SILCK

Statewide Independent Living Council of Kansas, Inc.

RESOURCE PAPERS

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ATTACHMENT
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RESOURCE PAPERS

Table of Contents **Pages**

Table of Contents	Pages
Introduction	2-3
The Historical Background of HCBS	4-6
Employment-Working Healthy	7-9
The Work of the CILs	10-13
Five Good Reasons	14-17
Future Opportunities for KS	18-19

Introduction

The first Amendment to the Kansas Bill of Rights provides **Equal Rights**.

That means, "All men and women are possessed of equal and inalienable natural rights among which are life, liberty and the pursuit of happiness."

There are long-standing statuary provisions implementing the intent of the Constitution. A part of the statement of the purpose of social welfare in Kansas reads, ".... it is the policy of the state to assist the needy and where necessary the relatives in providing the necessary assistance for dependents."

The Constitution and the above provision of Kansas Law points in the direction of care and services for persons in need. One of these populations includes, persons with disabilities. In 1989 the legislature wrote into law what SRS had been doing for the previous 8 years. The legislature recognized and legally sanctioned the work of Home and Community Based Services. The legislation set the tone on how the state was going to make these important services available across the state.

> "individuals in need of in-home care who are recipients of attendant care services and the parent or guardians of individuals who are minors at least 16 years of age and who are in need of in-home care shall have the right to choose the option to make decisions about, direct the provisions of and control the attendant care services received by such individuals including , but not limited to, selecting , training, managing, paying and dismissing of an attendant." (KSA 39-7,100)

There is a Constitutional mandate for the care of the needy and it is further refined to a specific population (frail elderly persons and persons with disabilities) by the above legislation related to Home and Community Based Services (HCBS). To implement HCBS in the spirit intended; key provisions were included.

The over-arching principle is persons using HCBS should be considered like all other Kansans; persons wanting to live in their own community and home.

Over the last 30 years, SRS working with Centers for Independent Living (CILs), the Statewide Independent Living Council of Kansas (SILCK) and others, has been at the task of transforming the institutional biased service delivery system to one oriented to personal choice and persons wanting to stay in their own home.

The goal of this transformed system is choice and independence on the part of an individual needing services. The system will be comprehensive physical and social services. The system will emphasize consumer control based on needs. The services will be delivered in such a way as to ensure public and consumer accountability. The services provided will be comparable through-out the system. The system will emphasize functional assessments; mental/physical/cognitive.

The State of Kansas has a long history of being concerned about neighbors down the road or the street. We are confident our elected public officials of 2011 and beyond will provide guidance and direction and financial support to a program such as HCBS.

The Historical Background of Home and Community Based Services

By the mid-1970's, SRS was paying for approximately 14,000 persons in nursing homes. At that time there was a serious move to look at alternatives which would be beneficial to the consumer and cost effective to SRS. Beginning in the 1980's, Health and Human Services (HHS) started giving waiver options to the states. An option was Home and Community Based Services(HCBS). SRS began with a modest pilot program affecting several hundred persons with physical disabilities and frail elderly persons. The result of that early effort means, in our state where the elderly population continues to grow and there is an ever-increasing need to meet the current needs of persons with disabilities, the nursing home population is going down. The nursing home population of persons being paid for by the State continues in the range of 10,000 persons. At the close of FY 2010 there were 6964 persons with physical disabilities and 5813 elderly persons were receiving HCBS services. These are all persons who have met the **medical** and **financial** qualifications to be in a nursing home and quite likely many, if not all, of these persons would be in nursing homes if it were not for Home and Community Based Services. If these persons had no other alternative than a nursing home, the State would be in clear violation of the provisions of the U.S. Supreme Court Olmstead Decision. One of the main provisions of the Olmstead Decision is that persons needing services should be able to choose and secure that service in the least restrictive environment. Home and Community Based Services provides that opportunity. The nursing home setting does not.

To get an idea of the effectiveness of Home and Community Services consider the following information derived from the end of FY 2010. 10,561 persons in nursing homes at an annual cost of $358.5M. means an annual per person cost of $33,973. For the purpose of illustration, assume the 6964 persons with disabilities and the 5813 frail elderly persons all needed to move into a nursing home, the cost would be 6964 plus 5813 persons = 12,777 persons X $33,973. (the annual cost of a person in a nursing home) = $434.M.

