

**Executive Summary and  
Key Findings**

**The PAD-CO Survey:  
Parent's Viewpoints on Colorado's Developmental  
Disability Delivery System**

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## EXECUTIVE SUMMARY

***Introduction/Background:*** In February of 2007, Parents of Adult Children with Disabilities in Colorado (PAD-CO) conducted an on-line survey regarding Colorado's developmental disability delivery (DDD) system. Though PAD-CO is a group of parents of adult children, the survey solicited respondents of all age groups. Parents were asked to describe their experiences with and rate the quality of services in Colorado. This survey is unique in that it is a survey for parents by parents.

The survey consists of 59 questions, 14 of which request open-ended, qualitative responses. Question topics include: biographical information, past and present services received, services denied, the waitlist, Medicaid waivers, planning, case management, quality of Colorado services, Colorado compared to other states, personal experiences and respondent outlook (hope/despair).

Two hundred thirty-nine respondents completed the survey. The typical respondent is a 41-50 year old parent, with a child older than 21 years of age. Several types of disability are widely represented including cognitive, behavioral, physical, learning and neurodevelopment. (Note: henceforth, the term "parent" is used to describe a parent, guardian or representative of an individual with developmental disabilities).

To organize and assemble the survey information into a coherent picture of Colorado's DDD system, written responses were rated along a scale ranging from one to five. In this case, the scale was established as follows:

- 1 = VERY POOR/MUCH IMPROVEMENT NEEDED
- 2 = POOR/IMPROVEMENT NEEDED
- 3 = ADEQUATE/ACCEPTABLE
- 4 = GOOD
- 5 = EXCELLENT/VERY GOOD

The results were then combined to generate an aggregate numerical score in the areas of service quality, case management and turnover. (Note: The raw data from the survey used for this document is available at <http://members.aol.com/padcoweb/survey.htm> or <http://dnvrfox.googlepages.com/index.htm>).

The data set is organized by age bracket and includes four groups: 1) Infant up to 3 years (henceforth referred to as 0-2); 2) 3 to 14 years; 3) 15 to 21 years; and 4) 21 and older. Analysis

of the PAD-CO survey is purely descriptive in nature. There is no attempt to reach statistical significance. These results cannot be used to describe the population at large. Rather, this report represents a look at the views of 239 parents/guardians of children with developmental disabilities residing in Colorado in the year 2007.

**Results:** In general, services scored below the adequate/acceptable mark. Reference Table 1 below for a breakdown of results.

**Table 1**  
**PAD-CO Survey Results by Age Bracket**

Age Group	Percentage of Respondents that Feel Optimistic/Hopeful	Adequacy of Services – Overall	Adequacy of Services – CCB	Adequacy of Services – School	Adequacy of Services - Vocational Rehab	Case Management	Case Management Turnover
<b>0-2 (n=11)</b>	83.3%	4.50	**N/A	N/A	N/A	3.67	2.00
<b>3-14 (n=98)</b>	42.0%	2.67	2.60	2.41	N/A	3.15	1.80
<b>15-21 (n=47)</b>	29.7%	2.58	2.75	2.50	N/A	2.96	1.60
<b>21+ (n=83)</b>	47.1%	2.82	2.92	N/A	1.84	2.71	1.29

\*Ratings based on scale of 1-5, where 1 = very poor and 5 = excellent

\*\*CCB service scores were not tabulated for the 0-2 group because there are too few CCB-specific responses. Instead, CCB services are rolled into the ‘overall’ services category.

Taken as a whole, the data reveal several trends.

*Hope/Despair:* With regard to outlook, those representing children aged 0-2 are by far the most optimistic. On the other hand, the two school aged groups feel the most discouraged and the least hopeful, especially the 15-21-age bracket.

*Adequacy of Services:* The only age bracket satisfied with the quality of services is the 0-2 group. All others report their services to be inadequate or below a level three on the rating scale. Satisfaction with overall services in the 15-21 group is the lowest.

However, when broken down further, satisfaction with CCB and school services is lowest

in the 3-14 age bracket. Vocational rehabilitation, rated by the 21+ group, represents the only service to score below a 2.0, indicating much improvement is needed.

