OVERVIEW OF JURISDICTIONS, EXPERIENCES AND LESSONS LEARNED

A review of jurisdictions and experiences was conducted to identify and learn from existing socio-demographic collection and disaggregated data strategies in municipalities, health and social services, and other public services in Canada, the United States and internationally. The review did not identify other existing municipal strategies focusing on disaggregated data. However, several jurisdictions had existing socio-demographic data collection and disaggregated data use practices in specific public services.

Since the 1990s, governments and institutions around the world have increasingly made efforts to collect and use socio-demographic data, recognizing that high quality, consistent socio-demographic data are essential for monitoring and taking action to address inequities. To date many of these efforts have focused on race, ethnicity and to a lesser extent language data. Fewer efforts have been made to collect and use data for other equity-seeking groups such as lesbian, gay, bisexual, trans, queer and Two-Spirit (LGBTQ2S+) and disabled people. Socio-demographic data on race and ethnicity has often been fragmented and inconsistent, with some improvements happening over time.

Overview of Context in the United States

Several public service agencies in the United States (US) have a long history of collecting socio-demographic data, particularly race and ethnicity. Race and ethnicity data is collected in education, birth and death registrations, and health care.

Schools and post-secondary institutions in the US report student enrollment data including race and ethnicity to the National Center for Education Statistics. Ethnic and racial differences in educational attainment and performance in elementary, secondary and post-secondary schools are analyzed at the national and state level and reported annually. This publicly reported information on gaps in educational achievement between ethno-racial groups has informed and helped monitor national and state educational policies to address disparities in education for racialized, immigrant and low income students. The national No Child Left Behind Act, and the Every Child Succeeds Act that succeeded it, requires US states to identify goals and standards for educational achievement, measure these through standardized testing, address gaps in achievement and support success in college and fulfilling careers for all students, regardless of race, income, disability, ethnicity, or proficiency in English.

All US states include race and ethnicity data on birth and death certificates. This data enables the US Centres for Disease Control and Prevention to analyze and publicly report ethnic and racial differences in health outcomes including inequities in low birth weight babies and life expectancy between non-Hispanic white, Black and Hispanic populations.

The US health care system has been collecting race, ethnicity and language data for many years, with an estimated 90% of US hospitals collecting race and ethnicity data in 2008[1]. Research from the US has shown that health care organizations collecting race, ethnicity and language are more likely to focus on inequities and improve quality of care. More recently, data collection has been expanding to include a wider range of socio-demographic characteristics including mandating the collection of disability data and planning for the collection of sexual orientation and non-binary gender identity data. An important limitation to the US experience is that it is fragmented and inconsistent, with individual health care organizations, service agencies and local governments collecting data in ways that are not standardized and are often incomplete.

A few jurisdictions have standardized their approach to data collection, such as the state of Massachusetts which has required all hospitals to collect and report on self-reported race, ethnicity and preferred language information from patients using standardized methodology. In Massachusetts, resources including training and support materials are provided and have been widely used by health care organizations. Since the state regulation, the number of hospitals using disaggregated patient race and ethnicity data increased substantially. Many hospitals are using race, ethnicity and language data to understand the socio-demographic profile of their patients and to identify differences in health care access and patient outcomes by race and ethnicity. This data has been used to develop improved patient services, including interpretation and translation services to better reflect the language needs of patients, tailoring staff education and cultural competency training, developing patient outreach programs to increase clinic access for under-represented groups, and designing community-specific services and outreach programs for at-risk and underserved groups such as a mobile unit providing free vaccines in racialized neighbourhoods, ethno-specific diabetes programs and cancer screening[2].

Overview of Context in the United Kingdom

In the United Kingdom (UK), ethnicity data is collected regularly in several public services including education, the justice system and health care. The national Race Disparity Unit compiles, analyzes and publishes government data available by ethnicity on an accessible website called Ethnicity Facts and Figures. The UK's Department for Education requires all schools to collect and submit data on student demographics including ethnicity once per year through their school census. This data is used to analyze and report on ethnic differences in

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[1] IOM (Institute of Medicine). 2009. Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement. Washington, DC: The National Academies Press.

