BETWEEN THE LINES

CDDC Advocacy Inclusion Systems Change

COLORADO DEVELOPMENTAL DISABILITIES COUNCIL Spring 2011

LOWERING THE BARRIERS TO EMPLOYMENT FOR PEOPLE WITH DISABILITIES

Last year, this country celebrated the 20th anniversary of the Americans with Disabilities Act (ADA) and reflected, once again, upon the meaning of full inclusion into their communities for all citizens, including those who live with disabilities. Many of today's civil rights laws recognize that "…disability is a natural part of the human experience that in no way diminishes the right of individuals to: enjoy full inclusion and integration into the economic, political, social, cultural, and educational mainstream of American society…" including meaningful employment in the community. Even after 20 years of the ADA, people living with disabilities continue to face barriers to employment as illustrated by the differences in the employment rate for people living with disabilities (21%) and without (70%).

Many studies have been done to identify these barriers nationally and in Colorado. Last fall, representatives from the Division of Vocational Rehabilitation (DVR) and the Department of Health Care Policy and Financing (HCPF, which administers Medicaid programs in Colorado) conducted public forums and heard from Coloradans about their barriers to employment. Not surprisingly, the barriers experienced in Colorado are similar to those found nationwide:

- Fear of the loss of health care and related services from public programs due to working, increases in income, and/or assets
- Lack of or inaccurate information about how employment may affect benefits
- Lack of information about available employment services and how to access them
- Lack of adequate and affordable transportation
- Difficulties asking for and receiving accommodations at work
- Assisting employers to understand why hiring people with disabilities makes "good business sense"
- Availability of personal assistance services at home and at work

The greatest barrier to employment reported in Colorado and the nation is the fear of the loss of health care and other Medicaid related services. In 1999, the US Congress recognized the significant impact of this barrier and took action by passing the Ticket to Work and Work Incentive Improvement Act (TWWIA). Through TWWIA, states can initiate Medicaid Buy-In Programs that allow working adults with disabilities to buy into Medicaid—addressing the fear of the loss of benefits due to employment, increased income and/or assets.

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The Centers for Medicare and Medicaid are supporting this new state option through Medicaid Infrastructure Grants (MIG). States use these grants to accomplish two things: implement Buy-In Programs and, develop or strengthen their employment infrastructure to better support workers with disabilities. States must either have or be planning to implement a Buy-In program when they apply for a MIG grant. MIG grants were first awarded in 2000 and the program is scheduled to conclude nationally in 2011.

Colorado set its Buy-In Program in motion when it passed the Colorado Health Care Affordability Act, legislation that expands the availability of public health insurance. HCPF then applied for a MIG grant in 2009, and in 2010, Colorado became the 42nd state to receive a Medicaid Infrastructure Grant.

In September, 2010, a steering committee made up of disability community leaders, advocates, service providers, health insurance representatives and employers began meeting to lay the groundwork for and provide guidance to the state's MIG effort. From these initial meetings, work groups were created to design the Buy-In Program and plan ways to share information around the state.

An additional work group focused on employment infrastructure in the state has been studying many of the barriers identified during last year's public forums and has initiated activities including:

- Producing several video vignettes featuring successfully employed people with disabilities
- Creating and supporting a network of individuals trained to provide general to intermediate-level information about employment and the impact of earnings on state and federal benefits
- Creating and disseminating information and resources about self-employment as an alternative career path
- Educating employers on the business case for hiring persons with disabilities
- Creating and distributing materials that increase expectations for competitive, integrated work
- Examining options for effectively braiding funding between systems to enhance employment of individuals with significant disabilities

The steering committee and work groups have come a long way since the kick-off meeting in September; but there is still a lot of work to do and seats at the table for those who are interested in participating. Working together, we can continue lowering the barriers to employment for ourselves, family members, and employees, so that all Coloradans who wish to work—can. If you would like more information on the Buy-In Program or the MIG, or to volunteer for a work group, contact Kimberley Smith at 303.866.3991 or kimberley.smith@state.co.us or visit the Buy-In web page at **http://www.colorado.gov/hcpf**.

