



POSITION STATEMENT OF THE COLORADO DEVELOPMENTAL DISABILITIES COUNCIL ON MANAGED CARE FOR PEOPLE WITH DISABILITIES

The Colorado Developmental Disabilities Council is opposed to managed care as an approach to providing services and supports to people with disabilities.

The Colorado Developmental Disabilities Council states its position on managed care to the disability community, to service providers, to policy makers and to the legislative and executive branches of government. The Council is mandated in federal law to advocate for the best interests of people with disabilities in systems change arenas. The mandate for the Council in state statute is to serve in an advisory capacity to the Governor and the General Assembly.

The concept of managed care began in the health care field but over time has translated itself into a number of service systems' mechanisms intending to limit the cost of services and influence their utilization of service delivery systems. Long term care as well as health care have adapted some of these mechanisms into systems of service delivery to meet the increasing pressures of limited resources for Coloradoans with disabilities.

Whether the Managed Care mechanisms are being called managed care or by some other name is not the issue. It is far more important to evaluate the nature and scope of the system controls rather than focus on the name attached to them. Given that, the Council determined the quality features that need to be included in whatever controls are adopted. **The position statement applies to managed care principles used in any state agency or contractor provider services, i.e. health care, long term care, acute care, Community Centered Boards, Mental Health Assessment and Service Agencies, etc.** These features serve as the Council's benchmark for evaluating managed care components. The quality features the Council has developed consider what those services look like, how they are accessed, delivered and administered.

Definition of Managed Care... the attempt to control systemic spending by offering the price for systemic services, inserting economic incentives into the service delivery system for suppliers to hold down their costs, controlling/influencing consumer provide selection patterns, better coordinating services and exercising tighter controls over consumers service utilization. (Adapted from Managed Care and People with Developmental Disabilities: A Guidebook)

QUALITY FEATURES OF SYTEMS UTILIZING MANAGED CARE MECHANISMS

- ❖ **AUTHORITY AND CHOICE** to decide how to expend funds in support of the person with the disability must reside with the individual with a disability, his/her family or guardian; choice must be inherent in any service design, provider, program, activity array, treatment, or opportunity; choice must entail the possibility of developing creative or new ways to meet goals if current choices are not desirable;
- ❖ **INDEPENDENCE** of people through adequate support, and facilitation must be the program's goal. Within that goal is the recognition that needs change over time, services and supports will be available to people to meet those changing needs and that;
- ❖ **LONG TERM SUPPORTS AND MEDICAL SERVICES** for people with disabilities should be clearly identified and separated to permit adequate resource allocation planning as well as flexibility to meet both sets of needs; bundled funding should only occur when it is proven to support higher quality services or able to fill gaps in services requested by an individual;
- ❖ **EFFECTIVE AND EFFICIENT INDIVIDUAL SUPPORTS** must be measured in terms of quality, accessibility, stability, and achievement of cost containment without sacrificing meeting people's needs; system outcomes for people must be publicly reviewed for achievement.
- ❖ **QUALITY ASSURANCE FOR SYSTEMS ADMINISTERED BY THE STATE** needs to assure that the quality assurance program results in:
 1. accountability in the areas of physical and psychological environments; timely and appropriate attention to physical and mental health; meaningful activities that are individualized and driven by informed choice; and adequate, inclusive community engagement.
 2. continuing quality improvement including broad recognition for optimal outcomes thereby encouraging replication
 3. full participation by people with disabilities and their families, including the setting of quality assurance criteria and conducting quality assurance reviews;
 4. an independent third party review;
 5. a good, clearly defined and meaningful grievance process;
 6. the state recognizing ultimate responsibility for quality assurance; and
 7. open and accessible public records of both processes and outcomes with records residing in a repository easily accessed for public review at minimal or no cost for reproduction.

