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OA/ID Number: 52164
Folder ID Number: 52164-012

Folder Title:
6-10-98 [Managed Care - 1998]

Stack: **Row:** **Section:** **Shelf:** **Position:**

MEMORANDUM

TO: Sabrina Smith

FROM: Lex Frieden

DATE: June 15, 1998

As you requested, we have prepared the attached materials for your use in constructing our Year 2 contract for the RTC on Managed Care and Disability. Please call me if you need further details or elaboration. Thank your for your help.

LF:rf
Attachment

STATEMENT OF WORK

Training Project 1--Year 2

Project Objectives:

1. Conduct a Delphi survey to identify the health plan decision-making information needs of people with disabilities.
2. Identify existing gaps in the information tools presently available to people with disabilities.
3. Assess the utility of various information formats in assisting persons with disabilities in making the best choices among various health plan options.
4. Disseminate the information obtained from Objective 2 and 3 to key organizations and individuals involved in the development of information tools for people with disabilities.
5. Conduct "train-the-trainer" activities to prepare persons with disabilities to serve as health information extenders, assisting other individuals with disabilities in effectively securing and using information on health plans.

Project Tasks:

1.	Produce interim report on gaps in information tools.	September 1, 1998
2.	Identify gaps in information tools.	November 1, 1998
3.	Place information tools set on web site.	January 1, 1999
4.	Prepare preliminary set of training materials.	March 1, 1999
5.	Design consumer survey and prepare draft for review and circulation.	June 1, 1999

STATEMENT OF WORK

Training Project 2--Year 2

Project Objectives

1. Establish an Information Center as a central resource for materials on managed care and disability.

2. Develop a corresponding Managed Care and Disability Web Site on the Internet, facilitating access to Internet resources as well as the resources collected at the Information Center.

3. Use current technology to create a variety of information vehicles for the dissemination of information and resources, tailored to the needs of target audiences.

4. Disseminate information on managed care and disability through other conventional media, including such vehicles as newsletters, newspapers, and radio.

5. Evaluate information-sharing strategies to assess consumer satisfaction and timeliness of information delivery.

6. Identify strategies for sustaining the most effective information-sharing vehicles beyond the period of grant funding.

Project Tasks:

1.	Add consumer and provider information to web site.	August 1, 1998
2.	Review alternative technologies for providing real time discussion option on web site.	September 1, 1998
3.	Implement trial of real time discussion on web site.	January 1, 1999
4.	Implement bulletin board-type discussion group on web site.	March 1, 1999
6.	Expand on-line reading resources.	June 1, 1999

STATEMENT OF WORK

Research Project 4--Year 2

Project Objectives:

1. Prepare a description of protections currently afforded persons with disabilities, including gaps and weaknesses in current protective legislation and regulations.

2. Compile and evaluate the health-related complaints reported to protection and advocacy (P&A) agencies and the characteristics of individuals who file these reports.

3. Research and review federal and state case law relative to persons with disabilities and treatment rendered in managed care organizations.

Project Tasks:

1.	Initiate requests for information from selected P&A agencies and others.	September 1, 1998
2.	Evaluate input from agency questionnaires.	December 1, 1998
3.	Construct protocol for soliciting information from state insurance commissions,	January 1, 1999
4.	Summarize protections afforded people with disabilities in managed care settings.	February 1, 1999
5.	Prepare one or two informational briefs based on agency data.	March 1, 1999
6.	Conduct research on case law.	June 1, 1999

Tod (713) 799-7095

Message

Von: MAILER-DAEMON@t-online.de
Betreff: mail failed, returning to sender
Gesendet am: 10.Jun.1998 14:41:58 +0200
Abgeholt am: 11.06.98 07:38

|---------- Failed addresses follow: ----------
-------|
<Lex@t-online.de> ... unknown user / Teilnehmer existiert nicht
|---------- Message text follows: ----------
-------|
Received: from ermail00.btx.dtag.de (03633283-0002(btxid)@[172.16.
35.1])
by fwd09.btx.dtag.de with smtp
id <m0yjkCE-0003R1C>; Wed, 10 Jun 1998 14:41:42 +0200
Received: by ermail00.btx.dtag.de with
(S3.1.29.1) id <m0yjkBc-0003jJC>; Wed, 10 Jun 98 14:41 MET
DST
Date: Wed, 10 Jun 98 14:40 +0100
From: 03633283-0002@t-online.de
Subject: Correspondence
To: Lex Frieden
Cc: willie_trotty@pvamu.edu
Message-Id: <m0yjkBc-0003jJC@ermail00.btx.dtag.de>

PD Dr.E.W.J.Mikus
sanmeda.querschnitt@tonline.de

Prof.
Lex Frieden
Senior-Vice President
TIRR
Housten/Real Texas

Dear Lex Frieden:Today,I am back from the European congress Resear
ch in
Rehabilitation in Berlin.
I regret that it was unable to come for you to Berlin,but I am loo
king forward
to my next visit in Houston or your next visit in Germany.
This year,I spent any time in Atlanta(Jule 19.-August 02.).I visit
the Thomas
A.Gordy Group,Inc.And I will have two highlights,I can fly too a n
avy Carrier
and see J.Carter,he is a relativ from Th.Gordy.
I am aquelly excited about the possibilty to come with our company
to the
Americen market.What about our skoliosekonception?