Sue Fager is a MIG Program Specialist working for CO DVR, and a member of the Colorado Developmental Disabilities Council.

(Disclaimer)
The views expressed by authors in Between the Lines, the quarterly newsletter of the Colorado Developmental Disabilities Council, are not necessarily those of the Council, its individual members or the staff. Letters to the Editor are encouraged, as are requests for correction of factual information. Please direct such to the newsletter editor at marna.ares@state.co.us.

Colorado Assistive Technology Coalition

Membership includes representatives from:

Department of Education:
Exceptional Student Leadership
Talking Book Library

Department of Human Services:
Early Intervention
Vocational Rehabilitation
Colorado Aging/Adult Services

University of Northern Colorado
Colorado State University

The Legal Center for People with Disabilities and Older People

University of Colorado, Anschutz Medical Campus
Assistive Technology Partners.

Family Voices Colorado

Colorado Developmental Disabilities Council

US Department of Aging

Office of Workforce Development

American Council for the Blind Colorado

TO: Anyone Interested in Assuring that People with Disabilities and Older People have the opportunity to live as independently as possible at home, school, work or in the community.

RE: Attached is a paper from the Colorado Assistive Technology Coalition on the importance of considering Assistive Technology in health care planning AND the cost savings benefits when the right technology is available to the consumer. In addition, the document defines Assistive Technology in layman's terms.

BACKGROUND:

The Colorado Assistive Technology (AT) Coalition is a group that historically has represented agencies and organizations that serve people with disabilities and people who have disabilities or their caretakers. In recent years, the AT Coalition has assumed the responsibilities of the advisory council for the statewide AT Program for Colorado which is federally funded under the Assistive Technology Act of 1998, P.L. 105-394.

In this role, the council has produced the attached document: Assistive Technology: An Essential Component of Health Care Reform.

WHY ASSISTIVE TECHNOLOGY IS IMPORTANT!

As the Money Follow the Person grant unfolds and with the Olmstead decision, Assistive Technology must be considered as an essential tool that can save public and private funding, keep people in their homes or community, and improve the quality of life for people in Colorado.

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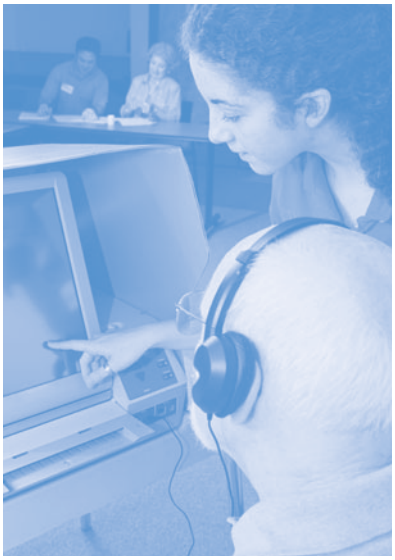
Assistive Technology: An Essential Component of Health Care Reform

(Written for the Colorado Assistive Technology Coalition—the advisory council for the Assistive Technology Program of Colorado, a federally funded program under the Assistive Technology Act of 1998, P.L. 105-394, March 2011)

Assistive technology (AT) is an essential part of any health care program, because access to these tools, both low tech and high tech devices and equipment, can result in improved health and quality of life for the recipient and ultimately, significant savings in health care costs. For multiple reasons, people do not always get the technology they need. If a person does not have access to the needed technology, they are often dependent on others including paid professionals to care for them. In many cases this care is only available in a nursing home, hospital, or other health care facility at increased overall costs. The cost of providing care to someone in a nursing home is five times the cost of providing that same level of care in a person's home.

