NEW YORK ASSOCIATION ON Independent Living INC.

independence!

Comments on OPWDD's "People First Waiver" Concept Paper
June 1, 2011

Executive Summary

The New York Association on Independent Living (NYAIL) is a membership organization representing people with disabilities and Independent Living Centers (ILCs) across New York State. Independent Living Centers are community-based not-for-profit providers of advocacy, services and supports for New Yorkers with disabilities of all ages, controlled by and largely staffed by people with disabilities. Independent Living Centers provide a wide range of services through the OPWDD system, as well as through the Consumer Directed Personal Assistance Program (CDPAP) and other state funded programs. ILCs have served as the voice of the disability rights movement, working to remove barriers to community integration and to ensure individual choice and control over services for all people with disabilities. ILCs have helped the State to advance policies of community integration by transitioning and diverting people from costly institutional settings in the OPWDD system as well as nursing facilities for more than 20 years. ILCs have played a critical role in creating and implementing the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Medicaid Waiver programs, including serving as Regional Resource Development Centers (RRDC) and service providers.

Vision

The Americans with Disabilities Act and the US Supreme Court's *Olmstead* decision require the State to provide services and supports to individuals with disabilities in the most integrated setting appropriate to the individual's needs. This principle must drive state policy for all disability and long term services and supports, including those provided by OPWDD under a new People First Waiver.

In designing a People First Waiver, OPWDD must act in concert with all other State disability service agencies, under the clear direction of Governor Cuomo, to implement a consistent disability services policy. All State operated and funded services should be guided by a "community first" policy, which supports independence and individual choice of services in home and community based settings. This policy should include a comprehensive plan to move all people with disabilities out of settings that are less integrated than they need, into settings that are as integrated as possible.

Our state cannot afford to continue its reliance on an outdated, institutionally biased system, when innovative service models are available to serve people in the community, where they choose and have the right to live. We recommend a long-term, step-by-step process to achieve this vision, developed in collaboration with advocates, consumers and families. As a first step, we offer the following recommendations in response to the *Concept Paper: New York State's 1115 Waiver, Research and Demonstration Project*, produced by the New York State Office for People with Developmental Disabilities and New York State Department of Health, 2011.

- OPWDD must apply the new definition of "home and community-based" settings proposed by CMS (CMS-2296-P) for 1915(c) home and community based (HCBS) waivers to all residential services provided, under either a 1915(c) waiver or a new 1115 waiver. The regulations proposed by CMS would disallow provision of HCBS waiver services in facilities that have "institutional qualities," defined as "regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual's ability to engage freely in the community." In addition, community-based settings must not be housing that is "designed expressly around an individual's diagnosis or

disability", and must enable "individuals with disabilities to interact with individuals without disabilities to the fullest extent possible." Unfortunately, many existing community-based OPWDD services have these institutional qualities. We question whether OPWDD is substituting an 1115 waiver to avoid compliance with the new definition of "home and community-based" services for 1915(c) waivers.