Message

Our projekt-telemedicine-is in progress.In the next days,we get th
e equipment in
the hospitel.(now,i am not more deputy,I am chief).
Thank you again for the introductions in Housten.So far everyone t
hat you have
introduced me in Housten and also in the Prärie-View University ha
ve been warm
and incredibly and bright people.You keep in a exellent company.
Again,I look forward to seeing you soon and I will call you,when w
e have the
telemedicine equipment.
Kind regards to your charming wife.

Yours very truly

Dr.Mikus

'IF MANAGED HEALTH CARE DOESN'T WORK FOR PEOPLE WITH DISABILITIES, IT'S NOT GOING TO WORK FOR ANYONE."

The **"Empowerment in Managed Health Care: People with Disabilities in a Changing Health Care Environment"** conference was held in Houston, Texas on March 1-2, 1998. Participants in the conference, approximately 80, represented many of the leaders in the disability community from across the country. Prior to the conference, invitees received articles about the managed health care issues facing people with disabilities. Invitees were asked to indicate their preference for participation in one of the five workshops at the time they registered for the conference. The five workshops were titled: 1) Governing principles for managed health care from a disability perspective, 2) Consumer rights, protections, and responsibilities, 3) Consumer health-plan decision making and health-plan accountability, 4) Medicare and Medicaid managed care, and 5) Making managed care work for people with disabilities.

Most of the time for the conference was spent in the five group work sessions as reflected in the conference agenda. Each of the groups were assigned a facilitator and recorder to provide leadership and accurate documentation of the groups discussions. Specific questions were developed for each of the workshops to guide the group's process, and stimulate discussions of key issues.

Participant evaluations (N=38)

The majority of participants indicated that the conference exceeded their expectations, that they had obtained information they could use, and the conference provided a framework for important dialogue among people with disabilities related to managed health care.

GOVERNING PRINCIPLES FOR MANAGED HEALTH CARE FROMA DISABILITY PERSPECTIVE

"Health is not merely the absence of disease, but good quality of life."
WHO

Principles governing managed health care services should include:

- Accessibility
  - Physically accessible
  - Financially accessible
  - Communication accessible
  - Dignity of service
  - Array of treatment options
  - Alternative treatments

Cost effectiveness studies that include:

- Quality of services
- Quality of care in the appropriate setting
- Scope should be broad – measure many aspects

Outcome measures:

- Need for standardized measures (equitable)
- Data should be "inclusionary", not exclusionary
- Services must be provided on the basis of need
- Who determines whether health care is successful?

Research Issues

- Additional data about health care experiences of people with disabilities
- Generate cost data on individual models (rather than institutional)
- Education of health care professionals

CONSUMER RIGHTS, PROTECTIONS, AND RESPONSIBILITIES

Consumer Bill of Rights and Responsibilities

- Access to an independent Ombudsperson and information service
- Information on physical access of providers and facilities
- All financial arrangements between providers and the health plan
- Choice of health care providers and plans (point-of-service option)
- Gatekeeper issues (referrals, specialists as gatekeeper)
- Access to emergency services
- Participation in treatment decisions
- Respect and nondiscrimination
- Confidentiality of health information
- File complaints and appeal benefit decisions
- Opportunities for consumer involvement
- Access to services that are functionally equivalent

CONSUMER HEALTH-PLAN DECISION MAKING AND HEALTH-PLAN ACCOUNTABILITY

Type of information consumers need

- Basic understanding (Managed Care 101:The rules have changed)
- Standard language across plans (standard definitions, i.e., disability)
- Information from other consumers who have challenged the system
- Plan coverage for disability impairment needs
- True limits of the plan (e.g., experimental treatments)
- Costs of the plan (routine, medications, emergency, hospitalization)
- Areas of access and restrictions
- Appeals procedures (how to challenge adverse decisions)
- Access to specialists (geographical restrictions)
- Does the plan address their specific health care needs?
- Functional independence measure from rehab by hospital
- Quality of Life issues
- Disability accommodation specialist (ombudsperson)
- Number of enrollments and disenrollments of people with disabilities
- Risk sharing arrangements with providers
- Mortality rate of people with disabilities under the plan
- Percent of service facilities that meet universal accessibility guidelines
- Continuing education for providers
- Procedures for monitoring providers
- Prevention and management of secondary conditions
- Access to medical records

