

Roles and Responsibilities

The consulting physician is not a required team member but rather an option contingent on the needs of the client. The consulting physician is responsible for ongoing case consultation and recommendations for the health action plan and may contribute to the provision of BHH services through case consultation.

Team Member: External Professionals

Required Qualification

Professionals from organizations that provide:

- Housing
- Food
- Special education
- Criminal/justice system
- Chemical dependency
- Respite care
- Social support services
- Employment services

Roles and Responsibilities

The external professional is not a required team member but rather an option contingent on the needs of the client. As needed and appropriate, external professionals will provide recommendations for the health action plan and ongoing consultation, and may contribute to the provision of BHH services through case consultation.

Health Home Monitoring, Quality Improvement and Performance Measures

There are specific state monitoring, quality improvement reporting, and evaluation requirements expected under the federal health home provision. In addition, DHS has identified further performance measures to demonstrate outcomes for those served by BHH and to monitor service providers.

Monitoring

DHS will ensure there is a defined methodology, including data sources and measurement specifications, for:

- Tracking avoidable hospital readmissions
- Calculating cost savings that result from improved chronic disease management, and
- Tracking the use of health information technology in providing health home services to improve coordination and management of care and consumer adherence to recommendation made by their provider.

Quality Improvement

As part of the continuous quality improvement process, DHS is required to report on a set of CMS quality measures including:

- reduction in hospital admissions,
- emergency room visits, and
- skilled nursing facility admissions.

Evaluation

DHS must provide assurance that it will report to CMS information submitted by behavioral health home providers to inform the evaluation and Reports to Congress as described in Section 2703(b) of the Affordable Care Act as described by CMS. DHS must also assure the completion of a state evaluation that assesses the impact of behavioral health home services on consumer and family experience; health care utilization, and costs.

Additional State Performance Measures

DHS must create a set of performance measures specific to the targeted populations of adults and children with serious mental illness. These measures will include:

- Follow-up after hospitalization for mental illness,
- Use of Child and Adolescent Service Intensity Instrument (CASII) and Early Childhood Services Intensity Instrument (ECSII),
- Consumer experience of care,
- Use of routine and preventative primary care,
- Use of dental care,
- Well-child physician visits,
- Screening for alcohol and other drug use, and
- Depression remission using PHQ-9 for adults.

State Plan Amendment

The Medicaid Health Home State Plan Option, authorized under the Affordable Care Act (Section 2703), allows states to design health homes to provide comprehensive care coordination for Medicaid beneficiaries with chronic conditions, of which serious mental illness is an identified chronic condition. States are required to submit a State Plan Amendment (SPA) and enter into negotiations the Centers for Medicare and Medicaid Services (CMS). Services may not begin until federal approval is obtained.

The BHH SPA is in draft form and will be posted for public comment in February 2015. DHS is scheduled to submit the SPA in 2nd quarter of 2015. As noted previously, DHS must also obtain a legislative appropriation to implement the proposal as currently developed. If the legislative proposal does not move forward this legislative session the model, services, and payment must fit under the existing Health Care Program.

Fiscal Analysis

A 2013 program utilization and claims analysis identified that approximately 109,644 people in Minnesota Health Care Programs (MHCP) met criteria of SMI, SPMI, and SED. As noted previously, BHH services are voluntary and an individual cannot receive duplicative case management/care coordination services such as target case management (TCM), home and community base waived case management (HCBS), or Assertive Community Treatment (ACT). This same analysis determined that

23,334 people received TCM, 16,388 received HCBW services, and 1,931 received services through ACT. This leaves a total of 73,212 individuals who are potential consumers of BHH services.

Our goals within the Olmstead Plan include:

- By January 1, 2017, 15% (10,981) of eligible individuals will choose to access care through this model;
- By January 1, 2018, 20% (14,642) of eligible individuals will choose to access care through this model;
- By January 1, 2019, 25% (18,303) of eligible individuals will choose to access care through this model.

Our original timeline had Minnesota implementing BHH services on July 1, 2015; however, the Governor's budget proposal pushes back the start time of BHH services by six months to January 1, 2016. The fiscal estimate, with an effective date of January 1, 2016, has a net cost to the General Fund of \$6.9 million in the FY2016-17 biennium and \$23.8 million in the FY2018-19 biennium once the federal match is no longer 90%.

MHCP claims data indicate that persons meeting the criteria to be served in a behavioral health home are very expensive relative to other consumers. Even after removing costs for behavioral health and chemical dependency services, long term care services, and access services, those meeting the criteria for behavioral health homes have an additional \$4,100 in annual professional, inpatient hospital, and pharmacy claims when compared with other consumers. The services offered under this proposal are expected to reduce this difference in cost.

A legislative appropriation is necessary to provide the administrative dollars necessary to develop the operation framework including MMIS system changes, certification portal, contractual reporting mechanism's necessary to allow designated providers to report on all mandated quality measures and state required outcome measures.

Conclusion

The implementation of behavioral health homes is a first step in the development of a framework to provide services in a person-centered system of care. This framework will facilitate access to and coordination of the full array of primary, acute, and behavioral health care and findings from implementation will be used to determine populations to serve under subsequent models.

For More Information

For additional information, please contact Jennifer Blanchard at Jennifer.Blanchard@state.mn.us

Appendix A

Minnesota Behavioral Health Home Planning and Community Engagement

Preliminary Report- Final Report Available March 2015

By the Department of Human Services in partnership with National Alliance on Mental Illness (NAMI) Minnesota

12/15/2014

Background:

The Community Supports and Health Care Administrations of Minnesota's Department of Human Services (DHS) are working together to design a Behavioral Health Home (BHH) model which will operate under a "whole person" philosophy and assure access to and coordinated delivery of primary care and behavioral health services for adults and children with serious mental illness.

DHS is developing a framework that will require a standard of integrated care which encompasses mental, behavioral, physical health conditions and considers the influence of multiple conditions, social factors, social function, and consumer preferences to personalize assessment, treatments, and goals of care. DHS believes that more integrated care, regardless of setting, contributes to improved health and decreases the risk of adverse outcomes, including hospital admissions. DHS is starting with the population with serious mental illness because of the known barriers of health care access, high co-occurrence of chronic health conditions, and early mortality. DHS may build on this framework to serve other complex populations in the future.

Methods:

In planning the Minnesota Behavioral Health Homes (BHH), the Department of Human Services has contracted with the National Alliance on Mental Illness (NAMI) Minnesota to engage people living with mental illness across the State in an opportunity to shape policy. Through their participation in focus groups, Medicaid participants from a very wide range of communities are providing feedback on topics that will inform the development of Minnesota's Behavioral Health Home model. The focus group questions concentrate on topics such as: accessing physical and mental health care, transition of care experiences, methods of obtaining health information, opinions surrounding the facets of integrated care, the ways in which individual, cultural, spiritual, and gender values should be incorporated into the care process.

This report provides an overview of focus groups completed to date. Focus groups began in September 2014 and at this time, 22 focus groups have been conducted, reaching 182 individuals with mental illness, family members, and transition aged youth. Please see table 1 for details. A total of 28 focus groups were scheduled, six groups were rescheduled; five for non-attendance and one due to inclement weather. In total, eight additional focus groups are scheduled to be conducted and two non-English focus group transcripts are pending translation. The final report will include a detailed analysis of the data and recommendations for its integration within BHH policy.

Results:

Initial analysis of focus group data reveals the following themes:

Relationship: Trust and relationships with providers were the most salient themes that have emerged across all focus groups thus far. Having a good relationship with providers was identified as affecting the following: fostering trust, receiving appropriate care, increased follow-through with care plans, increased medication adherence, and increased hope for recovery.

Trust: Most focus group participants mentioned trust as an important component in determining issues such as: when and how care was accessed, level of disclosure to providers, perceived level of personal wellness one has the ability to achieve, the quality of provider recommendations, and the likelihood of their adherence to their provider's recommendations. In each of the focus groups, participants discussed factors that either cultivated or impeded trust between them and their health providers. The following factors were consistently identified as contributors to building trust: providers asking questions about the whole person instead of just focusing on the illness, providers sharing information about themselves, providers actively listening, providers taking time to give and discuss information (rather than simply providing pamphlets), and found to be most important, was the perception that the providers cared. In contrast, the following factors were identified as impeding trust: provider rushing appointments, not being listened to (identified as a sign that providers didn't care), providers recommending medications without enough perceived participant input or information, and providers recommending medications without the discussion of other treatments.

Barriers to Wellness and Care: The following elements were discussed as the barriers that impede a participant's ability to receive effective medical care and manage their needs: wait times, cost, previous negative experiences, emergency room use when not connected to a primary care provider and being barred from making appointments or using the ER when money is owed. Many participants reported negative experiences with care where they felt stereotyped, disrespected, or where medical issues were dismissed by providers as a symptom of their mental illness.

Barriers that impeded participant's ability to receive effective mental health care included: unavailability of appointments when needed, lack of providers, lack of systems to respond to an emerging crisis, inadequate transition services and planning, HIPAA regulations that prevent families/support network from being involved in care or being given information, and lack of a care system for mental illnesses that are not yet crisis's but are unmanageable by the consumer or family members.

Overall, similarities in positive and negative experiences were loosely based on location, cultural group, and age. In two focus groups a particular service provider was spontaneously identified as a place where parallel positive experiences seemed to occur regularly. This hospital/clinic described by participants was structured and functioned in a manner similar to the projected Behavioral Health Home model and resulted in reported high levels of care, trust, wellness, adherence, and satisfaction.

Education: Most participants reported getting the majority of their information about health conditions or wellness on the internet, or by talking to a trusted friend, family member, or someone with the same experience. Many participants expressed a preference for getting health or mental health information from their providers but they had not had positive experiences in attempting to obtain it from them. Participants had experienced that providers did not have the time to give information to them or their family members in way where the implications of the information was discussed, but rather opted to give written information to be read at home.

Self-Advocacy: Adults and youth with mental illness along with their family members, all discussed the need for self-advocacy as a means for getting their needed care, needed support services, and

preferences considered in treatment planning. These participants discussed the distress they experienced by not knowing how to navigate the system, what questions to ask, or who to turn to for help. Individuals with mental illness voiced an inability to self-advocate at times. Additionally, they indicated that it was difficult to know that self-advocacy was needed when they were in crisis, when they were experiencing certain mental illness symptoms, or when they were experiencing chronic disease flare-ups. For many of them, the need to engage in self-advocacy occurred in response to situations where it was felt that providers were not listening, were not including information felt to be important, or were not making recommendations that aligned with their or their family's desires. Family members discussed experiencing a continuing need to advocate for the consumer while highlighting the stress they experience in researching their loved one's illness and exploring the possible systems and services that could be utilized for assistance.

Discussion and Recommendations:

These focus group findings exemplify a broad range of experiences, preferences, values and views that highlight the difficulty of addressing complex and diverse health needs in a model of services and systems meant to be universally responsive to diverse target populations. However, a number of practical recommendations identified in the spectrum of groups emerged. Practices such as increased appointment time for a new patient's first few appointments would allow the provider and patient to get to know each other better, thereby initiating a strong basis for trust within their future relationship. Simple behaviors such as new providers saying to patients, "I am going to be your doctor," and employing a practice of asking "get to know you" questions in addition to the "what is the problem" questions are believed to provide a fruitful set of initial discussions. Integrating the final focus groups and analyzing the data from the complete set will be fruitful terrain for additional recommendations grounded in consumer experience.

Conclusion:

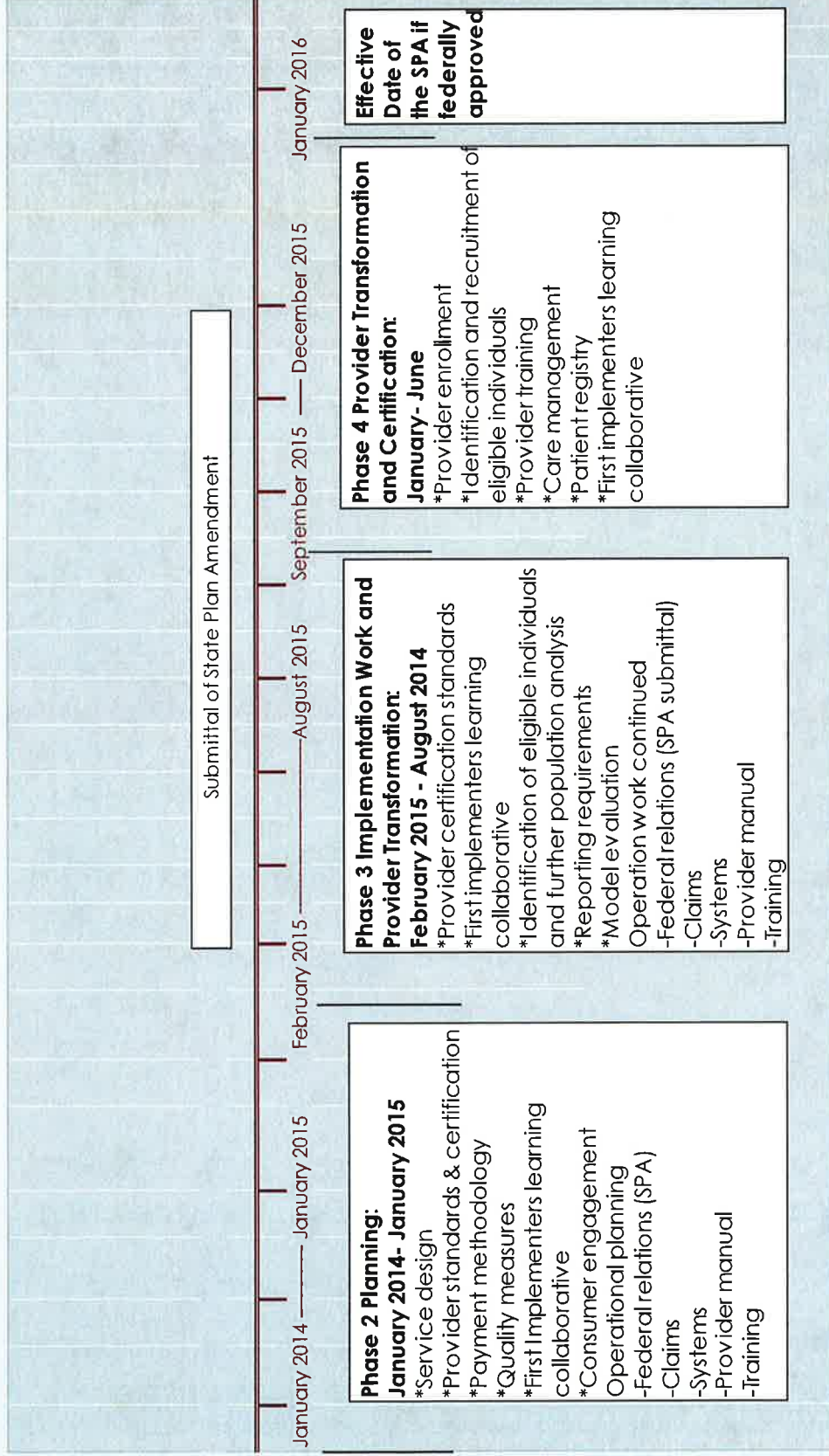
The range of experiences elucidated in the completed and forthcoming focus groups will be further elaborated on in the final report due in March 2015. Additional information will include detailed demographics of the participants, more health discussion themes, specific examples of participant experiences, a full analysis of the data, and focused recommendations to implement within the BHH program. This data has the potential to be extremely valuable not only for this program, but for anyone providing health services for this population.

Table 1:

Adult Participants			
Subgroup	Date	Location	# Attending
Spanish Speaking	11/18/2014	Centro Cultural Center	22
Russian	12/9/2014	Jewish Family Center	8
Veterans	11/18/2014	St. Cloud Library	6
Criminal Justice	10/14/2014	Phillis Wheatley Community Center	4
Criminal Justice	10/15/2014	Phillis Wheatley Community Center	4
African American	10/24/2014	Ujamaa	8
Homeless	10/19/2014	St. Stephens	22
Bemidji (Northwest region)	10/6/2014	Hope House	8
Brainard (Central region)	10/14/2014	1 st Lutheran	16
Worthington (Southwest)	10/28/2014	Southwest Mental Health	7
Winona (Southeast)	11/3/2014	Connection Support Group	35
Hoffman (Western)	12/10/2014	Hoffman Community Center	10
Hmong Elders	12/16/2014	Park Ave Elder Center	11
Transition-Age Youth			
Subgroup	Date	Location	# Attending
Homeless/American Indian	10/20/2014	Aun Dah Yun	5
Homeless	10/24/2014	The link	2
Spanish Speaking	10/26/2014	Aqui Para Ti	2
Brainerd (Central Region)	10/14/2014	Northern Pines Youth Act	8
Duluth (Northeast)	11/6/2014	Amberwing	4
Family Members			
Subgroup	Date	Location	# Attending
Parents with Mental Illnesses	10/27/2014	Phillis Wheatley	3
Bemidji (Northwest region)	10/6//2014	Hope House	5
Worthington (Southwest)	10/28/2014	SW Mental Health	7
Duluth (Northeast)	11/6/2014	Amberwing	2

Appendix B

Behavioral Health Home Planning and Implementation Timeline



Home and Community-Based Supports and Services Waiver Waiting List Report

March 3, 2015

I. Executive Summary

A. Legal Requirements

Olmstead Plan. The Olmstead Plan requires the Department of Human Services to report to the subcabinet recommendations for improving the home and community-based services waiting list, including prioritizing based on urgency and need, and describing how these practices will result in the waiting list moving at a reasonable pace.(SS 4B, p. 68).

Olmstead v. L.C. The phrase “reasonable pace” comes from the U.S. Supreme Court’s decision in *Olmstead v. L.C.*, where the Court said that a state could meet its responsibility for providing home and community-based services “if, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated...”¹ The Court also said the state must have “leeway” to “maintain a range of facilities and to administer services with an even hand.” *Id.*

Jensen v. DHS. On January 9, 2015, the Court in *Jensen v. DHS* found Minnesota’s waiting list goals inadequate (specifically, the goal of prioritizing the waiting list and the goal of providing home and community-based services to 80 residents of intermediate care facilities for developmentally disabled persons). The Court stated, “This proposal does not adequately address the current baseline of 3,502 individuals who have requested a ‘Developmental Disabilities (DD) waiver’ and 1,450 individuals who have requested a ‘Community Alternatives for Disabled Individuals (CADI) waiver.’ If the State wishes to address existing services and support needs, the State must provide a deadline for completion of the waiting list.” *Jensen, et.al. v. DHS, et.al.*, (Minn. Dist.) 09-cv-01775 DWF-FLN, Doc. 378, p. 10.

B. Wait List Recommendations

DHS has four recommendations to ensure that individuals will receive the services they need in the community at a reasonable pace that allows the state “to maintain a range of facilities and to administer its services with an even hand.”²

Recommendation 1: Enhanced Assessment.

By December 1, 2015, DHS will require lead agencies to enhance their assessment of individual need through a person-centered planning process that includes planning for when the individual may need waiver services.

¹ 119 S.Ct. 2176, 2189; 527 U.S 581, 605-6 (1999).

² 119 S.Ct. at 2189; 527 U.S. at 605.

Recommendation 2: Wait list categorization.

DHS will divide the waiting list into four categories:

A. Institutional Exit: This category includes any person in an intermediate care facility for persons with developmental disabilities (ICF/DD) or nursing facility who does not oppose leaving the facility. For this category, service planning will begin within 45 days after a needs assessment or other indication shows the person is not opposed to leaving the facility.

Waivered services will begin as soon as practicable, but no later than 180 days after the indication that the person is not opposed to leaving the facility.

Once waiver services are authorized, the person will be removed from the wait list.

B. Immediate Need: This category includes any person in the community who meets at least one of the criteria listed in Minn. Stat. §256B.092, subd. 12(b) and Minn. Stat. §256B, subd. 11a(b) (has an unstable living situation due to age, incapacity, or sudden loss of caregivers; is moving from an institution due to bed closure; experiences a sudden closure of their current living arrangement; requires protection from confirmed abuse, neglect, or exploitation; experiences a sudden change in need that can no longer be met through state plan services or other funding resources alone; or meets other priorities established by the department).

Waivered services will begin as soon as practicable, but no later than 90 days after the person meets criteria in Minn. Stat. §256B.092, subd. 12(b) or Minn. Stat. §256B, subd. 11a(b).

Once waiver services are authorized, the person will be removed from the waiting list.

C. Defined Need: This category includes any person who is assessed as needing waiver services within a year from the date of assessment.

Waivered services will begin as soon as practicable, but no later than 365 days after the date of the assessment.

Once waiver services are authorized, the person will be removed from the wait list.

D. Future Need: This category includes any person who is assessed as needing waiver services more than a year after the assessment date.

The person is not placed on the wait list, but will be tracked on a “future interest” list.

The person will be assessed annually, and will be placed on the wait list upon meeting the definition of “defined need or “immediate need.”

Recommendation 3: Data capture and reporting.

The enhanced assessment will capture information we do not have now that will show how long it takes for authorization of a waiver in each category.

By December 1, 2015, DHS will require lead agencies to begin tracking the information captured by the enhanced assessment process. By June 1, 2016 DHS will report the first six months' of data to the Subcabinet. After we have a year of data, beginning December 31, 2016, DHS will report the information twice a year to the subcabinet.

DHS will require lead agencies to track:

- why individuals are on wait lists for services;
- how many individuals are in each urgency category;
- the time it takes for individuals to move off the wait list in each category;
- gaps in services and resources; and,
- any other important information about the pace at which people move off the wait list revealed by the enhanced assessment.

Recommendation 4: Oversight

Through training, technical assistance, outreach, and monitoring, DHS will work with lead agencies to implement the new waiting list process.

II. Discussion

A. What “waiver” means.

Minnesota provides home and community-based services funded by Medical Assistance to people who require the level of care that would otherwise be provided in institutional settings. Because the federal government waives some of the institutional requirements of Medical Assistance funding, these home and community-based services are called “waivers.” Minnesota has five home and community-based service waivers that provide community alternatives to nursing homes, intermediate care facilities for persons with developmental disabilities, and hospital settings. Of these five waivers, two currently have waiting lists: 1) the Developmental Disabilities (DD) Waiver; and 2) the Community Alternatives for Disabled Individuals (CADI) Waiver.

B. What causes a waiver waiting list?

Waiver services are not an entitlement, which means that states can set limits on the growth of these programs. In Minnesota, waiting lists occur because the budgets for the waivers are limited, both by: 1) the amount the federal government approves in the state

waiver plans; and, 2) the amount the legislature appropriates for the state share of the service costs. A wait list is created when people who cannot access the waiver.

C. How many people are on the waiting list?

As of January 3, 2015, there were 1,412 people on the waiting list for the CADI Waiver and 3,462 people on the waiting list for the DD waiver.

The CADI waiver waiting list, however, is likely to disappear in July 2015. This is because, under current law, as of July 1, 2015, there will be no growth limits for the CADI waiver, effectively eliminating this waiting list. In addition, the DD Waiver allows for greater growth than in the past.³

D. How long do people wait for waiver services?

1. Institutional settings:

CADI Waiver: Data for the last four years shows that individuals who resided in a nursing facility within 90 days of their most recent assessment started CADI waiver services between 224 and 322 days from the time of their initial assessment for services. See Appendix B, Table 4.

DD Waiver: Data for the last four years shows that individuals living in intermediate care facilities for persons with developmental disabilities (ICF/DD) who did not oppose moving to the community and requested to move within a year had a median wait time between 9 days and 84 days. See Appendix B, Table 3.

2. Non-institutional settings:

CADI Waiver: Data for the last four years shows that individuals who did not reside in a nursing facility within 90 days of the most recent assessment started services between a median of 59 days and 134 days from the initial assessment for services. See Appendix B, Table 6.

DD Waiver: Data for the last four years shows that individuals who were not living in an ICF/DD when starting DD Waiver services had a median wait time between 19 and 315 days after they were classified as having a need for services within one year. See Appendix B, Table 5.

³ Appendix A shows the average monthly enrollment limits for the CADI and DD waivers for the past five years.

E. Waiting list totals do not tell the whole story.

While we know how many people are on the waiting list and the median number of days some categories of individuals waited to receive services, these facts do not tell the whole story. Other important information includes:

1. Most people receive other MA-funded services and supports while on the waiver waiting list.

Being on a waiting list does not mean the person is not receiving any supports or services. People typically are eligible for one or more state plan services that are entitlements, such as home care services. Federal and state law requires that people access state plan services first and use waiver services only if the state plan services are insufficient to meet their needs. Minnesota has a robust set of state plan services. Almost all individuals on the DD Waiting list receive some type of service, assessment, or case management. (See Appendix B, Table 7 showing types of state services).

Transition-age youth who have left school and are on a waiver waiting list may be able to access state or county funded services, in addition to Medical Assistance state plan services. As of January 3, 2015, 23.5% of individuals on the DD Waiver waiting list access county funded services, often day training and habilitation, 7.8% access the Family Support Grant and 5.0% access non-ICF/DD or nursing facility respite care. (Appendix B, Table 10).

2. Statute sets priorities for receipt of waiver services.

Where state-funded services are insufficient to meet needs, Minnesota law establishes priorities for waiver services, giving top priority to individuals who:

- (1) No longer require the intensity of services provided where they are currently living; or
- (2) Make a request to move from an institutional setting.⁴

Minn. Stat. §256B.092, subd. 12 (2014)(DD waiver).

The next priority is for individuals who:

- (1) have unstable living situations due to the age, incapacity, or sudden loss of the primary caregivers;
- (2) are moving from an institution due to bed closures;
- (3) experience a sudden closure of their current living arrangement;

⁴ The language—"make a request to move" is different from the standard in the *Olmstead* decision, which requires states to provide community-based care when appropriate and "the affected persons do not oppose" it. 119 S.Ct. at 2190 527 U.S. at 607.

- (4) require protection from confirmed abuse, neglect, or exploitation;
- (5) experience a sudden change in need that can no longer be met through state plan services or other funding resources alone; or
- (6) meet other priorities established by the department.

Id.

3. Waiting list totals don't reveal whether people receive services when they need them.

The total number of people on the waiting lists only tells us the number of people eligible for but not yet receiving waiver-funded services. The wait list totals do not reveal:

- why an individual is waiting for services (e.g., whether it is availability of the waiver or another reason--such as development of the person-centered plan, recruitment of a provider, or completion of modification to housing);
- the urgency of an individual's need for waived services, and, if urgent, how many days have passed since the need became urgent;
- whether an individual does not desire waived services to begin at the time placed on the waiting list, but rather, at some future point, and when (e.g., a family with a child living at home planning for adulthood; a person meeting current needs with state plan services who anticipates a future need for waived services); and
- the extent to which an individual receives other supports and services.

The waiting list does not differentiate between people who have immediate needs and those who desire to reserve a spot for future access to services when the need arises. The data captured by the enhanced assessment process will help answer these questions.

F. Capacity

DHS has forecasted significant growth in the disability waivers during the next biennium (starting July 1, 2015). Enrollment limits on the CADI waiver will expire on that date and the DD waiver will have additional growth. DHS forecasts that nearly \$300 million additional dollars will be spent on disability waivers in the next biennium. This will allow more individuals to access waiver services.⁵

⁵ Appendix A shows the average monthly enrollment limits for the CADI and DD waivers for the past five years.

G. How we will ensure our wait lists move at a reasonable pace.

1. We will enhance our assessment of individual need.

In order to better serve the needs of individuals on the waiting list, we will implement a new, comprehensive needs assessment.

The needs assessment will use person-centered planning to help people make decisions about their goals and to identify which services can meet them. The enhanced needs assessment will connect people to the right services and supports when they are needed, which may include a waiver at the time of assessment or at some time in the future. Lead agencies will conduct the assessments and develop community support plans.

Enhanced assessment will answer why a person is on a waiver waiting list and whether there is an immediate need for waived services.

Lead agencies will begin using enhanced assessment by December 1, 2015.

2. We will divide the waiting list into four urgency categories.⁶

Urgency Category	Definition	Commencement of Services
1. Institutional Exit	Any person in an ICF/DD or nursing facility who does not oppose leaving the facility.	Service planning begins within 45 days after a needs assessment or other indication shows the person is not opposed to leaving the facility. Waivered services begin as soon as practicable, but no later than 180 days after the indication that the person is not opposed to leaving the facility. Once allocated the waiver, the person will be removed from the waiting list.

⁶ Stakeholders recommended this categorization during a series of three sessions held to gather suggestions for improving processes related to waiver waiting lists. Appendix C contains a list of workgroup members.

2. Immediate Need	A person who meets at least one of the criteria listed in Minn. Stat. §256B.092, subd. 12(b) or Minn. Stat. §256B.49, subd. 11a(b).	<p>Waivered services will begin as soon as practicable, but no later than 90 days after the person meets criteria in Minn. Stat. §256B.092, subd. 12(b) or Minn. Stat. §256B.49, subd. 11a(b).</p> <p>Once allocated waiver services, the person will be removed from the waiting list.</p>
3. Defined Need	A person who is assessed as needing waiver services within a year from the date of assessment.	<p>Waivered services will begin as soon as practicable, but no later than 365 days after the date of the assessment.</p> <p>Once allocated waiver services, the person will be removed from the wait list.</p>
4. Future Need	A person who is assessed as needing waiver services more than a year after the assessment date.	<p>The person is not placed on the waiting list, but will be tracked on a “future interest” list.</p> <p>The person will be assessed annually, and will be placed on the waiting list upon meeting the definition of “defined need Or “immediate need.”</p>

3. We will report what the enhanced assessment teaches us to the subcabinet.

The enhanced assessment will answer the questions we do not currently know. By December 31, 2016, we will have enough experience with the enhanced assessment to begin reporting twice each year to the subcabinet what we learn about:

- why individuals are on waiting lists for services;
- how many individuals are in each urgency category;
- the time it takes for individuals to move off the wait list in each category;
- gaps in services and resources; and,
- any other important information about the pace at which people move off the waiting list revealed by the enhanced assessment.

4. We will report available waiting list data to the subcabinet during the transition.

DHS will continue to provide bimonthly status reports to the subcabinet until data from the enhanced assessment is available. DHS will enhance these reports by including information similar to the data contained in this report.

5. We will provide waiting list data to lead agencies during the transition.

By July 1, 2015, DHS will provide waiting list information to lead agencies on a quarterly basis. Information will include a list of people on the lead agency's waiting list and the length of time that has passed since their initial assessment. Statewide summary data of this information will be provided to the subcabinet as described in number 4.

6. We will work to implement the new waiting list process.

Assuring effective implementation of these changes will require technical assistance, outreach and compliance monitoring and reporting. DHS will engage in the following quality implementation activities.

a. We will provide technical assistance to lead agencies.

To ensure individuals are placed in the appropriate waiting list categories and data is collected consistently, DHS will provide statewide technical assistance to lead agencies.

If lead agencies do not comply with timelines, DHS will undertake steps to learn why, and provide appropriate technical assistance. Additionally, DHS will consider reallocating resources if a county is unable to serve individuals with urgent needs within their county waiver budget.

b. We will reach out to individuals and families.

DHS will engage with its partners, including organizations such as Arc Minnesota and local Arc chapters, through July – December, 2015, to educate individuals and families about changes to waiver waiting lists.

c. We will monitor lead agencies' compliance with timelines.

In January 2016, DHS will begin monitoring lead agency compliance on a monthly basis. DHS already reviews county waiting lists and provides technical assistance

during its county waiver review. We will add a monthly compliance report which will include:

- Any assessed individuals who were not assigned an urgency category;
- An overall compliance score based upon assignation of urgency categories; and
- A list of individuals whose service start date is within 30 days of the report.

III. Recommendations Summary

DHS recommends that DHS commence the following actions by the following dates:

A. July 1, 2015:

1. For each lead agency, DHS will report on the number of individuals on disability waiver waiting lists and how long individuals have been on the lists.
 - a) DHS will report each lead agencies' data to each lead agency, and will report aggregate state-wide data to the subcabinet.
 - b) DHS will provide these reports on a quarterly basis until June 1, 2016, at which time DHS will begin reporting on the data specified in Recommendation 3 to the extent it is available.
2. DHS will engage with partners to educate individuals and families about changes to waiver waiting lists.

B. October 31, 2015:

1. Provide lead agencies with a mechanism to track the data specified in Recommendation 3 for all disability waivers;
2. Provide training and technical assistance, as needed, to lead agencies on enhanced assessment, classifying waiting list categories, and using the tracking mechanism.

C. December 1, 2015:

1. Require lead agencies to use the enhanced assessment;
2. Require lead agencies to track data according to the mechanism DHS provides;
3. Require lead agencies to authorize waiver services to individuals within the time periods specified herein;
4. Begin to track lead agencies' compliance and take steps to assist lead agencies with achieving compliance;
5. Collect the data specified in Recommendation 3.

- D. **June 1, 2016:** Report to the Subcabinet on the data collected since December 1, 2015.
- E. **January 15, 2016:** Report the waiting list data specified in Recommendation 3 to the subcabinet twice each year.

Appendix A: Historic Waiver Enrollment Limits

CADI Waiver Average Monthly Enrollment Limits (2010 – 2015)

Fiscal Year	Average Monthly Enrollment Limit
2010	95 people
2011	60 people
2012	60 people
2013	60 people
2014	85 people
2015 ⁷	Unlimited

DD Waiver Average Monthly Enrollment Limits (2010 – 2015)

Calendar Year	Average Monthly Enrollment Limit
2010	15 people
2011	6 people
2012	6 people
2013	6 people
2014	15 people
2015 ⁸	25 people

⁷ As of July 1, 2015

⁸ As of July 1, 2015

Appendix B: Data Analysis Results

Table 1 displays the total number of individuals who started DD Waiver services by calendar year.⁹

Table 1

Calendar Year	Number of Individuals
2011	657
2012	573
2013	631
2014	509
TOTAL	2,370

Table 2 displays the total number of individuals who started CADI Waiver services by calendar year.¹⁰

Table 2

Calendar Year	Number of Individuals
2011	2,958
2012	2,114
2013	2,823
2014	2,432
TOTAL	10,327

Table 3 reports the median number of days that passed between the date an individual indicated they needed waiver services within a year and the start of waiver services. This data is for individuals who resided in an ICF/DD within 90 days of their most recent assessment.

Table 3

Calendar Year	Median Number of Days from Waiver Need Index of "1" to Service Agreement Start
2011	84 days
2012	11 days
2013	19 days
2014	9 days

⁹ Waiver start numbers include all people, not just those starting from a waiting list.

¹⁰ Waiver start numbers include all people, not just those starting from a waiting list.

Table 4 displays the median number of days from the initial assessment to the start of CADI Waiver services for individuals who resided in a nursing facility within 90 days of the most recent assessment.

Table 4

Calendar Year	Median Number of Days from Initial Assessment to Service Agreement Start
2011	224 days
2012	265 days
2013	275 days
2014	322 days

Table 5 reports the median number of days that passed between the date an individual indicated they needed waiver services within a year and the start of waiver services. This data is for individuals who did not reside in an ICF/DD within 90 days of their most recent assessment.

Table 5

Calendar Year	Median Number of Days from Waiver Need Index of "1" to Service Agreement Start
2011	315 days
2012	15 days
2013	23 days
2014	19 days

Table 6 displays the median number of days from the initial assessment to the start of CADI Waiver services for individuals who did not reside in a nursing facility within 90 days of the most recent assessment.

Table 6

Calendar Year	Median Number of Years from Initial Assessment to Service Agreement Start
2011	59 days
2012	62 days
2013	130 days
2014	134 days

Table 7 displays non-waiver services individuals received the year before starting CADI or DD waiver services. These individuals did not reside in a nursing facility or ICF/DD at the time of the last assessment. This data displays totals between calendar year 2011 and 2014.

Table 7

Service	Number of Individuals Using this Service	Percentage of Individuals Using this Service
Mental Health Services	4,421	34.8%
Transportation Services: • Access Services • Transportation	3,839	30.2%
Home Care Services: • Consumer Directed Home Care • Home Health Services • Personal Care • Private Duty Nursing	3,415	26.9%
Assessments: • DD Screenings • Long-Term Care Consultation Pre-Admission Screening • Pre-Admission Screening and Resident Review	2,780	21.9%
Case Management Services: • Child Welfare Targeted Case Management • HIV Case Management • Home Care Targeted Case Management • Relocation Services Coordination • Vulnerable Adult Targeted Case Management	1,974	15.6%
School-Based Services: • IEP Nursing	1,120	8.8%
Nursing Facility Services	865	6.8%
Child & Teen Check-up Services: • Child and Teen Check-Up Outreach • Child and Teen Check-Up Services	324	2.6%
Chemical Dependency Services	286	2.3%
Administrative Services: • Buy-In • Collections, Miscellaneous • Financial Transactions • Premium Payments/Collections • Primary Care Utilization Review • Spenddown	280	2.2%
ICF/DD Services	173	1.4%
HCBS Services: • HCBS Waiver Conversion/Diversion • DT&H • Alternative Community Services • Moving Home Minnesota Waiver Services • Respite Care • Semi-Independent Living Services • Diversion	119	1.0%
Other Services: • Undetermined Services	116	0.9%

Table 8 displays the number and percentage of individuals living at home at the start of CADI or DD waiver services between 2011 and 2014.

Table 8

Calendar Year	Number of Individuals Living at Home at Start of Waiver Services	Percentage of Individuals Living at Home at Start of Waiver Services
2011	1,022	28.3%
2012	753	28.0%
2013	991	28.7%
2014	835	28.4%

Table 9 displays characteristics of individuals who are currently waiting to start CADI Waiver services. Service categories displayed indicate that an individual has received a service within the last year. For a description of what is included in service categories, see Table 7. These figures are current as of January 9, 2015.