Many organizations and agencies are faced with the implementation of Health Care Reform and find themselves on a sharp learning curve to understand how the use of technology can benefit people with disabilities and the aging population as well as serve as a cost effective measure for delivering services. The more independent a person is in meeting their own health care needs, the less costly it is for the health care agencies. Technology allows individuals to be more independent in their homes, or in health care facilities. Devices as simple as a reminder to take medications, dressing aids, or activity monitoring promote independence. More complex devices such as computer programs that support communication for someone unable to type or speak increase independence as well. Daily, the technology that is available grows exponentially. It is difficult for any individual or entity to stay current on all that is available at any given time. Costs for some of the unique new technologies can appear prohibitive in these times of reduced resources and yet, costs for some of the more mainstream devices are coming down as the demands for them increase. The challenge is how every entity delivering health care benefits can know the most appropriate, yet most cost effective technology option, for each individual they serve.



Unfortunately, it is often the "person who writes the check" who makes the decision about what technology a consumer can have. In other words, the third party payer has a pool of devices that are considered appropriate for people with a specific diagnosis. One example of the ineffectiveness of using an approved list is a 12 year old who came to the Assistive Technology Partners Clinic in Denver, Colorado. He had a speech and language disability and was referred for an evaluation to determine if technology could help him communicate. It was determined that he could benefit from the use of an iPod Touch and some other software and devices totaling less than $3,000. When this was submitted to his insurance, it was denied with the recommendation, per their policies, that another device costing $6-8,000 would be more appropriate. This more costly device would only meet part of his needs and the young boy was too embarrassed to use it. This illustrates that a newer and less expensive technology was the most appropriate, but because it was not on the approved list, it could not be funded.

Assistive technology can minimize long term health care costs in the provision of adaptations or specialized tools for daily living which permit an individual to independently perform personal care activities, prepare meals, and take medications, relieving high-cost care givers from those duties. Mobility aids and devices to allow for independent movement and travel decreases the need for others to assist an individual as he/she moves around a home, the office, or in the community. Because of rapidly changing technology, maintaining an approved list of devices for which a consumer is eligible is not effective for determining what is appropriate for an individual. Additionally, the Medicaid rule around technology being specific to a 'designated user' is no longer relevant given the concept of 'social' media. Many of the available technology options today that are designed to be used as a social connection tool also happen to be an effective communication device for someone with a disability.

Assistive technology provides the tool(s) that an individual needs to function independently at work, school, or in an independent living environment. Devices can be as simple as a specialized pencil grip for someone unable to write with a typical pen or pencil or as complex as uniquely developed switches to allow a person with significant physical or communication disabilities to use a computer for research or communication. Assistive Technology is defined in law as *"any item, piece of equipment or product system whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain or improve functional capabilities of individuals…"* and *"any service that directly assist an individual with a disability in the selection, acquisition or use of an assistive technology device."* (The Assistive Technology Act was first passed by Congress and signed by the President as the Technology-Related Assistance Act of 1988 (P.L. 100-407). It's often called the Tech Act for short and has been reauthorized in 1994, 1998, and 2004.)

Durable medical equipment (DME) is also considered to be assistive technology. Each state defines what is considered DME for their Medicare program. For example, in Colorado, DME is defined as equipment which is suitable for use outside of a medical facility, which can withstand repeated use, which has a medical purpose, and which would not be useful to the client in the absence of illness, injury or disability [1]. Augmentative Communication Devices for people who are non-speaking are considered DME in Colorado because they are considered medically necessary to maintain the health and safety of the individual. These regulations vary from state-to-state.

Assistive technology is not disability specific. It is a tool to meet the functional need(s) of a person, allowing for increased independence. For example, two individuals with similar visual impairments might choose two very different options to meet their needs. One might need the more expensive text-magnifying device and the other might prefer a bright light and a simple hand held magnifier, depending on their lifestyles and visual needs.