Looking specifically at the 'overall' adequacy of services category, the data reflects two trends. First and most generally, the perception of service quality tends to decline as the individual with DD ages (the 21+ group represents an anomaly, as it rated services higher than either of the school aged groups). Second, the 'overall' adequacy of services appears to be correlated with the level of respondent hope, or lack thereof. Those pleased with services report higher levels of hope, while those in despair rate services poorly.

*Case Management:* As individuals with developmental disabilities age, two effects occur: 1) the quality of case management services declines and 2) the rate of case management turnover increases. Accordingly, respondents with children aged Infant to 14, rate case management services as acceptable, while individuals over the age of 15 do not. At the same time, the 21+ group reports the highest level of dissatisfaction with turnover and the 0-2 group the lowest. As such, quality of case management services and turnover look to be directly linked.

*Planning:* There were no conclusions available from an analysis of the planning responses. The most commonly utilized plans include Early Intervention, Individual Family Support Plan (IFSP), Individual Education Plan (IEP), Medicaid Waiver plans and the Individualized Plan (IP). Respondents rated all plans as somewhat effective or effective, though the IEP was least favored and received several unflattering remarks.

***Common themes:*** Regardless of age, respondents need better access to information. They desire more funding for, and external oversight of, Colorado's system. They demand an end to the waitlist, more self and consumer-directed control, and a less complicated and bureaucratic system. They have observed that Colorado services are inadequate compared to other states. Bright spots in their struggle for services are external to the system and include other parents, the ARC and Special Olympics.

**Conclusion:** Based on the experience of parents, the PAD-CO survey clearly demonstrates the need for improvement in Colorado's developmental disability delivery system.

In the words of survey respondents:

*“At some point, it would be nice to be able to trust that the system will work. But, we ain't there yet!!”*

*“Th[e] lack of knowledge, insight, accommodation, planning, values, community [and] caring exemplifies the stupidity in the system for our young adults today.”*

*“I guess it's the whole system. I know Colorado is better than it was, but as a parent you want so much for your child and every opportunity they can get. It is very frustrating to have to fight for most everything!”*

*“Working outside the system has been more positive than work inside.”*

*“‘My story is much too sad to be told -- cause practically everything (in the system) leaves me totally cold’ - With apologies to Cole Porter for stealing his words. But they fit so well I feel!”*

Note: all quotes in this report are words borrowed from respondents of the PAD-CO survey. The identity of each speaker is to remain anonymous.

## Introduction

Thousands of individuals with developmental disabilities reside in Colorado. Several organizations, non-profit businesses, service providers and alliances exist to serve their needs. At the very heart of this service system, lay the individual's parent. As such, a group of parents came together in 2002 to form a “parents only” online discussion group, Parents of Adult Children with Disabilities in Colorado (PAD-CO). Initially, PAD-CO formed to discuss the concerns, joys and successes of parents or anyone in a parental role of adults with disabilities. However, PAD-CO has since developed a more political agenda.

In February of 2007, PAD-CO conducted a 59-question survey regarding the developmental disability delivery system (DDD) in Colorado. Though PAD-CO is a group of parents of adult children, the survey solicited respondents of all age groups. Parents were asked to describe their experiences with and rate the quality of services in Colorado. This survey is

unique in that it is a survey for parents by parents. The following report is an examination of the data generated by the PAD-CO survey.

## 0 to 2 years of age: Results and Analysis

### KEY FINDINGS

As the newest group to the Developmental Disability Delivery (DDD) system, parents of children aged 0-2 represent 4.6 percent of the sample accounting for only 11 of the 239 respondents. The average respondent in this group can be characterized as a 22-30 year old parent residing in Larimer County, whose child has a learning or neurodevelopmental disability. The primary system utilized by this group is Early Intervention.

By in large, these individuals are optimistic/hopeful and report satisfaction with the overall adequacy of services, case management and planning. In fact, all service areas examined scored above the adequate/acceptable mark, with overall services rated the highest at 4.50. Compared to the overall service rating for the entire sample (2.74), 4.50 is quite high approaching 'excellent' on a scale of one to five.

