Conference Call - August 3, 1998
PAS Blue Ribbon Panel
Participants: Pamela Dautel
Lex Frieden
Mark Johnson
Bob Kafka

- Create an executive summary from Charlene Harrington's report to HCFA. Highlight the policy recommendations.

- Give the status of PAS legislation (MiCasa, Feingold, Kennedy/Jeffers)

- "Real Choice" – Talking Points

- Recommendations from last Blue Ribbon Panel meeting – items written on flip chart

- "Most integrated setting appropriate to the individuals needs"
  - Janet Reno's speech at the 1998 NCIL conference (we have this)
  - Clinton's recent press release (we have this)
  - Letter to Medicaid Directors
  - Steve Gold's recent interview (215-627-7300)

- State "minimum" criteria for a nationwide PAS program
  - Tony Young – CCD report
  - "Real Choice" – choice and control
  - Somehow combine Medicare and Medicaid

- Primary recommendation of Panel – Title 22 – **Long Term service provision** vs. a medically driven system. Long Term service with a health care component. Instead of what is happening now – the health care system is trying to add LTC. Emphasize LT services with linkages to health care. Carve out LTC in other sections of Medicaid. **Long Term Service Reform**

- Develop "Package of Recommendations" – not just one recommendation.

- Interim (short-term) steps –
  - Personal Care Option – Make it mandatory (offer real choice)
  - DD, ADD, RSA, Adm on Aging, etc – some way to talk about Long Term care on disability in a unified way. Current system is too fragmented.
  - Mechanism of how to transition slowly – incentives/disincentives for States that are/not putting up money for PAS. Encourage community based alternative. Kennedy/Jeffers – enriched match by Govt. (economic incentive). Disincentive – if state's don't choose to offer PAS, don't give them federal dollars for highway funds.
  - Voucher idea – if you meet "functional criteria". Add on, like Virginia, aid and attendant (get assessed and then get money).

- High level meeting with all the players – IRS, American Nursing Association, National Association of Home Care, National Association of Assisted Living Facilities (?) to discuss: (1) cultivate progressive providers in the community, and (2) change the existing system.

- Recommend that HCFA enforce and implement "most integrated setting" and provide mandatory training for states.

- Consumer controlled attendant services $2 million (not new money). HCFA has confused this money with demonstration money "state certain." Money was intended for review of progressive community-based providers, to develop progressive providers and help change existing delivery system to incorporate consumer control and choice. - Need to do like HUD did --

PERSONAL ASSISTANCE SERVICES BLUE RIBBON PANEL MEETING
FEBRUARY 28, 1998

Themes, Messages, Principles

Change Change Change

Birth- Death, cross-disability, mental & physical families.
Real choices, including eqitable funding
- give people what they want
- encourage provider index
-money follow person & choice
-personal & family empowerment, family values

Demographics = this is a priority
Action not talk (or studies)
Civil/Human rights = protection = opportunity
Cost effective, self-determination, independence, self-efficiency, encourages work
Needs of people, not bureaucrats
One size fits all
Bi-partisan

Problem Statement

- instit. bias
- [emotional] toll on individual & family
- inconsistent with market demand
- inconsistent with basic policy goals of M outmoded 1998 not equal 1960
- medical & acute care bias
- inconsistent with precepts of ADA-hollow
- divides families against family values
- fosters dependency
- lack of real choice
- bureaucrat decision making vs. Consumer decision making
- bias towards bureaucrat structured programs interest group vs. Individual
- devalues disabled & aging
- expensive solution
- fragmented service system complicated ssystem
- impedes decision making

Hearing Purpose

- Get Administration (WH) attention
- Raise issue on grand scale - radar screen
- Recognize other vehicles
- Lay framework for multi-year campaign-elections
- Implement Hclen L decision by statute
- Original tool
- Unify discommunity
- Bi-partisan, constructive-friendly message
- Election issue

Logistics

Travel/Accomm. $

Feed questions to hrg members (TY, MC)

T/A to witnesses (BS,GD)

Memo (BS)

Forward HC test (TY, MC)

Oped piece - local papers

Viable Policy Options
Stat., Reg., Research

HR 2020
Expand waivers/demos
Extract promises from candidates

Types of Witnesses
NH Administration (ME)

S. Feingold
Newt, [Gephart] [Gov.]
Shalala Deparles, (NCD)
Carol Hughes, Holly Caudill

Pro: family caregiver		Justin	Tom Hamilton	ADAPT
	alder		State Admin./work	

Con:	polly spare	Victoria Brown	

Next Steps

K - J Hrg
5879
Work out definition
Bunning - K hrg
Mtg ADAPT VCIL/LTC
Incremental change

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0. Carol Kronen

0. Ms. Sharp from Gerben

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Kenny Kirby
Roselee Kane
Peter Thomas
Linda Mitchel
Bob Silverstein
Rosmarie Gibson
Nancy Miller
Charleen Harrington
PVA guys

Alan Bergman presentation
On the Webb/consultant fee

Gary and Gerben
thanks and consultant fee

Jane Irwin -- tape?

need new attendence list with new names

Stu Hansen
insurance company execs

~~RCF~~
A HSPE sponsorship?

EXPERTS MEETING ON MANAGED CARE
AGENDA
August 28, 1998

9:00 – 9:15 a.m.	Welcome and Introduction Lex Frieden, Co-Director, Research and Training Center on Managed Care and People with Disabilities and Glenn Fujiura, Director, Center on Emergent Disability at the University of Illinois at Chicago
9:15 – 9:35 a.m.	Introduction - Managed Care and People with Disabilities – State of the Art Allan Bergman, Director, Institute on Disability and Managed Care, United Cerebral Palsy Association, Inc.
9:35 a.m.	Panel Discussion - Managed Care and Under-Served Populations Moderator – Lex Frieden Panel Members: Oregon: Doug Stone, Department of Human Resources Edie Walsh, Health Economic Research Texas: Pam Coleman, State Medicaid, Star Plus Program Hope Morrison, State Medicaid, Star Plus Program Wisconsin: Steve Landkamer, Wisconsin Dept. of Health & Family Services Barbara Bowers, University of Wisconsin - Madison
10:30 - 10:45 a.m.	Break
10:45 – 11:45 a.m.	Questions and Answers (Panel and Participants)
11:45 a.m. – 12:00	Summary of Panel Discussion
12:00 – 1:45 p.m.	Lunch
2:00 p.m.	Panel Discussion - Roles of Independent Living Centers in Managed Care Systems Moderator: Bob Kafka Panel: Dennis Fitzgibbons, Alpha One Owen McCusker, Community Living Alliance Karen Hodgson, Independent Living for Western Wisconsin Lee Schulz, Independence First Mark Obatake, Hawaii Centers for Independent Living
3:30 - 3:45 p.m.	Break
3:45 p.m.	Questions and Answers
4:30 p.m.	Closing Remarks – Conference Summary