Long Term Care Cost /per person/ per year-FY2010 *

Frail Elderly	Physical Disabled	Institutional Care
$12,798 All Funds	$20,160 All Funds	$33,973 All Funds

For FY' 10 the Medicaid Long Term Care Budget

	All Funds	# Served
Nursing Facility	**$358.5M**	**10,561**
HCBS/FE & PD	**$215.2M**	**12,777**

*KHPA
Medical Assistance Report

If the reliance was on nursing home care the total cost would have been $792.5M. That is a difference of **$218.8M**, due to the utilization of HCBS.

Additionally, persons with disabilities in KS are in the job market and employed at twice the national rate. All of these positive results don't happen by chance. There are a number of people across the State working to insure that persons with disabilities and frail elderly persons are having a good and fruitful life. They are living by their choice in a place pleasing to them and being afforded maximum independence. This kind of living arrangement needs to be a part of the 21st century Medicaid equation.

Employment-Working Healthy

Through the dedicated work of the Centers for Independent Living (CILs), a significant change has taken place in terms of the cost of persons with disabilities who are employed and those who remain unemployed. KU conducted a five year study of consumers who were working and were able to maintain their medical card. They found not only were the persons continuing to work but the monthly cost of their medical services substantially decreased.

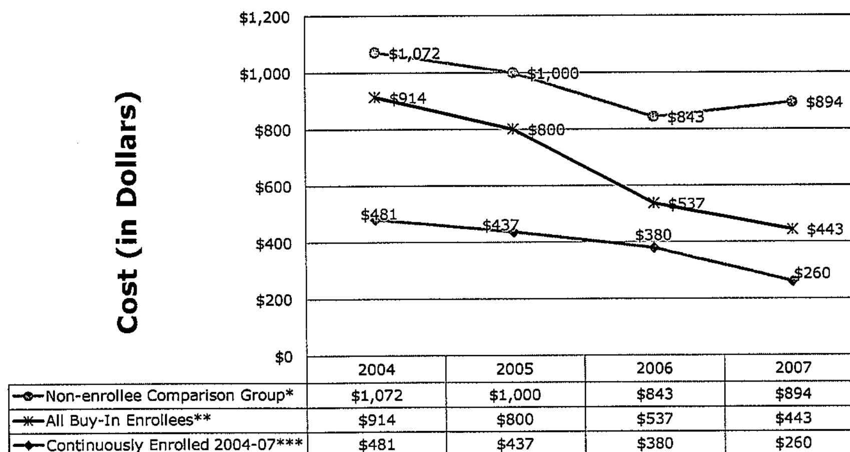
People with disabilities CAN and WANT to Work!

Through the Medicaid Buy-In or Working Healthy Program, there are over 1,100 people with disabilities currently enrolled. The Working Healthy Program...

- allows people with disabilities to return to or increase their work effort without losing critical Medicaid Coverage.
- encourages people to work, increase their income and accumulate assets in order to reduce long term reliance on public supports.
- some people may be required to pay a monthly Premium for Medicaid coverage.
- premium amounts are based on the household's countable income and are payable monthly.

Medicaid Expenditure Trends

Outpatient per Member per Month Costs



	2004	2005	2006	2007
Non-enrollee Comparison Group*	$1,072	$1,000	$843	$894
All Buy-In Enrollees**	$914	$800	$537	$443
Continuously Enrolled 2004-07***	$481	$437	$380	$260

Data Source: Kansas Medicaid Management Information System (iMMIS); Note: Expenditures were adjusted to 2007 prices using the Consumer Price Index for medical care. * For 2004-2007, n=1200 ** Due to increasing Buy-In enrollment each year, for 2004 n=1025, for 2005 n=1230, for 2006 n=1275, and for 2007 n=1303. *** For 2004-2007, n=254

Working Healthy One Way to Cut Costs

TOPEKA-Researchers at the University of Kansas say one of the surest ways to reduce Medicaid spending on people with disabilities is also one of the most underutilized.

It's called work.

"The problem is most people aren't aware of Working Healthy," said Nicolle Kurth, a researcher at KU's Center for Research on Learning.

Working Healthy is a program that since July 2002 has allowed people with disabilities to hold on to their Medicaid coverage while they work.

"They have to pay a premium," Kurth said, "but the premium is based on a sliding scale and can't be more than 7.5 percent of their income."

In Kansas, around 1,100 disabled people take part in Working Healthy. Almost 40 percent of them are mentally ill; more than 20 percent are physically disabled.

Earlier this year, a KU Center for Research on Learning study found that between 2004 and 2007, Medicaid spending on outpatient services per beneficiary per month went from $816 to $718. For the same period, Medicaid outpatient spending on Working Healthy participants went from $434 to $232.

