UNITED STATES DISTRICT COURT
FOR THE EASTERN DISTRICT OF VIRGINIA
Richmond Division

UNITED STATES OF AMERICA,	)	
	)	
Plaintiff,	)	
	)	
v.	)	Civil Action No. 3:12-CV-00059 JAG
	)	
COMMONWEALTH OF VIRGINIA,	)	
	)	
Defendant.	)	
	)	

BRIEF AMICI CURIAE ON BEHALF OF THE NATIONAL ASSOCIATION OF STATE DIRECTORS OF DEVELOPMENTAL DISABILITY SERVICES, THE AMERICAN ASSOCIATION OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, THE ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES, TASH AND ROBERT M. GETTINGS IN SUPPORT OF THE SETTLEMENT AGREEMENT

Victor M. Glasberg
Bar No. 16184
Victor M. Glasberg & Associates
121 S. Columbus Street
Alexandria, VA. 22314
(703) 684-1100
vmg@robinhoodesq.com

Robert D. Fleischner (*pro hac vice*)
RFleischner@cpr-ma.org
Steven J. Schwartz (*pro hac vice*)
SSchwartz@cpr-ma.org
Deborah A. Dorfman (*pro hac vice*)
DDorfman@cpr-ma.org
J. Paterson Rae
PRae@cpr-ma.org
Center for Public Representation
22 Green Street
Northampton, MA 01060
(413) 586-6024

FINANCIAL DISCLOSURE STATEMENT

Pursuant to Local Rule 7.1, *amici curiae* in the above-captioned matter, submit the following financial disclosure statements:

The **National Association of State Directors of Developmental Disability Services** ("NASDDDS") states that it does not have a parent corporation. It is a nonprofit corporation operating under §501(c)(3) of the Internal Revenue Code that does not issue stock. As it has no stock, no publicly held corporation owns 10% or more of NASDDDS' stock and it does not have any parties in any partnerships, general or limited, or owners or members of non-publicly traded entities such as LLCS or other close held entities. There is, therefore, nothing to report under Local Civil Rule 7.1(A)(1)(a).

The **American Association of Intellectual and Developmental Disabilities (**"AAIDD") states that it does not have a parent corporation. It is a nonprofit corporation operating under §501(c)(3) of the Internal Revenue Code that does not issue stock. As it has no stock, no publicly held corporation owns 10% or more of AAIDD's stock and it does not have any parties in any partnerships, general or limited, or owners or members of non-publicly traded entities such as LLCS or other close held entities. There is, therefore, nothing to report under Local Civil Rule 7.1(A)(1)(a).

The **Association of University Centers on Disabilities** ("AUCD") states that it does not have a parent corporation. It is a nonprofit corporation operating under §501(c)(3) of the Internal Revenue Code that does not issue stock. As it has no stock, no publicly held corporation owns 10% or more of AUCD's stock and it does not have any parties in any partnerships, general or limited, or owners or members of non-publicly traded entities such as LLCS or other close held entities. There is, therefore, nothing to report under Local Civil Rule 7.1(A)(1)(a).

TASH states that it does not have a parent corporation. It is a nonprofit corporation operating under §501(c)(3) of the Internal Revenue Code that does not issue stock. As it has no stock, no publicly held corporation owns 10% or more of TASH's stock and it does not have any parties in any partnerships, general or limited, or owners or members of non-publicly traded entities such as LLCS or other close held entities. There is, therefore, nothing to report under Local Civil Rule 7.1(A)(1)(a).

TABLE OF CONTENTS

In its Order of March 6, 2012, this Court provided an opportunity for all interested persons and organizations to submit written comments or *amicus curiae* briefs to the Court regarding the proposed Settlement Agreement. The Court indicated that it would consider all of these comments in determining whether the Agreement is adequate, fair and reasonable, whether it is lawful, and whether it is against public policy. Order at 3, 5. Pursuant to this invitation, the national organizations and individual described below submit this brief *amici curiae* in support of final approval and entry of the Agreement.

INTEREST OF AMICI

The national organizations submitting this *amici* brief are comprised of the state officials who administer developmental disability service systems in all fifty states, professionals who serve and support individuals with intellectual or developmental disabilities (ID/DD), professors and researchers who study developmental disability systems, and persons with disabilities themselves. They all are interested in the maximizing the developmental potential of all individuals with ID/DD, including the current residents of the State Training Centers. They have a wealth of knowledge and experience regarding best practices in the care and treatment of individuals with ID/DD. They also have extensive, direct experience regarding the closure and downsizing of state institutions for individuals with ID/DD, the transition of residents of such facilities to alterative service settings, the ability of community-based service delivery systems to meet the needs of individuals with ID/DD, including the needs of individuals with severe or complex medical or psychiatric conditions, and the systems required to ensure that the needs of individuals who are transferred from state institutions to other settings are, in fact, being met.

This brief is supported by the detailed affidavit of *amicus* Robert Gettings, a resident of Virginia and one of the leading experts in the country on public service systems for persons with ID/DD. His affidavit provides an historical perspective on the evolution of these systems, the opportunities for expanding federal funding, new legal requirements that must be met by all States in operating their systems, and the challenges of administering ID/DD services in a manner that reflects professional standards, consumer needs, and family concerns.

The **National Association of State Directors of Developmental Disability Services** ("NASDDDS") is the leading organization in the nation for state-sponsored services for persons with intellectual and developmental disabilities. NASDDDS is comprised of the public agencies in all fifty States and the District of Columbia with a statutory mandate to serve persons with ID/DD. NASDDDS members are responsible for providing, financing, and overseeing the delivery of long-term supports for persons with ID/DD in the context of institutional, home, and community-based programs. NASDDDS assists State agencies to build person-centered systems of services and supports for persons with ID/DD and their families. It also provides technical assistance in organizing, financing and delivering services to eligible individuals and families.