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Gustave A. Dyer
Sally Richardson
Clinton letter

Clinton
FBI
Secret Service

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PAS BLUE RIBBON PANEL
AGENDA

Saturday, August 29, 1998

- update since last meeting -- legislation -- HCFA letter
- Looking back – a review of the Blue Ribbon Panel = Pamela
- Looking ahead – the Final Report of the Blue Ribbon Panel
- Prioritize and organize policy options (HCFA Report)
- ILRU PAS Web Site – need materials
  List Serve?

future meetings?
materials needed?
web-site needs?
research/ data needs?
funding possibilities?
best practice guide?

Many Cmrs old. monograph -- other how to

Grassroots Strategies

Attendance at hrg - members
- bodies

Cross Disability

Outreach to:
- parents
- aging /Alz.
- mental dis. community
- families
- all political parties

Media

Visit member staff at home
Cultivate State good guys

Targeted hits

Group endorsements

Reality Check

Ain't broke, don't fix it

No definition cost CBO

Use waivers why legislate

NAOTD

VOR/Unions AFSME

Some people fear community-based service

Safety, quality, paternalism

home health agencies

fraud, waste and abuse

Research/data

WH/HCFA/HHS/OMB

State/NGA Opposition

- Bob Kafka gave an update on HR 2020. The Commerce Committee has scheduled a hearing for March 12th. There will be a press conference at 9 a.m. on March 12th before the hearing.

- Andy Imparato of NCD talked about Social Security Reform needed regarding work disincentives. He mentioned a new bill introduced by Senators Jeffers and Kennedy that has a strong PAS component.

  - SSI and SSDI – those who intend to work – pre-employment – access to PAS through State Medicaid
  - 1618 and 1619 (b) buy-in – access to PAS and drugs under a waiver
  - SSDI, employment – free Medicaid – continued Part B
  - SSDI – never been on – access through waiver
  - Very broad definition of PAS (broader cross disability audience) – includes people with sensory disability and DD.
  - Funding – capped entitlement; optional; formalizing waivers (institutionalizing the ability of states to get waivers). Capped entitlement represents "new money."

- Feingold bill – reported increased interest (members of the House are looking at combining with another bill)
- BPA Amendment – only SSI, not SSDI.
- HCFA letters coming out sometime next month.
- Mark Johnson made 3 points

  - What numbers are we going to stand behind?
  - What kind of investment are we going to make, if we don't do this (HR 2020)? How can we reduce number of nursing home beds?
  - U.S. is willing to invest in child care, but not LTC.

- Only $10 billion was spent on home health care. The "80/20 bias" refers to the large amount of money spent in nursing homes as compared to the amount spent in home health. Demographic shifts taking place – aging, children, young adults.
- Costs of keeping in community versus institution. 50% of the beds will be refilled. (Demand for nursing homes is going down - currently have an 87% occupation rate).
- Costs
- Goals of what we're trying to accomplish "to give people more choices".
- Families – economic impact
- HCFA Report – review of Federal statutes. Should prioritize items included. Only those that address the 80/20 bias. Some of the recommendations could be harmful.
- Consumer choice – consumer oriented care – location of services – ease of use by consumer (consumer friendly).

COST GROUP

- Included the following participants: Gerben, Simi, Charlene, Mitch, Stephanie, Jodi, Jay, Ruth, Dan, Phil, Hale, Nancy, Jane, Pamela, Lex.
- Utilization rate of HR 2020

- Woodwork effect
- Cost/benefit savings
- Opportunity costs for caregivers
- 80/20 split – valid?
- Work income savings
- Consensus on costs? Cost model. Critique the CBO estimates. No. of people eligible? Cutoff – 1 ADL? Or 2 ADL?
- Minimum wage for attendants? Wage levels
  $8,000 – 16,000 per person 800,000 people in the community
  $6 ½ - 18 billion
  IADL can help include cognitive

  140,000 people in ICFMR
  1.3 million people x 16,000 = $20 billion
  1.3 people x 8,000 = $10 billion
  $6.8 billion + _____

- Write article in NY Times – critique CBO's cost estimates.
- Make an offer to CBO to help them critique their numbers.
- Have some nos. to put in the testimony.
- ASPE nos. (people) cross disability/cross age, stand by and hands on 3+ ADL, <300% SSI
- Do we want to restrict to 3+ ADLs?
- Some people and agencies who should be contacted for input on numbers:
  Med Stat, NRH, M. Salo, NIMH, WID, AARP, John Weinner, CBO, Mitch/Charlene, Robin Stone, Michelle Adler, ASPE, Charlie Lankin (money), Lisa Alexin (Luen), DLS

  2 million x $29,000 = $35 billion

No. of ADLs	Avg. Costs	
1	$2,000	
2	$4,000	$22 Bil — $16 Bil
3	$16,000	

  Has 300% poverty by no. of ADL's.
  Needs average annual costs (CBO $8,000).

- Critique of CBO model costs
- Trade offs – no. of people and costs, net current costs
- Go public (NY Times, March 12 testimony)
- Long term (round table discussions, conference call)
- Look at states utilization rates, with mature programs (personal care option states – CA, OR, MI)
- ASPE cost estimates – 170 hours/month , $13/hr (CD and agency)
- Limit to 3+ ADL to minimize costs of MiCasa?
- Nursing home + ICFMR
- Certify need for nursing home eligibility for Medicaid
- Contest CBO cost estimates by giving examples of states where CD LTC is working well.