- As OPWDD works to develop a specialized care management model for medical and long term services and supports, we urge OPWDD to consider adopting the successful DOH NHTD and TBI waiver Regional Resources Development Center (RRDC) model of care management, which is regionally administered. RRDCs, private not for profit community-based organizations with extensive expertise serving people with disabilities, are required to maximize the extent to which individuals are integrated into their communities; maintain cost neutrality; and recruit, train, and provide technical assistance to service providers to ensure that sufficient services are available and state-of-the-art techniques are implemented.
- OPWDD must adopt a phased plan to move people out of congregate segregated settings—not just the large institutions, but all of the Individualized Residential Alternatives (IRAs) that have institutional qualities. By shifting people out of these facilities, the State will significantly reduce Medicaid expenditures because individual integrated residential services are far less costly than segregated services. In addition, OPWDD must discontinue provision of directly-operated services and instead contract with not-for-profit agencies to operate all services. Recent public reports have shown that system regulation based on state employee rights and performance, not the rights of individuals with disabilities, does not work.
- OPWDD should continue its policy of eliminating sheltered workshops, which will save the State money and increase community integration. Under the People First Waiver, OPWDD should follow a phased plan, with specific goals and timetables, to convert all segregated congregate day programs to supported employment or one-on-one integrated community habilitation services.
- OPWDD should cease supporting residential schools, in or out of the state. OPWDD should adopt the DOH TBI waiver's successful model for repatriating people from out-of-state facilities to enable returning minor children to their family homes, by providing a broad array of suitably intensive in-home support services.
- OPWDD should take a proactive approach to ensure early intervention with, and prevention or remediation of, behavioral issues in young children in their natural homes by ensuring that generous levels of in-home positive behavioral support services, parent training, and respite are available to families immediately upon the identification of need.
- OPWDD should establish specific protocols for quality compliance. All serious incidents must immediately be reported to an independent investigative authority outside the OPWDD system. This authority should investigate all such incidents, addressing the conduct not only of OPWDD and/or its contractual service providers, but also that of school officials, county Adult Protective and Child Protective services, and police. The findings of all such reports should be made public and communicated to the authorities that oversee all involved parties.
- All people with developmental disabilities should have the ability to creatively design and control their service plans and budgets to meet their individual goals. Individuals must have control over *all* of their services and should be able to self-direct services, including selecting, training, scheduling and supervising people who provide services and supports that help maintain their independence in the community. For individuals who require assistance with self-direction, friends, family members or employed staff should be able to provide assistance.

NYAIL and its member Independent Living Centers look forward to working with Governor Cuomo and Commissioner Burke to reform the OPWDD system to reflect the goals of full community integration, choice and control over services, and independence for all people with disabilities.

For further information, please contact Melanie Shaw, Executive Director, email mshaw@ilny.org, ph. 518-465-4650.

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Introduction

The New York Association on Independent Living (NYAIL) is a membership organization representing people with disabilities and Independent Living Centers (ILCs) across New York State. Independent Living Centers are community-based not-for-profit providers of advocacy, services and supports for New Yorkers with disabilities of all ages, controlled by and largely staffed by people with disabilities. Independent Living Centers provide a wide range of services through the OPWDD system, as well as through the Consumer Directed Personal Assistance Program (CDPAP) and other state funded programs. ILCs have served as the voice of the disability rights movement, working to remove barriers to community integration and to ensure individual choice and control over services for all people with disabilities.

ILCs have helped the State to advance policies of community integration by transitioning and diverting people from costly institutional settings in the OPWDD system as well as nursing facilities for more than 20 years. ILCs have played a critical role in creating and implementing the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Medicaid Waiver programs, including serving as Regional Resource Development Centers (RRDC) and service providers. In addition, through contracts with DOH, NYAIL and ILCs are helping the State to rebalance the long term care system through the federal Money Follows the Person Rebalancing Demonstration (MFP). NYAIL works to increase accessible, affordable, integrated housing for seniors and people with disabilities, so that housing is available in the community for those who wish to avoid or leave institutions and ILCs are working to identify and assist individuals in nursing facilities who wish to live in the community.

NYAIL is uniquely qualified to offer the following comments on the People First Waiver *Concept Paper*, including our vision of a OPWDD system which supports individual choice and control and removes barriers to full community integration, including for people with the most severe disabilities.

Vision

The Americans with Disabilities Act and the US Supreme Court's *Olmstead*[1] decision require the State to provide services and supports to individuals with disabilities in the

[1] *Olmstead v. L.C.* [527 U.S. 581 (1999)]

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most integrated setting appropriate to the individual's needs. This principle must drive state policy for all disability and long term services and supports, including those provided by OPWDD under a new People First Waiver. It is our understanding that one of the primary reasons the state is shifting to an 1115 waiver is to control costs. A significant reason why the OPWDD system is very expensive is that it remains unnecessarily biased towards institutional care, or offers community facilities with institutional qualities, at a time when the State's resources are stretched and costs can be reduced under alternative community-based models that support independence and integration.