The **American Association on Intellectual and Developmental Disabilities** ("AAIDD") is the oldest and largest interdisciplinary organization of professionals and others concerned about intellectual and related disabilities. Founded in 1876 to discuss all questions relating to the causes, conditions, and statistics of intellectual and developmental disabilities and to develop best practices in education and services, today AAIDD represents professionals and others in the United States and more than 50 other

countries. AAIDD members are united by the ideal that each person with a disability has the right to develop personal potential to the maximum extent possible, to satisfy his or her individual needs and preferences, and to become an independent and useful member of the community. The major functions of the Association are to (a) support its members' leadership in activities that impact people with intellectual and developmental disabilities; (b) publish cutting edge research and materials that inform policy and practice; (c) develop and implement educational opportunities for professionals, policy makers, and others; and (d) engage in activities that promote progressive public policy.

The **Association of University Centers on Disabilities** ("AUCD") is comprised of a network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities. Based in Maryland, AUCD currently represents sixty-seven University Centers for Excellence in Developmental Disabilities Education, Research, and Service, with at least one center in every state. AUCD's mission is to advance policy and practice for and with people with developmental and other disabilities, their families, and their communities via supportive research, education, and service activities.

TASH is an international leader in disability advocacy, based in Washington, D.C. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs, particularly those vulnerable to segregation and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. TASH members include a diverse array of individuals and

perspectives, including researchers, professionals, direct service workers, family members and people with disabilities.

Robert M. Gettings is a nationally renowned expert on systems of care for individuals with ID/DD. Mr. Gettings was the Executive Director of NASDDDS from 1970 to 2007 and, during that time monitored and assisted States' efforts to improve the quality of care for individuals with ID/DD, including the movement away from care in large institutions to care in the community. He has written extensively on these subjects and continues to provide training, support and assistance concerning systems of care for individuals with ID/DD. As a long-time citizen of the Commonwealth and an expert on the delivery of services to individuals with ID/DD, he has a particular interest in the Settlement Agreement in this case.

ARGUMENT

The *amici* are not unsympathetic to the concerns raised by the families of the residents of the State Training Centers. In many cases, the Training Center may have been a resident's residence for an extended time. The possibility that the resident might have to relocate to another setting is, understandably, unsettling and challenging for both the resident and family.[1] That possibility, however, even were it to occur, would not justify rejection of this Agreement, given the vast experience, research, and successful strategies that have been developed and tested over the past four decades, as many States

[1] It is important to note that the Agreement does not require the closure of any facilities. Any decision to close any Training Center will, of necessity, be made by the General Assembly, not this Court. Such a decision is not required by this Agreement, nor is the implementation of the terms of the Agreement dependent upon legislative action authorizing the closure of any Training Centers. *See* Order of March 6, 2012 at 2-3. Rather it is a political decision entrusted to the General Assembly. Nevertheless, because much of the opposition to the Agreement is predicated upon the possibility that some of the Training Centers will be closed and the residents required to relocate to settings ill-equipped to meet their needs, this brief also will address the reasons why such concerns, while understandable, do not justify rejecting the Agreement.

have closed some or all of their large institutions and safely transitioned residents to new homes in the community.

The Agreement contains all of the protections, and more, that are necessary to ensure that any transfers from the Training Centers are done in a fashion that is safe, sensitive to the needs and wishes of the individual and designed to maximize the individual's abilities and opportunities for independence and self-determination.

I. Many States Have Significantly Expanded Community Services, Successfully Phased Down Institutions, and Safely Transitioned Residents from Institutions to the Community.

States have increasingly implemented more effective, community-based services while closing expensive and outmoded institutional facilities like the State Training Centers.[2] In the last twenty-five years, States have closed more than 190 public institutions or special units of 16 or more ID/DD persons.[3] All fifty states and the District of Columbia have reduced their reliance on state-operated institutions.[4] Twelve States and the District of Columbia now operate without a single public institution for persons with developmental disabilities.[5]

As discussed below, the successful experience of many States in transitioning their public service systems from ones that rely upon large institutions to ones that

---

[2] Throughout this brief, *amici* cite to numerous studies and reports. Many are available online and, where this is the case, the web address is included. In the interest of space, *amici* have not attached copies of the studies. Should the Court desire a paper copy of any cited report or study, *amici* will promptly provide it.

[3] K.C. Lakin, S. Larson, P. Salmi *et al*., *Residential Services For Persons With Developmental Disabilities: Status And Trends Through 2009* at iv, 18 (2010) (hereinafter K.C. Lakin *et al.*, *Residential Services*) (and also indicating 5 additional closures slated for 2010) (copy available at http://rtc.umn.edu/docs/risp2009.pdf); Affidavit of Robert M. Gettings at 3 (hereafter Gettings Aff.), attached as Exhibit 1.

[4] K.C. Lakin *et al.*, *Residential Services*, *supra* n. 3, at 5 (from 1980 to 2009, the population of large state-operated ID/DD residential facilities declined by more than 70%); Gettings Aff. at 3.

