

The Arc of Massachusetts
Key Policy Issues for the Deval Patrick Administration
November 30, 2006

Background-Who We Are

The Arc of Massachusetts and The Arc of the United States have provided leadership in disability policy since the 1950s. Founded by parents of children with intellectual and developmental disabilities, The Arc has been a presence both on Beacon Hill and Capital Hill. The success of the Arc is in part due to the collaboration between 21 local chapters across the state, from Cape Cod to the Berkshires. While The Arc of Massachusetts provides education and advocacy on a statewide basis to reach the 120,000 constituents and families, local chapters provide concrete services including employment, housing, recreation and in-home supports.

Our efforts have focused on gaining supports through budget allocations, legislation, system reform and judicial intervention when necessary. Today's services such as special education, housing, and family support were championed by The Arc. Some examples of successes include:

- Chapter 766, special education law
- Chapter 688, law related to supports for high school graduates with special needs who require adults services
- Legal settlements including Boulet, Rolland and Consent Decrees

The Arc believes that everyone has value and should have opportunities to live a full and useful life with their families in their own communities.

Disability Policy

Children and adults with intellectual disabilities have faced significant barriers within society, health care, education and employment. The disparaging use of the word "retard" is a powerful reminder of the isolation that children or adults with intellectual disabilities often face. There are several global issues to consider before decision makers grapple with specific policies.

1. We face an opportunity for a new era in services. By allowing self-direction of services by individuals and families, we can build on community capacity.
2. The present service system evolved as a response to conditions in institutions. It brought some of the institutional concepts and systems to the community. If not for the advocacy of The Arc and other groups, institutions may have continued to be the norm.
3. Most individuals with disabilities live with their families or semi-independently in the community. This may include living in a group home, an independent apartment or a state operated facility for those with significant disabilities.
4. Specialized therapies, i.e. speech, physical therapy, occupational therapy need to be greatly enhanced for individuals with complex medical needs or significant behavioral needs. Interventions can translate into dramatic improvements for

- individuals. Public policy has tended to stall such advances in favoring of maintaining a large institutional capacity.
5. The demand for a well-developed and better supported workforce is at an all-time high.
 6. We know that youth and adults with disabilities can live and thrive in their neighborhoods. Additional flexible supports and recreational opportunities can make a big difference in a person's life.

Policy: Early Childhood

Families are often overwhelmed when a child with a developmental or intellectual disability is born. In some cases parents don't discover this fact until a child is a toddler. But whenever the moment arrives, it is a time of surprise or shock. A range of organizations in addition to The Arc are there to help connect families with other families so they can adjust to this new development emotionally and learn over time that there will be milestones ahead to celebrate.

One key public support is Early Intervention services administered by the Department of Public Health. Through a network of thirty- five providers, children from birth to three years can receive education and treatment to address their disability or developmental delay. In Massachusetts, children at environmental risk are also eligible for services.

Approximately 30,000 children are part of the EI network statewide. Trained therapists provide in-home supports ranging from speech pathology, physical therapy, nutrition counseling, nursing, etc. Therapists work directly with the parents or caretakers to assure that the young child can thrive within the family unit.

The only criticism of Early Intervention is that it ends when the child turns three. At that time the child receives an Individual Education Plan (IEP) and begins the journey through the public school system.

Department of Public Health, Line Item 4513-1020

Early Intervention also receives federal funding through Part H, Medicaid reimbursement and Third Party reimbursement through private insurance.

Long term issues for early childhood include:

- Address reimbursement rates as the philosophy of EI services has shifted to natural environments without the accompanying dollars
- Develop a better transition process (a theme throughout children/adult lives) so that the child doesn't lose needed supports in his or her movement to the LEA (Local Education Authority or school system)
- Address status of early childhood programs and day care services so that more children with disabilities can be included in generic community programs
- Address Medicaid State Plan and Waiver Services (see discussion on Medicaid at end of children and adult sections) to ensure access

Short term Action: Early Intervention requires an additional \$2 million to address rate problems and avoid waiting lists.

Policy: Childhood and Adolescence

Since 1974, Special Education has changed the world for persons with disabilities. Chapter 766, the first in the nation special education law became the model for the federal special education law, IDEA. By allowing children with special needs to attend public schools with their brothers and sisters, Massachusetts has kept families together. Inclusion, integration and being part of the family unit are the values that drive the special education system. This has further reinforced the fact that institutions are a model of the past. However funding, like all education money is driven by individual cities and towns so educational opportunities for children with special needs vary dramatically.

