***Community Task Force on Oral Health Needs of People with Developmental Disabilities***

**Sponsored by: Golisano Foundation**

**Led by: Eastman Institute of Oral Health**

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EXECUTIVE SUMMARY

*“Oral Health Needs of People with Intellectual and Developmental Disabilities”*

In January 2012, a community task force sponsored by the Golisano Foundation and spearheaded by the Eastman Institute of Oral Health was convened to describe the Rochester-area landscape of oral health and related services for individuals with IDD and to set forth a series of actionable recommendations to improve care.

**BACKGROUND**

Oral health is integral to and inseparable from overall health.  Yet it is widely recognized that the oral health of individuals with intellectual and developmental disabilities (IDD) is significantly compromised and that access to dental care is diminished relative to the general population.In 2010, a comprehensive study, based on the dental records of over 4,700 patients with IDD, thus far the largest study undertaken on the oral health of this group, was conducted by [John Morgan](http://jada.ada.org/search?author1=John+P.+Morgan&sortspec=date&submit=Submit) and colleagues at Tufts University School of Dental Medicine. These researchers foundthat individuals with IDD have significantly higher plaque levels and poorer oral hygiene than the general population.  Individuals with IDD also had a higher prevalence and greater severity of periodontal disease than the general population, in addition to consistently greater levels of untreated caries.

Several disability-related factors contribute to the relatively poorer oral health and hygiene of individuals with IDD. These include the presence of significant physical limitations or congenital malformations, coexisting/complex medical conditions, increased incidence of early caries and of dental attrition from grinding, irregular adherence to home care regimens, access to care and the ability to undergo or tolerate dental treatment. Additionally, residential status (home or facility) and geographic placement (urban or rural), along with access to transportation, can be determinative. Similarly, age (pre- or post- 21-year, transitional age and associated comprehensiveness of healthcare benefits; young or elderly), socioeconomic standing, family involvement, complicating health or behavioral issues, and severity of disability are important factors to consider in reviewing barriers to obtaining care.

To complicate the picture further, other issues impact oral health care of individuals with IDD. These include the varying education, capabilities, experience, comfort and motivation of oral health care practitioners that may treat individuals with IDD, adequate and accessible facilities, and the willingness to accept often woefully inadequate reimbursement for care. (Regarding the latter, see DM Rapalo, et al., “Cost as a Barrier to Dental Care among People with Disabilities: A Report from the Florida Behavioral Risk Factor Surveillance System,” Special Care Dentistry 2010 (Jul-Aug); 30(4):133-9.)

The urgent need to systematically address oral health care needs among people with IDD is recognized at national and state levels, and comprehensive, integrated, and systematic responses are under development. Based on a meta-analysis of twenty-seven high quality research studies looking at oral health among individuals with IDD, Dr. Patrick Anders, faculty at SUNY Buffalo School of Dental Medicine, noted, “The greatest opportunity to improve oral health for people with intellectual disabilities lies in the development of effective prevention.” *Special Care Dentistry* 2010, May-June 30. Unfortunately this is sorely lacking.

As Dr. William Calnon, former President of the American Dental Association, has said, “We can’t drill our way out of this problem.” Clearly, we have great strides to make and prevention appears to be a logical starting point.

**LOCAL CONTEXT**

The 10 county Finger Lakes Region is home to more than 12,000 individuals with IDD (representing a significant portion of the 126,000 individuals receiving services through the NYS Office for Persons with Developmental Disabilities (OPWDD). The vast majority of these individuals, in keeping with national trends toward de-institutionalization, live in community-based group residences or at home with their families. Increasingly, these individuals look to providers in their communities to meet their dental care needs. However, while many individuals with IDD can theoretically be cared for in a general practice community setting, most general practice dentists are ill-prepared to provide coverage that addresses the unique needs of this population. At present, accreditation standards for dental and dental hygiene training programs stipulate only that providers leave educated to “manage” individuals with IDD i.e., to appropriately identify and refer (to specialist care) individuals with IDD oral health issues and needs, not that providers be competent or committed to treat such patients themselves. As dental service provision to individuals with IDD patients is often demanding and time-consuming, requiring considerable and creative adaptation of skills, providers require additional expertise and are unfortunately neither trained nor motivated by current reimbursement mechanisms to take on the challenge.

With numerous facilities across the state reducing or eliminating dental services for patients with IDD and routine care less and less available, the Eastman Institute for Oral Health, and a select other group of institutions, have become safety net providers for individuals with IDD in our region. Based on the consequent landscape of burgeoning waiting lists, and of rising numbers of those presenting for urgent and acute care, we have a keen and emerging sense of the need to improve oral healthcare for individuals with IDD in our region. However, we did not have an assured understanding of how many individuals need to be served and in which service provision categories, the regional strengths and challenges, and opportunities for improvement, or who at present among the population of individuals with IDD are most often or apt to “fall through the cracks” and why. This gap in our understanding of the care of individuals with IDD in our area led us to propose a community task force approach to answer these and related questions to the best of our ability, and to develop well-grounded recommendations for improving oral healthcare service coverage for individuals with IDD in our region.

**PROCESS**

**The Community Task Force**

In January 2012, a community task force sponsored by the Golisano Foundation and spearheaded by the Eastman Institute of Oral Health was convened to describe the Rochester-area landscape of oral health and related services for individuals with IDD and to set forth a series of actionable recommendations to improve care.

A steering committee was established representing the region’s various service organizations for individuals with IDD, parents of individuals with IDD, dentists and hygienists in private practice, academic and public health settings, the Eastman Institute for Oral Health, and the Finger Lakes Developmental Disabilities Services Office (FLDDSO). The steering committee was assisted in its work by Dr. Paul Glassman, a national leader in developing programs for maintaining and improving the oral health of individuals with IDD. Please see Appendix 2.

Two open community meetings, involving a broad cross section of the area’s stakeholders for individuals with IDD support and services, were convened to review and discuss the project.  One was held in March 2012, at which Dr. Steven Perlman (Founder, Special Olympics Special Smiles) was the keynote speaker and the other in May 2012, at which Dr. Paul Glassman was the keynote speaker. A public website <http://www.urmc.rochester.edu/dentistry/developmental-disabilities/index.cfm> was developed and has been maintained throughout the community task force process. The website invites input from interested parties as well as provides access and updates to the work of the taskforce along with links to related articles, research, information and events.

A third community meeting is planned for October 2, 2013 where the Community Taskforce report and recommendations will be presented and discussed with individuals with IDD families, caregivers, community and government agencies, and the general public interested in the oral health of persons with developmental disabilities.

**Work Groups**

The Steering Committee established five (5) work groups charged with the task of utilizing statistical data, surveys, focus groups, interviews, and literature reviews to explore their topic areas:

1. Demographics: *Who is Receiving What from Whom*?
2. Consumer Perceptions and Satisfaction
3. Provider Experiences and Expectations
4. Current and Unfolding Policy
5. Model IDD Oral Health Care Programs

Given the scope of the task and the time available for collecting information, the steering committee recognized that the charge to the work groups was not to conduct academic research for publication, but to gather information that would serve as the basis for making action-oriented recommendations. A decision was made to focus on a five (5) county, greater Rochester area: Monroe, Wayne, Livingston, Orleans and Ontario.