The issues faced by national and state entities regarding assistive technology are threefold. **How does one find the most appropriate technology? How do the individuals and their caretakers learn to use it? And how do they pay for it?** Research has shown that AT usage is most effective when the consumer is part of the selection process and that they have a chance to try the technology out for a period of time prior to making a decision. Often costly technology is discontinued or abandoned, if the user is not involved [2-5]. Therefore, a successful outcome is more likely, if the AT user has access to a trained assistive technology specialist who can assess their needs, identify appropriate technology for them to try out and work with them so they can make an informed decision. Ultimately, with access to current information, training, and consumer involvement, costs savings and less abandonment of expensive devices can be realized.

Trained assistive technology specialists who understand the range of available technology are not always readily available. **The field is relatively new. However, every state has a statewide assistive technology program funded by the US Department of Education.** Under the Tech Act, Congress authorized grants to support state and territorial efforts to improve the provision of assistive technology to individuals with disabilities of all ages through comprehensive, statewide programs that are consumer responsive. These statewide programs assure that assistive technology devices and services are accessible and available to individuals with disabilities and their families. The program provides one grant to each of the states, the District of Columbia, Puerto Rico, and outlying areas. **Primary goals of the statewide programs are:**

- to demonstrate assistive technology for users,
- to make referrals to appropriate resources for individuals to get evaluations or to purchase technology, and
- to assist individuals to find funding for their technology.

It is important to note that not every clinician or technology vendor is qualified to make appropriate

recommendations for assistive technology. In addition to their professional license, it is recommended that clinicians have accreditation through RESNA (Rehabilitation Engineering and Assistive Technology Society of North America) as an Assistive Technology Practitioner (ATP). The statewide assistive technology programs are the most current resource on finding qualified evaluators and resources for acquiring technology and can be accessed directly by any individual or organization.

Additionally, the statewide programs have the expertise to help health care providers and others who serve people with disabilities to expand their capacity for understanding assistive technology and how it can benefit those they serve. Because the AT programs serve all ages from birth through the aging population, and all disabilities, training and technical assistance can be tailored to the needs of those served to a specific organization or agency whether it be medical facilities, Area Agencies on Aging, Independent Living Centers, schools, early intervention programs, employment programs, or health benefit programs. Greater awareness about assistive technology among the professionals brings more opportunities to those they serve.

Assistive technology must be considered when planning for transition from hospital to nursing home or a nursing home to living independently. It can mean the difference between completing tasks of daily living independently or needing help from another individual. Or, technology can be the means for communication for someone who cannot speak for themselves. Technology can allow a person to feel safe in their own home. Studies have shown that states save significant Medicaid dollars when they use the funds to support people in their own homes rather than paying for the high costs of nursing homes. In addition, once an individual is in their own home, with the appropriate technology, the need for costly home services and/or attendant care can be reduced.

On the preventative side, assistive technology can provide the essential tools to keep people with disabilities or the aging population safe and more independent in their homes. Through home accessibility assessments and the application of appropriate technology, people with chronic conditions can remain independent and safe from accidents or deprivation, resulting in improved health. Augmentative and alternative communication devices are available to keep them connected to the world outside their homes. Moreover, maintaining an independent high quality life staves off depression. “Depression increases the risk of disability from all other causes in the elderly” [6]. Clearly, the multiple benefits of keeping the aging population in their own homes are more than just an argument for cost savings. It is an issue of safety and improved quality of life.

With the potential of the Money Follows the Person grant in Colorado as well as the Olmstead decision, it becomes more critical that supports exist in the community and individual homes, as an option to nursing homes. As Centers for Medicaid and Medicare Services move to level the playing field of the institutional bias in their funding, the use of technology can be of great benefit to access supports on an individual basis in non-institutional settings.

