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122 C Street NW – Suite 125, Washington D.C. 20001 - 202-626-7949

Public Comment of Ken-Crest and Lutheran Services in America Disability Network before the HHS Bipartisan Commission on Medicaid Reform

William J. Nolan, CFP – Executive Director, KenCrest Centers, Chair, Lutheran Services in America – Disability Network – January 25, 2006

My name is Bill Nolan. I am the Executive Director of KenCrest Centers. My organization just celebrated its 100th Anniversary – and I am privileged to serve as its CEO for the past twenty-five years.

Before I go on, I want to say thanks to each of you for your service on this commission. You are helping to shape the future of Medicaid and in a very real sense taking responsibility for decisions that will affect the lives of millions of Americans.

Today I come to you on behalf of my organization, KenCrest, and as the chair of Lutheran Services in America - Disability Network.

I am joined today by Jennifer Graham, Catherine Nold and Jay Grimes, parents of children with developmental disabilities. We are here to speak with you about Medicaid as it supports people with developmental disabilities in being productive, engaged citizens of their communities and this nation.

KenCrest provides supports and services from birth through retirement for people with developmental disabilities. Last year alone our organization touched the lives of more than 6,600 residents of the greater Philadelphia area and the state of Delaware. Our supports are community-based and our services range from in-home early intervention, parent education, and preschool developmental day care to therapy services, long-term residential and employment services, and, most recently, services for high school special education students transitioning into the adult service network.

Virtually all the people we support are considered "dual-eligible" – they are well below the poverty level and use both Medicaid and Medicare funds to survive. They are people with mental retardation or developmental delay. Some of our

clients are also medically fragile and would otherwise be long-term residents in hospital settings.

KenCrest is a member of Lutheran Services in America (LSA) and its Disability Network. Lutheran Services in America is an alliance of national Lutheran church bodies and their health and human service organizations.

LSA has 300+ member organizations with combined annual budgets totaling just over 8 billion dollars. Quietly and effectively, as non-profit agencies, this faith-based network directly serves over 6 million unduplicated clients annually. That is one out of every 50 people in the United States.

Our supports and services take place in community and campus settings in over 3,000 communities in every state in the nation. Together we provide a paid and unpaid (volunteer) workforce of over a quarter of a million people.

The LSA-Disability Network is comprised of 13 LSA member organizations supporting individuals with developmental disabilities. Our network provides support to more than 12,000 individuals in 30 states and the U.S. Virgin Islands. Network members share expertise and best practice in developing and providing high quality, individualized support, including rehabilitation services, employment support, residential services, respite care and independent living.

We come to you today to speak specifically to Medicaid eligibility for people with developmental disabilities, a group for whom Medicaid has made a considerable difference in encouraging them to live as independently and productively as possible in their communities.

By and large they qualify for SSI or SSDI. This means they are the lowest-income citizens in our country. They can have personal resources of no more than $2,000. Most receive a payment of $603 a month and some states supplement that raising their income to $7,400 a year. But, even this is not true since by regulation they are required to contribute to "room and board" in most settings. In ICF facilities this leaves the individual with $30 spending money a month. In community supports a mandatory 72% contribution leaves $169 a month or just over $2,000 a year for everything else a person might want or need.

The people we are talking about must have a severe, "medically determinable physical or mental impairment." The individual must also, by reason of impairment, be unable to engage in any "substantial gainful activity." Although somewhat modified, "to work" still threatens the loss of health care, or to risk losing a placement and falling back into deep waiting lists.

It is important to realize that this "eligibility" does not mean getting needed services, or for that matter any services at all. Although not recognized by the

federal government or by many states there are deep existing waiting lists for service. There is also a "shadow" waiting list that looms quite large. For example in Pennsylvania there are over 37,000 people living with caregivers over 60 years of age. The national estimate is over 700,000 people and growing. There is little question that the overwhelming majority of these people and their caregivers will become eligible and require Medicaid services sometime in the next couple of decades.

You already know many of the facts of Medicaid. You know how complex Medicaid is and how that complexity multiplies for people like ours who are dependent on both Medicaid and Medicare. You have been told that Medicaid is expensive and it is. Long-term care for people with mental retardation who are housed in state-institutions averages $400 a day and can cost upwards of $783 in New York and $503 in Pennsylvania (I am using data from the latest Coleman Institute's State of the State report issued by Dr. David Braddock, Coleman Institute for Cognitive Disabilities – The University of Colorado 2005).

