RESPONSE

Maryland Civil Rights Coalition for People with Disabilities

to the

FINAL REPORT
of
The Community Access Steering Committee
Presented to
Governor Parris N. Glendenning

September 21, 2001

Maryland Civil Rights Coalition for People with Disabilities

The Arc of Maryland
Maryland Disabilities Forum
The Brain Injury Association of Maryland
Independence Now
The League for People with Disabilities
Maryland Statewide Independent Living Council
MCIL Resources for Independent Living
Maryland ADAPT
Maryland Association of Community Services for
People with Developmental Disabilities
Maryland Association of Psychiatric Support Services
Maryland Developmental Disabilities Council
Maryland Disability Law Center
Mental Health Association of Maryland
On Our Own of Maryland
People on the Go
Public Justice Center
Revisions, Inc.

On July 25, 2000, Governor Glendening issued Executive Order 01.01.2000.15[1] creating the Community Access Steering Committee (CASC), charged with responsibility to "develop a comprehensive plan to expand community access opportunities for a broad spectrum of individuals with disabilities." Issued on the tenth anniversary of the landmark civil rights legislation, the Americans with Disabilities Act (ADA), the Executive Order raised the hopes of thousands of Marylanders with disabilities held in state institutions and private nursing homes that freedom was on the horizon. Unfortunately, the final draft of the CASC effectively dashed those hopes.

In June 1999, the United States Supreme Court ruled in *L.C. v. Olmstead* that inappropriate segregation and institutionalization of people with disabilities was illegal discrimination under the ADA. The Court also noted that states may develop "comprehensive, effectively working plans" to defend themselves against charges of discrimination. Under such plans, states *may* set up waiting lists to move people to more integrated settings (*i.e.*, community placements) rather than move all people illegally held in institutions immediately, but these waiting lists must move "at a reasonable pace."

In Maryland, there are over 4,000 people with disabilities *under the age of 65* stuck in nursing homes, over 500 people with mental retardation held in state residential centers, and hundreds of people held unnecessarily in state psychiatric hospitals. Under the *L.C. v. Olmstead* decision, these individuals are the victims of state-sponsored discrimination. Yet despite direction from the U.S. Supreme Court, guidance and technical assistance from the federal government, and a mandate from the Governor, the CASC failed to produce anything resembling a "comprehensive plan." The Executive Order, the final report of the CASC issued on July 13, 2001, fails to answer the basic questions: Who is coming out? How many? When?

The CASC authors characterize the final report as identifying "effective practices and other strategies that will allow individuals with disabilities additional choices for living in the community." Despite repeated assertions made to the legislature, to the federal government, and to the Governor that the work of the CASC would result in some version of a comprehensive plan, even the CASC admits that this document does not meet that goal. There are no timelines for bringing the State into compliance with federal law, no proposals for reallocation of resources to reverse the State's history of institutional bias, nor even a commitment to actually spend the resources allocated by the Governor and the legislature for the current fiscal year. There are simply "strategies." This is not enough. The report does not move a single person nearer to freedom than they were prior to July 25, 2000, when the Governor issued his Executive Order.

In a pointed dissent, the four community members of the CASC – three people with disabilities and a parent of a person with a disability -- noted that the report "fails to set goals and timelines to bring freedom to the thousands of Marylanders with disabilities held in state and private institutions against their will." (See attached letter to the Governor from the four

[1] The Executive Order was reissued on September 25, 2000 as Executive Order 01.01.2000.17 with minor changes.

community representatives.) This "minority" of four participants in fact represented the majority of Marylanders with disabilities, whose voices would not otherwise have been heard. Because the very articulate views of these four members did not carry the day, because the interests of the majority were not heard, the Maryland Civil Rights Coalition for Civil Rights for People with Disabilities is compelled to issue the following response.

Notes on the Coalition's Response

Members of the Maryland Civil Rights Coalition for People with Disabilities participated in the Community Access Steering Committee and served on each of the four workgroups organized under the Executive Order. Many individuals with disabilities did the work of the CASC as unpaid volunteers. Although outnumbered on every Committee and workgroup by State officials and employees, Coalition members advocated consistently for development of a meaningful, effective, and comprehensive plan. (See attached "Olmstead Workgroups Principles" document developed by the Civil Rights Coalition in October 2000.)

