

Issue Paper 2003

I. Purpose: The purpose of the Issue Paper is to delineate the major issues and trends (national and state) impacting Colorado's Developmental Disabilities Service System from which a Strategic Plan will be developed.

II. National Standard:

A. Medicaid Compliance: State General Funds and Medicaid represent \$260 million dollars to provide waiver services in Colorado. As a result, Colorado must be in compliance with the Center for Medicare and Medicaid Services' new waiver protocols entitled: HCFA Regional Office Protocol for Conducting Full Reviews of State Medicaid Home and Community-Based Services Waiver Programs, December 20, 2000. The protocols are predicated upon six core areas of Quality Assurance:

1. Design and Implementation of Quality Assurance system for Assuring Waiver Participant Health and Welfare;
2. Design and Implementation of a System for Reviewing Plans of Care;
3. Design and Implementation of a System for Assuring All Waiver Services Are Provided By Qualified Providers;
4. Use of Processes/Instruments for Determining Level of Care Need;
5. State Administrative Authority Over the Waiver; and
6. Design and Implementation of the State's System for Assuring Financial Accountability.

B. Medicaid State Plan Foundations In Federal Law which are Relevant to Colorado:

1. **Freedom of Choice of Providers** (42 USC 139a(23) (42 CFR 431.51) Any individual eligible for Medicaid may obtain Medicaid services from any institution, agency, pharmacy, person or organization that is qualified to furnish the services and willing to furnish them.
2. **Reasonable Promptness** (42 USC 1396a(a)(8) (42 CFR 435.911) and (42 CFR 435.930) The state agency must determine eligibility for Medicaid within specified time periods and must furnish Medicaid services promptly to recipients without any delay caused by the state agency's administrative procedures; continue to furnish Medicaid regularly to all eligible individuals until they are found to be ineligible; and make arrangements to assist applicants and recipients to get emergency medical care whenever needed, 24 hours a day and seven days a week.
3. **Single State Medicaid Agency** (42 USC 139a(a)(5) and (42 CFR 431.10) A State plan must specify a single State agency established or designated to administer or supervise the administration of the plan. That agency must have legal authority to administer or supervise the administration of the plan and

make rules and regulations that it follows in administering the plan or that are binding upon local agencies that administer the plan. In order for an agency to qualify as the Medicaid agency, it must not delegate, to other than its own officials, authority to exercise administrative discretion in the administration or supervision of the plan, or issue policies, rules and regulations on program matters. The authority of the Medicaid agency must not be impaired if any of its rules, regulations, or decisions are subject to review, clearance, or similar action by other offices or agencies of the state. If other state or local agencies or offices perform services for the Medicaid agency, they must not have the authority to change or disapprove any administrative decision of that agency, or otherwise substitute their judgment for that of the Medicaid agency. In Colorado, Health Care Policy Financing is the "Single State Medicaid Agency".

4. **State Matching Funds** (42 USC 1396a(a) 2, (42 CFR 433.50), 42CFR 433.51) and (42 CFR 433.53) A state must provide matching funds for carrying out the State plan on a basis which will assure that the lack of adequate funds from local sources will not result in lowering the amount, duration, scope, or quality of care and services available under the plan.

Generally, public funds may be considered as the State's share in claiming Federal Financial Participation (FFP) if "the public funds are appropriated directly to the State or local Medicaid agency, or transferred from other public agencies to the State or local agency and under its administrative control, or certified by the contributing public agency as representing expenditures eligible for FFP."

5. **1915 (c) Waivers** (42 USC 139n (c), (42 CFR 430.25) and 42 CFR 441.300 through 42 CFR 441.30) Allows a state to include as "medical assistance" under its plan, home and community based services furnished to recipients who would otherwise need inpatient care that is furnished in a hospital, SNF, ICF, or ICF/MR, and is reimbursable under the State plan.

Under a "1915(c)" waiver, any of the following three State requirements in 42 USC 1396a can be waived: Statewide, Comparability of Services, Income and resource rules. Freedom of choice is not waivable under a 1915(c) waiver.

III. National Issues and Trends:

A. National Developmental Disabilities Service Systems' Issues: The National Association of State Directors of Developmental Disabilities Services, based upon a survey of its members in 2002, identified "five high priority system change goals" listed in priority:

1. Strengthening System-wide Quality Assurance and Improvement Capabilities;
2. Building the Community Infrastructure Needed to Under-Gird a System of Individualized Supports;
3. Building Community Capacity to Support People with Multiple and Complex Needs;
4. Developing a Skilled Workforce; and
5. Developing Responsive Financial Systems and Strategies.

B. Braddock, David: Disability At the Dawn of the 21st Century and The State Of The States, 2002:

“Public Financial Support”

1. “Medicaid is by far the largest long-term care financial assistance program. State-federal spending was \$57.9 billion for the program in 1997, representing 53% of total spending for long-term care services in the United States.” (p. 68)
2. Colorado’s percentage of public spending for long-term care allocated to community care services for persons with mental retardation and other developmental disabilities in 1997 was 85% (p. 69). Colorado was one of twelve states, which committed more than one half of its Medicaid resources for community services in 1997. (p. 70).
3. “Two factors that do predict community services spending levels in the states for mental retardation/developmental disabilities, however, are degree of state participation in the HCBS Waiver Program and a state political culture historically supportive of civil rights for minorities, i.e., early adoption of state civil rights statutes promoting nondiscrimination in public accommodations, housing, and employment.” (p. 70)
4. ...“a new legal framework on disability support has begun to emerge in the United States based on self-determination, community and family support, independent living, inclusive education, and broad civil rights protections. The new framework is embodied in statutes such as the Individuals with Disabilities Education Act, the Medicaid HCBS Waiver program, the Fair Housing Act, the Rehabilitation Act, and in numerous federal and state court rulings on the rights of persons with disabilities (Silverstein, 2000) p. 73.

“Community Residential Services”

5. “Supported Living was defined for purposes of this study to include housing in which individuals choose where and with whom they live, ownership is by someone other than the support provider, and the individual has a personalized support plan that changes as her or his needs and abilities change.” (p. 87)
6. “Direct support staff in community residential settings work for lower compensation and fewer benefits compared to institutional personnel (Association of Developmental Disabilities Providers, 1999; Larson, 1993; Rubin, Park, and Braddock, 1998). Community residential service providers must also cope with difficulties in direct service staff recruitment, training, and retention (Larson, Hewitt, and Lakin, 1994; Larson et al., 1998). p. 89

“Public Institutions”

7. “Since 1977, total spending for the nation’s public institutions has declined 13% in inflation-adjusted terms. Average daily costs per person have advanced dramatically, however, from \$45 in 1977 to \$321 in 2000. Improved staffing levels accounted for some of the cost increases.” (p. 91) Colorado’s institution daily costs in 2000 were \$358.92. (p. 95)

“Privately Operated Institutions and Nursing Facilities”

8. “In 2000, no public funds were used to support private institutions in the 10 states of Alabama, Alaska, Colorado, Massachusetts, Michigan, Montana, Nevada, South Dakota, Vermont and Wyoming.” (p. 95)
9. “The national average utilization of nursing facilities for persons with developmental disabilities was 13 per 100,000 of state population.” (p. 96) In 2000, Colorado had 270 individuals residing in nursing homes which represents 7 per 100,000 of the state’s population. (p. 96)

“Impact of Economic Recession in the States”

10. “...the record-setting pace of economic growth during the 1990’s has faltered. State budgets began slowing in the fall of 2000 (Eckl and Perez, 2001), and the September 11 attacks exacerbated the economic problems the states were beginning to experience (National Association of State Budget Officers, 2001a). Unemployment rates have climbed, and state and local tax revenues have declined to their lowest rates since the 1950’s (Zandi, 2001)...As of October 31, 2001, state budget shortfalls were estimated to exceed \$15 billion for fiscal year 2002, and most states had cut, or were planning to cut, their budgets (National Association of State Budget Officers, 2001b). pp. 98-99

“The HCBS Waiver”

11. “The types of services financed by the Waiver (HCBS) include case management, assistive technology, homemaker assistance, home health aides, personal care, residential habilitation, day habilitation, respite care, transportation, supported employment, adapted equipment, home modification, and occupational, speech, physical, and behavioral therapy. No state financed all of these options, and there was considerable variability in the services that states opted to fund via the Waiver.” (p. 101)
12. “The role played by the HCBS Waiver seems likely to grow even larger in the years ahead due to the increasing flexibility of the Centers for Medicare and Medicaid Services (CMS) in permitting innovation in the states, and due to state’s efforts to utilize currently unmatched state and local funds to draw down additional federal HCBS Waiver revenue (Hemp, Braddock, Parish, and Smith. 2001). P. 101
13. “...the Supreme Court’s recent landmark ruling in the Olmstead case (Olmstead v. L.C., 1999) is likely to stimulate increased utilization of the Waiver to finance community long-term care supports. Judge Ruth Bader-Ginsburg, writing for the 6-3 Court majority, described the essence of the Court’s ruling: ‘We confront the question of whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes’ (Olmstead v. L.C., 1999).” P. 101

“Local Funding”

14. “Local government resources allocated for community MR/DD services are derived from county, township, or municipal entities, and grew from \$691.4 million in 1996 to \$904.9 million in 2000, an inflation-adjusted advance of 18%.” (p. 103)

“Variations in State Commitments for MR/DD Services”

15. “Public spending for community services in the United States first exceeded institutional spending in 1989. In 2000, all states but Mississippi were spending more for community services than for institutional services. Alaska, in 1981, and Colorado and Michigan, in 1982, were the first three states to allocate a majority of their total MR/DD funding base to community services...” (p. 110)
16. “Nationally, 75% of total MR/DD resources was dedicated to community services and supports in 2000....Twelve states dedicated at least 90% of their total resources to community services in 2000: Arizona, Colorado, the District of Columbia, Hawaii, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, and West Virginia.” (p. 111)

“Individual and Family Support”

17. “Fifty percent of the nationwide funding for individual and family support was allocated for supported living and personal assistance, 31% for family support, and the remaining 19% funded supported employment activities...Individual and family support represented the fastest-growing portion of most states’ MR/DD budget during 1996-2000.” (p. 112)
18. “A national initiative with potential impact on individual and family support was the Self-Determination for Persons with Developmental Disabilities project financed in 1997 by the Robert Wood Johnson Foundation. Nineteen states received from \$100,000 to \$400,000 to initiate projects consistent with principles of consumer freedom, authority, support, and responsibility (‘Declaration of Self-Determination’, 1998).” (p. 112)