For more information about assistive technology, contact a statewide AT Program. http://resnaprojects.org/scripts/contacts.pl
RESNA Catalyst Project
1700 North Moore Street, Suite 1540
Arlington, VA 22209-1903
Phone: 703/524-6686 Fax: 703/524-6630 TTY: 703/524-6639
Email: Catalyst@resna.org **http://www.resnaprojects.org/**

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References:

1. Section 8.591.02(E), 10 Code Colo. Regs. 2505-10, cited in T.L. v. COLORADO DEPARTMENT OF HEALTH CARE POLICY AND FINANCING, 42 P.3d 63 (Colo. App. 2001).)
2. Scherer, M., Jutai, J., Fuhrer, M., Demers, L. & DeRuyter, F., A framework for modelling the selection of assistive technology devices (ATDs). Disability and Rehabilitation: Assistive Technology, 2007. 2(1): p. 1-8.
3. Scherer M, S.C., Vanbiervliet A., Cushman L., Scherer J., Predictors of assistive technology use: The importance of personal and psychological factors. Disability and Rehabilitation 2005. 27(21): p. 1321-1331.
4. Bodine, C., Assistive Technology in Physical Medicine and Rehabilitation, in Physical Medicine & Rehabilitation, R. Braddom, Editor. 2009, Elsevier: Cambridge, MA.
5. Martin, J.K., et al., The impact of consumer involvement on satisfaction with and use of assistive technology. Disability and Rehabilitation: Assistive Technology, 2010. Early Online: p. 1-18.
6. Magee, M. Health Politics: Power, Populism and Health. New York: Spencer Books, 2005

CDDC Advocacy Inclusion Systems Change
The Legal Center for People with Disabilities and Older People
Colorado's Protection & Advocacy System
JFK Partners
Promoting Families, Health and Development

Training about Intellectual Disabilities developed for Emergency Medical Technicians (EMT's)

By Corry Robinson

Contacts with EMT's for families who have a member with intellectual or developmental disability may be difficult experiences. EMT's may not know how to communicate with individuals with disabilities. With this concern in mind, two medical students at the University of Colorado School of Medicine, who are certified EMT's, decided to look into what resources were available to help address the need for better understanding and preparation. Certainly their concern was substantiated by the experience of the Autism Commission when hearings were conducted around the state. Encounters with first responders were an issue of concern for many families.

These students, Spencer Tomberg and Chris Rogers, found a program that had been commissioned by the State of New Jersey and developed at Rutgers University. The developers were quite willing to modify the program for use outside of New Jersey. Through a collaborative effort, modifications were made and the course is now available as a free online continuing education course. Other resources developed include a 30-minute training that is an autism-specific EMT Training, a Parent Resource List, a Wandering Resource Plan, a Person Specific Information form, and a First Responder Tip Card. These materials may all be accessed at **www.tinyurl.com/JFKFRT**.

Spencer and Chris are interested in receiving feedback about the materials and also are interested in making contact with other first responder groups interested in learning more about how to communicate with people with developmental disabilities. If you want more information, please visit **www.tinyurl.com/JFKFRT** or contact Dina Johnson at dina.johnson@ucdenver.edu.

☞ Nomination forms are due by June 1st. Please fax or mail to CDDC. ↘

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Nomination Form for the 2011 Dan B. Davidson Excellence in Inclusion Awards

(You may also print this form on our website: www.coddc.org)

The Dan B. Davidson Award for Excellence in Inclusion honors Dan Davidson, whose very life defined *inclusion*. Dan defied the odds, set aside the advice of others, and followed his dream to live independently in the community.

In honor and recognition of Dan's spirit, the Colorado Developmental Disabilities Council recognizes exemplary practices of inclusion that support persons with disabilities to become fully participating members of their community.

Awards will be given to individuals, agencies or organizations that have demonstrated visionary practices— providing exemplary service and supports — for persons with disabilities that lead to inclusion as active and valued members of their communities. The Council will recognize outstanding examples of inclusion in the following categories:

- **Education**
- **Employment**
- **Community Life**

Winners will be recognized at the **Council's annual celebration** (this year, on July 20th). Winners in each category will receive an award honoring their efforts, along with a $500 honorarium.

