Should Colorado Launch an Ombuds Program for People with Developmental Disabilities?

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I. Introduction

The rapid-paced expansion of community services for people with developmental disabilities poses many complex quality assurance and management challenges for states. The number of sites where community services are furnished has grown exponentially as has the sheer number of service providers. It is now commonplace for individuals to receive services and supports from multiple, predominantly private sector vendor organizations. It is challenging for states to maintain close oversight and monitoring of highly diverse and diffuse community service systems.

It is important that a state's quality assurance and management system have effective individual safeguards and protections. Individuals with developmental disabilities can be especially vulnerable to abuse, neglect and exploitation and violations of their rights. As a consequence, states frequently employ multiple safeguard and protection strategies. These include frequent monitoring by case managers, provider quality reviews, mandatory critical incident reporting and investigative follow-up, and mandatory reporter laws that require service system personnel and others to report suspected abuse or neglect to protective services authorities. These strategies are "system" safeguards and protections.

More and more states are implementing additional strategies in this arena. Some states, for example, now sponsor independent monitoring teams composed of individuals with disabilities, family members, and other citizens. Often, such teams can provide a fresh perspective concerning service quality by enlisting individuals with disabilities, family members and others to gauge quality from a third-party perspective.

Another important quality management dimension is the avenues that a state makes available to individuals and families for them to directly surface problems, complain about services or decisions that affect their services and/or obtain aid and assistance in resolving their problems. Such avenues may include formal informal dispute resolution, grievance processes, and hearing/appeal mechanisms. In one form or another, every state makes one or more of these avenues available in its service system – that is, ways within the system to respond to and correct consumer-identified problems.

In the arena of long-term services, third-party mechanisms also have emerged to provide additional safeguards and protections to individuals. These mechanisms operate independent of the service system (e.g., they are not operated by state or local funding/administering agencies or service providers) and aim at overcoming the "fox guarding the henhouse" problem sometimes associated with system-operated protections and safeguards. These mechanisms vest disinterested third parties with the authority to intervene and/or advocate on behalf of individuals. One of the best known such mechanisms is the Long-Term Care Ombudsman program, which operates in all the states with federal sponsorship on behalf of nursing facility residents.

Why This Report?

In conjunction with its evaluation of Systems Change Project, the Human Services Research Institute was asked to gather information about ombuds programs and explore the pros and cons of Colorado's establishing such a program for people with developmental disabilities who receive community services funded by the Colorado Department of Human Services. The interest in Colorado's establishing an ombuds

program stems from long-standing and ongoing concerns on the part of some stakeholders that CCBs and other service agencies in Colorado are not responsive to individual and family concerns and complaints about services. Some stakeholders believe that creating an ombuds program for people with developmental disabilities would aid in overcoming problems in the state's present complaint/grievance resolution process as well as give individuals and families access to an independent third party to assist them in problem resolution.

Backdrop: Ombuds Programs

In the United States and especially in human services, the commonly understood template for ombuds programs is the long-term care ombudsman program that each state operates on behalf of residents of nursing and certain other long-term care facilities. These programs date from the 1970s. In 1978, Congress mandated in the Older Americans Act that each state establish an ombudsman program to assist nursing home residents. This mandate stemmed from serious widespread concerns about the abuse and mistreatment of seniors in nursing facilities. In 1981, Congress also directed that ombudsman programs expand to include the residents of "board and care" facilities. Federal mandates concerning the operation of long-term services ombuds programs are contained in Title VII, Chapter 2 of the federal Older Americans Act. The essential activities of long-term care ombudsmen are succinctly described in the text box.

The essential characteristics of an ombuds program are clear enough. A program must

Fundamental activities include:

- Investigating and resolving complaints made by or on behalf of residents of long term care facilities;
- Establishing procedures for ombudsman access to facilities and patients' records;
- Creating a statewide reporting system to collect and analyze data relating to complaints;
- Mandating procedures to assure client confidentiality;
- Providing information to public agencies regarding the problems of long term care facilities' residents; and
- Other responsibilities include educating the public, training staff and volunteers, and helping to develop resident and family councils in facilities.

Ombudsmen take on a variety of roles at different levels. Two levels of advocacy include resident-level and systems-level. On a systems-level, ombudsmen attempt to solve broader or underlying causes of problems by advocating for policy change. This is done by evaluating laws and regulations, educating public and facility staff, analyzing program data, and promoting resident and family councils. On a resident-level, the ombudsmen's responsibilities include working cooperatively with outside agencies and providing assistance and training to facility staff. It is important that ombudsmen ensure residents have timely access to the ombudsman program and resolution to complaints.

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have independent standing so that it is able to act solely on behalf of the individuals it serves. The program must have legal standing to access to individuals, investigate their complaints and pursue their resolution. This standing is conferred in legislation. Ombuds programs do not have the authority to order changes to redress consumer grievances and complaints. Instead ombuds programs advocate on behalf of individuals and seek a satisfactory resolution of verified complaints or grievances by working with provider agencies and state administering agencies.

An effective ombuds program is neutral, independent, visible, staffed appropriately, and has acknowledged authority to investigate and validate complaints and pursue their resolution. The work of ombuds programs focuses on individual complaint resolution. However, as previously noted, successful ombuds programs also can provide important systems-level information by identifying systemic problems that might be addressed in any of a variety of ways. An ombuds program does not displace other quality management programs. Instead, ombuds programs operate side-by-side with such programs but at the individual consumer level.

Long-term care ombuds programs succeed to the extent that they are visible. They conduct frequent visits to nursing facilities, meet with residents, and frequently conduct training and information sessions for residents, families, and facility staff. Even though nursing and other long-term care facilities frequently are heavily and closely regulated by government, long-term care ombuds programs still field a high volume of complaints. These programs have demonstrated considerable success in resolving a high percentage of these complaints.

This Report

Colorado presently does not have an ombuds program for individuals with developmental disabilities who receive state-funded community services. However, the state does have mechanisms in place to resolve "disputes" as well as another mechanism for individuals and families to register complaints and grievances with CCBs and other service providers and seek to resolve their issues. In the next section of the report, we describe these mechanisms. We also describe other avenues of assistance to address problems and concerns that are available in Colorado to individuals and families. We also identify and describe Colorado's existing ombuds programs.

We then report the results of our investigation concerning which other states have established ombuds or ombuds-like programs that furnish assistance and advocacy for individuals with developmental disabilities and families. We also profile selected programs that we judge to be more or less consistent with the commonly understood template of ombuds programs.

In the final section of the report, we discuss the pros and cons of Colorado's establishing an ombuds program for individuals with developmental disabilities and outline how the state might proceed if it believes that having such a program would be beneficial. We also sketch out alternatives to an ombuds program that might merit discussion.

II. Colorado's Current Dispute and Grievance/ Complaint Resolution Mechanisms

By law and regulation, Colorado has established formal mechanisms for individuals with developmental disabilities to "dispute" decisions that are made about their eligibility for services and/or the services that they are authorized to receive. "Disputable" decisions are narrowly defined. There also is a mechanism for persons to file a formal complain or grievance about other problems that they might encounter that have not been resolved informally to their satisfaction. We describe Colorado's mechanisms in the next section along with other avenues of assistance available to individuals and families in resolving problems. We also briefly describe Colorado's current ombuds programs, even though these programs are not designed to furnish assistance to individuals with developmental disabilities who encounter problems with their services in the community developmental disabilities system. Lastly, we offer our observations concerning the present state of affairs in Colorado with respect to the resolution of individual complaints and grievances.