With regard to case management, the 0-2 group boasts the highest score of any age bracket, at 3.67, and the lowest incidence of turnover. The Individual Family Support Plan and Early Intervention represent two areas of planning utilized by this group. Respondents deemed both effective.

Parents of children aged 0-2 require more information about services for younger children, respite, Applied Behavior Analysis therapy (geared towards children with autism), supplemental insurance programs and in the words of one young parent, "Everything!"

Based on the experiences of this group, services for developmentally disabled children aged 0-2 represent a bright spot in Colorado's DDD system, as its clients are both hopeful and pleased with services. The same cannot be said of services provided to other age groups.

*"We've had an excellent experience with them so far -- I don't know what will happen in the future."*

## 3 to 14 years of age: Results and Analysis

### KEY FINDINGS

The group with children aged 3 to 14 comprises the largest of all four-age brackets and accounts for 98 of the 239 respondents or 41 percent of the total. Respondents in this group are, on average, parents aged 41 to 50 with children who have neurodevelopmental disabilities. They most often reside in Arapahoe, El Paso, Denver and Jefferson counties.

The overall adequacy of services received a rating of 2.67, while CCB services received a 2.60, indicating respondents are dissatisfied with services. Both fall below the score derived by the larger sample of 239 respondents. A majority (53.1%) of the group feels discouraged.

Within the ‘overall services’ umbrella, respondents cite special education as the system most in need of improvement. A score of 2.41 makes it one of the lowest rated services, second only to vocational rehabilitation. Respondents repeatedly identify three problems with special education. The first is an absence of programs designed to fit the needs of children with autism, while the second stems from a lack of properly trained and well-qualified teachers/staff. The third, and probably most substantial, problem is the school systems’ inability to understand and implement the Individuals with Disabilities Education Act (IDEA) and the Individualized Education Plan (IEP).

The vast majority of children aged 3 to 14 have an Individualized Education Plan (IEP). Analysis of the planning process in this particular group presents difficulties because the data seem to contradict one another. The quantitative data demonstrate that IEPs are developed by qualified personnel and implemented somewhat effectively/effectively. However, parents’ qualitative responses tell a slightly different story. Specifically, many parents express frustration with the IEP process and the fact that teachers/plan developers are ill informed when it comes to creating and implementing the IEP.

Only 52.9 percent of respondents claim to have a case manager, by far, the lowest of the four age brackets. Said individuals are satisfied with the quality of case management service, which received a rating of 3.15. With regard to turnover, more than three-quarters (76.7%) of respondents ‘always’ or ‘usually’ meet with the same case manager.

The information needs of this group are not being met. In fact, 87.9 percent do not believe parents are provided with the information they need to apply for services for their



children. As such, many require help navigating the “maze of available systems.” Parents are also looking to the future needs of their children. They desire information about transition programs and adult services. When should parents apply, what do the services entail and how will they transition their child into adult life?

Though this group is discouraged and considers services, with the exception of case management, inadequate; at least one parent is able to stay positive,

*“I hope people know that their child can do anything! It takes a lot of hard work but my child has never disappointed me! She is wonderful and everyone has weaknesses, those with disabilities and those who are not [disabled]. Look for the wonderful strengths in your child and yourself!!!!”*

Others are not,

*“My husband and I are both post graduate educated, married 25 years, 4 children. We own our own home, always pay our bills, spend within our means, and don't break the law. We have reached the lowest point of low in our travels with our son's mental illness in the last 9 years. I believe that most people in our shoes would have given up much longer ago and ended up divorced, on drugs, in jail, or dead due to suicide. It has been unbelievable, worse than any nightmare you can imagine.”*

## **15 to 21 years of Age: Results and Analysis**

### **KEY FINDINGS**

Individuals aged 15 to 21 with developmental disabilities are a unique group. Still a part of the school system, but no longer a child, these individuals represent a period of transition in which they prepare to move from the school system to adulthood. Forty-seven, or 19.7 percent, of the entire sample fall into this transitional category. The average respondent is a 41-60 year old parent of a child with a cognitive disability. Most live in one of five counties including Arapahoe, Jefferson, Boulder, Douglas and El Paso.