- ❖ **LOCAL SERVICE PROVIDER DESIGNATION** should be based on the following criteria: 1) that people with disabilities and their family members dominate the selection process, including the setting of selection criteria, 2) that the selection process focuses on community outcomes for people with disabilities, and, 3) that the applicant is a local community based organization.
- ❖ **SERVICE ORGANIZATIONS** or other similar managed care “management mechanisms” must be under local citizen control; policy in such organizations must be made locally and “profits” made through delivery of services and supports must be publicly accounted for and committed to stay in the local community to serve people with disabilities, not sent to a distant corporate headquarters or reverted to the state general fund.
- ❖ **GOVERNING BOARDS** of service organizations must be comprised of at least 51% persons with disabilities and family members, including persons with developmental disabilities, and the composition of such governing boards must reflect the community to be served and membership on such boards must be rotated on a regularly scheduled basis.

Quality Discussion

AUTHORITY AND CHOICE QUALITY- authority and choice to decide how to expend funds in support of the person with a disability must reside with the individual with a disability, his/her family or guardian. Choice must be inherent in any service design, provider, program, activity array, treatment, or opportunity; choice must entail the possibility of developing creative or new ways to meet goals if current choices are not desirable.

The Council has had many debates on issues relating to authority, decision-making and control of limited resources. However, these issues are not the core of the real concern. At the heart of all of these debates is the struggle within the system related to turning the control and direction of services and support over to individuals and families. This is the real struggle. Change is difficult, but difficulty in the process of change does not alter the inevitability of the change itself.

A key issue in managed care for persons with disabilities is that of authority for making decisions. Any service system design needs to include the principle that people with disabilities or their families/guardians have the authority to make decisions on the services and supports provided. This means that the person would not have services authorized if they did not agree and would have only those services authorized with which they did agree.

Having the authority to make decisions often gets mixed up with the issue of managing resources. Although these issues are often thought of together, they are separate issues and need separate consideration.

Managed care organizations have historically been administered through treatment and care decisions influenced by fiscal incentives, second-guessed and constrained through practice guidelines and utilization management procedures. In other words, what the person with a disability needs and wants could be put aside because other influencing factors (fiscal incentives, guidelines, procedures) are determined to be more critical. Consumer choices thus become limited. In the developmental disabilities system, a great emphasis over the years has been placed on consumer choice. The term used in managed care to limit choice and access is referred to as “gatekeeping”. Limiting the choices of a person with a disability is a conflict with this Council’s values.

Consumer choice service delivery needs to be based on the recognition that the people with the disability or his/her family or guardian make decisions to best meet the needs of the person with the disability. It implies more than spending and more than having the money in hand. Decisions about what services or supports to purchase from whom, when, where and how frequently must be under the direct control of the person with the disability. Traditionally, in managed care systems, many decisions are made before consulting with the person receiving the services. If the consumer is given the authority

to make decisions, those decisions tend to be insignificant when compared to the range and scope of other decisions that have already been made. Decision-making in these situations turns out to be patronizing and is not empowering.

Choice must include going beyond the array of options available. It must allow an individual and/or family to find another solution to meet the goals of the individual if that is desirable and is within the scope of an appropriate budget.

The Council accepts the reality that resources are limited and that not all people with disabilities will have all of their needs met to the maximum. However, we must all recognize that public funding is only one type of resource. There are other supports that families and communities provide to persons with disabilities. Neither the family, the community nor the individual should be penalized for having access to other types of resources. Individuals and families need to be assured of the financial support available through public funding so they can put the other pieces of the puzzle in place. Some will do this independently while others will need support. The bottom line is that even in the environment of limited funding, individuals and families need assurances about the level of funding available to them to meet individual needs and the determination of funding should be needs based.

The Council recognizes that not all persons or families receiving services want authority to make decisions or want to control the funding for their services. We are in changing times with more and more families and people with disabilities seeking authority and responsibility over services while using creative solutions and mitigating barriers. For some, it may be too overwhelming; while for others there may not be an interest in doing so. When considering consumer control over service dollars, many other issues emerge. Typical concerns center on spending the money on things other than services and supports. Incidents of perceived abuse often get sensationalized to the point of becoming horror stories. Following these stories, the issues of trust and accountability inevitably get raised. There has been considerable discussion in the developmental disabilities system about trust and accountability. The reality is that in similar programs in Colorado, in which individuals control their resources, the abuses are minimal. It is not a valid concern. The point is that whether resources are controlled by individuals, their families, managed care or pseudo managed care entities, the same standards of accountability need to apply.