- Lex will distribute a copy of the article written by Tom Irvin that appeared in Disability News recently.
- Mitch LePlante and Simi Litvak – what's wrong with CBO nos. and what do we need; assumptions made.
- Mitch and Simi Litvak will get the information to Lex for distribution.
- Lex will set up a conference call for the week of March 18 or later.
- Report from HCFA – comments in 30 days. Round table discussions. ILRU will send a reminder. Those things in the report that are on target – prioritize recommendations.
- Facilitate a conference call. March 23rd, discuss hearing, what to do.
- Compose info discussed today and distribute – Bobby (strategy) and Gerben (costs)
- Survey of candidates – LTC campaign – 1998. John _____ (director) Opinion Polls. Lee Page will be liaison for Blue Ribbon Panel to LTC Campaign.

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To: Sharon.Finney@bcm.tmc.edu
Subject: email to Blue Ribbon Panel members
Date: Tue, 25 Aug 1998 10:32:51 PDT

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The next scheduled meeting of the PAS Blue Ribbon Panel is this Saturday, August 29, 1998. The primary purpose of this meeting is to discuss the accomplisments of the Panel over the past 18 months, and to begin developing the final report of the PAS Blue Ribbon Panel.

We need your help as we prepare for the meeting. The attached document contains policy options that were identified by Charlene Harrington of the University of California at San Francisco in her report to HCFA. Please review the attached document, and be prepared to discuss this information at the meeting. As you review the attached document, consider how you would priortize and organize the policy options.

For those of you who do not plan to attend the meeting this Saturday, please provide your comments by email by September 1, 1998. Thanks.

We are looking forward to a good meeting. See you there!

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ILRU is a program of TIRR

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NOTE: The policy options shown below were identified in the HCFA report written by Charlene Harrington at the University of California at San Francisco.

HOME HEALTH

STUDY

Policy Option 1. HCFA could study the relationship between Medicare and Medicaid home health definitions and benefits and the impact of the BBA of 1997 on dual eligibles in the Medicaid program. HCFA could study the extent of demand for Medicaid home health care and how state Medicaid programs respond to the demand after the BBA changes.

Policy Option 2: A survey of states could be conducted to determine the number and type of agencies which deliver personal care services and whether state home health licensing requirements and Medicare/Medicaid home health certification rules are limiting factors in the provision of personal care services. If this appears to be a problem, HCFA could provide information in the Medicaid Manual or transmittal letters to advise states of the potential problems for personal care providers where Medicaid licensing is linked directly to the Medicare certification requirements.

REGULATION

Policy Option 3. HCFA could study state Medicaid home health benefit packages to

determine the extent to which state Medicaid home health benefits are linked to the Medicare benefits and whether some state home health requirements are overly restrictive. If there is a problem with linkage through state statutes, HCFA could encourage the link between Medicaid and Medicare certification in the statutes and regulations by eliminating the Medicare regulation at 42 C.F.R. 484.36(e). The Medicaid home health agencies regulations could then be changed to allow them to offer long term and chronic care services including personal care services, without the authorization and supervision of a physician and without nursing service supervision. The Medicaid regulation at 42 C.F.R. 440.70(a)(1) could be modified to eliminate the requirement that services must be provided at the recipient's place of residence.

Another option is to clarify the services that may be offered by Medicare and Medicaid agencies by changing the statutes and regulations. The statute could be changed to state that although Medicare is primarily for short term and intermittent care, Medicare and Medicaid certified HHAs may offer long term, chronic care and personal care services. These personal care services would not be subject to the requirements under 42 C.F.R. 440.167 and would not be required to meet the same regulations as home health aides.

Licensing
Policy Option 4: The contents of the state home health licensing requirements have not been studied and should be the subject for further research to determine the extent to which states require home health agencies to meet Medicare certification. If state licensing laws are serving as a barrier to Medicaid certification, HCFA could encourage states to remove state statutory language that link home health agencies to the Medicare definitions of home health agencies. HCFA could consider clarifying their interpretation to state officials and providers that the definitional links between Medicare and Medicaid services are not considered appropriate people with chronically illness and disability.

Training
Policy Option 5: The Medicare/ Medicaid regulations on conditions of participation for home health agencies could be amended to clarify that personal care attendants may have different training requirements from home health aides. These regulations could also clarify that individuals receiving services should be involved in the selection, training, and supervision of both personal care attendants and home health aides where they are able to be involved and chose to be involved.

Policy Option 6: The level of inservice training and performance for personal care attendants should be studied. If training and performance standards are higher than necessary or inappropriate for personal care attendants, then the conditions for participation for home health agencies could be changed to clarify that personal care attendants do not need to meet the inservice education and the performance review requirements for home health aides.

Supervision
Policy Option 7: The conditions of participation for home health agencies could be changed to allow for different supervision requirements for personal care attendants. Perhaps a supervisory visit every six months or a year is appropriate for some individuals, while in other situations more frequent visits may be needed. The decisions regarding the frequency of supervision could be made on an individual basis, but could be set to be at least once a year.

LAW

TECHNICAL ASSISTANCE

PERSONAL CARE OPTION

STUDY
Policy Option 8: HCFA could take advantage of the different features of the personal care state plan option and the HCBS personal services program in states to evaluate these alternative approaches and their multiple outcomes. Although there may be political opposition to a mandatory program, there are good arguments for making the personal care services a mandatory Medicaid program. At least the program could be made mandatory for those individuals who would otherwise require institutional care or be at risk for needing institutional care. This would be a way to reduce institutionalization and to facilitate

deinstitutionalization of some nursing home residents. The cost arguments against a mandatory program are not persuasive since all states are offering some personal care services. Alternatively, a financial incentive (such as a one-time higher FFP for start-up costs for those states that currently do not have a comprehensive program or simply a higher FFP for all personal care services) may be an effective alternative way to encourage states to increase the personal care services to those individuals at risk of institutionalization.

Policy Option 9: The cost and outcomes from the current state-funded programs only programs could be evaluated as to whether they prevent or delay non-Medicaid low income individuals from becoming institutionalized and spending down to Medicaid. HCFA could study the benefits and feasibility of a policy option for allowing a sliding fee scale for individuals above the minimum financial eligibility level (including perhaps the 300 percent of the SSI level) or some type of buy-in arrangement for those meeting targeted needs financial eligibility criteria. A statutory change would be required for such a program.

