

To: Don Berwick and David Marsh
From: Chris Palames
Re: Towards a progressive disability policy agenda

The following are key points around which a progressive disability policy statement/agenda can be built.

Disability is a universal human experience, crossing all categories of race, class, gender, age, sexual preference and socio-economic status. 15%-20% of the residents of the Commonwealth at any point in time have some form of physical, sensory, cognitive, developmental, neurological or psychological disability that limits major life activities.

But the real picture is not a snapshot frozen in time but viewed over the course of a lifetime is that disability is a universal experience, an experience that touches every individual and every family. It has been estimated that every man, woman and child will, in the course of a lifetime, experience a substantial impairment to one or more major life activity for an average of 7 years.

Don Berwick recognizes that there is a fundamental connection between the advancement of the civil rights of people with disabilities and his progressive vision for the reform of health-care.

As the next Governor of Massachusetts Don Berwick will lead the Commonwealth towards

- Achieving full integration of people with disabilities at all levels of community and society.
- Ending *discrimination* in housing, transportation, education and employment.
- Strengthening community-based services that support and empower people with disabilities and their families to live with independence and dignity in the homes and communities of their choice.

- Building the capacity of agencies and institutions of the Commonwealth to fully comply with the anti-discrimination, accessibility and effective communications obligations of Title II of the ADA.
- Strengthening the Commonwealth's Olmstead planning to:
 - Ensure that highest quality health care, mental health and social services are provided in fully integrated community settings.
 - Reform service delivery practices that force people with disabilities into separate and segregated settings *and that impoverish individuals and families as a condition of eligibility for services they need.*
 - Adopt the principle of "money follows the person" to guide policies that breakdown bureaucratic service system boundaries and segmented service delivery "silos".
 - Reform prior approval procedures in all state funded health care services to eliminate denials and excessive delays in the delivery of services, supplies and durable equipment consistent with established best standards of care.

To eliminate burdensome and repetitive documentation requirements on primary care physicians (catheters and urological supplies for persons with neurogenic bladder, wound care for treatment of decubitis ulcers, pressure relief mattresses, seat cushions, power wheelchairs with raiseable leg rests etc.).
- Inadequate allocation of time for primary care physicians to communicate with and effectively coordinate health care services.
- Loss of coordination by primary care physicians on entering acute settings when responsibility is transferred to "hospitalist" most of whom have no specialized disability knowledge.
- Failure to fulfill promise to disseminate model practices including outreach-in home services by nurse practitioners pioneered

by the Boston Medical Group under Bob Masters.

- Risks created by loss of personal care assistance services on entering acute care settings where nursing personnel do not have the experience and are not prepared to meet complex disability related needs.

Decisive action would be to convene a blue ribbon commission of advocates (representing diverse segments of the disability community), human service and health care expert-providers to evaluate the current status of health care and independent living support services for people with medically complex disabilities,

- Commission leadership would ideally include people with knowledge and experience from origins of Independent Living and Personal Care Assistance in the mid 70s to Dukakis's Mass Health in the late '80s to the present – (names that come to mind are Cathy Dunham, Paul Corcoran, Bob Masters, Charlie Carr (now Commissioner of Mass Rehab).
- Such a Commission would recommend policies directly to the Governor aimed at transparent systemic reforms committed to providing the highest quality health-care and independent living support services including primary and acute care, personal care assistance, durable medical equipment, wellness and preventative services.

To promote continued progress on ADA Title II compliance:

- Direct the Secretary of Administration and Finance to continue to direct and support state agencies and institutions of public higher education to make Massachusetts the national leader in ADA compliance planning and coordination, in employment of people with disabilities, in adopting cutting edge technology promoting effective communication, and in applying the best practices of Universal Design to the planning, construction and operation of state buildings and facilities.

Because Full participation of people with disabilities is essential to good

government and democratic process, *Massachusetts should be in the forefront in adapting digital technology and new media to* strengthen the Open Meeting Law . . . adopting new technology to democratize government operations and to make public hearings and decision making accessible to people with disabilities and to all the citizens of the Commonwealth.

<http://www.mass.gov/eohhs/consumer/disability-services/living-supports/community-first/>