What may not be as clear are two points:

> **The growing ability of Medicaid to allow supports and services to individuals through a variety of "waivers" and flexibility in service definitions is a good thing.** In the same "State of the State" report quoted in the last paragraph you will find the average "personal support service" daily cost of $42 for New York and $15 for Pennsylvania
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> This ability of Medicaid to be used at the point of need - in community - and with decision makers close to the individuals served is a part of Medicaid that should be encouraged and expanded.
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> Of course, my example is of two very different levels of service and that is the point. There should be more and more options for people so that they are not, as in the recent past, forced to choose from only the most expensive option.
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> This leads to the second point: That the ability to more precisely tailor and fund those supports is also a good thing. One size cannot fit all and proposals that support **funding following the person are valuable**. Given the financial ability to offer appropriate locally based alternatives, people who are directly involved will make more cost-effective decisions. Information will drive efficiencies. I will drive across the street to get cheaper gasoline.

My last point is discussed only rarely and is especially important in my non-profit world – the world of Lutheran Services in America. Simply stated, **we are helping make Medicaid dollars an investment rather than an expense**. Seen

in this light Medicaid dollars are positive investments – in people and in communities.

As part of the economic fabric of each municipality, township and county, we generate revenue, provide jobs, use local vendors, pay taxes (KenCrest and its employees pay about 6 million) and spend in ways that strengthen the whole local economy.

We gather community support, some call it community capital. We give people opportunity, we train people and find them employment and help make them members of the community – and taxpayers.

Lutheran Services in America agencies have learned much in our many years of public service. Our member agencies can and should continue to be invited to the table and challenged to help find better ways to deliver our services to people with mental retardation and developmental delay in all the life-long supports and services needed by this population. We are struggling with you and remain committed to making our dialogue positive and productive. Thank you for the time and again, thank you for your service to our country.

Attachments from Presidents Commission on Intellectual Disability and David Braddock's State of the States in Developmental Disabilities 2005 publication – Citations Follow.

People with intellectual disabilities, like all Americans, share the American dream to advance their social and economic freedoms, and more and more people are doing so successfully. Self-determination has become a nationwide movement that commands the attention of policymakers at every level of federal, state, and local government. There are increasing numbers of individuals with intellectual disabilities included in mainstream classrooms and post-secondary schools and training. Many adults are living independently or with supports in the community, marrying, having families, and working, just as other Americans. The self-advocacy movement has grown tremendously and there are now self-advocacy organizations in forty-four states.[9]

Although these examples represent significant progress, such progress is often not reflected in the life of the average person with intellectual disabilities. It is estimated that between seven and eight million Americans of all ages, about 3 percent of the general population, have intellectual disabilities.[10] Taking the year 2002 as an example:

- Around 90 percent of adults with intellectual disabilities were not employed.[11]
- Less than 1 percent of people with intellectual disabilities owned their own home.[12]
- 26 percent of youth with intellectual disabilities dropped out of school.[13]
- Fewer than 15 percent participated in post-secondary education.[14]
- Over 365,000 people were employed in sheltered workshops or were in day programs or prevocational services.[15]
- Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) were a major source of income for people with intellectual disabilities. In December 2001, there were almost 1.1 million adults and children receiving SSI payments based on intellectual disabilities. There were almost 600,000 receiving SSDI benefits.[16]
- At least 50,000 people with intellectual disabilities were on waiting lists for Medicaid waiver services for individual and family supports.[17]
- Over 700,000 people with intellectual disabilities lived with parents aged 60 or older.[18]

These dismal statistics describe a situation that would clearly be unacceptable for any group of people in this great nation in the 21st Century. Applied to such a significant portion of the population, they are simply intolerable and must be improved.[i]

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[i] The PCPID considers the terms "mental retardation" and "intellectual disabilities" to be synonymous, covering the same population in number, kind, level, type and duration of the disability, and the need by individuals for specific services and supports. Thus, the American Association on Mental Retardation's definition for "mental retardation" serves as the definition for "intellectual disabilities." The PCPID is aware that there is a strong need for continued improvement in both quantity and quality of data collected and used in this report and other publications in the field.

Table 14
AVERAGE DAILY RESIDENT COSTS IN STATE-OPERATED INSTITUTIONS

State	FY 2001	FY 2002	Real Change 2002-2004[2]
Alabama	$521	$469	5%
Alaska			
Arizona	$286	$296	-8%
Arkansas	$241	$222	3%
California	$581	$459	20%
Colorado	$380	$410	-12%
Connecticut	$697	$693	-5%
Delaware	$453	$395	8%
District of Columbia			
Florida	$308	$252	16%
Georgia	$226	$217	-2%
Hawaii			
Idaho	$718	$576	18%
Illinois	$331	$316	-1%
Indiana	$563	$500	6%
Iowa	$399	$348	8%
Kansas	$327	$338	-9%
Kentucky	$459	$382	13%
Louisiana	$328	$291	7%
Maine			
Maryland	$457	$387	12%
Massachusetts	$512	$523	-7%
Michigan	$637	$475	27%
Minnesota	$813	$682	13%
Mississippi	$247	$248	-6%
Missouri	$287	$278	-2%
Montana	$618	$372	57%
Nebraska	$327	$258	20%
Nevada	$543	$430	19%
New Hampshire			
New Jersey	$404	$321	19%
New Mexico			
New York	$783	$831	-11%
North Carolina	$386	$344	6%
North Dakota	$394	$320	16%
Ohio	$345	$327	0%
Oklahoma	$380	$384	-6%
Oregon	$541	$1,732	-70%
Pennsylvania	$503	$432	10%
Rhode Island			
South Carolina	$300	$303	-7%
South Dakota	$307	$270	7%
Tennessee	$698	$568	16%
Texas	$268	$239	6%
Utah	$394	$377	-1%
Vermont			
Virginia	$316	$317	-6%
Washington	$403	$379	0%
West Virginia			
Wisconsin	$474	$421	6%
Wyoming	$636	$420	43%
United States	**$400**	**$365**	**4%**