Although we are advocates, consumers, and family members, we are not State officials, and we do not have access to the resources and information available to the State. The Civil Rights Coalition cannot create the comprehensive plan proposed by the U.S. Supreme Court on our own. Instead, this document highlights the opportunities for change squandered by the CASC process and report, and makes recommendations for basic policy and programmatic changes that must be included in any comprehensive plan in Maryland. Most importantly, this document recognizes that the continuing denial of basic civil rights to thousands of Marylanders is a matter of the highest priority for this state, and in many cases a question of life and death for our community. This is not a perspective shared by the authors of the CASC report.

It is not our preference to separate people with disabilities into separate and distinct categories, and we are committed to addressing public policy issues from a cross-disability perspective. However, in addressing specific policy goals and objectives, and to effectively critique the CASC report, it was necessary to segregate some of our recommendations by disability. Yet, as this document demonstrates, that approach is inevitably short-sighted and incomplete. For this reason, we have also included an Executive Summary with general policy recommendations applicable to people with different disabilities, a section on housing, and a section on individuals with Traumatic Brain Injury, a community that does not seem to fit within any of the State-defined disability groups.

Executive Summary

The movement of people with disabilities from confinement in institutions to freedom in the community will require a concerted effort by State officials, in real collaboration with people with disabilities and advocates. This document contains numerous recommendations about how to achieve this important goal, but they can be summarized into six general points:

- **Closure of State Institutions:** Maryland cannot afford the maintenance of two systems of service delivery for people with disabilities: institutional care and community-based services. The State continues to fund enormously expensive institutions to hold decreasing numbers of people with disabilities: fewer than three percent of people with developmental disabilities live in state residential centers, and fewer than two percent of people served by the public mental health system enter a state psychiatric hospital annually. Yet these facilities drain funds from the resource-starved community-based services system that most people with disabilities utilize, and prefer. These state institutions exist in their current forms only because State officials are unwilling to accept the political risks of downsizing and closing them.

- **Bring in More Federal Dollars to Support Community Living:** There are numerous instances where additional federal funds (primarily Medicaid) could be brought into Maryland, yet they are not sought. Since the *Olmstead* decision in 1999, federal officials have provided technical support to the states on how to use expanded Medicaid funds to support community integration, yet Maryland has been slow to accept these opportunities. Even more critically, despite significant guidance from the federal government to support community-based services, Maryland continues to pour Medicaid funds into private nursing facilities, where the majority of people with disabilities are unnecessarily institutionalized.

- **Expand Community Capacity:** For over ten years, advocates and state officials have recognized the need to expand the community-based workforce to provide direct care services for people with disabilities, and the need for mechanisms to ensure quality in community programs. Today, the CASC report raises these issues as the primary impediments to community integration, but it provides virtually no guidance about how to secure a stable, well-paid and well-trained, community-based labor force.

- **Support Consumer-Directed Outreach and Support for People in Institutions:** Although there are state-sponsored programs to support self-advocacy for people with developmental disabilities and psychiatric disabilities, these programs are limited. There are no state-funded programs for outreach in nursing homes. The State must fund expanded outreach and support programs that enable people with disabilities to reach out to their peers stuck in institutions and to support them as they navigate the discharge process.

- **Raise the Income Limit for Eligibility for Medicaid to 100 Percent of the Federal Poverty Level:** The current monthly income ceiling for Medicaid eligibility is only $350 (only 49 percent of the federal poverty level), leaving many impoverished recipients of Social Security Disability Insurance ineligible for essential services unless they enter a nursing facility or qualify for a Medicaid waiver slot. Even if important changes are made to reform the Medicaid system, thousands of people with disabilities with below-poverty level incomes will be denied access to Medicaid services through overly restrictive eligibility rules.

- **Implement the Medicaid Buy-In:** Those individuals with a disability who are so severely impoverished as to be Medicaid- eligible are actually deterred from seeking employment for fear of losing those benefits. Implementation of the Medicaid Buy-In will remove this disincentive, enabling Medicaid recipients to pay a premium to maintain their Medicaid coverage after they have entered the job market.

People with Physical Disabilities

There are over 4,000 people under the age of 65 living in nursing facilities across Maryland, and Medicaid provides payment for services for over 2,600 of them. This is the largest group of people with disabilities living in institutional settings in the state, and the group for whom the CASC report does the very least. DHMH provided little or no information about people living in nursing facilities to either the CASC or to the workgroups, beyond very basic demographic information. Prior to the CASC process, it appears that the State had barely recognized the obligation to integrate the nursing facility population into the community, despite the fact that this is by far the largest number of individuals in the state affected by the *L.C. v. Olmstead* decision.