Role of public and private agencies

- Point of influence is the Department of Insurance (sets basic requirements for all information about coverage)
- Standard set of definitions
- HR Director determines which plan is purchased
- State Departments issue RFPs for Medicaid HMOs

Standardization of reporting and uniformity of definitions

- Benefits provided
- Co-pays
- Deductibles, limitations, exclusions, mandates
- Option benefits – distinguishes the plan from others
- Appeals process
- Standardized quality measures (FIM, mortality) to assess the outcomes of the program
- Status of disability access (compliance with ADA)

Expectations of consumers

- The right to expect accrediting agencies to develop and enforce requirements of both plans and providers
- Expect clear and easily understood information about coverage of a plan
- Expect relevant information about the actual providers of services

Research Issues

- Portfolio of consumers self-assessment of medical service needs (track contacts)
- Develop treatment protocols for people with disabilities
- Identify emergent state policies

Advocacy Issues

- Establish coalitions with others groups (e.g., aging, children's health, HIA, AAHP)
- Talk with States and get them into MCO contracts
- Express support for NCMRR, NIDRR, CDC, and NCH

MEDICARE AND MEDICAID MANAGED CARE

Conditions that HCFA and Medicaid agencies should include in RFPs to health plans

- Cultural sensitivity
- Consumer driven versus medical model services
- Involve advocates and consumers in outreach and program development
- Impose Federal minimum standards
- Establish process of contracting with ombudsperson/outside advocates
- Adherence to the ADA (HMO's, providers)
- Consumer participation in "readiness review"
- Ensure HMO network includes providers with experience with people with disabilities

Research Issues

- Identify the elements of an effective quality assurance and quality monitoring program

What can federal and state agencies do to make sure health plans compete on price and quality?

- Involve consumers from beginning to end
- Develop report cards that include issues important to consumers with disabilities (risk adjustment)
- Plans should include full description of value added services
- Create a Better Business Bureau for insurance plans

What should Medicaid and Medicare require as a minimum benefit package for people with disabilities?

- Modify definition of medical necessity: to allow for services that increase independence
- Include personal assistance services
- Mental health services
- Ombudspersons

Research Issue

- What benefits do people use and to what extent?

Advocacy Issues

- Develop advocate networks in "at risk" populations
- Develop strategies to support community networks
- Train advocates (Managed Health Care 101)

How many health plans should be offered as a minimum?

Minimum of two plans to ensure choice.

Research issues

- Design a survey to determine
  - What is the minimum number of plans
  - Is there a maximum number
  - What factors need to be considered
  - Rural versus urban communities
  - What information does a consumer need to make a choice

MAKING MANAGED CARE WORK FOR PEOPLE WITH DISABILITIES

How can managed care be more responsive to the needs of people with disabilities?

- Consumer control
- Focus of accountability
- Specialists should be PCPs
- Look at benefit design of plan (include DME, maintenance therapy)
- Prevention of secondary conditions and secondary disabilities
- Define "medical necessity" to include functional needs
- Develop and strengthen ADA guidelines for managed care facilities/programs
- Include peer review boards with HMOs
- Independent external review process

Research issues

- Should the care coordinator be housed with the managed care system?
- External versus internal care coordinators/advocates – which works best and are most satisfactory for the HMO and consumers?
- How effective is risk-adjustment? Who benefits? Who gets the adjusted dollars?
- Can a managed care program be consumer-controlled and still be managed care?
- What are the cost savings and benefits to MCOs for providing high quality care to people with disabilities?
- Collect data on the experience of people with disabilities in various models of managed care.

Advocacy issues

- Teach consumers to be more informed about their health care plans and how to advocate for the plan that best meets their needs.
- Educate MCOs about needs of people with disabilities (IL Perspective)
- Educate advocates on risk adjustment and how risk is calculated

RTC on Managed Care & Disability
Advisory Committee
Work Group Recommendations & Suggestions

May 30, 1998

R1: Evaluating the Impact of Managed Care on Individuals with Disabilities: Secondary Data Analyses

1. Consider breaking out, where possible, data to evaluate the experiences of dual eligibles, i.e., individuals participating in both Medicare and Medicaid because of their dual DI/SSI status.

2. Consider breaking out, where possible, data that compares the experiences of the young old and the very old (85+ years).

R2: Evaluating the Impact of Managed Care on Individuals with Disabilities: A Consumer-based Longitudinal Study

3. Compile comments and suggestions by annotating the survey instrument and distribute to workshop participants.

4. Schedule a conference call in June to discuss suggestions; have staff highlight specific areas for discussion.

- Most participants had reviewed the survey instrument before the meeting and made numerous suggestions for improvement. Both written and verbal statements are being compiled in preparation for a conference call in June.

R3: Evaluating State-sponsored Health Care Reform Initiatives in Managed Care for People with Disabilities

- Staff outlined the criteria for selecting states to be studied and identified the states selected to date.