It is important to understand what parents are experiencing when they face barriers in raising their child in the community. Friends in the neighborhood may avoid them and other neighbors may not invite them to gatherings because of the needs of one of their children. In urban areas, members of diverse communities may not even be informed of basic special education rights or processes. Youth grow into adults without a chance to become productive members of their communities.

There are also two significant sub-populations that have grown significantly. Through improvements in medical technology there has been a rise in youth with complex medical needs. This population is continuing to grow and will require medically intensive care beyond the school years.

Secondly, we have witnessed a rise in children who are identified with symptoms falling within the autism spectrum disorder or ASD. Supports vary dramatically for families, particularly when a young adult leaves the public school system and transfers into the adult system of services.

For some children, special education is not enough. While most children attend the local public school system, there are some who are perceived as too challenged. Depending on the capacity of the school system, these students often attend “out of placement” private day and residential schools. Wrap around services outside of schools have not been developed adequately for children with such complex challenges. School systems and Governors complain bitterly about private placements being very expensive and that they deplete limited school budgets. However, little is done to provide community supports. One exception is the DOE-DMR (Department of Mental Retardation-Department of Education) project which provides intense in-home supports for children with complex challenges, thus, reducing out of district placements.

Over the past five years a new line item in the budget, called the Circuit Breaker, provides state funding to local school systems to supplement out of district placement

costs. Although this is a necessary short-term solution for cities and towns, we need to be careful to reinforce in-district education and supports. We need to couple relief to cities and towns with the right supports to help kids stay at home.

A major impediment to full community participation is the difficulty to access EPSDT (Early Periodic Screening Diagnosis and Treatment) and other Medicaid state plan services. This is particularly difficult for children with behavioral and emotional challenges. This is the focus of the federal Rosie D. case that targets supports for children with behavioral and emotional challenges.

Long term issues for child/adolescent include:

- Address incentives to LEAs (Local Education Authorities) so that youth can remain with families
- Address Medicaid state plans and waiver services so that there is adequate family support and other systems in place. Target specific state plan programs which could address the needs of youth. Massachusetts Department of Mental Retardation is in the process of submitting a children's' waiver. This should be complemented with a second children's' waiver, deeming parent income and providing access to state plan services.
- Developing strategies to include youth in more generic school/community activities
- Better prevention programs to address behavioral symptoms
- A broader funding stream for family support services

Short Term Action: Look at relief to cities and towns with the Circuit Breaker (7061-0012) account. Increase the DOE-DMR (5948-0012) account by \$3 million to begin addressing community supports. Begin to look at incentives for cities and towns to keep youth at home. Increase Family Support and Autism Division allocations within DMR budget.

Another compelling issue to The Arc is the transition from special education to the community. Since education is an entitlement, youth can receive services based upon their educational plans. In some cases these programs are year-round. Once a person leaves special education, he/she moves into a new and frightening world without any guarantee of service and funding levels. Services offered are often well below those allocated while the student is in school.

The Arc encourages families to consider keeping their child in school until the young person's twenty-second birthday because it provides a secure funding base. Preparation for the world of work can continue during this period. School systems argue that if an individual has passed the MCAS or wishes to graduate, they should leave high school. Recent initiatives in the state budget are providing pilot programs in community colleges as another alternative to maximize students' opportunities to work after school.

Transition to Adulthood

Turning 22

This period of time is very difficult for families. Parents are forced with the choice of leaving their jobs so that their son or daughter is not left unattended during part or all of the day. This could mean families needing state assistance if the working parent needed to stay at home. If the student or parent has not been educated about the implications of graduation, he/she may agree to early graduation without any plan for work.

Most students with special needs do not transition to the adult services system. About eight percent require adult supports due to the level of their impairment. These students are assigned to a state agency through an Individual Transition Plan (ITP) under Chapter 688, Massachusetts' Turning Twenty Two law. Massachusetts has maintained a commitment to students with intellectual disabilities by annually funding a Turning Twenty account at the Department of Mental Retardation. An additional ten per cent of graduates are assigned to the Massachusetts Rehabilitation Commission and about eight to ten people who are blind and have intellectual disabilities are assigned to the Massachusetts Commission for the Blind.