Even worse, Maryland officials appear to be committed to continuing to warehouse people with disabilities in private nursing homes for the indefinite future, committed to its own institutional bias. At a cost up to of $70,000 annually to support someone in a nursing facility in Maryland, and with costs accelerating every year, the beneficiaries of this system are operators of nursing facilities, not people with disabilities. In FY 2001, *the State approved a $20 million wage increase for nursing home staff, in addition to significant rate increases for nursing facility owners in FY 2001.* At the same time, Maryland Medicaid continued to limit community-based care options, with most Medicaid recipients in the community limited to $20 per day to cover personal care expenses.

During the 2001 legislative session, individuals and organizations associated with the Civil Rights Coalition and behind the leadership of Delegate James Hubbard, advocated for passage of House Bill HB 702, "Maryland Community Attendants and Supports Act." The legislation was based on a simple proposition: people eligible for Medicaid services in a nursing facility should be able to use the same funds that keep them in a nursing home to obtain services in the community. Most people in nursing facilities can receive services in the community for the same amount – or much less – than the cost of keeping them locked in a nursing facility. Unlike the funding issues associated with people stuck in state residential centers (for people with developmental disabilities) or state psychiatric hospitals, the State does not operate the overwhelming majority of nursing homes in Maryland, making the transition to community services a far simpler process.

In the wake of HB702, the State has appropriated funds for 500 Medicaid waiver slots with which to provide opportunities for nursing facility residents 21 to 59 years of age to live in the community. As of the end of August 2001, not a single person had been served under the waiver and moved out of a nursing facility; one person moved out as of early September. Moreover, the State is not actually using the waivers to stop discrimination or reverse the institutional bias. The CASC report cites four waivers as tools currently used to move individuals from unnecessary institutionalization to the community. The report claims that the "Older Adults" waiver (for individuals 50 and above) is funded it to serve 2,135 individuals in fiscal year 2002. As of September 2001, 630 individuals are enrolled in the waiver program, but the State has no idea how many of these individuals are former nursing facility residents. The state has so far refused to use the waivers as a strategy to achieve community integration.

The reasons for the failure of the State to seize these opportunities are numerous, among them the erection of unnecessary bureaucratic barriers to prevent successful use of the waivers. It is clear that nursing facility administrators would prefer that these waiver slots remain unfilled, but the State's inability to drop its bureaucratic, pro-institutional bias is even more troubling.

Yet even in the absence of bureaucratic barriers, a significant level of outreach and consumer education will be necessary to make the waiver programs successful. Residents of nursing facilities are generally unaware of their options to live in the community. Most came to live in the facilities out of desperation, when it became impossible for them to live in the community due to the unavailability of adequate personal care services. It will be necessary to undertake broad-based outreach to inform nursing facility residents of their options, then to work with them to determine the services they will need to live in the community.

Immediate First Steps

- **During this fiscal year, DHR and DHMH must facilitate the movement of 500 individuals currently living in nursing facilities to the community**, as funded in the Governor's FY 2002 budget for the Personal Assistance waiver. During the first five months of the waiver period, *not a single individual was served under it.* DHR must streamline the process of enrolling service providers, remove artificial caps on services, and eliminate the bureaucratic barriers that keep people in nursing facilities.

- **Streamline the process for participation in the Older Adults waiver**, which is similarly beset by bureaucratic barriers, lack of effective outreach, and an inability to spend funds appropriated for this purpose.

- **Immediately identify nursing facility residents who are ready for discharge.** DHMH is required to submit to the federal government on a quarterly basis "Minimum Data Sets,"[2] listing potential candidates for discharge from nursing facilities. If DHMH is unable to produce any names, an independent assessment process must be implemented immediately to develop this information.

- By January 1, 2002, DHMH is required (under HB702) to report to the General Assembly on its identification efforts, and its plan to integrate nursing facility residents to the community. To assist in identifying people who may be interested in living in the community, and to offer peer support to people trying to get out, **the State must immediately create an outreach program to identify nursing facility residents who may be interested in living in the community.** The State must contract with community-based consumer organizations composed of people with physical disabilities, developmental disabilities, and psychiatric disabilities to make contact with residents and to provide peer support.