- The group discussed at some length whether certain access and quality issues were specific to people with disabilities or applied to all people, e.g., office waiting times.

In developing case studies for each state, the workgroup suggested that project staff:

5. Address the issue of access for hearing-impaired persons, including the use of interpreters and TDDs.

6. Address whether providers allocate the additional time needed to communicate with individuals who have cognitive impairments.

7. Determine whether state-sponsored health plans include restrictions on the number of primary care providers.

8. Determine the extent to which physicians tend to focus on disability issues when the individual's problem is not disability related.

9. Examine disenrollment data, where available, for specific disability populations, as an indicator of health-plan satisfaction.

10. Examine the grievance and appeals processes made available to people with disabilities.

- Elizabeth Wehr of the Center on Health Policy at George Washington University presented the instrument she is using to review disability provisions in Medicaid contracts. She requested that participants telephone or fax their comments to her.

R4: Legal Protections for People with Disabilities

- This project commences in Year 2.

R5-6: Evaluating Alternative Managed Care Delivery Approaches for People with Disabilities *and* Enhancing Consumer Choice through Quality Indicators for People with Disabilities

11. Once data are assembled, simplify, where possible, the proposed typology for alternative managed care delivery approaches for people with disabilities. Consider the use of a three dimensional grid in refining the typology.

12. Limit the consumer survey to people who qualify as reasonably "informed" consumers to obtain the best possible information.

13. Have the consumer survey reviewed by consumers prior to distribution.

14. Consider working through the Office of Personnel Management (OPM) as well as HCFA to obtain leverage with NCQA.[1]

[1]This recommendation came in response to the difficulty expressed by the staff in obtaining NCQA's full participation and buy-in at a time of staff turnover and competing NCQA demands.

T1-2: Informed Consumer Choice *and* Managed Care & Disability Information Service

15. Consider how the website could be made helpful to employers and other health-plan sponsors who are making decisions about which health plans to make available to their employees or members.

16. Make the web site "culturally sensitive." [Pamela: What does this mean in operational terms? What did the person who suggested this have in mind or what did this individual perceive to be a problem?]

17. Consider the use of "information brokers" who can help translate the arcane language of health plans and health-plan choices for people who need to make informed choices but may not be able to understand how the information can be useful to them.

18. Consider different ways of reaching people who do not have access to the web. Consider how community networks that already have an established infrastructure for disseminating health care information, i.e., sources that consumers would normally contact when seeking information. [Pamela: Could you explain what the person had in mind who made this suggestion?]

19. Make dissemination an ongoing process.

20. Advertise the availability of the website and information service through ILC and consumer organization (e.g., UCP, MS) newsletters.

21. Consider establishing an 800 number that people can call for information. Evaluate HCFA's experience with their 800 number and web site.

22. Include links to *Health Pages* and HCFA websites.

T3: Health Policy Research Fellowship for People with Disabilities

- Project commences in Year 4.

T4: Conferences

- See summary from March 1 & 2 consumer conference in Houston

Marymargaret Sharp, Ed. D., M.P.H.
Senior Consultant
Technology Evaluation Center
Health Management Systems

BlueCross BlueShield Association

225 North Michigan Avenue
Chicago, Illinois 60601-7680
Phone: 312.297.6348
TTY: 312.297.6307
Fax: 312.297.6575
E-mail: us993msp@ibmmail.com

Memorandum

To:	Lex Frieden, MA, Senior Vice President, TIRR
CC:	Pam Dautel, MPH, Project Associate, ILRU
From:	Marymargaret Sharp-Pucci, RTC Advisory Committee Member
	Blue Cross Blue Shield Association
Date:	06/02/98
RE:	*Follow-up information*
	RTC on Managed Care & Disability
	Medicaid Managed Care, Ombudsman Programs

The information I reviewed on the provision of ombudsman programs is no longer in my possession. Unfortunately, my memory is not crisp enough to recall the source. I can give you two sources that may offer similar information.

- The National Summary of State Medicaid Managed Care Programs

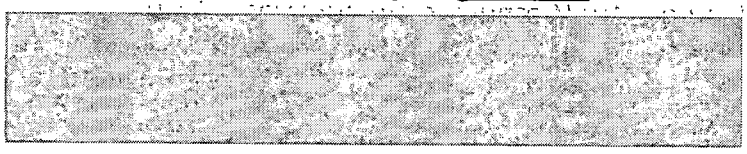
  HCFA compiles this report annually through its Medicaid Managed Care Team. The 1996 report is probably the most recent summary. I would anticipate the 1997 report to be available in late summer. HCFA contacts in the past were Loan Swisher (410 / 786-4650) and Ann Wade (410 / 786-4175).