A. Dispute/Grievance Mechanisms Available for Individuals Who Receive DDS-Administered Services

Disputes. In Colorado, there are two formal "system-operated" dispute resolution mechanisms that are available to individuals with developmental disabilities served in CDHS/DDS-administered programs. These mechanisms offer an avenue for individuals to dispute specified categories of decisions that adversely affect their eligibility or the services they receive. These mechanisms are:

- **Medicaid Fair Hearing Process**. The specialized services and supports that nearly all adults with developmental disabilities receive through DDS-administered programs are underwritten by Medicaid dollars, principally through the state's two home and community-based services (HCBS) waiver programs. Federal law dictates that each state Medicaid agency (in Colorado's case, Health Care Policy and Financing) operates a "fair hearing" process that permits Medicaid beneficiaries to appeal adverse decisions that affect their eligibility and/or services. As a condition of HCBS waiver program approval, Colorado must guarantee that waiver participants can avail themselves of the fair hearing process. DDS and HCPF have assured that the state will make the fair hearing process available to individuals served in both the Comprehensive and Supported Living Services waiver programs.[1] The rules concerning the Medicaid fair hearing process are located in Volume 8 of the HCPF Staff Manual (specifically, Sections 8.058 and 8.059).

  As noted previously, the fair hearing process gives each Medicaid beneficiary the right to dispute adverse decisions affecting his/her eligibility or services. In particular, the types of decisions that a person may appeal through the fair hearing process include: (a) denial of eligibility; (b) termination of eligibility; (c)

[1] In particular: The standard HCBS waiver application requires that the state "…. will provide an opportunity for a fair hearing, under 42 CFR Part 431, subpart E, to beneficiaries who are not given the choice of home or community-based services as an alternative to the institutional care indicated in item 2 of this request, or who are denied the service(s) of their choice or the provider(s) of their choice."

denial of services (including services the person chooses but is not provided); and, (d) termination or reduction of services. Federal rules require that a beneficiary receive proper notice of these adverse actions at least 10 days in advance of their effective date so that the beneficiary can file a timely appeal. The notice of adverse action also must inform the beneficiary how to file an appeal. Until an appeal is decided, the adverse action that is the subject of the appeal is stayed. If the adverse action involves the termination or reduction of services, the services must continue during the period while the appeal is under consideration. The Medicaid fair hearing process is quasi-judicial in nature. Appeals are heard by administrative law judges and are subject to evidentiary rules.

A state cannot substitute an alternate process for the mandatory fair hearing process (e.g., use a grievance process operated by another agency). However, a state may provide that beneficiaries can voluntarily avail themselves of an alternate dispute resolution process by agreeing that fair hearing proceedings will be stayed while the alternate process is underway. In such cases, beneficiaries must be free to accept or reject the outcome of the alternate process and be permitted to reinstate the original appeal.

The fair hearing process in Colorado operates outside the developmental disabilities system and thereby is not managed or controlled by DDS or CCBs. It is available to all HCBS waiver participants. The scope of issues that are subject to the fair hearing process is circumscribed. For example, the fair hearing process generally is not designed to address problems that a person or a family might have with the quality of services that are furnished by a provider. The fair hearing process is not intended to serve as "complaint/grievance" process; instead it is safeguard for beneficiaries to protest adverse decisions about eligibility or the authorization of services. Federal Medicaid law does not mandate or otherwise provide that state Medicaid programs operate a complaint or grievance process on behalf of beneficiaries apart from the fair hearing process.

Because the Fair Hearing process is quasi-judicial in nature, it is often is regarded as especially burdensome for individuals and families to use, especially persons who do not have access to legal or other informed advisers to assist their filing and pursuing an appeal. While states attempt to make the process as "user-friendly" as possible, it still can be daunting for many individuals and families.

- **Dispute Resolution within the Developmental Disabilities System**. Colorado law (CRS 27-10.5-107) and CDHS regulations (2 CCR 503-1, Section 16.320 *et seq.*) establish dispute resolution procedures that extend to all individuals who receive community services or are served at the Regional Centers.[2]

  In many respects, the dispute resolution procedures spelled out in CDHS regulations parallel the Medicaid fair hearing process. In the case of individuals,

[2] The CDHS rules also spell out a dispute resolution process when the dispute is between a CCB and an approved service agency. This process falls outside the scope of this report.

four types of disputes decisions fall under the dispute resolution procedures: (a) a determination that a person is not eligible for services; (b) a finding that a person no longer is eligible; (c) the termination of services and supports; and, (d) terminating, changing, reducing, or denying services that have been spelled out in a person's individual plan. In the case of these types of decisions, CDHS rules provide that individuals must receive notice of an adverse decision fifteen days in advance of its effective date and be provided information concerning how to file a complaint to protest the decision. As in the Medicaid fair hearing process, services and supports continue until the dispute is resolved one way or another.

CDHS regulations dictate that the parties first attempt to resolve a dispute through "informal negotiation." If the dispute is still unresolved, then CDHS rules permit individuals to demand that an "impartial decision maker" hear the dispute. The "impartial decision maker" must be a person who was not directly involved in making adverse decision but may be the director of the agency (CCB or approved service agency) that initiated the adverse action. CDHS rules also outline procedural requirements that must be followed in resolving a dispute through this formal process, including establishing a record of the proceedings. By mutual agreement, the parties may employ impartial mediation to resolve the dispute. Impartial mediation was added in the hope that it would aid in resolving disputes. The addition of this alternative was the highest priority expressed by the Systems Change Project stakeholder Quality Assurance Committee and a great deal of effort was expended in its design and implementation. However, by report this option has been little used. The procedural requirements contained in the CDHS rules are less prescriptive than the parallel requirements set out in the Medicaid fair hearing process. If the dispute is not resolved to the satisfaction of the individual, then the individual can carry his/her complaint on appeal forward to the Executive Director of CDHS or his/her designee to review the local decision. The Department's decision is considered the final agency action in a dispute.

The Medicaid fair hearing and CDHS/DDS dispute resolution processes address much the same types of disputes. The CDHS/DDS process is distinguished from the Medicaid fair hearing process by being double-tiered – disputes are first handled locally and, if not resolved, move on to state review. In the case of the fair hearing process, appeals flow directly to the state. Colorado's processes parallel similar processes in other states.

Grievances and Complaints. CDHS rules also mandate that CCBs and approved service agencies establish procedures "for the timely resolution of grievances or complaints of the person receiving services, parents of a minor and/or authorized representative." The rules do not spell out the classes of problems that might constitute a grievance or complaint and consequently this process is relatively open-ended but presumably excludes disputable decisions. CDHS rules minimally set forth the procedures and processes that CCBs and approved service agencies must follow in addressing grievances and complaints. In the case of grievances and complaints, the final decision of the CCB or the approved service agency ends the matter. There is no provision for CDHS/DDS review or intervention in the event that the individual is not satisfied with the outcome of the local grievance/complaint resolution process. The process spelled out in CDHS rules concerning the disposition of grievances and

complaints is not materially different from processes in other states. States commonly require service providers and local authorities to establish a complaint/grievance resolution process. Rarely, however, do states intervene in these processes or provide that an unresolved complaint/grievance will flow up to the state administering agency for a final decision.

Other Resources. There are two other resources available to individuals served in DDS-administered programs that may assist such persons in dealing with problems or issues that they encounter. These are:

- **The Legal Center (Protection and Advocacy)**. In the 1970s, in the Developmental Disabilities Act and Bill of Rights, Congress provided for the establishment of a network of Protection and Advocacy (P&A) agencies nationwide. P&A agencies operate under the aegis of and are funded by the federal Administration on Developmental Disabilities, U.S. Department of Health and Human Services and the states. The federal DD Act mandates that P&A systems "empower, protect, and advocate on behalf of persons with developmental disabilities." A state's P&A system must be administratively independent of funding agencies, including state developmental disabilities authorities such as DDS/CDHS. P&As are authorized to "provide information and referral services and to exercise legal, administrative and other remedies to resolve problems for individuals and groups of clients." In most states, P&As are independent non-profit organizations located outside government.