[5] K.C. Lakin *et al.*, *Residential Services*, *supra* n. 3, at iii (listing Alaska, the District of Columbia, Hawaii, Maine, Michigan, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont and West Virginia); Gettings Aff. at 4 (reporting one additional state, Indiana, that has closed its large institutions).

provide most services for most persons in the community demonstrates that the basic goal and specific provisions of the Settlement Agreement are consistent with national experience and professional standards. In transforming their service systems for persons with ID/DD, these States have maximized funding, minimized per person costs, and vastly expanded the number of individuals served. The Agreement provides the foundation for Virginia to do the same. While system transformation is challenging, and may cause concerns from families who are understandably anxious about change, numerous States have successfully addressed these concerns and safely transitioned thousands, if not tens of thousands, of persons with ID/DD from institutions to new community homes.[6] Based upon the experiences of other states, the Agreement's requirements of enhanced services, for person-centered planning and discharge processes, for quality and risk management systems, and for ongoing monitoring by the independent reviewer, are strong indications that expanded community services and transitions to community living will result in improved lives for thousands of Virginians with ID/DD.[7]

---

[6] An argument that all current Training Center residents should be allowed to choose to remain at their current facility indefinitely would be predicated upon an assumption that several Training Centers will be closed if the Settlement Agreement is approved and entered by this Court. These concerns, however, are not only predicated upon a speculative assumption which the Agreement does not require and may never come to pass, but also run counter to the overwhelming national consensus on how to best deliver services to persons with ID/DD. Any assertion that Training Center residents will be irreparably harmed if they are required to transition into new environments would be erroneous. This assertion is unsupported by, and inconsistent with, *amici's* experience in the field and a growing body of careful research which demonstrates that individuals with ID/DD who transition from institutional to community-based care do better in the community. Gettings Aff. at 4-6.

[7] Residents of Training Centers are specifically covered by the Agreement and are included in the target group. Agreement at III.B.1.a. It also bears noting that, even were some Training Centers to close, there is no requirement that any resident be transferred to a community setting. Based upon the person-centered planning process set forth in the Agreement with its emphasis on informed choice by the individual with ID/DD, any resident who wishes to transfer to an alternative ICF setting will be permitted to do so. *See* Commonwealth's Brief in Opposition to Motion to Intervene at 6, 9, 10.

A. *Case Studies Nationwide Demonstrate that Residents of ID/DD Institutions Can Be Successfully Transitioned into Integrated Community Settings.*

In the *amici's* years of experience across all fifty States and the District of Columbia, a large number of States that have closed all or some of their ID/DD institutions and transferred residents into alternative service settings, including more effective community care. As demonstrated time and again, with proper planning, sensitivity, and funding, residents young and old can successfully and effectively be transitioned into different environments. That result is equally true when residents' families and guardians initially oppose the transfer.[8]

Amici know, from direct experience in administering, monitoring, and evaluating the expansion of community services and the transition of institutional residents to new homes in the community, that the most successful transitions require substantial investment in the capacity and quality of the community service system. Good fiscal planning and use of available federal funding for transition activities help reduce the cost of maintaining a "dual system" of institutional and community-based services. Moreover, involving those persons who are most affected by movement from institutions to other settings is important to a successful transition. By creating open dialogue and building trust among all stakeholders, the transition process should allay fears and identify solutions.

With these principles in mind, *amici* have overseen the successful transition nationwide of facility residents into different environments – primarily community-based care – with very positive results. These transitions, often related to facility closure or

[8] Gettings Aff. at 5-6.

consolidation, have occurred in a large number of States and an even larger number of institutions. *Amici* focus here on the experiences in Pennsylvania, Indiana and Massachusetts, where institutional closures posed challenges that were comparable to, if not greater than, those that may occur if some of the Training Centers are closed. These case studies demonstrate the overwhelming likelihood of an effective transfer process for any Training Center residents who might relocate to new community homes or other ICF/MR facilities.

1. Pennsylvania

The Commonwealth of Pennsylvania has closed eleven state-operated ID/DD institutions and special units, including three large facilities that were the subject of litigation: Pennhurst Center in 1987, Embreeville Center in 1997, and Western Center in 2000. All these institutions served a large number of residents many of whom had been institutionalized since childhood. The Commonwealth's Office of Mental Retardation established transition teams that oversaw the entire planning process, assured the availability of adequate funding to develop community-based services before the facilities were closed, and completed follow-up visits to monitor services, health care, therapies, behavioral services, and to obtain feedback from former residents and their families. These teams worked closely with families throughout the entire process to ensure they were apprised of the changes and the benefits of transitioning to community-based services.[9] Despite opposition from some guardians and families who were initially opposed to any change in residential settings, Pennsylvania's closure of these institutions

[9] Nancy Thaler, Review of the Tennessee State Arlington Developmental Center Closure and Community Transition Plan, *United States of America v. State of Tennessee,* Civil Action No. 92-2062 (W.D. Tenn) (2006) at 7 (*Thaler Report*).

has been heralded as an unqualified success by public officials, legislators, involved professionals, and, most importantly, the residents themselves.[10]

Opposition to closing Western Center was probably the most strident that the Commonwealth encountered. The families and guardians of Western Center residents litigated to prevent community placements; however, the courts declined to interfere with the State officials' policy choices and refused the invitation to dictate which specific facilities and programs must be maintained by Pennsylvania's public agency.[11] Despite their opposition, however, the families of all but fifty-six out of 380 residents actively participated in the development of individual transition plans. Perhaps most telling was the fact that after the institution was closed, the fifty-six families who did not participate were very pleased with their sons' and daughters' community living arrangements, and only one family sought to have a former resident returned to the institution.[12]

---

[10] *See, e.g.,* "Independent Monitoring for Quality: What Consumers in Pennsylvania Say About Their Services," and "What Families, Friends and Guardians Say About Services," Dep't of Public Welfare, Office of Mental Retardation. *Report of Independent Monitoring for Quality in the Pennsylvania Mental Retardation System* (2002) at 7, 10; Pennsylvania Dep't of Public Welfare, Office of Mental Retardation, *Everyday Lives: Making it Happen* (2001); S. Kim, S.A. Larson & K.C. Lakin, *Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999* (2001) at 3, 5 (studies of deinstitutionalization in Pennsylvania consistently show growth and development after community placement) (available at http://ici.umn.edu/products/prb/101/101.pdf) (hereafter "Kim, *et al*. *Behavioral Outcomes: 1989-1999*"); J. W. Conroy and V. J. Bradley, *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* (1985) at 322-23 ("the people deinstitutionalized under the *Pennhurst* court order *are* better off in *every* way measured … the results are not mixed") (emphasis in original) (hereafter *Pennhurst Study*) (copy available online at http://aspe.hhs.gov/daltcp/reports/5yrpenn.pdf); J. W. Conroy, *Selected Findings from Two Decades of Research on Community versus Institutional Living*, (n.d.) (copy available online at http://www.outcomeanalysis.com/DL/pubs/DITASHNwsltr.PDF).