NYAIL has previously recommended to the SAGE Commission that the State's long term goal should be the full integration of all disability services, under an Office of Aging and Disability Services, and the elimination of existing State agency service system "silos," including those in DOH, OPWDD, OMH, SOFA and OASAS[2]. Even without full integration of the state's disability services, in designing a People First Waiver, OPWDD must act in concert with all other State disability service agencies, under the clear direction of Governor Cuomo, to implement a consistent disability services policy. All State operated and funded services should be guided by a "community first" policy, which supports independence and individual choice of services in home and community based settings. We believe that many residential settings considered by OPWDD to be "community-based" are in fact not integrated in the community. State policy should describe a comprehensive plan to move all people with disabilities out of settings that are less integrated than they need, into settings that are as integrated as possible. Best practices from New York and across the nation are available to guide policy makers in developing innovative programs and services which support community living and full community integration, as the State is required to provide under the *Olmstead* decision.

The Centers for Medicare and Medicaid Services (CMS) recently issued proposed rules for Section 1915(c) waivers[3], including a definition of "home and community based" services outlined below. The proposed regulations would disallow provision of home and community-based (HCBS) waiver services in facilities that have "institutional qualities" or are "designed expressly around an individual's diagnosis or disability." The proposed regulation requires services to be provided in settings that enable "individuals with disabilities to interact with individuals without disabilities to the fullest extent possible." OPWDD should adopt CMS's proposed definition of home and community-based settings for 1915(c) waivers in implementing the People First Waiver, even though this regulation may not apply to an 1115 waiver.

We applaud OPWDD's plans to restructure community-based service options to create real choice for people living both in institutions and the community, to reduce its remaining institutional capacity, provide better care coordination, improve quality and reduce costs, and place person-centered planning, individual responsibility and self-determination at the forefront of service delivery. We recognize that changes to a system created over 40 years

[2] *Recommendations to the SAGE Commission on Disability and Aging Services Restructuring*. New York Association on Independent Living. April 15, 2011.
[3] "Medicaid Program; Home and Community-Based Services (HCBS) Waivers." Centers for Medicare & Medicaid Services. 42 CFR Part 441 [CMS–2296–P].

cannot be achieved overnight. We recommend a long-term, step-by-step process to achieve this vision, developed in collaboration with advocates, consumers and families. With a new Governor and recently appointed OPWDD Commissioner, there is an opportunity for the State to adopt a new vision. As a first step, we offer the following recommendations in response to the *Concept Paper: New York State's 1115 Waiver, Research and Demonstration Project*, produced by the New York State Office for People with Developmental Disabilities and New York State Department of Health, 2011. We look forward to working together to develop goals and timetables for implementation, as well as a new structure accountable to consumers.

Five Year Plan: Designing Specialized Care Management Systems for the Developmentally Disabled

OPWDD plans to develop, in collaboration with stakeholders, a specialized care management model for medical and long term services and supports. As evidenced by the recommendations submitted by the New York State Medicaid Redesign Team and ultimately enacted in the 2011-2012 budget, the state is moving toward a managed care system. Our concern is that managed care will be managed "cost" and will not adequately serve people with the most significant disabilities in the community. Medicaid HCBS waiver services are already "managed" in that they have restrictive eligibility and needs assessment requirements, and require individualized service plans that must be clearly justified.

Models to be examined by OPWDD include "provider-based regional care management/coordination models" (*Concept Paper*, pg 3). As noted above, several ILCs have served for years as Regional Resource Development Centers for the NHTD and TBI waiver programs. **We urge OPWDD to consider adopting the successful DOH NHTD and TBI waiver Regional Resource Development Center (RRDC) model of care management, which is regionally administered.** RRDCs are private not for profit community-based organizations with extensive expertise serving people with disabilities. RRDCs are required to maximize the extent to which individuals are integrated into their communities; they are required to maintain cost neutrality; and they continuously recruit, train, and provide technical assistance to service providers to ensure that sufficient services are available and state-of-the-art techniques are implemented. There is no conflict of interest with the authorization and administration of services by an RRDC as there may be with a traditional care management organization.