[2] **Minimum Data Set (MDS)** - A Federally mandated resident assessment instrument used to assess nursing home residents' clinical condition including physical, mental, emotional, cognitive and functional limitations and strengths. The MDS must be administered to all residents in Medicare or Medicaid certified facilities at time of admission, every 90 days (quarterly), annually, and when a significant change in a resident's condition occurs

- After convening the consumer panel (as required under HB702) that will review the attendant care provider regulations, the State must use the consumer panel's input to **simplify its application process so as to enable consumers to hire relatives and friends to provide personal assistance services** if requested.

- By executive action, **adopt the Medicaid Buy-in option under the federal Ticket to Work legislation** to encourage people with disabilities to return to the workforce, without fear of losing Medicaid benefits.

Longer Term Efforts

- **Completely overhaul the Maryland Medical Assistance Personal Care (MAPC) option.** Limitations in the structure of this program limit services and force people into nursing facilities. During 1999, advocates worked closely with State officials to overhaul that program, but their recommendations never appeared in the final *Return to the Community* report (1999). The State must utilize a consumer-directed and -authorized review panel to revisit those recommendations and determine other necessary changes to the MAPC program that will be most effective in providing community-based care and prevent institutionalization.

- **Expand and simplify the Attendant Care and Older Adults waivers** to move larger numbers of nursing facility residents into the community.

- **Modify the Medicaid State Plan to adopt the targeted case management option** for all those identified as interested in leaving a nursing facility. This will enable case managers to spend up to six months to secure housing, attendant care, and other services with a *federal match* prior to the consumer's return to the community.

- **Raise the income limit for eligibility for Medicaid to 100 percent of the federal poverty level.** The current limit is $350 (only 49 percent of the federal poverty level), leaving many impoverished recipients of Social Security Disability Insurance ineligible for personal assistance and other essential services unless they enter a nursing facility or qualify for a Medicaid waiver slot.

- **Aggressively address the shortage of community-attendant care services staff** by facilitating the creation of stable, well-paying professional jobs in the community.

People with Developmental Disabilities

The Developmental Disabilities Administration (DDA) has rightfully adopted a strong position that all persons with developmental disabilities, regardless of the nature or severity of their disability, can be appropriately served in the community, with quality supports. However, the CASC Report takes only modest steps toward implementing this position and making it the basis for its policies and procedures. Nearly 500 individuals currently reside in state residential centers - many have been waiting years for budgets and services to come together to enable them to live in the most integrated setting appropriate to their needs.

The CASC process was intended to *accelerate* the pace of movement of people out of the four remaining state residential centers (SRCs) and into appropriate community placements. However, there is no increase in the rate of placements proposed in the 1999 *Movement to the Community* report (prepared by the Governor's Office for Individuals with a Disability). Even more disturbingly, despite appropriated funding in FY 2001 to place 56 individuals in community programs, DDA placed fewer than 50 people in 2001.

Currently, more than 97 percent of Marylanders with developmental disabilities live in the community. However, in FY 2002, the State will spend nearly $68 million to serve 471 people living in SRCs, over $130,000 per person per year. It costs more than twice as much to provide services in an institution as it does to support someone in the community; it is 2.6 times as expensive to keep someone at Rosewood State Hospital (the largest SRC) as it is to provide services in the community. The *per diem* costs at each the four SRCs are particularly illuminating:

SRC	Daily Cost	Annual Cost	Number of Residents
Brandenburg	$296/person	$107,869	39
Holly	$348/person	$126,910	130
Potomac	$324/person	$118,298	80
Rosewood	$462/person	$168,784	222

Given the State's position that everyone in SRCs can live in the community, as well as the Department's huge Medicaid deficits, spending on SRCs is a scandalous waste of taxpayer funds. The CASC report does not calculate the enormous savings that would result from any significant downsizing and closure of SRCs, nor does it call for immediate cessation of capital expenditures at SRCs (other than for health and safety reasons), permitting the state to continue throwing money into this very expensive and unnecessary institutional system. Although conditions have improved in SRCs, they do not provide a quality of life similar to that which is available in the community.

The CASC Report justifies its very limited approach to community integration and compliance with *L.C. v. Olmstead* by citing some significant issues facing community programs,

including the difficulties in recruiting staff to accept extremely low wages offered in the community. These problems have existed for years, and have been identified and documented extensively in previous reports, yet the State has yet to seriously confront them. The existence of these problems does not justify further denial of basic civil rights, but instead requires an aggressive strategy to resolve them, and concrete steps to achieve full community integration. As proven by the closure of the Great Oaks Center in 1996 – the last SRC the State closed after shutting down four SRCs from 1989 through 1996 -- the State has the technical resources to achieve the goal of community integration, but the absence of substantive recommendations in the CASC report indicates it does not have the political will to do so. Many states have no institutions for people with developmental disabilities; Maryland should move quickly toward this goal.