Table 9

Total Number of Individuals on a CADI Waiver Waiting List	1,412 people
Percentage of Individuals on a CADI Waiver Waiting List who Reside at Home	21.3%
Average Age of Individual Currently Waiting for CADI Waiver	42.1 years old
Median Number of Days on CADI Waiver Waiting List Since Initial Assessment	829 days or 2.3 years
Number of People on a CADI Waiver Waiting list who have started the DD Waiver since September 2014	5 people
Number of Lead Agencies without anyone on a DD Waiver Waiting list	21
Percentage of Individuals Who Have Received Home Care Services	53.5%
Percentage of Individuals Who Have Received School-Based Services	28.4%
Percentage of Individuals Who Have Received Mental Health Services	25.4%
Percentage of Individuals Who Have Received Transportation Services	19.4%
Percentage of Individuals Who Have Received Case Management Services	19.0%
Percentage of Individuals Who Have Received Child & Teen Check-up Services	8.3%
Percentage of Individuals Who Have Received HCBS Services	5.7%
Percentage of Individuals Who Have Received Assessments	2.8%
Percentage of Individuals Who Have Received ICF/DD Services	1.9%
Percentage of Individuals Who Have Received Other Services	1.0%

Percentage of Individuals Who Have Received Administrative Services	0.9%
Percentage of Individuals Who Have Received Nursing Facility Services	0.6%
Percentage of Individuals Who Have Received Chemical Dependency Services	0.6%

Table 10 displays characteristics of individuals who are currently waiting to start DD Waiver services. Service categories displayed indicate that an individual has received a service within the last year. These figures are current as of January 3, 2015.

Table 10

Total Number of Individuals on a DD Waiver Waiting List	3,462 people
Percentage of Individuals on a DD Waiver Waiting List who Reside at Home	91.6%
Average Age of Individuals Currently Waiting for DD Waiver Services	15.4 years old
Median Number of Days on DD Waiver Waiting List Since Initial Assessment	2,012 days or 5.5 years
Number of People on DD Waiver Waiting List who have started the CADI Waiver since September 2014	8 people
Percentage of Individuals who have Received Case Management Services	99.2%
Percentage of Individuals who have Received School-Based Services	75.2%
Percentage of Individuals who have Received Home Care Services	34.1%
Percentage of Individuals who have Received County Funded Services	23.5%
Percentage of Individuals who have Received Family Support Grants	7.8%
Percentage of Individuals who have Received Respite Services (Not ICF/DD or NF)	5.0%
Percentage of Individuals who have Received CCB Waiver Services	3.0%
Percentage of Individuals who have Received Home Modifications or Equipment	2.6%
Percentage of Individuals who have Received ICF/DD Services	2.5%
Percentage of Individuals who have Received Jobs & Training Services	1.8%
Percentage of Individuals who have Received Other Services	0.5%
Percentage of Individuals who have Received Homemaker Services	0.3%
Percentage of Individuals who have Received Relocations	0.2%

Service Coordination	
Percentage of Individuals who have Received Adult Education Services	0.1%
Percentage of Individuals on DD Waiver Waiting List who have Received No Services	0.3%

Appendix C: Olmstead Wait List Workgroup Participants

Workgroup meetings held:

June 26, 2014

July 15, 2014

July 31, 2014

August 21, 2014

Stakeholders:

Sue Abderholden, National Alliance on Mental Illness – Minnesota

Rebecca Covington, Minnesota Consortium for Citizens with Disabilities

Andrew Ervin, Hennepin County

Sandra Foy, Ramsey County

Cindy Grosklags, Renville County

Carol Huot, Dakota County

Tim Jeffrey, Stearns County

Steve Larson, The Arc of Minnesota

Bud Rosenfield, Minnesota Disability Law Center

Bill Velte, Hennepin County

Minnesota Department of Human Services:

Alex Bartolic

Curtis Buhman

Patti Harris

Lorraine Pierce

Colin Stemper

Nan Stubenvoll

Management Analysis & Development:

Renee Raduenz

Barbara Tuckner

Minnesota Employment First Policy

Adopted by the Olmstead Subcabinet on September 29, 2014

Policy Statement:

Employment First means raising the expectation that all working age Minnesotans with disabilities can work, want to work, and can achieve competitive integrated employment; and each person will be offered the opportunity to work and earn a competitive wage before being offered other supports and services.

Introduction:

The State of Minnesota is committed that all Minnesotans including those with disabilities have a wide range of employment opportunities within the general workforce. The Minnesota Employment First Policy guides state agencies in their planning, decision making, implementation, and evaluation of services and supports for Minnesotans with disabilities to make employment the first and expected option considered. The Minnesota Employment First Policy provides state agencies with:

- A clear statewide vision supporting transformational change and a long-range goal of working-age youth and adults with disabilities participating in the workforce at levels similar to their peers who do not have disabilities
- A guiding vision to increase public and business expectations about employing the abilities and capacities of all people with disabilities to work in the right job with the right level of support
- A policy framework that guides present and future decisions related to people with disabilities who receive public services
- Guidance to provide clarity on how this policy will be applied across state agencies
- Instruction to act to develop and implement plans to ensure the Employment First principles and informed choice are integrated into new and existing employment-related policies, services and supports for people with disabilities.

Vision, Values and Guiding Principles:

Vision

The Employment First Policy envisions a future where all people with disabilities can achieve competitive, integrated employment. Competitive employment means:

- Full-time, part-time, or self-employment with and without supports
- In the competitive labor force
- On the payroll of a competitive business or industry

- Pays at least minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by workers without a disability.

This policy increases options and choices for people with disabilities by aligning policies, funding practices and collaborative efforts among state agencies. This will help people who choose to work to enter an integrated, competitive workforce or become self-employed.

Values

Three core values ground the Minnesota Employment First Policy. These core values reflect that people with disabilities, including people who have complex and significant disabilities:

- Want to work
- Can be competitively employed or self-employed, earning at least the minimum wage and benefits
- Should be fully integrated physically, functionally and socially within the workplace.

Guiding Principles

1. Integrated, competitive employment is the first and expected service option.
2. Employment is prioritized as an outcome of services and supports.
3. Employment and support services are grounded in informed choice practices, which include but are not limited to:
 - Community-based experiences on which to base decisions
 - Knowledge about the potential impact of employment on their quality of life
 - Information and support to understand their options related to employment
 - Understanding of how work affects public benefits and resources so that work can be part of the plan without fear of losing essential benefits.
4. Individuals with disabilities have increased control and direction over services and supports.
5. Effective interagency coordination will be demonstrated in the delivery of innovative employment, education, and support services, and improved employment outcomes.
6. State agencies will be accountable for monitoring and reporting progress and for establishing interagency quality assurance procedures.

Call to Action: Implementation Requirements for the Minnesota Departments of Education, Employment and Economic Development, and Human Services

1. State agencies are required to use these guiding principles to develop agency plans for transformational changes in the provision of employment services and supports for people with disabilities, including:
 - Identification and provision of supports and services to achieve employment
 - Incorporation of additional standards that adhere to Employment First principles into regulations, quality assurance, and agency program monitoring

- Expansion and promotion of the use of promising and best practices for employment supports.
2. The Minnesota Departments of Education, Employment and Economic Development and Human Services (MDE, DEED and DHS) must define, operationalize, and document a process to ensure a person-centered approach and informed choice is used without conflicts of interest or bias to work. Informed choice must include community exploration and experienced-based opportunities.
 3. After an informed choice process has been followed and if a person chooses not to work, then, documentation will be maintained by the appropriate agency of the reason(s) for the decision. This will help MDE, DEED and DHS determine what, if any, changes are necessary to address barriers to employment that resulted in the choice not to work. People with disabilities may choose to reconsider their decision at any time. Additionally, MDE, DEED and DHS must establish a process to regularly review with the person his/her decision regarding work and any options to address barriers that may have existed in the past.
 4. MDE, DEED and DHS will work together to align programs, funding and policies to support people with disabilities to choose, secure and maintain competitive and self-employment, including:
 - Provision of information, technical assistance and training opportunities to adopt policies and promising processes that improve the employment outcomes of working age youth and adults across educational and adult service systems
 - Incentives for innovation that increase competitive employment in the general work force
 - Expanding the flexibility in funding and services to increase competitive employment outcomes.
 5. MDE, DEED and DHS must develop uniform data collection and reporting procedures, and make public data that documents implementation of the Employment First Policy, including outcome measures.

Successful implementation of this policy will be demonstrated by increased competitive employment of persons with disabilities in the most integrated community work setting.

“The opportunity and freedom for meaningful choice, self-determination, and increased quality of life, through: opportunities for economic self-sufficiency and employment options; choices of living location and situation, and having supports needed to allow for these choices.” ---Subcabinet Vision Statement – MN Olmstead Plan (p. 21 plan version with proposed modification July 10, 2014).

Olmstead Plan Employment Goal: People with disabilities will have choices for competitive, meaningful, and sustained employment in the most integrated setting (p. 40 of July 10, 2014 plan version)

Minnesota will adopt an Employment First Policy and use these principles in service design and delivery... By September 30, 2014, the state will adopt an Employment First Policy (page 42 of the July 10, 2014 plan version, Employment Section under Action two: Align policies and funding)



Oral Health Program



Minnesota Oral Health Plan

Advancing Optimal Oral Health for All Minnesotans

2013-2018

January 2013

“The past half century has seen the meaning of oral health evolve from a narrow focus on teeth and gingiva to the recognition that the mouth is the center of vital tissues and functions that are critical to total health and well-being across the life span.”

Former United States Surgeon General Dr. David Satcher
Oral Health in America: A Report of the Surgeon General (2000)

Minnesota Oral Health Plan 2013-2018
Minnesota Department of Health
Oral Health Program
PO Box 64882
85 E. Seventh Place
St. Paul, MN 55164-0882

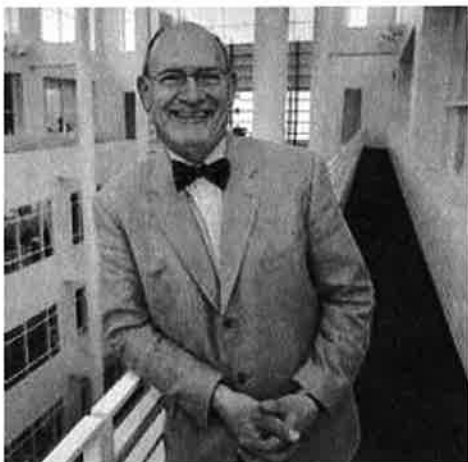
Phone: 651-201-3749
Email: health.oral@state.mn.us
www.health.state.mn.us/oralhealth

Funding was made possible by grants to support statewide oral health related activities from the Health Resources and Services Administration, Award T12HP1465, and Centers for Disease Control Prevention, Cooperative Agreement Grant Number 5U58DP0011579.



MISSION: To promote, protect, maintain and improve oral health because it is integral to the health of all Minnesotans.

VISION: Advancing optimal oral health for all Minnesotans.



Dear Minnesotans,

It is a pleasure to present the state's first ever Minnesota Oral Health Plan. This strategic plan recognizes that oral health and overall health are inextricably linked. This plan also marks a turning point in how MDH will integrate oral health into its overall mission.

While Minnesotans enjoy good oral health when compared to the nation, still far too many residents needlessly suffer poor oral health because of the lack of routine oral health care, especially low-income children and adults, people of color, and the elderly. Oral health is fundamental to our quality of life; it impacts other chronic illnesses; affects children's growth and development and ability to learn; determines what foods we eat and whether we smile; and our very sense of self-worth. Untreated oral disease can even lead to death.

Fortunately, this plan identifies both the barriers to and solutions for improving the oral health of Minnesotans. Among the most effective solutions are school-based dental sealant programs and fluoridated water. Another promising solution includes increasing the public's access to affordable dental care through new workforce models like collaborative practice agreements between dentists and hygienists. These innovative approaches to improve oral health care are being rounded out by the cutting-edge work of establishing "health care homes" whereby a patient's total care is coordinated among dental, medical and behavioral health care providers across the health care system.

The Minnesota Oral Health Plan was developed through the hard work of MDH's Oral Health Program staff and our many partners and stakeholders who spent countless hours determining the state's burden of oral disease and the goals, objectives and strategies for reducing these diseases. One of our key collaborators in this endeavor has been the Minnesota Oral Health Coalition, which represents a cross-section of public health, oral health providers and payers, and educational and professional organizations. We thank all of these partners for making the Minnesota Oral Health Plan possible.

As we move forward to tackle the obstacles to oral health, these partnerships will be more critical than ever. We hope that as you review the strategies in this plan, you will identify areas that your organization will help support. By working together, we may indeed *achieve optimal oral health for all Minnesotans*.

Best of health,

Edward Ehlinger, MD, MSPH
Commissioner of Health

Acknowledgements

Thank you to our partner organizations and service providers:

3M
 Apple Tree Dental
 Century College
 Children's Dental Services
 Children's Dental Health Services
 Community Dental Care
 Delta Dental
 Early Childhood Dental Network
 HealthPartners
 Just Kids Dental
 LPaC Alliance, Halleland Habicht
 Minnesota Analysis and Development
 Minnesota Dental Association
 Minnesota Dental Hygienists' Association
 Minnesota Department of Human Services
 Minnesota Oral Health Coalition
 Normandale Community College
 Northern Dental Access Center
 Ronald McDonald House Charities
 School Nurse Organization of Minnesota
 University of Minnesota – School of Dentistry
 Smiles Across Minnesota

Thank you to the Minnesota Oral Health Data Advisory Group:

Behavioral Risk Factor Surveillance System
 Center for Health Statistics, Minnesota Student Survey
 Environmental Impacts Analysis Unit, Birth Defect Information System
 Environmental Health Division, Water Fluoridation Reporting System
 Minnesota Cancer Surveillance System
 Minnesota Department of Health
 Office of Rural Health and Primary Care, Health Workforce Database
 Pregnancy Risk Assessment Monitoring System

Special thanks to the efforts of the:

Transition Task Force
 Work Group Chairs:
 Access to Care Work Group
 Prevention and Education Work Group
 Workforce Work Group

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Introduction

Over the past 50 years, the significant improvement in oral health of Americans is a public health success story, with community water fluoridation being one of the most effective public health initiatives of the twentieth century. Oral health is integral to overall health, as former United States Surgeon General Dr. David Satcher concluded in the groundbreaking report *Oral Health in America: A Report of the Surgeon General* (2000).

The report emphasizes that the mouth not only reveals signs of poor nutrition and diseases such as infections, immune disorders, injuries, and certain cancers, but research has shown associations between chronic oral infections and heart and lung diseases, stroke, low-birth-weight, premature births, as well as diabetes. Among the top risk factors for oral disease are high-sugar beverages and foods (which also contribute to obesity), along with tobacco and alcohol. Conversely, a healthy mouth can provide protection against chronic infection and disease.

Dr. Satcher also called for action to promote better access to oral health care for all Americans, especially vulnerable

populations found to be at greatest risk for severe medical complications resulting from a lack of proper oral care and treatment.

There are several ways in which people suffer from pain and discomfort because of poor oral health: tooth decay; oral and craniofacial diseases; periodontal (gum) diseases; cleft lip and palate; oral and facial pain syndromes; traumatic injury; and oral and pharyngeal (mouth and throat) cancers. Many of these conditions and diseases are preventable.

Minnesotans in general enjoy a high level of oral health, ranking top in the nation for prevention and treatment of oral disease among third graders. In 2011, Minnesota also received a grade 'A' from The Pew Center on the States for achieving six of the eight oral health benchmarks, including enacting policies to improve access to dental care for children on Medicaid.

Despite these high ranks, there is room for improvement, especially among underserved populations who bear the brunt of oral diseases such as children and adults living in poverty, people of

color, and the elderly. Through a Basic Screening Survey conducted in 2010, Minnesota children of color were found to be 12 percent more likely to experience caries (decay) and 7 percent more likely to have untreated caries when compared to their white peers.

The poorest adults, defined as making \$15,000 or less yearly, were three times less likely to visit a dentist in the past year than adults making \$50,000 or more. And among the elderly, a person without a high school degree was 10 times more likely to have all his or her teeth extracted than someone with a college degree.

Furthermore, the shortage of dental professionals serving high-risk populations combined with insufficient dental insurance is straining the health care system. With few means for affordable dental care, people seeking treatment for acute dental needs are forced to seek out the only option they have: hospital emergency department care. In Minnesota, the cost for hospital-treated "non-traumatic" conditions that could have been treated by a dentist was \$148 million from 2008 to 2010.

To address these disparities and gaps in care, we must support the expansion of proven community-based disease prevention strategies across the state such as school-based dental sealant programs and ensuring optimal water fluoridation levels. Equally important is improving access to routine oral care through a more diverse dental workforce. Recruiting people from diverse backgrounds into the field of dentistry and providing incentives for working in rural areas will cultivate a workforce with the capacity to meet the needs of the underserved. In turn, providing more affordable dental care through new dental professional classifications such as dental therapists and advanced dental therapists and innovative workforce models like “collaborative agreements” between dentists and hygienists are increasing the public’s options for better access to dental providers.

Additionally, transforming patient care through “health care homes” whereby dental and primary care providers work together to deliver integrated care to Minnesotans, and especially our most vulnerable populations, stands to significantly improve oral health while tamping down health care

costs. The sooner oral health problems are diagnosed and treated, the less chance they will have to develop into more expensive chronic conditions that threaten people’s lives and quality of life. While this health care model shows great promise, much work still needs to be done to raise the awareness among health care providers and policy makers about the social and environmental factors that are largely responsible for health inequities. Without full recognition for communities’ economic and cultural needs, serious barriers to health will persist.

Minnesota’s First Oral Health Plan

In 2009, the Minnesota Department of Health established a dedicated Oral Health Program to address disparities in oral health and to develop and implement the state’s first Minnesota Oral Health Plan. The following plan is a result of a collaborative effort between the Minnesota Department of Health and many community partners. It is Minnesota’s first comprehensive blueprint for improving oral health and reducing the prevalence of oral disease and provides a five-year strategic plan spanning from 2013 to 2018.

To establish a baseline to monitor the state’s progress and focus resources, MDH carried out the first open-mouth screening of children in third grade through the Association of State & Territorial Dental Directors Basic Screening Survey in 2010. The Basic Screening Survey is based on a standardized set of data tools designed to collect:

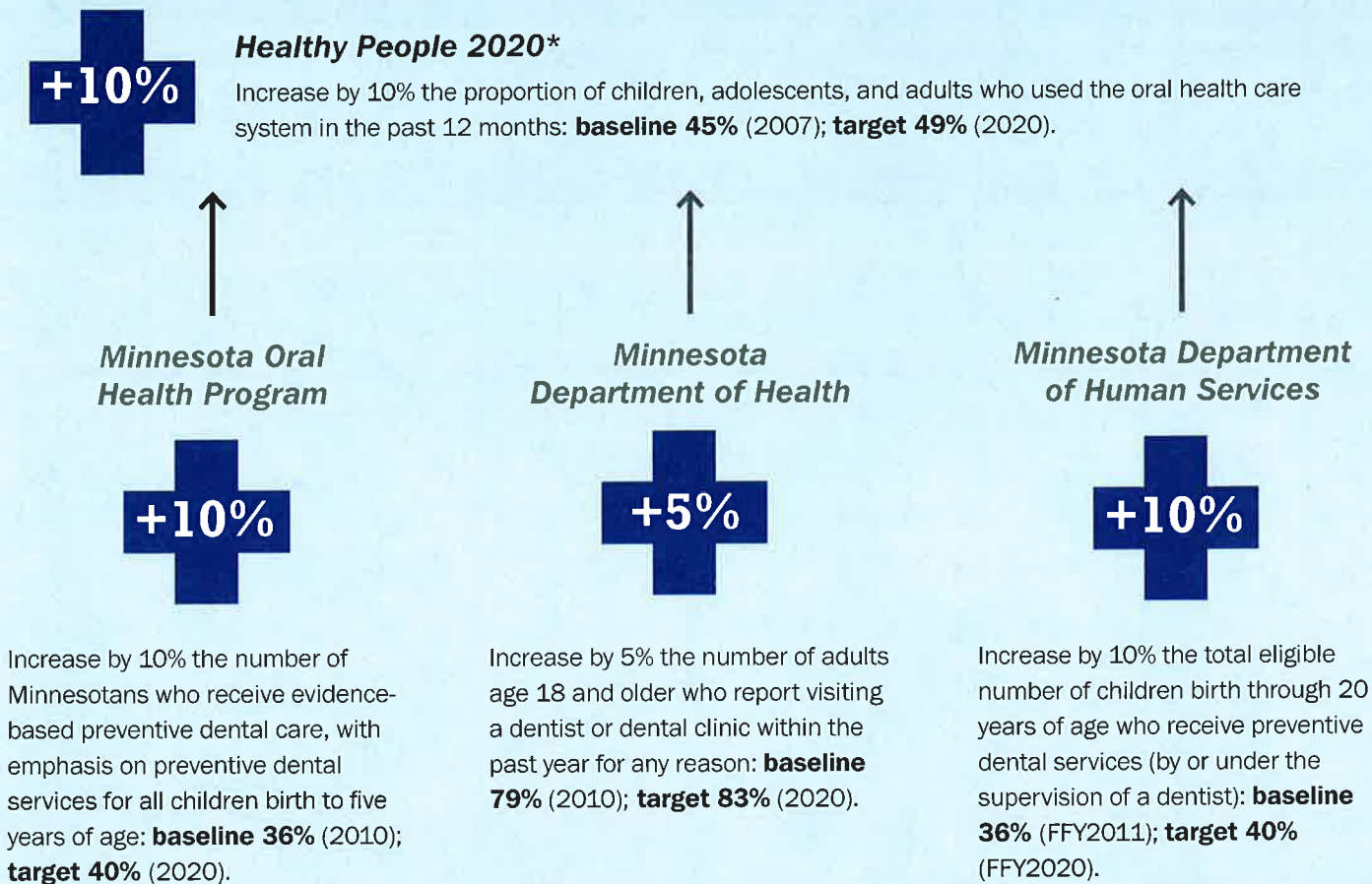
- Information on the observed oral health of participants.
- Self-reported or observed information on age, gender, race and Hispanic ethnicity.
- Self-reported information on access to care for preschool, school-age and adult populations.

With these data in hand, Oral Health Program staff convened dentists, dental hygienists, educators, representatives from health plans and consumer groups, and other stakeholders to inform and prioritize efforts to improve Minnesotans’ oral health. That teamwork produced the underpinnings of the Minnesota Oral Health Plan’s top priority areas and goals as seen below, along with related objectives and strategies (see Appendix A for the full list).

Minnesota Oral Health Plan: Priority Areas and Goals

Priority Areas	Goals
1. Public Health Infrastructure	Goal 1: Minnesota’s oral health infrastructure is stable and sustained.
2. Prevention and Education	Goal 2: Strategies are implemented that reduce oral disease and mitigate risks. Goal 3: Oral health literacy is increased across all ages and cultures.
3. Health Care Integration and Access to Oral Health Care	Goal 4: Professional integration is enhanced between oral health care providers and other providers in the broader health care system. Goal 5: Access is increased to preventive, restorative, and emergency oral health care services. Goal 6: The dental workforce is prepared for and addresses the oral health needs of all Minnesotans.
4. Surveillance	Goal 7: Access to population statistics, population-level oral health surveillance information, and aggregate data on oral health indicators is readily available to all.

Measuring Success: Leading Health Indicators



*Healthy People 2020 provides public health organizations across the nation with an evidence-based framework to improve the nation's health by setting 10-year benchmarks and monitoring progress on various health indicators.

Measuring Success

Healthy People 2020 provides an evidence-based framework to improve the nation's health by setting 10-year benchmarks and monitoring progress on selected health indicators. Significantly, Healthy People 2020 was the first time the framework included oral health as one of its leading health indicators (LHI).

This recent shift among the top echelon of public health leadership in emphasizing oral health and recognizing its critical role in general health presents an exciting opportunity for Minnesotans: the opportunity to enjoy a higher quality of life, one without needless pain and suffering and filled with broad, confident smiles.

As the Minnesota Oral Health Program moves forward to implement strategies to reduce the prevalence of oral disease, it will measure its success against Healthy People 2020's LHI for the nation:

Increase by 10 percent the proportion of children, adolescents, and adults who used the oral health care system in the past 12 months: **baseline 45 percent** (2007); **target 49 percent** (2020).

Three complementary indicators have been identified by the Minnesota Oral Health Program to measure progress locally. These indicators are from the Minnesota Oral Health Plan, Minnesota Chronic Disease and Injury Plan, and Minnesota Department of Human

Services. Aligning strategies around indicators that address oral health in different population groups can move us closer to the Healthy People 2020 target.

The Minnesota Oral Health Program's oral health indicator is:

Increase by 10 percent the number of Minnesotans who receive evidence-based preventive dental care, with emphasis on preventive dental services for all children birth to five years of age: **baseline 36 percent** (2010); **target 40 percent** (2020).

While this indicator is focused on young children, it complements MDH's statewide strategic health improvement framework, Healthy Minnesota 2020: Chronic Disease

and Injury, which also includes the following oral health indicator for the first time ever:

Increase by 5 percent the number of adults age 18 and older who report visiting a dentist or dental clinic within the past year for any reason: baseline 79 percent (2010); target 83 percent (2020).

MDH's and the Oral Health Program's work also correspond with the Minnesota Department of Human Services' initiative to increase access to oral health care for low-income children

and young adults eligible for Medicaid. This initiative seeks to:

Increase by 10 percent the total eligible number of children birth through 20 years of age who receive preventive dental services (by or under the supervision of a dentist): baseline 36 percent (FFY2011); target 40 percent (FFY2020).

MDH's Oral Health Program has been charged with convening stakeholders to implement strategies and evaluate progress as outlined in the Minnesota Oral Health Plan. To ensure forward

momentum, program staff are working closely with key organizations such as the Minnesota Oral Health Coalition, which is composed of a broad cross-section of professionals representing dental, health care, educational, business, public health and non-profit sectors. It is only through this broad collaborative effort that we will be able to truly *advance optimal oral health for all Minnesotans.*

Minnesota Oral Health Highlights

Children

- 55% of 3rd graders experienced dental decay (caries experience) (2010)
- 18% of 3rd graders had untreated cavities (2010)
- Children of color were 12% more likely to experience caries and 7% more likely to have untreated caries as compared to white children (2010)
- Minnesota's 64% school-based sealant rate far exceeds the national average of 32% (2010)
- 59% of children with Medicaid coverage did not receive any dental services by or under the supervision of a dentist during Federal Fiscal Year 2011.
- 403 cases out of 361,109 births or 1 in 1,000 births had an orofacial defect such as clefting (2005-2009)

Adults and the Elderly

- 79% of adults 18 years and older reported visiting a dentist or dental clinic within the past year (2010)
- The poorest adults (<\$15K) were 3 times less likely than their most affluent peers (\$50K+) to visit a dentist in the past year (2010)
- Natural teeth extractions fell by 50% for older adults as compared to 36% drop in the national rate (1999-2010)
- An older adult without a high school diploma was 10 times more likely to have all his/her teeth extracted than one with a college degree (1999-2010)

Cancer of the Oral Cavity and Pharynx

- Minnesota incidence rate is 11.2/100,000 population for oral and pharyngeal cancers compared to 10.9/100,000 population nationally (2004-2008)
- Minnesota mortality rate for oral and pharyngeal cancers is 2.0/100,000 population compared to 2.5/100,000 nationally (2004-2008)

- Oral and pharyngeal cancer is highest (23%) among Minnesota's American Indian men living on or near Indian reservations (2004 and 2008)

Emergency Department Visits and Hospitalizations

- Hospital treated non-traumatic dental emergencies – which could have been treated by a dentist – cost nearly \$148 million from 2008-2010

Community Water Fluoridation

- 78% of Minnesotans received community fluoridated water compared to 64% of people across the nation (2010)
- Nearly all (99%) Minnesotans who were connected to public water supplies received fluoridated drinking water (2010)

Dental Workforce

- 47% of dentists were 55 years or older (2009-2010)
- Of the 3,908 dentists who renewed their Minnesota license, only 26% were practicing in rural areas (2010)
- Just over half (53%) of practicing dentists submitted at least one dental claim for patients on public programs to the Minnesota Department of Human Services (2010)
- Only 7% of dentists and 6% of hygienists work with a "collaborative agreement" (2009-2010)
- Only 23% of dentists are female (2010)
- Only 6% of dentists are people of color (African American, Native American, Asian or multiracial); 2% are Hispanic (2010)
- In 2009, Minnesota signed into law two new types of "mid-level" dental providers: dental therapist and advanced dental therapist



The Burden of Oral Disease in Minnesota

Optimal oral health allows us to speak, smile, smell, touch, taste, chew, swallow, cry out and have facial expressions without pain or discomfort. Conversely, oral diseases seriously affect our quality of life, diminishing our health, ability to enjoy food, smile and speak confidently, and the ability of children to focus on school learning and adults on their workplace jobs. Oral disease and infection can also lead to death.

Over recent decades, tremendous advances have been made in developing effective treatment and prevention programs such as dental sealants and fluoridated water. Yet, far too many Minnesotans needlessly suffer from tooth decay and tooth loss, gum disease, injuries, cancer and birth defects. Both nationally and in Minnesota, those who bear the greatest burden are low-income children and adults, people of color, and people with disabilities.

Barriers to oral health care, while still poorly understood, may include economic factors such as inadequate insurance coverage and an insufficient number of dental providers accepting public program patients. Other factors include a possible shortage of dental providers, especially in rural locations; overly-restrictive supervision of dental professionals who

could otherwise provide services for people in need; transportation issues; dental health literacy; and cultural and language barriers.

The Minnesota Oral Health Plan provides a multitude of strategies for addressing many of the barriers experienced by vulnerable populations. The following account provides an overview of where the greatest oral health needs are among Minnesotans.

Children

Even though dental caries (tooth decay) is preventable, it is the most common chronic childhood disease and is five times more common than asthma. If unchecked, caries can result in the destruction of tooth structure, inadequate tooth function, unsightly appearance, pain, infection, and can affect nutrition, growth and weight gain, and can result in death. Nationally, students ages five to 17 years miss more than 1.6 million school days due to acute dental problems. Children from low-income families are nearly 12 times more likely to have restricted-activity days (e.g., missing school) than children from families with higher incomes due to dental problems. To assess the status of oral health

among Minnesota's children, in 2010 MDH conducted the state's first baseline "open mouth" Basic Screening Survey (BSS) on students in third grade, the time when most children would have had sealants placed on a first molar by a dental provider. The BSS was conducted at 40 randomly selected public schools with a third-grade classroom size of 10 or more students. A total of 1,766 third graders were observed for the presence of sealants (on at least one molar) on treated and untreated cavities. The 2010 BSS results, combined with Healthy People 2010 (HP2010) health status indicators, Healthy People 2020 (HP2020) targets, and other measures can be used to monitor the state's progress in reducing oral diseases.

Even though dental caries (tooth decay) is preventable, it is the most common chronic childhood disease and is five times more common than asthma.

Data on previous caries experience and the presence of untreated caries can be used to better target future prevention and treatment efforts. When compared to the nation, Minnesota children fared well with only 18 percent of children surveyed having untreated caries, exceeding both the national HP2010 status and the HP2020 target of 26 percent (Figure 1).

However, 55 percent of Minnesota third graders had experienced caries, which was slightly higher than the nation (53 percent) for children six to eight years years (Figure 2). To meet the target for HP2020, Minnesota has to reduce caries experience in children by 6 percent.

In general, lower-income populations bear a disproportionate burden of oral diseases and conditions. Using a school's Free or Reduced Price Lunch (FRL) eligibility statistics as an indication of socio-economic status, the 2010 BSS data confirms that low-income children were far more likely to have dental caries experience than their more affluent peers. As seen in Figure 3, caries experience and untreated caries rise as income declines: the poorest children (>75% FRL) were almost one and a half times more likely to experience tooth decay and almost three times more likely to have their tooth decay go untreated than students at more affluent schools.

Likewise, race and ethnicity can be risk factors for compromised oral health. Minnesota children of color (non-white, non-Hispanic) were 12 percent more likely to experience caries and 7 percent more likely to have untreated caries as compared to their white counterparts (white non-Hispanic) (Figure 4). Hispanic children were almost on par (1 percent higher) with white children for untreated caries.

A majority of Minnesota third graders (64 percent) showed evidence of dental sealants on at least one permanent molar, which is two times higher than the national rate (32 percent) and supersedes the HP2020 goal of 28

FIGURE 1
Untreated Caries in Children, Comparison of HP2010, HP2020 with MN Data

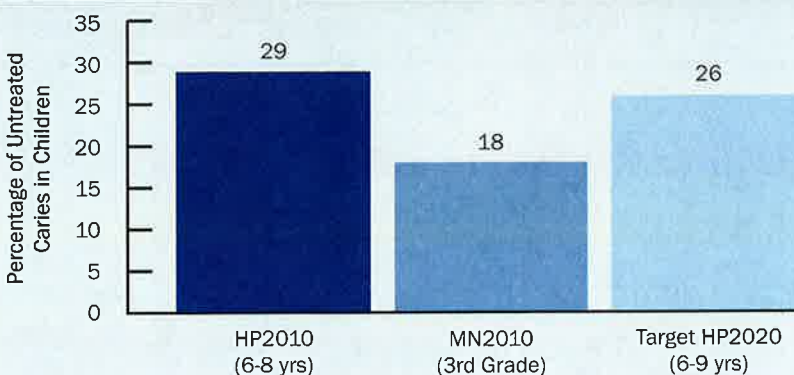


FIGURE 2
Dental Caries Experience in Children Comparison of HP2010, HP2020 with MN Data

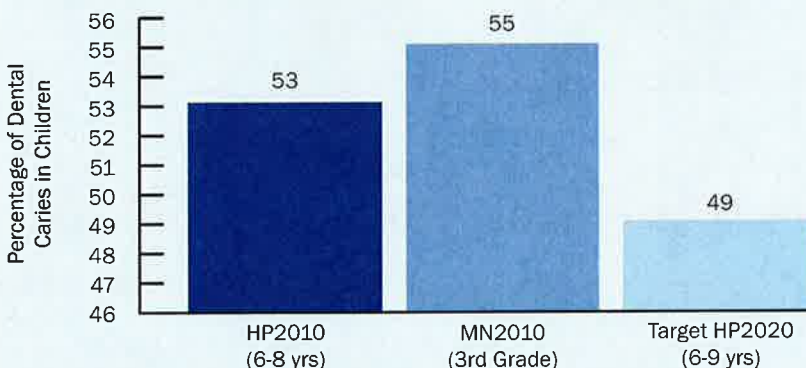
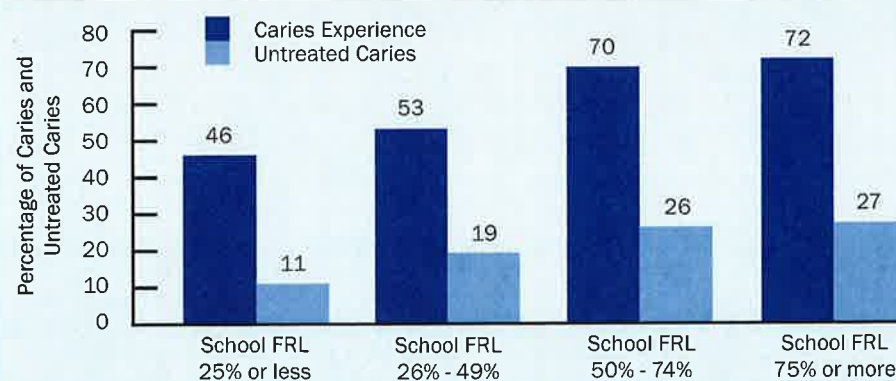


FIGURE 3
Caries Experience and Untreated Caries in Students in 3rd Grade by Free and Reduced Lunch Eligibility in Minnesota - BSS2010



percent (Figure 5). Troubling though, is Minnesota's high sealant rate drops steadily by income to the low rate of 42 percent when we look at the poorest children (>75% FRL). The dental sealant

prevalence rate is lowest among Hispanic children both nationally and locally, with the gap between Hispanic and white children being almost twice as big at the national level than in Minnesota.

When comparing rural versus urban areas, caries experience is 6 percent more prevalent among rural children (57 percent) than their urban counterparts (51 percent); untreated caries is 5 percent higher among rural children (20 percent) as compared to urban children (15 percent). Sealant rates, however, are nearly identical at 64 percent. This bright spot may point to the success of school-based sealant programs that focus on reaching children who do not have adequate access to dental care.

Adolescents

While Minnesota does not currently monitor the oral health status of adolescents, national data tell us that 56 percent of adolescents (15 year olds) had experienced caries, according to an HP2020 report. Data also show a higher prevalence of caries experience in females (60 percent) than males (53 percent). The national HP2020 target is to reduce the proportion of adolescents (13 to 15 years) with dental caries experience in their permanent teeth to 48 percent.

Adults

Most adults have suffered from tooth decay and gum disease, which are the most common oral diseases affecting both health and productivity. Nationally, 164 million hours of work are lost annually due to dental problems, with adults in lower paying jobs losing two to four times more work hours than higher-paid workers.