[2] Jorgensen, S., Thorlby, R., Weinick, R., & Ayanian, J. 2010. Responses of Massachusetts hospitals to a state mandate to collect race, ethnicity and language data from patients: a qualitative study, BMC Health Services Research, 10.

early childhood learning goals, educational achievement at the elementary and secondary school level, and attainment of post-secondary degrees. The availability of data on ethnic disparities in educational achievement helped provide an evidence base and rationale that informed the development of the national Ethnic Minority Achievement Grant policy, which allocated local education funding based on the number of students from disadvantaged ethnic groups and with English as a second language from 1999 to 2011.

Police in the UK are required to collect ethnicity data whenever they stop and search or arrest someone. The court system and prisons also collect ethnicity data, resulting in data that shows differences in sentencing, violent incidents in prison and use of restraints in prison by ethnicity. This data was used to publish the [Lammy Review](#) on treatment and outcomes in the UK's criminal justice system for Black, Asian and "Minority Ethnic" people, which showed persistent and worsening racism in the justice system. The report made 35 recommendations for how to increase transparency and ensure fair treatment, including improved ethnicity data collection, public sharing of data sets, strong analysis and reporting of disparities in the justice system, and a series of actions to address disparities, reduce bias and increase fairness in sentencing and prisons. The UK Ministry of Justice has taken steps to address all 35 of the Lammy Review recommendations and reports annually on progress. Examples of initiatives underway include community-based crime prevention programming for at-risk youth, early rehabilitation pilots, pre-sentence reports to reduce bias in sentencing, addressing use of force and improving complaints processes in prisons, increasing awareness of racial inequities among judges and court officials, recruiting more racialized people to work as judges, in prisons and in probation services, and continuing to improve and publish data on racial disparities[3].

In the UK health care system, ethnicity data has been collected as part of patient health records in primary care practices since 1991 and in hospitals since 1995. This data is either self-reported by patients using a form or collected by a health care professional. Initially the UK government mandated this collection but did not provide a strong system-wide implementation plan, resulting in incomplete, inconsistent and poor quality data for many years. Since 2006, the completeness and consistency of this data collection have improved, with ethnicity being recorded for approximately 90% of newly registered patients in primary care and 77% of hospital data as of 2010[4]. This is partly due to the introduction of a Quality and Outcomes Framework that includes government incentives for primary health care providers to improve the ethnicity data collected from their patients. All mental health service

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[3] United Kingdom Ministry of Justice. 2020. [Tackling Racial Disparity in the Criminal Justice System: 2020 Update](#).
[4] Mathur R., Bhaskaran K., Chaturvedi N., Leon D.A, vanStaa T., Grundy E., Smeeth L. 2014. [Completeness and usability of ethnicity data in UK-based primary care and hospital databases](#). *Journal of Public Health*, Volume 36, Issue 4, 684–692.

providers are required to collect ethnicity and other relevant data, such as language and religion from patients.

From 2005 to 2010 under the Delivering Race Equality in Mental Health Care Action Plan, data collection activities included an annual survey of the experience of Black and Minority Ethnic users of mental health services and a national census of patients in mental health hospitals. This plan included a strong focus on improving the collection and analysis of socio-demographic data for the purpose of monitoring inequities, improving and developing new services, and increasing equity in outcomes in mental health services. Mental health system data was used to measure progress on goals such as reducing the percentage of racialized mental health inpatients and the percentage of racialized people committed to psychiatric care involuntarily. Actions under the Delivering Race Equality Plan included funding community development workers to help build bridges between communities and mental health services; local mental health organizations developing partnerships with government mental health services; and 17 focused projects bringing together local mental health services to address inequities, make local mental health services more appropriate and responsive, and meet the needs of racialized patients. These focused projects used data to identify local inequities such as longer stays and involuntary admissions in mental health facilities for specific racialized groups, then did partnership and engagement work to better understand and address these inequities. Examples of responses include integrating religion and faith leaders to improve mental health recovery, such as providing spiritual therapy for male Muslim patients, developing culturally appropriate therapy approaches, tailoring services and outreach to increase access to mental health services for specific racialized groups, and cultural competency training for mental health staff[5].

Overview of New Zealand Context

In New Zealand, ethnicity data is routinely collected across many government services including education, health services, birth and death registrations and the prison system. Over time, these activities have moved from inconsistent approaches to a standardized approach that is consistent across sectors. Statistics New Zealand's Standard for Ethnicity provides standards to ensure that this data is collected, categorized and analyzed consistently.