Outpatient services include visits to the doctor, mental health counseling and most other regular services, excluding pharmacy benefits, that do not require hospitalization.

"Being on Working Healthy reduced Medicaid spending by almost 50 percent," said Shannon Jones, executive director for the Statewide Independent Living Council of Kansas.

“The fact of the matter is that people with disabilities would much rather be out working than staying home, watching their health deteriorate,” Jones said. “The reason they don’t (work) is they are scared to death of losing their health insurance, which happens to be Medicaid. Working Healthy lets them stay on Medicaid,” she said.

Adapted from a NEWS report by Dave Ranney, KHI, October 25, 2010.

The Work of the Centers for Independent Living

An important part of making all of this happen is the staff at the local Centers for Independent Living (CILs). The expenditure for the 12 CILs across the state is approximately $2.7M federal and state funds. For over 30 years, CILs have helped thousands of Kansans with disabilities live on their own, find work, raise families and become active, autonomous members of their communities.

The opportunity for disabled people to become independent is the crux of the CILs mission, allowing persons with disabilities to live by themselves, get married, find a job – anything they want to do – in order to be out on their own and make their own choices and live their own lives.

CILs are run almost solely by persons with disabilities showing those they serve exactly what they are capable of is a great example of the peer approach that sets CIL's apart from other organizations.

CILs give their practical experience on how people with disabilities live their lives, and how they can be independent, make choices, and take control of their life. Too often, people with disabilities when they're growing up, may have people taking care of them, albeit well-intended, what happens is you raise people who can't make their own decisions. CILs help people with disabilities figure out how to make their own decisions and how to take charge of their lives.

The Core Services Provided by All Centers for Independent Living are:

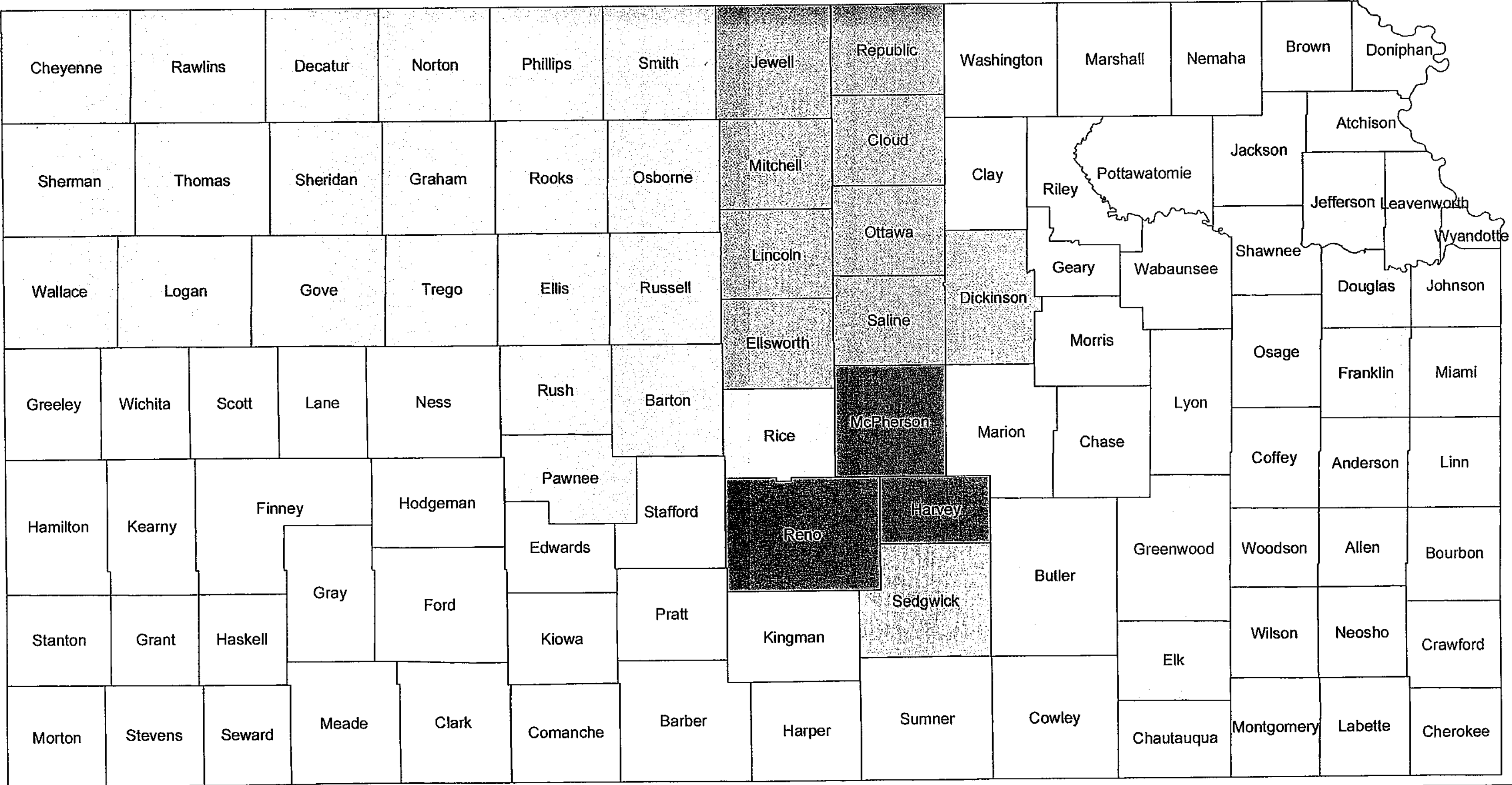
- Individual and Systems Advocacy, assistance with individual human rights issues as well as making system changes on a larger scale for people with disabilities as a whole.
- Information and Referral Services, information on specific disability related topics are referred to the appropriate work area of the CIL or another agency.
- Peer Counseling, an individual with a disability mentors, counsels and /or acts as a role model to another individual with a disability about a variety of issues.
- Independent Living Skills Training, basic life skills training such as cooking, budgeting, transportation skills and social skills.