“Family Support Services”

19. “Family support consisted of any community-based service administered or financed by the state MR/DD agency providing for vouchers, direct cash payments to families, reimbursement, or direct payments to service providers which the state agency identified as family support. Examples of family support programs included cash subsidy payments, respite care, family counseling, architectural adaptation of the home, in-home training, sibling support programs, education and behavior management services and the purchase of specialized equipment.” The national average spending per family for the allocation of family support resources for cash subsidy and other family support is \$2,722 for FY 2000. Colorado’s average per family was \$1,112. (pp. 112-115)

“Supported Employment”

20. “In the early 1980’s, state MR/DD agencies began providing long-term support for workers with developmental disabilities...Research since that time, along with

advances in employment services and legislative mandates such as the Americans with Disabilities Act of 1990 (Pub. L. 101-336), have reinforced the need for supported employment (Blanck, 1998; Wehman, West, and Kane-Johnston, 1997), even though most states have maintained their commitments to sheltered work settings (McGaughey, Kiernan, McNally, and Gilmore, 1995). Longitudinal studies of people moving from sheltered to supported employment have also pointed to benefits for both consumers and taxpayers (Helms, Moore and McSewyn, 1991; Hill and Wehman, 1983; Kregel, Wehman, and Banks, 1989; Lagomarcino, 1986; Thompson, Powers, and Houchard, 1992; Vogelsberg, Ashe, and Williams, 1985)." P. 115

21. "Supported employment was defined in the present study to include MR/DD state agency-financed programs for the long-term support of individuals in integrated work settings, work stations in industry, enclaves, or work crews, where developing independent work skills and earning competitive wages were the goals." (p. 115)
22. "In 2000, 23% of all vocational and day program participants in the United States worked in supported or competitive employment, while the remaining 77% of participants received services in sheltered employment, day activity, or day habilitation programs." In Colorado during this same reporting period, 39% of all vocational and day program participants worked in supported or competitive employment whereas, the remaining 61% received services in sheltered employment or community participation. (p. 115)

"Supported Living and Personal Assistance"

23. "Supported living was first initiated in Colorado, Florida, Missouri, North Dakota, Ohio, Oregon, and Wisconsin in the mid-1980's (Bauer and Smith, 1993; Pittsley, 1990; Smith, 1990). The increased funding to emphasize individual choice, control over housing, and individualized, person-centered planning reflected in part the growing strength of self-advocacy organizations." (Dybwad and Bersani, 1996; Hayden and Senese, 1996; Longhurst, 1994). p. 117

"Supported living was defined for purposes of this study to include housing in which individuals choose where and with whom they live, in which ownership is by someone other than the support provider (i.e. by the individual, the family, a landlord, or a housing cooperative), and in which the individual has a personalized support plan that changes as her or his needs and abilities change." (pp. 87, 117)
24. "In recent years, the federal government has encouraged supported living by increasing flexibility in the HCBS Waiver program (Smith, 1998; Smith and Gettings, 1997)...In 1996, Colorado, Wisconsin, and Florida established new HCBS Waiver programs as a continuation of their CSLA (Community Supported Living Arrangement) initiatives."

"Significance of Medicaid"

25. "...Medicaid is the essential financial underpinning for MR/DD services in the United States. Combined federal and state Medicaid spending in 2000 constituted 75% of all MR/DD spending of \$29.3 billion...Medicaid funding is attractive to states, because state spending is matched by federal reimbursement

of between 50% - 79%, depending on the level of state per capita personal income...The proportion of states' community services budgets that are made up of federal Medicaid funds and state/local matches has increased substantially in recent years, from 35% in 1990 to 94% in 2000." (p. 119)

"Continued expansion of family-scale homes and individual and family support initiatives hinges on continued efforts by the states to redirect institutional ICF/MR funding to community alternatives." (p. 119)

26. "Moderate Medicaid spending growth in the late 1990s was due primarily to the strong economy, which reduced the need for access to publicly funded health care, and to the impact of managed care, which controlled costs (Starr, 1999). The recent downturn in the economy could redirect the attention of elected officials to containing Medicaid spending." (p. 120)

"Assessing Fiscal Effort In The States"

27. "Fiscal effort was defined as a state's spending for MR/DD services per \$1,000 of total state personal income....In 1977, \$2.26 per \$1,000 of aggregate United States personal income was expended for MR/DD services across the nation. In 1990, fiscal effort had increased by 42% to \$3.21, and in 2000 the figure was \$3.65 per \$1,000. The composition of this robust 24-year trend consists of two major sub-components: the dynamic and continuing growth of community services resources and the slow but steady decline in states' spending for institutions, that has accelerated since 1991." (pp. 122-123)

Colorado's fiscal effort for FY 2000 for Community Spending was \$2.22 per \$1,000 compared with \$0.86 cents per \$1,000 in 1977. This ranks Colorado 36th among the states in FY 2000 compared with a ranking of 8th in 1977.

Colorado's fiscal effort for FY 2000 for Institutional Spending was \$0.14 cents per \$1,000 compared with \$1.32 per \$1,000 in 1977. This ranks Colorado 43rd among the states in FY 2000 compared with a ranking of 39th in 1977.

Colorado's fiscal effort for FY 2000 for Total Spending was \$2.36 per \$1,000 compared with \$2.18 per \$1,000 in 1977. This ranks Colorado 44th among the states in FY 2000 compared with a ranking of 23rd in 1977.

"Aging Caregivers and the Growing Demand for Services"

28. "The aging of our society directly influences demand for developmental disabilities services. This occurs because the majority of people with developmental disabilities in the United States currently reside with family caregivers. As these caregivers age beyond their caregiving capacities, formal living arrangements must be established to support their relatives with disabilities." (p. 124)
29. "The aging of our society is the product of several forces, primary among them the size of the baby boom generation, consisting of persons born during 1946-64, declining fertility rates, and increased longevity." (p. 124)
30. 61% of the estimated population of 4.3 million persons with mental retardation

and developmental disabilities in the United States in FY 2000 are living with family caregivers. (p. 124)

31. "It is an unfortunate reality that many family caregivers must die before the relative with a disability for whom they are caring can receive services from the publicly financed system." (Braddock, 1999). p. 126.
32. In Colorado, it is estimated that there were 7,810 individuals with developmental disabilities living in households with caregivers aged 60+ years in 2000. (Braddock, 1999) p. 126.

"Waiting Lists in the States"

33. "Prouty, Smith, and Lakin (2001) reported that, in 2000, an estimated nationwide total of 71,922 persons with developmental disabilities were on formal state waiting lists for residential services." (p. 126)
34. "Demographic trends clearly suggest that as baby boomers age, waiting lists will accelerate markedly in the states, unless a concerted state-federal effort is mounted to address this issue." (p. 126)
35. "Lakin (1998) has noted that waiting list initiatives in the states have generally involved expanding family support to prevent or delay the need for placement, and obtaining new or reallocated resources from the following sources: institutions, ICF/MR conversion to HCBS Waiver programs, capping reimbursement for existing programs, or seeking additional Medicaid funding." (pp. 126-127)

"Civil Rights and Advocacy"

36. "Spending for MR/DD community long-term care services was associated with a history of innovativeness on civil rights issues promoting racial equality in the states, a strong advocacy group presence, and state utilization of the HCBS Waiver." (p. 127)

"Litigation in the States"

37. "In the late 1990s, three types of class-action litigation emerged in the states: Lawsuits filed to force states to expand services to people on waiting lists; lawsuits filed to force states to meet the requirements of the Olmstead decision; and lawsuits filed on behalf of individuals who had been found eligible for Medicaid services, but did not receive them." (p. 130)

Note: As of February 2003, there were: (a) twenty-three "waiting list" lawsuits pending in the United States; (b) sixteen "Olmstead" lawsuits; and (c) fourteen "access to benefits" lawsuits (Smith, Gary: "Status Report: Litigation Concerning Medicaid Services for Persons with Developmental and Other Disabilities, February 14, 2003, pp. 1-36).

IV. Colorado Issues, Trends and Recommendations: Issues, trends and recommendations referenced in the following, emanate from the varied constituencies within and outside the developmental disabilities services system. Each constituent organization is identified prior to the summarization of its issues, trends and recommendations.

National Consultants

A. **Smith, Gary: "An Evaluation of the Colorado Systems Change Project Evaluation" (December 24, 2002)**

1. "As a first order of business, we believe it especially important that system stakeholders collaborate in the development and adoption of a 'quality framework' for community developmental disabilities services." (p. 44)
2. "...we urge that a major emphasis be placed on quality improvement at both the state and local levels....establishing a Colorado Quality Improvement Council" (p. 46)
3. "Colorado should give serious consideration to implementing a direct funding/self-determination pilot program" (p. 47)
4. "Colorado should consider potential steps to improve system operational efficiency." (p. 50) and
5. "...consideration might be given to instituting a performance audit program of CCB operations." (p. 52)

B. **Smith, Gary: "Should Colorado Launch an Ombuds Program for People with Developmental Disabilities? (December 26, 2002)**

1. "We 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." (p. 19)
2. "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 limited pilot program in order to gauge its utility and impact before committing to a full-scale program." (p. 19-20)
3. "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....Operating a full-scale statewide program that is modestly staffed likely would cost in the neighborhood of \$500,000 to \$700,000 annually." (p. 23)

C. **Smith, Gary: "Gauging How Well Colorado Supports Its Citizens with Developmental Disabilities" (January 1, 2003)**

1. "...the best use of performance measures is to support quality improvement as opposed to policing the system." (p. 18)
2. "Our recommendations should be thoroughly discussed by stakeholders and their input solicited before proceeding with implementation." (p. 18)
3. "We recommend that the performance measures span six broad domains:
 - a. Personal Outcomes

- b. Satisfaction
- c. Quality, Health and Safety
- d. Accessibility
- e. Efficiency
- f. Agency Strength” (p. 19) (pp. 24-32)

“In each of these domains, we recommend specific measures or indicators...The full set of measures includes many for which DDS already collects or possesses information. Some are new and would require additional data collection.” (p. 20)

4. “The four indicators that we recommend dropping are:

- a. Integration
- b. Stability
- c. Appeals
- d. Fund Utilization” (p. 20) (See Note 1-3 below.)

