

## Self-Determination Cross-disability Advocates/CMSO Issues Agenda

On July 23<sup>rd</sup>, 2009, Cindy Mann, Director of Medicaid and State Operations met with a coalition of advocates/researchers (organized by the Center for Self-Determination) representing a variety of people with disabilities. The meeting included Tom Nerney, Executive Director and Pat Carver, Center for Self-Determination, Dan Fisher MD, PhD, National Empowerment Center, Susan Goodman Esq., National Down Syndrome Congress, Dr. James Conroy, Conroy Outcome Analysis, Eli Cohen, Esq. Former Commissioner on Aging PA, Public Interest Law Center, and Ari Ne’eman, the Autistic Self Advocacy Network. Absent from this meeting were Judith Cook PhD, Professor, Department of Psychiatry, U of Illinois at Chicago and Mike Oxford, ADAPT, Center for Independent Living and Topeka Independent Living Resources Center.

Cindy Mann committed to ongoing regular meetings with this group. The inventory of the issues raised at the meeting below will be updated periodically to reflect our progress. Future agenda topics can be drawn from those noted.

	Issue	Source	Lead Division	Response/Action Taken
<b>Self Determination</b>				
	The philosophy of independent living and self determination should govern all home and community services and supports programs.	ADAPT		
	CMS should continue to support <u>and expand</u> these systematic approaches (New Hampshire, Michigan, California, and New Jersey) of which self-directed models and Cash & Counseling are less intensive subsets. The self-determination and self-direction approaches should be included as an integral part of overall health care reform in America.	Judith Cook		
	Aided by the explosive expansion of information, Americans have become, and will continue to	Judith Cook		

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	<p>become, more and more able to consider their own individual options in treatment and supports. This trend cannot be reversed, and should be embraced in CMS policy. It includes the systems targeting intellectual and developmental disabilities, physical disabilities, mental health, and aging. These previously disparate and competing “interest groups” are joining together in an historic agreement: the desire to take a strong part in the construction of lives and supports that they want for themselves. The magnitude of this nascent shift in the aging field cannot be overstated. Extremely rapid-response research efforts must be set in motion immediately if we are to understand them quickly and detect/avoid potential errors.</p>			
	<p>Put policies in place to maximize the principles of self-determination, person-centered planning and community integration for all people with disabilities.</p>	Ari Ne’eman		
<b>Medicaid Program Features/Flexibilities</b>				
	<p>Review the court decision giving CMS (HCFA) the right to interpret the statute to prohibit room and board expenses for those in the community.</p>	Tom Nerney		
	<p>Provide leadership to the states (and pilots as well) under section 1115 to allow for Medicaid dollars to supplement Social Security benefits with the proviso that total community costs not exceed on average institutional costs.</p>	Tom Nerney		
<b>Consumer Involvement</b>				

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	All home and community services and supports programs' oversight should include consumers of services.	ADAPT		
	Establish a regular mechanism for mental health consumer participation in Medicaid and Medicare policy development at the federal and state levels.	Dan Fischer		
	Create a National Consumer advisory Committee to CMS which is representative of state mental health consumer-run organizations.	Dan Fischer		
	Ensure that the mandated "Medicaid Advisory Councils" Code of Federal Regulations 42, Section 431.12 have meaningful consumer participation.	Dan Fischer	DEHPG/OGD	7/23/09: Cindy Mann committed to looking into offering guidance to States to ensure that Medicaid Advisory Councils have meaningful consumer participation.
	CMS would collaborate with SAMHSA to make grants available to statewide consumer groups to involve them in Medicaid policy development and implementation (similar to the role MPOWER plays in MA)	Dan Fischer		
	Establish a regular mechanism for all self-advocate consumer participation in Medicaid and Medicare policy development at the federal and State levels	Ari Ne'eman		
<b>Transition to the Community</b>				
	Add "any congregate facility of any size" to the category allowing one-time expenditures of Medicaid dollars such as security deposits and furniture for those who want to live in their own	Tom Nerney		