Policy Option 10: State definitions of personal care services are offered could be studied to determine whether these definitions are serving as barriers to deliver needed services. The definition of personal care services could be clarified in the Medicaid regulations and the Medicaid Manual to include assistance with ADLs, IADLs (including monitoring and cueing), and supervision and monitoring for persons with cognitive and other mental impairments, and/or behavior problems which endanger health and safety.

Policy Option 11: A study could conducted which would examine the need for additional respite services and its potential costs and benefits. If such a study provided evidence of benefits, short term respite care could be added as a personal care benefit to the Medicaid regulations and the Medicaid Manual for individuals who meet the basic level of need requirements.

Policy Option 12: First, to foster the adoption of objective need-based criteria, the Secretary could convene an expert panel to develop a consensus on a set of need criteria and measures for personal care services, which could be periodically reevaluated. Second, recognizing the desirability for greater objectivity in need-based criteria for personal care within states and across states, a uniform definition of minimal need criteria for personal care services could be developed which would include ADL and IADL criteria along with behavioral and cognitive and other types of mental disorders/impairments, social isolation, and safety. Although the state of the art in needs assessment continues to evolve, and the predictive utility of alternative combinations and weighting of these criteria have yet to be tested, more study and development is needed to establish detailed specific need criteria. In the interest of fostering innovation in this area, and assuring dissemination of experience, an ongoing research program (working with selected states) could be developed to design and evaluate alternative needs determination processes, weighting criteria, and verification processes.

Policy Option 13: The Secretary could allocate funds for the evaluation of the benefits of targeting efforts for those that are at risk for institutionalization compared with targeting preventive and supportive services to those with less disability in order to prevent deterioration in health status. Such an evaluation could inform states about targeting benefits and establishing need criteria.

Policy Option 14: The Secretary could (1) periodically confer with a panel of experts from states to develop approaches for achieving a common or core minimum data set for client screening and assessment for the personal care services program; (2) evaluate the effectiveness of different state assessment systems for different long term care services; (3) disseminate the results of this evaluation to other states so that any appropriate modifications can be made; (4) move to develop a single uniform screening and assessment instrument for states to use in determining the need for personal care services within and across states, and (5) move to develop a single uniform screening instrument which could assess need for different types of services and settings (e.g. personal care, home care, HCBS, and institutional care).

Policy Option 15: As a starting point that might result in single entry point systems, states could be encouraged or required to submit state plans that assure a coordinated screening and assessment system for their long term care programs. HCFA and/or states could develop estimates of community-level disability rates and service use and plan to address gaps or identified inequities in delivery system access for different financial eligibility groups. States could be encouraged to develop a single entry point approach

for the personal care services, HCBS waiver program, and other long term care services. Financial incentives (e.g. higher FFP) could be considered for states that develop and use such an integrated system (on a one-time basis to help cover the costs of such initial reorganization). Studies of the effectiveness of different state organizations could be undertaken.

REGULATION

Policy Option 16: The personal care regulations could be changed to encourage or require states to make provisions for allocating hours and types of services based on an individual's needs and their ability to benefit from services and that total services should not have arbitrary volume limits or dollar limits. Since the purpose of offering personal care services is to prevent institutionalization and/or to serve as an alternative to institutionalization, live-in care or up to 24 hour per day care would need to be offered to be a meaningful alternative to institutional care. At the same time, states may want to assure that their overall personal service program costs for recipients would be no more costly than their costs would have been in institutions.

Policy Option 17. The HCFA regulations and manual could clarify that client and family involvement are essential components of the assessment and planning process for personal care services that could generally facilitate consumer choice and satisfaction with the program. A clear federal philosophy of individual empowerment, independence, and understanding of a social model of disability is important for HCFA to articulate. Each state could be asked to address this in its state plan.

Policy Option 18: The regulations could be amended to clarify that states are required to develop methods to facilitate access to and choice among qualified personal care providers, including information sources such as provider registries. The following rights for home care could also be established for personal care services: the right to choose a provider, to be fully informed in advance about care and treatment; changes in care and treatment and to be informed about alternative services.

Policy Option 19: A statutory change would be required to in order to remove the physician authorization provision to eliminate a medicalized approach to authorization. Alternatively, the regulations and/or the Medicaid Manual could be changed to encourage or require states to develop their own objective and standardized authorization procedures as a means of ensuring greater access and equity in personal care services for clients. This would be consistent with a broadened definition of service needs to include the provision of assistance to address functional limitations caused by physical, cognitive and other mental impairments, behavioral problems as well as medical conditions.

Policy Option 20: In order to reduce unnecessary medicalization, the federal rules could encourage or specify that states should ensure access to case management for personal care services when case management is desired by recipients, regardless of which type of providers deliver the services. At the same time, individuals capable of supervising their own personal care workers should have the option to do so. The state could be expected to retain enough oversight over the care plan to assure that client care needs are being adequately met. Implicit in the implementation of these policies is that would there be a reasonable standard by which the state can determine the circumstances when self-directed care is appropriate. Neither the operations of self-directed case management systems, nor the quality of care issues arising under these programs have been extensively studied in the U.S. HCFA could work with the states in designing and evaluating alternative approaches to self-directed care.

LAW

Policy Option 21. It seems appropriate that financial eligibility provisions for personal care services within a state be related to the care needs of the individual. First, for those whose level of care needs make them eligible for nursing home placement, the financial eligibility provisions could be changed to make them the same as those for institutional care (like the HCBS service program); this would require a statutory change in the Medicaid program. Second, for those not meeting institutional financial eligibility criteria, standard financial eligibility criteria could continue to apply as is the current requirement. This would allow the personal care services program to target services to those eligible for or at risk for institutionalization and make the program comparable to the personal care services under the HCBS waiver.
Policy Option 22. A statutory change could be considered to make the spousal protection

provisions for the institutional program apply to the personal care services optional program. This would allow states to provide a meaningful option for individuals with disabilities to remain in the community with personal care services and remove financial incentives for institutionalization.

Policy Option 23. The special post financial eligibility provisions that allow people with disabilities to remain in the community in the HCBS program could also be extended to the personal care service option. If these special financial eligibility requirements could also be applied to personal care services, then more states may be willing to combine all their personal care services under the state plan option, rather than to provide personal care under both the state plan option and the HCBS waiver program. Perhaps this would result in some administrative savings and a more understandable care delivery system.