The New Zealand Ministry of Education requires all schools to report on numbers of students enrolled by age, gender and ethnicity once a year. The New Zealand Corrections Department conducts a census of all prison inmates that collects inmates' age, gender and ethnicity every two years. Birth and death registration forms in New Zealand collect ethnicity data, allowing for analysis and reporting of disaggregated birth, death and life expectancy data. The New Zealand Ministry of Health's National Health Index system assigns a unique number to each person using health care and maintains a record that includes their name, address, date of

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[5] United Kingdom Department of Health. 2009. Delivering Race Equality in Mental Health Care.

birth, gender and ethnicity. This data is collected by doctors, nurses, hospitals and other health professionals, reported to the Ministry of Health, verified and updated periodically to maintain accurate records. The quality and completeness of this data has improved rapidly in the past decade, with ethnicity data recorded for almost all primary care records in 2017. To help ensure consistency and accuracy, a set of Ethnicity Data Protocols provides standard procedures for collecting, storing and using ethnicity data in the health care system.

Much of the socio-demographic data collected by New Zealand's government agencies is reported publicly and used to monitor inequities for ethnic groups such as Maori and Pacific populations in health, education, employment and justice system outcomes.

Overview of Canadian Context

In comparison to Canada, several jurisdictions including the US, UK and New Zealand have a stronger culture and longer history of collecting race and ethnicity data widely. In the US, UK and New Zealand, race and/or ethnicity are collected from all residents who complete the census and are generally included in most government social surveys including health, household and labour force surveys. In contrast, Canada only collects race and other detailed socio-demographic data from 25% of all census respondents. Statistics Canada's Canadian Community Health survey has included race or ethnicity questions for many years, but it was not until July 2020 that it began collecting race in its monthly Labour Force Survey, a closely watched economic indicator that measures unemployment, job losses and job gains. A similar pattern can be seen in data collection by Canadian public services, which typically do not collect race and other socio-demographic data, or have just begun to collect or explore it recently.

Overview of Canadian Municipalities

This review did not identify other City-wide disaggregated data strategies in Canada that are already being implemented, but several municipalities were found to be in the process of developing disaggregated data approaches and strategies. The City of Calgary is currently piloting the use of disaggregated data in various city projects and plans to develop a disaggregated data strategy to support its Gender, Diversity and Inclusion Strategy. Other municipalities including Waterloo Region and the City of Ottawa are currently exploring municipal strategies and approaches. Waterloo has begun this work by developing guidelines to help Region staff use consistent and inclusive practices when collecting socio-demographic data in research or other data collection, as one of several initiatives to support its Diversity and Inclusion Strategy and Corporate Strategic Plan for improving access to services.

Many other cities and provinces across Canada also collect extensive socio-demographic data through health and social surveys in specific sectors and use disaggregated data to inform service planning. These include:

- Counts and needs assessments of the homeless population across many Canadian cities, which included Toronto's Street Needs Assessment and 60 other communities in 2018.
- The Citizen's Survey in Halifax which collects socio-demographics and disaggregates results on quality of life, municipal service satisfaction, needs and priorities collected from a sample of residents.
- The My Health My Community survey which disaggregates data on health and wellbeing in the Vancouver Coastal Health region, including Vancouver and other British Columbia municipalities.
- Talk Vancouver, an online public consultation survey tool and registration system which collects socio-demographics from residents to help understand who is being heard from and if public consultation participants are representative of the city's diverse population. It also enables outreach to people from specific socio-demographic or interest groups for specific initiatives.

Local and Provincial Experiences

Some ongoing collection and use of socio-demographic and disaggregated data has been implemented in Toronto and other parts of Ontario in education, legal aid, health care, public health, police services, child welfare, youth justice and social assistance. Some of these initiatives are at very early stages and others have several years' experience that enable some assessment of how successful they have been and what lessons can be learned. During the recent COVID-19 pandemic, all Manitoba public health offices and several Ontario public health units began collecting expanded socio-demographics for all positive COVID-19 cases. Later on in the pandemic, all Ontario health units were mandated to collect race and income data. A summary of local and provincial experiences is provided below.

