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Readers are encouraged to photocopy and distribute this document. Acknowledgement of the source (Parent to Parent of Virginia and Medical Home Plus, Inc.) of the material is appreciated.

Event Organizers Planning Committee

VA INFO staff brought together parents, advocates, medical and dental health professionals, and state agency representatives, each of whom was interested in sharing a unique perspective on quality oral health care for children and youth with disabilities. It was the responsibility of planning committee members to identify and explore the most vital dental issues around the state. Issues the committee identified became part of the summit.

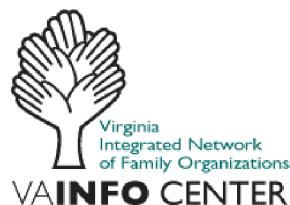
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- John Unkel, DDS, Virginia Commonwealth University
- Rachel Valenti, Parent
- Dana Yarbrough, Parent

Parent to Parent of Virginia

Parent to Parent of VA (PTPofVA) is part of a national network of state Parent to Parent programs that provide emotional, informational and advocacy support to parents of children with disabilities through one-to-one matching with a trained, experienced parent. Through a collaborative effort, PTPofVA co-directs Virginia's Family to Family Health Information Center (called VA INFO Center) at Medical Home Plus, Inc.

Medical Home Plus

Medical Home Plus, Inc. (MHP) was created to help facilitate family, professional and community partnerships to improve the quality of life for children with special health care needs – connecting the dots to a more seamless system of service delivery.



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Planning Alternative Tomorrows with Hope – PATH

Ongoing Training for Providers

Dentists have incentives to pursue in-service training



Kids get care when they need it



Experiential opportunities to treat children with special needs

- Hygienists
- Dentists

Education



Prevention

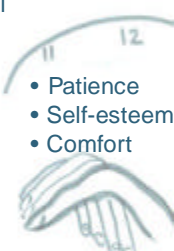
Medical Home



Dental Home

Every child has good oral health

- Patience
- Self-esteem
- Comfort

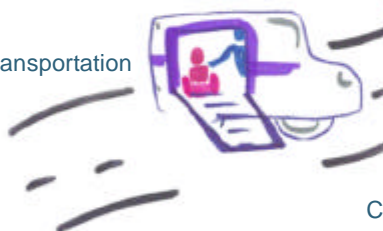


Facility is wheelchair accessible

Rural and urban

Increased Access

Transportation



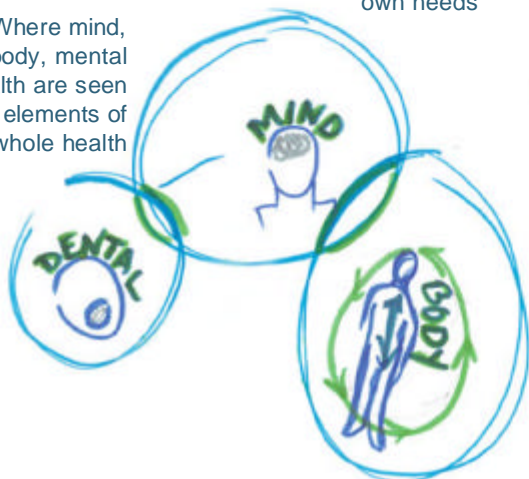
Children practice dental care for their own needs



Patient-centered
Capacity for vision and willingness to care for children with special needs.



Where mind, body, mental health are seen as elements of whole health



Money is not a barrier to quality care



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Summit Overview

Children and youth with disabilities are at greater risk for health problems, require extra support, and rely on others to achieve and maintain good health. Oral health is no exception. A clean mouth is one of their most important health needs for life and will be influenced by the ability to receive necessary dental care. Despite the advances in oral health that have been made over the last half century, there is still much work to be done. The Surgeon General's report (*Oral Health in America, 2000*) makes it abundantly clear that there remain significant and far-reaching disparities in oral health.