Policy Option 24: Changes in the SSI and Medicaid statutes could be considered to increase the asset levels for individuals living in the community who would otherwise be forced into institutional care. These statutes could be modified so that asset limitations are indexed for inflation. Another option would be to allow personal care recipients to retain the equivalent of 6-12 months of expenses (for housing, utilities, food, and other expenses) in assets. This would require a statutory change that may be opposed because of its cost implications.

Policy Option 25: HCFA could seek statutory authority to extend Miller trusts to individuals eligible for personal care services in states with income caps. In addition, HCFA could consider requiring states to provide information about the availability of Miller trusts and assistance in establishing such trusts.

TECHNICAL ASSISTANCE

Policy Option 26. The HCFA regulations and manual could clarify that client and family involvement are essential components of the assessment and planning process for personal care services that could generally facilitate consumer choice and satisfaction with the program. A clear federal philosophy of individual empowerment, independence, and understanding of a social model of disability is important for HCFA to articulate. Each state could be asked to address this in its state plan.

Policy Option 27: The regulations could be amended to clarify that states are required to develop methods to facilitate access to and choice among qualified personal care providers, including information sources such as provider registries. The following rights for home care could also be established for personal care services: the right to choose a provider, to be fully informed in advance about care and treatment; changes in care and treatment and to be informed about alternative services.

Policy Option 28: A statutory change would be required to in order to remove the physician authorization provision to eliminate a medicalized approach to authorization. Alternatively, the regulations and/or the Medicaid Manual could be changed to encourage or require states to develop their own objective and standardized authorization procedures as a means of ensuring greater access and equity in personal care services for clients. This would be consistent with a broadened definition of service needs to include the provision of assistance to address functional limitations caused by physical, cognitive and other mental impairments, behavioral problems as well as medical conditions.

Policy Option 29: In order to reduce unnecessary medicalization, the federal rules could encourage or specify that states should ensure access to case management for personal care services when case management is desired by recipients, regardless of which type of providers deliver the services. At the same time, individuals capable of supervising their own personal care workers should have the option to do so. The state could be expected to retain enough oversight over the care plan to assure that client care needs are being adequately met. Implicit in the implementation of these policies is that would there be a reasonable standard by which the state can determine the circumstances when self-directed care is appropriate. Neither the operations of self-directed case management systems, nor the quality of care issues arising under these programs have been extensively studied in the U.S. HCFA could work with the states in designing and evaluating alternative approaches to self-directed care.

Policy Option 30: Current quality standards for personal care programs could be studied to determine their adequacy. If problems are identified, minimum federal standards

for quality could be established.

Policy Option 31: The regulations could be changed to (1) allow for exceptions to the spouse or parental payment prohibition, when necessary, to assure access for individuals in need of personal care services; and (2) HCFA could evaluate the effects of access to and the quality of personal services under conditions when family members are reimbursed and when they are not, including the effects on family caregiving, sheltered housing, residential care, and nursing home placement.

Policy Option 32: The effect of additional family member restrictions (beyond spouse or parent of a minor child) could be evaluated for its relationship with sheltered housing, residential care, and nursing home placement effects. These additional restrictions on family members may reduce access to personal care and increase the use of home health agency services or institutional services.

Policy Option 33. The Medicaid personal care regulations could be amended to encourage or require states to give individuals the right to select, train, and manage their own personal care attendants to the greatest extent possible as a means of allowing social models of care rather than medical models. The Medicaid personal care regulations could explicitly address the different personal care models that states may use and require more than one provider option be made available. This would help ensure that recipients have greater choice and access to the kind and type of services that they would like to have. Studies could be undertaken to evaluate the effect on the quality and cost of care and client outcomes under varying state regulatory conditions relative to provider qualifications, registration, certification, and training.

Policy Option 34: An easily implemented resolution to these issues is for the regulations and the Medicaid Manual to encourage or require that states make recipients aware of the supervision option and give recipients (or their caregivers) the option to request or refuse such services where the recipient believes such a service would be beneficial or detrimental. States would retain the right to require such supervision when deemed necessary (such as where there is evidence of poor self-management of care).

Further study is needed on the types of situations or circumstances where self-directed care may be adverse to the health and safety of the individual. The relative service use and quality of care consequences of different supervisory models could be examined (e.g., agency based providers, individual providers with and without case manager supervision, coordinated self-directed home care program with other forms of primary health care management).

Policy Option 35: HCFA could consider specifying a minimal level of training required for personal care workers, but such training could be provided by clients who are capable of their conducting their own training. States could be asked, in the federal regulations and/or the Medicaid manual, to develop plans for consumer training in how to manage individual providers. Training programs for providers could be required to include consumer directed approaches to care and descriptions of how to maximize the independence of individuals. HCFA and/or states could present examples of "best practices" for consumer directed care and disseminate the information broadly to providers, consumer advocacy groups, and state officials.

Policy Option 36. The nature and extent of consumer advisory committees and other means of consumer input into the personal care program in states could be identified, and comparisons made of state policy and program management in states having consumer input and those with little or no such involvement. Those states providing best practices could be identified and the results disseminated to other states. A statutory requirement for a consumer advisory council for Medicaid personal care services, HCBS waiver programs, and home care could be considered.

Policy Option 37: To be consistent with the statute and the intent of the ADA legislation, HCFA regulations could be changed to require that personal care services be provided in "other locations." "Other locations" could be defined as community settings such as grocery stores, schools, banks, business establishments, and libraries, recreational facilities, as well as work sites and assisted living facilities. The cost implications could be studied along with potential savings to Medicaid from reduced nursing home care, and tax revenues from the employed disabled to help off-set the marginal costs of any program expansion. The variation among states in current practices relative to the interpretation of "other location," is a ready source for comparative research on costs and program outcomes.

Policy Option 38: Because personal care service regulations do not have any specific provisions about rights and the ability to file complaints about care, HCFA regulations could consider giving the recipients of personal care services rights about their care services which are identical for those for home health agency care recipients. HCFA could also assure that personal care service recipients would have access to the state long-term care ombudsman upon request.

Policy Option 39. HCFA regulations could clarify the rights of applicants for personal care services and they should enforce the requirement that states assure the right to a fair hearing and an appeals process for clients whose services are reduced or terminated.