INDEPENDENCE QUALITY- independence of people through adequate support, and facilitation must be the program's goal. Within that goal is the recognition that as needs change over time services and supports will be available to people to meet those changing needs.

Individual needs should drive the allocation of resources. People must never be considered too needy, or their services too expensive, to warrant not getting their needs met. People with severe disabilities must have access to services and supports as their

needs dictate. On the flip side, the system needs to manage resources such that those with fewer or less intense needs are not left wanting without their needs being met at all because all of the resources were allocated to persons with the most severe needs.

A danger exists in assuring only those with the most severe needs will be met first. If that were the case, there would be an incentive to appear in greater need in order to get needed services. The system would be rewarding maintaining a high level of needs.

A partial answer may be found in redefining resources. We need to think of resources in a different light. Resources are not only public funds, but include such things as family, community supports, friendships and other relationships. All types of resources, not just money, must be considered in meeting individual needs. If concentrated efforts are directed at garnering all types of resources, the strain on public funding will not be so great. Also, there needs to be substantive incentives for utilizing other types of resources that ultimately reduce the need for public funds.

Regardless of the type or origin of resources, people with disabilities need to be assured that resources will be available to meet their needs. The corollary is that the assurance must continue. Resource allocation principles need to be flexible enough to adjust to the changing needs of the individual over time. People should never be labeled as being at one level of resource forever and ever. Rather, people should get the resources appropriate to their needs at a point in time and, as those needs change over time, resources likewise need to change.

LONG TERM SUPPORTS QUALITY- long term supports for people with disabilities should be clearly identified and separated to permit adequate resource allocation planning as well as flexibility to meet both sets of needs; bundled funding should only occur when it is proven to support higher quality services or able to fill gaps in services requested by an individual.

Applying pure managed care principles to the disability system leads to the merging of two very different things: 1) long term supports; and 2) medical services for people with disabilities.

In the semantics of managed care, combining medical services and long term supports together is referred to as “bundling”. The managed care organization receives payment from the state for both types of services without necessarily making an accountable distinction between the two. Services are not paid for by the state on an individual basis, but all services are combined together into a single payment structure. In other words, if medical services cost more than anticipated, savings from long term care supports could be used to offset that loss. Savings or profits from one type of service option can be shifted to another category of services to offset a loss.

A critical issue in bundling of medical and long term support services relates to maintaining a separation of values and principles. Managed care organizations are

comfortable with the medical model and its driving values and philosophies. They are not comfortable with the values and philosophies associated with long term supports for people with disabilities.

Since the nature and scope of long term supports and medical services are so different and the values and philosophies that drive each are so different, the Council believes they typically should not be “bundled” together. For people eligible for Medicaid medical benefits, they are ensured that they will have full access to the range of benefits they are entitled to including durable medical equipment. The integrity of medical services for an individual is maintained and accountable.

In the future, should an opportunity to increase service quality or fill needed service gaps be fulfilled by bundling funding streams, the state must ensure that the Medicaid entitlement or medical benefits under another funding stream are not compromised and are tracked for quality outcomes along with long term services. Providers are to be held contractually accountable for services as designed by the individual and their team.

EFFECTIVE AND EFFICIENT INDIVIDUAL SUPPORTS QUALITY- Effective and efficient individual supports must be measured in terms of quality, accessibility, and stability. Systems are publicly obligated to achieve cost containment, without sacrificing meeting people’s needs. System outcomes for people must be publicly reviewed for achievement.

As organizations develop, including managed care organizations, policies, procedures, rules and regulations are established to manage their current realities. After a relatively short period of time, these policies, procedures, rules and regulations combine to form the foundation upon which the organization is maintained. They become a part of the culture. They create an identity. They form the internal and external perceptions of what the organization is all about. They shape the thinking of everyone in the organization from the top on down. The policies, procedures, rules and regulations become institutionalized and are very difficult to change.