The reasons for disparities in oral health are complex. In many instances, socioeconomic factors are the explanation. In other cases, disparities are exacerbated by the lack of community programs. People may lack transportation to a clinic and flexibility in getting time off from work to attend to health needs. Having a disability may limit access to services. Lack of resources to pay for care, either out-of-pocket or through private or public dental insurance, is clearly another barrier. Fewer people have dental insurance than have medical insurance, and public dental insurance programs are often inadequate. Another major barrier to seeking and obtaining professional oral health care relates to a lack of understanding of disabilities on the part of providers and a lack of public awareness of the importance of oral health.

The Strong Roots for Healthy Smiles oral health summit brought together stakeholders interested in

discussing experiences, barriers and possible solutions to providing access to quality oral health care for children and youth with disabilities. The intent of this summit proceedings is to provide a glimpse into this discussion and a summary of key ideas.

Virginia faces several barriers in preventing dental disease for children and youth with special health care needs/disabilities including:

- **Patchwork of fragmented services.** Families are not aware of which door to enter, and frequently when they do enter one or more doors, they discover they have entered the wrong door(s), they are not eligible for the services, or long waiting lists exist.
- **Lack of providers.** The Virginia Department of Health estimates that there are 3,500 licensed dentists practicing in Virginia.



Approximately 85 specialize in the treatment of children. From parent calls for assistance with access to health services, it is speculated that a very small percentage of pediatric dentists are knowledgeable and comfortable serving children with disabilities.

- ***Too few numbers of providers who accept Medicaid.*** Relatively few dentists in Virginia accept Medicaid/FAMIS patients citing low Medicaid/FAMIS reimbursement rates and cumbersome paperwork as the primary reasons that they are not participating providers.

The first order of business was to create a shared vision for, and commitment to, a Virginia oral health summit on children with disabilities using a person-centered planning tool called PATH.

In January 2007, Medical Home Plus, Inc. (MHP), in collaboration with Parent to Parent of Virginia (PTPofVA), received a grant from the Association of State and Territorial Dental Directors to plan and hold a dental summit devoted to increasing

access to quality oral health care for children and youth with disabilities. A planning committee met in person, via telephone and through email exchange seven times between February and July 2007. The first order of business was to create a shared vision for, and commitment to, a Virginia oral health summit on children with disabilities using a person-centered planning tool called PATH. Additional planning group work included generating a complete list of summit invitees; identifying summit presenters; researching recent oral health data in Virginia; determining outcomes of the 2003 Virginia oral health plan and Early Head Start/Head Start oral health strategic plan; and supporting MHP and PTPofVA staff in the summit meeting logistics.

The Strong Roots for Health Smiles Oral Health Summit on children and youth with disabilities was held on July 27, 2007 at the Sheraton West Broad Hotel in Richmond, Virginia. The summit brought together 50 family members (20%), advocates (10%), medical and dental providers (25%), and state and local agency representatives and officials (45%). The diversity of people created an open, accepting and engaging environment that welcomed the thoughts and

perspectives of all participants. Summit speakers provided timely and important information on national oral health care issues and the state picture of dental services to children and youth with special health care needs/disabilities. During a small group activity, facilitators gathered information from participants about their own expertise and experience with the issues under discussion. The following is a summary of these findings and solutions.

To request copies of summit public awareness materials, agenda, attendees list, budget and powerpoint presentations, please contact Dana Yarbrough at PTPofVA@aol.com.