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	place. (SMDL #02-008)			
	CMS should develop an effective method for identifying individuals who wish to move out of facilities and institutions. This method should include an individualized assessment of needs and strengths that substantially involves the individual, including others that the individual wishes to participate in the assessment. People with disabilities of all ages and disability rights advocates should be included in, and should oversee, all levels of development and implementation of this method.	ADAPT		
	CMS should track savings accrued from people leaving, and avoiding entering, facilities and institutions. CMS should require States to track and report the same savings. Savings, both state and federal, should be targeted toward paying for home and community-based services and deinstitutionalization efforts.	ADAPT		
	Undertake a policy initiative directed at general hospitals to shift the current focus from discharge <i>out</i> of the hospital at the end of a patient stay to discharge <i>to</i> the patient's home or other primary residence. This policy initiative requires significant changes in state and local social service agency policies and priorities, particularly those responsible for in-home and community based services, and particularly Area Agencies on Aging and the State Unit on Aging. The ultimate	Eli Cohen		

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	<p>outcomes of such a policy initiative include the following:</p> <ul style="list-style-type: none"> <li>• Standardized policies and procedures by general hospitals that include initiation of planning for discharge to home and/or family at <i>admission</i> of the patient to the hospital.</li> <li>• Development of Agreements of Understanding to be entered into by CMS and the Administration on Aging to undertake the development of the policy initiative.</li> <li>• Involvement in the policy initiative of major interest groups including state agencies administering Medicaid and social service programs, the American Hospital Association, trade associations for long term care associations, NASW, AARP and the Center for Self-Determination.</li> <li>• Careful tracking of discharge destinations of hospitalized elderly patients, with particular attention to residence at different time periods (e.g. 60 days, 120 days and 180 days following hospitalization).</li> <li>• Economic analysis of the impact of new and changed discharge planning</li> </ul>			

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	policy.			
<b>Olmstead Planning/Enforcement</b>				
	CMS should require development of comprehensive, effectively working Olmstead plans. Development should include people with disabilities of all ages and disability rights advocates. Plans should contain clear goals to end the institutional bias within 5 years.	ADAPT		7/23/09: Cindy Mann recognized the need for more CMS involvement in Olmstead enforcement including coordinating with the Office of Civil Rights.
	The Department of Health and Human Services through Office of Civil Rights and the U.S. Department of Justice should take the lead in requiring strong enforcement of Olmstead through third-party independent review. This could be accomplished by identifying and assessing individuals who want to live in the community and developing individualized plans of support based on principles of self determination.	Susan Goodman		
	Alter state reimbursement structures to support the movement of individuals with disabilities with developmental or other disabilities into the community and to reward states for taking steps to implement Olmstead.	Ari Ne'eman		
<b>Waiting lists</b>				
	CMS should require states to gather and report waiting list data. This data should be published and shared on a regular basis. Effective, streamlined methods to get this data in the hands	ADAPT		

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	of disability rights advocates and service providers so that individuals can be contacted and assisted should be developed and implemented with significant involvement of people with disabilities of all ages and disability rights advocates. CMS should require states to make significant, meaningful progress toward reducing the size (numbers) of waiting lists. CMS should set standards for length of time anyone waits for services. Wait time should be reasonable			
<b>Self-Direction</b>				
	Self direction and control of financial resources should be an available choice within all home and community services and supports programs.	ADAPT		
<b>Services for People with Mental Illness</b>				
	Create a Mental Health Recovery Demonstration to ease the process of increasing coverage for recovery-oriented services in the community.	Dan Fischer		
	Alternatives to Psychiatric Hospitalization and Prisons: To decrease the utilization of emergency rooms, police, psychiatric hospitalization, and jails Medicaid could fund peer-run crisis respite, warm lines, and in home supports.	Dan Fischer		
	Peer support reimbursement by Medicaid: Peer providers (known as Peer Specialist) have been shown to be effective in providing recovery-based services to people with psychiatric disabilities, and don't need mental health professionals as	Dan Fischer		