[11] *See, e.g., Richard C. v. Houston,* 196 F.R.D. 288, 289 (W.D. Pa. 1999), *aff'd.,* 229 F.3d 1139 (3d Cir. 2000) (denying parents' motion to intervene to stop community placement); M. Bucsko, "Western Center Moves Delayed," Pittsburgh Post-Gazette, February 1, 2000, http://www.post-gazette.com/regionstate/20000201western1.asp; J. Ackerman, "Judge won't hear Western Center parents' petitition," Pittsburgh Post-Gazette, March 31, 2000, http://www.post-gazette.com/regionstate/20000331western6.asp; J. Ackerman, "State closing home for mentally retarded amid continued appeals, protests," Pittsburgh Post-Gazette, April 12, 2000, http://www.postgazette.com/regionstate/20000412western1.asp.

[12] *Thaler Report*, *supra* n. 9, at 8.

2. Indiana

Indiana closed its last large institution, the Fort Worth State Developmental Center ("Fort Worth") on April 18, 2007. Like their Virginia counterparts, officials in Indiana were concerned about the disproportionate funds that were maintaining old, less effective institutional facilities, and instead sought to promote more effective and less wasteful community-based services. The State had closed other institutions successfully, including New Castle and Northern Indiana State Developmental Centers, where longitudinal studies showed that after a year in the community, former residents demonstrated statistically significant and meaningful gains in skills, and professionals and involved families expressed the view that residents were far better off in their new homes.[13] Nevertheless, the State's decision to close the facility in January 2005 was particularly controversial because the 239 Fort Worth residents had complex needs, were considered difficult to serve, and indeed, were regarded as some of the most severely disabled persons in the public service system.

When the institution closed, only eight of the 239 residents were placed in mental health facilities, while the remaining 231 moved to community settings.[14] Although critics predicted that many of these residents with severe disabilities would not be successful in the community, the State's careful planning and appropriate funding helped ensure an effective and successful transition into integrated community-based services. Specifically, the State formed a special team to follow former Fort Worth residents for

---

[13] J. Conroy and J. Seiders, *Outcomes of Community Placement at One Year for the People Who Moved from New Castle and Northern Indiana State Developmental Centers, Report Number 6 of the Indiana Community Placement Quality Tracking Project* (2000) at 23.

[14] Peter Bisbecos, *Closing Institutions and Opening Doors to the Community*, 14 Community Services Rptr. 6 (2007).

one year after placement and to monitor their treatment. The State also enlisted community providers to build "extensive support needs" homes for people with the most significant behavioral challenges. By closing the institution, the State freed up substantial funds that it then reinvested to build community services and to provide much needed services to hundreds of other non-institutionalized persons on waiting lists.[15]

3. Massachusetts

Massachusetts has closed several large state institutions for individuals with ID and, like the other states described above, has demonstrated that transitions from institutional to community-based care can be beneficial for even those residents with the most significant disabilities. With strong planning and sensitivity to residents' and family members' concerns during the closures of the Belchertown and Dever State Schools in 1992 and 2001, respectively, the transfers of the residents was accomplished in a manner that resulted in a better quality of life for them and, despite initial reservations, positive feedback from the families. Both institutions were the subject of long-standing court involvement and consent decrees designed to remedy constitutionally-deficient conditions at the facilities.

a. Belchertown State School

To plan for the downsizing of Belchertown, the facility superintendent and the Department of Mental Health's community service system managers created a collaborative process to systematically develop community services for Belchertown residents. As a result, the Commonwealth created a comprehensive array of community services to respond to the identified needs of each individual resident. Residents and

[15] *Id.*

families were engaged in the transition process; they were encouraged and assisted to visit new homes and to express preferences about roommates and staff; and when new residences were constructed, families were asked to participate in their design. As the service system grew, so did supervision, oversight, and quality assurance.

In the early phases of community placement, residents were given the option of returning to Belchertown. This, however, was rarely necessary. Initially, Massachusetts officials focused on developing community services without considering whether to close Belchertown. As more successful transitions occurred, however, it became less feasible and more wasteful to operate a large institution when so few residents remained. Moreover, the great majority of Belchertown residents had chosen a new home in the community.[16] When the decision was made to close the institution, most of the remaining residents and families – including those who had lived at Belchertown for many decades – chose community living. The few who preferred to continue living in an institution were offered a transfer to another ICF/MR, just as the Virginia Training Center residents who are assessed to need ICF/MR level of services will be allowed to transfer to another Training Center or ICF/MR facility.

Shortly after the plan to close Belchertown was announced a study was conducted to measure family satisfaction and family and resident perceptions of the quality of life both for those who had moved from Belchertown to the community and for those who

---

[16] E. A. Eastwood & G.A. Fisher, *Skills Acquisition Among Matched Samples of Institutionalized and Community-based Persons with Mental Retardation*, 93 Am. J. on Mental Retardation 75 (1988) (hereafter "Eastwood *et al*., *Skills Acquisition*") (indicating that the group of Belchertown residents who transferred to the community had significantly greater level of cognitive and social skills after placement than the matched group that remained in the institution); *see also* V. J. Bradley, C. S. Feinstein, *et al*., *Results of the Survey of Current and Former Belchertown Residents and their Families: The Belchertown Follow-Project* 20 (Dec. 1992) (reporting results of Eastwood & Fisher study) (hereafter "*Belchertown Follow Study*") (copy available online at http://bit.ly/Hg0S8z).

remained at the facility at the time of the study. Although 78% of the residents who left Belchertown were reported to have severe or profound mental retardation and the level of disability was "not at all different" from those who remained, 89% of the families of residents who moved were satisfied or very satisfied with the move and only 2% expressed any dissatisfaction.[17] The researchers found that "[w]hen comparing Belchertown families to community families, the community families were happier overall, perceived their relatives to be happier, [and] believed that their relatives were continuing to learn new things."[18]

b. Dever Developmental Center

An even more sophisticated transition planning process was initiated several years later, when Massachusetts decided to close the Dever Developmental Center. This policy decision was strongly opposed by family members and guardians who protested the closure and argued for "Dever Forever." Eventually, through careful planning, engaged participation and an emerging history of successful placements, the opposition waned. Over several years, hundreds of residents with severe disabilities were carefully transitioned to other settings, the vast majority to the community. All were offered, and a few requested, placements in other institutions.