  Under federal law, P&As also are mandated to: (a) investigate incidents of abuse and neglect and follow up reports of incidents, or investigate if there is probable cause to believe that such incidents have occurred; and (b) get access to all client records when provided with client or representative authorization, and to access records without such authorization when there is probable cause that abuse or neglect is involved. Federal courts have ruled that P&As also have standing in their own right to bring suit against a state for alleged systematic violations of the rights of individuals. Over the years, Congress has assigned P&As additional responsibilities, including advocacy and assistance on behalf of persons with mental illness and other non-developmental disabilities. In addition, many P&As also operate federally funded Client Assistance Programs on behalf of persons who encounter difficulties in obtaining Vocational Rehabilitation services.

  Colorado's designated P&A agency is The Legal Center. The Legal Center also happens to house the Colorado Older Americans Act Ombudsman Program. The operation of the Ombudsman Program, however, is administratively separate from The Legal Center's P&A responsibilities. With respect to persons with developmental disabilities, the scope of The Legal Center's activities is not confined solely to services funded by CDHS. For example, the Center's responsibilities also extend to protecting the rights of children in special education under the Individuals with Disabilities Education Act (IDEA). In Colorado and elsewhere, a significant proportion of P&A activities are devoted to children's services.

  In theory, P&As may conduct a broad scope of activities on behalf of individuals with developmental and other disabilities. However, in practice, P&As must

carefully pick and choose when to intervene and at what level. P&As have limited funding from the federal government and have to address many priority areas. This means that they do not have resources to investigate all allegations of abuse or neglect or intervene on behalf of every individual when disputes arise. P&As are oriented to addressing legal rather than programmatic issues. P&As often concentrate their energies on intervening when a problem appears to be widespread and intervention will result in broad-based improvement or change. In a few states, P&As receive additional state funding that permits them to take on additional responsibilities. For example, Ohio Legal Rights Services – Ohio's P&A – operates a state-funded Ombuds Program on behalf of persons with mental illness and developmental disabilities. However, absent additional state funding, P&As lack the resources to operate systemwide grievance/complaint response systems. Federal law neither provides nor mandates that P&As operate such systems.

Center officials report that they may assist individuals and families who encounter problems in the DDS-administered system. However, the extent of the assistance that the Center can make available is circumscribed by both resources and their other priorities. As a practical matter, P&As do not have the resources to operate full-scale ombuds programs.

- **Advocacy Organizations**. The Arc of Colorado and its local chapters furnish considerable direct assistance to individuals and families in resolving disputes about their services. Such assistance includes information and referral. Arc chapters also assist individuals in accessing services and, when invited, can support individuals and families at meetings concerning their services. Under either the Medicaid fair hearing process or the CDHS dispute resolution process, Arc advocates may assist individuals in pursuing appeals if requested by the person. By report, local chapters furnish considerable assistance along these lines. However, Arc chapters have limited resources and lack official standing to conduct ombuds-like activities.

B. Grievance/Complaint Mechanisms Operated by Other Colorado Human Service Systems

We also looked for other grievance/complaint resolution mechanisms and/or ombuds programs in operation in the Colorado human services arena. There are a few. However, because of their restricted scope, these mechanisms generally are not available to individuals with developmental disabilities to assist in their resolving issues with DDS-administered services. These other mechanisms include:

- **Vocational Rehabilitation Services**. As previously noted, The Legal Center operates Colorado's Client Assistance Program. This program assists individuals with disabilities in accessing and receiving vocational rehabilitation services. The Legal Center provides information and technical assistance about obtaining VR services and also can represent individuals in dispute resolution processes to resolve disagreements. These services would be available to individuals with developmental disabilities who seek vocational rehabilitation services. However, this assistance would not be available to persons who seek or receive vocational or employment services funded by DDS/CDHS. In other words, this program is

tied to the federal vocational rehabilitation funding stream and its associated programs.

- **Colorado Ombudsman Program**. The Colorado Ombudsman Program is authorized under federal and state law to investigate complaints made by long-term care facility residents about their services or treatment. The program is authorized under the federal Older Americans Act. Similar programs operate in all states nationwide. As previously noted, this program also is housed at The Legal Center and operates under contract with the Aging and Adult Services Division at CDHS. Nursing facility residents along with individuals served in certain types of other congregate living arrangements may be assisted by the Ombudsman Program. However, such arrangements would not include group homes or foster homes. The Ombudsman Program operates through dispersed sites in tandem with local area agencies on aging. The program receives and addresses a relatively high volume of complaints each year (approximately 13,000). It works directly with individuals and facility operators to resolve these complaints, reportedly at a high rate of success.

  The program's scope, however, does not extend to individuals who receive EBD HCBS waiver services or other types of community services and supports. The federal law that authorizes the program does not provide for furnishing assistance to individuals who receive community alternatives to nursing or other congregate care services. Nationwide, due to funding limitations, only a handful of long-term care ombuds programs have broadened the scope of their operations to include individuals who receive Medicaid or other home and community services. Individuals who receive CDHS/DDS-administered community services are not eligible for assistance through the Ombudsman Program.

- **Managed Care Ombudsman Program**. Colorado also has an Ombudsman for Managed Care. This Ombudsman's primary responsibility is to assist Medicaid recipients in resolving complaints involving state-contracted Medicaid managed health care plans by helping them navigate the complaint and appeals processes established by such plans. HCPF has contracted with a private organization to serve as the Ombudsman for Managed Care. DDS-funded services are outside the scope of this Ombudsman Program.

- **Governor's Advocate Corps**. First established in 1993, the Corps is a network of organizational units operated by the principal cabinet departments to increase state government's responsiveness to citizen concerns. The Department of Human Services has a "consumer relations" unit, which has been set up to register complaints, answer questions about the Department and provide information to citizens. While this unit undoubtedly furnishes valuable assistance, it is not an ombudsman program as commonly understood.

Current Mechanisms: Summary

In essence, Coloradoans with developmental disabilities have access to one universally available mechanism to resolve grievances and complaints concerning community developmental disabilities services – the mechanism that CDHS regulations require that CCBs and approved service agencies operate. There is no freestanding ombuds

program – as commonly understood – in Colorado that is specifically available to individuals with developmental disabilities to assist in their resolving grievances and complaints about community services. The Legal Center provides ombuds-like assistance but has only limited capacity to intercede on behalf of people with developmental disabilities to address grievances and complaints. The assistance Arc chapters provide takes place within the framework of the processes set forth in the CDHS regulations. Colorado's existing human services ombuds programs serve distinct population groups, none of which include individuals who principally receive their services through the DDS-administered service system. The Ombudsman Program is confined to assisting individuals who reside in nursing facilities and other long-term care facilities.

Colorado's two formal dispute-resolution mechanisms parallel one another but address the same relatively narrow classes of actions and decisions that adversely affect individuals with developmental disabilities. Neither dispute resolution mechanism can be characterized as a grievance/complaint resolution program, as commonly understood. The disputes addressed through both mechanisms concern adverse actions that affect eligibility or the authorization of services. Their scope does not include complaints about service quality nor provider agency willingness to accommodate the needs of persons, topics that are commonly addressed by and through freestanding ombuds programs.

Colorado, of course, has other mechanisms in place that serve as safeguards and protections for people with developmental disabilities. These include the state's CCB and provider agency quality review system, requirements concerning the operation of Human Rights Committees, case manager service monitoring, local CCB quality management efforts and so forth. These quality management systems can play an important role in assuring that individuals are receiving appropriate and effective services.

At the end of the day, whether individuals with developmental disabilities obtain satisfactory responses to their grievances or complaints hinges on how well the process – formal and informal – operated by CCBs or approved service agencies function. During our interviews with stakeholders, we found that views about this process are mixed.