**RECOMMENDATIONS**

1. **Principles for Care of Individuals with IDD**

Through its review of relevant statistics, as well as data from literature reviews, surveys, focus groups, and interviews with local providers, families and caregivers, nine general principles for a community-based approach to maintaining and improving oral health for individuals with IDD have emerged:

* An explicit system of coordinated care from prevention to complex procedures;
* A comprehensive and integrated collaboration involving medical, community and government services;
* A commitment to individualized care that incorporates the physical, medical, social, and behavioral facets of individuals with IDD, their families and caregivers;
* Recognition of oral health as matter of lifetime care rather than a series of episodic dental interventions to treat acute exacerbations of chronic conditions;
* The effective decentralized utilization of current technologies, such as teledentistry, to monitor care and support the delivery of care;
* A system of training, education and recognition for all oral health care providers;
* Safe, physically accessible, high quality and appropriately equipped care environments;
* A reimbursement system that provides fair reimbursement to providers, that incentivizes prevention and is sustainable in a managed care or capitated environment;
* Evidence-based protocols and practices that encourage best care.

1. **Education**

* Maintain the centrality of educational institutions in the education process by the creation of academic centers of excellence in the care of individuals with IDD in these institutions.
* Continue the education of providers, care givers and individuals with IDD in institutions such as Eastman Institute for Oral Health (EIOH) and Monroe Community College School of Dental Hygiene.
* Increase the skill and number of oral health providers (caregivers, hygienists and dentists) serving individuals with IDD through education, training, support and recognition. Consider the establishment of a fellowship in Special Needs Dentistry at Eastman Institute for Oral Health and modeled after existing programs.
* Publicize and host existing CE courses and public speakers on topics related to care for people with developmental disabilities
* Create three-part CE teaching program for practitioners, comprising the following components:

1. Didactic learning with local speakers
2. Hands-on experience in clinic and operating room
3. Network following participation to encourage case presentations and second opinions

* Provide in-service learning opportunities for staff, family members and residents of facilities for persons with disabilities.
* Reinstitute an operating room training program for community dentists.

1. **Prevention**

* Recognize that prevention is the essential element in improving oral health and is best provided where individuals with IDD gather, live, and learn.
* Ensure that hygienist play a key role in preventive programs for group homes, school settings, home and community-based settings.
* Develop preventive care program, which utilize hygienists in the field to reduce the need for acute dental treatment (i.e. modeled after Special Olympics Family Health Forums).
* Use new technologies and innovation in programs focused on oral disease prevention.

**4. Care Coordination**

* Manage the gap between identifying the need for oral health care and servicing that need, as well as ensuring the most efficient use of specialized resources like operating room care by systematic care coordination.
* Ensure that individuals with IDD receive the appropriate monitoring and follow up care for optimal oral health that includes the optimal scheduling and utilization of operating room resources.
* Emphasize prevention and systematically coordinating and monitoring dental treatment to produce better oral health at a lower cost than the current system which focuses on procedures and lacks a prevention orientation.

**5. Role of Institutions**

* As institutions in the greater Rochester area, notably EIOH, Rochester General Hospital (RGH) and CP Rochester, are the safety net providers for individuals with IDD as well as venues for education and research in the dental care of individuals with IDD, ensure that their commitment to the oral health care of individuals with IDD continues.
* Maintain the important role institutions have in lobbying for adequate reimbursement for individuals with IDD and in securing funds for innovative education programs, demonstration projects and research.

1. **Identify and Capitalize on Existing Opportunities**

* Capitalize on existing opportunities in the care of individuals with IDD. An example is illustrated below.

Over the last two years, a relationship between philanthropist B. Thomas Golisano and Special Olympics International (SO) has culminated in a $12 million gift from Mr. Golisano to Special Olympics. The gift is being used to pilot a new international health initiative, Healthy Communities. New York’s Genesee Region is one of the funded sites. The vision of this initiative is to expand athlete health services, increase partnerships, expand the use of technology, and promote awareness of the health disparities facing individuals with IDD. After reviewing athlete health needs and the opportunities and resources in the Genesee Region, oral health and obesity have been selected as the first two health issues the project will address.

In addition to SO’s Healthy Communities, the Genesee Region has a significant array of other relevant resources. For example: the Eastman Institute for Oral Health; the Strong Center for Developmental Disabilities; Rochester General Hospital; the dental hygiene degree program at Monroe Community College; outstanding community service organizations devoted to the needs of the population of individuals with IDD; knowledgeable dentists and dental hygienists who are already providing care to individuals with IDD; and the Community Oral Health Taskforce. Furthermore, there are opportunities to expand relationships with state and community offices and professional organizations, e.g. the New York State Academic Dental Centers and the New York State Office for Persons with Developmental Disability Task Force on Dentistry.

Bringing these opportunities and resources together in an integrated, comprehensive system of oral health care will make a lasting difference in the general health and quality of life for people with developmental disabilities in our region and serve as a model for other communities.

1. **Research**

* Recognizing the great need for basic science and clinical research related to oral health for individuals with IDD, develop study ideas and conduct research in the oral health care of individuals with IDD. The recently funded National Dental Practice-Based Research Network with an administrative hub at the EIOH offers an excellent opportunity for conducting research in this area.
* Encourage faculty to do research in the oral health care of individuals with IDD through pilot program funding.

1. **Innovation in oral health care prevention and delivery through pilot programs:**

* Develop innovative demonstration projects and pilot programs in oral health care delivery and prevention. Two examples, are presented in the report and summarized below:
  1. Use of Mobile Devices in Follow-up and Oral Health Care Coordination.

This will be a “prospective cohort study” in which we will seek; using a phone text based preventive approach, to elicit positive behavior change in athletes, as indicated by their daily oral hygiene habits, a goal in line with the Healthy Communities objective. Additionally it will establish a dental home for all athletes, and appropriately triage and treat 100% of athletes identified at events as having either non-urgent or urgent treatment needs. A database of athlete phone numbers will be created for future use. A dental care coordinator will assist in registering athletes for the program, in obtaining referrals to appropriate providers and in creating community partnerships.

* 1. Use of Dental Hygienists in Group Home Settings.

To address the issue of access to care for individuals with IDD and to focus on preventive services delivered in a patient-centered setting, we propose placement of a dental hygienist in group home settings to deliver preventive care, oral cancer screening and oral hygiene instruction. Oral hygiene instruction will be provided for residents, staff and family members, where appropriate. Pre- and post-testing, at 6 month intervals, on oral hygiene concepts will be given to staff to ensure retention of skill sets. For residents identified as needing treatment, a dental care coordinator will assist in finding an appropriate dental office or in scheduling general anesthesia services. Pre- and post-intervention behavior and oral health will be assessed. Oral health indices and behavioral ratings will be used at every recall appointment. Success will be based on improvements in these ratings and ability of dental health coordinator to connect residents needing services with dental homes.

**REPORT**

In January 2012, a community task force sponsored by the Golisano Foundation and spearheaded by the Eastman Institute of Oral Health was convened to describe the Rochester-area landscape of oral health and related services for individuals with intellectual and developmental disabilities (IDD), and to set forth a series of actionable recommendations to improve care. This report represents the efforts of that taskforce.

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Two open community meetings, involving a broad cross section of the area’s stakeholders for individuals with IDD support and services, were convened to review and discuss the project.  One was held in March 2012, at which Dr. Steven Perlman (Founder, Special Olympics Special Smiles) was the keynote speaker and the other in May 2012, at which Dr. Glassman was the keynote speaker. A public website <http://www.urmc.rochester.edu/dentistry/developmental-disabilities/index.cfm> was developed and has been maintained throughout the community task force process. The website invites input from interested parties as well as provides access and updates to the work of the taskforce along with links to related articles, research, information and events.