Massachusetts was a pioneer in person-centered planning – a systematic individual planning process characterized by searching actively for a person's gifts and capacities in the context of community life and by strengthening the voice of the person and those who know her best to define desirable changes in her life. By 1995, this

[17] *Belchertown Follow Study* at 17.
[18] *Id.*

process was being used for people leaving Dever.[19] Subsequently, Massachusetts developed the concept of building "social units" as part of the transition planning for each resident, in which the consumer and family/guardian had the opportunity to identify staff who would remain with the client through the transition and into the community.[20]

B. The Provisions of the Settlement Agreement Regarding Discharge Planning, Quality and Risk Management, and Monitoring by the Independent Reviewer Ensure that Transfers Will B Done Safely and in Accord with Professional Standards.

As the above-examples demonstrate, as well as the other similar expenses in most states throughout the country, institutions can be closed and residents safely transitioned to new homes in the community, without compromising the health or continuing development of the individual. Indeed, despite skepticism or outright opposition by family members, study after study demonstrates that when the resident transfers are based upon a person-centered discharge planning process, with support provided to assist the individual and family with the transition, transfers to the community are not only safe, but result in improvement in the individual's cognitive and social development, particularly for people with the most significant disabling conditions, resulting in increased satisfaction both by the individual with ID/DD and the family.[21]

The Agreement incorporates all of the key safeguards, processes, and strategies that many other States, like those discussed above, have used to successfully reduce reliance on institutions and expand community services. The Agreement ensures that any

---

[19] C.L. O'Brien and J. O'Brien, *The Origins of Person Centered Planning: A Community of Practice Perspective* (2000) at 3.

[20] E.G. Enbar *et al. A Nationwide Study of Deinstitutionalization and Community Integration: Massachusetts* (2004).

[21] Gettings Aff. at 6, 9; *Pennhurst Study*, *supra* note 10, Executive Summary at p. 7 (Finding that "the people with the most severe impairments turn out to be among those who benefit the most from community placement.").

transfers, whether to the community or to another ICF facility, will be undertaken in accord with professional standards. The Agreement sets forth a detailed person-centered discharge planning process. It requires that a case manager be assigned to any individual being considered for discharge or transfer. It mandates that the resident and family be provided with the ability to visit any proposed transition, prior to any final decision about transfer, in order to ensure that any concerns of the individual and family are addressed. The entire process is based upon the "informed choice" of the resident and family. All of these protections, and more, are derived from the lessons learned over the past thirty years during which hundreds of institutions have been closed and residents transferred.[22]

The Agreement reflects current professional standards regarding how to implement transitions and transfers from institutional settings. There is every reason to expect that Virginia will be as successful as the States described above with respect to any transfers that may be undertaken pursuant to the Agreement. Indeed, with the quality and risk management system set forth in the Agreement, coupled with oversight by the Independent Reviewer, the Department of Justice and this Court, there is every reason to anticipate that any transfers will be more successful and satisfying to residents and families than those described above, many of which did not have these additional protections.[23]

---

[22] Gettings Aff. at 6, 10.

[23] Gettings Aff. at 10. Thus, the concerns and fears of the families of Training Center residents, while understandable, are belied by the experience of similarly-situated families in most other States that have phased down their institutions.

II. The Professional Literature Establishes That Residents of Institutions Benefit from Transfer to the Community.

A substantial body of professional literature, as well as the direct experience, informal evaluations, and formal research by *amici*, convincingly demonstrates that community living offers far greater benefits for persons with ID/DD than large institutions. These proven benefits have been shown in a variety of community settings, and for individuals with varying degrees of disability. Importantly, gains from community living include improvements in adaptive behavior, control of challenging behaviors, independence, self-care skills, social skills and vocational skills.

While there may be an initial adjustment period, transition to the community generally is successful for persons with ID/DD. This is particularly true where, during the transition process, the individual and family are able to meet with the new provider, visit the new home, and gradually adjust to the new environment. Community living also provides individuals with ID/DD with opportunities not generally available in large institutions like the Training Centers, including regular interactions with individuals without disabilities and greater freedom to experience day-to-day community life, such as shopping in the grocery store, participating in religious services, going to the movies, and visiting friends. These experiences cannot be duplicated in the isolation of an institutional setting. Community living also allows persons with ID/DD to develop fuller lives and to enjoy the benefits and experiences that those without an intellectual disability experience daily.

A. Community Integration and its Benefits Are Well Supported by Professional Research and Literature.

The advantages of community living are powerfully and convincingly supported by a large body of professional literature. These results have been consistently reconfirmed in the United States and around the world over the past 30 years. It is well-documented that individuals who leave institutions and move into the community have a better quality of life, improve adaptive behaviors and acquire more skills that help them on a daily basis. Transition to a community home makes "a significant impact on acquisition of the more complex cognitive and social skills."[24] While transitions can be challenging,[25] the long term impact of moving from institutions to community living is almost universally positive of all ages and disability levels.[26]

The *Pennhurst Longitudinal Study* was a seminal study in the field of intellectual disability. The study was launched in connection with a landmark class action lawsuit, which provided the researchers with the opportunity to study a sizable population as they moved into community placement. Research and analysis were conducted for five years and followed over 1,100 individuals involuntarily moved into the community following the court-ordered phase down of the Pennhurst State School and Hospital.