Some advocates contend that the grievance/complaint process by and large does not function very well. Advocates question the legitimacy of a process where an agency that might have caused the problem in the first place also ultimately disposes of a grievance or complaint. Advocates report that individuals and families do not pursue grievances and complaints out of fear that they might lose their services or because they find the process burdensome.

For their part, CCB managers point out that relatively few formal grievances and complaints are filed in any event and that they are diligent in addressing individual concerns before they reach the stage of the filing of a formal grievance or complaint. In the view of some CCB managers, Colorado already has multiple safeguards in place that work effectively on behalf of individuals and families.

For better or worse, there appears to be little in the way of systematic evidence one way or the other about the effectiveness of local grievance/dispute resolution processes, formal or informal. However, based on DDS surveys, it is known that a relatively high percentage of individuals and families have expressed satisfaction about their services

and the performance of CCBs. In 2000, for example, the rate of expressed satisfaction by adult individuals with their services exceeded 90% for all types of services and generally expressed satisfaction had increased from 1998 rates.[3] This does not mean that there are no problems in the Colorado system.

[3] DDS (2001). "Accountability Focus Series: Key Indicators of Performance"

III. Ombuds and Similar Programs for People with Developmental Disabilities in Other States

HSRI was asked to identify other states that have ombuds or ombuds-like programs in operation that provide assistance to people with developmental disabilities. When we began this investigation, we did not expect to find many states with such programs. It was known that all states operate long-term care ombuds programs like Colorado's because the Older Americans Act dictates their operation. However, there is no similar dictate in federal law for states to operate ombuds programs for people with developmental disabilities. To the extent that such programs are in operation, they would have to been voluntarily created by the state.

Our initial survey of states surfaced seventeen[4] states that represent that ombuds assistance is available to individuals with developmental disabilities. In thirteen of these states,[5] ombuds programs are portrayed as focusing specifically on individuals with mental illness, mental retardation, and/or developmental disabilities; elsewhere, people with developmental disabilities are portrayed as able to access assistance through a broader long-term services ombuds program. A few additional states have considered establishing ombuds programs for people with developmental and other disabilities but have not. In 2001, Georgia passed legislation to establish an ombuds program for people with developmental disabilities and mental illness but funding so far has not been provided to implement the program. On various occasions in recent years, the Washington State legislature has considered but not enacted legislation to establish an ombuds program for persons with developmental disabilities.

We investigated in more depth the states that represented that ombuds assistance is provided or available to people with developmental disabilities. We were concerned that, while the "ombuds" label may have been attached to a program, the program might actually be a consumer assistance endeavor (a.k.a., "customer relations") or very circumscribed in its scope. This proved to be the case in several states.

In a few states that represented that an ombudsman was available to people with developmental disabilities, it turned out that the Older Americans Act ombuds program was available to a limited number of individuals with developmental disabilities who reside in "board and care" facilities for elderly but not broadly available to other individuals who receive community services. Elsewhere, state agencies have staff or offices labeled as ombudsmen but in fact were "consumer relations" offices with a relatively limited scope of operations. In one case, an ombuds program was set up specifically for members of a class-action lawsuit but was not available to other individuals. There are still other states that at first blush seem to have ombuds or ombuds-like programs that assist people with developmental disabilities but the scope of these programs is relatively circumscribed.[6]

[4] CA, CT, DE, IA, IN, KY, LA, ME, MN, NE, NY, OH, OR, SC, WV and WY

[5] CA, CT, DE, IN, KY, LA, ME, MN, OH, OR, WV and WY

[6] For example, there is an Office of Client Advocacy located in the Oklahoma Department of Human Services. However, the central focus of this office is individuals who are members of a lawsuit class or served in state-operated institutions. There also is an office of "constituency

Ultimately, we winnowed the list of states down to only those that operate an ombuds or ombuds-like program that is reasonably independent, broadly available and oriented to furnishing direct and personal assistance to individuals and families. We profile these programs next. These programs vary considerably from state to state.

A. Profiles of Ombuds Programs

Louisiana. One of the longest standing ombuds programs that focuses solely on people with developmental disabilities is the Louisiana Community Living Ombudsman Program. This program was created in 1993 by state law[7], which assigned responsibility for its operation to the Louisiana Attorney General's office. However, the program did not become operational until 1996, when it was piloted in and around Baton Rouge. The program now is operated nearly statewide under contract by the Louisiana Advocacy Center, the state's P&A agency.

The scope of this program is limited to individuals served in private (non-state) ICFs/MR. Louisiana has a relatively high number of such facilities (which serve about 3,800 individuals, usually in group-home type settings). However, access to this ombuds program does not currently extend to individuals served in Louisiana's HCBS waiver program for persons with developmental disabilities or persons served in other community programs. This program was designed to provide much the same type of ombuds assistance to persons who reside in ICFs/MR as is available to nursing facility residents through Older Americans Act ombuds programs. The program's responsibilities are:

1. "To receive, investigate, and resolve complaints made by or on behalf of residents concerning any act, omission, practice, or procedure that may adversely affect the health, safety, or welfare of any resident."
2. Regularly visit facilities to become familiar with residents, family, and staff/ administrators
3. Be a liaison between residents, family, staff/administrators
4. Facilitate problem resolution by encouraging self-advocacy among residents and making recommendations to administrators
5. Increase awareness of Ombudsman

This program employs 10 advocates who are responsible for about 2,700 individuals served in ICFs/MR in most regions of the state. These advocates visit each ICF/MR quarterly to meet with residents. State law empowers these advocates to have direct and private access to residents and receive and investigate complaints made by residents and other individuals. There were about 260 complaints fielded and investigated by ombuds advocates in 2001 (about one for every ten residents). The most common complaints concerned employment, resident funds and individual rights. About two-thirds of the complaints were resolved satisfactorily and another 20% were partially resolved. Annual funding for this program is approximately $700,000.

California. A few states have established ombuds-like capabilities by providing supplemental funding to and contracting with their P&A agencies. This is the case in

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services" in the Mississippi Department of Mental Health that has been set up to handle complaints about services furnished in state-operated programs.

[7] Louisiana statute R.S. 28:398 (Act 835 of 1993)

California. In 1998, the California legislature passed a measure to create independent "client rights advocates" (CRAs) at each of the state's 21 regional centers (which are similar to Colorado CCBs). Previously, each regional center was required to employ its own CRA. The state legislature decided that the CRA function should be separate from regional center administration to avoid potential conflict of interest or the appearance of conflict of interest.

Protection and Advocacy, Inc. (PAI), the state's P&A agency, operates the Office of Client Rights Advocacy (OCRA) under contract with the California Department of Developmental Services. CRAs are stationed at each regional center and have support staff. PAI has entered into a memorandum of understanding with each regional center concerning the exact method of furnishing CRA services at each center. CRAs provide information and referrals, aid individuals in obtaining services (including non-regional center services and benefits), provide representation or technical assistance to individuals at administrative hearings, and investigate complaints. While this program does not operate under an "ombuds" label, it is functionally equivalent to an ombuds program.

During the first full year of operation in 2000, 40+ OCRA staff statewide fielded 7,500 calls from individuals, families and others. OCRA also conducts training for individuals, families, regional center staff, and services providers concerning rights. In many respects, the additional funding the state furnishes PAI to operate OCRA permits PAI to address a far greater number of individual and family complaints and concerns than is typical of P&As elsewhere. The collocation of OCRA with PAI also enables the activities of both to be coordinated. Other states that provide additional funding to their P&As to operate ombuds-like programs to provide more in-depth assistance to individuals include Wyoming (as part of its settlement of the Weston lawsuit litigation) and Ohio.