Ontario Anti-Racism Data Standards and Provincial Social Services

In 2018, the province of Ontario released the [Data Standards for the Identification and Monitoring of Systemic Racism](#), also known as the Ontario Anti-Racism Data Standards (ARDS). The ARDS set out requirements, rationale and guidance for the collection and use of race-based data by public sector organizations to support evidence informed decision making and public accountability towards the elimination of systemic racism and promotion of racial equity. This includes guidance for collecting, managing, analyzing, disclosing, de-identifying and reporting information. Implementation of the ARDS and the collection of additional socio-demographic data has begun across the province in the justice, child welfare, social assistance and education sectors. In the education sector, some school boards have begun to collect race-based data as part of a broader provincial education strategy to collect, analyze and use voluntary data about students' social identities to improve equitable outcomes for all students.

In 2018, child welfare agencies and youth justice programs began collecting extensive socio-demographic data through local Children's Aid Societies, youth justice services delivered by the provincial government and community-based youth justice programs.
Centrally developed questions, guidelines for data collection, data entry and processing, educational and resource materials, and information sheets for staff and clients were provided. Local organizations and sites delivering services were responsible for delivering staff training, ongoing support for staff carrying out the data collection, and many other aspects of day-to-day implementation.

In late 2019, Ontario Works and Ontario Disability Support Program began collecting expanded socio-demographic information including race, Indigenous identity and gender identity from all social assistance recipients to better understand who uses their services, to help inform policies and programs, and to improve services. This data is provided on a voluntary basis and is not required for social assistance eligibility determination purposes. Socio-demographic questions and fields were developed centrally and integrated into the provincial case management system used for service delivery and data collection. Processing and analysis of this data is managed centrally by the Ministry of Children, Community and Social Services. Educational and resource materials were centrally provided and a 30-60 minute webinar was offered for municipal Ontario Works staff across the province to orient them to the new data collection. Ongoing support, troubleshooting and training for staff carrying out the data collection has been led by the local municipalities delivering Ontario Works.

Toronto Police Service
In 2020 the Toronto Police Service (TPS) began to collect race data for all police interactions involving the use of force, including taking out or shooting a gun, and all strip searches involving the removal of a person's clothing and visual inspection of their body. Their data collection approach is aligned with the Ontario Anti-Racism Data Standards. While the TPS have just started to collect data, their planning was informed by extensive community engagement and consultation with their Anti-Racism Advisory Panel which consists of experts in anti-racism, mental health and substance use and people with lived experience of these issues. The TPS plans to continue to engage and be informed by community and expert perspectives at various stages of implementation through the establishment of a Community Advisory Panel and continued community engagement on topics including data analysis, reporting and interpreting findings and implementing the next phase of data collection focused on self-identity.

Legal Aid Ontario
Legal Aid Ontario (LAO) has been collecting Indigenous identity data since 2009 and race-based data since 2018 from their applicants and service users, in support of LAO's Aboriginal Justice and Racialized Communities strategies. This data is used to determine eligibility for

enhanced services for First Nations, Inuit and Métis, Black and racialized clients and to identify which groups are underrepresented among legal aid clients. This data is also used to identify gaps in the LAO service delivery model and to ensure that LAO is effectively providing legal services to Indigenous, Black and racialized clients throughout Ontario. The Aboriginal Justice Strategy has succeeded in providing increased services for Indigenous clients, partnering with Indigenous organizations, providing Indigenous cultural competency training for legal aid staff, and implementing recruitment efforts to ensure Indigenous representation on the Board of Directors and among legal aid staff. The Racialized Communities Strategy has resulted in the provision of cultural competency training for legal aid staff and private bar lawyers, and partnerships with organizations.

Toronto District School Board
The Toronto District School Board's (TDSB) Student and Parent Census is an example where there has been strong success collecting socio-demographic data and reporting on and using disaggregated program data. The TDSB has many years of experience collecting good quality data, linking it to educational records, analyzing it and reporting publicly on demographics and various outcomes for different identity-based groups, and using findings to identify and address inequities.