Reduce Reliance on Institutional Care

OPWDD's operative definition of "institutional" is tied to the size and location of physical residential facilities. A facility over a certain size is deemed "institutional"; a facility smaller than that size and not located on the grounds of an "institution" is deemed "community-based". Much of the success of OPWDD's "de-institutionalization" is not attributed to the actual movement of people to their own homes, but rather to the classification of

"residential" settings by OPWDD. According to a brochure issued by OPWDD[4], residential service options include, "programs licensed by OPWDD to provide housing and services and, when appropriate, overnight supports to individuals living in group homes. These community residential programs are operated by either OPWDD or not-for profit provider agencies whose programs are certified by OPWDD," and include Individualized Residential Alternatives (IRAs), Community Residences (CRs), Intermediate Care Facilities (ICFs), Family Care, and Non-Certified Housing Options. The majority of these residential programs are congregate settings and are not fully integrated homes that enable meaningful interaction and involvement in the community for their residents. According to the most recent United Cerebral Palsy report of state rankings in *The Case for Inclusion 2011*[5], New York State ranks 36 in percentage of individuals who live in the community in settings with one to three residents.

Meanwhile, the definition of "home and community-based settings" has evolved, through both case law and proposed regulatory action, to more closely approximate what ordinary people mean when they use these terms. In *DAI v Paterson*[6], the US District Court found that the State had discriminated against people with psychiatric disabilities living in adult homes. The Court found that while the size of the facilities was an issue, the primary problem was restriction of residents' civil rights and liberties. The Court also found that facilities are "institutional" that don't let people with disabilities come and go freely, decide with whom they live, set their own bedtimes and mealtimes, have privacy, or choose who visits them and when. The Court did not rely for this finding on the facilities' written regulations and procedures, some of which describe greater theoretical freedom than residents actually experience. Instead, it credited testimony about actual conditions in the facilities. The court also rejected the argument that adult homes are not segregated because they are located in ordinary residential neighborhoods.

The proposed CMS rule for 1915(c) waivers noted above states that a community-based setting cannot have "qualities of an institutional setting", defined as "regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual's ability to engage freely in the community." In addition, community-based settings must not be housing that is "designed expressly around an individual's diagnosis or disability", and must enable "individuals with disabilities to interact with individuals without disabilities to the fullest extent possible." This rule, if adopted, would disallow use of HCBS waiver funds in nearly all of the IRAs now operated or funded by OPWDD. The IRAs have the "institutional qualities" described by *DAI v Paterson* and CMS in the proposed rule and they are "designed expressly around an individual's diagnosis or disability[7]." The question then becomes, is OPWDD substituting an 1115 waiver to avoid compliance with the new, more stringent definitions of "home and community-based services" about to be introduced by CMS for 1915(c) waivers?

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[4] *Facts About OPWDD*. New York State Office for People with Developmental Disabilities. http://www.opwdd.ny.gov/document/image/hp_brochures_factsaboutopw.pdf

[5] *The Case for Inclusion: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities*. United Cerebral Palsy. 2011.

[6] 653 F. Supp. 2d 184 (EDNY 2009)

[7] "Medicaid Program; Home and Community-Based Services (HCBS) Waivers." Centers for Medicare & Medicaid Services. 42 CFR Part 441 [CMS–2296–P].

Too often, individuals with significant support needs or behavioral issues continue to be institutionalized when alternatives are available. The state operates costly large Developmental Centers, specialty "intensive treatment" and "multiple disability" units for people with behavioral issues, and smaller ICFs. The most recent CMS expenditure data indicates that there was a 3.5% *increase* in total ICF-MR expenditures in New York State in 2009[8]. According to the *Poughkeepsie Journal*'s[9] recent investigation of the state's developmental disability system, "the last time New York closed a developmental center was in 1998 …", however, we understand OPWDD recently announced the closure of the West Seneca Developmental Center and the opening of several new "homes." The *Concept Paper* indicates that OPWDD will seek to end its reliance on institutions to house people with behavioral issues. We are pleased that OPWDD recognizes this problem but we are concerned that OPWDD will continue to use the specialty units. These units amount to a system of incarceration without trial for people with developmental disabilities. The *Poughkeepsie Journal*[10] noted that, "Lee Cannon, director of the Wassaic facility for two years until 1997, is troubled by the possibility, as he put it, that such units have 'no backdoor.' 'There's no definition of what 'intensive' is and there's no definition of 'treatment,'' he said. 'If treatment is only being in an intensive treatment unit, that's really not treatment. That's really a form of incarceration.'" We agree. We are concerned about OPWDD's plans for continuing "highly structured" services in an institution, even on a "temporary" basis.