Note 1: This recommendation is in reference to the “Key Indicators of Performance” presently used by the Colorado Division of Developmental Disabilities Services. (p. 11)

Note 2: “The Key Indicators” are a short list of performance measures that were adopted to provide an overall picture of the health of the Colorado service system for persons with developmental disabilities. They were selected as the best measures for summarizing how our service system is performing out of a much larger set of performance measures collected by the Division of Developmental Disabilities Services. The Key Indicators of Performance are conducted annually.

Note 3: A second survey is conducted bi-annually by DDS and is referred to as the Core Indicators Outcomes Survey (CIOS) that compiles information related to outcomes that adults with developmental disabilities are experiencing. (p. 12)

5. “In order to better measure performance CCB-by-CCB, we recommend increasing the size of the CIOS sample. We do not recommend changing the two-year CIOS administration cycle.” “We recommend a 50% increase in the number of individuals served by CCBs included in the sample.” (p. 33)
 “Increasing the CIOS sample...would cost an additional \$45,000 over and above the \$90,000 contract cost to administer CIOS.” (p. 35) (CIOS refers to Core Indicators Outcomes Survey conducted by DDS – see note 3 above)

6. Re recommendations to add a survey of families... “We recommend that this survey be conducted by mail based on a random sample of individuals served by funding block and that the sample size be sufficient to ensure that the results are statistically reliable in making comparisons CCB-to-CCB.” (p.33) “We estimate the non-staff expense of just the data collection phase of this survey at approximately \$15,000” (p. 35)

7. “This measurement lag and the inability to produce CCB-by-CCB data clearly are major obstacles to tying CCB funding to performance. Without augmented DDS capability to shorten the time between CIOS administration and producing results

(including results CCB-by-CCB), neither individual outcomes nor individual satisfaction can serve as a basis for linking CCB performance to funding.” (p.43)

8. “We strongly recommend that DDS have sufficient resources to turn around the 2002 CIOS data as early as possible in FY 2003-2004, including, if feasible, preparing CCB-by-CCB results to establish a performance baseline.” (p. 35) “As a consequence, we recommend that the addition of two FTEs dedicated to performance measurement occur as soon as possible but no later than July 2003. We estimate the personal services costs of these two positions at \$90,000 plus fringe benefits and other necessary operating expenses. If it is feasible to outsource the processing of the third-party survey data, then the number of FTEs added at DDS might potentially be reduced to 1.5 and \$30,000 made available to DDS to contract for analysis of the third-party survey data.” (p. 36)
9. “There are various complex issues and challenges that must be resolved in tying funding to performance and outcome measures, which is why it is not common practice in human services, including developmental disabilities.” (p. 39) “In the end, Colorado might be able to establish this link but not without considerable time and effort. There is little in the way of relevant experience from elsewhere available to guide these efforts. In our view, the better near-to-mid term strategy would be to concentrate attention on quality improvement strategies as the principal tool to increase performance rather than focus energy on searching for a mechanical link to database performance measures that will be complicated to construct.” (p. 44)

D. Rowe, June: “Technical Assistance Summary Recommendations and Resources: Incident Management System, Human Services Research Institute (December 16, 2002)

Incident Reporting

1. “Formal reporting of incidents from CCBs to DDS should be instituted....Three categories of incident reporting should be instituted with specific timelines for each category. Proposed categories of incidents in order of severity:
 - a. Reportable incidents
 - b. Serious incidents
 - c. Critical incidents” (pp. 4-5)
2. “DDS should develop and manage a single, statewide database of serious and critical incidents and investigation outcomes. This would allow data on incidents to be available to CCBs (for individuals specifically served by that CCB) and DDS (for all individuals).” (p. 5)

Investigations

1. “There is an inherent conflict of interest in CCBs conducting investigations that may involve their own provider staff or staff from their provider service agencies. CCBs are in some cases service providers and in all cases the case managers are employees of the CCB. ...consideration should be given to creating a statewide pool of investigators, contracting out investigations, sharing investigators between adjacent CCBs, or a combination of the above.” (p. 5)

2. "It is recommended that ongoing training and technical assistance be provided to staff conducting investigations." (p. 5)
3. "It is recommended that DDS develop additional capacity to conduct investigations." (p. 6)
4. "It is recommended that DDS pursue regulatory authority that defines the agency's roles and responsibilities for conducting investigations." (p. 6)

Risk Planning

1. "Each CCB should establish a committee to provide for oversight and monitoring of incidents, as well as efforts to reduce the risk of harm to individuals." (p. 6)
2. "DDS should institute a comparable statewide committee to review incident data in the aggregate and make recommendations for statewide quality improvement initiatives." (p. 6)
3. "DDS should also consider a statewide risk management approach, designed to prevent or reduce the incidence of harm to individuals, which could be fully integrated into the daily work of supporting individuals." (p. 6)

Colorado's Constituency

A. CACCB Service Provider Organization

1. **Case Management:**
 - a. Recognize the potential for conflict of interest within the CCB MSO function with enhanced transparency and review to assure proper independence and processes are followed;
 - b. Adopt changes to the Request For Proposal process recommended by the SPO organization;
 - c. Increase business and management training to improve skills and recognition of following the business standards and processes established through the CCB; and
 - d. Re-evaluate the role of the Case Manager function. Perhaps it should be restructured along the lines of intake, assessment and re-determination functions due to the size of case loads with advocacy/interdisciplinary team responsibilities with other personnel within the CCB organization. Currently, it is the local service, CCB or SPO, Program Coordinator that is closest, most knowledgeable and has the most contact in the day-to-day primary health and safety interests of the consumer.
2. **Supported Living Services:**
 - a. Review the current "Guide Book" and "Interpretive Guidelines" that have made SLS services function like the Comprehensive model in order to increase flexibility in meeting consumer's needs;

- b. Program administration policies of services vary between CCBs; and
- c. Approve of SPOs to perform the role of Supported Living Consultant to achieve lower service management cost.

3. **System Unification:**

- a. SPOs operate across many CCBs and must utilize varied reports such as Incident Reports, ISSPs, Safety Plans, Assessments, 6-month Summary Reports, Comprehensive Life Reviews, Human Rights Committee Reports are examples. System wide unification of processes could reduce administrative burden/costs and assist in selective data capture. In addition, DDS should approve the use of electronic media as acceptable documentation. Necessary authentication requirements can be achieved;
- b. SPOs find wide variety of requirements across CCBs in contract language. An example of Professional Liability Insurances for PASAs and Host Homes, Paid Absence Days and Satisfaction Surveys across several CCBs is attached for reference;
- c. Increased training on system requirements, processes and practices from DDS staff would improve service provider efficiency and effectiveness;
- d. Varied service payment methodologies exist across the CCB system; and
- e. The value of choosing vocational activity by consumers should be emphasized through program direction and funding support.

B. Colorado Association of Community Centered Boards (February 2003)

- 1. To manage the DD community budget in order to minimize potential negative impacts on consumers and families in times of reduced state revenues;
- 2. To assist the State and all stakeholders in realigning resources to meet potential budget shortfalls;
- 3. For DDS to allocate any new resources with the exception of emergency resources at the onset of each fiscal year in order that consumers and families can obtain the full benefit of limited resources and to request rates which have the potential to result in the highest quality of services and supports;
- 4. To work with DDS and stakeholders to facilitate the implementation of self-determination principles and practices in Colorado, and to create opportunities for consumers to lead self determined lives;
- 5. To address quality issues in the DD community system including State and local quality assurance systems and improvement strategies;
- 6. To reduce rules, regulations and processes including unfunded mandates (HIPAA and Sex Offender Management Board requirements) which lead to inefficiencies and unrealistic expectations at a time of diminished resources and to keep limited resources focused on consumer services and supports;

7. To obtain resources to reduce waiting lists for services and supports in Colorado;
8. To work with DDS and all stakeholders to develop a plan to address the future of persons living in state funded Regional Centers to transition homes and funding with backup and specialized services in the community DD system;
9. To develop strategies and services for providing supports and services to those persons most challenging to serve in community settings; and
10. To develop productive and meaningful methods of communication with stakeholders including consumers and families, which result in quality community services and supports, based upon shared values.

C. Colorado Association of Private Resource Agencies: "Issues Faced By Colorado Service Providers" (November 1, 2002 and January 24, 2003)

1. The need to establish a more collaborative effort between CCBs and Service Agencies;
2. The need to establish a Colorado Quality Improvement Council per the recommendation of the Human Services Research Institute (p. 46)
3. The need to establish CCB Performance Audits per the recommendation of the Human Services Research Institute (p. 52)
4. The need to focus on CCB Administration issues and possible solutions (pp. 12 – 14).

D. Colorado Department of Human Services Footnotes: The Colorado General Assembly often attaches footnotes to the annual Appropriations Bill (commonly referred to as the Long Bill). These footnotes request special reports on issues of interest to the legislature. The FY 2002-03 Appropriations Bill contained three footnotes (94, 95, 96) that requested reports related to developmental disabilities issues. The basic findings and recommendations of those reports are summarized below.

1. **Footnote 94 – Olmstead** – The U.S. Supreme Court ruled that unnecessary segregation of individuals with disabilities constitutes discrimination in violation of the Americans with Disabilities Act (ADA). They ruled that states must place individuals in community settings, instead of institutions, when (1) professionals determined this was appropriate, (2) the individual does not oppose the placement, and (3) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other persons with disabilities. The legislature asked that the Department demonstrate that any funding requests associated with the Olmstead ruling were coordinated with the Colorado statewide plan for Olmstead. The response to this footnote made the following points.
 - a. Colorado has reduced the number of persons with developmental disabilities served in institutional settings by 82% in the past 21 years;
 - b. This progress demonstrates both a strong commitment to community

based services and is evidence of “an effectively working plan” (as suggested within the Olmstead Decision); and

- c. The Department will continue to submit funding requests tied to the Olmstead decision that are aligned with the state’s legal obligations.

2. Footnote 95 – High Staff Turnover - Community agencies serving our population have been experiencing very high turnover in direct care staff due to an inability to pay competitive wages. The legislature has appropriated two rate increases towards addressing this workforce crisis (in FY 2002 and FY 2003). Footnote 95 asked the Department to report on progress toward addressing the workforce crisis, how the FY 2002 rate increases had been used, and what additional wage increases are needed. The following findings were reported.

- a. Turnover has remained high at 58% on average for community direct care staff in 2002 and as compared to 27% at Regional Centers in 2002;
- b. Average wages paid to RC direct care staff were 50% higher than those paid in the community in 2002;
- c. Wages of community direct care staff increased by 6.2% from 2000 to 2002 due to the rate increase provided by the legislature to address this problem. Unfortunately, competing employers, such as the RCs, increased wages by 8.9% over the same time period and so the gap in wages remains; and
- d. The Department recommended a target wage for community staff that is comparable to that paid by competing employers. To reach this goal would require a 48.4% increase in wages for direct care workers. It was further suggested that this goal be achieved over a 5 year period requiring an estimated annual base rate increase of approximately 6.6% for Comprehensive Services and 12% for Case management services.