Policy Option 40: HCFA could study the extent to which states ensure mechanisms for timely payment for personal care services, especially in the initial start up period, to ensure access to and availability of personal care services. If these are found to be inadequate, HCFA could provide guidelines and technical assistance to states regarding payment mechanisms for independent providers.

Policy Option 41: If the demonstration proves to be effective, a statutory change could be made in the Medicaid Act to clarify that cash advance payments may be made directly to clients under a cash and counseling program. Specific procedures would need to be developed for disregarding these cash payments in determining financial eligibility for Medicaid and for SSI. Legislation would also need to amend the Medicaid, SSI, IRS provisions, and the food stamp program requirements so that the cash payments to clients would not be counted as income and would not lose their income-related benefits.

Policy Option 42 HCFA could study the relationship between state disability rates (defined as need for assistance in self care) and service availability and the possibility of providing additional FFP funds for personal care services in states with the highest disability rates. Alternatively, HCFA could mandate that the amount of personal care services be available in proportion to the level of disability and impairment in the state Medicaid population.

Policy Option 43: FFP incentives and other policies could be studied as a way to encourage states to expand their personal care services program. Studies of the effects of personal care service utilization on the use of nursing home, assisted living, employment, and health care services could be encouraged.

HCBS WAIVER

Policy Option 44: Because of the critical importance of the HCBS waiver program for preventing institutionalization, the HCBS waiver program could be made a state plan option, or even a mandatory benefit, for Medicaid by a change in the statutes. There are many administrative benefits both for the federal and state governments in moving the program from a waiver with paperwork and review requirements to a state plan option. A mandatory benefit would give the program comparable status to that of the nursing home program under Medicaid and could then offer individuals with disabilities a real choice between home and community based care and institutional care.

Improved cost estimates are needed for the expansion of the HCBS waiver program. Since a mandatory program may increase expenditures for some states, increased FFP may be needed at least in the first few years of expansion. An alternative approach to a mandatory benefit is to establish an optional state plan program with higher FFP payments as financial incentives for a time-limited period (possibly for a five year period), that would be coupled with controls on institutional capacity. At the same time, the model HCBS waivers could possibly be retained for small special populations.

Policy Option 45: HCFA needs to determine how many HCBS waivers are currently in effect for statewideness and what would be the estimated costs for expanding HCBS waivers statewide. Because states have had considerable experience with their waiver programs, HCBS waiver programs could be extended to all geographical areas of a state. Having different HCBS waivers available in different parts of a state creates an inequitable situation for a state's residents. This change could be made by new legislation or by placing a limit on the number of times a waiver for statewideness can be renewed through regulation or by a time limit (sunshine clause).

Policy Option 46: In order to accomplish greater equity and prevent inappropriate

institutionalization, the HCBS waiver program would need to be extended to all eligible groups within a state. This could be accomplished by requiring a statutory change to eliminate the waiver of comparability for different eligibility groups. Another possibility is to place a regulatory limit on the number of times a waiver can be renewed for comparability through regulation. An alternative approach is to increase the FFP for a time-limited period (for example for five years) as an incentive program for states to expand comparability to all groups. Special technical assistance could be given to the states for the transition period.

Policy Option 47. Although the limits on the total number of persons eligible for each waiver program protect states financially from having to expand their programs, the limits may prevent some individuals in need of extensive services from receiving the services in the community. The limits are also an administrative barrier to program flexibility and expansion. Although states can amend their waiver programs to expand the waiver limits with a minimal effort, this requirement could be removed by regulation. This removal could also be accomplished if the HCBS waiver program was made into an optional or mandatory Medicaid program.

Policy Option 48. The importance of the special institutional financial eligibility and spend down provisions for HCBS waiver services should not be underestimated. This financial eligibility provision, however, is optional to the states, so that 12 percent of the states were not taking advantage of the maximum institutional eligibility in 1996. Where this option is not used, the financial incentives are for individuals to enter institutions over remaining at home. Efforts are needed by HCFA to encourage all states to use these special financial eligibility provisions for the HCBS waiver program. An alternative is to make the special financial eligibility mandatory through a statutory change, so that no differences would be allowed between the basic financial eligibility for institutional care and for the HCBS waiver program.

Policy Option 49: The spousal impoverishment rules are an important component of preventing institutionalization. HCFA could consider ways to encourage the remaining 16 states to elect this option and/or could request statutory changes that would require all states to use the spousal impoverishment rules for the HCBS waiver program. This change would remove financial incentives for institutionalization.

Policy Option 50. The special financial eligibility provision allows states to provide a real option for individuals with disabilities to remain in the community with the HCBS waiver program. The current financial spend down provisions and the post eligibility treatment of income are essential parts of the HCBS waiver program that should be maintained. If the special financial eligibility requirements could also be applied to personal care services, then more states may be willing to combine all their personal care services under the state plan option, rather than to provide personal care under both the state plan option and the HCBS waiver program. Perhaps this would result in some administrative savings and a more understandable care delivery system.

Policy Option 51: Changes in the SSI and Medicaid statutes could be considered to increase the asset levels for individuals living in the community who would otherwise be forced into institutional care. These statutes could be modified so that asset limitations are indexed for inflation. Another option would be to allow HCBS waiver recipients to retain the equivalent of 6-12 months of expenses (for housing, utilities, food, and other expenses) in assets. This would require a statutory change that may be opposed because of its cost implications.

Policy Option 52: HCFA could seek statutory authority to extend Miller trusts to individuals eligible for HCBS waiver services in states with income caps. In addition, HCFA could consider requiring states to provide information about the availability of Miller trusts and assistance in establishing such trusts.

Policy Option 53: If the HCBS waiver program specified a minimum set of benefits, clients would have access to a fuller range of services to allow them to stay in the community as an option to institutional services. The eight services that are currently specified in the regulations as optional, or a subset of the eight services, could be considered as a minimum benefit package for states to offer, and other services could be optional. Need criteria for the services, however, could continue to be tied to the specific needs of those who qualify for the program. For example, habilitation services would be given only to those who need assistance in improving their self-help, socialization and adaptive skills. A minimum set of services could be required by a statutory change or financial incentives could be added to encourage states to provide all

eight services. A minimum package of HCBS waiver benefits could be established if and when the HCBS waiver program was moved from a waiver to a state plan option.