In an effort to reduce reliance on institutional care, OPWDD must apply the new definition of "home and community-based" settings proposed by CMS for 1915(c) HCBS waivers to all residential services provided, under either a 1915(c) waiver or a new 1115 waiver. An important result of adopting this definition would necessarily be an end to using "step-down units"—group homes with many institutional qualities—as a place to move people released from developmental centers and specialty units. Individuals transitioning from these settings should have natural homes with individualized integrated residential supports.

Reimbursement Reform

The OPWDD service system is far too costly because of the institutional bias and direct operation of service facilities. The *Poughkeepsie Journal*[11] noted, "…Medicaid rates, which skyrocketed at developmental centers from $39 a day in 1975 to $2,149 by 2000, have become so lucrative that they may in fact be perpetuating institutional care in New York." A follow up investigation by the *Poughkeepsie Journal*[12] found that, "the current funding system 'generates' $5,118 per person, per day in Medicaid reimbursements – or $1.9 million a year — turning residents into 'cash cows' in the view of many observers. The rate, raised by 12 percent this year and paid half each by the state and federal governments, is

[8] *Medicaid Long-Term Care Expenditures in FY 2009*. Thomson Reuters. Steve Eiken, Kate Sredl, Brian Burwell and Lisa Gold. August 17, 2010.
[9] Pfeiffer, Mary Beth. (2010, June 20). At $4,556 a day, N.Y. disabled care No. 1 in nation. *Poughkeepsie Journal*.
[10] Pfeiffer, Mary Beth. (2010, September 8). New York: A Leader in Confining Mentally Disabled. *Poughkeepsie Journal*.
[11] Pfeiffer (2010, June 20) At $4,556 a day, N.Y. disabled care No. 1 in nation. *Poughkeepsie Journal*.
[12] Pfeiffer, Mary Beth. (2011, April 22). State Looks to Close Centers for Disabled. *Poughkeepsie Journal*

the highest in the nation by a factor of four." Interestingly, while New York State clearly leads the nation in spending on institutions for individuals with developmental disabilities, the state did not even rank in the top ten for quality of service according to the most recent United Cerebral Palsy report on the *Case for Inclusion 2011*[13]. **OPWDD must adopt a phased plan to move people out of congregate segregated settings—not just the large institutions, but all of the IRAs that have institutional qualities, as described above.**

By shifting people out of these institutions, the State will significantly reduce Medicaid expenditures because individual integrated residential services have been demonstrated to be one-third to one-fifth as expensive as segregated services for people with the same needs. For example, according to Onondaga Community Living[14] (OCL), their Community Support Services, which are personalized supports for people to live in their own homes, including people with intense 24-hour needs, cost on average, $55,556 per person annually. In contrast, the Central New York Developmental Disabilities Service Office rates per individual are as follows: Supervised IRA, $89,000; ICF, $135,000; and Institutional/Forensic Centers, $385,000 per person annually. In this example, moving people to integrated settings with personalized supports would reduce Medicaid expenditures by a minimum of $33,444 per person annually.

In addition, OPWDD must discontinue provision of directly-operated services and instead contract with not-for-profit agencies to operate all services. People with disabilities cannot entrust their rights to a system which values employee rights higher than those of individuals with disabilities. Recent public reports have shown that system regulation based on state employee rights and performance, not the rights of individuals with disabilities, does not work.[15] In addition, cost savings would accrue to the State in shifting to not-for-profit service delivery as current wage and benefit packages for OPWDD employees cost more than those of employees who do the same kind of work in nonprofit agencies[16].

Safety Net Pool

An integrated community-based life for people with developmental disabilities includes more than housing supports. Currently, New York ranks only 36 for states who support meaningful work, as a percentage of individuals with intellectual and developmental disabilities in supportive or competitive employment[17]. OPWDD has previously supported downsizing and closing all sheltered workshops operated or funded by the agency.