3. Footnote 96 – Comprehensive Services Waiting List – The legislature requested that a survey be conducted to verify when individuals on the waiting list for Comprehensive Services would need that service. This survey involved telephoning individuals whose timeframes had not been already verified in the last year and checking the records for all other individuals to assure that the computer records matched the case records. The results of this survey determined that:

- a. 663 individuals were requesting a Comprehensive Service by June 30, 2004; and
- b. 2,324 additional individuals either want the service after that date or are unsure when they will need the services.

E. Colorado Developmental Disabilities Council (FY 02 Performance Targets)

- 1. Support and sustain successful community inclusion and employment of people with developmental disabilities;
- 2. Support community groups to help self-advocates buy-rent homes of their own;

3. Facilitate dialogue and training with relevant constituents relative to home ownership for people with disabilities;
4. Provide information and support advocacy and training in the provision of person-centered health services;
5. Provide information and training on person-centered planning/inclusion/self-determination as related to inclusive opportunities (i.e. employment, transportation, housing, community access, etc.);
6. Monitor accessibility of transportation in Colorado; and
7. Monitor regulation process and implementation of 1998 Colorado legislation on seclusion and restraint.

F. Community Centered Boards:

1. Arkansas Valley: Serves 3 counties (August 27, 2002 visit)

- a. Recruitment and retention of educated and qualified staff. The ability to raise our starting salary to the next level, we currently have a starting salary of \$7.00 per hour for our direct support positions. Having the ability to raise our starting salary could attract a newer type of staff for us but is currently inconceivable given our rates, future budget cuts, and anticipating other economic and business related factors;
- b. Continued lack of available resources within our community to support difficult to serve individuals, medically fragile, those requiring complex mental health intervention, offenders, and children transitioning to adult services. We would certainly look at economic factors facing our community which also contribute to the lack of those resources. The inability to attract health care professionals, continued drought which creates lost tax revenue for the counties and therefore lost ability to provide even the basic of community based safety net services; and
- c. Continued low rates coupled with little or no ability to add to our Comprehensive or SLS base because of, having a very small or non-existent waiting list, population density, people leaving rural communities or not entering communities, and death of consumers with no one to "backfill". Also, during the initial phases of looking at CSAT data, AVCC on average, is serving more difficult individuals than several other CCBs, who receive higher rates, yet our rate remains historically low for those hard to serve individuals because of historical and unresolved inequities. These concerns have the potential of lost revenue despite having the associated fixed costs of continuing to operate the business. This trend, if continued 5 years hence, could create a scenario where our Comprehensive Program would continue to decrease due to death, movement to other catchment areas or not being able to support hard to serve individuals and having to. The budgetary and service implications are self-explanatory.

2. Blue Peaks Developmental Services: Serves 6 counties (August 29, 2002 visit)

- a. Our ability to deal with any upcoming budget cuts and the impacts on our consumers and their families. Areas affected could include, but are not limited to, range of services, quality of services, and numbers of consumers to be served, transportation, recruitment and retention of staff;
- b. Seek reductions in rules, regulations and processes in order to assist us in continuing to provide quality services and supports for consumers while dealing with decreased resources; and
- c. Increased liability issues and vulnerability for our agency as we continue to serve individuals with more challenging behaviors and complex health needs in the community.

3. Centennial Developmental Services: Serves 1 county (August 21, 2002 visit)

- a. Insufficient Funding: The CCB is looking at a mill levy to generate new funding. Additionally, insufficient rates are a major issue for the CCB;
 - (1) Information Management: Need to develop and integrate systems that handle billing, payment, program and case management processes. Upgrade CCMS to more current database software and provide HIPA compliance;
 - (2) Personnel: Pay rates are not comparable to the community at large. Pay rates remain low compared to competitors and the CCB tends to attract the least qualified employees, particularly for direct care. Staff turnover is highest in direct care staff positions.
 - (3) Training: The need for additional funding to support ongoing training to develop staff with low levels of education and skills.
 - (4) Lack of accessible and affordable housing for consumers; and
 - (5) It is recommended that CCBs be permitted to transfer unused funds and convert between SLS and Comp.
- b. The SLS waiver, in its present form, is problematic statewide (i.e. rigid Reporting requirements). Additionally, there is a conflict between the desire for natural supports and the concern for health and safety. Inherent conflict of interest also exists, if the SLC is also employed by the agency providing services
- c. Internal CCB system training issues and community education in order to develop additional cooperative/collaborative relationships:

- (1) Technical Assistance. DDS offers technical assistance, when they're able, however, due to insufficient resources, this need is not being adequately addressed. Areas of need include:
 - Rate setting/negotiation with providers for SLS, EI and Comprehensive;
 - Identifying consumer needs and developing meaningful goals;
 - Developing intervention programs for consumers with behavior problems;
 - Developing effective staffing patterns in PCA homes; and
 - Developing a transportation system.
- (2) Mental Health: The CCB is experiencing resistance from Mental Health Services even though there exists a Memorandum of Understanding;
- (3) Transportation: Public transportation unavailable;
- (4) Need to develop financial incentives with the Division of Vocational Rehabilitation Services to encourage community employment opportunities; and
- (5) Resistance in the medical community to serve individuals is a significant problem.

4. Colorado Bluesky Enterprises, Inc: Serves 1 county (September 11, 2002 visit)

- a. Our agency is concerned about the future in terms of funding and stability of services. We recognize the dilemma the state is in with the state of the economy and therefore have been working to reduce our costs of operation. However, the issue of keeping staff because of low salaries continues to plague us. Now it will become somewhat worse because there will be no likelihood of salary increases this year and possibly next. We have experienced a 26% turnover rate in direct services providers;
- b. CBE's population is skewed because of the presence of the Pueblo Regional Center and Colorado Mental Health Institute-Pueblo as well as having several department of correction facilities in the area. Over 50% of individuals receiving Comprehensive services have a dual diagnosis. Also, CBE is serving a number of individuals at the lowest rates who have a dual diagnosis; CBE also serves more than 10 individuals in a highly structured and highly supervised programmatic setting funded at 50% of the cost of reimbursement. This is a state and nationally recognized program which has been published in an AAMR book on Crisis and several University of Minnesota publications; and

- c. We will work to minimize the effects of budget cuts on individuals' supports and services. However, depending on what the legislature has to do to balance the budget, consumers may also feel the effects of budget reduction.

5. Community Connections: Serves 5 counties (October 3, 2002 visit)

- a. Extreme direct service staff turnover (almost 200% annually) caused by a high cost of living, low wages and a highly transient labor force;
- b. Seventy-five percent (75%) of direct service comes from out of state. As a result, background checks can be prolonged and take as long as three months. Consequently, an additional cost is incurred because regular full time staff "shadow" new staff until the background checks are completed; and
- c. The need for affordable and accessible housing.

6. Community Options: Serves 6 counties (October 25, 2002 visit)

- a. The overriding issue is maintaining service quality and programmatic integrity in the face of massive statewide budget cuts;
- b. It is very difficult to recruit and retain qualified staff. Direct service staff turnover due to low wages and high cost of living is a major challenge;
- c. The CCB is faced with high health insurance and Workers' Compensation costs. Last year, health insurance premiums increased by 70%;
- d. Local fund-raising efforts (particularly consideration of a mil levy) to generate revenue for staff wages are extremely difficult due to a poor local economy and demographics that include significant numbers of retirees and farmers/ranchers; and
- e. Transportation is a major expense, serving a six county area that encompasses 11,000 square miles.

7. Denver Options: Serves 1 county (August 16, 2002 visit)

- a. There is need for an emergency back up system to provide long-term placements (91 days and longer) and short-term emergency placements (90 days or less) among the three Regional Centers;
- b. Liability exposure from lawsuits and serving more challenging behaviors;
- c. Level of state funding (i.e. rates)

8. Developmental Disabilities Resource Center: Serves 4 counties (September 30, 2002 visit)

- a. Issues confronting DDRC include:

- (1) Inadequate rates and insufficient resources;
 - (2) Staff reduction and turnover;
 - (3) Unable to afford to compensate hourly wages of direct service staff that approximates or equals wages paid to their counterparts in Regional Centers;
 - (4) Unable to provide benefits compared with staff employed in Regional Centers; and
 - (5) Health insurance premiums increased by 15%.
- b. Due to the economy and significant state revenue shortfall, the developmental disabilities services system will be in a survival mode for some time to come; and
 - c. Over the past 1-½ years, DDRC has reduced staff by 180. 90% of this number (162) was full time staff; whereas 10% (18) were part-time employees. Reasons for the reduction relate to lack of rate increases and inflationary costs.

9. Developmental Opportunities: Serves 3 counties (September 12, 2002 visit)

- a. First priority:
 - (1) Low rates received for older resources allocated in 1986 have never been adjusted;
 - (2) Funding issues in general are a major concern. Local tax base inequities among the twenty community centered boards is an issue. The CCB doesn't benefit from local support of any kind;
 - (3) Fund raising is difficult because of competition;
 - (4) Inadequate funding for individuals from Regional Centers and Mental Health Institutes (i.e. specialized equipment);
 - (5) Cumbersome aspect of SLS documentation; and
 - (6) There is a dichotomy between paying rate to provider and booking the rate as an expense as opposed to the CCB as provider having to record actual expense.
- b. Second priority:
 - (1) Issue of trust between CCB and DDS; and
 - (2) Rules being developed by DDS for exceptions identified in the community.
- c. Third priority:
 - (1) The perception of inconsistent interpretation of Rules and "Interpretive Guidelines" amongst DDS surveyors;

- (2) When developing a "Self-Determination" model for Colorado, there will be need for flexibility of funding; and
- (3) Concern expressed about the validity of fiscal auditors (Wade Thorton Audits) data on waiting lists.

10. Developmental Pathways: 2 counties (August 6, 2002 visit)

- a. Explosive population growth in our counties, resulting in growing waiting lists and more and more individuals and families in serious distress that we don't have the capacity to help;
- b. At a time of stagnant or diminishing resources, serving individuals who are medically complex; individuals with problematic sexual behaviors; and individuals with other behavioral challenges that place themselves or others at risk; and
- c. Costly litigation of issues that once were the subject of discussion and problem-solving, resulting in greatly increased insurance costs and the risk of becoming uninsurable, and the potential for services to high needs individuals becoming too risky to provide.