Summit Keynotes— Highlights from Presentations

An Olympian Task: Universal Access to Preventative and Comprehensive Dental Services for Children with Disabilities

Sanford J. Fenton, D.D.S., M.D.S

Dr. Fenton jump started the Strong Roots for Healthy Smiles oral health summit with a review of the individual, provider and societal barriers to quality oral health for children and youth with disabilities. According to Dr. Fenton, with 18% of US children and youth under the age of 18 having a chronic condition or disability, dental care is the number one unmet health need. In his discussion of “individual” barriers, Dr. Fenton shared that children and youth with disabilities may not have the physical or intellectual ability to perform oral hygiene, may have a poor diet, and may be unable to communicate needs. He also stated that many parents/caregivers are reluctant to seek or accept dental care or may place oral hygiene at the bottom of their priority list if the child has more pressing issues. Two of the top “provider” barriers cited by Dr. Fenton are a poor reimbursement system and a lack of skill, training and confidence in working with children and youth with disabilities. On the “societal” level, Dr.

Fenton stated that values and attitudes about individuals with disabilities continue to be the top barriers to a quality oral health sys-

According to Dr. Fenton, with 18% of US children and youth under the age of 18 having a chronic condition or disability, dental care is the number one unmet health need.

tem as reflected by inadequate access to oral health providers, poor reimbursement rates, and low expectations.

Dr. Fenton shared disturbing trends in dental school curriculum – almost 33% of 3rd/4th year dental students nationally reported having never treated an individual with intellectual disabilities; 82% reported less than five hours of educational time devoted to treating individuals with intellectual disabilities; and 75% reported they did not feel prepared to treat individuals with intellectual disabilities. He also reported trends in oral hygiene education – 48% of 170 dental hygiene programs nationally had 10 hours or less of educational time devoted to disabilities and 57% of the programs reported no clinical experience with disabilities at all.

In closing, Dr. Fenton stated that individuals with disabilities need comprehensive dental services and not just lip service. In keeping with this statement, the American Dental Association resolved in 2002 to support legislation to improve the oral health of



Patient-centered
Capacity for vision and
willingness to care for
children with special needs.

individuals with disabilities and to encourage dental programs to educate its students about the oral health needs and issues of individuals with disabilities.

Dr. Fenton's complete Powerpoint presentation can be found electronically at www.medhomeplus.org.

Children with Special Needs: Oral Health Quality of Life

Tegwyn H. Brickhouse, D.D.S, Ph.D.

Following Dr. Fenton's national snapshot of oral health for children and youth with disabilities, Dr. Brickhouse shared results of two Virginia oral health studies. Dr. Brickhouse began her presentation discussing the impact on families of children and youth with disabilities in terms of lost days of work and time and money spent on accessing dental care. She stated that the aim of the 2006 quality of life study was to use a Parental/Caregiver Perceptions Questionnaire to analyze the effects of oral health on the general well-being and family life of children and youth with disabilities participating in the Care Connection for

Dentists report that they are more likely to accept and treat individuals with disabilities in the future if they were more adequately prepared clinically and educationally in dental school

Children program (Virginia's Title V program). Dr. Brickhouse reported that four domains were tested to ascertain oral health quality of life: oral symptoms, functional limitations, emotional well-being, and family well-being/parental distress.

After a review of the data collection from 137 surveys (out of 429 surveys sent equals a 32% response rate), Dr. Brickhouse presented a summary of the survey findings:

- The majority of caregivers surveyed felt that oral health did have an impact on the child's well-being.
- Family caregivers of children and youth with disabilities report a variety of oral

symptoms, daily life problems, and parental concerns related to their child's oral health that impact the child's and family's quality of life.

- In this population of children and youth with disabilities, it appears that oral symptoms and family well-being outweighed functional limitations and emotional well-being in impacting oral health quality of life according to parental perceptions.

Dr. Brickhouse also shared information about a 2006 study that examined the relationship of how dental education plays a role in the future acceptance and treatment of patients with disabilities:

- Although many providers in Virginia feel it is part of their mission as a dentist to accept and treat individuals with disabilities, the study found that 75% of Virginia dentists do not routinely treat children and youth with disabilities
- While many dentists in Virginia are confident in their ability to treat a patient with disabilities, 72% of Virginia dentists reported that they never had a course that taught treatment of individuals with disabilities and 67% reported that they never treated a patient with disabilities while in dental school
- Dentists report that they are more likely to accept and treat individuals with disabilities in the future if they were more adequately prepared clinically and educationally in dental school

Dr. Brickhouse's complete Powerpoint presentation can be found electronically at www.medhomeplus.org.