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[13] *The Case for Inclusion: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities*. United Cerebral Palsy. 2011

[14] Onondaga Community Living is a non-profit agency that provides non-segregated, individualized residential supports to people with developmental disabilities in Central New York.

[15] Hakin, Danny. (2011, March 12). "At State-Run Homes, Abuse and Impunity." *New York Times*.

[16] For example, according to the former Director of the Central New York DDSO, a Medicaid Service Coordinator employed directly by the state earns approximately $39K annually, while a service coordinator employed by a nonprofit earns approximately $28K annually to perform the same job.

[17] *The Case for Inclusion: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities*. United Cerebral Palsy. 2011

According to the Executive's agency presentation for OPWDD for the 2011-2012 budget[18], "funding for workshop, day training and other day services will be reduced to encourage placements into other more effective community-based integrated day and employment programs." We commend New York State for making a commitment to reduce reliance on sheltered and day services. Yet, this section of the *Concept Paper* appears to endorse sheltered workshops, which is both confusing and concerning. Nationally, for every $1 spent on supported employment, $4 are used for segregated day programs[19]. **We believe OPWDD should continue the policy of eliminating sheltered workshops, which will save the State money and increase community integration.** Rather than providing funding to support sheltered workshops under the People First Waiver, OPWDD should follow a phased plan, with specific goals and timetables, to convert all segregated congregate day programs to supported employment or one-on-one integrated community habilitation services.

We agree that OPWDD should provide services which "allow individuals with developmental disabilities to remain in their natural home settings" (*Concept Paper*, pg.4). A long-term residential setting for a minor child that is not the child's natural home is not the most integrated setting appropriate to the need, if appropriate home and community based services are available as an alternative. OPWDD should cease supporting residential schools, either in or out of the state. **OPWDD should adopt the DOH TBI HCBS waiver's successful model for repatriating people from out-of-state facilities to enable returning minor children to their family homes, by providing a broad array of suitably intensive in-home support services.**

Families of people with developmental disabilities have identified the need for intensive in-home behavioral supports as well as crisis intervention and temporary respite services as a top priority. Although crisis services are lacking, important, and must be provided, we believe OPWDD should also provide essential early intervention and prevention services. Intensive behavioral remediation services are critical for young children. Addressing behavioral issues when they first appear can extinguish them before they become severe, and provide opportunities to teach parents to interact in more beneficial ways with their children and prevent new behavioral issues from appearing. **OPWDD should take a proactive approach to ensure early intervention with, and prevention or remediation of, behavioral issues in young children in their natural homes by ensuring that generous levels of in-home positive behavioral support services, parent training, and respite are available to families immediately upon the identification of need.**

A coordinated system of disability service programs will greatly ameliorate the service access problems experienced by people with dual diagnoses of developmental and psychiatric disabilities. OPWDD, OMH, and other state disability service agencies should work collaboratively in designing and reforming services for this population, identifying and removing eligibility and procedural barriers, as well as administrative redundancies.

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[18] Agency Presentation for FY 2011-2012. Office for People with Developmental Disabilities. http://publications.budget.state.ny.us/eBudget1112/agencyPresentations/pdf/opdd.pdf

[19] *Segregated and Exploited: A call to action!* National Disability Rights Center. January 2011. http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Segregated-and-Exploited.pdf

Quality Improvement

In our collective experience with the developmental disabilities system in New York State, segregated congregate settings are not as safe as integrated community settings due to an "institutional culture" which tolerates low standards for interaction between staff and clients and low expectations for quality of life. Because these settings are primarily workplaces, not natural homes or real community living, procedures and practices are inevitably designed for the convenience and efficiency of staff. While there are many dedicated and well-meaning people working in these settings, this does not effectively prevent people with disabilities from being neglected and abused, as described in the recent *New York Times*[20] article. We appreciate steps OPWDD has recently made to address these extremely troubling revelations. We are concerned that the policy of reminding providers and staff to report crimes that occur in these settings to the police may not produce the desired result of actually protecting individuals or punishing staff. Police often refuse to consider people with developmental disabilities as credible witnesses and do not consider staff of segregated disability facilities to be under their jurisdiction, and it has been our direct experience that police usually will not investigate these reports. Similarly, increased internal review of incidents will not improve this situation. Requiring OPWDD or voluntary service providers to investigate themselves and determine whether an incident should be reported to an independent authority, as is current practice, is an obvious conflict of interest.