11. Eastern Developmental Services: Serves 10 counties (August 22, 2002 visit)

- a. One third of those individuals served under the Comprehensive Services waiver, are receiving a low, historical rate that no longer exists with newer resources. As a result, rate equity is a major issue;
- b. Travel time between program locations and capital costs associated with vehicles is a major cost to the CCB. Transportation costs can represent the majority of an individual's SLS waiver, which can diminish the number of program days;
- c. Under funded case management services. Billable services are available only after enrollment; and
- d. The need for ongoing staff training from DDS represents a major need.

12. Foothills Gateway: Serves 1 county (August 20, 2002 visit)

- a. **Priority #1: Insufficient Resources – Community Employment and Residential**
 - Lack of incentives to encourage community employment.
 - Inadequate reimbursement levels applied to job coaching services related to community employment.
 - Community Participation options (rates) and choice availability provides a disincentive to work opportunities in the community.
 - Rate increases for all services and supports, adaptive equipment, dental and medical have not kept pace with cost of living.

- CCBs want DDS to allow them to retain SSI annual COLA adjustments rather than decreasing Medicaid rates equal to the SSI adjustment.
 - Post Eligibility Treatment Income (PETI) is a disincentive to consumers earning more money.
 - Recommendation that DDS meet with the Division of Vocational Rehabilitation Services to address incentives for community employment.
 - Provide adequate funding and appropriate rules and regulations in support of programs for "Hard to Serve" (High Need).
- b. **Priority #2:** Supported Living Services Program
- There is a need to increase the \$35,000 cap, which presently cannot be waived.
 - There is a need for clarification of roles and responsibilities between Case Management and Supported Living Coordinators.
 - Supported Living Services, as a program, is too cumbersome and unclear.
- c. **Priority #3:** Critique of DDS Office
- Micromanages the CCB system in certain areas
 - Manages by exception (establishing rules by exception)
 - Unfunded mandates
 - DDS should lead system by mediating between "progressive" and "traditional" service approaches.
 - DDS should develop new vision and strategic plan.
 - DDS should develop waivers, in concert, with all constituencies, to provide and support Self-Determination options.

13. Horizons Specialized Services: Serves 5 counties (October 22, 2002 visit)

- a. Rates need to be higher to reflect actual costs and to raise direct care salaries;
- b. Our enrollment trends reflect increasing elderly, medically fragile and behavioral populations; and
- c. The increased cost of health insurance and Workers' Compensation.

14. Imagine!: Serves 2 counties (August 19, 2002 visit)

- a. The lack of ability to provide extensive supports to adults in their own homes or the homes of their families in order to avoid out of home placement (blend SLS and comp.);
- b. The lack of a standard "curriculum" or set of standards for all providers, consumers and the ccb's to use when using State funds in individual plans (e.g. should employment be a mandatory topic addressed in the plans of all adults?);

- c. Individualization drives up costs, and has resulted in fewer hours of day services (especially vocational) for many consumers;
- d. The obscene Waiting List situation in our State and others;
- e. The benign neglect of the State with respect to children and family services (EI and FSSP); and
- f. The growing needs of an aging population (55 +).

15. Mesa Developmental Services: Serves 1 county (October 24, 2002 visit)

- a. Recruitment and retention of staff and insufficient resources to provide competitive wages;
- b. Significant increases in:
 - (1) Workers' Compensation insurance premiums;
 - (2) Health insurance premiums;
 - (3) Liability insurance premiums; and
- c. Resources and options for increasingly fragile, multiply handicapped, and people with severe behavioral/mental health issues, including emergency backup systems.

16. Mountain Valley Community Centered Board: Serves 4 counties (October 23, 2002 visit)

- a. The turnover of direct service staff approximates 200%;
- b. Significant rising costs of insurance premiums related to:
 - (1) Workers' Compensation;
 - (2) Health Insurance; and
- c. Support resources and the number of people willing to serve as guardians are very limited for persons needing a guardian or conservator.

17. North Metro Community Services: Serves 1 county (August 5, 2002 visit)

- a. Program Quality Reviews:
 - (1) Should focus more on outcomes and less on process;
 - (2) Interpretive Guidelines are nebulous and result in different interpretations by as many reviewers;
 - (3) Duplication of effort. DDS reviews both CCB's and SPO's; whereas, CCB's review their respective SPO's;

- b. Would like to become CARF accredited in Residential Services and have this standard in place of Rules and Regulations and Interpretive Guidelines;
- c. The long standing log jam related to CCB's inability to access placements (i.e. long term and emergency respite up to 90 days) in Regional Centers and Mental Health Institutes is a major concern;

18. Southeastern Developmental Services: Serves 3.5 counties (August 26, 2002 visit)

- a. Difficulty in recruiting qualified direct care staff;
- b. Difficulty in recruiting professional staff (i.e. physical, occupational and speech therapists, etc.); and
- c. The need for equitable funding rates.

19. Southern Colorado Developmental Services: Serves 2 counties (August 28, 2002 visit)

- a. Funding levels for Comprehensive services. There is disparity in the rates that providers receive around the state for services. Historical rate setting during deinstitutionalization, does not match the level of need of these individuals today;
- b. The increased costs related to providing services. Increased costs related to:
 - (1) Workers/ Compensation premiums;
 - (2) Health Insurance premiums;
 - (3) Professional Liability premiums; and
- c. The regulatory requirements and associated paperwork, duplication of effort, cumbersome SLS reporting requirements. There is need for more flexibility in how we can utilize the funding pool.

20. The Resource Exchange: Serves 3 counties (September 10, 2002 visit)

- a. Funding inequity;
- b. Growing waiting list; and
- c. The need to focus on outcomes not standards and regulations.

G. Division of Developmental Disabilities Services Staff (2/19/03)

The following are issues, trends and recommendations identified through a Central Office Staff meeting of Developmental Disabilities Services (DDS) dated 2/10/03. These items are not listed in any particular order.

1. **Waiting List:** There are insufficient resources allocated by the Legislature in comparison with the ongoing growth of those awaiting residential, day and Supported Living services. A waiting list lawsuit was filed in Colorado.

Recommendation: Continue to develop budget requests as possible to address this issue.

2. **Staff Turnover and Cost of Living Issues:** Inadequate staff wages, removal of COLA provisions and the significant numbers of direct service staff turnover is a major concern for the system.

Recommendation: Continue to survey the community related to these issues if possible every 2-3 years and develop budget requests as possible to address these issues.

3. **Data System Problems:** The current Community Contract and Management System (CCMS) is inadequate to keep up with new and growing demands such as:

- HIPAA
- Incident Tracking
- Need to update current reporting system
- Internet interface to replace CITRIX to provide better service to customers
- Improved Waiting List tracking
- Meeting new Departmental Standards for data systems infrastructure
- Reduce duplication of data entry at CCBs and RCs through new import feature. Additionally, staffing reductions due to budget cuts resulting from state revenue shortages may impact the Department's ability to maintain the existing CCMS and address the current backlog of maintenance needs and changes requested.

Recommendation: Pursue 90-10 federal match for CCMS re-development costs and develop budget request. Continue to lobby OITS for sufficient resources to support CCMS.

4. **Self- Determination:** The overall system has not realized the potential options for self-determination that are currently available and the state of Colorado has not developed new options for self-determination within the developmental disabilities system.

Recommendation: Work with system partners to: (1) develop new service options to promote greater self-determination and (2) identify approaches for improving implementation and understanding of self-determination options that already exist within current services.

5. **Employment and Community Participation Services:** DDS is concerned about the trend away from Community Employment outcomes to Community Participation services.

Recommendation: Potentially get a workgroup together to review employment and community participation trends, and make recommendations for change including a look at the intent and design of Community Participation services.

6. **Case Management Funding:** Specific activities related to persons on the Waiting List are not currently funded and as a result, the quality of these services is not always what it should be. This relates to eligibility determinations, IP development, service coordination and annual IP updates for persons on the Waiting List.

Note: The average active caseload for a Case Manager in Colorado approximates 60-65 individuals.

Recommendation: Look at options for funding some of these functions for persons on the Waiting list. Consider a study to look at the adequacy of case management rates. Consider budget request at some point in the future.

7. **Case Management:** There appear to be some inconsistencies across CCBs in the area of eligibility determinations. In addition, there is a lack of information and/or training available for case management staff related to Individual Plan development, ISSP development, Medicaid Waiver enrollment, self-determination choices available and service options available both internal and external to the DD system.

Recommendation: 1) Continue the work started by the Eligibility Committee related to a technical assistance manual. 2) Explore options for more Case Management training through peer training by other CCBs and/or Regional Meetings, other options. Topics for training could include IP development, ISSP/IP Planning, Medicaid Waiver enrollment, self-determination, an overview of services available both within and external to the DD system. Training on ISSP development and how it interfaces with the IP may also need to include direct providers.

8. **DDS Staffing:** DDS has lost approximately 40% of its staff resources over the past 10 years. The decline of staff resources within the Division of Developmental Disabilities Services over the past ten years, combined with the growth of responsibilities has and continues to present a real challenge. It causes delays in addressing issues and impacts our ability to respond to inquiries on a timely basis.

Recommendation: DDS will need to redefine its role, look at ways to utilize community resources to fulfill its mission and continue to request increased staffing.

9. **CCB Fiscal and Data Management:** The skills and resources related to the areas of fiscal and data management available among the twenty Community Centered Boards vary. As a result, there are service providers (CCBs and Service Provider Organizations) that would benefit from ongoing in-service training. In

addition, it appears that some parts of the system may not recognize the importance of or need for specific kinds of data to be updated such as how Waiting List data is used in planning and budget request development.

Recommendation: Take advantage of those CCBs who do well in this area and who would be willing to provide such training. Continue to provide CCMS training to CCBs and include training to CCB case management on areas related to their functions. Fiscal management training might include:

- PETI
- Tracking over and under utilization of resources
- Rejected billings
- Reversions
- Related CCMS & CM training might focus on:
 - a. Accuracy of information
 - b. Level of need
 - c. Billings
 - d. Waiting List

Note: The significant state revenue short fall may prohibit DDS from providing stipends to CCBs for travel costs related to attending CCMS training in the future.