Why Dentists Don't Treat Patients with Special Needs

Keith Beasley, D.D.S, Harry Gewanter, M.D. and Parent, and Matthew Cooke, D.D.S and M.D.S

Summit attendees were treated to a panel discussion lead by Dr. Keith Beasley, DDS, MAGD; Dr. Harry Gewanter, MD; and Dr. Matthew Cooke,

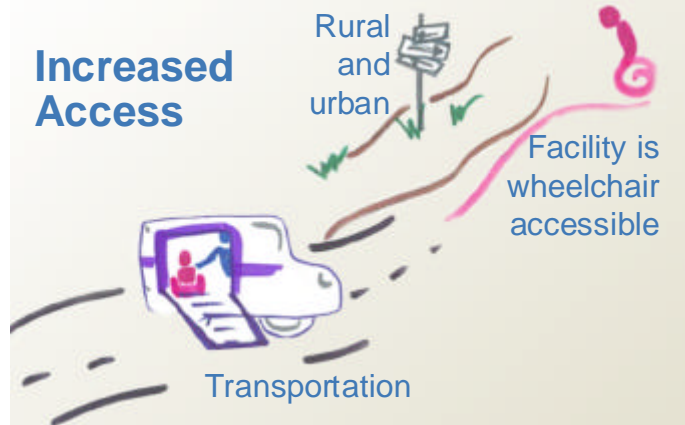


Finances



Billing codes reviewed to better enable doctors and dentists to provide link between Medical and Dental Home

Increased Access



DDS, MDS. Dr. Gewanter, a pediatrician and parent of a young man with Down Syndrome, provided personal insight to the joys and challenges of being a parent of an individual with intellectual disabilities as well as a physician who treats children and youth with disabilities. Dr. Cooke, a pediatric dentist from Charlottesville, discussed his experiences treating children with disabilities. Dr. Cooke's varied experiences led him, after years of practicing pediatric dentistry, to enroll in medical school. Dr. Cooke believes his medical degree will provide him more opportunities to treat individuals with disabilities. Dr. Beasley discussed the myths of why dentists do not treat individuals with disabilities. Myths discussed were:

- Children and youth with disabilities disrupt the normal routine of the dental practice
- Financial compensation is not in line with the time spent treating a child/youth with disabilities
- Children and youth must be treated in a hospital setting and the dentist doesn't have hospital privileges
- Children and youth with disabilities are on Medicaid and many dentists don't accept Medicaid

- Dentists do not feel trained or experienced in treating children and youth with disabilities
- The office is not set up to treat children and youth with disabilities
- Money can not be made treating children and youth with disabilities
- Children and youth with disabilities will scare other patients

Dr. Beasley is currently developing, with the assistance of the Virginia Academy of General Dentistry (VAGD), a continuing education course to facilitate the comfort level of the dental team in treating individuals with disabilities.

Small Group Activity

Attendees were split into three issue tables: education, funding, and systems. Using ASTDD state practice examples, attendees were tasked with brainstorming strategies/recommendations/solutions for their table's issue and reaching consensus on the three to five "best" suggestions. A list of suggested solutions can be found on pages ten – twelve.



Evaluation

Attendees completed an evaluation form indicating their level of satisfaction with the oral health summit and soliciting additional information action plan recommendations.

- 88% rated the oral health summit as excellent/very good in terms of learning new information
- 80% rated the oral health summit as excellent/very good in terms of networking

Families want a dentist who links to their child's other providers and wish for an oral health care provider who shares their own commitment to their child.