The study found that people who moved into the community were more independent and showed improvements in adaptive behavior.[27] The individuals who left Pennhurst (called "Movers" in the study) increased their adaptive behavior scores on the

---

[24] *See* Eastwood *et al., Skills Acquisition*, *supra* n. 16, at 75.
[25] *See generally* D. Braddock, *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines*, at 23-24 (2006) (hereafter *North Dakota Study* (available at http://www.arccassnd.com/images/ClosingGraftonPDFonline.pdf).
[26] Gettings Aff. at 4-5.
[27] *See Pennhurst Longitudinal Study*, *supra* n. 10, at 314-315.

Behavior Development Survey significantly, improving their scores by over 11 points, while those who remained in the institution (the "Stayers") improved their scores by less than 1 point.[28] These results demonstrate that "Movers" experienced the significant increases in adaptive behavior, while their counterparts who remained showed no similar growth.[29] As such, the study established that the gains were largely due to community living, rather than aging or natural development, and all occurred notwithstanding the fact that many transfers were opposed by families.

An overwhelming number of studies, meanwhile, have corroborated the *Pennhurst* results, finding a statistically significant increase in overall adaptive behavior scores associated with community living. In 1989, for example, Larson and Lakin published a survey of eighteen studies on changes in adaptive behavior for formerly institutionalized individuals who had transitioned to the community.[30] Fully 1,358 subjects were involved in the 18 studies, from 13 different States from all regions of the country. Studies included both consented to and opposed transitions. The review found that institutions were "consistently less effective than community-based settings in promoting growth, particularly among individuals diagnosed as severely or profoundly retarded."[31] Based on these findings, Larson and Lakin noted that:

> It must be recognized that based on a substantial and remarkably consistent body of research, placing people from institutions into small, community-based facilities is a predictable way of increasing their capacity to adapt to the community and culture.[32]

---

[28] *Id.* at 56.
[29] *Id.* at 57.
[30] *See* Sheryl A. Larson & K. Charlie Lakin, *Deinstitutionalization of Persons with Mental Retardation: Behavioral Outcomes*, 14 J. of the Ass'n for Persons with Severe Handicaps, 324-32 (1989).
[31] *Id.* at 330.
[32] *Id.* at 331.

They concluded that "available research denies support for the assertion that people obtain greater or even equal benefit in adaptive behavior from living in institutions. In fact, this research suggests that those benefits very consistently accrue more to the people who leave institutions to live in small community homes."[33]

In a follow-up to their ground-breaking 1989 work, Kim, Larson and Lakin reviewed 33 more studies and found that the literature continued to support their earlier findings that improvements in adaptive behaviors are consistently found in individuals who moved from large institutions to smaller homes in the community.[34] The more recent studies, in addition to showing an increase in adaptive behaviors, also showed a decrease in challenging behaviors among those who moved to the community.[35] The authors concluded that:

> The studies reviewed here demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. The studies suggest that community experiences increasingly provide people with environments and interventions that reduce challenging behavior. And, a growing body of research suggests that people enjoy a better quality of life along dimensions that have been quantified differently by different researchers.[36]

Kim, Larson and Lakin updated their work again in 2011 to include analysis of studies up through 2010. This most recent report once again documents that individuals

---

[33] *See* Kim, *et al*., Behavioral *Outcomes: 1980-1999*, *supra* n. 10 at 6 *quoting* Larson & Lakin, Deinstitutionalization of Persons with Mental Retardation, *supra* n. 30.
[34] *Id.*
[35] *Id.*
[36] *Id.* at 8 (additional areas of improvement noted by some researchers included: self-care or domestic skills; academic skills; communication; community living skills; social skills; and vocational skills).

ho move from institutions to the community experience significant improvement in their adaptive behavior skills.[37]

Additionally, a study of over 2,000 persons with ID/DD in California from 1993 to 2001 yielded similar results -- confirming the unquestionable benefits of community living.[38] This study analyzed over 700 items of information for each individual. These results were compared before and after the transition to the community. The researchers primarily asked one question: "[A]re the people who moved better off than they were when living in Developmental Centers?"[39] The results showed that individuals who left institutions "benefited considerably from community living."[40] Quality of life for individuals who transitioned from large institutions to the community "improved in more than three times as many dimensions as they have declined."[41] The study found improvements in several quality of life dimensions, including progress in personal goals, individualized treatment, integration, challenging behavior and choice-making.[42] The researchers also concluded that families were "unexpectedly and overwhelmingly happy with community living, even those who formerly opposed the change."[43]

As the literature shows, community living provides persons with ID/DD with opportunities to improve adaptive behavior and acquire useful skills. Improvements are

---

[37] *Behavioral Outcomes of Deinstitutionalization for People with Intellectual and/or Developmental Disabilities: Third Decennial Review of U.S. Studies*, 1977-2010 at 8 (2011) (copy available at http://ici.umn.edu/products/prb/212/212.pdf.

[38] *See* M. Brown, A. Fullerton, J.W. Conroy & M.F. Hayden, *Eight Years Later: the Lives of People who Moved from Institutions to Communities in California. Year 2001 Report of the Quality of Life Evaluation of People with Developmental Disabilities Moving from Developmental Centers into the Community, Final Report (Year 2)* (2001) (hereafter California Study) (copy available online at http://www.outcomeanalysis.com/DL/pubs/ca2r4.pdf).

[39] *Id.* at 2.

[40] *Id.*

[41] *Id.* at 27.

[42] *Id.* at 26.

