



## **The Arc of Massachusetts**

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To: Randi Wiggins on behalf of Patrick-Murray Transition Health Care Working Group  
Fr: Leo Sarkissian, Executive Director & Mary Ellen Mayo, R.N., M.S., President  
Re: Individuals with Intellectual/Developmental Disabilities and Health Care Policy  
Date: December 11, 2006

We appreciate the opportunity to submit a policy paper to the Health Care Working Group. Ms. Janet S. Rico, RN, CNP, Board Member of The Arc, Nurse Practitioner in the Emergency Department of Boston Medical Center; Assistant Professor in the Graduate School for Health Studies at Simmons College prepared this brief. It reflects the concerns and policy of The Arc and its Health Care Committee.

The Arc of Massachusetts and The Arc of the United States have provided leadership in disability policy since the 1950s. Founded by parents, our mission is to enhance the lives of individuals with intellectual and developmental disabilities and their families. We accomplish this through advocacy of supports and services based in the community.

Individuals with intellectual disabilities (ID) face significant barriers within society, health care, education and employment. In this paper we utilize the term, "mental retardation", instead of our new terminology for the benefit of the readers. Most of the recommendations are applicable to other disability populations. Systemic barriers are particularly problematic when individuals present communication or physical limitations. In addition, individuals with "ID" or mental retardation are sometimes devalued for their intellectual limitations. This in itself may result in inadequate treatment.

The Special Olympics commissioned a research group from Yale in 2000 to assess the healthcare needs of those with mental retardation, after they found their athletes to have major gaps in health care promotion, including problems with obesity and poor dental and eye care. In a very in-depth analysis of national and international studies, the researchers found individuals with mental retardation to experience poorer health, shorter lifespans, and less access to professional health care than people without this condition (Horowitz et al., 2000). The U.S. Surgeon General's 2002 Report on Health Disparities and Mental Retardation (U.S. Public Health Service, 2001) which soon followed this study highlighted the huge inadequacies in meeting this population's healthcare needs. In this report, Tommy Thompson the Former Secretary of Health and Human Services highlights areas in need of improvement to ensure quality healthcare services to this population. These problematic areas included addressing societal misunderstanding, lack of healthcare provider experience and knowledge in caring for those with developmental disabilities and improving provider incentives to ensure the health of this population. He goes on to emphasize the need for more research related to the healthcare needs of this population.

Healthcare providers often lack training and experience in caring for this population. In a healthcare environment already seriously strapped by fiscal constraints, this population is truly vulnerable. They may require more provider resources, especially time, to adequately work with communication issues, complex medical concerns, poly-pharmacy effects and adaptations needed to meet physical impairments. The movement toward deinstitutionalization for those with "mental retardation" and mental illness began in the 1970s and is still ongoing. It has made it possible for this population to become part of their communities. Along with this transition, however, has come a need for more community-based health services. While health professionals in the institutional setting were specialists in the care of this population, the

community-health-service providers now serving this population have sometimes been unprepared (Kozma, 2003). There is little research assessing if this population's healthcare is being provided comprehensively, although we do know there are serious concerns.

The Special Olympics provided health screenings at their last Summer and Winter Games. They found many of their athletes were unable to pass the hearing exam and 33% of those aged 8 to 17 had never had an eye exam. 14 % of the participants required urgent dental care. (<http://www.specialolympics.org>) The Special Olympics found similar issues several years ago. The obvious lack of preventive healthcare seen in this group of athletes was the impetus for a Yale University research project by Horwitz et al. (2000), assessing the present healthcare needs of the developmental disabled. The Surgeon General's summit and report to the nation on the gaps in healthcare followed the next year.

Research assessing the quality of primary care services to this group is fundamental to any policy considerations and urgently needed. The Massachusetts Department of Mental Retardation (DMR) mandates an annual physical for all those served by the department and living in group residencies. Preventive health screening recommendations have been adapted from recommendations made for the general population based on sex, age and medical history (Commonwealth of Mass., 2003). However, we do not know whether individuals with developmental disabilities are actually receiving the routine health screenings such as mammograms, pap smears and colonoscopies offered to the general population during routine exams because the DMR has only put these forth as recommendations, not requirements.

Few studies document the quality of primary care services provided. Lewis (2002) found serious inadequacies in dental care, pap screenings and immunization updates. Horwitz et al. (2000) highlights the need for more comprehensive mental health services, ophthalmologic and dental services for those with developmental disabilities.

It would be unethical for this population not to receive the primary care services offered to all others. It could also prove to be increasingly more costly as we now see an aging population of individuals with developmental disabilities with many chronic illnesses. Our failure not to identify problems early and to poorly manage chronic illnesses will increase our overall healthcare costs. It will also adversely affect their quality of life and their abilities to maintain whatever independent functions they now have.

There are many factors felt to be affecting the quality of healthcare provided to individuals with intellectual and developmental disabilities. Researchers, consumers and family members have felt disparities are related to lack of physician and other health providers' lack of knowledge and experience in caring for individuals with mental retardation. They may feel reluctant to assume clinical responsibility for their care due to lack of knowledge and their perceived inability to meet their needs due to communication and physical barriers.

Providers are not reimbursed for providing the time that can often be necessary in meeting the needs of this population when they access care. They may often need more time for communication, behavioral or physical adaptations. They may also require sedation for certain screenings that can also require more time and expertise. Services may be poorer in quality because of societal assumptions that people with mental retardation cannot participate appropriately in their own health care (Surgeon General's Listening Session and Senate Appropriations Committee Report). For years, families, providers, and these individuals have sought, with varying degrees of success, to improve their health and health care. (Braden)

Our work in addressing the healthcare issues appears massive but should not be. We should begin with strategies to improve access to appropriate health care services for individuals with mental retardation. Access can be impeded by communication issues, transportation problems and funding. Improving primary care services at day programs, individual residencies

and group homes would do much to circumvent the transportation issues and provide care in the individual's environment. Primary care services could also be improved with increased utilization of nurse practitioners.

Improving the knowledge and experience of health care providers is key. There needs to be curricula that include discussion of our population in basic health professional education programs. We also need to work on the education of families and long-term care providers.

Coordination of specialty services and improved dental and ophthalmologic services are direly needed. The care of those with intensive medical needs is another area the system much address as we have more children with special needs living longer lives as well as many with mental retardation with chronic illnesses related to aging.

Improvements in health promotion will occur with improved education on all levels. Consumers, health care providers, families, and direct care staff need to all understand the importance of disease prevention and that everyone is capable and entitled to health promotion and screening activities.

Recommendations to improve the healthcare services would include the following:

- An assessment of the issue in Massachusetts. Surveys should query providers, families, clients and direct care staff. Areas to research would be exactly what care they are receiving, concerns, attitudes and satisfaction. We should also survey for exemplary providers/health programs, highlighting them in key avenues and provide incentives for expanding successful programs and increasing provider numbers.
- Strengthen coordination and communication between state agencies to identify problematic health concerns, areas of unmet needs
- Provide incentives, opportunities for healthcare provider education programs to work with individuals with mental retardation

- Improve reimbursement for providing care for those with physical, intellectual and communication disabilities
- Identify successful health promotion, primary care delivery, streamlined primary and specialty care initiatives and intensive medical care programs in other states that could be replicated in Massachusetts.

### **References**

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