Organizational motivation must also be considered. In managed care organizations, economic efficiency is the driving value. Economic efficiency means what is most economical for the organization or for the majority is what needs to be done, not necessarily what is most effective for the individual. The emphasis is placed on the population of service recipients as a whole, not on individuals within that population. This acceptance of utilitarianism (the greatest good for the greatest number) surfaces as the key factor in decisions and policies.

This philosophical bias has significant and negative implications for people with disabilities.

Under managed care, it is not difficult to imagine that an individual’s needs will be weighed against the needs of others. An individual’s needs may be too expensive, too

exotic, or too unique when compared to the “average” needs of the recipient population. What happens then? Are we prepared to tell the individual that because of the nature of his/her needs, we are unable to meet those needs?

Historically, the principle of economic efficiency within managed care organizations has saved money by limiting unnecessary institutional care. Elsewhere in the country, where managed care organizations are anxious to contract for long term services for people with disabilities, there are large institutional populations. There is money to be made by taking people out of higher cost institutions and placing them in lower cost community settings. However, Colorado has already saved this money through years of deinstitutionalization. The savings simply are not there. Therefore, managed care organizations, driven by the need to demonstrate an economic efficiency, will look elsewhere. The logical place to look for economic efficiency is at the level of services provided in community settings. In 2001, the Council is observing denial of services, curtailment of services, abolishment of services to the most costly and difficult populations all due to the need to demonstrate economic efficiencies.

Applying the principle of community services has implications, especially for the people with the greatest needs. A first question that comes to mind is whether or not individual residential supports are more expensive than congregate care. There are those who would argue that it is cheaper to provide services in an 8-bed group home than to maintain 8 people in individual apartments. There are those who would likewise argue that it is cheaper to provide services in a sheltered workshop than to maintain 35 or 40 people on individual supported employment jobs. There probably will develop many such scenarios pitting the values of this Council against economic efficiency.

We must be careful that we do not appear to promote inefficiency simply because we advocate for value based services. The issue is not one of being either for or against economic efficiency. Rather, the issue is one of how to efficiently meet individual needs. Many people with disabilities now receive what they neither want nor need. That certainly is not efficient. Providing services to people based on what they need can be efficient if it is done correctly. The challenge is in meeting needs in the most efficient way, not in cutting needed services to become efficient.

Managed care was originally developed in the health care arena. This model of care has been modified and adapted to parts of the disability services system though some say that is debatable due to contractors not having to take on all risk. In Colorado, managed care models were initially piloted in the mental health system but quickly garnered the attention of state developmental disabilities policy makers.

The medical model, first of all, is propositioned on the fact that people are sick and not only capable of, but expected to recover. This is a natural and normal assumption to make in the case of illness. However, this proposition creates not only an erroneous but also a dangerous mindset when considering long term supports for people with disabilities. Furthermore, it sets up a series of contradictions between managed care models and the underpinning values of services and supports for people with disabilities.

Lets first examine, from a managed care model, what happens when people are sick. Generally, there is an acute period during which intensive medical services are available. After the crisis ends or the acute phase passes, the need for medical services diminishes until services are no longer needed and recovery has been achieved. The expectation of the managed care provider is that the need for services in acute episodes eventually diminishes to the point that no further services are needed as recovery occurs. This diminishing need for services is the norm.

The exception to the norm occurs when long term care is needed. Managed care providers do get into the issue of long term care with geriatric populations. Nursing homes are where long term care is generally provided. However, the experience is tainted by the fact that in most cases, “long term” means a relatively few number of years before the person dies. Managed care providers generally do not understand that in services to persons with disabilities, the “long” in “long term” may mean an entire life span of 70, 80, even 90 years. There is neither the experience base nor the recognition of this fact in traditional managed health care systems.