Nationwide, 28 percent of adults ages 35 to 44 years and 18 percent of adults age 65 years and older had untreated caries. In Minnesota, 79 percent of adults 18 years and older reported having visited a dentist or dental clinic within the past year. Despite this high rate, significant disparities exist across income levels. Minnesota's poorest adults (<\$15K) were three times less likely than their most affluent counterparts (\$50K+) to visit a dentist in the past year (Figure 6). It

FIGURE 4

Caries Experience and Untreated Caries in Students in 3rd Grade by Race, Minnesota - BSS 2010

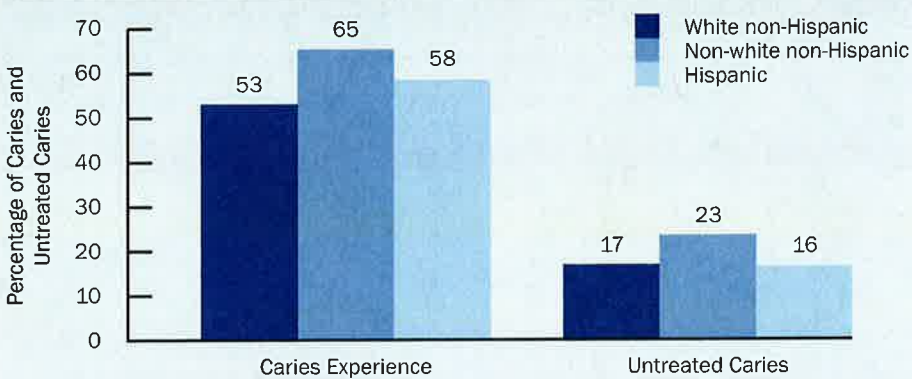


FIGURE 5

Minnesota and National Population Prevalence Estimates for Dental Sealant

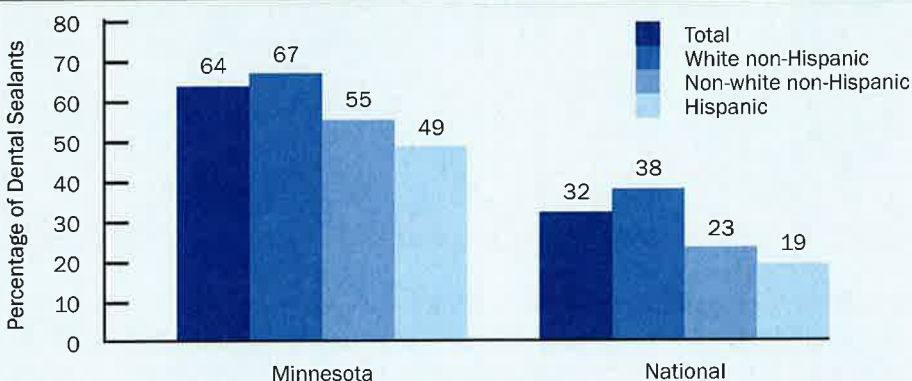
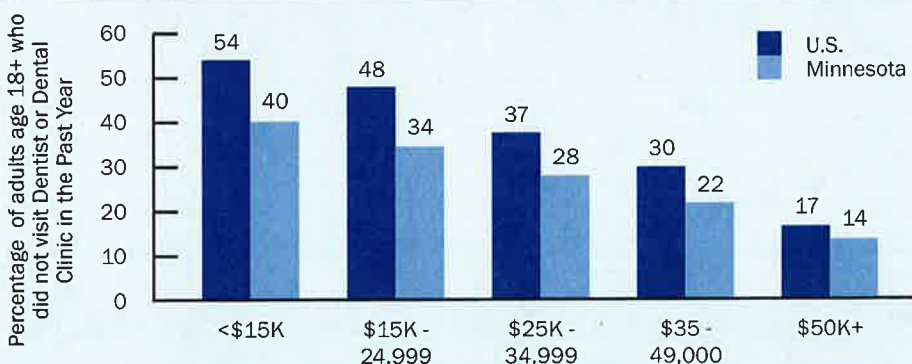


FIGURE 6

Adults 18+ Who did not Visit a Dentist or a Dental Clinic in the Past Year by Income - BRFSS 2010



is possible this disparity exists because public insurance programs provide limited dental benefits for low-income adults and eligible recipients may not be knowledgeable of, or seek out, these programs.

According to the Centers for Disease Control, almost half of all adults in the U.S. are affected by gum disease (periodontal disease). Periodontal disease is a bacterial infection that affects the gums and bone supporting

Through the benefits of water fluoridation and fluoride toothpastes, adults 60 years and older represent the first generation where the majority will keep their natural teeth over their lifetime.

the teeth. Gingivitis is the mildest form of periodontal disease and is often caused by inadequate oral hygiene. Gingivitis is reversible (health can be restored) with professional treatment and good oral home care. Gum disease can cause tooth loss if left untreated. Cigarette smoking is one of the leading risk factors of gum disease and inhibits the healing process; gum disease prevalence is three times higher in smokers than non-smokers.

Elderly

Historically, the elderly have been at higher risk for poor oral health due to their lack of preventive care when they were young and the lack of Medicare dental benefits for older adults. However, through the benefits of water fluoridation and fluoride toothpastes, adults 60 years and older represent the first generation where the majority will keep their natural teeth over their lifetime.

Both nationally and in Minnesota, the number of older adults (65+) missing all their natural teeth declined significantly in the past decade. From 1999 to 2010, natural teeth extractions fell by 50 percent for older Minnesotans, much higher than the national rate of a 36 percent drop (Figure 7). As of 2010, 17 percent of adults 65+ years across the nation had all their natural teeth extracted compared to 11 percent of Minnesotans.

FIGURE 7

Adults Aged 65+ Who Have Had All Their Natural Teeth Extracted BRFSS Data 1999 - 2010

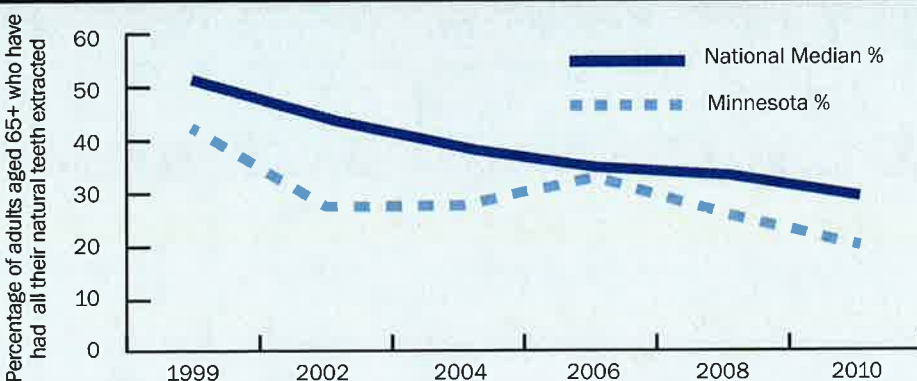
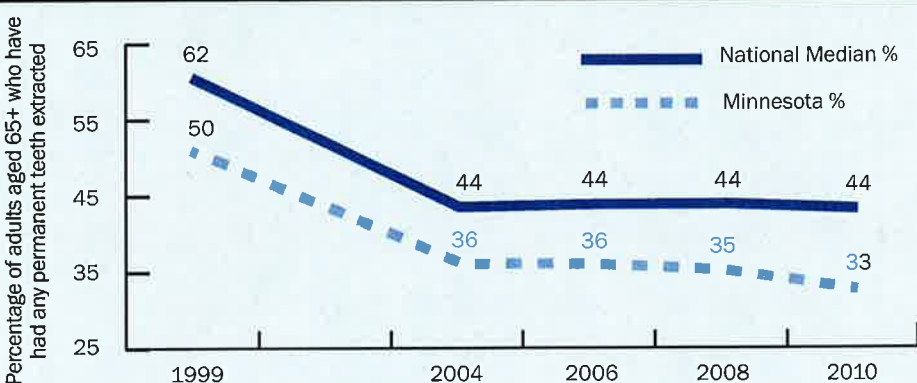


FIGURE 8

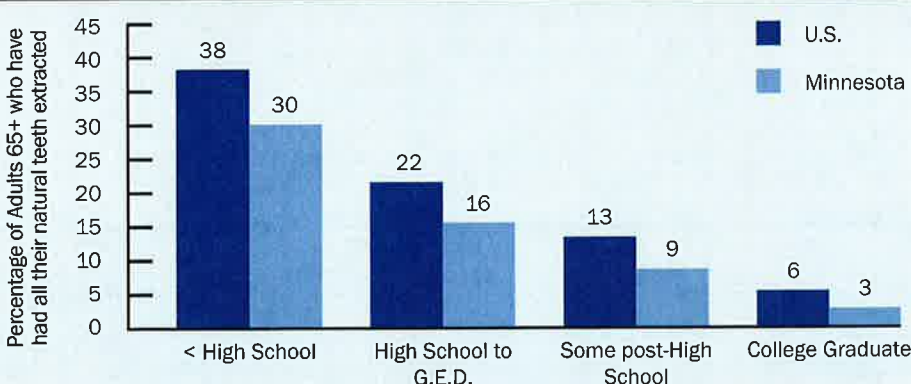
Adults Aged 65+ Who Have Had Any Permanent Teeth Extracted BRFSS Data 1999 - 2010



Note: Data between 1999-2004 is unavailable.

FIGURE 9

Adults Aged 65+ Who Have Had All Their Natural Teeth Extracted by Education Level, BRFSS Data 2010



Between 2004 and 2010, the rate of older Minnesotans who had any permanent teeth extracted declined slightly from 36 to 33 percent as national trends remained stagnant at 44 percent (Figure 8). While

these downward trends are encouraging, with no Medicare dental benefits, older adults on fixed incomes are less likely to seek oral health care, compromising their quality of life and health.

Given persistent disparities, the lower a person's educational level the more likely his or her natural teeth will be extracted. In Minnesota, an older adult without a high school diploma was 10 times more likely to have all their teeth extracted than an older adult with a college degree. Minnesota's older adults without a high school degree did fare better than their national counterparts who were 8 percent more likely to have had all their natural teeth extracted (Figure 9).

Cleft Lip and Palate

Cleft lip and/or cleft palate is the fourth most common birth defect in the U.S., affecting about one child per 700 births. Cleft lip and cleft palate occur when a baby's lip or palate do not form properly. These conditions affect a child's ability to breastfeed, eat, talk, and can lead to ear infections, hearing loss, and jeopardize tooth health.

The exact cause of cleft lip and palate is not known; however, it is thought to be caused by a combination of genetic and risk factors such as environmental exposures, the mother's tobacco use and diet while pregnant, as well as certain medications. Women with diabetes have also been shown to be at higher risk of having a child with a cleft lip with or without cleft palate.

Cleft lip with and without cleft palate affects boys twice as much as girls whereas cleft palate without cleft lip affects girls twice as much as boys. In Minnesota, there were 403 cases of orofacial defects such as clefting recorded for births between 2005 and 2009; that is 403 cases out of 361,109 births or one case per 1,000 births. This number is likely higher as this figure is based on access to only 50 percent of birth records.

Women can take steps before and during pregnancy to reduce the risk of having a baby born with birth defects. Such steps include taking a daily multivitamin with

FIGURE 10
Incidence Rates for Cancer of Oral Cavity and Pharynx by Gender
US and Minnesota Populations 1988-2008

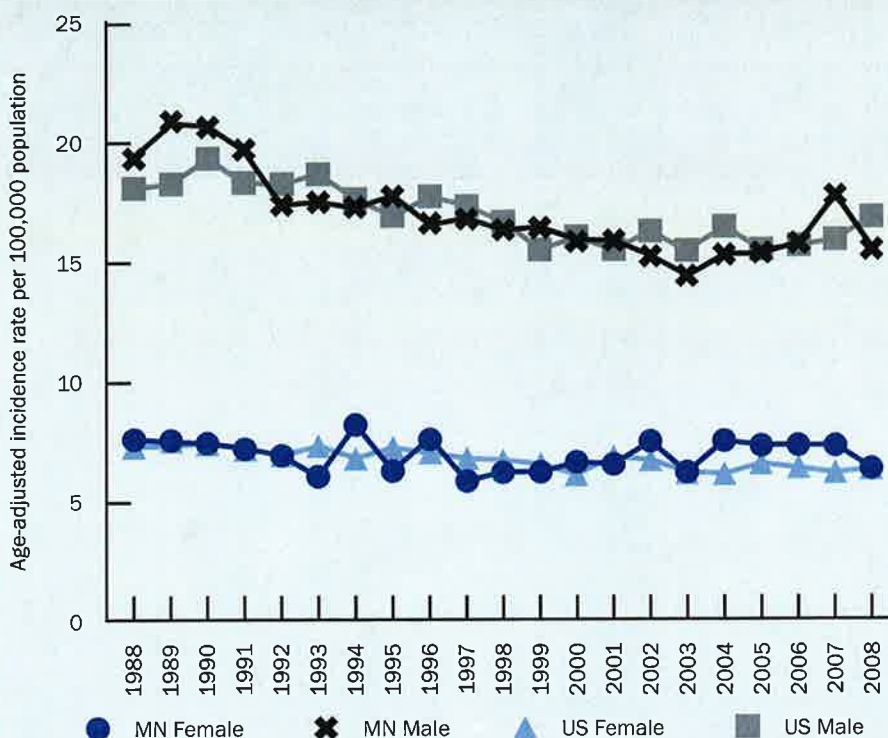
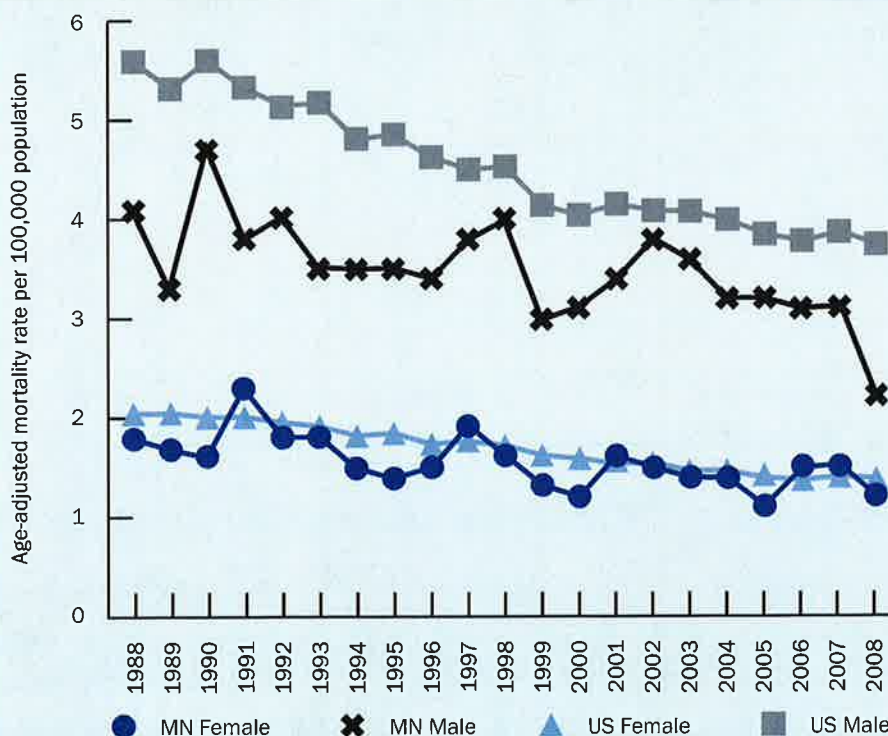


FIGURE 11
Mortality Rates for Cancer of Oral Cavity and Pharynx by Gender
US and Minnesota Populations 1988-2008



folic acid (400 micrograms), not smoking, and not drinking alcohol during pregnancy.

Treatments and rehabilitation begins within the first few months of life. As the process involves multiple specialists and procedures, the average treatment costs for treating cleft lip or cleft palate per patient over their lifetime is estimated at \$250,000.

Cancers of The Oral Cavity and Pharynx

The American Cancer Society estimates that 35,000 people get oral cavity and pharyngeal cancers each year and that 6,800 people will die from these cancers.

These cancers affect males twice as much as females and most often occur in people ages 62 and older. Oral and pharyngeal cancer occur most often on the tongue, tonsils, and minor salivary glands while the remainder are found on the lips, gums, the floor of the mouth, and other sites.

Use of tobacco and heavy consumption of alcohol are widely considered major risk factors for oral and pharyngeal cancer. Recently, exposure to the human papillomavirus (HPV) and infection have been documented as strong risk factors for certain types of oral and pharyngeal cancer, particularly in men. Reducing exposure to tobacco and alcohol is the most effective strategy to lower the risk of developing these types of cancer.

In Minnesota, from 2004 to 2008 an average of 603 cases of oral and pharyngeal cancer were diagnosed – 2.4 percent of all new cancer cases – resulting in 111 deaths and representing 1.2 percent of all cancer-related mortality. The average annual incidence for oral and pharyngeal cancer was 11.2 per 100,000 Minnesotans compared to 10.9 per 100,000 nationally; the mortality rate was 2.0 per 100,000 population, slightly lower than the average for the nation at 2.5. Oral cancer is devastating: although incidence rates

FIGURE 12

Incidence of Cancer of Oral Cavity and Pharynx by Age and Gender, 2004-2008 (Source: MCSS)

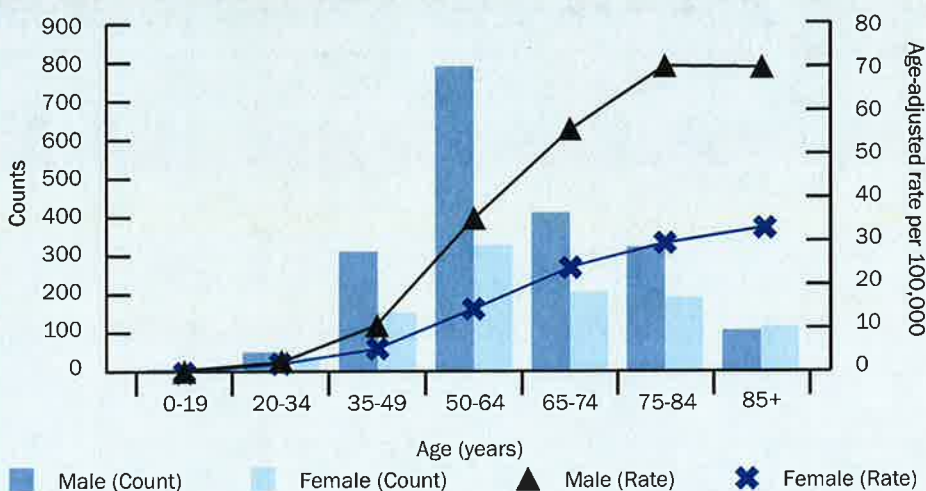
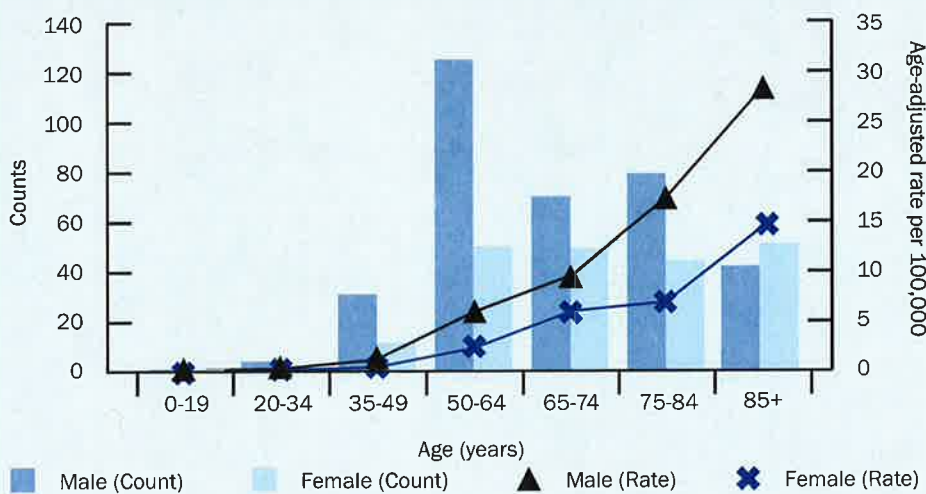


FIGURE 13

Incidence of Cancer of Oral Cavity and Pharynx By Age and Gender, 2004-2008, (Source: MCSS)



are low compared to other cancers, one out of every six cases results in death.

Following national trends, the incidence rate was two times higher (15.9 per 100,000 males) among Minnesota males than females (7.1 per 100,000) (Figure 10). While the Minnesota incidence rate for oral and pharyngeal cancer in women has been stable, the rate among males fell by 20 percent from 1988 (19.6 per 100,000) to 2006 (15.7 per 100,000), with a slight increase in 2007 (17.8 per 100,000).

Oral and pharyngeal cancer mortality rates for the state decreased significantly among males since 1988. Through 2008, rates declined by 27.2 percent in the state for males as compared to national mortality rates. Mortality rates were consistently lower in the state for males (41.5 percent) and females (13.0 percent) as compared to national rates; Minnesota mortality rates for females were steady and closer to the national figures (Figure 11).

Incidence, Mortality and Lifetime Risk by Age, Gender and Race

In Minnesota, the median age for oral and pharyngeal cancer diagnosis for males is 61 years and 65 years for females. The incidence rate in both males and females increases with age and more than two-thirds of the new oral and pharyngeal cancer cases are identified after the age of 74 years (Figure 12).

Incidence rates are two times higher in males than females. Starting in the 20 to 34 year range, both the number of cases and rate of oral and pharyngeal cancer between men and women begins to diverge with the biggest spread occurring between the ages of 50 and 64 years.

Mortality rates for oral and pharyngeal cancer increase sharply after age 64 years in both males and females (Figure 13). As with incidence rates, males have higher oral and pharyngeal cancer mortality rates than females.

Between 2004 and 2008, the occurrence of oral and pharyngeal cancer in Minnesota males was highest (23 percent) among American Indian men living on or near Indian reservations, followed by blacks (21 percent). Among females, American Indian females (12 percent) had the highest incidence rate.

Interestingly, mortality rates were higher in Asian/Pacific Islander populations.

The average, annual incidence rate among Minnesota populations living on or near Indian reservations was 17 percent higher (23 new cases/100,000 population) than among American Indians (19 new cases/100,000 population) living outside these areas (Table 1).

Oral Diseases and Other Health Conditions

Over the past few decades, the rise in chronic disease has emerged as a major threat to the well-being of Americans, while costing the health care system billions of dollars. These factors reinforce the need for better integration between oral health care and general health care systems and for professionals to raise awareness, maximize resources and streamline efforts in the interest of achieving a common goal: improving the health of Minnesotans.

There is an inextricable relationship between oral and chronic diseases such as diabetes, cardiovascular diseases, stroke, and adverse pregnancy outcomes. Studies have shown that the mouth can signal the presence of diseases in other

parts of the body as well as be a gateway for infections that can spread throughout the body. In addition, people with certain chronic diseases are at an increased risk for developing periodontal (gum) disease, further compromising their health and recovery.

Periodontal disease is often considered the "sixth complication of diabetes." Since people with diabetes are more susceptible to contracting infections, they are more likely to have periodontal disease than people without diabetes. Children with diabetes often develop gum diseases earlier in life than those without diabetes and show more plaque and gingival inflammation than non-diabetic children. Research also suggests the relationship goes both ways, as periodontal disease may make it more difficult for diabetic patients to control their blood sugar, increasing the risk for diabetic complications.

Additionally, while periodontal disease may not be conclusively linked as a causal agent for heart disease and stroke, a strong case can be made that risk factors for periodontal disease are shared with heart disease and stroke.

Another startling fact is that only 22 to 34 percent of women in the U.S. consult a dentist during pregnancy. According

TABLE 1

Oral Cavity and Pharyngeal Cancer Average Annual Rates in Minnesotans by Race and Ethnicity, 2004-2008

Race	Average Annual Incidence Rate		Mortality Rate	
	Male	Female	Male	Female
Contract Health Services Delivery Area*	23%	~	~	~
Blacks	21%	8%	~	~
American Indians	19%	12%	~	~
Non-Hispanic whites	16%	7%	2.8%	1.3%
Asian/Pacific Islanders	15%	8%	7.8%	~
Hispanic all races	6%	7%	~	~
All Races combined	16%	7%	2.9%	1.3%

* Contract Health Services Delivery Area: American Indians living on or near reservation

~ Race-specific rates based on fewer than 10 cases or deaths are not presented.

TABLE 2

Minnesota Indicators for Medicaid Recipients birth through the age of 20 years

	FFY2010		FFY2011	
	Number	Percent	Number	Percent
Total individuals eligible for EPSDT for 90 continuous days*	436,388	---	453,502	---
Total eligible receiving any dental services [any service by or under the supervision of a dentist]	181,137	42%	183,929	41%
Total who did not receive dental services	255,251	58%	269,573	59%
Total eligible receiving preventive dental services [by or under the supervision of a dentist]	162,986	33%	164,432	36%
Total eligible receiving dental treatment services [by or under the supervision of a dentist]	81,942	19%	79,335	17%
Total eligible (only children 6-9 years) receiving a sealant on a permanent molar tooth	14,273	17%	13,590	15%

TABLE 3

Charges for Minnesota Hospital-treated Oral Trauma and Non-Traumatic Conditions, 2008-2010

	Hospital-treated Oral Trauma			Hospital-treated		
	2008	2009-2010	Percent of Increase	Number	2009-2010	Percent of Increase
Mean	\$453.16	\$483	7%	\$1,053.75	\$1,148	9%
Median	\$187	\$208	11%	\$242	\$291	20%
Total	\$11,720,194	\$12,755,259	9%	\$67,378,817	\$80,356,318	19%

to the National Maternal and Child Oral Health Resource Center, most infants and young children acquire caries-causing bacteria from their mothers. Therefore it is essential for health professionals to provide pregnant women and new mothers with appropriate and timely oral education and health care. While the research is not conclusive, many studies have found periodontitis (inflammation of gums) to be associated with poor pregnancy outcomes including preterm birth, low birth weight, or both. What is clear is that oral health programs need to focus more on educating and improving prenatal education and oral health care for pregnant women. These conditions drive home the fact that to maximize a patient's health outcomes, a more coordinated approach is needed among dental and medical providers to use a shared risk factor approach to treat patients.

Oral Health Financing

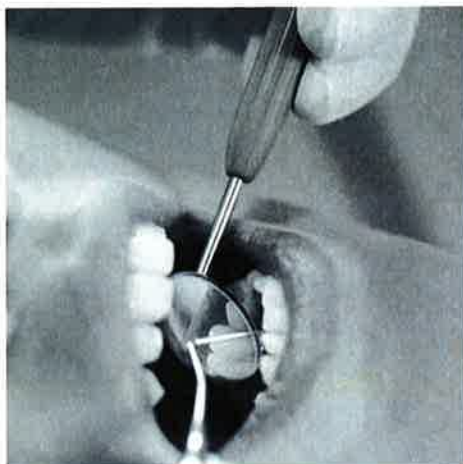
Increasing Use Rates of Public Insurance Programs for Children

Medicaid is a government-sponsored program that provides health and dental coverage for low-income children and vulnerable adults such as those with disabilities and refugees. The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid. It is required in every state and is designed to improve the health of low-income children by financing appropriate and necessary pediatric services. Child and Teen Checkups (C&TC) is the name for Minnesota's EPSDT Program.

C&TC is a comprehensive child health program provided to children and teens from birth through the age of 20 who are enrolled in Medicaid or MinnesotaCare. Comprehensive and periodic screenings are the foundation of the C&TC program and delivered according to a set schedule, ensuring that health problems are diagnosed and treated early before they become more complex and treatment more costly.

Despite these resources, dental services continue to be under used by low-income children. In Federal Fiscal Year 2011 (FFY2011), of the 453,502 eligible EPSDT children in Minnesota, the vast majority (59 percent) did not receive dental services (Table 2). In Minnesota, there was a 4 percent increase in those under 21 years of age eligible for Medicaid from FFY2010 to FFY2011.

Hospital treated non-traumatic dental emergencies — which could have been treated by a dentist — cost nearly \$148 million from 2008-2010.



According to the Pew Charitable Trusts, by 2014 an estimated 5.6 million more children will be eligible to receive Medicaid dental benefits under the Affordable Care Act.

The Centers for Medicare & Medicaid Services (CMS) reviewed the causes of low dental use rates among children on Medicaid and identified the following key barriers:

- Limited availability of dental providers
- Low insurance reimbursement rates to dental providers
- Lack of clear information for beneficiaries about dental health benefits
- Missed dental appointments
- Transportation
- Cultural and language barriers
- Need for consumer education about the benefits of dental care

To address these barriers, CMS developed national objectives in April of 2011 that are in line with the HP2020 oral health goals:

- To increase the rate of children ages one to 20 enrolled in Medicaid or Children's Health Insurance Program (CHIP) who receive any preventive dental service by 10 percentage points over a five-year period; and
- To increase the rate of children ages six to nine enrolled in Medicaid or CHIP who receive a

dental sealant on a permanent molar tooth by 10 percentage points over a five-year period (this goal will be phased in during year two or three of the initiative).

Through its school-based sealant program, MDH's Oral Health Program and the Minnesota Department of Human Services are working together to ensure the CMS objectives are implemented. Currently, the Oral Health Program coordinates five school-based sealant programs and three sealant demonstration sites in at-risk schools (targeting second grade children) throughout the state.

TABLE 4

Profile of Minnesota Hospital Treated Patients with Oral and Dental Conditions, 2000-2010

	Traumatic (2000-2010)		Non-traumatic (2007-2010)	
	Number	Percent	Number	Percent
Total number of cases	32,553	---	136,982	---
Male	18,816	58%	65,340	48%
Female	13,737	42%	71,642	52%
Urban Residents	20,443	63%	74,655	55%
Rural Residents	12,110	37%	62,327	46%
Patients treated in Emergency Dept.	32,293	99%	131,914	96%
Patients hospitalized	260	1%	5,068	4%

Dental Care for the Uninsured and Under-insured

While Medicaid and CHIP provide dental coverage for low-income children, 30 percent of children across the nation with private health insurance do not have dental insurance. Across the nation, disparities between the insured and uninsured are significant: more than 80 percent of low-income children with health insurance (Medicaid and/or private insurance) in 2010 had a dental visit within the past 12 months compared to only half of low-income children without insurance.

In Minnesota, low-income children are eligible to receive dental benefits under Medicaid and low-income adults are eligible for limited dental benefits. According to CMS, in 2009 the national dental services expenditure was \$102.2 billion with 42 percent of that amount spent on out-of-pocket payments. This gap in dental benefits coverage often discourages low-income adults and families from seeking dental care in the first place, which points to the need for more affordable treatment options.

The lack of adequate access to dental care has flooded hospital emergency departments (EDs) with patients suffering from dental problems. The main factors contributing to this situation are insufficient insurance benefits; lack of enough providers accepting uninsured or under-insured individuals; and a shortage of dental care providers. These gaps force children without insurance and uninsured or under-insured adults to seek treatment in EDs. Often, the care offered may result in additional visits and corrective procedures as ED staff are not generally trained in handling oral health problems.

Hospitals diagnose oral conditions as either “oral trauma” or “non-trauma.” Hospital-treated oral trauma often occurs through injuries and includes broken teeth and open wounds in the mouth.

FIGURE 14
Hospital-treated Oral Non-trauma by Age, Minnesota 2000-2010
Rate/100,000 cases

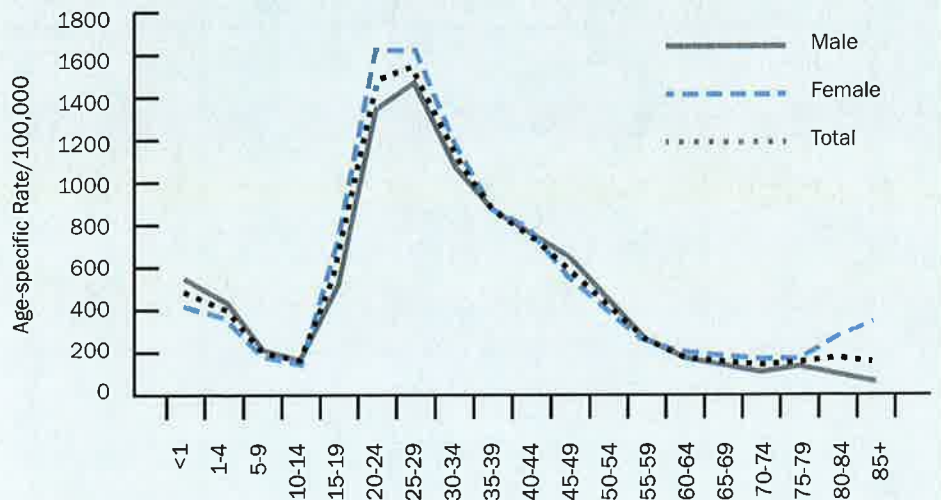


TABLE 5
Minnesota Hospital-treated Oral Non-trauma Rates by Age (2000-2010)

Age group	Rates in Males/100,000	Rates in Females/100,000	Rate differential
20-24	1,345	1,616	20% higher
25-29	1,468	1,610	10 % higher

Non-trauma conditions include tooth development and eruption disorders, abscesses, periodontal disease, gingivitis, dentofacial anomalies, malocclusion and other diseases of the internal structures of the mouth. Non-trauma conditions can best be treated by a dental provider, rather than in a hospital emergency room.

The increased use of EDs for preventive and less severe oral health problems (non-trauma) has serious financial implication to the overall health care system: hospital treatment of non-traumatic conditions cost nearly \$148 million from 2008 to 2010 (Table 3). Within a two-year span in Minnesota, the average hospital charges increased significantly for both traumatic (7 percent)

and non-traumatic (9 percent) conditions.

In Minnesota, the rate of hospital treatment is much higher for non-traumatic versus traumatic oral emergencies, which may be attributable to the under-insured/uninsured using hospital services for more regular dental care needs. Four times more people sought treatment for non-traumatic oral emergencies at hospitals as compared to those seeking treatment for traumatic conditions (Table 4). From 2000 to 2010, just over a third (37 percent) of patients visiting EDs with traumatic conditions were from rural communities – even though these areas are more sparsely populated – which may be due to the lack of enough dentists in rural locations.

Significantly, people who sought treatment from a hospital for non-traumatic oral emergencies were four times more likely to be admitted to the hospital than those seeking treatment for oral trauma (Table 4). This may be due to preventable dental conditions having evolved into more complicated and costly ailments that needed hospitalization. When charges like this are not paid by uninsured or under-insured patients, the burden falls to the hospital or health care organization which in turn may pass the cost on to insured patients through higher health care charges.

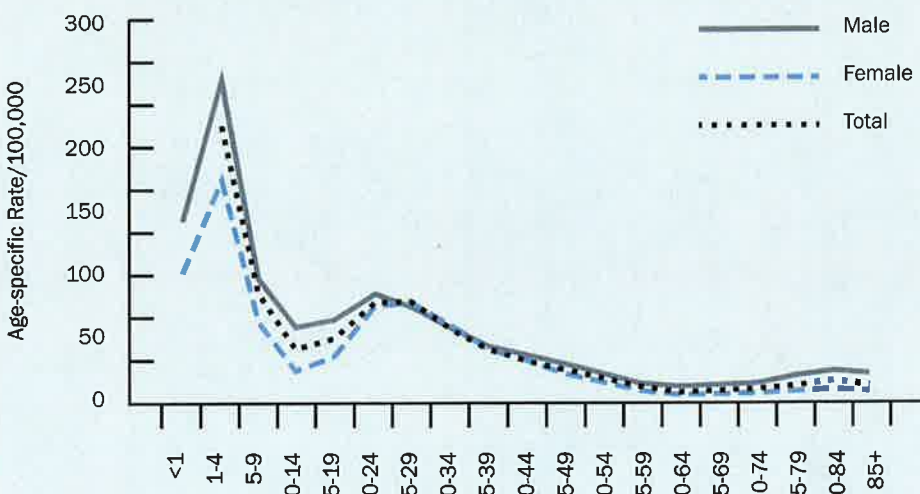
The incidence of non-traumatic hospital-treated oral emergencies is higher among 20 to 29 year olds and is 20 percent higher in females 20 to 24 years old as compared to males in the same age group (Figure 14 and Table 5). The higher rate among this age group may be due to young adults no longer being eligible for coverage through their parents' insurance plans; still being in college without dental benefits; or employed in jobs without dental benefits. The rate in this age group may decline as the Affordable Care Act is implemented and provides coverage for young adults through age 26 on their parents' health care plan.

Minnesota hospital-treatment rates for dental conditions vary significantly by age, with oral trauma being highest in children ages one to four followed by adults ages 20 to 29 years; males and females show the same pattern (Figure 15).



FIGURE 15

Hospital-treated Oral Trauma by Age, Minnesota 2000-2010 Rate/100,000 cases



Public Health Infrastructure

Goal 1: Minnesota's oral health infrastructure is stable and sustained.

Prevention and Education

Goal 2: Strategies are implemented that reduce oral disease and mitigate risks.

Goal 3: Oral health literacy is increased across all ages and cultures.

Health Care Integration and Access to Oral Health Care

Goal 4: Professional integration is enhanced between oral health care providers and other providers in the broader healthcare system.

Goal 5: Access is increased to preventive, restorative, and emergency oral health care services.

Goal 6: The dental workforce is prepared for and addresses the oral health needs of all Minnesotans.

Surveillance

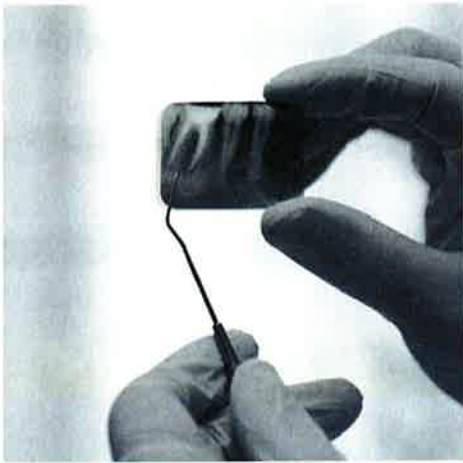
Goal 7: Access to population statistics, population-level oral health surveillance information, and aggregate data on oral health indicators is readily available to all.



Priority Areas: Oral Health Goals, Objectives and Strategies

The Minnesota Oral Health Plan defines specific goals, objectives and strategies for advancing oral health for all Minnesotans. These priority areas were identified by a cross-section of public health and oral health professionals and recognize that oral health is dependent on a complex, interrelated set of factors that range from good oral hygiene and optimal water fluoridation to providing more equitable access to oral health care services.

This overview of priority areas and goals below is followed by a more in-depth analysis of the factors impacting oral health and suggested strategies for dismantling barriers and bolstering health care integration in order to improve oral health for all Minnesotans.



Priority: Oral Health Infrastructure

To sustain continued progress in reducing the burden of oral diseases across Minnesota, it is imperative to devote attention to the status of oral health and amplify the prevention strategies that address them. Further embedding the Oral Health Program's mission with the Minnesota Department of Health's goals and objectives is a first step in that direction. The Minnesota Oral Health Plan also supports Minnesota's statewide health improvement framework: Healthy Minnesota 2020 which emphasizes common themes:

- A Healthy Start for All: capitalize on the opportunity to influence health in early childhood.
- An Equal Opportunity for Health: Assure that the opportunity to be healthy is available everywhere and for everyone.
- Communities Creating Health: Strengthen communities to create their own healthy futures.

Equally critical to this state-level integration is the continued development of collaborative partnerships with other public health and social welfare sectors, educational and health care organizations, and private organizations concerned with oral care. The establishment and continued support of

the Minnesota Oral Health Coalition as an independent entity will provide the groundswell of action needed to prioritize and address the complexities of oral diseases.

Through this combined stable leadership, it will be possible to leverage and maximize resources, augment data collection, streamline interventions and address policy barriers while expanding oral health literacy among both professional sectors and the public at large. Working together, we may indeed achieve optimal oral health for all Minnesotans while reducing health care costs.

Goal 1: Minnesota's oral health infrastructure is stable and sustained.

Objective 1.1: Fully integrate the Oral Health Program into the Minnesota Department of Health infrastructure.

Suggested strategies

- A. Increase the sustainability of the state oral health program and support the state oral health program as the central agency for oral health promotion.
- B. Continue to apply for grants and increase the amount of grant money obtained.
- C. Promote integration opportunities with other funded programs.

