

IMPLEMENTING A 21ST CENTURY DISABILITY POLICY



The mission of the Massachusetts Alliance for 21st Century Disability Policy (MA21) is to advance full community participation for individuals with intellectual and developmental disabilities.

Massachusetts Alliance for 21st Century Disability Policy (MA21)

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FOREWORD

This document was developed in 2008-2009 by the Massachusetts Alliance for 21st Century Disability Policy (MA21). It is intended for families and individuals — as well as elected officials and other policymakers — to help them conceptualize what a comprehensive disability policy can and should look like. MA21 is a partnership of some of the Commonwealth's leading statewide disability advocacy organizations: Massachusetts Families Organizing for Change (MFOFC), Massachusetts Advocates Standing Strong (MASS), Massachusetts Developmental Disabilities Council (MDDC), and The Arc of Massachusetts (The Arc), with additional contributions from Advocates for Autism of Massachusetts (AFAM) and the Massachusetts Down Syndrome Congress (MDSC). We hope and expect that other advocacy organizations and providers will embrace this document as well, creating consensus on a unified framework through which to view and improve public policy for individuals with intellectual and developmental disabilities and their families.



Photo by Tom Rettig, Worcester Telegram & Gazette

INTRODUCTION

“Disability is Natural” is more than just a saying. It is a guide to how we – people with disabilities and our families – would like to interact with the world and how we would like the world to interact with us. Though what we are asking is simple – to have the same opportunities as anyone else – we realize the sea-change this represents from our long and often troubled history in this country.

We are individuals, first and foremost, with our own individual cultures, tastes, emotions, wants, needs, and opinions. We deserve the same access to education, medical care, social activities, employment opportunities, and transportation options as anyone. While we may rely on our families and/or communities to help us, it is everyone’s primary responsibility when making decisions on our behalf to ascertain our personal wishes and abide by them. This is how anyone would expect to be treated.

We recognize the huge task before us. From the moment a disability is diagnosed, society treats us and our families differently. This is true not only of laypeople, but even of many of the best-trained professionals and those with experience treating and interacting with people with disabilities. People with disabilities have rarely been treated as equals, as highlighted by our exclusion from America’s historic civil rights struggle.

Despite this history, we acknowledge the great advances that have been made and are optimistic that the future can and will be brighter still. We repeat: Disability is Natural. We have no doubt society will one day appreciate this, but we intend to make it happen sooner rather than later.

GUIDING PRINCIPLES

1. Disability is Natural.
2. Our lives should be self-directed (with whatever supports are necessary), and our desires the predominant consideration.
3. We all need families – the most fundamental of natural supports – be it parent(s), sibling(s), or others to whom we are close.
4. We and our families are the most important stakeholders (though we recognize the crucial role played by all stakeholders).
5. Families should receive the supports we need so that our children can remain at home.
6. Supports should be designed to help us and our families recognize our true potential and achieve our potential.
7. Services should be designed to build and strengthen integrated — as opposed to segregated — lives, helping us and our families within the community, not outside of it.

SYSTEM BARRIERS

1. Investment: Providing essential services for us and our families requires significant investment. The individual and societal payoff outweighs the financial cost.
2. Bureaucracy: By definition, public supports are administered through a “system,” but that system does not have to be overly-bureaucratic or onerous. To the contrary, the system should be transparent, flexible, collaborative, supportive, innovative, and straightforward.
3. “They-ism”: In considering people with disabilities, society-at-large tends to apply an “Us vs. Them” framework. This construction opens the door to discrimination, as accommodating “them” becomes a burden. Through public education, society can come to recognize our valued roles and understand that there’s much more that connects us than separates us. Until then, discrimination and insensitivity will continue to be the rule rather than the exception, e.g. — doctors failing to give us enough time (resulting in inferior medical care), employers refusing to (or resenting having to) provide accommodations, and people — in the mass media and on the street — using “retard” like it’s a garden-variety insult.
4. “Us-ism”: We and our loved ones are not immune to societal discrimination; and in fact we often internalize these prejudices. We and our families must learn not to be ashamed of who we are and of our appearance, vocalizations, communication difficulties or behaviors.

