six categories of health-related behaviors that contribute to the leading cause of death and disability among youth and adults. This is similar to BRFSS, but is specific to a youth population.[36]

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