Immediate First Steps

- **Accelerate the funding and implementation of increases to the wages of direct support staff in community programs** to ensure quality programs and enable community provider agencies to recruit and retain the caliber of staff required to support individuals transitioning from state residential centers.

- In FY 2002**, transition 65 persons with developmental disabilities from state residential centers** to quality, appropriate community supports.

- In FY 2002, retain a consultant **to conduct a cost analysis of the actual costs to transition 400 additional persons to community programs over three years**, including any net savings generated from cottage closures at state residential centers.

- In FY 2002, retain expert(s) to **examine Maryland's developmental disabilities Medicaid waiver for home and community-based services** and recommend any additional resources to maximize federal revenue, to aid in furthering consumer-driven supports and self-determination, and to streamline funding procedures for quicker access of funds to start up new services and supports.

- **Cease all capital expenditures at SRCs**, except to protect the health and safety of residents.

- **Support self advocacy projects and focus on assisting persons currently living in SRCs to express their needs and preferences.** Many people with mental retardation and developmental disabilities have not had the opportunity to learn the skills or have the daily experiences that will enable them to take more control and make choices in their lives. Instead, they are often overprotected and segregated, and not included in making decisions that have an impact on their lives and have limited opportunities to make choices as well as limited options from which to choose. Once individuals have indicated a preference to live in the community, peer support must be available to help navigate them through the discharge process.

Longer Term Efforts

- **Fund the DDA base budget at a level that continues to address the needs of individuals in the community waiting for services.** The Governor's Waiting List Initiative has demonstrated the success of providing services in a non-emergency context with generally lower service costs and greater consumer satisfaction.

- **Provide funding, training and technical assistance to enable conversion of sheltered workshops** to the provision of supports that help people with developmental disabilities to contribute to their communities and engage in meaningful work in the community.

- There must be **renewed focus in the state special education system and in local school systems to improve access to inclusive educational settings**. Maryland has the *fourth worst ranking* out of the 50 states in the rate of segregation of students with disabilities into separate schools. Particularly high is the segregation of students with mental retardation into separate classes and separate schools. Unfortunately, early segregation into separate settings in school leads to continued segregation as students move through the education system and beyond. Maryland's children should not be taught by our State government that segregation is acceptable, and that in their own lives it is expected. The most effective way to ensure community integration for adults is to provide inclusive educational settings to children.

- **Include children with disabilities placed in private institutions, such as Mt. Washington, in *Olmstead* planning efforts**. All children with disabilities placed in private institutions should be supported in home and community-based supports, such as family or specialized foster settings, with appropriate wrap-around supports.

- **The OCYF "Return/Diversion" program and MSDE Autism Waiver must ensure their policy and funding cohesion with assisting children with significant disabilities to remain out of institutions** as well as out of state residential schools and receive services in the most integrated setting appropriate to each child's needs.

People with Psychiatric Disabilities

Public policy issues affecting people with psychiatric disabilities in Maryland have been the topics of almost innumerable workgroups, task forces, and special committees over the last twenty years. In 1999, the Mental Hygiene Administration released the *Statewide Needs Assessment for Mental Health Services and Mental Hygiene Administration's Five-Year Plan for Downsizing and Consolidating of State Psychiatric Hospitals.* This report, finalized in July 1999, made concrete recommendations regarding essential services and numbers of individuals who could be released from institutional settings at appropriate funding levels. Two years later, this same report – whose recommendations had not been implemented -- became the basis for the mental health services section of the CASC report.

Despite all of the studies and analyses, Maryland still maintains eleven psychiatric hospitals, including the three RICAs (Regional Institutes for Children and Adolescents), with a capacity of 1,310 and serving 3,756 individuals annually, a hughly disproportionate number of psychiatric hospitals for a state of this size. As the CASC report notes, out of an overall FY 2001 appropriation of $637.5 million, MHA spent $235.9 million on state-operated institutions, *almost all of which is state dollars.* This amount represents 38 percent of the overall MHA budget to serve fewer than five percent of the individuals served by the public mental health system.