Policy Option 54: HCFA could consider specifying the definitions of each of the services for reporting purposes for the HCBS waiver program, the home health care program, and the personal care services program in order to clarify the distinctions between each category. This would facilitate tracking and comparing program financial eligibility, utilization and expenditure data across states.

Policy Option 55: The extent to which these prevocational, educational and employment services are actually being provided under the HCBS waiver program could be examined along with whether other agencies are meeting the needs of waiver recipients.

Policy Option 56: The prohibition against living with caregivers should be studied to examine its impact and to determine whether this has a negative effect on living in the community and outside of residential, foster care, or nursing home care.

Policy Option 57: The respiratory care benefit appears to be a valuable one for the program to offer. Its outcomes should be studied by HCFA and disseminated to all the states. HCFA could consider collecting and disseminating information about best practices for respiratory care services to encourage states to expand this HCBS waiver program.

Policy Option 58: The respite care benefit appears to be a valuable one for the program to offer and its outcomes should be studied by HCFA and disseminated to all the states.

Policy Option 59: HCFA should study the needs and services for the mentally ill Medicaid recipients and examine the barriers to expanded services, especially for those between the ages of 22 and 64. HCFA could encourage states to cover mentally ill persons between the ages of 22 and 64 under the HCBS waiver program, even though this population is not eligible for Medicaid FFP in IMD facilities. A statutory change in HCBS coverage for individuals age 22 to 64 with MI could be considered as a way to provide cost effective and humane care. HCFA could provide information to states regarding the types of waivers for mentally ill adults that are currently approved or would be considered by HCFA and provide assistance in designing such waivers.

Policy Option 60: Limits on the amount, duration and scope can create problems if the total services are not sufficient to maintain an individual at home with care on a 24 hour per day basis. HCFA should conduct a survey of state programs to determine whether limitations in the amount, duration, and scope of benefits are creating an institutional bias. The HCBS regulations could make it clear that states are required to provide services in a sufficient amount, duration, and scope as to be useful to prevent institutionalization and that states are not exempt from Section 440.230(b) and (c). The regulations could provide guidelines that services are offered for up to 24 hours per day and other services must be sufficient to allow individuals the choice of remaining at home. If not, then the choice of remaining at home or in the community may be unavailable to many with severe disabilities.

Policy Option 61: First, to foster the adoption of objective need criteria, the Secretary could convene an expert panel to develop a consensus on a set of need criteria for institutional care and for HCBS and to reevaluate the criteria periodically. Second, recognizing the desirability for greater uniformity in need standards both within states and across states, a federal un
continues to evolve, and the predictive utility of alternative combinations and weighting of these criteria have yet to be tested, more work is needed in this area. In the interest of fostering innovation in this area, and assuring dissemination of state experiences, HCFA could develop an ongoing research program (working with selected states) to design and evaluate alternative needs determination processes, weighting criteria, and verification processes.

Policy Option 62. There is no doubt that the HCBS waiver program should continue to focus first and foremost on those individuals who would be eligible or at risk for institutional care. Medicaid HCBS waivers should be considered for those individuals do not meet the institutional need criteria. HCFA could study the desirability and feasibility of removing the link between HCBS and institutional need criteria. This would allow states to expand their HCBS waiver program by targeting those who are at risk for becoming more impaired.

Policy Option 63: The Secretary could (1) periodically confer with a panel of experts from states to develop approaches for achieving a common or core minimum data set for client screening and assessment for the HCBS waiver program; (2) evaluate the effectiveness of different state assessment systems for different long term care services; (3) disseminate the results of this evaluation to other states so that any appropriate modifications can be made; (4) move to develop a single uniform screening and assessment instrument for states to use in determining the need for HCBS within and across states, and (5) move to develop a single uniform screening instrument which could assess need for different types of services and settings (e.g. personal care, home care, HCBS, and institutional care).

Policy Option 64: HCFA could conduct research and evaluations of assessment and care planning processes (e.g. the RAPs for nursing homes) that may be effective for the HCBS waiver program, ensuring that such processes address the needs of different client populations with chronic illness and disability and distribute the findings to the states. HCFA could consider more detailed state requirements for individualized care plans.

Policy Option 65. The HCFA regulations and Medicaid manual could clarify that individual client and family involvement are essential components of the assessment and planning process for personal care services, that could generally facilitate consumer choice and satisfaction with the program. A clear federal philosophy of individual empowerment, independence, and understanding of a social model of disability is important for HCFA to articulate. Each state could be asked to address this in its state plan.

Policy Option 66: Medicaid regulations could give more guidance to the states about the assessment and planning processes, which should, at a minimum, be conducted by qualified professionals. HCFA could also sponsor research that compares the differences between provider-based assessments and independent assessments and care planning and the findings could be distributed to the states. If provider-based assessments and plans are biased over those of independent assessors, HCFA could require all assessments to be made independent of providers. HCFA could identify and disseminate information on "best practice" models for assessment and planning.

Policy Option 67: As a starting point that might result in single entry point systems, states could be encouraged or required to submit state plans that assure a coordinated screening and assessment system for their long term care programs. HCFA and/or states could develop estimates of community-level disability rates and service use and plan to address gaps or identified inequities in delivery system access for different financial eligibility groups. States could be encouraged to develop a single entry point approach for the personal care services, HCBS waiver program, and other long term care services. Financial incentives (e.g. higher FFP) could be considered for states that develop and use such an integrated system (on a one-time basis to help cover the costs of such initial reorganization). Studies of the effectiveness of different state organizations could be undertaken.

Policy Option 68: The HCBS regulations or the Medicaid Manual could be amended so that state plans are encouraged or required to develop methods to facilitate access to and choice among qualified providers, including information sources such as provider registries. States could be encouraged or required to present a state plan that maximizes consumer choices among HCBS providers. This should ensure a choice of different types of provider services such as adult day care, personal care, respite care and other long term care services in the community as well as choices between agency providers and independent personal care providers.

Policy Option 69: The current requirement for states to provide information about available alternatives is an important provision of the HCBS waiver program.
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ardized authorization procedures. HCFA could distribute information on how to simplify and streamline the authorization procedures and clarify that physician authorization is not necessary and appropriate in most situations.