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Work Groups

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1. Demographics: *Who is Receiving What from Whom*?
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5. Model IDD Oral Health Care Programs

Given the scope of the task and the time available for collecting information, the steering committee recognized that the charge to the work groups was not to conduct academic research for publication, but to gather information that would serve as the basis for making action-oriented recommendations. Because of logistic reasons and because these are thought to be representative, a decision was made to focus on a five (5) county, greater Rochester area: Monroe, Wayne, Livingston, Orleans and Ontario.

1. **Demographics: *Who is Receiving What from Whom*?**

The purpose of this Work Group was to determine;

* How many individuals with developmental disabilities reside in the greater Rochester area;
* How many of these individuals are receiving dental services; and
* And to identify trends and gaps in service.

Consumer Profile:

Data from the FLDDSO shows there were 9,300 individuals in 2012 with “active client status” in the greater Rochester area (Monroe, Wayne, Ontario, Livingston, Orleans. This is out of 12,000 in the 11 county Finger Lakes region). More than half of these individuals live in Monroe County (55%); with 40% between the ages of 21-44 years; and 35% living in some type of certified residence.

Who is Receiving Dental Services and from whom:

The Workgroup found it was difficult to determine how many individuals are receiving dental services. First of all, we know that private practice dentists are reluctant to accept Medicaid patients (less than 17% in NYS), which is the dominant payer for individuals with IDD. And, secondly, while we were able to identify five (5) local area clinics providing the majority of care to individuals with IDD (EIOH, RGH, Anthony Jordon, CP Rochester and FLDDO Dental Clinic), they do not consistently track or identify disability type.

With the above realities in mind, the clinics who participated in our survey reported serving 2,786 patients with IDD in 2011, which is far fewer than the 9,300 individuals living in the greater Rochester region. The reported wait-time between appointment scheduling and actual visit in the outpatient setting is six months or less, with a much longer wait time – up to one year or more – for the Operating Room setting. All of the clinics rated themselves moderately to fully accessible.

Suggestions for improvement from the Demographics Workgroup include:

* Development of a standard patient classification system to be used by the community-based clinics as well as private practice dentists serving individuals with IDD in order to accurately identify number served, types of disabilities, services received, etc.
* Clarify the actual number of individuals receiving dental services on an annual basis by using DOH Medicaid claims data.
* Determine how many individuals are not receiving routine, preventative dental services and why?
* Work collaboratively with local area hospitals to reduce wait-time for needed OR services; while simultaneously working with community-based organizations and caregivers to improve oral health and hygiene to mitigate the need for OR services.

1. **Consumer Perceptions and Satisfaction**

The objective of this work group was to:

* Determine areas of oral health satisfaction, perception and need, by understanding the family/patient experience for individuals with developmental disabilities.

Two methods – surveys and focus groups – were used to collect information on demographics of the population served, current oral health status, frequency of health services utilization, and barriers to utilization, with the purpose of identifying gaps in the current oral health services system for individuals with IDD.

Local agencies serving adults and children with IDD in the 5-county Greater Rochester region were contacted by key members of the subcommittee to request their participation in this assessment. After internal agency review, the surveys were distributed to the participating agencies either as a paper copy to be filled out, and/or as a link to an online version of the survey hosted by Survey Monkey. Potential survey respondents consisted of individuals with developmental disabilities, caregivers, family members, and staff or service coordinators of people with developmental disabilities.

Local agencies included in the survey:

|  |  |
| --- | --- |
| * Mary Cariola Children’s Center * Urban League of Rochester * Monroe Community Hospital Dental Clinic * Arc of Orleans County * CDS (Continuing Developmental Services) * Finger Lakes Parent-2-Parent * Lifetime Assistance Incorporated * AutismUp | * Community Place * Baden Street Settlement * Ibero-American Action League * CP Rochester * Boys & Girls Club * Heritage Christian Services * Special Olympics * Arc of Monroe |

Respondent Demographic Data

Findings from survey responses show the total number of individuals in the target population was estimated to be 9,785; there is likelihood that this estimated number may be higher as individuals may receive services from more than one targeted agency. The total number of survey responses was 655, of which 419 (64%) completed online and 236 (36%) completed paper surveys. Among those who completed the survey, (see demographic data below) 7.6% were individuals with a disability, 32.1% were parents, 2.4% were legal guardians, 28.5% were residential care providers, and 29.3% were listed as other (majority were service coordinators). Respondents were asked to answer questions based on either their own experience (if they were an individual with IDD) or based on the experience of the individual with IDD. For instance, “household income” was the income of the individual with IDD, rather than the caregiver.

Oral Health Access

Oral health access was assessed by asking questions about last dental visit and regularity of past dental appointment attendance. Figure 1 shows the percentage of respondents for last dental visit. Clearly, the majority of respondents (two-thirds) had their last dental visit within the last 6 months. Figure 2 illustrates the percentage of respondents who had regular, occasional and only if in trouble dental visits. Table 3 provides reasons for those not receiving regular dental care.

Respondents were asked if there was a time during the last 12 months when one needed a dental exam or treatment, or had a dental problem but did not receive care; only 11% responded affirmatively. However, 31.7% definitely felt anxious or nervous about going to the dentist, 42.3% to some extent and about one-quarter (26%) responded that they did not experience dental anxiety.

**FIGURE 1**



**FIGURE 2**



**Table 3**

**Reasons for Not Receiving Regular Dental Care; the top 3 reasons are highlighted in red**

|  |  |
| --- | --- |
| **Reasons** | **n (%)** |
| Afraid of the dentist | 76 (11.6%) |
| Hard to find a dentist who treats patients with DD | 75 (11.5%) |
| Lack of dental providers | 67 (10.2%) |
| Other reasons | 57 (8.7%) |
| Transportation | 42 (6.4%) |
| Did not think it was important | 27 (4.1%) |
| Dental insurance | 23 (3.5%) |
| Cost or financial hardship | 24 (3.7%) |
| Don't know where to go | 20 (3.1%) |
| Waitlist | 19 (2.9%) |
| Office is not accessible | 18 (2.7%) |
| Hard to take time off from work | 15 (2.3%) |
| Dental clinic too far away | 14 (2.1%) |
| Inadequate office equipment | 7 (1.1%) |
| NA – Dental care was obtained | 196 (29.9%) |

Perception of Oral Health

Figure 3 depicts the self-reported perception of oral health among this population. Interestingly, almost 70% of respondents reported that oral health was important for overall health. While 53% rated their oral health as poor to fair, a very small percentage (ranging from 9.3% to 14%) rated their dental health, appearance of teeth and gums as well as effect of oral health on social relationship as “poor”. About one-fifth of the respondents did not experience pain, anxiety or fear when receiving dental services. Only 11 % responded positively to the question that if there was any time during the last 12 months when one needed a dental exam or treatment, or had a dental problem, that they did not receive care. However, 31.7% definitely felt anxious or nervous about going to the dentist, 42.3% to some extent and only 26% responded not at all

**FIGURE 3**

The Focus Group sessions with parents and siblings of youth and adults with individuals with IDD were rich sources of information in several key areas.

1. On a personal level, family members would like professionals to realize that although oral health is important, it is not the only aspect of the person’s life for which they are responsible. Creating and maintaining a team of professionals to support the individual throughout his or her life is their most urgent task, always. Their desire is to work closely with each medical specialist and in return, to be included in communication and planning, and to have their knowledge of the individual respected.
2. At the direct service level, they would like dentists, hygienists and office staff to receive and participate in more education and clinical training about individuals with IDD, pain, symptoms, anxiety, and adaptive strategies for good oral hygiene. This training would ideally take place before professionals enter the dental field, but also as on-going education once in the field.
3. Finally, at the health care systems level, lack of insurance coverage for more frequent cleanings (every 3 months), lack of providers that accept Medicaid, and long waiting lists for procedures requiring sedation due to lack of providers and operating room space are hindrances to receiving adequate, timely and cost-effective care.