The 15-21 group lacks hope (more so than any other age bracket) and reports dissatisfaction with the adequacy of services currently consumed. An analysis of overall, school, CCB and case management services revealed each to be unacceptable. Respectively, the scores are: overall services - 2.58; school services - 2.50; CCB services - 2.75; and case management

services - 2.96. (These figures are calculated based on a scale of one to five, where “1” is ‘very poor’ and “5” is ‘excellent’). The overall services score falls below the sample average of 239 respondents. It further represents the lowest score, according to an age-by-age comparison, in the ‘overall adequacy of services’ category. Within school services, the transitions program represents an area of frustration.

More than 93 percent of respondents have had or currently have an individualized plan for their child. The majority uses an Individualized Education Plan (IEP), which they report to be somewhat effective. One-third of respondents have experience with the transitions program plan. As with the IEP, respondents deemed their plan somewhat effective, though no respondent characterized the plan as highly effective.

Parents in this group are focused on their child’s transition to adulthood and all that it entails. Informational needs therefore include post-secondary educational opportunities, workforce/jobs, community day programs for individuals 21+, housing options, respite, adult services and self-determined/managed services.

To say the least, the transition towards adulthood can be both frightening and tumultuous for the individual with DD and their parent/guardian. This fear is compounded when respondents feel the programs designed to aid the transition process are inadequate.

## **21+ years of age: Results and Analysis**

### **KEY FINDINGS**

As individuals with developmental disabilities surpass the age of 21 (21+), they enter the adult system where schools no longer provide services. Instead, individuals are serviced primarily through Community Centered Boards (CCB), or they leave the state DDD system altogether. The 21+ group account for 83 of the 239 replies and represent the second largest group of respondents. The typical respondent is a 51-60 year old parent of a child with a cognitive disability. The counties with the most respondents are Arapahoe, Denver, Jefferson and El Paso.

The services provided in the adult system are below the adequate/acceptable mark. Overall adequacy of services, CCB services, vocational rehabilitation and case management

services were rated on a scale of one to five, with “1” being ‘very poor’ and “5” equaling ‘excellent.’ Each of the four service areas received a rating below three. The ratings are as follows: Overall services generated a score of 2.82; Limited responses yielded a CCB score of 2.92; Case management received a 2.71 (a major problem is turnover); and, vocational rehabilitation scored the lowest at 1.84. In relation to the entire sample, overall services and CCB services scored slightly higher, while case management services and vocational rehabilitation received lower ratings.

Just over 75 percent of respondents have had, or currently have an individualized plan in place for their child. The two most frequently utilized plans are the Individualized Education Plan (IEP) and the Individualized Plan (IP). Respondents consider both the IEP and the IP somewhat effective or effective. However, they do not consider the planning system as a whole effective.

Access to information is a problem. This particular group of respondents needs more information regarding jobs and housing. Specifically, people need help finding a good job for their child. In terms of housing, many are looking for creative residential options and living alternatives other than host homes.

In summary, most of the key service areas - overall services, CCB services, vocational rehabilitation, and case management - need improvement. Two parent quotes from this group suggest that the problem can be especially acute in the adult system.

*“I would rather have died in childbirth than contemplate what has happened to her since leaving high school.”*

*“Why [do] Coloradans care so much about infants and care nothing about adults?”*

## Common Themes

Respondents to the PAD-CO survey, regardless of age, echoed several sentiments similar to one another. The common themes to emerge are: 1) Funding in Colorado is not sufficient to provide the services needed; 2) The waitlist needs to be eliminated; 3) Compared to other states, the developmental disability delivery (DDD) system in Colorado is inadequate; 4) Parents are extremely frustrated with the complexity, rigidity and bureaucracy of Colorado’s DDD system;

5) The CCB and school system need independent evaluation by an outside party to ensure better accountability; and finally 6) Parent support networks, the advocate association ARC and Special Olympics enjoy high levels of respondent praise. (Note: This list is not exhaustive; rather it touches on the major themes as observed by the author. There is simply too much data to report each varied fact, thought or idea. Every effort was made to reasonably represent the information).