POLICY FOUNDATIONS

A 21st Century disability policy incorporates the following:

1. Supports for ourselves involve ourselves. Individuals and families are involved in the planning, development, and implementation of supports.
2. Supports are as flexible as possible; an inflexible support is rarely a support at all.
3. Supports are individual/family-friendly in that they are understandable, easy to access, culturally-sensitive, multilingual if necessary, etc. This user-friendliness is reflected in all communications — be it presentations, meetings, or daily interactions.
4. The system is transparent; those receiving services have easy access to the amount allocated and actual costs.
5. Funding is personalized, not cookie-cutter. Allocations are flexible, and we have the ability to shop around for supports and/or providers.
6. There is substantial consultation with us and our families over changes in regulations and policies. This is a reflection of the fact that the system is there to serve us, not the other way around.
7. Supports and education are maximized, rules and regulations minimized.
8. The system promotes and supports innovation and creativity.
9. The system is free of “us-ism” and “they-ism,” both by working collaboratively with us and our families and by valuing our roles in society.

POLICY RECOMMENDATIONS

1. *Enhance supports for individuals and families through agencies and advocacy organizations.* Increase public and private investment in non-governmental agencies, which provide essential direct services. Increase investment in advocacy organizations which assist individuals, families, and groups through outreach and education.
2. *Properly fund and implement in-home, in-school and in-community supports for children.* Allow children to remain home with their families instead of being sent to schools or residential programs away from home. This creates a healthier society and saves public funding in the long-term.
3. *Establish a comprehensive policy that makes school inclusion central to the culture of public education.* Value all individuals, support all students and ensure that no person or group is marginalized or excluded. An inclusive education ensures that a child with disabilities remains on a path to an adult life as an engaged member of his/her community.
4. *Develop and support a comprehensive transition policy beginning promptly at age 14 (as required by law).* Include benchmarks and standards, track outcomes, and adhere to principles of self-directed lives (as described in this document). Students are considered valued members of the planning team, directing the process as much as possible, and family members are central to the process. The transition period is seamless and looks at the needs of the whole person — as prescribed by the federal Individuals with Disabilities Education Act (IDEA) — not just employment needs.

5. *Streamline the waiver system to eliminate unnecessary bureaucracy, demonstrate trust in families, and save money.* Bring the waiver system into line with our Policy Foundations, making it a flexible, family-friendly, transparent, personalized system that encourages innovation and collaboration among providers, individuals and their families, and ultimately saves the state money.

6. *Develop a comprehensive policy for monitoring, measuring, and safeguarding inclusion and self-direction, taking full advantage of community supports.* Use community supports to advance self-direction and inclusion throughout the lifecycle and in all aspects of life, including friendships, intimate relationships, employment, home life/independent living, transportation, etc. (Institutions and aversive therapy are antithetical to self-direction and inclusion.) Set goals for maximizing community participation/inclusion.

7. *Ensure that long-term supports are available throughout the lifecycle.* Assure that there is access to high-quality healthcare regardless of age or disability, recognizing that the medical system must be adequately funded to provide essential training and compensation. Never allow long-term supports to be compromised, with particular vigilance as we age or develop medical conditions when these supports are most at-risk. Plan in advance to provide substitute care when caregivers become incapacitated or die.

STRATEGIES

1. *Bring other groups into the fold, taking full advantage of the breadth and brawn of disability policy stakeholders.* Approach other stakeholders early on – such as disability-specific groups, disability providers, Department of Developmental Services, and other state agencies – to solicit their endorsement of this document, and garner their participation going forward. Begin the process of promoting recommendations.
2. *Build on existing outreach and educational programs with successful track records to train leaders.* Use models — such as the MDDC/MASS self-advocacy leadership series, MFOFC’s family leadership series, The Arc’s training series & educational conferences, and continuing education and parent group programs — to develop leaders among advocates, self-advocates, and public policymakers.
3. *Take full advantage of marketing/media strategies to tell success stories, demonstrate needs, and increase community supports and services.* Leverage Rolland Settlement and other institution-to-community placements as proof that even those with the most profound needs can have real-life choices and — with sufficient funding — can thrive in the community.
4. *Ensure that schools have necessary tools to fully and effectively practice inclusion and transition planning.* Help schools understand

the need — when implementing inclusion and transition policies — for accountability and consistency, and help them understand that requiring individuals/families to *demand* inclusion is antithetical to the principle. Provide logistical support to schools around how to track outcomes and how to take full advantage of outside expertise and local family organizing efforts. Good transition planning may require the use of a standardized evaluation instrument (similar to the Massachusetts Comprehensive Assessment System exam) and/or teacher certification to ensure that students are getting appropriate transition services.

5. *Develop short-term priorities, in consultation with advocacy groups and provider organizations, that reflect 21st Century goals.* Target legislative and administrative changes in addition to funding objectives that are consistent with the policies put forth in this document.



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Massachusetts Advocates
Standing Strong



*English and Spanish language versions of this paper are available online at www.arcmass.org
and some other MA21 member websites*