Key Findings and Implications:

* The data show that in the respondents surveyed there is a rather small percentage of this population that is not able to access dental care and is dissatisfied with dental services. This finding was surprising but may be a result of the low respondent rate and sample bias. It is well established that 80% of dental disease occurs in approximately 20% of the population and that this population is the most underserved and least likely to access services and care. It is possible that this same phenomenon exists in the population of individuals with IDD.
* Overall, while almost two-thirds of the respondents were satisfied or very satisfied with dental services and three-fourth of the respondents were satisfied with the dental care received, less than half, 47%, regarded their oral health as good/excellent and 20% had issues with accessing providers.
* Suggestions for improvement from the Consumer Perceptions and Satisfaction Workgroup included:
  + Patient-centered care: the patient is respected and included to the extent possible in the treatment team. Decisions made and treatment options presented are in accordance with the needs, desires and abilities of the patient, not for the ease or convenience of the health care provider or caregiver.
  + Knowledgeable staff and practitioners: ensuring staff and dentist/hygienists have a basic understanding of individuals with IDD and can accommodate different communication and learning styles in order to facilitate health literacy and informed decision making.
  + Universal design: facilities are welcoming and barrier-free to the extent possible. Equipment and waiting areas are accessible and able to be individualized to some extent (e.g. background music, lighting).
  + While there are no quick solutions to any of these issues identified, the input of this cohort is essential in the path forward to decreasing health disparities experienced by people with IDD. The concerns and requests of the family members should be incorporated into any systemic design of oral health services for this population.

1. **Provider Experiences and Expectations**

The objectives of this workgroup were to determine:

* Which providers care for people with developmental disabilities in the Greater Rochester area?
* What training do oral health care providers have and what type of training is desired?
* What are providers’ self-reported comfort levels in caring for people with mobility, behavioral and communication challenges? What are the referral patterns for patients with IDD?
* What office accommodations and treatment setting options are available for care for people with IDD?
* What are provider-identified strengths and opportunities for improvement of dental care for people with IDD?

Data collection methods included:

* Survey research:
* Electronic surveys were created using Survey Monkey and were distributed via listservs of the 7th District Dental Society and 7th District Dental Hygiene Society, Rochester General Hospital Department of Dentistry, and Eastman Institute for Oral Health.
* 151 providers responded. Of these, 59% were dentists and 41% were dental hygienists.
* Focus group research
* Three focus groups were held with a total of twelve participants, spanning multiple disciplines of dentistry and treatment settings: dental hygienists, general dentists and pediatric dentists in private practice, public health clinics, and academic settings.
* A set series of questions were proposed to focus group participants, although the conversation was allowed to diverge as directed by participants. Focus group sessions were taped, transcribed and analyzed for common themes.
* **Findings of the workgroup**
* Survey research: 151 respondents
* Within a month of survey distribution, respondents treated patients with autism spectrum disorder (68.9% of respondents), cerebral palsy (43.7%), Down syndrome (58.3%), epilepsy (64.2%), intellectual disability (78.7%) and other developmental disabilities (72.8%).
* More than 80 percent of the offices of respondents had accessible parking and walkways doorways, restrooms and operatories for people with disabilities. Only 26.5% of offices also had devices available for transport of patients from wheelchair to an examination chair.
* Providers who care for patients with IDD report that patients find their office via word of mouth (68.9%), advertising (7.9%), referrals from social service agencies (29.8%), referrals from other community dentists (39.7%), referrals from facilities such as group homes (39.7%), and referrals from non-dental health care providers (32.5%).
* If a provider cannot care for a patient with IDD, the patient is referred to a community dentist (4%), a community pediatric dentist (25.8%), a community clinic (15.2%), or a hospital-based clinic (63.6%). A small percentage of respondents noted that they have no location to refer the patient (3.3%).
* Respondents feel very prepared to treat patients with behavioral (39.1%), mobility (53%) and communication challenges (35.8%). Respondents feel somewhat unprepared to treat patients with behavioral (9.9%), mobility (8.6%) and communication challenges (16.6%). Respondents feel very unprepared to treat patients with behavioral (1.3%), mobility (0.7%) and communication challenges (4.0%).
* Respondents are already treating individuals with behavioral challenges (70.2%), mobility challenges (84.1%) and communication challenges (66.9%). Respondents may in the future be interested in treating individuals with behavioral challenges (11.3%), mobility challenges (11.3%) and communication challenges (19.2%). Happily, a small portion of respondents were unwilling to care for individuals with behavioral challenges (3.3%), mobility challenges (1.3%) and communication challenges (1.3%). However, we do need to consider sample bias, i.e. people that were interested in and willing to treat individuals with IDD were more likely to respond to the survey.
* A portion of respondents (12.6%) were not interested in increasing the percentage of their patient pool devoted to people with IDD. Another group (29.8%) did not feel the need for additional support in order to increase their patient pool devoted to people with IDD. Of respondents interested in increasing their patient pool of people with IDD, some requested the option to discuss cases and treatment plans with more experienced providers (30.5%), the development of a referral system to refer patients that were beyond their expertise (27.2%), logistical assistance with scheduling, transportation, etc. (27.2%), additional training via continuing education courses (33.1%), and an increase in fee schedules (27.8%).
* A majority of respondents (70.2%) received training either in residency or dental/hygiene school in treatment of patients with IDD in the form of classroom training (49%), video-based training (13.2%), shadowing opportunities (39.1%), hands-on opportunities (61.6%), or self-teaching with books (23.8%) or webinars (6.6%).
* Topics that respondents were interested in for additional education are depicted in the figure below.
* Formats preferred for future continuing education forums include classroom training (66.9%), video-based training (39.1%), shadowing opportunities (37.7%), hands-on opportunities (45.7%), or self-teaching with books (13.9%) or webinars (25.2%).
* The majority of respondents seldom use restraint (25.8%), N2O anxiolysis (23.3%), sedation (19.9%), and general anesthesia (11.3%).
* Over their time in practice, 25.2% of respondents perceive an increase in the number of patients with IDD, 53% perceive no change in patient numbers, and 4.6% report that numbers of patients with disabilities have decreased.
* Over the course of their practices, 23.8% of respondents noted that access to care for persons with IDD has improved, 15.9% report that access has worsened, and 33.8% report that there has been no change.
  + 1. Over half of respondents (51.8%) did not have a personal connection with a person with IDD.
    2. 59% of respondents were dentists; the remaining respondents were dental hygienists. 37 respondents were in solo practice, 34 were in group practice and 36 were in community clinic or public health setting. 42 respondents were general dentists, 15 were in academics, and 32 were pediatric dentists.
    3. Nearly three-fourths of respondents did not have hospital privileges (73.4%). 57.9% of respondents reported interest in obtaining hospital privileges in order to treat patients with IDD in the operating room under general anesthesia.
* Focus group research
* In addition to the survey, the group conducted three focus groups with a total of 12 participants. The focus group sessions were attended by general dentists, pediatric dentists, and dental hygienists from both private practice, and academic and community health settings. At the start of the one-hour session, participants were informed that the session would be audiotaped, and all information would be de-identified and kept confidential. Participants were given the option of leaving the focus group at any point during the discussion if they felt uncomfortable. The federal definition of an intellectual and developmental disability was read to participants and examples of disabilities were provided.
* Initially, a structured approach was used with questions to prompt and direct discussion. Guided topics included participants’ experience in treating individuals with IDD, suggestions regarding changes that could be made to improve care for this population, and interest in receiving training to deliver care in the operating room. Finally, the concept of a dental care coordinator was introduced to participants and their input was solicited regarding impact this position would have on their ability to care for patients with IDD.