	State Funds (%)	Number of People Served	Per capita Cost
State Hospitals	$235.9 million (38%)	3,756	$62,806
Community Programs	$396.2 million[3] (62%)	74,184	$ 5,340

These numbers actually understate the costs of state psychiatric hospitals; on an annualized basis, *costs per bed exceed $180,000 per person*, covered almost exclusively by state funds.

As a result of the overwhelming costs of maintaining this array of state psychiatric hospitals, MHA has struggled with enormous budget deficits over the last several years. In response, rather than move to consolidate services at state hospitals or close them, MHA has cut spending on community services. For over a year, MHA has refused to permit the opening of additional community-based residences for individuals leaving state hospitals, citing fiscal pressures. Yet the MHA plans to spend millions to renovate the aging and deteriorating physical plant at some of the oldest state hospitals.

MHA's failure to close some psychiatric hospitals and end the institutional bias in its programs has contributed significantly to its financial deficit, and has harmed thousands of people with mental illness. Two years after the release of its 1999 Five-Year Downsizing Plan, MHA has yet to begin implementation of its recommendations. Now in 2001, MHA has re-released the same report, with a similar lack of enthusiasm for its recommendations.

[3] This amount includes over $155 million in federal funds.

Immediate First Steps

- **Reduce the population in the state hospitals by 100 people during FY 2002**, simultaneously reconfiguring the hospitals so that whole units can be closed once a sufficient number of people are integrated into the community. Savings must be immediately transferred to community services, with an emphasis on developing additional community-based services.

- Retain a consultant to **conduct a cost analysis of the actual costs to transition 300 additional persons to community programs over four years**, including any net savings generated from closure of one or more state hospital. *All capital expenditures at state psychiatric hospitals must be frozen until the completion of this report.*

- **Hold local Core Services Agencies (CSAs) to strict timelines to discharge individuals from hospitals to their communities** when discharge is recommended.

- As state hospital beds are closed, **develop a personnel staffing plan to provide viable opportunities for state hospital employee**s to transfer their skills to the community.

- **Lift the freeze on residential rehabilitation and crisis residential programs**, which effectively prevents the movement of individuals with mental illness from state psychiatric hospitals to community-based residential treatment.

- **Immediately inform Medicaid beneficiaries, health care professionals, educators, juvenile justice personnel, and child welfare workers about the full range of EPSDT (Medicaid) entitlements** to rehabilitative treatment, including one-on-one in-home behavioral aides and other intensive, community-based mental health services ("wraparound services") for children that will help prevent placement in residential treatment centers (RTC).

- **Prevent any child from being "stuck" in a RTC** by offering an individually-tailored placement when RTC placement is inappropriate to meet a child's needs. Children in these out-of-home placements must have a targeted case manager who can help secure public benefits, meaningfully include the child's parents in all decisions, inform health care providers about EPSDT treatment entitlements, and facilitating cooperation with any other public or private agencies involved.

- Retain expert(s) to **examine Maryland's utilization of Medicaid dollars in the public mental health system** and the possibility for expansion of these dollars.

- **Develop a shared fund of MHA, DDA, DHR and other identified agencies to serve individuals who have multiple disabilities**. Each of these agencies must make a similar contribution to this shared fund and representatives from each agency will determine the

spending of these dollars. This collaborative workgroup would identify needs of children and adolescents with multiple disabilities as well as adults.

- **Create opportunities for outreach efforts in state psychiatric hospitals**, working with consumer advocates and family groups to inform residents about community options and services, and to provide ongoing consumer support to support them in expressing their needs and preferences. Many residents of state hospitals have not had the opportunity to learn the skills or have the daily experiences that will enable them to take more control and make choices in their lives.

- By executive action, **adopt the Medicaid Buy-in option under the federal Ticket to Work legislation** to encourage people with psychiatric disabilities to return to the workforce, without fear of losing Medicaid benefits.

- In collaboration with the advocacy community, the legislature, the State Insurance Commissioner, and the Governor, MHA must **address the transfer of costs from private insurance to the public mental health system.**

Longer Term Efforts

- By 2003, **set – and meet -- specific goals for moving individuals to the community for at least the next five years**, ensuring that the annual targets are met. These goals should be consistent with the recommendations of the 1999 workgroup and must be part of MHA's *Olmstead* plan.

- Present a plan to the legislature/governor regarding **consolidation of the administration of the state hospitals and residential treatment centers** (RTCs). At least one unit in each major state hospital should be closed, and plans for closure of one or more state hospitals over the next two years should be finalized.