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	supervisors: need a new letter to state Medicaid Directors.			
	Medicaid reimbursement of Consumer Directed Personal Care Assistants (PCA) in Mental Health: That CMS issue interpretive guidelines to the state Medicaid Authorities detailing the ways that PCA's can be used for mental health. The guidelines could draw on Oregon and New York as examples.	Dan Fischer		
<b>Services for People with Development Disabilities</b>				
	No entity should be allowed to receive Medicaid reimbursement for services/programs allegedly provided to a disabled child with an IEP who is Medicaid-eligible if the entity is permitted to use seclusion – by law, regulation, guidance or custom- on any person of any age with a developmental disability.	Ari Ne'eman		7/23/09: Cindy Mann committed to consult with the Department of Education.
	Develop and expand existing state grants intending to serve as bridge funding for the elimination of Developmental Centers and the development of community services and housing capacity to shift their population towards.	Ari Ne'eman		
<b>Person-centered Planning</b>				
	Personal self-determination accounts and Person-driven recovery Planning: To increase the consumer control and consumer choice, persons with psychiatric disabilities should have a self-determination account, broker, and life plan by	Dan Fischer		

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	which they can budget and pay for a variety of community services as in Iowa and Florida.			
<b>Quality</b>				
	<p>Review the federal guidelines as well as all state quality assurance plans to include outcome based quality standards that move from simply accepting satisfaction with human services to measuring outcomes in the lives of individuals who are served. These would include at a minimum (TN):</p> <ul style="list-style-type: none"> <li>• The presence of long term committed relationships especially as a feature of keeping healthy and remaining safe</li> <li>• The ability to truly belong in one's community through membership and relationships</li> <li>• The ability to address impoverishment in positive ways through employment, self employment, asset development and asset protection through insurance and reverse mortgages</li> <li>• The ability to have a place to call home where whoever enters the front door is invited by the person with a disability</li> <li>• Providing for the individual to select those who may assist in planning and budgeting</li> </ul>	Tom Nerney		

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	<p>creatively through a fair allocation process. This would include authority over all hiring and purchasing decisions.</p> <ul style="list-style-type: none"> <li>• Include family issues on children’s plans that enable the family to remain cohesive and supportive</li> <li>• Show increased respect for individuals with disabilities and families by reducing the bureaucracy and paperwork they have to face</li> <li>• Take definitive steps to evaluate and replace sub minimum wages, segregated work activities centers/sheltered workshops and group “community experience” programs.</li> </ul>			
	Peer-directed recovery-based evaluation and CQI: Traditional quality assurance which is professionally directed needs to be replaced by peer-directed, continuous quality improvement based on recovery outcomes, like ROSI.	Dan Fischer		
<b>Medical Necessity</b>				
	Broadening Medical Necessity to cover Medicaid reimbursement of community-based, holistic services: The state Medicaid authorities narrowly interpret CMS’s term medical necessity to mean only medically directed services, disallowing many community-based services, despite there	Dan Fischer		

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	being no federal mandate for such a narrow definition,( as MI has done)			
<b>Economic Self-Sufficiency</b>				
	Income and Assets and Economic Self-Sufficiency Central to the lack of real community participation and ongoing committed relationships is what amounts to the forced impoverishment of individuals who are both Medicaid and Social Security beneficiaries.	Tom Nerney		
	Provide leadership to the states in creating Individual Development Accounts (matched savings accounts) that do not jeopardize current benefits. These accounts would enable individuals to save for housing down payments, purchasing transportation, self employment and post secondary education or training.	Tom Nerney		
	In line with point above, collaborate with the Social Security Administration in providing a very large waiver/demonstration of the utility of moving the threshold for the 50% reduction in SSI benefits (for every dollar earned) from \$85 a month to \$500 a month for working age beneficiaries of both Medicaid and Social Security. Provide Individual Development Account opportunities with this Waiver and explore the legal possibilities for doing this with those who are SSDI beneficiaries.	Tom Nerney		
	Assist the states in helping individuals especially those who are older obtain long term care	Tom Nerney		

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	insurance and ethical reverse mortgages that would blend seamlessly with Medicaid dollars and allow individuals/couples to keep more resources.			
<b>Transportation</b>				
	Direct the states in clarifying that 42 CFR 431.53 must cover transportation under community participation.	Tom Nerney		