These basic services are provided to any Kansan who walks through the door of any CIL and without cost. This array is truly one stop shopping. For FY '10, the 12 centers saw over 18,000 persons at an annual cost of $2.1M(AF) which amounts to $117/person/yr.

In FY '10 independent living services were provided to the following disability groups:

- Cognitive 1,083 persons
- Mental/emotional 1,148 persons
- Physical 10,191 persons
- Hearing Impairment 488 persons
- Visual Impairment 490 persons
- Multiple disabilities 2,502 persons
- other 2,156 persons

KANSAS CENTERS FOR INDEPENDENT LIVING



Kansas Centers for Independent Living

- Center for IL for SW KS
- Prairie Independent Living Center
- SE KS Independent Living Center
- Independent Living Resource Center
- Resource Center for Independent Living
- The Whole Person
- Access to Living/Coalition for Independence
- Independence Inc
- Topeka IL Resource Center
- IL Center of NE KS
- Three Rivers
- Independent Connection
- LINK
- Counties served by any CIL on request

Kansas Centers for Independent Living

LINK
2401 E. 13th
Hays, KS 67601
1-800-569-5926

Independent Connection/ OCCK
1710 W. Schilling Rd.
Salina, KS 67401
1-800-526-9731

Three Rivers
PO Box 408,
408 Lincoln Ave.
Wamego, KS 66547
1-800-555-3994

Advocates For Better Living For Everyone, Inc.
P.O. Box 292
521 Commercial, Suite C
Atchison, KS 66002
1-888-845-2879

Topeka Independent Living Resource Center
501 S.W. Jackson, #100
Topeka, KS 66603
1-800-443-2207

Independence Inc.
2001 Haskell
Lawrence, KS 66046
1-888-824-7277

Coalition for Independence
4911 State Ave.
Kansas City, KS 66102
1-866-201-3829

The Whole Person
7301 Mission Road
Prairie Village, KS
1-877-767-8896

Resource Center for Independent Living
P.O. Box 257
1137 Laing
Osage City, KS 66523
1-800-580-7245

Independent Living Resource Center
3033 W. 2nd
Wichita, KS 67203
1-800-479-6861

SKIL Resource Center
1801 Main Street,
PO Box 957
Parsons, KS 67357
1-800 -688-5616

Prairie Independent Living
17 S. Main
Hutchinson, KS 67501
1-888-715-6818

Center for Independent Living for Southwest Kansas
1802 E. Spruce
PO Box 2090
Garden City, K S 67846
1-800-736-9443

Five Good Reasons Why States Shouldn't Cut Home- and Community-Based Services in Medicaid