- The National Health Law Program, Inc

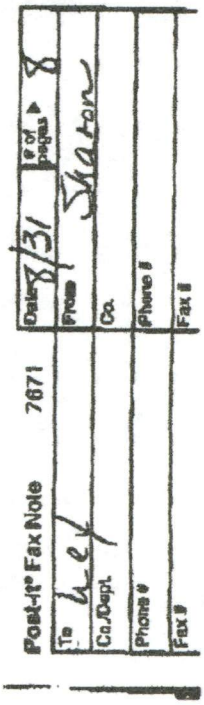
  NHeLP has developed "Medicaid Managed Care Contracts: An Advocacy Checklist for People with Disabilities". The document is essentially a tool for exercising due diligence in reviewing managed care contracts. The full source is available on the web at http://www.healthlaw.org/checklist-disabilities.html.

  The Consumer Involvement section of the checklist lists a number of criteria, which address the availability of ombudsman-like services or programs (criteria #124-131). It may be worth investigating whether NHeLP has compiled data on these threshold standards on a state by state basis.

If I can be of any further assistance on this project, please do not hesitate to contact me at marymargaret.pucci@bcbsa.com or 312 / 297-6348 voice.



EXPERTS MEETING IN MANAGED CARE
EVALUATION SUMMARY



I. PROBLEMS

1. How to make providers learn to comply with the ADA - more education? More grants to do this?
2. How to get commercial HMOs to better train providers in handling certain disabilities. Providers are generally unprepared to handle some disabilities – especially primary care physicians.
3. How to give the new MCOs the necessary technical expertise.
4. How will ILC sponsored MCOs be positioned when states decide to make SSI disabled individuals mandatory Medicaid managed care customers – as is the growing trend. Will these plans be able to compete? Or will they be ignored?
5. We have not defined a benefit package. Traditional HMOs address only primary and acute care. People with disabilities who require long-term support are not receiving those benefits now, should they? If so, how do you pay? Are we only talking MCO or private pay HMO?
6. Create a sound definition of an acceptable "independent" advocacy function within health care.
7. DME quality.
8. Issues of creeping definitions like "assistive living" must be clearly defined and evaluated for what they really are.
9. The paternalism that seems to pervade the operations of MCOs.
10. The move toward segregated service systems.
11. The tendency to let MCOs off the hook re: serving people with significant disabilities.
12. Reimbursement bureaucracy dictates how services are developed.
13. No consensus on how models should be developed.
14. I believe resources are going to dwindle rather than become more abundant. How do we respond.
15. Developing MCO usable definition and protocol that separate long-term care and medical needs.
16. Incentiving the health delivery systems/MCO to service.
17. How to approach changing the medical education and health care industry to prepare professionals with a new paradigm of care.
18. Understanding and addressing the needs of those currently not formally involved in long-term care systems – but eligible.
19. Moving from capitation and risk to "total costs" and effectiveness.
20. Why MCOs do not want people with disabilities – answer because they don't want high cost people. Data shows that people with significant disabilities cost a lot more than typical employees. If you do not play right HMOs will not compete for the business. The issue is convincing HMOs that it is in their best interest to produce the data that allows HCFA and the states to risk adjust based on case mix rather than just discounting payments to HMOs – very tall order.
21. How do we steer demonstrations to be inclusive of all people rather than for disabled only or elderly only.
22. The IL movement is confronted with ongoing issues in many areas how do we build on capacity to take on managed care. Individual CIL's are typically not able to take on this giant.

23. Adequate risk adjustment mechanisms. If we are to have a market based health care system, we have to solve the risk competition/adverse risk adjustment problem.
24. If ILCs are not creating service models who will?

II. SOLUTIONS

1. More programs that replicate the experience of ILCs in forming their own MCOs to provide services to persons with disabilities. This would involve getting states to go to the federal government to fund these programs.
2. More access by states to use assisted living centers for individuals with disabilities.
3. Enrollment Process: Oregon used case workers from Medicaid and long-term care systems to explain managed care options and do the enrollment. Part of the rationale was because of (a) familiarity with SSI population and (b) advocacy orientation of those workers (assumed). Although imperfect, this approach is working. Makes the case that an advocacy group could provide this service.
4. Protocol Development: A strength (potentially) of managed care is to improve quality of care through expecting providers to deliver appropriate care. This currently includes things like immunizing their members, having the right eye exams for diabetes, cancer screenings such as mammograms and pap smears. ILCs could develop (and market?) clinical protocols appropriate for persons with disabilities – routine evaluation of mobility equipment, identification of whether the consumer is aware of other services available, etc. – to expect/disseminate to the primary care providers, preferably as part of an electronic system. See work of Richard Besdine regarding use of managed care to improve geriatric medicine.
5. Other Technical Assistance: Tremendous need for education and training of HMO staff – medical directors, customer service, etc. Could develop (& sell) trainings.
6. Do a survey of physicians re: why they do not want to be a PCP.
7. Develop an incentive program for enticing specialists (i.e. physiatrists) in becoming PCP's.
8. Find basic communication venues for educating consumers about MCOs. Web sites won't do it when many consumers don't have reliable telephone service.
9. Standardize definitions, particularly "medical necessity" and "case manager". I am finding that insurance case managers are basically UR nurses who are conduits to the insurance physician reviewer. I still have to call different people to find out preferred vendors, benefits information, etc. May concept of case manager is someone who has a wholistic view of the case and who is a "one-stop" contact to answer all questions.
10. Provide "best practice" or "best model" scenarios for managed care and disability issues. What is working?
11. Involve consumers in accountability roles (grievance boards, etc.).
12. MCOs spun off from the ILCs
13. Integrating acute and long-term care.
14. All health care providers mandated to pay 5% of all income into an advocacy pool.
15. DME provider must have a contract that is enforceable guaranteeing working adaptive equipment.
16. The advocates must continue our own education and maybe think about derailing the train or at least sending it on a new track.
17. Assisted living trend is spreading. In long-term care infusing the social, non-medical community based model.
18. Carefully study this Wisconsin IL as a MCO model.