Objective 1.2: Support development of a strong Minnesota Oral Health Coalition that works closely with the Minnesota Department of Health.

Suggested strategies

- A. Support the coalition in determining leadership structure and other administrative and organizational issues related to its development into a self-supporting organization.
 - i. Obtain best practices guidance from more mature organizations, access assistance available from National Association of Oral Coalitions and coalition experts e.g. "Coalitions Work", etc.).
 - ii. Sustainability of Oral Health Coalition; establish development fund.
 - iii. Inform membership.
 - iv. Summarize in-kind support from MDH.
- B. Complete a vision, mission, goals (identity) process.
- C. Work with the coalition leadership to explore pros and cons of establishing the Minnesota Oral Health Coalition as a non-profit organization (501 (C)3 status).
- D. Utilize the CDC framework and other recognized coalition resources to increase diversity of the membership in the coalition.
- E. Develop an independent, interactive web presence for the Minnesota Oral Health Coalition.

Objective 1.3: Develop and sustain collaborative partnerships to implement the Minnesota Oral Health Plan.

Suggested strategies

- A. Create new partnerships that ensure diversified funding is available to implement the Minnesota Oral Health Plan.
- B. Identify innovative action plans that are easily adopted by stakeholders.

Objective 1.4: Seek commitment for long-term data collection and surveillance on Minnesota's oral health indicators.

Suggested strategies

- A. Investigate the cost (along with data and information technology experts and programmers) to create an interactive web-based data source known as the Minnesota Oral Health Surveillance System (MNOHSS).
- B. Prepare planning and implementation process including data documentation to Minnesota Technology Services.
- C. Approach potential funders or add to grant proposals to launch a full-scale sustainable interactive data portal.

Objective 1.5: Seek funding sources that support the review, professional evaluation, and updates to the current Minnesota Oral Health Plan.

Suggested strategies

- A. Oral health leaders and stakeholders seek sustainable funding and program changes to implement the plan.

Objective 1.6: Assess opportunities for policy change through environmental analysis tools such as the environmental and policy scan and share results with decision makers.

Suggested strategies

- A. Utilize resources available through the CDC to support a facilitated process for oral health stakeholders to join together to make decisions about priorities based on suggested criteria.

Priority: Prevention and Education

Prevention and education strategies work hand-in-hand to mitigate the risk of oral diseases. Protecting children and adults from developing caries is the first line of defense for related health complications such as tooth loss, infection and compromised immunity. Informing the public about the risk factors associated with oral cavity and pharynx cancers is also critical.

Two of the most effective and proven strategies for preventing the development of caries are dental sealants and fluoridated drinking water. These interventions, mixed with efforts to increase oral health literacy among the public through education campaigns and those working directly with vulnerable populations such as school nurses, prenatal and primary care providers, and public health workers are proven strategies to preventing most oral diseases.

Dental Sealant Programs

The risk of developing tooth decay can begin as early as when teeth first erupt in an infant's mouth. Tooth decay is caused by bacteria on teeth that break down foods and produce acid that destroys tooth enamel resulting in tooth decay.

The best defenses against cavities are good oral hygiene, regular dental visits, a healthy diet low in sugary foods and beverages, fluoride, and dental sealants. Dental sealants are highly effective—nearly 100 percent – in preventing decay among vulnerable children and

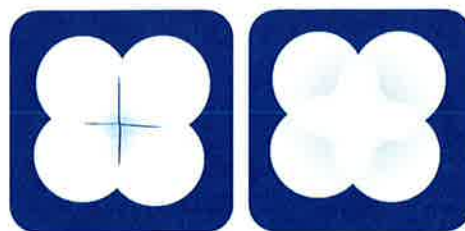
adults. Dental sealants are a thin coating bonded to the chewing surfaces of back teeth (molars) to protect them from decay.

Providing children with sealants through school-based sealant programs has been shown to be an efficient and cost-effective strategy for providing children in need with preventive oral health care. The State of Colorado estimated a \$1.2 million per year saving if a statewide school sealant program were implemented.

The 2009 to 2010 Minnesota Basic Screening Survey (BSS) revealed that of those surveyed, 64 percent of third graders had sealants on at least one of their permanent molars, though that rate falls steadily with income levels to the low rate of 42 percent for Minnesota's poorest children (>75% FRL).

MDH is working closely with the Minnesota Department of Human Services and other partners to reach the goal set by the Centers for Medicare and Medicaid Services (CMS) of increasing the rate of dental sealants by 10 percent over a five-year period in children ages six to nine enrolled in Medicaid or Child and Teen Checkups (Minnesota's Early and Periodic Screening, Diagnosis and Treatment Program). To this end, in 2011, MDH's Oral Health Program, in cooperation with federal agencies, 3M and Delta Dental, funded school-based sealant programs to reach children who did not have easy access to sealants.

Minnesota's coordinated sealant program targets second grade students at schools where more than 50 percent of students are eligible for the Free or Reduced Price Lunch Program (FRL). As seen in Table 6, in 2009 less than 25 percent of "high-risk schools" (>50% FRL) had sealant programs, but within a year's time that number climbed to 29 percent for the 2010 to 2011 school year as a result of the MDH-sponsored dental sealant program. Data from the program show that one-third (34 percent; n=6,356) of the children in second grade participated



Chewing surface
before sealant

Tooth protected
by sealant

Community water fluoridation has been recognized by the CDC as one of the 10 greatest public health achievements of the twentieth century.



when compared to states with less than one-quarter of the communities with fluoridated water.

In 2010, approximately 78 percent of Minnesotans benefited from community water fluoridation compared to 64 percent of the population nationally, ranking Minnesota fourth in the nation after Kentucky, Maryland and Illinois. Nearly all (99 percent) Minnesotans who are connected to public water supplies receive fluoridated drinking water. While this is a great success, we must be vigilant in maintaining this high ranking while also addressing fluoridation needs for rural communities that rely on private wells that may not have the optimal amount of fluoride.

and that, on average, three dental sealants were applied per student.

As part of MDH's sealant program, oral health education is also provided to parents, children and school staff through presentations, conferences, classroom activities, informational meetings, and other promotional methods. This approach to oral health care also resulted in referrals to partner clinics for continued care.

Fluoride Varnish

Fluoride varnish has also been found to be another cost-effective preventive treatment, reducing decay on tooth surfaces by 50 percent to 70 percent. Fluoride varnish is applied on high-risk teeth through a resin-based solution and must be reapplied at regular intervals to be effective.

Water Fluoridation

Fluoride is a naturally occurring mineral found in water, air and soil. At proper levels, fluoride provides significant health

benefits by preventing tooth decay. Minnesota Statute 144.145 requires the fluoridation of water in all municipal water supplies except where natural levels are sufficient. By law, Minnesota is required to monitor drinking water fluoride concentrations to ensure optimal levels are maintained. Municipal water supplies monitor system performance, collect daily samples, and submit reports and results to MDH on a monthly basis, making adjustments to fluoride levels accordingly.

Community water fluoridation has been recognized by the CDC as one of the 10 greatest public health achievements of the twentieth century, providing one of the most cost-effective and equitable means to prevent tooth decay. Economic analysis conducted by the CDC found that in communities with more than 20,000 people, every dollar invested in water fluoridation yields \$38 in savings for dental treatment costs. In states where more than half of the communities have fluoridated water, there is 26 percent less tooth decay among 12 year olds

Goal 2: Strategies are implemented that reduce oral disease and mitigate risks.

Objective 2.1: Determine the baseline for the number of providers who use standardized, evidence-based oral disease risk assessment tools.

Suggested strategies

- A. Implement an educational campaign that raises understanding of risk assessment, benefits of using risk assessment, and introduces tools used to assess risk.
- B. Promote use of risk assessment (periodontal disease, diabetes, tobacco use, etc.) among medical and dental providers.
- C. Collect data that is valid and reliable on current usage of tools for caries risk assessment in practice.
- D. Choose a tested caries and periodontal disease risk assessment tool to use in Minnesota that is valid and reliable.
- E. Use the Minnesota Oral Health Surveillance System (MNOHSS) as a clearinghouse for sharing standardized information on caries and periodontal disease risk in Minnesota.

TABLE 6

Minnesota Elementary High-risk Schools, 2010-2011 School Year

	Number of Schools	Percent of Schools
Elementary schools	946	---
High-risk schools*	392	41%
High-risk schools with school-based dental sealant program	115	29%

* >50 percent rate of students on Free or Reduced Price Lunch Program

Objective 2.2: Reduce caries experience in Minnesota children.

Suggested strategies

- A. Partner with Maternal and Child Health, pre-school, Early Head Start and Head Start oral health programs, early care and education settings on tooth brushing promotion programs targeted toward pregnant women and children under the age of five (review National Association for the Education of Young Children accreditation standards for oral health).
- B. Partner with Early Head Start and Head Start on oral health programs that help meet Head Start and Child and Teen Checkups (the Minnesota version of Early Periodic Screening, Diagnosis, and Treatment) requirements.
- C. Develop and offer trainings for preschool staff, Head Start coordinators and home visitors to recognize signs of and identify risk factors for early childhood caries.
- D. Promote fluoride varnish programs as part of immunization and well child visits.
- E. Increase programmatic coordination between risk-reduction programs, e.g., preschool and Women, Infants and Children (WIC) programs.
- F. Include oral health screening requirements in childhood screenings.
- G. Educate caregivers of infants/toddlers about appropriate amounts of topical fluoride or fluoride toothpaste.
- H. Increase availability and ease of access to oral health supplies.

School-based Dental Sealant Programs

Objective 2.3: Develop and coordinate comprehensive, statewide school-based prevention programs that target high-risk children.

Suggested strategies

- A. Conduct the statewide third grade Basic Screening Survey at least once every five years.
- B. Convene a school-based sealant work group that includes providers,

school representatives, school nurses, public health professionals, health plans, Minnesota public programs representatives, Board of Dentistry, researchers, community representatives, parent representatives, and parent-teacher associations.

- i. Conduct a needs assessment and compile information on existing sealant activities in the state.
 - ii. Seek and acquire sustainable financial support, i.e., foundations, Title V funding, industry (3M, dental supply companies), Smiles Across Minnesota, Oral Health America, etc.
 - iii. Create and publish a comprehensive state sealant plan.
 - iv. Create a variety of easily understood messages targeted to parents/caregivers about efficacy and safety of pit and fissure sealants, why they are needed and the importance of sealants in caries prevention.
- C. Develop parameters for and post a request for proposal (RFP) for at least five school-based sealant mini-grant projects.
 - i. Plan and conduct projects that provide documentation of components of successful sealant programs and identify barriers to sustainability.
 - ii. Promote limited authorization/collaborative practice as a model for school-based programs.
 - D. Convene a transdisciplinary panel for review and development of a comprehensive coordinated plan for fluoride varnish programs and to develop quality improvement initiatives, i.e., through learning collaboratives and health care home initiatives.
 - E. Create an education campaign about how fluoride works and the importance of the appropriate use of fluoride varnish in caries prevention.

Water Fluoridation

Objective 2.4: Ensure that the percentage of public water supply systems providing fluoridated water are within the optimal range and meet the CDC optimal monitoring and surveillance requirements of meeting or exceeding 90 percent.

Suggested strategies

- A. Collect community water fluoridation information and submit data to the CDC on 510 reports.
- B. Identify ways to provide support to communities to maintain or update aging fluoridation equipment.
- C. Support statewide educational campaigns that promote drinking tap water.
- D. Educate water works operators about the importance of the water fluoridation process and its link to oral health.
- E. Recognize water workers and engineers as oral health leaders on a consistent basis.

Objective 2.5: Ensure that at least 50 percent of Minnesota's schools have achieved oral health targets.

Suggested strategies

- A. Remove cariogenic foods and beverages from vending machines.
- B. Increase the number of non-cariogenic food items accessible outside the lunch program (vending machines, fund raisers, concessions, classroom celebrations and a la carte) in Head Start and school menus.
- C. Increase tobacco use prevention/cessation and nutrition information in health education programs.
- D. Provide resources to strengthen curricula that emphasize how healthy eating can improve and maintain oral health.
- E. Reduce the impact of soda/beverage marketing by educating schools to resist marketing strategies.
- F. Promote the understanding of the preventive properties of xylitol gum and xylitol products and their proper use.

- G. Partner with the Minnesota School Nutrition Association and the Minnesota Department of Education to collect data on candy and pop available in schools in order to tailor oral health campaigns to school needs.

Objective 2.6: Promote awareness of the effect of diet and nutrition on oral health among hospital food service directors, older adult service establishments, and nutrition staff.

Suggested strategies

- A. Partner with the Minnesota Hospital Association (MHA), hospital food service directors, and registered hospital dietitians to provide information about creating tooth-healthy menus and increasing health snack choices for patients, visitors, staff, and in vending machines.
- B. Provide educational sessions at MHA conferences about the relationship of diet to dental disease.
- C. Promote partnerships with assisted living and nursing home providers and organizations to increase understanding about the impact of diet on the oral health of older adults.

Public Education

Good oral hygiene combined with good nutrition are the building blocks to personal oral health. Bolstering oral health literacy as early as possible among both vulnerable populations and the general public can be done most effectively through those who work directly with children and their caregivers, especially pregnant women receiving prenatal and maternal health care. Through broad and consistent public education efforts to raise awareness, the risk factors associated with poor oral health can be decreased, leading to better health outcomes and significant health care cost savings.

Among the most significant risk factors jeopardizing oral health are tobacco use, along with the consumption of alcohol and sugared beverages. Tobacco use is a major risk factor in oral cavity and pharyngeal cancers. According to the

American Academy of Periodontology, tobacco use may be one of the most significant risk factors in the development and progression of periodontal disease; smokers are four times more likely to develop gum diseases compared to non-smokers.

Over the past decade, smoking rates have been steadily decreasing for both teens and adults in Minnesota. In 2011, 26 percent of Minnesota high school students reported smoking cigarettes in the past 30 days, compared to 39 percent in 2000. Adult tobacco use rates have decreased from 22 percent in 1999 to 16 percent in 2000. No doubt this decline is due to the Minnesota's strong tobacco laws and prevention strategies implemented as a result of the landmark tobacco settlement won by the state of Minnesota and Blue Cross and Blue Shield of Minnesota against tobacco companies in 1998.

Alcohol use also shows an overall declining pattern among 12th graders, both nationally and in Minnesota. Since 1995, Minnesota alcohol use for this age group fell below the national level to 69 percent and has remained lower, declining steadily to 55 percent in 2010 compared to the national rate of 62 percent. Conversely, alcohol consumption among Minnesota adults is higher when compared to the nation, though rates have decreased fairly steadily in Minnesota from 67 percent in 2001 down to 60 percent in 2010 as compared to national rates in 2001 at 56 percent and 55 percent in 2010.

Excessive consumption of sugar sweetened beverages increases the risk of caries. In certain brands of soda, there is the equivalent of 10 teaspoons of sugar in a 12-ounce can. The combination of high sugar content and high level of acidity in soda significantly increases the risk of dental caries. Encouraging Minnesotans to drink tap water and milk instead of soda and other sugary drinks is another important way to decrease caries.

Goal 3: Oral health literacy is increased across all ages and cultures.

Objective 3.1: Increase oral health evaluation and caregiver education in early childhood screenings, vaccination visits, episodic care visits, prenatal, and Child and Teen Checkups.

Suggested strategies

- A. Support health literacy and cultural competency training for health professionals in the community, including health care providers and public health officials.
- B. Provide technical assistance to those interested in becoming proficient in patient-centered literacy skills.
- C. Educate prenatal and maternal health care providers about the importance of increasing oral health literacy among pregnant women so they are well informed about caries etiology, caries prevention, and infant oral health care.
- D. Create a campaign to increase understanding regarding the importance of tooth brushing and sponsor distribution of oral health information and materials in prenatal and maternal care programs.

Objective 3.2: Build awareness of oral disease prevention strategies and increase oral health knowledge in school-based health systems.

Suggested strategies

- A. Strengthen partnerships with and provide resources to the Minnesota Department of Education and Minnesota school nurses to evaluate oral health curricula (including early childhood and after school programs) on evidence-based strategies.
- B. Develop and disseminate information about the efficacy of pit and fissure sealants, water fluoridation, topical fluoride therapy and other strategies that prevent and control oral disease.
- C. Investigate programs to introduce evidence-based xylitol therapy in early childhood programs and schools.
- D. Partner with the Minnesota Department of Health Injury and

Violence Prevention Unit to develop promotional programs that focus on preventing and reducing oral injury.

- E. Develop and disseminate information to parents and schools about fluoride varnish, sealants and the health care home.

Objective 3.3: Increase exposure to oral health knowledge through targeted and culturally sensitive campaigns that focus on prevention strategies.

Suggested strategies

- A. Develop and disseminate fluoridation messages that provide culturally and age appropriate information to population groups, adults, and children. e.g. “safe to drink fluoridated tap water” messages.
- B. Increase oral health literacy among young adults emphasizing smoking, diet, smokeless tobacco, alcohol and tobacco, periodontal disease and importance of oral care.
- C. Increase oral health literacy among the elderly and their caregivers; emphasize medications that increase xerostomia (dry mouth), root caries etiology, periodontal disease and oral cancer.
- D. Ensure educational materials are available in multiple languages, including visuals for the non-reading population.
- E. Create electronic media and monitor hits/visits to web pages and internet sites.

Objective 3.4: Increase awareness of oral health among policy and decision makers about the benefits of oral disease prevention.

Suggested strategies

- A. Engage legislators in an annual oral health initiatives forum.
- B. Partner with the Minnesota Oral Health Coalition to support oral health promotion policies, tobacco control policies, and to promote policy change.
- C. Identify and utilize oral health resources in the state to target areas of greatest need.

In Illinois, the state saved \$140 million in 2009 through its health care home initiative.



- D. Increase understanding of federal mandates and funding, or lack of funding.

Priority: Health Care Integration and Access to Oral Health Care

To truly prevent oral diseases, it is critical that changes are made upstream within the health care system and provider education programs to achieve a broader understanding among health care providers of the relationship oral health has to overall health. Building partnerships across care sectors — dental, primary care, dietary, public health, health plans, community health — to achieve a more patient-centered approach to health care will have the triple advantage of decreasing oral and other diseases, while slashing health care costs.

This holistic approach to health care, combined with efforts to provide more affordable dental care through new dental provider types and workforce models, will help reach more people who often lack adequate or any access to oral health care and treatment.

Health Care Home Model

The “health care home” is one of the most promising solutions to improving the health of Americans while significantly reducing health care costs. The

development of health care homes in Minnesota is part of the ground-breaking 2008 Minnesota Health Care Reform Act to provide a patient-centered model focused on primary care and prevention that is culturally appropriate. Ideally, a health care home also connects a patient’s dental and primary care records so that treatment and care is fully integrated. In turn, health care homes keep health care costs down by addressing adverse health conditions early so that expensive emergency department visits and hospital stays can be avoided. In Illinois, the state saved \$140 million in 2009 through its health care home initiative.

To ensure oral health care is considered an essential component of a patient’s overall health and is embedded in the health care home model, the concept that “the mouth is a part of the body” must be elevated in health education. A better understanding of the interrelatedness of oral and systemic health stands to improve a patient’s overall health. Both dental and non-dental professionals must be educated in this concept: obstetrics, family practice, pediatrics, internal medicine, nurses, dietitians, health plan case managers, community health workers, social workers, and others. In time, this health care integration will give rise to a team of people working together to better meet the health needs of all Minnesotans, especially the underserved.

This increased appreciation for oral health across sectors should also extend to medical providers in private practice and hospital settings, along with long-term care facilities. Integrating oral disease assessment into medical protocols will also ensure that everyone is receiving the best care possible.

Public Health and Health Integration

The environmental strategies employed by the public health sector present numerous partnership opportunities with oral health agencies. The links between oral disease and chronic disease have been well documented; they also share common risk factors such as poor nutrition, tobacco and alcohol use.

Increasing awareness among local public health agencies of the interrelatedness of oral health to other preventable diseases widens the field for greater collaboration to meet common health goals. Including oral health in public health agencies' missions is an important step in integrating proven oral health prevention strategies that lead to total health.

Banding together, public health and oral health agencies can speak with one voice to address policies that create barriers to health. Together, they can also more effectively heighten awareness among health care providers and policy makers of the social and environmental factors that are largely responsible for health inequities.

Goal 4: Professional integration is enhanced between oral health care providers and other providers in the broader health care system.

Objective 4.1: Promote the understanding and development of the health care home concept.

Suggested strategies

- A. Create and nurture non-traditional partnerships in oral health to establish a coordinated strategic direction.

- B. Gather information and evaluate the effect of reimbursements/incentives for improving care.
- C. Increase training opportunities in oral health for non-dental professionals (public health nurses, dietitians, health plan case managers, community health workers, and interpreters) that build patient-centered skills (preventive, therapeutic, and remedial) and provide technical assistance for working with patients, clients and the public.
- D. Increase the number of local public health agencies that address oral health.
- E. Increase integration activities and partnerships with nutrition, obesity, tobacco, alcohol, etc. (i.e., American Dietetic Association, American Lung Association, American Heart Association).
- F. Plan demonstration projects that create innovative health care home models.
- G. Work with educators to investigate the potential role of teledentistry and policy makers to address payment issues.

Objective 4.2: Increase the number of non-dental provider education programs (physician's assistant, nurse practitioner, dietitians, medical schools, and nursing schools) that incorporate oral health into their curriculum.

Suggested strategies

- A. Partner with the Minnesota and American Pediatric Association and work to determine current continuing medical education curriculum that encompasses an oral health component.
- B. Work with the University of Minnesota College of Continuing Education to create continuing medical education curriculum focused on oral health.
- C. Use evidence-based strategies to develop core competencies in oral health within educational settings.

- D. Provide one conference in each of the next two years for oral health and medical providers that focuses on:
 - i. Oral and systemic health interrelatedness.
 - ii. Understanding and promoting risk assessment of oral and systemic health.
 - iii. Participate in "Many Faces Conference" and Accountable Care Conference with medical and dental professionals.

Objective 4.3: Develop collaborative opportunities throughout the health care community by educating and training physicians, dentists, nurses, hygienists, nurse practitioners, dental assistants, dental therapists, and social workers to work as a single team addressing oral health disparities and unmet dental needs of the underserved.

Suggested strategies

- A. Promote research on the impact of oral health on overall health.
- B. Support the development and evaluation of programs that promote disease prevention and increase collaborative health care.
- C. Provide incentives for allied dental personnel to work in medical settings under collaborative supervision by a licensed dentist.
- D. Reduce barriers to dental hygienists working in public health agencies and other settings.
- E. Move primary oral health care into every obstetrics, primary care, family practice, pediatrics, and internal medicine practice in Minnesota by incorporating "The mouth is a part of the body" concept.



- F. Investigate further development of innovative collaborative strategies for serving elderly and youth populations with different provider types.
- G. Explore the development of a centralized network for identifying excess capacity, sharing resources, and communicating needs that utilizes the public health infrastructure.

Objective 4.4: Promote collaboration among dental providers and medical care providers that increase information sharing, understanding of eligibility requirements, and access to and utilization of oral health care benefits.

Suggested strategies

- A. Create demonstration projects that gather and analyze preventive services utilization data and propose new models that coordinate collaboration between dental and medical providers and eliminate disparities.

Objective 4.5: Promote the adoption and meaningful use of the electronic dental record.

Suggested strategies

- A. Disseminate information about the Office of the National Coordinator efforts to create standardized guidelines for the utilization of Health Information Technology and reporting.
- B. Improve collaboration and follow up by aligning with at least two objectives of the local and national Office of the National Coordinator for Health Information Technology.
- C. Seek funding to create incentives for private and public health dental and medical systems to create and adopt centralized network tools.

Objective 4.6: Call for the development and promotion of clinical preventive oral health guidelines for use in settings outside the dental office: medical and long-term care, prison, juvenile, and hospital settings.

Suggested strategies

- A. Support and promote the development and use of dental diagnostic codes.

- B. Develop partnerships that integrate oral health into the current case management system.
- C. Promote public health research, standardized protocols for care, and use of evidence-based practices.
- D. Promote inclusion of oral evaluation in care guidelines for the aging and persons with diabetes and special health care needs.
- E. Create a web-based tracking and referral mechanism for oral health information and treatment.
- F. Promote Health Insurance Portability and Accountability Act compliant communications between dental providers and primary care providers (family medicine, obstetrics, pediatrics, internal medicine, etc.) and allied health professionals, (dietitians, pharmacists, etc.) when assessing and referring for medical conditions and non-dental issues.

Objective 4.7: Increase the number of primary care medical providers who integrate prevention of oral disease as part of overall health care by 10 percent for patients of all ages.

Suggested strategies

- A. Create a recognizable symbol and/or standardized message that captures the concept of the interrelatedness of oral health and overall health.
- B. Develop a marketing campaign targeted to medical providers that promotes oral health as integral to overall health.
- C. Determine a baseline number (early adopters) and evaluate barriers to the utilization of oral disease prevention strategies by medical practitioners.
- D. Develop an integrated approach among medical and dental providers that promotes oral exams/evaluation, referral, and access to oral health care by age one.
- E. Promote treatment and diagnostic information sharing between pediatricians, physicians and dentists.



Access to Oral Health Care

Inadequate access to oral health care is due to a variety of complex factors including a shortage of dental providers, especially in rural areas; not enough providers willing to accept people on medical assistance due to low reimbursement rates; and a gap in affordable insurance options. The need for more accessible and affordable dental care has led people to seek oral health care in emergency departments and hospitals, resulting in exorbitant health care costs that could be prevented.

Health Professional Shortage Area (HPSA) is a designation given by the Department of Health and Human Services (DHHS) to identify shortages of primary medical, dental or mental health providers within a geographic area, population group or facility. The designation uses a provider-to-population ratio based on the available primary care provider FTE (full-time equivalent) serving the specified area, population or facility, as well as the availability of health care resources in contiguous areas. For instance, a dental HPSA for a geographic area requires a ratio of dentist FTE-to-population ratio of 1:5000 or greater in addition to lack of contiguous services available to the area.

A population HPSA, based on a specific population subset within a geographic area, uses only dentist FTE serving the specified population subset. For example, the ratio for a low-income population designation would be based on the

dentist FTE serving Medicaid and/or low-income patients to the population with income status at or below 200 percent of the Federal Poverty Level. The ratio threshold for a population HPSA is 1:4000 or greater. Additionally, the designation requires that the percentage of the population with incomes at or below 200 percent of the Federal Poverty Level be at 30 percent or higher and that contiguous services are unavailable. An exception is that Native American and Alaskan Native Tribal populations have been afforded automatic population HPSA designations by Congress.

As of September 2012, there were 112 dental HPSAs in Minnesota. The majority of these HPSAs are located in rural parts of the state. There are 13 HPSAs designated in Hennepin County (four population and nine facilities) and five in Ramsey County (two population and three facilities). In five other metropolitan counties (Anoka, Washington, Carver, Dakota and Scott), there are two correctional facilities and one Native American tribal population designations.

More than half (66 out of 112) of the dental HPSAs in Minnesota are low-income population designations. Based on the dentist FTE data serving Medicaid and/or low-income populations in these areas, DHHS estimates that 166,200 people have access to dental services and 362,569 experience barriers to accessing dental care. (See Appendix C for the map of Minnesota Health Professional Shortage Areas - Population/Low-Income Dental Care Designation).

To meet the increasing oral health needs of Minnesotans, the workforce capacity must be bolstered through more innovative strategies to recruit, prepare, retain and equitably distribute oral health care providers. According to the Pew Charitable Trusts, by 2014 an estimated 5.6 million more children will be eligible to receive Medicaid dental benefits under

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the Affordable Care Act. This, coupled with the looming tidal wave of retiring baby boomers will further strain the capacity of the dental care system to serve Minnesotans, especially low-income people and residents in rural areas.

Minnesota has been a trailblazer in sanctioning mid-level dental professionals such as dental therapists and advanced dental therapists and collaborative practice agreements between dentists and hygienists.¹ Yet, to truly maximize the potential in these workforce models, a concerted effort needs to be made to better promote these professional opportunities and encourage more dentist to negotiate collaborative/management agreements with hygienists and therapists.

Better preparing the next generations of oral health professionals is essential to retaining qualified providers willing to work with underserved communities. Strategies such as mentorship programs and teledentistry, whereby patients receive diagnostic and basic primary care through video conferencing and health professionals receive continued educational opportunities, can offer needed support to professionals who might feel isolated in more rural settings.

The dental workforce must also become more versed in meeting the needs of a

more diverse population by incorporating cultural competency into the curriculum of oral health provider education programs. There is also a dire need to recruit more people of color and women into the field of dentistry, especially as dentists.

A more diverse workforce enriches oral health care delivery as people tend to be more comfortable seeking treatment from people of their own ethnic or racial background. Caregivers from diverse backgrounds are also more likely to serve underserved populations. In a 2010 survey of Minnesota dentists (1,867 out of 3,908 responders), the following dental provider demographics were gathered:

- 23% are female; 77% are male
- 47% of dentists are 55 years or older
- 50% of dentists under age 35 are female
- 94% of dentists are white; the remaining 6% of dentists identified themselves as African American, Native American, Asian or multiracial; 2% identified their ethnicity as Hispanic.

Taken together, strategies to increase access can do much toward reinforcing the Minnesota oral health workforce and improving care across the state.

1. Alaska was the first state to use dental therapists in 2005, but was established under federal law and is limited to native villages through the Alaska Native Tribal Health Consortium. Minnesota is the first and only state to license dental therapists under a 2009 law; see statutes 150A.105 (law on dental therapists) and 150A.106 (law on certification for advanced dental therapist).

Dental Workforce Capacity

As of 2010, there were 3,908 Minnesota dentists who renewed their licenses with 3,244 practicing in the state providing 61 dentists per 100,000 population (Table 7). Most of the dentists (57 percent) planned to practice in Minnesota for more than 10 years. Based on a 2010 MDH licensee survey, 47 percent of dentists were 55 years or older indicating that the gap in services will increase over the next decade as dentists begin to retire.

One-third (74 percent) of dentists were practicing in urban areas, whereas only 7 percent worked in small rural areas. Solo practice is the most common type of dental practice especially in rural areas (44 percent) followed by small group practice (37 percent), leaving rural populations with fewer options when solo practitioners are unavailable or retire.

According to the Minnesota Department of Human Services, in 2011 just over half (53 percent) of practicing dentists had submitted at least one dental claim for patients on public programs. This figure may serve as a proxy indicator for the number of Minnesota dentists seeing Medicaid patients.

In 2011, Minnesota had only 77 certified pediatric dental specialists; approximately 6 pediatric dentists per 100,000 children (Table 7). Pediatric dental services are available in fewer than 20 of Minnesota's 87 counties, which are clustered in and around the seven-county Minneapolis/St. Paul metropolitan area and in larger cities such as Duluth, Rochester, St. Cloud, and Mankato. Very few pediatric dentists, if any, are located in rural Minnesota.

Dental hygienists are licensed dental professionals who specialize in preventive dental and periodontal care. As of 2009, a total of 3,594 practicing dental hygienists provided approximately 68 dental hygienists per 100,000 people in the state (Table 7). In 2012, the Minnesota Office of Rural Health and Primary Care reported that there is an excess capacity in the dental hygienist workforce with more than three times as many dental hygiene graduates than available jobs. Based on preliminary findings, 18 percent of the dental hygienists working in Minnesota are seeking different or additional employment.

Dental assistants are licensed dental practitioners who work with supervision by a licensed dentist. A total of 7,146

dental assistants renewed their licenses from 2008 to 2009, according to the Minnesota Board of Dentistry licensing data; 6,288 (88 percent) were practicing in Minnesota (Table 7). The vast majority (73 percent) were working in urban areas with only 8 percent located in rural areas.

Enhancing Workforce Models and Creating New Providers

Minnesota is leading the nation in providing one of the best solutions to the dental workforce shortage and bridging gaps in dental care by creating new licensed "mid-level" dental providers such as advanced dental therapists and dental therapists, and supporting new workforce models such as hygienists working under "collaborative agreements" with dentists. These leading-edge workforce solutions have been hailed nationally by leaders in public health as a viable means to close the gap in affordable dental care.

In 2009, Minnesota became the first and only state to establish licensed dental therapists and dually licensed advanced dental therapists (ADTs) (licensed as both a dental hygienist and a dental therapist) to better serve underserved populations. These new dental professionals offer evaluative (ADTs only), preventive,

TABLE 7

Ratio of Dental Provider Types per 100,000 Population

Dental Professionals	*Minnesota: Number per 100,000 population	**National: Number per 100,000 population
Dentists (practicing)	3,244 (61 dentists per 100,000)	195,628 (63 dentists per 100,000)
Collaborative Agreement Dentists	274 (5 dentist per 100,000)	~
Pediatric Dental Specialists	77 (6 dentists per 100,000 children <18 years)	6,181 (8 dentists per 100,000 children <18 years)
Advanced Dental Therapists	~	~
Dental Therapists	16 (3 per 1,000,000)	~
Hygienists (practicing)	3,594 (68 per 100,000)	152,000 (49 per 100,000)
Collaborative Agreement Hygienists	276 (5 per 100,000)	~
Dental Assistants (practicing)	6,288 (119 per 100,000 pop)	297,200 (96 per 100,000)

*Total Minnesota population: 5,303,925; children under 18 years (24%): 1,267,638

**U.S. Population: 308,745,538; children under 18 years (24%): 73,172,69

In 2009, Minnesota became the first and only state to establish licensed dental therapists and dually licensed advanced dental therapists (ADTs) (licensed as both a dental hygienist and a dental therapist) to better serve underserved populations.

restorative, and minor surgical dental care with dentist supervision and a collaborative management agreement. The first wave of dental therapy students graduated in 2011 and it is anticipated there will be between 70 to 75 graduates in the next five years.

While dental hygienists must work under the general supervision of a dentist, the Minnesota dental law also provides the opportunity for hygienists with a collaborative agreement with a dentist to work without the dentist first seeing the patient, in turn expanding the reach of dental care into more settings, e.g., elementary schools. Despite this opportunity for workforce expansion, when surveyed only 6 percent of hygienists were actively practicing under a collaborative agreement; 20 percent did not know if they were practicing under a collaborative agreement or not.

Increased awareness about these new dental providers and the opportunity for collaborative agreements is needed. While these new job classifications and dental workforce models offer promise for providing more people with better access to more affordable disease prevention and treatment care, not enough dentists have entered into these collaborative opportunities: only 7 percent of Minnesota dentists had a collaborative agreement with a dental hygienist.

Goal 5: Access is increased to preventive, restorative, and emergency oral health care services.

Objective 5.1: The legislative intent to increase the supply and distribution of dental services through creation of new dental providers and appropriate utilization of the entire dental team is achieved.

Suggested strategies

(See Minnesota statutes 150A.10 Subd.1a., 150A.105 and 150A.106)

- A. Maximize the opportunity that Minnesota has to provide positive leadership in creating new oral health care providers and innovative workforce models.
- B. Support and engage with other agencies to research the impact of new and existing oral health care providers on improved access to services by collecting and analyzing outcomes data.
- C. Increase the number of dentists, health care facilities, programs, or nonprofit organizations that employ dental hygienists with collaborative agreements.
- D. Develop relationships with providers in older adult services settings (e.g., nursing homes, assisted living) to connect providers with elderly populations.

Objective 5.2: Increase by 10 percent the number of underserved Minnesotans who receive evidence-based preventive dental care, with emphasis on children under age one, low-income uninsured adults, people with developmental disabilities, pregnant women, children with special health care needs, low income and immigrant populations, those with chronic diseases, and individuals in long-term care facilities.

Suggested strategies

- A. Educate general dentists to be more comfortable caring for infants and toddlers (birth to three years old), making appropriate referrals, and using best practices.
- B. Work with state agencies and commissions to analyze issues (including funding) regarding care for children, adults, the aging, developmentally disabled, and special health care needs populations, low income and under insured, and participate in developing policy recommendations.
- C. Use Basic Screening Survey results to determine preventive service initiatives.
- D. Encourage local and county public health agencies to utilize dental hygienists in prevention programs.
- E. Identify and work with agencies engaged in dental programs to explore alternative delivery systems that improve communication with local dentists, improve sustainability, and increase continuity of care.
- F. Partner with agencies on a centralized website or helpline for the public to increase access to referral information and information on current systems in place for Minnesota health care programs and the uninsured.
- G. Develop compliance initiatives that increase comprehensiveness of oral health programs for children under age one, uninsured adults, people with developmental disabilities, children with special health care needs, and individuals in long-term care facilities.

Objective 5.3: Reduce the proportion of Minnesotans who experience difficulties, delays, or barriers to restorative oral health care service by 20 percent.

Suggested strategies

- A. Partner with state agencies that have been mandated to document the impact of existing and new Minnesota oral health care workforce models on improved access to restorative services using outcome data.
- B. Establish baseline information on barriers to oral health care involving target populations by conducting a statewide survey and adding questions to both the Basic Screening Survey and Behavioral Risk Factor Surveillance System regarding Minnesota's accessibility to dental care.
- C. Investigate best practices for sustainability of public health and safety net clinics.

Objective 5.4: Reduce the number of emergency room visits for dental related reasons by 15 percent.

Suggested strategies

- A. Develop and disseminate materials that educate caregivers about dental injuries and the appropriate response.
- B. Collaborate with hospitals and providers in older adult service settings to provide information on local public health dental programs so that patients presenting in emergency departments are provided with appropriate referral and preventive education information.
- C. Develop a campaign to educate the public about seeking professional dental care and guidance after an oral injury has occurred.
- D. Develop a campaign focused on oral injury prevention and promoting the appropriate use of mouth-protecting equipment in sports, e.g., mouth guards.
- E. Collaborate with hospital medical staff to ensure diagnostic codes are utilized for non-traumatic dental related emergency department visits and are coded correctly in order to establish baseline data.

Objective 5.5: Increase the number of individuals who receive oral and pharyngeal cancer screenings by 10 percent.

Suggested strategies

- A. Determine a baseline number of dental and medical professionals that currently integrate oral and pharyngeal cancer screenings into comprehensive exams.
- B. Emphasize the importance of screening for oral and pharyngeal cancer and how it can affect critical functions, such as speaking, swallowing and eating.
- C. Increase the number of health care providers who deliver consistent and appropriate messages to help people quit smoking.
- D. Partner with the National Cancer Institute on developing health care provider competencies in prevention, diagnosis, and management of oral and pharyngeal cancers.
- E. Aid the American Cancer Society in incorporating oral and pharyngeal cancer screenings in the "Welcome to Medicare" physical examination.
- F. Promote the development of a community-based oral cancer prevention and early detection program.