10. **Persons with Challenging Behaviors and Persons in Need of Intensive Medical Services:** DDS has lost capacity in the area of behavioral and medical expertise in terms of staff resources to address community issues and needs in these areas. There is a need for ongoing in-services for direct service staff on how to best serve individuals who are behaviorally or medically complex. This is especially important considering that this is a growing population and Colorado is experiencing a high turnover of direct service staff. In addition, RCs, CCBs and private providers are taking on more and more difficult persons and are struggling to provide for their needs. The DDS training budget has been cut more than 50% this fiscal year which impacts system ability to provide training for this and other issues.

Recommendation: Explore methods to provide greater in-service and shared in-service across the system related to these areas. Request to restore training resources in future budget requests.

11. **CORE Indicators Survey:** The loss of operational funds within the DDS budget will make funding for the CORE Indicators Project more challenging. The typical cost for collection of data approximates \$90,000. The operational fund has been reduced from \$41,000 to \$17,000.

Recommendation: Seek restored funding and/or reduce sample survey scope and/or alter collection method.

12. **Equity of Resource Distribution:** The Equity Funding formula for distribution of new resources and rates, currently includes a factor for COLA differences across CCB region and needs to also take into consideration case mix (level of need and the financial resources to meet such needs). Caseload (the number of individuals served relative to general population in a service region) is another

indicator of the equity of resource distribution. The present equity formula will not address the inequity of resources already distributed.

Recommendation: Explore adding a case mix aspect to the rate equity formula and potential budget requests to fund an adjustment to the base. Request additional resources to address caseload issues.

13. **Appropriateness of Placement for Some Regional Center Consumers:** There continues to be problems with moving persons from RCs who may be appropriate for CCB community services whose parents or guardians oppose the move. This means that persons who need this level of support do not have access to RC services in a timely way.

Recommendation: Finalize Regional Center Admission and Discharge Criteria. Continue to work with the Office of Adult, Disability and Rehabilitation Services on Regional Center Admissions and Discharge Procedures. Continue to work with the RCs to identify individuals who do not require RC services.

14. **HIPAA** – the Health Insurance Portability and Accountability Act (HIPAA) mandates many changes in how health related information is transmitted and maintained including privacy, security and new consistency standards for Medicaid related billings. These changes impact the DDS data system (CCMS) as well as require creation and implementation of new privacy and security policies and practices at DDS and the CCBs. The extent of the changes needed to CCMS is impacting the ability to address other changes needed in that system. (See Data system issue listed earlier)

Recommendation: Continue to stay abreast of new rules and standards as they are released by the federal government. Continue to implement the CCMS plan for addressing HIPAA changes that impact that data system.

15. **SAO Audit** – The State Auditors Office performed an audit of the DDS community system and developed several recommendations. Due to staff shortages, illnesses and emerging priorities, DDS has been unable to address all recommendations as quickly as planned.

Recommendation: Continue to work towards addressing those recommendations.

16. **Budget Shortfall** – The revenue shortfall for funding Colorado government supported services is impacting the ability to address many of the issues identified herein. Particularly, this shortfall will impact DDS' ability to obtain increased funding for addressing: emergencies, foster care transitions, the waiting list, workforce wage and turnover issues, equity of resource distribution, and staffing shortages at DDS. It will also impact DDS' ability to address training issues and to conduct consumer outcome surveys (since the funds for training and performance measures have been substantially reduced). In addition, concerns over potential cuts to specific areas and programs have forced staff at DDS to start and stop certain projects a number of times thereby wasting valuable time that is available.

Recommendation: Request funds to address budget issues as the economy permits including restoration of special funding categories for training and core

indicators (outcome) surveys. Attempt to prioritize any future cuts in order to minimize the impact on critical consumer services. When possible, seek other ways to augment funds, including additional federal refinancing, grants, etc.

17. **Olmstead** - The ruling [Olmstead v. L.C. (98-536) June 22, 1999] requires states to place persons with disabilities in community settings rather than institutions when (1) deemed appropriate per professionals, (2) not opposed by the individual and (3) it can be reasonably accommodated, taking into account the resources available to the state and the needs of other persons with disabilities. A plan is not required by the Olmstead ruling, but was instead mentioned within the ruling as a means for states to address the 'reasonable accommodation' portion of the ruling. While the State of Colorado has not issued such a plan, DDS has historically made significant inroads towards providing community options for individuals who reside in institutional settings and we would like to continue that trend.

Recommendation: Continue to request community funds to enable persons to leave institutional settings or to be diverted from these settings (regional centers, mental health institutes, nursing homes) to more appropriate settings as possible and within current fiscal crisis. Continue to use any targeted resources available to address these individuals.

18. **CMS Audit & Ensuring the overall safety of individuals who receive services** – The federal Centers for Medicare and Medicaid (CMS) will be conducting audits of the DDS related waivers during 2003. Recent CMS audits in other states have demonstrated more stringent oversight of quality and health and safety issues. It is important that Colorado learn from the lessons in other states and new guidelines released by CMS.

Recommendation: DDS should attempt to identify and address shortcomings that may exist relative to these newer trends prior to audits by CMS. Training should be provided on new CMS standards and how to address shortcomings, including critical incident tracking.

19. **Quality Assurance in more diversified community settings:** The more diverse services are becoming, the more challenging it becomes to monitor these services both at the day-to-day local level and through broader state oversight. There are numerous challenges to service delivery to meet the health and safety needs of individuals including providing various medical and therapy services for individuals with significant health issues and providing specialized behavioral services for individuals with potentially dangerous behaviors and psychiatric issues. Incident management systems are sometimes lacking which result in inadequate recording, investigation, and follow up to serious incidents. These challenges along with the changing models in service delivery including the trend toward smaller, more dispersed settings, result in greater difficulty in both the service delivery and the monitoring of these services. In addition, there is a concern with the gap in the monitoring of day program agencies that receive national accreditation since DDS does not monitor health and safety issues or IP implementation for individual.

Recommendation: DDS should continue to explore technical assistance and training opportunities for agencies to assist in addressing these challenges. DDS

should work with the community system to devise new strategies to monitor services including accredited programs.

20. **Emergency backup and Stabilization systems:** State operated services (i.e. Regional Centers) are at capacity and have waiting lists. The community-based system is being asked to serve more difficult individuals without having adequate backup supports or the ability to address cyclical or acute crisis situations that may take several weeks or months to stabilize. In addition, budget cuts to other systems and programs will mean less support to persons with developmental disabilities.

Recommendation: DDS should work with the community system and the Regional Centers to implement the recommendations in, "An Update on Developmental Disabilities System Planning Efforts in Colorado", and request additional funding specific to these systemic needs.

H. Legal Center for People with Disabilities and Older People (August 1, 2002)

1. Individuals residing within the two mental health institutes have been determined ready for and want to be living in the community;
2. Concern for the developmental disabilities services system inability to provide quality services because of:
 - a. Insufficient resources
 - b. Staff turnover
 - b. Service Provider Organizations going out of business
3. The system lacks an effective emergency backup system among the three Regional Centers and community relative to:
 - a. Longer term placements; and
 - b. Emergency respite
4. Inherent conflict of interest of CCBs to investigate themselves and the lack of an Incident Tracking and Reporting System to DDS; and
5. The two dispute resolution processes (HCPF and CDHS) need to be clarified and shared with families when services are denied reduced or terminated.

I. Speaking For Ourselves Of Colorado (November 24, 2002)

1. Issues and concerns identified:
 - a. Losing supports (e.g. budgeting, checkbook management, cooking instruction in the home, grocery shopping assistance, psychological counseling)
 - b. Employment support is not very good (e.g. poor job coach services, poor job development services)
 - c. Waiting for services since 1999;

- d. Service provider is not timely in taking care of my adaptive equipment needs when I have them;
 - e. Wheelchair service is hard to get because they are located far from me;
 - f. Agency doesn't respect my opinion. They do what they want to do instead of what I want to do (e.g. Community Participation partner, Host Home provider).
2. Recommendations to improve services and supports in Colorado:
- a. Don't criticize us – be supportive of us;
 - b. Provide employers with training to work better with people with developmental disabilities;
 - c. Provide all of the services that we need;
 - d. Evaluation of CCB staff members by the people they serve; and
 - e. Evaluation of service providers by the people they serve.
3. Recommendations for the new Director of DDS:
- a. Visit each CCB area at least once per year with intention of hearing from all the people receiving services (i.e. town meetings for clients and their families)
 - b. Serve everyone that needs services – fight for enough funding to eliminate the waiting list;
 - c. Develop and implement Self-Determination for people with developmental disabilities in Colorado;
 - d. Publish an Olmstead Implementation Plan that describes what will be done and in what time frame;
 - e. Eliminate the use of "Intermediate Care Facilities for the Mentally Retarded" at existing regional centers;
 - f. Eliminate the use of group homes which house more than four residents;
 - g. Increase the use of Comprehensive support in individual apartment settings;
 - h. Increase the use of 1 and 2 person host home settings;
 - i. Support our "Close the Doors – Campaign for Freedom." Meet with our committee at least once per year to communicate progress on your plan to close Grand Junction Regional Center; and
 - j. Meet with us periodically to stay current with our advice and concerns.