Policy Option 71: The federal rules could encourage or require states to ensure access to case management for long term care services where such services are desired by recipients, regardless of which type of providers deliver the services. At the same time, individuals capable of supervising their own personal care workers should have the option to do so. The state would be expected to retain enough oversight over the care plan to assure that client care needs are being adequately met. Implicit in the implementation of these policies is that there be a reasonable standard by which the state can determine the

circumstances when self-directed care is appropriate. Neither the effect of self-directed case management systems nor case management quality issues have been extensively studied in the U.S. HCFA should work with the states in designing and evaluating alternative approaches to self-directed care and quality assurance.

Policy Option 72: The issue of independent case managers could be studied by HCFA and states to determine the most effective approaches to case management. Such research could provide guidance for future state programs. Examples of best practices from state case management programs could be disseminated.

Policy Option 73: To facilitate the development of policy and procedures relative to managed care and the role of these organizations in managing community care, HCFA could work with health plans and states in developing and evaluating alternative models for case management.

Policy Option 74: Studies could be encouraged to examine social models of care and the quality of life in different sizes and types of community facilities. Depending upon the findings, HCFA may wish to set more guidelines on the size and types of residential facilities for the HCBS waiver program or on the quality assurance mechanisms for such facilities. HCFA could distribute "best practice" models for the appropriate size of facilities and environmental design considerations.

Policy Option 75: HCBS regulations could be amended to encourage or require states to give individuals the right to select, train, and manage their own HCBS providers to the greatest extent possible. Consumer directed care could reduce the risk of institutionalization and unnecessary medicalization of services. Studies could be encouraged to evaluate the effect on the quality and cost of care and patient outcomes under varying state regulatory conditions relative to provider qualifications and training.

HCFA could study the effects of the supply of different types of HCBS providers on access to HCBS and the quality of HCBS and could convene a national panel for establishing some minimum standards for long term care provider supply for HCBS. Federal regulations could be changed to require state agency plans to assure the availability of a range of long term care providers in communities in order to ensure that recipients have greater choice and access to the kind and type of services which they would like to have. This should have benefits for preventing unnecessary medicalization and institutionalization.

Policy Option 76: The HCBS regulations could be changed to (1) allow for exceptions to the spouse or parental payment prohibition, when necessary, for the health and safety of the individual in need of personal care services; and (2) HCFA could evaluate the consequences on family caregiving, sheltered housing, residential care, and nursing home placement under conditions when family members are reimbursed and when they are not.

Policy Option 77: In order to encourage social models of care and to ensure access to appropriate HCBS services, HCFA could study the general quality of care in the HCBS waiver program and factors that affect variations across states and whether quality standards need to be made more explicit. The HCBS waiver program could establish similar protections to those for home health agencies, which allow for the process and timely review and investigation of allegations of neglect, abuse, and misappropriation of property.

Policy Option 78: HCFA could study the variation in the supervision of HCBS waiver programs and providers across states and the effects of these differences on access, quality, and costs of the programs. Findings from such a study would assist HCFA in establishing minimum quality standards that do not over medicalize the program but at the same time, protect individuals receiving services.

Policy Option 79: Because there are so many questions about details of how states are implementing the HCBS waiver programs, HCFA could have a national independent evaluation of the programs to provide descriptive information on the processes of care as well as evaluative information on the costs and the outcomes of the programs.

Policy Option 80: HCFA could study the variations in provider and client training requirements across states and how such training may effect the quality of HCBS waiver program services. The federal regulations and/or the Medicaid manual, could require states to develop training plans for consumer directed approaches to care and could provide guidelines on how to maximize the independence of individuals. Alternatively, HCFA could encourage and publicize best practices for provider and client training.

Policy Option 81. The Medicaid regulations and Medicaid Manual could clarify that individual client and family involvement are essential components of an assessment and planning process, that should generally facilitate consumer choice and satisfaction with the program. A clear federal philosophy of individual empowerment, independence, and understanding of a social model of disability is important for HCFA to articulate. Each state could be encouraged or required to address this in their state plan. Studies of the extent to which individual and family input in the assessment and planning process and whether consumer directed models are provided by states.

Policy Option 82: HCFA or the HCBS regulations could encourage states to develop methods for involving consumers in an evaluation of their HCBS services. This could enhance the consumer-directed focus that HCFA is attempting to achieve. HCFA could disseminate information on "best practice" models that states are using to obtain consumer evaluations of services.

Policy Option 83: The nature and extent of consumer advisory committees and other means of consumer input into the HCBS waiver program could be identified and comparisons made of state policy and program management in states having consumer input regulations and those with little or no such involvement.

Policy Option 84: HCFA regulations could encourage or require that HCBS waivers be provided in "other locations" outside the home to be consistent with the ADA statute and its implementation. 'Other locations' should be defined as "community settings such as grocery stores, schools, banks, business establishments, and libraries, recreation sites, as well as work sites, residential care and assisted living facilities." This would improve the social model of care and move away from a medical model, and may, in the long run, reduce institutionalization.

Policy Option 85: Because HCBS waiver regulations do not have any specific provisions about rights and the ability to file complaints about care, HCFA regulations could consider giving the recipients of personal care services rights about their care services which are identical for those for home health agency care recipients. HCFA could also assure that HCBS waiver recipients would have access to state long term care ombudsman services upon request.

Policy Option 86: HCFA regulations and the Medicaid Manual could clarify that the rights of applicants and recipients of HCBS waivers are the same as those for other Medicaid services. HCFA could actively monitor its requirements that states assure the right to a fair hearing and a timely appeals process for clients whose services are reduced or terminated.

Policy Option 87: The special financial reporting requirements and cost neutrality requirements could be removed from the HCBS waiver program by statutory change. Some type of state and federal review of institutional long term care expenditures may be a more useful undertaking than the current reporting requirements. States could be given an financial incentive for reducing institutional costs rather than HCBS costs or for increasing the percentage of expenditures for HCBS in comparison to expenditures for institutional care. For example, higher FFP payments could be given to states who meet a specified standard ratio of HCBS expenditures to institutional expenditures, e.g. for more than 10-15 percent of the total state LTC expenditures are for HCBS.

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