Objective 5.6: Increase the proportion of local health departments that have an oral health program focused on prevention.

Suggested strategies

- A. Build capacity in local health departments by providing technical expertise and evidence-based oral health information.
- B. Determine a baseline number of local health departments that currently have an oral health care program.
- C. In collaboration with existing local oral health care program personnel, identify local health departments that do not have an oral health program and offer resources and guidance in creating and structuring their own oral health component.

- D. Partner with the Local Public Health Association of Minnesota to convene a conference on integrating oral health into local public health systems.

Objective 5.7: Promote policies and programs that ensure that 95 percent of Minnesotans have access to a dental care provider within a 90-minute drive or by public transportation from their place of residence.

Suggested strategies

- A. Conduct at least one public health/nonprofit clinic pilot project to investigate and gather data on current equitable distribution of services.
- B. Promote school-based programs and older adult service settings.
- C. Determine existing excess provider capacity and transportation services available to patients, including the uninsured and public programs patients.
- D. Work with local safety net programs in supporting existing and creating new volunteer programs that provide patients transportation to and from dental and health appointments.
- E. Convene a conference focused on policy tools that will help achieve equity in population health, featuring best practices and expert panel presentations, moderated discussions, as well as working groups.
- F. Reduce supervision barriers and increase utilization of collaborative agreements.

Objective 5.8: Increase partnerships that explore effective policy initiatives to stabilize the availability of oral health care services to the most vulnerable populations.

Suggested strategies

- A. Develop a planning checklist to move forward strategically once consensus about priorities is achieved.
- B. Increase data and information gathering efforts that support policy decisions among stakeholders, oral health care providers and primary care providers.
- C. Promote philanthropic programs among specialty dental organizations.

increase networking and information sharing among collaborative providers.

Objective 6.4: Ensure that at least 90 percent of oral health provider education programs incorporate health literacy concepts and cultural competency training into curriculum.

Suggested strategies

- A. Promote the CDC health literacy certification program.
- B. Disseminate information about health literacy and promote the use of a usability checklist that ensures that oral health information meets health literacy principles.
- C. Partner with professional associations to create continuing education courses for oral health professionals focused on health literacy and cultural competency concepts.
- D. Seek ways to enhance or support opportunities for community health workers to promote culturally sensitive oral disease prevention strategies in their communities.

Objective 6.5: Increase cultural competency training related to oral health in health professional education programs.

Suggested strategies

- A. In collaboration with existing local cultural organizations, develop and disseminate cultural competency educational materials for health professionals.
- B. Encourage the Board of Dentistry to focus a self-assessment on the subject of cultural competency.
- C. Partner with Minnesota state-supported higher education institutions to provide community outreach and cultural center personnel with a basic oral health education course.

Objective 6.6: Encourage all oral health provider education programs to focus on recruiting classes that reflect the state's population diversity.

Suggested strategies

- A. Strengthen existing and develop new outreach programs that recruit future dental professionals from diverse backgrounds.



Goal 6: The dental workforce is prepared for and addresses the oral health needs of all Minnesotans.

Objective 6.1: Promote innovative and effective oral health care delivery practice models for rural populations.

Suggested strategies

- A. Continue to work with Area Health Education Centers to explore and strengthen strategies that will achieve better retention and distribution of oral health care providers graduating from state supported institutions.
- B. Develop mentoring programs for the dental workforce.
- C. Investigate the role of teledentistry.

Objective 6.2: Promote broader discussion of ways the social compact between dentistry and society can be reinforced.

- A. Develop a Patient Centered Principles document.
 - i. Create a document that states principles and objectives that are patient centered.
 - ii. Develop bullet points about what patients need for oral care as part of general health care.
 - iii. Create a list of evidence-based studies that support oral health effects on general health.
- B. Convene workshops with medical providers.
- C. Promote continuing education programs.

- D. Encourage the creation of at least one internship opportunity for students and one work experience for professionals.

Objective 6.3: Collaborate with agencies and educational institutions to gather and disseminate information on practice models, collaborative agreement dental hygiene practice, and the dental therapist/advanced dental therapist management agreement.

Suggested strategies

- A. Maximize utilization of tools available: support infrastructure for collaborative agreement hygienists and restorative function allied personnel, dental therapist and advanced dental therapist.
 - i. Develop a checklist on payment protocols and credentialing.
 - ii. Develop a fact sheet/resource sheet describing definition of, roles of, and scope of practice levels of all oral health professionals to be used by the profession, payers, and the public to understand the current state of oral health care delivery.
- B. Convene an educational forum or summit of collaborative practice hygienists and dentists to promote collaborative practice.
- C. Develop a conference on advancing the implementation of workforce models.
- D. Identify and develop a method for tracking current collaborative practice agreements and collaborative management agreements in order to

- B. Seek funding for the expansion of dental education scholarships and loan repayment efforts.

Priority: Surveillance

Monitoring the status of oral diseases among Minnesotans is the underpinning to improving oral health. Public health surveillance is the ongoing, systematic collection, analysis, interpretation and dissemination of data regarding a health related event. In turn, data inform policy development and target public health initiatives to improve the health of all Minnesotans.

While baseline data for third graders is now available through the 2010 Basic Screening Survey, the state must continue to monitor the status of oral health to continually evaluate and refine prevention programs. In addition, there are large data gaps that hamstringing efforts to better target resources. The most significant lack of data is on caries incidence, service coverage, and disease estimates in certain pockets of the population. Better data is needed on dental caries prevalence and untreated caries among very young children and adolescents, along with the adult population, particularly the older adults living in elder care facilities. Data is limited on the burden of disease among migrant and native populations, school-based sealant coverage, oral birth defects, and pregnant women.

Despite these gaps, several indicators related to the objectives outlined in this plan are collected through existing surveillance systems. The Minnesota Oral Health Surveillance System (MNOHSS) is the state's main mechanism for monitoring trends in morbidity in early childhood caries, edentulism (being toothless), and oral and pharyngeal cancer. In addition, MNOHSS data informs the efficacy of preventive services such as dental sealants, community water fluoridation and the use of dental services. MNOHSS uses the following

secondary sources to generate oral health indicators:

- Behavioral Risk Factor Surveillance System (BRFSS)
- Dental workforce data from Office of Rural Health and Primary Care (Minnesota Department of Health)
- Hospital discharge records from Minnesota Hospital Association
- Medicaid data from Department of Human Service (DHS)
- Medical and Expenditure Panel Survey (MEPS)
- Minnesota Birth Defects Information System (BDIS)
- Minnesota Cancer Surveillance System (MCSS)
- Minnesota Student Survey (equivalent of National Youth Risk Behavior Surveillance System (YRBSS)
- Pregnancy Risk Assessment and Monitoring System (PRAMS)
- U.S. Census Bureau (demographic data)
- Water Fluoridation Reporting System (WFRS)

To assist public health efforts across the state, the Oral Health Program has been developing a public, web-based data system to assess and monitor the status of oral disease in Minnesota based on the following set of oral health indicators:

- Demographic data including state population by age
- Percentage of population below 100% and 200% of poverty level; total number of schools
- Percentage of schools with 50% or more of students eligible for the free and reduced price meal program
- Percentage of total county population enrolled in a Minnesota Health Care Program
- Number and percentage of Minnesota Health Care Programs enrolled-population with a dental visit

- Percentage of population served by optimally fluoridated water
- Number of licensed dental professionals
- Ratio of Minnesota Health Care Program enrollees to dentists who treat them
- Number of Dental Health Professional Shortage Areas based on "facility"

To address the data gaps in the current system, efforts are being made to convene partners and stakeholders to identify and prioritize data needs and mapping out ways to disseminate this information to policy makers and public health officials.

Goal 7: Access to population statistics, population-level oral health surveillance information, and aggregate data on oral health indicators is readily available to all.

Objective 7.1: Collaborate with data partners and key stakeholders to identify key oral health indicators and to increase the visibility and effectiveness of the Minnesota Oral Health Surveillance Advisory Group.

Suggested strategies

- A. Convene the Advisory Group annually.
- B. Develop and maintain data sharing agreements with partners.
- C. Acquire and analyze data, and interpret findings.



- D. Prepare and publish the Minnesota Surveillance Plan and the Burden of Oral Disease in Minnesota documents.
- E. Review, update and publish the Burden of Oral Disease document regularly.
- F. Evaluate progress, trends and direction.

Objective 7.2: Develop a secure data system that identifies and tracks key oral health indicators and has the capability to provide specific data affecting policy and existing programs upon request.

Suggested strategies

- A. Develop quality assurance measures to ensure accuracy.
- B. Continue to develop and implement the Minnesota Oral Health Surveillance System (MNOHSS).
- C. Share summarized surveillance information with local public health, educational institutions, insurers, social services, policy makers, community-based organizations, community health clinics, and other partners as appropriate.
- D. Increase the capacity of the MDH Oral Health Program to serve as a primary resource for oral health information by providing links to educational materials, oral health initiative information, and oral health curriculum.
- E. Monitor and respond to data requests.
- F. Ensure data security/confidentiality.
- G. Explore use of (or develop) a secure web-based data entry portal (i.e., a web page for sealant grantees to enter data).

Objective 7.3: Increase capacity of the Minnesota Oral Health Program to collect data and conduct surveillance activities.

Suggested strategies

- A. Investigate ways to sustain the surveillance activities of the oral health program.
- B. Provide staff and stakeholder training opportunities that increase the ability of the program to manage large data projects.

- C. Evaluate surveillance and outcome data.
- D. Increase support for acquiring data and increase demand for oral health data.

Future Action: Next Steps

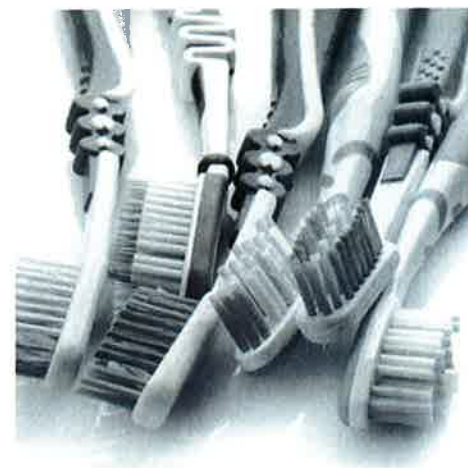
Minnesota is well poised to meet the oral health needs of its residents. As this report has shown, oral health is dependent on multifaceted, interrelated factors that range from personal care and awareness to the changing role of dental and health providers, and from the complexities of the health care system to a more integrated approach to total health. As we move forward to reduce both the prevalence and disparities of oral diseases, a full deployment of a varied dental workforce combined with proven prevention strategies and integration with other health organizations will be critical.

To implement the Minnesota Oral Health Plan, MDH's Oral Health Program is working closely with the Minnesota Oral Health Coalition and other key partners. Working groups have been organized to advance the strategies outlined in this plan while creating a process for the continuous review and revision of the plan. Pressing issues are being addressed to move the work forward in the following key areas.

Dental Sealants

The Minnesota school-based sealant program is a proven strategy that prevents caries among young children. The program targets high-risk, second grade students at schools where more than 50 percent of students are eligible for the Free or Reduced Price Lunch Program (FRL), a proxy for identifying low-income children. The Oral Health Program is working to expand and improve the program by:

- Identifying schools that need sealant programs and have the greatest need



(>50% FRL) so school-based dental sealant providers can target their services to those schools.

- Fostering relationships with school-based dental sealant service providers to help families navigate both the dental insurance and dental care systems so children receive their dental benefits and are connected to a "dental home" for ongoing care and treatment.
- Communicating with school boards, district superintendents and school nurses to smooth the way for establishing sealant programs at their schools.
- Establishing a strong relationship with the local dental community to facilitate the ongoing dental care needs of children.
- Securing additional funding to reach more high-needs children across the state.

Water Fluoridation

In collaboration with stakeholders and other MDH programs, the Oral Health Program is working to maintain the state's high community water fluoridation status. Grant programs are increasing the number of Minnesotans who receive the oral health benefits of optimally fluoridated drinking water. The grants enable community public water systems to: improve aging fluoride treatment



infrastructures; improve or replace aging analytical equipment; and assist with fluoridation implementation. Efforts include:

- Ensuring Minnesota communities are receiving proper levels of fluoridated water by securing and providing funding to municipalities to upgrade or replace water fluoridation equipment. More than 50,000 people are being better served in Bayport, Centerville, Murdock, North Mankato, and Victoria as a result of MDH funding and technical assistance. MDH is continuing to seek sustainable funding sources to provide additional communities with equipment updates on an ongoing basis.
- Supporting quality assurance by providing technical training to community water operators and engineers statewide so they can keep pace with the latest engineering,

operation, and management practices for maintaining new fluoridation water systems.

- Highlighting the critical role water fluoridation has in public health by convening a panel of fluoridation experts (educators, scientists, water workers, providers, communications) to develop a plan to raise awareness among dental and public health professionals, policy makers, the public, and even water fluoridation operators themselves about the importance of water fluoridation to oral and overall health.

Increasing Public Insurance Programs Use Rates

To ensure low-income children are getting the dental care they need, the Oral Health Program is working with the Minnesota Department of Human Services and the Centers for Medicare & Medicaid Services to develop training materials and provide technical assistance to health care providers. These programs focus on improving diagnostic dental services, early referral, primary care integration, and guidance on prevention strategies during well child visits. These efforts will help the state meet the national and local leading health indicators for increasing dental visits and use of the oral health care system by low-income children.

Specific strategies include:

- Advocating for Child and Teen Checkups' protocols that assess children's dental health status and needs by age one and establishing a "dental home" for them through immediate referrals to a dentist.
- Providing technical support to child health consultants and training materials for Child and Teen Checkups to enable primary care and dental providers to increase the rates of fluoride varnish applications among at-risk children.

- Working with dental providers to become more comfortable in pediatric dentistry and proficient with working with very young patients (aged one to three years).

Health Care Integration

The advent of the "health care home" concept is a promising model for providing more integrated and effective health care for underserved populations. Health care homes are focused on early detection and addressing the spectrum of patients' health needs (physical, dental, mental), while lowering health care costs. Health integration is also accomplished through other strategies that work to change policies to reduce risk factors to oral disease. To ensure that oral health is considered a high-priority, work is focused on:

- Raising awareness of the importance of oral health to overall health among health care and public health leaders by meeting with stakeholders and finding opportunities to integrate oral health into their strategic plans, policies and protocols.
- Collaborating with state-level, obesity initiatives to decrease access to sugar-sweetened beverages through policies that would increase taxes and pricing on these beverages and encourage drinking tap water.
- Working with the Minnesota Physical Activity and Nutrition Program to include height and weight measurements of third graders in the Minnesota Basic Screening Survey to investigate and analyze data on the relationship of healthy weight to oral health.
- Funding a pilot project with Head Start, an early childhood education program for low-income children, to embed on-site dental prevention services and referral system to a "dental home" for ongoing care.

New Dental Providers and Workforce Models

Minnesota has developed innovative solutions to improving access to dental care through the creation of new dental provider types and expanding how and where dental treatment and preventive services can be delivered. However, many barriers still exist in maximizing these dental care options so that low-income children, adults and the elderly get the care they need. To this end, the Oral Health Program is:

- Increasing awareness and addressing misperceptions among dentists, hygienists, dental therapists (DTs), and advanced dental therapists (ADTs) about how collaborative agreements and new service models can be integrated into their practice; resources include free, online courses addressing these issues.
- Promoting to dental professionals and policy makers the Oral Health Program's "Collaborative Agreement Dental Hygiene Assessment" report which includes findings and recommendations for increasing the use of this dental service model to improve access to preventive dental services.
- Ensuring that advanced dental therapist (ADT) services are widely available to those in greatest need by funding the development of a refresher course for ADT graduates to attain their advanced dental therapy certification so they can deliver dental care.
- Seeking funding to create incentives for dentists to partner in innovative employment models for DTs and ADTs.
- Assessing whether the penetration of DTs and ADTs into the workforce will indeed improve Minnesotans' access to more affordable dental care or if barriers persist that need to be addressed.



- Funding outreach programs through the University of Minnesota School of Dentistry to recruit more people from diverse backgrounds into dental careers by working with Area Health Education Centers, Minneapolis Public Schools, rural communities, and providing dental students with rotation experiences through Community Health Centers and underserved rural dentistry clinics.
- Providing technical assistance and learning opportunities to organizations on how to use MNOHSS to inform policy and practice, set benchmarks, implement evidence-based interventions, and measure impact.
- Leveraging funding to fill in data gaps and to continually refine intervention strategies to better meet the needs of underserved populations. The most pressing data gaps are dental caries incidence and prevalence among toddlers and adolescents; older adults living in elder care facilities; migrant and native populations; school-based sealant coverage; and pregnant women.

Surveillance

Identifying and addressing the barriers to oral health is a complex process requiring a variety of integrated solutions involving private-public partnerships and a commitment to prevention. To assist state and local health agencies to work more efficiently and effectively, the Oral Health Program has been developing the state-wide Minnesota Oral Health Surveillance System (MNOHSS). MNOHSS provides easily accessible county-level data on more than a dozen oral health indicators with mapping functionality that uses Health Professional Shortage Area (HPSA) data. To ensure this dynamic tool is employed to its full capacity, the Oral Health Program is:

- Working to widely promote MNOHSS to public health professionals, health care providers and other stakeholders.

To stay the course on these initiatives, the Minnesota Oral Health Program is committed to regularly reporting on the progress of these efforts and will convene stakeholders to address the changing oral health needs of Minnesotans across the state. The Minnesota Oral Health Program looks forward to partnering with even more organizations in *advancing optimal oral health for all Minnesotans*.

Appendices

Appendix A: Minnesota Oral Health Plan Goals, Objectives and Strategies

Goal 1: Minnesota's oral health infrastructure is stable and sustained.

Objective 1.1: Fully integrate the Oral Health Program into the Minnesota Department of Health Infrastructure.

Suggested strategies

- A. Increase the sustainability of the state oral health program and support the state oral health program as the central agency for oral health promotion.
- B. Continue to apply for grants and increase the amount of grant money obtained.
- C. Promote integration opportunities with other funded programs.

Objective 1.2: Support development of a strong Minnesota Oral Health Coalition that works closely with the Minnesota Department of Health.

Suggested strategies

- A. Support the coalition in determining leadership structure and other administrative and organizational issues related to its development into a self supporting organization.
 - i. Obtain best practices guidance from more mature organizations, access assistance available from National Association of Oral Coalitions and coalition experts e.g. "Coalitions Work", etc.).
 - ii. Sustainability of Oral Health Coalition; establish development fund.
 - iii. Inform membership.
 - iv. Summarize in kind support from MDH.

- B. Complete a vision, mission, goals (identity) process.
- C. Work with the coalition leadership to explore pros and cons of establishing the Minnesota Oral Health Coalition as a non-profit organization (501 (C)3 status).
- D. Utilize the CDC framework and other recognized coalition resources to increase diversity of the membership in the coalition.
- E. Develop an independent, interactive web presence for the Minnesota Oral Health Coalition.

Objective 1.3: Develop and sustain collaborative partnerships to implement the Minnesota Oral Health Plan.

Suggested strategies

- A. Create new partnerships that ensure diversified funding is available to implement the Minnesota Oral Health Plan.
- B. Identify innovative action plans that are easily adopted by stakeholders.

Objective 1.4: Seek commitment for long-term data collection and surveillance on Minnesota's oral health indicators.

- A. Investigate the cost (along with data and information technology experts and programmers) to create an interactive web-based data source known as Minnesota Oral Health Surveillance System (MNOHSS).
- B. Prepare planning and implementation process including data documentation to Minnesota Technology Services.
- C. Approach potential funders or add to grant proposals to launch a full-scale sustainable interactive data portal.



Objective 1.5: Seek funding sources that the support review, professional evaluation, and updates to the current Minnesota Oral Health Plan.

Suggested strategies

- A. Oral health leaders and stakeholders seek sustainable funding and program changes to implement the plan.

Objective 1.6: Assess opportunities for policy change through environmental analysis tools such as the environmental and policy scan and share results with decision makers.

Suggested strategies

- A. Utilize resources available through the CDC to support a facilitated process for oral health stakeholders to join together to make decisions about priorities based on suggested criteria.

Goal 2: Strategies are

implemented that reduce oral disease and mitigate risks.

Objective 2.1: Determine the baseline for the number of providers who use standardized, evidence-based oral disease risk assessment tools.

Suggested strategies

- A. Implement an educational campaign that raises understanding of risk assessment, benefits of using risk assessment, and introduces tools used to assess risk.
- B. Promote use of risk assessment (periodontal disease, diabetes, tobacco use, etc.) among medical and dental providers.
- C. Collect data that is valid and reliable on current usage of tools for caries risk assessment in practice.
- D. Choose a tested caries and periodontal disease risk assessment tool to use in Minnesota that is valid and reliable.
- E. Use the Minnesota Oral Health Surveillance System (MNOHSS) as a clearinghouse for sharing standardized information on caries and periodontal disease risk in Minnesota.

Objective 2.2: Reduce caries experience in Minnesota children.

Suggested strategies

- A. Partner with Maternal and Child Health, pre-school, Early Head Start and Head Start oral health programs, early care and education settings on tooth brushing promotion programs targeted toward pregnant women and children under the age of five (review National Association for the Education of Young Children accreditation standards for oral health).
- B. Partner with Early Head Start and Head Start on oral health programs that help meet Head Start and Child and Teen Checkups (the Minnesota version of Early Periodic Screening, Diagnosis, and Treatment) requirements.

- C. Develop and offer trainings for preschool staff, Head Start coordinators and home visitors to recognize signs of and identify risk factors for childhood caries.
- D. Promote fluoride varnish programs as part of immunization and well child visits.
- E. Increase programmatic coordination between risk-reduction programs, e.g., preschool and Women, Infants and Children (WIC) programs.
- F. Include oral health screening requirements in childhood screenings.
- G. Educate caregivers of infants/toddlers about appropriate amounts of topical fluoride or fluoride toothpaste.
- H. Increase availability and ease of access to oral health supplies.

School-based Dental Sealant Programs

Objective 2.3: Develop and coordinate comprehensive, statewide school-based prevention programs that target high-risk children.

Suggested strategies

- A. Conduct the statewide third grade Basic Screening Survey at least once every five years.
- B. Convene a school-based sealant work group that includes providers, school representatives, school nurses, public health professionals, health plans, Minnesota public programs representatives, board of dentistry, researchers, community representatives, parent representatives, and parent-teacher associations.
 - i. Conduct a needs assessment and compile information on existing sealant activities in the state.
 - ii. Seek and acquire sustainable financial support, i.e., foundations, Title V funding, industry (3M, dental supply companies), Smiles Across Minnesota, Oral Health America, etc.
 - iii. Create and publish a comprehensive state sealant plan.
 - iv. Create a variety of easily



understood messages targeted to parents/caregivers about efficacy and safety of pit and fissure sealants, why they are needed and the importance of sealants in caries prevention.

- C. Develop parameters for and post a request for proposal (RFP) for at least five school-based sealant mini-grant projects.
 - i. Plan and conduct projects that provide documentation of components of successful sealant programs and identify barriers to sustainability.
 - ii. Promote limited authorization/collaborative practice as a model for school-based programs.
- D. Convene a transdisciplinary panel for review and development of a comprehensive coordinated plan for fluoride varnish programs and to develop quality improvement initiatives, i.e., through learning collaboratives and health care home initiatives.
- E. Create an education campaign about how fluoride works and the importance of the appropriate use of fluoride varnish in caries prevention.

Water Fluoridation

Objective 2.4: Ensure that the percentage of public water supply systems providing fluoridated water are within the optimal range and meet the CDC optimal monitoring and surveillance requirements of meeting or exceeding 90 percent.

Suggested strategies

- A. Collect community water fluoridation information and submit data to the CDC on 510 reports.
- B. Identify ways to provide support to communities to maintain or update aging fluoridation equipment.
- C. Support statewide educational campaigns that promote drinking tap water.
- D. Educate water works operators about the importance of the water fluoridation process and its link to oral health.
- E. Recognize water workers and engineers as oral health leaders on a consistent basis.

Objective 2.5: Ensure that at least 50 percent of Minnesota's schools have achieved oral health targets.

Suggested strategies

- A. Remove cariogenic foods and beverages from vending machines.
- B. Increase the number of non-cariogenic food items accessible outside the lunch program (vending machines, fund raisers, concessions, classroom celebrations and a la carte) in Head Start and school menus.
- C. Increase tobacco use prevention/

cessation and nutrition information in health education programs.

- D. Provide resources to strengthen curricula that emphasize how healthy eating can improve and maintain oral health.
- E. Reduce the impact of soda/beverage marketing by educating schools to resist marketing strategies.
- F. Promote the understanding of the preventive properties of xylitol gum and xylitol products and their proper use.
- G. Partner with the Minnesota School Nutrition Association and the Minnesota Department of Education to collect data on candy and pop available in schools in order to tailor oral health campaigns to school needs.

Objective 2.6: Promote awareness of the effect of diet and nutrition on oral health among hospital food service directors, older adult service establishments, and nutrition staff.

Suggested strategies

- A. Partner with the Minnesota Hospital Association (MHA), hospital Food Service Directors, and Registered

Hospital Dieticians to provide information about creating tooth-healthy menus and increasing health snack choices for patients, visitors, staff, and in vending machines.

- B. Provide educational sessions at MHA conferences about the relationship of diet to dental disease.
- C. Promote partnerships with assisted living and nursing home providers and organizations to increase understanding about the impact of diet on the oral health of older adults.



Goal 3: Oral health literacy is increased across all ages and cultures.

Objective 3.1: Increase oral health evaluation and caregiver education in early childhood screenings, vaccination visits, episodic care visits, prenatal, and Child and Teen Checkups.

Suggested strategies

- A. Support health literacy and cultural competency training for health professionals in the community, including health care providers and public health officials.
- B. Provide technical assistance to those interested in becoming proficient in patient-centered literacy skills.
- C. Educate prenatal and maternal health care providers about the importance of increasing oral health literacy

among pregnant women so they are well informed about caries etiology, caries prevention, and infant oral health care.

- D. Create a campaign to increase understanding regarding the importance of tooth brushing and sponsor distribution of oral health information and materials in prenatal and maternal care programs.

Objective 3.2: Build awareness of oral disease prevention strategies and increase oral health knowledge in school-based health systems.

Suggested strategies

- A. Strengthen partnerships with and provide resources to the Minnesota Department of Education and Minnesota school nurses to evaluate oral health curricula (including early

childhood and after school programs) on evidence-based strategies.

- B. Develop and disseminate information about the efficacy of pit and fissure sealants, water fluoridation, topical fluoride therapy and other strategies that prevent and control oral disease.
- C. Investigate programs to introduce evidence-based xylitol therapy in early childhood programs and schools.
- D. Partner with the Minnesota Department of Health Injury and Violence Prevention Unit to develop promotional programs that focus on preventing and reducing oral injury.
- E. Develop and disseminate information to parents and schools about fluoride varnish, sealants and the health care home.

Objective 3.3: Increase exposure to oral health knowledge through targeted and culturally sensitive campaigns that focus on prevention strategies.

Suggested strategies

- A. Develop and disseminate fluoridation messages that provide culturally and age appropriate information to population groups, adults, and children. e.g. “safe to drink fluoridated tap water” messages.
- B. Increase oral health literacy among young adults emphasizing smoking, diet, smokeless tobacco, alcohol and tobacco, periodontal disease and importance of oral care.

- C. Increase oral health literacy among the elderly and their caregivers; emphasize medications that increase xerostomia (dry mouth), root caries etiology, periodontal disease and oral cancer.
- D. Ensure educational materials are available in multiple languages, including visuals for the non-reading population.
- E. Create electronic media and monitor hits/visits to web pages and internet sites.

Objective 3.4: Increase awareness of oral health among policy and decision makers about the benefits of oral disease prevention.

Suggested strategies

- A. Engage legislators in an annual oral health initiatives forum.
- B. Partner with the Minnesota Oral Health Coalition to support oral health promotion policies, tobacco control policies, and to promote policy change.
- C. Identify and utilize oral health resources in the state to target areas of greatest need.
- D. Increase understanding of federal mandates and funding, or lack of funding.

Goal 4: Professional integration is enhanced between oral health care providers and other providers in the broader health care system.

Objective 4.1: Promote the understanding and development of the health care home concept.

Suggested strategies

- A. Create and nurture non-traditional partnerships in oral health to establish a coordinated strategic direction.
- B. Gather information and evaluate the effect of reimbursements/incentives for improving care.
- C. Increase training opportunities in oral health for non-dental professionals (public health nurses, dietitians, health plan case managers, community health workers, and interpreters) that build patient-centered skills (preventive, therapeutic, and remedial) and provide technical assistance for working with patients, clients and the public.
- D. Increase the number of local public health agencies that address oral health.

- E. Increase integration activities and partnerships with nutrition, obesity, tobacco, alcohol, etc. (i.e., American Dietetic Association, American Lung Association, American Heart Association).
- F. Plan demonstration projects that create innovative health care home models.
- G. Work with educators to investigate the potential role of teledentistry and policy makers to address payment issues.

Objective 4.2: Increase the number of non-dental provider education programs (physician’s assistant, nurse practitioner, dietitians, medical schools, and nursing schools) that incorporate oral health into their curriculum.

Suggested strategies

- A. Partner with the Minnesota and American Pediatric Association and work to determine current continuing medical education curriculum that encompasses an oral health component.
- B. Work with the University of Minnesota Continuing Education Division to create continuing medical education curriculum focused on oral health.
- C. Use evidence-based strategies to develop core competencies in oral health within educational settings.



- D. Provide one conference in each of the next two years for oral health and medical providers that focuses on:
 - i. Oral and systemic health interrelatedness.
 - ii. Understanding and promoting risk assessment of oral and systemic health.
 - iii. Participate in “Many Faces Conference” and Accountable Care Conference with medical and dental professionals.

Objective 4.3: Develop collaborative opportunities throughout the health care community by educating and training physicians, dentists, nurses, hygienists, nurse practitioners, dental assistants, dental therapists, and social workers to work as a single team addressing oral health disparities and unmet dental needs of the underserved.

Suggested strategies

- A. Promote research on the impact of oral health on overall health.
- B. Support the development and evaluation of programs that promote disease prevention and increase collaborative health care.
- C. Provide incentives for allied dental personnel to work in medical settings under collaborative supervision by a licensed dentist.
- D. Reduce barriers to dental hygienists working in public health agencies and other settings.
- E. Move primary oral health care into every obstetrics, primary care, family practice, pediatrics, and internal medicine practice in Minnesota by incorporating "The mouth is a part of the body" concept.
- F. Investigate further development of innovative collaborative strategies for serving elderly and youth populations with different provider types.
- G. Explore the development of a centralized network for identifying excess capacity, sharing resources, and communicating needs that utilizes the public health infrastructure.

Objective 4.4: Promote collaboration among dental providers and medical care providers that increase information sharing, understanding of eligibility requirements, and access to and utilization of oral health care benefits.

Suggested strategies

- A. Create demonstration projects that gather and analyze preventive services utilization data and propose new models that coordinate collaboration between dental and medical providers and eliminate disparities.

Objective 4.5: Promote the adoption and meaningful use of the electronic dental record.

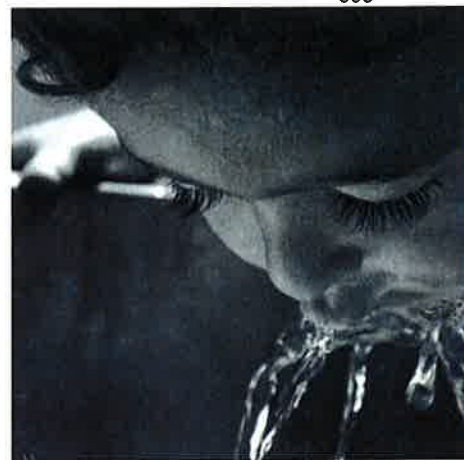
Suggested strategies

- A. Disseminate information about the Office of the National Coordinator efforts to create standardized guidelines for the utilization of Health Information Technology and reporting.
- B. Improve collaboration and follow up by aligning with at least two objectives of the local and national Office of the National Coordinator for Health Information Technology.
- C. Seek funding to create incentives for private and public health dental and medical systems to create and adopt centralized network tools.

Objective 4.6: Call for the development and promotion of clinical preventive oral health guidelines for use in settings outside the dental office: medical and long-term care, prison, juvenile, and hospital settings.

Suggested strategies

- A. Support and promote the development and use of dental diagnostic codes.
- B. Develop partnerships that integrate oral health into the current case management system.
- C. Promote public health research, standardized protocols for care, and use of evidence-based practices.
- D. Promote inclusion of oral evaluation in care guidelines for the aging and persons with diabetes and special health care needs.
- E. Create a web-based tracking and referral mechanism for oral health information and treatment.
- F. Promote Health Insurance Portability and Accountability Act compliant communications between dental providers and primary care providers (family medicine, obstetrics, pediatrics, internal medicine, etc.) and allied health professionals, (dietitians, pharmacists, etc.) when assessing and referring for medical conditions and non-dental issues.



Objective 4.7: Increase the number of primary care medical providers who integrate prevention of oral disease as part of overall health care by 10 percent for patients of all ages.

Suggested strategies

- A. Create a recognizable symbol and/or standardized message that captures the concept of the interrelatedness of oral health and overall health.
- B. Develop a marketing campaign targeted to medical providers that promotes oral health as integral to overall health.
- C. Determine a baseline number (early adopters) and evaluate barriers to the utilization of oral disease prevention strategies by medical practitioners.
- D. Develop an integrated approach among medical and dental providers that promotes oral exams/evaluation, referral, and access to oral health care by age one.
- E. Promote treatment and diagnostic information sharing between pediatricians, physicians and dentists.

Goal 5: Access is increased to preventive, restorative, and emergency oral health care services.

Objective 5.1: The legislative intent to increase the supply and distribution of dental services through creation of new dental providers and appropriate utilization of the entire dental team is achieved. (See Minnesota statutes 150A.10 Subd.1a., 150A.105 and 150A.106)

Suggested strategies

- A. Maximize the opportunity that Minnesota has to provide positive leadership in creating new oral health care providers and innovative workforce models.
- B. Support and engage with other agencies to research the impact of new and existing oral health care providers on improved access to services by collecting and analyzing outcomes data.
- C. Increase the number of dentists, health care facilities, programs, or nonprofit organizations that employ dental hygienists with collaborative agreements.
- D. Develop relationships with providers in older adult services settings (e.g., nursing homes, assisted living) to connect providers with elderly populations.

Objective 5.2: Increase by 10 percent the number of underserved Minnesotans who receive evidence-based preventive dental care, with emphasis on children under age one, low-income uninsured adults, people with developmental disabilities, pregnant women, children with special health care needs, low income and immigrant populations, those with chronic diseases, and individuals in long-term care facilities.

Suggested strategies

- A. Educate general dentists to be more comfortable caring for infants and toddlers (birth to three years old), making appropriate referrals, and using best practices.

- B. Work with state agencies and commissions to analyze issues (including funding) regarding care for children, adults, the aging, developmentally disabled, and special health care needs populations, low income and under insured, and participate in developing policy recommendations.
- C. Use Basic Screening Survey results to determine preventive service initiatives.
- D. Encourage local and county public health agencies to utilize dental hygienists in prevention programs.
- E. Identify and work with agencies engaged in dental programs to explore alternative delivery systems that improve communication with local dentists, improve sustainability, and increase continuity of care.
- F. Partner with agencies on a centralized website or helpline for the public to increase access to referral information and information on current systems in place for Minnesota health care programs and the uninsured.
- G. Develop compliance initiatives that increase comprehensiveness of oral health programs for children under age one, uninsured adults, people with developmental disabilities, children with special health care needs, and individuals in long-term care facilities.

Objective 5.3: Reduce the proportion of Minnesotans who experience difficulties, delays, or barriers to restorative oral health care service by 20 percent.

Suggested strategies

- A. Partner with state agencies that have been mandated to document the impact of existing and new Minnesota oral health care workforce models on improved access to restorative services using outcome data.
- B. Establish baseline information on barriers to oral health care involving target populations by conducting a statewide survey and adding questions to both the Basic Screening Survey and Behavioral Risk Factor Surveillance System regarding

Minnesota's accessibility to dental care.

- C. Investigate best practices for sustainability of public health and safety net clinics.

Objective 5.4: Reduce the number of emergency room visits for dental related reasons by 15 percent.

Suggested strategies

- A. Develop and disseminate materials that educate caregivers about dental injuries and the appropriate response.
- B. Collaborate with hospitals and providers in older adult service settings to provide information on local public health dental programs so that patients presenting in emergency departments are provided with appropriate referral and preventive education information.
- C. Develop a campaign to educate the public about seeking professional dental care and guidance after an oral injury has occurred.
- D. Develop a campaign focused on oral injury prevention and promoting the appropriate use of mouth-protecting equipment in sports, e.g., mouth guards.
- E. Collaborate with hospital medical staff to ensure diagnostic codes are utilized for non-traumatic dental related emergency department visits and are coded correctly in order to establish baseline data.

Objective 5.5: Increase the number of individuals who receive oral and pharyngeal cancer screenings by 10 percent.

Suggested strategies

- A. Determine a baseline number of dental and medical professionals that currently integrate oral and pharyngeal cancer screenings into comprehensive exams.
- B. Emphasize the importance of screening for oral and pharyngeal cancer and how it can affect critical functions, such as speaking, swallowing and eating.
- C. Increase the number of health care providers who deliver consistent and

appropriate messages to help people quit smoking.

- D. Partner with the National Cancer Institute on developing health care provider competencies in prevention, diagnosis, and management of oral and pharyngeal cancers.
- E. Aid the American Cancer Society in incorporating oral and pharyngeal cancer screenings in the “Welcome to Medicare” physical examination.
- F. Promote the development of a community-based oral cancer prevention and early detection program.

Objective 5.6: Increase the proportion of local health departments that have an oral health program focused on prevention.

Suggested strategies

- A. Build capacity in local health departments by providing technical expertise and evidence-based oral health information.
- B. Determine a baseline number of local health departments that currently have an oral health care program.
- C. In collaboration with existing local oral health care program personnel,

identify local health departments that do not have an oral health program and offer resources and guidance in creating and structuring their own oral health component.