J. State Auditor's Office: "Department of Human Services for People with Developmental Disabilities Performance Audit (May 2000)"

1. "Work with Regional Centers and Community-Centered Boards to develop a valid method for assessing service levels and resource needs consistently across the State developmental disabilities system." (p. 22);
2. "Improve the information available for assessing the quality of community-based and Regional Center services by analyzing outcomes data across the State's entire developmental disabilities system." (p. 28)
3. "Control service utilization and increase efficiency at the Regional Centers by expanding managed care principles for people with developmental disabilities statewide." (p. 31)
4. "Propose legislation authorizing the Department to require Regional Centers and community providers to conduct background investigations consistent with the authority in the child care licensing system." (p. 35)
5. "Work with other state agencies serving people with developmental disabilities to obtain reliable information on the number of people with developmental disabilities, providing training on eligibility criteria to other state agencies, and provide input through presentencing investigations and ongoing review of the appropriateness of placements in the mental health and correctional systems." (39)
6. "Undertake further analysis to plan for Regional Center downsizing. The analysis should develop a valid estimate of downsizing savings and result in an operational plan that establishes placement criteria for the Regional Centers, analyzes the need for Regional Center services for children under the age of 18, defines service volume and staffing requirements, and evaluates the cost-efficiency of service locations and administrative structures." (p. 42)
7. "Undertake a comprehensive financial analysis of Regional Center and community costs to assist with identifying appropriate community funding allocations and to maximize downsizing savings." (p. 44)
8. "Establish admissions and discharge criteria and standardized guidelines to assist Regional Centers and Community-Centered Boards with successfully transitioning people with developmental disabilities from the Regional Centers to the community." (p. 46)
9. "Consider options for addressing shortages of specialty services in some community programs by making Regional Center and other centralized resources available to communities for consulting and technical assistance." (p. 47)
10. "Develop minimum and ongoing training requirements for community direct-care staff to ensure all staff have adequate knowledge and skills to provide quality care to people with developmental disabilities." (p. 48)
11. "Include language in contracts requiring CCBs to obtain all covered mental health services for Medicaid-eligible persons from the capitated mental health system

and require CCBs to discontinue purchasing mental health services with developmental disabilities system funds." (p. 57)

12. "Require MHASAs to acquire the expertise needed to provide mental health services to people with developmental disabilities." (p. 63)
13. "Require MHASAs to improve the availability of experts and emergency services, participate in individual planning and staffing meetings, provide progress notes, and establish communication channels on an ongoing basis to improve continuity of care." (p. 65)
14. "Increase monitoring of mental health services provided by MHASAs to people with developmental disabilities." (p. 65)
15. "Improve the accuracy of information on people who are diagnosed with both a developmental disability and mental illness." (p. 66)
16. "Continue to work with MHASAs to improve the accuracy of encounter data, enforcing fiscal penalties as permitted by contracts if necessary." (p. 67)
17. "Work with Community-Centered Boards and Regional Centers to develop criteria for identifying and tracking high-risk people with developmental disabilities who are receiving comprehensive services and supported living services, and who are on waiting lists." (p. 71)
18. "Address community safety risks by promulgating minimum security management guidelines for high-risk populations." (p. 73)
19. "Investigate the feasibility of using additional tools, such as mechanical restraints and seclusion, to maintain the safety of high-risk people with developmental disabilities during emergency situations." (p. 75)

K. The Arc of Colorado and Affiliates (October 1, 2002)

1. "Direct Funding Consumer Directed Services Waiver (an SLS model) that utilizes a less costly Fiscal Intermediary and that incorporates payment to family members to reduce cost of services and increases capacity. This model should allow people with developmental disabilities to choose where they live, with whom they live, the community activities in which they wish to participate, what support services they want and need, and whom they want to provide these services."
2. "Development of Day Programs that provide all people with developmental disabilities the opportunity for natural community competitive employment and that connects them to their community and builds natural supports and access to natural community programs. Areas to investigate are utilizing incentives to employ people with developmental disabilities in the community and contracts with provider agencies that refuse funding community participation programs without evidence that the programs connect people to their community or provide community access that build natural supports and that build natural access to community activities."

3. "DDS must investigate the possibility of developing a council of businesses in Colorado to increase funding for employment services and the opportunity of employment of people with developmental disabilities, and reduce the need for costly community participation programs in favor of a model that connects people to their community and builds natural supports and accesses natural community programs."
4. Positive Behavioral Supports: The health and safety of a significant number of adults with developmental disabilities is dependent upon the quality of the support they receive relative to their behavior. Standard behavior management techniques can be punitive, artificial or negative. Positive behavioral support addresses behavioral concerns for an individual without putting him/her in danger of receiving punishing or incomplete intervention. In order to provide effective positive behavioral support, direct service staff and management must be properly trained. The Arc of Colorado believes that the volume and frequency of training in Positive Behavioral Support must be increased substantially. In addition, to avoid unintended consequences, the Arc of Colorado believes that Colorado standards must be established and used, to assure that staff understand how to perform assessments and how to provide Positive Behavioral Support.

L. Director of DDS Observations - Perceived Issues and Concerns: The following observations are based upon interactions with constituent representatives since assuming the Director's responsibilities on July 1, 2002:

Fiscal

1. Historically, there has been an unequal distribution of resources among the twenty Community Centered Boards. An Equity Funding Formula was developed by the CACCB and adopted by DDS in the summer of 2002, which will improve the distribution of new resources. However, to address historical inequities, consideration should be given to:
 - a. Expand the formula to include mix (i.e. the various levels of need served); and
 - b. Explore application of the funding formula to those resources that become available through attrition.
2. The impact of the state's fiscal crisis will be an ongoing challenge to the limited resources available. Colorado's current economy is experiencing a revenue shortfall approximating \$870 million in FY 03 which has resulted in 1.5%, 4%, and 6% reductions respectively, in the DDS Operational budget. More recently, a 1.2% reduction in the Community Line was realized. A similar revenue shortfall is projected for FY 04;
3. Because of its per capita income, Colorado receives the lowest ratio of Medicaid Medical Assistance Percentages (50%) compared with most other states:
 - a. Colorado shares this same ratio with eleven other states; and
 - b. The state with the highest ratio, is Mississippi (77.08%) NASDDS: "Perspectives", December 2002.

4. New sources of revenue that are being, or will be explored, include:
 - a. Using local tax dollars as match for Medicaid federal financial participation;
 - b. Leveraging existing state, unmatched resources;
 - c. Review of Colorado's Systems Change Grant and its relevance and opportunities to the developmental disabilities service system; and
 - d. Exploration of engaging in a financial partnership with families (i.e. Public/Private trusts).

Programs, Services and Supports

1. Day Program trends appear to be toward more restrictive options:
 - a. Community Participation; and
 - b. Sheltered Employment.

Individuals and families should have the opportunity to make informed decisions, which may or may not result in their choosing a more restrictive day program alternative. The system should provide as many options for individual choice from existing opportunities, or new alternatives;

2. There is a need to re-establish a meaningful financial incentive paid to CCB's and Service Provider Organizations who provide integrated employment opportunities for adults (i.e. work enclaves and community employment). This will require the partnership of the Divisions of Developmental Disabilities Services and Vocational Rehabilitation Services to explore new models that are consistent with the 1992 Rehabilitation Services Act;
3. Trends in residential alternatives appear to be toward Host Homes, in part, because of cost savings compared with group homes;
4. Health and safety of persons enrolled would be enhanced with the development and implementation of:
 - a. An Abuse Registry for adults;
 - b. A statewide Incident Tracking System;
 - c. An Emergency Backup System for CCB's and their provider network; and
 - d. Fair wages for staff to promote a reduction in staff turnover and consistency in the continuity of services and supports provided.
5. There is an inherent "Conflict of Interest" regarding the provision of Case Management services by CCBs. To mitigate this concern, consideration should be given to having all case management staff report to the Director of Case Management Services, who in turn reports directly to the Executive Director.

Note 1: In those instances in which the CCB must investigate itself, there ought to be a formalized system of "checks and balances" in place to mitigate

the perception of impropriety.

Note 2: An obvious consideration would be to separate the Case Management function from the CCB; however, this has been found in another state (Ohio) to be a more expensive alternative (i.e. duplication of administrative costs) and the services were fragmented.

6. The definition of developmental disability used is more liberal than the federal definition (i.e. deficits in 2 or more areas of adaptive behavior compared with 3 or more deficits in major life activities). As a result, the developmental disabilities services system is probably serving more capable individuals with cognitive disabilities than would be otherwise served using the federal definition to determine eligibility. Considering this, it seems ironic that:
 - a. There appear to be inconsistent opportunities for consumers to make real choices about their services and supports; and
 - b. Day program trends are more restrictive.
7. Basic but critical components of the system, as described below, are not consistently monitored or addressed by some service provider entities:
 - a. Health and safety assurances
 - b. Eligibility determination
 - c. Level of care determination
 - d. Plan of care (IP)
 - e. Service provision by qualified providers
 - f. Quality assurance reviews
 - g. Financial accountability
8. The Developmental Disabilities Services System is splintered by design and organization (i.e. Early Childhood Services, Family Services and Supports Program, CES Waiver, School Age Services, Adult Services, Regional Centers, SLS and Comprehensive Services Waivers). As a result, it requires a commitment to effective communication, teamwork, coordination and sharing of resources among state and local entities to provide meaningful and effective transition services.
9. Community Centered Boards and their provider network, are experiencing increased costs related to:
 - a. Workers Compensation premiums;
 - b. Professional liability insurance premiums;
 - c. Loss of insurance carriers;
 - d. Health insurance premiums;
 - e. Overtime costs related to staff turnover;
 - f. Increased hiring and recruiting costs related to staff turnover; and
 - g. Increased training costs.
10. Community Centered Boards are experiencing trends and associated increased costs related to providing services and supports to:
 - a. Individuals who are seniors;

- b. Individuals who are medically fragile;
- c. Individuals who have significant behaviors; and
- d. Individuals who represent risks to themselves and/or others.

Self-Advocates, Families and the Advocacy System

1. The national trend and practice is to empower self-advocates and families (i.e. policies emanating from CMS and the President's New Freedom Initiatives).
 - a. Freedom of Choice of Providers (CMS);
 - b. Reasonable Promptness (CMS);
 - c. Individual and family supports (CMS); and
 - d. Independence Plus Waivers (CMS/President's Freedom Initiatives).
2. Self-Determination is a process and value that lacks a uniform definition within the developmental disabilities services system. It is a process that enables self-advocates to make informed, reasonable and responsible decisions about their future consistent with principles of: (a) freedom; (b) authority; (c) support; and (d) responsibility.
3. The system of services and supports is very complex, and can be confusing, frustrating and at times overwhelming to staff, families and self-advocates;
4. A significant number of adults are living at home with aging parents/care givers (Braddock: 7,810 adults living at home with parents/caregivers who are 60 + in Colorado);
5. Protection and Advocacy Services, administered by The Legal Center for People with Disabilities and Older People, is limited due to insufficient staffing resources;
6. The inherent fear and subsequent challenge associated with a commitment to inclusive practices, is the risk to the health and safety of Colorado's most vulnerable citizens and associated costs to provide adequate measures with limited resources;
7. There is the perception among some leading advocates that individuals receiving Supported Living Services pay twice for administrative expenses when receiving services from more than one provider. This reduces the amount of resources available for direct service needs. As a result, this has reinforced their argument that a fiscal intermediary is a more cost efficient option to curtail administrative overhead at the expense of limited direct service resources; and
8. Knowledge of and access to other waiver options (i.e. Elderly, Blind Disabled waiver) should be a focus for those individuals awaiting services.