Managed care systems were designed for the management of medical services. Medical values and philosophies provide the foundation upon which their policies and decisions rest. The “medical model” thinking is inherent in those who designed managed care systems. Medical Models of services for people with developmental disabilities, long ago abandoned, are deemed inappropriate and must never return. The disability system has been there and has evolved past that type of thinking. Accepting the “medical model” would put us back at least 25 years. Finally, there is no evidence available anywhere in the country to support the premise that the principles of managed care will work when applied to long term supports for people with disabilities.

QUALITY ASSURANCE FOR SYSTEMS ADMINISTERED BY THE STATE

QUALITY- Quality assurance for systems administered by the state needs to assure that the quality assurance program results in:

- 1. accountability in the areas of physical and psychological environments; timely and appropriate attention to physical and mental health; meaningful activities that are individualized and driven by informed choice; and adequate, inclusive community engagement.**
- 2. continuing quality improvement including broad recognition for exceptional outcomes thereby encouraging replication**
- 3. full participation by people with disabilities and their families, including the setting of quality assurance criteria and conducting quality assurance reviews;**
- 4. an independent third party review;**
- 5. a supportive, clearly defined and meaningful grievance process;**

- 6. the state recognizing ultimate responsibility for quality assurance; and**
- 7. open and accessible public records of both processes and outcomes with records residing in a repository easily accessed for public review at minimal or no cost for reproduction.**

Standards, accountability, monitoring, quality assurance and enforcement are issues that need to be addressed in detail. The Council has considered the merits of different types of reviews: peer reviews, consumer reviews, state and federal reviews and 3rd party reviews. The discussion focused on whether these were four separate review processes or a single review with four different components. If there were four separate reviews, such a process would probably be too inefficient and too bureaucratic. Therefore, the Council recommends a single review process with multiple components or input from various constituencies.

Trust with the review process is of concern to many Council members. There is a fear that in the review process the best interests of people with disabilities are pitted in a losing battle against a variety of financial issues. History confirms that negative information often gets buried and never surfaces for the sake of political or fiscal expediency. Council members want to make sure that no single entity controls the review process to the extent that important information gets buried for political or financial purposes. The state is ultimately responsible for quality assurance. Therefore, the state needs to assure an open review process. The point the Council makes is that the process and the outcomes need to be open and accessible and advocates for such with the state.

The Council does not prescribe the details of the review processes, the mechanisms of who, what and how often. The Council does, however, want to protect against reviews that are so controlled, contrived and political that they are of little value. One suggested way to guard against that from happening was to have a third party review built into the process. Some see third party reviews as a pure review untainted by politics and relationships. Others see the third party reviews as being more comprehensive. Council members generally agree that third party reviews can be very useful if they are truly impartial.

As critical as a third party review is, the need to include people with disabilities and family members in the quality review process is even more important. This does not take the place of third party reviews. What is being stated is that it is absolutely essential that people with disabilities and their families be included in a meaningful way in both the setting of criteria as well as in the conduct of the actual quality reviews. If there are barriers, such as lack of funds, inhibiting or prohibiting people with disabilities or their families from fully participating, then the barriers must be removed. It is the responsibility of the state or service organization to assure that such barriers are removed.

As people's needs change and evolve, continuous quality improvement must be the catalyst to ensure the system changes and evolves accordingly. Evaluations must entail measurements against ideal outcomes and not solely minimum standards. The entire review process needs to be looked at from the dual perspectives, on one hand, compliance with federal and state regulations, and on the other hand, of assuring quality outcomes for people with disabilities. These are not necessarily the same. A service provider can comply with all the regulations and still not provide quality community outcomes for people with disabilities. When thinking in terms of review processes, although regulatory compliance is important, it is not as critical to the Council as are quality outcomes for people with disabilities. What we are talking about are the outcomes for people with disabilities in their communities, whether service organization activities support those outcomes, and whether the customer is satisfied. These basic questions of quality are far different from questions relating to meeting standards.

The Council believes that people with disabilities and their families from the local community must be included in whatever quality assurance mechanisms are put in place. This point cannot be over-emphasized. The issue is not one of mere input, but one of meaningful partnership. People with disabilities and their families must be empowered to not only identify what is working and what is not working, but empowered to force necessary changes in the service organization. Furthermore, people with disabilities and their families must have access to a constructive, efficient and effective process for resolving conflicts when disagreements over services arise. Whether improved services in a local community result from conflict resolution or from quality assurance reviews, people with disabilities and their families must be integral components of the change process.