- D. Partner with Local Public Health Association of Minnesota to convene a conference on integrating oral health into local public health systems.

Objective 5.7: Promote policies and programs that ensure that 95 percent of Minnesotans have access to a dental care provider within a 90-minute drive or by public transportation from their place of residence.

Suggested strategies

- A. Conduct at least one public health/nonprofit clinic pilot project to investigate and gather data on current equitable distribution of services.
- B. Promote school-based programs and older adult service settings.
- C. Determine existing excess provider capacity and transportation services available to patients, including the uninsured and public programs patients.
- D. Work with local safety net programs in supporting existing and creating new volunteer programs that provide

patients transportation to and from dental and health appointments.

- E. Convene a conference focused on policy tools that will help achieve equity in population health, featuring best practices and expert panel presentations, moderated discussions, as well as working groups.
- F. Reduce supervision barriers and increase utilization of collaborative agreements.

Objective 5.8: Increase partnerships that explore effective policy initiatives to stabilize the availability of oral health care services to the most vulnerable populations.

Suggested strategies

- A. Develop a planning checklist to move forward strategically once consensus about priorities is achieved.
- B. Increase data and information gathering efforts that support policy decisions among stakeholders, oral health care providers and primary care providers.
- C. Promote philanthropic programs among specialty dental organizations.

Goal 6: The dental workforce is prepared for and addresses the oral health needs of all Minnesotans.

Objective 6.1: Promote innovative and effective oral health care delivery practice models for rural populations.

Suggested strategies

- A. Continue to work with Area Health Education Centers to explore and strengthen strategies that will achieve better retention and distribution of oral health care providers graduating from state supported institutions.
- B. Develop mentoring programs for the dental workforce.
- C. Investigate the role of teledentistry.

Objective 6.2: Promote broader discussion of ways the social compact between dentistry and society can be reinforced.

Suggested strategies

- A. Develop a Patient Centered Principles document.
 - i. Create a document that states principles and objectives that are patient centered.
 - ii. Develop bullet points about what patients need for oral care as part of general health care.
 - iii. Create a list of evidence-based studies that support oral health effects on general health.
- B. Convene workshops with medical providers.

- C. Promote continuing education programs.
- D. Encourage the creation of at least one internship opportunity for students and one work experience for professionals.





Objective 6.3: Collaborate with agencies and educational institutions to gather and disseminate information on practice models, collaborative agreement dental hygiene practice, and the dental therapist/advanced dental therapist management agreement.

Suggested strategies

- A. Maximize utilization of tools available: support infrastructure for collaborative agreement hygienists and restorative function allied personnel, dental therapist and advanced dental therapist.
 - i. Develop a checklist on payment protocols and credentialing.
 - ii. Develop a fact sheet/resource sheet describing definition of, roles of, and scope of practice levels of all oral health professionals to be used by the profession, payers, and the public to understand the current state of oral health care delivery.

- B. Convene an educational forum or summit of collaborative practice hygienists and dentists to promote collaborative practice.
- C. Develop a conference on advancing the implementation of workforce models.
- D. Identify and develop a method for tracking current collaborative practice agreements and collaborative management agreements in order to increase networking and information sharing among collaborative providers.

Objective 6.4: Ensure that at least 90 percent of oral health provider education programs incorporate health literacy concepts and cultural competency training into curriculum.

Suggested strategies

- A. Promote the CDC health literacy certification program.
- B. Disseminate information about health literacy and promote the use of a usability checklist that ensures that oral health information meets health literacy principles.
- C. Partner with professional associations to create continuing education courses for oral health professionals focused on health literacy and cultural competency concepts.
- D. Seek ways to enhance or support opportunities for community health workers to promote culturally sensitive oral disease prevention strategies in their communities.

Objective 6.5: Increase cultural competency training related to oral health in health professional education programs.

- A. In collaboration with existing local cultural organizations, develop and disseminate cultural competency educational materials for health professionals.
- B. Encourage the Board of Dentistry to focus a self-assessment on the subject of cultural competency.
- C. Partner with Minnesota state-supported higher education institutions to provide community outreach and cultural center personnel with a basic oral health education course.

Objective 6.6: Encourage all oral health provider education programs to focus on recruiting classes that reflect the state's population diversity.

Suggested strategies

- A. Strengthen existing and develop new outreach programs that recruit future dental professionals from diverse backgrounds.
- B. Seek funding for the expansion of dental education scholarships and loan repayment efforts.

Goal 7: Access to population statistics, population-level oral health surveillance information, and aggregate data on oral health indicators is readily available to all.

Objective 7.1: Collaborate with data partners and key stakeholders to identify key oral health indicators and to increase the visibility and effectiveness of the Minnesota Oral Health Surveillance Advisory Group.

Suggested strategies

- A. Convene the Advisory Group annually.
- B. Develop and maintain data sharing agreements with partners.
- C. Acquire and analyze data, and interpret findings.
- D. Prepare and publish the Minnesota Surveillance Plan and the Burden of Oral Disease in Minnesota documents.
- E. Review, update and publish the Burden of Oral Disease document regularly.
- F. Evaluate progress, trends and direction.

Objective 7.2: Develop a secure data system that identifies and tracks key oral health indicators and has the capability to provide specific data affecting policy and existing programs upon request.

Suggested strategies

- A. Develop quality assurance measures to ensure accuracy.
- B. Continue to develop and implement the Minnesota Oral Health Surveillance System (MNOHSS).
- C. Share summarized surveillance information with local public health, educational institutions, insurers,

- social services, policy makers, community-based organizations, community health clinics, and other partners as appropriate.
- D. Increase the capacity of the MDH Oral Health Program to serve as a primary resource for oral health information by providing links to educational materials, oral health initiative information, and oral health curriculum.
- E. Monitor and respond to data requests.

- F. Ensure data security/confidentiality.
- G. Explore use of (or develop) a secure web-based data entry portal (i.e., a web page for sealant grantees to enter data).

Objective 7.3: Increase capacity of the Minnesota Oral Health Program to collect data and conduct surveillance activities.

Suggested strategies

- A. Investigate ways to sustain the surveillance activities of the oral health program.

- B. Provide staff and stakeholder training opportunities that increase ability of the program to manage large data projects.
- C. Evaluate surveillance and outcome data.
- D. Increase support for acquiring data and increase demand for oral health data.

Appendix B: Minnesota Populations by Race and Hispanic Ethnicity

Racial Groupings	2010 Census	Percentage of population	Change 2000-2010
White	4,524,062	85.3%	+2.8
Blacks, African American	274,412	5.2%	+58.9
American Indian Alaskan Native	60,916	1.1%	+10.8
Asian	214,234	4.0%	+50.9
Native Hawaiian/Other Pacific Islander	2,156	0.04%	+8.9
Other race	103,000	1.9%	+56.5
Two or more races	125,145	2.4%	+51.2
Ethnic Origin			
Hispanic or Latino origin*	250,258	4.7%	+74.5
Non-Hispanic or Latino	5,053,667	95.3%	+5.8
Total	5,303,925	100%	+ 7.8

*People of Hispanic ethnicity may be of any race

Source: Minnesota Department of Administration, Office of Geographic and Demographic Analysis, Office of the State Demographer / U.S Census; 2010

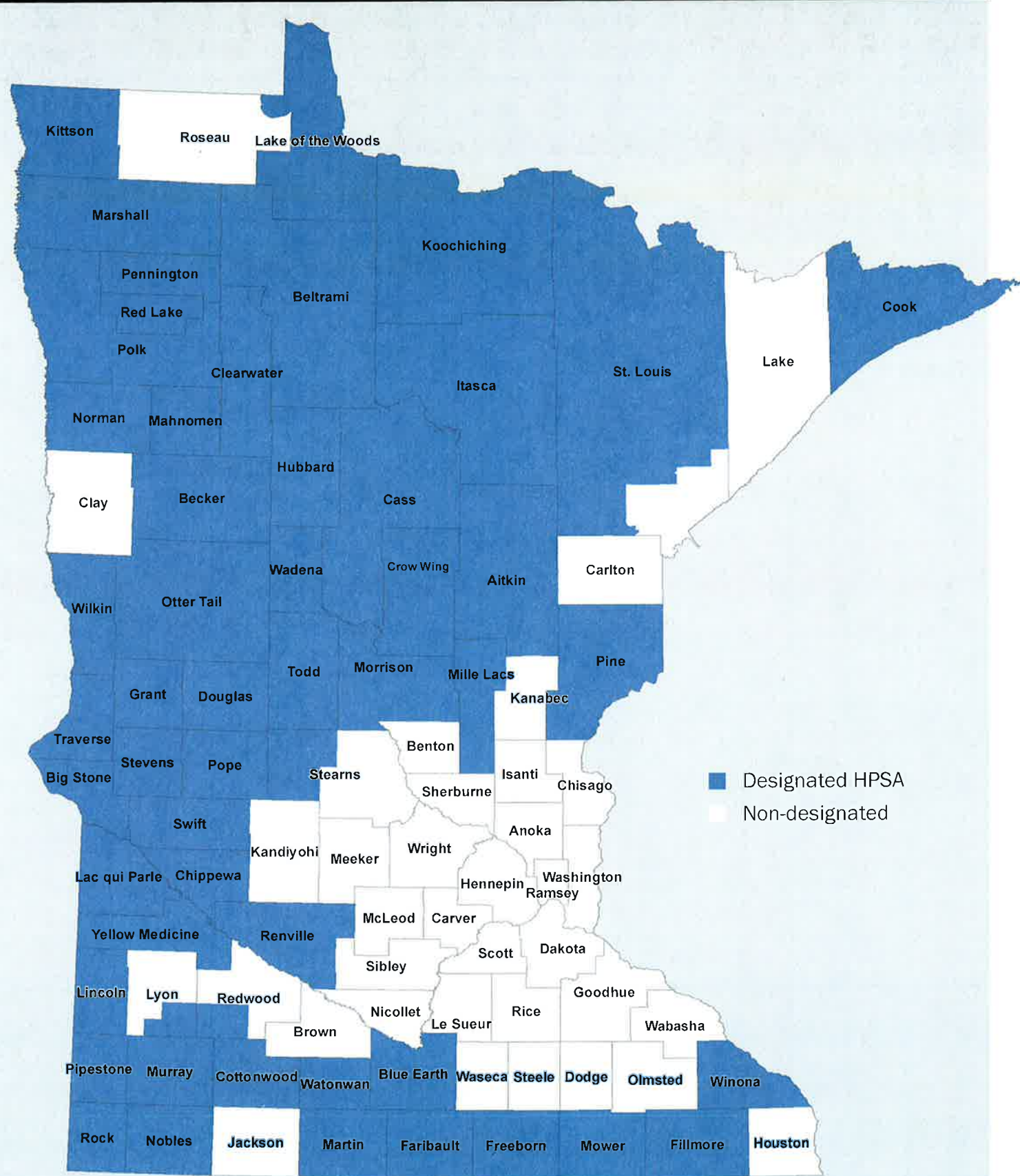
Appendix C: Minnesota Health Professional Shortage Areas – Population/Low-Income Dental Care Designation

Note: HPSA designations reflected in the following map only include those based on a geographic area and low-income population designations which are still bound by a geographic service area.

Designations not reflected in the map include any facility (e.g. comprehensive health center, correctional facility, rural health clinic) and tribal designations. For further information about Minnesota

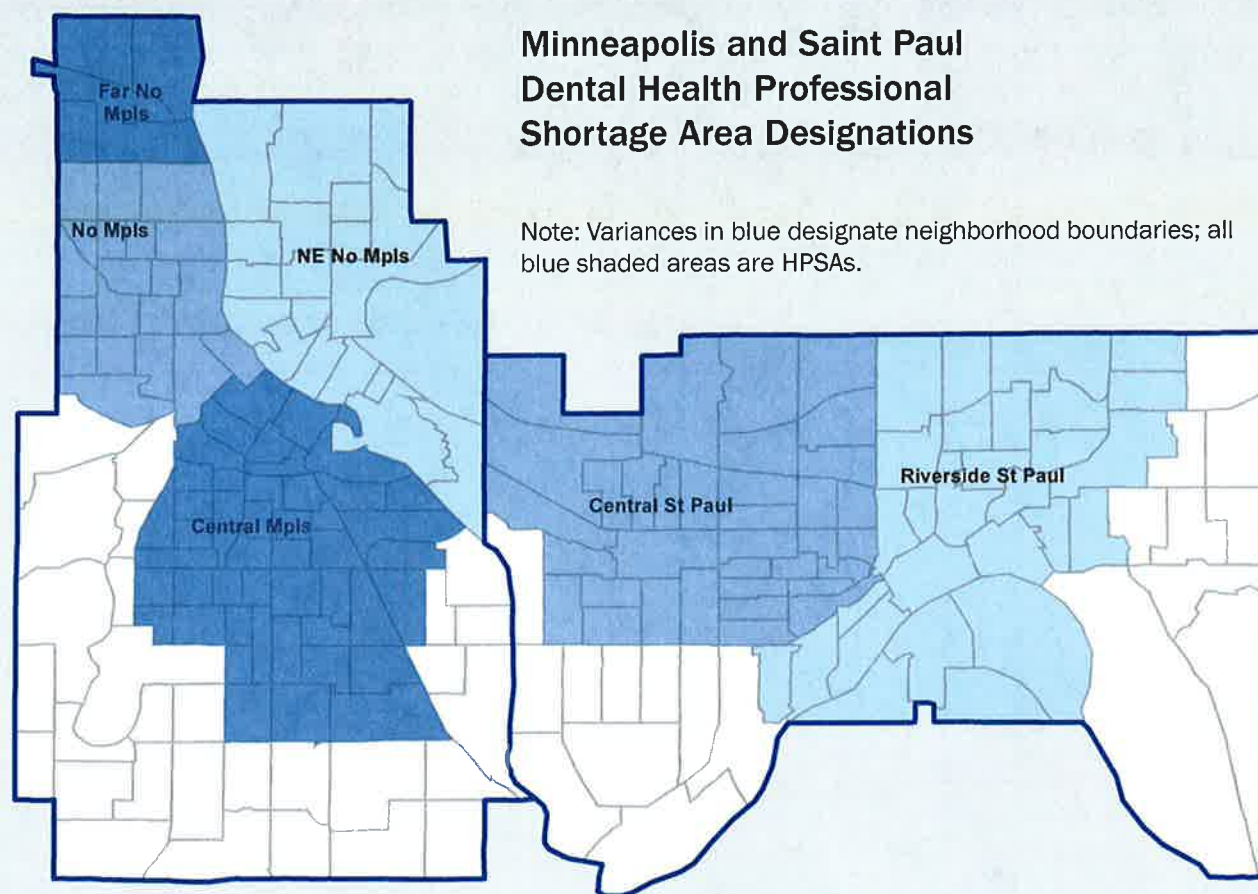
HPSA, please visit the Minnesota Department of Health Office of Rural Health and Primary Care website: www.health.state.mn.us/divs/orhpc

Map 1: Minnesota Health Professional Shortage Areas (by county) – Population/Low-income Group Dental Care Designation (identified in blue)



Data Source: Minnesota Department of Health, Office of Rural Health and Primary Care, State DD HPSA May 2012.

Map 2: Minneapolis-St. Paul Health Professional Shortage Areas – Population/Low-income Group Dental Care Designation (identified in blue)



Data Source: Minnesota Department of Health, Office of Rural Health and Primary Care, September 2010

Minneapolis Neighborhoods:

- Far North
- North
- Northeast-North
- Central

St. Paul Neighborhoods:

- Central
- Riverside

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FIGURE 3: Caries Experience and Untreated Caries in Minnesota Students in 3rd Grade by Free and Reduced Lunch Eligibility. SOURCE: Minnesota Department of Health, Oral Health Program. Basic Screening Survey, 2010.

FIGURE 4: Caries Experience and Untreated Caries in Minnesota Students in 3rd Grade by Race. SOURCE: Minnesota Department of Health, Oral Health Program. Basic Screening Survey, 2010.

FIGURE 5: Minnesota and National Population Prevalence Estimates for Dental Sealants. SOURCE: Minnesota Department of Health, Oral Health Program. SOURCE: Basic Screening Survey, 2010; National Health and Nutrition Examination Survey 1999-2004, children age 8 years old.

FIGURE 6: Adults Aged 18+ who did not Visit a Dentist or a Dental Clinic in the Past year by Income. SOURCE: Behavioral Risk Factor Surveillance System, 2010.

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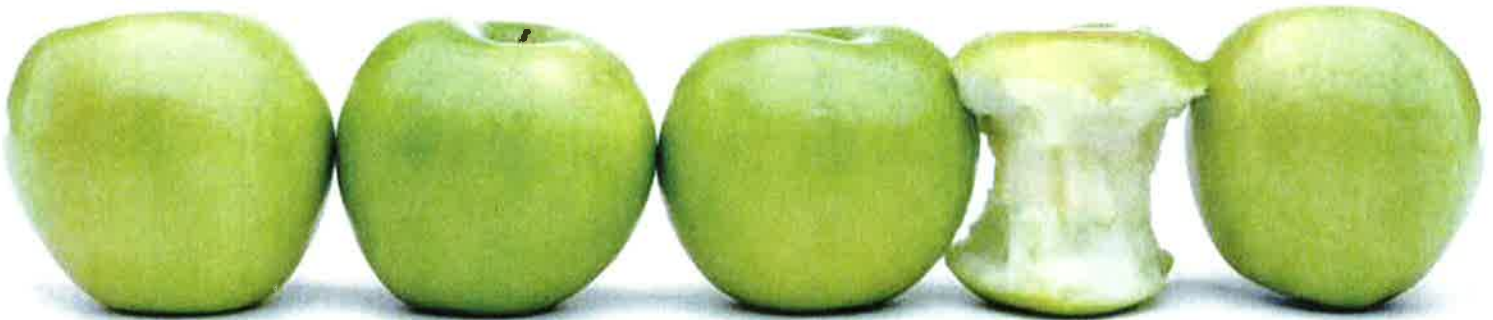
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For a copy of the complete Minnesota Oral Health Plan, please contact us or visit our website.



Oral Health Program

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Minnesota Transit Funding Primer

Technical Report

Prepared for:

Minnesota Council on Transportation Access

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Introduction

In the state of Minnesota, state and federal funding for public transit systems is administered by a number of different agencies, with coordination efforts encouraged by the Minnesota Council on *Transportation Access (MCOTA)*. *The Minnesota Legislature established MCOTA in 2010.* MCOTA was established in order to “study, evaluate, oversee, and make recommendations to improve the coordination, availability, accessibility, efficiency, cost-effectiveness, and safety of transportation services provided to transit public¹”. MCOTA is tasked with duties related to the following key areas: vehicle and client sharing, cost sharing and purchasing, communication and coordinated planning, reporting and evaluation, and research and demonstration².

This MCOTA Research Project is aimed at providing an inventory of the transportation funding programs available from the federal and state government in Minnesota, including funding levels and details about the administration of each program. The goal is to identify opportunities for coordination.

What is Human Services transportation (community-based transportation)?

Human Services transportation includes broad range of transportation services for transportation-disadvantaged population; primarily persons with disabilities, veterans, seniors, low-income individuals, and children. Since Human Service transportation is not centrally coordinated in Minnesota, the goal of this report is to more fully understand all sources that fund this service. As stated on MCOTA's website, "While there have been significant investments in transit at the federal, state, and local levels, serious gaps in service exist in many communities. Unfortunately, a multitude of funding programs and requirements across dozens of departments and agencies make transportation coordination and communication a daunting task."

What are the purposes of human Services transportation?

In order to support and increase transportation options for transportation-disadvantaged people, funding would be allocated to different organizations with various transportation purposes. Transportation-disadvantaged people have different needs and require a variety of transportation services with different trip purposes. Based on the survey results, most trip purposes would be as following:

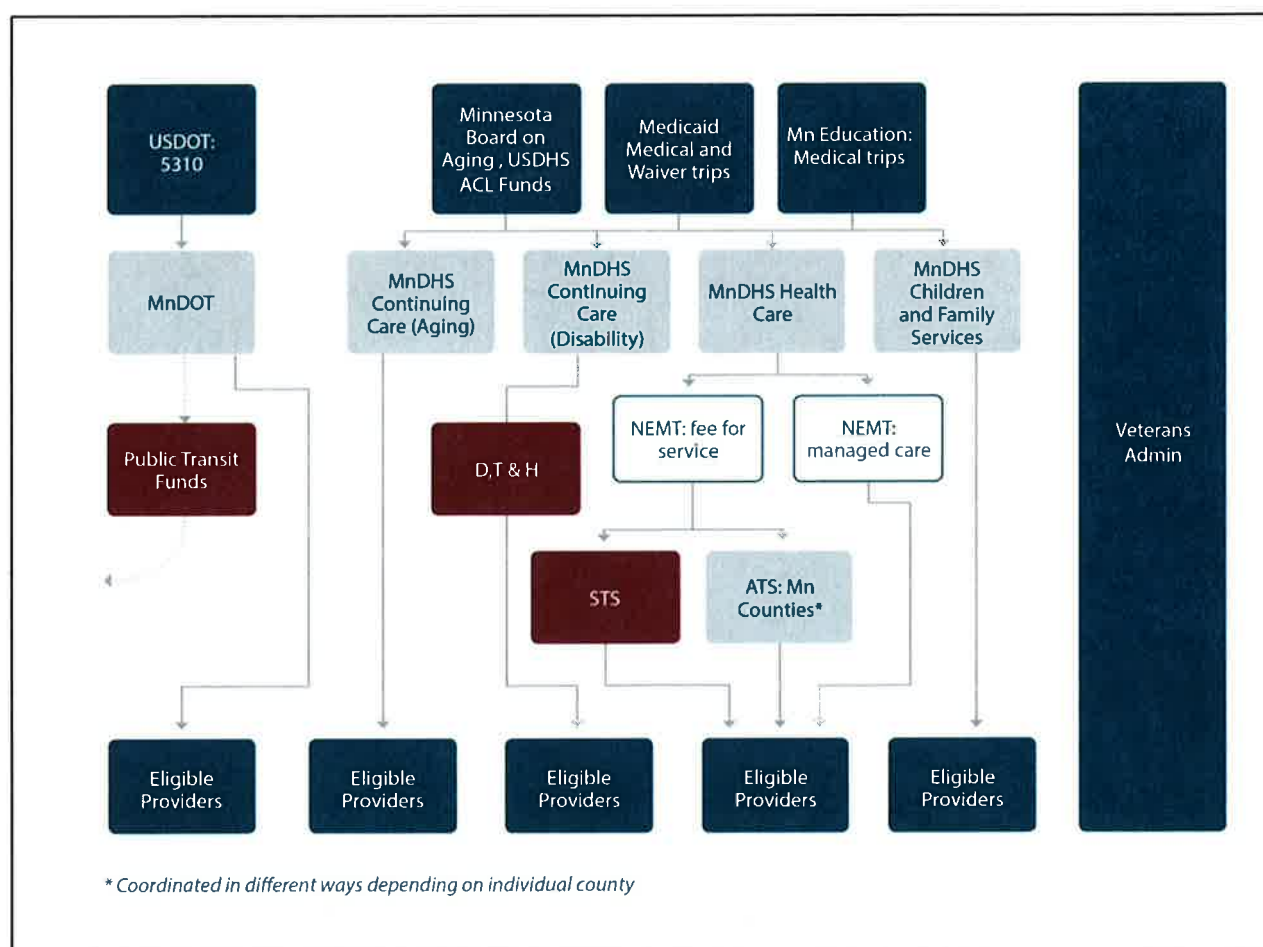
- Health/medical (e.g., single or periodic trips to doctor, clinic, drug store, treatment center)
- Health maintenance (e.g., dialysis or other recurring and frequent trips that require regular transport)
- Nutrition
- Income maintenance (e.g., trips to food stamp or social security office)
- Social trip (e.g visit to friends/relatives)
- Recreation (e.g., trip to cultural or athletic events)
- Education/ training
- Employment (e.g., trips to work, including job interviews. welfare-to-work trips)
- Social services (e.g., trips to meet with counselors, social workers, and other staff related to the receipt of social services)
- K-12 education (school children)

What types of organizations are eligible to receive funding for Human Services transportation?

Organization that might be eligible to receive funding for their transportation services to transportation-disadvantaged people could fall in different categories. Primarily there are public transportation operator, human services agencies, private for profit or private nonprofit organizations.

Who are the Federal and State Agencies funding Human Services transportation?

The following agencies are involved in funding transit in Minnesota.



United States Department of Transportation

The mission of the United States Department of Transportation is to “serve the United States by ensuring a fast, safe, efficient, accessible and convenient transportation system that meets our vital national interests and enhances the quality of life of the American people, today and into the future”³.

MAP-21

Section 5310 formula grants for the enhanced mobility of elderly individuals and individuals with disabilities. MAP-21 consolidated the Section 5317 New Freedom program (a formula-based federally-funded program established under SAFETEA-LU. The goal of the New Freedom grant program is to provide additional tools to overcome existing barriers facing Americans with disabilities seeking integration into the workforce and full participation in society) into the Section 5310 program.

Section 5310 Elderly Individuals and Individuals with Disabilities Program (a capital program as a part of the amended Federal Transit Act of 1991, that provides grant funds for the purchase of accessible vehicles and related support equipment for private non-profit organization to serve elderly and/or disabled people, public bodies that coordinate services for elderly and disabled, or any public body that certifies to the state that non-profits in the area are not readily available to carry out the services) provides capital and operating assistance grants for organizations that serve elderly and/or persons with disabilities. Section 5310 funding is approximately \$2,483,572.

Section 5310 pays for vehicles and other capital equipment for elderly individuals and individuals with disabilities. After the consolidation of Section 5317 New Freedom program, Section 5310 allows for additional funds used to provide transportation for low-income individuals.

Minnesota Department of Transportation

The mission of the Minnesota Department of Transportation is to “plan, build, operate and maintain a safe, accessible, efficient and reliable multimodal transportation system that connects people to destinations and markets throughout the state, regionally and around the world”⁴. “In creating the Department of Transportation in 1976, the Legislature determined that the Minnesota Department of Transportation would be the principal agency to develop, implement, administer, consolidate and coordinate state transportation policies, plans and programs”⁵.

The Minnesota Department of Transportation allocates funding to both public transit and to eligible providers that provide services to individuals covered under the United States Department of Transportation 5310 funding programs.

State funding for public transit is appropriated from the general fund and from a percentage of motor vehicle sales tax revenue. For Greater Minnesota Transit, the public transit assistance

general fund is \$16,451,000 in 2014. The Twin Cities Metro Area Transit public transit assistance general fund was \$107,889,000 in 2014.

The Minnesota Department of Transportation “disburses funds for Greater Minnesota transit through the Public Transit Participation Program⁶”. State law requires local participation in funding public transit services in Greater Minnesota. A statutory fixed share funding formula sets a local share of operating costs by system classification as follows: elderly and disabled 15%, rural 15%, small urban 20%, and urbanized 20%⁷.

United States Department of Health and Human Services

The United States Department of Health and Human Services is the government’s “principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves”⁸. The United States Department of Health and Human Services is responsible for approximately 25 percent of all federal outlays and administers the largest amount of grant money in comparison to all other federal agencies⁹.

Administration for Community Living

The United States Department of Health and Human Services’ Administration for Community Living. The mission of the Administration for Community Living is to maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

The Administration for Community Living “brings together the efforts and achievements of the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the Health and Human Services Office on Disability to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan”¹⁰.

Minnesota Board on Aging

The Minnesota Board on Aging is the “gateway to services for Minnesota seniors and their families”¹¹. The Minnesota Board on Aging allocates funding that is established by the Older Americans Act. The Older Americans Act authorizes “grants to states for community planning, services, research, and demonstration and training projects in the field of aging”. The Older Americans Act also provides grants for local needs identification, planning and funding of services¹².

The Minnesota Board on Aging distributes money to the 7 Minnesota Area Agencies on Aging that award the money to partners at the local level.

Minnesota Department of Human Services

The Minnesota Department of Human Services “helps people meet their basic needs so that they can live in dignity and achieve their highest potential”¹³. The Minnesota Department of Human Services oversees Continuing Care for both aging and disability. The Minnesota Department of Human Services also oversees health care and children and family services.

Continuing Care

The Continuing Care Administration of the Minnesota Department of Human Services' goals are to: "support and enhance the quality of life for older people and people with disabilities, manage an equitable and sustainable long-term care system that maximizes value, continuously improve how we administer services, promote professional excellence and engagement in their work"¹⁴.

For the aging and the disabled, Continuing Care distributes its funds directly to eligible providers.

Medicaid Medical Trips

Medicaid Waiver Trips

Medicaid waivers are "vehicles states can use to test new or existing ways to deliver and pay for health care services in Medicaid"¹⁵.

The Disability Services division oversees four Medicaid disability waivers. Medicaid disability waivers include: BI Waiver-Brain Injury Waiver for people with a brain injury who would otherwise need neuro-behavioral hospital care or a specialized nursing facility care, CAC Waiver- Community Alternative Care for medically fragile people who otherwise would need hospital care, CADI Waiver- Community Alternatives for Disabled Individuals Waiver for people with a disability that would need nursing facility care, DD Waiver- Developmental Disability Waiver for people with a developmental disability for people who would otherwise need an intermediate care facility level of care.

The Aging and Adult Services Division oversees elderly waiver (a Medicaid waiver) which extends transportation for fee-for-service expenditures. The Aging and Adult Services also oversees alternative care which extends transportation for fee-for-services expenditures.

Section 1115 Research and Demonstration Projects waivers are waivers that Minnesota can apply for program flexibility to test new or existing approaches to financing and delivering Medicaid. Section 1915(b) Managed Care Waivers are waivers that Minnesota can apply for waivers to provide services through managed care delivery systems or otherwise limit people's choice of providers. Section 1915(c) Home and Community-Based Services Waivers are waivers that Minnesota can apply for waivers to provide long-term care services in home and community settings rather than institutional settings. Concurrent Section 1915(b) and 1915(c) Waivers are waivers that Minnesota can apply to simultaneously implement two types of waivers to provide a continuum of services to the elderly and people with disabilities, as long as all Federal requirements for both programs are met¹⁶.

Medicaid Waiver trips allocate funding to both the Continuing Care for those with disabilities and to Health Care.

Health Care

Minnesota Department of Human Services' Health Care programs include medical assistance, MinnesotaCare, Minnesota Family Planning Program, Home and community-based waiver programs, and Medicare Savings programs. These programs may help pay for all of part of health care costs for those who do not have insurance, cannot get affordable health insurance

through a job, have a disability or chronic condition and need assistance paying for care and services to stay in one's home, need help paying for care in a nursing home, hospital or other medical facility, have other insurance or Medicare but need help paying the premiums, deductibles and copays or need services not covered¹⁷. Minnesota Health Care allocates funding to both NEMT fee for service and managed care.

NEMT

Non-Emergency Medical Transportation refers to non-emergency transportation services provided to Medicaid recipients so they can obtain covered medical services from health care providers outside their home. The type of Non-Emergency Medical Transportation assistance generally covers the cost of transportation and other costs associated with travelling to health service providers, such as meals and overnight accommodations.

In Minnesota, Non-Emergency Medical Transportation services are provided through the state's MA program. About two-thirds of MA recipients in Minnesota are enrolled in managed healthcare plans (Managed MA) and generally receive NEMT through these plans. The balance of recipients are covered by a fee-for service system operated by the Department of Human Services.

Non-Emergency Medical Transportation fee-for service allocates funding through Minnesota Counties, which then provide funding to eligible providers.

Non-Emergency Medical Transportation managed care allocates funding directly to eligible providers.

Counties

Counties report their social services expenditures to Minnesota Department of Human Services through the quarterly Social Services Expenditure and Grant Reconciliation Report.

Minnesota Education

School districts in Minnesota receive general education basic revenue in which there is an amount earmarked for transportation. In addition, districts receive state funding for certain situations including special education transportation and homelessness.

The Minnesota Department of Human Services administers the claims that school districts make for reimbursement for transporting students to medical assistance programs.

Children and Family Services

The Minnesota Department of Human Services' Children and Family Services allocates funding directly to eligible providers.

Veterans Administration

The United States Department of Transportation awarded \$1.19 million to Minnesota Department of Transportation under a Veterans Transportation and Community Living Initiative

discretionary grant in late 2011. Using these funds, Minnesota Department of Transportation, Minnesota Department of Veterans Affairs, Minnesota Board on Aging, and Minnesota Department of Human Services are partnering to enhance the existing MinnesotaHelp Network, a virtual call center and website that facilitates referrals among human service agencies using a common communications platform. This project will extend this technology to transportation providers and veterans' organizations that provide rides to veterans, enabling these partners to easily refer customers to other agencies in the network or to call center staff who can provide customers individual assistance.

Although the Minnesota Department of Veterans Affairs is collaborating with other agencies through MinnesotaHelp Network, the Minnesota Department of Veterans Affairs has generally separated its services to vulnerable adults from the services of other non-Veteran individuals. The existence of the Minnesota Department of Veterans Affairs separate statutory chapter and language regarding vulnerable adults supports the Minnesota Department of Veterans Affairs' commonly practiced risk averse policies and actions related to vulnerable adults in the transportation provided solely to vulnerable adults with Veteran status.

Federal Funding

5310 (elderly persons and person with disabilities) Statewide	\$2,483,572
5316 (job access) Greater Minnesota	\$ 751,000
5316 (job access) MET Council	\$1,169,463
5317 (new freedom) Greater Minnesota	\$ 552,000
5317 (new freedom) Met Council	\$ 415,324
Veterans Transportation	\$1,100,000
5311 (non-urbanized area grant) Greater Minnesota	\$ 8.2 M
5311 (non-urbanized area grant) MET Council	\$ 642,668
5307 (urbanized) Greater Minnesota	\$ 3.5 Million
Older American Act Title III - Statewide	\$1,000,000

State Funding

MVST	\$ 225,127,379+ \$24.6 m (OP)+\$ 6.2m (CAP)
Public transit assistance	\$ 152,255,021+ \$14.2m (OP) + \$ 800,000 (CAP)

Others

Medical Assistance	\$6,300,000
Non-Emergency Medical Transportation	\$24,000,000
Extended Transportation & Disability Waivers	\$31,900,000

Funding Based on Recipients (Estimations based on Survey Responses)

Persons with disabilities	\$40.7 M
Elderly	\$18.2 M

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- ¹ <http://www.coordinatemntransit.org/MCOTA/>
- ² http://www.coordinatemntransit.org/MCOTA/documents/MCOTA_Overview_Jun2011.pdf
- ³ <http://www.dot.gov/mission/about-us>.
- ⁴ <http://www.dot.state.mn.us/vision/>
- ⁵ Minn. Stat. Ch. 174.
- ⁶ 2013 MnDOT transit report.
- ⁷ 2013 MnDOT transit report
- ⁸ <http://www.hhs.gov/about/>
- ⁹ <http://www.hhs.gov/about/>
- ¹⁰ http://www.acl.gov/About_ACL/Index.aspx
- ¹¹ <http://www.mnaging.net/en/About%20Us/WhoWeAre.aspx>
- ¹² <http://mn4a.org/policymakers/policies-that-matter/>
- ¹³ <http://mn.gov/dhs/about-dhs/mission-and-values.jsp>
- ¹⁴ http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_166609
- ¹⁵ <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html>
- ¹⁶ <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html>.
- ¹⁷ http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_136855

Minnesota's Olmstead Plan Quality of Life Survey Pilot Study Report

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Quality of Life Survey Pilot Study Executive Summary

Purpose of the Study

Since June 2014, the Improve Group has supported the Olmstead Implementation Office in piloting the Center for Outcome Analysis Quality of Life Survey tool. The purpose of the pilot study is twofold. First, we tested the survey tool to ensure that it was effective a number of different settings, and across diverse groups of people with disabilities. Second, we identified and addressed challenges in the survey administration process so that the survey process goes as smoothly as possible in future iterations.

Survey tool

The Center for Outcome Analysis Quality of Life survey tool was selected because it is reliable, valid, low-cost, and repeatable, and it applies to all people with disabilities. In early 2014, Olmstead Implementation Office staff reviewed seven tools used locally and nationally to examine how well they would measure participant quality of life over time for the Olmstead Plan. The criteria used to judge the tools include applicability across multiple disability groups and ages, validity and reliability, ability to measure changes over time, and whether integration is included as an indicator in the survey. The Center for Outcome Analysis Quality of Life survey tool was the only tool to fully meet all the requirements listed. Studies about the reliability and validity of the tool are found in [Appendix D](#). Olmstead Implementation Office staff presented the survey options to the Olmstead Sub-Cabinet at the April 22, 2014 meeting. At that time, the Sub-Cabinet voted to approve the Center for Outcome Analysis Quality of Life survey tool.

Methodology

Samples and Settings

The Improve Group worked with the Minnesota Department of Employment and Economic Development, the Department of Human Services and the Department of Education to obtain survey samples. We sampled over 400 people and conducted 105 surveys in nine settings. This includes Adult Foster Care, Boarding Care, Board and Lodging, Center-Based Employment, Day Training and Habilitation, Intermediate Care Facilities for Persons with Developmental Disabilities, School Settings, Nursing Home, Assisted Living and Supervised Living Facilities.

Disability populations

Through the pilot process, the survey was tested with people with physical disabilities, people with intellectual disabilities, people with mental illness, people with brain injuries, people who are Blind, and people who are Deaf. The majority of the surveys were administered by interviewers with disabilities recruited by the Improve Group for this project.

Pilot Results

A rigorous analysis of quantitative and qualitative data shows that the Center for Outcome Analysis Quality of Life Survey tool worked well across disability groups and across settings. We recommend a few adjustments to the tool, and all recommended adjustments to the tool have been approved by the developer.

Key Recommendations

A complete list of recommendations for survey administration is available in the body of the report, starting on page 47.