**Funding:** According to respondents, funding in Colorado is not sufficient to provide the services needed. Nearly 10 percent of all records generated (or 130 out of 1,323) focused on the issue of funding. The score derived is 1.58 or [much] improvement needed. In fact, not a single respondent termed funding ‘excellent’ (level 5), ‘good’ (level 4) or even ‘adequate’ (level 3). To help alleviate the funding shortage, respondents suggest the elimination of the Tax Payer’s Bill of Rights (TABOR) mentality, coupled with a campaign to educate citizens about the needs of the developmentally disabled population. One parent suggests that a portion of lottery proceeds be re-directed to the DDD system.

*“Expose and make tax payers aware of the horrors committed to our most vulnerable citizens so we can redirect & increase taxes necessary to, at the very least, equal what the zoo animals get for their physical & mental care.”*

*“Eliminate TABOR for good! Educate the constituents about the value for their taxation dollar. Emphasize fiscal responsibility so that people don't feel their taxes are going to wasteful programs that most consider pork.”*

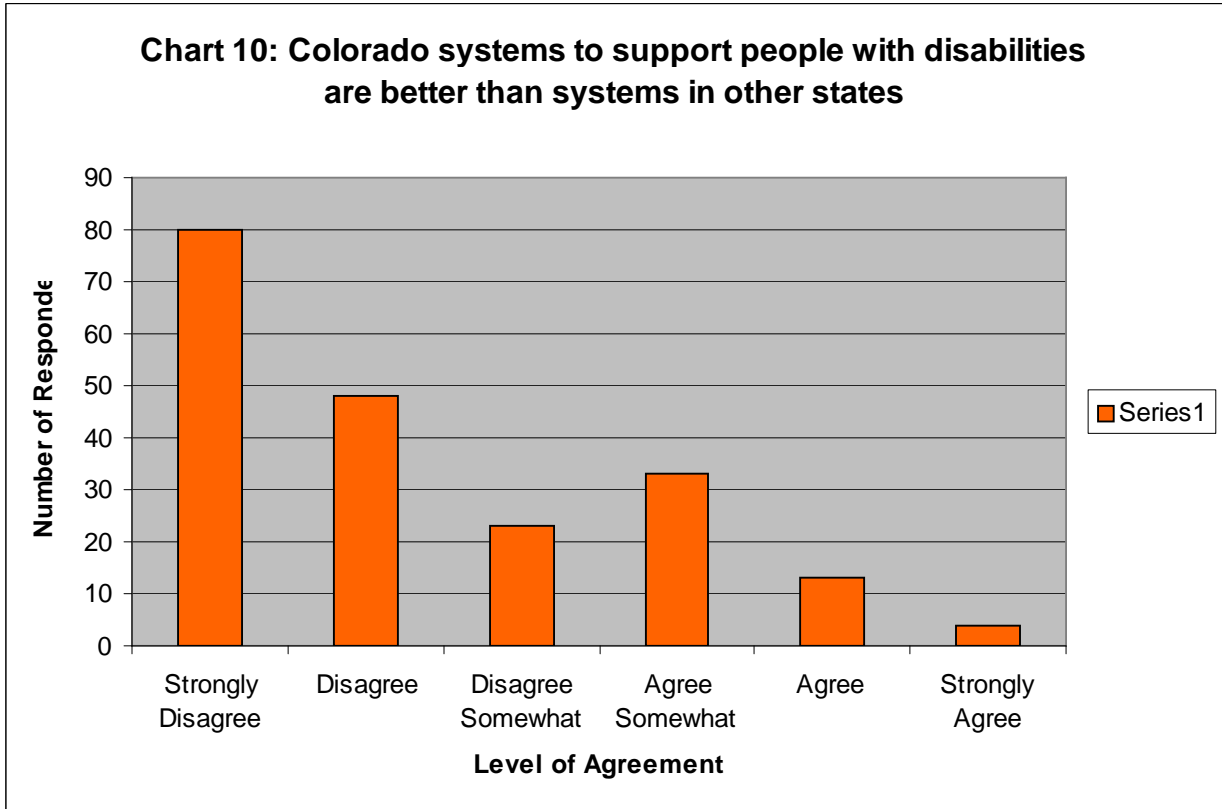
*“It seems interesting to me that we can continue to build huge prisons and fund all kinds of needs for people in the justice system but we can't come up with the money to fund the needs of people with DD. Why can't some of the money that comes in from the lottery be used for DD? While parks are important, people are more so!”*