The Department of Mental Retardation, Turning 22 budget line item was originally created in 1984 in response to advocacy by grass roots groups to prevent growth of the DMR waiting list. While the program has been hailed for its success in helping to close the "back door" of the DMR waiting list, funding has not expanded at a sufficient pace to address cost of living increases, and new demands placed upon the program. There is a significant rise in the number of people with autism as well as adults with complex medical needs. More people are now served by the program today (599 for 2006) than ten years ago (455 in 1996), although funding has not kept pace. In fact in addition to services not being provided due to underfunding of this account, employment for individuals has declined. Theoretically this account is both a long term and short term solution. Long term, with changes in the Medicaid Home and Community Based waiver, adults and/ or family members can receive control of Turning 22 dollars to develop more individualized adult supports in the community. To accomplish this there needs to be adequate funding not only for those students in residential schools but for the majority who continue to live with their families. The per capita annual cost for work/community/transportation supports is approximately \$25,000.

Department of Mental Retardation: Turning 22, Line Item, 5920-5000.

Short Term Action: This year, \$2,000,000 was added for students Turning Twenty Two (which would annualize to \$17.6 Million). This amount was also cut through the 9-C mechanism. This additional money must be maintained. The students who require these supports are severely disabled and simply must be served.

Adulthood

The world has changed mightily since the 1950s when institutions or nothing at all was the norm. More than 10,000 individuals receive some level of support so that they can live in their own communities without solely depending on parents who are middle aged

or elderly. We see positive values underpinning these services even if the funding is not always available. We have the knowledge and some of the technology to support individuals with disabilities. What we lack is the funding and sometimes the staff to do the right job consistently to help those in need.

At best, many adults with intellectual disabilities face an uncertain future. Parents who continue to care for their loved ones are provided limited resources. State plan services for allied health therapies (occupational, physical, speech) are basically inaccessible. The rates to provide services in the Purchase of Services system are not at all tied to other public systems or financial measures (special needs schools, state employees, economic index). For DMR funded services, no cost of living allocation has been allocated since 1986 and the salary reserves have been an inconsistent allocation.

Although there are serious challenges facing this service system, federal dollars can be leveraged to address these needs.

Long term strategies or issues include:

- Flexibility to allow consumers to direct their supports within their communities
- More flexible funding streams for adults as needs evolve due to aging or medical concerns
- Addressing historical rate deflation in community programs
- Ensuring waivers have growth built-in to allow for new recipients
- Address employment and transportation accounts
- Incentives for doctors, nurse practitioners, dentists and specialties to work with those who have intellectual disabilities and receive MassHealth
- Educational opportunities for health professionals in improving the quality of care provided
- Use of federal waivers' cost increment factor to address rates on an ongoing basis

Specific Policy-Programs

Flexible Family Supports

The major supports for individuals with intellectual disabilities are made up of family members. Of the 32,000 people served by the Department of Mental Retardation, approximately 21,000 live at home or semi-independently. There are thousands of others who do not ask for or cannot obtain services. The Family Support system in Massachusetts serves many people well. There is a great deal of flexibility and most families are grateful for the help and support provided by DMR and their local family support agency. Structural questions remain, however, concerning both the issues of **equity** and **consistent quality** in our system of care. In 2000, the allocation for this line item was \$48,006,485. Prior to the 9c cut, the 2007 level was to be 53,094,228. Most of this increase reflects minor increases due to the needs of individual students Turning 22 over the past seven years as opposed to any additional dollars. More investment in individual and family supports can reduce the demand for costly, residential services.

Department of Mental Retardation: Flexible Supports/Respite care, Line Item 5920-3000.

Short Term Action: This program should be closely examined and expanded significantly, \$5,000,000.

Day/Employment Services and Transportation

Employment resources have declined over the past decade as Turning 22 funding per capita has decreased. Transportation, a separate DMR account also has hindered employment as funding has been decreasing over the past decade. In FY'2004, Employment funding was at \$106.45 Million. It is projected to be \$117.4 Million for FY'07 (prior to 9C), an increase of less than \$11 million dollars over four fiscal years. Since there was no new money for employment, these additional dollars reflect distributions of the salary reserve and Turning 22 account during the four year period. This means that less than \$7 million was allocated for the employment needs of a combined total of 2,040 graduating students. During the same period, transportation funding decreased. As a result employment and opportunities for employment have decreased.

It's critical to have adequate employment, day and transportation funding so that individuals are participating meaningfully in their society. Further this can help to decrease demand for residential services.

The recommendations for adults in the preceding paragraphs addressing leveraging Medicaid waiver funds to offer packages for support services.