1. Use the Center for Outcome Analysis Quality of Life Survey tool, with the modifications listed in the body of the report, to conduct the Olmstead Quality of Life baseline survey. By surveying approximately 3,000 individuals in the settings selected each year, the State will be able to extrapolate the results to the general population with a 95% confidence level and a 5% confidence interval. The survey developer has proposed a follow-up strategy in which 500 participants are surveyed each subsequent year to measure changes over time.
2. Plan for a three- to six-month design phase for the study followed by a survey period of at least four to five months.
3. The Olmstead Implementation Office should work to secure access to participant data through the support of the Sub-Cabinet, by using legislation, a court order, or other means. Establish a plan or structure for each agency to share data (survey samples) with the Olmstead Implementation Office and the Survey Administrator.
4. The Survey Administrator should work with liaisons in each agency to draw the survey sample. It is recommended that the sample be a stratified random sample, with stratification by setting. The data request should include disability and demographic information for each person included in the sample.
5. The Survey Administrator should have the state agencies select a sample four times larger than the number of individuals the State hopes to interview. For example, to achieve 3,000 participants, the sample should include 12,000 people.
6. The survey should be arranged so that the sections of greatest interest for the Olmstead Plan are at the beginning of the survey. This will ensure that the most important sections have the highest response rate.
7. Future trainings with survey interviewers should include more depth about survey content, methods for recording responses, and how the results will be used. State agencies should also provide tools for training interviewers about programs and services. This will prepare interviewers to respond to questions from survey participants and their loved ones.
8. The Olmstead Implementation Office should develop a marketing strategy for the survey so that participants and providers are familiar with the survey efforts before they are asked to participate. Take advantage of existing communication channels to market the survey to providers and potential survey respondents.

Background

About Olmstead

The Olmstead Decision

In the 1999 civil rights case, *Olmstead v. L.C.*, the U.S. Supreme Court held that it is unlawful for governments to keep people with disabilities in segregated settings when they can be supported in the community. This means that states must offer services in the most integrated setting, including providing community based services when possible. The Court also emphasized it is important for governments to develop and implement a plan to increase integration. This plan is referred to as an Olmstead Plan.

The Jensen Settlement

In 2009, a federal class action lawsuit was filed on behalf of individuals who had been secluded or restrained at the Minnesota Extended Treatment Options (METO) program. The resulting settlement agreement requires policy changes to significantly improve the care and treatment of individuals with developmental and other disabilities. One provision of the Jensen settlement agreement is that Minnesota will develop and implement an Olmstead Plan.

Minnesota's Olmstead Plan

Minnesota is required to develop and implement an Olmstead Plan as a part of the Jensen Settlement agreement. An Olmstead Plan is a way for government entities to document its plans to provide services to individuals with disabilities in the most integrated setting appropriate to the individual. In January 2013, Governor Mark Dayton signed an executive order establishing an Olmstead Sub-Cabinet to develop the Olmstead plan. The 2013 plan has been provisionally accepted, and the US District Judge overseeing the Jensen settlement agreement must approve all plan modifications.

The goal of Minnesota's Olmstead Plan is to make Minnesota a place where "people with disabilities are living, learning, working, and enjoying life in the most integrated setting."

About the Olmstead Quality of Life Project

The Quality of Life survey is one component of the Quality Assurance and Accountability section of the Olmstead Plan. The Plan requires Minnesota to conduct annual surveys of people with disabilities on quality including level of integration and autonomy over decision-making. The survey will be used to measure changes in the lives of people with disabilities over time.

The project is a longitudinal study. In the first year, people with disabilities from across the state will be surveyed to collect a baseline. Throughout the report, this is referred to as the baseline survey. In the following years, it has been recommended by the survey developer that a smaller sample will be selected from the baseline participants to complete the survey again. The results will be used to track Minnesota's progress on the Olmstead Plan.

About Quality of Life Survey Tool

The Quality of Life survey was created by the Center for Outcome Analysis to measure changes in quality of life as people with disabilities move to more integrated settings. The tool was selected because it is reliable, valid, low-cost, and repeatable, and it applies to all people with disabilities. In early 2014, Olmstead Implementation Office staff reviewed seven tools used locally and nationally to examine how well they would measure participant quality of life over time for the Olmstead Plan. The criteria used to judge the tools include applicability across multiple disability groups and ages, validity and reliability, ability to measure changes over time, and whether integration is included as an indicator in the survey. The Center for Outcome Analysis Quality of Life survey tool was the only tool to fully meet all the requirements listed. Studies about the reliability and validity of the tool are found in [Appendix D](#). Olmstead Implementation Office staff presented the survey options to the Olmstead Sub-Cabinet at the April 22, 2014 meeting. At that time, the Sub-Cabinet voted to approve the Center for Outcome Analysis Quality of Life survey tool.

The Quality of Life survey will measure:

- How well people with disabilities are integrated into and engaged with their community;
- How much autonomy people with disabilities have in day to day decision making; and
- Whether people with disabilities are working and living in the most integrated setting that they choose.

Several areas of the survey are required as a part of the Olmstead Plan and cannot be changed. This includes the target population, the primary sampling method, and the timeline. These aspects of the project are strictly defined, and the Quality of Life survey must be implemented according to these requirements.

The Quality of Life survey is only one way in which the experiences of people with disabilities will be gathered. The survey is intended to a tool for providing oversight and accountability for the plan. Minnesota will use additional methods including collecting individual stories to enhance the survey data.

About the Pilot

The purpose of the pilot survey is to learn how best to administer the baseline and follow-up surveys, including identifying challenges that may arise from conducting the survey in a variety of settings. The data collected during the pilot study will be used to evaluate the project and will not be publicly available.

The primary goal of the pilot is to test the tool in a variety of settings and with people with a range of disability types. In addition, the pilot is an opportunity to test and reflect on elements of the project in order to plan for the baseline study including:

- Recruitment plan
- Sampling strategy
- Sample size
- Survey locations

- Interviewer recruitment and training

Key Players in the Olmstead Quality of Life Survey Pilot Study

In June 2014, the Improve Group was selected to conduct the pilot study through a contract with Minnesota Management Analysis & Development (MAD). The work has been guided by the Olmstead Implementation Office, with support by individuals listed below. Collectively, this group is referred to as the “Olmstead Team” throughout the report.

Olmstead Implementation Office

The Olmstead Implementation Office (OIO) was created by the Olmstead Sub-Cabinet to assure the “Promise of Olmstead” becomes a reality. The OIO is responsible for making sure the vision, goals, and time-sensitive tasks of the plan are achieved. Overseeing the Quality of Life Survey is one of the OIO’s responsibilities. The OIO will report the survey progress and results to the Olmstead Sub-Cabinet.

The Improve Group

The Improve Group, an independent research and evaluation consulting firm located in St. Paul, is responsible for administering the pilot survey, as well as drafting recommendations for administering the baseline survey. The Improve Group has expertise in evaluating health and human services programs, with significant experience in the area of home and community-based programs and mental health service delivery systems in Minnesota.

The Olmstead Team

Improve Group staff worked closely with the Olmstead Implementation Office throughout the study. In addition, individuals from multiple agencies contributed to the study by providing information about Minnesota’s systems that serve people with disabilities. Collectively, this group is referred to the “Olmstead Team” throughout the report.

Funder

The study was funded by the Minnesota Housing Finance Agency.

About the Report

The purpose of this report is to evaluate the process of administering the Olmstead Quality of Life Survey. The report is divided into sections depending on the phase of the project. Each section of the report includes the steps taken in the phase. Each step has the original plan (either based on the contract or scope of work or early decisions made by the Olmstead Team), what actually happened, and the recommendations for future surveys based on the pilot.

Planning Phase includes selecting the survey instrument, the settings, identifying the population of interest, the timeline, and selecting the contractor.

Design Phase includes the steps taken before individuals are invited to participate in the survey such as working with agencies, selecting the sample, provider outreach, and interviewer training.

Administration Phase includes working with providers, scheduling interviews, and data collection.

Analysis Phase includes reviewing the data, analyzing response patterns, identifying problematic questions and terms, and recommendations for the baseline.

Planning Phase

Selecting the Survey Tool

The Olmstead Implementation Office contracted with the Center for Outcome Analysis to use a Quality Of Life (QOL) assessment tool that is specific to the Minnesota Olmstead Plan's requirements. The Center for Outcome Analysis has previously developed QOL scales that can be used across multiple disabilities, ages, and setting types. The tool was delivered to Minnesota on March 31, 2014.

The Quality of Life tool was selected from a small number of survey instruments that met the rigorous requirements of the Olmstead Plan, including being a valid and reliable tool that has been tested with people with a wide range of disabilities. The contract includes survey development, administration instructions, documentation of validity and reliability studies, and the authorization to use the tool through December 2018. This agreement providing authorization to use the tool could be renewed beyond December 2018. The author of the tool, Jim Conroy, was the content expert for Minnesota's Olmstead Plan.

Population

The population of interest for the Quality of Life survey is people with disabilities who are living, working, or going to school in segregated settings. While the level of segregation varies person to person, the intent is to survey people who will be most impacted by the state's efforts to provide services in the most integrated setting appropriate to the individual.

The sample should also reflect the diversity of Minnesota's population including: disability type, culture, race and ethnicity, location within the state, and other demographics. The primary disability types included in the sample are:

- People with physical disabilities
- People with intellectual / developmental disabilities
- People with mental health needs / dual diagnosis
- People who are deaf or hard of hearing
- People who are blind or visually impaired
- People with traumatic brain injury

Settings

Participants were selected from nine different settings where people with disabilities receive services. The setting list represents the most segregated settings where people receive services.

The settings included in the pilot were:

- Center Based Employment, a Minnesota Department of Employment and Economic Development (DEED) setting
- Children in segregated school settings, a Minnesota Department of Education (MDE) setting
- Day Training & Habilitation, a Minnesota Department of Human Services (DHS) setting
- Board and Lodging, a DHS setting

- Supervised Living Facilities, a DHS setting
- Boarding Care, a DHS setting
- Nursing Homes and Assisted Living, a DHS setting
- Adult Foster Care, a DHS setting
- Intermediate Care Facilities for Persons with Developmental Disabilities (ICF-DD), a DHS setting

Timeline

Original Plan

Table 1 below shows the original timeline for the study at the initial proposal from the Improve Group, the modified proposal at contract execution, and the actual timeline for the four phases of the study.

TABLE 1: PILOT STUDY TIMELINE

Phase	Original Timeline at Initial Proposal	Modified Timeline at Contract Execution	Actual Timeline
Kick-off	April 2014	June 2014	June 2014
Design Phase	May – July	June – July	June – September
Data Collection	July – October	Late July – October	October – November
Analysis Phase	November – December	November – December	November - December

What Really Happened

Getting access to participant data in order to contact people to take the survey took significantly longer than expected, resulting in a longer design phase and a truncated data collection period. In order to have access to the names of people receiving services in Center Based Employment and Segregated School Settings, each agency had to obtain consent to release information from participants and, if applicable, their guardians. For participants in other settings, the Improve Group was able to secure a data sharing agreement with DHS that allowed for access to participant data without an additional consent to release information.

The invitation process also impacted the time available for conducting surveys. For everyone except participants living in Adult Foster Care and Supervised Living Facilities, the process was to send a packet to the provider about the survey, and request the provider's help with inviting people to participate and scheduling interviews. This process, including initial and follow up phone calls, provider follow up with clients, and scheduling an interview time, took no less than 2 weeks. If we needed to obtain a consent to release information or guardian consent, it could take more than a month to schedule an interview.

Turnaround time was calculated from the date the initial invitation was mailed to the date interviews were scheduled and to the date the interviews were completed. If all of the participants at location declined to participate, the date the provider informed us of this was record as the interview scheduled date. Providers that did not respond to outreach efforts or refused to participate are not included in the calculations.

TABLE 2: TIME TO SCHEDULE AND COMPLETE INTERVIEWS BY SETTING

Setting	Average days to schedule interviews after first invitation	Average days to complete interviews after first invitation	Minimum number of days to schedule interviews after first invitation	Maximum number of days to schedule interviews after first invitation
Adult Foster Care	33	39	30	44
Boarding Care	13	25	20	33
Board And Lodge With Special Services	8	18	7	29
Center-Based Employment	26	36	24	56
Day Training and Habilitation	18	29	23	36
Intermediate Care Facility for Persons with Developmental Disabilities	43	49	43	60
Segregated School Settings	16	16	12	19
Nursing Homes and Assisted Living	12	26	14	34
Supervised Living Facilities	2	6	2	6

Because it took so long to get access to participant data, the data collection phase was 8 weeks long instead of 13-16 weeks. In order to conduct as many interviews as possible during the shortened timeframe, most of the providers we selected were in the Minneapolis-St. Paul metro area. In addition, interviews were conducted in St. Louis County, Stearns County, Goodhue County, and Renville County. Because not all of the settings or populations of interest were reached during the data collection phase, additional interviews were scheduled in December with deaf individuals and individuals receiving services in greater Minnesota.

See recommendations for the planning phase in future survey administration [on page 46 of this report](#).

Design Phase

Research Approvals and Human Subjects Protection

Original Plan

The Improve Group's original proposed approach was to determine whether the study required approval from an Institutional Review Board (IRB). If IRB approval was deemed necessary, the plan was to work with an independent IRB to get research approval. At contract execution with the Improve Group, the plan for obtaining consent from individuals had not been finalized.

What Really Happened

It was determined that the Olmstead Quality of Life Survey is exempt from IRB approval under [Federal regulation §46.101](#), available at <http://www2.ed.gov/policy/fund/guid/humansub/overview.html>.

Before it was determined that this study was exempt from IRB approval, the Improve Group completed an application for the Heartland Institutional Review Board. This application was ultimately not submitted. However, the application outlined steps for protection of human subjects and data security that were incorporated the study's data security plan.

Additionally, the Improve Group used an internal review process for project materials. The team also required active consent from all survey participants and obtained guardian consent for participants who are unable to give informed consent.

Internal Review

All project materials, including surveys, consent forms, communication materials, and questionnaires, were reviewed by the Olmstead Team. Additional review was provided by the Advisory Group and Improve Group Directors that were involved in the study.

Informed Consent

Participants were asked to give informed consent at the time of the interview. If the individual did not give consent, or if they did not understand the consent form, they were not interviewed. Alternate documentation of consent, such as a witness observing a participant's verbal or visual consent, was used with individuals with disabilities that limited their ability to sign a consent form. Participants who were not able to give informed consent, such as people under 18 and individuals under guardianship, were asked to provide assent at the time of the interview, and were only contacted after the guardian gave consent.

Data Security

The Improve Group developed a project-specific data security plan, and the Olmstead Team reviewed the plan. Protections include:

- storing project materials in locked cabinets

- encrypting files and folders with personal or protected data
- limiting access to encrypted files to project staff
- training staff and contractors in data security, confidentiality, and human subjects protections

See recommendations for Human Subjects Protections in future survey administration on [page 46 of this report](#).

Preparing the tool

Original Plan

Consult with Jim Conroy to finalize the survey instrument with the Minnesota context in mind (with particular attention to demographic questions) and make sure we collect the data in a way that can be compared to national results.

Prepare the survey for administration using a laptop or tablet as well as a web-based version of the survey for people who would prefer to take the survey on their own or without an interviewer present.

What Really Happened

Finalizing the survey was an ongoing process that extended into the administration phase. There were no major changes to the structure or content of the survey after the interviews started. However, there were minor changes to language and question routing in reaction to notes from survey administrators. Question routing allows interviewers to skip questions that are not relevant to the participant. These changes were made to improve the interview flow and to clarify the meaning of questions or response options.

Changes to the survey

The biggest change to the survey was adding response options to make the survey more inclusive or better suited to the current context. For example, “something else” was added as a response option for questions about gender or race and ethnicity. A “Don’t Know” option was added to the questions that did not already have that option. In addition, scripts were added to smooth the transition between sections and to help interviewers explain the survey. Finally, question routing and question piping was added. Question piping customizes each survey for participants by taking a response from one question and automatically inserting it into a future question.

A complete list of changes to the survey, including the rationale for each change, can be found in [Appendix A](#).

Preparing the tool for administration

The survey was prepared for administration using laptops or tablets using SNAP Survey software, which has the capability of creating surveys for the web or for paper and pencil administration. Question routing, piping and scripts for interviewers were added to the survey to streamline administration and make the survey more consistent across interviewers.

In addition to routing and piping, a question was added to end of each page or section about any items or terminology the primary respondent had difficulty with. The responses to these questions were used to identify questions that were difficult for participants and to make technical changes to the survey. Interviewers also used these questions to make notes about technical problems with the survey.

A modified web-based version of the survey was created for people who would prefer to take the survey on their own. The modified survey was the same as the interview version except that some of the scripts and interviewer instructions were removed. The feedback questions at the end of each section were reworded to address the participant. The web version of the survey was made it available to people who requested it.

Accessibility

The survey tools and communication materials were used by Improve Group staff and interviewers. The materials were read to participants. Neither the survey nor the communication materials were tested for accessibility. A plain text version of the survey was created; however that version was not used or tested. None of the pilot participants requested a version of the survey for screen readers or large print versions of the survey; however only a small number of individuals who are blind or visually impaired were surveyed.

See recommendations for Preparing the Tool for future survey administration [on pages 47 of this report](#).

Translation and Interpretation

Original Plan

Translation and interpretation were not included in the original pilot plan or scope of work. As a result, no funds were available for providing alternate versions of the survey for the deaf or hard of hearing, blind or visually impaired, or non-English speakers.

What Really Happened?

The Improve Group entered into an agreement with an American Sign Language (ASL) interpretation provider for individuals who requested an interpreter. For other non-English speakers, the Improve Group provided an interpreter if one was needed and requested. All materials, including consent forms and recruitment materials, were only available in English and were interpreted onsite. Two interviews were conducted in ASL and one was conducted in Amharic.

We asked providers when we scheduled interviews if any of the participants needed any accommodations, including if any of the participants would need an interpreter. However, the providers did not always have this information. Some participants completed the survey even though their primary language was something other than English. One interview had to be stopped early because the participant requested a Mandarin interpreter during the survey. We were not able to reschedule that interview.

One set of ASL interviews and the Mandarin interview had to be cancelled because we were unable to schedule interpreters. We attempted to reschedule the Mandarin interview twice and interpreters were not available either time.

See recommendations for Translation and Interpretation [on page 47 of this report.](#)

Sampling Strategy

Original Plan

Randomly select 200-250 people to participate in the survey using setting as the primary selection criteria, disability type as a secondary selection criteria, and demographic and other characteristics as tertiary selection criteria.

The nine settings to be included in the sample were:

- Center-based employment
- Children in segregated school settings
- Day Training & Habilitation (DT&H)
- Board & Lodging
- Supervised Living Facilities
- Nursing Home / Assisted Living
- Adult Foster Care
- Intermediate Care Facilities for Persons with Developmental Disabilities (ICF / DD)

The proposed secondary selection criteria were:

- Physical Disabilities
- Developmental Disabilities
- Mental Health Needs
- Brain Injury
- Deaf or Hearing Impaired
- Blind or Visually Impaired

Demographic and other characteristics tertiary selection criteria included:

- Geographic location
- Race / ethnicity
- Age
- Make extra efforts to include culturally diverse populations

What Really Happened

An initial sample of 455 individuals in eight of the settings was selected to take the survey. In addition, volunteers were recruited in order to ensure the survey was tested in all of the settings and with all of the populations of interest.

With input from the Olmstead Team, the Improve Group selected five to ten providers per setting to participate in the pilot. Providers were selected that represent diverse disability groups and some providers were selected for the diverse demographic populations they serve. Once the providers were selected, the secondary selection criteria were only used to identify individuals with hearing or vision needs in DHS settings. Because the data structure and information maintained about individuals receiving services varies by agency and provider, demographic information was not used as a selection criterion for individual participants after the providers were selected.

Setting

The Olmstead Team used licensing information and agency guidance to identify organizations that provide services in each of the setting types. The agencies then helped to select a sample of individuals from each provider to invite to the survey. Forty-nine providers were selected as pilot sites. In all, we conducted interviews with participants from 29 providers. Of the 20 providers for which we did not conduct interviews:

- Six providers declined to participate.
- We were unable to schedule interviews with the other nine providers for which we had a sample.
- Additionally, we were not able to get a sample for nine providers, but four of those providers allowed us to interview volunteers.

Identifying providers to select a sample from was more complicated than expected, especially for DHS providers. The biggest challenge is that the different settings are not clearly defined, and providers may offer services for multiple setting types at the same location. It is also possible that providers may also provide services for participants through multiple funding streams. This complexity poses a challenge for ensuring the setting types are well represented without looking at the participant's funding source.

Disability Type

During the early planning stages, the Improve Group created a grid of settings and disability types with the impression that the Olmstead Team would be able to identify which settings would have a greater number of individuals with certain disability types.

Each of the state agencies collects and report disability type differently, which made it difficult to consistently use disability type as a selection criteria. Disability type was not included in the sampling criteria for DEED or MDE participants because the Improve Group did not have access to participant data. For participants in DHS-funded settings, we attempted to capture variety in disability type by selecting providers that specialize in working with certain disabilities. In addition, the houses in the adult foster care and supported living services sample were selected because one or more individuals in the home had hearing or vision needs.

The number of people with vision or hearing disabilities in the initial sample was not large enough to provide reliable feedback about the survey. In order to reach enough people to test the survey, organizations that provide services that do not fall into the 9 survey settings were approached to serve

as pilot locations. Individuals who were surveyed in these locations were asked to provide additional feedback about accessibility and interpretation.

Demographic and Other Characteristics

Selecting the sample required working with state agencies to define setting types and to select appropriate providers. A different approach was used to select the sample from each state agency. The approaches reflect the different data structures and level of data access for each agency.

See recommendations for Sampling Strategy [on page 47 of this report](#).

Working with State Agencies

The settings included in the sample are funded by three different agencies: Minnesota Department of Human Services (DHS), Minnesota Department of Education (MDE), and Minnesota Department of Employment and Economic Development (DEED). The Olmstead Team worked with the agencies to find liaisons to help access data and generate the survey sample. Each agency has different data structures and different data sharing requirements. The process for working with each agency follows.

Department of Employment and Economic Development

DEED holds the data for people who receive services through Center Based Employment. In order to share participant data with the Improve Group, DEED required Consent to Release Information Form from each program participant or their guardian. DEED maintains data on participant's legal representatives, but the Improve Group could not access that information to contact guardians directly.

The process for selecting and inviting DEED participants to the survey was as follows:

- The Olmstead Team, with guidance from DEED about appropriate providers, identified 5 metro area center-based employment providers from which to select the sample;
- DEED selected the sample using guidance from the Improve Group;
- The Improve Group prepared a provider packet that included project information, consent to release information forms, and guardian consent forms for participants with legal guardians. The packet included instructions on completing and returning the forms as well as contact information for the Improve Group. DEED sent the packets along with a cover letter from DEED employee John Sherman encouraging providers to participate to the sites;
- Providers were asked to manage collecting first consent, including obtaining consent from participants' guardians; and
- Interviews were scheduled at the providers' offices to make it easier for participants to take the survey during the workday.

Challenges

- Staff turnover at DEED caused a delay in selecting the sample and sending information to providers.

- The arrangement with DEED required obtaining consent to release information from participants and guardians before the Improve Group could contact them about the survey. This meant that significant “leg work” for the survey had to be completed by DEED staff.

Department of Human Services

DHS holds the data for individuals in seven of the nine settings. The Improve Group was able to secure a data sharing agreement with DHS, which gave the Improve Group permission to contact individuals directly. The Olmstead Team selected providers to sample from, and DHS provided the sample of individuals within each setting if that information was available. However, the data for several settings was limited, and the lack of participant information in Supervised Living Facilities, Boarding Care, and Board and Lodge with Special Services presented an additional challenge. DHS maintains information guardianship status for some participants. However, guardian contact information for people receiving DHS services is held at the county level.

The process for selecting the DHS sample is as follows:

- The Olmstead Team, with guidance from DHS, selected 5-10 providers from which to select the sample. The number of providers depended on the type of service, with smaller settings having more providers.
- DHS data liaisons selected a sample from each provider. If the provider had fewer than 15 participants, all of the people receiving services at that setting were included in the sample.
- DHS transmitted the sample directly to the Improve Group, and the Improve Group obtained first consent.
- The Improve Group requested support from providers with obtaining guardian consent to contact individuals to participate. Providers also helped to facilitate the survey by encouraging individuals to participate and arranging interview times.

Challenges

- DHS uses multiple systems to manage data for individuals in different settings, which caused a delay in getting data for multiple settings. Determining which system to use to pull data for each setting, creating the code, and searching for providers within the system was also time consuming.
- There is no plain language definition of settings, and many of the providers hold multiple licenses. This made selecting providers and the sample difficult. In addition, not all of the providers we selected were in the databases, particularly Board and Lodging and Boarding Care providers.

Minnesota Department of Education

MDE oversees programs for students with disabilities up to age 22. However, each district maintains information on students and their guardians, and neither MDE nor the Improve Group had access to the data.

The Improve Group worked with MDE to identify metro-area schools to include in the pilot. The schools were selected based on the number of students in segregated school settings over age 7 and geographic location. Two schools, one in the south metro and one in the west metro, were selected to participate in the pilot. MDE contacted district superintendents about the project, and the Special Services office of each school worked with the Improve Group to recruit participants.

The process for selecting the MDE sample was as follows:

- Two school districts were selected to participate based on student population and geographic location. The schools were selected because MDE data showed they had 30-50 students in segregated school settings;
- MDE contacted the School Superintendent in each district, requesting their participation in the project;
- The Improve Group worked with the Special Services Offices to send invitations to all families with students receiving services in Federal Special Education Settings 3 and 4. The invitations included background information about the project and guardian consent forms;
- Parents and guardians returned consent forms to the Improve Group; and
- Interviews were scheduled with the families in their homes or at a neutral location.

Challenges

- Both school districts had nearly 90 students in segregated settings, not the 30-50 we expected based on the information from MDE.
- Not having access to student data limited the options for follow up. Both school districts provided additional support with encouraging families to participate, but only 11% of families returned a consent form.
- Both schools used their resources to encourage families to participate in the project, but the relationship between the schools and the families was not as conducive to getting people to participate as the other providers. There are some fundamental differences in education programs and residential or vocational programs.

See recommendations for Working with State Agencies [on page 47 of this report.](#)

Advisory Group

Original Plan

The Improve Group recommended engaging an advisory group to provide insights about recruiting, administration, and interpretation of data. The advisory group would have 6-10 members and would meet up to four times during the project. The advisory group would help the Olmstead team to make sure that the concerns and needs of the community were heard throughout the process. The advisory group would provide feedback on surveys and communication tools to make sure the Olmstead Team was “speaking the language” of the community.

The ideal advisory group member would:

- Have a disability or be an advocate for people with disabilities
- Be close to the survey experience
- Be from the community rather than a government agency
- Be an advocate for the Olmstead Quality of Life Survey

What Really Happened

The Olmstead Team identified members of the community and advocates for people with disabilities to invite to the advisory group. Five people from a range of backgrounds and experience agreed to join the group. Extra effort was made to help ensure the advisory group was inclusive of people from multiple disability groups.

The advisory group met once, in early November. Several attempts were made to schedule an in-person meeting in August or September, but it was difficult to find a time when everyone could meet. In order to get advisory group feedback before starting surveys, the Olmstead Team asked group members to review documents and provide feedback individually. Advisory group members provided feedback on the pilot review questionnaire, interview topics, and lessons learned from other initiatives.

At the November meeting, the Olmstead Team shared how the project was working so far, and asked for feedback about the project. It was a time for members to meet, here progress about the survey and share feedback about the process. The Advisory Group members shared that it is important that individuals with disabilities and individuals that represent the diverse communities of Minnesota conduct the survey as much as possible. Racial, ethnic, and cultural diversity were shared as being particularly important.

The plan was to meet with the Advisory Group in December to share initial findings. The condensed time of the study did not allow for this meeting. The Olmstead Team will share a summary of findings with Advisory Group members and invite their participation in future discussion about the study in the baseline year.

See recommendations on the Advisory Group [on page 48 of this report](#).

Reporting Abuse and Neglect

The Olmstead Team identified the need to develop a protocol for documenting interviews in which people threaten to hurt themselves or others or incidents of reported or suggested abuse or neglect. The Improve Group developed a protocol for reporting suspected abuse or neglect using DHS resources for mandated reporters. This protocol required that all incidents or self-reported, observed, or suspected abuse or neglect be reported to the common entry point within 24 hours of the interview. If the participant was in immediate danger, the interviewer was to call 911 immediately. The Improve Group created a form for internally documenting reports of abuse or neglect.

In all, there were three incidents of suspected abuse or neglect. Of these cases, one resulted in a report to the common entry point, and the other two were cases that were previously reported and resolved.

See recommendations on Reporting Abuse and Neglect [on page 48 of this report](#).

Administration Phase

Working with Providers and School Districts

Original Plan

Send at least two letters to providers to let them know about the survey and their role as well as to help get information to participants about the survey and encourage them to participate.

What Really Happened

Providers had an active role in supporting the survey, including helping to obtain first consent from participants and their guardians, scheduling appointments, and arranging space for interviews. Providers also played a huge role in getting people to participate in the survey. For all of the settings except schools, most of the interviews were conducted on-site. The school districts helped with outreach and provided space to conduct surveys; however, families of school-aged children generally preferred to be interviewed at home or in a neutral location.

In residential and vocational settings, the close relationship between the providers and participants also helped to prepare interviewers for the appointment. Staff members shared tips for communicating with individuals, provided context about participant's situation, and supported participants during the survey when requested. Many of the providers played the dual role of advocating for the project and their clients.

While most of the providers were supportive of the project, some were hesitant to get involved and a few refused to participate. Providers that were hesitant cited multiple surveys from different agencies, demands on staff, or the likelihood that their participants would not be interested in the project. Providers were surprised they had not heard about the Olmstead Quality of Life survey prior to receiving the provider packet, and some were concerned that DHS might not sanction the project. Reasons some providers gave for opting out of the survey included: clients would not be interested, lack of time, or lack of information. Other providers did not return phone calls.

The letter providers received from the state agency inviting them to participate was often the first they had heard of the project. If the provider did not receive the letter or if the packet got shuffled around and lost, the phone call was the first they heard of it. Because the project was a surprise, it was hard to find the appropriate contact, which sometimes ended up leading to calling in circles. Also, because the packets were sent to the individual homes for ICF / DD and foster care settings, sometimes we had guardian consent forms before the provider had figured out what the next steps were.

Because the providers were the primary method of reaching potential participants, gaining their support was essential to the project. To gain this support, someone from the Improve Group contacted each provider at least twice before attempting to schedule interviews. While the letters sent by agency liaisons helped to establish credibility and authority with the providers, many of the providers required additional evidence that their participants' rights and privacy would be protected.

On the whole, the providers we talked to were aware of the Olmstead Plan and supported efforts to improve services for their participants. Many of them said they thought the project was important, and

that they were encouraging people to participate. Several providers rescheduled interviews to make sure that everyone who had agreed to take part in the survey was available.

See recommendations on Working with Providers and School Districts [on page 48 of this report](#).

Recruitment and Communication Strategies

Original Plan

Develop recruitment and communication tools for providers and survey respondents. Two letters to providers and facilities about the survey letting them know that we would be contacting them and participants.

What Really Happened

The Improve Group worked with state agencies to reach out to providers about the survey. The Improve Group prepared packet of materials to the providers or school districts that included information about the survey, provider roles, guardian consent forms, and, if available, a list of participants. For every setting except Adult Foster Care and ICF / DD, materials were sent from the state agency. The Improve Group contacted ICF / DD providers and adult foster care participants directly.

After the packet was sent, the Improve Group called providers to give them more information and answer questions. As soon as the providers were onboard, we began coordinating guardian consent and scheduling interviews. Scheduling and coordination was also done via email. Depending on the setting and provider, the turnaround time ranged from a couple of days to over a month. Recruitment efforts took much longer in Adult Foster Care and ICF / DD because the packets were sent directly to homes instead of to the provider's main office. This approach made tracking down the right person to talk to much more difficult.

Some providers contacted the Improve Group as soon as they got the packet to ask questions and coordinate scheduling, while others never received the packet. The contact information and mailing addresses for some providers were out of date or incorrect.

See recommendations on Recruitment and Communication Tools [on page 49 of this report](#).

Consent Process

Original Plan

Obtain informed consent from all participants before starting the survey. For participants with guardians, obtain guardian consent and participant assent. Allow for alternate documentation of consent for participants with disabilities that keep them from signing their name.

What Really Happened

All participants were given the option to opt out of the survey before an interview was scheduled and at the time of the appointment. Even if the person agreed to participate, the survey was not conducted if the interviewer did not think the person understood the consent form. Some individuals who agreed to participate declined at the time of the interview, either by not showing up for the appointment or by

declining to answer questions. People were most likely to decline at the time of the interview in residential settings, especially Boarding Care and Nursing Homes / Assisted Living. In several cases the contact person could not find the person at the time of the interview, and the contact person felt those individuals were passively opting out of the survey. In other cases the guardian had given permission to contact the individual but the person was not interested in participating.

The Improve Group obtained guardian consent before contacting individuals to participate in the survey. However, the Improve Group did not have access to guardian information, so providers were asked to help obtain guardian consent either by contacting guardians directly or by providing contact information.

If a person who could not consent had a guardian present, the guardian was given the option to complete the survey. Seventeen guardians were present for the survey, and in seven cases the guardian was the primary respondent. In all of the cases where guardian was the primary respondent, the focus person was a student in segregated school settings.

See recommendations on the Consent Process [on page 49 of this report](#).

Survey Administration

Original Plan

The Improve Group will administer 85 surveys. We hope to administer 40-45 surveys among our staff and then reflect on and document lessons learned. At that point will recruit and train people with disabilities to administer the surveys, and then co-administer the remaining 40-45 surveys as training and coaching opportunities. Each survey administrator would then administer up to 30-40 additional surveys. In total, we anticipate that 205-245 surveys will be administered.

What Really Happened

The shortened survey timeline and longer design phase meant that Improve Group staff did not administer the first group of surveys. Instead, the first round of interviews were used for training and coaching purposes, and Improve Group staff administered surveys when other interviewers were not available. Having interviewers conduct the surveys instead of Improve Group staff allowed for conducting more surveys because of budget constraints that resulted in more time spent during the design phase gathering samples than was originally anticipated.

At the end of the administration phase 105 surveys were attempted or completed. Because some of the target populations were not reached during the administration period, an additional four surveys were completed in December. In addition, six partial surveys were conducted at Vision Loss Resources to get feedback from people with vision loss about the survey.

The original plan estimated 3 hours per survey including scheduling, travel, meeting and greeting participants, and survey administration. In practice, it took an average of 4 hours to schedule and complete each survey. This estimate includes 2 hours for coordinating with providers and scheduling interviews, an hour to conduct the interview, and one hour for travel, setup and breakdown. The coordination time includes time spent explaining the survey to providers and family.

Most of the surveys were conducted using laptops and an internet-based survey program. Each interviewer had a password-protected hotspot to bring with them to survey participants rather than relying on the survey location for internet access. We chose this administration method because we were able record participant responses and transmit data securely to the Improve Group servers. In most cases this administration mode worked well; however, there are some limitations to using computers to administer the survey.

First, there were many settings where the hotspot did not work or it worked intermittently. This meant interviewers had to move rooms to complete the survey or switch to paper part of the way through the interview. In addition, sometimes the hotspot worked, but the signal was not strong enough to move fluidly through the survey. The problems with internet access were disruptive enough that we do not recommend using an internet-based survey.

Second, many of the interviews were conducted in small spaces such as the participant's bedroom or a small office. The interviewers had a hard time navigating the small spaces with the laptop while trying to be respectful of the participant's space. If the interviewer had several interviews in one day they would have to find a place to plug in the computer during the survey, limiting the where the survey could be administered.

When we were not able to use a computer because of internet access or other barriers, the survey was conducted on paper. This allowed for the interviewer to take notes about the responses and made it easier to go back to sections if the participant provided more information during the interview. However, paper surveys did require extra time for data entry after the interview.

See recommendations on Survey Administration [on page 49 of this report](#).

Special Populations

Survey Administration in Greater Minnesota

Original Plan

We will chose three additional locations in greater Minnesota to provide some geographic representation, including one rural area with few services or resources and an "outstate hub" with more services and resources.

What Really Happened

A total of 15 interviews were conducted in greater Minnesota. Eleven during the survey administration period and four after the administration phase ended. The interviews were conducted in St. Louis County, Stearns County, Goodhue County, and Renville County. The St. Cloud provider was selected because it is a service provider for several rural counties. In addition, we contacted providers in Pope and Faribault Counties, but were unable to schedule interviews.

A Center-Based Employment provider in Goodhue County and two providers in Duluth, an ICF / DD and a Board and Lodge with Special Services, were included in the original sample. Six people at the Center-

Based Employment provider and one person at the ICF / DD agreed to participate and were interviewed. The Board and Lodge declined to participate.

We sent information to six foster care houses and a DT&H in Pope County. The notification inadvertently was delayed for Pope County and providers were asked to participate at the end of the survey administration period. The DT&H declined because of the tight timeline for getting guardian consent and scheduling interviews. No one from the foster care houses agreed to participate.

In order to include more individuals receiving services in rural areas in the survey, the Improve Group reached out to providers in greater Minnesota. In order to schedule interviews quickly, we selected settings where participants were less likely to have guardians based on our experiences in the metro area.

When confirming the appointment time with one provider, we found out that all of the participants would require guardian consent. The contact person said it was a common practice in rural areas to obtain guardian consent over the phone. However, we felt the guardian consent form was too complicated to administer over the phone and rescheduled the interviews in order to allow more time to obtain guardian consent.

In general, the challenges with scheduling and conducting interviews in greater Minnesota were similar to the challenges in the metro area. However, the process was complicated by travel time and interviewer travel limitations. For example, it was difficult to find interviewers who were available to travel outside of the metro area at the times that worked for the participants. This challenge was even greater for interviews that required overnight travel.

[See recommendations on Survey Administration in Greater Minnesota on page 50 of this report.](#)

Blind or Visually Impaired or Deaf and Hard of Hearing

We attempted to include people who are blind or deaf in the sample by using vision and hearing needs as a sampling criteria. The Adult Foster Care and Supported Living Services houses that were selected as survey locations were selected because at least one resident had vision or hearing needs. However, approach was not successful in recruiting blind participants. Some providers declined to participate because of the resident's vision or hearing needs, particularly in homes where participants were receiving Supported Living Services

DEED was not able to use hearing or vision needs as a sampling criteria because there are very few individuals with these needs in Center-Based Employment, particularly in the metro area. We also attempted to survey students at the Minnesota Academies, but were not able to schedule interviews.

One boarding care provider was selected as a survey location because they have a program that specializes in deaf services. However, only two interviews were conducted at that provider. In order to test the survey with more individuals who required ASL interpretation, we scheduled interviews with

participants receiving services from the Minnesota Employment Center (MEC) for People Who are Deaf or Hard of Hearing, but were not able to conduct the interviews.