19. Press for passage of a Consumer Bill of Rights for Health Care that requires all health care organizations to offer comprehensive I&R, counseling, and case management services. This will send MCOs looking for and paying for services from organizations like ILCs.
20. Press for full compliance with ADA among all health care providers and insurers.
21. Use ILC based MCO as places to percolate and develop models that can be over layed over mainstream programs.
22. Centralize many of the disjointed funding streams into one pot. Also centralize disability groups.
23. Develop a system that is market driven. If consumers become purchasers of services (rather than recipients) than markets will develop services based on what they want to purchase.
24. Think outside the box and begin to experiment with alternatives to managed care.
25. Develop protocols for services for persons with disabilities for managed care settings and find ways (legislation) to insure implementation.
26. Develop advisory/ombudsman committees to work with individual HMOs and enlist or regulate support, or develop on state basis commission with insurance commission or other agency that regulates MCOs.
27. In cases where personal care and other services are being "medicalized" because of delegation issues – develop negotiated risk contracts as is becoming more common in assisted living.
28. Develop and fund an "Institute for Quality Design" with the mission of redefining and centering the definition on the quality outcomes people want/need and links them to the system performance characteristic that promote those outcomes.
29. "Incubator Role" for ILCs is – avoid the either or debate by promoting the role of ILCs as incubators of model managed care programs that are then expanded and mainstreamed into the broader system.
30. Develop a new paradigm of care – directed at chronic care systems which have the ability to promote outcomes at clinical, functional, and quality of life outcomes.
31. Move the issues of health care to the training arena for plan providers; re-defining medical culture terms to appropriately match consumer situations.
32. Identify potential activities for plan providers to contract with ILCs for rendered services, i.e., enrollment, case management training, information and referral, etc.
33. Design and implement actuarial research focuses on specific preventative services to show results.
34. If IL wants to successfully have an education and advocacy role related to health care they need to: a) get educated about issues and language, etc. from providers point of view as well as the consumers. b) understand that at least with the managed care population, providers and HMOs not only are not clamoring to serve these folks, but are often actively trying to avoid serving them. Be aware that a "watch dog" advocacy role will not make our facts and rationale any more acceptable to them.
35. Unite the various disability groups (& aging) that are so splintered on these issues. Look at how it worked with ADA.
36. ILC must tolerate diversity in thinking and activities among other ILCs.
37. National disability leadership training in health care/managed care/long-term care funded by the Feds.
38. Collaborative meeting a) national level by HHS with HCFA, AAHP, NGA, NCSL, and disability advocacy leaders to begin to develop common ground and solutions.
39. Working on development of quality "outcomes" measures in heath care/long-term care with NCQA and AARP through employer groups and state/federal purchasers.