[43] *Id.* at 3.

consistently found in reading/writing skills, quantitative skills, independent living skills, vocational skills, and social interaction skills.[44] The body of professional literature shows that these gains are significant and that those who left the institutions are decidedly "better off."

B. Community Integration Provides Individuals With an Opportunity to Participate in their Communities.

Integration into the mainstream of community activities is fundamental in supporting those with disabilities who have transitioned from institutions to the community. Integration can be defined as the opportunities people with disabilities possess for contact with people without disabilities.[45] Studies consistently have found integration to significantly improve after transition from institutions.[46] Brown concluded that individuals who entered the community were involved in an additional 13.3 community events per month and that this almost doubling of integrative activities was statistically significant.[47] Conroy showed increases in 15 of 16 types of integrative activities, six of which were significant.[48] These results were found to be consistent with data from other States.[49] Individuals who left institutions greatly increased their opportunities to go places and interact with citizens without disabilities.[50]

---

[44] *See* Eastwood *et al*., *Skills Acquisition* at 80; *see also* J.W. Conroy, J. Garrow, *et al*., *Initial Outcomes of Community Placement for the People who Moved from Stockley Center*, (2003) at 47-48 (copy available online at http://www.dhss.delaware.gov/ddds/files/conroyrep.pdf) (hereafter "J.W. Conroy, *et al*. Stockley Study"); *see also* S. Kim*, et al*., *Behavioral Outcomes: 1980-1999*, *supra* n. 10 at 6-8; Gettings Aff. at 4-5.
[45] *See* J. W. Conroy, *et al*., *Stockley Study*, *supra* n. 44, at 33.
[46] *See California Study*, *supra* n. 38, at 31; *see also* Eastwood *et al*., *Skills Acquisition*, *supra* n. 25 at 80; Kim, Larson & Lakin, Behavioral Outcomes: 1980-1999, *supra* n. 10, at 6.
[47] *California Study*, *supra* n. 38, at 31.
[48] J.W. Conroy, *et al*., *Stockley Study*, *supra* n. 44, at 35.
[49] *Id.* at 36.
[50] *Id*.

Community integration is compelling precisely because it seeks to maximize inclusion for persons with ID/DD and enhance their integration into society.[51] Not only does it lead to a marked increase in adaptive behaviors, it results in a richer and more satisfying overall quality of life.

C. Community Integration Leads to Improvements in Challenging Behavior.

Community integration also has been found to diminish challenging behavior. While studies in the 1980s suggested that community living may lead to some deterioration in challenging behavior, more recent studies have shown conclusively that behavior actually improves upon moving to community placements.[52] Brown identified the largest improvements ever documented in research on behavior, finding a substantial increase for the ability of persons who moved to the community to control challenging behaviors.[53] From this research, the researchers determined that "[t]he proper conclusion is that these 191 Movers are far better off now, in the community, in terms of being able to control their own potentially challenging behavior."[54]

The ability to control challenging or maladaptive behavior is particularly significant, since many individuals with ID/DD initially were placed in institutions precisely because of such behaviors. As community providers have developed services,

---

[51] *See* 42 U.S.C. § 12101(a) (Congressional finding that "historically, society has tended to isolate and segregate individuals with disabilities;" *see also Olmstead*, 527 U.S. at 600 (holding that "unjustified institutional isolation of persons with disabilities is a form of discrimination" because "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment").
[52] S. Kim, *et al*., *Behavioral Outcomes: 1980-1999*, *supra* n. 10, at 6, 8 (noting that while early studies in the 1980s showed some increase in challenging behaviors, all of the studies from 1990 onward showed a decrease in such behaviors, suggesting that community integration services and supports have improved and developed strategies to not only enhance adaptive behaviors, but decrease maladaptive behavior).
[53] *California Study*, *supra* n. 38, at 40-43.
[54] *Id.* at 43.

supports and strategies to address these challenges, it is no longer necessary or appropriate to continue to isolate and segregate these individuals.[55]

D. Families of Relatives Who Move to the Community Are Consistently Supportive of the Transfer.

Studies unequivocally show that families of individuals who move to the community are overwhelmingly satisfied with the results of the transition. Notably, even where families initially opposed the transfer, the great majority ultimately become supporters of community living.[56] Many of these families have been studied since the late 1970s, with the studies consistently demonstrating that, after transitioning to the community, families report lower levels of satisfaction with earlier institutional placement and higher levels of satisfaction with community living.[57]

These changes in family attitudes were highly statistically significant.[58] Brown found that families saw improvements in their relative's quality of life following their transition to the community, which led to a clear shift from opposition to support for community living.[59] This trend grows stronger the longer their relatives are out of institutions.[60] In those instances, families felt that their relatives were "happy" or "very happy" with living in the community and strongly opposed the idea of relatives moving back to institutions.[61]

---

[55] Gettings Aff. at 4-5.
[56] *See North Dakota Study*, *supra* n. 25, at 11; *see also Pennhurst Study*, *supra* n. 10, at 79-80, 108-09; *see also* Braddock, David & Heller, Tamar, *The Closure of Mental Retardation Institutions: Trends and Implications (a Working Paper)* at 20-21(1984) (copy available online at http://www.mnddc.org/parallels2/pdf/80s/84/84-PPM-UOI.pdf); Gettings Aff. at 9-10.
[57] Braddock & Heller, *Closure of Mental Retardation Institutions* at 20-21; *California Study*, *supra* n. 38, at 124-124.
[58] *Pennhurst Study*, *supra* n. 10, at 105.
[59] *California Study*, *supra* n. 38, at 125-26.
[60] *Id.* at 127.
[61] *Id.* at 127-28.