Several themes emerged from the discussion:

* Overall, participants expressed deriving extreme personal and professional satisfaction from their care for individuals with IDD. However, there were many suggestions for improvement. Foremost, participants reported paltry reimbursement rates in light of the time, skill and staffing needed to manage patients with IDD. Many providers do not want to take Medicaid, possibly based on misinformation regarding which patients they are required to treat while in contract with Medicaid.
* From a treatment perspective, wait lists for operating room services were lengthy and coordination between operating room sites in the community would maximize use of existing resources.
* In the office, most providers noted on-the-job training in gaining experience with this patient population and would like continuing education for themselves and colleagues to increase comfort level in providing care.
* They also suggested that organized dentistry at both state and local levels advocate in support of providers and patients to improve the reimbursement and access landscape. Judging from the lively discussion, great momentum and desire for change exists within the dental community and should be harnessed in driving improvements in care for this population.

Key Findings and Implications

* The high percentage of specialist practitioners and a large number of institutional practitioners (two venues which primarily treat individuals with IDD) may account for the large number of the respondents who affirmatively responded that they treat individuals with IDD and their relative comfort and sense of competence in treating this population. Notably dentists felt more competent and prepared to treat patients with mobility issues than they did with patients who had communication and behavioral limitations; this information may prove useful in planning future continuing education events (please see Figure 4 for additional training topics).
* Seventy percent of respondents reported receiving some training in providing oral health care to persons with IDD, reflecting additional training beyond dental school. Nevertheless a majority indicated that they would like additional education and identified areas of training necessary.
* Over the course of their practices, nearly half of respondents perceive that access to care for individuals with IDD in the Rochester area is either unchanged or has worsened and were concerned about reimbursement issues.  This sobering statistic from providers on the front lines of care serves as a call to action for our dental community to care for those who are most vulnerable.
* Additional actionable recommendations from the workforce group included:
  + Creation of a fellowship-level training program housed at Eastman Institute for Oral Health to provide upper-level training for established dentists and dental hygienists
  + Encouragement of providers, with support from local dental and dental hygiene societies, to participate in Special Olympics Special Smiles screening programs
  + Development of continuing education program with nationally-renowned speakers, hands-on learning, and didactic teaching
  + Placement of dental hygienists in group homes to provide routine preventive care in familiar settings
  + Establishment of care coordinator to serve as link between patient and dental community to schedule appointments, complete paperwork, arrange transportation and link treatment needs with appropriate providers
  + Creation of electronic directory of providers with care for patients with IDD that is accessible to allied health care professionals, social workers, etc.

1. **Current and Unfolding Policy**

The objective of this work group was:

To investigate three significant non-clinical dimensions that play an important part in the oral health services available to individuals with IDD:

* Reimbursement policy
* Licensing/educational requirements
* Limited and inefficient us of operating room facilities

It is no surprise that reimbursement for oral health care for individuals with IDD is a major issue. Currently providers are reimbursed for treating individuals with IDD at standard Medicaid fee-for-service andAPG (Ambulatory Procedure Groups) rates; the latter covers certain in-hospital procedures, including operating room care. However as part of NYS Medicaid reform, the Office for People with Developmental Disabilities (OPWDD) is in the process of overhauling the system by which it provides support and service to persons who qualify as developmentally disabled.  OPWDD’s role will change from a provider of services, either directly or through community service agencies, to a funder that contracts for services through financial intermediary.  The goal of this model is to establish entities that will manage and coordinate care for people with IDD.  At this point, little is known about how the plan will operate and in particular how dental services will be handled under this model. To have input into the process, a subset committee of the State Dental Task Force for individuals with IDD was established. This committee, known as the Dental Disco Advisory Group (DDSG), has as its mission toprovide ongoing input to OPWDD regarding the implications of managed care on oral health care throughout NYS and serve as a think tank for possible solutions to issues as they arise. The report of this group in PowerPoint format is attached (Appendix 4).

Two issues are of concern in licensing and educational requirements related to care for individuals with IDD. First, accreditation standards for undergraduate dental programs as well as postgraduate programs, with respect to treating patients with IDD, are quite bare and there is little prospect of adding more stringent curricular requirements. There has been significant lobbying on this matter on a national level with little result, as adding these requirements to dental academic centers adds significant resource and curricular demands.

Secondly, much of the care rendered to individuals with IDD falls under preventive treatment, albeit in a special environment. Hygienist could have a more independent and active role in this, particularly in an agency setting. However, there is some concern about doing this because of some ambiguity about the state law requirement on supervision of the hygienist. Essentially, an interpretation which would allow hygienists to provide care under general supervision of a dentist in sites like group homes would facilitate innovative and on-site preventive programs important to improving the oral health of this population.

An area of special concern is the limited and inefficient use of operating rooms for care of individuals with IDD. About 25% of individuals with IDD require dental care in the operating room as behavioral or medical conditions preclude delivery of care in the outpatient or clinic setting. There are many limiting factors to the provision of this care, poor reimbursement inadequate training of providers notable among them. However, limited access to operating rooms in our community is a significant concern. Poor reimbursement to institutions for this care makes it a smaller priority than procedures with higher reimbursement. A further complicating factor is the uneven distribution of access to OR time and the lack of coordination of this treatment option across the community.

Key Findings and Implications

* The fragile and ever-changing dental reimbursement picture for individuals with IDD makes it imperative that there be active engagement of individuals and institutions at a state level to ensure the case for oral health for individuals with IDD is presented convincingly.
* It is imperative that preventive approaches to care of individuals with IDD be explored as an opportunity to ultimately reduce the cost of oral health care and the morbidity associated with oral disease.
* Care coordination would allow for proper allocation of resources, especially treatment in the operating room setting, but also would ensure that much needed preventive and restorative care is received.
* Numerous facilities across the state are reducing or eliminating dental services for individuals with IDD and as a result, routine oral health care is becoming less and less available. In addition, there is an immediate pressing need for better use of operating room facilities. Historically, there has been a general lack of coordination among human service agencies, an unclear commitment among healthcare institutions to the oral health of the Greater Rochester area’s population of individuals with IDD, and an almost total lack of preventive programs. Other barriers exist as well, e.g., inefficient use of operating room resources, difficulty navigating Medicaid payment systems, and more broadly, a failure to understand the health and dental care needs of individuals with IDD.
* Currently, accreditation standards for dental and dental hygiene training programs stipulate that students learn to “manage” individuals with IDD. This often means only that students learn to refer individuals with IDD to specialists when care is needed —not that they be competent or committed to treat these patients themselves. Further, virtually no education and training is provided to dentists and hygienists on how to promote good oral hygiene and preventive oral health behaviors among individuals with IDD. And even with the intention to expand systematic education and training little is known on what works best.

1. **Model IDD Oral Health Care Programs**

The objective of this work group was to:

* investigate existing models for delivering oral health care to individuals with IDD and assess their relative strengths and weakness

It is of note that one of the programs listed below (Tufts) was closed because of financial constraints as the report was being prepared. We decided that the review of Tufts’ program remain in the report to demonstrate the fragility of the reimbursement systems for oral health programs for individuals with IDD.  One fairly typical example is the dental clinic established in the Atlantic County Special Services School District by University of Medicine and Dentistry of New Jersey.  The clinic serves students with developmental disabilities who range in age from three to twenty-one years.  The clinic provides comprehensive dental services. There is a referral mechanism for patients who require general anesthesia, and liaisons with other referral sources.  The clinic is open 2 days a month for 10 months, from 9:00 am to 3:00 pm.