**Waitlist:** Closely connected to the funding issue is the waitlist. Several respondents cite the need to end the wait for services. “I don't know specifics but the waiting list in Colorado for people to receive services is embarrassing and needs to be addressed immediately.” At least one respondent has waited as long as 16 years, others 10 years and others still, seven years.

The wait for services frustrates and discourages respondents; especially in light of the fact that states like California have no waitlist. A recent California transplant laments, “[i]t was

so discouraging to call the CCB when I was getting ready to move from CA to CO. I was expecting to just transfer all his services and was shocked to learn that he would have to be on a huge waiting list and even then wouldn't be getting much help after he reached the top of the list. I haven't even filled out the application yet since it seems pointless.” A respondent familiar with services in Arizona adds, “She was on it, we left the state for 10 months, had to go to Arizona, got right in their plan immediately, returned to Colorado and had to start all over like we were never here! Very poor! How sad that you are [a] tax payer for 24 years in a state, go to a new state, get right in their Medicaid plan, return to your home state and now have to re-apply and be put on a waiting list???”

***Compared to other states:*** Twenty-eight percent of all survey respondents have received services (mostly Early Intervention and Special Education) in states other than Colorado. Fifty-two percent are familiar with systems in other states. Based on either direct experience or through word of mouth, respondents feel that Colorado services are substandard when compared with other states. As such and on a scale of one to five, Colorado scored a 1.87 or [much] improvement needed. When asked to respond to the statement – *Colorado systems to support people with disabilities are better than systems in other states* – 75.1 percent of respondents disagreed. (See Chart 10 below).



According to the qualitative survey data, states reported to provide superior services include Arizona, California, Florida, Illinois, Massachusetts, Michigan, Minnesota, Missouri, New Jersey, New Mexico, New York, North Carolina, Oregon, Pennsylvania, South Carolina, Texas and Wisconsin, while those reported to be inferior are Indiana, Ohio, Oklahoma and Vermont. Respondents disillusioned with Colorado services have the following to say:

*“They [other states] are far superior to Colorado. When families ask if they should move here for services I always advise against it - both the educational and state support services are terrible. It is an embarrassment to be one of the wealthiest states with the least amount of support.”*

*“I have lost many of my friends because they have moved for better services.”*

*“I was very disappointed when I arrived to find such a splintered service system.”*

*“We are very discouraged at the level of service provided here as compared to the state we moved from where we were on [a] Medicaid waiver and had a great school system for special education.”*

*“... [W]e were told by social services at the hospital how horrible Colorado services’ availability [is] AND WERE ENCOURAGED TO CONTACT RELATIVES IN OTHER STATES TO FIND BETTER SERVICES!!!! If that is not a kick in the Colorado State Department’s butt, then I don’t know what would be!”*

*“I am a member of the Board of Directors for Colorado Cross Disability Coalition and we learn about disability issues from across the nation. The statistics show that Colorado is one of the worst. More barriers to access and longer determination of benefits and once an individual is finally approved for benefits it is a constant struggle to understand, access, and keep the benefits.”*

**Ease of system:** Parents find Colorado’s DDD system to be complex, rigid and bureaucratic. A parent vents, “I wish someone had told me how to be prepared to navigate through the impossible red tape and time-consuming insanity of the CO process.” As a group, respondents rate the ‘ease of the system’ at 1.59 or [much] improvement needed.