Name of Nominee:
(Individual/Organization):_____
Address:_____
_____
Phone Number_____ / Email_____
Nominated By:_____

(*continued on next page*)

Address(es) of
Nominator(s):_____

_____

Phone Number_____ / Email_____

Check award category for nomination:

Inclusion in Education:

- ☐ Individual Indi
- ☐ Agency/Group/Organization

Inclusion in Employment:

- ☐ vidual
- ☐ Agency/Group/Organization

Inclusion in Community:

- ☐ Individual
- ☐ Agency/Group/Organization

Biographical Sketch (Background Information, attach additional sheets if necessary):

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Reason for nomination (include additional sheets if necessary):

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References (if self-nominated):

1. Name_____
   Address_____ Phone_____
2. Name_____
   Address_____ Phone_____

I LOVED THE MOVIE "WRETCHES AND JABBERERS."

I have seen it twice and it is great for the message it shares about people who do not speak. I need everyone to see it. Larry and Tracy go to Sri Lanka and Japan and Finland to visit others who use facilitated communication (FC) to type. It is fun to have the people sitting typing to the others as the jabberers sit quietly by in the restaurant. I loved having Tracy think of things to ask the Buddhist monk about life's purpose. I loved that Larry hated sushi because I do, too.

I think I need for FC users to get the word out that the method is valid. I think I need to thank the Council for supporting the advocacy work of Watch Our Words. The Autism Society of Colorado helped promote the movie in theatres around the country in April. It will be on DVD so if you missed it be sure to get the DVD. Thanks to Betty Lehman for asking me to answer questions after the movie in Westminster April 2. I got to be interviewed at 9 News the day before.

The best thing is the excitement of being part of opening minds to new communication and opening doors to new possibilities in people's lives. That's all for now.

— Mike Hoover

Mike Hoover is a member of the Colorado Developmental Disabilities Council, and an effective and persistent advocate at the State Legislature as a member of the Council's Legislative & Public Policy Committee.

CONGRESS REPORT ON ASD

Colorado, along with most other states, has focused attention and resources on the incidence of autism and the need for understanding the experience of individuals on the autism spectrum and that of their families. The Colorado Autism Commission was created by the Colorado General Assembly in 2008, and was to obtain information about life with autism for people in Colorado, and also to identify existing services and gaps in services, determine actions to remedy the gaps in services, and to detail their recommendations and action plan by issuing a Ten-Year Strategic Plan for Colorado. The Council's ad hoc Autism Committee is continuing the work begun by the Colorado Autism Commission. If you are interested in knowing more about the Committee's work or joining the Committee in their work, you may contact Corry Robinson or Carol Meredith, co-chairpersons for the ad hoc committee.

Below are excerpts from the report released by the Congressional Autism Caucus. You may find the entire report by going to **http:doyle.house.gov/autism.shtml** and typing "Report to Congress" in the search box.

Report to Congress on Activities Related to Autism Spectrum Disorders and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006–FY 2009)

Prepared by the Office of
Autism Research Coordination
National Institutes of Health
Department of Health and Human Services
December 2010

Executive Summary

This Report to Congress is required by Public Law 109-416, the Combating Autism Act of 2006 (CAA). The report describes progress and expenditures made in autism spectrum disorder (ASD) research and services activities since the enactment of the CAA. Information from the following Federal departments, agencies, and offices that address ASD research or services is included:

- Department of Health and Human Services:
- Administration for Children and Families (ACF)
- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)
- Health Resources and Services Administration (HRSA)

- National Institutes of Health (NIH)
- Office on Disability (OD)
- Substance Abuse and Mental Health Services Administration (SAMHSA)
- Department of Education (ED)