Connecticut. In a few states, ombuds programs have been established and located at state administering agencies. For example, in 2001 an Independent Office of the Ombudsman for Mental Retardation was established at the Connecticut Department of Mental Retardation (DMR) by the enactment of state legislation. The responsibilities of this Office include: (a) providing information and assistance to DMR clients regarding DMR rules/procedures; (b) reviewing grievances and passing them on to appropriate officials or initiating resolution; and, (c) facilitating resolution for grievances not resolvable at local level. The Office has two staff and a budget of $150,000. It operates a toll-free hot line. In its first six-months of operation in 2001, the Office fielded 2,000 calls, opened 125 cases and resolved 89% of them. Although located at the state administering agency, state law provides that the ombudsman will be independent. The ombudsman is appointed by a special selection committee.

Indiana. Another state that has located an ombuds program within a state administering agency is Indiana. In 1997, the state established – at the direction of its Commission on Mental Health and Developmental Disabilities – the Developmental Disability Waiver Ombudsman at the Division of Disability, Aging and Rehabilitation Services in the state's Family and Social Services Administration. In 1999, the Indiana legislature enacted legislation (Appendix A) that spells out the Ombudsman's powers and authorities. This ombudsman program fields and seeks to resolve complaints about HCBS waiver services for people with developmental disabilities. There is one ombudsman who has limited assistance from Division support staff. Access to the

ombudsman is via a toll-free number. Principally, the ombudsman troubleshoots problems that individuals and families encounter in accessing HCBS waiver services.

Minnesota furnishes the sole example of a state that has created a standalone, independent state ombuds agency that assists persons with developmental and other disabilities that is not located in a state administering agency, co-located with a long-term ombudsman program or operated through a P&A agency. Minnesota has several independent ombuds programs, including programs for crime victims, managed care enrollees, families, and seniors.

Created in 1987, the Office of the Ombudsman for Mental Health and Mental Retardation assists persons served in state-sponsored residential facilities or who receive any other licensed program services for mental illness, developmental disabilities, chemical dependency, or emotional disturbance. The aim of this Office is to "promote the highest attainable standards of treatment, competence, efficiency and justice for persons receiving services for mental health, developmental disabilities, chemical dependency, or emotional disturbance."[8] The lead ombudsman is appointed by the Governor and is advised by a 15-member committee, also appointed by the Governor. In addition to its ombuds responsibilities, the Office also is vested with the authority to conduct independent investigations of deaths and serious injuries. In 2000, the Office handled approximately 7,300 complaints.

B. Summary

Based on our investigation, we found only a few states that have established ombuds programs for people with developmental (and other) disabilities that are based on much the same principles as the Older Americans Act long-term care ombuds programs. Except in the case of the California, Louisiana, Minnesota and Wyoming programs, the scale of these programs is relatively small. It is not uncommon for these programs to be operated by the state's P&A although two are housed in state administering agencies. All of these programs are undergirded by state legislation to assure their independence and give them sufficient standing and authority to access individuals and investigate complaints. Personnel at these programs with whom we spoke believe that these programs are fulfilling a real need by giving individuals and families a place to go to resolve problems and complaints. None of these programs is directly linked to the state's long-term care ombudsman program operated under the Older Americans Act.

It is unclear why so few states operate full-scale, independent ombuds programs for people with developmental disabilities. In part, the reason may be the lack of a federal mandate (and funding) that spurred the creation of the Older Americans Act ombuds programs nationwide. Another factor – rightly or wrongly – might be the presence of the P&A system, which might be perceived as a substitute for an ombuds program because of the wide-ranging authority of P&As. At the same time, it also is worth noting that in only a few states have Older Americans Act long-term care ombuds programs widened their operations to include seniors who receive home and community services. Ombuds programs remain identified with institutional services.

[8] Vision, Mission, and Value Statements. Office of the Ombudsman for Mental Health and Mental Retardation. http://www.ombudmhmr.state.mn.us/about/vision.htm.

Whatever the reason for the small number of developmental disabilities ombuds programs, there is only a little direct experience from elsewhere that can be called upon to guide decision making in Colorado about launching an ombuds program.

IV. Should Colorado Establish an Ombuds Program for People with Developmental Disabilities?

Ombuds programs aim at protecting the civil and human rights of individuals who receive services, resolving and mediating their problems, furnishing reliable information to individuals and families, and serving as objective investigators of complaints. Ombuds programs inherently must be independent and conflict free. The question Colorado is attempting to answer is whether the state should create an ombuds program specifically for people with developmental disabilities who receive services in the community.

On balance, we believe that creating establishing such an ombuds program merits consideration but stop short of recommending its creation because it is difficult to predict the potential impact and value of such a program. There are other alternatives that Colorado might consider to address certain intertwined issues. These alternatives are not the same as an ombuds program but might contribute to system improvement.

A. Pros and Cons of Creating an Ombudsman Program

The ombuds programs operated under the Older Americans Act have a long history and have demonstrated considerable success in Colorado and elsewhere in facilitating the resolution of complaints and grievances, even though they do not have the direct authority to order or enforce corrective actions. While government closely regulates nursing and other long-term care facilities, regulation of these facilities is limited in what it can accomplish and operates at a facility/program level rather than the individual level. The high volume of complaints fielded by the Colorado Ombudsman Program demonstrates the need for this individual level assistance.

Community developmental disabilities services obviously are not the same as nursing facility services. However, people with developmental disabilities have many of the same vulnerabilities as older persons. Despite all best efforts by DDS to assure that individuals receive high quality services and efforts by CCBs to promote the quality of life of individuals in their service areas, chances are that individuals are having problems and these problems are not being identified or attended to as well as they might. Chances also are that some individuals and families find complaining intimidating, rightly or wrongly. In the few instances where states have created ombuds or ombuds-like programs for people with developmental disabilities, complaints have surfaced that have merited attention.

Colorado's developmental disabilities system likely does not perform appreciably better or worse than systems elsewhere in responding to individual and family concerns. However, Colorado's system has some special challenges along these lines. Authority and responsibility for community services have been concentrated with CCBs. CCBs have many responsibilities, including authorizing services and overseeing their provision. To varying degrees, CCBs also furnish services directly and thereby problems potentially can arise under Colorado's present grievance/complaint mechanism when individuals and families are unhappy about CCB-delivered services and the issues do not rise to the level of a dispute. In addition, relative to other states, case managers in Colorado have high workloads; to one degree or another, this potentially detracts from their capacity to

conduct active oversight and intervene to advocate on behalf of individuals. In addition, some stakeholders are concerned that, because case managers work for CCBs, they might not be objective observers.

As previously noted, our interviews revealed a climate of mistrust on the part of some Colorado stakeholders concerning how fairly and appropriately individuals with developmental disabilities are being supported and the extent to which their problems and issues are addressed. A few but not many stakeholders expressed specific support for creating an ombuds program so that there would be an objective third-party to whom individuals and families could turn in order to complain and obtain assistance. Among these stakeholders, there is a strong conviction that there should be a source of assistance for individuals that is independent of CCBs and other stakeholders as well as CDHS/DDS.

However, there is no systematic evidence one-way or another to gauge how serious or extensive these problems are. DDS consumer and family interview results tend to show that individuals and families are usually satisfied with the services and supports they receive from CCBs and other service agencies. While these results are encouraging, the truth likely is that most individuals and families are satisfied with their supports but others are not.

In the end, creating an ombuds program for people with developmental disabilities in Colorado probably would have the following potential benefits:

- There is little doubt that access to an independent third-party to investigate and verify complaints and assist in their resolution would benefit individuals and families, in much the same fashion as have the long-term ombudsman programs operated under the Older Americans Act. Having access to trained and well-informed individuals rather than families and individuals having to go it alone might be beneficial, especially in the case of persons who do not have highly involved families.
- An ombuds program potentially could contribute to overcoming the climate of mistrust – right or wrong – that surrounds CCB administration of community services. Having an independent ombuds program potentially could surface the extent of problems in the Colorado system – great or small – and, hence, aid in determining how responsive CCBs and other service agencies are in responding to problems and issues.
- An effective ombudsman program clearly could contribute to the quality of services that individuals receive. At the end of the day, success in resolving problems improves quality.
- Information about the volume and nature of complaints received by an ombuds program potentially also could furnish valuable information that would aid Colorado's systemwide quality improvement endeavors. Such information could be used to identify areas where there are opportunities for improvement.