[1] States with no data reported did not finance 16+ state-operated institutions.

[2] Adjusted for inflation.

Source: Braddock, Hemp, & Rizzolo, Coleman Institute and Department of Psychiatry, University of Colorado, 2005.

Table 6
ANNUAL COST OF CARE PER RESIDENT IN SIX SETTINGS: FY 2004[1]

State	Institutions for 16+ persons			ICFs/MR for 15 or fewer persons		Supported Living/ Personal Assistance
	Private					
	ICF/MR	Non-ICF/MR	State-Operated	Private	Public	
Alabama			$190,221	$49,673		$14,201
Alaska						$52,371
Arizona	$173,398		$104,507		$91,895	$14,756
Arkansas	$74,711	DNF	$87,818	$51,104		$22,968
California	$51,798	$15,033	$212,096	$48,898		$15,336
Colorado			$138,608	$70,167		$15,224
Connecticut		$15,049	$254,560	$147,162		$33,321
Delaware	$94,283		$165,232			$22,992
District of Columbia		$85,442		$106,699		DNF
Florida	$72,934	$50,009	$112,576	$133,376		$7,374
Georgia	$57,735		$82,358			$19,999
Hawaii	$155,114			$83,591		$20,275
Idaho			$262,170	$103,562		$15,586
Illinois	$49,386	$44,975	$120,969	$42,401		$11,162
Indiana	$54,900		$205,659	$61,045		$33,994
Iowa	$88,463	$20,961	$145,671	$76,833		$23,283
Kansas	$153,536		$119,238	$87,094		
Kentucky	$117,655		$167,546		$281,340	$9,252
Louisiana	$46,162	DNF	$119,872	$52,863	$59,116	$7,916
Maine	$127,494	DNF		$144,581		$66,264
Maryland		$150,045	$166,761			$32,031
Massachusetts			$186,896			$29,213
Michigan		$34,000	$232,439			$23,276
Minnesota	$49,499		$296,779	$76,197	$108,919	$14,794
Mississippi	$63,888		$90,328		$67,849	$7,829
Missouri	$373,002	DNF	$104,877	$61,448		$30,902
Montana			$225,527			$13,584
Nebraska	$71,270		$119,391	$77,297		$12,161
Nevada			$198,364	$80,300		$26,989
New Hampshire	$76,910					$4,187
New Jersey	$285,219	$38,792	$147,415			$23,764
New Mexico				$63,560	$280,253	$67,886
New York	$92,179	DNF	$285,900	$112,102	$166,988	$15,480
North Carolina	$61,218	DNF	$140,829	$71,504		$20,698
North Dakota	$150,380	DNF	$143,632	$87,842		$26,250
Ohio	$64,463	DNF	$126,017	$85,432		$29,763
Oklahoma	$28,866		$138,618	$39,002		$92,709
Oregon		$235,495	$197,539			$25,572
Pennsylvania	$92,098	$33,620	$183,640	$103,053		$5,289
Rhode Island	$193,485				$198,498	$56,026
South Carolina			$109,337	$42,976	$69,869	$9,733
South Dakota		DNF	$112,193			$5,272
Tennessee	$77,917		$254,752	$138,275		$52,933
Texas	$54,353		$97,713	$43,450	$50,753	$5,453
Utah	$44,349		$143,953	$49,824		$9,695
Vermont				$264,511		
Virginia	$89,685		$115,188	$177,032		$10,897
Washington		$18,149	$146,970	$72,123		$28,171
West Virginia	$77,427			$112,691		$23,766
Wisconsin	$76,700	$141,956	$173,069	$65,088		$16,333
Wyoming			$231,978			$43,569
United States	**$68,163**	**$18,959**	**$146,325**	**$75,431**	**$85,945**	**$21,021**

[1] Computed from average daily resident and financial data provided by the states; a blank space indicates the state did not provide the service and "DNF" indicates that data were not furnished.

Source: Braddock, Hemp, & Rizzolo, Coleman Institute and Department of Psychiatry, University of Colorado, 2005.