Adapted from Families USA • July 2010

Kansas is facing tough economic times, as we confront budget shortfalls, some are looking to cut Medicaid benefits, including home- and community-based services (HCBS). Home- and community-based services are vital to helping seniors and people with disabilities stay in their communities and out of institutions.[1] If home- and community-based services cuts are on the table please consider the following:

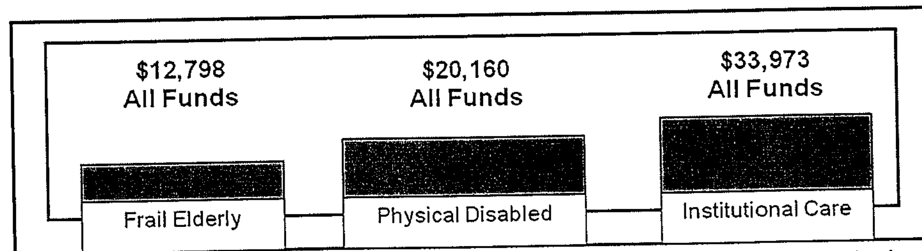
1 Cutting home- and community-based services can cost Kansas more in the long run.

Home- and community-based care costs less than institutional care. On average, home- and community-based care costs one-fifth as much per person per year as nursing home care. In addition, average costs for home- and community-based services are rising at a slower pace than costs for institutional care.

Cutting home- and community-based services can increase the use of more costly institutional care. Higher state spending on home- and community-based services reduces the use of institutional care among childless seniors.

States that spend more on home- and community-based services see a decrease in Medicaid long-term care spending over time. A 2009 study of Medicaid long-term care spending found that, over a 10-year period, states that offered few Medicaid home- and community-based service options experienced an average increase of nearly 9 percent in Medicaid long-term care spending, while states with well-established home- and community-based care programs saw an 8 percent reduction in spending.

Long Term Care Cost /per person/ per year-FY2010 *



For FY' 10 the Medicaid Long Term Care Budget

	All Funds	# Served
Nursing Facility	$358.5M	10,561
HCBS/FE & PD	$215.2M	12,777

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2 Cutting home and Community-Based services can be bad for Kansas economies.

Cutting home-and community-based services can reduce or eliminate jobs and hurt economic growth. Medicaid brings new money into states in the form of federal matching dollars. These new dollars create jobs and stimulate economic growth. Cuts to home- and community-based services reduce the amount of federal matching dollars that states receive, resulting in lost jobs and reduced business activity.

3 Cutting home- and community-based services increases the burden on informal caregivers, which has implications for U.S. businesses and state economies.

Demands on caregivers already affect their financial stability and health. Over the course of a year, it is estimated that more than 50 million people nationwide provide informal care to those who need long-term services. They are vital sources of support for people needing care and a critical supplement to existing care delivery systems. These informal caregivers—mostly family members and friends of those who require long-term care—often risk their own financial stability and health in performing caregiving functions. The typical family caregiver, who already has a job, loses approximately $110 per day in wages and health benefits due to caregiving responsibilities. More than one-third of caregivers cut back on household spending, one-third limit their work hours, and approximately one-quarter postpone personal medical care.

Cutting home and community-based services increases the burden on caregivers. Medicaid home- and community-based services such as adult day care can provide essential support to caregivers and give them an opportunity for respite. These services can also reduce caregivers' stress and help them to participate more fully in the workforce. Cutting home- and community-based services takes away valuable support for informal caregivers and increases their medical, emotional, and financial stress, which can negatively affect state economies.

The demands of caregiving cost U.S. businesses billions annually. The workplace accommodations that caregivers must make, such as reducing hours or taking unpaid leave, affect businesses as well. Costs to employers include increased absenteeism, workday interruptions, reduced employee hours, reduced productivity, and costs associated with replacing workers who leave the workforce because of caregiving responsibilities. Businesses lose an estimated $33.6 billion annually because of the demands that caregiving places on full-time employees.

The burden on caregivers also has implications for state economies. Demands of caregiving affect caregivers themselves, the businesses they work for, and, in turn, state economies. Economic activity is reduced because caregivers earn and spend less, and their medical costs end up being higher because they postpone their own medical care until their health problems are more advanced and more expensive to treat. Lost business productivity affects business receipts and, ultimately, state revenue.

4 Cutting home- and community-based services runs counter to consumer preferences.

Most consumers who need long-term care prefer to remain in their homes or in the community. About 80 percent of people needing long-term services would prefer community-based care over institutional care.

Kansas can both serve their residents better and save money by shifting their service focus to home- and community-based care. Kansas has actively shifted their long-term care delivery from institutional to home- and community-based care have not only given their residents better choices, they have also been able to serve more people at lower overall cost.