In support of a coordinated Federal strategy for ASD research and services, the Combating Autism Act of 2006 reconstituted the Interagency Autism Coordinating Committee (IACC). Members include the above-listed HHS agencies (with the exception of AHRQ), the Department of Education and public members, including people with autism, parents of people with autism, leaders of national autism organizations, a researcher and a physician. This report provides a summary of the IACC's efforts, in addition to those of individual Federal agencies, over the past four years. These collaborative and coordinated efforts have served well to identify promising ASD research areas as well as to pinpoint both best practices and gaps in ASD research and supports. Recent highlights in ASD research include the development of new diagnostic tools, identification of novel genetic and environmental risk factors, clinical trials of interventions, and measures of the efficacy and cost-effectiveness of evidence-based services for people with ASD. In addition to descriptions of Federal ASD-related research and services-related efforts, this report also presents current ASD prevalence estimates, the present diagnostic and intervention landscape, ongoing efforts to identify gaps in and develop effective new ASD supports and services programs, and forward-looking strategies to address the continuing needs of diverse ASD communities

Conclusion

In the past four years under the provisions of the CAA, significant advances have been made in our understanding of ASDs. Notably, reliable estimates of the prevalence of ASDs and a clearer picture of both the opportunities and gaps that exist in ASD research and services are now available. With substantial Federal support, researchers continue the crucial task of evaluating interventions that provide lasting, meaningful benefit to people with ASDs. Large-scale efforts in data collection, consolidation, and sharing are empowering researchers and health practitioners with knowledge not available only a few years ago. With increasing phenotypic and biological knowledge, medical practitioners are beginning to classify sub-categories of the wide spectrum of autistic disorders, which will be crucial in future efforts to provide individually tailored interventions. Within the biomedical research community, there is optimism that a continued rigorous focus on identifying genetic and environmental triggers to ASDs will yield innovative treatment and prevention strategies.

Through intensive surveillance and research efforts, researchers and Federal agencies can also better identify the unmet societal needs surrounding ASDs. While the median age for ASD diagnosis (~4.5 years of age) appears to be favorably on the decline, CDC data indicates a critical need for improved access to early evaluation and diagnostic services. The typical time gap from developmental concern to diagnosis is over 2 years. With a continued focus on ASD awareness and training, within both the public and healthcare spheres, this critical time gap can be lessened. Increased attention is being given to pinpointing underserved communities where diagnostic and intervention support is in the greatest need. Strategic efforts aimed at underserved populations are under way to encourage ASD awareness, early diagnosis, and intervention, but additional efforts will be needed to provide the necessary evidence base to support a wide variety of new interventions and services and supports to provide for the needs of people on the autism spectrum. In addition, services and supports programs across several Federal agencies are actively identifying best practices and implementing programs to increase quality of life for people with ASD across the lifespan. Finally, the Federal coordination provided by the Interagency Autism Coordinating Committee (IACC), has successfully identified key research and services priorities and has fostered enhanced communication and collaboration between Federal agencies, private foundation partners and the public. This Federal coordination will continue to be needed to monitor progress, provide a forum for public input into Federal ASD policy, and help agencies bring critical research into practice in the form of effective programs to help people with ASD and their families.

Affirming Attributes

The federal department that has developed materials and training for first responders who are called on to help people with disabilities: Health and Human Services
(http://www.hhs.gov/od/tips.html)

The person who said: "A key part of health care reform involves the use of technology to address a number of issues such as access, value, and cost." Former Senator Bill Frist, R-Tennessee
(http://www.webmd.com/healthy-aging/features/technology-plays-key-role-in-health-care-reform)

The date on which the 9th International Congress Autism-Europe was held: October 8-10, 2010
(http://www.autismeurope2010.org/)

The Congressional Session in which Representatives Chris Smith and Mike Doyle founded the Coalition for Autism Research and Education: 107th (January 3, 2001 to January 3, 2003
(http://doyle.house.gov/autism.shtml)

The year in which Facilitated Communication Training Standards were first published: 2000
(http://soeweb.syr.edu/centers_institutes/facilitated_communication_institute/About_the_FCI/training_standards.aspx)

The nine states that were the early implementers of the Medicaid Buy-in Program:
Alaska, Connecticut, Iowa, Maine, Minnesota, Nebraska, Oregon, Vermont and Wisconsin
(http://aspe.hhs.gov/daltcp/reports/2002/Ellesson.htm)

CDDC
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Systems Change

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