- 96% rated the oral health summit as excellent/very good in terms of quality of presentations

Summary of Issues Identified and Solutions Suggested

It is clear from the summit presentations and small group discussion that families

want oral health services for their children and youth with disabilities that is accessible. They want a dentist who is knowledgeable about their child's diagnosis. They want oral health care that is affordable and special oral treatments not priced out of their range of access. Families desire a dentist whose office is physically accessible (i.e., wheelchair accessible, on a bus line). They want a dentist who links to their child's other providers and wish for an oral health care provider who shares their own commitment to their child. They want treatment that is individualized based on the unique needs of their child.

Summit attendees know that children and youth with disabilities present unique challenges to Virginia's oral health care system – services and knowledgeable providers are limited, of unsure quality, and isolated in a system of care that is not integrated or adequately financed. Officials are under great pressure to reduce state budget, changes in dental school curriculum and educational programs, and even the addition of a new dental school, take years to accomplish, and policy shifts are years in the making. Summit

attendees offer the following short term suggestions and solutions:

Education

1. Develop a mandatory continuing education course on disabilities for oral health providers
2. Start training on disabilities early – get to the students in dental and medical school, dental hygiene and nurse programs, VA LEND program, etc.
3. Identify resources available in Virginia – identify, expand and utilize, replicate
 - a. Funding to relieve dentists of cost of continuing education
 - b. Loan forgiveness/repayment programs for dentists working with children/youth with disabilities
 - c. Intensive hands on training program being considered/developed at Virginia Commonwealth University pending funding
 - d. Care Connection for Children program
4. Develop materials for parents on good oral hygiene at home

Funding

1. Enhance reimbursement for children and youth with disabilities by creating incentives for those who provide this care
2. Allow dental hygienists to be reimbursed as oral health providers
3. Change dental billing codes to reflect the increased time needed for individualized treatment for children and youth with disabilities
4. Develop a state oral health resource website – resources, on line dentist directory, training opportunities, etc.

Systems

1. Develop a database to track providers who will see children and youth with disabilities – work with Department of Health Professions to identify folks
2. Increase preventive services for children and youth with disabilities – train non-dental providers to do fluoride varnish and other preventive pro-



- grams, increase/create reimbursement for varnish
3. Develop alternate delivery system – research successful workforce models; don't reinvent wheel (i.e., expand practice laws for dental hygienists, train non-traditional providers like home visitors to conduct screenings)
 4. Develop a "Health Home" model rather than a Medical Home and a Dental Home and a Home – get everyone together to work collaboratively

Miscellaneous Suggestions

1. Advocate for funding for adults with disabilities – work with Governor's Health Care Commission to carve out Medicaid funding oral health services for adults with disabilities
2. Promote programs that provide free services for those that are uninsured, undocumented – Mission of Mercy (MOM) project, Donated Dental Service (DDS), Give Kids a Smile Day, Free Clinics, etc.
3. Provide mobile clinics that reach many of Virginia's isolated communities
4. Make dental case management an allowable Medicaid expense



Planning Alternative Tomorrows with Hope – PATH



Availability of care

Training for dentists



Provider Directory

Training for other health providers/allies

Outcome A

Speakers bureau on dental health

Outcome B

Online module to be integrated into other conferences and trainings

Outcome C

Compile existing materials (Bright Futures, etc) into easily accessible format

Training materials should cover general preventative health, awareness of the importance of oral health, disability sensitivity, and developing a comforting environment.

Finances



- Billing codes reviewed to better enable doctors and dentists to provide a link between Medical and Dental Home
- Medicaid and commercial plan reimbursement rates
- Funding for training and treatment (dental schools, oral health assessment, fluoride varnish)



Education

- Speakers bureau should include parents
- Parent-developed materials disseminated through listservers, newsletters, etc.
- Bright Futures materials should be disseminated by way of OBGYN and pediatricians
- Special Olympics initiative on Dental Home



Access

- More statewide implementation of MOM project
- Culturally sensitive mobile dental clinics
- Dental Home spread
- Provider directory (Care Connection for Children example)