The Special Smiles Program (not to be confused with a same-named program associated with the Special Olympics), is a private dental practice operated by Pediatric Dental Associates in Philadelphia, Pennsylvania.  It addresses the need for expansive and advanced dental treatment in this patient population.  The practice provides full-mouth rehabilitation under general anesthesia to Medicaid-eligible patients, thus serving as a dental home for most of these patients who are unable to receive dental care in other practices.  The program is effective because it uses Medicaid funds to create a new source of specialized care. Dental care is provided to patients in a hospital-based outpatient suite.  The practice contracts for general anesthesia services, and obtains the hospital space as an in-kind contribution from the hospital, making its operations cost-effective.

A more expansive clinical model is Tufts Dental Facilities Serving Persons with Special Needs which consists of 8 dental clinics throughout the state of Massachusetts, with a Special Needs Community Dental Health Program that includes 200 community locations where preventive services are offered by traveling dental hygienists.  It is a collaborative effort between Tufts University School of Dental Medicine and Massachusetts Department of Developmental Services.  By sheer numbers, the Tufts/MA system and its facilities is the largest program of its kind, serving between 5,000 to 9,000 persons with IDD across the state of Massachusetts.  The approach includes hygiene, prevention, and treatment by trained staff in appropriate clinic environments, as well as referrals to four hospitals for persons who need intravenous sedation or general anesthesia for dental care. (Please note: this program was very recently abandoned due to fiscal constraints.)

These three exemplary programs are designed to provide dental interventions and treatments. This is in sharp contrast to the program led by Dr. Paul Glassman, a visionary in the field who is pioneering a more fundamental, prevention-centered approach to dental disease for persons with IDD.

Glassman’s programs utilize alternative/allied dental providers (dental hygienists) in collaborative practice and congregate settings, such as group homes and sheltered workshops, to address prevention and access to care. The approach represents a new and comprehensive model for oral health – a model no longer focused solely on dental treatment, but rather emphasizing prevention and health promotion and a culture of oral health. Specifically, the Glassman model:

* Focuses on prevention of dental diseases rather than treating acute episodes
* Utilizes a case management approach where oral diseases are identified and patients are referred to care settings that best match their situation and needs
* Employs  a tiered delivery system where complex care is provided by health care professionals with the most extensive training, and less complex care is provided by professionals with less extensive training
* Provides care as close as possible to where  individuals with IDD disabilities  live, work and go to school
* Enables hygienists to play a major role in oral health maintenance, as well as in education of  family and caregivers to support the practice of oral health for people in their care
* Integrates oral health activities into general health and social service settings
* Uses existing community health professionals in new ways with oral health professionals serving as coaches, mentors, and supporters of other health and social service professionals
* Reforms oral health delivery and reimbursement systems to reward services that will improve oral health, such as promotion of preventive practices, early identification of potential and actual health problems, and application of least invasive solutions.

It is of note that Dr Glassman’s model is funded through foundation monies and has a special exemption from California licensing laws to allow for hygienists to work independently under “general and remote supervision.”

Key Findings and Implications

* The models described offer different and appropriate approaches to the care of individuals with IDD but the sobering reality is that reimbursement issues create an enormous fragility to delivery of care to this population and that the long term solution to this issue has to lie in preventive and care coordination models that ultimately reduce cost.
* The short term solutions are to maintain, through lobbying, current reimbursement levels and to find venues and resources for demonstration projects that can show reduced cost while expanding care. Leveraging of current activities in treatment of individuals with IDD and prevention and care coordination would appear to provide the best opportunities.
* The central role of community institutions in maintaining their commitment to the care of individuals with IDD and to education and research in this area is pivotal.

**RECOMMENDATIONS**

Based on the data developed in the work groups and the steering group and community meeting discussions there were 8 areas where suggestions and recommendations were developed:

1. **Principles for Care of Individuals with IDD**

Through its review of relevant statistics, as well as data from literature reviews, surveys, focus groups, and interviews with local providers, families and caregivers, nine general principle**s** for a community-based approach to maintaining and improving oral health for individuals with IDD have emerged:

* An explicit system of coordinated care from prevention to complex procedures
* A comprehensive and integrated collaboration involving medical, community and government services;
* A commitment to individualized care that incorporates the physical, medical, social, and behavioral facets of individuals with IDD, their families and caregivers;
* Recognition of oral health as matter of lifetime care rather than a series of episodic dental interventions to treat acute exacerbations of chronic conditions;
* The effective decentralized utilization of current technologies, such as teledentistry, to monitor care and support the delivery of care;
* A system of training, education and recognition for all oral health care providers;
* Safe, physically accessible, high quality and appropriately equipped care environments;
* A reimbursement system that provides fair reimbursement to providers, that incentivizes prevention and is sustainable in a managed care or capitated environment;
* Evidence-based protocols and practices that encourage best care.

1. **Education**

* Maintain the centrality of educational institutions in the education process by the creation of academic centers of excellence in the care of individuals with IDD in these institutions.
* Continue the education of providers, care givers and individuals with IDD in institutions such as Eastman Institute for Oral Health (EIOH) and Monroe Community College School of Dental Hygiene.
* Increase the skill and number of oral health providers (caregivers, hygienists and dentists) serving individuals with IDD through education, training, support and recognition. Establish a fellowship in Special Needs Dentistry to be housed at Eastman Institute for Oral Health and modeled after existing programs
* Publicize and host existing CE courses and public speakers on topics related to care for people with developmental disabilities
* Create three-part CE teaching program for practitioners, to be comprised of the following components:

1. Didactic learning with local speakers
2. Hands-on experience in clinic and operating room
3. Network following participation to encourage case presentations and second opinions

* Provide in-service learning opportunities for staff, family members and residents of facilities for persons with disabilities.
* Reinstitute an operating room training program for community dentists.

1. **Prevention**

* Recognize that prevention is the essential element in improving oral health and is best provided where individuals with IDD gather, live, and learn.
* Ensure that hygienist play a key role in preventive programs for group homes, school settings, home-based settings and to Special Olympics’ athletes and their families through family health forums.
* Develop preventive care program, which utilize hygienists in the field to reduce the need for acute dental treatment.
* Use new technologies and innovation in programs focused on o oral disease prevention.

1. **Care Coordination**

* Manage the gap between identifying the need for oral health care and servicing that need, as well as ensuring the most efficient use of specialized resources like operating room care by systematic care coordination.
* Ensure that individuals with IDD receive the appropriate monitoring and follow up care for optimal oral health that includes the optimal scheduling and utilization of operating room resources.
* Emphasize prevention and systematically coordinating and monitoring dental treatment to produce better oral health at a lower cost than the current system which focuses on procedures and lacks a prevention orientation.

1. **Role of Institutions**

* As institutions in the greater Rochester area, notably EIOH, Rochester General Hospital (RGH) and CP Rochester, are the safety net providers for individuals with IDD as well as venues for education and research in the dental care of individuals with IDD, ensure that their commitment to the oral health care of individuals with IDD continues.
* Maintain the important role institutions have in lobbying for adequate reimbursement for individuals with IDD and in securing funds for innovative education programs, demonstration projects and research.

1. **Identify and Capitalize on Existing Opportunities**

* Capitalize on existing opportunities in the care of individuals with IDD. An example is illustrated below.

Over the last two years, a relationship between philanthropist B. Thomas Golisano and Special Olympics International (SOI) has culminated in a $12.5 million gift from Mr. Golisano to the Special Olympics. The gift is being used to pilot a new international health initiative, Healthy Communities. New York’s Genesee Region is one of the funded sites. The vision of this initiative is to expand athlete health services, increase partnerships, expand the use of technology, and promote awareness of the health disparities facing individuals with IDD. After reviewing athlete health needs and the opportunities and resources in the Genesee Region, oral health and obesity have been selected as the first two health issues the project will address.