40. To define the role of disability organizations in managed care. Assuming the requirement for running an HMO will become increasingly stringent as the government tries to balance consumer protections with HMO cost containment incentives. ILCs will not typically be able to play. What they do to the locally based disability organizations can do is to act as patient advocates. Learn what rights the federal and state government confer on patients. Learn what the service benefits are that people are entitled to. Learn how medical necessity is defined. Target disabled MCO enrollees and help them understand how to play the managed care game, that "no" does not usually mean no if you go up the food chain. Create disability support groups so that people can help each other. Learn the game. This role requires an ILC to understand how to play the game and no just trash it.
41. CIL's contracted as evaluators of health plan readiness to serve people with disabilities: a) ADA compliance, b) network capacity – primary, specialty, ancillary care.
42. CIL's contracted as ombudsman service/program.
43. Establish public policy to require consumer governance in MCOs.
44. Effective advocacy has to be both inside and outside a given system.
45. Carve outs may work
46. Solutions have cultured and geographic components that cannot be overlooked.
47. These discussions need to continue face-to-face (better dialogue) and the attendees need to bring opposing, conflicting viewpoints (like today). These are critical issues, may be we are not ready to feel good yet (have consensus) of the solutions.
48. PAS is different (very clearly to me) than "health care". PAS is IL movement programs. Health care clearly is not.
49. A recurring theme in the managed care – disability discussion was the need to have a "voice" in the deliberations. This was juxtaposed against the sense that disability was often "not on the radar" of the larger managed care concerns. While not a direct solution, I believe much can be gained by building coalitions to constituencies beyond the disability community, in particular, to those struggling with health care issues and income inequality issues among Americans generally. There are common concerns regarding access and equity that need to be addressed and much intersection between disability and poverty in the U.S.
50. Risk adjusted health plan payment that adequately captures the higher than average health care needs of people with disabilities. This is needed to induce mainstream health plans in service people with disabilities and will minimize the need for separate systems for people with disabilities.
51. ILCs need to be involved in developing health plan quality indicators that are responsive to the needs and concerns of people with disabilities. ILCs need to work with state agencies and others in developing standards for quality indicator disclosure.
52. Require health plans, as a condition for participation in the state, to have their staff participate in training related to IL concepts and needs of people with disabilities.
53. ILCs provide case management for states for people with disabilities in managed care organizations. These services would be fee for service based.
54. Ongoing technical assistance for centers to develop expertise in the following areas: a) training of MCOs case managers in IL principles and cost-efficient ways to deliver services. b) reviewing MCO contracts to assure services, grievance procedures, c) organizing consumers of MCO services to advocate for better services, d) identification of community services to get people out to keep people out of institutions, e) how to provide community-based attendance services in a managed care environment.

III. NEXT STEPS

1. It might be useful to focus – either in meetings or other formats on narrower areas.
2. Some ideas:
   a. Models of consumer involvement in managed care
   b. Consumer Protections
   c. Mechanisms in design, in reality, and potential additions/alternatives
   d. Any one of the topic areas from the outline you created from canvassing participants about their questions for today's meeting.
   e. How ILCs can contribute to data collection or data collection efforts on needs
3. More meetings such as this, but publish findings from meeting (even if only problems); also put findings on Internet!
4. Internet dialogue
5. Put together brochure of some of the funded programs or HMOs for persons with disabilities.
6. Meet with MCOs – present at venues where they "congregate". We should spend more time converting rather than preaching to the converter.
7. Meet with State Medicaid people to convince them to require HMOs and MCOs they contract with to provide services needed for people with disabilities and policies and procedures that address their needs.
8. Email listener to faster ongoing communication.
9. Continued meetings – ongoing dialogue with state officials and perhaps HMO personnel.
10. Develop a definition "medical necessity" for long-term services funded in public systems and require "cultural disability" training to purchasers (public & private).
11. Fund independent Ombudsman to assist people in public health system to resolve grievances.
12. Require publicly funded medical services systems to use/have voucher mechanism to be used by members of health plans for long-term care.
13. Bring policy for Medicaid and Medicare together and make the "HCFA sections" talk together and be educated together.
14. Bring back anti-poverty platform to address needs of people trying to access public managed care services (housing, transportation, etc.).
15. Quality – develop people defined outcome. More national meetings with key actor, more research and papers on key issues.
16. The summaries of the last meeting and this meeting should be sent to all CIL's and to other disability related organizations. Comments back from the non-participants should be sent to participants.
17. A web site could be used for a monthly discussion group.
18. The NCIL should be encouraged to provide a forum at the National conference on appropriate roles for Centers in Health Care Reform.
19. Synopsis of any kind of consensus on health care issues should be shared with legislators.
20. NCD should be encouraged to help facilitate this discussion across the country.
21. Regular six month meetings by this group to identify common goals to develop reform.
22. Meetings with a more in-depth look at analyzing what have we learned from existing/past demonstration models i.e. Boston.
23. Meetings to look at successful disability-related managed care legislation changes at state levels.
24. In-depth advocacy strategy meeting.
25. Training MCOs to deal with disability related concerns.