Finally, the Council recommends making the quality assurance process a fully accessible public record. This includes giving total access on all parts of the process, including criteria determination and assessment. There needs to be a repository of such information that provides an objective place people can get the information they seek about quality services in a given community. Not only must the information be open, it must also be accessible, which includes providing supports such as aid in reading and understanding. Records must be accessed at minimal or no cost for reproduction.

LOCAL SERVICE PROVIDER DESIGNATION QUALITY- Local service provider should be based on the following criteria: 1) that people with disabilities and their family members dominate the selection process, including the setting of selection criteria, 2) that the selection process focuses on community outcomes for people with disabilities, and, 3) that the applicant is a local community based organization.

The selection of the local managed care or service provider organization needs to be an open process with significant input by people with disabilities and their families. The input occurs not only at the point of selection, but is woven throughout the entire process,

including the point of setting the selection criteria. Again, the issue is one of local people know what is best for their community. This level of involvement is consistent with the entire movement of consumer control and self direction, with government becoming more customer friendly and responsive and with the Department of Human Services goals of putting power and decision-making under local control.

The Council expects any bidding that occurs for the designation of any managed care or service provider organization to be an open process, above reproach. The selection criteria should not be determined by who can offer the cheapest services. There always will be the “bargain basement” operators who will undercut everyone else. The problem is that the quality of services of such organizations typically fades. Selection needs to be based on real community quality outcomes for people with disabilities that will be sustained over the life of the contract. It is important that the managed care or service provider organization not only relate to the community it serves, but also be a part of that community. Managed care and the issues related to managed care deeply touch the lives of people with developmental disabilities. The decisions, policies and regulations made by the managed care or service provider organization directly impact people’s lives in ways that most people do not realize. Therefore, it is critical that people with developmental disabilities and their families be able to form a partnership with the managed care or service provider organization in order to influence those decisions, policies and regulations.

SERVICE ORGANIZATIONS QUALITY- Service organizations or other similar managed care “management mechanisms” must consider and be responsive to local citizen input; policy in such organizations must be made locally and “profits” made through delivery of services and supports must be publicly accounted for and committed to stay in the local community to serve people with disabilities, not sent to a distant corporate headquarters or reverted to the state general fund.

It is important that the managed care or service provider organization not only relate to the community it serves, but also be a part of that community. Managed care and the issues related to managed care deeply touch the lives of people with disabilities. The decisions, policies and regulations made by the managed care or service provider organization directly impact people’s lives in ways that most people do not realize. That is why it is critical that people with disabilities and their families be able to form a partnership with the managed care or service provider organization in order to influence those decisions, policies, and regulations through a local advisory component .

The managed care or service provider organization ideally needs to be controlled locally as opposed to being controlled out of a corporate headquarters in some remote location. When this is not occurring, a local citizen advisory board should be created. The decisions, policies and regulations need to be made close to the local community that will be impacted by those decisions. Local people have a much stronger sense of what is needed for their community than isolated decision makers in some remote location. Communities throughout Colorado do not want an out of State Corporation telling them

how to run their business. For example, a corporate officer in New Jersey should not make decisions that affect the lives of people who live in La Junta. People in La Junta are in a far better position to decide what is best for its citizens.

The issue of local governance raises questions regarding what happens to the “profits” made by the managed care or service provider organization. There is, within the disabilities community, a great deal of concern on this issue. It is difficult to discuss the issue of profit without also debating the merits of for-profit versus not-for-profit organizations. On the one hand, there are those who will say that the for-profit sector understands outcomes and efficiency better than the not-for-profit sector. On the other hand, arguments are presented that the not-for-profit organization better understands the values, vision and philosophies that drive the disabilities service system. The answer probably lies somewhere in between.