5 Cutting home- and community-based services may violate the Supreme Court's *Olmstead* decision.

Kansas must have a plan for placing individuals with disabilities in the least restrictive care setting. In the 1999 case *Olmstead v. L.C.*, the Supreme Court held that unjustified institutionalization of people with disabilities who were able to function in the community constituted a form of discrimination that violates the Americans with Disabilities Act (ADA). To comply with *Olmstead,* states must have a working plan for placing individuals in the least restrictive setting that is appropriate to their needs.

Recent court cases challenge state cuts to home- and community-based services that violate *Olmstead.* The Obama Administration is taking action to enforce *Olmstead.* As part of its enforcement activities, the Department of Justice has recently filed briefs in several cases arguing that state reductions in home- and community-based services or failure to provide sufficient home- and community-based services violate *Olmstead* and the Americans with Disabilities Act because they place individuals at risk of institutionalization.[4]

Patients and their advocates can challenge state home- and community-based services cuts based on *Olmstead.* Final decisions have not yet been reached in the cases noted above. However, when cuts in home- and community-based services limit services to the point that individuals are placed at risk of institutionalization, patients and their representatives can argue that the cuts may constitute an *Olmstead* violation and could consider a court challenge.

Conclusion

State cuts to home- and community-based services in Medicaid can be shortsighted. While they might produce some short-term cost savings, those savings can result in higher costs to states in the long term, including increased use of higher-cost institutional care, lost caregiver wages and the associated negative economic effects, and lost Medicaid matching funds. In addition to being a bad idea from an economic perspective, cuts are contrary to the wishes of the majority of constituents who need these services, and, in addition, they may violate the Supreme Court's *Olmstead* decision.

There are better options for states. Among them is the option to expand home- and community-based services through new opportunities that are available in health reform. These include improvements to the Medicaid state plan option for home- and community-based services (section 1915(i) of the Social Security Act) as well as two new programs that will start in October 2011.[5] The new programs, the Community First Choice Option and the State Balancing Incentives Payments Program, include added federal matching dollars to help states expand home- and community-based services. (For more information on these programs, see Families USA's publication, Helping People with Long-Term Care Needs: Improving Access to Home- and Community-Based Services in Medicaid, available online at http://www.familiesusa.org/assets/pdfs/health-reform/help-with-long-term-health-needs.pdf.)

Rather than cutting home- and community-based care programs, states should maintain their current programs and explore health reform's new options to expand home- and community-based care. This could save money in the long term, provide economic benefits, and better serve state residents.

Future Opportunities for Kansas

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Among them is the option to expand home- and community-based services through new opportunities that are available in health reform. These include improvements to the Medicaid state plan option for Home and Community-Based Services (section 1915(i) of the Social Security Act) as well as two new programs that will start in October 2011.5 The new programs, the Community First Choice Option and the State Balancing Incentives Payments Program, include added federal matching dollars to help states expand home- and community-based services.

Community First Choice Option (CFC)

The Community First Choice (CFC) Option will provide individuals with disabilities who are eligible for nursing homes and other institutional settings with options to receive community-based services. CFC will support the Olmstead decision by giving people the choice to leave facilities and institutions for their own homes and communities with appropriate, cost effective services and supports. It will also help address state waiting lists for services by providing access to a community-based benefit within Medicaid. The option will not allow caps on the number of individuals served, nor allow waiting lists for these services. **A significant enhanced Federal Medical Assistance Percentages (FMAP) will be provided, depending on cost, to encourage states to select this option.**

Summary of Core Provisions:

- Amend Medicaid to allow state Medicaid plan coverage of community-based attendant services and supports for certain Medicaid-eligible individuals.
- Services must be provided in a home or community setting based on a written plan.
- Services must be made available statewide and must be provided in the most integrated setting appropriate for the individual.
- Services must be provided regardless of age, disability, or type of services needed.
- States will establish and maintain a comprehensive, continuous quality assurance system, including development of requirements for service delivery models; quality assurance to maximize consumer independence and consumer control; and external monitoring; along with other critical state and federal responsibilities/requirements included in S. 683/H.R. 1670.
- Service delivery models must include consumer directed, agency-based, and other models, along with requirements to comply with all federal and state labor laws.
- CFC services will not affect the states' ability to provide such services under other Medicaid provisions.

These incentives include an increased federal Medicaid matching rate for new home and community based attendant care services.