Department of Mental Retardation: Employment/Day, Line Item 5920-2025, Transportation, Line Item 5920-2000.

Short Term Action: Increase these line items respectively by \$3,000,000 and \$1,000,000 for employment options.

Residential Services

In the mid seventies, The Arc of Massachusetts along with parents who had children living in large residential facilities filed a law suit in federal court challenging that the constitutional rights of the residents were being violated. The lawsuit settlement (actually reflecting three legal actions including MARC v. Dukakis, Massachusetts Consent Decrees or Ricci vs.Greenblatt) changed the course of history for persons with disabilities. Funding has consistently been an issue and continues to this day. Two more recent legal actions, Boulet v. Cellucci and Rolland v. Cellucci directly address the need for more community residential supports. Since 1975, hundreds of community based programs have evolved through a large network of human service providers. These providers have received little in the way of increases over the past 16 years except through a salary reserve for their direct support staff and supervisors. They are some of the lowest paid workers in the Commonwealth. One of the only line items completely cut through 9-C was the salary reserve for direct care workers: 1599-6901, \$28,000,000.

Short Term Action: Reinstate the \$28,000,000 that was cut through 9-C cuts. 1599-6901.

Unmet needs

Though the Commonwealth has made incredible progress in providing care and supports for people with intellectual disabilities, parents are frantic when their child is Turning 22 and leaving special education. This also occurs when the primary caretaker is no longer able to provide care. Parents become desperate for a residential placement. This is not a new issue. In 2000, a legal settlement, Boulet vs. Cellucci, took place mandating that 2437 individuals, who were in need of residential placement, must be served. This initiative ended on June 30, 2006. However, new parents are knocking on our door every day looking for services.

What is difficult for an advocacy organization, is there is no system in place to determine who needs services and who does not. There is a climate of crisis that determines who gets served.

Action: Establishing a baseline is important in implementation and future planning of services. Only with empirical data may the Commonwealth anticipate the unmet need.

It is critical that planning begins to address the immediate needs of people with intellectual disabilities, and to build a case with public and elected officials that policies need to be adopted and funds appropriated before the number of unserved people reaches crisis proportions. This results in increased costs through reactive programming and/or litigation.

Medicaid Waiver

Massachusetts has received significant Medicaid dollars for people receiving comprehensive 24/7 services through the Department of Mental Retardation. Approximately 10,000 people receive these supports and the state receives \$440,000,000 annually in Medicaid reimbursement.

The Department of Mental Retardation is in the process of filing four additional Medicaid Waivers in addition to its existing 24 hour/ 7 day waiver (comprehensive) to maximize reimbursements:

- A Supports Waiver for Families who are caring for their child at home.
- A Supports Waiver for adults who need limited supports, less than fifteen hours a week, to live independently or who are living with family members and primarily use state plan services
- A Supports Waiver for adults who need less than 24/7 support to live independently or with a family member but more than fifteen hours per week.
- An autism waiver to provide intense behavioral supports for children from birth to 8 years

Action: The Arc of Massachusetts supports maximizing federal reimbursements but has a list of contingencies developed with several other stakeholder organizations to maximize the impact of the waiver. We have specific recommendations in this area which we have shared with the administration. Federal dollars can be leveraged to establish

- ***More self directed and integrated supports with community participation***
- ***Access to the unserved***
- ***Address deflation in the POS (purchase of services system) by utilizing the cost-increment factor existing in waivers***

Institutional Facilities

Though litigation has driven the system of services for persons with intellectual disabilities, there are still six institutions in the Commonwealth: Fernald, Wrentham, Monson, Hogan, Glavin and Templeton, serving a total of 1100 people.

Parents have fought bitterly for these facilities to stay open but The Arc of Mass believes that people should have the opportunity to live full lives in their own communities. Admissions to these facilities have been closed since 1975 so the people who live there now are quite elderly. A cultural lag phenomenon exists where a model of service delivery has outlived its time but people with multiple disabilities still live there. This is an exhausting issue for policy makers. Most importantly, institutions are used as a last resort even today. This supplants investing into necessary specialized supports in the community.

The line item for these facilities is \$172,013,458, Line Item 5930-1000.

Action: The Arc of Massachusetts encourages policy makers to continue closing large institutional facilities. Besides the costs of supporting an antiquated infrastructure, supporting a model of care that isolates innocent people due to a disability should not be continued.