The Council is not taking a position on the debate between for-profit and not-for-profit entities. The form is not as important as the function. Regardless of whether or not managed care or service provider organization is a not-for-profit entity, there are definite criteria, standards and outcomes that are expected. It is to the point of these criteria, standards and outcomes that the Council is addressing its concerns.

Whether or not the managed care or service provider organization is a for-profit entity, revenue received to provide services to people with disabilities needs to be directed towards those services. There is much controversy in the system about how much of the actual allocation is spent on administration. However, the purpose of this discussion is not to address that separate issue. It is a subject that does need discussion; but that discussion can best occur elsewhere. For the point at hand, the Council is concerned with “profits” that may accrue as a result of efficient management of resources. What happens to those profits is of concern. The Council is suggesting, in the essence of the spirit of stewardship of public funds, that whatever profits do accrue be converted to additional services for people with disabilities in the local community. In other words, ideally any profit to be realized needs to remain in the local community and not be sent to a corporate headquarters or reverted to the state general fund. If this is not occurring, a limit needs to be established with a reasonable profit margin and any excess returned to service.

GOVERNING BOARDS QUALITY- Governing boards of service organizations must be comprised of at least 51% persons with disabilities and family members, including persons with developmental disabilities, and the composition of such governing boards must reflect the community to be served and membership on such boards must be rotated on a regularly scheduled basis.

People with disabilities and their families need to be a significant part of the governance of the local managed care or service provider organization. The interests of people with disabilities, the primary customer, need to be ever present in the policies that are set for the organization. Therefore, the Council advocates for people with disabilities and their families to be on boards of directors of the managed care or service provider

organization. This representation is not token representation, but true governance. The governing board must be made up of at least 51% people with disabilities or their family members. It is also important that governing boards do not become power bases unto themselves. We have seen examples where a board of directors starts out as a creative problem solver but over time becomes the problem itself. Turnover on the board tends to protect against such entrenchment and allows new ideas, new energy and a new level of responsiveness to remain a part of the board structure. For this to happen, local governing boards must be subject to regular rotation of membership.

APPENDIX SUMMARY

DISCUSSIONS SURROUNDING THE POSITION STATEMENT OF THE COLORADO DEVELOPMENTAL DISABILITIES COUNCIL ON MANAGED CARE FOR PEOPLE WITH DISABILITIES

There is a tremendous amount of confusion and controversy about managed care and its application to systems serving people with disabilities. The current argument has pitted policy makers and agencies against people with disabilities and their families. On the one hand is the clear recognition that Medicaid budgets are escalating out of control and that something needs to be done. On the other hand are the values and philosophies of the disability community that contradict the values and philosophies of managed care. Reaching a mutually supportive resolution to these inherent contradictions is extremely complex. There is no simple solution.

Recognizing the complexity of the problem, the Colorado Developmental Disabilities Council set out to frame its position on managed care for persons with disabilities. The Colorado Developmental Disabilities Council is comprised of persons with disabilities, state agency policy makers, parents, advocates and representation from the Colorado state legislature. Members of the Council are a microcosm of the larger community and Council members reflect and bring to bear the variety of interests that exist in that larger community.

The Council created an *ad hoc* committee in 1996 to identify and lay out these issues in such a way as to facilitate a full Council debate. The *ad hoc* committee membership, like the Council, reflected the multiplicity of interests and opinions. The committee met over the course of two months, reviewed multiple articles, documents and other pieces of information, pulled in additional resource people and ultimately produced a paper which served as a point of reference for the full Council. At a meeting of the full Council, the issues were debated.

The Council's deliberations were less controversial than one might expect. Against the backdrop of the Council's policies on *Inclusion*, *Individual Choice*, and *Family Support*, the Council developed its position on managed care for persons with disabilities. The Council has since subsumed *Individual Choice* into the other two policies as a basic Council value. In the summer of 2001, the Council's Community Inclusion Committee reviewed and updated this position statement to reflect the current thinking on Managed Care.

Position Statement of the Colorado Developmental
Disabilities Council
on Managed Care for People with Disabilities

Adopted December 14, 2000

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Marcia Tewell, Executive Director