The system is bureaucratic, “I am so vastly discouraged, devastated, sickened by the bureaucratic processing that I have gone through in the past 6 years that it is amazing that I still have the capacity to sit here and take this survey.” For example, duplicate paperwork/information is often required with little communication between agencies. According to one parent, “[t]he most ludicrous thing is the amount of duplicate paperwork that must be filed. I had to submit many packages of the very same information to several different agencies that supposedly ‘work together’.” Another recalls, “[t]he number of intake people amazed us when we were going from agency to agency trying to find services. We answered the same questions over a dozen times. I started asking if anyone had heard of a fax machine?!” Accordingly, respondents frequently cite the need for better coordination between agencies.

Respondents also claim that the system is too rigid. “The CCB, at least in our county, leave little, if any, choice to clients and their families. We are told who, what, where, how often, whether it qualifies, is valid, is needed...I know there are rules and reg[ulations], but give the power to the clients to make those choices. It is sad to think that they truly believe they know more about what is right for our children than we do.” As such, survey respondents desire greater access to self-directed services. A new program, Consumer Directed Attendant Support (CDAS) designed with that very goal in mind, has received many accolades. To quote, “CDAS is so wonderful, we love it. We are so happy with this new program!!!!!!!!!!”

Stringent guidelines prevent children with an IQ of 71 (the cut off is 70) from receiving services, even though they might be in need. In fact, 16 percent of respondents have been turned down for services because their child's IQ is too high. A parent notes, "[t]oo many people who are in desperate [need] of services don't qualify because of the arbitrary IQ score used. An IQ number never has indicated needs or capabilities."

Finally, the system is complicated by the fact that parents feel they must fight for services. To quote, "[I wish someone had told me] that I was going to have to fight for everything that he receives and that no one but me will advocate for him. I wish someone would have told me that I don't need to feel like the 'bad guy' every time I ask for something to make my son's life easier."

**Better accountability:** To improve accountability, several respondents feel that the CCB and school system require oversight by an external party. Those calling for oversight opine,

*"They [CCBs] have way too much local control with little to no oversight and as a result services vary greatly according to where someone lives."*

*"We have NEVER participated in any kind of outside review of any agency or system we have been involved with...the state needs to do an independent eval[uation] of the CCBs that includes lots of interaction with the parents."*

*"There needs to [be] more accountability for schools regarding Sp[ecial] Ed[ucation]. IDEA is very open to interpretation and someone needs to be watching the schools."*

Without external oversight, retaliation has become a fear for many. A few respondents in this survey detailed examples of retaliation. Typically, retaliation resulted when the respondent opposed their school/CCB, expressed their opinion or acted as a 'difficult parent' by advocating for their child.

**Praise for Parent networks, ARC and Special Olympics:** Respondents have come to value the importance of networking within the DD community. Specifically, parent networks provide an invaluable service to those navigating the system. "It was through other parents in my own community that I develop[ed] and found what I needed for my son."



The ARC, an advocacy organization devoted to improving supports and services for the developmentally disabled, is highly valued by respondents. As illustrated by one parent, “[t]he ARC of Colorado [is] the only organization that has accurate info[rmation] and is willing to teach us how to advocate positively for our child.” Another adds, “[t]he ARC of Aurora has been a tremendous resource for advocacy for my son.” And a third, “ARC of Arapahoe & Douglas is wonderful... the advocates are wonderful and understanding.”

The Special Olympics Program enjoys similar praise. Tasked to provide year-round athletic training and competition to individuals with intellectual disabilities, Special Olympics “is the best program around for people with disabilities and most of the workers are unpaid totally exhausted parents.” Another parent recalls, “Special Olympics in Colorado is so far beyond wonderful I can't put it into words. There is so little for the kids to be part of and Special Olympics is so well run and offers so many choices.”

## **Discussion/Conclusion**

The PAD-CO survey generated an enormous amount of varied data. Some respondents report positive experiences, others report negative. Typically, each respondent has encountered a bit of both within Colorado's DDD system. Taken as a whole, the data reveal several trends.