In addition to the SOI’s Healthy Communities, the Genesee Region has a significant array of other relevant resources. For example: the Eastman Institute for Oral Health; the Strong Center for Developmental Disabilities; Rochester General Hospital; the dental hygiene degree program at Monroe Community College; outstanding community service organizations devoted to the needs of the population of individuals with IDD; knowledgeable dentists and dental hygienists who are already providing care to individuals with IDD; and the Community Oral Health Taskforce. Furthermore, there are opportunities to expand relationships with state and community offices and professional organizations, e.g. the New York State Academic Dental Centers and the New York State Office for Persons with Developmental Disability Task Force on Dentistry.

Bringing these opportunities and resources together in an integrated, comprehensive system of oral health care will make a lasting difference in the general health and quality of life for people with developmental disabilities in our region and serve as a model for other communities.

1. **Research**

* Recognizing the great need for basic science and clinical research related to oral health for individuals with IDD, develop study ideas and conduct research in the oral health care of individuals with IDD. The recently funded National Dental Practice-Based Research Network with an administrative hub at the EIOH offers an excellent opportunity for conducting research in this area.
* Encourage faculty to do research in the oral health care of individuals with IDD through pilot program funding.

1. **Innovation in oral health care prevention and delivery through pilot programs:**

* Develop innovative demonstration projects and pilot programs in oral health care delivery and prevention. Two examples, utilizing the process, principles and findings of the task force, are presented:

1. Use of Mobile Devices in Follow-up and Oral Health Care Coordination and
2. Use of Dental Hygienists in Group Home Settings., with action steps.

**Model 1:** **Use of Mobile Devices in Follow-up and Oral Health Care Coordination**

**Overview:**

At the February 2013 Special Olympics Healthy Athlete Special Smiles screening event at the regional winter games, 39% of athletes presented with untreated decay (a number which would increase if radiographic examination were added) at this screening compared to the 2007-2012 average of 21.5%. Additionally, oral pain at time of examination was 8.8% compared to the 2007-2012 average of 5.7%. At that same screening event, 44% of athletes presented with gingival signs despite 83.6% reporting good oral hygiene practices. This may indicate a disconnect between perceived good oral hygiene practices and implementation of those life skills. These statistics signal a significant unmet need for dental care in this population and the need for some intervention. Importantly after Special Olympics athletes leave the Special Smiles screening events and return to their families, homes and communities, we are unclear of their oral hygiene habits; follow up with specific treatment recommendations, and ability to access to services to receive such care. The need for coordination of the athletes’ oral health care and exposing them to a preventive program is evident.

Use of text messaging programs has proved beneficial in management of chronic illness such as diabetes and asthma in both adolescent and adult populations. Combined with the ever increasing number of athletes with cell phones capable of text messaging, use of text messaging reminders is an unexplored avenue for bridging the gap between dental screening at Special Olympics events and dental care in the community. The recently established Healthy Communities project, supported by the Golisano Foundation, is a logical partner in this effort as the goal of the initiative is to “achieve improved health outcomes for people with intellectual disabilities with the ultimate goal of ensuring that all are receiving health services and are able to reach their full potential. It will expand services to more athletes, increase partnerships with local organizations, expand the use of technology, and promote awareness of the health difficulties facing people with intellectual disabilities.”

We envision collaboration with Health One Global One to utilize SMS text technology to promote good oral hygiene practices and to gather data on follow-up for concerns identified at Special Olympics Special Smiles screening events. Athletes who register at the Special Olympics Special Smiles screening events will be asked for cell phone numbers if they’d like to participate. All participating athletes will be given twice weekly text messaging reminders about oral hygiene using a script such as the following:

|  |  |  |  |
| --- | --- | --- | --- |
| Q: | Brushing teeth keeps them strong and healthy! Did you brush your teeth today? |  | Yes/No |
| Q: | [If no] Please brush your teeth and text 1 in response after you brush your teeth. Good job! |  |  |
| Q: | [If yes or after 1 response] Great job keeping your teeth healthy and clean! Don’t forget to brush tomorrow. Was this reminder helpful? |  | Yes/No |

For participants who were identified as having maintenance needs, a script such as the following will be used:

|  |  |  |  |
| --- | --- | --- | --- |
| Q: | To keep our teeth healthy, it is important to see the dentist twice a year for a cleaning and exam. Do you have a dentist? |  | Yes/No |
| Q: | [If yes] We’re so happy to hear that! Please call your dentist to schedule your next 6-month checkup and cleaning. |  |  |
| Q: | [If no] We’re happy to help you find a dentist. Would you like free help from our dental care coordinator to take care of your teeth? |  | Yes/No |
| Q: | [If yes] We’re happy to help. Our dental care coordinator will call you at this number to help you find a dentist. |  |  |
| Q: | [If no] We’re sorry to hear that. Please feel free to text us with TOOTH HELP if you’d like help in the future. |  |  |

For participants who were identified at the event as having non-urgent or urgent treatment needs, a script such as the following will be used:

|  |  |  |  |
| --- | --- | --- | --- |
| Q: | At your last Special Olympics screening event, we found some problems with your teeth. You need to see a dentist. Did you get to the dentist? |  | Yes/No |
| Q: | [If no] Why not?  1 = I could not find a dentist.  2 = I did not have time.  3 = I do not have dental insurance.  4 = I do not know how to make the appointment.  5 = I do not have a ride |  |  |
| Q: | [If yes] Wonderful! Thank you for taking care of your teeth. Do you need help with anything else related to your teeth? |  | Yes/No |
| Q: | [If no] Thank you for taking care of your teeth. See you at the next Special Olympics Special Smiles event! |  |  |
| Q: | [If yes] We’re happy to help. Our dental care coordinator will call you at this number to help you. |  |  |
| Q: | At your last Special Olympics screening event, we found some concerns. You need to see a dentist. Did you get to the dentist about your teeth? |  | Yes/No |
| Q: | [If no] Why not?  1 = I could not find a dentist.  2 = I did not have time.  3 = I do not have dental insurance.  4 = I do not know how to make the appointment.  5 = I do not have a ride. |  |  |
| Q: | [Following numbered response] Would you like free help from our dental care coordinator to take care of your teeth? |  | Yes/No |
| Q: | [If yes] Our dental care coordinator will call to help you. We’re so happy you’re interested in taking care of your teeth. |  |  |
| Q: | [If no] We’re sorry to hear that. Please feel free to text us with TOOTH HELP to ##### if you’d like help in the future. |  |  |

This will be considered a prospective cohort study in which we will seek to elicit positive behavior change in 30% of athletes by the end of the project period as indicated by their daily oral hygiene habits, a goal in line with the Healthy Communities objective. We additionally seek to establish a dental home for all athletes, and to appropriately triage and treat 100% of athletes identified at events as having either non-urgent or urgent treatment needs. A database of athlete phone numbers will be created for future use. A dental care coordinator will assist in registering athletes for the program, in obtaining referrals to appropriate providers and in creating community partnerships.