- By 2004, **develop and implement a comprehensive plan for statewide crisis services** – including diversion services.

- By 2004, **establish transitional, step-down services in the community for youth** to decrease lengths of stay in the RICAs, including in-home supports, after-school programs, cases management, and respite care.

- In collaboration with ADAA, **develop crisis access to substance abuse services for individuals with co-occurring disorders** as well as substance abuse disorders alone to reduce placement of these individuals in general and state hospitals inappropriately. These crisis services would be co-funded by MHA and ADAA. Such crisis access must be in place by 2004 throughout the state.

- By 2004, develop specialized services for older citizens with serious somatic problems as well as psychiatric illnesses, enabling them to move from nursing homes and psychiatric facilities.

Persons with Traumatic Brain Injury

The CASC report failed to address the special needs of persons with traumatic brain injury (TBI), despite strong interest in these issues among participants in at least two of the CASC workgroups. Further, the issue of inappropriate institutionalization of people with TBI in state psychiatric hospitals is the subject of the still-pending *Williams v. Benjamin* lawsuit filed in 1996 by the Maryland Disability Law Center (and vehemently opposed by the State). The Governor has refused to include any budgetary allocations specifically earmarked for TBI and has failed to actively support efforts to pass legislation creating a dedicated fund for community-based TBI services. The failure to address the needs of people with TBI in the final CASC report simply continues the State's neglect of this growing and grossly underserved group.

One of the challenges facing persons with Traumatic Brain Injury (TBI) is the dichotomy of funding mechanisms based on the age of the individual when the injury took place. Persons injured at age 21 or younger may be able to receive ongoing services through DDA (although many continue to be shut off from these services). If the injury occurred when the individual was over 21, there is virtually no funding mechanism to provide community-based services for them. Although private insurance often covers the cost of acute care (such as emergency room and short-term therapy), there are few options for persons needing long-term, community-based supports. Those injured after age 21 have extremely limited access to needed services, often relying on family members for needed care or winding up in nursing homes or state-run psychiatric facilities.

There are approximately 50 people with TBI warehoused in state psychiatric facilities, a group that includes persons who were injured before and after age 21. Many have been awaiting community placement for several years, and endure continuing harm as their conditions deteriorate due to lack of appropriate therapy. They are being held in these inappropriate and harmful environments at a cost of over $170,000 annually per person, with minimal Medicaid reimbursement. Additionally, according to data provided by State officials, there are 204 persons with TBI under the age of 64 in nursing homes and 121 in rehabilitation hospitals.

Like persons with developmental or psychiatric disabilities, persons with TBI need access to a broad range of community supports, including housing, case management, crisis intervention, transportation, and vocational services. However, unlike persons with other disabilities, there is no specific funding allocated to provide community services for people with TBI. Rather than continue to support only institutional care for persons with TBI, the State must support community-based alternatives.

Immediate First Steps

- **Expand the use of the current DDA Home and Community-Based Services (HCBS) waiver to serve more people with TBI**. Recognizing that persons with TBI, particularly those injured after age 22, are often last on the priority list or totally ignored for HCBS, the Health Care Finance Administration (now the Center for Medicare and Medicaid Services) stated in a memo to State Medicaid Directors that "States have historically provided habilitation services under an HCBS waiver to individuals with mental retardation or related conditions which occurred before age 22. However, neither the law nor implementing regulations restrict who may receive habilitation services in an HCBS waiver. *Other individuals who do not have mental retardation or related conditions, such as persons with traumatic brain injury or other physical disabilities that occurred after age 22, may also benefit from habilitation services under the waiver*." (July 25, 2000) (Emphasis added).

  Even if the DDA HCBS waiver were open only to those individuals with TBI injured before age 22, it could be very helpful in addressing the needs of persons stuck in institutions or receiving inadequate care in the community.

Longer Term Efforts

- **Develop a HCBS waiver specifically for persons with TBI**. Although Maryland's existing HCBS waivers for persons with developmental disabilities and the elderly can serve individuals with TBI, many persons with TBI are left out because they do not meet the eligibility requirements of the waiver. In addition, the current waivers already face an overwhelming demand from persons for whom they were designed. By developing a waiver specific to persons with TBI, the design of the supports and services can reflect the particular needs of individuals with this disability. MHA has been working on a TBI waiver for over three years that will serve only 10 people. The waiver must be expanded to serve more people and should be completed and implemented by the beginning of next fiscal year (FY 03).