There are potential drawbacks to creating such a program:

- Ombuds programs succeed or fail to the extent they can work out mutually agreeable complaint resolutions between the person and program administrators. No ombuds program has the authority to order change or the expenditure of

funds. While experience with ombuds programs in long-term care and the few in other states that serve people with developmental disabilities demonstrate relatively high rates of success in resolving complaints and problems, such a result is by no means guaranteed. If there are significant problems in resolving complaints today or individuals and families are reluctant to complain, it is not clear that creating an ombuds program will have a major impact. To the extent that complaints arise as a result of funding limits, an ombuds program may not be able to effect significant change, only identify the extent to which complaints are resource based. For example, staff turnover and staff inexperience are the two most significant "big problems" identified by parents, guardians and others who are involved with individuals.[9] These problems are intertwined and are significantly affected by funding.

- Even a modestly resourced ombudsman program would be costly to operate and thereby claim dollars that might be used elsewhere in system. In addition, it is not clear what, if any, impact the creation of an ombuds program would have in terms of affecting the volume of formal complaints/grievances with which CCBs and other service agencies deal. If an ombuds program is successful in resolving complaints before they reach the formal filing stage, resources might be saved. To the extent that the creation of an ombuds office elicits a high volume of complaints that individuals and families have been reluctant to express in the past, both CCBs and service agencies might experience increased costs.
- Until an ombuds program has been in operation for a while, it will not be possible to assess its impact or effectiveness one way or another. An ombuds program will take time to bring on line and make individuals and families aware that it exists and how they can access it.

Recommendation. On balance, it appears to us that there are potential but uncertain benefits in Colorado's establishing an ombuds program for people with developmental disabilities. Service quality potentially would be improved by adding an independent, third-party system of complaint investigation, resolution and advocacy. Colorado presently lacks such an independent, dedicated capability and having access to such a third-party might be beneficial to individuals and families. However, Colorado is not alone in this regard since only a few states have taken this step.

Hence, we only can recommend that Colorado consider establishing an ombuds program for people with developmental disabilities but we stop short of endorsing this step because it is virtually impossible to gauge the exact extent of how beneficial it might be. We observed in our report evaluating the Systems Change Project that there are widespread concerns about quality in Colorado. It is important that stakeholders collaborate in proactively addressing these concerns. An ombuds program may ultimately fit into the mix of strategies that stakeholders select. However, it may be premature to thrust another yet another mechanism into Colorado's system about which there are uncertainties concerning its benefits.

If the decision is made to proceed in creating an ombuds program for people with developmental disabilities, we believe it would be wise for Colorado to implement a

[9] DDS (2002). "Accountability Focus Series: Outcomes of Services and Supports"

limited pilot program in order to gauge its utility and impact before committing to a full-scale program.

B. Design of an Ombuds Program

If the decision is to proceed with establishing an ombuds program for people with developmental disabilities in Colorado, then it will be necessary to make decisions about its scope, location and funding. We have the following recommendations concerning the design of an ombuds program:

- **Pilot program**. Uncertainties attend establishing an ombuds program. Going in, it will not be possible to reliably gauge workload. Hence, a "walk, then maybe run" strategy makes sense before Colorado commits to operate a broad-scale program. We therefore believe it would be appropriate to consider creating a pilot ombuds program that would sunset in three-years. This would provide a reasonable opportunity for the Colorado legislature and developmental disabilities stakeholders to appraise the usefulness and effectiveness of such a program before committing to a permanent program or extending its operation statewide.
- **Geographic Scope**. Again, in the "walk, then maybe run" spirit, we recommend that the pilot program be tested in one or possibly two areas of the state rather than tested statewide. In order to operate a statewide program, staff would have to be outstationed around Colorado and costs would be greater. Confining the operation of the program to one or possibly two areas of the state initially would hold down costs and make the program less complicated to implement. One possibility along these lines would be to operate the pilot program in the Denver Metropolitan area and perhaps a second satellite program somewhere else north or south along the Front Range or on the Western Slope.
- **Program Organizational Location**. There are two choices here. One choice is to locate an ombuds program within state government (either at DDS or CDHS). Indiana and Connecticut elected this course and located their programs in the state-administering agency. Both states, however, took the step of enacting legislation to assure that the program would have independent standing and authority. Housing the program within state government has some potential advantages, including ready access by ombuds advocates to state officials. Neither the Connecticut nor Indiana ombudsmen expressed to us that their location within state government has caused appreciable problems in their carrying out their responsibilities.

  The second choice is to outsource the program – that is, operate it outside government. This is the more common choice that states have made – to operate the program by contracting with an independent, non-governmental organization, most commonly the state's P&A agency. This alternative has several important advantages, including assuring the independence of the program and avoiding the potential for interference in its operations by the state administering agency. In addition, P&As clearly have related and highly relevant expertise in advocating on behalf of individuals with developmental disabilities. Colorado's own history is to outsource its ombuds programs.

On balance, we believe that outsourcing is the better of the two choices. However, we believe that it is better to outsource by letting an RFP to solicit proposals from interested organizations rather than directing that the program be housed in a specific organization. While The Legal Center might be an appropriate location for an ombuds program (by virtue of its standing as a P&A agency and its potentially synergistic collocation with the Older Americans Act Ombudsman Program), other organizations (e.g., possibly a consortium of Arc chapters) might want to put forward proposals as well. The main decision is whether to outsource rather than decide in advance where the program will be located.

- **Legislation**. In nearly all instances, the creation of an ombuds program has been accompanied by the enactment of substantive legislation. Such legislation spells out the powers and authorities of the ombuds program, including assuring that ombuds advocates have access to individuals and records in order to investigate complaints. Such legislation can parallel the present provisions in Colorado law concerning the Ombudsman Program or can be modeled on the Indiana legislation (Appendix A) with appropriate modifications. The American Bar Association (ABA) has prepared a Model Ombudsman Act for State Governments, outlining sample legislation that would cover all the issues of concern. While generic, the ABA document outlines the rights and responsibilities of a typical ombuds program.[10] If Colorado decides to implement an ombudsman, accompanying legislation must specify the target population, where/how to structure the office, methods of outreach and operation, and the specific responsibilities and authorities the program will have.

  Arguably, legislation might not be needed if the ombuds program is housed in CDHS, since the operation of such a program possibly could be deemed an extension of the Department's existing authority to oversee the provision of community services. However, we do not recommend this course because it is important to ensure the unambiguous independence of the ombuds program and that its duties and responsibilities be clearly spelled out in state law. Substantive legislation is virtually mandatory if the decision is made to outsource the ombuds program in order to ensure that the designated organization has clear standing to conduct its duties.