For example, analysis by racialized groups showed that Black students in the TDSB had lower academic achievement rates in Grade 6 reading, writing and math skills and Grade 10 literacy assessments than TDSB students overall, particularly for some sub-groups. As a result of these and other findings, the TDSB has developed programs focused on improving academic achievement for Black students. The TDSB's Black Student Success and Excellence initiative is a recent example created in response to persistent gaps in school achievement and students' sense of belonging at school, particularly among students who self-identify as Black, and includes a set of successful practices and conditions to build the critical consciousness of educators and students in relation to race and learning in schools and classrooms. This includes fostering the ability to recognize, understand and take action against societal patterns of anti-Black racism and oppression.

In addition, each school in the TDSB receives school-specific data and support to use this information when developing their school improvement plans.

The TDSB's approach has been to have a centralized system that is integrated across all schools using the same methods, with substantial support at all levels and dedicated resources to data collection, management, analysis, reporting and applying findings, including engagement with and accountability to community. The TDSB's experience, expertise and good practice in socio-demographic data collection and use has been informing implementation in other school boards across the province.

Toronto Central LHIN Health Care Providers: Measuring Health Equity

Beginning in 2012-2013, all hospitals and community health centres (CHCs) funded by the Toronto Central Local Health Integration Network (LHIN) were mandated to collect standardized socio-demographic data from patients and clients. This initiative is called Measuring Health Equity and was developed from the We Ask Because We Care pilot research project which included a review of experiences, multiple question refinements and implementation testing in three hospitals and in Toronto Public Health services. The Measuring Health Equity Project and the staff team supporting this work were based at Sinai Health System, a Toronto hospital network, with support from the Toronto Central LHIN.

Measuring Health Equity data collection began in 16 Toronto hospitals in 2013 and in 16 CHCs in 2014 and has been sustained and improved over time. Data collection methods vary by site, taking place at the time of registration or when a patient is staying in a hospital, with patients filling out paper or electronic forms in some sites and data collectors interviewing patients in others. Implementation at the different service sites focused on using a standard data collection tool while adapting best practices to fit with existing work flows and operations. Some key principles were applied across all settings, including highlighting the importance of staff training, checking for missing data, and ensuring patients and clients are informed of the purpose of data collection, who has access to their information and that their responses are voluntary. The Measuring Health Equity team provided substantial support to assist health organizations with implementation, data quality improvement and data analysis, as well as a collection of tools and resources on their website such as data collection guidelines, training modules and scripts on how to ask socio-demographic questions.

After about four years of Measuring Health Equity data collection, socio-demographic data had been collected from 39% of patients across all hospitals and 70% of clients across all CHCs. Completion rates varied substantially between hospitals and CHCs, with some organizations achieving high levels of success and others experiencing substantial challenges. Key challenges that have impacted the success of data collection and use have included entering and extracting data in IT systems, challenges integrating data collection into some hospital services, lack of staff comfort and awareness about the data collection and its goals, and lack of leadership and commitment to improved and expanded collection.

Hospitals and community health centres have used patient and client socio-demographic data to develop demographic profiles and dashboards of who is being served, identify inequities in service access and health care outcomes, develop quality improvement plans, conduct outreach to specific communities, support funding applications, and inform clinical care. For example, data on language needs have been used to tailor interpretation and translation services; a transportation program was developed to improve hospital service access for racialized children; data showing lower cancer screening rates for Middle Eastern women and trans people have informed outreach and clinical services to improve access to screening; data showing a gap in access to youth programs has led to program improvements to be

more responsive to LGBTQ2S+ youth communities; and health care providers have used demographic data to better meet patient and client needs, such as connecting clients to appropriate and needed services and addressing dietary needs and transportation help for low income patients.

Socio-demographic data from hospitals has also been linked to provincial administrative health records to examine differences in chronic illness and health service use across hospitals in the Toronto Central LHIN area. Analysis of this data has shown disparities in chronic illness, rates of multiple chronic conditions, hospital emergency department use, inpatient hospitalizations and primary care access by race and other socio-demographic characteristics. These findings has been used by anti-racism and equity leaders to support their work on health inequities and the collection and use of race-based data. Groups of health care providers working together to develop Ontario Health Teams have used the data to help identify needs in their catchment areas and as part of their applications for provincial funding and recognition.

The Measuring Health Equity Project is an important Canadian example demonstrating that socio-demographic data collection and use can be integrated and sustained in ongoing service provision. This experience has shown that planning and implementing data collection in a variety of different service settings, work processes, staff training environments and technology systems requires substantial staff resources, the need for support is ongoing, and success can vary greatly in difference service contexts. This example also highlights the importance and value of providing guidelines, tools and resources to support all stages of implementation.