Action Items:

1. Seek out potential funders
2. Meet with Onolee Stephan to gain support of Special Olympics and make contact with Health One Global.
3. Apply for grant funding – Golisano Foundation, Delta Dental/Dentaquest
4. Hire dental care coordinator and write job description
5. Review texting application and rewrite text messaging app with scripts
6. Pilot test with sample of athletes for usability and readability
7. Create network of supporting dentists for treatment and re-care referrals for participating athletes
8. Promote participation at Special Olympics events
9. Launch text messaging software and data collection for 1 year
10. Analyze how many athletes received care and improved oral hygiene

**Model 2**: **Use of Dental Hygienists in Group Home Settings**

Dental care is the most frequently cited unmet healthcare need among individuals with developmental disabilities (DDs). The ten-county Finger Lakes Region is home to thousands of individuals with DD, nearly 80% of whom—if in keeping with national trends toward de-institutionalization—live in community-based group residences or at home with their families. Increasingly, these individuals look to oral health care providers in their communities to meet their dental needs. Many people with DDs can theoretically be cared for in a general practice community setting; however, most general practice dentists are ill-equipped to provide coverage that addresses the unique needs of this population.

Beginning January 2012, a multi-disciplinary task force investigated the current state of access to care for individuals with developmental disabilities in the Greater Rochester Area and capacity of the local dental workforce to care for these individuals. Out of this undertaking, it was determined that coordinated care efforts may be the solution that provides services focused on prevention of acute and chronic oral disease, provision of care in the most appropriate, least-restrictive setting, efficient use of mid-level dental providers (i.e., dental hygienists), desensitization to oral hygiene examination practices through repeated exposure, and ultimately, reduction in need for higher-level services in surgical center settings. This proposed pilot program seeks to implement those task force recommendations.

Additionally, Special Olympics Special Smiles screening events provide a wealth of data regarding oral health measurements. At the February 2013 Special Olympics Healthy Athlete Special Smiles screening event at the regional winter games, 39% of athletes presented with untreated decay (a number which would likely increase if radiographic examination were added) at this screening compared to the 2007-2012 average of 21.5%. Additionally, oral pain at time of examination was 8.8% compared to the 2007-2012 average of 5.7%. At that same screening event, 44% of athletes presented with gingival signs despite 83.6% reporting good oral hygiene practices. This statistic may indicate a disconnect between perceived good oral hygiene practices and satisfactory implementation of those critical skills.

To address the issue of access to care for this population and to focus on preventive services delivered in a patient-centered setting, we propose placement of a dental hygienist in group home settings to deliver preventive care (exam, prophy, scaling, and placement of topical fluoride twice yearly), oral cancer screening and oral hygiene instruction. Oral hygiene instruction will be provided for residents, staff and family members, where appropriate. Pre- and post-testing at 6 month intervals on oral hygiene concepts will be given to staff to ensure retention of skill sets. For residents identified as needing treatment, a dental care coordinator will assist in finding an appropriate dental office or in scheduling general anesthesia services. A mobile dental unit will be purchased for delivery of care. Before the project is implemented, examinations will be completed to determine Silness and Low plaque indices and Silness and Low gingival health indices. Additionally, a Frankl behavioral scale rating will be provided to assess behavior pre- and post-intervention. Oral health indices and behavioral ratings will be used at every recall appointment. Success will be based on improvements in these ratings and ability of dental health coordinator to connect residents needing services with dental homes.

Action Items:

1. Seek out potential funders
2. Seek out potential partners in services for individuals with disabilities (Heritage Christian Services, Easter Seals, etc.). Based on number of residents, create preliminary schedule to determine how many hygienists are needed in order to provide twice yearly visits.
3. Clarify general vs. direct supervision as delineated in dental practice act to ensure appropriate regulations are met
4. Create network of supporting dentists for treatment and recall referrals for participating residents
5. Determine if program can directly bill Medicaid in order to become self-sufficient
6. Apply for grant funding
7. Hire dental hygienists and dental care coordinator
8. Recruit residents and staff for project participation
9. Complete pre-intervention educational training and indices examinations
10. For three years, provide oral health recalls at q6month intervals. Provide educational training with all new employees and annually for current employees.
11. Analyze data

**Appendix 1**

**REFERENCES – TO BE ADDED**

**Appendix 2**

**Community Task Force on Oral Health for Persons with Developmental Disabilities**

|  |  |
| --- | --- |
| **Name** | **Name** |
| Dr. Cyril Meyerowitz  Grant Project Director  Regional Director, North-East Region National Dental PBRN | Dr. Gary Goldstein  NYS OPWDD Task Force on Special Dentistry |
| Ann Costello  Director  B. Thomas Golisano Foundation | Brian Klafehn (WGL)  CEO  CP Rochester |
| Dr. Larry Belle  Grant Project Coordinator | Dr. Dorota Kopycka-Kedzierawski  Associate Professor  Eastman Institute for Oral Health |
| Dr. Maricelle Abayon (WGL)  Assistant Professor  Eastman Institute for Oral Health | Dr. Jay Kumar  Assistant Director  New York State Bureau of Dental Health |
| Karen Black  Senior Public Relations Associate  Eastman Institute for Oral Health | Dr. Wayne Lipschitz  Associate Professor  Eastman Institute for Oral Health |
| Onolee Stephan, MPH  Director, Community Health Program  Special Olympics International | Andrea Pedersen  Dental Hygienist  Eastman Institute for Oral Health |
| Lenora Colaruotolo (WGL)  Social Worker  Eastman Institute for Oral Health | Laura Robinson  Associate, Neurodevelopmental & Behavioral Pediatrics  Strong Center for Developmental Disabilities Department of Pediatrics  University of Rochester Medical Center |
| Dr. Lisa DeLucia (WGL)  Pediatric Dentist  LEND Fellow (URMC) | Elizabeth Sheen, RN  Coordinator  Monroe Arc |
| Doug Fisler  Parent Representative  Heritage Christian Services | Dr. Richard Speisman (WGL)  General Dentist  Rochester General Hospital Dentistry |
| Dr. Sangeeta Gajendra  Assistant Professor  Eastman Institute for Oral Health | Dr. Patricia Stege  Dentist  Finger Lakes Dev. Dis. Service Org (FLDDSO) |
| Dr. Susan Hetherington  Assistant Professor  Neurodevelopmental & Behavioral Pediatrics  Strong Center for Developmental Disabilities Department of Pediatrics  University of Rochester Medical Center | Dr. Stephen Sulkes  Professor  Neurodevelopmental & Behavioral Pediatrics  Strong Center for Developmental Disabilities Department of Pediatrics  University of Rochester Medical Center |
| Dr. Adela Guset  Resident Representative  Eastman Institute for Oral Health | Dr. Nirmala Tasgaonkar  Assistant Professor  Eastman Institute for Oral Health |
| Beth Kettell  Librarian  Eastman Institute for Oral Health |  |

**Appendix 3**

**PROJECT PARTNERS**

Given its established organizations and existing resources, the Genesee Region is an ideal location in which to demonstrate a system of integrated and comprehensive oral health care for people with IDD.

The Strong Center for Developmental Disabilities (SCDD) has been collaborating with the disability community in upstate New York for the last 40 years, providing leadership in IDD research, policy, service and education.

Eastman Institute for Oral Health is a leading provider of dental treatment and care to special needs populations. EIOH provided dental care to patients with IDD and serves as the primary provider of operating room dental procedures for the IDD population in Western New York.

Special Olympics International has become the largest global public health organization dedicated to serving people with intellectual disabilities. The Genesee Region has been selected as among the first communities in which this new the SOI Health Communities Projects will be launched.

Rochester General Hospital provides diagnosis, evaluation, and treatment of children and adolescents with behavioral disorders, learning disabilities, and emotional disorders. And their Department of Dentistry strives to train their dental residents to plan and provide multidisciplinary oral health care for a wide variety of patients including those with special needs.

**Appendix 4**

**DENTAL DISCO ADVISORY GROUP (DDAG) PRESENTATION**













































