***Hope/Despair:*** With regard to outlook, those representing children aged 0-2 are by far the most optimistic. On the other hand, the two school aged groups feel the most discouraged and the least hopeful, especially the 15-21-age bracket. One cannot presume to know what drives one group to be more/less hopeful than another. But, perhaps this is a reflection of the fact that the 15-21-age bracket is approaching a major transition from the school system to the adult system, fraught with uncertainty as to whether or not they will be able to obtain services for their child. In contrast, some of those already in the adult system (21+ group) have weathered the wait and currently receive services.

***Adequacy of Services:*** The only age bracket satisfied with the quality of services is the 0-2 group. All others report their services to be inadequate or below a level three on the rating

scale. Satisfaction with overall services in the 15-21 group is the worst. However, when broken down further, satisfaction with CCB and school services is lowest in the 3-14 age bracket. Vocational rehabilitation, rated by the 21+ group, represents the only service to score below a 2.0, indicating much improvement is needed.

Looking specifically at the ‘overall’ adequacy of services category, the data reflects two trends. First and most generally, the perception of services tends to decline as the individual with DD ages (the 21+ group represents an anomaly, as it rated services higher than either of the school aged groups). Second, ‘overall’ services quality appears to be correlated with the level of respondent hope, or lack thereof. Those pleased with services report higher levels of hope, while those in despair rate services poorly. (See Table 30 below).

**Table 30**  
**Adequacy of Overall Services compared to Hope by Age Bracket**

Age Group	Adequacy of Services Rating/Score	% of Respondent Group that Report Feeling Hopeful and/or Optimistic
0-2 (n=11)	4.50	83.3%
3-14 (n=98)	2.67	42.0%
15-21 (n=47)	2.58	29.7%
21+ (n=83)	2.82	47.1%

\*Ratings based on scale of 1-5, where 1 = very poor and 5 = excellent

Analysis by county reveals that most are rated around the 2.75 mark for ‘overall’ services, with Adams the only county to score 3.0.

**Case Management:** As individuals with developmental disabilities age, two effects occur: 1) the quality of case management services declines and 2) the rate of case management turnover increases. Accordingly, respondents with children aged Infant to 14, rate case management services as acceptable, while individuals over the age of 15 do not. At the same time, the 21+ group reports the highest level of turnover and the 0-2 group the lowest. As such, quality of case management services and turnover look to be directly linked. (See Table 31 below).

**Table 31**  
**Case Management, Turnover and Frequency of Contact by Age Bracket**

Age Group	Case Management Services Rating/Score	% of Respondent Group that Always Meets w/the Same Case Manager	**Case Management Turnover Rating/Score
0-2 (n=11)	3.67	83.3%	2.0
3-14 (n=98)	3.15	44.6%	1.80
15-21 (n=47)	2.96	30.6%	1.60
21+ (n=83)	2.71	21.5%	1.29

\*Ratings based on scale of 1-5, where 1 = very poor and 5 = excellent

\*\*The lower the turnover score, the more the respondent group views turnover as a problem.

**Planning:** There were no conclusions available from an analysis of the planning responses. The most commonly utilized plans include Early Intervention, Individual Family Support Plan (IFSP), Individual Education Plan (IEP), Medicaid Waiver plans and the Individualized Plan (IP). Respondents rated all plans as somewhat effective or effective, though the IEP was least favored and received several unflattering remarks.

**Common themes:** Regardless of age, respondents need better access to information. They desire more funding for, and external oversight of, Colorado's system. They demand an end to the waitlist, more self and consumer-directed control, and a less complicated and bureaucratic system. They have observed that Colorado services are inadequate compared to other states. Bright spots in their struggle for services are external to the system and include other parents, the ARC and Special Olympics.

Based on the experience of parents, the PAD-CO survey clearly demonstrates the need for improvement in Colorado's developmental disability delivery system. In the words of one parent:

*“My story is much too sad to be told -- cause practically everything (in the system) leaves me totally cold’ - With apologies to Cole Porter for stealing his words. But they fit so well I feel!”*

From July 18 through October 10, 2007, Colorado's General Assembly will be convening a series of six meetings to address the long-term support needs of the developmentally disabled population. Perhaps, this movement will be the genesis for system-wide improvement.