Laws, Policies and Culture

1. Colorado's Constitutional Amendments limit growth in revenue and expenditure (i.e. TABOR). Other laws identify the proportionality of local tax collections (i.e. Gallagher Amendment) or guarantees public school financing (i.e. Amendment 23). These provisions will slow Colorado's economic recovery in comparison with most other states when the national economy improves. As a result, the constituency needs to explore other and more creative methods of generating

new resources and finding new ways to operate more efficiently with those resources available;

2. Concern that Colorado's Developmental disabilities service system has not adequately addressed compliance with CMS standards relative to:
 - a. Assurances for the health and safety of individuals on the waiver;
 - b. A formal reporting of critical incidents from CCBs to DDS;
 - c. A single, statewide database of serious and critical incidents and investigation outcomes;
 - d. Need for ongoing training and technical assistance for staff conducting investigations;
 - e. Eligibility determination (DD, SSI and Medicaid);
 - f. Level of Care determination;
 - g. Plan of Care development (IP);
 - h. Provision of services and supports by qualified providers; and
 - i. Financial Accountability.

Note 1: Last Medicaid review (Comprehensive Services: 10 years ago; SLS/CES: 5 years)

Note 2: Explore contracting with a qualified investigator (i.e. retired state patrol trooper) to assist CCBs in conducting investigations upon request.

3. Recognizing "natural tensions" exist within and among the constituencies, the result of political conservatism and inadequate resources will require the constituency to be more creative, honest and to form new and more meaningful partnerships;
4. The culture of "local control" or "home rule" has created practices that can be perceived at times as intimidating and inconsistent with regulations. Such practices can contribute to divisiveness among service provider organizations, families, self-advocates and advocate organizations;
5. Each of the twenty catchment areas in the DDS system are unique and need the flexibility to meaningfully address its issues and concerns proactively; however, such practices must be consistent with federal and state laws and regulations;
6. The DDS system can and should be influenced by a common Vision, a commitment to basic Core Values and specific goals and priorities. There appears to be no uniform vision, core values or priority. Each CCB is doing the best it can to address its unique community issues, concerns and priorities. As a result, "home rule" seems to be the predominant core value within the system;
7. The definition of Supported Living in Colorado is more expansive (i.e. employment) than the usual definition, which reflects a residential services model. Additionally, the Colorado model may not be consistent with individuals choosing where and with whom they wish to live; and
8. There appear to be two distinct parent cultures. The first, are those who pioneered civil rights and created many of the services and supports that exist today for children and adults. Many of these individuals still care for their sons

and daughters at home. The second, are those younger families who have benefited from the "civil rights" and "entitlements" resulting from the work of the former. They have enjoyed access to civil rights (i.e. due process and impartial hearings) inclusive practices and other resources that they will expect when their sons/daughters transition out of the school system and into the adult services system.

Management, Leadership and Staff Development

1. There is a need for the opportunity for ongoing staff development (i.e. management, professional and paraprofessional staff); and
2. There appears not to be a uniform curriculum for management staff development or certification. Assuming responsibilities of leadership and management for a human service organization (i.e. Community Centered Boards, Service Provider Organizations) represents a profession unto itself. Many individuals in the humans services professions have been promoted into management positions because of their professional success in another discipline. Few have been prepared for the rigors associated with management and leadership responsibilities.

Division of Developmental Disabilities Services

1. Role clarification of DDS and its primary responsibilities need to be revisited and better understood:
 - a. Program Development and Operations
 - b. Budget Development
 - c. Information Management
 - d. Medicaid Operations
 - e. Program Quality
 - f. Fiscal Accountability
 - g. Ethical, Trusted and Visionary Leadership
 - h. Legislative/Policy Development
 - i. Training and Technical Assistance
 - j. Public Relations/Communication
2. DDS has experienced a reduction in staff resources, approximating forty percent (40%) over the past ten years. Because of limited staff and financial resources, DDS has been or will be exploring new partnerships and opportunities with:
 - a. The CACCB (i.e. mutual problem solving);
 - b. Self-Advocates and the Advocacy System (i.e. mutual problem solving with CCBs and PASAs)
 - c. The Division of Aging and Adult Services (i.e. Adult Protective Services; Older Americans Act)
 - d. The Division of Vocational Rehabilitation Services (i.e. developing incentives for community employment outcomes);
 - e. The Department of Education (i.e. transition planning);
 - f. The Division of Mental Health Services (i.e. serving those individuals with a dual diagnosis; positive behavior supports)
 - g. The Division of Child Welfare (i.e. transition planning);

- h. The Coleman Institute (i.e. exploring/identifying adaptive equipment related to enhancing community access, safety and communication);
 - i. JFK Partners (i.e. staff training, research and service);
 - j. The Health Care Policy and Financing (i.e. Single State Medicaid Agency responsible for waiver services)
3. The need for CCMS (Community Contract Management System) upgrade or replacement,
 4. There is the perception that DDS:
 - a. Is inconsistent among its surveyors when applying "Interpretive Guidelines" ;
 - b. Establishes new rules for exceptional events (i.e. "How Hot Is Too Hot", "Aspiration Standard Guidelines" and "Personal Needs Manual") and
 - c. Duplicates records reviewed during surveys (i.e. IRRS and GRRS surveys)
 - d. Duplicates effort (i.e. DDS reviews both CCB's and SPO's; whereas, CCB's review their respective SPO's; waiting list surveys)
 - e. Program Quality reviews focus on weaknesses without regard to strengths and accomplishments of the agency; and
 - f. Collects information that is seemingly not used or responded to in a timely manner.
 5. There is a need to explore facilitated self-reviews and focus Program Quality Assurance reviews more on outcomes than on process. That said, the Program Quality Review Process is considered one of the more effective models referenced by the Human Services Research Institute;
 6. There is a need to explore and identify ways/means to enable CCBs to convert/transfer resources (i.e. SLS to Comprehensive Services and vice versa) that will enable them to respond to changing needs and avoid under-utilization (i.e. reversions) or over-utilization of resources

Community Relations

1. The print media seems to be viewed more as a threat rather than as a resource. The media (print and electronic) can be a viable component of a systemic infrastructure of checks and balances; and
2. There is an ongoing need to build a system of community supports if inclusive practices are to be realized:
 - a. Affordable, accessible housing;
 - b. Accessible public transportation; and
 - c. Natural supports.

General Observations

1. The Colorado system, for the most part, is an effective system which is compromised by inadequate funding, and in some instances, poor practices;

2. In partnership with the DDS constituency, all waiver designs ought to be reviewed in terms of relevance and responsiveness to need;
3. The only options presently available to Developmental Disabilities Services when faced with a provider agency who seemingly is unable to comply with standards and Plans of Correction, include:
 - a. Recommending to the Executive Director of Human Services to withhold in part, or in whole, funding (i.e. administrative); or
 - b. Recommending termination of the contract.

Such options can have a negative impact upon individuals enrolled, their families and staff. As a result, other, more viable options need to be explored.

4. The Colorado Association of Community Centered Boards and its members are well regarded and have credibility in state government and within the various communities served;
5. DDS and the Community Centered Boards want to simplify the system and make it more user friendly; yet, they're both obligated to implement services and supports consistent with federal and state laws/regulations, which will challenge the system to reach a satisfactory outcome;
6. Approximately fifty percent (50%) of those currently receiving Supported Living waiver services, are eligible for and awaiting Comprehensive Service waiver services; and
8. The lack of trust among providers, advocates and DDS has compromised effective communication and the opportunity for shared problem solving. This can ultimately erode public trust and the political support presently enjoyed.

References

Braddock, David: Disability At The Dawn Of The 21st Century And The State Of The States, American Association on Mental Retardation, 2002: "Cross Disability Perspectives" (pp. 63 – 81); and "The State Of The States In Developmental Disabilities" (pp. 83 – 347)

Developmental Disabilities Services: "Accountability Focus Series: Key Indicators Of Performance" December 2002, Colorado Department of Human Services;

Developmental Disabilities Services: "Impact of the 5.3% Base Rate Increase" In Response to Footnote 95 of the FY 2002-03 Appropriations Long Bill HB 02-1420, Colorado Department of Human Services, Submitted to the Joint Budget Committee of the Colorado General Assembly, November 1, 2002;

Developmental Disabilities Services: "Response to Footnote 94 of the FY 2003 Appropriations Long Bill: Plans for Compliance with Olmstead v. L.C. Supreme Court Decision" Colorado Department of Human Services, Submitted to the Joint Budget Committee of the Colorado General Assembly, November 1, 2002;

Developmental Disabilities Services: "2002 Survey of the Comprehensive Services Waiting List Registry for Persons with Developmental Disabilities", Response to Footnote 96 of the FY 2003 Appropriations Long Bill, Colorado Department of Human Services, Submitted to the Joint Budget Committee of the Colorado General Assembly, November 1, 2002;

"HCFA Regional Office Protocol for Conducting Full Reviews of State Medicaid Home and Community-Based Services Waiver Programs", Version 1.2 December 20, 2000, U.S. Department of Health and Human Services, Health Care Financing Administration;

Human Services Research Institute, Rowe, June: "Technical Assistance Summary Recommendations and Resources: Incident Management System", December 16, 2002, Submitted to: Developmental Disabilities, Colorado Department of Human Services;

Human Services Research Institute, Smith, Gary: "An Evaluation of the Colorado Systems Change Project", December 24, 2002, Submitted to: Developmental Disabilities Services, Colorado Department of Human Services;

Human Services Research Institute, Smith, Gary: "Gauging How Well Colorado Supports Its Citizens with Developmental Disabilities", January 1, 2003, Submitted to: Developmental Disabilities Services, Colorado Department of Human Services;

Human Services Research Institute, Smith, Gary: "Should Colorado Launch an Ombuds Program for people with Developmental Disabilities?", December 26, 2002, Submitted to: Developmental Disabilities Services, Colorado Department of Human Services;

Human Services Research Institute, Smith, Gary: "Status Report: Litigation Concerning Medicaid Services for Persons with Developmental and Other Disabilities", February 14, 2003;

"Joint Budget Committee Staff Presentation on FY 2003-04 Budget"

National Association of State Directors of Developmental Disabilities Services, Gettings, Bob: "NASDDDS Strategic Plan", September 2002;

National Association of State Directors of Developmental Disabilities Services, Gettings, Bob: "Perspectives" publication: "FMAP Percentages for FY 2004 Available", December 2002

Office of the State Auditor: "Department of Human Services: Services for People with Developmental Disabilities Performance Audit" May 2000 (pp. 1 – 8)

Ohio Department of Mental Retardation and Developmental Disabilities: "ODMR/DD Medicaid Analysis of Selected Federal Requirements"

Rice, Don: "Colorado's Spending On Developmental Disabilities Vs. The State Of Colorado's Economy: A Chartbook", January 2000;