- **Stakeholder Input in Design**. In advance of launching an ombuds program, it would be enormously valuable to convene Colorado stakeholders to spell out in more detail their expectations for the operation of such a program. This would assist in framing a RFP and a contract. It also would aid in making clear all stakeholder expectations concerning the operation of such an office. This stakeholder input might be framed by the following recommendations that were developed by the National Health Law Project concerning the operation of managed care ombuds programs but have been modified here for a

[10] ABA Model Ombudsman Act, Section 11
http://www.abanet.org/adminlaw/ombuds/usoamodel1.html.

developmental disabilities ombuds program[11]: These recommendations describe desired characteristics of an ombuds program. In particular: the ombudsman:

1. Should have clear goals and responsibilities, rules of program conduct, and the authority to implement these responsibilities.
2. Should not assume responsibilities that have been designated to other players in the developmental disabilities system.
3. Should have adequate time and funding for planning and design. Input should be solicited from community organizations and beneficiaries during the planning and design phase.
4. Should be adequately funded and available free of charge to eligible participants and their families in the developmental disabilities system.
5. Should be staffed with those who have knowledge/experience with the developmental disabilities system and serving the unique needs of its consumers.
6. Should have one central office (with outreach offices if possible) that is respected and known to be competent and consumer-oriented.
7. Should be well-advertised and readily accessible both by telephone and in-person.
8. Should produce reports that are publicly available.
9. Should be evaluated by an independent entity.

- **Program Capabilities**. Obviously, the capabilities of an ombuds program will hinge on its funding level, a topic we address below. It is important to point out that an effective ombuds program hinges on the easy access of individuals and families to advocates and vice versa. An ombuds program that is operated solely over the telephone will not be especially effective in addressing complaints although, obviously, many inquiries can be handled over the telephone simply by providing individuals and families with information. As a consequence, program staff must be able to meet with individuals, families, and provider/CCB staff face-to-face, especially in order to work out solutions. In addition, the effectiveness of ombuds programs also hinges on ombuds advocates being visible and accessible to individuals. In long-term care ombuds programs, a common strategy is periodically visiting nursing facilities so that residents are aware of the availability of ombuds assistance. In some instances, ombuds advocates also conduct training and information sessions for individuals and families and program agency staff. It also would be helpful for the ombuds program to have the capability to recruit, support and empower (at least to a limited extent) volunteers to conduct some of its activities. Long-term care ombuds programs typically make extensive use of volunteers to expand their capabilities.
- **Scope**. In our view, the ombuds program should be available to all individuals who receive DDS-funded services within the pilot geographic area(s). We do not

[11] Ombudsprograms and Member Advocates: Consumer-Oriented Approaches to Problem-Solving in Medicaid Managed Care. (1998) Perkins, J, Olson, K, & Rivera, L. National Health Law Program.

recommend restricting access to the program based solely on HCBS waiver participation (as is the case in Indiana) or confining it to individuals served in community residences (as is the case in Louisiana).

- **Costs**. We estimate that a modestly resourced pilot ombuds program located in the Denver metropolitan area would require approximately $150,000 - $175,000 annually to operate. These costs are based on staffing the office with three full time employees (a senior/lead advocate, a second advocate and an administrative support position). We estimate the personnel costs including fringe benefits for these individuals at approximately $130,000 to $135,000 per annum. Additional funds are provided for office space, telephone, mileage and printing/copying expense. These costs could be scaled back somewhat if the second advocate were a part-time position, at least initially. This staffing level would ensure that telephone inquiries still could be fielded continuously while enabling advocates to spend time in the field. A minimalist program (one advocate plus one additional staff person) would cost in the range of $115,000 to $140,000. Some costs might be avoided if the program were operated by an existing organization that could contribute office space. A higher budget might ultimately prove appropriate if justified by workload. However, "walk, then maybe run" argues for launching the program with a modest budget. We believe attempting to operate an ombuds program with only one staff-person would be self-defeating and would not provide a fair trial for the program. Adding a second pilot program area (with two staff) would require about $115,000 to $140,000. If the decision is made to outsource the program but precede its implementation by involving stakeholders in design, it is likely that a pilot ombuds program could not be implemented until at least six months into the state fiscal year. This means that the first year appropriation could be reduced to account for part-year operation.

  Operating a full-scale statewide program that is modestly staffed likely would cost in the neighborhood of $500,000 to $700,000 annually. Achieving statewide program coverage likely would involve setting up offices in 4-6 locations.

In a nutshell, we believe the most appropriate course in Colorado is to pilot an ombuds program in one-two areas of the state, outsource the program to a non-state organization, accompany creation of the program by the enactment of legislation, and precede implementation by empanelling a stakeholder design group.

C. Other Alternatives

While creating an ombuds program for developmental disabilities likely would be beneficial by giving individuals and families an alternative independent means of registering and resolving complaints, there are other alternatives that might be considered. These alternatives are not equivalent to an ombuds program in providing direct assistance to individuals. They are best described as quality and/or performance improvement strategies. In particular:

- **Performance Audit of CCB Operations**. An alternative to establishing an ombuds program is to conduct an independent assessment of the performance of CCBs in resolving individual complaints and grievances. In our report evaluating the Systems Change Project, we suggested that Colorado consider

implementing a performance audit program to take a focused look at the effectiveness of CCB management of services. We believe such a system could furnish all stakeholders with solid information concerning CCB performance and potentially serve as a platform for quality improvement. If such a system were implemented, then how well CCBs respond to individual and family complaints and grievances could be made one of the subjects of such a review. This would leave the state's current arrangements in place and potentially negate the need to establish an ombuds program if CCB grievance and complaint processes are found to work reasonably well and, if not, CCBs take steps in response to such a review to make improvements. The estimated costs of initiating a performance audit program are discussed in the Systems Change Project evaluation report.

- **Direct Involvement by Individuals, Families and Others in Assessing Quality.** Colorado's present quality assurance and quality management strategies do not include the active and direct involvement of people with developmental disabilities, families, and other concerned citizens in appraising service quality. DDS conducts relatively extensive surveys of individuals, families and others to obtain information concerning service quality and system performance. This type of feedback is valuable and important. However, people with developmental disabilities, families and other citizens have not been enlisted to participate in quality review teams or conduct complementary quality appraisals.

  Several states have decided to complement their "official" quality review process by forming up independent quality review teams composed of individuals with disabilities, families and others to gain their perspective and active input concerning service quality. The work of these teams furnishes additional perspective concerning service quality. We raise the formation of such independent teams as a possible alternative to an ombuds office because some stakeholders expressed that one of their major concerns about the community service system was the lack of an independent appraisal of service quality from the individual and family perspective. Active participation by and support for individuals and families in appraising quality and outcomes might serve this purpose as well or better. An independent ombuds program also can function as a means of collecting certain information about service quality but only along certain dimensions.

  Pennsylvania's provides an example of a state that has taken this direction. Pennsylvania initially set up its Independent Monitoring for Quality (IM4Q) in response to recommendations by the Office of Mental Retardation's Planning Advisory Committee in 1997. The Planning Advisory Council is composed of stakeholders and has played a major role in shaping state initiatives over the past several years. The development of IM4Q was part of a broader plan to assure and improve quality within the state's mental retardation system. Briefly, IM4Q uses well-established performance indicators grounded in self-determination to evaluate how well service providers and facilities perform in achieving critical individual outcomes and providing high quality services and supports. Monitoring teams are comprised of consumers, family members, and support personnel to continually examine and report on the quality of services based on these performance indicators. This information is compiled by

conducting extensive interviews with individuals receiving services and families. IM4Q team members also record their other impressions of how well the person is being supported. IM4Q does not replace traditional quality assurance; instead, it concentrates on outcomes and contributes the perspective of people with disabilities, families and other concerned citizens about the quality of supports.

After running a pilot in 20 counties with individuals served in licensed residential settings only, it recently expanded to monitor individuals who receive home and community-based services in all types of settings. The expanded program bases its monitoring and improvement on the measures outlined in National Core Indicators (a collaboration by the National Association of State Developmental Disabilities Directors and HSRI) and other areas of focus in Pennsylvania. With the assistance of Temple University, the newest IM4Q teams have completed surveys with individuals in various counties around Pennsylvania to assess quality and satisfaction. These teams now are using this data to talk with state and local officials about how to improve the system on an individual, provider county and system-wide basis. County mental health/mental retardation programs work with these teams to identify providers to monitor. This type of effort is a more collaborative approach than the ombudsman. It is very much framed as a quality improvement initiative. One of its clear advantages is that it provides a picture of service quality through different eyes than can be accomplished via standard quality assurance methods.