Instead, **all serious incidents must immediately be reported to an independent investigative authority outside the OPWDD system**. This authority should thoroughly investigate all such incidents, addressing the conduct not only of OPWDD and/or its contractual service providers, but also that of school officials, county Adult Protective and Child Protective services, and police, as it relates to the reported incident. The findings of all such reports should be made public and communicated to the authorities that oversee all involved parties.

Because institutions are isolated from society's eye, we believe that people with disabilities are safer in integrated natural settings, where they frequently interact with a mixture of people, most of whom are not paid to serve them. The DOH TBI waiver program has demonstrated that when people are served in their homes by workers employed by several agencies, those workers provide an effective "check" on each other to detect and quickly resolve problems. Refraining from putting people into segregated congregate settings, and moving people out of them as quickly as practicable, is ultimately the only effective way to address the likelihood of abuse.

In the meantime, service coordinators for people living in residential facilities must not be employed by the agencies that own/operate those facilities. This will remove another serious conflict of interest that frequently results in incidents not being properly reported or resolved. Caseloads for service coordinators whose clients live in segregated congregate facilities should be reduced (with a commensurate increase in rates paid for service

[20] Hakin, Danny. (2011, March 12). "At State-Run Homes, Abuse and Impunity." *New York Times*.

coordination), and a minimum requirement of one face-to-face meeting per week should be applied. This will provide much-needed independent oversight for people who are at the highest risk of neglect and abuse.

Self-Determination and Self-Direction

According to the *Concept Paper*, "A transformed long-term care delivery system that places person-centered planning, individual responsibility and self-determination at the forefront can enhance care and individual satisfaction and lower Medicaid costs" (*Concept Paper,* pg. 2). While we support the concept of self-determination, the model as it currently operates is flawed. It is our observation that the program is difficult to navigate, confusing to consumers, and not truly supported by OPWDD staff.

According to the Self Advocacy Association of New York State, the key elements of self-determination are: "Freedom, Control, Authority, Support, a Portable Budget and the contribution of Self-Advocacy[21]." **We believe that all people with developmental disabilities should have the ability to creatively design and control their service plans and budgets to meet their individual goals.** Self-determination should be offered as the first option. As individuals are moved out of institutional settings, funds should shift from institutional programs to community-based programs for self-determination. The Consolidated Supports and Services program's "circle of support" has proven to be very successful but not all individuals can take advantage of it. Many people lack involved friends and family, while others have informal supports who are unwilling to assume liabilities for participation. For some individuals, a service coordinator could serve this purpose. Finally, individuals must have control over *all* of their services and should be able to self-direct services, including selecting, training, scheduling and supervising people who provide services and supports that help maintain their independence in the community. For individuals who require assistance with self-direction, friends, family members or employed staff should be able to provide assistance.

Conclusion

People with developmental disabilities want to live meaningful, independent lives as full participants in their communities. As Commissioner Burke has recently noted, New York has the opportunity to create a nationally recognized system which promotes person-centered planning and quality care and allows increased self-direction. Our state cannot afford to continue its reliance on an outdated, institutionally biased system, when innovative service models are available to serve people in the community, where they choose and have the right to live. NYAIL and its member Independent Living Centers look forward to working with Governor Cuomo and Commissioner Burke to reform the OPWDD system to reflect the goals of full community integration, choice and control over services, and independence for all people with disabilities.

For further information, please contact Melanie Shaw, Executive Director, email mshaw@ilny.org, ph. 518-465-4650.

[21] *Making it Happen! Stories of Self-Determination Using Consolidated Supports and Services in New York State*. The Self-Advocacy Association of New York State, Inc. 2006.