Preferences to stay in institutions are often "based on lack of experience with other alternatives and fear of something new and different."[62] Interestingly, family members are often surprised by their own change in feelings and report unexpected changes for the better in their own lives, and in the lives of their relatives with disabilities.[63]

The transfers are not simple, of course. To help address legitimate concerns or fears, families must be informed that adjustment issues may occur during and following transfer to a new home. Concerns of both the individual and family can be mitigated by involving them in the process and enabling them to visit their new home, meet the provider, and assist in selecting potential house mates. Clinical judgment, a critical aspect of the relocation process, utilizes professional standards to ensure best practices and enhanced accuracy, precision and integrity in decision-making. As study after study has shown, when done well and in accord with professional standards, transitions from institutional settings are not only safe, but result in significant growth and improvement by the individual.[64]

The Agreement contains detailed procedures to ensure that the individual and family are involved in a person-centered planning process that is predicated upon "informed-choice." The planning process will be done by the individual's Personal

---

[62] B. Shoultz, P. Walker *et al*., *Status of Institutional Closure Efforts in 2005* at 3 (2005) (copy available at http://ici.umn.edu/products/prb/161/161.pdf).

[63] *Pennhurst Study*, *supra* n. 10, at 109.

[64] While opponents often assert that such moves will result in "transfer trauma," even suggesting that there is a significantly increased risk of death, the data demonstrates the opposite. In a study focused directly on the risk of increased mortality due to transfers out of an institutional placement, the authors concluded that "[t]he evidence … clearly indicates that being a mover or having stability in placement did not account for differentials in the rates of deaths." P. Lerman, D.H. Apgar *et al*., *Deinstitutionalization and Mortality: Findings of a Controlled Research Design in New Jersey*, 41 Mental Retardation 225, 234 (August 2003) (copy available online at http://www.closevineland.org/Deinstitutionalization_20and_20Mortality.pdf).

Support Team, which includes the individual, family members, the CSB case manager, Training Center staff and any other individuals chosen by the individual. Discharge plans developed by the team will identify all needed supports, protections and services. Individuals and their family members will be provided with the opportunity to visit any proposed home to assess whether it has the staffing and resources to meet the individual's needs. All individuals who transition to the community will have a case manager. Mobile crisis intervention and crisis stabilization resources will be available 24 hours per day, 7 days per week to respond to any individual who experiences a problem in the community. Quality and risk management systems will monitor the quality and safety of the services and supports provided in the community, and require prompt corrective action of any deficiencies. An Independent Reviewer will be charged with the responsibility to collect data and conduct investigations to determine whether the Commonwealth is complying with the Agreement, and to report his findings to the Court and parties. In addition to the Independent Reviewer, the Department of Justice will also be monitoring the Commonwealth's compliance with the Agreement.

The Agreement contains all of these protections, and more, to ensure that any transfers from the Training Centers are done in a fashion that is safe, sensitive to the needs and wishes of the individual and designed to maximize the individual's abilities and opportunities for independence and self-determination. The protections that the Agreement provides far exceed those present in many of the closures that were the subject of the studies cited in this brief. [65] They offer reasonable assurances of safety,

[65] Just as the fears of the families who objected to facility closures and resultant transfers in other States proved to be unfounded, so too the projections of unsafe outcomes presented by the objectors to this

the decidedly better hope of improved outcomes, and the undeniable expansion of community services for persons currently denied all supports from the Commonwealth while they languish on waiting lists.[66]

CONCLUSION

For the foregoing reasons, this Court should approve the Settlement Agreement as a fair, just and adequate resolution of the claims raised by the United States' Complaint against the Commonwealth of Virginia.

Dated: April 5, 2012

Respectfully submitted,

/s/ Victor M. Glasberg_____
Victor M. Glasberg, Bar No. 16184
Victor M. Glasberg & Associates
121 S. Columbus Street
Alexandria, VA. 22314
(703) 6841100
vmg@robinhoodesq.com

Robert D. Fleischner (*pro hac vice*)
RFleischner@cpr-ma.org
Steven J. Schwartz (*pro hac vice*)
SSchwartz@cpr-ma.org
Deborah A. Dorfman (*pro hac vice*)
DDorfman@cpr-ma.org
J. Paterson Rae
PRae@cpr-ma.org
Center for Public Representation
22 Green Street
Northampton, MA 01060
(413) 586-6024

Agreement are likely to be exaggerated, since they are similarly based upon unjustified fears and assumptions.

[66] *See* Gettings Aff. at 10.

CERTIFICATE OF SERVICE

I hereby certify that on the 5th day of April, 2012, I electronically filed the foregoing with the Clerk of the Court using the CM/ECF system, which will then send a notification of such filing (NEF) to the following:

Aaron Zisser
Alison Barkoff
Benjamin O'Tayloe, Jr.
U.S. Department of Justice
Civil Rights Division
Special Litigation Section
950 Pennsylvania Ave., NW
Washington, D.C. 20530
Aaron.Zisser@usdoj.gov
Alison.Barkoff@usdoj.gov
Benjamn.Tayloe@usdoj.gov

Robert P. McIntosh
Assistant United States Attorney
600 East Main Street, Suite 180
Richmond, VA 23219
Robert.McIntosh@usdoj.gov

Allyson Kurzmann Tysinger
Office of the Attorney General
900 East Main Street
Richmond, VA 23219
(804) 786-2071
atysinger@oag.state.va.us

Gerald T. Schafer
Schafer Law Group
5265 Providence Road, Suite 303
Virginia Beach, VA 23464
rschafer@scaferlawgroup.com

Thomas York
Donald Zavcosky
Cordelia Elias
The York Legal Group, LLC
3511 North Front Street
Harrisburg, PA 17110
tyork@yorklegalgroup.com
celias@yorklegalgropu.com
dzaycosky@yorklegalgroup.com

Victor M. Glasberg_____
Victor M. Glasberg, Bar No. 16184
Victor M. Glasberg & Associates
121 S. Columbus Street
Alexandria, VA. 22314
(703) 684-1100 (telephone)
(703) 684-1104 (facsimile)
vmg@robinhoodesq.com