- **Enact legislation creating a TBI trust fund.** Maryland, like most states, is concerned about the cost of providing services to persons with disabilities. One way to spread the burden is to create a surcharge on moving vehicle violations that would fund community-based services for persons with TBI. Recognizing that car accidents are by far the leading cause of TBI, twelve states have created such a trust fund. Legislation will be introduced before the Maryland General Assembly in the 2002 session to follow suit. The Governor and the Department of Budget Management should strongly support this initiative.

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HOUSING

Affordable, accessible, integrated housing in the community is a critical resource for people who want to leave institutions and nursing facilities. Without an affordable place to live, even people with a full complement of support services available to them will be unable to move to the least restrictive setting in the community. This is a key issue that cuts across all disabilities.

As documented in *Priced Out in 2000,*[4] people with disabilities are the poorest people in the nation, and the income disparity between people with disabilities receiving Supplemental Security Income (SSI) benefits and a typical non-disabled individual's income is growing rapidly. This national analysis found that in 2000, people with disabilities receiving SSI benefits could not afford to rent a modest efficiency or one-bedroom unit *anywhere*. In Maryland, this situation is even worse; the income of a person with a disability receiving SSI was equivalent to 13.1 percent of the average income of a single, non-disabled person. It is virtually impossible for someone receiving SSI benefits to afford housing without some sort of public subsidy.

The State must develop a clear strategic plan to increase affordable, integrated, and accessible housing in all geographic areas in the state. At the same time, however, state and local officials must maximize the use of existing opportunities to expand housing while also piloting new and promising ideas. This issue is not unique to Maryland, and State agencies should look for successful housing models both across Maryland and in other states.

Finally, it is also important to recognize housing as a basic need, separate from the need for medical care or community-based services. For example, unsuccessful participation in a community service program should never be the basis for eviction from community housing, nor should participation in any kind of treatment program be a requirement for housing. While expanding the availability of affordable housing for people with disabilities, it is also necessary to maximize consumer choice and independence in selecting housing options.

Immediate First Steps

- **Develop a program to provide interim rental assistance to eligible individuals with disabilities**. Recipients of these "Transition Subsidies" would be required to apply for federal Section 8 vouchers and then trade in their state subsidy when they received a federal voucher. The state subsidy would then be available to another eligible individual with a disability.

[4] Produced by the Technical Assistance Collaborative, Inc. (Boston) and the Consortium for Citizens with Disabilities Housing Task Force (Washington, D.C.), 2001.

- The State Department of Housing and Community Development (DHCD), the Department of Health and Mental Hygiene (DHMH), and the Governor's Office on Individuals with a Disability must **establish a statewide "Housing and Disability Steering Committee."** The Committee must review the findings and recommendations being developed by the Technology Assistance Collaborative for DHMH, develop an action plan, and oversee implementation of that plan. Membership must include representatives from the highest levels of the Governor's Office for Individuals with Disabilities, DHMH, and the Department of Housing and Community Development (DHCD); people with disabilities; family members; affordable housing experts and developers; disability advocates; and others whose contributions could lead to solutions. The Committee should report annually to the Governor and the legislature.

- DHCD and DHMH should **develop a demonstration project using a portion of the State's Group Home Financing Program to assist non-profit affordable housing developers to build, acquire, and/or rehabilitate housing** that is then rented to people with disabilities, who choose where and with whom they live.

- **Provide incentives to non-profit housing developers to develop affordable, integrated, and accessible scattered site housing that they specifically rent to people with disabilities**. Following the demonstration phase, expand and replicate activities that prove most successful.

Longer Term Efforts

- DHCD must **fund the development and management of a regularly updated statewide central registry of accessible housing**. The Governor's FY2003 budget should include new funding to cover this project.

- In jurisdictions in which DHCD functions as the Public Housing Authority, **DHCD should establish local preferences for Section 8 vouchers for people with disabilities and maintain a waiting list**. DHCD should apply for HUD Section 8 Mainstream Vouchers based on the number of people waiting.

- Given that much work must occur on the local level, **fund training and technical assistance to local consumer and advocacy organizations that equip them to work with local Public Housing Authorities** to increase community housing opportunities for people with disabilities. The Governor's FY2003 budget should include an adequate allocation for this new project in OID's budget.

- **DHCD's Homeownership for People with Disabilities mortgage program should be made a permanent program** until private market programs use the same criteria to reach the same targeted population.

- The State should **support and enforce the Fair Housing Act**.