Other Local Health Care and Public Health Initiatives
In the Mississauga Halton LHIN, the Measuring Health Equity questions and approach have been implemented in programs at 25 local health service provider organizations, including community health and mental health agencies. Some public health units in Ontario have been collecting and using disaggregated data to inform programs and services for several years, including surveys such as the Rapid Risk Factor Surveillance System and the Toronto Public Health Student Survey, both of which include questions on several socio-demographic characteristics. Prior to COVID-19, Ottawa Public Health was working towards an organization-wide policy and procedure that would include the collection of socio-demographic data from clients of all front-facing services. As part of this work, the collection of socio-demographic data has been pilot tested with clients of Ottawa Public Health's Sexual Health Clinic and Immunization programs. Other public health units are also exploring similar socio-demographic data collection.

During the recent COVID-19 pandemic, several Ontario public health units including those representing Middlesex-London, Ottawa, Peel and Toronto began collecting expanded socio-

demographic data for positive and likely COVID-19 cases as part of their case and contact management process. The most commonly collected data points were race, Indigenous identity and income, with some also collecting disability, country of birth and length of time in Canada. Since early in the pandemic, the province of Manitoba required all its public health offices to collect race, ethnicity and Indigenous identity, and approximately two months later the province of Ontario mandated all its public health units to collect race, income and language data. Toronto Public Health's experience collecting this data is described in Attachment 3.

Challenges

These experiences and examples provide important insights into challenges to be aware of and how they can be addressed. The examples have demonstrated that socio-demographic data collection and disaggregated data use is complex and requires substantial time, resources, support for implementation and staff training. Key challenges identified in other jurisdictions and organizations that can pose barriers to data collection, storage and use include difficulty integrating data collection into existing processes, challenges with information technology systems, privacy issues, hesitance and discomfort among staff and leadership to collect or use data, lack of commitment, inadequate expertise, lack of ongoing supports for implementation, and insufficient ongoing resources dedicated to implementing, sustaining and improving data collection and use. Another key challenge can be a lack of equity-related policies and policy direction to justify the collection of data and enable its use to promote equity. All of these challenges can make the collection and use of high quality data difficult to implement successfully and sustain.

An important challenge in socio-demographic data collection and use is the need to ensure that the process of data collection, reporting and use does not create barriers to service, cause harm, perpetuate stereotypes, stigmatize groups of people or neighbourhoods, or lead to public mistrust. Research and experience has demonstrated that in Canada, the US, the UK and New Zealand, residents and service users are generally willing to share this data. However, important concerns have been commonly raised about how the data will be used. Generally, residents are willing to provide this data as long as they are informed that the data will be used to monitor services to ensure that all residents get the best services possible. As some residents are understandably concerned that this information may be used to discriminate against them, they need to be informed that the appropriate safeguards will be taken to protect their confidentiality and access to their data.

Promising practices

Many useful lessons have been learned from the experiences described above about what has worked and the conditions that enable success:

- Clearly articulated equity goals, priorities and policy direction

- Strong commitment from senior leadership to champion data collection and use to advance equity goals
- Alignment of socio-demographic data collection and use with organizational values and priorities
- Strong support from all levels of leadership, staff and community
- Having a consistent approach to data collection and centralized supports for implementation
- Integrating data collection practices into existing systems and processes
- Substantial resources dedicated to providing support for implementation and data analysis
- Considerable investment in staff training and capacity-building, including ongoing processes to gather staff feedback, respond to challenges and shift organizational culture towards respectful and high quality collection
- Ongoing efforts to improve data quality in collaboration with staff data collectors
- Meaningful use, including analysis, reporting and application of the data, which helps demonstrate value to staff and community members
- Ongoing engagement and accountability with community members and key stakeholders to build trust and to explain why data is being collected and how it will be used
- Providing information to the people providing their data, including the purpose of data collection, how data will be used, that all questions are voluntary (unless required), who will see the information, that data will be stored and managed appropriately, and that people's privacy and confidentiality will be protected
- Mandating the collection of socio-demographic data and requiring regular public reporting, to motivate programs to improve both data quality and the services they provide
- Providing incentives for programs to improve data quality