In order to reach more people with vision loss, we tested the survey at a peer counseling meeting at Vision Loss Resources. Due to time limitations, we divided the survey into two sections and had volunteers provide feedback on those sections.

See recommendations on Blind or Visually Impaired and Deaf or Hard of Hearing Participants on page 50 of this report.

Analysis and Reporting

Pilot Results

A rigorous analysis of quantitative and qualitative data shows that the Center for Outcome Analysis Quality of Life Survey tool worked well across disability groups and across settings. We recommend a few adjustments to the tool, and have consulted with the tool's developer about making those adjustments.

Qualitative Analysis

There were three main sources of data for the qualitative analysis of the pilot: the Pilot Review Questionnaire, interviewer notes recorded during the survey, and interviewer reflections. These sources were analyzed to evaluate the survey instrument and the administration process.

Survey Tool Questions

A question was added to the end of each section of the survey for interviewers to note any problems the participant had with the survey. This question was also used to report technical problems with the survey and to make notes about the participant's behavior. These responses were analyzed for trends related to questions and terminology that caused problems for the participant.

Pilot Review Questionnaire

For each survey the interviewers completed a Pilot Review Questionnaire that included information about the participant, the setting, and the survey process. These responses were compared to the survey results to identify patterns survey non-completion and problem areas.

The questionnaire also allowed the interviewer to share successful interview techniques or unusual situations. These responses were used to provide ongoing coaching to interviewers and to make adjustments to the administration process. The responses were also used to make recommendations for the baseline survey.

Interviewer Reflections

As the people working in the field, the interviewers had the most extensive knowledge of what worked well during the pilot and what needed to be changed. In order to share this experience, the interviewers regularly debriefed staff about their experiences in the field. These conversations were used to improve processes throughout the administration phase. Because the interviewers had time to reflect more on their experiences before debriefing, these reflections were often more in depth than the pilot review questionnaire allowed. Interviewers also provided feedback about the pilot project at the end of the survey administration period. Their feedback was used reinforce findings and recommendations.

Quantitative Analysis

The survey responses were analyzed for response rate, survey completion rates, and survey length. Participant's responses to race and ethnic identity and disability type and perceived significance questions were also compiled.

Response Rate

Approximately 450 individuals from 9 settings were invited to take the survey, and 105 individuals agreed to participate for an overall response rate of approximately 22%. A handful of providers volunteered to ask everyone they serve to participate in the study. Because the number of people these providers serve is unknown, it is not possible to calculate survey response rate. This includes an estimate of the number of people who were invited to participate during community meetings at the Anoka Metro Regional Treatment Center. Volunteers were recruited in Board and Lodging but were not used to calculate the response rate.

Two settings, Adult Foster Care and School Settings, had response rates around 10%. However, these settings had unique recruitment issues that may have depressed the response rate. The Adult Foster Care response rate includes participants receiving Supported Living Services, and no interviews were conducted in those homes. Of the participants receiving funding through the CADI, CAC, and BI waivers the response rate was 18%. For school settings, the response rate was likely affected by the fact that there was no way for the Improve Group to follow up with families after the initial letter.

At each setting there were individuals who agreed to take the survey but who declined at the time of the interview. In some settings, most notably Boarding Care and Nursing Homes, there were people who agreed to take the survey but did not show up for their appointment. Other people agreed to the survey but were unable to participate because of scheduling conflicts. A longer survey administration period would give these individuals more opportunities to participate.

TABLE 3: RESPONSE RATE BY SETTING

Setting	Number of Invitations	Number of Surveys	Response Rate
Adult Foster Care	57	5	9%
Boarding Care	28	12	42%
Board and Lodge with Special Services (participants were recruited at the time of the interview)	0	10	-
Center-Based Employment	60	22	35%
Day Training and Habilitation	47	9	19%
Intermediate Care Facilities for Persons with Developmental Disabilities	25	8	32%
School Settings	166	18	11%
Nursing Homes and Assisted Living	50	15	30%
Supervised Living Facilities	30	6	20%
Total	455	105	22%

Survey Completion

Overall, 88% of participants completed the required sections of the survey, and 60% completed all but the last section. Only 34% of participants completed all the survey sections. This is in part due to

participant fatigue and in part because interviewers were told to give the participant the option to stop the survey after 60 minutes. At least 80% of participants completed the required sections in every setting except DT&H and Boarding Care. The low completion rate (56%) in DT&H is because many of the participants had barriers to completing the survey that are related to their disabilities. The completion rate was also lower (67%) in Boarding Care. This is due to people who agreed to take the survey but who decided to stop during the first section. Survey completion rates by setting are shown in Table 4. The four surveys conducted after the survey administration period are not included in the results.

Most of the participants who stopped at the end of the required sections or after the Person-Centered Planning section stopped because of fatigue or because of other appointments. However, some participants declined to complete the Close Relationships Inventory because they were concerned the section would be too personal. In Segregated School Settings, only one participant completed the Close Relationship Inventory. Several parents declined to complete the section because their child “didn’t have any friends.” We recommend adding more training around framing this section to increase completion rates.

TABLE 4: SURVEY COMPLETION BY SETTING (PERCENT COMPLETED)

Setting	Attempted Surveys	Did Not Complete Required Sections	Completed Required Sections	Person-Centered Planning	All Sections
Adult Foster Care	5	0%	100%	40%	40%
Boarding Care	12	33%	67%	50%	17%
Board and Lodging	6	0%	100%	67%	67%
Center-Based Employment	22	5%	95%	68%	64%
Day Training and Habilitation	9	44%	56%	56%	33%
Intermediate Care Facilities for Persons with Developmental Disabilities	8	0%	100%	13%	13%
Segregated School Settings	18	0%	100%	94%	6%
Nursing Home / Assisted Living	19	16%	84%	42%	26%
Supervised Living Facility	6	0%	100%	67%	17%
All Settings	105	11%	90%	59%	32%

Survey Completion Time

The total time needed to complete the survey varied by setting. Across all settings, the average survey length was 42 minutes with a maximum length of 91 minutes. Average, minimum, and maximum survey length by setting is shown in Table 5. The minimum survey length includes surveys that were started but not completed. Unless noted, this calculation does not include interviews that were recorded using paper and pencil.

An important consideration in survey length time is the relationship between survey length and survey completion. Overall, the higher the survey completion rate the longer the survey took to finish. This is of particular importance in settings where participants have higher barriers to participation or communication needs that will lead to longer surveys such as DT&H. Also, interviews that took place at a provider were scheduled for 60 minutes and most surveys were stopped if they lasted over an hour. Participants were also reminded of their option to end the survey after the required sections or when they showed signs of fatigue.

TABLE 5: SURVEY LENGTH BY SETTING (MINUTES)

Setting	Average Survey Length	Minimum Survey Length	Maximum Survey Length
Adult Foster Care	46.7	34.6	60.7
Boarding Care	27.8	4.1	54.8
Board and Lodging	36.7	29	48.2
Center-Based Employment	46.5	30.8	70.4
Day Training and Habilitation	20.3	2.4	45
Intermediate Care Facilities for Developmental Disabilities	34.5	26.4	40.8
School Settings	54.3	29.9	90.7
Nursing Homes and Assisted Living	45.2	7.9	89.8
Supervised Living Facility (includes paper surveys)	32.2	22.5	46.7
All Settings	41.8	2.4	90.7

Respondent Characteristics

Participants were asked to provide their race and ethnic identity followed by primary ethnic identity. Participants could select more than one response for race and ethnic identity, but only one primary ethnic identity. If the participant only selected one race or ethnic identity, the interviewer chose the same response for primary ethnic identity.

When asked to choose their primary ethnic identity, 63% of participants identified as Caucasian or White, and 12% identified as African American or Black. Ten percent responded “Something Else” and 8% of participants refused or did not understand the questions. Respondent’s primary ethnicity identity is shown in Table 6.

TABLE 6: PRIMARY RACE AND ETHNICITY

Race and Ethnicity	Number	Percent
African American / Black	13	12%
American Indian or Alaskan Native	4	4%
Asian	1	1%

Race and Ethnicity	Number	Percent
Native Hawaiian or Other Pacific Islander	0	0.0
Hispanic or Latino	2	2%
Caucasian or White	67	63%
Something Else	11	10%
Refused, left blank	8	8%

The Quality of Life tool includes a list of disabilities. For each item on the list, participants were asked if that disability applied to them and, if yes, if they perceived the disability to be of “Major” or “Some” significance. At least one participant reported a “Major” disability for all of the items except Dementia. Some participants responded “None” for all of the items on the list.

People from all five of the disability types included in the sampling guidelines were interviewed during the pilot. The most frequently mentioned disabilities were Mental Illness (49%), Intellectual Disability (43%), Major Health Problems (38%), and Communication (36%). Walking (38%) was not included as an option on all of the surveys, as it was inadvertently left out of the first surveys administered. Four participants reported a “major” hearing disability and seven reported a “major” vision disability. These numbers reflect the difficulty we had with recruiting deaf and blind participants.

TABLE 7: DISABILITIES AND PERCEIVED SIGNIFICANCE

Disability	Major	Some	None	Percent Major / Some
Autism	10	7	83	17%
Behavior: Aggressive or Destructive	5	15	80	20%
Behavior: Self-Abusive	2	14	85	16%
Brain Injury	8	13	75	21%
Cerebral Palsy	4	4	90	8%
Communication	20	17	50	37%
Dementia (Including Alzheimer's Disease)	0	4	91	4%
Health Problems (Major)	20	18	50	38%
Hearing	4	20	74	25%
Intellectual Disability	21	21	55	42%
Mental Illness	26	22	50	57%
Physical Disability Other Than Ambulation (walking)	12	15	72	27%
Seizures	4	14	81	18%
Substance Abuse	8	8	82	16%
Swallowing: Inability to swallow independently	2	9	87	11%
Vision	7	19	74	26%
Walking (this item was not asked of everyone)	17	14	52	37%
Other	15	12	60	30%

Lessons learned by setting

Working in Different Settings

Initially, 46 providers were selected as pilot sites, and additional providers were added throughout the administration phase in order to reach all of the target populations. In total, we contacted 51 providers about the project, and interviewed participants from 29 providers. Reasons interviews were not conducted at the other providers include scheduling problems, lack of participant interest, and because the providers refused to participate. In addition, some of the providers were not appropriate settings for the Quality of Life Survey because they do not provide services to people with disabilities.

The process for working with providers in each setting follows.

Adult Foster Care

Invitations to participate in the pilot were sent from the Improve Group to participants that live in Adult Foster Care and receive services from the Community Alternatives for Disabled Individuals (CADI), Brain Injury (BI) or Community Alternative Care (CAC) waiver programs. A separate letter was sent to the provider explaining the survey and asking for help in obtaining guardian consent when needed. Interviews were either scheduled with the focus person or through a house manager depending on the number of people in the home who agreed to participate. All the residents of the home, including people who were not a part of the sample, were given the opportunity to participate in the pilot. Three of the four providers participated in the survey. The interviews were conducted in common rooms and resident's bedrooms.

Invitations for participants in living in Supported Living Services homes and receiving services from the Developmental Disabilities (DD) waiver were sent to the provider and to individual homes. The Improve Group then reached out to the providers and individual houses to recruit participants, but no interviews were scheduled. Two providers contacted us to discuss the project and to address concerns about the pilot and the baseline survey.

Scheduling interviews with foster care residents was complicated by the different schedules of the people living in the home. We tried to schedule multiple interviews for a single visit, but it was difficult to find times that worked for multiple residents. Many of the interviews had to be rescheduled or cancelled on short notice because the participant was not available. This happened both when the interview was scheduled through house staff or with the individual. For many of the participants work opportunities, leisure activities, and sleep took priority over participating in the survey.

Boarding Care

A packet of information, including a list of participants if available, was sent from DHS to Boarding Care providers. DHS was only able to pull a sample for two of the five providers that were selected as pilot sites. The other providers were not found in MAXIS. Although we were not able to get a sample for the provider, we reached out to a third Boarding Care provider that has a deaf services program. All the participants in that program were invited to participate.

We worked with providers to schedule a time when most of the participants would be available for interviews. Most of the interviews were conducted in a semi-public space such as a dining hall or multi-purpose room. Staff helped to coordinate interviews by finding participants and escorting them to the interview.

Getting individuals to start and to complete the survey was more difficult than at other settings. Although most of the people selected initially agreed to the survey, many participants could not be located when it was time for their interview. Based on feedback from providers we believe that at least some of those people did not feel comfortable declining to participate. Several participants consented to the survey, but stopped during the first section because they were uncomfortable with the questions and how their responses would be used. At one provider we recruited volunteers to complete the survey.

Board & Lodge with Special Services

A packet of information was sent from DHS to Board & Lodge providers. However, DHS was not able to select a sample for any of the providers. Instead of selecting a sample, we contacted the providers and asked for volunteer participants. One provider agreed, two declined, and we were unable to reach the contact person at the other two. The Improve Group reached out to an additional Board and Lodge provider greater Minnesota, and we were able to conduct interviews at that provider. The interviews were conducted in offices or semi-private spaces at the providers.

The biggest problem with selecting Board and Lodge participants was identifying appropriate providers. The lack of plain language definitions compounded this problem. All of the providers we selected were listed as receiving Group Residential Housing funding, but four of the providers could not be found in the eligibility databases. One provider we selected did not provide services based on participant's disabilities. The residents at one provider opted out of the survey because of concerns related to their disabilities, specifically mental health concerns. We were not able to make contact with the appropriate person at the other providers.

Center-Based Employment

A packet of information, including a list of participants, was sent from DEED to Center-Based Employment providers. The providers helped with obtaining consent to release information to the Improve Group from participants and their guardians. When applicable, the providers also obtained guardian consent to survey participants. The providers also scheduled interview times and reserved space in their offices to conduct the interviews during the participant's work day. Everyone who was available during the interview time was given the chance to participate. Some of the providers paid the survey participants for missed work time.

We were able to schedule interviews at four providers. The fifth provider agreed to participate, but no interviews were scheduled. Two of the providers rescheduled interviews to make sure most of the people who agreed to take the survey were available. One provider requested the web version of the survey, and two of their participants completed the survey online.

Some of the people in the Center-Based Employment sample work offsite in an enclave or job crew. It was difficult to schedule interviews with those individuals without either extending their work day or disrupting programming. Because of transportation limitations, it was not possible to move people from their worksite back to the interview location. The providers suggested trying to interview people at the end of the work day, but warned that most of the individuals would be ready to go home and likely not have enough energy to complete the survey. In addition, people who were interviewed at the end of the day were concerned about missing their ride home.

One solution to these problems is to schedule interviews with people in Center-Based Employment outside of work hours. These interviews could be scheduled at the person's home or at a location of the person's choice. However, the providers played a significant role in encouraging people to participate, including reminding them that they had made a commitment and needed to follow through. If interviews are scheduled outside of the work day, this support will be lost. Based on our experiences in other settings, it may be more difficult to schedule interviews without the provider support. Interviews could also be scheduled at the participant's work site.

Finally, the Decision Control Inventory scale was not relevant to people who live independently or with family. When interviewing people who do not have paid staff, we recommend using the alternate scale for people without staff to capture whether the participant feels like they have control over the choices that are being made. The alternate scale is explained on page 42 of this report in the "Decision Control Inventory" section.

Day Training and Habilitation

A packet of information, including a list of participants, was sent from DHS to Day Training and Habilitation (DT&H) providers. The providers managed obtaining guardian consent to survey participants. The providers also scheduled interviews, reserved space in their offices to conduct the interviews while the participant was on site, and served as a support person during interviews.

We were able to schedule interviews at four of the six providers we contacted. One provider declined to participate because of the short timeline for obtaining guardian consent. The other provider obtained guardian consent for several participants, but we were unable to connect with the contact person to schedule interviews.

All of the DT&H participants had barriers to completing the survey that were related to their disability. This included non-verbal participants, individuals who were deaf and had no way of communicating beyond communicating their basic needs, and deaf-blind participants. In addition, staff shared that the participants with Autism had difficulty participating in the survey because of the disruption to their normal routine. All of the DT&H participants required a support person to help complete the survey.

As with Center-Based Employment participants, some DT&H participants work offsite which makes it difficult to conduct those interviews at the provider. During the pilot at least one person who wanted to participate in the survey was not interviewed because he was not able to make the appointment. Because people who work offsite rely on the provider for transportation, there is a short window to

interview them at the provider. Interviews with those individuals should be scheduled at a time and place that is convenient for the person.

Intermediate Care Facilities for Persons with Developmental Disabilities

A packet of information, including a list of participants, was sent from the Improve Group to Intermediate Care Facilities for Persons with Developmental Disabilities (ICF / DD) providers. The providers managed obtaining guardian consent to survey participants. Provider staff also scheduled interviews and served as support people during interviews.

We were able to schedule interviews at four of the five ICF / DD homes, although all of the providers agreed to participate. Interviews were not scheduled at the fifth home because the participants' behavior issues were a safety concern. However, there were challenges to scheduling and conducting interviews at all of the ICF / DDs. In some cases difficult relationships with guardians were a barrier to obtaining consent.

We encountered challenges when administering the survey at ICF / DD providers. Many of the participants were non-verbal or had other barriers to participation related to their disability. For those individuals it was important to have a support person present, and a staff person was often the most appropriate person to help with the interview. For many participants, their support staff has the most experience communicating with them and knows most about their activities. This does cause a problem if the person wants to but does not feel comfortable providing negative feedback. We also had problems obtaining guardian consent and making contact with providers.

Nursing Homes and Assisted Living

A packet of information, including a list of participants, was sent from DHS to Nursing Home and Assisted Living providers. The providers managed obtaining guardian consent, scheduled interviews, and coordinated appointments.

Ten Nursing Home or Assisted Living providers were originally selected for the pilot. We conducted interviews at only four of the 10 providers due to time constraints and because there was a large enough sample at the four facilities for the needs of the pilot. We were not able to conduct surveys with any participants who had guardians. One provider did not reach out to guardians, and a second provider's sample included several individuals in a persistent vegetative state. The guardians of those individuals were not contacted for the pilot.

One provider scheduled appointments for each of the participants, and we were able to interview everyone who agreed to take the survey. The other providers scheduled a block of time during which to conduct interviews. At those providers, many of the participants chose to attend other activities or appointments during the interview time.

Most of the interviews were conducted in an office or a semi-public space in the facility. In some cases the interviews were conducted in the person's bedroom. In those situations, the small bedrooms made it hard to use the laptop and for interviewers with mobility limitations to get around.

Segregated School Settings

The individual school districts managed invitations and initial consent. The school districts sent letters to the families and guardians of students receiving services in Federal Special Education Settings 3 and 4 inviting them to participate in the survey. All students were invited to participate in the pilot. The mailings included background information about the project and a guardian consent form. The student's guardian was asked to complete and return the consent form to the Improve Group. An interviewer then contacted the parent or guardian to schedule an interview.

Because the initial mailing had a low response rate, the school districts provided additional support by attempting to recruit families during parent / teacher conferences and calling parents to encourage them to participate. Eighteen students and their guardians participated in the pilot. Most of the interviews were conducted at the student's home; one student was interviewed at school.

The biggest challenges with administering the survey to students in segregated school settings were scheduling appointments and interviewing students. Another concern is that the Decision Control Inventory is not appropriate for students who live with their family.

Almost all of the parents or guardians wanted to be present for the interviews, and some said they would prefer for their child to not be present. In addition, many of the parents wanted to complete the survey for their child, either because they felt the student was not capable of responding to a survey or because the student did not have the attention span for participating in the survey. Our policy was to allow parents or guardians to participate in the survey, but to ask to have the child present. In many cases, the student only answered a few questions or did not participate at all. Only one student completed the survey without a parent or guardian present. Because of the way the interviews were conducted, it is uncertain if the students would have been able to participate if their parents were not present.

A second consideration when scheduling interviews with students in segregated school settings is that interviews had to be scheduled in the evening or on weekends. This meant that many of the surveys were scheduled close to dinner time or at another time that was disruptive to the student's schedule. One parent did ask for the survey to be scheduled during the school day, and the interview was conducted in a school office. However, scheduling surveys during the school day requires coordination with the school and requires the student's service providers to be present.

Finally, the Decision Control Inventory scale was not relevant to children living in their parent's home because most of the decisions are made by parents. For this, we recommend using the alternate scale for people without staff to capture whether the participant feels like they have control over the choices that are being made. The alternate scale is explained [on page 42 of this report in the "Decision Control Inventory" section.](#)

Supervised Living Facilities

Supervised Living Facilities are various treatment and rehabilitation programs licensed by the Minnesota Department of Health. They include:

- Detoxification Programs
- Chemical Dependency Treatment Program
- Residential Facilities for Adults with Mental Illness
- Residential Services for People with Developmental Disabilities, not certified as ICF / DD
- Residential Services for People with Developmental Disabilities, certified as ICF / DD

It was very challenging to select a sample of Supervised Living Facilities for this study. As described above, ICF / DD facilities are licensed as a Supervised Living Facility, but they are already included in the sample. The Olmstead Team did not believe that it was the intent to include Detoxification Programs, Chemical Dependency Treatment Programs, or Intensive Residential Treatment Services (IRTS) as they are all limited-term treatment programs and not residential settings. The only program included in this sample is the Anoka Metro Regional Treatment Center. DHS did not have access to the names of people in the Supervised Living Facility, so the DHS liaison reached out to the provider for a list of people receiving services in the Anoka Metro Regional Treatment Center. The Anoka leadership team was not comfortable with DHS selecting a random sample, primarily due to treatment and safety concerns. They proposed inviting the residents to participate in the survey during a community meeting. The Olmstead Team agreed to this approach. The residents of two units were invited to participate in the survey. A representative from the leadership team presented the project to residents and collected interest forms. The interviews were scheduled through the nurses' station in each unit.

The team had three main concerns about selecting a sample of residents. The concerns were:

- **Involuntary clients:** people who are in Anoka are there by court order. Leadership felt that asking a sample to participate in the study would feel coercive, but making it a volunteer opportunity would be better.
- **Safety:** Leadership suggested it was not always safe to interview clients.
- **Length of stay:** The average length of stay is 90 days, so creating a sample using our guidance was not feasible. They suggested it would be easier to contact discharged patients.

We were not able to get a list of providers to contact. Based on the pilot experiences, the Olmstead Team should gather more information about Supervised Living Facilities to determine whether they should be included in the baseline sample.

Recommendations to Tweak the Survey Tool

After the completion of the pilot surveys, Improve Group researchers analyzed the completed surveys and the completed pilot review questionnaire to identify trends in problem questions or sections in the Olmstead Quality of Life survey tool. We analyzed trends in problem areas for all participants as well as by setting type. Overall, the tool performed well and consistently across settings. Therefore, it is the Improve Group's recommendation to that the Olmstead Implementation Office use the Center for Outcome Analysis Quality of Life Survey for the baseline and follow-up surveys, with the modifications listed below. These recommendations have been discussed with and approved by the survey author.

Survey respondents had the biggest challenges were with the demographic and housing questions at the beginning of the survey. For that reason, we are recommending creating a "prescreening" process to gather information that is particularly difficult for participants to share. There are also a few areas where survey questions need to be reviewed for content in order to reflect the experiences of the participants. Finally, there were instances where interviewers require more training and content knowledge, and / or the survey prompts are needed to ensure the questions are asked consistently across interviewers.

The complete list of questions that need to be tweaked, including the problem that needs to be addressed and our recommended approach can be found in [Appendix A](#).

Prescreening

A prescreening process should be developed to collect demographic, disability, and housing information about the participant. These questions were consistently the most difficult for participants to answer, and it is more important to have accurate information than to get the response from the participant. The answers to these questions can be obtained from other sources, including agency records, providers, and the county from which the participant receives services. The only exception is housing information for people who live independently or with family. For those individuals, the information may be obtained from the focus person or someone providing support.

Collecting disability information during a prescreening process would change how the perceived significance scale works. If the person is eligible for services because of a disability, then that disability would be recorded as "major." If a person has other disabilities, but is not eligible for services because of that disability, the disability would be recorded as "some." This method does not allow for capturing the person's perception.

According to Jim Conroy, the perceived significance of the person's disability is not an outcome measure, meaning significance is not expected to change greatly over time. However, it is possible that as people move into the community they will perceive their disabilities to be less significant. We recommend omitting these questions from the survey as they were such difficult questions for participants to answer. However, if it is decided to gather this information, disability information could

be collected before the interview so that the focus person was only asked about the significance of disabilities that pertain to them.

Content

Because the survey is designed to be modular, the order of the sections is not important. Therefore, the Olmstead Implementation Office should arrange the survey so that the sections greatest interest for the Olmstead Plan are at the beginning of the survey. This will ensure that the most important sections have the highest response rate.

Community Integration and Engagement: Time, Money & Integration – During the Day

State agencies should provide plain language definition of work settings and programs that reflect the participant's understanding of the services they are receiving. The Olmstead Implementation Office should work with an advisory group to ensure the plain language definitions provided by the agencies matches the participants' understanding of how they spend their time. Interviewers should also be given guidance on how to rephrase questions and explain terms to help participants answer questions, while still maintaining the integrity of the survey.

Community Integration and Engagement: Integrative Activities Scale

Some of the activities listed may not match the participant's experiences, either because common activities are not included or because some activities have become less common over time. After the baseline survey the list may need to be updated to include activities reflect the activities people are engaging in. This means adding "other" responses with a high frequency and removing activities that may be becoming less common such as going to the bank or the post office.

The scale for this question was difficult for interviewers and participants. Participants were asked "Do you normally have interactions with community members during this kind of trip or outing?" If they said yes, they were then asked if they had a little, some, much, or very much interaction with community members. Participants and interviewers had a hard time with the difference between much and very much. We could not find a way to phrase the question that was not awkward, and it took so long to explain the scale that the question had to be asked several times.

We propose changing the scale to a four-point scale: none, little, some, a lot. Simplifying the scale would reduce the burden on participants. Although changing the scale would mean the results from this section would not be comparable to those in other states, we believe the change would lead to higher quality data. If this change is made, Jim Conroy would work with the Olmstead Implementation Office and the survey administrator to validate the approach.

Decision Control Inventory

Overall, the Decision Control Inventory scale works well across settings with the exception of people who live independently or with family. For those participants, there was no way to differentiate between decisions that were being made for them by unpaid caretakers and decisions the person was making for themselves. The Center for Outcome Analysis created an alternate scale for people without paid staff that asks if decisions are made by the person or by relatives, friends, or advocates. The scores

for both scales measure how much power the focus person is able to exert in making choices, and the two scales can be analyzed together.

Elements of Person-Centered Planning

Each question in this section has an element of the person-centered planning process, a plain language statement about that element, and a definition of the term that uses technical language and jargon. The jargon was included in case the participant needed more explanation about the statement. Although some participants asked for more information about some of the terms, especially person-centered planning, the interviewers did not use the jargon. In addition, some of the interviewers found the jargon distracting. Therefore, we recommend removing the jargon from the survey.

Interviewer Training

The abbreviated training period did not allow enough time for thoroughly training interviewers on the survey content and context. While the interviewers had enough information to conduct the survey, they would have benefited from additional training in survey content and context to answer questions from participants. Future trainings with survey interviewers should include more depth about survey content, methods for recording responses, and how the results will be used. State agencies should also provide tools for training interviewers about programs and services.

In practice, the tool more closely resembles a supported interview than a survey, and learning how to best conduct the interview in the field was difficult for survey administrators. More time should be dedicated to breaking down and administering the scales and for recording “out of range” responses. Interviewers should be trained both in administering the survey as written and supporting participants through the survey. Trainings should also include an overview of how section scores will be calculated and compared over time. This training will help interviewers become more comfortable with using the scales and increase consistency across interviewers.

In order to feel comfortable explaining settings and terminology to participants, interviewers should have training on the services offered to people with disabilities. This training should include information about the different settings they will be visiting and programs in the Community Integration section. Interviewers should also have some training around person-centered planning and the types of planning groups participants may have. This training will provide content knowledge for supporting participants during the interview and increase the accuracy of recorded responses.

The list of questions that will need particular attention for interviewer trainings and recommendations for training is provided in [Appendix A](#).

First Steps for the Baseline Survey Planning Phase

Access to Data

One of the largest delays during the pilot project was securing access to data. These delays led to a shorter survey administration period because of the time it took to secure multiple releases or data sharing agreements. In addition, because we did not have access to guardian information, we had to rely on providers to communicate with guardians about the survey.

The Olmstead Implementation Office should work to secure access to participant data through legislation or court order. The legislation or court order should include access to data for contractors. If needed, state agency liaisons should make sure data sharing agreements are in place early in the process.

Finalize Sampling Strategy

The project budget and timeline are dependent on the number of interviews to be conducted during the baseline. The Olmstead Sub-Cabinet and Olmstead Implementation Office will need to determine a final sample size and sampling guidelines.

As demonstrated in [Appendix B](#), by surveying just under 3,000 individuals in the settings selected, you will be able to extrapolate your results to the general population with a 95% confidence level plus or minus 5%. The survey developer has proposed a follow-up strategy in which 500 participants are surveyed each subsequent year to measure changes over time. The agencies should select a sample four times larger than the number of individuals you hope to interview. For example, to achieve 3,000 participants, the sample should include 12,000 people.

Plain Language Definitions of Settings

State agencies should provide plain language definition of work settings and programs that reflect the participant's understanding of the services they are receiving. The Olmstead Implementation Office should work with an advisory group to ensure the plain language definitions provided by the agencies matches the participants' understanding of how they spend their time.

Translation of Survey Materials

Survey materials, including the Quality of Life tool, consent forms, and communication materials should be translated for non-English speaking participants. The materials should be translated into the languages spoken by a substantial number of people eligible for the survey, including American Sign Language.

Lead Agency Roles

In past projects, DHS has reached out to county and tribal case managers for help with obtaining guardian consent for survey participants. In most cases, DHS is able to identify if a particular participant has a guardian or conservator, but DHS does not hold information on the guardian name or contact information. The information is maintained at the county or tribal government level. Through the pilot study, this information was gathered through providers. In the baseline survey, the Olmstead

Implementation Office and Survey Administrator should consider working with DHS to contact county case managers for this information.

Recommendations for Baseline and Follow-Up Survey Administration

The recommendations below represent lessons learned from the pilot study. Many of the following recommendations are practical, technical recommendations for the Survey Administrator of the baseline and follow-up Olmstead Quality of Life surveys. Some recommendations are for the Olmstead Sub-Cabinet, the Olmstead Implementation Office, or others, and are labeled accordingly.

Recommendations for the Planning Phase

- The Olmstead Team should use the Center for Outcome Analysis Quality of Life Survey tool to conduct the Olmstead Quality of Life baseline survey. The Olmstead Sub-Cabinet and Olmstead Implementation Office will need to determine a final sample size. As demonstrated in [Appendix B](#), by surveying approximate 3,000 individuals in the settings selected, you will be able to extrapolate your results to the general population with a 95% confidence level and a 5% confidence interval. The survey developer has proposed a follow-up strategy in which 500 participants are surveyed each subsequent year to measure changes over time.
- The Olmstead Sub-Cabinet and Olmstead Implementation Office should create a survey timeline for the baseline study, including a three to six month design phase for the study, followed by a survey period of at least four to five months, and a reporting period of two to three months. The design phase should include up to four weeks to obtain participant data from state agencies after the request is submitted.
- The Olmstead Implementation Office should work to secure access to participant data through the support of the Sub-Cabinet, by using legislation, a court order, or other means. If using legislation or court order, it should include access to data for contractors. If needed, state agency liaisons should make sure data sharing agreements are in place early in the process.
- The Olmstead Implementation Office should ensure sufficient budget is included for translating project materials, providing interpreters, and interviewer training.

Recommendations on Human Subjects Protections

- The Olmstead Team should use multiple levels of review for documents, forms, and communication material, including obtaining feedback from advocates and self-advocates.
- The Survey Administrator should develop and institute a robust data protection plan and include several layers of human subjects protections for future surveys. The Olmstead Implementation Office and agency liaisons should review and approve the data protection plan.
- The Survey Administrator should empower individuals with disabilities to make their own decisions about whether or not to participate through a transparent consent / assent process that centers on protecting the rights and safety of the participants.

- The Olmstead Implementation Office and stage agencies should include language about the Institutional Review Board exempt status of the project in communication materials with providers.

Recommendations on Preparing the Tool

- Questions and response options should reflect Minnesota programs and offerings, especially in employment settings and housing questions. DEED, DHS, and MDE should provide the Olmstead Implementation Office with plain language definitions of these settings and programs for the survey.
- The Survey Administrator should prepare accessible and large print versions of the survey.
- A self-administered web-based version of the survey has limited appeal to participants. The Survey Administrator should provide other alternatives for interviewing people who might find an in-person interview disruptive should be explored, such as offering a Skype or video chat option.

Recommendations on Translation and Interpretation

- The Survey Administrator should include translation and interpretation costs in the project budget. This includes project materials, recruitment tools, communication tools, marketing and outreach materials, as well as the survey itself.
- The Survey Administrator should recruit interviewers who speak target languages, including American Sign Language, to help address potential issues with scheduling interpreters.
- The Survey Administrator should plan on additional time to schedule interviews with interpreters. The Survey Administrator should also consider working with multiple interpretation providers.

Recommendations on Sampling Strategy

- The Survey Administrator should work with liaisons in each agency to draw the survey sample. It is recommended that the sample be a stratified random sample, with stratification by setting. The data request should include disability and demographic information.
- The Survey Administrator should have the state agencies select a sample four times larger than the number of individuals you hope to interview. For example, to achieve 3,000 participants, the sample should include 12,000 people.

Recommendations on Working with State Agencies

- As stated above, securing access to data through legislation or court order will eliminate the need for obtaining consent to release information to the Olmstead Implementation Office or the contractor responsible for the survey.

- The Survey Administrator should engage agency liaisons early in the planning process to streamline access to data and selecting the sample.
- The Survey Administrator should be aware of and plan for needing time to engage agency liaisons and bringing them up to speed on the project and survey. Be aware that this is another item on the liaisons' and the data person's to do list.

Recommendations on the Advisory Group

- The Olmstead Implementation Office and Survey Administrator should collaborate on recruiting members for an advisory group. The advisory group should be engaged early in the planning process. The sooner the advisory group can provide ongoing feedback about outreach, communication, and recruitment, the more effective the group will be. Consider using Advisory Group members from the Pilot Study period.
- To gain legitimacy and to ensure that all voices are heard, the advisory group should include members from multiple disability. Members should be dedicated to gaining community support for the project and promoting transparency.
- Be creative about getting input from the advisory group. In person meetings are ideal, but not always feasible. Use technological solutions such as surveys, online discussion boards, and skype to convene virtual meetings and allow the group members to collaborate on their own schedule.
- Be honest and transparent about what can and cannot change as a result of the advisory group feedback. The details that are set in stone and the reasons for those decisions should be addressed from the beginning.

Recommendations on Reporting Abuse or Neglect

- The Survey Administrator should develop a protocol for documenting and reporting suspected abuse and / or neglect to the common entry point and to the Olmstead Implementation Office.
- The Survey Administrator should include a module on mandated reporting during interviewer training.
- Communications to providers should include notification that the interviewers are required to report suspected abuse and or neglect to the appropriate agency.

Recommendations on Working with Providers and School Districts

- The Survey Administrator should work with Agency Liaisons to identify the appropriate person at each provider to contact about the survey. This should be someone at the director level who is empowered to make decisions about the project.

- Many providers, especially providers receiving funding from DHS, are asked to support the administration of multiple surveys throughout the year. The Survey Administrator should be mindful of the various requests the providers are balancing.
- Communications to providers should include information about how the Survey Administrator and Olmstead Implementation Office will protect participants' privacy and rights during and after the survey.

Recommendations on Recruitment and Communication Strategies

- The Olmstead Implementation Office should develop a marketing strategy for the survey so that participants and providers are familiar with the survey efforts before they are asked to participate. Take advantage of existing communication channels to market the survey to providers and potential survey respondents.
- Establish credibility and authority with providers by having agency liaisons make first contact with directors about the Olmstead Quality of Life Survey. This shows that the state agency supports the project and the administration team. This outreach should start early in the planning phase of the baseline study, and can build on outreach efforts during the pilot study.
- The Olmstead Implementation Office should work with agency liaisons develop a strategy for gaining provider support for the baseline survey. Regardless of how the participants are invited to take the survey, having the providers support will increase response rates.
- The Survey Administrator should engage the advisory group in developing an outreach and marketing strategy for participants. The strategy should include reaching participants and their families through community programs and online communities such as Facebook groups.

Recommendations on the Consent Process

- The Survey Administrator should work with county case managers to collect guardian information for participants selected through DHS. Case managers could also be asked to help obtain guardian consent. Guardian information should be included in the data request to DEED and to districts through MDE.
- When it is not possible to work with case managers, the Survey Administrator should reach out to providers for help with obtaining guardian consent. The relationships providers have with participants and guardians added credibility to the pilot project, and that relationship could also be helpful for the baseline survey.
- The recruitment strategy should give participants time to formulate their response about whether they would like to take the survey. People may not feel comfortable saying no to a person in an authority position when they are first approached.

Recommendations on Survey Administration

- The Survey Administrator should plan for 4 hours per survey for coordination, travel, and survey administration in the Metro area. Travel in Greater Minnesota will be higher.
- The Survey Administrator should be prepared for no-shows and cancelled interviewers. A protocol for following up with participants who miss, cancel, or reschedule interviewers should be developed that ensures everyone has the opportunity to take the survey while respecting the right to decline in their own way.
- The Survey Administrator should select a survey administration mode that balances the need for data security and efficient data collection. The administrator should take into account the limitations of paper and computer administered surveys discussed in the report. We do not recommend administering the survey using an Internet-based platform because of unreliable wireless access in rural areas and buildings.

Recommendations on Survey Administration in Greater Minnesota

- Hire interviewers from greater Minnesota to reduce the travel time needed for surveys conducted outside of the metro area. In addition, interviewers from outside of the metro area may offer regional expertise that will add to the value of the survey.

Recommendations on Blind or Visually Impaired or Deaf and Hard of Hearing Participants

- The Advisory Group should help develop strategies for outreach and recruiting participants who are deaf or blind.
- The Survey Administrator should prepare the Quality of Life tool for administration with screen readers.
- The Survey Administrator should work with an American Sign Language interpreter to translate consent forms and the Quality of Life tool. The translation help to standardize interpreted interviews.
- The Survey Administrator should include modules on working with individuals who are blind, deaf, and deafblind in the interviewer training.