26. Call for and fund rigorous research on:
    a. Status of people with disabilities in MCOs compared to people without disabilities in MCOs and compared to people with disabilities in other types of health care plans.
    b. The effect of independent living services on health maintenance and prevention of secondary conditions.
    c. ADA compliance among MCOs.
27. Facilitate a direct dialogue with administrators of MCOs.
28. Involve policy makers, legislators and health care community move in the dialog. Create a summit that involves all stake holders.
29. Take a consensus position if possible and develop white papers that can be disseminated to policy makers.
30. Develop and issue a basic set of guide lines for health plans for NCQA etc. on issues related to people with disabilities.
31. Invite an advocate and the commissioner of Medicaid from each state.
32. Develop a seminar or series of seminars with HMO/MCOs and disability groups. Perhaps expand to include state and federal legislators.
33. Internet list serv to continue work on issues.
34. Future meeting.
35. Bob and Lex talk show on NPR – modeled after Car Talk!
36. Creation of vehicle for dialogue and quality outcomes.
37. Ask us all to email you what we learned, thought about, etc. three days after we leave here.
38. To move forward, all of the suggested solutions collected at this conference should be prioritized and earmarked for development. Could use participants from conference and other solicited people to form task forces for implementation.
39. Need to get more direct consumer feedback from existing Medicaid managed care programs. Develop questionnaire to tabulate results. Longitudinal studies – see how people are faring in different models.
40. Develop draft of outcome measures – let us discuss/see if we agree. Then let us test it out.
41. Do ILC staff members understand managed care? Perhaps education about managed care for them.
42. Definitely continue them through face-to-face forum discussions could intersperse with teleconferences to reach more people.
43. Consider including a representative or presenter from a regular managed care organization (equip them with armor and helmet of course) so we can learn through them how better to present our case/fight our battle.
44. Summit meeting with all stakeholders at national level: a) disability leaders/advocates, b) health plans, c) purchasers (private and public), d) regulators, e) accreditors.
45. Funding for longitudinal research on outcome measures.
46. Go to RWJ and get them to set up a new program office to fund ILC's and other disability advocacy groups at the local level to develop models for HMO patient advocacy on behalf of people with disabilities. Teach disabled people how to be effective HMO participants.
47. Work to establish strong cross-disability coalition to advocacy for public policies in health care (not just managed care). Public policies need to address inclusion, accommodation of disability, outcome measure development meaningful to people with disabilities and the creation of quality oversight mechanism at the national level.
48. Conduct a follow-up meeting.
49. Develop a list serv.
50. Form a special interest group (SIG) within NCIL.

51. Commission a monograph that describes: a) the experience of innovative programs, b) the characteristics and scope of services rendered by innovative programs, c) coordinate production of monograph with RTC on MC&D's Research Project 5.
52. Need some ongoing connection with RTC. Not sure exactly what it should look like.
53. Create political climate for implementation of these ideas to be moved forward. Begin to formulate clear goals and work to implement those goals.
54. Public forum – IL type and managed care.
55. Develop a manage care watch! Good/bad – MC and IL.
56. Train 50 managed care experts (for each state) committed to train others.

IV. PRODUCTS FROM MEETING

1. A compendium describing current ILC activities related to managed care – including contact information. (Something with more information than the list of participants)
2. 5 - Summary of dialogues of this meeting.
3. More information on HMOs and other MCO programs existing in different states that was mentioned today.
4. 5 - List of some of the recommendations made at this meeting.
5. 5 - Copies of Alan's slides.
6. Written summary of major points discussed (flip chart notes).
7. Copies of compilation of all suggestions/recommendations.
8. Information on all related web sites.
9. A draft proposal for best practices in IL involvement in health care.
10. A draft proposal for best practices of health care and long-term care to persons with disabilities.
11. Monographs of ILC's and MCOs, What is your role?
12. A synopsis of model programs that I could use to advocate in my own state. Include any data on benefits (i.e. savings quality).
13. Comparison of various models in place and to be implemented. Consider number served, capitation, risk adjustment, long-term goals, etc. The role of ILC (if any) in the models.
14. Synthesis of meeting – e.g. major themes. From the themes, if done, a series of topics for papers/training/and/or research.
15. A proposal to take to AAHP and NCQA and NAIC to begin a substantive and formal dialogue.
16. Being relatively new and naïve to the managed care arena, a transcript of the presentations, discussions, debates would be a wonderful resource. (I don't know if this would be "old stuff" to many of the participants). As an addendum – I would like to see descriptions of many of the programs speakers represented. This would help put the comments/discussion into perspective.
17. An annodated outline of topics. Full report not needed.
18. Make available on the RTC home page.
19. Identify which individuals who wish to move our discussions to a real agenda politically.
20. Checklist for IL and Managed Care - What can you do in your state and local community?
    a. System design – development of program
    b. Training/Education of MCOs
    c. Getting people out of institutions
    d. Advocacy/Accountability
    e. Service provision

V. Rating

1 - 0
2 - 1
3 - 6
4 - 6
5 - 6

Comments:

1. Not sure, I didn't have any particular expectations.
2. Need more time on issues.
3. Pretty damn good.
4. Need a forum for the debate on role of ILCs in all this could be the subject of a whole conference.
5. Good dialogue, next meeting needs to be expanded to include all stakeholders.
6. Today definitely exceeded my expectations.
7. I have to equivocate – it exceeded my expectations in terms of information on managed care. It did not meet my expectation in terms of the main theme. However, my contact with the Star Plus Program was valuable.
8. I learned a lot, it was a useful meeting.