



The Arc of Massachusetts

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Policy Summary for Patrick Murray Transition Team

This document is a top level description of salient issues affecting our constituency. It includes several recommendations. A full document has been submitted to the Human Services Workgroup. A second paper submitted to the Health Care Policy Workgroup identifies specific barriers and needs in the health care system.

For the past 50 years, **The Arc of Massachusetts** has been the leading civil rights advocate for people with intellectual and developmental disabilities in Massachusetts. Our cutting edge advocacy has included the 1970's special education legislation, the federal court consent decrees involving Massachusetts' state institutions and the 1999 lawsuit to end the DMR waiting list. The Arc, in collaboration with its national counterpart and 21 Massachusetts chapters has played a pivotal role in effecting positive change in government's relationship to individuals with intellectual disabilities. While we have chosen civil rights litigation in the past, we have done so only as a last resort. We welcome the opportunity to collaborate proactively with the Patrick administration.

Looking forward, The Arc of Massachusetts sees a truly transformational opportunity available to the Patrick –Murray administration. For The Arc, it is an opportunity to galvanize our community in pursuit of common goals after facing 12 years of adversarial politics and disinterested leadership.

The American dream for people with disabilities requires access to education, health care, employment and community. The dream is denied when the long term support services necessary for access are unavailable or ineffective due to quality. Some of the **Key Facts or Issues** facing our constituency include:

1. **The number** of children and adults requiring services continues to increase
 - a. Baby boomer adults who have "older" parents
 - b. Longer lifespan
 - c. Children with complex medical needs are surviving into adulthood
 - d. Incidence of Autism Spectrum Disorders has sharply risen
 - e. Lack of funds to keep pace with high school graduates with special needs

2. **A policy** of neglect in regard to community providers including "NO" allocation of cost of living since 1986 and no mechanisms to annually address salaries and benefits. Although the shift to community based services and supports has been an unmitigated success, recent contracting practices have negatively impacted the system.
 - a. Direct Care workers in the community receive, on average, less than \$11 per hour and many refuse benefits due to cost
 - b. Decline in community providers who are known by citizens and leaders and who can best leverage generic resources

3. **Most individuals** with disabilities live in the community without any public support. Those with intellectual disabilities are most often supported by family members NOT government programs.

Families do support their family member throughout childhood and into adulthood but they can't do it alone.

- a. No investment in family support since 1996 except for \$500,000 allocation in 2006
 - b. Individuals with disabilities and family members can make decisions on how support dollars should be spent but they're rarely allowed
 - c. Consequently, long term support options have been limited
 - d. When children leave high school, they find that some of the therapies and other services such as speech, occupational therapies are unavailable as adults
 - e. Individuals with communication and physical disabilities often can't receive health care in their communities
4. **Massachusetts has declined to implement Olmstead** as reflected in its operation of the six of seven institutions in New England **and** its refusal to engage in fair contracting practices with community providers.
- a. Physical plants are old and operating expenses are high
 - b. Individuals, beneficiaries of special education (and their parents) do not envision institutions as an option yet are sometimes told that is what is available
 - c. Segregation further breeds denial of need and causes devaluation in the broader society whether in health care settings or public venues

These are beginning **Recommendations** to the Patrick-Murray administration:

1. **Renegotiate** Purchase of Service contracts to reflect actual expenses including adequate worker salaries, benefits, and other costs such as provision for fuel and national criminal background checks. Address deflated rates.
2. Utilize **Massachusetts Medicaid State Plan and Waivers** to provide access to community based services for children and adults.
 - a. Allow all new dollars to be flexibly administered by individuals or families with incentives to leveraging community options
 - b. Provide reasonable dollar packages for adults so that employment, transportation and community supports can be purchased flexibly
 - c. Challenge communities, clubs, religious organizations, businesses and others to welcome individuals with disabilities; Partner and support organizations such as The Arc to build linkages
 - d. Allow all children to receive early intervention for the physical, medical, behavioral and emotional issues that exist, through MassHealth (EPSDT-early periodic screening diagnosis & treatment) and the DPH program for infants/toddlers
 - e. Allow middle and higher income families to have their children's needs addressed through state plan services
 - f. Ensure that adults retain access to state plan services
3. **Implement Olmstead** by phasing in the closure of institutions.
4. **Utilize the 50% reimbursement** from the federal government to jumpstart a flexible program for individuals with intellectual and developmental disabilities include an 8% allocation for FY'2008, 4% to address COLA in DD/MR and 4% to address the needs of Massachusetts citizens.
5. **Study the need.** The Commonwealth requires better statistics with which to plan. The effort needs to go beyond DMR, it must include health care and other sectors where individuals with intellectual disabilities are not typically considered.

Note: Longer Policy Paper and Health Care Policy at www.arcmass.org