This approach can be adapted to Colorado. DDS conducts the Core Indicators Outcome Survey (CIOS). There are similarities between CIOS and the instrument used in Pennsylvania. CIOS is administered by a third-party. Adopting the IM4Q approach would entail forming up and training teams to conduct interviews. This would be more costly than the present way of administering CIOS but also could provide richer information. In order to keep its IM4Q initiative manageable and hold down costs, IM4Q activities are rotated across the counties. IM4Q monitoring takes place in about one-third of the counties each year.

If Colorado were to follow Pennsylvania's lead to conduct IM4Q-like quality monitoring on a rotating CCB-by-CCB basis (e.g., possibly conducting monitoring of services and providers at each CCB every other year), we would estimate that the costs would be no greater than and possibly less than the annual costs of operating a full-scale ombuds program systemwide. Costs would depend on the scope of the monitoring that teams conduct (the extent of the topics teams address and whether monitoring would include all providers or just those that support a threshold number of individuals). DDS also would require 1-2 additional staff to support this type of effort (to train and support the teams) or alternatively necessary support could be outsourced to another organization.

There are other states as well that enlist individuals and families to conduct and participate directly in third-party monitoring of services and service quality. For example, in Kansas, Community Developmental Disabilities Organizations (CDDO) are required to set up third-party teams that include individuals, families and other citizens to conduct quality reviews of service agencies operating in each CDDO area. This type of monitoring does not replace standard,

compliance-based quality assurance programs conducted by the state. However, it can furnish enormously valuable and independent information about quality.

Florida has adopted a somewhat different approach. There the Developmental Disability Program Office operates the CHAMPS program (Citizens Helping to Assess, Maintain and Provide Supports). CHAMPS is a "statewide citizen monitoring program" funded by a grant from the state's Developmental Disabilities Council, depends entirely on citizen involvement (individuals, family members, advocates and other volunteers) to directly communicate their views concerning system performance – good and bad -- and their other experiences with the developmental disability system. This information then goes to the DD program office, where follow-up, feedback, and as appropriate corrective action is taken. CHAMPS is not a complaint resolution system. Instead, it is an active effort by Florida to establish a continuous means of obtaining stakeholder views concerning quality and performance to serve as means to identify problems and best practice. Such continuous feedback might fruitfully be linked to systemwide quality improvement efforts.

Again, we do not offer these alternatives as substitutes for an ombuds program. Ombuds programs concern providing very direct assistance to individuals and families in addressing their problems and complaints. These other alternatives can play a role in quality improvement. Especially with regard to strategies to enlist the direct involvement of individuals with developmental disabilities, families, and others, such strategies might be effective ways of systematically addressing the concern in Colorado about the lack of an independent appraisal of service quality.

Appendix A

Indiana's Ombudsman Legislation

IC 12-11-13 Chapter 13. Statewide Waiver Ombudsman

Sec. 1. This chapter applies only to an individual who:
(1) has a developmental disability; and
(2) receives services under a waiver under the federal home and community based services program.

Sec. 2. As used in this chapter, "ombudsman" refers to the statewide waiver ombudsman established by section 3 of this chapter. The term includes individuals approved to act in the capacity of ombudsmen by the statewide waiver ombudsman.

Sec. 3. The statewide waiver ombudsman position is established within the division.

Sec. 4. The director shall appoint an acting ombudsman within thirty (30) days of a vacancy in the position of the ombudsman. The acting ombudsman has the powers and duties of the ombudsman.

Sec. 5. The ombudsman may consult with experts in fulfilling the duties of the ombudsman.

Sec. 6. (a) The ombudsman shall receive, investigate, and attempt to resolve complaints and concerns that are made by or on behalf of an individual described in section 1 of this chapter.
(b) At the conclusion of an investigation of a complaint, the ombudsman shall report the ombudsman's findings to the complainant.
(c) If the ombudsman does not investigate a complaint, the ombudsman shall notify the complainant of the decision not to investigate and the reasons for the decision.

Sec. 7. (a) An ombudsman must be provided access to the following:
(1) An individual described in section 1 of this chapter.
(2) An entity that provides waiver services to an individual described in section 1 of this chapter.
(3) Records of an individual described in section 1 of this chapter, including records held by an entity that provides services to the individual.
(4) If an individual described in section 1 of this chapter is incapable of giving consent, as determined by the attending physician or as otherwise determined under state law, the name, address, and telephone number of the individuals legal representative.
Except as provided in subsections (c) and (d), the ombudsman must obtain consent under subsection (b) before having access to the records described in subdivision (3).
(b) Consent to have access to an individual's records shall be given in one (1) of the following forms:
(1) In writing by the individual.
(2) Orally by the individual in the presence of a witness.
(3) In writing by the legal representative of the individual if:
(A) the individual is incapable of giving consent, as determined by the attending physician or as otherwise determined under state law; and

(B) the legal representative has the authority to give consent.

(c) If consent to have access to an individual's records cannot be obtained under subsection (b), an ombudsman may inspect the records of the individual if the individual is incapable of giving consent, as determined by the attending physician or as otherwise determined under state law, and:

(1) has no legal representative;

(2) has a legal representative but the legal representative cannot be contacted within three (3) days; or

(3) has a legal representative but the legal representative does not have the authority to give consent to have access to the records.

(d) If an ombudsman has:

(1) been denied access to an individual's records by the individual's legal representative;

(2) reasonable cause to believe that the individual's legal representative is not acting in the best interests of the individual; and

(3) received written approval from the state ombudsman;

the ombudsman may inspect the records of the individual.

Sec. 8. A provider of waiver services or an employee of a provider of waiver services is immune from:

...(1) civil or criminal liability; and

....(2) actions taken under a professional disciplinary procedure;

for the release or disclosure of records to the ombudsman under this chapter.

Sec. 9. A state or local government agency or entity that has records that are relevant to a complaint or an investigation conducted by the ombudsman shall provide the ombudsman with access to the records.

Sec. 10. The ombudsman shall do the following:

(1) Promote effective coordination among the following:

(A) Programs that provide legal services for the developmentally disabled.

(B) The division.

(C) Providers of waiver services to individuals with developmental disabilities.

(D) Providers of other necessary or appropriate services.

(2) Ensure that the identity of an individual described in section 1 of this chapter will not be disclosed without:

(A) the individual's written consent; or

(B) a court order.

Sec. 11. The director of the division may adopt rules under IC 4-22-2 necessary to carry out this chapter.

Sec. 12. The ombudsman is not civilly liable for the good faith performance of official duties.

Sec. 13. (a) The ombudsman shall prepare a report each year on the operations of the program.

(b) A copy of the report required under subsection (a) shall be provided to the following:

(1) The governor.

(2) The legislative council.

(3) The division.

(4) The members of the Indiana commission on mental retardation and developmental disabilities established by P.L.78-1994.

Sec. 14. The ombudsman shall report:
...(1) annually; or
....(2) upon request;
to the Indiana commission on mental retardation and developmental disabilities established by P.L.78-1994.

Sec. 15. The division shall:
...(1) establish a statewide toll free telephone line continuously open to receive complaints regarding individuals described in section 1 of this chapter; and
...(2) forward all complaints received from the toll free telephone line to the statewide waiver ombudsman.

Sec. 16. A person who:
...(1) intentionally prevents the work of the ombudsman;
...(2) knowingly offers compensation to the ombudsman in an effort to affect the outcome of an investigation or a potential investigation; or
(3) knowingly or intentionally retaliates against a resident, a client, an employee, or another person who files a complaint or provides information to the ombudsman;
commits a Class B misdemeanor.